Colorectal Cancer: A Neuropsychological Approach to Non-adherence to Screening Guidelines of Individuals with Lynch Syndrome in the Western Cape

---

Amy Northam NRTAMY001

A minor dissertation submitted in partial fulfillment of the requirements for the award of the degree of
M A in Psychological Research

Faculty of Humanities
UNIVERSITY OF CAPE TOWN
2010

Supervisor: Prof Mark Solms
Department of Psychology
University of Cape Town

Co-supervisor: Prof Raj Ramesar
Division of Human Genetics
University of Cape Town

COMPULSORY DECLARATION

This work has not been previously submitted in whole, or in part, for the award of any degree. It is my own work. Each significant contribution to, and quotation in, this dissertation from the work, or works, of other people has been attributed, and has been cited and referenced.

Signature …….. Date: ……

Acknowledgements

I would like to acknowledge the following, whose contribution to the successful completion of this research project was invaluable:

- The participants, who so willingly gave of their time and shared their knowledge and experiences with me.
- Professor Mark Solms, my supervisor, for his invaluable input throughout the project, and particularly within the neuropsychological sections.
- Professor Raj Ramesar, my co-supervisor, for his input throughout the project, particularly within the sections pertaining to genetics and colorectal cancer.
- Ms Zandre Bruwer, my mentor, for her guidance during the initial stages of the research project, for her help with the construction of the interview guide, and for her continued support throughout the study.
- Ms Ursula Algar, the CRCGC, for her assistance in choosing appropriate participants and her guidance throughout the interviewing process.
- Mr Pieter Blaauw, for translating the interview schedule, information sheets and consent forms into Afrikaans.
- Ms Robyn Human, for her constant assistance and support.
- Mrs R Northam, my mother, for her patience, support, and unlimited assistance throughout the project.
- I would lastly like to acknowledge the following funding bodies for their financial assistance during my Masters degree:
    a. *The Harry Crossley Fund*
    b. *The University of Cape Town*

Table of Contents

List of Terms and Abbreviations

C1, C2 etc. = Reference participant one, two etc.

CES-D = Centre for Epidemiologic Studies-Depression

CNS = Central nervous system

CRC = Colorectal cancer

CRCGC = Colorectal cancer genetic counsellor

D-KEFS = Delis Kaplan Executive Function System

FAP = Familial adenomatous polyposis

FDRs = First degree relatives

GSH = Groote Schuur Hospital

HBM = Health Belief Model

HIV = Human immunodeficiency virus

HNPCC = Hereditary Non-polyposis Colorectal cancer

LS = Lynch syndrome

MMR = Mismatch repair genes

P1, P2 etc. = LS participant one, two etc.

PGT = Predictive genetic testing

R = Researcher

SES = Socioeconomic status

STAI = State Trait Anxiety Inventory

Std. = Standard

TB = Tuberculosis

WC = Western Cape

WMS III = Wechsler Memory Scale 3rd Edition

List of Figures

List of Tables

Appendix D:

Appendix E:

Appendix F:

Abstract

Lynch syndrome (LS), the most common form of inherited colorectal cancer (CRC), carries with it a lifetime risk of approximately 80% of developing CRC. Although regular colonoscopies can result in the treatment or prevention of CRC, non-adherence to screening guidelines is a common problem. The Health Belief Model predicts that for an individual to undertake protective health behaviour (e.g. screening), they need to be aware of both the health threat and an available protective action against that threat; and a lack of knowledge has been associated with non-adherence. Because the attainment of knowledge is dependent on a number of neuropsychological factors, this study aimed to investigate the neuropsychological functioning and knowledge of individuals with LS in the Western Cape (WC), as well as how these factors relate, both individually and together, to non-adherence. Sixteen LS participants (8 adherent and 8 non-adherent), and 16 (non-LS) matched reference participants were recruited from areas within the WC. Information pertaining to participant sociodemographic, psychological and medical characteristics was gathered, and their attention, working memory, comprehension, memory and executive functioning were assessed. LS participants were questioned, using a structured interview, on their knowledge of concepts relating to both health threat and protective health action. Results showed no statistically significant differences between the LS and reference participants on cognitive testing; and their knowledge of threat was poorer than that of protective health action. Results also suggest that the attainment of knowledge amongst this sample was not associated with neuropsychological functioning. With regards to adherers and non-adherers, the non-adherers performed better on the majority of tasks and significantly better on tasks of inhibition and set shifting. However, their knowledge was poorer than that of the adherers. Therefore, although a lack of knowledge appeared to be associated with non-adherence, neuropsychological functioning was not. Furthermore, knowledge did not appear to be exclusively dependant on neuropsychological functioning for its association with non-adherence. This study identified unexpected findings with regard to the relationships between neuropsychological functioning, knowledge and non-adherence within the context of LS, and highlights ways in which this might be investigated in the future.

Chapter One:
Introduction

Introduction

This chapter is concerned with the introduction of this research study. Sections such as the literature review, motivation for the study, as well as the study's aims and objectives, will be covered.

Colorectal Cancer

Colorectal cancer (CRC) is a worldwide problem, affecting both men and women, and is the third leading type of cancer, after lung and breast cancers, accounting for approximately half a million deaths per year (Kamangar, Dores & Anderson, 2006; Winawer, 2007). Although common in developed, Western nations, 6% of the global CRC cases occur in Africa (Kamangar et al., 2006). In South Africa, CRC is the fourth leading type of cancer. CRC carries a lifetime risk of 1 in 97 for South African men and 1 in 162 for South African women; and around 2500 South Africans die from this disease each year ("Overview of the latest NCR statistics", n. d.).

About 75% of CRC cases occur sporadically, without discernable risk factors other than age and environment. Fifteen to twenty percent of cases are familial, that is two or more immediate relatives of the patient have CRC (Lynch & de la Chapelle, 1999), potentially arising from a combination of genetic and environmental factors. The remaining portion of cases are mendelian in nature, meaning that the risk is clearly inherited (Lynch & de la Chapelle, 2003). Of the inherited types of CRC, familial adenomatous polyposis (FAP) accounts for less than 1%, while Lynch syndrome (LS), also known as Hereditary Non-polyposis Colorectal Cancer (HNPCC), accounts for approximately 5-8% of this group (Lynch & de la Chapelle, 2003).

Lynch Syndrome

LS[1] is the most common form of inherited CRC (Hughes Halbert et al., 2004; Lerman et al.,

[1] The term 'Lynch syndrome' refers to both a type of hereditary CRC as well as the pre-symptomatic individuals who possess the disease causing mutation and therefore have a risk of developing, but have not yet developed, CRC. This term is therefore used interchangeably, throughout the study, between individuals in whom the risk or mutation has developed, as well as those in whom the risk or mutation has not yet led to the development of CRC.

1999; Lynch & de la Chapelle, 2003). Worldwide, the incidence of LS is 1 in 3000 (Young, 2001), however, national and provincial incidence rates within South Africa are unknown. This disorder is caused by a germ-line mutation in any one of a number of mismatch repair (MMR) genes, with h*MLH1* and h*MSH2* accounting for almost 90% of all identified mutations (Hughes Halbert et al., 2004; Lynch & de la Chapelle, 1999; 2003). The LS mutation is inherited in an autosomal dominant manner. This refers to a pattern of inheritance where a genetic defect (mutation) in only one of the gene pairs is sufficient to cause the trait in question; and where the gene is inherited from an affected parent, and is not linked to the sex-chromosomes (i.e. X or Y), meaning that both males and females can inherit the mutated gene (Concrete vs. abstract thinking, n. d.).

As well as a predisposition for early onset of CRC, the mean age being around 44 years (Lynch & de la Chapelle, 1999; 2003), LS patients have a lifetime risk of approximately 80% of developing CRC. Studies conducted in South Africa, however, have predicted lifetime risks as high as 92% (Stupart, Goldberg, Algar & Ramesar, 2009). In addition, women with this mutation are at increased risk for endometrial and ovarian cancer, which carry lifetime risks of approximately 40 - 60% and 10 - 15% respectively (Aktan-Collan, Haukkala, Mecklin, Uutela & Kääriäinen, 2001a; Domanska, Nilbert, Soller, Silfverberg & Carlsson, 2007; Vasen et al., 2007). But, if these cancers are detected at an early stage, the cure rate is as high as 90-95% (Lerman, Marshall, Audrain & Gomez-Caminero, 1996). Individuals with LS are also at elevated risk for extra-colonic cancers such as gastric, stomach, small intestine, urologic tract, small bowel, hepatobiliary tract, gallbladder, breast, skin and central nervous system (CNS; including brain) cancer (Mecklin & Järvinen, 1991; Vasen et al., 2007; Watson & Lynch, 2001). The lifetime risk for these additional cancers, however, is much lower than that of colorectal or endometrial cancer, ranging from 1% lifetime risk of brain tumours to 12% lifetime risk of gastric cancer (Vasen et al., 2007; Watson & Lynch, 2001).

Over a period of time a “pathologic evolution” occurs from premalignant adenoma (a non-cancerous polyp or growth in the colon or rectum) to invasive CRC (Kamangar et al., 2006, p. 2145). Although individuals with LS do not usually have an excess of adenomas or polyps, the adenoma-to-carcinoma sequence tends to develop much more quickly in these individuals than in the general population (Kamangar et al., 2006; Lynch & de la Chapelle, 2003; Vernon et al., 1997). Therefore, ways of identifying individuals with LS and regular monitoring of their colon, via colonoscopies, are of great importance.

Predictive Genetic Testing

Advances in the field of genetic research have made predictive genetic testing (PGT) to assess the risk of developing hereditary types of CRC, such as LS, possible (Bunn, Bosompra, Ashikaga, Flynn & Worden, 2002). This allows for the identification of mutation-carriers, who may then undergo surveillance aimed at the early detection and treatment of CRC. Important, also, is the identification of those individuals who do not carry the mutation, whose fears may be alleviated, and who may be discharged from the burden of regular surveillance (Aktan-Collan et al., 2000; Aktan-Collan et al., 2001a).

First degree relatives (FDRs; parents, children and siblings) of patients with a known LS mutation are at 50% risk of carrying the mutation themselves, placing them at a resultant lifetime risk of 80% to 92% of developing the disease. The argument is therefore compelling that, once a mutation in an affected family member has been identified, his or her family members should be counselled and offered the possibility of PGT. If found to carry the mutation, such individuals should then ideally enter into an ongoing clinical surveillance program themselves (Andrykowski, Munn & Studts, 1996; Wakefield et al., 2007).

Screening

Regular clinical endoscopic surveillance, via the use of colonoscopies, in individuals with LS, is important for the detection of premalignant polyps and/or cancer in its early stage. The aim is to (a) interrupt the adenoma-to-carcinoma sequence, (b) remove the potentially malignant lesion, and (c) reduce CRC incidence and mortality (Kamangar et al., 2006; Lynch & de la Chapelle, 2003; Winawer, 2007). Therefore, once a mutation-carrier has been identified, it is imperative that they adhere to the recommended screening guidelines (Aktan-Collan et al., 2000; Codori et al., 1999).

Guidelines vary according to country and mutation status. For individuals with LS, the American Cancer Society recommend a colonoscopy every 1-2 years, starting at age 21, until age 40 years, and then annually thereafter (Smith et al., 2002). In South Africa, individuals with LS are recommended to undergo endoscopic surveillance every second year, starting at age 16 until age 30 years, then annually thereafter (Anderson, Goldberg, Algar, Felix & Ramesar, 2007). In female patients, the endometrium and ovaries should also be screened annually as these tissues are the second and third most at risk for cancers involved in the LS spectrum (Lynch & de la Chapelle, 2003). However, despite being identified as

"high risk", a significant number of individuals with LS do not attend surveillance endoscopies at the recommended frequency; and this has been highlighted as an important problem, internationally (Geary et al., 2007; Hadley et al., 2004; Hughes Halbert et al., 2004; Wagner et al., 2005).

Barriers to Adherence to Screening Guidelines

A large number of barriers, both amongst individuals at increased risk for CRC and LS patients, have been identified in the (predominantly international) literature. Sociodemographic barriers, including a lower education, lower literacy rates, and a lower income or socioeconomic status (SES) have been identified. (e.g. Andrykowski et al., 1996; Davis et al., 2001; Doak, C., Doak, L., Friedell & Meade, 1998; Friedman & Hoffman-Goetz, 2007; Glanz, Grove, Lerman, Gotay & Le Marchand,1999; Gorin & Heck, 2005; Guerra, Dominguez & Shea, 2005; Jacobs, 2002; Kruger, 2005; Lerman et al., 1999; Smith & Croyle, 1995; Vernon et al., 1997; Wee, McCarthy & Phillips, 2005). In addition, psychological and physical barriers including anxiety over finding cancer, coping with other significant life events at the time of the required screening, a lack of motivation, a preference for avoiding threatening information, a fatalistic approach: "when you've got it you've got it, you don't get cured", embarrassment or shame relating to the procedure and to talking about CRC-related issues, and procedural (i.e. colonoscopy) related pain and discomfort have also been identified by the literature (e.g. Gorin, 2005; Greiner, Born, Nollen & Ahluwalia, 2005; Harewood, Wiersma & Melton, 2002; James, Campbell & Hudson, 2002; Johnson, Trimbath, Petersen, Griffin & Giardiello, 2002; Lasser, Ayanian, Fletcher & DelVecchio Good, 2008; McCaffery et al., 2001, p. 684; Pylvänäinen, Kairaluoma & Mecklin, 2006; Rawl, Menon, Champion, Foster & Skinner, 2000; Seeff et al., 2004; Viiala & Olynyk, 2008; Wagner et al., 2005; Zheng, Saito, Takahashi, Ishibashi & Kali, 2006).

Furthermore, practical barriers and barriers associated with access to information and services, including a lack of visits to one's healthcare professional, interaction between patient and healthcare professional characterised by less inclusion, collaboration and education regarding risk and screening guidelines, non- or only partial-disclosure within the family, financial costs, travel difficulties, and difficulties due to working fulltime, have been acknowledged (e.g. Donovan & Syngal, 1998; Hadley et al., 2004; Jacobs, 2002; James et al., 2002; Johnson et al., 2002; Koehly et al., 2003; McCaffery et al., 2001; Mesters, Ausems,

Eichhorn & Vasen, 2005; Rawl et al., 2000; Seeff et al., 2004; Viiala & Olynyk, 2008; Zheng et al., 2006).

The Health Belief Model

The Health Belief Model (HBM) is a psychological model that was developed by Rosenstock, Hochbaum and Kegels in the 1950's to explain and predict health behaviours and public participation in health screening and prevention programs (Rosenstock, Strecher & Becker, 1994). It consists of two constructs that relate to a health threat: (a) perceived susceptibility, which refers to an individual's perception of their risk of developing the disease considered to be the threat; and (b) perceived severity, which refers to an individual's perception of the seriousness of the condition or disease and its consequences. It also consists of two constructs that relate to a protective health action: (a) perceived barriers, which are an individual's perception of the factors that discourage the taking up of a promoted behaviour, that is the protective action; and (b) perceived benefits, which are an individual's perception of the positive outcomes of adopting the protective action (Rosenstock, 1966).

Often used in the literature pertaining to screening within CRC and LS in an attempt to explain non-adherence, the HBM recognises the importance of perceived barriers in predicting whether or not an individual will take a protective health action (Rosenstock et al., 1994). However, it also regards the other constructs as being important. In accordance with this, all of the HBM constructs have been associated with non-adherence to screening guidelines amongst individuals with LS (e.g. Bleiker et al., 2005; Hughes Halbert et al., 2004; James et al., 2002; Liljegren et al., 2004; Madlensky, Esplen, Gallinger, McLaughlin & Goel; 2003; Pylvänäinen et al., 2006) as well as amongst individuals at increased risk for CRC (e.g. Greiner et al., 2005; Harewood et al., 2002; Jacobs, 2002; Mack, 2008; McCaffery et al., 2001; Menon et al., 2003; Seeff et al., 2004; Shapiro, Seeff & Nadel, 2001; Weinberg, Turner, Wang, Myers & Miller, 2004; Zheng et al., 2006). Furthermore, it predicts that, for an individual to undertake a protective health behaviour such as CRC screening (even before they weigh the benefits against the barriers) they must first perceive that (a) they are susceptible to CRC, (b) CRC is a serious disease with severe consequences should they become ill, (c) screening prevents cancer, and (d) this benefit outweighs any of the perceived barriers mentioned above (Rosenstock, 1966).

The above prediction means that taking part in a protective health behaviour depends on one's knowledge and awareness of a health threat, as well as one's knowledge and

awareness of the availability of a beneficial course of action that would protect against that threat (Davis et al., 2001). In accordance with this, factors associated with a lack of knowledge of LS and CRC (threat) and of screening (protective health action) have also been found to be associated with non-adherence among individuals at increased risk for CRC. These include: (a) inaccurate or incomplete knowledge and awareness of LS and CRC; (b) not taking part in genetic counselling or testing; (c) a lack of knowledge or uncertainty regarding mutation status; (d) the lack of a healthcare professional's knowledge of screening guidelines or appropriate screening methods; (e) patient's lack of knowledge of screening; and (f) not taking part in, or being aware of, other health protective behaviours including other screening practices (e.g. Donovan & Syngal, 1998; Greiner et al., 2005; Hadley et al., 2004; Harewood et al., 2002; Jacobs, 2002; Johnson et al., 2002; Mack, 2008; McCaffery et al., 2001; Menon et al., 2003; Seeff et al., 2004; Shapiro et al., 2001; Viiala & Olynyk, 2008; Weinberg et al, 2004; Zheng et al., 2006) as well as among individuals with LS (e.g. Bleiker et al., 2005; Hughes Halbert et al., 2004; James et al., 2002; Liljegren et al., 2004; Madlensky et al., 2003; Pylvänäinen et al., 2006).

A Neuropsychological Approach

As stated, in accordance with the HBM, making the decision to take a protective health action, such as screening, is dependent on knowledge and awareness of both threat and protective action. While the acquisition of knowledge is dependent on one's exposure to information, when one *does* come into contact with information, one's capacity for attending to this information, understanding it, remembering it and being able to use it to one's advantage (viz. one's neuropsychological functioning) will ultimately affect the knowledge and awareness one obtains. Therefore, if non-adherence is related to a lack of knowledge, because the attainment of knowledge is dependent on neuropsychological functioning, it is possible that a lack of knowledge is associated with poor neuropsychological performance, which may then also be associated with non-adherence.

Attention. The ability to focus on certain stimuli or information (focused attention) and maintain that focus over a period of time (sustained attention) is essential in the attainment of new information for later recall, and use in the planning of behaviour (Ahles & Saykin, 2007; Arciniegas et al., 1999).

Doctor's rooms are filled with bookshelves of informational brochures which are often ignored, and even when brochures are given to patients directly by health professionals, not all are read. In addition, when instructions are given verbally, the messages are not always attended to by patients or their families because they are anxious, distracted, or confused. (Houts, Doak, C., Doak, L. & Loscalzo, 2006). Being knowledgeable about LS, and adhering to screening guidelines, is dependent on patients attending to the information they receive from their healthcare professionals. Therefore, a lack of attention may impact on adherence.

A lack of attention may also result in a memory deficit, producing differential recall of central and peripheral aspects of an event (Wessel, van der Kooy & Merckelbach, 2000). For example, Kessels (2003) found that patients tend to focus on diagnostic-related information and fail to register instructions on treatment. This can result in peripheral information, such as screening guidelines, being forgotten; while other information, such as a patient's potential risk of developing CRC, may be attended to and remembered more readily.

Working memory. Working memory refers to one's ability to focus and control attention, and to actively hold and process information in conscious thought (Engle, 2002; Insel, Morrow, Brewer & Figueredo, 2006). If one is not able to hold a sufficient amount of information, for example regarding the guidelines for cancer screening, in mind long enough to understand and remember it, it is unlikely that one will be able to create and achieve a goal-directed plan using this information.

Comprehension. Comprehension refers to the "process of interpreting the meaning of words or pictures to understand their collective meaning" (Houts et al., 2006, p.178). Quite obviously, a lack of understanding of information concerning the severity of CRC, one's susceptibility to the cancer, the availability and importance of screening, and how one might set about going for a colonoscopy, could negatively impact adherence to screening guidelines (Jacobs, 2002; Wakefield et al., 2007).

In addition, a lack of understanding may lead to misconceptions regarding CRC, LS and screening practices. It has, for example, been demonstrated that (a) some LS patients do not comprehend the meaning of their genetic test results and misunderstand their risk which can result in poor adherence (Aktan-Collan, Haukkala, Mecklin, Uutela & Kääriäinen, 2001b; Jacobs, 2002; Wakefield et al., 2007), and (b) screening adherence rates are higher among

those who correctly understand the preventative aim of screening (Brotherstone, Miles, Robb, Atkin &Wardle, 2006).

Memory. Influenced by both attention and comprehension, memory may be defined as either audioverbal (usually spoken information) or visuospatial (for example pictures). Furthermore, it can be recalled, where words or pictures are retrieved from memory, or recognised, where a judgement is made as to whether or not the items are familiar and have been presented on a previous occasion (Haist, Shimamura & Squire, 1992; Houts et al., 2006). Patients are often required to encode, store and retrieve information relating to both the threat and the protective health action, that was given verbally, without a prompt or cue (Insel et al., 2006; Kessels, 2003). Therefore, recall, particularly that of audioverbal information, is important within the context of CRC.

Forty to eighty percent of medical information provided by healthcare professionals is said to be forgotten immediately (Jansen et al., 2008; Kessels, 2003) with recall worsening over time (Lavelle-Jones, Byrne, Rice & Cuschieri, 1993). For example, Griffin et al. (2006) demonstrated that, at the end of a five year clinical trial, where participants had been receiving either a trial medication or a placebo, even the most basic of medical information, such as the main side-effect of the medication they believed they had been taking, is often not retained. This means that important information regarding risk and screening may not be remembered and, as a result, may influence non-adherence.

Executive functioning. The term 'executive functioning' refers to the "control system that manages other cognitive processes" (Ahles & Saykin, 2007, p. 194). It includes, among others, functions such as the ability to (a) inhibit automatic responses, (b) shift between rules, (c) perceive abstract categories and connections between concepts, and (d) problem solve (Jurado & Rosselli, 2007; Lehto, 1996). These functions all play a role in optimal adherence and have been associated with adherence to medication regimens in patient groups such as older adults and those with diabetes and human immunodeficiency virus (HIV; e.g. Bagner, Williams, Geffken, Silverstein & Storch, 2007; Insel et al., 2006; Wagner, 2002).

Inhibition and set shifting. Inhibition and set shifting are associated with attention. Inhibition refers to an individual's ability to sustain attention while suppressing a dominant or

automatic response. Set shifting refers to being able to switch between tasks, focusing one's attention on the relevant information (Friedman et al., 2006). Both of these functions may, therefore, have an impact on adherence by influencing which information, and how much of it, is attended to and absorbed by the patient.

Abstraction. Abstract thinking or reasoning, is a level of thinking that is removed from the "here and now" and rather "reflects on characteristics and relationships separate from the objects that have those characteristics or share those relationships" ("Autosomal dominant inheritance", n. d.). For example, when seeing a boy and a man, a concrete thinker will think of them as separate objects, whereas an abstract thinker will be able to perceive the connection between the two, that is the development of the boy to the man. Therefore, in terms of LS and CRC, a concrete thinker may not perceive the connection between a polyp and cancer, whereas an abstract thinker may better understand the relationship between a presymptomatic genetic change, pre-cancerous polyps and the development of cancer; and may therefore better understand the preventative aim of screening.

Problem solving. The ability to problem solve, a higher executive function somewhat dependent on the other executive functions described above, may be associated with adherence to screening guidelines due to the strategic planning, putting into action, and carrying out of plans, involved in screening (Insel et al., 2006). Strategies aimed at increasing adherence rates in paediatric asthma patients by targeting these functions have shown positive results (Bartlett, Lukk, Butz, Lampros-Klein & Rand, 2002).

In summary, attention, comprehension, memory and both the individual functions involved, as well as executive functioning as a whole, may therefore play an important role in how an individual attains, remembers and uses information, as well as what information was attained, remembered and used. It is clear, therefore, how this may have an impact on adherence to screening guidelines amongst individuals with LS.

Factors, Relevant within the Current Population, that have the Potential to Influence Neuropsychological Functioning, Resulting in a Deficit in Knowledge, and Potentially in Non-adherence

Various factors, such as sociodemographic, psychological and certain medical issues can impact on neuropsychological functioning. Therefore, factors that are relevant within the

current study's population (that of LS mutation-carriers of the Western Cape; WC) will be discussed in terms of their impact on a patient's neuropsychological functioning, their ability to obtain, retrieve and use knowledge, and their resultant adherent (or non-adherent) behaviour.

Sociodemographic factors. Sociodemographic factors, such as age, SES, and education can influence cognitive functioning, resulting in a deficit of knowledge, which may impact on adherent (or non-adherent) behaviour.

***Increased age*.** Much research has been conducted on the effects of aging on cognition, with memory and information processing speed having been the most widely researched topics (Grady & Craik, 2000; Hess, 2005; Salthouse, 1996). A reduction in processing speed leads to impairments in cognitive functioning. This may either be because items are not encoded adequately, or because items that are held in mind decay by the time they are needed for subsequent processing due to cognitive slowing (Bopp & Verhaeghen, 2005; Salthouse, 1996). It is clear how this can affect memory. However, not all aspects of memory are affected equally. Tasks involving (a) free recall, that is remembering previously learned information without a prompt, (b) prospective memory tasks, that is remembering to carry out an action at a future time, and (c) working memory, that is being able to keep information in mind and manipulate it, are aspects of memory most often (negatively) associated with aging (Grady & Craik, 2000). In contrast, procedural (remembering how to drive a car) and semantic memory (remembering facts such as the capital of South Africa) generally remain intact (Kessels, 2003).

In addition, age-related conditions such as sensory deficits (Baltes, & Lindenberger, 1997; Valentijn et al., 2005), health status, brain atrophy (Hess, 2005) and depression (Pálsson, Johansson, Berg & Skoog, 2000) can impact negatively on memory and cognitive functioning. Therefore, age-related declines in processes such as comprehension and memory may leave older adults at a disadvantage for managing tasks such as adherence to screening guidelines (Brown & Park, 2003).

Socioeconomic status. Access to information and health services, a pre-requisite for gaining knowledge of medical information, is often limited for poor communities, and rural populations are often further disadvantaged (Noor, Zurovac, Hay, Ochola & Snow, 2003;

Thiede, 2005). In addition, certain individuals, such as those of a lower SES, the less-educated, and the elderly, are *also* more likely to experience poorer communication from their healthcare professionals when they do come into contact with healthcare. Relationships with these groups are often characterised by low levels of joint decision-making, poor active listening on the part of the healthcare professional, less patient education, less rapport between patient and healthcare provider, as well as shorter consultations (Fox et al., 2009; Zere & McIntyre, 2003). As a result, the very patients who may benefit from additional education, in order to obtain better insight into their condition, actually receive poorer treatment than those who are more educated and in a better position to obtain health-related information (Adelman, Greene & Ory, 2000; Johnson, Roter, Poew & Cooper, 2004).

Level of education. As a result of difficulties associated with lower levels of education and poor literacy skills, individuals who are having difficulties in comprehending, sometimes guess their way through an instruction, or read so slowly that they miss information or reach an incorrect conclusion. They may also pay inadequate attention to new information while they "tune out", trying to understand something that was said earlier (Doak et al., 1998, p. 152). Furthermore, individuals with a limited education are often also concrete in their thinking, processing only the 'here and now', or concrete information, rather than being able to understand connections and relationships (Cousins, 1989; Greenfield, 1972). This could, therefore, further limit a patient's capacity to understand concepts such as premalignant polyps. Furthermore, individuals who cannot understand disease prevention information will be less likely to perceive a risk to their health and take part in preventative action (Friedman & Hoffman-Goetz, 2007).

Furthermore, concepts such as risk are often described in terms of percentages in cancer; and lay people, and the less educated in particular, frequently experience great difficulty in understanding numeric estimates of risk (Weinstein, 1999; Yamagishi, 1997). Yamagishi (1997), for example, found that people rated a cancer as more risky when it was described as killing "1286 out of 10 000 people" (12.86%) than when described as killing "24.14 out of 100 people" (24.14%), and suggests that perceived risk increases when risks are presented using larger numbers, and that people often misunderstand percentages. This may, therefore, have implications for risk comprehension and perceived susceptibility, and may impact on rates of adherence.

Quality of education. Quality of education, defined in terms of pupil/teacher ratio, and level of education of teachers, has been associated with performance on cognitive testing (Alcock, Holding, Mung'ala-Odera & Newton, 2008; Manly, Jacobs, Touradji, Small & Stern, 2002), as well as with a greater number of years of schooling, the probability of employment, and with mean earning rates later in life (Card & Krueger, 1992; Case & Yogo, 1999). According to the 2001 General Population Census, 32% of South Africans attained merely a Grade 7 (Standard 5) education (Aitchison & Harley, 2004). Therefore, the quality of pre- and primary school education becomes even more important. Research shows that children who attend high-quality preschools and primary schools, characterised by greater levels of preparation, and disseminated by better-educated teachers, go on to succeed in adulthood, both academically and socially (Darling-Hammond, 1999; Espinosa, 2003; Heyneman & Loxley, 1983). Therefore, not only quantity, but also quality of education may play a role in the relationship between cognitive functioning, knowledge and adherence.

Health literacy. The term 'literacy' refers to one's capacity to read, write and perform basic arithmetic skills (Kickbusch, 2001); and is said to affect all types of communication: written, oral and visual (Doak et al., 1998). While people at all literacy levels have problems understanding and remembering medical information, people with poor literacy skills are at a greater disadvantage as the spoken instructions, on which they rely so heavily, may also be affected (Houts et al., 2006). To make matters worse, doctors often use technical terminology and communicate in the same way with their patients as they would with their peers (Houts et al., 2006). The power and education imbalances that exist between patient and healthcare provider, and the fear of appearing stupid, can also result in the patient being reluctant to admit that they are having problems understanding the information with which they are provided (Houts et al., 2006). As a result, the patient may miss out on important information (Friedman & Hoffman-Goetz, 2007; Parikh, Parker, Nurss, Baker & Williams, 1996), producing a shortfall in knowledge and understanding of a topic, which could influence the adherent behaviour of these individuals.

Today's definition of literacy is gradually including a variety of skills needed in order to function in society. Many now include scientific, technological, cultural, media, computer, and health literacy in the definition. Health literacy can be defined as the "ability to read, understand and act on health care information" (Kickbusch, 2001, p. 292). Poor health literacy is common among patients in public hospital settings and patients with poor health

literacy have communication difficulties which may further affect health outcomes (Williams, Davis, Parker & Weiss, 2002). Although access to healthcare may be limited among poorer communities, inadequate health literacy, and ignorance of medical terminology, leaves these patients at a further disadvantage, as they are not able to comprehend the information and use the services that are available to their full advantage (Thiede, 2005; Williams et al., 2002).

Psychological factors. Factors such as anxiety and depression, in relation to learning about LS, CRC, or one's risk, can impact on one's neuropsychological functioning, mainly concerning the functions of attention and memory, resulting in a deficit of knowledge, which may influence the decision to take a health protective behaviour.

Anxiety: attentional narrowing and avoidance. Particularly within the realm of cancer and LS, where individuals discover that they are at high-risk for developing CRC, receptivity to information can be affected by stress or anxiety, as well as the emotional nature of the information (Doak et al., 1998). This can lead to attentional biases and poor processing of information (Kessels, 2003; Naveh-Benjamin, McKeachie & Lin, 1987; Wessel et al., 2000), as well as avoidance of threatening information (Dalgleish & Watts, 1990).

Attentional narrowing can occur if events are perceived as stressful, with the central (threatening) message of risk becoming the primary focus. This limits one's attention for peripheral (non-threatening) information, such as information on screening (Wessel et al., 2000). This 'less important' information is not processed and stored into memory and therefore cannot be recalled (Kessels, 2003), producing a discrepancy between the amount of central and peripheral information of an event recalled (Wessel et al., 2000). Because less attention is paid to some, as opposed to other, information, attentional narrowing may also impact on comprehension, as pieces of information may be missing, making understanding the full message impossible (Wessel et al., 2000). In a study looking at the information needs of men with prostate cancer, it was found that even though the patients had received information in pre-operative consultations, as well as verbal and written information post-operatively, they were unprepared for the symptoms they experienced, stating that they were "too anxious to retain information" during consultations or on the day of discharge (Echlin & Rees, 2002, p. 40). This led to important deficits in knowledge and discrepancies between what the patients really knew and what their doctors believed they knew.

Anxiety can also lead to avoidance of threatening information, resulting in either poor or a complete lack of memory (Dalgleish & Watts, 1990). Patients with LS have been found to prefer not to think about their possibility of developing cancer, particularly when they are asymptomatic, and avoid information on CRC (McCaffery et al., 2001). Avoidance of information can influence screening behaviour, as a deficit in knowledge may result in ill-informed decisions that impact negatively on adherence.

Depression: mood congruency and a lack of motivation. Depression is associated with low self-esteem and decreases in appetite, sleep, energy, concentration, motivation (Kronish et al., 2006; Sévigny, Everett & Grondin, 2003), a loss of interest in life, withdrawal from activities, family and friends (Bottomley, 1998), and impairments in neuropsychological functioning, predominantly in the areas of memory and executive functioning (Brand, Jolles & Gispen-de Wied, 1992; Degl'Innocenty, Ågren & Bäckman, 1998; Elliot, 1998; Pálsson et al., 2000). The neuropsychological dysfunction is hypothesised to be due mainly to psychomotor retardation, not being able to sustain one's attention for long periods of time, decreased concentration, and/or to a lack of motivation (Elliot, 1998; Pálsson et al., 2000).

Depression is frequently associated with a memory bias for negative mood-congruent information (Mineka & Sutton, 1992). Mood congruent memory refers to the tendency to recall information that is congruent with one's current mood (Watkins, Mathews, Williamson & Fuller, 1992), and research on depression and mood congruent memory has identified a strong bias to recall negative information (Mineka & Sutton, 1992). The speed of retrieval for these unpleasant memories tends to be positively correlated with the severity of depression, while the recall of positive information is slowed (Dalgleish & Watts, 1990). This has implications for screening, as the positive message of prevention may be lost if the individual is suffering from depression or a negative mood state.

Unlike risk factors, such as unhealthy diet, physical inactivity and smoking, possessing an inherited genetic mutation such as LS is something that cannot be altered by the individual at risk (Croyle & Lerman, 1999). This may lead to feelings of depression, hopelessness, fatalism and a lack of motivation (Hadley et al., 2003; Lerman et al., 1999; McCaffery et al., 2001). Within the context of LS, a fatalistic approach (the belief that some things in life, regardless of actions, are predestined to occur; Straughan & Seow, 1998) as well as cancer fatalism ("a belief that death is inevitable when cancer is present"; Powe & Finnie, 2003, p. 454), have been identified as barriers to adherence to screening guidelines

(Gorin, 2005; Greiner et al., 2005; Lasser et al., 2008). Fatalism may also diminish an individual's motivation to seek out preventative or positive information (Hadley et al., 2003; Lerman et al., 1999; McCaffery et al., 2001). Should they be exposed to information, however, this attitude can negatively impact on their capacity for attention, as what would be the point in listening to information on prevention if one believes that death is inevitable regardless of what one does to prevent it? This, in turn, may influence one's capacity for comprehension and memory of important information, producing a shortfall in knowledge, essential in maintaining adherence to screening guidelines.

Anxiety, depression and socioeconomic status. Furthermore, research has established an association between SES, anxiety and depression (Everson, Maty, Lynch & Kaplan, 2002; Vernon et al., 1997); and suggests that the effects of SES on psychological functioning are cumulative, with the greatest risk of psychological impact being among those who have experienced sustained hardship over time (Everson et al., 2002). SES, defined in terms of both education and income, has been associated with increased levels of anxiety (Parikh et al., 1996; Vernon et al., 1997), as well as increased levels of depression (Everson et al., 2002; Lorant et al., 2003); and Vernon et al. (1997) state that these associations are important as they have been known to impact on patient comprehension of diagnostic information, treatment recommendations, and on motivation for adherence to screening recommendations.

Medical factors. Finally, medical factors such as the genetic mutation associated with LS, CRC and its treatment; as well as aspects including the use of alcohol, drugs and medication, head injuries, epilepsy, infections, and strokes, can influence cognitive functioning. In turn, this may result in a deficit of knowledge, which may impact on adherent (or non-adherent) behaviour.

Lynch syndrome. The genes involved in LS, namely h*MLH1* and h*MSH2*, are expressed ubiquitously throughout the body, including the CNS. Hippocampal, cerebellum, striatum, substantia nigra and spinal cord involvement have been found in rat and mice studies (Belloni et al., 1999; Francisconi, Codenotti, Toninelli, Uberti & Memo, 2006). The impact of this involvement on cognitive functioning, and memory in particular, in LS patients, however, has not yet been studied.

Cancer. LS patients are at increased risk for various extra-colonic cancers including brain tumours (Lynch & de la Chapelle, 1999; Vasen et al., 2007; Watson & Lynch, 2001), and also possess a small risk of other cancers metastisising to the brain (Cascino, Leavengood, Kemeny & Posner, 1983), both of which may result in cognitive impairment.

However, cancer itself can impact on neuropsychological functioning, as demonstrated by cognitive deficits being present after diagnosis but before treatment (Vardy, Wefel, Ahles, Tannock & Schagen, 2008). Furthermore, non-CNS cancers, including that of the breast, ovaries, testes, oesophagus, gastrointestinal tract, kidneys and colon, have been shown to impact on the CNS and brain (Burton, Bullard, Walther & Burger, 1988; Dalmau, et al., 2008; Gultekin et al., 2000; Meyers, Byrne & Komaki, 1995; Tuma & DeAngelis, 2000; Wilkinson, Croft & Urich, 1967). These autoimmune phenomena, often referred to as paraneoplastic neurological syndromes, or as the remote effects of cancer on the nervous system, exclude any malignancies that invade, put pressure on, or metastasise to the CNS (Scaravilli, An, Groves & Thom, 1999). These phenomena can also not be explained by metabolic disorders, or the complications of cancer or cancer therapies (Norris, 1972). While they have been associated with an impact on cognitive functioning, some impact specifically on the limbic system causing deficits in memory due to hippocampal involvement (Burton et al., 1988; Gultekin et al., 2000), which may obviously have a detrimental impact on memory for information pertaining to CRC and screening, as well as adherence to screening guidelines.

Cancer treatment. Direct trauma, such as cranial surgery and/or radiation therapy can obviously have an impact on the neuropsychological functioning of a patient. However, the CNS is vulnerable to many of the treatments for cancer and to some of the medications prescribed for the complications of cancer treatments, and, these too, can effect cognitive functioning (Vardy et al., 2008; Wefel, Kayl & Meyers, 2004).

Treatments that stimulate cytokine production, such as the use of interferon and chemotherapy, affect the CNS and have been associated with a variety of symptoms, including a constellation of cognitive deficits in the areas of attention, memory, learning, information processing speed, and executive functions, collectively known as “chemo brain” (Capuron, Ravaud & Dantzer, 2001; Scheibel, Valentine, O’Brien & Meyers, 2004; Staat &

Segatore, 2005). This may therefore influence one's capacity to attain knowledge and make the decision to take a health protective action.

Other medical features pertinent to individuals of the Western Cape. In addition, various medical factors relevant within the current population have been associated with cognitive impairment in areas such as attention, memory, comprehension, and executive functioning. These include: (a) chronic and excessive use of alcohol and drugs, such as dagga (cannabis) and Tik (a methamphetamine; Harvey, Sellman, Porter & Frampton, 2007; Lundqvist, 2005; Nordah, Salo & Leamon, 2003; Solowij & Battisti, 2008; Vik, Cellucci, Jarchow & Hedt, 2004); (b) traumatic brain injuries as a result of car accidents, falls or assaults (Arciniegas et al., 1999; Strangman et al., 2005); (c) childhood epilepsy (Lagae, 2006); (d) infections affecting the CNS, such as meningitis, encephalitis (Hokkanen & Launes, 2000; Nau & Schmidt, 2007; Schmidt et al., 2006) and, common in sub-Saharan Africa, malaria, tuberculosis (TB) and HIV (Carter, Neville & Newton, 2003; Glass & Johnson, 1996; Kihara, Carter & Newton, 2006; Nau & Schmidt, 2007; Robertson et al., 2007); (e) anoxia/hypoxia, or reduced supply of oxygen to the brain, as a result of complications at birth or cardiac arrest (Garcia-Molina et al., 2006; Moulaert, Verbunt, van Heugten & Wade, 2009); (f) cerebrovascular disease and stroke (Reitz, Luchsinger, Tang, Manly & Mayeux, 2006; Roberts et al., 2008; Strachan, Frier & Deary, 2003); (g) the risk factors for stroke, including hypertension and diabetes (Elias, P., Elias, M., Robbins & Budge, 2004; Luchsinger et al., 2007; Reitz, Tang, Manly, Mayeux & Luchsinger, 2007; Strachan et al., 2003); and (h) medication such as anti-convulsants, anti-psychotics, anti-retrovirals, as well as anti-depressant, anti-anxiety, and psychotropic medications (Turjanski & Lloyd, 2005).

Motivation for Study

Early detection is currently one of the most effective means of successfully treating cancers. The identification of genetic predisposing elements provides a means of identifying individuals at high risk for CRC, even before CRC develops. Clinical (endoscopic) surveillance of such 'high risk individuals', in the form of colonoscopies, can result in the treatment of CRC in its early stage, or in its prevention. Therefore, within the context of LS, identifying individuals who are at high-risk of developing CRC and ensuring they enter an ongoing surveillance program is imperative. However, non-adherence to screening guidelines is a common problem; and it is important that a concerted effort is made to understand potential barriers and reasons for non-adherence, as well as to minimise these hurdles with the aim of reducing CRC morbidity and mortality.

A number of barriers to adherence to screening guidelines within LS and CRC have been identified. Although few interventions have been attempted within LS, strategies among a wide variety of other patient groups to reduce barriers similar to those pertinent to LS and CRC have not resulted in greater rates of adherence. As a result, some suggest that neuropsychological functioning may be the missing factor (Haynes & McKibbon, 1996; McDonald, Garg & Haynes, 2002). As reviewed above, a lack of knowledge (regarding a health threat, the severity of that threat, one's risk, the availability and importance of a health protective action, as well as its barriers and benefits) has been associated with non-adherence. Furthermore, deficits in neuropsychological functioning (in the areas of attention, comprehension, memory and executive functioning, that can be brought about by sociodemographic, psychological and/or medical factors) are known to play a role in influencing the knowledge an individual attains. Consequently, should a deficit in neuropsychological functioning be present, a patient's ability to make informed decisions, regarding taking a health protective action, such as screening, may be compromised, due to a lack of knowledge, and this could result in non-adherence.

Neuropsychological functioning has not been investigated within the context of non-adherence to screening guidelines among patients with LS previously. Therefore, the current study was an attempt to address this area not previously studied, by investigating the non-adherence of LS patients in terms of knowledge, neuropsychological functioning as well as the relationship between these variables.

Aims and Objectives

This study aimed to investigate the neuropsychological functioning and knowledge, pertaining to both threat and protective health action (in terms of the HBM), of individuals with LS in the WC. Furthermore, it aimed to investigate how these factors relate, both individually and in combination, to non-adherent behaviour. It is hoped that the insight gained may add an important new area of research within the context of screening adherence; and that addressing barriers associated with neuropsychological functioning may help to increase rates of clinical screening, resulting in a decrease in the rates of CRC morbidity and mortality.

The objectives included:

1. To investigate the neuropsychological functioning of individuals with LS.
2. To explore the level of knowledge (in terms of the HBM) of individuals with LS.
3. To observe whether trends exist that suggest potential differences between adherent and non-adherent LS participants, concerning their neuropsychological functioning and knowledge; and whether those are associated with non-adherence to screening guidelines.
4. To investigate whether non-adherence to screening guidelines is associated with neuropsychological functioning by means of an impact on knowledge.

Chapter Two:
Methodology

Introduction

This chapter is concerned with the methodological processes used to conduct this research study. Aspects relating to the research design, setting, sample, instruments used, procedure, data analysis and concepts pertaining to ethics and validity will be discussed in depth.

Research Design

This study employed a combination of quantitative and qualitative methods within an exploratory, phenomenological and cross-sectional design. As non-adherence has not previously been investigated from a neuropsychological perspective, an exploratory design was employed in order to strive toward increasing knowledge and insight in this specific area of investigation, rather than to ensure generalisability to a large population (Neuman, 1994).

An important purpose of phenomenological research is being able to describe what people experience as well as the meaning those experiences hold for them (Brink, 2006).This design was therefore appropriate for this study, as the experience of being given information on a health threat and protective health action, and the potential resulting influence on adherence, was described from the perspective of the individuals themselves, resulting in a deeper understanding of this phenomenon.

