

# **Exploring illness perceptions of a group of adolescents living with diabetes while using continuous glucose monitoring (CGM)**

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## **Summary**

Type 1 diabetes (T1D) is regarded as one of the most rapidly growing chronic diseases globally, with an estimation that 1 in every 400 children diagnosed with diabetes mellitus every day (American Academy of Pediatrics, 2015). This diagnosis is accompanied by severe social, psychological, and behavioural consequences, especially during an already challenging developmental stage, as adolescents are expected to take more responsibility for their diabetes care plans. These young people develop a set of beliefs as part of making sense of their diagnosis, which directs them in the way they approach and manage their illness, and has been linked to their self-care management behaviours and treatment adherence outcomes. Only a few adolescents succeed in adequately controlling and managing their blood glucose levels as they confront multiple barriers in managing diabetes.

Research studies to determine the psychological barriers and benefits that the use of continuous glucose monitoring systems holds, indicated that these systems form part of diabetes care plans. Yet there is a scarcity of research exploring the illness perceptions of adolescents living with diabetes within the South African context, let alone while they are using continuous glucose monitoring (CGM). This study aimed to breach this gap in research by exploring the illness perceptions of adolescents living with type 1 diabetes while they were using CGM.

A qualitative approach was adopted and eligible participants were selected to participate in the study by using non-random purposive sampling as they had to meet clear predefined sample inclusion criteria. The selected population sample comprised of seven adolescents between the ages of 14 and 16 years living with type 1 diabetes mellitus and attending the Centre for Diabetes and Endocrinology (CDE) in Parktown, Johannesburg. Data were collected by semi-structured interviews, which lasted between 30 to 40 minutes. Data analysis was carried out by using Braun and Clarke's thematic analysis.

From the thematic analysis of each adolescent participant's responses, three themes emerged: (1) CGM creates a sense of control over diabetes management; (2) CGM assists in creating a new normal; and (3) being different creates an opportunity for positive outcomes.

From the findings it became evident that adolescents perceive diabetes management as challenging because it imposes barriers which inhibit them from living a so-called normal life. Nonetheless, it was apparent that, since using CGM, they regarded diabetes management as more convenient and manageable as they experienced an increased sense of control both over diagnosis and management. The continuous visibility of their blood glucose levels promoted predictability, allowing participants to experience their diabetes management as a positive experience that assisted them in feeling more normal in relation to their peers. Feeling in control of the diagnosis and the care plans that accompanied it empowered participants to ultimately accept the condition and its management with a newfound confidence for the future.

In conclusion, fresh insight is obtained into the illness perceptions of adolescents living with type 1 diabetes who are using CGM in the South African context. The findings could be beneficial to diabetes health care providers, caregivers of adolescents living with diabetes, or patients themselves. New insights may assist in broadening the understanding of the use of CGM devices and their impact on illness perceptions. With greater knowledge, adolescents living with diabetes may experience these diabetes care plans as more manageable. Through perceiving a greater sense of control over the diabetes care plans, adolescents living with diabetes may be able to identify a silver lining in the manageability of their diagnosis which may have been previously overlooked.

**KEY WORDS:** Diabetes mellitus; type 1 diabetes; illness perceptions; continuous glucose monitoring (CGM); adolescents.

## Preface

- This mini-dissertation is written in an article format, which complies with rule A4.4.2, laid down by the North-West University.
- The article *Exploring illness perceptions of a group of adolescents living with diabetes while using continuous glucose monitoring (CGM)* in Section 2 of this mini-dissertation will be submitted to the *Journal of Diabetes Research and Clinical Practice* for possible publication.
- Author guidelines set out in the *Journal of Diabetes Research and Clinical Practice* were followed in constructing the article.
- The mini-dissertation applied the editorial and reference style guidelines set out in the Publication Manual (6<sup>th</sup> edition) of the American Psychological Association (APA) guide.
- This mini-dissertation is presented consistently, with consecutive page numbering, commencing with the introduction and concluding with the references.
- The co-authors, Prof. E. Deacon and Prof. E. van Rensburg, of the article: *Exploring illness perceptions of a group of adolescents living with diabetes while using continuous glucose monitoring (CGM)*, assisted with the interpretation of the results obtained and were involved in the peer review aspect of the article.
- The co-authors of this mini-dissertation gave their consent for this article to be submitted for examination purposes in partial fulfilment of the requirements for an MA degree in Counselling Psychology.
- The numbering of data tables starts in Section 2.
- This mini-dissertation received satisfactory norms when submitted to Turn-it-in.



### **Declaration statement**

I, Letitia Williams, declare that this dissertation, *Exploring illness perceptions of a group of adolescents living with diabetes while using continuous glucose monitoring (CGM)*, submitted in partial fulfilment for the degree Master of Arts in Counselling Psychology at the North-West University, was completed in accordance with the Copyright Act No 98 of 1978 of the Republic of South Africa. In writing and compiling this dissertation, all academic and literary materials and sources consulted were referenced and acknowledged to the best of my ability in accordance with the American Psychological Association's Publication Manual (6<sup>th</sup> edition). Best attempts were made to paraphrase and rework these materials. I furthermore declare that this dissertation has not been submitted for any other purpose to another institution, but only for examination purposes to the North-West University, Potchefstroom Campus.



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Mrs. L Williams

### Permission letter from supervisors

We, the undersigned and supervisors of this study and co-authors of the journal manuscript, hereby declare that the mini-dissertation entitled *Exploring illness perceptions of a group of adolescents living with diabetes while using continuous glucose monitoring (CGM)* completed by Letitia Williams, does reflect the research regarding the subject matter and is her own work. Permission is granted that she may submit the manuscript for examination purposes and confirm that the mini-dissertation submitted is in partial fulfilment of the requirements for the degree Master of Arts in Counselling Psychology at the Potchefstroom Campus of the North-West University. The article may also be submitted to the *Diabetes Research and Clinical Practice* for publication purposes.



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Prof E Deacon

Supervisor



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Prof E van Rensburg

Co-supervisor

**Proof of language editing**

I hereby declare that I have language edited the manuscript

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# ILLNESS PERCEPTION OF ADOLESCENTS WITH TYPE 1 DIABETES

## **Exploring illness perceptions of a group of adolescents living with diabetes while using continuous glucose monitoring (CGM)**

### **SECTION 1: INTRODUCTION AND RATIONALE**

#### **1.1 Introduction**

Within this study, the illness perceptions of a group of adolescents living with type 1 diabetes were explored while they were using continuous glucose monitoring (CGM). The first part of this section comprises a general introduction, overview, and rationale for the study. The second part consists of the relevant literature to assist the reader in gaining a broader and more comprehensive understanding of each of the essential concepts pertaining to the present study. This literature covers pertinent findings and works concerning type 1 diabetes, continuous glucose monitoring, and illness perception. The third part presents the research aim and general objectives, followed by the research model and methodology which guided this study. The final part concludes with the relevant ethical considerations.

#### **1.2 Problem statement and orientation**

Type 1 diabetes (diabetes mellitus) is seen as one of the most rapidly growing chronic diseases, with severe social and psychological consequences (Hagger, Hendrieckx, Browne, Cameron, Pouwer, Skinner, & Speight, 2016; International Diabetes Federation, 2015). In 2015 it was indicated that over 542,000 children under the age of 14 years were living with type 1 diabetes, worldwide (IDF, 2015). Approximately 1 in every 400 children is being diagnosed with diabetes mellitus on a daily basis globally (American Academy of Pediatrics, 2015; Compas, Jaser, Dunn, & Rodriguez, 2012; Couch et al., 2008; Haller, Atkinson, & Schatz, 2005; Reynolds & Helgeson, 2011; Schabert, Browne, Mosely, & Speight, 2013).

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The prevalence of type 1 diabetes among South African adolescents (between the ages of 12-17 years) is unknown and this indicates a need for research (Dhada, Blackbeard, & Adams, 2014).

Adolescence is widely regarded as a challenging and vulnerable developmental stage during which adolescents are faced with multiple physiological and social changes while on their quest to develop their identity and to find their own niche in the world (Sadock, Sadock, & Ruiz, 2015). These challenges are exacerbated by type 1 diabetes, which is one of the most prevalent and serious endocrine disorders diagnosed during adolescence (Borus & Laffel, 2010; Patterson et al., 2014). The psychosocial development of adolescents living with diabetes may be significantly affected by their diagnosis if not managed effectively, leading to the possible development of depressive and anxiety symptoms as well as a sense of social and physical incompetence (Giani, Snelgrove, Volkening, & Laffel, 2017; Hood, Heustis, Maher, Butler, Volkening, & Laffel, 2006; Iannotti et al., 2006; Khemakhem et al., 2020). As such a diagnosis and the way it is managed can severely impact on adolescents' physiological, social and psychological functioning. It is therefore imperative to gain the perspective of those adolescents living with diabetes as it impacts their diabetes management. This study can therefore assist in determining the perceptions adolescents living with diabetes hold regarding their diagnosis while using CGM.

### **1.3 Type 1 diabetes**

Diabetes, also medically known as diabetes mellitus, is a disease in which people experience defects in insulin action or secretion, or a glucose imbalance, or even at times a combination of the two (American Diabetes Association, 2010; Centres for Disease Control and Prevention [CDC], 2014; Craig et al., 2014; Guariguata et al., 2013; Jerant, Von Friederichs-Fitzwater, & Moore, 2005; Van der Merwe, 2015). Type 1 diabetes (T1D),

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formerly referred to as juvenile-onset diabetes or insulin-dependent diabetes, is diagnosed as an autoimmune response. This diagnosis is made when the body's beta cells, responsible of producing insulin, are destroyed, causing the pancreas to not produce enough, or any, insulin, and resulting in the development of lifelong dependence on exogenous insulin (CDC, 2014; Chiang et al., 2014; Jones & Persaud, 2010; Matthews, 2007; Van der Merwe, 2015). Due to the abnormalities in the secretion of insulin, the body's ability to regulate the glucose in the bloodstream is reduced, resulting in subsequent disorders of carbohydrate, protein, and fat metabolism, and chronic hyperglycaemia (Kaul, Tarr, Ahmad, Kohner, & Chibber, 2012; Sherwood, 2010). There is no specific cause for type 1 diabetes, but there is existing evidence that sheds light on some genetic contributions to the disease formation which implicate a gene on chromosome 6 (Beaser, 2010; Chiang et al., 2014). Other evidence indicates that viruses that may also be responsible for the triggering of this chronic disease (Leslie, Ho-Le, & Beyan, 2012; Matthews, 2007; Patterson et al., 2014).

The policy regarding the diagnoses of type 1 diabetes was revised by the American Diabetes Association in 2010 to incorporate glycated haemoglobin (HbA1C) levels. This is a test that measures an individual's average blood glucose levels over three consecutive months. The HbA1C results should be below 7% (53mmol/mol) for glycaemic control to be regarded as effective (Sharma & Singal, 2015). Effective control assists in preventing the development or progression of diabetes complications such as ketoacidosis, hypoglycaemia, blindness, end-stage renal disease, cardiovascular diseases and lower-extremity amputation (Datye, Moore, Russel, & Jaser, 2015; Hinzman, Schlaeger, & Tran, 2010; Lung, Clarke, Hayes, Stevens, & Farmer, 2013).

There is a decreased risk of developing various complications and comorbidities which are often responsible for high mortality rates and morbidity among individuals living with type 1 diabetes if effective diabetes care plans are followed (Borus & Laffel, 2010; Roze

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et al., 2015; Wadén et al., 2009), but these add to the psychological burden of living with diabetes. The psychological experiences of individuals living with diabetes indicated that their psychosocial functioning had been negatively affected by their diagnosis and they expressed anxiety and stress as a result of the diabetes care plans to be followed (Hörsten, Norberg, & Lundman, 2002; Lustman, Carney, & Amado, 1981; Nicolucci et al., 2013; Turkat, 1982; Watts, O'Hara, & Trigg, 2010).

### **1.4 Diabetes management in adolescence**

Various studies indicated that adherence to an effective diabetes care plan generally declines at some stage of the adolescence developmental phase (Borus & Laffel, 2010; Bryden et al., 2001; Hilliard, Wu, Rausch, Dolan, & Hood, 2013; King, Berg, Butner, Butler, & Wiebe, 2014). Effective diabetes management implies various behaviours, including regular blood glucose testing, taking prescribed medication (insulin injections), regular exercise and restricting certain food choices (CDC, 2014; Silverstein et al., 2005; Van der Merwe, 2015). These management strategies are intrinsically regulated, but adolescents living with diabetes experience additional developmental difficulties (Freeborn, Dyches, Roper, & Mandleco, 2013). Most adolescents strive to be autonomous, try to fit in with peers, to feel socially accepted and gain a sense of belonging, while simultaneously having to take more responsibility for their diabetes care plans, which is often regarded as stressful and demanding in itself (Freeborn et al., 2013). These challenges often result in adolescents living with diabetes feeling different from peers, as testing and managing their blood glucose levels can be time-consuming, allowing less time for them to participate in activities with their friends (Freeborn et al., 2013). At times adolescents living with diabetes neglect their diabetes care plan in an attempt not to appear different, consequently provoking accompanying additional health risks (Freeborn et al., 2013). However, technological

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advancements in blood glucose monitoring in the past ten years have led to the development of continuous glucose monitoring (CGM).

One of the most challenging aspects of diabetes management involves constant glucose monitoring, which prompted the innovation of CGM in an attempt to make the management of diabetes more controllable. CGM devices are small sensors which are inserted beneath an individual's skin, most commonly on the abdomen or arm (Rewers, Pihoker, Donaghue, Hanas, Swift, & Klingensmith, 2007). The sensor provides continuous feedback on the individual's blood glucose levels which is wirelessly transmitted to the CGM monitor visible to the individual using the device. This CGM sensor can be used on its own with traditional insulin injection administrations, or in combination with an insulin pump which is also inserted under the skin, releasing insulin as needed (Rewers et al., 2007). CGM is a Food and Drug Administration (FDA)-approved electronic device which provides continuous, visual measures of an individual's specific glucose levels throughout the day. CGM differs from previous, single glucose readings in that blood glucose is measured every five minutes in real time with the device (Bode & Battelino, 2017; Chase et al., 2010; Reiterer, Polterauer, & Schoemaker, 2017). This is particularly beneficial for individuals living with diabetes by observing the variation of blood glucose and so assisting with direct diabetes management (Bode & Battelino, 2017; Breton & Kovatchev, 2008).

CGM is provided by different types of devices, such as DexCom G5®, Medtronic Enlite® and Freestyle Libre. South African research on the perspectives adolescents living with diabetes have of their illness and their use of CGM is scant. Prior research studies have concluded that CGM systems assist in the reduction of HbA1C levels and complications such as hypoglycaemia, irrespective of whether the individual is using insulin pump or injection therapy (Chase et al., 2010; Damiano, El-Khatib, Zeng, Nathan, & Russell, 2013).



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The quality of life of adolescents living with diabetes is affected because they experience various challenges in their everyday lives (Khemakhem et al., 2020). Academic performance is also affected in adolescents living with diabetes because they may be tired during the day due to poor or interrupted sleep from having to test their blood glucose levels or experiencing unexpected low blood glucose levels during the day (Iannotti et al., 2006; Perez et al., 2018). CGM can assist these young people living with diabetes to have a better quality of life by enabling them to spend less time on their continuous blood glucose testing and management, and consequently experiencing less anxiety and fewer depressive symptoms, but improved relationships with peers, and enhanced academic performance (Giani et al., 2017; Hood et al., 2006; Iannotti et al., 2006; Khemakhem et al., 2020).

It is important to note that the focus of the study was not on CGM as a medical intervention. The implementation of CGM is performed by a medical specialist who provides training in the use of the specific device, how to attach the device to the body, understand results and use these results in their diabetes management. Adolescents using CGM will receive an estimate of 288 readings within a 24-hour period, making their blood glucose levels more predictable, which may inform their diabetes management and can greatly affect their perceptions of the illness. These readings of glucose levels, direction, and speed are essential to managing diabetes proactively (Chase et al., 2010; Freckmann et al., 2013; Kovatchev, Patek, Ortiz, & Breton, 2015). Continuous visual cues about blood glucose levels obtained from CGM provides individuals with information to make informed decisions and so comprehend that the illness is linked to their perception of it. This is related to managing the consequences and ultimately the control of the illness.

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### **1.5 Illness perception**

Prior research indicates that self-care management behaviours and outcomes, such as glycaemic control of chronically ill patients, may be predicted by their beliefs and perceptions in relation to their illness (Broadbent et al., 2011; Griva et al., 2000; Hampson, Russel, & Toobert, 1990, Lange & Piette, 2006, Mc Sharry, Moss-Morris & Kendrick, 2011). These cognitive belief systems, more commonly referred to as illness perceptions or personal models, include emotional representations of the diagnoses or the illness (Leventhal et al., 1997). Cognitive beliefs mainly originate from the following three sources: (1) pre-existing knowledge regarding the illness acquired from external sources; (2) information obtained from authoritative and respected sources (the physician for example); and lastly (3) the individual's appraisal of his/her personal perception regarding the illness and its symptoms (Barker, McGee, Morgan, & Villiers-Tuthill, 2014; Carey et al., 2014; Hagger & Orbell, 2003).

Adolescents' illness perception will be studied here using Leventhal's Common Sense Model (CSM). This theoretical framework is based on the processes of self-regulation (Leventhal et al., 1997). Self-regulation refers to the manner in which individuals plan and set certain goals for themselves, and which guides their behaviour in an attempt to obtain these goals (Botha, 2013). This may inform how individuals' illness perception of their diabetes could impact and guide their approach to effective management behaviours. The common sense model (CSM) holds that an individual forms illness representations or perceptions to act as a guide for the management for health threats (Leventhal et al., 1997; Petrie & Weinman, 2012). Illness perceptions, according to this model, are seen as dynamic and open to adaptation. There is an ongoing process of appraisal of actions to either return to normal functioning or to adjust actions when they are not in the range of normal functioning (Leventhal et al., 1997; Mc Sharry, Bishop, Moss-Morris & Kendrick, 2013; Petrie &

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Weinman, 2012). These illness perceptions act in the common sense framework as symptoms that can be interpreted and behaviour that could ultimately be managed to prevent poor and ill health conditions (Leventhal et al., 1997). The process of regaining optimal glucose levels is initiated by an individual's belief that he/she is currently affected by the illness and that behavioural changes are required to return to the pre-illness baseline (Safo, Batchelder, Peyser, & Litwin, 2015). An individual's illness perception thus serves as a stimulus to create awareness of his or her current illness status by the interpretations made through the common sense framework (McAndrew et al., 2008). The awareness gained, in turn, prompts the individual to adopt specific disease-modifying and management behaviours for better treatment outcomes and to comply with medication regimens (McAndrew et al., 2008).

