Children’s Participation in decision-making at Rahima Moosa Mother and Child Hospital.

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Declaration

I, Nonqaba Cecilia Makiwane, declare that this dissertation is my own, unaided work. It is being submitted for M.Med at the University of Witwatersrand, Johannesburg. It has not been submitted before for any degree or examination at any other University.

(Signature of candidate)

28th day of November in 2016

Dedication

This works is dedicated to my late parents Ndzondelelo & Xoliswa Makiwane, and my daughter Mandilakhe Mangaliso Mbanga.

ABSTRACT

Children’s right to participate in decisions affecting them is still a challenge despite the laws and guidelines. In South Africa, this right has not received the attention it deserves, because of government’s commitment to issues like HIV/AIDS.

The aim of the research was to understand the views of children, parents and health professionals with regards to decision- making at Rahima Moosa Mother and Child Hospital.

A total of 51 health professionals, 28 children and 28 parents were interviewed using questionnaires. The study looked at participants’ knowledge of the right of children to participate in decisions and the way health professionals communicated with children and parents.

Findings: There was good knowledge amongst health professionals, but most children (75%) did not know their right. Most children were not consulted about diagnosis (60%), procedures and treatment (71%). Health professionals lacked age appropriate ways of communicating with children. On the whole, children (71.4%) preferred doctors to speak to parents.

Conclusion: There is a need to educate children about their rights and to train health professionals on effective communication with children. Health professionals need to give children a chance to express their opinion even if they do not make the final decision.

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List of Abbreviations

ACRWC- African Charter on the Rights and Welfare of the Child

ADHD- Attention Deficit and Hypersensitivity Disorder

AIDS- Acquired immunodeficiency syndrome

BMA – British Medical Association

CEO – Chief Executive Officer

CRC- Convention on the Rights of the Child

FPL- Food poverty line

HIV- Human Immunodeficiency Virus

IQ – Intelligence quotient

LBPL- Lower- bound poverty line

MacCAT-CR – MacArthur Competence Assessment Tool for Clinical Research

RMMCH – Rahima Moosa Mother and Child Hospital

Stats SA- Statistics South Africa

UBPL- Upper-bound poverty line

UK – United Kingdom

UNCRC - United Nations Convention on the Rights of the Child

1. Introduction

According to the Charter of the United Nations [1], recognition of basic human rights is the foundation of freedom, justice and peace in the world. Historically, children had no rights. This has changed over the years, and now children's rights are defined in international human rights laws such as the International Convention on Economic, Social and Cultural rights [2]; the United Nations Convention on the Rights of the Child (UNCRC) [3] and the African Charter on the Rights and Welfare of the Child [4]. These statutes recognize the right to the enjoyment of the highest attainable standard of physical and mental health. They also recognize that the best interest of the child should be a primary consideration; and that children must be allowed to express their views. 'Children are neither property of their parents, nor are they helpless objects of charity.' They are human beings and are subject to their own rights' [5]. The extent to which these laws are able to improve the lives of children depends on the implementation by the countries that adopt them.

South Africa is well known for its history on human rights. The United Nations Convention on the Rights of the Child was ratified in 1995. This means that national government has committed itself to protecting and ensuring children's rights and has agreed to be held accountable before the international community. Children's Rights are also enshrined in Section 28 of the Bill of Rights of the Constitution of South Africa (1996)[6].The Bill is based on the understanding that the child's best interests are of paramount importance in every matter concerning them. The South African Constitution [6] describes a child as someone under the age of 18 years. The Children's Act 38 of 2005[7] is another important legal instrument that requires children to participate in decisions about healthcare procedures and giving them power to consent, depending on age.

Currently, there is a huge gap between these laws and the reality. This is more evident in certain parts of Africa where there is constant conflict and the rights of children are undermined every day. Some children are forced to become child soldiers which goes against the African Charter on the Rights and Welfare of the Child [4]. Article 22 states that children should not be recruited as soldiers, nor should they take a direct part in fighting wars. Health facilities in developing countries are below standard despite the laws mentioned above. In the sub – Saharan region, where HIV infection and under five mortality rates are high, the realization of some of the children's rights has fallen behind; because of poverty, political and financial issues.

Hospitalized children are extremely vulnerable; they are children first and foremost, they are ill and most of the time are not involved in decisions about their health. Medical advances have improved people's lives through new technology, but the implementation of rights in hospital has not been considered. The general practice is to treat the condition that the child presents with and not the child as a whole. The Alma Alta Declaration on Primary Health Care defines health as 'a state of complete physical, mental and social well-being, and not merely the absence of disease.'[8] Current treatments do not always take into account the psychological, cultural and spiritual aspects of the patient. Parental and children's fears and anxiety are neglected. This is most evident in decision-making, where children are not afforded the opportunity to have a say about their health. Article 12 of the United Nations Convention on the Rights of the Child [3] states that, *'States Parties shall assure to the child who is capable of forming his or her own views the right to express these views freely in all matters affecting the child, the views of the child being given due weight in accordance with the age and maturity of the child. For this purpose the child shall in particular be provided the opportunity to be heard in any judicial and administrative proceedings affecting the child, either directly, or through a representative or appropriate body, in a manner consistent with the procedural rules of national law.'*

The issue of children's participation and listening to children has been discussed in various platforms. Research has been conducted around the topic but there is still paucity of information around children's views and participation in decision making in hospitals. There are several reasons for this: the view that children are young and will not understand the doctors, and the fact that 'the doctor knows best'. In certain African cultures, children are not allowed to voice their opinions. It is seen as being rude when a child talks back to an adult. Several studies have shown benefits in engaging children in all spheres of life; children now have representatives in parliament. Most of the research has been in developed countries. Ireland has done a lot of work and has come up with a

National strategy [9] that identifies children's needs and helps to find ways to meet those needs. Their vision is 'An Ireland where children are respected as young citizens with a valued contribution to make and a voice of their own; where all children are cherished and supported by family and the wider society.'[9] Their goal is the same as the UNCRC [3] where children have a voice in matters that affect them and their views are given due weight according to their age and maturity. This goal has been achieved through the commitment of government at national level, and having a children's Ombudsman to raise public awareness. In the United Kingdom, the focus has been on designing hospital services for children from the child's point of view.

In South Africa, the Children's Institute in Cape Town has done research in child policy and advocacy in South Africa. The Institution provides evidence to policy makers to assist them to create policies and programs that support the best interests of the country's children. There is limited research in developing countries around the topic of children's participation in healthcare. This research aims to look at the views of health professionals, parents and children, when it comes to children's participation in decision- making in hospital, in a South African setting.

Literature Review

1. Children's rights in general

The history of children's rights dates as far back as the 19th century where children were recognized as vulnerable individuals who needed protection. Prior to this, children were considered small adults. In 1924 the Geneva Declaration was adopted [10].This was the first international treaty on children's rights. After the Second World War, several declarations and treaties were adopted with the formation of the United Nations. In 1989 the United Nations Convention on the Rights of the Child [3] was adopted by the United Nations General Assembly.

South Africa ratified the United Nations Convention on the Rights in 1995. The obligation of the state to protect and respect the rights of children is also governed by The African Charter on the Rights and Welfare of the Child (1999) [4], The Constitution of the Republic of South Africa (Republic of South Africa 1996) [6]. The Children's Act No. 38 of 2005 [7], (as amended) provides the legislative framework for a holistic child protection strategy which includes the consideration of children's views in matters affecting them. Human rights are similar for children and adults, except that children cannot vote. The Constitution of the Republic of South Africa 1996 [6] makes special reference to children, in Section 28 of the Bill of Rights. The Bill outlines children's rights to family or alternative care, basic health care services, protection from abuse and neglect, and the right to have their best interests considered of paramount importance in every matter that affects the child. It is important for children to realize that having rights comes with responsibility, and giving them rights does not take away their childhood. Although children's rights are a legal obligation, they are not always a reality in children's lives [11].

South Africa is still battling with issues of poverty, inequality, unemployment and hunger [12]. Poverty is described as a state of being poor, other terms include hardship, destitute, inadequacy or a state of being inferior in quality [13]. All these terms describe what is happening to the majority of South African people. Unfortunately, children are the ones who suffer the most. According to Stats SA [12], in 2011 more than half (54%) of black Africans lived in poverty. Although there has been a decline in poverty between

2006- 2011, children (55.7%) displayed the highest levels. The drop in poverty in the country according to the report, translates to roughly 10.2 million South Africans living in extreme poverty (below the food line) in 2011, compared to 12.6 million in 2006; and 23 million living in moderate poverty (below the upper line), compared to 27.1 million in 2006.[12] In 2012, South Africa published a set of three national poverty lines: the food poverty line (FPL), lower-bound poverty line (LBPL) and upper-bound poverty line (UBPL) – to be used for poverty measurement in the country. The FPL is the level of consumption below which individuals are unable to purchase sufficient food to provide them with an adequate diet. Those below this line are either consuming insufficient calories for their nourishment, or must change their consumption patterns from those preferred by low income households. The LBPL includes nonfood items, but requires that individuals sacrifice food in order to obtain these, while individuals at the UBPL can purchase both adequate food and non-food items [12]. Poverty denies children their rights and there is a direct correlation between poverty and illnesses (especially infectious diseases and malnutrition). For those children living in poverty, every day is a struggle and dependency becomes a luxury, and as such they learn to make adult decisions at an early age. Some children are forced to leave school early to find jobs in order to help struggling parents. In the African culture it is common practice for children to take care of younger siblings. This practice may be viewed as preparing them for motherhood and or adulthood.

Children's rights in general have not been fully realized as stipulated by the United Nations Convention on the Rights of the Child [3]. Some of the proposed reasons are lack of financial resources and political will. Children are not allowed to vote, therefore they do not have a voice, and hence some of the issues affecting them are not always considered urgently. The high HIV / AIDS rates in the sub-Saharan has shifted the focus away from these rights, because available resources are used to try and treat infected individuals. According to the Centre for Economic Governance and AIDS in Africa [14] for the 2013/14 - 2015/16 medium term, the consolidated health budget receives as a share of total consolidated government budget an annual average of 11.3%, which is below the Abuja Declaration recommendation that governments should spent 15% of their annual national budgets on health.[14] The Centre reports that the consolidated national and provincial health HIV and AIDS allocations grew from 7.9% in 2012/13 to

8.8% in 2013/14, and 10% in 2015/16, despite the slow growth of the overall health share in the total national expenditure [14]. Corruption within the government structures and lack of accountability are some of the day to day issues facing South Africa.

It is therefore not surprising to see that children's right to participate in areas that affect them has not been considered. Children and parents in our hospitals are too often passive, and at times do not understand the meaning of these rights. Article 12 of the UNCRC [3] says, ' States Parties shall assure to the child who is capable of forming his or her own views the right to express those views freely in all matters affecting the child, the views of the child being given due weight in accordance with the age and maturity of the child.' This is supported by Article 7 of the African Charter on the Rights and Welfare of a Child [4]: 'Every child who is capable of communicating his or her own views should be allowed to express his or her opinions freely.' These laws do not give children the right to control all decisions irrespective of their implications either for themselves or others. They say children should be listened to and be heard.

Children have been vocal in politics for a long time, and their voices have changed and shaped some of the world's best constitutions. Examples date as far back as the 11th century. The Children's Crusade, a peaceful movement of the poor, mainly farm workers and shepherds, began in the spring of 1212 near Cologne, and was initiated by a 12-year-old boy [15]. In South Africa, June 16 1976 is a well-known example, where students took to the streets to protest against language policy in schools. It was during this 'peaceful' protest that Hector Peterson, who was 12 years old at the time, died from a gun shot fired directly at him by the police. His name has subsequently been used synonymously with June 16. A memorial was erected in 1990 in Orlando, Soweto; followed by a Hector Pieterson Museum in 2002 [16]. Several other children were killed and wounded, the first victim being Hastings Ndlovu [16]. These examples demonstrate that children are more than capable of expressing their views and to implement change on matters affecting them.

The government needs to start taking children and their needs seriously, because they are our future leaders. The former United Nations Secretary General, Mr. Kofi Annan, argued 'there is no trust more sacred than the one the world holds with children. There is no duty more important than ensuring that their rights are respected, that their welfare is protected, that their lives are free from fear and want and that they can grow up in peace.’[17] ‘In so doing, governments have an obligation to protect and promote the survival, development and well-being of children, which ultimately affects their quality of life.’[18] Research regarding children is very important in order to understand their needs. If children’s participation is to be a meaningful process, it is important that their engagement is directly linked to their own first-hand experience [19].

2. Hospitalization of children

Hospitalization of a child has negative effects for both the child and the family respectively [20]. Research around the topic dates back as far as the 1950’s, when it was thought that being in hospital was a positive experience [21]. It is now known that this is not the case. There have been positive changes in hospital environment with new technology, however in poor countries the standards are still low. Children constitute a large proportion of hospital visits and yet healthcare services are designed without consulting them; as a result some services are not well suited for a child’s development. Countries like the United Kingdom (UK) and Ireland have now adopted new strategies, whereby children are consulted in the design of hospitals. In Johannesburg, South Africa, a new hospital called The Nelson Mandela Children’s Hospital is being built. The hospital trust launched a campaign aimed at raising awareness about the Nelson Mandela Children’ Hospital (NMCH)) project among children and encouraging them to participate in raising funds.