The study was also cross-sectional in design, as data was collected from each participant at one point in time, rather than across several points, as in longitudinal studies. As are often reasons for using this design, it was employed due to limited resources being available. The disadvantages are, however, that one cannot measure changes over time as with longitudinal studies (Brink, 2006).

Research Setting

The research setting was limited to accessible areas within the WC, taking time, travel and cost limitations into consideration (see *Figure 1*).

The WC is home to around one tenth of South Africa's 44 million residents. Agriculture, forestry, fishing, mining, quarrying, tourism, the farming of fruit and vegetables and the clothing and textile industry all contribute to its economy (Bradshaw et al., 2000).

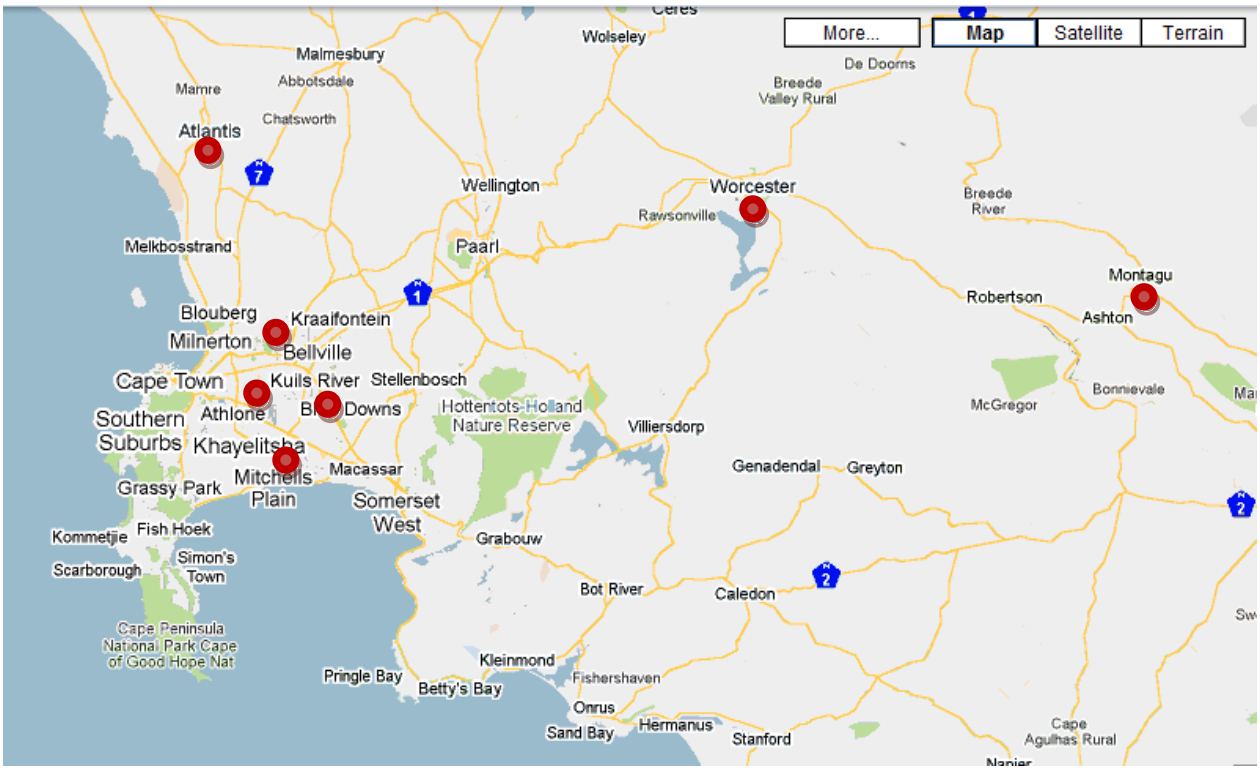

Figure 1. Map of part of the Western Cape showing the location of the towns or suburbs where the interviews took place. The red dots represent Atlantis, Durbanville, Kuils River, Bonteheuwel, Mitchells Plain, Worcester and Montagu.

As is usually preferable, the majority of the interviews were conducted in the homes of the participants, where the individuals were likely to feel more relaxed, and less inconvenienced (Neuman, 1994; Smith, Harré & Van Langenhove, 1995). A limitation of interviewing in the participants' homes, however, can be that privacy may be limited and that the physical surroundings may not be best suited to interviewing. Where the participants stipulated that they would prefer the interview did not take place in their home, the interview took place in a private room in one of the local Primary Healthcare Clinics in the area.

Study Population and Participants

Population. The participants of both the pilot and main study were selected from the LS Genetic Service database at the University of Cape Town, Division of Human Genetics. The database consists of 502 LS families, however, only individuals from families residing in the WC were selected.

Sampling method. The study employed non-probability sampling techniques in order to recruit the participants for both the pilot and main study. Convenience sampling was employed in order to select participants who were readily available and accessible for the study (Brink, 2006). This sampling technique was also selected due to time, travel, and cost limitations.

In addition, purposeful sampling was utilised in order to select participants who were either adherent or non-adherent and who were knowledgeable about the subject in question (Brink, 2006; Holloway & Wheeler, 1996; Pope & Mays, 1999). Adherent and non-adherent participants were defined as:

- **Adherent:** those who underwent colonoscopic screening at the frequency advised for South African LS patients (see p. 15), based on their age, since receiving their PGT mutation-positive result.
- **Non-adherent:** those who missed, without rescheduling within a year, one or more scheduled or recommended colonoscopies, based on their age, since receiving their mutation-positive result.

The researcher recognises that the characteristics of non-adherence may differ between those who have missed one colonoscopy and those who have missed ten. However, for the sake of simplicity in analysis, no distinction was made within the non-adherent group.

Eligibility criteria.

Inclusion criteria

1. Individuals identified as having received a mutation-positive result, and therefore required to attend regular colonoscopies
2. Individuals over the age of 18 (the age at which suspected LS patients may be tested and receive their genetic mutation result)
3. Individuals accessible for a personal interview
4. Individuals consenting to participate in this study

Exclusion criteria

1. Individuals with terminal stage cancer

The main aim of this study was to examine the reasons behind non-adherence from a neuropsychological perspective. There are many factors that can affect cognitive functioning, including (a) sociodemographic characteristics such as age, SES, level and quality of education, (b) psychological factors such as anxiety and depression, and (c) medical factors such as a heart attack, stroke, cancer, treatment for cancer, psychiatric disorder, head injury, current medication, alcohol, and substance use/abuse. It was, therefore, decided to rather document these variables than to exclude them, as these may be the very reasons for non-adherence in this population.

Selection process. The participants for both the pilot and main studies were selected by the colorectal cancer genetic counsellor (CRCGC), from the extensive database compiled by the Division of Human Genetics which includes data obtained from the Division of Surgical Gastroenterology at Groote Schuur Hospital (GSH). A record of attendance for surveillance is kept for each individual in the database. Adherent and non-adherent individuals were selected based on the eligibility criteria discussed above. Participants were then contacted via telephone by the CRCGC (who was known to the participants, unlike the researcher, whom they had never met) and invited to take part in the study. Once verbal consent was attained from the individuals, their names and telephone numbers were given to the researcher. She then contacted them telephonically, again discussed the background to the study and the approximate length of time of the interview process, determined if they were willing to participate, and set up the interviews at the convenience of the participants.

Total number of participants. Qualitative studies often involve smaller sample sizes, allowing for comprehensive in-depth interviewing, a deeper understanding of the phenomenon being investigated and information-rich data. The literature recommends using between 12 and 20 participants (Holloway & Wheeler, 1996). Therefore 16 participants (8 adherent and 8 non-adherent) between the ages of 21 and 63 years were enrolled in the study.

Reference group. The neuropsychological measures used, discussed in the next section regarding method and instrumentation, were developed in industrialised countries such as the United Kingdom and United States of America; and various studies have noted difficulties in interpreting the performance of individuals on tests that have been developed and standardised on different populations. This is due to differences in background such as

culture, language, level of education and experiences that may have placed them at risk of cognitive impairment, which can all affect neuropsychological test performance (Alcock et al., 2008; Roos et al., 2009). Because of this, once all the LS participants had been interviewed, their sociodemographic information was used to select normal healthy reference participants from the same greater population (that is of the WC). Their performance was used to better interpret the LS participants' performance on the neuropsychological measures. These reference participants were closely matched for gender, age, level of education and SES, but did not have a family history of CRC, or other LS related cancers, and therefore were not likely to possess the genetic mutation associated with LS.

The reference group was selected by the researcher, using the same sampling techniques, by visiting shopping malls and schools. The same ethical procedures were followed and they were invited to take part in the study and an interview time was agreed upon. The interviews took place in a private and quiet room at the place of their employment (13 of the 16) or in the reference participants' home (3 of the 16), and they only took part in the sociodemographic, psychological, medical and neuropsychological test component of the study, and not the interview on LS, CRC and screening.

Methods and Measuring Instruments

Interview schedule. An interview schedule, available in both English and Afrikaans, was created by the researcher based on the aims and objectives of the study as well as on previous research. This included: (a) the quantitative data regarding the sociodemographic, psychological and medical characteristics of the participants (see Appendix B) as well as the neuropsychological measures; and (b) the qualitative data, elicited by a structured interview, regarding the knowledge of participants concerning threat and protective action (see Appendix B). To help the participants feel more relaxed, the interview progressed from non-threatening to more sensitive questions.

As has been stated, the LS participants were questioned on both sections, while the participants of the reference group only completed the first section, that is the sociodemographic, psychological and medical details and neuropsychological measures.

Quantitative data.

***Participant characteristics*.** The sociodemographic details were recorded to describe the participants of the study. These included, but were not limited to (a) gender, (b) age, (c)

race/ethnicity, (d) level of education, (e) employment status, and (f) SES, based on combined household income per month (for the full list, see Appendix B).

The experience of anxiety and/or depression at the time of taking part in neuropsychological testing can impede one's performance on cognitive tasks. Therefore, measures of these variables were also included. Due to time limitations, the full scales were not used, however the researcher still wished to ask relevant and appropriate questions pertaining to anxiety and depression. Because of this, questions were adapted from well-known anxiety and depression scales, namely (a) the State Trait Anxiety Inventory (STAI) State part, a 20-item scale used to measure state (acute) anxiety (Spielberger, Gorsuch, Lushene, Vagg & Jacobs, 1983), and (b) the Center for Epidemiologic Studies-Depression (CES-D), a 20-item self-report scale designed to measure depressive symptoms in the general population (Radloff, 1977; see Appendix B for the adapted questions included). While no longer valid as tested and standardised scales, the adapted questions allowed the researcher to gauge an idea of the participants' current level of anxiety and depression via the use of questions, statements or words deemed appropriate for these variables.

With regards to anxiety, participants were asked to choose one of two statements that best described how they were feeling at that moment. The two statements consisted of words from the STAI State Part, and consisted of either items (a) demonstrating anxiety (e.g. tense, upset, frightened, nervous, indecisive, worried or confused) or (b) representing a lack of anxiety (e.g. calm, comfortable, relaxed, steady and content). Furthermore, with regards to depression, participants were asked to rate (from rarely [less than 1 day] to always [5-7 days]) how often they felt certain feelings in the past week. They were read five of the twenty statements pertaining to depression from the CES-D (e.g. "I was bothered by things that usually don't bother me"). A sixth statement, made by combining three of the scale statements ("I cried a lot and felt sad and depressed") was also used.

It was also important to note a prior history of any disease or disorder that may have resulted in cognitive dysfunction, so that the researcher was aware of them and their potential influence during the interpretation of the data. These included, but were not limited to (a) heart attack, (b) stroke, (c) cancer, (d) treatment for cancer, (e) psychiatric disorder, (f) head injury, (g) current medication, (h) alcohol, and (i) substance use/abuse (for the full list, see Appendix B).

Neuropsychological measures.

***Attention*.** Attention was assessed using the Digit Span forwards test from the Wechsler Memory Scale, 3rd edition (WMS III; Wechsler, 1997), which is often used in neuropsychological studies as a measure of attention (Nordahl et al., 2003; Rosen et al., 2003; Venkatesan, Selnes, Wojna, McArthur & Nath, 2006). The test involves the presentation of a sequence of numbers by the researcher, which the participant must then repeat back to the researcher in the same order. Attention is tested as the sequences presented become longer and longer; and the longest digit span was deemed representative of focused attention.

The participant is read two different trials per sequence length, allowing them a greater opportunity of completing the task, with scores ranging from 0-16. The forwards score is added to the backwards score (see working memory below) and a total attention score is calculated. This was deemed representative of sustained attention.

Working memory. This ability was assessed using the Digit Span backwards test from the WMS III (Wechsler, 1997), a well established test for working memory. Similar to the Digit Span forwards test, participants are presented with a sequence of numbers. However, in the backwards version, they are instructed to repeat the numbers back to the researcher in reverse order. Participants are therefore required to both hold information in mind, and to process and manipulate it, and are again presented with two different trials per sequence length. Scores can range from 0-14; and the participants receive a longest digit (backwards) sequence score.

***Comprehension*.** Five questions that have been designed to assess comprehension, and have been tested on both English-speaking and Afrikaans-speaking South African participants (Balchin, 2008, unpublished) were utlised. Examples of the questions include: "the cat was chased by the mouse, who did the chasing?", and "your mother's brother; what relation is he to you?". Participants could achieve scores ranging from 0-5.

Memory. The Babcock Story Recall Test, a well established test of audioverbal recall (and recognition) memory, was used for the English speaking participants (Lezak, 1983). If the participant requested that the test be administered in Afrikaans, the Township Brand Storie (Township Fire Story) was used. This is an equivalent version of the English story adapted for Afrikaans speaking participants; and has been tested and validated amongst

Afrikaans South Africans (Balchin, 2008, unpublished). These stories assess an individual's ability to encode, retain and recall information. Participants are asked to immediately recall the story just read to them, to recall it again after it is read a second time, to recall it after a delay, and to recognise information from the story with the use of standardised prompts. Scoring is based on 21 memory units and scores can range from 0-21.

Executive functioning.

Inhibition and set shifting. The Colour Word Interference Test, from the Delis Kaplan Executive Function System (D-KEFS; Delis, Kaplan & Kramer, 2001), was used as it is a good measure of executive functions such as impulsivity, disinhibition, set shifting and cognitive flexibility. Originally developed by Stroop (1935) to study the effects of verbal interference, the D-KEFS version is timed and includes two baseline conditions for evaluating the basic skills needed, that is naming and reading of words, for the higher-level tasks. The third condition measures inhibition and the participant is required to name the ink colour in which the word is written as quickly as possible, without making mistakes, while inhibiting the automatic response of reading the words denoting colours. On the fourth condition, the participant is required to switch back and forth between naming the ink colours and reading the words, again as quickly as possible without making mistakes. This condition is a measure of inhibition, ability to set shift and cognitive flexibility. Both the participants' completion time scores as well as the number of errors made are taken into account in the analysis of their performance.

Abstraction. The Twenty Questions Test, also from the D-KEFS (Delis et al., 2001), is an excellent test assessing an array of executive functions including abstract reasoning, the ability to perceive categories and sub-categories, the ability to formulate abstract questions that conform to particular rules, and the ability to incorporate feedback into one's performance. In the test, the participant is presented with a stimulus page including 30 pictures of common objects. They are told that the researcher has chosen one of those pictures and that they must ask the researcher the fewest number of questions, that may only elicit a "yes" or "no" response from the researcher, in order to identify the unknown target object. The 30 pictures can be divided into various categories, and subcategories, and since the participant has only 20 questions in which to identify the target picture, the most effective strategy is to ask questions that eliminate the maximum number of objects. Eliminating a

larger number of items reflects a high level of abstract thinking, while eliminating only one item reflects highly concrete, stimulus-bound thinking, and will result in the participant having to ask many questions to identify the target object. Participants obtain three scores pertaining to (a) the number of items eliminated by the first question, (b) the number of questions asked and (c) a weighted achievement score, which addresses the issue of guessing the correct option, with very few concrete questions, and obtaining an inflated total question score as a result. However, the number of items eliminated by the first question is deemed most representative of their ability for abstraction.

Problem solving. This ability was assessed by three verbal problems. The most well-known of these questions was that of the 18 Book Problem (Luria & Tsvetkova,1990) where participants are told they have 18 books and two shelves and must sort the books onto the shelves in such a way as to put twice as many books on one shelf as on the other. Scores ranged from 0-3.

Qualitative data. A structured interview was selected as it provided the researcher with the ability to obtain information, regarding their knowledge, from the participants. All participants were presented with the same questions. Closed-ended questions, that required a yes/no or specific response, were included and allowed the researcher to explore the participant's knowledge and understanding of threat and protective health action, as well as to gather information, such as the number of times they had missed a colonoscopy. Prompts were used where appropriate.

Ten categories of questions were included: (a) knowledge of health threat; or LS and/or CRC; (b) perceived severity; (c) perceived susceptibility; (d) knowledge of protective health action, or screening; (e) perceived benefits; (f) perceived barriers; (g) overall insight; (h) access to information; (i) psychological state at times of receiving information; and (j) the nature of the information. Further details regarding specific questions are reported before the presentation of the findings of each of the above sections.

Procedure

Participant observations. Observational sessions were undertaken in order to focus the research question, identify factors that could be relevant within this population group, and ensure the measurement instruments were appropriate and relevant. The sessions included

both a PGT session at GSH, where suspected carriers received information on CRC, LS and risk, as well an information session for oncology nurses, presented by an individual with LS who had undergone surgery to remove CRC.

Pilot study. A pilot study was conducted on two participants selected from the same population, using the same sampling techniques, eligibility criteria and selection processes and criteria as were used in the main study. It was used to (a) assess the suitability and appropriateness of the interview schedule (by determining if the items were understandable, unambiguous and accessible to participants), and (b) aid in approximating how much time would be needed to complete the interview.

It was found that the interview took approximately two hours to complete. The neuropsychological comprehension question, "Your father's sister; what is she to you?", was changed to "Your mother's brother; what is he to you?", due to language and cultural barriers. In addition, it was found that a number of questions pertaining to knowledge of threat elicited vague, uninformative and incomparable answers from participants. These included, for example, "If you think back to the very first time you came to the colorectal cancer department at Groote Schuur Hospital, do you remember why you came or why you were asked to come?", and "You received a lot of information in that first visit. Can you try to tell me everything you can remember being told?". Further review of the literature revealed different (more concrete and direct) questions that could replace these, such as, "What is colorectal cancer?", "Do you know what a 'polyp' is?", and "What is 'blood in the stool'?". This section was subsequently changed and the data gained from the two pilot studies was not included in the main study.

Data collection. The researcher travelled to various regions of the WC to collect the data (see *Figure 1* for a description of data capture location). This occurred between August of 2009 and March of 2010. The majority of the interviews (13 of the 16) were conducted in the homes of the participants. However, where the participants stipulated that they would prefer the interview did not take place in their home, the interview took place in a private room in one of the local Primary Healthcare Clinics in the area (3 of the 16, as well as the two pilot interviews).

The participants were given the information sheet and written consent was obtained. Following this, the participants were questioned regarding sociodemographic, psychological

and medical information and were administered the various neuropsychological measures, the answers to which were written down. They were then asked the questions regarding their knowledge of the threat and protective health action, and their answers were tape-recorded, with the participants' permission. Tape-recording enabled the researcher to generate a more complete record than hand-written notes would have allowed, by capturing the exact words of the interview. It also allowed the researcher to maintain eye contact with the participant, both of which are regarded as important in an interview setting (Holloway & Wheeler, 1996; Pope & Mays, 1999; Smith et al., 1995). All participants were asked the same questions and administered the same neuropsychological measures in the same order.

At a later stage these data were scored and transcribed by the researcher for analysis. The demographic information, neuropsychological test sheets and tapes were dated and labeled with the numeric participant code only, and were stored in a locked cupboard at the home of the researcher. The transcriptions and scored data (with numeric participant code only) was stored on the researcher's computer.

Data analysis. Both quantitative and qualitative data were elicited from the interview schedule.

Quantitative data. Descriptive statistics (i.e. frequencies and percentages) were used to describe the adherence, sociodemographic, psychological and medical participant data.

Many of the neuropsychological measures did not elicit comparable scores. Therefore z-scores were calculated for the normally distributed data to allow for a direct comparison of the performance of the LS participants on the different measures. Some data, specified within the results section, were corrected for normal distribution using LOG (100) transformation. Furthermore, because of the problems encountered when comparing the performance of South African participants with that of the international participants, on which the measures were tested and standardised, various tests were run in order to compare the performance of the LS participants with that of analogous, but non-LS, South African reference group. T-tests were run on the normally distributed data (and data corrected for normal distribution), and Cohen's d effect sizes were calculated. In addition, Mann-Whitney U-tests were run on the data not normally distributed (or data that could not be corrected using LOG transformation), and Vargha & Delaney's A, a comparative test of effect sizes for data that is not normally distributed, was calculated (Vargha & Delaney, 2000). The statistical tests were

performed using PASW Statistics (formally SPSS Statistics) version 18 (Polar Engineering and Consulting, 2009. Nikiski, USA).

Differences between the adherent and non-adherent LS participants were also compared. As this data was not normally distributed, Mann-Whitney U-tests were run, and effect sizes, using Vargha & Delaney's A, were calculated. While no claims are being made, the U-scores allowed for further description of both adherers and non-adherers as well as for the identification of trends that may be investigated in the future.

Qualitative data. The qualitative data concerning the knowledge of the participants was analysed using content analysis. This involved coding the qualitative data, regarding the knowledge of participants collected from the interviews, and organising it into conceptual frameworks in order to explain occurrences and identify common themes (Brink, 2006).

As opposed to analysis from the perspective of the researcher's preconceived hypothesis, verbatim transcription of the recorded interviews allowed for a greater efficiency of content analysis (Smith et al., 1995), and transcripts were read and re-read to identify and index the themes and categories. These were then examined by constant comparison where each item was checked or compared with the rest of the data to set up categories (Pope & Mays, 1999). The steps employed in this study included (Holloway, 2008):

1. Reading the data for meaning
2. Making sense of the data
3. Organising and ordering the data according to content
4. Describing and summarising the data
5. Dividing the data into segments
6. Coding (labeling or naming) sections of the data
7. Reducing (or collapsing) the codes to larger categories or themes
8. Searching for relationships between segments or categories
9. Reconceptualising the data
10. Searching for patterns

Following this, descriptive statistics (i.e. frequencies and percentages) were again utilised in order to describe the differences in knowledge between adherent and non-adherent participants as well as how that related to their neuropsychological functioning.

Assumptions

The researcher assumed that the responses of the participants were an honest and true reflection of their lives and feelings.

Reliability and Validity or Trustworthiness

Reliability refers to the accuracy of the research tool. The questions and prompts of the interview schedule were reviewed by experts in both the fields of LS and neuropsychology and were translated into Afrikaans. This was done to ensure that the questions were relevant, comprehensive and would be understood by all the participants.

Validity in qualitative research, also known as trustworthiness, is the extent to which the data and researcher's analysis accurately represents reality, as well as reflecting the aim or purpose of the study (Holloway, 2008; Neuman, 1994). Qualitative studies often obtain their validity from the meaningfulness and richness of their data and the thoroughness of their data analysis rather than the degree to which their results can be generalised as in quantitative research (Brink, 2006). The validity of the current study was established through:

1. An audit or decision trail: the researcher attempted to maintain transparency of the research method by providing a clear, detailed description of the methods and procedures (Holloway & Wheeler, 1996).
2. Peer debriefing and review: data analysis was verified by the supervisors to ensure minimal researcher bias in the interpretation and categorisation of the data (Brink, 2006; Holloway & Wheeler, 1996).
3. Member checking: interpretation of verbatim transcripts was checked with a sub-sample of participants to ensure the findings were not mis-interpreted (Brink, 2006; Holloway & Wheeler, 1996).
4. Thick description: all interviews were transcribed verbatim, ensuring an unbiased and complete account, recorded in the participant's own language (Brink, 2006; Holloway & Wheeler, 1996).

In addition to the above, Lincoln and Guba (1985) suggest the following four elements for demonstrating trustworthiness or validity within qualitative research.

Credibility. To establish credibility, the researcher ensured that the reality of the participants was presented accurately by using verbatim excerpts from their interviews

(Holloway & Wheeler, 1996; Lincoln & Guba, 1985). In addition, the researcher met with her supervisors on a regular basis to ensure that the data were interpreted accurately. As is often recommended (Brink, 2006; Holloway & Wheeler, 1996; Lincoln & Guba, 1985), portions of the interview (that is questions relating to 'knowledge of threat', 'perceived severity', 'knowledge of protective action', and 'overall insight') were also checked with a sub-sample (specifically adherers P6 and P8 and non-adherers P14 and P15) of the participants at a later date by telephone.

Transferability. The study's findings cannot be described as generalisable. Furthermore, due to the study's participants being able to speak and/or understand English, the findings may not be transferred to the purely Afrikaans or other (e.g. Xhosa, Zulu) speaking populations of South Africa. However, by describing the data as accurately and in as much detail as possible, the researcher strived to make the data understandable and recognisable by researchers in parallel situations or similar contexts (Holloway & Wheeler, 1996; Holloway, 2008; Lincoln & Guba, 1985).

Dependability. The study's consistency and accuracy was ensured through a decision, or audit trail, in which the researcher provided detailed descriptions of the methodology, so that readers could follow the decision-making process (Holloway, 2008; Lincoln & Guba, 1985). Furthermore, thick description and peer debriefing were used to create the opportunity for repeating the research and to ensure the accurateness of the research tools as well as the interpretation of the data.

Confirmability. The researcher ensured that the findings, conclusions and recommendations of the study were supported by the data, and that there was agreement between the researcher's interpretation and the actual data. This was achieved by obtaining confirmation of the researcher's interpretation of the meaning of statements with the participants themselves, and by checking the researchers' interpretation with her supervisors (Holloway & Wheeler, 1996; Holloway, 2008; Lincoln & Guba, 1985).

Ethical Considerations

This study maintained the ethical principles of participant autonomy, informed consent, anonymity, and confidentiality (Holloway, 2008).

Ethical approval. Application to the Research Ethics Committee of the University of Cape Town (Health Sciences Faculty) for ethical clearance was undertaken prior to commencing the study, and approval was granted with the project reference number: 318/2009. An amendment to the research protocol was submitted on 25 February 2010 with regards to the inclusion of the reference group and this was approved on 8 March 2010.

Confidentiality and informed consent. Because confidentiality is extremely important within a study involving genetics, the researcher did not have personal access to the database of LS patients, and all participants were first contacted by the CRCGC and invited to take part in the study. Once verbal consent had been obtained by the CRCGC and the patients had agreed for the researcher to contact them, the researcher contacted the LS patients by telephone and all participants were again asked if they would like to participate in the study, ensuring voluntary participation.

At the start of each interview, all participants were given an information sheet (see Appendix A) by the researcher, containing information on their voluntary involvement. They were made aware that they could withdraw from the research at any time without, in the case of the LS participants, it jeopardising any medical services, including genetic counselling and colonoscopic surveillance, offered to them or their families, should they choose to make use of them in the future. Written consent (see Appendix A) was obtained from all participants after they were given the opportunity to read the information sheet. Both the consent form and information sheet were available in English and Afrikaans, in accordance with the preference of the participant, and different forms, with specific information pertinent to LS or reference participants, were used.

Following this, all participants were asked for their permission for their sociodemographic, psychological and medical information, and their answers to the neuropsychological measures to be written down; and for the interviews to be tape-recorded. They were made aware that the tapes, and written information, would be kept in a locked cupboard until such time as they may be destroyed, five years after the completion of the study, to allow for publication requirements.

Following the interviews, a numeric coding system, known only to the researcher, was used to ensure all participants' anonymity and confidentiality. Further to this, all

identifying details were removed from excerpts, from the interviews, used to demonstrate particular responses.

Risk benefit. The participants were not asked questions that would raise highly emotional responses, however some chose to relate experiences that were sensitive or distressing in nature. Therefore, the researcher ensured that confidentiality and anonymity were maintained and was sensitive to the emotional state of the individuals. Where questions, or concerns, relating to LS were raised, participants were referred to the CRCGC.

The long term benefit of this study will be to use the information gained in order to (a) improve the genetic counselling process, (b) maximise surveillance adherence, and (c) decrease overall morbidity and mortality. This will be achieved by increasing the insight of the staff involved, as well as by supporting and educating the individuals who do not adhere to surveillance.

Limitations of the Study

The researcher recognises that no study can be devoid of limitations and acknowledges the following in the current study:

Limitations associated with the sample. Non-probability (non-random) sampling and the small sample size may have led to incorrect inferences and limited the transferability of the results. Key informant bias may have played a role as, due to the necessity of selecting a small number of participants who were able to understand and speak English and were knowledgeable about the subject in question, the view of these individuals may not be representative of the rest of the group. In addition, their language may have impacted on aspects such as their level and quality of education and employment status, which could influence their neuropsychological performance, their knowledge and understanding of the threat and protective action, and their resultant adherent or non-adherent behaviour. Participants may also have told the researcher what they thought she wanted to know and exaggerate their information (Holloway, 2008). Therefore, the accounts of these participants may not reflect reality. As questions regarding HIV status can evoke anxiety and discomfort (which may hamper both the interview and cognitive testing), participants were not asked this information. The LS participants' medical records were inspected for this data, but, in the majority of cases, it was not reported. This variable was therefore not included in the analysis

and interpretation of the neuropsychological performance of the participants, which represents a limitation. In addition, the full disclosure of other medical factors, such as the use of anti-depressants or a history of a psychiatric disorder may have been hampered by stigma or shame, again resulting in incomplete medical records of factors that may influence neuropsychological performance.

Limitations associated with the researcher. The researcher was aware that her social class, gender and race may have had an impact on the interview process. The researcher has had relatively little interviewing experience in the research setting and may not have had the necessary skills to identify all the verbal and non-verbal cues from the participants' responses. Thus, optimal probing might not have occurred. The researcher was not known to the participants and due to time constraints could not develop trust and rapport. Within a genetic study where patients with life-threatening genetic diseases often take several sessions to trust medical practitioners enough to discuss their experiences and feelings, this could be perceived as a weakness. The researcher may have made assumptions or demonstrated preferences of which she was not aware, thereby succumbing to researcher bias (Holloway, 2008). The researcher was not fluent in Afrikaans. Although the majority of the selected participants spoke Afrikaans as their first language, most were selected because they could also understand and speak English. This may not only have had an impact on the representativeness of the sample, but also on aspects such as level and quality of education and employment status of the participants. This could have impacted on their performance on the neuropsychological measures, their knowledge and understanding of the threat and protective action, as well as on their resultant adherent or non-adherent behaviour.

Limitations associated with the literature and study measures. A limited amount of literature on LS within South Africa was available. Therefore, much of the literature review pertains to international research. In addition, little research has been conducted specifically amongst LS patients. Therefore, much of the literature reviewed was conducted amongst individuals at increased risk for CRC, but not specifically due to an LS mutation. Caution therefore needs to be taken as these findings may not be transferable to a South African LS context. Most of the neuropsychological tests have been developed overseas and cultural, as well as language barriers, may therefore be a limitation. The interview questions were created by the researcher and, although checked by experts, may not have been fully

comprehensive. The participants were confronted with questions to which they previously may not have given much thought. Therefore, they may not have answered in an informed way. In addition, the study was dependant on self-reported data by the participants. As this can be unreliable, the study was vulnerable to such bias.

Strengths of the Study

While the above limitations are acknowledged, the present study also had a number of strengths. This study was the first of its kind and as a result the findings may be of considerable value in this field. Reference participants were used in order to interpret the performance of the study participants on the neuropsychological measures. The researcher conducted all interviews in person, and as a result had additional non-verbal information including tone that would not have been gained had a professional interviewer conducted the interviews. All interviews were transcribed by the researcher, allowing opportunity to insert and ascribe meaning to tone and non-verbal behaviour. While addressed in terms of a weakness, the fact that the researcher was not known to the participants could also be perceived as a strength, as it may have allowed the participants to speak more freely concerning their experience of endoscopic screening. Audio-taping of all interviews allowed for a more complete record than handwritten notes by the researcher. The interview schedule allowed for a large amount of data, which allowed for detailed understanding of the phenomenon. Finally, the interview schedule was presented to each participant in exactly the same way, with all LS participants being asked all of the questions, and this facilitated in minimising the influence of the interviewer, and in enabling a more objective comparison of results.

Chapter Three:
Findings and Discussion

Introduction

This chapter presents the reasons for non-participation in the study, the rates of adherence to endoscopic screening, as well as the sociodemographic, medical and psychological characteristics of the sample. In addition, it presents a description of the participants as a group, as well as differences between the adherent and non-adherent participants, in terms of their neuropsychological functioning, knowledge and the relationship between these two variables and non-adherence to screening guidelines. Within this chapter the eight adherent participants are referred to as P1 - P8; the eight non-adherent participants as P9 - P16; the sixteen matched reference participants as C1 - C16, with C1 corresponding to P1, C2 corresponding to P2 etc; and the researcher is referred to as R.

The findings presented below are preliminary data and should be interpreted with caution because of the small group sizes. However, the trends noted are important as they offer an idea of how the groups are performing for future research purposes or intervention.

Participation

All LS participants who were selected for this study had received their mutation-positive result and were, therefore, required to attend regular colonoscopies. They were all over the age of 18 and were accessible for a personal interview. As depicted below in Table 1, of those that provided verbal consent, 100% of adhering, compared with 72% of non-adhering, participants took part in the interview.

Table 1
Number of Adherent and Non-adherent Lynch Syndrome Participants who gave Verbal Consent Compared with the Number Interviewed for the Study.

Participants	Number providing verbal consent	Number interviewed
Adherent	8	8
Non-adherent	11	8

Note. Data presented are raw scores.

Of the three (non-adherent) participants who did not participate in the study, one was ill for the duration of three scheduled interviews and requested to withdraw from the study, one had

taken Tik (a methamphetamine) and declined to be interviewed, and one could not find a suitable time to be interviewed, despite being contacted on three separate occasions.

Only sixteen reference participants were interviewed as they were selected after the LS participant interviews had taken place, in order to match them according to gender, age, race, SES and level of education. Reference participants were also questioned on family history of CRC and other LS cancers and were not requested to take part in the study if such a history was reported.

Adherence Rates and Status

Adherence data was derived from the LS database and was taken from the year the LS participants received their genetic mutation-positive test result. To be deemed an adherer, the participant had to attend surveillance at the recommended frequency for South African LS patients (see p. 15) since the year of receiving their genetic test result. If a colonoscopy was missed, the participant needed to have rescheduled that appointment within a year. A non-adherer was any participant who had missed one or more scheduled, or recommended, colonoscopies since the year of receiving their genetic test result without rescheduling within a year. Non-adherence ranged from missing two out of seven, to missing six out of seven, recommended colonoscopies (see Table 2 below for adherence data, with the full data for each participant being represented in Table C1, Appendix C).

Table 2

Participant Adherence Rates from the Lynch Syndrome Database.

Surveillance method	Adherence %	
	Adherent (n = 8)	Non-adherent (n = 8)
Colonoscopy	100	43 (15-72)

Note. Data presented are average percentages with minimum to maximum range in parentheses. n = number of participants.

Participant Characteristics

Sociodemographic characteristics. The sociodemographic characteristics for each of the LS and reference participants are represented in Tables C2, C3, C4 and C5 (Appendix C), while the details for the groups are represented below in Table 3.

Table 3

The Sociodemographic Characteristics of the Lynch Syndrome and Reference Participants.

Sociodemographic characteristic	Adherers (*n* = 8)	Non-adherers (*n* = 8)	Total (*n* = 16)	Reference participants (*n* = 16)
Gender				
Male	4	3	7	7
Female	4	5	9	9
Age	36.4 (21 – 63)	40.5 (24 – 53)	38.5 (21 – 63)	38.5 (21 – 63)
Race/ethnicity				
Mixed ancestry	7	7	14	14
White	1	1	2	2
First language				
English	2	2	4	7
Afrikaans	6	6	12	9
Marital status				
Single	3	2	5	6
Married	5	5	10	6
Divorced	--	1	1	4
Participants with children	5	6	11	9
Number of children	2.2 (1 - 3)	2 (1 - 4)	2.6 (1 - 4)	1.6 (1 - 3)
Number of individuals in household	4.1 (3 – 6)	3.6 (2 – 5)	3.9 (2 - 6)	3.4 (1 – 6)
Level of education				
Primary school (Grade 7 or less)	1[a]	--	1	1
High school (Grade 8 - 12)	6	5	11	11
Tertiary education (diploma)	1	3	4	4
Years of education[b]	10.6 (3 - 14)	11.9 (10 - 14)	11.3 (3 - 14)	11.3 (5-14)
Employment status				
Unemployed	--	1	1	--
Full time employed	4	5	9	11
Part time employed	--	1	1	5
Housewife	2	--	2	--
Pensioner	1	--	1	--
Disability grant	1	1	2	--
Household income per month				
R801 – R1 600	--	1	1	1
R1 601 – R3 200	1	1	2	2
R3 201 – R6 400	4	2	6	6
R6 401 – R12 800	2	3	5	5
R24 601 – R51 200	1	1	2	2
Medical aid				
Yes	3	3	6	8
No	5	5	10	8

Note. The data on age, number of children and years of school attended are presented as averages with the minimum to maximum range in parentheses.

[a] = P8 obtained a Grade 3/Standard 1 education. [b] = Average years of education excluded pre-school and grade R, if they were present, and presumed the diploma to be a two year course.

The majority (87.5%; 14/16) of the participants in the study (with equal numbers of adherers and non-adherers) were of mixed ancestry, and although all could understand and speak a little English, 75% (12/16) of the LS participants (with equal numbers of adherers and non-adherers) spoke Afrikaans as their first language. There were slightly more females than males in the sample: 56.25% (9/16) of the participants were female. In addition, slightly more non-adherers (62.5%; 5/8), than adherers (50%; 4/8) were female.

The level of education was relatively high, with the majority (93.75%; 15/16) having attended high school. Four of these passed Grade 10 (Std. 8), three Grade 11 (Std. 9), three Grade 12 (Matric); and four, three of whom were non-adherers, went on to obtain a tertiary education. The average number of years of schooling attended was, therefore, lower amongst the adherers, than the non-adherers, by just over one year.

The majority (62.5%; 10/16) of LS participants were employed either on a full time or casual/ part time basis, with 60% (6/10) of this group being non-adherers. The SES of the LS participants appeared relatively high, with an average household income of between R6 526 and R13 300 per month. However, this is largely skewed by the two participants with monthly household incomes of between R24 601 and R51 200. When these are excluded, the average household income per month reduces to between R3 943 and R7 885, which had to support between two and six individuals.

The reference participants were matched closely to the LS participants of this study. Their genders, ages, ethnicities, and household monthly incomes were all precisely matched. However, their levels of education differed slightly (see Table C6, Appendix C, for the full data), but never by more than two years, and never when the difference would place the reference participant in a different category of education from that of the LS participant. For example, if the LS participant had a Grade 7 or Standard 5 education (i.e. primary school), but the reference participant had a Grade 9 or Standard 7 education (i.e. high school), they were not considered eligible. However, on average, this difference was equalised as is illustrated above.

Psychological characteristics. Participants were read two lists of words derived from the STAI (Spielberger et al., 1983) State type, one denoting feelings of anxiety and one the opposite, and were asked to state which best represented their current state. Anxiety was assumed to be present should they select the anxiety-related list of words. They were also asked to rate a number of statements relating to depression, derived from the CES-D

(Radloff, 1977). Recent feelings of depression were assumed to be present should they select three of the five statements and rate having experienced them three to four days or more that past week, or should they have selected four or more statements, but at a lower frequency. Furthermore, they were questioned on any past experience of depression and whether or not it had been diagnosed by a doctor. They were also questioned on how well they slept the night before.

As illustrated in Table 4 below (see Tables C7 and C8, Appendix C, for the full data), the majority (81.25%; 13/16) of LS participants neither felt anxious nor depressed at the time of the interview, although slightly less (62.5%; 10/16) reported having experienced a restful night's sleep. Similarly, the majority (93.75%; 15/16) of the reference participants neither felt anxious nor depressed at the time of the interview, and 81.25% (13/16) reported having had a restful night's sleep.

Table 4
The Psychological Characteristics of the Lynch Syndrome and Reference Participants.

Psychological characteristic	Adherers (*n* = 8)	Non-adherers (*n* = 8)	Total LS participants (*n* = 16)	Reference participants (*n* = 16)
Current anxiety				
Present	1	2	3	1
Absent	7	6	13	15
Current depression				
Present	--	3	3	1
Absent	8	5	13	15
Previous depression	2	4	6	2
Diagnosed by a doctor	1	2	3	1
Last night's sleep				
Restless/disturbed/ not enough	3	3	6	3
Sound/restful	5	5	10	13

Note. LS = Lynch syndrome.

Few participants reported a previous experience of depression, however, of those who had experienced depression in the past, LS participants (37.5%; 6/16) outnumbered reference participants (12.5%; 2/16) and non-adherers (50%; 4/8) outnumbered adherers (25%; 2/8).

Medical characteristics. The participants were questioned regarding various medical conditions, or incidents, that could impact on neuropsychological functioning, the findings of which are illustrated in Table 5 below (see Tables C9, C10, C11 and C12, Appendix C, for the full data). Not one of the LS or reference participants had had a heart attack, stroke, TB, childhood epilepsy, meningitis/encephalitis, a psychiatric disorder or malaria. Three LS participants, two of whom were non-adherers, had hypertension and a different non-adherer had diabetes (risk factors for stroke). In comparison, three reference participants had high blood pressure, two had high cholesterol and one had diabetes. Interestingly, LS participants were more likely to claim to be taking their medication daily. In addition to the above risk factors, 62.5% of LS (with equal numbers of adherers and non-adherers) and 37.5% of reference participants acknowledged smoking.

Table 5
The Medical Characteristics of the Lynch Syndrome and Reference Participants.

Medical characteristic	Adherers (*n* = 8)	Non-adherers (*n* = 8)	Total LS participants (*n* = 16)	Reference participants (*n* = 16)
High blood pressure	1	2	3	3
On medication	1	2	3	2
Taken regularly	1	2	3	1
High cholesterol	--	--	--	2
On medication	--	--	--	1
Taken regularly	--	--	--	--
Diabetes	--	1	1	1
On medication	--	1	1	1
Taken regularly	--	1	1	--
Cancer	3	4	7	--
CNS/brain	--	--	--	--
Treatment for cancer	3	4	7	--
Chemotherapy	1	--	1	--
Other (surgery)	3	4	7	--
Complications during pregnancy/birth	1	1	2	--
Head injury	1	--	1	2
Medication other than above	1	1	2	4
Alcohol	6	2	8	10
Smoking	5	5	10	6
Substance use	--	1	1	1
Dagga	--	1	1	1
Tik	--	1	1	--
Mandrax	--	1	1	--

Note. CNS = Central nervous system.

None of the reference participants had previously had cancer. Of the seven LS participants who had previously had cancer (57.1%; 4/7 of whom were non-adherers), none had previously had cancer affecting the CNS or brain. One adherer had received chemotherapy.

Two LS participants, one adherer and one non-adherer, stated that their mothers had experienced complications while giving birth to them (one participant had her cord wrapped around her neck and the other was “taken out with spoons”), and one adherer mentioned a car accident 10 years ago in which he briefly lost consciousness. In comparison, no reference participants reported complications during pregnancy or birth, but two had had head injuries.

None of the participants reported experiencing any lasting cognitive effects from these incidents.

One adherer and one non-adherer were taking medication at the time of their interviews, both taking Eltroxin for their thyroids. Seventy-five percent of adherent, 25% of non-adherent (that is 50% of the total LS participants), and slightly more (62.5%; 10/16) of the reference participants acknowledged drinking alcohol. No participants were suspected to abuse alcohol in large quantities. One reference participant smoked dagga, while one non-adherent LS participant acknowledged using other substances such as dagga (now and then), Tik (when he's stressed) and mandrax (regularly).

The Neuropsychological Performance of the Participants

The focused and sustained attention, working memory, comprehension, memory, and executive functioning of the participants was assessed, the findings of which are presented below.

The group as a whole. Neuropsychological functioning was investigated for its possible association with non-adherence. However, the differences in performance of the adherent and non-adherent participants could not be measured in isolation as both may be performing significantly below (the population, or reference group) average, indicating cognitive difficulties related directly to the biology of LS, rather than specifically to non-adherent participants.

The performance of the LS participants on the neuropsychological measures was compared with that of the reference group, using t-tests for data that was normally distributed (see Table D1, Appendix D) and Mann-Whitney U-tests for data that was not normally distributed (see Table D2, Appendix D). Because no presumptions were made, concerning a difference between the neuropsychological functioning of the LS participants in comparison with the reference participants, two-tailed p-values are reported. Z-scores were also calculated to standardise the normally distributed data in order to compare the LS participants' performance on each of the variables. These results are also illustrated in Table D1, Appendix D.