According to the abovementioned theory, CSM integrates the following five cognitive domains: 1) identity, which entails the individual's illness concepts, comprehension and how they create meaning from their illness (its associated symptoms, character and categorisation); 2) timeline, which entails the perception of the anticipated duration; 3) the probable causes of the illness; 4) the illness's consequences, which include the individual's likely beliefs regarding the gravity of their illness and its anticipated impact on their social, physical and psychological performance; and last (5) whether their illness can be managed or cured or the extent to which they have control over it (Fortenberry et al., 2014; Leventhal et al., 1997; Petrie, Jago, & Devcich, 2007; Petrie & Weinman, 2012). These domains are separate and different and can influence the ability to manage the illness and its outcomes in a variety of ways (Leventhal et al., 1997). The CSM is therefore regarded as a parallel-processing model according to which individuals naturally construct both emotional and cognitive representations of their specific illness through situational stimuli (for instance symptoms), which could be essential determinants of possible outcomes (Broadbent et al., 2006; Moss-Morris, Weinman, Petrie, & Buick, 2002).

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Illness perceptions are developed when someone attempts to understand and make sense of their illness, in this case diabetes, which acts as a guide for their illness management (Leventhal et al., 1997). Illness perception is further associated with illness- and psychologically-related outcomes (Hagger & Orbell, 2003). Individuals acquire illness perceptions when interpreting information from factual or social sources, physical experiences, or exposure to medical interventions, all of which contributes to the depiction of their illness perception as a range of certain beliefs regarding illnesses (Leventhal et al., 1997; Petrie et al., 2007). Research on illness perceptions during adolescence is scant (Fortenberry et al., 2014). This study can therefore contribute to the body of knowledge by using the findings to guide adolescents' illness management practices (Hagger & Orbell, 2003; Leventhal et al., 1997).

A cross-sectional research study by Olsen, Berg, and Wiebe (2008) found that illness perceptions are not fixed, but instead may vary across different age spans. This notion was supported by Jonker, Deacon, van Rensburg and Segal (2018), whose study found that adolescents' illness perceptions were possibly shaped over time through their acknowledging and accepting their diagnosis as part of their lives. This change in perspective was further informed by more knowledge and understanding of how to adequately to manage their illness and this helped adolescents living with diabetes to feel empowered by taking on more responsibility to manage the illness (Jonker et al., 2018). Subsequently, older adolescents had more insight into their chronic illness, with a tendency to be better aware of the significance of their HbA1C levels than younger adolescents (Patiño-Fernández et al., 2010). Smetana, Campione-Barr, and Metzger (2006) stated that, through maturation, adolescents' illness perceptions might vary and adapt as they develop socio-emotionally and gain cognitive awareness and insight. Adolescents are thus expected to take charge of and be more responsible for their diagnosis and care plan (Wiebe et al., 2014). To become more

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independent, they are expected both to identify and adapt their own perceptions regarding diabetes, and in turn, to change their behaviour accordingly to ensure that they exercise adequate control over the diagnosis through self-management behaviours (Wiebe et al., 2014).

In order to enhance disease management outcomes, it is vital to change patients' perceptions (Broadbent et al., 2006). Various studies indicated that the illness perception of adults living with diabetes strongly relates to the adherence of diabetes management as well as to psychosocial adjustments which could greatly benefit individuals living with diabetes (Broadbent et al., 2011; Hagger & Orbell, 2003). However, studies investigating the illness perception of adolescents using CGM are limited. This study aims to narrow this gap in diabetes research by investigating the illness perceptions in a group of adolescents using CGM.

### **1.6 Research aim/objective**

This study explored the illness perception of a group of adolescents living with type 1 diabetes while using CGM.

### **1.7 Research method**

This research study is comprised of a literature- as well as an empirical study.

#### **1.7.1 Literature review**

This research includes a theoretical desktop literature review, comprising the following data sources: EBSCO host, Google Scholar, books, journal articles. The review included the subsequent concepts: *diabetes mellitus, type 1 diabetes, illness perception, continuous glucose monitoring (CGM), adolescents, self-management*.

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### **1.7.2 Empirical study**

The empirical study will be described below.

#### **1.7.2.1 Research question**

Research on the illness perceptions of adolescents living with diabetes in the South African context is scant. To narrow this research gap, this study was driven by the following research question: *What are the illness perceptions of a group of adolescents living with type 1 diabetes while using CGM?*

#### **1.7.2.2 Research methodology**

The research question assisted in formulating the most appropriate research methodology in order to carry out the study. The methodology used aimed at exploring the illness perceptions of adolescents living with diabetes using CGM.

Qualitative research was indicated to obtain an in-depth understanding of individuals' experiences which underpin and drive their perceptions and behaviour (Bless, Higson-Smith, & Kagee, 2006). A social constructivist approach to the research was adopted to understand how meaning is created through the use of language within the social contexts in which adolescents function (Lock & Strong, 2012; Losantos, Montoya, Exeni, Loots, & Santa Cruz, 2016). According to Lock and Strong (2012), individuals define and develop their own thoughts, perceptions, behaviours and identities within particular contexts. By using a social constructionist approach, adolescents' different perspectives on the social reality of using CGM while living with type 1 diabetes illness can be obtained.

#### **1.7.2.3 Research design**

A qualitative description research design was followed to obtain a clear fundamental description of the phenomena being studied (Sandelowski, 2000), in this case, the illness perceptions of adolescents living with diabetes and using CGM. According to Sandelowski (2000), qualitative description involves presenting facts obtained from participants in

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everyday language, without detailed interpretations of the data obtained. This research design regards language to be the vehicle of communication, used to present the facts as they are to describe a particular phenomenon (Sandelowski, 2000). This assisted in fulfilling the aim of the study, to explore illness perceptions of the adolescents living with diabetes, as qualitative description provided a comprehensive summary of how adolescents view and perceive their use of CGM. This approach promoted descriptive validity as the researcher did not make her own interpretations of what had been conveyed by the participant, thereby providing an accurate account of participants' perceptions (Sandelowski, 2000).

### **1.7.2.4 Participants**

Non-random purposive sampling method was employed to select participants for this study. Eligible participants had to meet clearly defined, specific, pre-determined sample inclusion criteria (Ritchie, Lewis, Elam, Tennant, & Rahim, 2013). The participants included adolescents (12 – 17 years old) with diabetes mellitus who are using CGM. Participants were selected at this particular developmental stage, adolescence, because the literature indicates that an individual's beliefs and perceptions, as well as habits pertaining to diabetes are shaped during childhood and adolescence (Lawson, Bundy, & Harvey, 2008; Tripathy, 2012). This view was deemed to be a good indicator that the adolescent developmental stage forms the foundation for the management behaviours of diabetes mellitus in adulthood (Lawson et al., 2008; Tripathy, 2012).

The access point for the identification of potential participants was mainly the CDE in Parktown which specialises in paediatric diabetes and made it possible to include participants with in-depth knowledge of the phenomenon in this study. The centre is regarded as an ideal setting under the direction of Prof. David Segal, a paediatric endocrinologist at the CDE, who specialises in type 1 diabetes and attracts patients from across South Africa. This made it easier to find suitable participants between the ages of 12 and 17 years diagnosed with type 1

#### **1.7.2.5 Impact of COVID-19 on the research process**

The study was greatly affected by the Coronavirus disease (COVID-19). COVID-19 is an infectious respiratory disease which the World Health Organization (WHO) declared a public health emergency (International Society for Pediatric and Adolescent Diabetes, 2020). COVID-19 may be spread through close contact with an individual infected with the disease, as it is dispersed through airborne droplets via coughs, sneezes, talking or singing (Chen et al., 2020; ISPAD, 2020). Older individuals and those with pre-existing medical conditions, for example diabetes mellitus, are believed to be the most at risk and vulnerable to infection (Chen et al., 2020; IDF, 2020; ISPAD, 2020). Individuals living with diabetes may experience greater difficulty in being treated for COVID-19 once infected, as a result of potential diabetes complications and fluctuating blood glucose levels (IDF, 2020; ISPAD, 2020).

In light of the prevalent COVID-19 crisis, the government implemented lockdown to restrict person-to-person contact in an attempt to limit the spread of the disease (Chen et al., 2020; IDF, 2020). This meant that recruitment, screening, consenting, interviewing and debriefing were carried out virtually, with the use of video conferencing technology. Video conferencing is an online-based technological platform which enables individuals to engage in a synchronous face-to-face manner from different locations (Janghorban, Roudsari, & Taghipour, 2014; Nehls, Smith, & Schneider, 2015). The best interest principle was thus upheld for the participants because they were able to take part in the semi-structured interviews with the use of video conferencing technology in the midst of the COVID-19 crisis. This approach helped to limit in-person contact, which might have posed a risk of contamination to a group of participants who are already deemed to be vulnerable due to their diagnosis, and thereby inherently promoted their safety (ISPAD, 2020). Additionally,



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Prof. Segal's patients continued their sessions and communication with him through video conferencing technology during this lockdown period, thus familiarising those who participated with this virtual platform. Using the video conferencing technology may have also helped participants to feel more comfortable and open about being involved in semi-structured interviews because it was possible to conduct them in the comfort of their homes - a more informal and relaxed setting (Janghorban, Roudsari, & Taghipour, 2014; Nehls, Smith, & Schneider, 2015; Sedgwick & Spiers, 2009). Oates (2015) indicated that it was possible to establish sensitivity and rapport with participants through using video conferencing technology platforms. It was found that removing the tangible presence of the interviewer could put some participants at ease, allowing them to be less inhibited when sharing their perceptions and opinions (Lo Iacono, Symonds, & Brown, 2016; Sedgwick & Spiers, 2009). It was also in the participants' best interests as the health risks were dramatically reduced in the event that they experienced unexpectedly low or high blood glucose levels. This risk was reduced because the participants were able to test and control their own blood glucose levels in order to correct them, with the assistance of their caregivers who are trained in this procedure (IDF, 2020; ISPAD, 2020).

Conducting the interviews remotely in this way also made the research process more convenient for the participants because they did not have pay for travelling or give up more of their time to attend interviews as they could do it in the comfort of their homes (Janghorban et al., 2014; Lo Iacono et al., 2016). Participants used approximately 1 GB of data for the interview and were not reimbursed by the researcher, as they preferred and felt comfortable with using their own data.

### **1.7.2.6 Sample**

The sample will consist of six to ten participants, or until it becomes evident that data saturation has been reached, and no new themes or data comes to the fore (Braun & Clarke,

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2013; Vasileiou, Barnett, Thorpe, & Young, 2018). Although this sample size is small, it is accepted in qualitative research studies as data saturation occurs, which could result in the information obtained from the interviews not yielding any new or pertinent information (Richie, Lewis, & Elam, 2009). Richie, Lewis, and Elam (2009) further note that each participant in a study contributes a richness of information, which justifies a small sample size as being adequate in qualitative research. Onwuegbuzie and Leech (2007) also stated concurrently that in the case of a sample size being too large, the extraction of new, pertinent, and rich data might be halted. According to Creswell (2007), a minimum sample size for in-depth or semi-structured interviews is suggested to be between five and twenty-five, provided the sample meets specific predetermined inclusion criteria (Saunders, 2012). Creswell (2007) further noted that a larger sample size of twenty-five to thirty interviews is required for a heterogeneous population.

### **1.7.2.7 Inclusion and exclusion criteria**

Criteria for participants' inclusion in the current study were as follows:

- They had to be within the developmental period of adolescence (aged between 12 and 17 years).
- They had to have been diagnosed with type 1 diabetes more than 12 months prior to data collection in order to avoid the impact that ongoing adjustment to the diagnosis might have had on the reliability and validity of the data obtained.
- They had to have been using CGM for more than 3 months.
- They had to be patients at the CDE: Parktown, Johannesburg, in order to minimise treatment variables.
- Participants had to have access to internet connection and to have been willing to participate in the semi-structured interviews on video conferencing technology platform. This decreased the risk of COVID-19 spreading, thus ensuring the

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safety of the participant by making use of virtual interviews. Should participants have needed data to conduct the interview, this would have been supplied. In the event, this was not necessary.

- Participants had to be able and willing to participate in the semi-structured interviews in English or Afrikaans as the researcher is fluent in both of these languages and not in another African language. Furthermore, the CDE Parktown uses English as the primary form of communication with patients. Interpreters' services were not used in this study as trustworthiness could have been compromised during data collection.

The exclusion from the current study applied as follows:

- Individuals who were undergoing psychotherapy at the time the study was conducted were excluded because the psychotherapeutic process they were involved in might have had an impact on their perceptions of type 1 diabetes management.
- Individuals who also suffered from another chronic medical condition were excluded because their lived experience of managing another chronic illness might have influenced the lived experience of managing type 1 diabetes.

### **1.7.2.8 Recruitment process**

Participants were recruited from the CDE: Parktown by sending out an information leaflet which invited potential participants via e-mail to participate in the study. Each potential participant received both the parental information leaflet and the adolescent information leaflet. Upon the completion of the form, the information was forwarded (via scanning and e-mailing the document) to Prof. Elmari Deacon, who proceeded to contact the interested participants to carry out the screening. The willingness of parents and adolescents to participate was needed before Prof. Deacon contacted them.

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### **1.7.2.9 Screening**

Screening entailed asking eight pre-determined questions, as follows: 1) How old are you? 2) When were you diagnosed with diabetes? 3) Are you a patient at the CDE Parktown? 4) When did you start using CGM? 5) Do you have access to an internet connection and are you willing to take part in an online interview? 6) Do you suffer from any other chronic illness? 7) Are you currently receiving psychotherapy? 8) Are you willing to participate in an online video conferencing semi-structured interview in English or Afrikaans? Potential participants who did not meet the inclusion criteria were respectfully informed that they did not qualify for inclusion in the study. They were thanked for their time and willingness to participate and were offered the option of whether or not they would like to receive the results after completion of the study.

### **1.7.2.10 Consent**

After successful screening, Prof. Deacon explained the process of delayed remote consent to the participants, scheduled the interview and e-mailed the parental and adolescent consent forms and interview links to the participants. This was to ensure the safety of the participants by reducing the risk of spreading COVID-19, and thereby seeing to it that the best interest principle of the adolescent was upheld. Potential participants were given adequate time, about two weeks, to decide whether or not to participate in the study, before making a decision. Before the interviews, potential participants were allowed to ask the researcher questions about the research and research process, after which the consent forms were signed. This required that the parent and adolescent both signed the consent form while engaged in the online interview with the researcher, with all three parties having a witness present to co-sign. This meant that six people should have joined in the session and been visible to the other parties. The participants then scanned or faxed the consent forms or a photo and sent them to Prof. Deacon via WhatsApp or e-mail. As delayed consent was

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employed in this study, the in-person signing of the consent forms will be done at a later stage at the CDE, where the adolescent participants undergo treatment.

### **1.7.2.11 Data collection**

Data collection was carried out from October 2020 to November 2020, and included seven semi-structured interviews. Data saturation was reached after five interviews, which was established as the researcher transcribed, coded, thematically analysed and documented the data obtained from the interviews herself, which was reviewed by the researcher's supervisor. Two interviews were conducted additionally after data saturation was reached to decrease the likelihood that new data or themes would emerge (Guest, Bruce, & Johnson, 2006). All data gathering was based on the participant's preference in a secure and confidential space chosen by the participant through an online video conferencing platform. After obtaining delayed informed parental permission and adolescent consent, the semi-structured interview was conducted, and lasted approximately 30 to 40 minutes. Should the participant have preferred to be accompanied by their parent/legal guardian when conducting the interview, this was allowed. Each interview was recorded with the permission and written consent of the parent/legal guardian and the written informed assent of the adolescent participant. The rationale for the recordings was that the researcher could focus on the interaction and discussion with the participant when conducting the interview, without being concerned about making accurate comprehensive and detailed notes, which could be distracting (Nieuwenhuis, 2007). This also assisted the researcher in having secured access to each interview's rich data obtained for accurate transcribing and thematic data analysis (Nieuwenhuis, 2007). Confidentiality was maintained by limiting access to the data to only the researchers involved.

As this study adopted a qualitative approach, data collection consisted of semi-structured interviews to gain a holistic understanding of the participants. Semi-structured

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interviews were used to gain accurate biographical information on age, gender, ethnicity, and how long ago diagnosis was made. Information based on gender and ethnicity was obtained to provide a good sample description and cultural intelligence to accurately reflect the diverse population of adolescents living with type 1 diabetes. The semi-structured interview was also used to provide a more comprehensive understanding of each participant in regard to their illness perceptions and the use of CGM. This helped to obtain a better personal and authentic account of each participant's subjective experience (DiCicco-Bloom & Crabtree, 2006; Nieuwenhuis, 2007). The semi-structured interviews were guided by a set of central pre-determined open-ended questions; however, the researcher was able to explore the answers provided further by asking probing and follow-up questions as the need arose for clarification to achieve better comprehension of participants' experiences (DiCicco-Bloom & Crabtree, 2006; Nieuwenhuis & Smit, 2012). Following are some examples of questions which formed part of the semi-structured interviews:

- How old are you?
- How long have you been diagnosed with type 1 diabetes?
- Tell me about your journey with type 1 diabetes.
- How long have you been using CGM?
- What makes the use of CGM easier or more difficult?
- What are the advantages and disadvantages of using CGM?
- How did using CGM change how you view living with diabetes?

The researcher employed bracketing activities in an attempt to prevent preconceived ideas and biases from slipping into and contaminating the results of the study. Throughout the data collection process, the researcher approached each interview with Carl Rogers's three core constructs in mind (Ioannidou & Konstantikaki, 2008; Murdock, 2013), namely: 1) empathic understanding, which entails listening to and understanding the participants' unique

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experiences and perceptions; 2) unconditional positive regard, referring to accepting the participants' differences, experiences and perceptions without judgement; and 3) congruence, referring to being open and true to oneself within the interaction with the participant (Ioannidou & Konstantikaki, 2008; Murdock, 2013). These constructs helped the researcher to be aware of her own biases or preconceived ideas during the research process by means of continuous reflection. The core constructs were adopted in an attempt to limit the researcher's own preconceived ideas or biases from contaminating the interview process and consequently the results. Employing these constructs while being mindful of the researcher's own preconceived ideas serves to assist in creating an empathic atmosphere in which participants could feel more comfortable, at ease, and understood during the research process, prompting them to share their experiences openly and freely (Brinkmann, 2007; Murdock, 2013). By applying these three core constructs throughout the data collection process, the researcher was able to listen actively to the participants, assisting them in feeling valued and respected in sharing their unique personal experiences and perceptions without fear of judgment (Murdock, 2013). The interview schedule assisted the researcher in remaining focused on the purpose and goal of the research study, and not to get side-tracked by asking leading or irrelevant questions based on curiosity. This further prevented the researcher from drawing potentially inaccurate conclusions. More bracketing activities are consequently discussed below, in line with Braun and Clarke's phases of thematic analysis.