In the past, hospitals did not have dedicated space for children, and parents were not allowed to stay with them. Research now shows that it is crucial for parents to be with their child/ren in hospital. In a study done by Ekra et al (2012), which looked at adult’s views of their hospitalization as children from 1950-1980, only two of the twelve participants were admitted in paediatric wards. As children at the time, participants had no say and their parents were not allowed to stay with them. All the above made their hospital stay difficult. They were faced with fears of the illness (of which they were ignorant), and not knowing what will happen to them. [22] Fear of medical care amongst children is a well described phenomenon. It has been reported that hospitalized children experience fear and anxiety, especially separation anxiety from parents [20, 23]. ‘Children view medical care as a monster that is threatening to destroy the child' [24]. Children's fears include; fear of being hurt, being treated unfairly, being overpowered, a sense of alienation, and disruption of their usual routine [25]. These fears can intensify when the child is treated as an object with no feelings, rather than a person. Wilson et al (2010) reported that besides the common fear of needles, the fear of the unknown was also prevalent. [24] Other authors reported that children with repeated hospitalization suffer from psychological disorders, like anxiety, depression, and separation anxiety disorder. Some of the effects may be short lived with no long term complications. Excluding children from participating in decision-making increases fear, especially in difficult situations [26].

Wright [27] reported that age (the younger the child, the more likely they are to suffer from adverse effects) and duration of hospital stay affected children negatively. However, Wilson et al (2010) found that the experiences of new admissions and previously admitted children were similar. Most children reported feelings of sadness, loneliness, and missing companionship. However, some reported that the hospital was fun at times. The only difference was that children with previous admission used more medical terms and seemed to know the 'drill'. [24]

In 2010, Livesley and Long [25] reported that hospital staff and hospitalized children worked towards different goals and experienced different realities. Children wanted to be children whereas staff focused on the work being done. In response to this, some children disrupted the nurse's routine to resist being dehumanized. They also reported that children coped differently with the fears and stress they encounter during hospitalization and nurses should realize and support them. Children with repeated admissions have hospital experience and will tell if things do not go the way they should. 'Children with more experience of admissions to hospital develop a good understanding of the importance of being admitted to the right ward and having confidence in the skills of the ward staff.'[25]

A well-researched mechanism of coping with hospitalization is information-seeking behavior, which applies to children and their parents. Children use their parents to seek information or to clarify what they do not understand. Parents rely on health professionals or the primary care giver for information, whilst others will consult relatives and the internet [28]. The internet poses a challenge for health professionals, especially when there is conflict of ideas. Some parents do not want their children to know what is wrong with them. The type of information parents and children would like to receive varies greatly. Basiri- Moghaddam et al (2011) reported that knowledge of the disease can elicit anxiety especially those who were previously hospitalized. [29]

The perception of children and parents towards health professionals is very important in decision-making. The relationship with the doctor, the nurse and the whole treatment staff has an effect on experiences of children [29]. The parents also face challenges and anxieties which can be alleviated by communication and understanding staff [21]. Parents are sometimes uncertain of the child's feelings and what goes on in the child's head. This point once again highlights the importance of engaging with children.

3. Children's views and culture

Culture is defined as behaviors or beliefs characteristic of a particular social, ethnic or age group [13]. It is a way of passing information from one generation to the next through language, rituals, superstitions and art depending on the group. Most of the time the practices are one sided, with elders (who are men) dictating to women and children.

In Africa, there has been a call for a regime of children's rights not only founded upon the Convention on the Rights of the Child (CRC), but also informed by African cultural heritage [30, 31, and 32].The dilemma is merging the CRC with cultural beliefs whilst protecting children. The UNCRC [3] goes beyond what many families in most cultures would allow of their children [30]. According to the 1993 Vienna Declaration [33], all human rights are "indivisible, and interdependent and interrelated" (Article 5).The 1948 Universal Declaration of Human Rights recognizes cultural rights in Articles 22 and 27, focuses on the right of the individual to participate in the cultural life. Unfortunately cultural rights cannot be used as a collective because they change with time and they differ from population to population.

Africans are people who believe in humanity, respect and dignity; which goes hand in hand with the Convention on the Rights of the Child. The concept of Ubuntu (meaning human-ness) is synonymous with African countries. Whilst the African cultural belief systems protects children, certain practices are detrimental to their health. It is well known that some cultural practices violate children's rights (for example female circumcision). The practice carries high morbidity and mortality but it is still practiced in certain parts of Africa.

Male circumcision is practiced in most parts of South Africa, especially the Eastern Cape. The ritual is considered 'a passage of initiates into manhood or adulthood.' It comes with privileges and respect from the community [34]. For instance circumcised men cannot eat in the same place as uncircumcised peers. In the past 20 years there has been a rise in the number of deaths and complications associated with the practice. According to Kepe [34], from 1995 to 2005 in the Eastern Cape alone, 5 813 hospital admissions, 281 penile amputations and 342 deaths were reported. Other problems encountered by initiates include transfer of blood borne infections like HIV and hepatitis B and C (from unsterile equipment). The causes of morbidity and mortality range from dehydration, sepsis, physical abuse, psychological problems, and suicide. In 2000, after consultation with stakeholders, the government passed the circumcision Act (No 6 of 2001) which looks at the age of initiates, the people performing the surgery and basic hygiene [34]. One of the requirements is that initiates must be examined by a medical practitioner some of which are females. This is not popular with traditional leaders because they feel that women have no place in the ritual and females are considered 'unclean' [34]. There have been arguments between the government and traditional leaders who feel that the government cannot dictate to them, as they are the custodians of the ritual [34]. The government's response is aimed at reducing morbidity and mortality associated with the practice and to protect the initiates. Unfortunately, in the middle of the arguments, are the initiates, some of whom have lost their lives and families who have lost their sons and potential bread winners. Their views are not sought, in fact most of them are afraid of expressing an opinion, because of the secrecy around the ritual and fear of physical abuse. Culture is very important in Africans, this example once again highlights the difficulty that exists when trying to perform cultural rituals and respecting human rights (both adult and children).

The issue of children's participation is still not well practiced despite the laws and guidelines that are available. Twum-Danso [31] argues that the ratification of some of statutes was done without consulting the relevant stakeholders, which is why implementation is a challenge. ‘Children are still seen as objects that have things done to them without considering their views, which is a violation of their right.’ Unfortunately most of the practices are performed in secrecy and it is difficult to assess the extent of the problem. In South Africa the use of traditional healers is still very common. Friend-du Preez et al (2009) reported that in the early 1900s, it was estimated that over 200 000 traditional healers (Inyanga) and diviners (Isangoma) practiced in South Africa. [35] There are conditions called the ‘abantu childhood illnesses’, that parents believe can only be treated by traditional healers.[35] The treatment practices vary from scarification, enemas, prophet ropes and sometimes use of detergents. From this study, not only are the children not given the right to have a say; other rights are also neglected (the right to protection). This is important for health professionals to understand especially when it comes to communicating with parents because health messages may go unheeded.[35] The study also highlighted the importance of understanding parents’ health-seeking behavior in the context of local beliefs, as the success of medical treatment depends on family cooperation [35].

The issue of children being seen and not heard is not only prevalent in African communities, other countries (e.g. Pacific societies) do not put emphasis on civil equality. In South Africa, children’s participation has changed over time, albeit at a slow pace. The history of South African politics is full of examples of children who through voicing their opinions, have made changes in the political landscape. Despite these efforts, children are still not given the platform the express their views.

4. Children in hospital and decisions

It has been assumed that children are not competent to offer a legitimate viewpoint of their stay in hospital [36]. This has been disproven by several studies conducted with children. Van Staa et al (2011), showed that young people with chronic conditions are able and willing to express their views on the quality of healthcare services provided to them. [37]

Hospital is a place where children get medical help for their illnesses or conditions. One would expect children to be at the forefront and be part of decisions that affect their health. The United Nations Convention on the Rights of the Child [3] is based on four principles: non-discrimination, adherence to the best interest of the child, right to life, survival and development; and the right to participate. Article 12 of the African Charter on the Rights and Welfare of the child [4], states that every child who is capable of communicating his or her own views should be allowed to express his or her opinions freely. However in reality, children are not involved and when they are involved their opinions are disregarded. According to research, participation with children enjoys little success [38]. Livesley and Long (2013) showed that although hospitals are a place for children, the ward was a place in which there was little space for children's competence, and their voice was experienced as a challenge. [25]

Children's voices are dampened by society's need to protect them. By protecting children we are in fact silencing them. According to Van Staa et al (2011), this may be our own fears for children that cause us to silence them, so that we (parents and health professionals) do not have to think of any negative outcomes. [37] The issue of best interest of the child and protection; and the right to participate are difficult to balance at the best of times. The best interest is based on doing good for the child, but 'substituting an adult judgment of what is in the child best interest is not necessarily equivalent with the child's best interest [39].' Acting on the child's best interest requires consultation with the child.

Children in health care are not involved in their care, and even when they were asked for their views, decisions are made by others (parents and health professionals) [28]. This was also noted by Coyne [23, 40, 41, and 42] who reported that children's views and preferences were ignored. Children reported that their parents and health professionals took decisions and they had no option but to comply [23, 43]. This was supported by Runeson [26] who reported that children were not always allowed to participate in decision-making to the extent that is considered optimal. Their parents did not always support the children in difficult situations.

The benefits of involving children in their care are quite clear. Participation allows children to feel more in control and can help with their overall adjustment to hospitalization. It also helps health professionals to gain important information [28].

Coyne [43], showed that children who were consulted or involved in the decision-making felt happy and less anxious. They felt that the information received prepared them for what to expect. Those children who were not consulted felt disappointed, angry, betrayed, ignored and rejected [23]. Some authors hold a view that says children still need protection and time in which to develop self- determination. What is not known at the moment is whether participation directly affects outcome of their illnesses. However, some researchers have shown that by consulting children, they are more likely to be compliant with treatment which then improves outcome.

This brings us to the issue of what children want. Children want the hospital to pay more attention to their needs, and improve the age appropriateness of provider's attitudes and services .They want health professionals who are trustworthy and who listen to them. Research has shown that children want to be involved in decision-making, because it is them experiencing the illness. Their involvement in decision- making varies, as shown by Coyne [41, 44]. Some children would like to be involved in all decisions, others prefer minimal involvement (described as minor decisions). These include things like procedures, how to take medication, etc. Others are happy with their parents leading and making all the decisions, especially 'serious' decisions, like operations [38, 44].

The style of communication varies with age, the illness, their competence, upbringing and the type of decision to be made [39, 43].Some adolescents prefer direct communication, rather than through their parents [25].In a study of patients, parents and survivors of cancer, all participants agreed that having an open and honest communication from health professionals, parents and patients was very important [45]. Children spoke of the right to be fully informed about their illness and treatment, but there were differences in the amount and the type of information they wanted to receive.

Health professional's communication styles and behaviors have been noted to be barriers to communication and involving children in decision-making. Their limited knowledge and skills for communicating with children is also a barrier [28]. Other researchers have found that parents can also hinder the process, by imposing their beliefs. Some children felt that their parents inhibited participation by reprimanding them for interrupting discussions and withholding information [43]. Adult attitudes concerning capabilities and competence of children and the need to protect them do not allow children to be actively involved in their care. The child’s illness, personality and upbringing also hinders participation. Children with special needs and those with no parents in hospital are very vulnerable and unlikely to participate. The way health services are structured and how they accommodate children and their families can also hinder participation [28]. Lack of research around the subject and lack of funding are other barriers known to obstruct progress. Alderson (2006), also reported that children’s views are seldom reported in paediatric journals. Instead of taking children’s views as research evidence, they are regarded as anecdotal. [46] This calls for more research into the issue of children’s views and participation.

The issues of age and competence are considered some of the reasons for not involving children in their health care. According to the United Nations Convention on the Rights of the Child [3], the African Charter on the Rights and Welfare of the Child [2], and the South African constitution [6], a child is someone who is under the age of 18 years. This has been contested by some researchers, who feel that transition to adulthood should not be based on the age only. The definition of childhood in the almost universally ratified Convention on the Rights of the Child (CRC) is based on the modern western conception of childhood, which has been heavily criticized [31, 32].

To illustrate the point, Twum–Danso quotes De Waal, who says ‘the idea of a single (gender neutral) age of legal maturity reflects the western juridical tradition and concepts of citizenship built around the universal franchise and eligibility for conscription into the army.’ According to Twum–Danso, researchers like Welshman Ncube feel that ‘the notion of someone by some magical wand on the stroke of a pen turns into a fully competent mature, wise and autonomous individual upon attaining a certain arbitrary fixed age has no scientific empirical basis in fact and reality.’ [31] He further argues that the perception of children as mentally immature individuals has negative implications for the societal roles assigned to them. [31] In African tradition, chronological age in not an indicator of adulthood. The ending of childhood has little to do with achieving a particular age, and more to do with physical capacity to perform acts reserved for adults. Marriage and the establishment of a new homestead are traditionally two prime indications of adult male status. Childhood therefore refers more to a position in the social hierarchy than to biological age [31, 32]. Unlike the Western viewpoint, childhood in the African context is not necessarily a stage of incompetence. What this means is that children should be involved in decision- making at an early stage in order to prepare them for the future [26]. This was illustrated by Alderson [46] in a study that looked at the views of children with type 1 diabetes. The findings were that, children as young as 4 years old began to understand the principles of controlling diabetes. ‘They could make informed and ‘wise decisions’ in their own best interest.’ Children’s competence to consent developed through experience rather than age [46].

The issue of competence, consent and participation is an important point to consider when it comes to decision-making. The dictionary [13] defines participation as the action of taking part in something. Different authors describe participation differently. Roger Hart [15] describes the ladder of participation as consisting of eights stages or steps. The ladder was adapted from Arnstein’s original ladder of participation, and applies to children in general. The bottom three (manipulation, decoration, tokenism) are termed non-participation. The next stages are considered to represent some form of participation. (1) Children who are assigned but informed; (2) consulted and informed; (3) adult initiated, (4) shared decisions with children; (5) child initiated and directed; and (6) child initiated with shared decisions with adults. The ladder has been criticized because what is considered as the highest level and the most appropriate may not be suitable for some children. As shown by research, some children do not want to be involved in all decisions, especially serious decisions [39, 47]. This is true for some adults as well. Franklin and Sloper (2005) described Alderson and Montgomery’s four levels of participation. These include (1) Being informed, (2) expressing a view, (3) influencing a decision, and (4) being the main decider. [48] What is similar between the described models is the fact that children need to informed and they need to be given a chance to express their view. Franklin and Sloper (2005) also highlighted the fact that the first three levels of participation are part of the United Nations Convention on the Rights of the Child (UNCRC). They include every child who can understand information, a child who can form a view, and be considered to be able to form a view that can inform the decision-making process [48].