As anticipated, analyses showed no statistically significant differences between the performance of the LS participants and the reference group on any of the above measures. In addition, the performance of the LS participants, on all measures, was within the normal

range of the reference group. Furthermore, small effect sizes were found which indicate that the current findings are representative of the population and that similar findings would emerge from a larger sample. Because no homogeneous cognitive deficit, either general or specific, amongst LS patients, has been documented, this finding was expected and supports what is currently known on the subject.

Although the findings were not significant, the study is qualitative, and minor trends within the small sample sizes, which could be explored within a larger, quantitative study, are therefore worth noting. In accordance with this, and in comparison with the reference group, the LS participants performed slightly more poorly on the majority of tasks (focused and sustained attention, working memory and the majority of executive functioning tasks) with their worst performance being that of attention. Although they completed the inhibition and set shifting tasks more quickly than the reference group, the LS participants made slightly more errors, which is more representative of their performance. Therefore, their total performance for inhibition and set shifting was regarded as poorer than that of the reference participants.

The performance of the LS participants, on tasks of comprehension and memory, was equal to that of the reference participants. However, they performed better than the reference group on a task of abstraction.

The LS participants were closely matched to the reference group for sociodemographic variables including age, gender, SES and ethnicity. These factors were, therefore, unlikely to have resulted in these (insignificant) differences in performance between the two groups. However, the levels of education between the two groups differed slightly. The LS participants had a slightly lower average of total years of schooling (11.26 years versus 11.31 years, see Table C6, Appendix C); although this small difference is unlikely to account for their poorer performance. A difference in the quality of education, between the LS and reference participants, of those 11 years of education may, however, have influenced their performance on the neuropsychological measures. As has been reviewed, a higher quality of education has been associated with the probability of employment, earning rates and academic and social success in adulthood (Card & Krueger, 1992; Case & Yogo, 1999). In addition, quality of education has also been associated with performance on cognitive testing (Alcock et al., 2008; Manly et al., 2002). It is difficult to comment on the differences in quality of education between the LS and reference participants without an in-depth investigation into the schools attended by the participants and the

standard of education of those schools at the time. However, it is known that some South Africans, due to the Apartheid system, have been victim to marked differences in quality of education. Generally, individuals of mixed ancestry were marginalised and not afforded the same opportunities as white South Africans (Case & Yogo, 1999). The mean age of the participants was 38 years, and as new educational policies have only been adopted post 1994, the majority of participants would have been affected by these Apartheid policies or structures. Not unexpectedly, the white participants of the LS and reference groups performed better than the group means on all measures (except for comprehension where the white reference participants performed slightly more poorly than the group mean, $p = .483$). The white LS participants performed significantly better than the LS group mean for sustained attention ($p = .030$), working memory ($p = .024$), and abstraction ($p = .032$). The differences were also almost significant for problem solving ($p = .068$) and focused attention ($p = .081$). In contrast, the (LS and reference) participants of mixed ancestry performed more poorly than the group means on all measures (except for comprehension where the reference participants of mixed ancestry performed slightly better than the group mean, $p = .498$). As a result, one may tentatively posit that quality of education may be influencing the neuropsychological performance of the participants of this sample. It is therefore possible that should the LS participants have received an education of lower quality than the reference participants. This may account for their overall slightly poorer performance. The differences in performance between white participants and the previously disadvantaged participants of mixed ancestry may, however, also be due to other factors relating to, for example, SES. Therefore, once again, these findings should be interpreted with caution.

The participants also differed slightly in terms of first language, with 75% (12/16) of the LS participants but only 56.25% (9/16) of the reference participants noting Afrikaans as their first language. Although the neuropsychological measures were administered in Afrikaans, when requested, the fact that the researcher was not a first language Afrikaans speaker may have influenced the administration and explanation of the tests. This communication barrier could therefore explain the slightly poorer performance amongst the LS group.

Another explanation for the slightly poorer performance amongst LS participants may be associated with their employment status. While 62.5% (10/16) of the LS participants were employed on a full or part time basis, all (16/16) of the reference participants were employed, even though their combined household incomes were equal to that of the LS participants. Not

having to engage their cognitive faculties in work-related tasks on a daily basis may have resulted in the LS participants performing slightly more poorly on these neuropsychological measures. In accordance with this, of the three LS participants to perform the most poorly across the range of variables, none were employed (two were on disability grants and one was receiving a monthly pension). While, of the three LS participants who performed the best across all the variables, all were employed on a fulltime basis.

A third explanation may relate to anxiety and/or depression, which is known to hamper performance on cognitive testing. More LS participants (18.75%; 3/16) than reference participants (6.25%; 1/16) reported feelings of anxiety and depression at the time of the interview. In addition, double the amount of LS (37.5%; 6/16) than reference participants (18.75%; 3/16) acknowledged that they had experienced restless or disturbed sleep the night before the interview. Furthermore, 37.5% (6/16) of LS participants, in contrast to only 12.5% (2/16) of the reference group, reported having experienced depression previously, and 18.75% (3/16) of LS, in contrast to only 6.25% (1/16) of reference participants, said it had been diagnosed by a doctor. The experience of anxiety and/or depression may therefore have negatively influenced performance on the neuropsychological measures. In addition, because more LS participants appeared to have experienced these psychological factors, this may account for why the LS participants performed slightly more poorly than the reference participants.

While no conclusions may be drawn from these findings, the genes involved in LS, namely h*MLH1* and h*MSH2*, are expressed ubiquitously throughout the body, including the CNS; with their expression having been registered in the hippocampus, cerebellum, striatum, substantia nigra and spinal cord (Belloni et al., 1999). Therefore, although not yet studied in depth, the LS mutation in one or other MMR genes, which is important for integral cell function, may be associated with cognitive functioning. This could account for the LS group's slightly poorer performance on neuropsychological measures.

The other medical factors that may result in cognitive impairment, including current medication and alcohol and substance use, were comparable between the two groups. However, although none of the participants had had a cancer of the CNS, non-CNS cancers have also been shown to impact on the CNS and brain by way of an autoimmune response. Although more common in small cell lung cancer, autoimmune or paraneoplastic syndromes have been observed in systemic cancers such as that of the breast, ovaries, testes, oesophagus, gastrointestinal tract, kidneys, in leukemia, lymphoma and Hodgkin's disease as well as in

CRC (Burton et al., 1988 etc., see p. 28). Chemotherapy has also been shown to have an impact on cognitive functioning (Capuron et al., 2001; Scheibel et al., 2004; Staat & Segatore, 2005). In line with this, of the three LS participants who performed the most poorly across all the variables, all had had an LS cancer and one had undergone chemotherapy. In contrast, of the three LS participants who performed the best, none had had an LS cancer before, and, understandably, none had undergone chemotherapy. This finding may therefore indicate a trend that could be explored further in future research. However, these findings should be interpreted with caution due to a number of reasons, including (a) the small group sizes, (b) the mean age of the three poorest performing LS participants was 55.3, while the mean age of the three best performing LS participants was 43.6 (and increased age may have confounded the findings), and (c) the mean number of years of schooling of the three poorest performing LS participants was 7.6, while the mean number of years of schooling of the three best performing LS participants was 12.6 (and a lower level of education may have confounded the findings).

While the LS participants' performance was, in general across all the measures, slightly, *but not significantly*, poorer than that of the reference participants, they did perform slightly better than the reference group on a task of abstraction. One possibility for this finding is that they were simply better at perceiving abstract categories, formulating abstract questions that conformed to particular rules, and incorporating feedback into their performance, or that they better understood this task than the reference participants. However, when taking their general poor performance into account, it appears unlikely that they would perform better on one variable while they performed more poorly on all the rest, especially considering that this is an executive function and their performance on executive functioning, as a whole, was slightly poorer than that of the reference participants. This finding may therefore rather indicate an anomaly indicating the inappropriateness of this test for this particular population. In accordance with this, this measure was the least well understood of all the neuropsychological measures. Furthermore, although further instruction was requested by a number of participants, this was not given, as it had the potential of impacting on the test performance of the participants.

In conclusion, the LS participants performed similarly to the reference participants and no statistically significant differences between the two groups were found. These findings, therefore, support what is both known and expected and do not demonstrate any neuropsychological deficit amongst the LS participants of this sample.

Non-adherers compared with adherers. In order to investigate whether neuropsychological functioning in general, or a specific area in particular, was associated with non-adherence to screening guidelines amongst individuals with LS, the performance of the non-adherers on the neuropsychological measures was then compared with that of the adherers using Mann-Whitney U-tests. Because (a) the non-adherers were presumed to have less knowledge regarding CRC and screening, and (b) the attainment of knowledge is dependent on neuropsychological functioning, the non-adherers were expected to perform more poorly on the neuropsychological measures than the adherers. Therefore, one-tailed p-values, along with the rest of the findings, are reported in Table D3, Appendix D.

Statistical analyses revealed that the non-adherers completed the inhibition task slightly faster than the adherers (although this was not found to be significant; $p = .279$), and made significantly less errors than their adherent counterparts ($p = .026$). In addition, they took significantly less time than the adherers to complete the set shifting task ($p = .013$) and also made slightly fewer errors than the adherent group. Although this difference was substantial, it was not found to be significant ($p = .074$). In addition, although no further results of significance were found, minor trends were noted where the non-adherers performed slightly better on all remaining measures (including focused and sustained attention, comprehension and all executive functioning tasks). Small effect sizes were found for the majority of measures, except inhibition and set shifting (which were found to be significantly different among the adherers and non-adherers). This indicates that (a) similar findings would emerge from a larger sample, and (b) that large differences, concerning the executive functions of inhibition and set shifting, are likely to exist between adherers and non-adherers in the greater population. Because non-adherence has been demonstrated to be associated with knowledge, or a lack thereof; and because the attainment of knowledge is associated with neuropsychological functioning, this finding was unexpected and implies that non-adherence is not associated with poor neuropsychological functioning.

However, as expected, non-adherers performed slightly (but not significantly) more poorly on a memory task and slightly more poorly on a task of working memory, which could impact negatively on adherence. Possible explanations for these minor trends are explored below.

More non-adherers, than adherers, reported feelings of anxiety and depression at the time of the interview. Moreover, more non-adherers, than adherers, had experienced depression (both clinically diagnosed and un-diagnosed) previously. Therefore, these

psychological factors did not appear to account for the non-adherer's better performance. In addition, more non-adherers (50%; 4/8), than adherers (37.5%; 3/8), had previously had cancer. Therefore cancer, and the potential cognitive changes due to processes such as paraneoplastic syndromes, could not have accounted for the somewhat better performance demonstrated amongst the non-adherers on the neuropsychological measures.

In addition, while most medical details, including current medication, were comparable between the two groups, the only participant to have suffered a head injury was an adherer, and alcohol was more often used by the adherers (75%; 6/8), than the non-adherers (25%; 2/8). However, the adherer who suffered the head injury did not report any lasting cognitive effects and was one of the four best performing adherers on the neuropsychological measures. In addition, all of the four best performing adherers consumed alcohol. Therefore it is unlikely that either of these factors resulted in the adherer's slightly poorer performance on cognitive testing.

However, one adherent participant (P8) performed extremely poorly across all the neuropsychological measures (see Table E1, Appendix E). She (a) was the oldest participant in the study, (b) had the lowest level of education, (c) was currently receiving a pension but used to work as a housemaid, (d) had one of the lowest household monthly incomes, and (e) was the only participant to undergo chemotherapy. Furthermore, she performed significantly more poorly than the rest of the adherent group on working memory (p = .018), memory (p = .017), set shifting errors (p = .013) and abstraction (p = .046). In addition, her performance was almost significantly poorer than the adherent group on executive functioning (p = .054), inhibition errors (p = .051), and problem solving (p = .053). P8, therefore, appears to be a major contributor in accounting for why the non-adherers performed slightly better than the adherers. However, further analyses (see Table E2, Appendix E) revealed that removal of this outlier resulted in little change amongst the variables. The non-adherers still performed slightly better on the majority of measures. They also still performed more poorly on memory, and their scores for memory and working memory deteriorated even further, although did not become significant. Adherer P8's performance, therefore, does not appear to account for the general poorer performance of the adherers, or the slightly better performance of the non-adherers.

Lastly, neither increased age nor first language appear to account for the non-adherer's slightly better performance. However, a compelling explanation for the (statistically insignificant) findings appears to be found within the other sociodemographic variables. A

slightly greater number of non-adherers (62.5%; 5/8) than adherers (50%; 4/8) had a monthly household income of R6401 or more, the total number of years of schooling was higher amongst non-adherers than adherers, a greater number of non-adherers (37.5%; 3/8) than adherers (12.5%; 1/8) had a tertiary education, and a greater number of non-adherers (75%; 6/8) than adherers (50%; 4/8) were employed on a part or full-time basis. Therefore, greater opportunity due to a higher SES, greater education in terms of number of years of schooling, and greater opportunity to use one's cognitive functions on a daily basis may have resulted in the non-adherers' slightly better performance on the neuropsychological measures. Evidence for this statement is demonstrated by the following: of the four best performing adherers and non-adherers (a) 50% (2/4) of the adherers but 75% (3/4) of the non-adherers had a high SES, (b) none of the adherers but 75% (3/4) of the non-adherers had obtained a tertiary education, and (c) 75% (3/4) of the adherers but all of the non-adherers were employed.

While the non-adherers' performance was slightly better than that of the adherers across the majority of measures, they did perform slightly more poorly than the adherers on a task of memory. When adherer P8's significantly poor memory score is removed, the non-adherer's performance on memory worsens in comparison with that of the adherers. Although possible explanations within the current sample are worth exploring, these should be interpreted with caution as, the non-adherers' memory score was not significantly poorer than that of either the adherent or reference participants.

One possibility for a poorer memory score amongst non-adherers is that it represents an anomaly. Another is that the non-adherers of this group had poorer memories than their adherent counterparts, although the difference was not significant (p = .366, first analysis, with P8; and p = .197, second analysis, without P8). While they may not impact on neuropsychological functioning as a whole (thereby not impeding their overall performance), certain factors tend to influence memory in particular and may explain the poorer performance amongst the non-adherers of this sample on this specific variable. For example, increased age is known to impact specifically on memory (Bopp & Verhaeghen, 2005; Salthouse, 1996). In line with this, of the three participants to score less than 7 on the delayed recall task, all were over the age of 48 years. Because there were more non-adherers, than adherers, who were of an older age, this may have accounted for their poorer performance on this specific variable. Secondly, substances such as dagga and Tik have been shown to impact on memory, among other functions (Harvey et al., 2007; Nordah et al., 2003; Solowij & Battisti, 2008). The only participant to report use or abuse of such substances was a non-

adherer and was amongst the participants to recall less than the group mean on the memory task. This may, therefore, have contributed to the non-adherers' (as a group) poorer performance on this measure.

Thirdly, while having had a cancer did not appear to affect their overall performance, it is of interest to note that of the five participants (one adherer and four non-adherers) to score less than the mean score of 13, four had previously had cancer. Though no conclusions may be drawn, autoimmune responses such as paraneoplastic syndromes, which can result in a specific impact on the limbic system, causing deficits in memory due to hippocampal involvement (Burton et al., 1988; Gultekin et al., 2000), could potentially account for this finding.

Fourthly, no participant had experienced a stroke, which may obviously have implications for cognitive functioning. However, a greater number of non-adherers (25%; 2/8) than adherers (12.5%; 1/8) reported having hypertension; which has been reported, without a stroke having taken place, to be associated with cognitive impairment, particularly that of memory (Elias et al., 2004 etc., see p. 29). Hypertension, therefore, may also have contributed to the non-adherer's poorer performance on memory. In accordance with this, of the five participants to score less than 13 on the memory task, two had hypertension and were on medication.

Furthermore, while anxiety affects mainly attention, depression has been shown to impact negatively on memory (Brand et al., 1992 etc., see p. 26). A greater number of non-adherers (37.5%; 3/8), than adherers (0%; 0/8), reported feelings of depression at the time of the interview, and a greater number of non-adherers (50%; 4/8), than adherers (25%; 2/8) reported previously experiencing depression during their lifetime. In line with this, of the five participants to perform the most poorly, one (20%) reported experiencing depression at the time of the interview and two (40%) reported a previous experience of depression. Experience of depression may, therefore, also have accounted for why the non-adherers of this sample demonstrated slightly poorer recall memory.

Finally, although all the participants, adherent and non-adherent, carried the genetic mutation associated with LS; the genes involved (h*MSH2* in particular) have been found to be expressed in neurons in several areas of the rat brain including the hippocampus (Belloni et al., 1999). In addition, a lack of h*MSH2* (thereby simulating the LS mutation and defects in the repair or in response to DNA damage) has been associated with hippocampal neuronal loss in mice (Francisconi et al., 2006). Studies amongst (human) LS patients, concerning the

impact of observations in animal models, on memory (a function, in part, dependant on the hippocampus), do not appear to have been conducted yet. However, as a sub-group of LS participants of this sample (i.e. the non-adherers) performed slightly more poorly on memory, this could be both (a) a tentative explanation for the findings, and (b) an area of interest for future research pertaining to the reasons behind non-adherence. However, again, caution is urged in interpretation of these suggestions.

In conclusion, the non-adherers appeared, if anything, to perform slightly better than the adherers on the majority of neuropsychological measures. These preliminary findings, therefore, appear to suggest that poor neuropsychological functioning, in general, is not associated with non-adherence to screening guidelines amongst LS patients.

The Knowledge (in terms of the Health Belief Model) of the Lynch Syndrome Participants

The participants were questioned on their knowledge in terms of the four constructs of the HBM (i.e. perceived severity, susceptibility, benefits and barriers). However, because (a) two of the HBM categories pertain to threat and two to protective health action, and (b) various studies have found that knowledge of threat and knowledge of protective action are associated with non-adherence, the participants were also questioned on various aspects pertaining to LS, CRC and screening.

While each knowledge category and sub-category was analysed in terms of the same variables, only those that appeared to demonstrate a correlation were reported.

Knowledge of terminology. The terminology or language used by healthcare professionals has been shown to present a significant barrier to patients (Williams et al., 2002). This study's participants were asked about a number of terms relating to CRC and screening. However, during the interviews it was evident that, while they were able to relay their knowledge, when the terms or concepts were explained to them; when the words or terminology used were unfamiliar to them, they presented substantial barriers to communication. Therefore, although not a sub-category of the HBM, knowledge of terminology emerged as a theme or knowledge category in itself, the findings of which are represented in Table F1, Appendix F.

***The group as a whole*.** Supporting the findings of previous research, knowledge of terminology in this sample was poor. Although only two participants (12.5%; 2/16) did not know the meaning or had not heard of any of the terms discussed above, only three (18.75%; 3/16) were able to describe six, and only one (6.25%; 1/16), a 52 year old adherent female, all seven of the terms.

The lack of knowledge of the terms 'pre-malignant' or 'pre-cancerous polyp' and 'screening' or 'surveillance' was consistent with that of other findings amongst patients at increased risk of developing CRC (e.g. Brotherstone et al., 2006; Davis et al., 2001). These terms, and the terms 'Lynch syndrome' or 'Hereditary Non-polyposis Colorectal Cancer' and 'predictive genetic testing', were the four most poorly understood terms. Although the participants could understand and speak English, 75% (12/16) of participants listed Afrikaans as their first language. Furthermore, although the interview was conducted in Afrikaans and the correct terminology was checked with the CRCGC, the researcher was English and this may have presented a communication barrier. In addition, although the correct terms were used, the CRCGC may use descriptions and explanations in conversation more than terminology, particularly as terms such as 'Lynch syndrome' and 'HNPCC' are translated from English. The Afrikaans speaking participants may therefore have been at a disadvantage, having had less exposure to the terminology being investigated. In accordance with this, of the two participants unable to describe any of the terms, both spoke Afrikaans as their first language.

Moreover, while some terminology is commonly used, others, such as the four above, are not, and colloquial or more simple words may be favoured. It is therefore possible that the participants of this sample simply did not come into contact with these terms. In accordance with this, of the three participants who were able to describe at least three of these four terms, 66.6% (2/3) had attended tertiary education. Therefore (a) better literacy skills, better health literacy, superior comprehension abilities, a greater ability to perceive and understand abstract concepts, such as hidden or premalignant polyps, (b) more exposure to more technical terminology, and (c) being educated by the CRCGC at a higher level, due to her perceptions regarding their level of education, and capacity for understanding may all have influenced their knowledge of terminology.

However, in contrast to previous research, the terms 'polyp' and 'pre-cancer', along with 'blood in the stool', were amongst the three best described terms. As stated, little research investigating knowledge of terminology was found within LS patient groups and the

literature that found these terms poorly understood was based on individuals at increased risk for CRC. It is therefore probable that individuals at high risk and with a strong family history of CRC (due to a genetic mutation) would be more knowledgeable regarding its associated terminology. In line with this, of the eight participants able to describe at least two of the three best described terms, 50% (4/8) had had a personal cancer related to LS, 75% (6/8) had experienced the death of a family member and 50% (4/8) the death of a parent due to CRC. Greater exposure may have resulted in greater knowledge concerning these terms which are, of all the terms investigated, the most often associated with cancer.

In addition, of the participants who were able to describe at least two of the three terms investigated, 37.5% (3/8) had said that they were anxious when initially given information on LS, CRC and their risk, and 100% (8/8) acknowledged a high perceived severity. While anxiety can cause attentional narrowing (where peripheral information is attended to less than central, more threatening, information) and avoidance of information, it could also result in patients paying more attention to terms associated with the detection of cancer such as polyp, pre-cancer and blood in the stool. In line with this, 50% (4/8) and 25% (2/8) listed detection as an aim and benefit of colonoscopies respectively.

In conclusion, the knowledge of the LS participants concerning terminology was poor with only 18.75% (3/16) being able to describe six of the seven terms investigated, and 12.5% (2/16) not being able to describe a single one.

***Non-adherers compared with adherers*.** More adherers (37.5%; 3/8), than non-adherers (25%; 2/8), were consistently able to give good descriptions of three or more of the concepts investigated. However, more non-adherers (75%; 6/8), than adherers (62.5%; 5/8), knew at least two of the terms. But, although this was the case, 75% (6/8) of non-adherers had still only heard of two; and, therefore, demonstrated poor knowledge of the terminology associated with CRC and screening. Little research appears to have been conducted specifically regarding knowledge of terminology and non-adherence. However, this finding appears to be consistent with that of previous studies, suggesting an association between lack of knowledge of threat and/or protective action and non-adherence.

A lack of exposure to information and terminology due to less experience of personal cancer does not appear to account for the non-adherer's lack of knowledge, as a greater number of non-adherers (50%; 4/8), than adherers (37.5%; 3/8), had survived a personal cancer. However, not meeting with their doctors and genetic counselors on a regular basis,

due to not attending colonoscopies, might account for their lack of knowledge of terminology. In accordance with this, non-adherers displayed far less detailed knowledge concerning colonoscopies and presented far greater barriers to screening than did adherers.

Another possible explanation may relate to age. More non-adherers were in the older age group, ranging from 45 to 63 years. Younger individuals such as adherer P5 may be enthusiastic and want to learn more:

R: Does the thought of colorectal cancer scare you?

P5: Not really, because the first time they told me I was excited. I wanted to see that scan and things. For me it was like great. And you drink that stuff... (26 year old adherent male)

"And they lift you and move you as they're going through your colon. They look on the screen [excited gasp] I've seen my colon! [smile]." (P4; 26 year old adherent female)

"I like to watch sometimes, and then they just moving it and you can feel it in your stomach when they move it around." (P5; 26 year old adherent male)

In contrast, older individuals may 'just want to get on with it'.

"I don't take anaesthetic, because to me, it's a schlep. And he is so good that he can do it without causing too much discomfort, so I normally go there and I just have it done. 'Cause then I don't have to hassle about the whole can't drive story and whatever." (P6, 52 year old adherent female)

This may translate into younger individuals being more receptive to the terminology used, while the older individuals are not. This may result in the non-adherent (older) group appearing less knowledgeable. Alternatively, as increased age is associated with deficits in memory and information processing (Grady & Craik, 2000), it is possible that the terminology could, therefore, have been forgotten by the (older) non-adherent group.

In addition, while the sample as a whole did not tend to seek out additional information, non-adherers (12.5%; 1/8) were far less likely than adherers (50%; 4/8) to contact the CRCGC at a later stage for more information. They may also have been less inclined to ask questions or get clarification on terminology that they did not understand when they did have contact with her. Therefore, these initial deficits in understanding may have persisted and could have resulted in the non-adherers' greater lack of knowledge regarding terminology associated with CRC and screening.

In conclusion, the findings of this additional category of knowledge may suggest an association between a lack of knowledge of terminology and non-adherence.

Knowledge of the threat. Previous studies have found that the knowledge of patients at increased risk for CRC is generally poor (e.g. Harewood et al., 2002; Kim, K., Yu, Chen, Kim, J. & Brintnall, 1998; Yepes-Rios, Reimann, Talavera, A., de Esparza & Talavera, G., 2006). However, the knowledge of patients who are not adherent to recommended screening guidelines has, on occasion, been found to be worse. Research has reported an association between lack of knowledge of health threat (e.g. CRC) and non-adherence to screening guidelines amongst individuals at increased risk for CRC (e.g. Greiner et al., 2005; Harewood et al., 2002; Menon et al., 2003; Yepes-Rios et al., 2006; Zheng et al., 2006), as well as amongst individuals with LS (Madlensky et al., 2003).

Based on the above research, and on the HBM, the current participants were questioned on relevant concepts relating to the health threat. The following categories emerged from the interviews: knowledge of (a) LS, (b) CRC, and (c) how CRC develops.

***Knowledge of Lynch syndrome*.** Some studies have investigated the accuracy of LS individuals' recollection of their mutation status (e.g. Aktan-Collan et al., 2001b; Claes, Denayer, Evers-Kiebooms, Boogaerts & Legius, 2004; Wakefield et al., 2007). However, no studies were found that explored the knowledge pertaining to LS of patients with this genetic mutation, or their understanding of what the mutation means. When examining awareness of threat, they have rather focused on knowledge of CRC. However, inaccurate or incomplete knowledge of threat has been associated with non-adherence. Therefore, a patient's understanding of the concept of the genetic mutation is relevant to include within a study investigating knowledge of threat. The findings are illustrated in Table F2, Appendix F.

The group as a whole. Because when asked, 62.5% (5/8) of adherers and all (8/8) of the non-adherers, had either not heard of this term or did not know to what it referred, the question was rephrased by asking, "Can you tell me everything you know about going for the blood test where they looked for the gene?". Some participants still demonstrated difficulties with this question, or concept. Participants previously diagnosed with cancer had blood taken every time they went for a check up and, thus, knowledge concerning the 'blood test', and the reasons behind it, were often confused amongst some of these individuals. Four participants

(adherers P7 and P8, and non-adherers P14 and P15) in particular, demonstrated difficulties with this question, as evidenced by the following answers:

"Um.... It's actually where they also test the blood...to see if also there is cancer." (P14; 48 year old non-adherent female)

"They find if there's some more cancer. If there's some more, or if there's nothing, or what." (P8; 63 year old adherent female)

P15: It's important to go so they know there's no other cancer in your body, that I'm not affected again with the cancer.

R: Do you always have a blood test when you have a colonoscopy?

P15: Yes, I always have a blood test when I go. (51 year old non-adherent female)

These participants were aware that the disease "runs in the family" or is a "family issue" and, therefore, displayed knowledge of the hereditary nature of the mutation. However, they were unable to offer additional information regarding the genetic mutation or what it means, and were excluded from the analysis.

Of those to answer the question, few gave accurate descriptions of LS (in terms of non-polyposis CRC), although the majority were able to describe its implications. Because no previous research was found investigating people's understanding and knowledge of LS, the accuracy of these descriptions could not be compared with that of the literature. In discussion with experts on the subject in question, however, the descriptions identified were accurate and included important aspects relating to the LS genetic mutation.

The most often cited explanation was the fact that LS runs in the family, is a "family sickness" or is hereditary. This explanation made up 27% of all suggested explanations, and was suggested by the majority (83.3%; 10/12) of participants. This was followed by the suggestion that LS means you can get cancer (which made up 18.9% of all suggested explanations and was suggested by 58.3% [7/12] of participants). It is of interest to note that, of the participants to put forward this suggestion, only (a) 42.86% (3/7) had survived cancer personally, (b) 42.86% (3/7) had experienced the death of a family member, and (c) 28.57% (2/7) the death of a parent. Experience of cancer, therefore, does not appear to explain why this factor was important amongst this sub-group of participants. However, of these same participants, 57.14% (4/7) said that they were anxious initially when receiving information on LS, CRC and their risk, 85.71% (6/7) had high perceived severity, and, of the three

participants to have high perceived susceptibility, two described LS in terms of the potential for developing CRC. Worrying about cancer and the seriousness of the disease may, therefore, account for why this explanation of LS was offered.

Finally, the third most popular explanation was that having LS means you must go for colonoscopies (making up 13.5% of all listed explanations, being suggested by 41.66% [5/12] of participants). Of those who suggested this explanation, (a) 80% (4/5) had either never missed or had missed less than 50% of their recommended colonoscopies, possibly accounting for why this explanation was important amongst this sub-group, (b) 80% (4/5) were female and, as will be discussed in depth later in this chapter, were perhaps more knowledgeable regarding screening, (c) 80% (4/5) had a high SES (of R6401 or more combined household income per month), perhaps allowing them greater opportunity to concentrate on stressors that are deemed to be of a lower priority than providing for one's family, and (d) all had a high perceived severity, which may, too, account for why attending colonoscopies regularly is important to these particular participants.

In conclusion, knowledge of LS among the LS participants was poor with very few participants being able to give good descriptions of LS.

Non-adherers compared with adherers. Although two non-adherers did offer comprehensive descriptions as to what LS is, only adherers (P4, a 26 year old adherent female, and P6, a 52 year old adherent female) were able to accurately describe its characteristics. In addition, slightly more explanations were suggested by adherers (51.4%) than non-adherers (48.6%). Furthermore, it is pertinent to note that more adherers (37.5%; 3/8), than non-adherers (25%; 2/8), stated that having LS means "you need to go for colonoscopies". Therefore, although not specific to knowledge of LS, the present findings appear to support those that found an association between lack of knowledge of threat, in general, and non-adherence to screening guidelines.

In addition, when participants were questioned on a possible risk for other cancers due to LS, 75% (6/8) of adherers as opposed to 37.5% (3/8) of non-adherers were correct in thinking that LS mutation-carriers are at risk for other cancers, suggesting possible cancers such as "uterus" (P3), "breast" (P3 and P10), "skin" (P10 and P11) "liver" and "head" (P11). Furthermore, more adherers (50%; 4/8), than non-adherers (37.5%; 3/8) thought that they should participate in other types of screening practices, suggesting tests such as "Pap smears" (P3, P4, P6 and P14) and "mammograms" (P4, P6, P12). Additional findings of interest

included the fact that: (a) only one participant (P4, a 26 year old adherent female) was absolutely certain of having a risk for additional cancers; (b) there was only one participant, P2, a 22 year old adherent male, who believed that LS mutation-carriers are only at risk for CRC and that they need only participate in colonoscopic screening; (c) although "uterus" was suggested, no specific mention was made of "endometrial cancer" or "ovarian cancer", of which, as previously reviewed, the females of this population have an increased risk; and (d) of the five participants to suggest other types of cancers, four were female and only female participants suggested other types of screening.

It may not explain why the adherent group was more knowledgeable regarding LS and associated topics, as there were slightly greater numbers of female non-adherers (55.55%; 5/9) than female adherers (44.44%; 4/9). However, the finding of female participants being more knowledgeable regarding other screening practices is consistent with those who have demonstrated an association between being female and taking part in, or having knowledge of screening behaviours (Beeker, Kraft, Southwell & Jorgensen, 2000; Federici et al., 2006; Shapiro et al., 2001). Although the women appeared more knowledgeable, particularly regarding risk for other cancers and other types of screening, only one mentioned both "uterus" and "Pap smears" (the closest suggestions to endometrial or ovarian cancer offered) demonstrating a lack of knowledge amongst the sample regarding female specific LS-related cancer risk. Previous research amongst women with LS has found that very few women are being educated regarding endometrial and ovarian screening by their gynaecologists or gynaecological oncologists (Yang et al., 2006), and that lifetime risks of endometrial cancer are somewhat less well understood by LS patients than lifetime risks of CRC (Claes et al., 2004).

A possible explanation for why adherers were more knowledgeable regarding LS than their non-adherent counterparts could, however, relate to the fact that they were adherent. While a number of participants mentioned that they spoke with, and shared stories with, members of the community regarding CRC, it is unlikely they would have gained knowledge regarding their genetic mutation in this way. The key times they would have been educated regarding LS would have been at the hospital during communication with their doctors, genetic counselors or the CRCGC. Therefore, exposure to this setting may have resulted in greater knowledge of this subject.

In addition, of the most knowledgeable adherers, 75% (3/4) had experienced the death of a family member, and 50% (2/4) the death of a parent due to CRC. As such, having

knowledge pertaining to their "family sickness" may be of great importance to them. In accordance with this, 50% (2/4) listed having knowledge as a benefit of, and 50% (2/4) as an aim of screening.

Finally, the younger participants of this sample appeared more knowledgeable regarding LS. Perhaps related to their enthusiasm, referred to in the section on knowledge of terminology, or because their memory for school biology is slightly better than the older participants, they may have been more receptive to details concerning genes, chromosomes and mutations. Because young adherers (62.5%; 5/8) outnumbered young non-adherers (37.5%; 3/8), this may have accounted for the adherers' greater knowledge.

In conclusion, when the above is taken into consideration, the adherent group appeared slightly more knowledgeable regarding the meaning of the LS mutation and its associated risk with other cancers than did the non-adherent group. Therefore, a lack of knowledge of LS may be a contributing factor to non-adherence to screening guidelines.

Knowledge of colorectal cancer. Patients' knowledge and awareness of CRC has been investigated and discussed by a number of studies (e.g. Davis et al., 2001; Donovan & Syngal, 1998; Greiner et al., 2005; Harewood et al., 2002; Menon et al., 2003). In the current study, a number of descriptions of CRC emerged from the interviews (see Table F3, Appendix F).

The group as a whole. Knowledge of CRC amongst the participants was good. The most often cited category of explanations was that of treatment, making up 35.14% of all suggested explanations, and being suggested by 87.5% (14/16) of participants. This was followed by various symptoms (which made up 30.6% of all suggested explanations and was suggested by 75% [12/16] of participants), and ideas associated with explanations and descriptions of CRC (which made up 23.4% of all suggested explanations and was suggested by 93.75% [15/16] of participants). The majority of participants suggested the top three explanations. As such, analysis as to why these explanations were relevant or important to these particular participants was not possible. Furthermore, while a limited number of studies have investigated participants' knowledge of CRC, most have been quantitative studies that derive a knowledge score based on Likert rating scales of pre-determined descriptions. In addition, most have investigated knowledge of CRC in terms of its association with non-adherence rather than identify the specific knowledge of the participants (e.g. Harewood et

al., 2002; Menon et al., 2003). Therefore, the accuracy of these descriptions could not be compared with the literature. However, in discussion with experts on the subject in question, the descriptions identified were deemed accurate, comprehensive and all-inclusive.

In conclusion, knowledge of this sub-category was good with the majority of LS participants being able to describe CRC, its symptoms and its treatment.

Non-adherers compared with adherers. Non-adherers appeared to be more knowledgeable, suggesting more descriptions concerning CRC (55.9%) than did adherers (44.1%). In addition, their suggestions reflected an accurate understanding of CRC. Furthermore, as a group, non-adherers were the only participants to mention the importance of living a healthy, stress-free life. Therefore, the findings of this study appear to be the inverse of what one might expect given the research on the subject.

Seventy-five percent (3/4) of the top four most knowledgeable non-adherers and half (2/4) of the top four most knowledgeable adherers had previously had cancer. Because of this, these individuals may have been exposed to more information on this topic. Furthermore, because slightly more non-adherers (57.14%; 4/7) than adherers (42.86%; 3/7) had previously had cancer, this may account for why the non-adherers of this sample appeared more knowledgeable.

Another explanation may be because this question followed questions concerning LS, where non-adherers displayed less knowledge and understanding than the adherers. Because of this, the non-adherers may have given more information in answer to something they recognised, while the adherers may have been more constant in their answers throughout the interview. Moreover, as is discussed in greater detail within the section pertaining to perceived benefits, the non-adherers may have wanted to minimise the negative perceptions surrounding the idea of being non-adherent. They, therefore, may have given many details to demonstrate that, despite having missed a few colonoscopies, they were, never-the-less, knowledgeable.

While their first language did not appear to play a role (as equal numbers of adherers and non-adherers were first language Afrikaans), a further explanation could be linked to other sociodemographic characteristics. While CRC may be just one of many challenges for those struggling to make ends meet, those with a comfortable income may have more capacity to take in information concerning CRC. Individuals of a lower SES have also been found to experience inferior communication and education from their healthcare

professionals (Fox et al., 2009; Zere & McIntyre, 2003). Slightly more non-adherers (57.14%; 4/7), than adherers (42.86%; 3/7), had a higher income, earning a combined household income of R6401 or more per month. Furthermore, of the top four most knowledgeable non-adherers, 75% (3/4) were of the higher income group. A higher SES may, therefore, be a contributing factor as to why the non-adherers, as a group, appeared more knowledgeable concerning CRC than the adherers of this sample.

In addition, of those who received tertiary education, 75% (3/4) were non-adherers, and non-adherers had a slightly higher average number of years of schooling than adherers (see Table C6, Appendix C). As a result, they may have had greater exposure to information and may have absorbed more details concerning CRC from the CRCGC (in comparison with the less educated who may only have absorbed the basics). This too could account for the non-adherers' apparent greater knowledge of this sub-category.

In conclusion, the non-adherers appeared to be more knowledgeable regarding CRC than their adherent counterparts. Therefore, in this sample, a lack of knowledge of CRC does not appear to be a contributing factor to non-adherence.

Knowledge of how colorectal cancer develops. Brotherstone et al. (2006) found that the difference between the terms 'cancer' and 'pre-cancer' is not well understood amongst individuals at increased risk for CRC, and the two terms are often assumed to be synonymous. In addition, the concept of looking for 'hidden cancer' or 'premalignant polyps' has been found to be poorly understood, among the less educated, even after several explanations (Davis et al., 2001). Concepts such as these, which are related to the development of cancer, were investigated, the findings of which are illustrated in Table F4, Appendix F.

The group as a whole. Each of the terms depicted above were described for those who did not know what they meant in order to gauge the participants' understanding of the concepts, unhampered by their potential lack of knowledge of the terminology. Any answer that equated polyps with pre-cancer, implied a distinction between polyps and cancer, or denoted a development or change from polyp to cancer, was considered to be a good description.

While knowledge of the difference between a polyp or pre-cancer and cancer was good, knowledge of the process of how cancer develops was poor. In addition, only 25%

(4/16) of the total participants were able to answer all three questions relating to the development of cancer. This poor percentage is in line with the previous research concerning the general poor knowledge found amongst individuals at increased risk for CRC. Findings of interest include (a) the fact that, although 43.75% (7/16) of participants had survived CRC, exposure to information by way of a personal experience of cancer did not appear to increase participants' knowledge, (b) the only participant to incorrectly state that having a polyp means you have cancer and that there is no difference between cancer and pre-cancer, was a non-adherer, and (c) P4's statement regarding polyps within a mutation-carrier:

> *"Cancer, you've got it, you're going to die. Polyp, not yet, but eventually you will get it, then you will die. If you have the gene and you have a polyp, you will eventually get cancer. But if you have a polyp and no gene, don't worry about it, it's just a polyp."(P4; 26 year old adherent female)*

Of the four participants who could describe all three concepts, 75% (3/4) were English speaking which may either indicate a bias in the questions, which were developed from international (English) research, or a discrepancy between the knowledge of English and Afrikaans speaking LS patients. This may account for the lack of knowledge amongst the (predominantly) Afrikaans speaking majority. In addition 75% (3/4) were over the age of 45 years. This may have afforded them more opportunity to discuss LS and CRC in depth with healthcare professionals. Or, they may view the development of CRC as being more important due to their increased age, and therefore risk, accounting for their better knowledge. Furthermore, all were of the higher income group, possibly influencing their access to information, and 50% (2/4) had received tertiary education which may have influenced their exposure to information, their literacy and health literacy abilities, as well as their capacity for comprehension of such information. Therefore, SES and education may too accounted for their greater knowledge.

Finally, although the terminology of the concepts investigated above was explained to those who did not understand, 75% (3/4) of the four participants who could describe all three concepts displayed relatively good knowledge of terminology, being able to describe four or more of the seven terms investigated, and this may have positively influenced their ability to describe the concepts.

In conclusion, asides from being able to describe the difference between cancer and pre-cancer, the knowledge of the LS participants pertaining to how cancer develops was poor,

with only 25% (4/16) of the participants being able to answer all three questions relating to the development of cancer.

Non-adherers compared with adherers. More adherers (75%; 6/8), than non-adherers (50%; 4/8), were able to describe at least two of the three concepts investigated (see Table F4, Appendix F). Therefore, the current study's results appear to be consistent with previous research that suggests an association between a lack of knowledge or understanding of the development of cancer and non-adherence to screening guidelines (e.g. Brotherstone et al., 2006; Davis et al., 2001; Friedman & Hoffman-Goetz, 2007).

Davis et al. (2001) state that concepts relating to the development of cancer are closely associated with the idea of the preventative aim of screening, and that individuals who do not understand that colonoscopies can prevent cancer, by detecting and removing pre-cancerous polyps, will be less likely to take part in a preventative health action. The adherers demonstrated a better understanding of the preventative aims of screening in terms of removing the polyp before it develops into cancer, as well as greater knowledge of colonoscopies. Because these concepts are related, this may account for their greater knowledge of how CRC develops.

In addition, while personal cancer does not appear to account for knowledge of concepts relating to the development of cancer amongst this sample, exposure to the experience of cancer by a family member might. Of the ten participants who could explain two of the concepts, 83.33% (5/6) of the adherers, but only 25% (1/4) of the non-adherers, had experienced the death of a family member due to CRC; and 66.66% (4/6) of the adherers, and none of the non-adherers, had experienced the death of a parent. This may, potentially, have influenced their knowledge on the subject.

Furthermore, while the sample as a whole was not motivated to seek out additional information, of those who could explain two of the concepts above, 50% (3/6) of the adherers but only 25% (1/4) of the non-adherers had contacted the CRCGC at a later stage for additional information. This too could account for the adherer's greater knowledge.

In conclusion, a lack of knowledge of how cancer develops may be a contributing factor to non-adherence within this sample.

Therefore, in conclusion to the entire section concerning knowledge of threat (including knowledge of LS, CRC and of how cancer develops), in support of the findings of Harewood et al. (2002), Kim et al. (1998) and Yepes-Rios et al. (2006), the level of

knowledge of threat in general, amongst the participants of this sample, was somewhat poor, with only 50% (8/16) of participants being able to describe two, and 18.75% (3/16) all three of the concepts investigated.

When comparing the two groups, despite non-adherers' good level of knowledge of CRC, on the whole, the adherent group demonstrated slightly greater knowledge of threat than did non-adherers. Therefore, the findings of this sample appear to be consistent with those of previous research that found an association between a lack of knowledge of threat and non-adherence.

Perceived severity. Although little research has been conducted specifically amongst LS patients, previous studies have investigated the influence of perceived severity on adherence to screening guidelines within the context of CRC (e.g. Collins, Halliday, Warren & Williamson, 2000; Collins, Meiser, Gaff, St John & Halliday, 2005; Jacobs, 2002; Menon et al., 2003; Zheng et al., 2006). In order to gauge an understanding of the current participants' perceived severity, participants were asked if developing CRC would be bad. The findings of are illustrated in Table F5, Appendix F.

The group as a whole. A participant was classed as rating CRC as 'severe' if their answer included the words "yes", "it is bad", or if they mentioned death, suffering or fear in their explanation. A number of participants appeared hesitant to commit to stating that CRC was bad and rather treated cancer as something you just deal with, if and when it happens. Thus, they were classed as rating CRC as 'moderately severe' as their answers included the words "it would not be good", "it is not a good thing", "it is not something you would welcome", and "I cannot say it is bad". The remaining participants did not think that developing CRC would be bad, and were classed as rating CRC if 'not severe' as their answers included words such as "no", "not at all", and "it is not". Therefore, 75% (12/16) of the total participants tended toward recognising the severity of CRC, by being classed in the 'severe' or 'moderately severe' groups.

The previous studies that have investigated this HBM category of knowledge, have done so in terms of its association with non-adherence. As a result, few have reported the severity ratings of the group. However, it is of interest to note that, although 75% (12/16) of participants acknowledged that CRC is a serious disease, of the 25% (4/16) who rated CRC as 'not severe', all were from the lower income group (combined household income per

month of R6400 or less) and all spoke Afrikaans as their first language. This may have impacted on their quality and level of education, their access to information on the severity of CRC, as well as on their understanding of this information, possibly accounting for their lack of perceived severity.

In conclusion, the majority (75%; 12/16) of LS participants accurately acknowledged that CRC is a serious disease.