### **1.7.2.12 Data analysis**

The unprocessed data obtained from the individual interviews were digitally captured on the video conferencing platform and subsequently transcribed. Analysis was carried out by employing Braun and Clarke's (2006, 2013) thematic analysis. This allowed for detailed and rich data description, by rigorously studying the data at hand. This is done through identification, analysis, integrating and reporting of themes derived from the data and turning

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them into meaningful accounts (Braun & Clarke, 2006; 2013). This comprehensive process assists in enhancing the trustworthiness in the study, as an organised chronological method was followed for optimal and accurate data analysis (Morgan, 2013). The researcher consequently used Braun and Clarke's proposed phases to outline bracketing activities, which were followed throughout the research process, for example, making use of a reflexive journal, making detailed notes, co-coding data, as well as incorporating Prof. Deacon's review of the research process to ensure that no preconceived ideas will creep in.

Braun and Clarke (2006, 2013) proposed six distinct phases for analysing the magnitude of data obtained, which guided the data analysis for this study.

### **1. Familiarisation with the data**

The initial phase required the researcher to immerse herself in the data obtained, by close and thorough reading and re-reading in order to familiarise herself with the content (Braun & Clarke, 2006). The transcription of the voice section of the digital video-recordings was the start of this step, followed by reviewing the scripts multiple times in an attempt to ensure the familiarity and accuracy of the content and by searching for potential patterns and meanings (Braun & Clarke, 2006; 2013). For this study, the researcher transcribed the digital recordings herself to become familiar with the content, as patterns had already emerged in the course of the transcription process.

### **2. Initial coding generation**

The second phase called for the development of specific codes in accordance to significance, as data were organised and assigned into meaningful clusters (Braun & Clarke, 2006; 2013). To ensure the accuracy of the coding process, this process was repeated. The researcher coded the data herself and made use of an experienced co-coder to ensure accuracy and reduce the likelihood of bias forming.

### **3. Theme searching**



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Braun and Clarke (2006, 2013) noted that in the third phase potential themes might be derived from codes in phase 2, and be categorised into prospective overarching themes and subthemes. The researcher identified potential themes from the data obtained by re-reading the transcripts and organising the data obtained into meaningful clusters.

### **4. Theme reviewing**

The fourth phase required the identified overarching themes and subthemes to be reviewed and revised, to ensure validity in relation to the research questions and accuracy in reflecting the essence of the respective data sets (Braun & Clarke, 2006; 2013). The co-coder assisted the researcher in reviewing the identified themes by re-reading the transcripts to establish consensus and accuracy of the data sets.

### **5. Defining and naming the emerging themes**

Braun and Clarke (2006, 2013) noted that the fifth phase called for clear distinction to be made between the themes. The essence of each theme was identified so that the researcher could to assign a distinct label to each theme and subsequently identify potential subthemes for each of the main themes. The researcher and co-coder reviewed the data clustered into themes and subthemes and subsequently provided an appropriate label which captures the essence of the respective theme or subtheme.

### **6. Report writing**

The sixth phase of analysis entailed compiling a report in the form of a research article, which includes excerpts from the data sets in order to substantiate the findings of the study (Braun & Clarke, 2006; 2013). The researcher conveyed the findings of different themes in a final report, which was reviewed by the co-coder to ensure that the results were portrayed accurately, without bias, and which promoted the confirmability of the study.

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### **1.7.2.13 Trustworthiness**

In order to ensure methodological adequacy and soundness, trustworthiness is fundamental because it assists in establishing ethical and quality research (Merriam, 2009). Four criteria to ensure trustworthiness within qualitative research were proposed by Lincoln and Guba (1985), namely credibility, transferability, confirmability, and dependability.

#### **1. Credibility**

According to Creswell (2009), credibility refers to consistency and confidence in the findings. To ensure credibility, authenticity of research needs to be established from the perspectives of the participant and the researcher (Janesick, 2000). Lincoln and Guba (1985) proposed that credibility might be acquired through peer debriefing and member checking. Peer debriefing involves informal consultations with a research colleague to assist with obtaining a more objective perspective towards the study and data (Lincoln & Guba, 1985). The colleague may assist in examining, exploring and uncovering potential biases held by the researcher and in testing hypotheses (Lincoln & Guba, 1985). Member checking requires that the summarised preliminary findings are sent via e-mail, or provided in hard copy to each participant in order to allow an opportunity to review these findings and, if desired, to provide feedback (Lincoln & Guba, 1985). Prof. Deacon reviewed the research process throughout and Prof. van Rensburg took on the role of a critical reader to assist in identifying and addressing potential biases held by the researcher which might negatively or inaccurately have affected the findings. This assists in promoting the credibility and soundness of the results.

#### **2. Transferability**

Transferability refers to the degree to which data may be applied to various contexts (Tobin & Begley, 2004). Qualitative research lacks statistical analysis because of the small sample size, with the result that it is not possible to generalise the results to a larger group or

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population (Morrow, 2005). Denscombe (1998) stated that there might be an opportunity of transferability when using a qualitative approach because an individual, irrespective of his or her unique attributes, can still be seen as representative of a larger population or group. The transferability of a study may be enhanced when a rich and comprehensive description of the research methodology utilised in this study, is provided for future researchers to replicate. Transferability in this study was enhanced by looking at various aspects through biographical data from the semi-structured interviews, such as age, gender and ethnicity, to ensure that an adequate sample description was obtained for adolescents living with type 1 diabetes.

### **3. Dependability**

According to Creswell (2009), dependability depends on whether results obtained from a study could be reproduced by other researchers in the future within a similar context or with the same participants, in other words referring to the consistency of the data. Lincoln and Guba (1985) noted that dependability might be acquired by providing a comprehensive and holistic description of the details of the research procedures followed in the study. This can be achieved by making ample detailed field notes, referred to as audit trails, which consist of possible questions which could arise throughout the data gathering process, or any other relevant significant events which were noted (Lincoln & Guba, 1985). The researcher made detailed notes throughout the research process, which was discussed with Prof. Deacon to identify and eliminate any potential biases which might have emerged to promote the robustness of the findings. These detailed notes informed the findings, limitations and recommendations of this study and will be relevant in future studies.

### **4. Confirmability**

Within research, it is often difficult to ensure complete objectivity as a researcher's biases may creep in unconsciously (Morrow, 2005). Confirmability, therefore, entails that the research process is free from the researchers' interests and biases while aiming to ensure

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neutrality (Creswell, 2009; Morrow, 2005; Tobin & Begley, 2004). Researcher triangulation and reflexivity are ways to ensure neutrality as proposed by Lincoln and Guba (1985).

Researcher triangulation can be achieved through collecting data from the interviews' digital voice-recordings, observations, as well as literature reviews which assists in refining the themes (Lincoln & Guba, 1985). The researcher's biases may be modulated by using a reflexive journal in which the researcher notes ideas pertaining to the research process (Lincoln & Guba, 1985), which was done in this study. Prof. Deacon and the co-coder reviewed the research process throughout to assist in identifying and addressing potential biases held by the researcher, which might negatively or inaccurately affect the findings of this study. The making of detailed notes throughout the research process by the researcher also assisted in lowering the likelihood of personal biases from arising in the study's findings.

### **1.8 Ethical considerations**

The researcher is subject to the rules and ethical obligations of the North-West University, due to her being registered as a Counselling Psychology Master's student at the North-West University, Potchefstroom campus. She is also subject to the ethical guidelines of the Health Professions Council of South Africa (1974) as stipulated in Act 56, as she is also registered as a Student Psychologist, No. PS S 0144240. The researcher received comprehensive research training regarding qualitative research methods and designs presented from 27 to 30 November 2017. The researcher also completed "The Basics of Health Research Ethics" training on 22 and 23 January 2018, No. PSB002/037/01/2018.

Further permission was obtained from Prof. David Segal, a gatekeeper, to carry out this research at the CDE, and scientific approval was granted by Optentia on 23 October 2018. The Health Research Ethics Committee (HREC) of the NWU approved the original study. An amendment relating to the data collection was made to the study, which was

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approved by HREC on 07 August 2020 before starting the research (NWU-00125-18-A1).

The researcher has no conflict of interest to declare for this study.

As this study included adolescents amidst the COVID-19 crisis, it falls within the category of greater than minimal risk, with a direct benefit to the participants. The following ethical guidelines were adhered to:

Independent written informed parental permission and adolescent consent were obtained through means of delayed remote consent prior to conducting the semi-structured interviews, to establish willingness to participate. These consent forms were sent to participants well in advance, two or more weeks beforehand, in order to provide enough time for them to make an informed decision regarding their taking part in the study. They were provided with an explanation of the following: the voluntary nature of the study, its aim and purpose, its requirements, possible expectations from the participants, potential risks and benefits of participating in this study, information regarding privacy and confidentiality as well as its limits, and the contact particulars of the researcher. The participants were given an opportunity to ask questions to clarify any aspect of the study.

Participation was entirely voluntary, in that no one was coerced into participating by the medical specialist or research team. Coercion was prevented as the participants had ample time to familiarise themselves with the information leaflet and informed consent documents, which stated clearly that their participation in the study was not related to the treatment they received at the CDE and served solely to further knowledge in this field of research. The participants had ample time to ask questions, deliberate and make an informed decision about whether to take part or not. With this in mind, only participants truly interested in participating freely were included. They were clearly informed that they were free to decline or withdraw from the study at any time, without any consequences.

It was of utmost importance to ensure that the researcher maintained confidentiality

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of the data in order to guarantee anonymity of the sample participants and to inform them of such steps taken. Each participant's anonymity was protected by assigning an individual code, which was recorded in the transcribed material. The data were stored separately after the written report had been compiled, to ensure that no association could be drawn between the personal identities of the participants and the results. Regarding the conducting of the semi-structured interviews, the participants were advised to find a quiet, safe, secure, and confidential space to be interviewed at their home through video conferencing technology to reduce the risk of COVID-19 spread and contamination. All participants' personal particulars and information or data in hard copy, such as documents, were securely stored in a locked cabinet, in a locked room on the NWU Potchefstroom premises. All electronic data, such as the recorded data, were securely and confidentially stored on a password protected computer, with access limited to the researcher and the research supervisors. Participants were informed that no identifying particulars would be made available in reporting findings as these would be kept private and confidential. Data will be stored for 10 years, after which they will be destroyed by shredding hard copies and deleting them from the computers. The interview sessions were recorded on a video conferencing platform for transcription purposes. Digital recordings were deleted from computers when transcribing was completed.

The adolescent participants were treated with sensitivity as they belong to and form part of a vulnerable group (due to being diagnosed with diabetes, and being minors, i.e., under 18 years of age). As the participants are adolescents, consent was obtained separately from them and from their parents. It is important to note that the young people were approached only after having received parental permission to participate in the study. It was recognised that diabetes could be a sensitive topic to discuss or think about when participating in interviews, and that this could increase levels of discomfort or stress in the participants. This required the research team to take care not to infringe the participants'

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rights, by not disclosing confidential information, and by affording them the right to absolute voluntary participation, with the opportunity to withdraw from the research process at any point without consequences.

As adolescents are considered a vulnerable population, there was a possibility that a need might arise for counselling or psychological services as a result of any discomfort which might be experienced during the interviews. Participants were informed verbally and in writing that psychological counselling services would be made available free of charge as the need arose. They were informed that debriefing would be offered by video conferencing immediately after the interview and subsequently, should they feel the need to consult with a psychological professional, to be paid for by the researcher. After the completion of the interview, qualified psychological professionals were available for all participants in the course of debriefing through video conferencing technology. None of the participants expressed the need to consult with the psychological professionals.

The possibility existed that participants, having been diagnosed with type 1 diabetes, could experience unexpected low and high blood glucose levels during interviews, even though the study was not expected to harm or affect their health. It was thus essential to inform participants that they ought to let the researcher and caregiver know if they were feeling ill at any time during the interview so that they, or their trained caregiver, could test their blood glucose levels in order to correct them.

There were no expenses involved for the participants as they did not have to travel for this study and data collection was done through the use of video conferencing technology in the comfort of their homes. The use of video conferencing technology required the participant to have access to an internet connection and a compatible device, such as a cell phone, tablet, or laptop for the interviews to be conducted. Prof. Segal communicated effectively with his patients by using video conferencing, which indicated that participants

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did have access to the necessary devices and internet connection. Participants were also familiar with video conferencing technology because they had used this technology in consultations with Prof. Segal. Whenever participants encountered difficulties on the day of the scheduled interview, the researcher contacted them to guide them in setting up the video conferencing technology. The participants were informed that they would be reimbursed should they be using their own data, estimated to be approximately 1 GB of data for a 30- to 40-minute virtual interview on most video conferencing technology platforms. All participants turned down the offer as they were happy to use their own data.

The participants chose a private location where they felt comfortable for the interview, and were free from distractions and any disturbances. The individual semi-structured interviews lasted approximately 30 to 40 minutes.

As a direct benefit for the adolescents taking part in the research, a workshop on the influence of illness perception on diabetes management will be arranged for them and their families at a convenient time. It will include practical guidelines to improve their diabetes management and general well-being. There were no indirect benefits for participants in this study.

A short report, with a summary of the findings, is to be forwarded to participants on completion of the study. This may enhance and contribute to their knowledge of type 1 diabetes, illness perception, and CGM. Upon completion of the study, the research will be presented as an article (see section 2) and will be submitted for publication to the journal *Diabetes Research and Clinical Practice*, the peer-reviewed official publication of the International Diabetes Federation. This study may contribute to the field in that it sheds light on the effect of CGM on adolescents' illness perception of their type 1 diabetes, given the limited information on this topic in the South African context, especially with regard to the use of CGM. The research may serve to guide and inform future studies, thereby assisting in



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developing intervention programs or models for adolescents living with diabetes. The advancement of knowledge gained on this topic could indirectly benefit the community at large by using it to develop workshops for the community to psycho-educate and raise awareness for individuals with type 1 diabetes. This may assist in normalising type 1 diabetes by making it more understandable, thus removing unnecessary social pressure from adolescents in an already challenging developmental period.

This research process and progress was continuously monitored by the research supervisor to ensure ethical conduct and the approved procedures have been adhered to. Care was also taken to be mindful of the ethical considerations in other countries, which could potentially form part of the project.

The project and the researcher have risk insurance through the North-West University, which has insurance at its disposal to cover the risk of claims against the University in case of damage to participants due to professional negligence – the maximum cover is currently R100 million per annum (all studies included). However, this is only available if studies have been ethically approved and researchers have adhered to the proposal.

### **1.9 Outline of study**

Section 1 of this mini-dissertation consists of a broad general introduction to the central concepts, namely type 1 diabetes, continuous glucose monitoring, and illness perception. It includes the problem statement, objectives, research model and methodology which guided the research.

Section 2 comprises the defined author guidelines as set out by the *Journal of Diabetes Research and Clinical Practice*, which is followed by the article titled: *Exploring illness perceptions of a group of adolescents living with diabetes while using continuous*

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*glucose monitoring (CGM)*, which will be submitted to the journal for possible publication.

Section 3 gives an account of the researcher's critical reflection regarding the research process, including the study limitations of the study and recommendations.

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## SECTION 2: INTENDED JOURNAL AND AUTHOR GUIDELINES

### 2.1 Manuscript format and structure for Diabetes Research and Clinical Practice

The intended journal for publication of this manuscript is *Diabetes Research and Clinical Practice*. The APA (6<sup>th</sup> edition) referencing style was selected for section 2, as the author guidelines stipulate that any referencing style can be followed. The referencing style will be adjusted if required by the journal of *Diabetes Research and Clinical Practice* upon submission. More author guidelines as set out by this journal will be mentioned below.

#### Journal Principles

All manuscripts submitted to *Diabetes Research and Clinical Practice* should report original research not previously published or being considered for publication elsewhere, make explicit any conflict of interest, identify sources of funding and generally be of a high ethical standard.

Submission of a manuscript to this journal gives the publisher the right to publish that paper if it is accepted. Manuscripts may be edited to improve clarity and expression.

Submission of a paper to *Diabetes Research and Clinical Practice* is understood to imply that it has not previously been published and that it is not being considered for publication elsewhere.

#### Submission checklist

You can use this list to carry out a final check of your submission before you send it to the journal for review. Please check the relevant section in this Guide for Authors for more details. Ensure that the following items are present:

1. One author has been designated as the corresponding author with contact details:
  - E-mail address
  - Full postal address
2. All necessary files have been uploaded:

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### Manuscript:

- Include keywords
- All figures (include relevant captions)
- All tables (including titles, description, footnotes)
- Ensure all figure and table citations in the text match the files provided
- Indicate clearly if color should be used for any figures in print

Graphical Abstracts / Highlights files (where applicable)

Supplemental files (where applicable)

### 3. Further considerations

- Manuscript has been 'spell checked' and 'grammar checked'
- All references mentioned in the Reference List are cited in the text, and vice versa
- Permission has been obtained for use of copyrighted material from other sources (including the Internet)
- Relevant declarations of interest have been made
- Journal policies detailed in this guide have been reviewed
- Referee suggestions and contact details provided, based on journal requirements

### **Role of the funding source**

You are requested to identify who provided financial support for the conduct of the research and/or preparation of the article and to briefly describe the role of the sponsor(s), if any, in study design; in the collection, analysis and interpretation of data; in the writing of the report; and in the decision to submit the article for publication. If the funding source(s) had no such involvement then this should be stated.

### **Language (usage and editing services)**

Please write your text in good English (American or British usage is accepted, but not a mixture of these). Authors who feel their English language manuscript may require editing

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to eliminate possible grammatical or spelling errors and to conform to correct scientific

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Studies on patients or volunteers require ethics committee approval and informed consent which should be documented in your paper.

Patients have a right to privacy. Therefore identifying information, including patient's photographs, pedigree, images, names, initials, or hospital numbers, should not be included in the submissions unless the information is essential for scientific purposes and written informed consent has been obtained for publication in print and electronic form from the patient (or parent, guardian or next of kin). If such consent is made subject to any conditions, Elsevier must be made aware of all such conditions. Written consents must be provided to the journal on request.