The Royal College of Paediatricians and Child Health distinguished four levels of participation: (1) informing children; (2) listening to them; (3) taking account of their views so that they can influence decisions; and (4) respecting the competent child as the main decider about proposed health care interventions [41]. These levels require different degrees of competence [26]. Competence is defined as having the necessary ability, knowledge, or skill to do something [13]. In clinical practice competence is generally addressed as decision making [49]. If a child cannot give consent, an assent should be sought. An assent is described as an agreement to something or an expression of approval [13]. From a clinical perspective, competence is assumed to involve many factors including the developmental stage, the influence of parents and peers, and life experience [49, 50]. The law of a country determines the age at which a child can consent to certain procedures. In South Africa, the Children's Act of 2005, states that children as young as 12 years can consent to HIV testing without parental consent. They can also consent to medical and surgical treatment, provided they are mature enough to understand the implications of the treatment, and the child is assisted by an adult when it comes to surgical decisions. A girl of any age can consent to terminate pregnancy. [7] In Europe, domestic law determines whether or not people are competent to consent to healthcare interventions. In some countries decision-making is considered legal at age 18, while in other countries minors are allowed to take healthcare decisions from a fixed age below legal majority, e.g., 14 years in Portugal and 15 years in Denmark [49]. 'A more flexible system exists in most Canadian provinces and Switzerland where the competence of children to consent is evaluated on a case-by-case basis. In the United States, statutes often specify various minimum ages (usually 12, 14, or 16 years) for independent consent by children for specific types of treatment.' [49]

Some authors have associated competence with developmental age, based on developmental stages of childhood. Hart [15] reports that it is misleading to use simple developmental stages or age related norms to determine what children are capable of. He goes on to say that, it is useful to be familiar with the some of the most common sequences of development, such as the ability to take perspective of others. This milestone starts to develop after the age of three, but the ability to take perspective of others whilst maintaining one's own view, continues to develop through adolescence.

Currently there are no available standardized tools to assess children's competences in a clinical setting, which makes it difficult for health professionals. The MacArthur Competence Assessment Tool for Clinical Research (MacCAT-CR) has been shown to be useful in assessing children's competence to consent to clinical research. Hein et al 2015, showed that age was a key factor in children's competence to consent, followed by IQ. [50] More research is needed to assess the association between competence and age in a clinical setting.

Most researchers agree that children should be treated as individuals with needs that vary according to each situation [47]. There should be a balance between what is done for the best interest of the child whilst giving the child an opportunity to express their views. Participation is not an isolated event, but a process that varies depending on the child. Many children will be competent if the information received is appropriate and they are supported by adults.

5. Health professionals' views

In most countries, doctors take the Hippocratic Oath where they swear to uphold certain ethical principles. The four principles of clinical ethics are beneficence, respect for autonomy, doing no harm and justice. Health professionals are obliged to enhance patients' participation. They are well placed as advocates for children, because they see the suffering of patients every day. Society still holds the view that doctors 'know what is best'. This paternalistic approach usually goes against the rights of the child, and the decisions made may not be right for the patient and family. Doctors also use the utilitarian approach (Act utilitarianism), which aims to do what the doctor thinks is best for the patient, based on experience and evidence. This is good practice, however, if the patient is not consulted and not involved in decision-making, it does more harm than good.

There is sufficient research on what children think and how they feel about health professionals [23, 25, 42, 46]. Children report unhappiness with health professionals' attitudes towards them and the style of communication. This is more evident in studies where children were not involved in decision-making [23, 25, 42].The relationship between health professionals and children should be bidirectional. The way doctors and nurses relate to children is influenced by several factors: culture, the illness of the child, age and competence. The issue of using age to assess competence has been challenged. In some countries health professionals are the ones who judge the child's maturity to make a decision. This agrees with article 12 of the United Nations Convention on the Rights of the Child [3], which says: 'The right to information and participation should be in accordance to age and maturity.' In a South African setting, research found that medical professions and parents lack the skills and harbor social and cultural norms related to ill children that are inimical to the attitudes, knowledge and practices necessary to implement the provisions in the Children's Act related to children's informed consent [28].

Studies that have looked at health professionals' views on children's participation found that nurses agree that it is important to engage children. However, involvement depended upon factors like the child's age, attitude, levels of well-being and mental status [40]. Some felt that children of any age could participate provided they possessed the ability and cognitive maturity to understand the rationale for care. There were also views that only those children who were knowledgeable about their care and treatment should be involved. The nurses also felt involving children will empower them, which can be difficult for nurses (when children question their care) [40]. These varying practices call for more research on ways to assess competence of children in health care. Fiks et al (2011) looked at parents and doctors' perceptions on shared decision-making in children with Attention Deficit Hyperactivity Disorder (ADHD).[51] In this study, both parents and doctors agreed that shared decision making was important, but their interpretation and understanding was different. For doctors, it meant trying to convince parents to accept a particular treatment. [51] This was based on the knowledge that most parents cannot afford behavioral therapy, and the only thing available to them was medication. Despite the differences parents still believed that the doctors had more knowledge about the illness. Some doctors felt that they alone should make the decision [52]. Most of the research on oncology patients and children with chronic illness, the common finding is that decisions are made for 'the benefit of the child', and the doctors feel that the treatment has to be done. This gives the family little time to consider other options.

6. Parental views

The African Charter on the Rights and Welfare of the Child [4] and the United Nations Convention of the Rights of the Child [3] recognize the importance of family. Articles 18 of the African Charter on the Rights and Welfare of the Child, states that families are the natural unit and basis for society, and should enjoy special protection. Article 5 of the United Nations Convention on the Rights of the Child [3] says, 'States Parties shall respect the responsibilities, rights and duties of parents or, where applicable, the members of the extended family or community as provided for by local custom, legal guardians or other persons legally responsible for the child, to provide, in a manner consistent with the evolving capacities of the child, appropriate direction and guidance in the exercise by the child of the rights recognized in the present Convention.' The issue of children's participation is still foreign to some parents. The view that the 'parent knows what is best for the child' is still prevalent. In some cultures children are objects to be seen and not heard. These views are slowly changing with the introduction and implementation of new laws. The shift from not being consulted to being expected to make decisions creates confusion for both the child and parents [19]. Children need to learn that having rights comes with responsibility, which can be achieved by involving adults. Hart [15] highlights the importance of adult involvement not only for guidance but also for learning purposes. Parents with adequate economic resources value independence and autonomy, while those in low income place value on obedience from children. Obedience is seen as a means to economic success. Children see their parents go through everyday challenges (being oppressed at work with no say), and assume that this is normal.

Parents of hospitalized children feel the need to protect and to do what is best for the child. Sometimes, balancing the right of the child to participate and the parents' need to protect the child can be difficult. In most studies, majority parents realize the importance of children's participation in their care, however, their preferences are varied [51, 53, 54]. Tait et al (2001) looked at parental involvement regarding their child's anesthetic care. [54] Some parents wanted active involvement in certain parts of the child's care (for example, being there when the child woke up from surgery). They were more passive when it came to detailed medical care. African-American parents were more likely to be passive decision-makers compared to Caucasians, although this was not explained. [54] By and enlarge parents agree on the importance of shared decision-making [51, 53, 54]. Shared decision-making definition can be defined as a process that allows patients and health professionals to make health care decisions together. Decision-making involves (1) active participation of both clinician and families in treatment decisions; (2) exchange of information; (3) discussion of preference; (4) joint determination of treatment plans [55]. Fiks et al (2011) reported that parents preferred a situation where there was ‘equal partnership’ between the doctor and the parent. [51] They believed that doctors had the knowledge about the illness whereas parents knew the child better. Parents are now becoming more knowledgeable about treatment options which puts pressure on health professionals to engage them more. This becomes a challenge when there is conflict between parental sources of information and health professional’s views.

Another important aspect is the collaboration between the child and parent. It is not about who the main decision maker is, it is about having a discussion about the illness and finding ways to deal with it [53]. The various ways of collaboration between parents and children included information sharing, asking for other’s opinions and expressing one’s point of view.

3.0 STUDY DESIGN

Literature shows that there is growing research around the topic of children's participation in decisions affecting them. However, the implementation is still a challenge. Trying to understand the stakeholder's views in any institution is an important step before any recommendation can be made or implemented. This is one of the reasons for looking at this topic. Secondly, most of the research comes from developed countries with better resources, and the recommendations from these areas might not hold true in a developing country like South Africa. Understanding what is relevant in our setting becomes crucial. If children are to be involved in decision-making, they must be involved in the design of policies which require some form of reflection or investigation. In other words, children need to take part in research topics that affect them directly. Studies with children have shown that children can partake in research and their views should be taken seriously.

The aim of the study was to describe the views of health professionals, parents and children, in relation to children's participation in decision making at Rahima Moosa Mother and Child Hospital.

The objectives of the study are:

- To describe the socio-demographic characteristics of participants (children, caregivers and health professionals) in the study.
- To assess the views of health professionals regarding the knowledge of the children's right to participate in decision-making. To assess how they engage with the selected children and parents or care givers, in ward 2 and 3 at Rahima Moosa Mother and Child Hospital.
- To describe the views of children and parents or care givers regarding the knowledge of the right to participate in decision-making; and their views on the information received from health professionals.

3.1 Methodology

The study was an observational (cross sectional) study which is different to what other authors have done before. Previous researchers employed mostly a qualitative approach, which has been shown to yield a better understanding when it comes to perceptions [40, 44] .However, the aim of this research was to look at the demographic profile of participants and to quantify their views. ‘To be effective in research with children, researchers need to be flexible in the methodology they use in order to ensure that children’s rights and needs are respected in the research processes. ‘Research methods should be flexible enough to take account of differences in age, individual personalities, context and preferred form of communication.’[41]

The study was performed at Rahima Moosa Mother and Child Hospital (RMMCH). The hospital is situated west of Johannesburg, it offers maternity and child services. The paediatric department has four inpatient wards, and children are allocated according to age. The study took place in ward 2 and ward 3 between the 01/09/2015 – 30/09/2015. Ward 2 admits children between the ages of 2-12 years. It is a mixed ward with medical and surgical (ENT, dental, plastic, orthopaedic) patients. Ward 3 is the infectious diseases ward that admits children above 6 months. The initial plan was to collect data over a 2 month period, however, due to administrative problems, this was not possible.

3.1.1 Sampling:

No sample size was calculated. All children between the ages 6 and 12 years and one of the parent/s or care-giver/s were approached. The demographic data of missed eligible participants or those who did not want to participate was captured in order to reduce selection bias. Children with mental impairment or severe chronic neurological disorders were not included in the study. All health professionals (doctors and nurses) who looked after the children were invited.

3.1.2 The setting:

Interviews for children and their parents were held in the respective wards (ward 2 and ward 3). A small area was made into a small office (for privacy). For children who were bed bound, interviews were conducted at their bedside, with the parent or care giver present.

3.1.3 Research tools:

Children and parents' interviews were conducted by the researcher. Questionnaires were used as the only research tool. Doctors' and nurses' questionnaires were self-administered. The researcher collected completed questionnaires on a daily basis. The languages used were English, Zulu and Xhosa (which are languages that the researcher speaks fluently). Johannesburg is a diverse city with different languages, but there were no challenges experienced during the interviews in terms of language. A questionnaire is a very useful research tool for data collection, however, it requires the respondent to read and understand the questions. A pilot was performed to verify the questions and to assess how easy it would be to complete the questionnaire. A total of six health professionals, four parents and their children participated in the pilot. This was conducted in English and Zulu. The pilot also helped to determine the reliability and validity of the questionnaire. At the end of the pilot study, some questions were modified. Children's questionnaires were designed such that it was easy for them to answer the questions (yes or no). This was important in our setting where children are not used to being asked about their views.

3.1.4 The variables:

Questionnaires looked at the demographic profile (age, gender, ethnicity, citizenship and education) of all participants. They were asked about their knowledge of the right to participate in decision-making. Health professionals were asked about how they communicated with parents and children, and the type of information they gave to them. The study also explored whether parents and children were part of the decision-making, by asking if they were allowed to ask questions during consultations. Parents and children were asked how they perceived the information they received and how they preferred to receive information. Children's questionnaires asked about the knowledge of their illness and whether they felt they could speak to health professionals. The study also looked at the participants' views on the importance of involving children in decisions affecting them, in a health care setting.

3.2 Implementation and ethical issues

Permission to perform the study was obtained from the Human Research Ethics Committee (Medical), at the University of Witwatersrand. Permission was also granted by the CEO, the Head of Department of Paediatrics and the Matron at Rahima Moosa Mother and Child Hospital. Health professionals were informed of the study and their co-operation was requested. They were given an information page with consent. Once the consent was signed, the questionnaire was filled in. Children and parents or care-givers were approached by the researcher to ask permission to participate in the study. An age appropriate information leaflet was given to children explaining the study. Children and parents were given enough time to decide whether to participate or not; which meant that some interviews were performed a day or two later. This time was used to build some form of relationship with the child and parent or care- giver. Consent was obtained from all participants (Appendix D & E) and an assent form (Appendix C) was signed by both parent or care-giver and the child. The consent explained to all participants their ability to withdraw at any time from the study and highlighted that participating in the study was not going to compromise the child's treatment in hospital. Confidentially issues were addressed by ensuring that no names appeared on the data set. Raw data with sensitive material were stored in a safe place. The questions asked did not reveal sensitive information about the child's illness. In order to allow for normal ward routine, interviews occurred between 10h30 and 12h00, and resumed in the afternoon after 14h00 until 16h00.