Non-adherers compared with adherers. Each severity rating included equal numbers of adherers and non-adherers. Therefore, there was no apparent tendency in either group toward higher or lower perceived severity. Although little research has investigated this knowledge category specifically amongst LS patients, these findings appear to be consistent, both with those amongst individuals at increased risk for CRC, as well as amongst suspected LS carriers, that do not report an association between non-adherence to screening guidelines or uptake of genetic testing respectively, and perceived severity (e.g. Claes et al., 2004; McCaffery et al., 2001; Smith & Croyle, 1995; Zheng et al., 2006). However, when analysing exactly what was said, the non-adherers' answers to this question were somewhat non-committal and vague. For example:

R: Would developing colorectal cancer be bad?

"I reckon so." (P16; 53 year old non-adherent male)

"I think so." (P10; 28 year old non-adherent female)

Whereas the adherers were more likely to emphasise the severity:

R: Would developing colorectal cancer be bad?

"Yes, a person can die with this thing." (P3; 26 year old adherent female)

"It's bad. It means I must go... if they can operate and take it out, I must go for operation and treatment and that kind of stuff." (P2; 22 year old adherent male)

In addition, when the participants were asked what they thought would happen should someone develop CRC or if they developed it themselves, the non-adherers as a group tended to minimise the severity and focus on the positive. For example, more non-adherers (25%; 2/8), than adherers (12.5%; 1/8) mentioned that "you don't get so ill" and that "I can do still everything I need to do if the operation was successful", while only adherers (37.5%; 3/8) mentioned that "you can die". When listing symptoms, non-adherers were more likely to

minimise the severity of symptoms, while adherers more often listed them. For example, 50% (4/8) of non-adherers but only 12.5% (1/8) of adherers mentioned that you can "carry on and not be aware of it", while 25% (2/8) of adherers and only 12.5% (1/8) of non-adherers listed symptoms such as "pain", "fatigue" and "not wanting to eat". Furthermore, only non-adherers (25%; 2/8) reported that "you can survive if it is caught early". Whereas an adherer reported that if you don't have an operation or get treatment you "won't get better".

Although perceived barriers are known to play a large role, some studies have found perceived severity to be influential in non-adherence to screening guidelines. Jacobs (2002), for example, found that perceived severity predicted participation in "health maintenance visits" and screening amongst first degree relatives of individuals with CRC (p. 252). In summary, although the majority (75%; 6/8) of non-adherers did acknowledge that CRC is a serious disease, in line with Jacobs (2002), they did appear to have a tendency to minimise this severity more than their adherent counterparts.

A possible explanation for their tendency to minimise the severity of CRC as well as for their continued non-adherent status despite a relatively high, albeit reluctant, perceived severity, may lie in their experience of cancer. Of the six adherent participants who were classed as rating CRC as 'severe' or 'moderately severe', although two had survived cancer themselves, five had not only experienced the death of a close relative due to CRC, but the death of a parent, which has been shown to have a significant influence on adherent behaviour amongst LS individuals (Domanska et al., 2007; McCann et al., 2009) as well as individuals at risk for other cancers (Lerman et al., 1993; Wardle, 1995). In contrast, of the six non-adherent participants who were classed as rating CRC as 'severe' or 'moderately severe', only one had experienced the death of a parent due to CRC, while all had witnessed at least one close relative survive, in five of the six cases a parent, and three had survived cancer themselves. Therefore, although the non-adherers may note the severity of CRC when pushed for an answer, it appears that experiencing survival of cancer may lead them to believe that it is actually not so serious. This, in turn, may influence their non-adherent behaviour.

Moreover, of the six non-adherers to rate CRC as 'moderately severe' or 'severe', 66.66% (4/6) were employed on a fulltime basis, 50% (3/6) were the sole breadwinners of their families and 50% (3/6) listed difficulties associated with work or taking time off work, as barriers to attending colonoscopies. In addition, one non-adherer was in the opposite position, being unemployed, and listed this as a barrier to attending colonoscopies. In contrast, of the six adherers to demonstrate high perceived severity, only 50% (3/6) were employed

fulltime, none were the sole breadwinners and none mentioned any barriers associated with taking time off work. Furthermore, two were amongst the only participants who did not need to work and were supported financially by someone other than themselves. It is possible, therefore, that the latter adherent individuals may be in a position financially stable enough to take advantage of screening. However, the former individuals may be minimising the severity of CRC as a coping mechanism or type of denial. Although they recognise that CRC is a serious disease, they may not be in a position where they can easily attend screening and, as a result, need to protect themselves against the anxiety this might cause.

In conclusion, although non-adherence to screening guidelines in this sample does not appear to be associated with lower perceived severity, the non-adherers did demonstrate a tendency to minimise severity, whereas the adherers did not. This suggests that other factors may be influencing their non-adherence.

Perceived susceptibility. Previous studies have investigated the influence of perceived susceptibility and the understanding of risk on adherence to screening guidelines within the context of LS (e.g. Aktan-Collan et al., 2001b; Collins et al., 2005; Hughes Halbert et al., 2004; Liljegren et al., 2004; Wagner et al, 2005) and individuals at increased risk for CRC (e.g. Jacobs, 2002; Menon et al., 2003; Weinberg et al., 2004; Zheng et al., 2006).

In order to gauge an understanding of the current participants' perceived risk, participants were questioned on their perceived risk of developing CRC, the findings of which are illustrated in Table F6, Appendix F. Adherer P7 could not give a description of his risk and was excluded from this analysis.

The group as a whole. Although South African patients with LS stand as much as a 92% risk of developing CRC (Stupart et al., 2009), the internationally recognised risk, and the risk of which these participants would have been informed, during counselling and information sessions, is that of 80%. Therefore, a participant was classed as having an 'accurate' rating if their answer included numbers or a percentage that equated to 80% or an explanation that rated their risk as 'high' or 'very big' without a statement qualifying that they either will or will not get it. In line with this, a participant was classed as rating their perceived risk as 'high' if their answer included the words "I will get it", or a percentage or number that equated to more than 80%. They were categorised as having 'low' perceived risk if they used words such as "might get it", "not going to get it", "I do not intend getting it", "I

am hopeful that it will not happen again", used explanations emphasising a form of prevention or protection against getting CRC such as "God is with me and I use my tablets", or numbers or a percentage equating to less than 80%.

Only 40% (6/15) of participants rated their perceived risk accurately, or as 'high'. This means that 60% (9/15) of the participants underestimated their risk. This finding is consistent with those of other studies of LS patients. Both Aktan-Collan et al. (2001b) and Wagner et al. (2005) found that the majority of LS mutation-carriers underestimated their cumulative lifetime risk of colorectal cancer as being less than 50%; and Liljegren et al. (2004) demonstrated even lower rates of perceived risk amongst their sample, where 61% of LS individuals reported their perceived risk as being 40% or less and 36% perceived only a 1-20% lifetime risk of developing CRC. However, while Aktan-Collan et al. (2001b) asked their participants to rate their perceived susceptibility "without regular cancer surveillance aimed at the prevention of cancer" (p. 788), the current participants were just asked about their perceived susceptibility. As such, they may have taken the protective action of screening into account in their estimations of risk. This may have contributed to their lower perceived susceptibility.

Of the nine participants to consistently (across both questions) have a 'low' rating, 66.66% (6/9) spoke Afrikaans as their first language. This may either indicate a misunderstanding or miscommunication between researcher and participant, or a deficit in understanding of the Afrikaans speaking participants of this sample. Additionally, only 33.33% (3/9) had previously had cancer themselves and only 33.33% (3/9) had experienced the death of a parent due to cancer. Therefore, the low perceived susceptibility of this sample may, in fact, be correct, with the lack of personal experience potentially accounting for the finding. Furthermore, 77.77% (7/9) had not acquired more information from places other than the hospital, 88.88% (8/9) had not contacted the CRCGC later on for additional information and 77.77% (7/9) had not relied on a family member for information they had missed or forgotten. This lack of motivation to seek out information may also account for their low perceived susceptibility.

In conclusion, perception of risk was low among this sample of LS participants, with only 40% (6/15) accurately perceiving their susceptibility to the disease.

Non-adherers compared with adherers. Only non-adherers accurately rated their risk in response to the question discussed above. In addition, non-adherers (50%; 4/8) were less

likely, than the adherers (71.43%; 5/7), to incorrectly position their perceived risk of developing CRC as being 'low'. This is inconsistent with a number of studies amongst both LS patients as well as individuals at increased risk for CRC, who found that lower perceived susceptibility was associated with non-adherence to screening guidelines (e.g. Collins et al., 2005; Hughes Halbert et al., 2004; Mack, 2008).

However, the participants were also asked what 'being at risk' means, a question less centred around numeric estimates of risk. Among the participants who answered this question, far more non-adherers (87.5%; 7/8), than adherers (57.14%; 4/7), stated that being at risk means that you "***can***" or "***might*** get CRC". Furthermore, far fewer non-adherers (12.5%; 1/8), than adherers (42.86%; 3/7), stated that it means "you ***will*** get CRC". However, overall, risk estimates to this question remained low with 68.75% (11/16) of participants saying that they only "might" get CRC.

The adherers were largely consistent in their ratings of risk, across the two questions. That is, the majority (80%; 4/5) of those who rated it as 'high', in the first question, also rated it as 'high', in the second; while those who rated it as 'low' consistently did so. Only one adherer first rated her risk as 'low', then as 'high'. In contrast, three non-adherers demonstrated inconsistent ratings, first rating their risk as 'high', then as 'low'. This may imply either a misunderstanding of risk, or, like perceived severity, a tendency to minimise susceptibility despite an acknowledgement of risk amongst the non-adherers of this sample.

It has been shown that lay people, and the less educated in particular, frequently have difficulty in understanding numeric estimates of risk (Weinstein, 1999; Yamagishi, 1997). In line with this, of the three non-adherers to provide inconsistent ratings of risk (a) two were amongst the least educated of the sample, in terms of years of schooling attended, which could have impacted on their understanding, (b) all three were first language Afrikaans which may have further impacted on their misunderstanding of the question, (c) although all three stated that their risk was "greater than the general population", one said, "No, it's not actually people who have the gene that can get cancer, um, colon cancer. Everybody can get colon cancer" (P14; 48 year old non-adherent female), thereby confusing this statement, (d) despite placing her risk as 'high' initially, P14 also said that, "If you've got the gene, then you stand a 50/50 to get the cancer" possibly demonstrating a misunderstanding between risk of inheriting the gene and risk of developing cancer, (e) one struggled with an additional question relating to numeric estimates of risk (Yamagishi, 1997), incorrectly selecting the

larger numbers, but smaller percentage, as being more risky, and (f) one demonstrated a misuse of numeric risk in other portions of her interview:

> *"I know that like, for instance, say my mom has... 5% [risk of having the gene], then I have maybe like 10%, then if I have children one day, I guess they will be more... One of them or something, like 15%. Until it one day stops..." (P10; 28 year old non-adherent female).*

A second explanation could relate to the non-adherers' propensity to minimise perceived severity despite an acknowledgement of the seriousness of the disease. Similarly, although some non-adherers acknowledged their high risk in answer to the first question, most (87.5%; 7/8) said that you only "might", rather than "will" get CRC in answer to the second, thereby minimising their perceived susceptibility to the threat. In addition, it is of interest to note that of the four non-adherers to demonstrate low perceived susceptibility, 75% (3/4) were amongst the most non-adherent, having missed between 60% and 85% of their recommended colonoscopies. Missing such a large percentage of colonoscopies may add to their need to minimise their perceived susceptibility to the threat.

In conclusion, it is possible that the non-adherers did in fact have lower levels of perceived susceptibility than their adherent counterparts, particularly when the answers to the second question, the inconsistencies between the first and second questions, and the possibility of minimisation of threat, are taken into account. Therefore, one may tentatively posit that a lack of perceived susceptibility may be an influencing factor with regards to non-adherence in this sample.

Knowledge of protective health action. In order for an individual to partake in a protective health behaviour, it is important that they are aware of the health threat, its severity, and their susceptibility to it. However, it is also imperative that they are aware of a protective health action that protects against the threat (Rosenstock et al., 1994). A lack of knowledge of endoscopic screening will directly impact on adherence rates of individuals with LS.

The current participants were questioned on issues relating to knowledge of protective health actions. The following categories emerged from the interviews: knowledge of (a) colonoscopy, (b) the recommended frequency of colonoscopies, (c) the (preventative) aims of screening, and (d) other protective actions.

***Knowledge of a colonoscopy*.** Relatively little research, either amongst LS mutation-carriers or amongst individuals at increased risk for CRC, appears to have investigated individuals' knowledge of CRC screening tests. However, knowledge or awareness of screening tools is a very important sub-category of knowledge pertaining to protective health actions. The population, from which this sample was drawn, are only recommended for endoscopic screening via colonoscopies, as this is the most reliable test for the detection of premalignant polyps. Therefore, the current participants were only questioned on their knowledge of colonoscopies, and not other screening tests for CRC. Their descriptions are illustrated in Table F7, Appendix F.

The group as a whole. Although the answers provided a correct description of the procedure, some parts of the procedure, that is the most relevant parts, were (accurately) mentioned more than others. The parts most often described were the necessity to drink the preparation liquid to clear out the colon and the fact that they insert 'something' into one's rectum. These descriptions both made up 15.8% of all listed descriptions, and were suggested by 93.75% [15/16] of participants. The suggestions as to what that 'something' is ranged from a "camera", a "pipe", a "needle", a "tube with a globe" or "light", to a "scope with a claw". These were followed by what colonoscopies look for. This element made up 12.6% of all listed descriptions, and was suggested by 75% [12/16] of participants. The suggestions as to what they look for ranged from (a) to see "if your colon is clean", or if there is "anything wrong", to (b) "little white spots", "small cancer cells", "the gene", "polyps", a "pimple like thing", and "cancer". As this type of knowledge does not appear to have been investigated previously, there are no studies with which to compare these findings. However, all but one participant (93.75%; 15/16) had heard of and knew what a colonoscopy was without explanation of the term. Therefore, the current participants appear more knowledgeable than those of previous studies such as (a) McAlearney et al. (2008), who found that only 39% of their participants reported being aware of a test that checks for CRC, and only 15% were able to name colonoscopy, and (b) Kim et al. (1998), who found that only 53.4% of their male and 30.9% of their female participants had heard of two very popular CRC screening tests. These were, however, conducted using samples of individuals at increased risk for CRC and not LS mutation-carriers who may be expected to be more knowledgeable.

All participants had attended at least one colonoscopy. Therefore, it is not surprising that they are relatively well-informed concerning this procedure. The only participant to not recognise the name had the second highest rate of non-adherence, having missed 75% of his recommended colonoscopies. He was also the only participant to mis-understand his mutation status thinking he does not carry the genetic mutation. In addition, he knew only two of the seven terms investigated in this study, and was amongst the participants with the lowest perceived susceptibility. Lack of exposure, basic knowledge of mutation status and terminology, and lack of perceived risk, may all have contributed to his lack of knowledge of this sub-category.

In conclusion, knowledge of the screening procedure utilised amongst this population, the colonoscopy, was good; and the majority of participants were able to describe the main aspects of this screening tool.

Non-adherers compared with adherers. Although non-adherers knew the main aspects of a colonoscopy, adherers demonstrated far more knowledge and offered almost double the amount of details about the procedure than did non-adherers (64.2% of the descriptions were suggested by the adherers, while non-adherers suggested only 35.8%). For instance while non-adherer P10 suggested that on the morning of the colonoscopy you need to drink the preparation liquid they give you, adherers P1, P2, P4, P6 and P7 not only added details such as only being able to drink "clean" liquids, such as coffee or soup "without noodles", and were able to name various preparation liquids, but they also added that one drinks this liquid the day before a colonoscopy as well. Furthermore, while non-adherers P12 and P13 stated that the doctors sedate you during the procedure, adherers P1, P2, P3, P4, P5 and P6 added to the richness of the description by stating that they put you on a drip or give you an injection to relax and so that you don't feel the pain, and sometimes ask you to count down from ten. In addition, while all adherers were able to suggest at least five points of description, only 37.5% (3/8) of non-adherers were able to do so.

Although LS patients' knowledge and awareness of colonoscopies in particular has not been researched in detail, these findings are consistent with those of, for example, McAlearney et al. (2008) who found, in their study of individuals at increased risk, that women who could name a colonoscopy were seven times more likely, than those who could not, of having had a CRC screening test.

An obvious reason for adherers' greater knowledge could be related to their exposure to the procedure. However the average number of colonoscopies attended by adherers is only 0.5 higher than that of non-adherers (adherers attended on average 3.5 colonoscopies and non-adherers attended 3). On the other hand, the adherers' attendance rate was obviously 100%, while the non-adherers' attendance rate ranged from 15 to 72%. Although they were not made aware that the researcher knew whether or not they were adherent, they were told that the study was investigating the reasons as to why people go or don't go for colonoscopies. As a result, it is possible that being adherent was of great importance to the adherers and because of this they wanted to give as many details as possible in answer to the procedure on which the study appeared to be based. This could, therefore, account for why the adherers appeared more knowledgeable on this topic.

Furthermore, barriers such as a dislike of colonoscopies and a dislike of talking about CRC, were listed by the non-adherers. Therefore, although they may not mind relating the main aspects of colonoscopies, they may prefer not to talk about the procedure in depth; and this reluctance may account for their apparent lack of knowledge.

In conclusion, while it could be a resultant rather than a causative factor, a lack of knowledge concerning colonoscopies appears to be associated with non-adherence within this sample.

Knowledge of recommended frequency of colonoscopies. No studies were found in the limited research specifically concerning individuals with LS. However, several studies amongst individuals at increased risk for CRC have investigated participants' knowledge of the recommended frequency of colonoscopies. In South Africa, LS mutation-carriers are recommended to attend endoscopic surveillance every second year, starting at age 16 until age 30 years, and then annually thereafter (Anderson et al., 2007). However, at GSH, if a polyp is found in a patient under the age of 30 years, they are also recommended to attend annually.

In order to gain an understanding of their knowledge of this recommendation, the current participants were asked how often they, because of their high risk status, should be attending colonoscopies, the results of which are tabulated in Table F8, Appendix F.

The group as a whole. Fifty percent of participants were under the age of 30 years and therefore would have been recommended to attend endoscopic screening every two years. As

polyps had been found in two of this group, these two were accurate in stating their recommended frequency as being annually. Therefore, 75% (6/8) of the younger participants answered this question correctly, while the others either over- (12.5%; 1/8) or under-estimated (12.5%; 1/8) the frequency at which they should be attending colonoscopies. The other 50% of total participants were over the age of 30 years and should be undergoing a colonoscopy annually. Again 75% (6/8) understood or recalled their recommended frequency accurately. However, misunderstandings of colonoscopy frequency also existed, with 12.5% (1/8) over- and 12.5% (1/8) under-estimating the frequency at which they should be screening.

Therefore, 75% (12/16) of the total participants correctly stated the recommended frequency for endoscopic screening, which means that 25% (4/16) either over or under-estimated the recommended frequency, demonstrating misunderstanding of this sub-category of knowledge. Although no studies were found amongst LS mutation-carriers, various studies amongst individuals at increased risk have demonstrated that as many as 66% (McAlearney et al., 2008), 76% (Kim et al., 1998), and 85% (Greiner et al., 2005) of participants did not know the recommended age at which CRC screening should commence, or the correct frequency at which screening should take place. The abovementioned studies were, however, conducted within samples from the general population at increased risk, due to age or environmental risk factors. One might, therefore, expect individuals with LS to have more accurate knowledge.

Of the four participants to under- or over-estimate the frequency at which they should be attending colonoscopies, (a) one, who had had CRC before, appeared to be confusing colonoscopies with general cancer check-ups, which cancer patients managed by GSH are required to undergo every six months, possibly accounting for his overestimation, (b) three spoke Afrikaans as their first language, potentially adding to their confusion on this question, (c) three were from the lower SES group (earning a combined household income of R6400 or less per month) and it has been shown that individuals of lower SES and education have difficulty in understanding risk in terms of numbers (Weinstein, 1999; Yamagishi, 1997) which may translate into a misunderstanding of numbers in general, and (d) one misunderstood his genetic test result thinking that he did not possess the mutation, possibly accounting for his under-estimation of frequency:

R: What were they looking for in your blood?

P11: For more genes of my father... To see if maybe I can develop the sickness. Cause

it's a father, a family sickness. That's my understanding of it.
R: And what did they find with you?
P11: Oh nothing, they only said 50/50. But they actually find nothing. They didn't find the gene you see. (28 year old non-adherent male)

In addition, 75% (3/4) of the four participants to inaccurately estimate the frequency were non-adherent and all had missed more than 60% of their recommended colonoscopies. They may, therefore, have forgotten the frequency originally told to them. Furthermore, 75% (3/4) were male and, as has been discussed in the section on LS, may have been less likely to have known about, and taken part in, other screening behaviours, which has been shown to impact on knowledge of and adherence to CRC screening (Shapiro et al., 2001).

In addition to recommended frequency, there were also misunderstandings regarding the age at which this will change or how it will change. For example (a) P13, a 47 year old non-adherent male, incorrectly thought there was no change and that the frequency is the same for everyone, (b) P2, a 22 year old adherent male, incorrectly thought the year at which he will start attending colonoscopies annually was 35 years, and (c) P10, a 28 year old non-adherent female, thought that she will go every year until 30 years, and then every second year thereafter, when in fact it is the other way around. The suggested reasons as to why the frequency in endoscopic screening changes, were also of interest. While six (37.5%; 6/16) correctly quoted "age", or the fact the "risk increases with age", as a factor, one incorrectly thought it depends on the size of the polyps:

"Various people sometimes get big growths... Occasionally people get big ones, sometimes little. And I think the people with the big ones can go every six months and those that have the little ones can go every year" (P9, 24 year old non-adherent female).

Although the current participants demonstrated slightly different misunderstandings, misconceptions regarding screening, such as believing screening to be unnecessary unless symptomatic, or unnecessary for a particular age group, have been demonstrated amongst individuals at increased risk for CRC (e.g. McCaffery et al., 2001; Seeff et al., 2004; Zheng et al., 2006).

In conclusion, knowledge of this sub-category, amongst the LS participants of this sample, was also good, with 75% (12/16) of participants accurately stating the recommended frequency for screening.

Non-adherers compared with adherers. The non-adherers appeared less knowledgeable on this topic than did the adherers. Eighty-seven and a half percent (7/8) of adherers, but only 62.5% (5/8) of non-adherers, accurately recalled the recommended frequency at which they should be screening. In addition, of the six participants to demonstrate misconceptions surrounding the age at which the frequency changes and the reasons for this change, 66.66% (4/6) were non-adherent. Both of these findings are consistent with previous research. For example, (a) Johnson et al. (2002) proposed, on the basis of their findings, an association between lack of knowledge of the recommended frequency of screening and non-adherence, and (b) various authors have found that misconceptions regarding screening were associated with non-adherence to screening guidelines (e.g. McCaffery et al., 2001; Seeff et al., 2004; Zheng et al., 2006).

As discussed, of the three non-adherers to demonstrate misconceptions regarding screening frequency, all had missed more than 60% of their recommended colonoscopies, and one suggested the second highest number of barriers to colonoscopies. Therefore, a lack of exposure to the information, or long periods of time between colonoscopies, resulting in forgetting the information, may have accounted for their lack of knowledge. It is of further interest to note that, of the three non-adherers to inaccurately state the frequency, 66.66% (2/3) under-estimated it, saying that they need to attend colonoscopies less often than their actual recommendation; while the only adherer to inaccurately state the frequency, over-estimated it, saying he should attend more colonoscopies than the actual recommendation.

In addition, although there were more female non-adherers than male, two of the three non-adherers to demonstrate misunderstanding regarding frequency were male and, as discussed within the section pertaining to the group, may have had less exposure to information on CRC screening, accounting for why, in this sample, non-adherers had poorer knowledge regarding recommended frequency of screening.

Finally, of the six non-adherers to both demonstrate inaccuracies regarding frequency as well as misconceptions regarding age and reasons for change in frequency, only (a) 50% (3/6) had learned more information from somewhere other than the hospital, (b) 16.66% (1/6) had contacted the CRCGC at a later stage for more information, and (c) 16.66% (1/6) had relied on a family member for information that they had forgotten or did not understand. Therefore, avoidance of information, or a lack of motivation to seek out information amongst these participants, may have accounted for why the non-adherers of this sample were less knowledgeable on this topic.

In conclusion, these findings appear to propose an association between a lack of knowledge concerning recommended frequency of screening and non-adherence to screening guidelines.

***Knowledge of the (preventative) aims of colonoscopies*.** Various studies have investigated participants' perceptions of the aims of screening tools, including colonoscopies, amongst individuals at increased risk for CRC (Weinberg et al., 2004) as well as amongst suspected and confirmed LS mutation-carriers (Codori, Petersen, Miglioretti & Boyd, 2001; Wagner et al., 2005). The current participants were questioned on the aims and importance of colonoscopies, and the aims identified are illustrated in F9, Appendix F.

The group as a whole. Seven aims were identified. Ideas associated with the prevention were the most cited aim (making up 42.4% of all listed aims, and being suggested by 87.5% [14/16] of participants). Similar trends concerning the importance of the aim of prevention have been demonstrated among family members of CRC patients and LS mutation-carriers in the Codori et al. (2001) and Wagner et al. (2005) studies respectively. However, it is of interest to note that although they perceive the accurate aim of preventing cancer, adherers P2 and P3 both emphasise the importance of preventing the "gene" from developing into cancer, demonstrating a lack of understanding either of the concept, or of the terminology used.

The second most suggested aim related to detection (making up 30.3% of all listed aims, and being suggested by 62.5% [10/16] of participants). This was followed by the importance of having knowledge regarding whether or not you have cancer (which made up 12.1% of all listed aims and was suggested by 25% [4/16] of participants). These aims do not appear to have been suggested by previous literature.

A possible reason as to why 'detection' was suggested by this sample may relate to these participants' perceived effectiveness of colonoscopies. Of the participants to suggest this aim, (a) 60% (6/10) had survived a personal cancer, (b) 50% (5/10) claimed they were not anxious or depressed when told information regarding CRC, LS and their risk, and (c) 80% (8/10) demonstrated low perceived susceptibility. As a result, they may regard colonoscopies as an effective way of identifying polyps and preventing cancer, or of detecting early cancer which can be removed or cured. Furthermore, 70% (7/10) were over the age of 30 years and 80% (8/10) had children. As a result, detection of premalignant

polyps, or of cancer, may be of particular importance to these individuals, as they are both at increased risk, and have a vested interest in catching the cancer early.

In addition, of those participants to suggest 'detection', 60% (6/10) also named detection as a benefit of colonoscopies, and of those to suggest 'knowledge', both also listed having knowledge and information as a benefit of colonoscopies. Therefore, these themes may be important to these specific individuals. Alternatively, the participants could have viewed the benefits as being similar to the aims of colonoscopies; indeed there was considerable overlap in the suggestions, and simply repeated similar statements as they were top of mind.

One of the most often cited aims found within studies of suspected and confirmed LS mutation-carriers, that of screening reducing risk (Codori et al., 2001; Wagner et al., 2005; Weinberg et al., 2004), was, however, not elicited within the current sample. Adherer P1 did, however, state that by not attending colonoscopies one increases one's risk of developing CRC. While it is possible that the participants did not view this as an important aim, they were questioned on this aspect specifically earlier in the interview and, as a result, may deliberately not have mentioned it again, thinking it had already been addressed.

In conclusion, a number of inclusive, comprehensive aims were identified by the participants indicating good knowledge of this sub-category amongst the LS participants of this sample.

Non-adherers compared with adherers. A slightly higher percentage of the total aims were suggested by the non-adherers (54.5%) in comparison with the adherers (45.5%). However, it is not simply the quantity of aims that is important, but rather the understanding of the preventative aim of screening: that is the detection and removal of premalignant polyps. While more non-adherers than adherers suggested the aim of prevention, they more often explained it in terms of preventing cancer (without describing the process), the spread of cancer and of death, sickness and pain. In contrast, of those who more accurately mentioned the prevention of the development of cancer, in terms of the polyp or gene developing into cancer, only 28.57% (2/7) were non-adherers, while 62.5% (5/8) were adherers. In addition, adherers were the only participants to suggest the testing and removal of polyps as an aim. Furthermore, slightly more adherers (60%; 3/5) than non-adherers (40%; 2/5) suggested 'prevention' as a general aim of colonoscopies without being specifically questioned on it. The findings, therefore, do appear to be in line with the literature. For

example, Weinberg et al. (2004) and Codori et al. (2001) found that the belief that screening reduces CRC risk and the belief that CRC can be prevented, respectively, was positively associated with adherence to screening guidelines amongst individuals at increased risk for CRC. In addition, Friedman & Hoffman-Goetz (2007) state that individuals who lack an understanding of the preventative aim of screening will be less likely to perceive a risk to their health and to take part in a protective health action.

While no other correlations were found, a possible explanation as to why the non-adherers appeared to be less accurate in their understanding of the preventative aims of screening may be linked to their lack of knowledge of other concepts. Davis et al. (2001) state that the understanding of preventative aims is linked to an understanding of concepts relating to the development of cancer. Non-adherers demonstrated poorer knowledge and understanding with regards to how CRC develops. Therefore, this may account for their poorer knowledge in this sub-category.

In conclusion, although to be interpreted with caution, a lack of knowledge of the preventative aims of screening may be a contributing factor to non-adherence within this sample.

***Knowledge of other protective actions*.** Of the studies focusing on knowledge of protective health actions amongst individuals at risk for CRC, few have investigated participants' knowledge of actions, other than screening, that might protect against CRC. As diet, exercise and healthy living can play a role in preventing CRC (Bostick et al., 1994; Fuchs et al., 1999), participants were asked if they knew of anything else they could do to protect against CRC. They were also read a list of items and were asked whether or not they thought each item would help to protect against CRC. While the majority of participants agreed with most of the relevant, or correct options, a number of participants (43.75%; 7/16) disagreed with the suggested protective behaviours or thought that they would not make a difference. The findings are presented in Table F10, Appendix F.

The group as a whole. Knowledge of other protective actions was relatively poor. However, the behaviours suggested were largely accurate in terms of the literature. Only half (50%; 8/16) of the participants were able to list other actions that may protect against CRC and 43.75% (7/16) disagreed with behaviours that would, in fact, help.

However, of the participants to suggest the protective health behaviours noted, 75% (6/8) had previously had cancer, and most recollected being given a list of foods to avoid. Rather than specifically for protection against CRC, this list of foods was likely given to them due to their operation, as when parts of, or the whole bowel or colon, is removed, absorption decreases, and patients are required to change their eating habits and diet. Therefore, the suggestions presented may reflect knowledge of how to manage post surgical changes, rather than protection against CRC. Consequently knowledge of this sub-category may be even worse than reported.

A possible explanation for a lack of knowledge of other protective actions may be that the participants of this sample were simply not told about other things they can do. When participants were asked if they had learned information from other sources, only (a) 37.5% (6/16) said that they had sought out further information from sources other than the hospital, (b) 31.25% (5/16) had contacted the CRCGC for additional information at a later stage, and (c) 25% (4/16) recalled relying on a family member for information they had either forgotten or didn't understand. Therefore, should they not be told something, it is possible that they would not have learned it from somewhere else, as they did not appear to be individuals who were highly motivated to seek out information.

In addition, 87.5% (7/8) of the participants who could not list other protective actions were employed full time and 62.5% (5/8) had a combined household income of only R6400 or less per month, with some supporting more than four family members on that income. Because of this, they may not have had the time or inclination to seek out additional information or preventative measures not already suggested to them. Evidence for this statement comes from, P1, a 21 year old adherent male, who, on being questioned whether he had ever sought out additional information, stated that, "I didn't get the time".

Furthermore, of the eight participants not to suggest other protective actions, 62.5% (5/8) were under the age of 26 years and, as a result, may view cancer as something they might only have to deal with, or protect against, in the future. In addition, 87.5% (7/8) spoke Afrikaans as their first language; and this may have had an impact on their understanding of the question as well as on their access to such information.

In conclusion, although the behaviours suggested were accurate, when considering the group as a whole, knowledge of this sub-category was poor.

Non-adherers compared with adherers. Inconsistent with most of the rest of the findings of this section, pertaining to knowledge of protective health action, fewer adherers (37.5%; 3/8), than non-adherers (62.5%; 5/8), were knowledgeable regarding this topic. In addition, when looking at the number of suggestions offered, adherers suggested only 23.6% of the items, while 76.4% were suggested by the non-adherent group. Further to this, slightly more adherers (50%; 4/8), than non-adherers (37.5%; 3/8), incorrectly thought that the behaviours suggested would not help. While this particular aspect of knowledge, or its association with non-adherence, has not been widely researched, this finding does appear to be inconsistent with the previously reviewed research suggesting an association between knowledge of protective action and adherence.

Within the sample, slightly more non-adherers (50%; 4/8), than adherers (37.5%; 3/8), had previously had cancer. This could possibly account for the discrepancies in knowledge between these two groups, especially when the explanation concerning dietary changes following surgery is taken into account. However, two of the adherers to incorrectly disagree with actions that would protect against CRC, had previously had cancer and would have received the same information. In contrast, none of the non-adherers who had previously had cancer incorrectly answered these questions. This therefore highlights further the lack of knowledge amongst adherers of this particular sub-category. As discussed above, the sample did not appear to be proactive in terms of seeking out information. Furthermore, when the two groups are compared, fewer adherers, than non-adherers, had sought out additional information. This could provide a possible explanation as to why adherers, in particular, were less knowledgeable. In addition, of the adherers who could not suggest other protective actions, 80% (4/5) were amongst the adherers to present the highest number of (preventative) aims of screening. Therefore, they may place greater emphasis on the effectiveness of colonoscopies and less on other protective actions.

In contrast, the non-adherers appeared more knowledgeable. As discussed, a greater number of non-adherers than adherers in this sample had experienced a personal cancer and their knowledge may, in fact, be of post-surgical care, rather than of other protective actions. However, the only two participants to not previously have had CRC and to suggest protective actions, were non-adherers, thus highlighting their greater, and potentially accurate, knowledge of protective actions. In contrast to the adherers, who may favour colonoscopies, of the five knowledgeable non-adherers within this sub-category, three were the same top three to suggest the highest number of barriers to screening, and four had missed 60% or

more of their recommended colonoscopies. This may imply a trend toward non-adherers being more inclined to seek out alternative protective behaviour other than that of, or in favour of, colonoscopies.

In conclusion, non-adherence to screening guidelines in this sample does not appear to be associated with a lack of knowledge of other protective health actions, although there may be a possible link worth investigating between ***having*** knowledge of protective actions other than colonoscopies and non-adherence.

Therefore, in conclusion to the entire section concerning knowledge of protective health action (including knowledge of colonoscopies, the recommended frequency of colonoscopies, the aims of screening, and of other protective actions), the level of knowledge in general, amongst the participants of this sample, was poor with only 25% (4/16) of the participants being able to describe three, and no participant all four of the concepts investigated.

When comparing the two groups, despite non-adherers' good level of knowledge of other protective actions, on the whole, the adherent group demonstrated slightly greater (and more accurate) knowledge of screening related topics than did non-adherers. Therefore, the findings of this sample appear to be consistent with those of previous research that found an association between a lack of knowledge of protective health action and non-adherence.

Perceived benefits. Various studies have investigated the influence of perceived benefits on adherence to screening guidelines within the context of LS (e.g. Liljegren et al., 2004; Wagner et al., 2005) as well as amongst other individuals at increased risk for CRC (e.g. Jacobs, 2002; Menon et al., 2003; Weinberg et al., 2004; Zheng et al., 2006). The current participants were asked for their opinion on what they thought the benefits of colonoscopies might be, as well as why they attended colonoscopies. The benefits identified by the participants are presented in Table F11, Appendix F.

The group as a whole. Five categories of benefits were identified. Benefits associated with prevention, such as catching it early enough to cure or prevent it, and benefits concerning cancer detection, were the most often cited benefits (each making up 26.9% of the listed benefits, and being cited by 43.75% [7/16] of participants). This is consistent with previous studies, amongst individuals at increased risk for CRC and individuals with LS respectively, which have found that benefits such as "will help find polyps", "will help find

CRC early", "will decrease the chance of dying from CRC" (Zheng et al., 2006, p. 277), "ability to remove polyps" and "finding cancer early" (Rawl et al., 2000, p. 36) were the most often suggested benefits of colonoscopies.

These benefits were followed by having information regarding what's going on and knowing where you stand, in terms of having polyps or cancer (which made up 23.1% of all listed benefits, being suggested by 37.5% [6/16] of participants). Previous research does not appear to have demonstrated similar benefits. However, James et al. (2002) did find that 75% of their participants suggested the benefit of "will have better control over health", which may be related to having knowledge of one's health situation (p. 531). Therefore, it is possible that other studies coded answers pertaining to knowledge in a different category such as cancer detection or psychological benefits and, as a result, revealed different findings. Another explanation is that knowledge may have been particularly important to this group of individuals. In accordance with this, of the six participants to mention the attainment of knowledge as a benefit of endoscopic screening, (a) one also listed knowledge or information as an aim of colonoscopies and, when questioned as to whether she felt overwhelmed by the information she'd received concerning LS and CRC, stated that her family "has always been hungry for knowledge... very inquisitive people, so something like that would be more interesting than scary to us" (P6; 52 year old adherent female), (b) one said that instead of feeling anxious he was rather happy that they'd found something following his genetic test and he was "excited" to find out more (P5; 26 year old adherent male), (c) one reported that the fears he'd experienced when finding out about his risk subsided after receiving more information and that it was "important to know" (P13; 47 year old non-adherent male), and (d) two also listed knowledge, or knowing "what's going on inside your body" (P2; 22 year old adherent male and P13; 47 year old non-adherent male) as the most important aspect of their situation.

The third most often suggested benefit was that of psychological benefits (which made up 15.4% of all listed benefits, being cited by 25% [4/16] of participants). Although less prominent amongst this sample than that of the literature, the benefits suggested are consistent with those of other studies amongst individuals at increased risk for CRC, such as "reduce uncertainty", "relief from fear of getting CRC" (Zheng et al., 2006, p. 277); as well as amongst LS patients such as "will worry less" (James et al., 2002, p. 531), "freedom from worry about cancer", and "reassurance that they were healthy and cancer-free" (Rawl et al., 2000, p. 36). Again, different coding systems may account for the lack of prominence of this

benefit amongst the current sample. However, only four participants suggested this benefit, and of them, 75% (3/4) had a combined household income of R6401 or more per month. In contrast, 66.66% (8/12) of the participants who did not list psychological benefits of endoscopic screening, had a combined household income of less than R6400 per month. Like P11, who in the next section on barriers, states that he needs to have fundamental issues such as work and money in place, before he can worry about attending colonoscopies; perhaps individuals struggling financially, perceive different motivational factors surrounding screening, and different benefits of attending colonoscopies, while those who are more financially stable, may be more able to perceive psychological benefits.

Another possibility may be linked to the fact that 75% (3/4) of the participants to list psychological benefits had previously had cancer and, as a result, may feel more relief following a colonoscopy, knowing they are clear, than someone who has never had CRC.

Unlike previous research, no mention was made of direct benefits of the procedure itself such as "availability of immediate results", "confidence in the accuracy of the results", and "being sedated" (Rawl et al., 2000, p. 36). The population from which this sample was drawn, however, are only offered colonoscopies as a screening tool, as they are the most reliable means of detecting premalignant polyps. Therefore, the current participants would probably not have been aware of other means of screening and, therefore, may not have listed the benefits of colonoscopies over the other types.

In conclusion, a number of comprehensive benefits of colonoscopies were identified by the LS participants, indicating high perceived benefits, of this screening tool.

Non-adherers compared with adherers. Perceived benefits are deemed important in the decision to take a protective health action, and have been found to be both significantly associated with colonoscopy use (Liljegren et al., 2004) as well as adherence to screening guidelines (Madlensky et al., 2003) amongst individuals with LS. However, some studies have found that perceived benefits are less predictive of behaviour than perceived barriers and perceived susceptibility (Janz & Becker, 1984; Henning & Knowles, 1990), and, in some cases, perceived severity (Jacobs, 2002). In line with this, when comparing the two groups in the current study, 53.8% of the benefits listed were suggested by non-adherers, while adherers suggested only 46.2%. In addition, of the participants to suggest two benefits, 62.5% were non-adherers and the only participant to mention more than two benefits was a non-adherer. Furthermore, a greater number of non-adherers, than adherers, suggested benefits

concerning early detection or prevention and cancer detection, which are, very often, the most cited benefits of endoscopic screening. Consequently, the non-adherers of this sample appear to demonstrate (accurate) higher perceived benefits of endoscopic screening than their adherent counterparts.

One possible explanation for non-adherer's higher perceived benefits is that 62.5% (5/8) of the participants over the age of 30 years were non-adherers. Being at greater risk due to their increased age, the benefits of screening may have been top of mind. However, they remained non-adherent and a contradictory finding worth noting is that of the five non-adherers to present high perceived benefits, 60% (3/5) had missed 62% or more of their recommended colonoscopies and 60% (3/5) had experienced CRC themselves.

A finding that may account for their higher perceived benefits, despite their continued non-adherence, may be related to their adherent status, or their perception of their adherence status. It may be possible that because of their good attendance record the adherers assumed that the researcher knew that they understood the value of colonoscopies and suggested fewer benefits. However, the non-adherers, due to their non-adherent status, may have felt that it was important to demonstrate, despite being viewed as someone who has missed colonoscopies, that they did understand that colonoscopies are important. Related to this idea was a tendency to understate, or underestimate, the number of colonoscopies they had missed. Sixty-two and a half percent (5/8) did so, with one even saying she'd only missed one when in fact she'd missed six, according to the criteria for non-adherence. Additionally, ono-adherers tended to deny or downplay their non-adherent status, as evidenced by the following quotes:

R: How many colonoscopies have you missed?

"Just last year's one." (P12; 45 year old non-adherent female) [Had missed six]

"It was only last year. (P13; 47 year old non-adherent male) [Had missed four]

"No, we sometimes have them 2 times in the year."
(P14; 48 year old non-adherent female) [Had missed two]

"No, I don't miss any of them. That's the most important thing."
(P15; 51 year old non-adherent female) [Had missed two]

R: Why don't you go for colonoscopies?

P15: I will never miss one. Nothing will keep me away because it's for my own health. My children won't allow that.

R: What about the procedure?

P12: No, no, I've overcome that already, the... awkwardness about it, and having to drink that stuff, it has become part of, part of my... I just have to do it. There's no thing that I would say is a barrier, 'cause I have to do it.

Despite what they've said above, they were non-adherent and, on prompting, did list a number of barriers to screening. The denial, or minimising, of their perceived negative label, as someone who does not attend colonoscopies, may have influenced them to give more details concerning the benefits of screening.

In conclusion, a lack of perceived benefits does not appear to be a contributing factor to non-adherence within this sample.

Perceived barriers. Finally, perceived barriers are known to play a large role in predicting whether an individual will take part in a protective health action such as screening (Rosenstock et al., 1994). Perceived barriers have been investigated in terms of their influence on non-adherence to screening guidelines amongst individuals with LS (e.g. Bleiker et al., 2005; Pylvänäinen et al., 2006) as well as those at increased risk for CRC (e.g. Greiner et al., 2005; Jacobs, 2002; Menon et al., 2003; Weinberg et al., 2004; Zheng et al., 2006). The current study's participants were asked about what barriers to screening, if any, they had experienced, the findings of which are presented in Table F12, Appendix F.

The group as a whole. All eight adherers stated that they had not experienced any barriers. Some said they would "have to be dead or something to miss one" (P4, 26 year old adherent female, and P5, 26 year old adherent male), or said if they were to miss one, they would reschedule the appointment (P3 and P4, both 26 year old adherent females), and most were adamant in their lack of barriers. For example:

R: What about the costs involved? Would that not prevent you from going?

P8: No, nothing keep me away.

R: And the difficulty in getting there?

P8: No, it's not difficult.

R: What about if you're dealing with other things and you don't have time?

P8: No, I make time. I make time for me. Dr [X] said I must make time for me. The house is standing and I'm going, yes. (63 year old adherent female)

However, a large number of barriers, fitting into seven categories, were identified by the non-adherent participants. The most often cited barrier was that of difficulties in getting to the hospital, including transport difficulties, the financial cost of transport and walking up the hill to GSH. This barrier made up 26% of all listed barriers, and was suggested by 50% (4/8) of the non-adherers. Although far more prevalent amongst this sample than that of the literature, the barriers listed are consistent with those that have been demonstrated by previous studies amongst individuals at increased risk for CRC (e.g. Hadley et al., 2004; McCaffery et al., 2001; Viiala & Olynyk, 2008; Zheng et al., 2006). The four non-adherers to suggest this barrier are the same four non-adherers who earn a combined household income of R6400 or less per month. Therefore, organising and paying for transport may pose a significant barrier to this subset of the sample.