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Our online submission system guides you stepwise through the process of entering your article details and uploading your files. The system converts your article files to a single PDF file used in the peer-review process. Editable files (e.g., Word, LaTeX) are required to typeset your article for final publication. All correspondence, including notification of the Editor's decision and requests for revision, is sent by e-mail.

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### **Abbreviations**

Abbreviations should be avoided in most cases or at least fully defined on first use.

Clinical research values and units should be in Système International (SI) form. Kilocalories should be used rather than kilojoules. The term 'diabetic' should be avoided. Preferred terminology is, for example, 'person with diabetes' or 'in the group without diabetes'. The terms 'Type 1' and 'Type 2 diabetes mellitus' should be used.

### **HbA1c Values**

Author should report glycated haemoglobin (HbA1c) measurement in derived NGSP units (%; to one decimal point) in addition to IFCC (International Federation of Clinical Chemistry) units (mmol/mol; no decimal point). NGSP units should be listed first followed by IFCC units in parentheses. The abbreviation for haemoglobin A1c / glycated haemoglobin - should be HbA1c, not the American version of A1C.

### **Article structure**

#### **Subdivision - numbered sections**

Divide your article into clearly defined and numbered sections. Subsections should be numbered 1.1 (then 1.1.1, 1.1.2, ...), 1.2, etc. (the abstract is not included in section numbering). Use this numbering also for internal cross-referencing: do not just refer to 'the text'. Any subsection may be given a brief heading. Each heading should appear on its own separate line.

### **Introduction**

State the objectives of the work and provide an adequate background, avoiding a detailed literature survey or a summary of the results.

### **Material and methods**

Provide sufficient detail to allow the work to be reproduced. Methods already published should be indicated by a reference: only relevant modifications should be

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described.

## **Results**

Results should be clear and concise.

## **Discussion**

This should explore the significance of the results of the work, not repeat them. A combined Results and Discussion section is often appropriate. Avoid extensive citations and discussion of published literature.

## **Essential title page information**

- Title. Concise and informative. Titles are often used in information-retrieval systems. Avoid abbreviations and formulae where possible.

- Author names and affiliations. Please clearly indicate the given name(s) and family name(s) of each author and check that all names are accurately spelled. Present the authors' affiliation addresses (where the actual work was done) below the names. Indicate all affiliations with a lower-case superscript letter immediately after the author's name and in front of the appropriate address. Provide the full postal address of each affiliation, including the country name and, if available, the e-mail address of each author.

- Corresponding author. Clearly indicate who will handle correspondence at all stages of refereeing and publication, also post-publication. Ensure that the e-mail address is given and that contact details are kept up to date by the corresponding author.

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### **Structured Abstract: Original Research Articles**

An abstract of no more than 250 words should be structured as per following:

- **Aims:** Reflects the purpose of the study (the hypothesis that is being tested);
- **Methods:** The setting for the study, the subjects (number and type), the treatment or intervention, and the type(s) of statistical analysis used;
- **Results:** The outcome(s) of the study and, if appropriate, its/their statistical significance;
- **Conclusions:** The significance of the results.

Abstracts for other articles (Commentaries and Reviews) should be written as a single paragraph not to exceed 200 words.

### **Article Types**

N.B. For reasons of available space, manuscripts that exceed the required word limits (below) will be declined automatically. All articles other than Editorials and Letters to the Editor are subject to full peer review.

**Research Article** should be designated either (a) Basic Research (b) Clinical Research or (c) Epidemiology and should be a maximum of 5000 words. The word limit includes a combined total of five figures or tables with legends, but does not include up to 50 references and an abstract of up to 200 words structured according to Aims, Methods, Results, Conclusions and Keywords. Divide the manuscript into the following sections: Title Page; Structured Abstract; Introduction; Subjects, Materials and Methods; Results; Discussion; Acknowledgements; References; figures and tables with legends.

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Highlights are a short collection of bullet points that convey the core findings of the article. Highlights are optional and should be submitted in a separate editable file in the online submission system. Please use 'Highlights' in the file name and include 3 to 5 bullet

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points (maximum 85 characters, including spaces, per bullet point). You can view example

Highlights on our information site.

### **Keywords**

Immediately after the abstract, provide a maximum of 6 keywords, avoiding general and plural terms and multiple concepts (avoid, for example, 'and', 'of'). Be sparing with abbreviations: only abbreviations firmly established in the field may be eligible. These keywords will be used for indexing purposes.

### **Acknowledgements**

All contributors who do not meet the criteria for authorship as defined above should be listed in an acknowledgements section. Examples of those who might be acknowledged include a person who provided purely technical help, writing assistance, or a department chair who provided only general support. Authors should disclose whether they had any writing assistance and identify the entity that paid for this assistance.

### **Formatting of funding sources**

List funding sources in this standard way to facilitate compliance to funder's requirements: Funding: This work was supported by the National Institutes of Health [grant numbers xxxx, yyyy]; the Bill & Melinda Gates Foundation, Seattle, WA [grant number zzzz]; and the United States Institutes of Peace [grant number aaaa]. It is not necessary to include detailed descriptions on the program or type of grants and awards. When funding is from a block grant or other resources available to a university, college, or other research institution, submit the name of the institute or organization that provided the funding. If no funding has been provided for the research, please include the following sentence: This research did not receive any specific grant from funding agencies in the public, commercial, or not-for-profit sectors.

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### **Tables**

Please submit tables as editable text and not as images. Tables can be placed either next to the relevant text in the article, or on separate page(s) at the end. Number tables consecutively in accordance with their appearance in the text and place any table notes below the table body. Be sparing in the use of tables and ensure that the data presented in them do not duplicate results described elsewhere in the article. Please avoid using vertical rules.

### **References**

#### **Citation in text**

Please ensure that every reference cited in the text is also present in the reference list (and vice versa). Any references cited in the abstract must be given in full. Unpublished results and personal communications are not recommended in the reference list, but may be mentioned in the text. If these references are included in the reference list they should follow the standard reference style of the journal and should include a substitution of the publication



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date with either 'Unpublished results' or 'Personal communication'. Citation of a reference as 'in press' implies that the item has been accepted for publication.

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Increased discoverability of research and high quality peer review are ensured by online links to the sources cited. In order to allow us to create links to abstracting and indexing services, such as Scopus, CrossRef and PubMed, please ensure that data provided in the references are correct. Please note that incorrect surnames, journal/book titles, publication year and pagination may prevent link creation. When copying references, please be careful as they may already contain errors. Use of the DOI is encouraged.

A DOI can be used to cite and link to electronic articles where an article is in-press and full citation details are not yet known, but the article is available online. A DOI is guaranteed never to change, so you can use it as a permanent link to any electronic article. An example of a citation using DOI for an article not yet in an issue is: VanDecar J.C., Russo R.M., James D.E., Ambeh W.B., Franke M. (2003). Aseismic continuation of the Lesser Antilles slab beneath northeastern Venezuela. *Journal of Geophysical Research*, <http://dx.doi.org/10.1029/2001JB000884i>. Please note the format of such citations should be in the same style as all other references in the paper.

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As a minimum, the full URL should be given and the date when the reference was last accessed. Any further information, if known (DOI, author names, dates, reference to a source publication, etc.), should also be given. Web references can be listed separately (e.g., after the reference list) under a different heading if desired, or can be included in the reference list.

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**Text:** Indicate references by number(s) in square brackets in line with the text. The actual authors can be referred to, but the reference number(s) must always be given.

**List:** Number the references (numbers in square brackets) in the list in the order in which they appear in the text.

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Examples:

Reference to a journal publication:

[1] Van der Geer J, Hanraads JAJ, Lupton RA. The art of writing a scientific article. J Sci Commun 2010;163:51–9.

Reference to a book:

[2] Strunk Jr W, White EB. The elements of style. 4th ed. New York: Longman; 2000.

Reference to a chapter in an edited book:

[3] Mettam GR, Adams LB. How to prepare an electronic version of your article. In: Jones BS, Smith RZ, editors. Introduction to the electronic age, New York: E-Publishing Inc; 2009, p. 281–304.

Reference to a website:

[4] Cancer Research UK. Cancer statistics reports for the UK, <http://www.cancerresearchuk.org/aboutcancer/statistics/cancerstatsreport/>; 2003 [accessed 13.03.03].

Note shortened form for last page number. e.g., 51–9, and that for more than 6 authors the first 6 should be listed followed by 'et al.' For further details you are referred to 'Uniform Requirements for Manuscripts submitted to Biomedical Journals' (J Am Med Assoc 1997;277:927–34) (see also Samples of Formatted References).

### **Authorship**

The Corresponding Author must submit a completed Author Consent Form to DRCP with their manuscript. All authors must sign the Author Consent Form.

All authors should have made substantial contributions to all of the following: (1) the conception and design of the study, or acquisition of data, or analysis and interpretation of data, (2) drafting the article or revising it critically for important intellectual content, (3) final

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approval of the version to be submitted.

**2.2 Manuscript: Exploring illness perceptions of a group of adolescents living with diabetes while using continuous glucose monitoring (CGM)**

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Word count (5000)

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### **Structured Abstract**

#### *Aims:*

This study explored the illness perceptions of a group of adolescents living with type 1 diabetes and using CGM.

#### *Methods:*

A qualitative research approach using semi-structured online interviews was used to gather data from seven adolescents (mean age= 14.9) who had been using CGM for more than three months. Data analysis was carried out through thematic analysis.

#### *Results:*

Themes emerging from the data confirmed that CGM creates a sense of control over diabetes management as blood glucose measures were more visible, limiting the likelihood of medical emergencies. A sense of normalcy was established as CGM influences a new routine and a way of life, allowing for them to engage in more activities. Despite challenges of diabetes management, CGM assisted in creating a sense of belonging and feeling of empowerment.

#### *Conclusions:*

The sense of control obtained from using CGM empowered participants to be more responsible with their diabetes management, contributing to developing a better quality of life. The new insights may benefit diabetes health care experts, caregivers and patients living with diabetes, as the findings can enhance greater understanding of the use of CGM devices and their impact on illness perceptions, which may enhance their quality of life.

### **Keywords**

Diabetes mellitus; type 1 diabetes; illness perceptions; continuous glucose monitoring (CGM); adolescents.

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### 1.1 Introduction

Type 1 diabetes (T1D) is regarded as one of the most rapidly growing chronic diseases (Hagger, 2016; International Diabetes Federation, 2015), with an estimated 1 in every 400 children currently diagnosed with diabetes mellitus every day (American Academy of Pediatrics, 2015). This diagnosis is accompanied by severe social, psychological, and behavioural consequences (Sadock, Sadock, & Ruiz, 2015), especially during adolescence, an already challenging developmental stage (Compas, Jaser, Dunn, & Rodriguez, 2012; Hunter 2016; King, Berg, Butner, Butler, & Wiebe, Man Chow, Palmer, Butner, Butler, Osborn & Berg, 2014). Adolescents are expected to take more responsibility for their diabetes care plan (Gonzalez & Tanenbaum, 2016) than during previous developmental stages. Diabetes care plans reduce the risk of various complications from developing when followed effectively (Borus & Laffel, 2010), but they contribute to the psychological burden of living with diabetes, which negatively affects individuals' psycho-social functioning (Giani, Snelgrove, Volkening, & Laffel, 2017; Hood, Heustis, Maher, Butler, Volkening, & Laffel, 2006; Iannotti et al., 2006; Khemakhem et al., 2020). Individuals with chronic diseases develop a set of beliefs to make sense of their diagnosis, which guides them in how they approach and manage their illness (Leventhal, Benyamini, Brownlee, Diefenbach, Leventhal, Patrick-Miller, & Robitaille, 1997). Illness perceptions, also known as cognitive belief systems, are acquired sets of beliefs regarding one's illness obtained by gathering information and individual interpretations of personal experiences or subjugation to a disease or illness (Hagger, 2016; Petrie, Jago & Devchic, 2007; Petrie & Weinman, 2012). Individuals' perceptions and belief systems have been linked to their self-care management behaviours and treatment adherence outcomes (Broadbent, Donkin, & Stroh, 2011; Hagger & Orbell, 2003; Mc Sharry, Bishop, Moss-Morris & Kendrick, 2011). These perceptions, in turn, prompt them to adopt specific disease-modifying and management behaviours to

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achieve better treatment outcomes (Hagger, 2016). Studies have shown that these illness perceptions have also been independently associated with treatment adherence, metabolic control and coping strategies (Broadbent, Donkin, & Stroh, 2011; Graue, Wentzel-Larsen, Bru, Hanestad, & Sjøvik, 2004) among individuals living with type 1 diabetes.

The main aim of a diabetes care plan is to accomplish normal to near-normal glucose levels to reduce the likelihood of chronic or acute complications. Only a few adolescents succeed in achieving this aim (Hillard, Wu, Rausch, Dolan, & Hood, 2013; King, Berg, Butner, Butler, & Wiebe, 2014) because they encounter multiple barriers to managing diabetes adequately. These include the peer pressure and psychological turmoil characteristic of their developmental phase, limited knowledge or understanding of the treatment plans needed, and potential associated health risks, which results in their becoming fatigued and encountering increased insulin resistance and physical changes as a result of puberty (Borus & Laffel, 2010; Datye, Moore, Russel, & Jaser, 2015; Lostein, McPherson, Strickland, & Newacheck, 2005).

Technological advancements in blood glucose monitoring in the past ten years led to the development of continuous glucose monitoring (CGM), which provides a continuous visible measure of real time variations of the individual's glucose levels (Bode & Battelino, 2017; Chase, Beck, Xing, Tambirlane, Coffey, & Fox, 2010; Reiterer, Polterauer, & Schoemaker, 2017). Research studies to determine the psychological barriers and benefits that accompany the use of continuous glucose monitoring systems indicated that employing these systems to form part of the diabetes treatment regimen holds multiple benefits for the users (Halford & Harris, 2010). It was found that patients using CGM have an increased chance of achieving greater control over managing their blood glucose levels which, in turn, offers the possibility of decreased levels of fear, improved quality of life and a sense of empowerment (Halford & Harris, 2010; Rewers, Pihoker, Donaghue, Hanas, Swift, & Klingensmith, 2007).



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South African literature on adolescents living with diabetes illness perceptions has recently received attention (Jonker, Deacon, Van Rensburg, & Segal, 2018; Lesage, 2019), although literature that looked at their experiences, when combined with using CGM, is scant. In an attempt to narrow the identified research gap, this study set out to explore the illness perceptions of a group of adolescents living with type 1 diabetes who are using CGM by asking the following research question “*What are the illness perceptions of a group of adolescents living with type 1 diabetes and using CGM?*”

### **1.2 Materials and methods**

The materials and methods which guided this study will consequently be discussed.

#### **1.2.1 Rationale for a qualitative design**

Qualitative research on the illness perceptions of adolescents living with T1D in the South African context has been increasing (Jonker, Deacon, Van Rensburg, & Segal, 2018; Lesage, 2019), but this investigation will be the first to explore the impact of the use of CGM on the perceptions of diabetes by adolescents living with the illness in the South African context.

A qualitative description research design was adopted to obtain a clear fundamental description of the phenomena being studied (Sandelowski, 2000). This approach assisted in meeting the aim of the study, as it provides a comprehensive summary of how the adolescents view and perceive their diagnosis and their use of CGM. A social constructivist approach was used to understand how meaning is created through the use of language in the social contexts in which adolescents function. This revealed individuals’ different perspectives on the social reality of living with type 1 diabetes illness (Lock & Strong, 2012; Losantos, Montoya, Exeni, Loots, & Santa Cruz, 2016).

#### **1.2.2 Study participants**

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Adolescent participants (12 – 17 years old) with type 1 diabetes mellitus were selected by means of non-random purposive sampling as they had to meet predetermined inclusion criteria to become eligible for inclusion in this study. Recruitment was carried out at the Centre for Diabetes and Endocrinology (CDE) in Parktown, South Africa, which specialises in pediatric diabetes. Information leaflets were sent to potential participants and when sufficient positive replies had been received, screening took place using the following eligibility criteria: participating adolescents had to be between 12 and 17 years of age and should have been diagnosed with type 1 diabetes more than twelve months preceding data collection to minimise any impact on the trustworthiness of the data as a result of ongoing adjustment to the diagnosis. To minimise treatment variables, participants had to be patients at the CDE: Parktown, Johannesburg, and had to have been using CGM for more than three months. They needed access to an internet connection and had to be willing to participate in the online semi-structured interviews in English or Afrikaans. Adolescents undergoing psychotherapy at the time of the study were ineligible as the psychotherapeutic process might have had an impact on their perceptions of diabetes management. Adolescents living with another chronic medical condition were also ineligible as their lived experience of managing it might have affected their lived experience of managing type 1 diabetes.

The final sample as seen in table 1 below, consisted of 3 male (Caucasian) and 4 female (3 Caucasian and 1 Indian) adolescents between the ages of 14 and 16 years (mean age 14.9). Participants comprised of 2 who were Afrikaans speaking and 5 English speaking. The mean age at which they were diagnosed with type 1 diabetes was 7 years and the mean duration of CGM use was 3.4 years.

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Table 1

*Characteristics of participants selected through non-random purposive sampling*

<b>Pseudonym</b>	<b>Sex</b>	<b>Age</b>	<b>Time since diagnosis</b>	<b>Time using CGM</b>
<b>Amelia</b>	Female	14	2 years	2 years
<b>Ava</b>	Female	14	4 years	4 years
<b>Darla</b>	Female	15	14 years	2 years
<b>Hanna</b>	Female	15	10 years	3 years
<b>Harry</b>	Male	15	10 years	5 years
<b>Ian</b>	Male	15	4 years	4 years
<b>Ryan</b>	Male	16	5 years	4 years

## 1.2.3 Data collection

Data collection was carried out from October 2020 to November 2020, and included seven semi-structured interviews. Data saturation was reached after five interviews, as no new pertinent data and themes had come to light. Two additional interviews were conducted to ensure that data saturation had in fact been reached by ensuring that the likelihood of new data or themes from emerging is decreased (Guest, Bruce, & Johnson, 2006). Data were gathered by online methods to ensure the safety of the participants as their diagnosis makes them particularly vulnerable to COVID-19. All data gathering took place in the participant's preferred secure and confidential space. After obtaining delayed informed parental permission and adolescent consent, the interview lasting approximately 30 to 40 minutes was conducted and recorded on the online video conferencing platform. The interviews were guided by a schedule, ensuring that the general interview structure was consistent for all participants in line with the research aim. Examples of the interview questions include: *What*

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*are the advantages and disadvantages of using CGM? and How did using CGM change how you view living with diabetes?* The researcher wrote down reflections and made pertinent

notes after each interview to reduce the likelihood of bias from creeping in. Confidentiality was upheld by limiting access to the data to the researchers involved.