At the end of the interview, there were no rewards given to participants, but they were informed that a report of the study will be available from the Paediatric department should they wish to access it.

3.3 Data Analysis

3.3.1 Data Management:

The demographic profile and responses of participants were exported into an excel spreadsheet. Children's questionnaires were different in the way the questions were asked, their answers were yes or no. This meant that each group of participants needed to be coded for analysis (health professionals were coded as 1, parents were coded as 2 and children's responses were coded as 3). Missing variables and numbers were identified and corrected.

3.3.2 Data analysis:

Data was analysed using data analysis software STATA. A do file was created with commands. The socio-demographic characteristics of all participants (age, gender, ethnicity, citizenship, level of education, occupation) were analysed using frequencies and percentages. Age was classified in categories for health professionals and parents and care-givers, therefore frequencies and percentages were used. Age was treated as a numerical variable for children, therefore mean and standard deviation would have been appropriate. However, the distribution of the study population was skewed, therefore the median was used. To assess how health professionals communicated with children and parents/ care givers and to assess the parents' or care givers' responses, a five point Likert-type scale was used. A Likert scale is used to assess people's attitudes, views or preference about a topic. It is used widely in surveys as a way of self -reporting. Likert scale and Likert- type scale are often used interchangeably but they are not the same. In a traditional Likert scale, participants are asked to respond to a statement and the choice of responses is usually balanced with equal numbers of positive and negative options, with a neutral value in the middle. A Likert-type scale is a variation of the above with many labels for each response option. They do not use the traditional disagree – strongly agree response continuum [56].

4. RESULTS

4.1 Demographic profile

Table 1: Demographic profile

Demographics	Child	Parent/ care-giver	Health Professional
Age (child)	Median age = 7 IQR = 6 – 10 years		
Age:			
❖ < 25 years		2 (7%)	4 (8%)
❖ 26-30 years		3 (11%)	23 (45%)
❖ 31-40 years		14 (50%)	10 (20%)
❖ > 40 years		9 (32%)	14 (27%)
Gender:			
❖ Female	11 (39%)	25 (89%)	43 (84%)
❖ Male	17 (61%)	3 (11%)	8 (16%)
Ethnicity:			
❖ Black African	24 (86%)	24 (86%)	28 (55%)
❖ Mixed race	3 (11%)	3 (11%)	5 (10 %)
❖ Indian	1 (3%)	1 (3%)	9 (17%)
❖ White			9 (17%)
Citizenship:			
❖ South African (SA)	25 (89%)	25 (89%)	51 (100%)
❖ Non- SA	3 (11%)	3 (11%)	0

Education(child)	Median grade= 1		
Education (parent): ❖ Below matric ❖ Matric ❖ Post matric		12 (43%) 9 (32%) 7 (25%)	
Training: ❖ Paediatric training ❖ No peadiatric training			30 (59%) 21 (41%)

The demographic profile of all participants is summarized in table 1. A total of 51 health professionals were enrolled; n= 34 (67%) were doctors and n= 17 (33%) were nurses. The response from the paediatric doctors was very good. Recruiting doctors from other disciplines was a challenge because they were not always in the wards. The nurses' response could have been better, considering the total number of nurses working in the wards. Most of the nurses were concerned about their responses, which can explain the low response rate. The majority of health professionals were females (both doctors and nurses). Almost fifty nine percent of all health professionals had some form of paediatric training. Of these, 79% (n=27) were doctors, and only 18% were nurses. The majority of health professionals were between the age group 26 -30 years, but this constituted mostly of young doctors. Most of the nurses fell in the 27- 40 years category. The majority of all participants were Black Africans and all health professionals were from South Africa. Parents were mostly female (89%), but it was encouraging to see fathers being involved in the care of their children. There were only 10% non-South Africans. A high percentage did not have a matric certificate.

A total of thirty three (n= 33) children qualified for the study, and three (n=3) did not participate because their parents refused. They were siblings of mixed race who were admitted for a similar procedure. There were two (n= 2) Black African children that were missed because of they came back late from theatre and were discharged early the next morning. Their median age was eight years. A total of twenty eight children were enrolled in the study. Most children were males and Black African. The median age was seven years with an interquartile range between six and ten years.

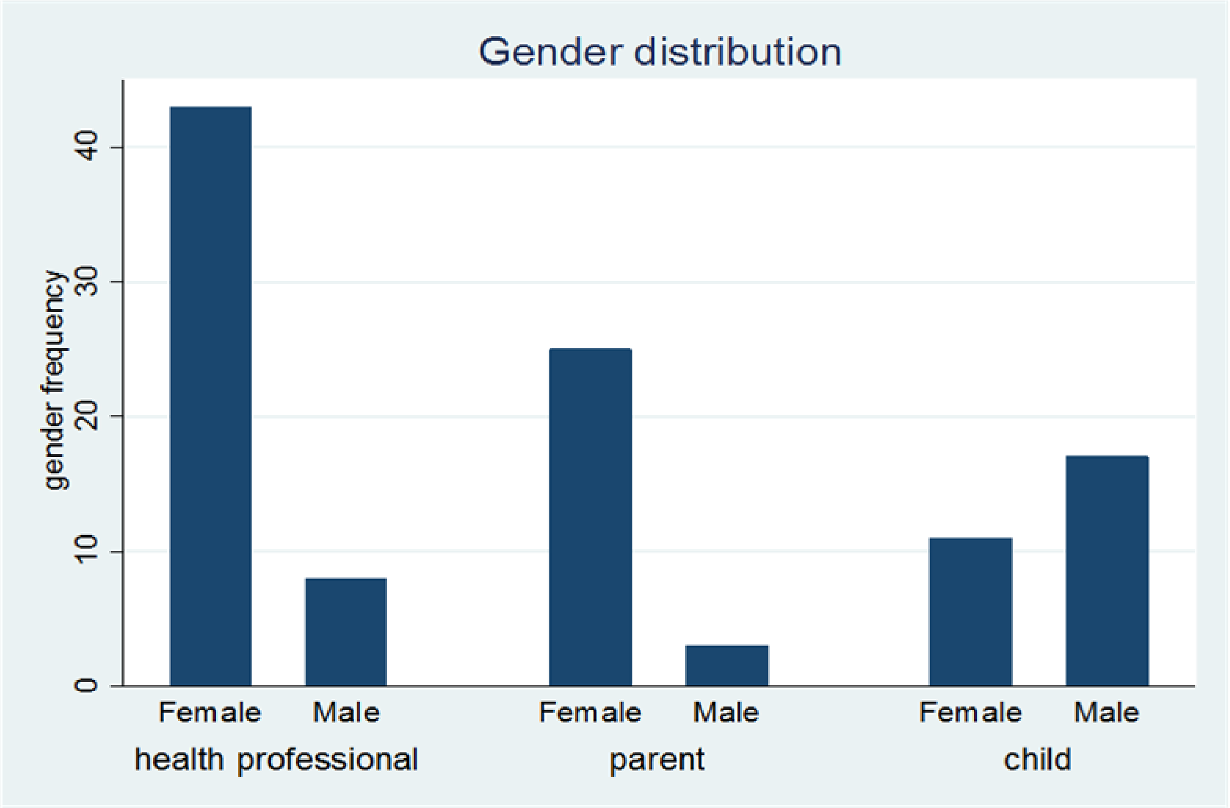
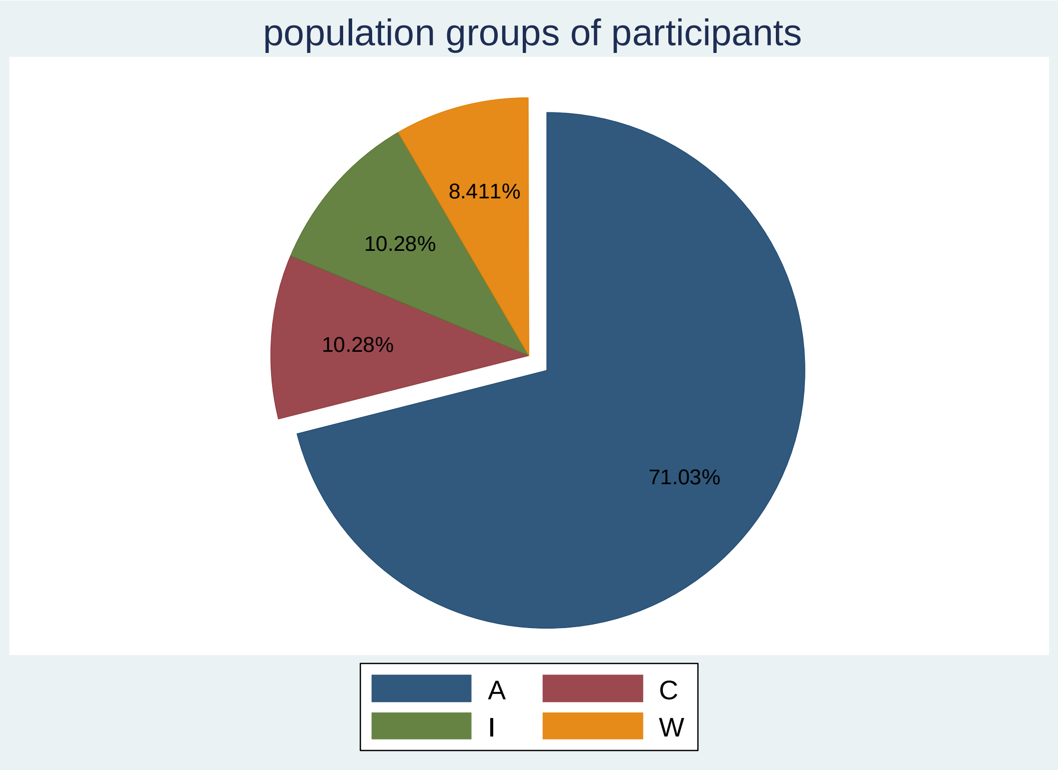


Fig 1. Gender distribution



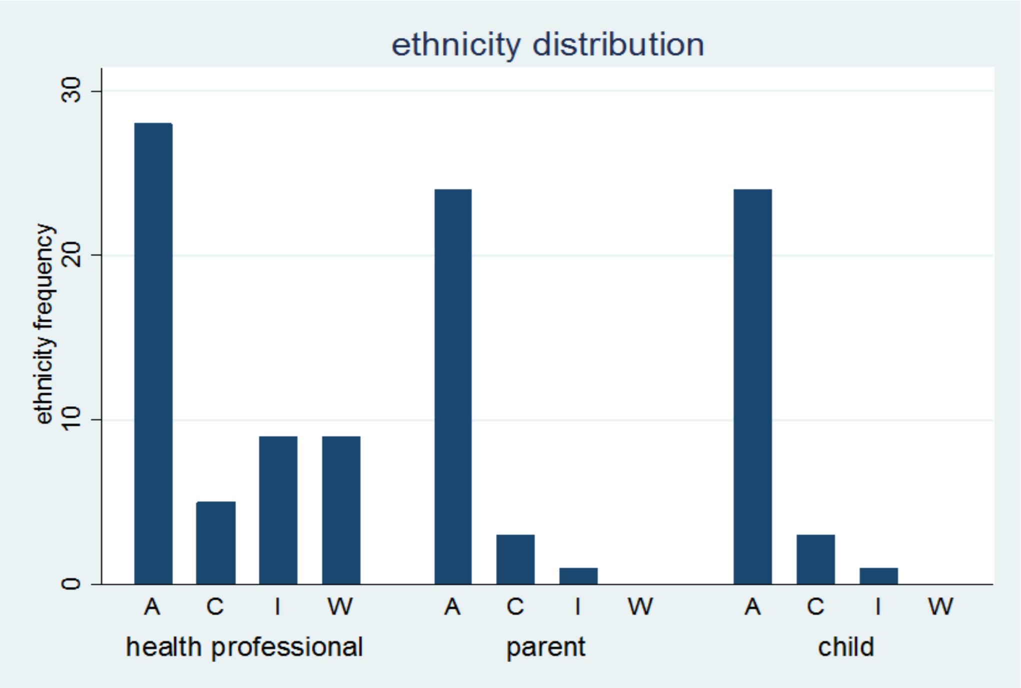


Fig 2 and 3. Population groups and Ethnic distribution

Table 2. Participants' responses

Variables	**Child**	**Parent/ care-giver**	**Health professional**
Knowledge of right:			
❖ Yes	**7 (25%)**	**14 (50%)**	**47 (92%)**
❖ No	**21 (75%)**	**14 (50%)**	**4 (8%)**
Training in communication:			
❖ Yes			**9 (18%)**
❖ No			**42 (82%)**
Explain diagnosis:			
❖ Yes			**14 (28%)**
❖ No			**37 (72%)**
Knowledge of diagnosis:			
❖ Yes	**11 (40%)**	**24 (86%)**	
❖ No	**17 (60%)**	**4 (14%)**	
Receiving information:			
❖ Parent	**20 (71%)**	**17 (61%)**	
❖ Child	**2 (7%)**	**2 (7%)**	
❖ Health professional	**6 (21%)**	**9 (32%)**	
Children's views			
Asking questions:			
❖ Yes	**6 (21%)**		
❖ No	**22 (79%)**		

Information on procedures/treatment:			
❖ **Yes**	**8 (29%)**		
❖ **No**	**20 (71%)**		
Talking to health professionals:			
❖ **Yes**	**15 (54%)**		
❖ **No**	**13 (46%)**		

Table 3. Health professionals’ views on their day to day to practice

Variables / Responses	Explain procedure or treatment	Child asks questions	Parent asks questions	Age appropriate information	Speak to 6-9 year old	Speak to 10-12 year old
Always	**6 (12%)**	**8 (16)%**	**39 (77%)**	**1 (2%)**	**19 (37%)**	**34 (67%)**
Often	**23 (45%)**	**19 (37%)**	**9 (18%)**	**2 (4%)**	**19 (37%)**	**9 (18%)**
Sometimes	**16 (31%)**	**15 (29%)**	**1 (2%)**	**3 (6%)**	**7(14%)**	**5 (10%)**
Seldom	**4 (8%)**	**8 (16%)**	**1 (2%)**	**12 (24%)**	**5(10%)**	**2 (4%)**
Never	**2 (4 %)**	**1 (2%)**	**1(2%)**	**33 (65%)**	**1(2%)**	**1 (2%)**

Table 4. Parents' or Caregivers' experiences

Variables / Responses	**Explain procedure/treatment**	**Child asks questions**	**Parent asks question**
Always	**8 (29%)**	**4 (14%)**	**9 (32%)**
Often	**6 (21%)**	**3 (11%)**	**5 (18%)**
Sometimes	**4 (14%)**	**1 (4%)**	**3 (11%)**
Seldom	**4 (14%)**	**0**	**3 (11%)**
Never	**6 (21%)**	**20 (71%)**	**8 (29%)**

4.2 Knowledge of the right to participate

Majority of health professionals (92%) knew about the right of children to participate in decisions affecting them, but this was not reflected in their day to day practice. There was an equal distribution between the parents who knew about the right and those who did not. The knowledge of the rights to participate in decisions affecting the child was not related to the level of education or any specific training. The majority of children (75%) did not know about their right to participate in decisions affecting them in health care.