This was followed by a dislike of procedural related issues, such as discussing CRC and related topics, drinking the preparation liquid, the actual procedure and of hospitals (which made up 21.7% of all listed barriers, and was cited by 37.5% [3/8] of non-adherers). This barrier is common in previous research, and is often slightly more prevalent in the literature than in the current study. The barriers raised, however, are consistent with those demonstrated by previous studies amongst both LS individuals as well as individuals at increased risk of CRC (e.g. Harewood et al., 2002; James et al., 2002; McCaffery et al., 2001; Pylvänäinen et al., 2006; Wagner et al., 2005; Zheng et al., 2006). A possible explanation for its lower prevalence amongst this sample may be that, while participants were not limited in the number of barriers they listed, most tended to discuss one theme in detail, and while procedural related barriers may have, in fact, played a role for them, they might not have been the main barrier and, therefore, were focused on less. In accordance with this, no participant noted only procedural related barriers and rather listed them as being secondary to travelling difficulties, work-related issues or feeling healthy/not experiencing any symptoms.

Both work-related issues (such as having to take time off work to attend the colonoscopy and not having enough time to do so), and psychological issues relating to screening (such as anxiety over what they might find, wanting to wait for emotional support, the denial of symptoms and the need for mental preparedness), were the third most often suggested barriers. These made up 17.4% of the listed barriers but being suggested by 50% (4/8) and 37.5% (3/8) of the non-adherers respectively. These findings are consistent with previous research amongst LS patients and individuals at increased risk for CRC both in terms of the barriers identified as well as the frequency at which they were suggested (e.g.

McCaffery et al., 2001; Rawl et al., 2000; Viiala & Olynyk, 2008; Wagner et al., 2005; Zheng et al., 2006).

As adherers did not spontaneously offer any examples, they were asked to think of what might prevent them from adhering to colonoscopic screening. In response, they too proposed several of the barriers listed, emphasising the relevance or importance of barriers associated with travelling difficulties, taking time off work, a dislike of hospitals and procedural-related issues.

A lack of a doctor's recommendation as well as pain or procedural related embarrassment, two of the most often cited barriers in the literature, were, however, not mentioned by the current participants. The population from which this sample was drawn is part of a large ongoing research project within the Division of Human Genetics at the University of Cape Town in conjunction with GSH. The genetic coordinators are in constant contact with them, forming family pedigrees and recommending genetic counselling and testing, as well as endoscopic screening, to all members on the database. It is, therefore, unlikely that this particular sample, or population as a whole, would report not having been recommended to attend screening.

Concerning pain and embarrassment, the non-adherers had attended, on average, three colonoscopies each. Overcoming this barrier, may, therefore, account for its lack of prevalence within this sample. In support of this, P12, a 45 year old non-adherent female, stated, "No, no, I've overcome that already, the awkwardness about it".

In conclusion, the LS participants appeared to demonstrate high perceived barriers to screening via colonoscopies.

***Non-adherers compared with adherers*.** Only non-adherers listed barriers and many listed more than one perceived barrier. In addition, the barriers listed most often correspond with previous research. Consequently, the non-adherers appear to demonstrate (accurate) higher perceived barriers to screening than the adherers of this sample, which appears to be consistent with the previous research, that has found higher perceived barriers to be associated with non-adherence amongst individuals with LS (e.g. Bleiker et al., 2005; Pylvänäinen et al., 2006) as well as those at increased risk for CRC (e.g. Greiner et al., 2005; Jacobs, 2002; Menon et al., 2003; Weinberg et al., 2004; Zheng et al., 2006). Furthermore, while no statistics were performed on this qualitative data, the extent of the differences in knowledge or perceived importance of this particular HBM category, between adherers and

non-adherers, appears to demonstrate a large influence of this category on non-adherent behaviour. This, too, is consistent with previous studies, such as that of Bleiker et al. (2005), who found perceived barriers to be the only variable significantly related to screening delay or non-adherence.

An obvious explanation as to why non-adherers presented more barriers than the adherers is that they are non-adherent. The simple fact that they had missed a colonoscopy, and that many had missed more than one, indicates that they have experienced difficulties of some sort. It is also of interest to note that the two non-adherers to list the most barriers are also amongst the top four most non-adherent participants, having missed between 75% and 85% of their recommended colonoscopies. This may highlight a possible trend, where non-adherence is not only associated with perceived barriers, but where higher perceived barriers are also associated with a greater degree of non-adherence.

A further finding of interest is that of the four non-adherers to list the most barriers, 75% (3/4) had survived a personal cancer and none had experienced the death of a parent due to CRC. As has been demonstrated throughout, experience of cancer appears to play an enormous role amongst these participants, and the experience of survival of a cancer has been suggested as possibly being a contributing factor in minimising the threat of CRC. Therefore, surviving cancer may again be playing a role within screening, or adherence to screening, by diminishing the perceived importance of protecting against an already minimised threat.

Just as being non-adherent highlights an obvious difficulty with barriers, being adherent, and never having missed a colonoscopy, could indicate a general lack of barriers, which would account for the adherence rates, as well as the lack of perceived barriers amongst adherers. However, as the adherent group had similar sociodemographic characteristics to the non-adherent group, and should have encountered similar barriers, it is also possible that the adherers were more likely to overcome potential barriers, than the non-adherent group. For example, the most listed barrier was that of travelling difficulties, with a possible link to lower SES. However, 62.5% (5/8) of adherers earned a combined household income of R6400 or less per month. In fact, there were more adherers (62.5%; 5/8) than non-adherers (50%; 4/8) in this low SES group, and yet they did not suggest this barrier. In addition, of the participants to live a considerable distance from GSH, potentially contributing to the difficulties with transport, 75% (6/8) were adherers and, therefore, must have overcome barriers of various kinds to remain adherent.

One explanation for this propensity to overcome barriers may be related to their belief in the importance of colonoscopies in preventing cancer. Although non-adherers demonstrated high perceived benefits of colonoscopies, adherers demonstrated better knowledge and understanding of the aims of colonoscopies in the prevention of cancer. In addition, of the seven participants to experience the death of a parent due to CRC, 85.71% (6/7) were adherers. Where experiencing survival may have a minimising effect on the non-adherers, experiencing death may be a contributing factor to the minimisation of barriers and the continued adherence of the adherent group. Another explanation for their overcoming of barriers could be their belief in following their doctor's or the CRCGC's advice. When asked if they felt it was important to follow a doctor's recommendation, all of the adherers, but only 62.5% (5/8) of the non-adherers, believed it was, thereby potentially influencing their ability, or need, to overcome barriers.

A further reason as to why adherers may have perceived lower barriers than their non-adherent counterparts could relate to their psychological make-up. While the non-adherers tend to minimise the severity of CRC, the adherers tend to emphasise it. Further to this, slightly more adherers (57.14%; 4/7), than non-adherers (42.86%; 3/7), said they had experienced anxiety or depression at the time of receiving information on CRC, LS or their risk. They may, therefore, have an underlying worry, not present among the non-adherent group, which maximises threat, minimises barriers and influences their adherence.

In conclusion, non-adherence to screening guidelines in this sample appears to be associated with greater perceived barriers.

Conclusion. The knowledge of the LS participants differed according to category. Knowledge of terminology was poor with only 18.75% (3/16) being able to describe six of the seven terms investigated, and 12.5% (2/16) not being able to describe a single one. Apart from knowledge of CRC and the difference between pre-cancer and cancer (which was good), knowledge of threat was also generally poor. That is, very few participants were able to give good descriptions of what LS is, and only 25% (4/16) were able to answer all three questions relating to the development of cancer. In addition, only 40% (6/15) accurately perceived their susceptibility to the disease and one did not understand the concept of risk at all. However, 75% (12/16) accurately acknowledged that CRC is a serious disease.

In contrast, apart from knowledge of other protective actions, which was poor, knowledge of screening and associated ideas was comparatively good. That is,

comprehensive descriptions were given for colonoscopies, 75% (12/16) accurately stated the recommended frequency for screening, and seven comprehensive aims of screening were identified. In addition, a number of benefits and barriers to screening were identified. Therefore, in general, knowledge of the protective health action of screening by means of colonoscopies was good, while (apart from a high perceived severity) knowledge of threat was, in general, poor.

The knowledge of the non-adherers also differed according to category. The non-adherers demonstrated poorer knowledge and understanding, than the adherers, of terminology, and (apart from knowledge of CRC which was good) of threat. That is, in addition to suggesting fewer explanations, no non-adherers described the characteristics of non-polyposis CRC, none stated that having LS requires one to attend regular colonoscopies, and fewer non-adherers (50%; 4/8), than adherers (75%; 6/8), were able to answer two of the three questions relating to the development of cancer. In addition, a greater number of non-adherers, than adherers, demonstrated inconsistent ratings of risk (and, either a misunderstanding of, or a tendency to minimise risk) and a propensity to minimise severity of cancer (where the adherers tended to emphasise it). Furthermore, (apart from knowledge of other protective actions which was good), they demonstrated poorer knowledge, than their adherent counterparts, of screening and associated ideas. That is, although they listed the main aspects of colonoscopies, non-adherers suggested almost half the detail of adherers; 37.5% (3/8) non-adherers but only 12.5% (1/8) adherers demonstrated misperceptions regarding frequency of screening; and although slightly more aims were suggested by non-adherers, adherers were more likely to better explain the prevention of the development of cancer and were the only participants to suggest the testing and removal of polyps.

However, the non-adherers had high perceived benefits of colonoscopies and were the only participants to list barriers to colonoscopies. Therefore, in general, apart from benefits and barriers, the knowledge of the non-adherent participants appeared poorer than that of their adherent counterparts.

Neuropsychological Performance, Knowledge and Non-adherence

The findings pertaining to the neuropsychological functioning and knowledge of the LS participants have been reported in the previous two sections. The relationship between these variables, as well as their association with non-adherence, both individually and together, will now be discussed.

The group as a whole. The neuropsychological functioning of the LS participants was unremarkable. No statistically significant differences between the LS and the reference participants were found; and the performance of the LS participants was within the normal range of the reference group on all measures. Therefore, no deficit, either general or specific, was found among the LS participants of this sample.

The LS participants appeared to have poor knowledge concerning terminology and demonstrated low perceived susceptibility. In addition, apart from knowledge of CRC and the difference between pre-cancer and cancer (which was good), knowledge of threat was also generally poor. In contrast, apart from knowledge of other protective actions which was poor, knowledge of screening and associated ideas was good. In addition, the LS participants, as a group, demonstrated high perceived severity of CRC, as well as high perceived benefits of and barriers to screening.

Because the attainment of knowledge is dependent on one's cognitive functioning, it was expected that the most knowledgeable LS participants would also be the participants to perform the best on the neuropsychological measures. However, not only were the top four most knowledgeable participants ***not*** the best performing on the measures, but two consistently scored below the group mean, indicating a performance poorer than that of the average of the group. This finding was unexpected and implies that the attainment of knowledge, amongst this sample of LS participants, may be dependent on factors other than, or in addition to, that of their neuropsychological functioning.

Various suggestions, with regard to these other factors influencing the attainment of knowledge, have been raised in the previous section. For example, younger LS patients may be more motivated to learn and may have greater access to information than their older counterparts. Moreover, because being female has been associated with having knowledge of screening behaviours (see Beeker et al., 2000; Federici et al., 2006; Shapiro et al., 2001), it may also be associated with having knowledge of the other HBM categories. In accordance with this, 75% (3/4) of the four most knowledgeable participants were below the age of 28 years and were female.

Furthermore, those of a lower SES may have a number of more pressing and urgent obstacles and worries, such as providing for their families. These issues may, understandably, take precedence over the need for information regarding something that is perceived to be less pressing. In addition, a lower SES may, in a compounded way, through, for example, financial and transport barriers, limit access to information (and therefore knowledge). In

contrast, those of a higher SES are expected to have better access to information on CRC and screening. In this regard, 75% (3/4) of the four most knowledgeable participants were classed as being higher SES, earning a combined household income of R6401 or more per month.

Moreover, although level and quality of education is associated with performance on cognitive testing, education may also influence the attainment of knowledge in other ways. For example, more years of schooling may result in greater exposure to information (i.e. sources and volume of information). In addition, the perceptions of healthcare professionals, regarding the level of education of LS patients, may influence the way in which they educate them. This could result in more information, both in quantity and depth, being passed on to those deemed more capable of understanding and processing it. In accordance with this, 75% (3/4) of the four most knowledgeable participants had a tertiary education, suggesting that their level of education may have influenced their acquisition and retention of knowledge.

Psychological factors may also play a role. Of the most knowledgeable participants, 75% (3/4) had acquired information elsewhere and 50% (2/4) had subsequently made an effort to contact the CRCGC for additional information. Therefore, motivation to seek out information may be associated with greater knowledge.

Finally, as one would expect in a setting of familial cancers, experience of cancer is a consistent theme throughout this study; and personal experience of cancer may be an influential factor in the attainment of knowledge. This may be due either to increased exposure to information, resulting from more time spent at a healthcare facility (e.g. GSH) and with healthcare professionals, or to a greater motivation to acquire information in order to prevent the disease from recurring. However, regardless of the mechanism, as 75% (3/4) of the four most knowledgeable participants had previously had cancer themselves, surviving cancer appears to be associated with greater knowledge of the disease.

In this sample, therefore, while no neuropsychological deficit was noted, the LS participants demonstrated poor knowledge of threat, but better knowledge of protective action. It also appears probable that factors such as (a) sociodemographic variables including age, gender, SES and education, (b) psychological factors such as motivation to seek out information, and (c) survival of personal cancer, may be more important, than neuropsychological functioning, in the attainment of knowledge within the context of LS and CRC.

Non-adherers compared with adherers. Unexpectedly, although within the normal range of the reference participants, the non-adherers performed slightly better than the adherers on the majority of tasks. While no other results of significance were found, statistical analyses revealed that the non-adherers were slightly faster and made significantly less errors on the inhibition task ($p = .026$); and that they were significantly faster ($p = .013$) and made slightly fewer errors on the set shifting task. Therefore, poor neuropsychological functioning does not appear to be associated with non-adherence within this sample.

The non-adherers appeared to demonstrate poorer knowledge and understanding, than the adherers, of terminology, perceived susceptibility, and (apart from knowledge of CRC and of other protective actions, which was good) of threat as well as screening and associated ideas. However, the non-adherers demonstrated high perceived benefits of and barriers to colonoscopies.

Because non-adherence has been demonstrated to be associated with knowledge; and because the attainment of knowledge is dependent on one's neuropsychological functioning, it was expected that the non-adherers would (a) demonstrate poorer knowledge and (b) perform more poorly on the neuropsychological measures. However, although the non-adherers demonstrated poorer knowledge, as a group they performed slightly better on cognitive testing. In addition, two of the three ***least*** knowledgeable non-adherers consistently scored higher than the average of the LS group on the neuropsychological measures. While, in contrast, of the three ***most*** knowledgeable adherers, two consistently scored below the LS group mean, indicating a performance poorer than that of the average of the group. This finding implies that the attainment of knowledge, amongst this sample of LS participants, may be dependent on factors other than, or in addition to, neuropsychological functioning. This also implies that, although knowledge may be associated with non-adherence, poor neuropsychological functioning does not appear to be associated with non-adherence in this sample, nor does knowledge appear to be dependent on neuropsychological functioning alone, for its association with non-adherence.

Suggestions similar to those discussed above, may represent the other factors which may be influencing the attainment of knowledge. For example, all three of the least knowledgeable non-adherers had a low SES, earning a combined household income of R6400 or less per month, which may have contributed to their lack of knowledge due to barriers such as lack of access to information and lack of motivation for issues that are not a priority at present. In addition, although there were equal numbers of adherers and non-adherers who

spoke Afrikaans as their first language (therefore not accounting for the lack of knowledge amongst non-adherers as a group), all three of the least knowledgeable non-adherers were Afrikaans speaking. It is, therefore, possible that a communication barrier between the healthcare professionals and the researcher (generally English speaking) and the participants (generally Afrikaans speaking) reflected an unsatisfactory environment for the transfer of knowledge.

Although non-adherers had a greater level of education (therefore not accounting for their lack of knowledge), more non-adherers, than adherers, were employed on a part, or fulltime, basis. Moreover, the only participant to be unemployed was a non-adherer. Being too busy to take time off work and the priority of finding work were listed as barriers to adherence, and although non-adherers had less knowledge, most were aware that colonoscopies are important. Therefore, if employment related barriers are preventing them from attending an important procedure, they will probably be even less likely to take time off work to receive information on CRC and screening; and employment status may, thus, be an influential factor in the attainment of knowledge. In accordance with this, 66.66% (2/3) of the least knowledgeable non-adherers were employed on a fulltime basis, and 33.33% (1/3) were unemployed.

Quite obviously, direct exposure to information, as a result of their adherence status, could also be a large contributing variable to a lack of knowledge. Only the non-adherers had missed a colonoscopy, and 66.66% (2/3) of the least knowledgeable non-adherers had missed 50% or more of their recommended colonoscopies. This could, therefore, represent an important factor (other than neuropsychological functioning) that may influence the attainment of knowledge.

Although anxiety may motivate patients to pay more attention, when an individual is stressed or anxious, attentional narrowing may also cause only the primary message to be remembered (Kessels, 2003; Wessel et al., 2000). This can result in a considerable amount of information not being processed and, therefore, not being recalled, accounting for a deficit in knowledge. In accordance with this, although slightly fewer non-adherers (42.86%; 3/7), than adherers (57.14%; 4/7), acknowledged feelings of anxiety when initially receiving information (calling into question the accountability of this variable for the lack of knowledge of non-adherers as a group), 66.66% (2/3) of the least knowledgeable non-adherers admitted to feeling anxious initially. In addition, psychological factors may play a role. Although equal numbers of non-adherers and adherers had low susceptibility, 66.6% of

the three least knowledgeable non-adherers had low perceived risk. On average, non-adherers appeared less motivated to seek out additional information and, of the least knowledgeable non-adherers, (a) only 33.33% (1/3) had learned information elsewhere, (b) none had contacted the CRCGC later on, and (c) none had relied on a family member for information they did not understand or had forgotten. As a result, a lack of worry concerning personal risk, and a lack of motivation to seek out information, may also influence the attainment of knowledge.

Finally, the experience of cancer may be a contributing factor in obtaining knowledge. Although fewer non-adherers, than adherers, had experienced the death of a relative or parent, a greater number of non-adherers (57.14%; 4/7), than adherers (42.86%; 3/7), had survived cancer themselves. Moreover, only 33.33% (1/3) of the least knowledgeable non-adherers had survived cancer personally, only 33.33% (1/3) had experienced the death of a close relative and none had experienced the death of a parent. Therefore, a lack of exposure in these less knowledgeable non-adherers may have contributed to their lack of knowledge.

Therefore, in this sample, it appears likely that, although non-adherence may be related to a lack of knowledge, it is not related to poor neuropsychological functioning. Furthermore, the findings suggest that the association between non-adherence and knowledge, is not dependent on poor neuropsychological functioning, but rather on other factors such as (a) sociodemographic variables including age, SES, first language, and employment status, (b) exposure to information as a result of adherence, (c) psychological factors such as the experience of anxiety, as well as a lack of worry and motivation, and (d) experience of cancer.

Chapter Four:
Conclusions and Recommendations

Summary and Conclusion

The aim of this study was to investigate the neuropsychological functioning and knowledge, based on the HBM knowledge categories, of individuals with LS in the WC. In addition, it aimed to investigate how these factors relate to non-adherent behaviour.

The neuropsychological functioning of the participants (i.e. attention, comprehension, memory, and executive functioning) was assessed using well established neuropsychological measures. Because the norms for these tests are based on international populations, the performance of the LS participants was compared with that of a reference group, in order to better interpret their performance.

The LS participants were also questioned on their knowledge, in terms of the HBM constructs. In addition, knowledge of threat, and of protective health actions, has also been associated with non-adherence. Therefore, participants were also questioned on their knowledge of LS, CRC and of how cancer develops (ideas associated with the health threat) and on colonoscopies, the recommended frequency of colonoscopies, the (preventative) aims of screening, and other protective health actions (ideas associated with the protective health action).

The LS participants were first described as a group. On cognitive testing, no statistically significant differences were found between the LS and reference participants. Therefore, no deficit, either general or specific, was demonstrated among the LS participants of this sample. Knowledge of the protective health action of screening appeared good, while (apart from a high perceived severity), knowledge of threat was, in general, poor. In addition, it appeared that the attainment of knowledge, among the LS participants of this sample, was not necessarily dependent on their neuropsychological functioning, and that other sociodemographic and psychological factors may be playing a role.

The non-adherers were then compared with the adherers. Unexpectedly, although within the normal range of the reference participants, the non-adherers performed slightly better than the adherers on the majority of tasks, and significantly better on executive functioning tasks of inhibition and set shifting. Therefore, non-adherence did not appear to be associated with neuropsychological functioning in this sample. However, as expected, apart from high benefits, the knowledge of the non-adherent participants appeared poorer than that of the adherent participants. Therefore, in this sample, knowledge, or more importantly a lack

thereof, appeared to be associated with non-adherence. Furthermore, it was demonstrated that the attainment of knowledge appeared to be dependent on factors other than, or in addition to, that of neuropsychological functioning.

In conclusion, non-adherence has been demonstrated to be associated with a lack of knowledge, and the attainment of knowledge is known to be dependent on neuropsychological functioning. However, the findings of this study suggest that, in this limited sample of LS participants from the WC, although knowledge may be associated with non-adherence, neuropsychological functioning does not appear to be associated with non-adherence, and knowledge does not appear to be exclusively dependant on neuropsychological functioning for its association with non-adherence. This study, therefore, identified unexpected findings with regard to the relationships between neuropsychological functioning, knowledge and non-adherence within the context of LS.

Recommendations for the Division of Human Genetics

Factors, associated with neuropsychological functioning, that could be addressed to improve rates of screening via intervention were not identified. However, knowledge amongst the participants in general, and amongst non-adherers in particular, was found to be poor. While a lack of knowledge amongst non-adherers may be a resultant factor due to lack of exposure, it may also be a causative factor in remaining non-adherent to screening guidelines. Therefore, strategies to improve knowledge, pertaining to both threat and protective action, may be beneficial in increasing adherence rates and decreasing rates of CRC morbidity and mortality.

Recommendations for Future Research

During the course of this research, and as a result of the findings, a number of ideas building on this study emerged:

1. A minor trend of poorer performance on memory was demonstrated by the non-adherers. Future studies might, therefore, investigate the genes implicated in LS, and particularly that of h*MSH2,* and their impact on memory; and the impact of potential paraneoplastic syndromes as a result of CRC.
2. Furthermore, the memory task utilised in the current study was an audioverbal recall task, as patients within the context of LS are often required to encode and remember information given verbally, without a prompt or cue. However, prospective memory

(i.e. remembering to carry out an action at a future time) may also be implicated in screening.

In a study concerning prospective memory by Verdaha et al. (2004), older adults more often made errors of omission (i.e. forgetting to perform the task) than commission (i.e. performing the task more often than required). However, when cues were given, the prospective memory performance of the participants improved three fold. Therefore, because screening involves remembering to implement an action in the future (often without prompting), difficulties with this type of memory may be associated with non-adherence. Inclusion of a measure of prospective memory may, therefore, highlight important findings regarding non-adherence to screening guidelines.

3. A recommendation has been made above, for the Division of Human Genetics, to investigate ways of improving knowledge amongst LS patients in order to increase adherence rates. However, insight into ***why*** there is a lack of knowledge amongst this group is of equal importance. This study found that neuropsychological functioning does not appear to account for the lack of knowledge amongst this group. However, because knowledge amongst this group was poor, it is clear that something else is accounting for this finding.

   Additional possibilities are, therefore, worth exploring in future research. While this was not the main focus of the study, a number of factors influencing the attainment of knowledge, other than that of neuropsychological functioning, were suggested. These included (a) sociodemographic variables including age, gender, SES, first language, employment status and education, (b) psychological factors such as the experience of anxiety, as well as a lack of worry and motivation to seek out information, (c) exposure to information as a result of adherence, and (d) experience of cancer. Therefore, a possibility for future research could be to explore these suggestions, as well as additional hypotheses, in more depth, in order to better understand the relationship between knowledge (or a lack thereof) and non-adherence.

4. Although also not the main focus of the current study, a number of interesting findings, which could be explored further, emerged from the data concerning knowledge. For example, (a) whether knowledge is a causal or resultant factor in non-adherence, (b) the non-adherers' apparent tendency to minimise perceived severity and susceptibility and the impact of this on non-adherence, (c) the non-adherers'

tendency to underestimate their number of missed colonoscopies and to deny or downplay their non-adherent status, and (d) the influence of knowledge of other protective actions on non-adherence to endoscopic screening.

5. In addition to knowledge, a number of other barriers to adherence, such as difficulties in taking time off work, being unemployed and being part of a lower SES group, were also identified by the current study. However, the extent to which these, as individual variables or in conjunction with knowledge, influence non-adherence in the South African LS population is not known. Therefore, future research could explore barriers pertinent to a South African population by way of a factor analysis. This may identify which barriers, alone or in which combinations, are the most influential in terms of non-adherence.
6. Although the effects of different degrees of non-adherence were recognised in the methodology, for simplicity in analysis, the current study employed strict criteria for non-adherence, including anyone who had missed one (or more) colonoscopy, without rescheduling within a year. Taking different degrees of non-adherence into account, or a change in behaviour (i.e. becoming adherent after a number of years of being non-adherent) may reveal interesting findings in terms of quantity and quality of knowledge, as well as reasons for non-adherence.
7. Finally, incomplete medical records may have been obtained due to stigma, embarrassment or forgetfulness. Inclusion of variables such as HIV status, and accurate records of the other medical factors, will be useful within a future neuropsychological approach to non-adherence. Furthermore, while none of the participants noted current use of medication such as anti-depressants, anti-anxiety or psychotropic medication, a comparison of those taking and those not taking such medications, may reveal findings of interest regarding neuropsychological functioning, knowledge and non-adherence.

List of References

Adelman, R. D., Greene, M. G., & Ory, M. G. (2000). Communication between older patients and their physicians. *Clinics in Geriatric Medicine, 16,* 1-24.

Ahles, T. A. & Saykin, A. J. (2007). Candidate mechanisms for chemotherapy-induced cognitive changes. *Nature Reviews: Cancer, 7,* 192-201.

Aitchison, J. & Harley, A. (2004). *South African Illiteracy Statistics and the Case of the Magically growing number of literacy and ABET learners.* Pietermaritzburg: Centre for Adult Education, University of KwaZulu-Natal.

Aktan-Collan, K., Haukkala, A., Mecklin, J-P., Uutela, A., & Kääriäinen, H. (2001a). Psychological consequences of predictive testing for hereditary non-polyposis colorectal cancer (HNPCC): A prospective follow-up study. *International Journal of Cancer, 93,* 608-611.

Aktan-Collan, K., Haukkala, A., Mecklin, J-P., Uutela, A., & Kääriäinen, H. (2001b). Comprehension of cancer risk one and 12 months after predictive genetic testing for hereditary non-polyposis colorectal cancer. *Journal of Medical Genetics, 38,* 787-792.

Aktan-Collan, K., Mecklin, J-P., Jarvinen, H., Nystrom-Lahti, M., Peltomaki, P., Soderling, I., Uutela, A., de la Chapelle, A., & Kaarianen, H. (2000). Predictive genetic testing for hereditary non-polyposis colorectal cancer: Uptake and long-term satisfaction. *International Journal of Cancer, 89,* 44-50.

Alcock, K. J., Holding, P. A., Mung'ala-Odera, V., & Newton, C. R. J. C. (2008). Constructing tests of cognitive abilities for schooled and unschooled children. *Journal of Cross-Cultural Psychology, 39,* 529-551.

Anderson, D. W., Goldberg, P. A., Algar, U., Felix, R., & Ramesar, R. S. (2007). Mobile colonoscopic surveillance provides quality care for hereditary nonpolyposis colorectal carcinoma families in South Africa. *Colorectal Disease, 9,* 509-514.

Andrykowski, M. A., Munn, R. K., & Studts, J. L. (1996). Interest in learning personal genetic risk for cancer: A general population survey. *Preventive Medicine, 25,* 527-536.

Arciniegas, D., Adler, L., Topkoff, J., Cawthra, E., Filley, C. M., & Reite, M. (1999). Attention and memory dysfunction after traumatic brain injury: Cholinergic mechanisms, sensory gating, and a hypothesis for further investigation. *Brain Injury, 13,* 1-13.

Autosomal dominant inheritance (n. d.). Retrieved October 15, 2010, from http://www.inheritedhealth.com/condition/Patterns_of_Inheritance/253.

Bagner, D. M., Williams, L. B., Geffken, G. R., Silverstein, J. H., & Storch, E. A. (2007). Type 1 diabetes in youth: The relationship between adherence and executive functioning. *Children's Healthcare, 36,* 169-179.

Balchin, R. (2008). *The genesis and development of the Groote Schuur neurocognitive screening battery: A neurocognitive screening tool for the South African context.* (Unpublished doctorate thesis). University of Cape Town, South Africa.

Baltes, P.B. & Lindenberger, U. (1997). Emergence of a powerful connection between sensory and cognitive functions across the adult life span: A new window to the study of cognitive aging? *Psychology and Aging, 12,* 12-21.

Bartlett, S. J., Lukk, P., Butz, A., Lampros-Klein, F., & Rand, C. S. (2002). Enhancing medication adherence among inner-city children with asthma: Results from pilot studies. *Journal of Asthma, 39,* 47-54.

Beeker, C., Kraft, J. M., Southwell, B.G., & Jorgensen, C. M. (2000). Colorectal cancer screening in older men and women: Qualitative research findings and implications for interventions. *Journal of Community Health, 25,* 263-278.

Belloni, M., Uberti, D., Rizzini, C., Ferrari-Toninelli, G., Rizzonelli, P., Jiricny, J., Spano, P., & Memo, M. (1999). Distribution and kainite-mediated induction of the DNA mismatch repair protein MSH2 in rat brain. *Neuroscience, 94,* 1323-1331.

Bleiker, E. M. A., Nenko, F. H., Taal, B. G., Kluijt, I., Wever, L. D. V., Gerritsna, M. A., Vasen, H. F. A., & Aaronson, N. K. (2003). Experience of discharge from colonoscopy of mutation negative HNPCC family members. *Journal of Medical Genetics, 40,* 55-56.

Bleiker, E. M., Menko, F. H., Taal, B. G., Kluijt, I., Wever, L. D., Gerritsma, M. A., Vasen, H. F., & Aaronson, N. K. (2005). Screening behaviour of individuals at high risk for colorectal cancer. *Gastroenterology, 128,* 280-287.

Bopp, K.L. & Verhaeghen, P. (2005). Aging and verbal memory span: A meta-analysis. *Psychological Sciences, 60B,* 223-233.

Bostick, R. M., Potter, J. D., Kushi, L. H., Sellers, T. A., Steinmetz, K. A., McKenzie, D. R., Gapstur, S. M., & Folsom, A. R. (1994). Sugar, meat, and fat intake, and non-dietary risk factors for colon cancer incidence in Iowa women (United States). *Cancer Causes and Control, 5,* 38-52.

Bottomley, A. (1998). Depression in cancer patients: A literature review. *European Journal of Cancer Care, 7,* 181-191.

Bradshaw, D., Nannan, N., Laubscher, R., Groenewals, P., Joubert, J., Nojilana, B., Norman, R., Pieterse, D., & Schneider, M. (2000). *South African National Burden of Disease Study: Estimates of Provincial Mortality 2000*. Western Cape Province: Burden of Disease Research Unit.

Brand, A. N., Jolles, J., & Gispen-de Wied, C. (1992). Recall and recognition memory deficits in depression. *Journal of Affective Disorders, 25,* 77-86.

Brink, H. (2006). *Fundamentals of research methodology for health care professionals (2nd ed.)*. Lansdowne, Cape Town: Juta & Co. (Pty) Ltd.

Brotherstone, H., Miles, A., Robb, K., Atkin, W., & Wardle, J. (2006). The impact of illustrations on public understanding of the aim of cancer screening. *Patient Education and Counseling, 63,* 328-335.

Brown, S.C. & Park, D.C. (2003). Theoretical models of cognitive aging and implications for translational research in medicine. *The Gerontologist, 43,* 57-67.

Bunn, J. Y., Bosompra, K., Ashikaga, T., Flynn, B. S., & Worden, J. K. (2002). Factors influencing intention to obtain a genetic test for colon cancer risk: A population based study. *Preventive Medicine, 34,* 567-577.

Burton, G. V., Bullard, D. E., Walther, P. J., & Burger, P. C. (1988). Paraneoplastic limbic encephalopathy with testicular carcinoma: A reversible neurologic syndrome. *Cancer, 62,* 2248-2251.

Capuron, L., Ravaud, A., & Dantzer, R. (2001). Timing and specificity of the cognitive changes induced by interleukin-2 and interferon-alpha treatments in cancer patients. *Psychosomatic Medicince, 63,* 376-386.

Card, D. & Krueger, A. B. (1992). Does school quality matter? Returns to education and the characteristics of public schools in the United States. *The Journal of Political Economy, 100,* 1-40.

Carter, J. A., Neville, B. G. R., & Newton, C. R. J. C. (2003). Neuro-cognitive impairment following acquired central nervous system infections in childhood: A systematic review. *Brain Research Reviews, 43,* 57-69.

Cascino, T.L., Leavengood, J.M., Kemeny, N., & Posner, J.B. (1983). Brain metastases from colon cancer. *Journal of Neuro-Oncology, 1,* 203-209.

Case, A. & Yogo, M. (1999). Does school quality matter? Returns to education and the characteristics of schools in South Africa. *National Bureau of Economic Research: Working Paper Series, 7399.* Retrieved August 15, 2009, from http://www.nber.org/papers/w7399.

Claes, E., Denayer, L., Evers-Kiebooms, G., Boogaerts, A., & Legius, E. (2004). Predictive testing for hereditary non-polyposis colorectal cancer: Motivation, illness representations and short-term psychological impact. *Patient Education and Counseling, 55,* 265-274.

Codori, A-M., Petersen, G. M., Miglioretti, D.L., & Boyd, P. (2001). Health beliefs and endoscopic screening for colorectal cancer: Potential for cancer prevention. *Preventive Medicine, 33,* 128-136.

Codori, A-M., Petersen G. M., Miglioretti, D. L., Larkin, E. K., Bushey, M. T., Young, C., Brensinger, J. D., Johnson, K., Bacon, J. A., & Booker, S. V. (1999). Attitudes toward colon cancer gene testing: Factors predicting test uptake. *Cancer Epidemiology, Biomarkers and Prevention, 8,* 345-351.

Collins, V., Halliday, J., Warren, R., & Williamson, R. (2000). Cancer worries, risk perceptions and associations with interest in DNA testing and clinic satisfaction in a familial colorectal cancer clinic. *Clinical Genetics, 58,* 460-468.

Collins, V., Meiser, B., Gaff, C., St. John, D. J. B., & Halliday, J. (2005). Screening and preventive behaviors one year after predictive genetic testing for hereditary nonpolyposis colorectal carcinoma. *Cancer, 104,* 273-278.

Concrete vs. abstract thinking (n. d.) Retrieved October 20, 2009, from http://www.bianys.org/learnet/tutorials/concrete_vs_abstract_thinking.html.

Cousins, S. D. (1989). Culture and self-perception in Japan and the United States. *Journal of Personality and Social Psychology, 56,* 124-131.

Croyle, R. T. & Lerman, C. (1999). Risk communication in genetic testing for cancer susceptibility. *Journal of the National Cancer Institute Monographs, 25,* 59-66.

Dalgleish, T. & Watts, F. N. (1990). Biases of attention and memory in disorders of anxiety and depression. *Clinical Psychology Review, 10,* 589-604.

Dalmau, J., Gleichman, A. J., Hughes, E. G., Rossi, J. E., Peng, X., Lai, M., Dessain, S. K., Rosenfeld, M. R., Balice-Gordon, R., & Lynch, D. R. (2008). Anti-NMDA-receptor encephalitis: Case series and analysis of the effects of antibodies. *The Lancet Neurology, 7,* 1091-1098.

Darling-Hammond, L. (1999). *Teacher quality and student achievement: A review of state policy evidence*. University of Washington, U. S. A.: Centre for the Study of Teaching and Policy.

Davis, T. C., Dolan, N. C., Ferreira, M. R., Tomori, C., Green, K. W., Sipler, A. M., & Bennett, C. L. (2001). The role of inadequate health literacy skills in colorectal cancer screening. *Cancer Investigation, 19,* 193-200.

Degl'Innocenty, A., Ågren, H., & Bäckman, L. (1998). Executive deficits in major depression. *ACTA Psychiatrica Scandinavica, 97,* 182-188.

Delis, D. C., Kaplan, E., & Kramer, J. H. (2001). *Delis Kaplan Executive Function System (D-KEFS).* U. S. A.: The Psychological Corporation.

Doak, C. C., Doak, L. G., Friedell, G. H., & Meade, C. D. (1998). Improving comprehension for cancer patients with low literacy skills: Strategies for clinicians. *CA Cancer Journal for Clinicians, 48,* 151-162.

Domanska, K., Nilbert, M., Soller, M., Silfverberg, B., & Carlsson, C. (2007). Discrepancies between estimated and perceived risk of cancer among individuals with hereditary non-polyposis colorectal cancer. *Genetic Testing, 11,* 183-186.

Donovan, J. M. & Syngal, S. (1998). Colorectal cancer in women: An underappreciated but preventable risk. *Journal of Women's Health, 7,* 45-48.

Echlin, K. N. & Rees, C. E. (2002). Information needs and information-seeking behaviours of men with prostate cancer and their partners: A review of the literature. *Cancer Nursing, 25,* 35-41.

Elias, P. K., Elias, M. F., Robbins, M. A., & Budge, M. M. (2004). Blood pressure-related cognitive decline: Does age make a difference? *Hypertension, 44,* 631-636.

Elliott, R. (1998). The neuropsychological profile in unipolar depression. *Trends in Cognitive Sciences, 2,* 447-454.

Engle, R. W. (2002). Working memory capacity as executive attention. *Current Directions in Psychological Science, 11,* 19-23.

Espinosa, L. M. (2003). High-quality preschool: Why we need it and what it looks like. *National Institute for Early Education Research: Preschool Policy Facts, 1,* 1-10.

Everson, S. A., Maty, S. C., Lynch, J. W., & Kaplan, G. A. (2002). Epidemiologic evidence for the relation between socioeconomic status and depression, obesity, and diabetes. *Journal of Psychosomatic Research, 53,* 891-895.

Federici, A., Marinacci, C., Mangia, M., Borgia, P., Rossi, P.G., & Guasticchi, G. (2006). Is the type of test used for mass colorectal cancer screening a determinant of compliance? A cluser-randomized controlled trial comparing fecal occult blood testing with flexible sigmoidoscopy. *Cancer Detection and Prevention, 30,* 347-353.

Fox, S. A., Heritage, J., Stockdale, S. E., Asch, S. M., Duan, N., & Reise, S. P. (2009). Cancer screening adherence: Does physician-patient communication matter? *Patient Education and Counseling, 75,* 178-184.

Francisconi, S., Codenotti, M., Toninelli, G. F., Uberti, D., & Memo, M. (2006). Mitochondrial dysfunction and increased sensitivity to excitotoxicity in mice deficient in DNA mismatch repair. *Journal of Neurochemistry, 98,* 223-233.

Friedman, D. B. & Hoffman-Goetz, L. (2007). An exploratory study of older adults' comprehension of printed cancer information: Is readability a key factor? *Journal of Health Communication, 12,* 423-437.

Friedman, N. P., Miyake, A., Corley, R. P., Young, S. E., DeFries, J. C., & Hewitt, J. K. (2006). Not all executive functions are related to intelligence. *Psychological Science, 17,* 172-179.

Fuchs, C. S., Giovannucci., E.L., Colditz, G. A., Hunter, D. J., Stampfer, M. J., Rosner, B., Speizer, F. E., & Willett, W. C. (1999). Dietary fiber and the risk of colorectal cancer and adenoma in women. *The New England Journal of Medicine, 340,* 169-176.

Garcia-Molina, A., Roig-Rovira, T., Ensenat-Cantallops, A., Sanchez-Carrion, R., Pico-Azanza, N., Bernabeu, M., & Tormos, J. M. (2006). Neuropsychological profile of persons with anoxic brain injury: Differences regarding physiopathological mechanism. *Brain Injury, 20,* 1139-1145.

Geary, J., Thomas, J. W., Mackay, J., Dorkins, H., Barwell, J., & Hodgson, S. (2007). The management of families affected by hereditary non-polyposis colorectal cancer (HNPCC). *Familial Cancer, 6,* 13-19.

Glanz, K., Grove, J., Lerman, C., Gotay, C., & Le Marchand, L. (1999). Correlates of intentions to obtain genetic counselling and colorectal cancer gene testing among at-risk relatives from three ethnic groups. *Cancer Epidemiology, Biomarkers and Prevention, 8,* 329-336.

Glass, J. D. & Johnson, R. T. (1996). Human immunodeficiency virus and the brain. *Annual Reviews Neuroscience, 19,* 1-26.

Gorin, S. S. & Heck, J. E. (2005). Cancer screening among Latino subgroups in the United States. *Preventive Medicine, 40,* 515-526.

Gorin, S. S. (2005). Correlates of colorectal cancer screening compliance among urban Hispanics. *Journal of Behavioural Medicine, 28,* 125-137.

Grady, C.L. & Craik, F.I.M. (2000). Changes in memory processing with age. *Cognitive Neuroscience, 10,* 224-231.

Greenfield, P. M. (1972). Oral or written language: The consequences for cognitive development in Africa, the United States, and England. *Language and Speech, 15,* 169-178.

Greiner, K. A., Born, W., Nollen, N., & Ahluwalia, J. S. (2005). Knowledge and perceptions of colorectal cancer screening among urban African Americans. *Journal of General Internal Medicine, 20,* 977-983.

Griffin, J. M., Struve, J. K., Collins, D., Liu, A., Nelson, D. B., & Bloomfield, H. E. (2006). Long term clinical trials: How much information do participants retain from the informed consent process? *Contemporary Clinical Trials, 27,* 441-448.

Guerra, C. E., Dominguez, F., & Shea, J. A. (2005). Literacy and knowledge, attitudes, and behaviour about colorectal cancer screening. *Journal of Health Communication, 10,* 651-663.

Gultekin, S. H., Rosenfeld, M. R., Voltz, R., Eichen, J., Posner, J. B., & Dalmau, J. (2000). Paraneoplastic limbic encephalitis: Neurological symptoms, immunological findings and tumour association in 50 patients. *Brain, 123,* 1481-1494.

Hadley, D. W., Jenkins, J. F., Dimond, E., de Carvalho, M., Kirsch, I., & Palmer, C. G. S. (2004). Colon cancer screening practices after genetic counselling and testing for hereditary nonpolyposis colorectal cancer. *Journal of Clinical Oncology, 22,* 39-44.

Hadley, D. W., Jenkins, J., Dimond, E., Nakahara, K., Grogan, L., Liewehr, D. J., Steinberg, S. M., & Kirsch, I. (2003). Genetic counselling and testing in families with hereditary nonpolyposis colorectal cancer. *Archives of Internal Medicine, 163,* 573-581.

Haist, F., Shimamura, A. P., & Squire, L. R. (1992). On the relationship between recall and recognition memory. *Journal of Experimental Psychology, 18,* 691-702.

Harewood, G.C., Wiersma, M.J., & Melton, L.J. (2002). A prospective, controlled assessment of factors influencing acceptance of screening colonoscopy. *The American Journal of Gastroenterology, 97,* 3186-3194

Harvey, M. A., Sellman, J. D., Porter, R. J., & Frampton, C. M. (2007). The relationship between non-acute adolescent cannabis use and cognition. *Drug and Alcohol Review, 26,* 309-319.

Haynes, R. B. & McKibbon, K. A. (1996). Systemic review of randomized trials of interventions to assist patients to follow prescriptions for medications. *Lancet, 348,* 383-386.

Henning, P. & Knowles, A. (1990). Factors influencing women over 40 years to take precautions against cervical cancer. *Journal of Applied Social Psychology, 20,* 1612-1621.

Hess, T.M. (2005). Memory and aging in context. *Psychological Bulletin, 131,* 383-406.

Heyneman, S. P. & Loxley, W. A. (1983). The effect of primary-school quality on academic achievement across twenty-nine high- and low-income countries. *The American Journal of Sociology, 88,* 1162-1194.

Hokkanen, L. & Launes, J. (2000). Cognitive outcome in acute sporadic encephalitis. *Neuropsychology Review, 10,* 151-167.

Holloway, I. & Wheeler, S. (1996). *Qualitative research for nurses*. Osney Mead, Oxford: Blackwell Science Ltd.

Holloway, I. (2008). *A-Z of Qualitative Research in Healthcare (2nd ed.)*. United Kingdom: Blackwell Publishing Ltd.

Houts, P. S., Doak, C. C., Doak, L. G., & Loscalzo, M. J. (2006). The role of pictures in improving health communication: A review of research on attention, comprehension, recall, and adherence. *Patient Education and Counseling, 61*, 173-190.