### **1.2.4 Data analysis**

The unprocessed data obtained from the individual interviews were digitally captured on the video conferencing platform and subsequently transcribed verbatim. The transcriptions were compared with the recordings to ensure accuracy. Thematic analysis was done by applying Braun and Clarke's thematic analysis, allowing for detailed and rich data to be collected by rigorously studying the data at hand (Braun & Clarke, 2006, 2013). Reliability and accuracy of the findings were enhanced by transcribing the raw data according to six distinct steps, namely (1) familiarisation of the data; (2) initial code generation; (3) theme searching; (4) theme reviewing; (5) defining and naming themes; and (6) report writing. This comprehensive process enhances the study's trustworthiness as an organised chronological method was followed for optimal and accurate data analysis (Morgan, 2013).

Bracketing was implemented throughout the research process to further enhance the trustworthiness of the study by following four criteria set out by Lincoln and Guba (1985).

*Credibility* was achieved by informal discussions during peer debriefings between the researcher and the research supervisor, who discussed ideas emerging from continuous data analysis. Adequate participant quotations support the research findings, which were grounded in and guided by the data obtained from the interviews. Findings were not obtained from biased interpretations or assumptions made by the researcher, thus promoting *confirmability*. Researcher reflexivity and triangulation enhanced confirmability. Triangulation occurred by collecting data from the interview recordings, observations and a comprehensive literature review. Through co-coding of the data, a consensus was reached on the findings and data

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saturation, which assisted in assuring *dependability*. Dependability was also enhanced by ample field notes made during the interview process. Attempting to enhance the study's *transferability*, a comprehensive contextualisation was provided for the research methodology and process.

### 1.3 Results

The aim of this study was to explore the illness perceptions of adolescents living with type 1 diabetes using CGM. From the thematic analysis carried out on each participants' responses, three themes emerged: (1) CGM creates a sense of control over diabetes management; (2) CGM assists in creating a new normal; and (3) being different creates an opportunity for positive outcomes. These interrelated themes are introduced below and illustrated with relevant verbatim extracts from the seven participants.

#### 1.3.1 Theme 1: CGM creates a sense of control over diabetes management

All participants reported that the use of CGM promoted a sense of control over their diabetes management which made it more efficient and manageable than traditional blood glucose monitoring. This sense of control was driven by the visibility of blood glucose levels and the predictability that resulted from that. This not only assisted in their normal day to day activities, but also prevented medical emergencies. Experiencing a sense of control empowered the participants to take more responsibility for their diabetes management.

Control was facilitated by the visibility, and “*being aware of [their] sugar 24/7*” (Hanna) in real time helps participants to predict the direction of their blood glucose levels without interfering with their activities, “*because now [they] can constantly see [their] levels without having to stop what [they are] doing*” (Darla). This predictability emerged as one of the main

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ways in which CGM created a sense of control as “*the [CGM] is a lot easier to use because [they] can see like the graph and everything and [they] know where [they are] going [...] [they] have a lot more control on the CGM*” (Ava).

Predictability and “*knowledge of where [their blood glucose levels] are at that time*”

(Amelia) also assisted in anticipating possible medical emergencies as “*it helps you a lot to look at your sugar so that it doesn’t go too high or low*” (Harry). As participants were aware of the directionality of their glucose levels pertaining to CGM’s predictions of “*where it’s going, where it might be, if [they are] high or low*” (Amelia) prompts participants to intervene in time: “*[CGM] can tell you if you’re stable or you’re going up slowly so you know, okay I need to do this or I mustn’t do this*” (Ava) and “*it will alarm [them]*” (Darla) when an emergency situation arises.

The experience of more control over diabetes management led to participants’ becoming “*a lot more responsible*” (Amelia, Darla, Ian, Hanna, and Ryan) and disciplined. Participants matured and embraced the hands-on experience of managing the CGM, as Hanna noted: “*[CGM readings] sort of puts you in the mindset of wanting to control it better*” (Hanna). Darla said: “*Since I’ve been using the CGM, it’s life-changing*”, which promoted overall improved diabetes management, illness perceptions and healthy lifestyles. This sense of control over their diabetes management decreased their “*worry about high or low blood sugar*” (Harry) and promoted a sense of self-confidence in their abilities because they felt empowered and “*more motivated to succeed*” (Ian), as Amelia commented: “*I’ve realised that I’m the boss*”. All participants noted that they “*see a very big difference*” (Hanna) because “*[they] feel like they have a little bit more control over it. So they can calm down*” (Ava) as their “*[blood glucose levels are] even more controlled now*” (Darla).

### 1.3.2 Theme 2: CGM assists in creating a new normal

All participants reported that the use of CGM made living with and managing type 1 diabetes more convenient. They could incorporate the management of diabetes and using CGM into their routines and create a new “normal” way of life, integrating diabetes into their identities.

All participants noted that the use of CGM had become routine and a way of life, as Darla noted: *“It’s become part of everyday life and I don’t even notice it”*. She explained: *“It’s like routine to me and it’s like something normal, it’s like brushing your teeth to me. It feels normal”*. This new routine involving CGM was less onerous and required less effort from their side *“because everything is laid down for you and now all you have to do is just remember”* (Hanna). Each participant noted that incorporating CGM as a routine made using *“[CGM] easier in terms of monitoring [their] levels in terms of feeling normal and everything”* (Darla), which *“just made [diabetes management] a lot more convenient and easier”* (Hanna).

Engaging in everyday activities were facilitated by using CGM. All participants pointed out that they would become highly *“frustrated when [they] didn’t have the CGM on”* because they *“had to stop everything just to go and check”* (Darla) and resort to the standard finger pricking. Participants also reported *“that without the CGM it caused a lot of disruptions”* (Darla, Harry and Ava), but Darla noted that *“now with the CGM [...] it’s like not so many disruptions in my life”*, which allowed them to take part in more activities than they used to. All participants said that *“[CGM] helped and made it easier because [they] have more control and [they] know where [they are] going”* (Ava) because *“[they] can see [their blood glucose readings] all the time so [they] can control it better”* (Hanna) without having to stop

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what they were busy with (linking with theme 1). This predictability, in turn, “*makes life as easy as it can get*” (Amelia) and “*makes [them] feel that [they] can live close to a normal life*” (Hanna) by engaging in the activities of an average teenager. This addresses the frustrations experienced regarding food constraints, inhibited outings with “*friends*” (Hanna and Darla) and not being able to keep up with playing “*more sports*” (Harry and Darla). Amelia’s response highlighted this improvement: “*Maintaining my sugars, living my life, being active, managing schoolwork have all become a lot easier because of it [CGM]. So I don’t constantly have to worry*”. As CGM provides participants with feedback to continuously monitor their blood glucose levels they were able to intervene in time, so that diabetes management tasks did not intrude in other activities. This became evident in Darla and Harry’s respective responses: “*Especiallly with sport because now I can constantly see my levels without having to go and stop what I’m doing and go and prick them. [CGM] kind of feels like an artificial pancreas*” and “*[CGM] helped quite a lot, because then I don’t have to worry every now and again about what my sugar is. And then I can do more things*”.

The sense of control created by the use of CGM led to participants being able to integrate the management requirements of their diabetes into their identity, which resulted in a new “*normal*” (Hanna, Darla, Ryan, Amelia, Harry) and “*made it seem less like a disability*” (Hanna). This had a role to play in the participants’ coming to terms with and accepting their diagnosis and its management which is reflected in Amelia’s and Darla’s responses: “*I have properly adjusted to my new life*” and “*this is my whole life [...] I can either be sad and sit in my room and cry about it all the time [...] or I should be happy and carry on with my life as I’m going.*” Participants saw the use of CGM as being an integral “*part of [themselves]*” (Ryan and Amelia) and their way of life, and not just as mere habit or routine.



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### 1.3.3 Theme 3: Being different creates an opportunity for positive outcomes

All participants considered that they were different as a result of diabetes management tasks.

Although CGM influences diabetes management in that the user can continue with normal activities without interruption, CGM is a visible device on the body and wearing it attracts attention. This creates opportunities for educating others and relating to others using CGM.

All participants noted that they had received baseless and uncalled-for comments from others and that *“there are also other children who will then go and speak behind your back”* (Harry) which is unpleasant, *“upsetting”* (Ava) and *“frustrating”* (Darla). These comments, in turn, blatantly drew attention to the participants’ differences, especially when they experienced bullying from other pupils, as Ava described: *“Like I hate doing it [using and scanning CGM] in public because in my primary school I was bullied a lot for it. So I just like hate doing it in front of people. So when I went to high school I’ve told very few people.”* Most participants noted that they took negative remarks in their stride and did not allow them to upset or define them. They were aware that the comments were a result of being uninformed, as Harry explained: *“I don’t really care about what they say because they don’t really know what the situation is. So I just carry on and ignore them”*.

Six participants noted that they had been somewhat self-conscious about the use and visibility of the CGM device at first, as explained by Darla: *“I’ve got like a tan [...] where the CGM was. And it looks a bit funny and that I’m a bit self-conscious about”*. But as time passed their perspective changed, as noted by Amelia: *“It doesn’t bother me at all”*. Most participants did, however, say that they at times still experienced *“a little bit of [self-consciousness] about [CGM’s visibility] but not to the extent that it was”* (Hanna), and they would try to *“hide it in a way”* (Darla).

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Participants were able to find the silver lining amid the challenges of their diabetes

management as people were “*curious about what’s this thing on [their] arm*” (Amelia).

Participants capitalised on what made them different - the visibility of the CGM device, the diabetes management and their diagnosis - by using it as a conversation starter and educational tool to raise awareness and impart knowledge about type 1 diabetes. Participants noted that when the CGM was visible others would “*ask [them] what’s that on your arm? What does it do? [...] [they] always tell them [...] what it is and what it does*” (Amelia) and “*[they] are really happy to share it*” (Darla). This awareness-raising, in turn, “*brings more self-confidence. Because it’s nice to educate people sometimes*” (Hanna).

Participants also noted that they “*get excited*” (Amelia) and experience a sense of belonging and community when encountering and connecting with other individuals who shared similar experiences, both in person, for example “*at school*” (Amelia and Hanna) or at “*diabetes camp*” (Ryan) and on social media platforms (Amelia, Ryan, and Ava). Amelia shared: “*I follow a lot of diabetes pages on Instagram as well. So I get daily tips and tricks. Stories from other people as well. So it’s awesome. ‘Cause you’ve got a community of people who understand what you are going through as a person. And it’s great to hear about other people’s experiences as well*”. As CGM also creates opportunities for adolescents to take part in everyday life, activities such as being able “*to sleep out with the CGM because it’s constant*” (Darla), and “*[CGM] helps with sport*” (Darla, Ryan, Harry and Amelia) where participants can also experience a sense of belonging as they are seen as part of the team, and this team culture helps to reduce their experience of being different as “*[they] can do everything everyone else does*” (Darla).

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### 1.4 Discussion

This study aimed to explore the illness perceptions of adolescents living with type 1 diabetes while using CGM, and is believed to be the first study to explore this topic in the South African context.

Diabetes management is regarded as challenging in general, but even more so from the perspective of adolescents who are inhibited from living a so-called normal life during their formative years (Davidson, 2004). However, findings from this research indicate the use of CGM could contribute to the process of normalising these identity forming years in relation to their peers as data confirmed that CGM creates a sense of control over diabetes management as blood glucose measures were more visible, limiting the likelihood of medical emergencies.

Participants constructed perceptions pertaining not only to their diagnosis but to their diabetes care plans as well, which informed their management behaviours. Even though this study followed an inductive approach, links with the theoretical Common-Sense Model (CSM) could not be overlooked. The CSM is regarded as a parallel processing model, which posits that individuals develop illness perceptions regarding their diagnosis and management requirements through cognitive and emotional representations (Broadbent et al., 2006; Moss-Morris, Weinman, Petrie, & Buick, 2002). These perceptions are shaped by interpretations developed from personal experience, and informs coping strategies employed and influences future outcomes. The CSM proposes five cognitive dimensions which guide the formation of illness representations and subsequent outcomes, which can be aligned with the current study's findings, namely (1) identity, (2) perceived cause, (3) consequences, (4) control/cure, and (5) timeline. The most prominent dimensions evident in this study included the cognitive representations of identity, control/cure and consequences, as well as emotional

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The *identity* domain refers to an individual's illness concepts, understanding of the illness and its management, and how meaning is formed and ascribed. From the study, participants were enabled to acknowledge and come to terms with the fact that their diagnosis and diabetes care plans would be lifelong as no cure exists at present. By coming to terms with their situation, participants were able to incorporate both the diagnosis and the diabetes care plans with using CGM as a way of life, by regarding it as normal and an integral part of themselves (Commissariat, Kenowitz, Trast, Heptulla, & Gonzalez, 2016). It is apparent how the individuals were able to form and ascribe meaning to the CGM way of life and progressed through a process of understanding their illness and its management. This is especially evident when looking at the *emotional progression* participants experienced from a range of negative emotions (such as disappointment, sadness and frustration due to feeling different from their peers) to experiencing a sense of normalcy in their daily lives since using CGM, specifically because medical emergencies were less possible with proper management. The findings are in line with the literature in terms of negative emotions experienced (Buchberger, Huppertz, Krabbe, Lux, Mattivi, & Siafarikas, 2016; Jonker, Deacon, Van Rensburg, & Segal, 2018; Lesage, 2019), but also that peace of mind and decreased worrying followed subsequent to using CGM. CGM thus allows individuals to better manage and intervene in their diabetes care plans as it results in the achievement of predictability and control (Halford & Harris, 2010).

The *control/cure* domain pertaining to the beliefs regarding the illness's controllability and curability was very evident in this study. These perceptions prompt individuals to adopt specific disease-modifying and management behaviours for better treatment outcomes and to comply with the medication treatment plans (McAndrew et al., 2008). Moreover, Fortenberry (2014) stated that better treatment adherence would result from individuals' experiencing a

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sense of control over their diagnosis and diabetes care plans. This was the case for participants in this study, whose sense of control and predictability of their blood glucose levels were enhanced by using CGM, thereby promoting better treatment adherence by serving as a motivational factor. As adolescents became familiar with and adjusted to using CGM and felt more in control, they were encouraged to accept more responsibility for their diabetes management (Hanna, 2010; Scholes, Mandelco, Roper, Dearing, Taylor, & Freeborn, 2012). This sense of control over their diabetes management empowered participants to take it seriously: it was more convenient to manage their blood glucose levels because it involved less effort, hence fewer disruptions to their everyday lives. This greater sense of control enhanced participants' confidence in their own abilities to manage the diagnosis, which in turn shaped their perceptions into becoming more accepting of and positive about the future.

Individuals' beliefs pertaining to the anticipated gravity of their illness and its impact on different aspects of their lives, such as their social, physical and psychological performance, make up the *consequences* domain. A sense of control, shapes participants' perspectives to perceive the diabetes care plan more positively as it is manageable and controllable. This has a ripple effect on their social, psychological and physical experiences as they are able to carry on with their daily lives, social situations and activities as normal with no interruptions which decrease the likelihood of feeling differently to their peers. Gaston (2012) showed that acknowledging the potential dangers and gravity of the consequences of the illness and its management requirements could encourage individuals to take more responsibility for their diabetes care plans to avoid medical emergencies. This was evident in this study: participants noted that they realised what the consequence – a medical emergency – could be, should they not adequately manage their blood glucose levels. This insight, with the sense of control

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derived from using the CGM, assisted participants to limit the likelihood of medical emergencies arising. Even though it is not guaranteed that they would avoid emergency situations as a result of high or low glucose levels, their situation is still seen as manageable (Gaston, 2012).

Incorporating the use of CGM as part of their diabetes care plans, was not immediate but it instead developed over time. The findings of this study is in line with literature, indicating that as adolescents mature in age, gain more knowledge of their treatment requirements and receive adequate support, their perceptions regarding their diagnosis and their management requirements are likely to change. Participants originally held multiple emotional representations which adjusted similarly to their cognitive representations. Initially participants perceived diabetes management as a very daunting and challenging task. Nonetheless, as they aged and adjusted to using CGM, they developed a more positive outlook on their diabetes care plans as they gained more confidence in their abilities to manage their diabetes effectively. This could be seen as normalising their lives to some extent. Literature suggests that this normalisation and eventual acceptance of their diabetes care plans may further decrease their experiences of being different, may promote better treatment adherence, and may ultimately improve their overall quality of life (Lewko, Polityńska, Kochanowicz, Zarzycki, Okruszko, & Sierakowska, 2007).

### **1.5 Conclusion**

This research sheds light on the experiences of adolescents living with type 1 diabetes who are using CGM in the South African context. The prominent findings included that the predictability of CGM created control of diabetes management and assisted in creating a new normal. The study's findings may inform diabetes health care providers, caregivers of

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adolescents living with diabetes, or patients themselves, and its new insights may assist in broadening understanding of the use of CGM devices and their impact on illness perceptions. By better understanding the use of CGM devices and their impact on illness perceptions will allow health care providers and caregivers to adapt diabetes care plans in a way that is effective and beneficial to the patient. It may furthermore serve as a motivator to suggest CGM to others, which will better prepare someone before receiving CGM devices. The limitations of the current study include the small sample size and limited demographic variability. Having a larger sample size and more diverse demographic variability could provide even more insights that are relevant to all groups, especially in the diverse context of South Africa. Nonetheless, this study could be a starting point for further research studies, which could include exploring potential similarities in experiences in more diverse groups.

### **1.6 Ethical considerations**

Ethicality was of utmost importance in guiding this study. Ethical approval (NWU-00125-18-A1) was granted by the Health Research Ethics Committee (HREC) in the Faculty of Health Sciences, at the North-West University Potchefstroom Campus before commencing this study. The best-interest principle was followed at all times, as the participants, adolescents, were considered to form part of a potentially vulnerable population due to their age, minority, and their type 1 diabetes mellitus diagnosis. These considerations guided the researcher throughout the process, thereby helping to take into account and uphold the prerequisites and rights of each participant to the best of the researcher's abilities. Data collection was carried out by using video conferencing technology to reduce the risk of COVID-19 spreading and contamination, following delayed informed parental permission and adolescent consent. Participants and their caregivers were fully informed of the voluntary nature of the study and the anonymity and confidentiality of their identities. The participants will receive a short

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report regarding the findings of the research study, presented in a comprehensible form, according to their age.

### **1.7 Conflict of interest**

There are no conflicts of interest to declare.