4.3. Explaining diagnosis

The majority of health professionals (73%) who participated in the study reported that they did not explain the diagnosis to children. Only 27.5% took time to explain the diagnosis. This was supported by children's responses, where 60% of children did not know what was wrong with them. The small percentage that had an idea of what was wrong with them, knew very little about their condition. Parents on the other hand knew what was wrong with the child. There are several possible reasons for this: (1) As parents they had brought the child to hospital for a specific reason, (2) the doctors explained the diagnosis to parents rather than children.

4.4. Importance of informing children about their illness and their involvement in decision- making.

Health professionals and parents views were sought in relation to the importance of informing children about their conditions and involving them in decisions affecting them. A four point Likert scale was used. The majority of health professionals strongly agreed. Although over 50% of parents also agreed, only 38% of parents strongly agreed. One healthcare worker strongly disagreed stating that children were too young to be worrying about their illness. A small number of parents disagreed highlighting the need to protect their children and not wanting their children to be under stress. About 6% of health professionals also disagreed. Their reasons were mainly around the issue of age and competence. Health professionals' responses showed that communication was better if the child was slightly older. A total of thirty four (67%) health professionals reported that hey always spoke to ten – twelve year olds, compared to 37% in the six – nine year age group.

Table 5. Importance of informing children

Scale	Health professionals	Parents / care-givers
Strongly agree	29 (57%)	10 (36%)
Agree	18 (35%)	16 (57%)
Disagree	3 (6%)	2 (7%)
Strongly disagree	1 (2%)	0

4.5 Information

Shared decision-making means that all stakeholders are given the right information and are able to voice their opinion based on the information given. Majority of health professionals reported that they did not use age appropriate information when communicating with children. Children were still not informed and not involved in decision-making. Majority of parents (61%) felt that the information should be given to them, 32% felt that both the parent and that child should be involved, and only 7% felt that health professionals should speak to the children directly. Children's responses were similar, 71% felt that health professionals should speak to their parents, 21% wanted to be involved with their parents, and only 7% wanted to speak to health professionals alone.

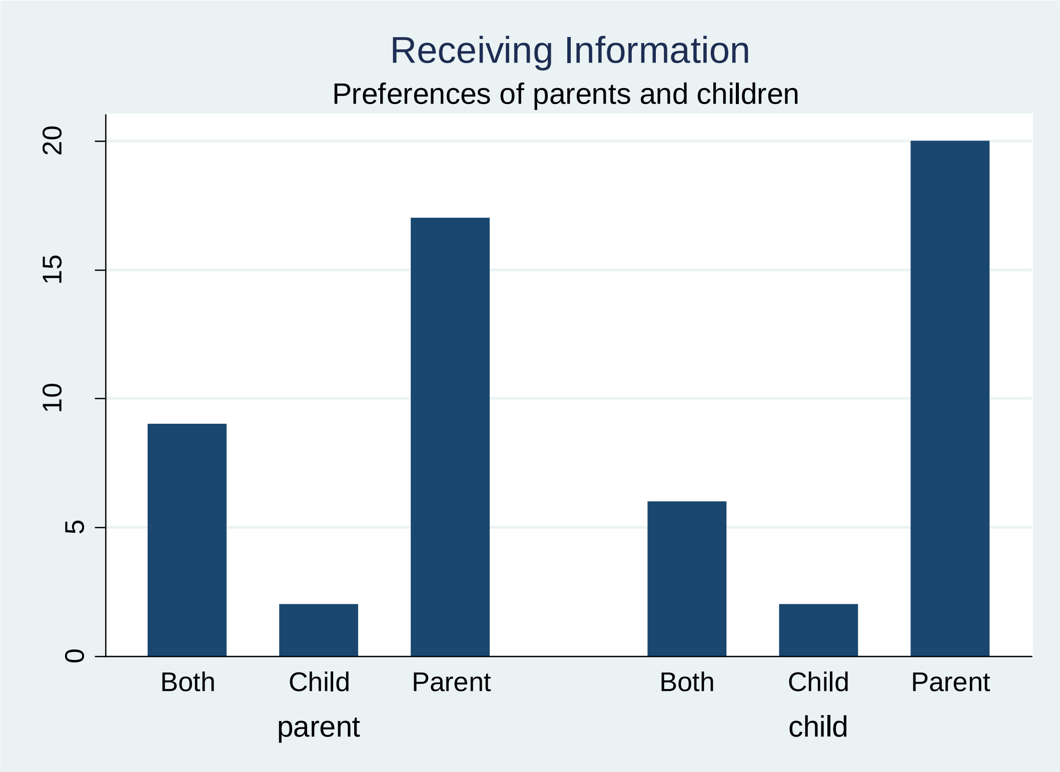


Fig 4. Receiving information

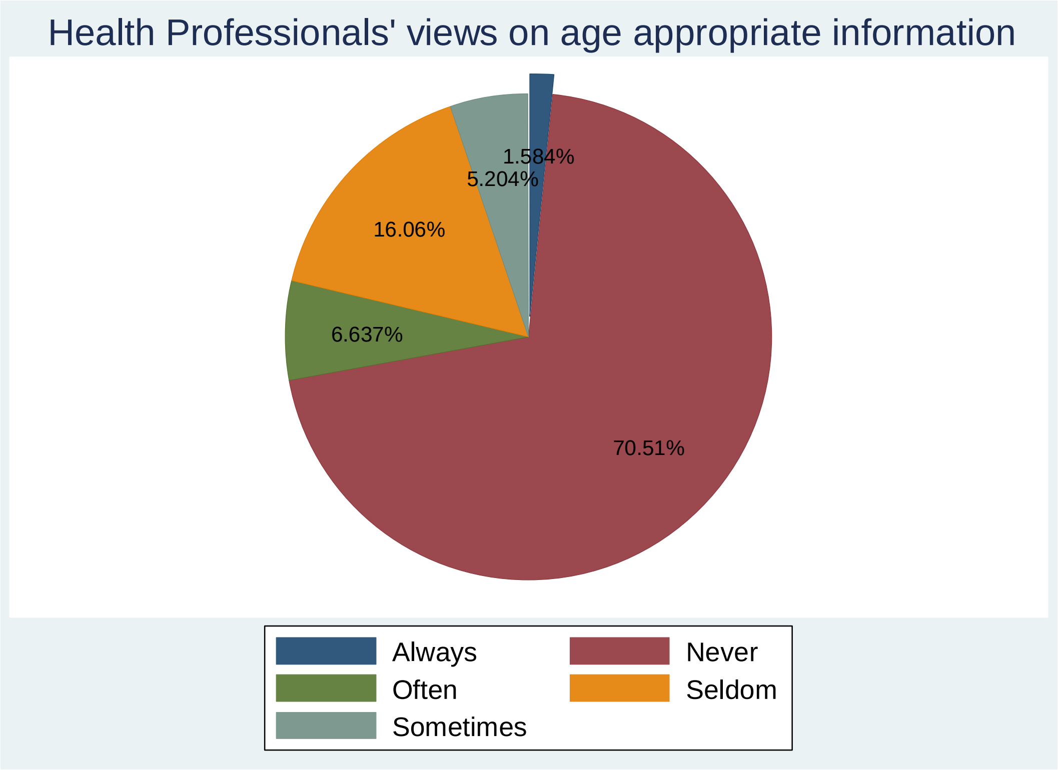


Fig 5. Health professionals’ views on age appropriate information

4.6 Children’s views

Children’s questionnaires were structured such that the questions were yes and no answers. They were asked if health professionals informed them about procedures and treatment. The majority of children (71%) reported that they were not informed, and only 29% were informed. Approximately (79%) of children were not given a chance to ask questions. About 53% of children felt comfortable talking to health professionals about their illness.