Hughes Halbert, C., Lynch, H., Lynch, J., Main, D., Kucharski, S., Rustgi, A. K., & Lerman, C. (2004). Colon cancer screening practices following genetic testing for hereditary nonpolyposis colon cancer (HNPCC) mutations. *Archives of Internal Medicine, 164,* 1881-1887.

Insel, K., Morrow, D., Brewer, B., & Figueredo, A. (2006). Executive function, working memory, and medication adherence among older adults. *Journal of Gerontology: Psychological Sciences, 61B*, 102-107.

Jacobs, L. A. (2002). Health beliefs of first-degree relatives of individuals with colorectal cancer and participation in health maintenance visits: A population-based survey. *Cancer Nursing, 25*, 251-265.

James, A. S., Campbell, M. K., & Hudson, M. A. (2002). Perceived barriers and benefits to colon cancer screening among African Americans in North Carolina: How does perception relate to screening behaviour? *Cancer Epidemiology, Biomarkers and Prevention, 11*, 529-534.

Jansen, J., Butow, P. N., van Weert, J. C. M., van Dulmen, S., Devine, R. J., Heeren, T. J., Bensing, J. M., & Tattersall, M. H. N. (2008). Does age really matter? Recall of information presented to newly referred patients with cancer. *Journal of Clinical Oncology, 26,* 5450-5457.

Janz, N. & Becker, M. H. (1984). The health belief model: A decade later. *Health Education Quarterly, 11,* 1-47.

Johnson, K. A., Trimbath, J. D., Petersen, G. M., Griffin, C. A., & Giardiello, F. M. (2002). Impact of genetic counselling and testing on colorectal cancer screening behaviour. *Genetic Testing, 6,* 303-306.

Johnson, R. L., Roter, D., Powe, N. R., & Cooper, L. A. (2004). Patient race/ethnicity and quality of patient-physician communication during medical visits. *American Journal of Public Health, 94,* 2084-2090.

Jurado, M. B. & Rosselli, M. (2007). The elusive nature of executive functions: A review of our current understanding. *Neuropsychological Review, 17,* 213-233.

Kamangar, F., Dores, G. M., & Anderson, W. F. (2006). Patterns of cancer incidence, mortality, and prevalence across five continents: Defining priorities to reduce cancer disparities in different geographic regions of the world. *Journal of Cancer Oncology, 24,* 2137-2150.

Kessels, R. P. C. (2003). Patients' memory for medical information. *Journal of the Royal Society of Medicine, 96,* 219-222.

Kickbusch, I. S. (2001). Health literacy: Addressing the health and education divide. *Health Promotion International, 16,* 289-297.

Kihara, M., Carter, J. A., & Newton, C. R. J. C. (2006). The effect of plasmodium falciparum on cognition: A systematic review. *Tropical Medicine and International Health, 11,* 386-397.

Kim, K., Yu, E. S. H., Chen, E. H., Kim, J., & Brintnall, R. A. (1998). Colorectal cancer screening: Knowledge and practices among Korean Americans. *Cancer Practice, 6,* 167-175.

Koehly, L. M., Peterson, S. K., Watts, B. G., Kempf, K. K. G., Vernon, S. W., & Gritz, E. R. (2003). A social network analysis of communication about HNPCC genetic testing and family functioning. *Cancer Epidemiology, Biomarkers & Prevention, 12,* 304-313.

Kronish, I. M., Rieckmann, N., Halm, E. A., Shimbo, D., Vorchheimer, D., Haas, D. C., & Davidson, K. W. (2006). Persistent depression affects adherence to secondary prevention behaviours after acute coronary syndromes. *Journal of General Internal Medicine, 21,* 1178-1183.

Kruger, B. J. (2005). *Hereditary nonployposis colorectal cancer: Factors contributing to adherence and non-adherence to surveillance for mutation carriers in rural areas of the Northern and Western Cape.* Masters thesis. University of Cape Town, South Africa.

Lagae, L. (2006). Cognitive side effects of anti-epileptic drugs: The relevance in childhood epilepsy. *Seizure, 15,* 235-241.

Lasser, K. E., Ayanian, J. Z., Fletcher, R. H., & DelVecchio Good, M-J. (2008). Barriers to colorectal cancer screening in community health centers: A qualitative study. *Bio Med Central Family Practice, 9,* 15.

Lavelle-Jones, C., Byrne, D. J., Rice, P., & Cuschieri, A. (1993). Factors affecting quality of informed consent. *British Medical Journal, 306,* 885-890.

Lehto, J. (1996). Are executive function tests dependent on working memory capacity? *The Quarterly Journal of Experimental Psychology, 49A,* 29-50.

Lerman, C., Daly, M., Sands, C., Balshem, A., Lustbader, E., Heggan, T., Goldstein, L., James, J., & Engstrom, P. (1993). Mammography adherence and psychological distress among women at risk for breast cancer. *Journal of the National Cancer Institute, 85,* 1074-1080.

Lerman, C., Hughes, C., Trock, B. J., Myers, R. E., Main, D., Bonney, A., Abbaszadegan, M. R., Harty, A. E., Franklin, B. A., Lynch, J. F., & Lynch, H. T. (1999). Genetic testing in families with hereditary nonpolyposis colon cancer. *The Journal of the American Medical Association, 281,* 1618-1622.

Lerman, C., Marshall, J., Audrain, J., & Gomez-Caminero, A. (1996). Genetic testing for colon cancer susceptibility: Anticipated reactions of patients and challenges to providers. *International Journal of Cancer, 69,* 58-61.

Lezak, M. D. (1983). *Neuropsychological Assessment (2nd ed.).* New York, NY: Oxford University Press.

Liljegren, A., Lindgren, G., Brandberg, Y., Rotstien, S., Nilsson, B., Hatschek, T., Jaramillo, E., & Lindblom, A. (2004). Individuals with an increased risk of colorectal cancer: Perceived benefits and psychological aspects of surveillance by means of regular colonoscopies. *Journal of Clinical Oncology, 22,* 1736-1742.

Lincoln, Y. & Guba, E. (1985). *Understanding and doing naturalistic inquiry.* Beverly Hills, Calif: SAGE Publications Ltd.

Lorant, V., Deliège, D., Eaton, W., Robert, A., Philippot, P., & Ansseau, M. (2003). Socioeconomic inequalities in depression: A meta-analysis. *American Journal of Epidemiology, 157,* 98-112.

Luchsinger, J. A., Reitz, C., Patel, B., Tang, M-X., Manly, J. J., & Mayeux, R. (2007). Relation of diabetes to mild cognitive impairment. *Archives of Neurology, 64,* 570-575.

Lundqvist, T. (2005). Cognitive consequences of cannabis use: Comparison with abuse of stimulants and heroin with regard to attention, memory and executive functions. *Pharmacology, Biochemistry and Behaviour, 81,* 319-330.

Luria, A. R. & Tsvetkova, L. S (1990). *The neuropsychological analysis of problem solving.* Orlando, Florida: Paul M. Deutsch Press Inc.

Lynch, H. T. & de la Chapelle, A. (1999). Genetic susceptibility to non-polyposis colorectal cancer. *Journal of Medical Genetics, 36,* 801-818.

Lynch, H. T. & de la Chapelle, A. (2003). Hereditary colorectal cancer. *The New England Journal of Medicine, 348,* 919-932.

Mack, L. A. (2008). *Colorectal cancer screening among first-degree relatives of colorectal cancer patients: Benefits and barriers.* Masters thesis. Department of Community Health Sciences, University of Calgary.

Madlensky, L., Esplen, M. J., Gallinger, S., McLaughlin, J. R., & Goel, V. (2003). Relatives of colorectal cancer patients: Factors associated with screening behaviour. *American Journal of Preventive Medicine, 25,* 187-194.

Manly, J.J., Jacobs, D.M., Touradji, P., Small, S. A., & Stern, Y. (2002). Reading level attenuates differences in neuropsychological test performance between African American and White elders. *Journal of the International Neuropsychological Society, 8,* 341-348.

McAlearney, A.S., Reeves, K. W., Dickinson, S.L., Kelly, K. M., Tatum, C., Katz, M. L., & Paskett, E.D. (2008). Racial differences in colorectal cancer screening practices and knowledge within a low-income population. *Cancer, 112,* 391-398.

McCaffery, K., Borril, J., Williamson, S., Taylor, T., Sutton, S., Atkin, W., & Wardle, J. (2001). Declining the offer of flexible sigmoidoscopy screening for bowel cancer: A qualitative investigation of the decision-making process. *Social Science and Medicine, 53,* 679-691.

McCann, S., MacAuley, D., Barnett, Y., Bunting, B., Bradley, A., Jeffers, L., & Morrison, P. J. (2009). Family communication, genetic testing and colonoscopy screening in

hereditary non-polyposis colon cancer: A qualitative study. *Psycho-Oncology, 18* 1208-1215.

McDonald, H. P., Garg, A. X., & Haynes, R. B. (2002). Interventions to enhance patient adherence to medication prescriptions. *Journal of the American Medical Association, 288,* 2868-2879.

Mecklin, P. P. & Järninen, H. J. (1991). Tumor spectrum in cancer family syndrome (hereditary nonpolyposis colorectal cancer). *Cancer, 68*,1109-1112.

Menon, U., Champion, V.L., Larkin, G.N., Zollinger, T.W., Gerde, P.M., & Vernon, S.W. (2003). Beliefs associated with fecal occult blood test and colonoscopy use at a worksite colon cancer screening program. *Journal of Occupational and Environmental Medicine, 45,* 891-898.

Mesters, I., Ausems, M., Eichhorn, S., & Vasen, H. (2005). Informing one's family about genetic testing for hereditary non-polyposis colorectal cancer (HNPCC): A retrospective exploratory study. *Familial Cancer, 4*, 163-167.

Meyers, C. A., Byrne, K. S., & Komaki, R. (1995). Cognitive deficits in patients with small cell lung cancer before and after chemotherapy. *Lung Cancer, 12,* 231-235.

Mineka, S. & Sutton, S. K. (1992). Cognitive biases and the emotional disorders. *Psychological Science, 3,* 65-69.

Moulaert, V. R. M. P., Verbunt, J. A., van Heugten, C. M., & Wade, D. T. (2009). Cognitive impairments in survivors of out-of-hospital cardiac arrest: A systematic review. *Resuscitation, 80,* 297-305.

Nau, R. & Schmidt, H. (2007). Long-term neuropsychological deficits after central nervous system infections despite adequate therapy. *Journal of Neurology, 254,* 80-83.

Naveh-Benjamin, M., McKeachie, W. J., & Lin, Y-G. (1987). Two types of test-anxious students: Support for an information processing model. *Journal of Educational Psychology, 79,* 131-136.

Neuman, W. L. (1994). *Social research methods: qualitative and quantitative approaches (2nd ed.).* Boston, Massachusetts: Allyn and Bacon.

Noor, A. M., Zurovac, D., Hay, S. I., Ochola, S. A., & Snow, R. W. (2003). Defining equity in physical access to clinical services using geographical information systems as part of malaria planning and monitoring in Kenya. *Tropical Medicine and International Health, 8,* 917-926.

Nordah,, T. E., Salo, R., & Leamon, M. (2003). Neuropsychological effects of chronic methamphetamine use on neurotransmitters and cognition: A review. *The Journal of Neuropsychiatry and Clinical Neurosciences, 15,* 317-325.

Norris, F. H. Jr. (1972). The remote effects of cancer on the nervous system. *Journal of Neurology, 201*, 201-210.

Overview of the latest NCR statistics (n.d.) Retrieved October 15, 2010, from http://www.cansa.org.za/cgi-bin/giga.cgi?cmd=cause_dir_news&cat=821&cause_id=1056.

Pálsson, S., Johansson, B., Berg, S., & Skoog, I. (2000). A population study on the influence of depression on neuropsychological functioning in 85-year-olds. *ACTA Psychiatrica Scandinavica, 101,* 185-193.

Parikh, N. S., Parker, R. M., Nurss, J. R., Baker, D. W., & Williams, M. V. (1996). Shame and health literacy: The unspoken connection. *Patient Education and Counseling, 27,* 33-39.

Pope, C. & Mays, N. (1999). *Qualitative research in Health Care (2nd ed.).* London, U. K.: BMJ Books.

Powe, B. D. & Finnie, R. (2003). Cancer fatalism. The state of the science. *Cancer Nursing, 26,* 454-467.

Pylvänäinen, K., Kairaluoma, M., & Mecklin, J-P. (2006). Compliance and satisfaction with long-term surveillance in Finnish HNPCC families. *Familial Cancer, 5,* 175-178.

Radloff, L. S. (1977). The CES-D scale: A self-report depression scale for research in the general population. *Applied Psychological Measurement, 1,* 385-401.

Rawl, S. M., Menon, U., Champion, V. L., Foster, J. L., & Skinner, C. S. (2000). Colorectal cancer screening belief: Focus groups with first-degree relatives. *Cancer Practice, 8,* 32-37.

Reitz, C., Luchsinger, J. A., Tang, M-X., Manly, J., & Mayeux, R. (2006). Stroke and memory performance in elderly persons without dementia. *Archives of Neurology, 63,* 571-576.

Reitz, C., Tang, M-X., Manly, J., Mayeux, R., & Luchsinger, J. A. (2007). Hypertension and the risk of mild cognitive impairment. *Archives of Neurology, 64,* 1734-1740.

Roberts, R. O., Geda, Y.E., Knopman, D. S., Christianson, T. J. H., Pankratz, V. S., Boeve, B. F., Vella, A., Rocca, W. A., & Petersen, R. C. (2008). Association of duration and severity of diabetes mellitus with mild cognitive impairment. *Archives of Neurology, 65,* 1066-1073.

Robertson, K. R., Nakasujja, N., Wong, M., Musisi, S., Katabira, E., Parsons, T. D., Ronald, A., & Sacktor, N. (2007). Pattern of neuropsychological performance among HIV positive patients in Uganda. *Bio Med Central Neurology, 7,* 8. Retrieved October 18, 2010, from http://www.biomedcentral.com/1471-2377/7/8.

Roos, A., Calata, D., Jonkers, L., Maritz, S. J., Kidd, M., Daniels, W. M. U., & Hugo, F. J. (2009). Normative data for the Tygerberg cognitive battery and mini-mental status examination in a South African population. *Comprehensive Psychiatry, 51,* 207-216.

Rosen, M. I., Beauvais, J. E., Rigsby, M. O., Salahi, J. T., Ryan, C. E., & Cramer, J. A. (2003). Neuropsychological correlates of suboptimal adherence to metformin. *Journal of Behavioural Medicine, 26,* 349-360.

Rosenstock, I., Strecher, V., & Becker, M. (1994). The Health Belief Model and HIV risk behaviour change. In R. J. DiClemente, & J. L. Peterson (Eds.), *Preventing AIDS: Theories and Methods of Behavioural Interventions* (pp. 5-24). New York, U. S. A.: Plenum Press.

Rosenstock, I. M. (1966). Why people use health services. *The Milbank Memorial Fund Quarterly: Health Services Research I. A Series of Papers Commissioned by the Health Services Research Study Section of the United States Public Health Service. Discussed at a Conference Held in Chicago, October 15-16 , 44,* 94-127.

Salthouse, T.A. (1996). The processing-speed theory of adult age differences in cognition. *Psychological Review, 103,* 403-428.

Scaravilli, F., An, S. F., Groves, M., & Thom, M. (1999). The neuropathology of paraneoplastic syndromes. *Brain Pathology, 9,* 251-260.

Scheibel, R. S., Valentine, A. D., O'Brien, S., & Meyers, C. A. (2004). Cognitive dysfunction and depression during treatment with interferon-alpha and chemotherapy. *Journal of Neuropsychiatry and Clinical Neuroscience, 16,* 185-191.

Schmidt, H., Heimann, B., Djukic, M., Mazurek, C., Fels, C., Wallesch, C-W., & Nau, R. (2006). Neuropsychological sequelae of bacterial and viral meningitis. *Brain, 129,* 333-345.

Seeff, L. C., Nadel, M. R., Klabunde, C. N., Thompson, T., Shapiro, J. A., Vernon, S. W., & Coates, R. J. (2004). Patterns and predictors of colorectal cancer test use in the adult U. S. population. *Cancer, 100,* 2093-2103.

Sévigny, M-C., Everett, J., & Grondin, S. (2003). Depression, attention and time estimation. *Brain and Cognition, 53,* 351-353.

Shapiro, J. A., Seeff, L., & Nadel, M. R. (2001). Colorectal cancer-screening tests and associated health behaviors. *American Journal of Preventive Medicine, 21*, 132-137.

Smith, J. A., Harré, R., & Van Langenhove, L. (1995). *Rethinking methods in psychology*. London, U. K.: SAGE Publications Ltd.

Smith, K. R. & Croyle, R. T. (1995). Attitudes toward genetic testing for colon cancer risk. *American Journal of Public Health, 85,* 1435-1438.

Smith, R. A., Cokkinides, V., von Eschenbach, A. C., Levin, B., Cohen, C., Runowicz, C. D., Sener, S., Saslow, D., & Eyre, H. J. (2002). American cancer society guidelines for the early detection of cancer. *CA: A Cancer Journal for Clinicians, 52,* 8-22.

Solowij, N. & Battisti, R. (2008). The chronic effects of cannabis on memory in humans: A review. *Current Drug Abuse Reviews, 1,* 81-98.

Spielberger, C. D., Gorsuch, R. L., Lushene, R., Vagg, P. R., & Jacobs, G. A. (1983). *Manual for the State–Trait Anxiety Inventory*. Palo Alto, C. A.: Consulting Psychologists Press.

Staat, K. & Segatore, M. (2005). The phenomenon of chemo brain. *Clinical Journal of Oncology Nursing, 9,* 713-721.

Strachan, M. W. J., Frier, B. M., & Deary, I. J. (2003). Type 2 diabetes and cognitive impairment. *Diabetic Medicine, 20,* 1-2.

Strangman, G., O'Neil-Pirozzi, T. M., Burke, D., Cristina, D., Goldstein, R., Rauch, S. L., Savage, C. R., & Glenn, M. B. (2005). Functional Neuroimaging and Cognitive Rehabilitation for People with Traumatic Brain Injury. *American Journal of Physical Medicine & Rehabilitation, 84,* 62-75.

Straughan, P. T. & Seow, A. (1998). Fatalism reconceptualized: A concept to predict health screening behaviour. *Journal of Gender, Culture, and Health, 3,* 85-100.

Stroop, J. R. (1935). Studies of interference in serial verbal reactions. *Journal of Experimental Psychology: General, 18,* 643-662.

Stupart, D. A., Goldberg, P. A., Algar, U., & Ramesar, R. (2009). Surveillance colonoscopy improves survival in a cohort of subjects with a single mismatch repair gene mutation. *Colorectal Disease, 11,* 126-130.

Thiede, M. (2005). Information and access to health care: Is there a role for trust? *Social Science & Medicine, 61,* 1452-1462.

Toglia, J. & Kirk, U. (2000). Understanding awareness deficits following brain injury. *Neuro Rehabilitation, 15,* 57-70.

Tuma, R. & DeAngelis, L. M. (2000). Altered mental status in patients with cancer. *Archives of Neurology, 57,* 1727-1731.

Turjanski, N. & Lloyd.G. G. (2005). Psychiatric side-effects of medications: Recent developments. *Advances in Psychiatric Treatment, 11,* 58-70.

Valentijn, S.A.M., van Boxtel, M.P.J., van Hooren, S.A.H., Bosma, H., Beckers, H.J.M., Ponds, R.W.H., & Jolles, J. (2005). Change in sensory functioning predicts change in cognitive functioning: Results from a 6-year follow-up in the Maastricht aging study. *Journal of the American Geriatrics Society, 53,* 374-380.

Vardy, J., Wefel, J. S., Ahles, T., Tannock, I. F., & Schagen, S. B. (2008). Cancer and cancer-therapy related cognitive dysfunction: An international perspective from the Venice cognitive workshop. *Annals of Oncology, 19*, 623-629.

Vasen, H. F. A., Möslein, G., Alonso, A., Bernstein, I., Bertario, L., Blanco, I., Burn, J., Capella, G., Engel, C., Frayling, I., Friedl, W., Hes, F. J., Hodgson, S., Mecklin, J-P., Møller, P., Nagengast, F., Parc, Y., Renkonen-Sinisalo, L., Sampson, J. R., Stormorken, A., & Wijnen, J. (2007). Guidelines for the clinical management of Lynch syndrome (hereditary non-polyposis cancer). *Journal of Medical Genetics, 44*, 353-362.

Vedhara, K., Wadsworth.E., Norman, P., Searle, A., Mitchell, J., Macrae, N., O'Mahony, M., Kemple, T., & Memel, D. (2004). Habitual prospective memory in elderly patients with type 2 diabetes: Implications for medication adherence. *Psychology, Health & Medicine, 9*, 17-27.

Venkatesan, A., Selnes, O., Wojna, V., McArthur, J. C., & Nath, A. (2006). Neuropsychological consequences of HIV and drug ause (sic.). *American Journal of Infectious Diseases, 2*, 90-97.

Vernon, S. W., Gritz, E., Peterson, S. K., Amos, C .I., Perz, C., Baile, W. F., & Lynch, P. M. (1997). Correlates of psychological distress in colorectal cancer patients undergoing genetic testing for hereditary colon cancer. *Health Psychology, 16*, 73-86.

Viiala, C. H. & Olynyk, J. K. (2008). Reasons for noncompliance with five-yearly screening flexible sigmoidoscopy. *Patient Preferences and Adherence, 2*, 27-33.

Vik, P. W., Cellucci, T., Jarchow, A., & Hedt, J. (2004). Cognitive impairment in substance abuse. *Psychiatric Clinics of North America, 27*, 97-109.

Wagner, A., van Kessel, I., Kriege, M. G., Tops, C. M. J., Wijnen, J. T., Vasen, H. F. A., van der Meer, C. A., van Oostrom, I. I. H., & Meijers-Heijboer, H. (2005). Long term

follow-up of HNPCC gene mutation carriers: Compliance with screening and satisfaction with counselling and screening procedures. *Familial Cancer, 4,* 295-300.

Wagner, G. J. (2002). Predictors of antiretroviral adherence as measured by self-report, electronic monitoring, and medication diaries. *AIDS Patient Care and STDs, 16,* 599-608.

Wakefield, C. E., Kasparian, N. A., Meiser, B., Homewood, J., Kirk, J., & Tucker, K. (2007). Attitudes toward genetic testing for cancer risk after genetic counselling and decision support: A qualitative comparison between hereditary cancer types. *Genetic Testing, 11,* 401-412.

Wardle, J. (1995). Women at risk of ovarian cancer. *Journal of the National Cancer Institute Monographs, 17,* 81-85.

Watkins, P. C., Mathews, A., Williamson, D. A., & Fuller, R. D. (1992). Mood-congruent memory in depression: Emotional priming or elaboration? *Journal of Abnormal Psychology, 101,* 581-586.

Watson, P. & Lynch, H. T. (2001). Cancer risk in mismatch repair gene mutation carriers. *Familial Cancer, 1,* 57-60.

Wechsler, D. (1997). *Wechsler Memory Scale (WMS-III) (3rd ed.).* U. S. A.: The Psychological Corporation Ltd.

Wee, C. C., McCarthy, E. P., & Phillips, R. S. (2005). Factors associated with colon cancer screening: The role of patient factors and physician counseling. *Preventive Medicine, 41,* 23-29.

Wefel, J. S., Kayl, A. E., & Meyers, C. A. (2004). Neuropsychological dysfunction associated with cancer therapies: a conceptual review of an emerging target. *British Journal of Cancer, 90,* 1691-1696.

Weinberg, D. S., Turner, B. J., Wang, H., Myers, R. E., & Miller, S. (2004). A survey of women regarding factors affecting colorectal cancer screening compliance. *Preventive Medicine, 38,* 669-675.

Weinstein, N. D. (1999). What does it mean to understand a risk? Evaluating risk comprehension. *Journal of the National Cancer Institute Monographs, 25,* 15-20.

Wessel, I., van der Kooy, P., & Merckelbach, H. (2000). Differential recall of central and peripheral details of emotional slides is not a stable phenomenon. *Memory, 8,* 95-109.

Wilkinson, M., Croft, P.B., & Urich, H. (1967). The remote effects of cancer on the nervous system. *Proceedings of the Royal Society of Medicine, 60,* 683-686.

Williams, M. V., Davis, T., Parker, R. M., & Weiss, B. D. (2002). The role of health literacy in patient-physician communication. *Family Medicine, 34,* 383-389.

Winawer, S. J. (2007). Colorectal cancer screening. *Best Practice and Research Clinical Gastroenterology, 21,* 1031-1048.

Yamagishi, K. (1997). When a 12.86% mortality is more dangerous than 24.14%: Implications for risk communication. *Applied Cognitive Psychology, 11,* 495-506.

Yang, K., Allen, B., Conrad, P., Powell, C. B., Terdiman, J., & Chen, L-M. (2006). Awareness of gynecologic surveillance in women from hereditary non-polyposis colorectal cancer families. *Familial Cancer, 5,* 405-409.

Yepes-Rios, M., Reimann, J. O. F., Talavera, A. C., de Esparza, A. R., & Talavera, G. A. (2006). Colorectal cancer screening among Mexican Americans at a community clinic. *American Journal of Preventive Medicine, 30,* 204-210.

Young, I. D. (2001). *Medical Genetics*. Oxford University Press: New York.

Zere, E. & McIntyre, D. (2003). Inequities in under-five child malnutrition in South Africa. *International Journal for Equity in Health, 2,*7. Retrieved October 18, 2010, from http://equityhealthj.com/content/2/1/7.

Zheng, Y-F., Saito, T., Takahashi, M., Ishibashi, T., & Kali, I. (2006). Factors associated with intentions to adhere to colorectal cancer screening follow-up exams. *Bio Med Central Public Health, 6,* 272. Retrieved April 13, 2009, from http://www.biomedcentral.com/1471-2458/6/272.

Appendix A:
Information Sheets and Consent Forms

Information Sheet

(For Lynch Syndrome Participants)

Title of Study:
Colorectal cancer: A Neuropsychological Approach to Non-adherence to Screening Guidelines of Individuals with Lynch Syndrome in the Western Cape

- You are invited to participate in a psychological study conducted by researchers of the University of Cape Town in conjunction with the Division of Human Genetics. Please read this Information Sheet carefully and do not hesitate to ask the researcher for any additional information.
- The purpose of the study is to investigate knowledge of colorectal cancer and the reasons behind non-adherence to screening for colorectal cancer.
- You are asked to take part in this study because of the number of times you have been seen for screening over the past few years.
- You are asked to participate in a one-on-one interview with the researcher and will be encouraged to answer all the questions and give as much detail as possible where required. Your answers will be marked down as well as tape-recorded, and will be kept until the research study has been submitted and will then be destroyed.
- There will be only one interview and it may take up to 2 hours to complete.
- There are no foreseeable risks for you as the participant, but should you experience increased mental and/or physical fatigue, or any form of psychological distress, please inform the researcher immediately.
- Your answers are, however, very important and will benefit everyone involved in the screening process in finding out why some people don't screen for colorectal cancer regularly. The interview may also highlight some things of which you weren't aware and may increase your knowledge on the subject of colorectal cancer.
- It is your choice to decide whether or not to take part. If you agree to take part you will be given this Information Sheet to keep and will be asked to sign a Consent Form. You will still be free to withdraw from the study at any time without this affecting possible future treatment for either yourself or your family offered by the Division of Surgical Gastroenterology at Groote Schuur Hospital or the mobile endoscopic service.
- The confidentiality of your answers and identity will be protected. All interviews will be coded in such a way that your name and all identifying features will be removed and your answers will be given a participant number rather than a name. This information will only be accessible to the researcher.
- This study is an educational project, forming part of a Masters research program at the University of Cape Town. The study will be carried out by researchers of the University of Cape Town.
- The study has been reviewed by the Research and Ethics Committee of the University of Cape Town (Health Sciences Department). **REC REF: 318/2009.**
- If you have any questions or concerns regarding the study, or would like to be informed of the results when the study is completed, please feel free to contact the researcher.

Amy Northam
Psychology Department
University of Cape Town
083 653 3048
E-mail: amynortham@gmail.com

Raj Ramesar
Department of Human Genetics
University of Cape Town
021 406 6297
E-mail: Raj.Ramesar@uct.ac.za

THE RESEARCH ETHICS COMMITTEE (REC) OF THE UNIVERSITY OF CAPE TOWN HAS REVIEWED THIS PROJECT FOR THE PROTECTION OF HUMAN PARTICIPANTS IN RESEARCH.

E52- 23 Old Main Building, Groote Schuur Hospital, Observatory, 7925
Tel: 021 406 6492 /Fax: 021 406 6411

Inligting Bladsy

(Vir Lynch Sindroom Deelnemers)

Titel van Navorsing:
Colorectal cancer: A Neuropsychological Approach to Non-adherence to Screening Guidelines of Individuals with Lynch Syndrome in the Western Cape

- U word uitgenooi om aan ’n sielkundige studie van die Universiteit van Kaapstad met die Departement van Menslike Genetika deel te neem. Lees asseblief die inligting in die blad deeglik, en indien nodig, vra die navorser vir verdere inligting.
- Die doel van die navorsing is om die algemene kennis van dikderm kanker vas te stel, so wel as die redes waarvoor ondersoek afsprake nie nagekom word nie.
- U word gevra om aan hierdie studie deel te neem as gevolg van die hoeveelheid kere wat u vir beskerming/beskutting in die afgelope paar jare gesien is.
- U word gevra om ’n persoonlike onderhoud met die navorser by te woon, en om alle vrae so deeglik as moontlik te beantwoord. Jou antwoorde sal neergeskryf word so wel as op band opgeneem word, en sal gehou word totdat die navorsing-studie ingedien is en dan vernietig word.
- Daar sal net een onderhoud wees, en dit kan tot twee ure neem.
- Daar is geen risiko verbonde tydens die deelname aan die onderhoud nie, maar indien u wel verhoogde fisiese of geestelike moegheid of enige ongemak van enige aard beleef, stel asseblief u navorser onmiddelik in kennis.
- Die antwoorde wat u verskaf, is belangrik, nie net vir u self, maar ook vir almal betrokke in die evaluasie proses. Dit gaan help om uit te vind hoekom pasiente nie vir hulle mediese-ondersoek kom nie. Die onderhoud sal hopelik vir u verdere inligting verskaf met betrekking tot dikderm kanker, en inligting verskaf wat u dalk nie geweet het nie.
- Die besluit om deel te neem aan die navorsing is u eie. Indien u sou instem om aan die studie deel te neem, sal u hierdie Inligting Bladsy behou, en gevra word om ’n Vrywarings Vorm te teken. U kan teen enige tyd van die studie onttrek sonder dat dit u, of enige van u familie-lede se behandeling by die “Division of Surgical Gastroenterology” by Groote Schuur Hospitaal of die mobiele endoskopiese diens, sal beïnvloed nie.
- Alle antwoorde, as ook u identiteit sal konfidensieel behou word. Alle onderhoude word op ’n nommer basis gedoen, en alle kenmerke wat moontlik u identiteit kan verskaf, word verwyder. Alle inligting wat uit die onderhoude kom word net deur die navorser gesien.
- Hierdie studie is deel van ’n Meestersgraad studie aan die Universiteit van Kaapstad en word gedoen deur navorsers by UCT.
- Die studie was geevalueer deur die “Research and Ethics Committee” aan die Universiteit van Kaapstad (Gesondheids Wetenskap Departement). **REC REF: 318/2009.**
- Indien u enige verdere vrae of bekommernisse het ten opsigte van die studie, of indien u sou belangstel in die resultaat van die studie, kan u enige tyd met die navorser kontak maak.

Amy Northam
Psychology Department
University of Cape Town
083 653 3048, E-mail: amynortham@gmail.com

Raj Ramesar
Department of Human Genetics
University of Cape Town
021 406 6297, E-mail: Raj.Ramesar@uct.ac.za

THE RESEARCH ETHICS COMMITTEE (REC) OF THE UNIVERSITY OF CAPE TOWN HAS REVIEWED THIS PROJECT FOR THE PROTECTION OF HUMAN PARTICIPANTS IN RESEARCH.

E52- 23 Old Main Building, Groote Schuur Hospital, Observatory, 7925
Tel: 021 406 6492
Fax: 021 406 6411

Information Sheet

(For Reference Participants)

Title of Study:

Colorectal cancer: A Neuropsychological Approach to Non-adherence to Screening Guidelines of Individuals with Lynch Syndrome in the Western Cape

- You are invited to participate in a psychological study conducted by researchers of the University of Cape Town in conjunction with the Division of Human Genetics. Please read this Information Sheet carefully and do not hesitate to ask the researcher for any additional information.
- The purpose of the study is to investigate knowledge of colorectal cancer and the reasons behind non-adherence to screening for colorectal cancer.
- You are asked to take part in this study because your sociodemographic information matches that of one of the participants in the study.
- You are asked to participate in a one-on-one interview with the researcher and will be encouraged to answer all the questions and give as much detail as possible where required. Your answers will be marked down and will be kept until the research study has been submitted and will then be destroyed.
- There will be only one interview and it may take up to 1 hour to complete.
- There are no foreseeable risks for you as the participant, but should you experience increased mental and/or physical fatigue, or any form of psychological distress, please inform the researcher immediately.
- Your answers are, however, very important and will benefit in the interpretation of the study participant's answers.
- It is your choice to decide whether or not to take part. If you agree to take part you will be given this Information Sheet to keep and will be asked to sign a Consent Form. You will still be free to withdraw from the study at any time.
- The confidentiality of your answers and identity will be protected. All interviews will be coded in such a way that your name and all identifying features will be removed and your answers will be given a reference participant number rather than a name. This information will only be accessible to the researcher.
- This study is an educational project, forming part of a Masters research program at the University of Cape Town. The study will be carried out by researchers of the University of Cape Town.
- The study has been reviewed by the Research and Ethics Committee of the University of Cape Town (Health Sciences Department). **REC REF: 318/2009.**
- If you have any questions or concerns regarding the study, or would like to be informed of the results when the study is completed, please feel free to contact the researcher.

Amy Northam
Psychology Department
University of Cape Town
083 653 3048
E-mail: amynortham@gmail.com

Raj Ramesar
Department of Human Genetics
University of Cape Town
021 406 6297
E-mail: Raj.Ramesar@uct.ac.za

THE RESEARCH ETHICS COMMITTEE (REC) OF THE UNIVERSITY OF CAPE TOWN HAS REVIEWED THIS PROJECT FOR THE PROTECTION OF HUMAN PARTICIPANTS IN RESEARCH.

E52- 23 Old Main Building
Groote Schuur Hospital, Observatory, 7925
Tel: 021 406 6492 / Fax: 021 406 6411

Inligting Bladsy

(Vir Verwysing Deelnemers)

Titel van Navorsing:

Colorectal cancer: A Neuropsychological Approach to Non-adherence to Screening Guidelines of Individuals with Lynch Syndrome in the Western Cape

- U word uitgenooi om aan 'n sielkundige studie van die Universiteit van Kaapstad met die Departement van Menslike Genetika deel te neem. Lees asseblief die inligting in die blad deeglik, en indien nodig, vra die navorser vir verdere inligting.
- Die doel van die navorsing is om die algemene kennis van dikderm kanker vas te stel, so wel as die redes waarvoor ondersoek afsprake nie nagekom word nie.
- U word gevra om aan hierdie studie deel te neem omdat jou sosiaal-demografiese inligting dieselfde is as een van die deelnemers in die studie.
- U word gevra om 'n persoonlike onderhoud met die navorser by te woon, en om alle vrae so deeglik as moontlik te beantwoord. Jou antwoorde sal neergeskryf word, en sal gehou word totdat die navorsing studie ingedien is en dan vernietig word.
- Daar sal net een onderhoud wees, en dit kan tot een uur neem.
- Daar is geen risiko verbonde tydens die deelname aan die onderhoud nie, maar indien u wel verhoogde fisiese of geestelike moegheid of enige ongemak van enige aard beleef, stel asseblief u navorser onmiddelik in kennis.
- Jou antwoorde is egter baie belangrik en sal baat met die interpretasie van die LS deelnemer se antwoorde.
- Die besluit om deel te neem aan die navorsing is u eie. Indien u sou instem om aan die studie deel te neem, sal u hierdie Inligting Bladsy behou, en gevra word om 'n Vrywarings Vorm te teken. U kan teen enige tyd van die studie onttrek.
- Alle antwoorde, as ook u identiteit sal konfidensieel behou word. Alle onderhoude word op 'n nommer basis gedoen, en alle kenmerke wat moontlik u identiteit kan verskaf, word verwyder. Alle inligting wat uit die onderhoude kom word net deur die navorser gesien.
- Hierdie studie is deel van 'n Meestersgraad studie aan die Universiteit van Kaapstad en word gedoen deur navorsers by UCT.
- Die studie was geevalueer deur die "Research and Ethics Committee" aan die Universiteit van Kaapstad (Gesondheids Wetenskap Departement). **REC REF: 318/2009.**
  Indien u enige verdere vrae of bekommernisse het ten opsigte van die studie, of indien u sou belangstel in die resultaat van die studie, kan u enige tyd met die navorser kontak maak.

Amy Northam
Psychology Department
University of Cape Town
083 653 3048
E-mail: amynortham@gmail.com

Raj Ramesar
Department of Human Genetics
University of Cape Town
021 406 6297
E-mail: Raj.Ramesar@uct.ac.za

THE RESEARCH ETHICS COMMITTEE (REC) OF THE UNIVERSITY OF CAPE TOWN HAS REVIEWED THIS PROJECT FOR THE PROTECTION OF HUMAN PARTICIPANTS IN RESEARCH.

E52- 23 Old Main Building
Groote Schuur Hospital, Observatory, 7925
Tel: 021 406 6492
Fax: 021 406 6411

Consent Form

(For Lynch Syndrome and Reference Participants)

Title of Study:

Colorectal cancer: A Neuropsychological Approach to Non-adherence to Screening Guidelines of Individuals with Lynch Syndrome in the Western Cape

Please circle as necessary

Have you read the Information Sheet?	YES / NO
Have you had an opportunity to ask questions and discuss the study?	YES / NO
Have you received satisfactory answers to all of your questions?	YES / NO
Have you received enough information on the study?	YES / NO
Do you understand that your involvement in this study is voluntary?	YES / NO
Do you understand that you are free to withdraw from the study	
• At any time	YES / NO
• And without it affecting your future treatment? (applicable only to LS participants)	YES / NO
Do you understand that your answers will be written down and tape recorded?	YES / NO
Do you consent to the confidential use of these recordings for scientific purposes?	YES / NO
Have you been given a copy of the Information Sheet and this Consent Form?	YES / NO
Do you understand that by signing this form you are agreeing to take part in this study?	YES / NO

Signed: _____ Date: _____

(Name in block letters) _____

Amy Northam
Psychology Department
University of Cape Town
083 653 3048
E-mail: amynortham@gmail.com

Raj Ramesar
Department of Human Genetics
University of Cape Town
021 406 6297
E-mail: Raj.Ramesar@uct.ac.za

THE RESEARCH ETHICS COMMITTEE (REC) OF THE UNIVERSITY OF CAPE TOWN HAS REVIEWED THIS PROJECT FOR THE PROTECTION OF HUMAN PARTICIPANTS IN RESEARCH.

E52- 23 Old Main Building
Groote Schuur Hospital, Observatory, 7925
Tel: 021 406 6492
Fax: 021 406 6411

Vrywarings Vorm

(Vir Lynch Sindroom en Verwysing Deelnemers)

Titel van Navorsing:

Colorectal cancer: A Neuropsychological Approach to Non-adherence to Screening Guidelines of Individuals with Lynch Syndrome in the Western Cape

Omkring die een van pas, asseblief

Het u die Inligting Bladsy gelees?	JA / NEE
Is u kans gegun om die navorsing te bespreek en vrae te vrae?	JA / NEE
Is al u vrae bevredigend beantwoord?	JA / NEE
Is u genoeg inligting gegee met betrekking tot die navorsing?	JA / NEE
Verstaan u dat u vrywillig aan die navorsing deelneem?	JA / NEE
Verstaan u dat u van die studie kan ontrek	
• Teen enige tyd	JA / NEE
• Sonder dat dit u behandeling in die toekoms beinvloed? (slegs van toepassing op LS deelnemers)	JA / NEE
Is u bewus daarvan dat alle antwoorde op band opgeneem en neergeskryf sal word?	JA / NEE
Gee u toestemming dat die opname konfidensieel gebruik sal word vir wetenskaplike navorsing?	JA / NEE
Is u met ’n afdruk van die Inligtings Bladsy en Vrywarings Vorm verskaf?	JA / NEE
Verstaan u dat met die teken van die vorm u instem om aan die navorsing deel te neem?	JA / NEE

Geteken: _____ Datum:_____

(Naam in druk skrif) _____

Amy Northam
Psychology Department
University of Cape Town
083 653 3048
E-mail: amynortham@gmail.com

Raj Ramesar
Department of Human Genetics
University of Cape Town
021 406 6297
E-mail: Raj.Ramesar@uct.ac.za

THE RESEARCH ETHICS COMMITTEE (REC) OF THE UNIVERSITY OF CAPE TOWN HAS REVIEWED THIS PROJECT FOR THE PROTECTION OF HUMAN PARTICIPANTS IN RESEARCH.

E52- 23 Old Main Building
Groote Schuur Hospital, Observatory, 7925
Tel: 021 406 6492/ Fax: 021 406 6411

Appendix B:

Interview Schedule

Sociodemographic Information (English Version for Both Lynch Syndrome and Reference Participants)

Date: _____ Participant Number: _____

Gender	
Male	
Female	
Date of birth	
Age	
Race/ethnicity	
Caucasian/white	
Mixed ancestry	
First language	
English	
Afrikaans	
Other	
Preferred language	
English	
Afrikaans	
Either	
Other	
Marital status	
Never married	
Widowed	
Divorced	
Separated but not divorced	
Married	
Living with partner	
Can you read English?	
Can you read Afrikaans?	
Level of education	
<Grade 7/Std. 5	
Grade 7/Std. 5	
Grade 10/Std. 8	
Grade 11/Std. 9	
Grade 12/Matric	
Trade/Apprenticeship	
Certificate from college	
Diploma	
Degree	
Other	
Quality of education	

What school did you attend?	
Where was the school?	
Employment status	
Full time employed	
Part time employed	
Self-employed	
Homemaker	
Full time student	
Part time student	
Retired	
Unemployed	
Permanently unable to work	
Disabled	
Other	
What is your occupation (if retired, your past occupation)?	
Socioeconomic status (What is your current [household] income per month?)	
No income	
Disability grant (plus value)	
R1 – R400	
R401 – R800	
R801 – R1600	
R1601 – R3200	
R3201 – R6400	
R6401 – R12 800	
R12 801 – R25 600	
R25 601 – R51 200	
R51 201 – R102 400	
R102 401 – R204 801	
More than R204 801	
Children	
No	
Yes	
1st child (gender and age)	
2nd child (gender and age)	
3rd child (gender and age)	
4th child (gender and age)	
5th child (gender and age)	
6th child (gender and age)	
Living situation	
Number of people in household	
Of the number listed, how many are:	
Spouse	

Dependent children (under 18)	
Adult children (18 and older)	
Parents	
Brothers and sisters	
Other relatives	
Non relatives	
Do you have medical aid	
How old were you when you received your mutation positive test result? (asked, but date in medical records/HNPCC database was deemed more accurate)	
Do you have a telephone, cellphone or both?	
Do you usually have airtime or do you only get airtime when you need to make a call?	

Sociodemographic Information (Afrikaans Version for Both Lynch Syndrome and Reference Participants)

Date: _____ Participant Number: _____

Geslag	
Manlik	
Vroulik	
Geboorte datum	
Ouderdom	
Ras/etnisiteit	
Kaukasies/wit	
Gemengde afkoms	
Eerste taal	
Engels	
Afrikaans	
Ander	
Verkiesde taal	
Engels	
Afrikaans	
Beide	
Ander	
Huwelikstaat	
Nooit getroud nie	
Weduwee/wewenaar	
Geskei	
Uitmekaar maar nie geskei nie	
Getroud	
Woon saam met ‘n lewensmaat	
Kan u Engels lees?	
Kan u Afrikaans lees?	
Vlak van opleiding	
<Graad 7/Std. 5	
Graad 7/Std. 5	
Graad 10/Std. 8	
Graad 11/Std. 9	
Graad 12/Matriek	
Handel/Vakleerlingskap	
Sertifikaat van kollege	
Diploma	
Graad	
Ander	
Gehalte van opleiding	

Watter skool het jy bygewoon?	
Waar was die skool?	
Werkstatus	
Voltydse werk	
Deeltydse werk	
Selfstandig/in eie diens	
Tuismaakster	
Voltydse student	
Deeltydse student	
Afgetredene	
Werklose	
Permanent onmoontlik om te werk	
Gestremd	
Ander	
Wat is jou beroep (as u afgetree het, jou vorige beroep)?	
Sosio-ekonomiese status (Wat is jou huidige [huishouding] inkomste per maand?)	
Geen inkomste	
Ongeskiktheidstoelae (plus waarde)	
R1 – R400	
R401 – R800	
R801 – R1600	
R1601 – R3200	
R3201 – R6400	
R6401 – R12 800	
R12 801 – R25 600	
R25 601 – R51 200	
R51 201 – R102 400	
R102 401 – R204 801	
Meer as R204 801	
Kinders	
Nee	
Ja	
1ste kind (geslag en ouderdom)	
2de kind (geslag en ouderdom)	
3de kind (geslag en ouderdom)	
4de kind (geslag en ouderdom)	
5de kind (geslag en ouderdom)	
6de kind (geslag en ouderdom)	
Lewensomstandighede	
Aantal mense in die huishouding	
Van die getal vermeld, hoeveel is:	
Gade	

Afhanklike kinders (onder 18)	
Volwasse kinders (18 en ouer)	
Ouers	
Broers en susters	
Ander familielede	
Nie familie	
Het jy ‘n mediesefonds?	
Hoe oud was jy toe jy jou mutasie positiewe toets resultaat ontvang het?	
Het jy ‘n telefoon, selfoon of albei?	
Het jy gewoonlik lugtyd, of kry jy net lugtyd as jy ‘n oproep moet maak?	