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### SECTION 3: CRITICAL REFLECTION

#### 3.1 Introduction

The critical reflection provided in section 3 consists of a concise overview of the research process, including the aim of the study, an epilogue and findings, as well as the study's limitations and recommendations, followed by its relevance. The section concludes with the researcher's reflexivity on the experience of writing this mini-dissertation.

#### 3.2 Research aim

This study aimed to explore the illness perceptions of a group of adolescents living with type 1 diabetes while using continuous glucose monitoring (CGM).

#### 3.3 Epilogue

##### 3.3.1 Research process

A qualitative research approach with a social constructionist framework was followed in this study. Participants were selected by a non-random purposive sampling method as they had to meet clearly defined, specific, predetermined sample inclusion criteria in order to become eligible to participate in this study. Ultimately the study comprised of seven adolescents, aged between 12 and 17 years, living with type 1 diabetes mellitus and using CGM (3 male and 4 female); all males and 3 females were Caucasian and 1 female was Indian; 2 were Afrikaans- and 5 were English-speaking).

The access points for the identification of potential participants was the CDE: Parktown, Johannesburg, a centre which specialises in paediatric diabetes. The CDE was chosen to minimise treatment variables. Potential participants had to have been using CGM for three or more months, between the ages of 12 and 17 years, and have been diagnosed



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with type 1 diabetes for twelve or months or more prior to data collection, to be eligible for inclusion in the study to minimise any impact of ongoing adjustment to the diagnosis. All participants were required to have access to an internet connection as the semi-structured interviews were conducted via a video conferencing technology platform. The participants had to be proficient in English or Afrikaans. Potential participants were ineligible for the study if they were undergoing psychotherapy at the time. Their exclusion was intended to limit any possible impact of the psychotherapeutic process on their perceptions of type 1 diabetes management. Adolescents living with another chronic medical condition were also ineligible to ensure that their lived experience of managing the other chronic illness did not impact their experience of managing type 1 diabetes.

Data gathering was carried out by means of semi-structured interviews conducted via online video conferencing technology in an attempt to curb the spread of the prevalent Coronavirus (COVID-19). The digitally made recordings of the interviews were transcribed verbatim and subsequently thematically analysed in accordance with the guidelines provided by Braun and Clarke (2006). The themes identified by closely investigating the illness perceptions of adolescents living with type 1 diabetes while using CGM constitute the findings to follow.

### **3.3.2 Research findings**

To the best of the researcher's knowledge, this is the first study to explore the illness perceptions of adolescents living with type 1 diabetes while using CGM in the South African context. Data saturation occurred after the fifth interview, but two more interviews were conducted to ensure that no new themes or information emerged. Three prominent themes emerged from the seven semi-structured interviews conducted.

#### **3.3.2.1 Theme 1: CGM creates a sense of control over diabetes management**

All participants noted that diabetes management, in general, is a challenging and

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daunting task because it is difficult to monitor and manage their blood glucose levels

adequately and continuously. Before starting to use CGM, participants noted that they were experiencing a range of negative emotions, such as fear and uncertainty, as they did not know how CGM would work or affect their lives.

However, they noted that the decision to use CGM could be regarded as one of the best of their lives because their blood glucose levels were continuously visible, which helps to promote predictability and decreases the likelihood of medical emergencies because they can intervene immediately if they need to. Through constant awareness of their blood glucose levels, they do not have to stop or interrupt what they were doing and miss out on the situation at hand, which was frustrating before CGM was adopted. This led participants to experience a sense of control and normality. Predictability and control over their blood glucose levels hold multiple benefits, which assisted in shaping their perspective into being more positive.

### **3.3.2.2 Theme 2: CGM assists in creating a new normal**

The predictability and control achieved by using CGM (theme 1) assisted in promoting routine in participants' lives as it required less effort and input from their side. Participants noted that not having to engage in traditional diabetes management to monitor and intervene in their blood glucose levels was made more convenient and manageable with the use of CGM, thereby helping them to carry on and live a close to normal life.

It is apparent that participants' perceptions adjusted over time to become more accepting and positive of their diabetes management with the use of CGM; they noted that it became a way of life which they barely noticed at times. This change in perception may be attributed to maturation with age, being more informed, and experiencing a sense of control from the use of the monitor (theme 1). This, in turn, assisted participants to carry on with their lives while promoting adherence to their diabetes care plans.

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### **3.3.2.3 Theme 3: Being different creates an opportunity for positive outcomes**

All participants noted apparent differences as result of their diabetes management using CGM. Previously, participants had found it highly frustrating to have to stop their activities to manage their blood glucose levels, which made them feel excluded at times. With the routine and normality CGM promoted, they could proceed with activities uninterrupted (theme 2), thanks to the predictability created by the continuous visibility of their blood glucose levels (theme 1).

Participants were able to find a silver lining, regardless of their challenging circumstances of being in the developmental phase of adolescence, having type 1 diabetes, and dealing with unpleasant remarks from others about their diabetes management. Participants took advantage of what made them different - the visibility of the CGM device - to serve as an educational medium for providing knowledge about type 1 diabetes, which in turn promoted self-confidence. Moreover, they felt a sense of belonging when they encountered others who shared similar experiences.

## **3.4 Limitations**

The current study's research aim was achieved successfully, but some limitations are apparent and are noted below:

- Demographic variability in the sample population was limited, which resulted in a limited representation of different socio-economic status and demographic groups obtained. The transferability of the findings might be hampered by this, as CGM interventions are expensive and not widely available.
- Research suggests that there is a difference in the illness perceptions among younger and older adolescents (Olsen et al., 2008; Jonker, Deacon, Van Rensburg, & Segal, 2018). Older adolescents are said to possess an advanced perception and

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understanding of their diagnosis and its management, which might not be the case for younger adolescents who lack lived experience and maturity (Olsen et al., 2008; Jonker et al., 2018). The variation in participants' ages is limited to a mean age of 14.9 years. Age variation was not as observable in this study due to the relatively narrow age range of participants.

- Semi-structured interviews were carried out by using online video conferencing technology, which might have led to the loss of some of the richness of the data as subtle observations could have been overlooked. Technical difficulties experienced during the interviews might have also affected the interview process by causing participants to become frustrated with the process. This could have affected the quality of data they provided. As this study was conducted during the COVID-19 pandemic, it could have had an impact on the results. Participants' experiences of living with type 1 diabetes and its management may have been affected by the lockdown regulations and heightened vulnerability, with potential psychological consequences.
- It became evident during the interview process that some participants were unable to distinguish between the CGM device and the insulin pump and would refer to them interchangeably. This makes it difficult to determine whether the changes in illness perceptions were as a result of using the CGM device, the insulin pump or a combination of the two. It is, important to note, however, that the use of CGM devices and insulin pumps go hand in hand as they work together to optimally correct participants' blood glucose levels. It is therefore difficult to credit the changes seen in the illness perceptions and diabetes management merely to the use of CGM devices, because the insulin pump also plays a crucial role in diabetes management by promoting a sense of control and normality.

### **3.5 Recommendations**

This study highlights the need for additional research to broaden and enhance empirical insight regarding adolescents' use of CGM systems and their illness perceptions.

Accordingly, the following proposals are recommended for future research:

- As this study only relied on semi-structured interviews as a form of data collection, it may be recommended that future studies adopt a mixed-method research design to gather more in-depth data from a quantitative and qualitative perspective. A more comprehensive understanding effects of the use of CGM systems on the illness perceptions of adolescents living with type 1 diabetes can be obtained from a mixed-methods research design.
- Future studies should also be aimed at developing interventions to assist adolescents living with diabetes to manage their condition and to enhance their illness perceptions to promote better quality of life. This would help to alleviate the challenging nature of diabetes management. This may be achieved by providing psycho-educational workshops for those working with and caring for adolescents living with type 1 diabetes. Workshops could address how illness perceptions adapt and affect the management behaviours of adolescents during the different developmental phases as they mature and take on more responsibility for their diabetes care plans. This may empower diabetes educators, caregivers and adolescents towards a better understanding and to give or receive adequate support and assistance. It may be particularly beneficial to develop cognitive and behavioural interventions for adolescents living with diabetes to be able to make sense of and understand their perceptions regarding their diagnosis and diabetes care plans. This may enable them to feel that they have more control over the management of their diagnosis, thus leading to better diabetes management.

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- Future studies would benefit from adopting a quantitative pre-experimental design, investigating the illness perceptions of adolescents pre-and post-CGM interventions. Future research can gauge whether it may be more effective for adolescents to use CGM intervention than conventional insulin therapy. It could also examine the role which adolescents' illness perceptions play on their diabetes care plans, which could be enhanced both for treatment approaches and improved outcomes.
- Future research could explore the use of CGM devices and insulin pump therapy, both separately and combined, as they go hand in hand. This may yield valuable information for adolescents living with diabetes to be more open to accept life-changing devices to promote improved diabetes management, adherence and overall quality of life.

### 3.6 Significance of the study

This study aimed to contribute to literature on the illness perceptions of adolescents living with type 1 diabetes and their use of CGM in managing diabetes, given that relevant literature is scarce. Most research available within the South African context is primarily focused on type 2 diabetes, with limited research on the use of CGM systems in adolescence and its potential impact of their illness perceptions.

- This study's findings may highlight the role of adolescents' illness perceptions on their diabetes management regimen, in particular the use of CGM systems, which could be communicated to the National Department of Health of the Republic of South Africa. This may assist in the promotion of the use of CGM systems, and in obtaining funding for adolescents in a lower socio-economic status so that they can receive more effective intervention and experience a better quality of life.
- Findings may assist future studies in exploring and possibly developing programmes

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for diabetes management, with particular focus on developing and enhancing

adolescents' illness perceptions to manage their diabetes better, or to best make use of their CGM systems.

### **3.7 Reflexivity of the researcher**

The research journey with this mini-dissertation had its ups and downs, but I experienced it as a mostly positive experience. From the outset I was very excited to embark on the study with Prof. Deacon, who presented as very dedicated and a hardworking. These are qualities with which I identified, and they made the research process a pleasant one. I could consult with Prof. Deacon at any time, and she would assist by offering insights and guidance while at the same time broadening and enhancing my knowledge through imparting her expertise. I am a firm believer in life-long learning and this prompted me to discover more about the field of diabetes and to go the extra mile in order to shed new light on the topic. This was done in the hopes of ultimately aiding adolescents to gain a better understanding of how their own illness perceptions may contribute to their diabetes treatment regimen. Further raise awareness on how the use of CGM systems could alleviate the challenges of a strict and demanding diabetes treatment regimen in an already difficult developmental stage can be of benefit to them.

With the information obtained through this research process, I can confirm that I have gained even more respect for adolescents living with diabetes. The condition appeared to confront them with an added challenge in a developmental stage which is already riddled with demands and difficulties. I particularly admired how the participants in this study shaped their illness perceptions to be more optimistic as they adjusted to using CGM by making it a way of life, which made diabetes management less of a burden for them.

This study also posted its own challenges for me as a researcher, which tested my

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patience at times. My research project changed many times, because it was difficult for me to recruit participants. This resulted in me having to an extended period of time before the first participant agreed to join the study. When I was confident that there were individuals interested in participating, another setback arose, the COVID-19 pandemic. This unforeseen crisis resulted in having to adapt the study to conduct semi-structured interviews via online telecommunication platforms instead of face to face interactions to ensure the best interests and safety of the already vulnerable participants. During this exceptional period, I sometimes became anxious and frustrated with the process, which prompted me to introspect, address, and work on my own perceptions in order to remember what a positive contribution this study could make to the lives of adolescents contemplating CGM interventions. I learned a great deal about myself in this process. This helped me to let go of situations that are out of my control, while grabbing on to and changing those I could.

This process broadened my skills as a qualitative researcher because it was the first time I had conducted online telecommunication semi-structured interviews. It was a daunting experience at first, until I became familiar with the design and process, which became very exciting given the broadened depth of data which would be obtained from it, and the contribution it would make to the field of social sciences.

I am grateful for this research opportunity as it assisted me to overcome both personal and professional challenges, while simultaneously providing wonderful memories and experiences which I can continue to learn and grow from.



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# ILLNESS PERCEPTION OF ADOLESCENTS WITH TYPE 1 DIABETES

## ADDENDUM A: Ethical Approval Certificate (Current study)



Prof E Deacon  
Psychology  
OPTENTIA

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Web: <http://www.nwu.ac.za>

Health Sciences Ethics Office for Research,  
Training and Support

North-West University Health Research Ethics  
Committee (NWU-HREC)  
Tel: 018-285 2291  
Email: [Wayne.Towers@nwu.ac.za](mailto:Wayne.Towers@nwu.ac.za)

7 August 2020

Dear Prof Deacon

### APPROVAL OF YOUR AMENDMENT REQUEST BY THE NORTH-WEST UNIVERSITY HEALTH RESEARCH ETHICS COMMITTEE (NWU-HREC) OF THE FACULTY OF HEALTH SCIENCES

**Ethics number: NWU-00125-18-A1**

Kindly use the ethics reference number provided above in all future correspondence or documents submitted to the administrative assistant of the North-West University Health Research Ethics Committee (NWU-HREC) secretariat.

**Study title: Exploring illness perceptions of a group of adolescents living with diabetes while using continuous glucose monitoring (CGM)**

**Study leader/Researcher: Prof E Deacon**

**Student: L Williams-29126789**

You are kindly informed that your amendment request (change of study from a quantitative methodology to a qualitative methodology) to the aforementioned project has been approved. Any future amendments to the proposal or other associated documentation must be submitted to the NWU-HREC, Faculty of Health Sciences, North-West University, prior to implementing these changes. These requests should be electronically submitted to [Ethics-HRECAppl@nwu.ac.za](mailto:Ethics-HRECAppl@nwu.ac.za), for review BEFORE approval can be provided, with a cover letter with a specific subject title indicating, "Amendment request: NWU-XXXXXX-XX-XX". The letter should include the title of the approved study, the names of the researchers involved, the nature of the amendment/s being made (indicating what changes have been made as well as where they have been made), which documents have been attached and any further explanation to clarify the amendment request being submitted. The amendments made should be indicated in **yellow highlight** in the amended documents. The e-mail, to which you attach the documents that you send, should have a *specific subject line* indicating that it is an amendment request e.g. "Amendment request: NWU-XXXXXX-XX-XX". This e-mail should indicate the nature of the amendment. This submission will be handled via the expedited process.

**Please note:** Due to the nature of the study i.e. (semi-structured interviews with Type 1 diabetic adolescents, undertaken via an online platform), this study will be able to proceed during the current alert level, following receipt of this approval letter. No additional COVID-19 restrictions have been placed on the study except that the researcher must ensure that before proceeding with the study that all research team members have reviewed the North-West University COVID-19 Occupational Health and Safety Standard Operating Procedure.

We wish you the best as you conduct your research. If you have any questions or need further assistance, please contact the Faculty of Health Sciences Ethics Office for Research, Training and Support at [Ethics-HRECAppl@nwu.ac.za](mailto:Ethics-HRECAppl@nwu.ac.za).

Yours sincerely

 Digitally signed by  
Prof Petra Bester  
Date: 2020.08.07  
14:22:50 +02'00'

Chairperson: NWU-HREC

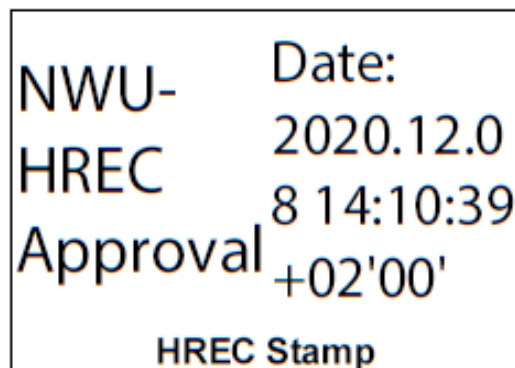
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30 April 2018  
File reference: 9.1.5.4.1

## ILLNESS PERCEPTION OF ADOLESCENTS WITH TYPE 1 DIABETES

### ADDENDUM B: Informed consent form for legal guardians of adolescent



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## PARENTAL PERMISSION DOCUMENTATION

**TITLE OF THE RESEARCH STUDY:** Exploring illness perceptions of a group of adolescents living with diabetes while using continuous glucose monitoring (CGM).

**ETHICS REFERENCE NUMBERS:** NWU-00125-18-A1

**PRINCIPAL INVESTIGATOR:** Prof Elmari Deacon

**POST GRADUATE STUDENT:** Mrs. Letitia Williams

**ADDRESS:** North-West University, Potchefstroom Campus, 11 Hoffman Street

**CONTACT NUMBER:** 073 990 6466

Your child is being invited to take part in a research project exploring the illness perception of a group of adolescents living with diabetes using continuous glucose monitoring (CGM), which forms part of a Masters study.

We would appreciate your support. Please take some time to read the information presented here, which will explain the details of this study. Please ask the researcher or person explaining the research to you any questions about any part of this study that you do not fully understand. It is very important that you are fully satisfied that you clearly understand what this research is about and how you might be involved.

## ILLNESS PERCEPTION OF ADOLESCENTS WITH TYPE 1 DIABETES

As researchers, we regard you as parent/guardian of an adolescent (aged between 12 and 17 years), as a co-participant, and we want you to be comfortable with the research process and all it entails. Your child's participation within this study is entirely voluntary, and if you decide to allow your child to be part of this study, you may change your mind and withdraw your approval at any time without any consequences. Along with your parental permission, your child will similarly be asked whether he or she would like to participate in this project. Your child may decline to participate or may withdraw from this study at any time. Refusal to participate or withdrawal from this study will have no consequences for you or your child, as it will not affect you or your child negatively.

The study was approved by Health Research Ethics Committee of the Faculty of Health Sciences of the North-West University and will be conducted according to the ethical guidelines and principles of Ethics in Health Research: Principles, Processes and Structures (DoH, 2015) and other international ethical guidelines applicable to this study. It might be necessary for the research ethics committee members or other relevant people to inspect the research records.