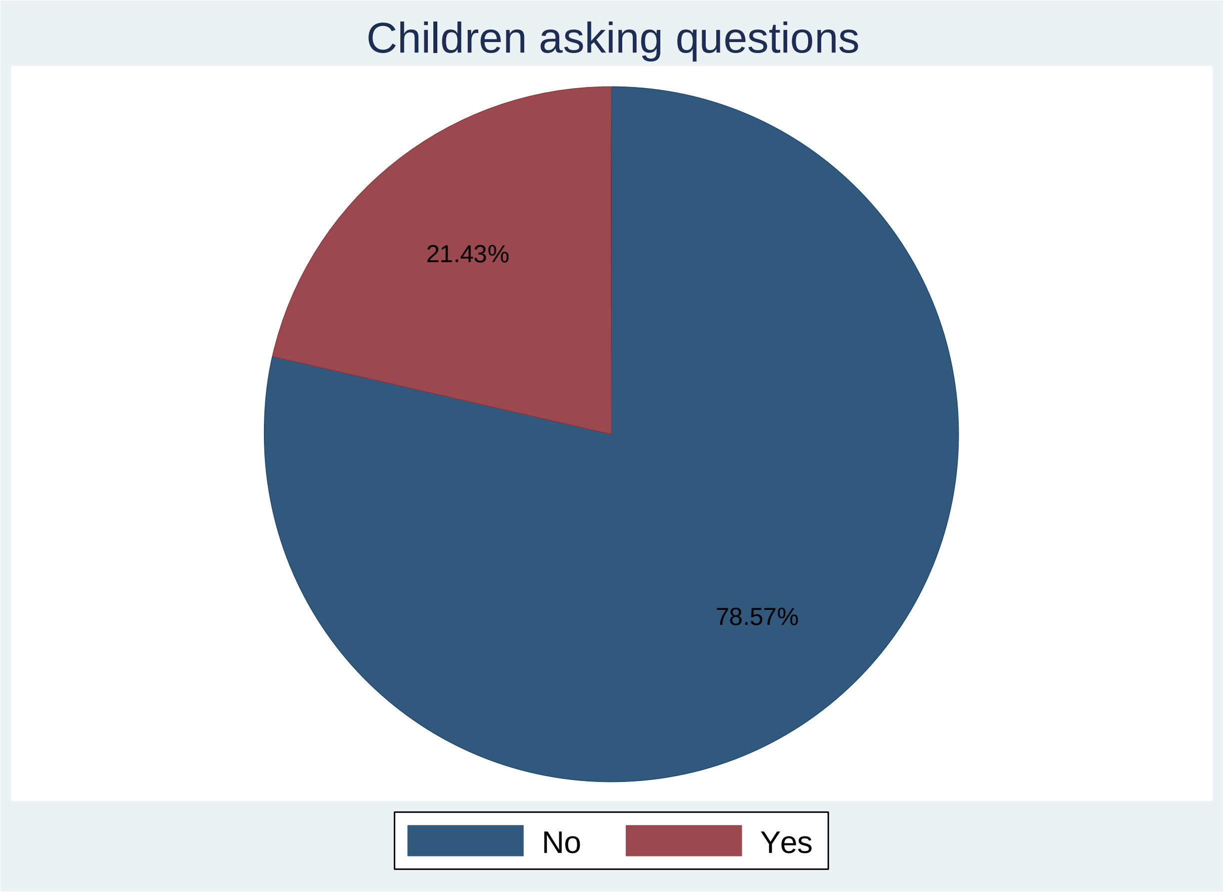


Fig 6. <u>Children's views on asking questions</u>

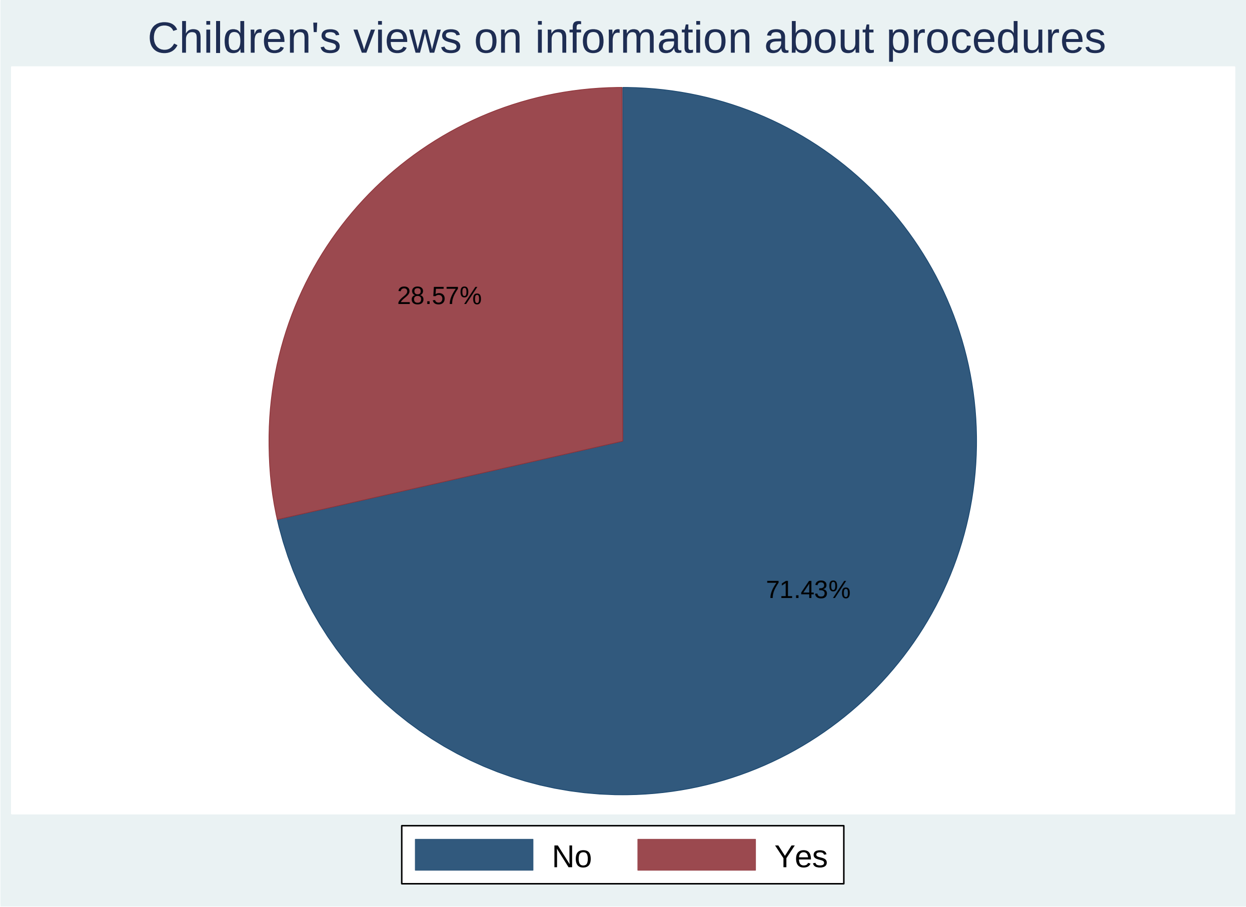


Fig 7. Children’s views on information about procedures

4.7 Good medical practice

Good medical practice requires health professionals to give patients the information they want or need to know in a way they can understand. According to the General Medical Council [57] (GMC), health professionals should work in partnership with patients, sharing with them the information they will need to make decisions about their care, including their condition, its likely progression and the options for treatment, including associated risks and uncertainties. Health professionals were asked their views about how they communicated with parents and children. Parents were asked similar questions in order to understand how they received the information given to them. The study looked at (1) Giving information about treatment and procedures, (2) allowing parents to ask questions; (3) allowing children to ask questions. A five point Likert-like scale was used to assess their views. Majority of health professionals' responses showed 'good practice', however, this was not supported or received by parents. This was different to parents' responses, especially when it came to their children asking questions. This highlights discrepancies between health professionals' views and the perceptions of parents and care-givers. It also calls for more research in order to understand the factors that influence the different views.

Table 6. Health professionals' views

Responses	Explain Procedure/ Treatment	Give children a chance to ask questions	Give parents a chance to ask questions
Always	6 (11.8%)	8 (15.7%)	39 (76.4%)
Often	23 (45%)	19 (37.2%)	9 (17.6%)
Sometimes	16 (31.3%)	15 (29.4%)	1 (2%)
Seldom	5 (9.8%)	8 (15.7%)	1 (2%)
Never	1 (2%)	1 (2%)	1 (2%)

Table 7. Parents' and care givers' views

Responses	Explain procedure/ treatment	Give children a chance to ask questions	Give parents a chance to ask questions
Always	8 (29%)	4 (14%)	9 (32%)
Often	6 (21%)	1 (4%)	5 (18%)
Sometimes	4 (14%)	3 (11%)	3 (11%)
Seldom	4 (14%)	0	3 (11%)
Never	6 (21%)	20 (71%)	8 (29%)

5. DISCUSSION

The researcher is careful about generalizing from the results of this small project, with small numbers. However, the study raises a few important aspects regarding children's participation in healthcare.

5.1. Demographics

According to census 2011 [58], the South Africa population is over 50 million. The breakdown according to population groups or ethnicity is as follows: Black Africans constitute 79.2%, mixed race (coloureds) make up 8. 9%, Indians make up 2.5% and the remaining 8.9% are whites. The study reported a high number of Black African participants, which is a representation of the distribution of the South African population. Rahima Moosa Mother and Child hospital is located in an area where mostly African and mixed race communities reside. The absence of white parents and children speaks to the inequalities in the country. It does not mean that there are no white families in the area, but they are a minority. Most white families (and some ethnic groups) can afford private medical care. People who use public health services are generally people from a low socio-economic background with very little resources. The fact that most of the parents had no matric certificate also highlights some of the challenges of poverty and inequality in South Africa.

The majority of health professionals (n= 43) were females. Nursing has always been considered a female role. Even in ancient times, females especially catholic nuns took the role of nursing, even before Florence Nightingale laid the foundation of professional nursing. The word nurse comes from a Latin word that means to 'suckle". The English dictionary describes a nurse as someone who looks after ill people. Society still views nursing as a female role, which deters men from joining the profession. It is not clear whether the origins of the term 'nurse' have an influence on this view or because of nursing practice in general. The few men who are nurses tend to go for surgical disciplines. These views pose a challenge for the nursing profession and also highlight the need to educate the public, especially now that we live in a democratic society that does not discriminate against gender, amongst other things. Doctors in pediatrics are generally females, which explains the high number that was noted in the study. In 2007, the number of female paediatricians were low, but this changed in 2010, with numbers almost equaling those of male counterparts [54]. Reasons for these findings could be that more females are enrolling in the field of Medicine. Females predominate in certain specialties for different reasons like working hours, financial incentives and the type of skill needed for that profession.

The study noted that most parents were females, and this can be explained by several reasons ;(1) Mothers nurture and look after children whilst their fathers are working. Although most women are now working, mothers are still the ones who are more involved in the care of children. (2) Cultural practices also play a role, in certain cultures women are not allowed to work and their main role is to look after children. (3) The issue of absent fathers, with children being raised by a single parent, also contributes to the findings. However, it was encouraging to see fathers looking after their children in hospital.

Most of the health professionals who took part in the study were doctors who were in training posts or already specialist in Paediatrics. This explains the high number of doctors with paediatric training. Although the study was not comparing the different groups of participants, it was noted that specific or specialized training did not have an impact on the involvement of children in decision-making.

5.2. Knowledge of the right of children to participate in issues affecting them.

Health professionals are obliged by law to protect children and to uphold their rights. Article 12 of the United Nations Convention on the Rights of the Children [3], makes specific reference to children's participation in decisions affecting them. The children's act states that 'every child that is of such an age, maturity and stage of development as to be able to participate in any matter concerning them, has the right to participate in an appropriate way and views expressed by the child must be given due consideration.' Research into children's rights fall into three categories; protectionist, liberationist and pragmatist views [41]. Protectionists believe that children are still developing and need to be protected. Liberalists believe that children should know their rights and responsibilities; and should be involved in society. The pragmatist view tries to strike a balance between the liberalist and protectionist views by allowing children to be involved whilst protecting them.

The results of the study showed that most health professionals (n= 47) knew about the right of children to participate in decisions affecting them, which was encouraging because health professionals are advocates for children in healthcare. However, knowledge of the right does not necessarily mean that it is implemented or practiced on a day to day basis. The current status is South Africa in child participation is largely ad hoc, and non- government organization (NGO) driven [60]. There is very little political commitment and lack of resources. Not understanding the process of participation and lack of skills to implement the right are other factors. Cultural and social attitudes of health professionals and parents also play a role. It is not only the government's responsibility to ensure that children are given a voice, community leaders and the community play an important role. Half of the parents knew about the right, but their responses indicate the need for further education. A major concern was the high percentage of children (75%), who did not know about their right. There are several reasons for this (some of which have been discussed in the literature review). Children are usually seen as objects rather than subjects, and are not taught about their rights. Cultural attitudes and views of parents or care-givers also impact negatively on the realization of the right.

These findings highlight the need for government and community commitment; and for parents to encourage children in matters affecting them. This will teach them responsibility and empower them to make decisions for themselves.

5.3. Explaining the diagnosis

The majority of health professionals (73%) in the study did not explain the diagnosis to children, opting to communicate with parents instead. This practice is very common and has been documented in several studies [40, 38].The view that the 'doctor knows best' is still prevalent. The issue of age and competence has also been shown to be one of the reasons for not engaging children. Some health professionals (especially doctors) make decisions on their own without consulting the child, on the basis of 'doing what is best for the child'. Research has shown that what is considered best for the child may have the opposite effect [39]. Parental and cultural attitudes also hinder the participatory process, by not challenging health professionals' views. Some parents do not want their children to know the diagnosis out of fear for their children. Studies demonstrate that the diagnosis affects how the health professionals communicate with children and parents. Paediatric oncology is an area where a child's diagnosis presents challenges for doctors and families. Sometimes families rely on doctors to make decisions for them, because of lack of treatment options or doing what is best for the child. Some decisions are taken out of fear of dying.

Most parents in the study knew what was wrong with the child. Reasons for this finding could be that hospital doctors had told them, they may have consulted the clinic or a general practitioner before coming to hospital. The third reason could be that they had consulted a traditional healer or a faith healer. A study done in Soweto revealed majority of African parents consult traditional healers first before seeking western medicine. There were several reasons cited, one of which was poor access to health care [35]. These results indicate the need to educate health professionals on how to communicate with children effectively, irrespective of the child's age.

5.4. <u>Importance of giving information to children and their involvement</u>

Good communication with patients and their families has been shown to have positive effects. Some of the reported positive effects include shorter hospital stay and fewer patients returning to hospital for the same condition. Better informed patients have improved outcomes [61]. Communication is defined as imparting or exchanging of information by speaking, writing, or using some other medium [13]. Lack of information leads to confusion and makes children's fears worse. In South Africa, the Health Professions Council of South Africa [62] expects doctors to give information to patients in the way they can best understand it. This information must be given in a language that the patient understands and in a manner that takes into account the patient's level of literacy, understanding, values and belief systems [62].

Health professionals and parents were asked if they agreed that it was important to give information to children and to engage them. Most of the health professionals strongly agreed. The question is 'why is it not the case in reality'? Research has cited lack of communication skills, busy schedules with limited time, as possible reasons. The child's age and maturity are other contributing factors [26, 46].Loss of power that comes with empowering of children has been reported in other studies [25, 54] .The issue of what constitutes participation poses a challenge for health professionals. The dictionary defines participation as taking part in something. [13] Different authors view participation differently. Hart [15] described the eight different levels of young people's participation in projects. Manipulation, decoration and tokenism are considered non-participatory mechanisms, because children are either not consulted, if they are, no feedback is given to them. Sometimes they are used for 'decorative' purposes without understanding their role. The common form of non-participation is tokenism, where children are seen to be given a voice, but have no choice about the subject or are not given an opportunity to express their views [15]. The rest of the steps in the ladder constitute what would be described as some form of participation. Children should be consulted and informed. Even when issues are initiated by adults, children should be part of the decision-making (adult initiated, shared decision with children) [15]. The last two steps of the ladder (child initiated and directed; and child initiated, decision shared with adults) raise the issue of autonomy, which can be challenging in the medical field. It is known that children as young as 2 months can express themselves through a display of their feelings. The example of a child who refuses treatment that is beneficial to him or her (out of fear and immaturity) is a common one. If we are to say we respect the child's right and his or her views, it means that doctors or nurses have to accept the child's opinion. But as Runeson [26] points out, 'Child autonomy and the right to participate grow side by side as the child matures'. Lansdown [19] also highlighted some principles of democratic participation, which are similar to Hart's findings. He highlights the importance of understanding what the process (procedure or treatment in the case of healthcare), the role of the child, allowing children to voice their opinion and that participation should be voluntary. Children's needs are different, some want full involvement, other very little [40, 44, 46], so the issue of participation being voluntary is important. Coyne et al (2006), devised a framework based on children's views (Appendix N).[41] Children described 7 levels of participation in consultations, which were being informed; asking questions; expressing a view; being listened to; being heard; involved in decision-making; shared decision-making; and being the main decider. Whichever approach one chooses, participation should be individualized and viewed as a process, and one of its key elements is allowing children to have a say.

Parents also agreed that it was important to inform and engage children in decision-making, but felt they needed to protect them. This finding has been noted in other studies. Young et al (2003) reported that parents may withhold information out of desire to protect their child rather than being difficult. [38] One of the ways to measure effective communication is satisfaction. Parents in the study reported satisfaction with the information given to them by health professionals. However, children are the patients, and unfortunately, the research did not go into that aspect.

5.5. Giving information

Decision-making is defined as a process of participation in making decisions. The Informed Medical Decisions Foundation describes shared decision-making as a collaborative process that allows patients and their providers to make health care decisions together, taking into account the best scientific evidence available, as well as the patient's values and preferences. It involves giving information and for the recipient to understand the information. As discussed in the previous section, both health professionals and parents agreed on the importance of giving information to children, but differed in how they preferred to receive the information.