Medical and Psychological Information (English Version for Both Lynch Syndrome and Reference Participants)

Date: _____ Participant Number: _____

Have you ever had any of the following?

Heart attack	
Stroke	
High blood pressure (hypertension)	
Are you taking medication?	
Do you take it regularly?	
High cholesterol	
Are you taking medication?	
Do you take it regularly?	
Diabetes	
Are you taking medication?	
Do you take it regularly?	
TB (tuberculosis)	
Colorectal cancer	
Other cancer	
Family history of cancer	
Have you ever had treatment for cancer	
Chemotherapy	
Radiotherapy	
Other treatment (including medication and surgery)	
Did your mother have any complications during her pregnancy with you or at your birth?	
Epilepsy in childhood	
Meningitis/encephalitis	
Have you ever been diagnosed with a psychiatric disorder?	
Have you ever suffered from depression?	
Was it diagnosed by a doctor?	
Head injury	
What happened?	
Did you lose consciousness?	
Malaria	
Other than the above, are you taking any other medication?	
What is the medication for?	
Do you drink alcohol?	

What do you drink?				
How much to do you drink?				
Do you smoke?				
How many cigarettes per day?				
Do you take any other substances?				
Dagga (cannabis)				
Tik (methamphetamine)				
Mandrax				
Cocaine				
How did you sleep last night (e.g. soundly/woke up worrying/restless/not much sleep)				
Which of the following describes best how you feel **right now**?				
Are you tense, upset, frightened, nervous, indecisive, worried or confused?				
OR, are you calm, comfortable, relaxed, steady and content?				
Here is a list of some feelings you may have felt recently. Please indicate how often you felt this way **during the past week**	Rarely (<1 day)			
I was bothered by things that usually don't bother me		A little (1-2 days)	Some (3-4 days)	Always (5-7 days)
I felt that I could not shake off the blues, even with help from my family				
I had trouble keeping my mind on what I was doing				
I cried a lot and felt sad and depressed				
I felt that everything I did was an effort				
I could not "get going"				

Medical and Psychological Information (Afrikaans Version for Both Lynch Syndrome and Reference Participants)

Date: _____ Participant Number: _____

Have you ever had any of the following? (Het u enige van die volgende gehad?)

Hartaanval	
Beroerte	
Hoë bloeddruk (hipertensie)	
Neem jy medikasie?	
Neem jy dit gereeld?	
Hoë cholesterol	
Neem jy medikasie?	
Neem jy dit gereeld?	
Diabetes	
Neem jy medikasie?	
Neem jy dit gereeld?	
TB (tuberkulose)	
Dikderm kanker	
Ander kanker	
Familiegeskiedenis van kanker	
Het jy al ooit behandeling vir kanker gekry?	
Chemoterapie	
Bestraling (radioterapie)	
Ander behandeling (insluitend medikasie en chirurgie)	
Het jou ma enige komplikasies tydens haar swangerskap met jou of by jou geboorte gehad?	
Epilepsie in jou kinderjare	
Meningitis/enkefalitis	
Het jy al ooit met ‘n psigiatriese stoornis gediagnoseer?	
Het jy al ooit aan depressie gely?	
Was dit deur ‘n dokter gediagnoseer?	
Hoofbesering	
Wat het gebeur?	
Het jy bewussyn verloor?	
Malaria	
Anders as die bogenoemde, neem jy enige ander medikasie?	
Waarvoor word die medikasie geneem?	
Gebruik jy alkohol?	

Wat drink jy?				
Hoeveel drink jy?				
Rook jy?				
Hoeveel sigarette per dag?				
Gebruik jy enige ander middele?				
Dagga (kannabis)				
Tik (methamphetamine)				
Mandrax				
Cocaine/Kokaïen				
Hoe het jy gisteraand geslaap? (bv. vas/bekommerd wakker geword/rusteloos/nie veel geslaap nie)				
Watter van die volgende opsies beskryf die beste, hoe jy **nou** voel?				
Is jy gespanne, ontsteld, bang, senuweeagtig, besluiteloos, bekommerd of verward?				
OF, is jy kalm, gemaklik, ontspanne, bestendig en tevrede?				
Hier is ‘n lys van sommige gevoelens u miskien onlangs gevoel het. Dui asseblief aan hoe gereeld jy op hierdie manier, die **afgelope week**, gevoel het.	Selde (<1 dag)			
Ek was gepla deur dinge wat my gewoonlik nie pla nie		‘n bietjie (1-2 dae)	Soms (3-4 dae)	Altyd (5-7 dae)
Ek het gevoel dat ek die “blues” nie sommer kan afskud nie, selfs met die hulp van my familie				
Ek het gesukkel om my gedagtes besig te hou, op dit waarmeer ek besig was				
Ek het baie gehuil en het hartseer en neerslagtig gevoel				
Ek het gevoel dat alles wat ek gedoen het inspanning geverg het				
Ek kon net nie aan die gang kon kom nie				

Knowledge and Understanding of Health Threat and Protective Health Action
(English Version for Lynch Syndrome Participants Only)

Knowledge of threat. First I'm going to ask you some questions about colorectal cancer. Pretend that I don't know anything about it and when you answer a question give me as much detail as you can.

1. Have you heard of Lynch Syndrome or Hereditary Non-polyposis Colorectal Cancer?
2. Please could you tell me as much about it as you know or can remember?
3. What is colorectal cancer? Please could you tell me as much about it as you know or can remember?
4. Do you know what a "polyp" is?
   Prompt: Have you heard of that word before?
5. If you have a polyp, do you have cancer?
   Prompt: Do they mean the same thing?
6. What is "blood in the stool"?
   Prompt: Have you heard of that before?
7. Where is the colon situated?
   Prompt: Can you show me?
8. How does colon cancer develop?
9. Do you know what predictive genetic testing is?
10. Why did you go for genetic testing?
    Prompt: Did your genetic test have something to do with LS/CRC risk?
11. Do you remember when you received your genetic test result/mutation carrier result?
    Prompt: Do you remember what year it was?
12. Did someone go with you?

Perceived severity

13. Would developing colorectal cancer be bad?
14. What do you think happens if someone develops colorectal cancer?
    Prompt: Will they get sick? If they get treatment will they get better?
15. If you developed colorectal cancer, how would it affect your life?
    Prompt: Would you feel ill? Would you still be able to do everything you need to?
16. Does the thought of colorectal cancer scare you?
17. Due to the genetic mutation that you have, do you know if you are at risk for other cancers?

18. Should you be having other types of screening?
    Prompt: Perhaps as a woman you know of some other tests you should have regularly?

Perceived susceptibility

19. What do you think it means to be "at risk" of developing colorectal cancer?
    Prompt: Do you think it means you might get colon cancer? Do you think it means you will get colon cancer?
20. Does being at risk for colon cancer have anything to do with the gene?
21. What do you think the average person in the street's risk is of getting colon cancer?
    Prompt: They will definitely get colon cancer. They might get colon cancer. They will definitely not get colon cancer.
22. What do you think your risk is of getting colon cancer?
    Prompt: You will definitely get colon cancer. You might get colon cancer. You will definitely not get colon cancer.
23. Do you think you have a greater or lesser chance of getting colon cancer than the general population?
24. Do you think having had colon cancer already affects your risk of getting it again?
    Prompt: Do you think because you've already had it that you're less likely to get it again? Or do you still have the same risk?
25. If a family member of yours has/has had colon cancer, do you have an increased risk of getting it?
26. Do you think having regular colonoscopies changes your risk of developing colon cancer?
    Prompt: Do you think you'll have more risk of developing colon cancer by having colonoscopies? Or will you have less risk of developing colon cancer?
27. Which do you think is worse or more risky? A cancer that kills "1286 out of 10 000 people", or a cancer that kills "24.14 out of 100 people".

Knowledge of protective health action

28. What is screening?
    Prompt: Have you heard of that word before?
29. What is a colonoscopy?
30. Why is screening or having colonoscopies important? What is the aim of screening/having colonoscopies?
31. Could you describe for me the "preventative aim of screening"?

32. What is a “premalignant” or “precancerous polyp”?
33. Can you tell me the difference between “cancer” and “pre-cancer”?
    Prompt: Do you think there is a difference?
34. Why do you think it is important to drink all that liquid the day before having a colonoscopy?
    Prompt: Does it help to clear your colon so that the doctor can see it better?
35. Where can you have one?
36. When last did you have a colonoscopy?
37. How many have you had?
38. How many have you missed?
39. How often should you or someone at high-risk have colonoscopies?
40. Has anyone recommended that you come for colonoscopies?
41. Is it important to you, to follow a doctor’s recommendation? Why?
42. Who could you speak to to arrange a colonoscopy?
43. Does someone remind you about your colonoscopy appointment?
44. Are you aware it’s your choice to come for a colonoscopy?
45. What else can you do to help prevent against colorectal cancer?
46. If I read you a list, could you tell me which ones you think are correct?
    1) Take regular exercise
    2) Maintain a healthy weight
    3) Eat little fat
    4) Eat lots of fibre
    5) Don’t drink alcohol
    6) Eat lots of fruit and vegetables
    7) Eat less red meat
    8) Don’t smoke
47. Do you recognise any of these now that I have told them to you?

Perceived benefits

48. Why do you go for colonoscopies?
49. Will you go for another one?
50. What do you think the benefits are of having colonoscopies?
51. Does what you know about colon cancer and your risk affect whether you come for regular colonoscopies?

Prompt: If I told you that having a colonoscopy meant that the doctors could remove something before it turned into cancer and prevent cancer, would that affect whether you came for one?

Perceived barriers

52. Why don't you go for colonoscopies?
53. How difficult/easy is it for you to get to GSH to have a colonoscopy?

Psychology of information sessions. Now I'm going to ask you some questions about your feelings or emotions. When I ask you about a particular time, try to really think about how you were feeling then and tell me in as much detail as you can.

54. I'd like you to think back to the times you received information on colon cancer or colonoscopies etc. How did you feel on those days?
    Prompt: Were you tense, upset, frightened, nervous, indecisive, worried or confused? Or were you calm, comfortable, relaxed, steady and content? Were you feeling sad and depressed at all? Do you remember crying a lot around that time? Did you have the feeling like you just couldn't shake off the blues and doing anything or going out was a real effort?
55. Do you remember how you were sleeping around those times?
56. Did having more knowledge about colon cancer make you more worried?
    Prompt: Perhaps you learned something you hadn't thought of before which made you worried?
57. Did having more knowledge about colon cancer reduce your anxiety?
    Prompt: Did knowledge give you power? Did you feel more in control?
58. Do you prefer to avoid information on colon cancer?
59. Have you ever thought that "once you've got cancer, it can't be cured"?

Access to information and practical barriers

60. Who first told you about your risk and that you should go for genetic testing?
    Prompt: Was is a doctor or a family member?
61. What were the barriers you faced in getting to your doctor or to Groote Schuur?
    Prompt: Financial, travelling difficulties, time off work, inconvenience.
62. What were the barriers you faced in receiving info from your doctor or the CRCGC?
    Prompt: Did they give you information? Did they give you an opportunity to ask questions? Did they answer your questions?

63. What were the barriers you faced in getting to your family? (sharing info with family)
    Prompt: No telephone, distant relatives.
64. What were the barriers you faced in receiving info from your family?
    Prompt: Strain on relationships, non-communication in family.
65. Have you learned more information about CRC/LS from somewhere other than the hospital and the people you've seen?
    Prompt: Have you spoken to your family or friends? Have you gone to the library to read books on colon cancer? Have you looked on the internet? Have you asked anyone else?
66. Who would you speak to if you had any questions about CRC/LS/ screening?

Cognitive capacity. We're almost done. The last thing I want to ask you about is the type of information you received from the CRCGC when you came for visits to the hospital. Try to think about all the times you've met with a sister at Groote Schuur and all the things they've told you.

67. Were you spoken to in your preferred language?
68. Did you understand everything you were told?
69. Did the doctors etc talk to you in language you could understand?
70. Was what you were told too complicated?
71. What was the most complicated part?
    Prompt: What about the genes or chromosomes?
72. Did you receive an information pamphlet to take home?
73. What language was it written in?
74. Did you understand the pamphlet?
    Prompt: Was it easy to understand? Was it difficult to understand? Was it easy to read? Did the pictures make sense?
75. Did you find it useful?
    Prompt: Why? Why not? Did you look at it later on? Did you use it to explain about colon cancer to your family?
76. Did you find it useful to refer back to the pamphlet?
77. What was the best form of information you received?
    Prompt: Talking. Written words. Pictures. Things you could take home.
78. In your visits to the hospital, did you receive enough information?
79. Was there too much information?
80. Did you feel overwhelmed by how much you were told?
81. Were you able to concentrate?

82. If you had someone with you when you received info, have you relied on that person for information that you forgot or didn't understand?
83. Did you ever call the CRCGC or another sister from Groote Schuur for more info later on?

Overall insight

84. Have you had colorectal cancer?
85. Has anyone close to you (family or friends) had colorectal cancer?
86. Do you think your own or the cancer in your family/friends has influenced how much you know about colorectal cancer?
    Prompt: Did you learn a lot from your family member's or friend's experience? Did they speak with you about it or did you learn by watching what they went through?
87. How knowledgeable do you feel you are about colon cancer, colonoscopies etc? Do you consider yourself well informed?
88. Do you feel you know enough about colon cancer and screening currently?
89. Is being knowledgeable about colon cancer and screening important to you? Why?
90. Out of all the times you've received info about CRC/LS/HNPCC etc – what was the most important thing you remember?
    Prompt: If I only asked you for one thing you remember being told, what would that be?
91. Why do you think you remembered that and not something else?
    Prompt: Why did that piece of info stick in your mind? Did you remember that because the doctor repeated it lots of times? Did you remember that because you experienced it in your family? Did you remember that because you heard that piece of information first or last? Did you remember that because it was easy to understand and everything else was complicated? Did you remember that because you were worried about it?

Knowledge and Understanding of Health Threat and Protective Health Action (Afrikaans Version for Lynch Syndrome Participants Only)

Knowledge of threat. Eerstens gaan ek vir jou ‘n paar vrae vra oor dikderm kanker. Verbeel jou dat ek geen kennis van dikderm kanker het nie en antwoord asseblief die vrae met soveel besonderhede as moontlik.

1. Het jy al van Lynch Sindroom of Oorerflik Nie-polipose Dikderm Kanker gehoor?
2. Kan jy my asseblief vertel wat jy daarvan weet of kan onthou?
3. Wat is dikderm kanker? Kan jy my asseblief vertel wat jy daarvan weet of kan onthou?
4. Weet jy wat ‘n “poliep” is?
   Prompt: Het jy al van die woord gehoor?
5. As jy ‘n poliep het, het jy kanker?
   Prompt: Beteken dit dieselfde?
6. Wat is “bloed in the stoelgang/ontlasting”?
   Prompt: Het jy al daarvan gehoor?
7. Waar is the dikderm geleë?
   Prompt: Kan jy vir my wys?
8. Hoe ontwikkel dikderm kanker?
9. Weet jy wat voorspelbare genetiese toetsing is?
10. Hoekom het jy vir genetiese toetsing gegaan?
    Prompt:Het u genetiese toets iets met LS/CRC/kanker risiko te doen?
11. Onthou jy wanneer jy jou genetiese-toets/mutasie-draer resultatt ontvang het?
    Prompt: Onthou jy watter jaar dit was?
12. Het iemand saam met jou ggeaan?

Perceived severity

13. Sou die ontwikkeling van dikderm kanker sleg wees?
14. Wat dink jy gebeur as iemand dikderm kanker ontwikkel?
    Prompt: Sal hulle siek word?As hulle behandeling kry, sal hulle gesond word?
15. As jy dikderm kanker ontwikkel, hoe sal dit jou lewe aantas?
    Prompt: Sal jy siek voel? Sal jy nog steeds kan doen wat jy nodig het om te doen?
16. Maak die gedagte van dikderm kanker jou bang?
17. Weens die genetiese mutasie wat jy het, weet jy of jy vir ander vorme van kankers ‘n risiko het?

18. Behoort jy ander vorme van skerming/beskutting (screening) te kry?
    Prompt: Dalk as 'n vrou weet jy van ander toetse wat jy gereeld moet ondergaan?

Perceived susceptibility

19. Wat dink jy beteken "om 'n risiko" te hê, vir die ontwikkeling van dikderm kanker? *Prompt: Dink jy dit beteken dat jy miskien dikderm kanker kan ontwikkel? Dink jy dit beteken dat jy dikderm kanker sal ontwikkel?*
20. Het die risiko vir dikderm kanker enigiets te doen met die gene?
21. Wat dink jy die gemiddelde persoon in die straat se kans is om dikderm kanker te ontwikkel?
    Prompt: Hulle sal beslis dikderm kanker ontwikkel. Hulle kan miskien dikderm kanker ontwikkel. Hulle sal beslis nie dikderm kanker ontwikkel nie.
22. Wat dink jy is jou risiko om dikderm kanker te ontwikkel?
    Prompt: Jy sal beslis dikderm kanker ontwikkel. Jy kan miskien dikderm kanker ontwikkel. Jy sal beslis nie dikderm kanker ontwikkel nie.
23. Dink jy dat jy 'n minder of meerdere kans het om dikderm kanker to ontwikkel as die algemene bevolking?
24. Dink jy die feit dat jy dikderm kanker al reeds gehad het jou kanse om dit weer te ontwikkel affekteer?
    Prompt: Dink jy omdat jy dit al reeds gehad het dat jy minder kans het om dit weer te ontwikkel? Of het jy nog steeds dieselfde risiko?
25. As 'n familielid van jou dikderm kanker het/gehad, het, het jy 'n verhoogde risiko om dit te ontwikkel?
26. Dink jy gereelde kolonoskopies jou risiko van die ontwikkeling van dikderm kanker verander?
    Prompt:Dink jy dat jy 'n grooter risiko vir die ontwikkeling van dikderm kanker deur kolonoskopies het? Of sal jy minder risiko hê van die ontwikkeling van dikderm kanker?
27. Watter een dink jy is erger of is 'n grooter risiko? 'n Kanker wat "1286 uit 10 000 mense" laat sterf, of 'n kanker wat "24.14 uit 100 mense" laat sterf.

Knowledge of protective health action

28. Wat is beskerming/beskutting (screening)?
    Prompt: Het jy al van die woord gehoor?

29. Wat is ‘n kolonoskopie?
30. Hoekom is beskerming/beskutting (screening) of kolonoskopies belangrik? Wat is die doel van beskerming/beskutting (screening)/kolonoskopies?
31. Kan jy die “voorkomende doel van beskerming/beskutting (screening)” beskryf?
32. Wat is ‘n “voor-kwaadaardige” of “voor-kanker poliep”?
33. Kan jy die verskil tussen “kanker” en “voor-kanker” verduidelik?
    Prompt: Dink jy dat daar ‘n verskil is?
34. Hoekom dink jy dit belangrik is om al daardie vloeistof die dag voor ‘n kolonoskopie te drink?
    Prompt: Help dit om jou dikderm skoon te maak sodat die dokter dit beter kan sien?
35. Waar kan jy een ondergaan?
36. Wanneer laas het jy ‘n kolonoskopie gehad?
37. Hoeveel het jy al gehad?
38. Hoeveel het jy gemis?
39. Hoe dikwels moet jy of iemand wat hoë-risiko is vir kolonoskopies gaan?
40. Het enigiemand aanbeveel dat jy vir kolonoskopies kom?
41. Is dit belangrik vir jou, om ‘n dokter se aanbevelings te volg? Hoekom?
42. Met wie kan jy praat om ‘n afspraak vir ‘n kolonoskopie te maak?
43. Herinner iemand jou oor jou kolonoskopie afspraak?
44. Is jy bewus daarvan dat dit jou keuse is om vir kolonoskopies te kom?
45. Wat anders kan jy doen om dikderm kanker te help verhoed?
46. As ek ‘n lys lees, kan jy my vertel watter een korrek is?
    1) Gereeld oefening
    2) Behoud van ‘n gesonde gewig
    3) Eet min vet
    4) Eet baie vesel
    5) Moenie alkohol drink nie
    6) Eet baie vrugte en groente
    7) Eet minder rooivleis
    8) Moenie rook nie
47. Herken jy enige van hierdie noudat jy van hulle gehoor het?

Perceived benefits

48. Hoekom gaan jy vir kolonoskopies?

49. Sal jy wir ‘n ander een gaan?
50. Wat dink jy die voordele van kolonoskopies is?
51. Affekteer jou kennis oor dikderm kanker en jou risiko daarvoor of jy vir gereelde kolonoskopies kom?
    Prompt: As ek jou vertel dat ‘n kolonoskopie beteken dat die dokters’n kans het om iets uit te haal voor dit in kanker ontwikkel, en kanker voorkom, sou dit’n verskil maak of jy vir ‘n kolonoskopie kom?

Perceived barriers

52. Hoekom gaan jy nie vir kolonoskopies nie?
53. Hoe moeilik/maklik is dit om by GSH vir ‘n kolonosopie te kom?

Psychology of information sessions. Nou gaan ek ‘n paar vrae vra oor jou gevoelens of emosies. As ek jou oor ‘n bepaalde tyd vra, probeer om regtig te dink oor hoe jy toe gevoel het en vertel vir my in soveel besonderheid as jy kan.

54. Ek wil hê dat jy terugdink aan die tye wat jy inligting oor dikderm kanker of kolonoskopies ens. ontvang het. Hoe het jy daardie dae gevoel?
    Prompt: Was jy gespanne, ontsteld, bang, senuweeagtig, besluiteloos, bekommerd, of verward? Of was jy kalm, gemaklik, ontspanne, bestendig en tevrede?Het jy treurig en depressief gevoel? Kan jy onthou of jy baie gehuil het daardie tyd?Het jy gevoel asof dit te veel moeite was om uit te gaan of enigiets te doen?
55. Onthou jy hoe jy geslaap het?
56. Het meer kennis oor dikderm kanker jou meer bekommerd gemaak?
    Prompt: Miskien het jy iets geleer wat jy nog nie gedink het nie wat jou angstig gemaak het?
57. Het meer kennis oor dikderm kanker jou angs verminder?
    Prompt: Het kennis vir jou krag gegee?Het jy meer in beheer gevoel?
58. Verkies jy om inligting oor dikderm kanker to vermy? Hoekom?
59. Het jy al ooit gedink dat “as jy kanker het, dit nie genees kan word nie”?

Access to information and practical barriers

60. Wie het vir jou eers van jou risiko vertel, en dat jy vir genetiese toetsing moet gaan?
    Prompt: Was dit’n dokter of ‘n familielid?
61. Wat was die hindernisse wat jy ervaar het om by jou dokter of GSH te kom?

Prompt: Finansiële, reis probleem, tyd af werk, ontrief

62. Wat was die hindernisse wat jy ervaar het om inligting van jou dokter of die CRCGC te kry?
Prompt: Het hulle jou inligting gegee? Het hulle jou 'n gelleentheid gegee om vrae to vra? Het hulle jou vrae beantwoord?
63. Wat was die hindernisse wat jy ervaar het om by jou familie te kom? (om inligting met die familie te deel)
Prompt: Geen telefoon, ver-af familie.
64. Wat was die hindernisse wat jy ervaar het om inligting van familie te kry?
Prompt: Stremmende verhoudinge, nie-kommunikasie in die gesin.
65. Het jy meer oor dikderm kanker/LS geleer, van iewers anders as die hospitaal en die mense wat jy gesien het?
Prompt: Het jy met jou familie of vriende gepraat?Het jy na die biblioteek gegaan om boeke oor dikderm kanker te lees?Het jy op die internet gekyk? Het jy iemand anders gevra?
66. Met wie sou jy praat as jy enige vrae oor dikderm kanker/LS/ beskerming/beskutting (screening) het?

Cognitive capacity. Ons is amper klaar. Die laaste ding waaroor ek jou wil vra is oor die tipe inligting wat jy by die CRCGC gekry het toe jy vir besoeke aan die hospitaal gekom het. Probeer om aan al die tye te dink wat jy met 'n suster by GSH ontmoet het, en alles wat hulle vir jou vertel het.

67. Was jy in jou verkisde taal toegespreek?
68. Het jy alles verstaan wat hulle jou vertel het?
69. Het die dokters ens. met jou gepraat in 'n taal wat jy kon verstaan?
70. Was wat hulle vir jou vertel het te ingewikkeld?
71. Wat was die ingewikkeldste deel?
Prompt: Wat van die gene of kromosome?
72. Het jy 'n inligting pamflet verskaf om huis-toe te neem?
73. In watter taal was dit geskrywe?
74. Het jy die pamflet verstaan?
Prompt: Was dit maklik om te verstaan?Was dit moeilik om te verstaan? Was dit maklik om te lees? Het die prentjies sin gemaak?
75. Het jy dit nuttig gevind?
Prompt: Hoekom? Hoekom nie?Het jy later daarna gekyk?Het jy dit gebruik om oor dikderm kanker aan jou familie te verduidelik?

76. Het jy dit nuttig gevind om na die pamflet terug te verwys?
77. Wat was die beste vorm van inligting wat jy ontvang het?
    Prompt: Praat/spraak.Geskrewe woorde. Prente. Dinge wat jy huis- toe kon neem.
78. In jou besoeke aan die hospitaal, het jy genoeg inligting ontvang
79. Was daar te veel inligting?
80. Het jy oorstelp gevoel deur hoeveel hulle jou vertel het?
81. Kon jy konsentreer?
82. As iemand saam met jou gegaan het tow jy die inligting ontvang het, het jy enigsins verder op hulle staat gemaak vir inligting, wat jy vergeet het of nie verstaan het nie?
83. Het jy al ooit die CRCGC of ‘n ander suster van GSH later vir meer inligting gebel?

Overall insight

84. Het jy al dikderm kanker gehad?
85. Het iemand naby aan jou (familie of vriende) al dikderm kanker gehad?
86. Dink jy jou eie kanker of die kanker in jou familie/vriende jy beïnvloed het oor hoeveel jy oor dikderm kanker weet?
    Prompt: Het jy baie van jou familie-lid of ‘n vriend se ondervinding geleer? Het hulle dit met jou daaroor gepraat, of het jygeleer net om hulle dop te hou?
87. Hoeveel kennis dink jy het jy oor dikderm kanker, kolonoskopies ens.? Dink jy dat jy goed ingelig is?
88. Voel jy asof jy op die oomblik genoeg oor dikderm kanker en beskerming/beskutting (screening) weet?
89. Is dit vir jou belangrik om kennis te hê oor dikderm kanker en beskerming/beskutting (screening)? Hoekom?
90. Uit al die tye wat jy inligting oor dikderm kanker/LS ens. ontvang het, wat was die belangrikste wat jy onthou?
    Prompt: Noem een ding wat die belangrikste is, wat aan jou vertel is?
91. Hoekom dink jy dat jy dit onthou, en nie iets anders nie?
    Prompt: Hoekom het daardie inligting in jou gedagtes gebly?Het jy dit onthou omdat die dokter dit baie herhaal het? Het jy dit onthou omdat jy dit in jou familie beleef het? Het jy dit onthou omdat jy dit eerste of laaste gehoor het? Het jy dit onthou want dit was maklik, en die res moeilik, om te verstaan? Het jy dit onthou omdat jy bekommerd daaroor was?

Appendix C:
Adherence Rates and Participant Characteristics

Table C1

Participant Adherence Data from the Lynch Syndrome Database.

Adherence status	Participant number	Year of PGT result	Number of colonoscopies recommended[a]	Number of colonoscopies attended	Number of colonoscopies missed	Attendance rate (%)	Non-adherence rate (%)
Adherers	P1	2007	2	2	0	100	0
	P2	2004	3	3	0	100	0
	P3	2004	3	3	0	100	0
	P4	2004	3	3	0	100	0
	P5	2004	3	3	0	100	0
	P6	2001	8	8	0	100	0
	P7	1999	3[b]	3	0	100	0
	P8	2004	3	3	0	100	0
Non-adherers	P9	2004	3	1	2	33	67
	P10	2002	5	3	2	60	40
	P11	2002	4	1	3	25	75
	P12	2003	7	1	6	15	85
	P13	1998	12	8	4	67	33
	P14	2003	7	5	2	72	28
	P15	2005	5	3	2	60	40
	P16	2002	5	2	3	40	60

Note. PGT = Predictive genetic test.

[a] = Number of recommended colonoscopies was based on the recommended rate for the age of each participant from the year of receiving their mutation positive result. [b] = P7 had a colostomy in 2002 and was not required to attend colonoscopies after that surgery.

Table C2

The Sociodemographic Characteristics of the Adherent Lynch Syndrome Participants.

Sociodemographic characteristic	P1	P2	P3	P4	P5	P6	P7	P8	Total (n = 8)
Gender									
Male	x	x			x		x		4
Female			x	x		x		x	4
Age	21	22	26	26	26	52	55	63	36.4 (21 – 63)
Race/ethnicity									
Mixed ancestry	x	x	x	x	x		x	x	7
White						x			1
First language									
English				x		x			2
Afrikaans	x	x	x		x		x	x	6
Preferred language									
English				x		x			2
Afrikaans	x		x				x	x	4
Either		x			x				2
Marital status									
Single	x	x			x				3
Married			x	x		x	x	x	5
Divorced									--
Participants with children			x	x		x	x	x	5
Number of children			1	2		3	3	2	2.2 (1 – 3)
Number living in household	6	5	3	4	3	6	3	3	4.1 (3 – 6)
Level of education									
Primary school (Grade 7 or less)								x[a]	1
High school (Grade 8 – 12)	x	x	x		x	x	x		6
Tertiary (diploma)				x					1
Years of education[b]	12	11	11	14	12	12	10	3	10.6 (3 - 14)
Employment status									
Unemployed									--
Full time employed	x	x			x	x			4
Part time employed									--
Housewife			x	x					2
Pensioner								x	1
Disability grant							x		1
Household income/month									
R801 – R1 600									--
R1 601 – R3 200								x	1
R3 201 – R6 400	x	x			x		x		4
R6 401 – R12 800			x	x					2
R12 801 – R24 600									--
R24 601 – R51 200						x			1
Medical aid			x	x		x			3

Note. The data on age, number of children, number of individuals living in household and years of school attended are presented as averages with the minimum to maximum range in parentheses.

[a] = P8 obtained a Grade 3/Standard 1 education. [b] = Average years of education excluded pre-school and grade R, if they were present, and presumed the diploma to be a two year course.

Table C3

The Sociodemographic Characteristics of the Non-adherent Lynch Syndrome Participants.

Sociodemographic characteristic	P9	P10	P11	P12	P13	P14	P15	P16	Total (n = 8)
Gender									
Male			x		x			x	3
Female	x	x		x		x	x		5
Age	24	28	28	45	47	48	51	53	40.5 (24 – 53)
Race/ethnicity									
Mixed ancestry	x	x	x	x	x	x	x		7
White								x	1
First language									
English				x				x	2
Afrikaans	x	x	x		x	x	x		6
Preferred language									
English								x	1
Afrikaans	x								1
Either		x	x	x	x	x	x		6
Marital status									
Single		x	x						2
Married	x				x	x	x	x	5
Divorced				x					1
Participants with children	x			x	x	x	x	x	6
Number of children	3			1	3	3	4	4	3 (1 – 4)
Number living in household	3	4	4	2	5	3	4	4	3.6 (2 – 5)
Level of education									
Primary school (Grade 7 or less)									--
High school (Grade 8–12)	x		x		x	x	x		5
Tertiary (diploma)		x		x				x	3
Years of education[a]	10	14	12	14	10	10	11	14	11.9 (10 – 14)
Employment status									
Unemployed			x						1
Full time employed		x		x	x		x	x	5
Part time employed	x								1
Housewife									--
Pensioner									--
Disability grant						x			1
Household income/month									
R801 – R1 600						x			1
R1 601 – R3 200							x		1
R3 201 – R6 400	x		x						2
R6 401 – R12 800		x		x	x				3
R12 801 – R24 600									--
R24 601 – R51 200								x	1
Medical aid				x	x			x	3

Note. The data on age, number of children, number of individuals living in household and years of school attended are presented as averages with the minimum to maximum range in parentheses.

[a] = Average years of education excluded pre-school and grade R, if they were present, and presumed the diploma to be a two year course.

Table C4

The Sociodemographic Characteristics of the First Eight Reference Participants.

Sociodemographic characteristic	C1	C2	C3	C4	C5	C6	C7	C8	Total (n = 8)
Gender									
Male	x	x			x		x		4
Female			x	x		x		x	4
Age	21	22	26	26	26	52	55	63	36.4 (21 – 63)
Race/ethnicity									
Mixed ancestry	x	x	x	x	x		x	x	7
White						x			1
First language									
English	x	x			x	x			4
Afrikaans			x	x			x	x	4
Preferred language									
English	x	x			x	x			4
Afrikaans								x	1
Either			x	x			x		3
Marital status									
Single	x	x	x		x			x	5
Married				x		x			2
Divorced							x		1
Participants with children						x	x		2
Number of children						2	1		1.5 (1 – 2)
Number living in household	4	2	6	2	4	3	5	1	3.4 (1 – 6)
Level of education									
Primary school (Grade 7 or less)								x	1
High school (Grade 8 – 12)	x	x	x		x	x	x		6
Tertiary (diploma)				x					1
Years of education[a]	12	12	12	14	12	12	8	5	10.9 (5 – 14)
Employment status									
Full time employed	x		x	x			x		4
Part time employed		x			x	x		x	4
Household income/month									
R801 – R1 600									
R1 601 – R3 200								x	1
R3 201 – R6 400	x	x			x		x		4
R6 401 – R12 800			x	x					2
R12 801 – R24 600									--
R24 601 – R51 200						x			1
Medical aid		x	x			x			3

Note. The data on age, number of children, number of individuals living in household and years of school attended are presented as averages with the minimum to maximum range in parentheses.

[a] = Average years of education excluded pre-school and grade R, if they were present, and presumed the diploma to be a two year course.

Table C5

The Sociodemographic Characteristics of the Second Eight Reference Participants.

Sociodemographic characteristic	C9	C10	C11	C12	C13	C14	C15	C16	Total (n = 8)
Gender									
Male			x		x			x	3
Female	x	x		x		x	x		5
Age	24	28	28	45	47	48	51	53	40.5 (24 – 53)
Race/ethnicity									
Mixed ancestry	x	x	x	x	x	x	x		7
White								x	1
First language									
English				x	x			x	3
Afrikaans	x	x	x			x	x		5
Preferred language									
English								x	1
Afrikaans						x			1
Either	x	x	x	x	x		x		6
Marital status									
Single		x							1
Married			x	x	x			x	4
Divorced	x					x	x		3
Participants with children	x	x	x	x	x		x	x	7
Number of children	1	1	1	3	1		3	2	1.7 (1 – 3)
Number of individuals living in household	5	3	3	5	3	1	3	4	3.4 (1 – 5)
Level of education									
Primary school (Grade 7 or less)									--
High school (Grade 8–12)	x		x		x	x	x		5
Tertiary (diploma)		x		x				x	3
Years of education[a]	12	14	11	14	10	10	9	14	11.8 (9 – 14)
Employment status									
Full time employed	x	x	x	x	x		x	x	7
Part time employed						x			1
Household income/month									
R801 – R1 600						x			1
R1 601 – R3 200							x		1
R3 201 – R6 400	x		x						2
R6 401 – R12 800		x		x	x				3
R12 801 – R24 600									--
R24 601 – R51 200								x	1
Medical aid	x		x	x	x			x	5

Note. The data on age, number of children, number of individuals living in household and years of school attended are presented as averages with the minimum to maximum range in parentheses.

[a] = Average years of education excluded pre-school and grade R, if they were present, and presumed the diploma to be a two year course.

Table C6

The Difference in Levels of Education Between Lynch Syndrome and Reference Participants.

Level of education	LS participants (n = 16)	Reference participants (n = 16)
Primary school		
Grade 3 (Std. 1)	1	--
Grade 5 (Std. 3)	--	1
High school		
Grade 8 (Std. 6)	--	1
Grade 9 (Std.7)	--	1
Grade 10 (Std. 8)	4	2
Grade 11(Std. 9)	3	1
Grade 12 (Matric)	4	6
Tertiary		
Diploma	4	4
Average years of formal education[a]	11.26 (3-14)	11.31 (5-14)

Note. Average years of education excluded grade R if it was present and presumed the diploma to be a two year course. LS = Lynch syndrome; Std. = Standard.

[a] = Data presented are means with range in parentheses.

Table C7

The Psychological Characteristics of the Lynch Syndrome Participants.

Psychological characteristic	P1	P2	P3	P4	P5	P6	P7	P8	Sub-total (n = 8)	P9	P10	P11	P12	P13	P14	P15	P16	Sub-total (n = 8)	Total (n = 16)
Current anxiety																			
Present				x					1					x	x			2	3
Absent	x	x	x		x	x	x	x	7	x	x	x	x			x	x	6	13
Current depression																			
Present									--	x		x			x			3	3
Absent	x	x	x	x	x	x	x	x	8		x		x	x		x	x	5	13
Previous depression				x[a]		x			2	x		x	x		x			4	6
Diagnosed by a doctor				x					1	x			x		x			2	3
Last night's sleep																			
Restless/disturbed/ not enough			x		x			x	3					x	x	x		3	6
Sound/restful	x	x		x		x	x		5	x	x	x	x				x	5	10

Note. [a] = P4 had suffered from postnatal depression.

Table C8

The Psychological Characteristics of the Reference Participants.

Psychological characteristic	C1	C2	C3	C4	C5	C6	C7	C8	C9	C10	C11	C12	C13	C14	C15	C16	Total (n = 16)
Current anxiety																	
Present									x								1
Absent	x	x	x	x	x	x	x	x		x	x	x	x	x	x	x	15
Current depression																	
Present									x								1
Absent	x	x	x	x	x	x	x	x		x	x	x	x	x	x	x	15
Previous depression									x[a]	x[b]							2
Diagnosed by a doctor									x								1
Last night's sleep																	
Restless/disturbed/ not enough	x	x							x								3
Sound/restful			x	x	x	x	x	x		x	x	x	x	x	x	x	13

Note. [a] = C9 had suffered from postnatal depression for 3 days. [b] = C10 had suffered from postnatal depression.

Table C9

The Medical Characteristics of the Adherent Lynch Syndrome Participants.

Medical characteristic	P1	P2	P3	P4	P5	P6	P7	P8	Total (n = 8)
Heart attack									--
Stroke									--
High blood pressure								x	1
On medication								x	1
Taken regularly								x	1
High cholesterol									--
Diabetes									--
On medication									
Taken regularly									
Tuberculosis									--
Cancer				x			x	x	3
CNS/brain									--
Treatment for cancer				x			x	x	3
Chemotherapy								x	1
Other (surgery)				x			x	x	3
Complications during pregnancy/birth						x[a]			1
Head injury					x[b]				1
Childhood epilepsy									--
Meningitis/encephalitis									--
Psychiatric disorder									--
Malaria									--
Medication other than above				x[c]					1

Medical characteristic	P1	P2	P3	P4	P5	P6	P7	P8	Total (n = 8)
Alcohol	x	x	x		x	x	x		6
Type	Beer	Rum and brandy			Whiskey	Bacardi Breezer	Beer and dry wine		
Quantity	Shares 3 cases with 5 friends on weekends	Occasionally (once per month)	On special occasions		Socially, on weekends	Rarely	Socially		
Smoking	x	x	x		x		x		5
Quantity per day	3	10	6		5-6		5-6		6 (3 – 10)
Substance use									--
Dagga									--
Tik									--
Mandrax									--

Note. CNS = Central nervous system.

[a] = P6 had her cord wrapped around her neck at birth (home birth). [b]= P5 was in a car accident 10 years ago in which he lost consciousness but suffered no lasting cognitive effects. [c] = P4 is taking Eltroxin which was prescribed for her Thyroid. Total quantity of cigarettes per day is presented as average with minimum to maximum range in parentheses.

Table C10

The Medical Characteristics of the Non-adherent Lynch Syndrome Participants.

Medical characteristic	P9	P10	P11	P12	P13	P14	P15	P16	Total (n = 8)
Heart attack									--
Stroke									--
High blood pressure					x	x			2
On medication					x	x			2
Taken regularly					x	x			2
High cholesterol									--
Diabetes								x	1
On medication								x	1
Taken regularly								x	1
Tuberculosis									--
Cancer		x		x		x	x		4
CNS/brain									--
Treatment for cancer		x		x		x	x		4
Chemotherapy									--
Other (surgery)		x		x		x	x		4
Complications during pregnancy/birth				x[a]					1
Head injury									--
Childhood epilepsy									--
Meningitis/encephalitis									--
Psychiatric disorder									--
Malaria									--
Medication other than above						x[b]			1

Medical characteristic	P9	P10	P11	P12	P13	P14	P15	P16	Total (n = 8)
Alcohol	x	x							2
Type	Cider	Breezers							
Quantity	Socially, on weekends	Socially, on weekends							
Smoking		x	x			x	x	x	5
Quantity per day		3	4			4	6-7	20-25	8 (3 – 25)
Substance use			x						1
Dagga			Now and then						1
Tik			When stressed						1
Mandrax			Regularly						1

Note. CNS = Central nervous system.

[a] = P12 noted that "they took [her] out with spoons" at birth. [b] = P14 is taking Eltroxin, which was prescribed for her Thyroid, as well as the occasional sleeping tablet. Total quantity of cigarettes per day is presented as average with minimum to maximum range in parentheses.

Table C11

The Medical Characteristics of the First Eight Reference Participants.

Medical characteristic	C1	C2	C3	C4	C5	C6	C7	C8	Total (n = 8)
Heart attack									--
Stroke									--
High blood pressure									--
On medication									
Taken regularly									
High cholesterol									--
On medication									
Taken regularly									
Diabetes									--
On medication									
Taken regularly									
Tuberculosis									--
Cancer									--
Colorectal cancer in family									--
Complications during pregnancy/birth									--
Head injury					x[a]				1
Childhood epilepsy									--
Meningitis/encephalitis									--
Psychiatric disorder									--
Malaria									--
Medication other than above				x[b]					1

Medical characteristic	C1	C2	C3	C4	C5	C6	C7	C8	Total (n = 8)
Alcohol	x	x		x	x	x	x		6
Type	Rum, beer, whiskey	Beer, whiskey		Wine, cider	Beer	Champagne	Beer		
Quantity	Socially, on weekends	Weekends or special occasions		Socially, occassionally	Weekends or special occasions	2 per day	Once a month		
Smoking		x					x		2
Quantity per day		5-6					6-8		6.25 (5 – 8)
Substance use							x		1
Dagga							1 per evening		1
Tik									--
Mandrax									--

Note. [a] = C5 was in a car accident but only lost consciousness for a few seconds. [b] = C4 is taking Spasmed for a spastic colon. Total quantity of cigarettes per day is presented as average with minimum to maximum range in parentheses.

Table C12

The Medical Characteristics of the Second Eight Reference Participants.

Medical characteristic	C9	C10	C11	C12	C13	C14	C15	C16	Total (n = 8)
Heart attack									--
Stroke									--
High blood pressure	x	x (when pregnant)		x					3
On medication	x			x					2
Taken regularly	No			x					1
High cholesterol	x				x				2
On medication	x				Diet				1
Taken regularly	No								--
Diabetes	x								1
On medication	x								1
Taken regularly	No								--
Tuberculosis									--
Cancer									--
Colorectal cancer in family									--
Complications during pregnancy/birth									--
Head injury					x[a]				1
Childhood epilepsy									--
Meningitis/encephalitis									--
Psychiatric disorder									--
Malaria									--
Medication other than above				x[b]	x[c]		x[c]		3

Medical characteristic	C9	C10	C11	C12	C13	C14	C15	C16	Total (n = 8)
Alcohol	x	x			x	x			4
Type	Cider	Red wine			Whiskey	Beer			
Quantity	2 x weekend	Socially			3-5 glasses per weekend	Weekends			
Smoking	x		x	x		x			4
Quantity per day	Hubbly bubbly 3 x day		1 pack x day	10 per day		7 x day			15.6 (7 – 30)
Substance use									--
Dagga									--
Tik									--
Mandrax									--

Note. [a] = C13 had a rugby concussion but had lost consciousness for only a few seconds. [b] = C12 is taking Omega 3 Joint support. [c] = C13 and C15 are on medication for asthma. Total quantity of cigarettes per day is presented as average with minimum to maximum range in parentheses (the hubbly bubbly is excluded from the total quantity of cigarettes per day).