### **What is this research study all about?**

- This study aims to explore the illness perception of a group of adolescents living with type 1 diabetes using CGM.
- This research study entails that your child will participate in a semi-structured interview via a video conferencing technological platform. The interview will take approximately 30 to 40 minutes to complete, with an optional 5 to 10-minute break. This interview will be recorded. If your child would prefer to have you as parents/guardians present during the interview, this is allowed. It will, however, not be allowed for you to assist or communicate with your child while answering the interview questions.
- In light of the recent Coronavirus disease (COVID-19) crisis, the recruitment, interviewing, and debriefing will be carried out virtually with the use of video conferencing technology. Video conferencing is an online-based technological platform which enables individuals to engage in a synchronous face-to-face manner from different locations

## ILLNESS PERCEPTION OF ADOLESCENTS WITH TYPE 1 DIABETES

- This study will be conducted through the use of video conferencing technology in a suitable, safe, quiet and comfortable venue which is free from distractions, selected and based on your child's preference. The interview will be done by experienced health researchers trained in conducting interviews. Six to ten participants will be included in this study.
- Should the lockdown regulations be lifted, a face-to-face meeting will be scheduled at the CDE where the researcher, independent person, your child and you as caregivers will meet to sign the written informed parental permission and adolescent consent forms. The CDE follows strict protocols to minimise the risk of COVID-19 contamination which is of utmost importance. The CDE will provide a safe, secure, and confidential room free from distractions for the meeting to take place, which will be disinfected before and after each meeting. All individuals will also be required to adhere to the protocols set out by the CDE to reduce the risk of contamination, such as social distancing, wearing of protective masks, and sanitisation of hands.

### **Why have you been invited to participate?**

- Your child has indicated interest to participate in this study. We have received the information leaflet from you which you completed and e-mailed back to us. Prof Elmari Deacon already contacted you to complete a screening, which was further followed by an e-mail with this informed consent form attached. It is important to note that permission was obtained from the CDE, in Parktown, to conduct this research.
- Your child also complied with the following inclusion criteria: willing to participate in an online video conferencing semi-structured interview with us in English or Afrikaans, between the ages of 12 and 17 years old, were diagnosed with type 1 diabetes more than 1 year ago and is a patient at the CDE (Parktown), have been using CGM for more than 3 months, and have access to internet connection and video conferencing technology.
- Your child will, unfortunately, not be able to take part in this research if you are currently undergoing psychotherapy or if you suffer from another chronic illness.

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### **What will your responsibilities be?**

- Your child will be expected to participate in a semi-structured interview via video conferencing technology (accompanied by his/her parent/legal guardian should they prefer), with the duration of approximately 30 to 40 minutes to complete.
- This research will take place in a suitable venue based on your child's preference as the interview will be conducted through video conferencing technology. Approximately 1 GB of internet data will suffice the 30 to 40-minute interview.
- It is important to remember that the participation is completely voluntary and your child is free to not participate or to withdraw at any point within the study without any consequences.

### **Will you benefit from taking part in this research?**

- The direct benefits for your child as a participant will probably be the following:
  - As a direct benefit, a workshop on the influence of illness perception on diabetes management will be arranged for you and your families. This will be arranged for a suitable time for you and will include practical guidelines to improve your diabetes management and general well-being.
  - A possible indirect benefit could be that your child might find his/her reflections based on the interview to be beneficial which may broaden their own perception and knowledge regarding their diagnosis.
  - You will also receive the results of this study, which may enhance your knowledge and understanding regarding the diagnosis, as well as inform your child's management behaviours in the future.
- The indirect benefit will probably be:
  - Due to this study's qualitative nature, the data may be used to broaden knowledge and understanding for you and society based on adolescents living with diabetes' illness perceptions while using CGM, as knowledge is currently limited.
  - The aforementioned may guide and inform future studies on this topic, which may assist in developing intervention programmes or models for adolescents living with type 1 diabetes.

## ILLNESS PERCEPTION OF ADOLESCENTS WITH TYPE 1 DIABETES

### **Are there risks involved in your taking part in this research and how will these be managed?**

- The risks in this study, and how these will be managed, are summarised in the table below:

<b>Probable/possible risks/discomforts</b>	<b>Strategies to minimise risk/discomfort</b>
As this study will include adolescents, it falls within the category of greater than minimal risk with a direct benefit to the participants.	<p>The best interest principle, as set out by the Children's Act will be adhered to and regarded as utmost important. You and your child will be informed that participation will be completely voluntary in that you will not be forced or coerced into participating by the medical specialist or research team. With the aforementioned in mind, if your child is truly interested in participating freely, then he/she will be included. Your child will also be clearly informed of the fact that they are free to decline or withdraw from the study at any time with no consequences. It will also be made clear that your child's participation in this study will not be linked to the treatment or care which they receive at the CDE.</p> <p>Independent written informed parental permission and adolescent consent will be attained prior to conducting the semi-structured interview to establish your child's willingness to participate. These consent forms will be sent to you</p>

## ILLNESS PERCEPTION OF ADOLESCENTS WITH TYPE 1 DIABETES

	<p>well in advance, 2 or more weeks, in order to provide enough time for you and your child to make an informed decision regarding participating in this study</p> <p>Due to adolescents being seen as a vulnerable population, a need might arise for the use of counselling or psychological services as a result of possible discomfort which might be experienced through participating in the interview.</p>
Due to your child having the diagnosis of type 1 diabetes, they are at an increased risk of being infected with COVID-19.	<p>Lockdown procedures were implemented in an attempt to limit the spread of the disease. The best interest principle will be upheld for your child by conducting the semi-structured interviews with the use of video conferencing technology amidst the COVID-19 crisis. The aforementioned will assist in limiting in-person contact, which might pose a risk of contamination to a group of participants who are already deemed to be vulnerable due to their diagnosis, inherently promoting their safety.</p>
Due to your child spending about 30 to 40 minutes participating in a semi-structured interview, he/she may possibly become fatigued.	<p>The researcher who will be facilitating the semi-structured interview may give the participants an optional 5 to 10-minute break about halfway through the interview.</p>

## ILLNESS PERCEPTION OF ADOLESCENTS WITH TYPE 1 DIABETES

Due to the semi-structured interviews asking questions regarding your child's biographical information and illness perceptions, this may result in your child thinking about how he/she perceive his/her diagnosis, which may make him/her feel uncomfortable.	Biographical information based on your child's age, gender, ethnicity, and time since diagnosis will be used to provide a good sample description to accurately reflect the diverse population of adolescents living with diabetes. There will be a psychological debriefing session available by Rosemary Flynn via online video conferencing technology.
The Continuous glucose monitor (CGM) will not be used as a form of intervention for this study. Adolescents will reflect on their illness perceptions while using CGM.	The researcher will not be involved in implementing the intervention herself. The medical practitioner will do the minor medical procedure and the researcher will merely obtain data via the semi-structured interviews as you would have been using CGM for more than 3 months.
Due to having the diagnosis of diabetes, the possibility exists for experiencing unexpectedly low and high blood glucose while your child participates in the semi-structured interviews, even though this study does not expect to harm or impact his/her health.	It is important to inform your child that he/she should let the researcher know when he/she are feeling ill at any time when participating in the semi-structured interview so that he/she can test and correct his/her blood glucose levels, or they can ask their trained caregiver for assistance.
This proposed research study will look at your child's illness perception while using CGM, which entails his/her HbA1C levels. The researcher will not necessarily be talking about the particular result,	The researchers will respect your child's human rights, such as the right to have his/her human dignity respected, which entails that he/she will be treated with respect. This entails that he/she will not be



## ILLNESS PERCEPTION OF ADOLESCENTS WITH TYPE 1 DIABETES

<p>however, your child may feel concerned about being judged on how well or not well he/she is managing his/her diabetes.</p>	<p>discriminated against on the basis of how well or how poorly he/she manages his/her diabetes. Your child will also be informed throughout the process that he/she will be able to see a psychologist when he/she feels uncomfortable at any point in time.</p>
<p>Your child might be concerned that others may become cognisant of his/her diagnosis and will treat him/her differently.</p>	<p>Due to semi-structured interviews being conducted via an online video conferencing technological platform, your child may feel more at ease and comfortable as he/she is familiar with the technology, due to him/her communicating with Prof. Segal in this manner. He/she may also feel more comfortable knowing that only the researcher is present during the interview, maintaining confidentiality and privacy.</p>
<p>As the semi-structured interview will be administered via an online video conferencing technological platform, you might encounter internet data costs.</p>	<p>Due to using online video conferencing technology for approximately 30 to 40 minutes, you might need to use your own data to participate in the study as it is estimated that the interview will use roughly 1GB of data. It is welcome for you to use your own data if you have uncapped internet access and feel comfortable with using your own data to participate in this study. If you do or don't have uncapped internet access and don't feel</p>

## ILLNESS PERCEPTION OF ADOLESCENTS WITH TYPE 1 DIABETES

	comfortable using it without being reimbursed for it, then your internet data costs will be reimbursed.
In order to take part in this proposed study, it might interfere with other activities.	As this study will make use of online video conferencing technology, a suitable time will be arranged for your child to participate in the semi-structured interview as to not interfere with his/her activities.

- The aforementioned is indicative that the benefits (as noted) outweigh the risks.
- Should it become apparent that your child is being harmed in some way by someone, or that there is an intent to inflict harm, or that your child intends to inflict harm to others, will it then require that the researcher should break confidentiality to inform someone to assist you or the child, or another individual.

### **Who will have access to the data?**

- Anonymity (entailing the way your child's results will be connected to him/her personal particulars) of his/her findings, will be protected by storing all electronic data securely and confidentially on a password-protected computer, with access limited to the researcher and the research supervisors.
- All recordings will be deleted from the computer after transcribing the data (verbatim). Your child's personal particulars will be protected by assigning a pseudo name which will be kept separate from the written informed consent forms.
- All hard copy documents will be securely stored in a locked cabinet, in a locked room on the NWU Potchefstroom premises. Only the researchers will be able to look at your child's findings.
- Transcribed and hardcopy data will be stored for 10 years, after which it will be destroyed by shredding it and deleting it from the computers.
- In order to be anonymous, none of your child's personal particulars will be made available when reporting the findings of this study.

## ILLNESS PERCEPTION OF ADOLESCENTS WITH TYPE 1 DIABETES

### **What will happen to the data?**

- The findings of this study may be used in future studies.
- The data from this study will be reported in the following ways: it will be written up in articles and research reports. It is important to remember that no personal particulars will be made available when reporting the results which maintains the confidentiality and privacy of participants.

### **Will you be compensated for taking part in this study and are there any costs involved?**

- Your child will not be paid for taking part in the study.
- The researchers aim at conducting the semi-structured interview via an online video conferencing technology platform to ensure the best interest of your child amidst the COVID-19 crisis. The online video conferencing technology platform will ensure that your child remains safe as no face to face interactions will take place, which might spread the disease. Your internet data costs will be reimbursed, resulting in no additional costs involved for you to participate in this study.

### **How will you know about the findings?**

- The researcher will provide you and your child with the results of this research study, via e-mail, upon completion thereof.
- Any new relevant findings will also be communicated to you and your child via e-mail.
- Posters will be displayed at the CDE Parktown, which will contain the main findings of this study.

### **Is there anything else you should know or do?**

- You can contact Prof Elmari Deacon at [elmari.deacon@nwu.ac.za](mailto:elmari.deacon@nwu.ac.za) or (018 299 1728) if you have any further questions or encounter any problems.
- You can also contact the Health Research Ethics Committee via Mrs Carolien van Zyl at 018 299 1206 or [carolien.vanzyl@nwu.ac.za](mailto:carolien.vanzyl@nwu.ac.za) if you have any concerns that were not answered about the research or if you have complaints about the research. You will receive a copy of this information and consent form for your own records.

## ILLNESS PERCEPTION OF ADOLESCENTS WITH TYPE 1 DIABETES

### Declaration by parent/guardian

By signing below, I ....., parent/guardian of ..... agree that my child can take part in a research study titled: **Exploring illness perceptions of a group of adolescents living with diabetes while using continuous glucose monitoring (CGM)**, provided that they give written consent, following my permission and consent.

I declare that:

- I have read and understood this information and consent form and it is written in a language in which I am fluent and with which I feel comfortable.
- I have been afforded the opportunity of posing questions to both the person obtaining consent, as well as the researcher (if this is a different person), and all my questions have been adequately answered.
- I understand that taking part in this study is **voluntary** and neither my child nor I have been pressurised to take part.
- I understand that my or my child's contribution (what we report/ say/ write/ draw/ produce visually) could be reproduced publically and/or quoted, but without reference to our personal identity.
- My child and I may choose to leave the study at any time and will not be penalised or prejudiced in any way.
- My child and I may be asked to leave the research before it has been completed if the researcher feels it is in my best interests, or if we do not follow the research plan, as agreed on.

Signed at (*place*) ..... on (*date*) .....  
20....

.....  
**Signature of parent**

.....  
**Signature of witness**

- You may contact me again ☐ Yes ☐ No
- I would like a summary of the findings of this research ☐ Yes ☐ No

## ILLNESS PERCEPTION OF ADOLESCENTS WITH TYPE 1 DIABETES

The best way to reach me is:

Name & Surname: \_\_\_\_\_

Postal Address: \_\_\_\_\_

Email: \_\_\_\_\_

Phone Number: \_\_\_\_\_

Cell Phone Number: \_\_\_\_\_

In case the above details change, please contact the following person who knows me well and who does not live with me and who will help you to contact me:

Name & Surname: \_\_\_\_\_

Phone/ Cell Phone Number /E-mail: \_\_\_\_\_

### Declaration by person obtaining consent

I (*name*) ..... declare that:

- I explained the information in this document to .....
- I encouraged him/her to ask questions and spent adequate time answering them.
- I am satisfied that he/she adequately understands all aspects of the research, as discussed above
- I did not use an interpreter.

Signed at (*place*) ..... on (*date*) .....  
20....

.....  
**Signature of person obtaining consent**

.....  
**Signature of witness**

## ILLNESS PERCEPTION OF ADOLESCENTS WITH TYPE 1 DIABETES

### **Declaration by researcher**

I (*name*) ..... declare that:

- I explained the information in this document to .....
- I encouraged him/her to ask questions and took adequate time to answer them.
- I am satisfied that he/she adequately understand all aspects of the research, as discussed above
- I did not use an interpreter.

Signed at (place) ..... on (date) .....

20....

.....

**Signature of researcher**

.....

**Signature of witness**

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25 April 2018

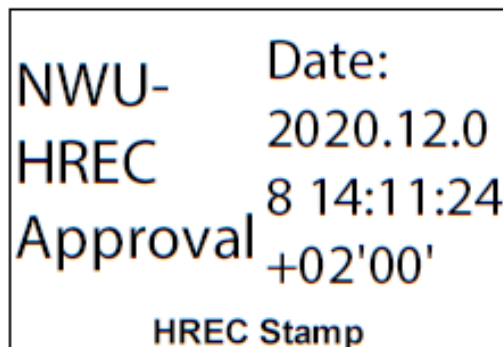
File reference: 9.1.5.6

## ILLNESS PERCEPTION OF ADOLESCENTS WITH TYPE 1 DIABETES

### ADDENDUM C: Informed assent form for adolescents



Private Bag X1290, Potchefstroom  
South Africa 2520  
Tel: +2718 299-1111/2222  
Fax: +2718 299-4910  
Web: <http://www.nwu.ac.za>



### INFORMED CONSENT DOCUMENTATION FOR ADOLESCENTS

**TITLE OF THE RESEARCH STUDY:** Exploring illness perceptions of a group of adolescents living with diabetes while using continuous glucose monitoring (CGM).

**ETHICS REFERENCE NUMBERS:** NWU-00125-18-A1

**PRINCIPAL INVESTIGATOR:** Prof Elmarie Deacon

**POST GRADUATE STUDENT:** Mrs. Letitia Williams

**ADDRESS:** North-West University, Potchefstroom Campus, 11 Hoffman Street

**CONTACT NUMBER:** 073 990 6466

You are invited to take part in a research project exploring the illness perception of a group of adolescents living with diabetes using continuous glucose monitoring (CGM), which forms part of a Masters study.

We would appreciate your support. Please take some time to read the information presented here, which will explain the details of this study. Please ask the researcher or person explaining the research to you any questions about any part of this study that you do not fully understand. It is very important that you are fully satisfied that you clearly understand what this research is about and how you might be involved.

## ILLNESS PERCEPTION OF ADOLESCENTS WITH TYPE 1 DIABETES

Your participation in this study is completely voluntary, and if you decide to take part in this study, you may change your mind and withdraw at any time without any consequences. Refusal to participate or withdrawal from this study will have no consequences for you, as it will not affect you negatively.

The study was approved by Health Research Ethics Committee of the Faculty of Health Sciences of the North-West University and will be conducted according to the ethical guidelines and principles of Ethics in Health Research: Principles, Processes and Structures (DoH, 2015) and other international ethical guidelines applicable to this study. It might be necessary for the research ethics committee members or other relevant people to inspect the research records.

### **What is this research study all about?**

- This study aims to explore the illness perception of a group of adolescents living with type 1 diabetes using CGM.
- This research study entails that you will participate in a semi-structured interview via a video conferencing technological platform. The interview will take approximately 30 to 40 minutes to complete, with an optional 5 to 10-minute break. This interview will be recorded. If you would prefer to have your parents/guardians present during the interview, this is allowed. It will, however, not be allowed for them to assist or communicate with you while answering the interview questions.
- In light of the recent Coronavirus disease (COVID-19) crisis, the recruitment, interviewing, and debriefing will be carried out virtually with the use of video conferencing technology. Video conferencing is an online-based technological platform which enables individuals to engage in a synchronous face-to-face manner from different locations.
- This study will be conducted through the use of video conferencing technology in a suitable, safe, quiet and comfortable venue which is free from distractions, selected and based on your preference. The interview will be done by experienced health researchers trained in conducting interviews. Six to ten participants will be included in this study.



## ILLNESS PERCEPTION OF ADOLESCENTS WITH TYPE 1 DIABETES

- Should the lockdown regulations be lifted, a face-to-face meeting will be scheduled at the CDE where the researcher, independent person, you as a participant and your caregivers will meet to sign the written informed parental permission and adolescent consent forms. The CDE follows strict protocols to minimise the risk of COVID-19 contamination which is of utmost importance. The CDE will provide a safe, secure, and confidential room free from distractions for the meeting to take place, which will be disinfected before and after each meeting. All individuals will also be required to adhere to the protocols set out by the CDE to reduce the risk of contamination, such as social distancing, wearing of protective masks, and sanitisation of hands.

### **Why have you been invited to participate?**

- You have indicated interest to participate in this study. We have received the information leaflet from you which you completed and e-mailed back to us. Prof Elmari Deacon already contacted you to complete a screening, which was further followed by an e-mail with this informed consent form attached. It is important to note that permission was obtained from the CDE, in Parktown, to conduct this research.
- You have also complied with the following inclusion criteria: you are willing to participate in an online video conferencing semi-structured interview with us in English or Afrikaans, you are between the ages of 12 and 17 years old, you were diagnosed with type 1 diabetes more than 1 year ago and you are a patient at the CDE (Parktown), have been using CGM for more than 3 months, and have access to internet connection and video conferencing technology.
- You will unfortunately not be able to take part in this research if you are currently undergoing psychotherapy or if you suffer from another chronic illness.