Children and parents were asked whether they wanted health professionals to speak to them directly or to speak to their parents or both. Majority of children (71%) wanted the doctors to speak to their parents. Only 7% wanted doctors to speak to them directly, and age was not shown to be a contributing to their preferences. Young et al (2003) reported that children used parents as 'buffers' to limit exposure to potentially worrying information. [38] Zwaanswijk et al (2007) also reported that children used their parents as facilitators, although they also preferred the information and questions to be addressed to them. [63] Some of the children in the study reported that they were afraid of talking to doctors, others did not understand what was being said. [63] The reasons given were not part of the objectives of this study, however, the responses were similar to what has been reported in other studies.

Approximately 61% of parents preferred health professionals to speak to them, because they were worried about their children, and wanted to protect them from distressing news. This finding was noted in other studies. Parents highlighted the importance of using less medical terms when communicating with children. Parents (in the same study) preferred that certain aspects like prognosis and survival rates, not to be discussed with children, out of fear for their children. Those parents who wished for direct communication with the child, felt that the doctor or health professionals were better qualified to explain the aspects of the child's illness [63]. Fiks et al (2011) reported that parents of children with Attention Deficit Hyperactivity Disorder (ADHD) preferred equal partnership between the doctor and parent.[51] These findings highlight the importance of understanding the family and their preferences. The issue of using information that is appropriate for the child's age and maturity has been mentioned in several studies. It is still not happening in practice, as shown in this study. This speaks to lack of skills or absence of material that can help health professionals. Materials can be in the form of information leaflets or cartoons that children can relate to. Doctors also need to simplify the language they use when speaking to children.

5.6. Children's views

Several studies have highlighted the importance of involving children in decision-making. At the same time, observational studies have shown how children are marginalized. Coyne et al (2006), reported how children felt when excluded from the consultation process. Children expressed feelings of sadness, disappointment, confusion, anger, shock, worry and betrayal. [41] Research has demonstrated good outcomes associated with involving children. Despite all this knowledge, we are still failing to engage children. This study like many studies showed that children were not informed about their diagnosis. Most children did not know their treatment options and were not informed about procedures to be carried out. Runeson [26] explored children's participation in decision-making during hospitalization and found that children were forced to undergo procedures with minimal preparation and information. The study also showed that most children (79%) did not ask questions during consultations. The question here was, were they not asking because they were not given a chance or because of fear of health professionals? Most of them reported that they were comfortable talking to health professionals. Sometimes parents can be the ones who hinder the participatory process, as highlighted in the literature review. Some parents still view children as minors who are not capable of making decisions, but expect them to be capable at the age of 18 years (when they are considered adults). ‘The lack of support from parents in relation to children’s active participation sends a clear message to children that they should be seen and not heard.’ [41] This view needs to change, because studies have shown that children are more than capable of expressing their views. In fact involving children early empowers them. Empowering children may pose a challenge to health professionals, because they will be more informed and may challenge their practices, which is a good thing. It will encourage a dialogue between all stake holders and hold health professionals accountable.

5.7. <u>Good medical practice</u>

The code of good medical practice highlights what is expected from registered health professionals. It is also intended for the community to know what to expect from doctors and nurses. The Health Professions Council of South Africa [62] recommends the following: (1) Listen to patients and respect their opinions. (2) Give information to patients in the way they can best understand it. The information must be given in a language that the patient understands and in a manner that takes into account the patient’s level of literacy, understanding, values and belief systems. (3) Respect the right of patients to be fully involved in decisions about their treatment and care even if they are not legally competent to give the necessary consent. These guidelines are similar to those that govern medical practice in other countries. For example the General Medical Council [57] also expects doctors to listen to patients, take account of their views, and respond honestly to their questions. The code goes on to say that children and young people must be involved as much as possible in discussions about their care, even if they are not able to make decisions on their own. Health professionals were asked to rate their day to day practice on three aspects; (1) Informing children about treatment and procedures, (2) giving patients a chance to ask questions, (3) giving parents a chance to ask questions. The majority of health professionals reported their practice as excellent or good, whereas most parents felt that the practice was average or poor. The differing views could mean that health professionals do not meet the parents’ expectations or preferences. This shows the need to understand the family and its preferences. Secondly, the health professionals’ assessment of their practice may be not be a reflection of reality. Whatever the causes are, this finding highlights the need to educate health professionals on how to communicate with patients and their families effectively. Doctors and nurses need to understand that people’s preferences differ. Parents and children need to be made aware of their rights, so that they can challenge what they perceive as treatment that is below standard.

6. CONCLUSION

This small study highlighted the inequalities of our country, those who can afford, use private health care, and the poor being dependent on state hospitals like Rahima Moosa Mother and Child Hospital. The general feeling is that private health care is better, however there is no research that compares the two. Parents in private hospitals are more educated and more likely to demand information from health professionals. All the above factors are conducive to better communication.

This research demonstrated the discrepancy between what the law expects from government, health professionals and parents versus the reality. The current economic state, lack of government commitment, lack of resources and skills and cultural views have been shown to contribute to this discrepancy.

The study also highlighted the need to involve children in health care. Their involvement should start with the design of their services and should continue in decisions about treatment. The United Kingdom and Ireland have done well in this regard. Both countries have legal frameworks that govern how children should be involved. There is a need to understand families, their cultural beliefs and preferences on how children should be involved in consultations.

In this study, most children and their parents wanted information to be given to parents. As much as the law advocates for children’s participation, it is important to understand that decision-making is a process that should be individualized. It is affected by culture, child’s illness, child’s personality, the relationship between the child and parent, and the relationship between parent and health professional. Health professionals need to give children an opportunity to voice their opinions and preferences, whilst cognizant that in most situations, children will not be the final decision makers.

Children’s lack of knowledge about their right to participate in decisions affecting them raises the question of whether they know about other rights. Children are the future leaders and consequently need to know about their rights and understand the responsibilities that come with having rights. They need to be empowered from an early age, so that as they grow, they develop skills to communicate with adults and their peers.

Article 5 of the United Nations Convention on the Rights of the Child [3] (UNCRC) respects the duties of parents, but also highlights the responsibilities of parents or guardians towards their children. Parental duties should be in a manner consistent with the evolving capacities of the child and in line with the convention. There is a need to educate parents about children's rights and the convention. Parents need to encourage children to speak up. Decision-making should involve all stakeholders. Children's voices need to be heard and considered.

There is a need for a cultural shift and a change in the way children are seen in health care. Whilst acknowledging the importance of protecting children and doing what is best for the child, a balance has to be created between protecting children and empowering them.

Health professionals' views on how they communicated with children was quite varied. The issue of age and competence was noted to be one of the reasons for not engaging children well. Health professionals need to be aware of the different ages of competence set out in the South African law. There are no policies or guidelines for health professionals on how to communicate effectively with children. Whilst consent and competence are important considerations, refusal to give consent is also participation. The lack of age appropriate information was highlighted in the study. This point raises another important question for health professionals: Is it age /competence that hinders the process of participation or the inability of health professionals to communicate effectively with children?

7. RECOMMENDATIONS

The following recommendations are made based on the above conclusions:

1. Government needs to commit to matters relating to children's rights in general, and especially in hospitals. More resources need to be allocated for training and to raise awareness. To raise awareness, the issue of children's rights must be discussed regularly. Hospitals need to educate staff and parents.

2. There is a need to raise awareness in communities, schools and hospitals about the children's right to participate in matters affecting them. The media and school curriculum can be ways of giving information to children and the community.

3. As part of raising awareness, a child friendly children's Charter should be made available and displayed in all hospitals that treat children.

4. Health professionals need training on how to communicate with children effectively.

5. A framework that guides nurses and doctors on how to engage children needs to be developed. This could mean adopting a framework that has been tried in other countries. (Appendix N)

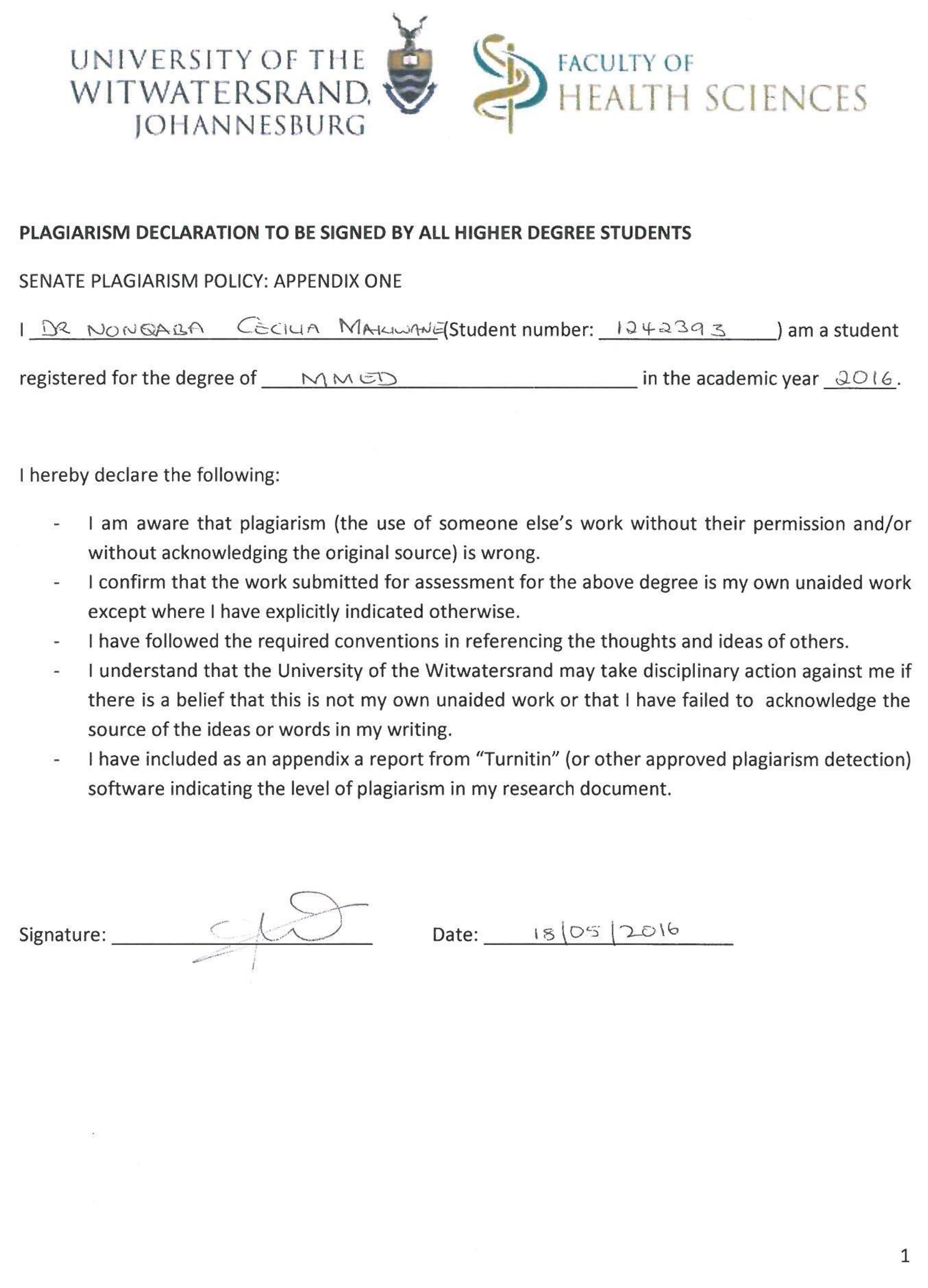
6. There is a need for a child friendly way of giving information. This could be in the form of leaflets and the use of cartoons that children can relate to. The language should be simple and easy to understand.

7. Community leaders and members of community (parents) need to understand the importance of empowering children with information, because they are the ones who will carry the country forward. Cultural practices that violate other children's rights need to be reviewed.

8. Further research is needed in the area of child advocacy in general. There is paucity of data in developing countries on research regarding children's views and children's rights. There is a need to encourage qualitative research in health sciences in order to understand the views of the communities we serve.

Appendix A

Plagiarism Declaration



UNIVERSITY OF THE
WITWATERSRAND,
JOHANNESBURG

FACULTY OF
HEALTH SCIENCES

PLAGIARISM DECLARATION TO BE SIGNED BY ALL HIGHER DEGREE STUDENTS

SENATE PLAGIARISM POLICY: APPENDIX ONE

I DR NONQABA CECILIA MAKWANE (Student number: 1242393) am a student registered for the degree of MMED in the academic year 2016.