Table C13

Experience of Cancer of the Adherent and Non-adherent Lynch Syndrome Participants.

Experience of cancer	P1	P2	P3	P4	P5	P6	P7	P8	Sub-total (n = 8)	P9	P10	P11	P12	P13	P14	P15	P16	Sub-total (n = 8)	Total (n = 16)
Personal cancer				x			x	x	3		x		x		x	x		4	7
Colorectal							x	x	2		x		x		x			3	5
CRC more than once																x		1	1
Uterus/endometrial								x	1				x		x			2	3
Thyroid				x					1										1
Relative with cancer	x	x	x	x	x	x	x	x	8	x	x	x	x	x	x		x	7	15
Death of a family member due to cancer	x	x	x	x		x	x	x	7			x			x		x	3	10
Death of a parent due to cancer	x	x	x	x			x	x	6						x			1	7

Note. CRC = Colorectal cancer.

Appendix D:
The Neuropsychological Performance of the Participants

Table D1

The Neuropsychological Performance of the Lynch Syndrome Compared with the Reference Participants for Normally Distributed Data.

Variable	LS participants (n = 16)	Reference participants (n = 16)	Z	p	t (df = 30)	p (2-tailed)	Cohen's d	Effect size r
Sustained attention	13.563 (4.732)	14.688 (4.483)	-0.251	.401	-0.690	.495	-0.244	-0.121
Working memory[a]	0.291 (0.067)	0.292 (0.076)	-0.010	.496	-0.030	.976	-0.014	-0.007
Memory	13.000 (4.227)	13.000 (3.386)	0.000	.500	0.000	1.000	0.000	0.000
Executive functioning (composite)[b]	-0.425 (3.654)	0.000 (3.002)	-0.142	.444	-0.360	.722	-0.127	-0.063
Inhibition error score[a c]	0.287 (0.216)	0.248 (0.158)	-0.248	.402	-0.586	.562	0.205	0.102
Set shifting error score[a c]	0.294 (0.177)	0.291 (0.161)	-0.015	.494	-0.041	.968	0.018	0.009
Abstraction[a]	0.583 (0.167)	0.576 (0.181)	0.039	.484	0.115	.910	0.040	0.020
Problem solving	1.563 (0.964)	1.750 (0.931)	-0.201	.420	-0.560	.580	-0.197	-0.098

Note. Participant data presented are raw score means with the standard deviation in parentheses. T-tests were run, and z-scores and Cohen's d were calculated for all data. LS = Lynch syndrome.

[a] = Data was not normally distributed and was transformed using LOG (100) transformation. [b] = The executive functioning composite score was created by calculating individual z-scores for each participant for the variables 'inhibition error score', 'set shifting error score', 'abstraction' and 'problem solving', which were then amalgamated into one composite score per participant. [c] = A higher error or completion time score denotes a poorer performance.

Table D2

The Neuropsychological Performance of the Lynch Syndrome Compared with the Reference Participants for Data not Normally Distributed.

Variable	LS participants (n = 16)	Reference participants (n = 16)	U	Z	p (2-tailed)	A
Focused attention	5.750 (1.612)	6.125 (1.408)	108.500	-0.758	.457	.424
Comprehension	4.375 (0.500)	4.375 (0.500)	128.000	0.000	1.000	.500
Inhibition completion time[a b]	61.125 (13.331)	65.813 (21.467)	111.500	0.622	.545	.436
Set shifting completion time[a b]	65.875 (13.145)	79.563 (31.190)	107.500	0.733	.450	.420

Note. Participant data presented are raw score means with the standard deviation in parentheses. Mann-Whitney U-tests were run, and Vargha & Delaney's A was calculated. LS = Lynch syndrome.

[a] = Although completion time scores are reported, error scores were deemed more indicative of ability and were included in the executive functioning composite score as being representative of capacity for inhibition and set shifting. [b] = A higher error or completion time score denotes a poorer performance.

Table D3

The Neuropsychological Performance of the Adherent Compared with the Non-adherent Lynch Syndrome Participants.

Variable	Adherers (n = 8)	Non-adherers (n = 8)	U	Z	p (1-tailed)	A
Focused attention	5.625 (1.506)	5.875 (1.808)	30.500	-0.163	.494	.477
Sustained attention	12.750 (4.268)	14.375 (5.317)	26.500	-0.580	.295	.414
Working memory[a]	0.292 (0.071)	0.291 (0.067)	28.500	0.384	.369	.555
Comprehension	4.250 (0.463)	4.500 (0.535)	24.000	-1.000	.304	.375
Memory	13.250 (4.097)	12.750 (4.621)	28.500	0.374	.366	.555
Executive functioning (comp) [b]	-1.621 (4.183)	0.771 (2.800)	23.000	-0.945	.191	.359
Inhibition error score[a c]	0.388 (0.214)	0.187 (0.177)	13.500	-1.963	.026*	.789[d]
Inhibition completion time[c]	65.500 (17.196)	56.750 (6.431)	26.000	-0.632	.279	.594
Set shifting error score[a c]	0.364 (0.170)	0.224 (0.164)	18.000	-1.486	.074	.719[d]
Set shifting completion time[c]	73.000 (11.711)	58.750 (10.820)	11.000	-2.207	.013*	.828[d]
Abstraction[a]	0.572 (0.202)	0.594 (0.138)	29.000	-0.316	.390	.453
Problem solving	1.500 (1.069)	1.625 (0.916)	30.500	-0.170	.489	.477

Note. Participant data presented are raw score means with the standard deviation in parentheses. Mann-Whitney U-tests were run, and Vargha & Delaney's A was calculated.

[a] = For consistency, the same LOG (100) transformed scores used in the first analysis were used in this analysis. [b] = The executive functioning composite score was created by calculating individual z-scores for each participant for the variables 'inhibition error score', 'set shifting error score', 'abstraction' and 'problem solving', which were then amalgamated into one composite score per participant (although completion time scores are reported, error scores were deemed more indicative of ability and were included in the composite score as being representative of capacity for inhibition and set shifting). [c] = A higher error or completion time score denotes a poorer performance. [d] = Large effect size (Vargha & Delaney, 2000).

* $p < .05$

Appendix E:
The Neuropsychological Findings Pertaining to P8

Table E1

The Neuropsychological Performance of Adherer P8 Compared with the Remaining Adherent Lynch Syndrome Participants.

Variable	Adherer P8 (n = 1)	Adherers (n = 8)	Z	p (2-tailed)
Focused attention	5	5.875 (1.808)	-0.465	.321
Sustained attention	7	14.375 (5.317)	-1.387	.083
Working memory[a]	0.151	0.291 (0.067)	-2.093	.018*
Comprehension	4	4.500 (0.535)	-0.750	.227
Memory	4	12.750 (4.621)	-2.129	.017*
Executive functioning (comp) [b]	-8.346	0.771 (2.800)	-1.608	.054
Inhibition error score[a c]	0.639	0.187 (0.177)	-1.632	.051
Inhibition completion time[c]	89	56.750 (6.431)	-2.091	.018
Set shifting error score[a c]	0.690	0.224 (0.164)	-2.238	.013*
Set shifting completion time[c]	0.929	58.750 (10.820)	-0.466	.321
Abstraction[a]	0.301	0.594 (0.138)	-1.683	.046*
Problem solving	0	1.625 (0.916)	-1.621	.053

Note. Adherer P8 values are raw scores. Adherer group values are raw score means with standard deviations in parentheses. Z-tests were run.

[a] = For consistency, the same LOG (100) transformed scores used in the first analysis were used in this analysis. [b] = The executive functioning composite score was created by calculating individual z-scores for each participant for the variables 'inhibition error score', 'set shifting error score', 'abstraction' and 'problem solving', which were then amalgamated into one composite score per participant (although completion time scores are reported, error scores were deemed more indicative of ability and were included in the composite score as being representative of capacity for inhibition and set shifting). [c] = A higher error or completion time score denotes a poorer performance.

* $p < .05$

Table E2

The Neuropsychological Performance of the Adherent Compared with the Non-adherent Lynch Syndrome Participants, after the Removal of Outlier P8.

Variable	Adherers (n = 7)	Non-adherers (n = 8)	U	Z	p (1-tailed)	A
Focused attention	5.714 (1.604)	5.875 (1.808)	27.000	-0.120	.528	.482
Sustained attention	13.571 (3.867)	14.375 (5.317)	26.500	-0.174	.444	.473
Working memory[a]	0.312 (0.047)	0.291 (0.067)	20.500	0.915	.207	.634
Comprehension	4.286 (0.488)	4.500 (0.535)	22.000	-0.816	.378	.393
Memory	14.571 (1.813)	12.750 (4.621)	20.500	0.886	.197	.634
Executive functioning (comp) [b]	-0.660 (3.436)	0.771 (2.800)	23.000	-0.579	.306	.411
Inhibition error score[a c]	0.352 (0.203)	0.187 (0.177)	13.500	-1.699	.049*	.759[d]
Inhibition completion time[c]	62.143 (15.486)	56.750 (6.431)	26.000	-0.232	.424	.536
Set shifting error score[a c]	0.318 (0.117)	0.224 (0.164)	18.000	-1.172	.129	.679
Set shifting completion time[c]	73.143 (12.642)	58.750 (10.820)	11.000	-1.967	.027*	.804[d]
Abstraction[a]	0.611 (0.183)	0.594 (0.138)	27.500	0.058	.490	.509
Problem solving	1.714 (0.951)	1.625 (0.916)	26.000	0.253	.469	.536

Note. Participant data presented are raw score means with the standard deviation in parentheses. Mann-Whitney U-tests were run, and Vargha & Delaney's A was calculated.

[a] = For consistency, the same LOG (100) transformed scores used in the first analysis were used in this analysis. [b] = The executive functioning composite score was created by calculating individual z-scores for each participant for the variables 'inhibition error score', 'set shifting error score', 'abstraction' and 'problem solving', which were then amalgamated into one composite score per participant (although completion time scores are reported, error scores were deemed more indicative of ability and were included in the composite score as being representative of capacity for inhibition and set shifting). [c] = A higher error or completion time score denotes a poorer performance. [d] = Large effect size (Vargha & Delaney, 2000).

* $p < .05$

Appendix F:
Knowledge of Lynch Syndrome Participants Pertaining to the Health Belief Model Categories

Table F1

The Lynch Syndrome Participants' Knowledge of Terminology.

Term	Group	Frequency (n = 8)[a]	Illustrative quote
Predictive Genetic Testing	Adherers	2	Ya, basically it just means that they can predict that your chances would be higher, um... according to various criteria according to whether you carry a gene or your lifestyle or whatever. (P6)
	Non-adherers	4	P11: Is that when they test your genes? R: Mmm... And do you know what it does? What the point is? P11: Is it maybe for research about your genes, and where you can come from, something like that? R: And what were they looking for in your blood? P11: For more genes of my father. To see if maybe I can develop the sickness. Cause it's a family sickness. That's my understanding of it. Uh, that's basically... Uh, you're looking at the causes or, not the causes, the symptoms that might cause it. Uh, so what you're looking at is like this gene, if the gene is there, then you can predict it could occur in you or not. (P16)
LS or HNPCC	Adherers	3	Yes... that was after they took that blood test. (P5) All I know is the non-polypoptic colon cancer. (P6)
	Non-adherers	0	
Polyp	Adherers	4	There are small cells inside your colon, and before it develops into cancer there are little white head/pimples that appear. From those small heads/pimples it can change into cancer. (P2; translated) It's like a little pimple thing that basically ... I mean I see the pictures and some things look really nasty when you see it. (P4)
	Non-adherers	4	Um... it's like a bump inside your colon. (P10) That's a little growth or bad cells on the wall of the colon. (P16)
Blood in the stool	Adherers	3	P4: It could be a number of things. R: Could it be a symptom? P4: Maybe, but not always. My uncle had blood in the stool, but he's negative for the gene, I think.
	Non-adherers	6	Blood in the stool means that the polyp has really progressed, and it is now so big that it bursts every time. And then, that... when it bursts, the blood goes into the stool... it's not fresh blood. Ya. It's, it's almost like... it's old, it's like in the sore, man. Only when they, the doctor asked for a sample of my stools, then he also explained to me it's so black, means there's blood in the stools. (P12) That is when you motion from the back and you see blood in it. (P15)

Term	Group	Frequency (n = 8)[a]	Illustrative quote
Pre-malignant polyp	Adherer	1	It's a polyp that forms... I think there are certain cells that actually show up certain kinds of cancer, um... say some polyps are not malignant and others are starting to change, and they can normally pick that up I think. (P6)
	Non-adherer	1	Ya, that it can develop into cancer. (P12)
Pre-cancer	Adherers	5	Well, pre-cancer's before it actually develops into a full blown cancerous type of cell. (P6)
	Non-adherers	2	Isn't pre-cancer, something that still has to turn into cancer? (P11)
Screening or surveillance	Adherers	4	Screening probably means having it checked regularly. Keeping an eye on it. (P4) It means checking for, um, signs of the cancer. Your pre-cancer cells, or any abnormalities in the colon. It means that they can actually prevent it or... stop it before it starts or whatever. (P6)
	Non-adherers	2	Um... screening is like saying... it's when you for this like barium thing, barium enema? They, is it like that? Or it's, where they have this thing where they see on the computer. (P12) P16: I think it's just to see if you've got it. R: So like a test? P16: Like a colonoscopy.

Note. LS = Lynch syndrome; HNPCC = Hereditary Non-polyposis Colorectal Cancer.

[a] = The participants not accounted for in this table either did not know the answer or gave incorrect answer.

Table F2

The Lynch Syndrome Participants' Knowledge of Lynch Syndrome.

Explanation	Sub-category	Group	Frequency (n = 6)[a]	Illustrative quote
Explanations/ descriptions		Adherers	2	Isn't that the cancer in the blood? (P2)
		Non-adherers	2	While you are being developed... Say, ok, say it's 2 by 2, by 2, and he had this long ladder kind of thing... And then he said that the one, he over develops, now instead of 2, he develops 3 or more than just 2, and then because of that... there's an abnormality there and that's how... It's like the reproduction is of that cell... the pattern is abnormal. (P12) Okay, what it is. There's almost like a traffic cop gene that sits and controls uh... mutated... cells, in your colon. This traffic cop gene is faulty and what it does is it lets mutated cells form, and then obviously they get too many, then your cancer starts. (P16)
Non-polyposis	Means you don't get many polyps/ they grow slowly	Adherers	2	My doctor said non-polyposis means no symptoms, there's really no polyps. (P4) It doesn't show up very quickly... like your polypoptics and things – you can get pains and stuff like that I imagine. The non-polypoptic doesn't show up as easily. (P6)
		Non-adherers	0	
	Doesn't just mean you can get CRC	Adherers	1	In March they told me they rather want me to have another operation to remove the whole thyroid because of the non-polyposis. I found out if you are diagnosed with non-polyposis colorectal cancer, it doesn't mean you're going to get it in your colon...it could be anywhere: breast, eye, brain, blood, anywhere. (P4)
		Non-adherers	0	
It means you can get cancer		Adherers	3	Um... If you have the gene, they don't say you have cancer. It's just...50/50 you got cancer. (P3; translated) Once Dr [X] said "you see that girl over there? Sooner or later she will have cancer because they have the gene. Sooner or later it will happen." (P4)
		Non-adherers	4	There is a big possibility that you will get the cancer.(P9; translated) I think having, knowing that you have this cancer gene in you, you sort of, um... you, at the back of your mind you will always wonder where else it will develop, because just a year or two after that I had to go for a hysterectomy and it was also cancer, so now it always somewhere else it might develop and you don't know. (P12)

Explanation	Sub-category	Group	Frequency (n = 6)[a]	Illustrative quote
It runs in the family/ it is hereditary		Adherers	5	This cancer is in the family, it is a family sickness. I must go because I don't want to fall in the same path as my father. (P1) My kids are also suffering. By the time they get older they will have to go through the same thing that I'm going through. (P4) If we had to get married and have children, our children have to, at the age of 18 or so, have to go for the test, although you don't have it, I have it, so our children still have to go for the test to see if it's in their blood. (P5)
		Non-adherers	5	It's a...family sickness. That's my understanding of it. (P11) She said [my son] must start, first for his blood test when he's 21, and then we take it from there. (P13) We do know that it seems to be hereditary. (P16)
They test your blood to see if you have the gene		Adherers	2	They did the test so they can see if it's maybe in my blood. (P5)
		Non-adherers	2	They took our blood to look if we have that gene. (P9)
Polyps		Adherers	1	All I know if that they find this little pimple like thing. They take it, they do tests on it. Sometimes it's like a bump on the inside of your colon, and sometimes it's like a huge thing. (P4)
		Non-adherers	2	It means that I will... I guess...get those polyps. (P10)
It means you must go for colonoscopies		Adherers	3	Uh... if you have the gene you must go for it, you must. Only the people who have the gene must go for a colonoscopy. (P1) You're not aware that you're getting it, until it's almost too late. I think that's one of the reasons why you go for screening, so that they can pick it up because it doesn't manifest. (P6)
		Non-adherers	2	Okay, you go for your colonoscopy and if you have the gene or you tested positive for maybe getting it, you go for your tests. (P10)
It means you must live a stress-free life		Adherers	0	
		Non-adherers	1	You mustn't be so highly strung, live a simple life and... And the stress just aggravates it. (P12)

Note. [a] = Two adherers and two non-adherers were excluded as they experienced difficulties with this question.

Table F3

The Lynch Syndrome Participants' Knowledge of Colorectal Cancer.

Categories	Explanations	Group	Frequency (n = 8)	Illustrative quote
Explanations/ descriptions	Definitions	Adherers	0	
		Non-adherers	2	I would explain it the way I understood it was that, while you still a, in this foetus in your mom, with the developing.... the multiplication of the cells, there was something, some cell that over developed and that caused, sort of in the... DNA... yes, there's a kink in there or something, and because of that... too much of something caused it to... the too much reproduction of that cell, that's how I understood... and then you are prone to have... that it will develop into cancer. (P12) Mmm. Basically the reproduction of your cells occurs normally, it just goes a bit haywire, and bad cells form.(P16)
	It has to do with colon/stomach	Adherers	3	Colon cancer has something to do with your colon. (P2) Yes, I can feel it in my stomach, I can feel it yes. Where the pain is, there's the sickness. (P8)
		Non-adherers	2	It's in your colon. (P10)
	It is cancer of colon/ stomach	Adherers	4	It's cancer of the colon. (P1)
		Non-adherers	2	Cancer in your stomach, that's all I can know. (P11)
	It is 'something' in the colon...	Adherers	3	Something small like a sore you get in your mouth, but just in your tummy. (P5)
		Non-adherers	3	A small type of um... small stuff that grow in this colon. (P13)
	...which develops into cancer/ might go septic	Adherers	1	Before it develops into cancer there are small white pimples that come out. Those white pimples can turn into cancer. (P2; translated)
		Non-adherers	3	And obviously being cancerous it might go septic. (P16)
	It is hereditary	Adherers	0	
		Non-adherers	3	I don't even really know how it happens, but it's like... I have the gene, got it from my mom.(P10)

Categories	Explanations	Group	Frequency (n = 8)	Illustrative quote
Symptoms	Pain/ burn/ cramping	Adherers	5	Anyone that's related to us complain about a stomach ache, my colon is curling. (P4) It's not nice, colon cancer, because there's a lot of pain. (P8)
		Non-adherers	5	Perhaps they get a pain. I don't think they have to lie in bed because the pain won't be too bad. (P9; translated) The only symptoms that I can recall, cause it's quite a long time ago that they discuss it with me... you have a burn in your tummy, it burn a lot when you eat, when you're going to the toilet then it also burn. (P13)
	Uncomfortable/ diarrhoea/ constipation/ nervous stomach/ can't eat certain things/wind/ heartburn	Adherers	1	Can't eat certain things, stomach was never right... My dad complained about heartburn. (P4)
		Non-adherers	5	I just remember when I was nervous or when I was upset, then would stomach would work and I would run to the toilet. And then... it was, the feeling... Sometimes it was like a diarrhoea, and then there were other times again that I was very constipated. (P12) No, my mom said she had a lot of wind and that was about it. (P16)
	Blockage	Adherers	2	Um.. you get, you can eat, when you have this cancer, you can eat né? But you can't uh... it's kind of blocked, because the growth of the cancer is blocking the way of the food that must come out. (P1)
		Non-adherers	2	Food doesn't go through the part that's affected. (P15)
	Tired/no strength	Adherers	2	You just want to lay. Your body feel tired. (P8)
		Non-adherers	2	So, I got, I grew tired. And then, it went... So bad, even in the malls when myself and my sister would be, there's lots of people walking and I must sit now and there's no chair, nothing, then I would sit next to the window of the shop, just to regain my strength again. (P12)

Categories	Explanations	Group	Frequency (n = 8)	Illustrative quote
Symptoms (cont.)	Dizziness/ blackouts/ vomiting	Adherers	1	It can give you a black out, my father get many black outs. (P1)
		Non-adherers	2	When I eat, I start vomiting. Sometimes I feel dizzy. (P15)
	Weight loss/ you don't want to eat	Adherers	1	You don't want to eat food. (P8)
		Non-adherers	2	It gets very thin; you lose a lot of weight, of cancer colon. (P14)
	Blood in the stool	Adherers	1	There is blood coming from... (P7)
		Non-adherers	1	I also didn't know that I was loosing blood in my stools. (P12)
	No symptoms/ you might not know you have it	Adherers	0	
		Non-adherers	2	You see, I don't.... I didn't really, I don't really know if I had the symptoms or whatever, but I do know that I... um... because I really never had any problems going to the bathroom, but then, I don't even know if people know that they might have colon cancer. (P10)
Tests confirm it	Stool sample, x-rays, colonoscopy, blood tests, tests on the polyp	Adherers	2	All I know if that they find this little pimple like thing. They take it, they do tests on it. And once the results come, they basically remove parts of your colon. (P4)
		Non-adherer	1	And then that doctor wanted a specimen of my stools and then when I took it to him and then he told me my blood is all in my stools, and then he took x-rays and he showed me how that the whole dark piece on the x-ray is that is, that's cancer there. (P12)
Treatment	You must go regularly for colonoscopies	Adherers	1	And that's why I have to go every second year til I'm 30, for the test, so that they can check if there's nothing inside me, or in my stomach or something like that. (P5)
		Non-adherers	1	Okay, you go for your colonoscopy. (P10)
	They can remove the polyp	Adherers	1	Oh, okay, so from my side, if they see something with the test, they somehow remove it. (P5)
		Non-adherers	0	

Categories	Explanations	Group	Frequency (n = 8)	Illustrative quote
Treatment (cont.)	They can operate	Adherers	6	In most cases they cut it out. (P2) All that they do is you get a operation. (P7)
		Non-adherers	6	If you do have it, then um... they cut it out or whatever. (P10) Um... for me, they always cut it out. (P15)
	They MUST operate	Adherers	1	P7: They must take it out yes. R: You can't give a person pills or something to make it go away? P7: No, you must remove it.
		Non-adherers	2	Everybody knows that you can't live with cancer. I mean it has to be taken out or...whatever. (P10)
	They can remove a piece of colon	Adherers	3	Once the results come, they basically remove parts of your colon. (P4)
		Non-adherers	2	If they found something wrong, they will take you in Groote Schuur and they cutting this piece out who had the cancer. (P13)
	They can remove the whole colon	Adherers	3	Maybe it's so far that you get... all the thing must come out. (P7)
		Non-adherers	3	P16: Apparently they cut the whole one out now R: Can they cut a piece out? P16: Apparently they did, but um... they don't anymore, they just take the whole thing out.
	If it is too far they can't cure it	Adherers	1	Now with my father it was too far, so they couldn't cure it. They say when it's too far, it's too far, that kind of cancer. (P1; translated)
		Non-adherers	0	

Categories	Explanations	Group	Frequency (n = 8)	Illustrative quote
Treatment (cont.)	After the operation	Adherers	1	When they take out that piece with the cancer, then you get better. Then they keep an eye on you for a few months, and if you're better then they put your colon back. (P1)
		Non-adherers	1	After the op to see if you have colon cancer and you getting the treatment, they remove the piece or they remove the whole colon... you have a life after that. You have a life – you can carry on the normal life that you had before. (P13)
	You can get a bag	Adherers	2	Not necessarily, I think. Because... the new technology, they don't use the bag anymore. (P5)
		Non-adherers	2	It means that you will wear a bag, but not necessarily. (P9)
	Other treatments (chemotherapy/ radiotherapy/ laser/ prayer)	Adherers	2	I know the chemo is there and radiology. My family would probably say prayer. (P4)
		Non-adherers	1	Or they do the laser treatment. (P15)
It can come back		Adherer	1	Sometime it don't come back again and sometime it does come back again. (P8)
		Non-adherers	3	My brother got it longer than me, and he got it for the second time. (P14)
It can spread		Adherer	1	The maybe spread it out in your body or so on. (P5)
		Non-adherer	1	I suppose it can get to other parts of the body. (P16)
You must live healthily	Live a stress-free life	Adherers	0	
		Non-adherers	1	I would saying knowing if you now know that you have that, like we went for this test, if you now know that you a prone to get cancer, then you should rather... then try to live a very stressless life, or to be calm about things, or try not to... just make your life very very, a calm kind of life. (P12)
	Eat correctly and exercise	Adherers	0	
		Non-adherers	2	You must always try to eat the right stuff. See that is very important, cause you haven't got a colon anymore, you can't eat heavy stuff, cause that make it all worse, your stomach. (P14)

Table F4

The Lynch Syndrome Participants' Knowledge of How Cancer Develops.

Theme	Group	Frequency (n = 8)[a]	Illustrative quote
Does polyp = cancer?	Adherers	6	P2: Not yet. R: What happens in between those times? P2: You must go for an operation and they cut it out before you have cancer. Well a polyp is not necessarily cancer; it could just be a growth. But your cancerous growth is obviously a form of the polyp. (P6)
	Non-adherers	7	No. It can develop into cancer, and while they're those.... perhaps if it's smaller, they can cut it out. (P9; translated) Not yet. They can burn it off. It hasn't developed into cancer yet. (P12)
Difference between "cancer" and "pre-cancer"	Adherers	6	Someone who has cancer and someone who will still get cancer. (P2) The cancer is the one that kills you and the polyp can just change over. (P3; translated)
	Non-adherers	5	The difference is that the cancer is the one that you will die of and the other one, it can still be treated to prevent it from growing into, um being fatal. (P12) The pre-cancer, they can cure it. They can prevent it to be cancer. (P13)
How does CRC develop?	Adherers	2	It just came up like a sore... if it does not receive any attention, then it turns into cancer. (P5) Ya, it's basically a mutated cell. It's like wildfire and it grows in excess. (P6)
	Non-adherers	2	New cells are formed all the time. And then the gene that we've got is faulty, it's supposed to monitor that and make sure it's good cells that form. That's not doing its job so it's actually forming bad cells. Uh... these bad cells start building and growing too fast and obviously the body doesn't get rid of it, the way it should, so uh... it starts accumulating in these polyps on the wall. (P16)

*Note.*CRC = Colorectal cancer.

[a] = The participants not accounted for in this table either did not know the answer or gave incorrect answers.

Table F5

The Lynch Syndrome Participants' Perceived Severity.

Rating	Group	Frequency (n = 8)	Illustrative quote
Severe	Adherers	4	It's bad. It means I must go... if they can operate and take it out, I must go for operation and treatment and that kind of stuff. (P2) Yes, a person can die of this thing. (P3; translated)
	Non-adherers	4	Yes, it's a bad thing, in the sense that if you don't get treatment, you can die. You can die. Cause I know, in this family, my dad's family... this half brother of mine died cause he never go for this test, he never go for treatment, this type of thing. 'Cause he said to himself he don't have it. And they were... I think my dad's brother also, don't want to go and also have it also and he died. So if you don't get treatment... (P13)
Moderately severe	Adherers	2	P6: Would it be bad? It wouldn't be good, 'cause nobody wants to have cancer. If it happens, well then it happens and you have to deal with it. Obviously, the treatment I wouldn't imagine would be very nice, but... I wouldn't like to get it, put it that way. R: But life's not over? P6: But life's not over, no. You deal with it as it comes along.
	Non-adherers	2	It's probably not something that you would welcome, or you know... But if it happens, if there's... nothing is as bad if there's a cure for it. So you need to be just aware of what you're going through and it's not bad at all, 'cause you can live your life... Your life can go on normal, as normal. (P12)
Not severe	Adherers	2	P5: For me, it's not... I don't see the big deal about it, also, the treatment, the testing, that kind of stuff that they go through... So I don't see a big deal about it. R: What about it...what makes you less worried? P5: Because, I know they will... maybe if they saw something in my tummy, they will rather tell me and say now 'Ok, this is what we gonna do...' So that's why I'm testing every second year. Like I said, the new technology, it helps you... The doctors know the ways how to do it, to prevent the maybe spread it out in your body or so on. So they will stop it somehow or someway.
	Non-adherers	2	I can't say it's bad. If something happens to you, it must just happen. (P11) Not at all. (P15)

Table F6

The Lynch Syndrome Participants' Perceived Susceptibility.

Risk Rating	Adherers (n = 7)[a]	Non-adherers (n = 8)
Low	5	4
Accurate	0	2
High	2	2

Note. [a] = Adherer P7 could not give a description of his risk and was excluded from this analysis.

Table F7

The Lynch Syndrome Participants' Knowledge of a Colonoscopy.

Description	Sub-category	Group	Frequency (n = 8)	Illustrative quote
Test/scope		Adherers	1	Uh... colonoscopy is a test. (P1)
		Non-adherers	2	Actually they do it with the scope, the scope at the bottom, colonoscos... (P14)
Preparation	Clear out colon	Adherers	8	The colon must be clean at all times so that the camera can see if there are not any polyps. (P1) So that you can make it clean. Then if they put the camera inside, they can see everything... what is wrong inside. (P3; translated) To clear it out, otherwise you've got too much stuff in the colon for the camera to see the sides of the walls. (P6)
		Non-adherers	7	It's yuggy. For me to drink that, I make sure I do a good job of it, so that when I go, it is completely clean so that they can see... for any polyps, so I make sure, when I get there it is clean, completely clean. (P12) To clean this now the colon, and then the colon is nice clean and then the doctor can see better, otherwise they can't see cause then the stool cover the colon. (P14) Oh well it's obviously to clean it out so the camera can go and see. (P16)
	Day/ night before procedure	Adherers	4	Before you go for the test they give you uh... some Propan I think to drink. You must drink a litre, uh, in an hour, in an hour's time. (P1) The day before, you go for the test. You is drinking some water they give for you. You mustn't eat from 6 o'clock til the next day, mustn't eat, then you must also drink that water to clean your stomach. (P7)
		Non-adherers	0	
	Morning of procedure	Adherers	4	In the morning you must only drink coffee... If you want to drink soup, you must drink it clean without noodles and something like that. When you come there you must drink it again before you go, go into the test. (P1) You arrive at the hospital, then they give me the ColoPrep thing, then my tummy run clean. (P2)
		Non-adherers	1	You drink the water. (P10)
Wait for doctor		Adherers	1	Then it's a few hours before they call you in. (P4)
		Non-adherers	0	

Description	Sub-category	Group	Frequency (n = 8)	Illustrative quote
Sedation		Adherers	6	First they dose you, so you can't feel the pain. (P1) They give you an injection, sometimes they ask you to count from 10 down. (P4) They drug you a bit. (P5)
		Non-adherers	2	They don't sedate you completely but you are a little bit off (P12)
Lie on bed, on your side		Adherers	4	They put you on the bed. (P4) They lay you on the bed. They get you to lay on your side. (P8)
		Non-adherers	0	
Doctor's greeting		Adherers	2	The doctor greets you. (P4)
		Non-adherers	0	
Lubricant		Adherers	1	They put some lubricant on. (P4)
		Non-adherers	0	
Preparation of colon		Adherers	1	They pump up your colon. (P1)
		Non-adherers	0	
Insertion of 'something' into rectum		Adherers	8	They take a pipe with the camera, stick in from the back, and then they put it in my colon. (P2) And then they put the camera in and then they look around. (P3; translated) This is actually what I think it is – it's a little camera scope, with a little claw at the bottom. (P4) They put that thing at the back and they push that thing in... in like a needle...Then just keep you for 2 minutes, put the light in. (P8)
		Non-adherers	7	They put the... it's like a little, um... I don't know if it has a camera in it, but they stick the thing up. (P10) It's like a tube thingy, with a little globe or that, and they push it through your rectal, your rectum né? (P12) Colonoscopy is where, where they take the pipe and they put it in...They put it in... and there's a light. (P13) They take a camera and they stick it up your butt and take pictures. (P16)
Check whole colon		Adherers	4	Then they go through the whole colon, they go back, then they go again. (P1) Then going right through your, right through. (P8)
		Non-adherers	4	Then they go right through your colon. (P12) They check and go through the whole colon. (P13)

Description	Sub-category	Group	Frequency (n = 8)	Illustrative quote
Lift/move you during procedure		Adherers	1	They lift you and move you as they're going through your colon. (P4)
		Non-adherers	1	When they ask you to move you can still operate, you know, co-operate with them. (P12)
Pain		Adherers	2	Then they make you sore, the last... Then they make you sore. (P8)
		Non-adherers	1	It can be really painful, if they take those polyps out. (P13)
Computer screen		Adherers	4	Through the camera on the screen. (P2) There's a light in and you lay on the bed and you can see by the TV there what they're doing. (P8)
		Non-adherers	2	They put that thing in and then it screens on this computer thing and they can see inside. (P10)
Detection of...		Adherers	7	If perhaps there is a small cell, a cancer cell that is there. They look for the cancer and the polyp. The gene and the polyp (P3; translated) Polyps. (P5) For cancer. (P7)
		Non-adherers	5	They go right through your colon to see for any signs of little polyps, that's growing. (P12) They check if there's anything wrong. (P13) They look on the colon and they look for any little spots and things to see if there's any cancer, the colon's clean or whatever. (P14)
Sample is taken		Adherers	1	If they see anything they take a sample. (P4)
		Non-adherers	0	
Sample/polyp sent away to be tested for cancer		Adherers	1	They take it, they do tests on it. (P4)
		Non-adherers	1	They can find out and let me know if there's any polyps, they take them away to test them and see if there's cancer or no cancer. (P15)
End of/after procedure		Adherers	1	When they don't get something, or something, they are finished, that is basically the colon. (P1)
		Non-adherers	1	And after all they sit with you and they tell you everything alright, there's no problem. (P13)

Table F8

The Lynch Syndrome Participants' Knowledge Regarding Recommended Frequency of Colonoscopies.

Accuracy of suggested frequency[a]	Adherers (n = 8)		Non-adherers (n = 8)	
	Under 30 (n = 5)	Over 30 (n = 3)	Under 30 (n = 3)	Over 30 (n = 5)
Under-estimators			1	1
Accurate estimators	5	2	1	4
Over-estimators		1	1	

Note. [a] = Accuracy was based on participants' answer in comparison with the recommended frequency for their age.

Table F9

The Lynch Syndrome Participants' Knowledge of the (Preventative) Aims of Screening.

Aim	Group	Frequency (n = 8)	Illustrative quote
Prevention (of the development of cancer, of the gene developing into cancer, of cancer, of the cancer spreading, or of sickness/death/pain)	Adherers	6	When they take the polyp out of it, out of the colon, it's safer for you. (P1) It's important to prevent the gene to go over to cancer." (P2) Not having cancer. (P4)
	Non-adherers	8	To prevent the cancer. (P9; translated) They can prevent death, and they can prevent sickness. If they pick it up early they can... before you go in this stage where you have a lot of pain, they can prevent this also. (P13) It's important for them to detect on an early stage if the polyps is cancerous or if it's not cancerous. (P15) Uh, you actually just prevent it from spreading, more than anything else. (P16)
Detection (of polyps, cancer or "the germ")	Adherers	3	They're looking for polyps (P5) That is a good thing. You can better see... see first time the cancer. (P7) Colonoscopy is very good, because they put that thing in and the light shows the doctor where is the germ, you see? (P8)
	Non-adherers	7	Just to check inside, if there's growing stuff inside of you. Maybe cancer. (P11) It's just to see whether your colon is clean, and that there's... they not spotting any small polyps. (P12) The point is to see if you have the cancer, if the cancer is growing in the colon. (P13) They're looking for polyps inside the colon. Where your food goes through. (P15)
Knowledge	Adherers	2	Um... because it's, when you don't, it increase your risk of getting this cancer, but if you go regularly, you will know all about it, what is happening. (P1) If you're going to get it, it's better to know sooner rather than later, if you've got it. (P6)
	Non-adherers	2	If you don't go, you won't find out if you've got the cancer, so you can get cured and you can live long. (P14) If I don't go and maybe it can develop again and I won't know about it if I don't go regularly for the colonoscopy. (P15)
Consequences of going for colonoscopies	Adherers	2	They make sure there's no polyps, or if there is polyps, they make sure it's not cancer. (P4) Well, it's to check whether you've got cancerous growths or whatever... so the sooner they find it before they grow too big, it lessens the damage done shall we say, if they can find it before then. (P6)
	Non-adherers	0	

Aim	Group	Frequency (n = 8)	Illustrative quote
Miscellaneous aims			Because it is a family sickness and we must go. (P3; translated)
	Adherers	2	Yes, I will say... it's better. You know that they got a machine, you going in and maybe... I don't know what's the machine called... but it's better that they test. (P7)
	Non-adherers	1	They won't tell me to go if it's not important. (P15)

Table F10

The Lynch Syndrome Participants' Knowledge of Other Protective Actions.

Protective action	Item relating to protective action	Adherer frequency (n = 2)	Non-adherer frequency (n = 5)
Symptom watching/ living healthily	Not getting constipated	1	2
	Eating healthy food		3
Eating the following	Greenery		2
	Spinach		1
	Parsley		1
	Onion		1
	Tomatoes		1
	Oranges		1
	Fruit and vegetables		1
	Fibre and roughage		2
	Less fat		1
	"Kruiewater"	1	
NOT eating the following	Red meat		1
	Acidic food like bananas and oranges		1
	Junk food		2
	Chip or fish oil		1
	Peanuts	1	1
	Biltong	1	
	Beans	1	
	Butter		1
	Food after 10pm	1	
Drinking the following	Lots of water		1
NOT drinking the following	Gas cooldrink	1	1
	Alcohol		1
Taking part in regular exercise			1

Table F11

The Lynch Syndrome Participants' Perceived Benefits of Colonoscopies.

Perceived benefits	Sub-category	Group	Frequency (n = 8)	Illustrative quote
Detection	Early detection/ prevention	Adherers	3	Benefits is when you get the gene [meaning polyp] in my colon and they can cure it still, there's a chance for them to cure it. (P2)
		Non-adherers	4	It ultimately prevents you getting the cancer, the colon cancer, and it prevents you wearing the bag, so it's important. (P9; translated) Well, the good thing is you can catch it early before it becomes a problem. (P16)
	Cancer detection	Adherers	3	For me it's very important. They can look to see if the gene has developed into cancer. I'm scared that they will find things. They must look, it's very important. (P3; translated) They can find the thing and the doctor knows exactly what to do and what to give me. (P8)
		Non-adherers	4	Actually I go for a check up to see if the colon is... if the other piece is there cancer or what. (P14) They can find out and let me know if there's any polyps, they take them away to test them and see if there's cancer or no cancer. Me not going for my colonoscopies, I will be the one to suffer. They won't be able to tell me if they found any polyps or anything. (P15)
Knowledge/ information		Adherers	3	At the end of the day I know my results... I know that there's no polyps that they saw or something like that. (P5) Well, to me, knowledge is always good. It's better to know that you're clear or if there is something. If you know you can do something about it. I mean it's stupid just sticking your head in the sand and hoping it'll go away, it doesn't go away. So, as long as you know that it's clear. (P6)
		Non-adherers	3	You know you're healthy, you know there's no cancer in your body, you understand? (P13) The benefit of having a colonoscopy is at least you know if you got the cancer, or you not have the cancer, I think that is very important. Do you know, okay did the doctor find something or didn't he find it. (P14)

Perceived benefits	Sub-category	Group	Frequency (n = 8)	Illustrative quote
Psychological benefits		Adherers	2	You know that once you've had it and they come to you and tell you, "We'll see you in 2 years", it's a nice feeling. (P4)
		Non-adherers	2	You know you are a high risk person, you can get it, so this is the positive – you're going on the 3rd, you know there's nothing wrong with you cause when the doctors are finished with it, then they talk to you and everything's fine, you can relax, see you next year again. (P13)
Health benefits		Adherers	1	Like I said, the first I did it just for plain curiosity, but now that I'm a bit older, it's more for my own health. (P5)
		Non-adherers	1	For me it's important because it's my health – I must look after myself. (P13)

Table F12

The Lynch Syndrome Participants' Perceived Barriers to Colonoscopies.

Barrier	Sub-category	Frequency (n = 8)	Illustrative quote
Difficulties in getting to venue	Transport	2	Transport for me man... Transport is my main thing ya. (P14)
	Financial cost	2	It's expensive, but it's for my own benefit, so what can you do? (P15)
	Walking up the hill	2	It's very difficult, it's difficult for me just to walk up that.... you get tired and your legs can't carry you but you have to go up there. (P14)
Procedural related issues	CRC discussion	1	Talking about all that stuff, it's not normal.(P10)
	Drinking the prep	1	It's gross you have to drink that stuff. (P11)
	Actual procedure	1	Ya, the whole thing... I didn't like it also, the way that they do it... I don't like people sticking things like that in me. (P10)
	Hospitals	2	It's just... Um [laughs]... Groote Schuur, somehow…how can I explain? With Groote Schuur, there's this whole thing of, the thing looks so much more... 'Ohhh, he's gonna die, he's gonna die...' the building man [laughs]. But if you go private man, with medical aid, and the frilly curtains and the colour of the floors and everything... So even if they do come with the bad news, it's not so bad [laughs]. (P12)
Work related issues	Taking time off work	2	Normally I work on a Saturday to take the day off to go for a colonoscopy. (P15) In fact last year I didn't go... Somehow it just happened that I couldn't make it, because I started working permanently. (P12)
	No time (due to work)	2	It's time. 'Cause unfortunately you can only go to general hospitals and it's waiting and waiting. I don't have time to do that. Basically it takes up a whole day. (P16)

Barrier	Sub-category	Frequency (n = 8)	Illustrative quote
Psychological factors	Anxiety re. what they might find	1	I missed one once, in the beginning, just after the gene, and then I didn't go because I was scared over what they would see. (P9; translated)
	Need for emotional support	1	But then... I think part of it was like "I'll just do it when I'm home, when my family's there. I don't want to do it in a strange country where... who knows how they're gonna treat you.(P10)
	Denial of symptoms	1	I don't know, I was just like... you know some people they go like into denial or something. I knew I had the, I was positive, I was just going to wish this thing away... there's nothing, I'm fine. (P10)
	Need for mental preparedness	1	P13: Last year's one I missed because for this type of test you must be really mentally prepared... So I told them I was not mentally prepared for last year. There was so much factors in my... at this stage, close to the date... I feel, no I rather just postpone... 'cause you must... for me it's this type of preparedness... A lot of factors. R: Can you tell me a little bit about that? Why were you not mentally prepared? P13: At this stage there was a lot of stress... my work, and I feel it was draining too much from me and I don't have the strength to go through this episode.
Feeling healthy/ no symptoms		2	P11: I thought I didn't have cancer, something like that man, in my mind. I just felt healthy that time and thought I didn't have to do it...Maybe if I feel sick or something I'll go maybe. If I get a small scare, I'll contact or something.
Being dependant on reminders		1	Man, somehow... I, I changed schools and sister[X] was supposed to drop it, and she... I told her with a phone-call 'No I'm not there anymore', and then she left it with my aunt, and then I got it, got it from my aunt late and then I didn't see the date... And I got so dependent on her phoning me, you know it got all so mixed up man. (P12)
Fundamental issues		1	P11: I would go [for another colonoscopy] yea, but, when I'm ready. Maybe not this year, maybe in this year still. But when I'm first, how can I say... feel good about myself man. Then I will come maybe. When I get work and stuff, I need to sort out my life, then maybe I will go for one. R: Do you think that's stopping you? P11: Yes, my mind's not focused on that stuff, it's just focused on my living stuff. Yea, you can't just think about the, if you got stress, you haven't got work to make money, stuff like that, my living...

Note. CRC = Colorectal cancer.