### **What will your responsibilities be?**

- You will be expected to participate in a semi-structured interview via video conferencing technology (accompanied by your parent/legal

## ILLNESS PERCEPTION OF ADOLESCENTS WITH TYPE 1 DIABETES

guardian should you prefer), with a duration of approximately 30 to 40 minutes to complete.

- This research will take place in a suitable venue based on your preference as the interview will be conducted through video conferencing technology. Approximately 1 GB of internet data will suffice the 30 to 40-minute interview.
- It is important to remember that the participation is completely voluntary and you are free to not participate or to withdraw at any point within the study without any consequences.

### **Will you benefit from taking part in this research?**

- The direct benefits for you as a participant will probably be the following:
  - As a direct benefit for you, a workshop on the influence of illness perception on diabetes management will be arranged for you and your families. This will be arranged for a suitable time for you and will include practical guidelines to improve your diabetes management and general well-being.
  - A possible indirect benefit could be that you might find your reflections based on the interview to be beneficial which may broaden your own perception and knowledge regarding your diagnosis.
  - You will also receive the results of this study, which may enhance your knowledge and understanding regarding the diagnosis, as well as inform your management behaviours in the future.
- The indirect benefits will probably be:
  - Due to this study's qualitative nature, the data may be used to broaden knowledge and understanding for you and society based on adolescents living with diabetes' illness perceptions while using CGM, as knowledge is currently limited.
  - The aforementioned may guide and inform future studies on this topic, which may assist in developing intervention programmes or models for adolescents living with type 1 diabetes.

## ILLNESS PERCEPTION OF ADOLESCENTS WITH TYPE 1 DIABETES

### **Are there risks involved in your taking part in this research and how will these be managed?**

- The risks in this study, and how these will be managed, are summarised in the table below:

<b>Probable/possible risks/discomforts</b>	<b>Strategies to minimise risk/discomfort</b>
As this study will include adolescents, it falls within the category of greater than minimal risk with a direct benefit to the participants.	<p>The best interest principle, as set out by the Children's Act will be adhered to and regarded as utmost important. You will be informed that participation will be entirely voluntary in that you will not be forced or coerced into participating by the medical specialist or research team. With the aforementioned in mind, if you are truly interested in participating freely, then you will be included. You will also be clearly informed of the fact that you are free to decline or withdraw from the study at any time with no consequences. It will also be made clear that your participation in this study will not be linked to the treatment or care which you receive at the CDE.</p> <p>Independent written informed parental permission and adolescent consent will be attained prior to conducting the semi-structured interview to establish your willingness to participate. These consent forms will be sent to you well in advance, 2 or more weeks, in</p>

## ILLNESS PERCEPTION OF ADOLESCENTS WITH TYPE 1 DIABETES

	<p>order to provide enough time for you to make an informed decision regarding participating in this study</p> <p>Due to adolescents being seen as a vulnerable population, a need might arise for the use of counselling or psychological services as a result of possible discomfort which might be experienced when participating in the semi-structured interviews.</p>
Due to your diagnosis of type 1 diabetes, you are at an increased risk of being infected with COVID-19.	<p>Lockdown procedures were implemented in an attempt to limit the spread of the disease. The best interest principle will be upheld for you by conducting the semi-structured interviews with the use of video conferencing technology amidst the COVID-19 crisis. The aforementioned will assist in limiting in-person contact, which might pose a risk of contamination to a group of participants who are already deemed to be vulnerable due to their diagnosis, inherently promoting your safety.</p>
Due to you spending about 30 to 40 minutes participating in a semi-structured interview, you may possibly become fatigued.	<p>The researcher who will be facilitating the semi-structured interview may give the participants an optional 5 to 10-minute break about halfway through the interview.</p>
Due to the semi-structured interviews asking questions regarding your biographical	<p>Biographical information based on your age, gender, ethnicity, and time since diagnosis will be used to</p>

## ILLNESS PERCEPTION OF ADOLESCENTS WITH TYPE 1 DIABETES

information and illness perceptions, this may result in you thinking about how you perceive your diagnosis, which may make you feel uncomfortable.	provide a good sample description to accurately reflect the diverse population of adolescents living with diabetes. There will be a psychological debriefing session available by Rosemary Flynn via online video conferencing technology.
The Continuous glucose monitor (CGM) will not be used as a form of intervention for this study. Adolescents will reflect on their illness perceptions while using CGM.	The researcher will not be involved in implementing the intervention herself. The medical practitioner will do the minor medical procedure and the researcher will merely obtain data via the semi-structured interviews as you would have been using CGM for more than 3 months.
Due to having the diagnosis of diabetes, the possibility exists for experiencing unexpectedly low and high blood glucose while you participate in the semi-structured interview, even though this study does not expect to harm or impact your health.	It is important to inform you that you should let the researcher know when you are feeling ill at any time while participating in the semi-structured interview so that you can test and correct your blood glucose levels, or you can ask your caregiver for assistance.
This proposed research study will look at your illness perception while using CGM, which entails your HbA1C levels. The researcher will not necessarily be talking about the particular result, however, you may feel concerned about being judged on how well or not well you are managing your diabetes.	The researchers will respect your human rights, such as the right to have your human dignity respected, which entails that you will be treated with respect. This entails that you will not be discriminated against on the basis of how well or how poorly you manage your diabetes. You will also be informed throughout the process

# ILLNESS PERCEPTION OF ADOLESCENTS WITH TYPE 1 DIABETES

	that you are able to see a psychologist when you feel uncomfortable at any point in time.
You might be concerned that others may become cognisant of your diagnosis and will treat you differently.	Due to semi-structured interviews being conducted via an online video conferencing technological platform, you may feel more at ease and comfortable as you may be familiar with the technology due to you communicating with Prof. Segal in this manner. He/she may also feel more comfortable knowing that only the researcher is present during the interview, maintaining confidentiality and privacy.
As the semi-structured interview will be administered via an online video conferencing technological platform, you might encounter internet data costs.	Due to using online video conferencing technology for approximately 30 to 40 minutes, you might need to use your own data to participate in the study as it is estimated that the interview will use roughly 1GB of data. It is welcome for you to use your own data if you have uncapped internet access and feel comfortable with using your own data to participate in this study. If you do or don't have uncapped internet access and don't feel comfortable using it without being reimbursed for it, then your internet data costs will be reimbursed.

## ILLNESS PERCEPTION OF ADOLESCENTS WITH TYPE 1 DIABETES

In order to take part in this proposed study, it might interfere with other activities.	As this study will make use of online video conferencing technology, a suitable time will be arranged for you to participate in the semi-structured interview as to not interfere with your activities.
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- The aforementioned is indicative that the benefits (as noted) outweigh the risks.
- Should it become apparent that you are being harmed in some way by someone, or that there is an intent to inflict harm, or that you intend to inflict harm to others, will it then require that the researcher should break confidentiality to inform someone to assist you, or another individual.

### **Who will have access to the data?**

- Anonymity (entailing the way your results will be connected to your personal particulars) of your findings, will be protected by storing all electronic data securely and confidentially on a password-protected computer, with access limited to the researcher and the research supervisors.
- All recordings will be deleted from the computer after transcribing the data (verbatim). Your personal particulars will be protected by assigning a pseudo name which will be kept separate from the written informed consent forms.
- All hard copy documents will be securely stored in a locked cabinet, in a locked room on the NWU Potchefstroom premises. Only the researchers will be able to look at your findings.
- Transcribed and hardcopy data will be stored for 10 years, after which it will be destroyed by shredding it and deleting it from the computers.
- In order to be anonymous, none of your personal particulars will be made available when reporting the findings of this study.

## ILLNESS PERCEPTION OF ADOLESCENTS WITH TYPE 1 DIABETES

### **What will happen to the data?**

- The findings of this study may be used in future studies.
- The data from this study will be reported in the following ways: it will be written up in articles and research reports. It is important to remember that no personal particulars will be made available when reporting the results which maintains the confidentiality and privacy of participants.

### **Will you be compensated for taking part in this study and are there any costs involved?**

- You will not be paid for taking part in the study.
- The researchers aim at conducting the semi-structured interview via an online video conferencing technology platform to ensure your best interest amidst the COVID-19 crisis. The online video conferencing technology platform will ensure that you remain safe as no face to face interactions will take place, which might spread the disease. Your internet data costs will be reimbursed, resulting in no additional costs involved for you to participate in this study.

### **How will you know about the findings?**

- The researcher will provide you with the results of this research study, via e-mail, upon completion thereof.
- Any new relevant findings will also be communicated to you via e-mail.
- Posters will be displayed at the CDE Parktown, which will contain the main findings of this study.

### **Is there anything else you should know or do?**

- You can contact Prof Elmari Deacon at [elmari.deacon@nwu.ac.za](mailto:elmari.deacon@nwu.ac.za) or (018 299 1728) if you have any further questions or encounter any problems.
- You can also contact the Health Research Ethics Committee via Mrs Carolien van Zyl at 018 299 1206 or [carolien.vanzyl@nwu.ac.za](mailto:carolien.vanzyl@nwu.ac.za) if you have any concerns that were not answered about the research or if you



## ILLNESS PERCEPTION OF ADOLESCENTS WITH TYPE 1 DIABETES

have complaints about the research. You will receive a copy of this information and consent form for your own records.

### Declaration by participant

By signing below, I ....., agree to take part in a research study titled: **Exploring illness perceptions of a group of adolescents living with diabetes while using continuous glucose monitoring (CGM),**

I declare that:

- I have read and understood this information and consent form and it is written in a language in which I am fluent and with which I feel comfortable.
- I have been afforded the opportunity of posing questions to both the person obtaining consent, as well as the researcher (if this is a different person), and all my questions have been adequately answered.
- I understand that taking part in this study is **voluntary** and I was not pressurised to take part.
- I understand that my contribution (what we report/ say/ write/ draw/ produce visually) could be reproduced publically and/or quoted, but without reference to our personal identity.
- I may choose to leave the study at any time and will not be penalised or prejudiced in any way.
- I may be asked to leave the research before it has been completed if the researcher feels it is in my best interests, or if we do not follow the research plan, as agreed on.

Signed at (*place*) ..... on (*date*) .....  
20....

.....  
**Signature of participant**

.....  
**Signature of witness**

## ILLNESS PERCEPTION OF ADOLESCENTS WITH TYPE 1 DIABETES

- You may contact me again ☐ Yes ☐ No
- I would like a summary of the findings of this research ☐ Yes ☐ No

The best way to reach me is:

Name & Surname: \_\_\_\_\_

Postal Address: \_\_\_\_\_

Email: \_\_\_\_\_

Phone Number: \_\_\_\_\_

Cell Phone Number: \_\_\_\_\_

In case the above details change, please contact the following person who knows me well and who does not live with me and who will help you to contact me:

Name & Surname: \_\_\_\_\_

Phone/ Cell Phone Number /E-mail: \_\_\_\_\_

### Declaration by person obtaining consent

I (*name*) ..... declare that:

- I explained the information in this document to  
.....
- I encouraged him/her to ask questions and spent adequate time answering them.
- I am satisfied that he/she adequately understands all aspects of the research, as discussed above
- I did not use an interpreter.

ILLNESS PERCEPTION OF ADOLESCENTS WITH TYPE 1 DIABETES

Signed at (*place*) ..... on (*date*) .....

20....

.....  
**Signature of person obtaining consent**

.....  
**Signature of witness**

**Declaration by researcher**

I (*name*) ..... declare that:

- I explained the information in this document to .....
- I encouraged him/her to ask questions and took adequate time to answer them.
- I am satisfied that he/she adequately understand all aspects of the research, as discussed above
- I did not use an interpreter.

Signed at (*place*) ..... on (*date*) .....

20....

.....  
**Signature of researcher**

.....  
**Signature of witness**

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25 April 2018

File reference: 9.1.5.6

## ILLNESS PERCEPTION OF ADOLESCENTS WITH TYPE 1 DIABETES

### **ADDENDUM D: Interview schedule**

**Exploring illness perceptions of a group of adolescents living with diabetes while using continuous glucose monitoring (CGM).**

#### **Examples of Interview Questions: English and Afrikaans**

Biographical information will be obtained to gain accurate information on age, gender, ethnicity, and time since the diagnoses. Information based on gender and ethnicity will be obtained to provide a good sample description to accurately reflect the diverse population of adolescents living with type 1 diabetes. The aforementioned may contribute to this study's findings, as males living with diabetes tend to have a better quality of life, as they live with their diagnosis more effectively than their female counterparts (Siddiqui, Khan, Carline, 2013). Males were found to experience anxiety and depressive symptoms to a lesser extent than females, and furthermore have more energy as well as a more positive optimistic attitude towards the management of diabetes (Siddiqui, Khan, Carline, 2013).

The following questions are included:

1. Tell me more about yourself? (Vertel my meer oor jouself?)

Possible prompt questions include:

- How old are you (Hoe oud is jy?)
- When did you receive the diagnosis of type 1 diabetes? (Wanneer het jy die diagnose van tipe 1-diabetes ontvang?)
- How long have you been using CGM? (Hoe lank gebruik jy CGM?)
- How do you currently manage your diabetes? (Hoe bestuur jy tans jou diabetes?)

2. Tell me about your experience of living with diabetes? (Vertel my van jou

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ervaring in die lewe met diabetes?)

Possible prompt questions include:

- Please elaborate on your experience of type 1 diabetes? (Brei asseblief uit oor u ervaring van tipe 1-diabetes.)
- Which aspects of your life are affected by type 1 diabetes? (Watter aspekte van jou lewe word deur tipe 1-diabetes beïnvloed?)

3. Tell me about your experience of living with diabetes while using CGM? (Vertel my van jou ervaring in die lewe met diabetes terwyl jy CGM gebruik?)

Possible prompt questions include:

- What makes the use of CGM easier and/or more difficult? (Wat maak die gebruik van CGM makliker en/of moeiliker?)
- What are the advantages and disadvantages of using CGM? (Wat is die voor- en nadele van die gebruik van CGM?)
- How did using GGM change how you view living with diabetes? (Hoe het die gebruik van CGM jou sienning verander in die lewe met diabetes?)

### Reference:

Siddiqui, M. A., Khan, M. F., & Carline, T. E. (2013). Gender differences in living with diabetes mellitus. *Materia Socio Medica*, 140-142.

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## ADDENDUM E: Thematic analysis summary table

Theme:	Description:	Example from the data:
Theme 1: <b>CGM creates a sense of control over diabetes management</b>	All participants noted that using CGM creates a sense of control due to being able to see their blood glucose levels 24/7. This enhances predictability which allows for more convenient and efficient diabetes management and intervention which decreases the likelihood of possible medical emergencies.	<p><b>Harry:</b> “It [CGM] helps a lot to monitor my sugar and my fingers aren’t full of holes from all the testing. It also helps that my sugar doesn’t go up and low. It [CGM] just makes it a lot easier.”</p> <p><b>Ava:</b> “I feel like its [CGM] helped and made it easier because you have more control and you know where you’re going. It can tell you, you’re stable or you’re going up slowly so you know [...] I feel like it kind of just helps make your life a lot easier.”</p> <p><b>Amelia:</b> “And so eventually we did come and started using the CGM. Which has been a great benefit to my life. It makes managing my condition so much easier.”</p> <p><b>Hanna:</b> “But I think the only thing that’s different now is that you can see it all the time so you can control it better.”</p> <p><b>Darla:</b> “And since I’ve been using the CGM, it’s life-changing and my levels are, or they were always controlled, but it’s even more controlled now than what it was.”</p> <p><b>Ian:</b> “It [CGM] made it easier [...] more breathing space” and “It becomes predictable, it makes a pattern.”</p> <p><b>Ryan:</b> “It feels safer, it’s something I can control”</p>
Theme 2: <b>CGM assists in creating a new normal</b>	The sense of control achieved in theme 1, creates a new normal as participants incorporate using CGM as part of their everyday routine and identity as it cannot be separated.	<p><b>Harry:</b> “It [CGM] helped quite a lot, because then I don’t have to worry every now and again about what my sugar is. And then I can do more things and so.”</p> <p><b>Ava:</b> “So I try to say to myself that even though I hate it, there are people</p>

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		<p>in a worse position than I am. So I kind of just need to get over myself and live life.”</p> <p><b>Amelia:</b> “I’m back to normal again.”</p> <p><b>Hanna:</b> “Uhm... It [CGM] made it seem a lot less like a disability. It made it, it didn't make it seem, it just made it seem like how some people have to take tablets every day, you can just punch a number every like 2 hours or so. So it definitely made it seem more... I can't think of the word. Uhm... it just makes you feel that you can live close to a normal life.”</p> <p><b>Darla:</b> “It’s [using CGM] kind of become like my everyday life, so it’s like routine to me and it’s like something normal, it’s like brushing your teeth to me. It feels normal”</p> <p><b>Ian:</b> “[...] make it look natural”</p> <p><b>Ryan:</b> “It’s [using CGM] part of my daily routine [...] I structure my life around it.”</p>
<p>Theme 3: <b>Being different creates an opportunity for positive outcomes</b></p>	<p>Participants experience untoward remarks and bullying which blatantly points out their differences. They, however, chose to took it in their stride by finding the silver lining in their situation, entailing becoming empowered through using CGM as an educational medium which enhances their sense of belonging.</p>	<p><b>Harry:</b> “I just carry on. I don’t really care about what they say because they don’t really know what the situation is. So I just carry on and ignore them and so. But most of the time I tell them what it [CGM] is and what it does and what it is used for and so.”</p> <p><b>Ava:</b> “And like I hate doing it [using and scanning CGM] in public because in my primary school I was bullied a lot for it. So I just like hate doing it in front of people. So when I went to high school I’ve told very few people.”</p> <p><b>Amelia:</b> “I follow a lot of diabetes pages on Instagram [...] ‘Cause you’ve got a community of people who understand what you are going through as a person. And it’s great to hear about other people’s experiences as well.”</p>

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		<p><b>Hanna:</b> “I think it’s still a little bit self-conscious about it [CGM and pump] but not to that extent as it was.” and “Uhm... I think it [CGM as educational medium] helped [...] with self-confidence”</p> <p><b>Darla:</b> “Uhm... But there’s a person, uh, there are people who ask what it [CGM] is. And I am really happy to share it.”</p> <p><b>Ian:</b> “questions are not annoying [...] I show them how it works”</p> <p><b>Ryan:</b> “when someone asks I usually start off with a joke [...] enjoy sharing.” and “I’m not shy when people see it, it is part of me.”</p>
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## ADDENDUM F: Turnitin report

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