I hereby declare the following:

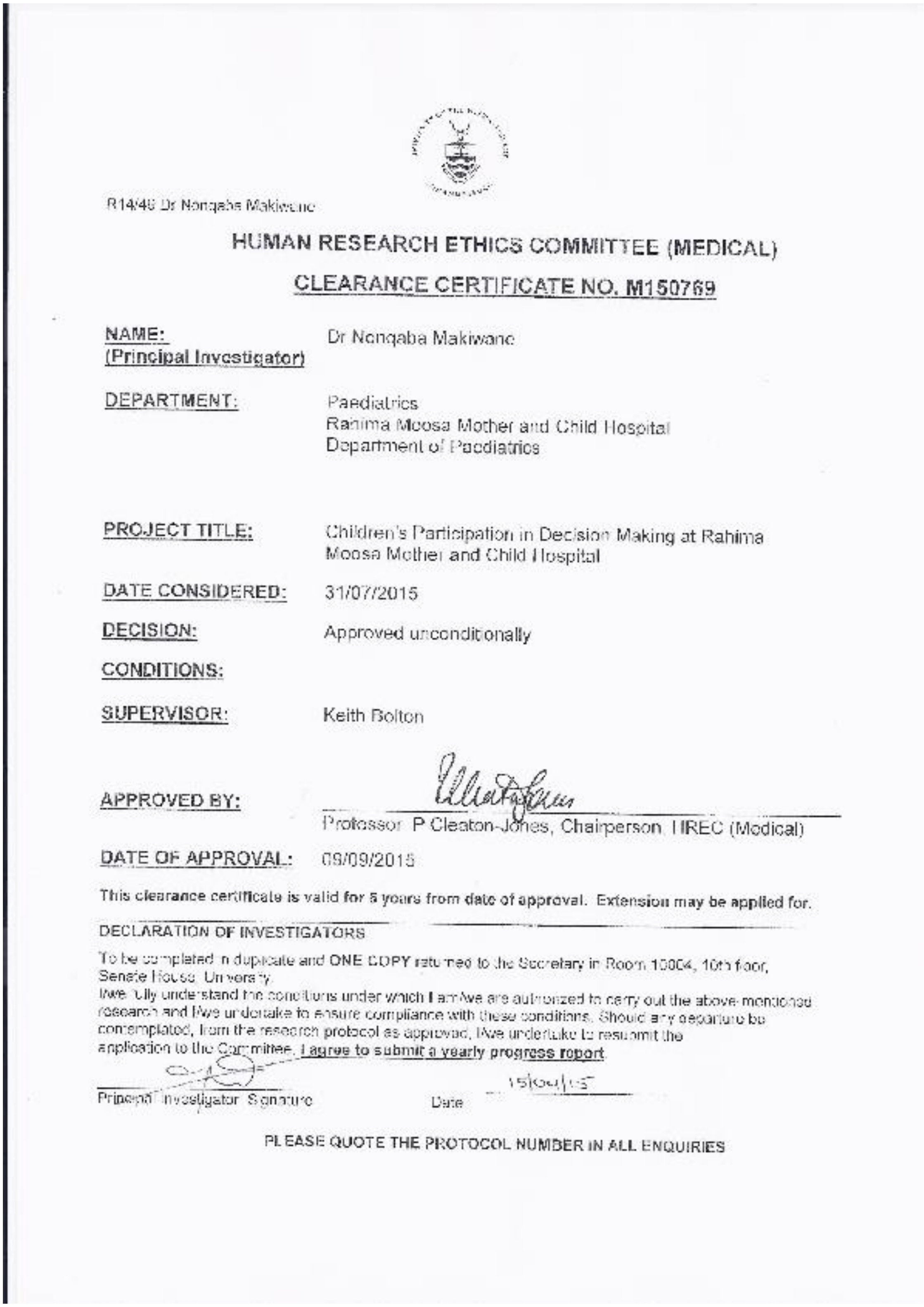
- I am aware that plagiarism (the use of someone else's work without their permission and/or without acknowledging the original source) is wrong.
- I confirm that the work submitted for assessment for the above degree is my own unaided work except where I have explicitly indicated otherwise.
- I have followed the required conventions in referencing the thoughts and ideas of others.
- I understand that the University of the Witwatersrand may take disciplinary action against me if there is a belief that this is not my own unaided work or that I have failed to acknowledge the source of the ideas or words in my writing.
- I have included as an appendix a report from "Turnitin" (or other approved plagiarism detection) software indicating the level of plagiarism in my research document.

Signature: ______________ Date: 18/05/2016

1

Appendix B

Ethics Clearance Certificate



R14/49 Dr Nonqaba Makiwane

HUMAN RESEARCH ETHICS COMMITTEE (MEDICAL)

CLEARANCE CERTIFICATE NO. M150769

NAME: (Principal Investigator)	Dr Nonqaba Makiwane
DEPARTMENT:	Paediatrics Rahima Moosa Mother and Child Hospital Department of Paediatrics
PROJECT TITLE:	Children's Participation in Decision Making at Rahima Moosa Mother and Child Hospital
DATE CONSIDERED:	31/07/2015
DECISION:	Approved unconditionally
CONDITIONS:	
SUPERVISOR:	Keith Bolton
APPROVED BY:	Professor P Cleaton-Jones, Chairperson, HREC (Medical)
DATE OF APPROVAL:	09/09/2015

This clearance certificate is valid for 5 years from date of approval. Extension may be applied for.

DECLARATION OF INVESTIGATORS

To be completed in duplicate and **ONE COPY** returned to the Secretary in Room 10004, 10th floor, Senate House, University.
I/we fully understand the conditions under which I am/we are authorized to carry out the above-mentioned research and I/we undertake to ensure compliance with these conditions. Should any departure be contemplated, from the research protocol as approved, I/we undertake to resubmit the application to the Committee. **I agree to submit a yearly progress report.**

Principal Investigator Signature

Date 15/04/15

PLEASE QUOTE THE PROTOCOL NUMBER IN ALL ENQUIRIES

Appendix C

STUDY NO: M150769

ASSENT FORM FOR CHILDREN BETWEEN AGES 6 – 12 YEARS

Topic: Children's Participation in decision-making at Rahima Moosa Mother and Child Hospital

Researcher: Dr Nonqaba Cecilia Makiwane

Paediatric Registrar (MBChB, DCH (SA), DRCOG- UK)

Tel: (011) 470 – 9078

Part 1

Information sheet:

Dear Master / Miss

My name is Dr Nonqaba Makiwane. I am a children's doctor at Rahima Moosa Mother and Child Hospital. I would like to ask you a few questions about how doctors and nurses talk to you when you are in hospital. I have asked for your parent/s' permission and s/he will sit with you when I ask the questions. You do not have to answer my questions if you do not want to, and you can stop at any time if you change your mind. Your answers will help improve the way doctors and nurses talk to children in hospital. The questions will take a very short time.

Part 2

I have read the above information and my questions have been answered to my satisfaction.

I agree that my child can be part of this research.

____

(Signature of parent)

____

(Right thumb print of the child/ Signature)

I do not agree for my child to be part of this research.

____

(Signature of parent)

____

(Right thumb of the child / Signature)

STUDY NO: M150769

Consent for Parents/ Caregivers

Topic: Children's Participation in decision-making at Rahima Moosa Mother and Child Hospital

Researcher: Dr Nonqaba Cecilia Makiwane

Paediatric Registrar (MBChB, DCH (SA), DRCOG- UK)

Tel: (011) 470 – 9078

Part 1

Information sheet:

Dear Sir / Madam

My name is Dr Makiwane. I am a doctor at Rahima Moosa Mother and Child Hospital. I am currently doing research.

I would like to invite you and your child to be part of a research project that will take place in ward 2 and 3, at Rahima Moosa Mother and Child Hospital, between 01/09/2015 – 3009/2015. The researcher will be interviewing all parents/ caregivers and their children between ages 6 – 12 years, admitted to ward 2 and 3 during the specified period.

The purpose of the research: To investigate the views of children, health professionals and caregivers/ parents when it comes to information given and involvement of children in decisions that are taken concerning their illnesses.

What do you need to do?

The interviewer (researcher) will ask you a few questions about your experience at Rahima Moosa Mother and Child Hospital, in relation to communication with doctors and nurses. This interview will take about 10 minutes. Participation in the study is voluntary and you can stop at any point, even if you had agreed before. Your name or your child's name will not be used and taking part in this research will not affect how the doctors and nurses treat your child. The results of the study will be handed over to management so that services at Rahima Moosa Mother and Child Hospital can be improved.

Part 2

I have read the above information and questions have been answered to my satisfaction.

I agree to be part of this research

(Signature of parent)

I do not agree to be part of this research

(Signature of parent)

(Witness)

STUDY NO: M150769

Consent for Health Professionals

Topic: Children's Participation in decision-making at Rahima Moosa Mother and Child Hospital

Researcher: Dr Nonqaba Cecilia Makiwane

Paediatric Registrar (MBChB, DCH (SA), DRCOG- UK)

Tel: (011) 470 – 9078

Part 1

Information sheet:

Dear Sir / Madam

My name is Dr Makiwane. I am a Paediatric registrar who is currently doing research. I would like to invite you to be part of a research project that will take place in ward 2 and 3, at Rahima Moosa Mother and Child Hospital, between 01/09/2015 – 30/09/2015. I am interviewing nurses and doctors working with children in these wards. I will also be interviewing the children and their parents.

The purpose of the study: To investigate if children are involved in decisions that are taken concerning their illnesses.

What do you need to do?

The researcher will hand out questionnaires which will ask about your practices in relation to communication with children in hospital. This will take about 5 – 10 minutes to complete. The researcher will collect the questionnaires the same day. You do not need to put your name on the questionnaire. Your participation is voluntary, you can stop being part of this research at any time. At the end of the study, the findings will be handed over to the head of department and management to try and improve services at Rahima Moosa Mother and Child Hospital.

Part 2

I have read the above information and questions have been answered to my satisfaction.

I agree to be part of this research

____

(Signature of parent)

I do not agree to be part of this research

____

(Signature of parent)

____

(Witness)

STUDY NO: M150769

QUESTIONNAIRE FOR HEALTH PROFESSIONALS

CHILDREN'S PARTICIPATION IN DECISION-MAKING AT RAHIMA MOOSA MOTHER AND CHILD HOSPITAL

RESEARCHER: DR NONQABA CECILIA MAKIWANE

Instruction: Please circle the applicable response

DEMOGRAPHICS

AGE (YEARS) : < 25 26 – 30 31 – 40 > 40

GENDER : Male Female

ETHNICITY : African Colored Asian White

CITIZENSHIP : South African Non- South African

EDUCATION : Below Matric Matric Post Matric Paediatric training

PROFESSION : Doctor Nurse

1. **Are you aware that children have the right to participate in decision-making concerning their health and to express their views?**

Comments	Yes	No

2. **Have you received specific training on how to effectively communicate with children in hospital?**

Comments	Yes	No

3. **How often do you explain to children what is wrong with them?**

Always	Often	Sometimes	Seldom	Never

4. **How often do you explain procedures and treatment to children?**

Always	Often	Sometimes	Seldom	Never

5. **How often do you speak to the child directly between the ages 6-9 years?**

Always	Often	Sometimes	Seldom	Never

6. **How often do you speak to the child directly between the ages 10 -12 years?**

Always	Often	Sometimes	Seldom	Never

7. **How often to you give children a chance to ask questions?**

Always	Often	Sometimes	Seldom	Never

8. **How often do you give the parent a chance to ask questions?**

Always	Often	Sometimes	Seldom	Never

9. **How often does the hospital provide you with age appropriate information (e.g. handouts) to hand over to children about their illness?**

Always	Often	Sometimes	Seldom	Never

10. **Do you agree that it is important to involve children when making decisions about their illness?**

Strongly agree	Agree	Disagree	Strongly Disagree

Thank you

Printed name of Interviewer…………………..

Signature of Interviewer…………………………. **Date ……………………….**

Appendix G

STUDY M150759

QUESTIONNAIRE FOR PARENTS/ CAREGIVERS

CHILDREN’S PARTICIPATION IN DECISION-MAKING AT RAHIMA MOOSA MOTHER AND CHILD HOSPITAL

RESEARCHER: DR NONQABA CECILIA MAKIWANE

DEMOGRAPHICS

AGE (YEARS): < 25 26 – 30 31 – 40 > 40

GENDER: Male Female

Ethnicity: African Coloured Asian Caucasian

CITIZENSHIP: South African Non- South African

EDUCATION: Below matric Matric Post matric

1. **Do you know about the children’s right to participate in decisions concerning their illness?**

Comments	Yes	No

2. **How often did the doctors / nurses tell you what is wrong with your child?**

Always	Often	Sometimes	Seldom	Never

3. **How often did the doctor/ nurse tell your child what is wrong with him/ her?**

Always	Often	Sometimes	Seldom	Never

4. **How often did the doctor/ nurse explain what they are going to do to him/ her or what medication he/ she needs to take?**

Always	Often	Sometimes	Seldom	Never

5. **How often did your child given a chance to ask questions?**

Always	Often	Sometimes	Seldom	Never

6. **How often were you given a chance to ask questions?**

Always	Often	Sometimes	Seldom	Never

7. **Do you agree that it is good for children to know what is wrong with them?**

Strongly agree	Agree	Disagree	Strongly disagree

8. **Would you like the doctor or nurse talked directly to your child about his or her illness (without telling you)?**

Comments	parent	child

9. **Overall, how happy were you with the way doctors and nurses talked to you about your child’s illness?**

Always	Often	Sometimes	Seldom	Never

Thank you

Printed name of Interviewer…………………..

Signature of Interviewer…………………………. Date ……………………….

STUDY NO: M150769

QUESTIONNAIRE FOR CHILDREN AGED 6 – 12 YEARS

CHILDREN'S PARTICIPATION IN DECISION-MAKING AT RAHIMA MOOSA MOTHER AND CHILD HOSPITAL

RESEARCHER: DR NONQABA CECILIA MAKIWANE

DEMOGRAPHICS

AGE:

GENDER: **Male** **Female**

LANGUAGE:

ETHNICITY: **African** **Coloured** **Asian** **Caucasian**

CITIZENSHIP: **South African** **Non- South African**

SCHOOL GRADE:

1. **Are you allowed to talk to doctors / nurses about your illness?**

Comments	Yes	No

2. **Did the nurse of doctor tell you what is wrong with you?**

Comments	Yes	No

3. **How much do you know about your illness?**

Comments	Nothing	Little	Everything

4. **Did the doctor or nurse talk directly to you or your parent about your illness?**

Comments	child	parent

5. **Did the doctor/ nurse tell you what they will do to you to make you better; and what medication you need to take to make you better?**

Comments	Yes	No

6. **Did you ask questions or tell the doctor /nurse how you felt?**

Comments	Yes	No

7. **Do you feel you can talk to the doctors and nurses about your illness?**

Comments	Yes	No

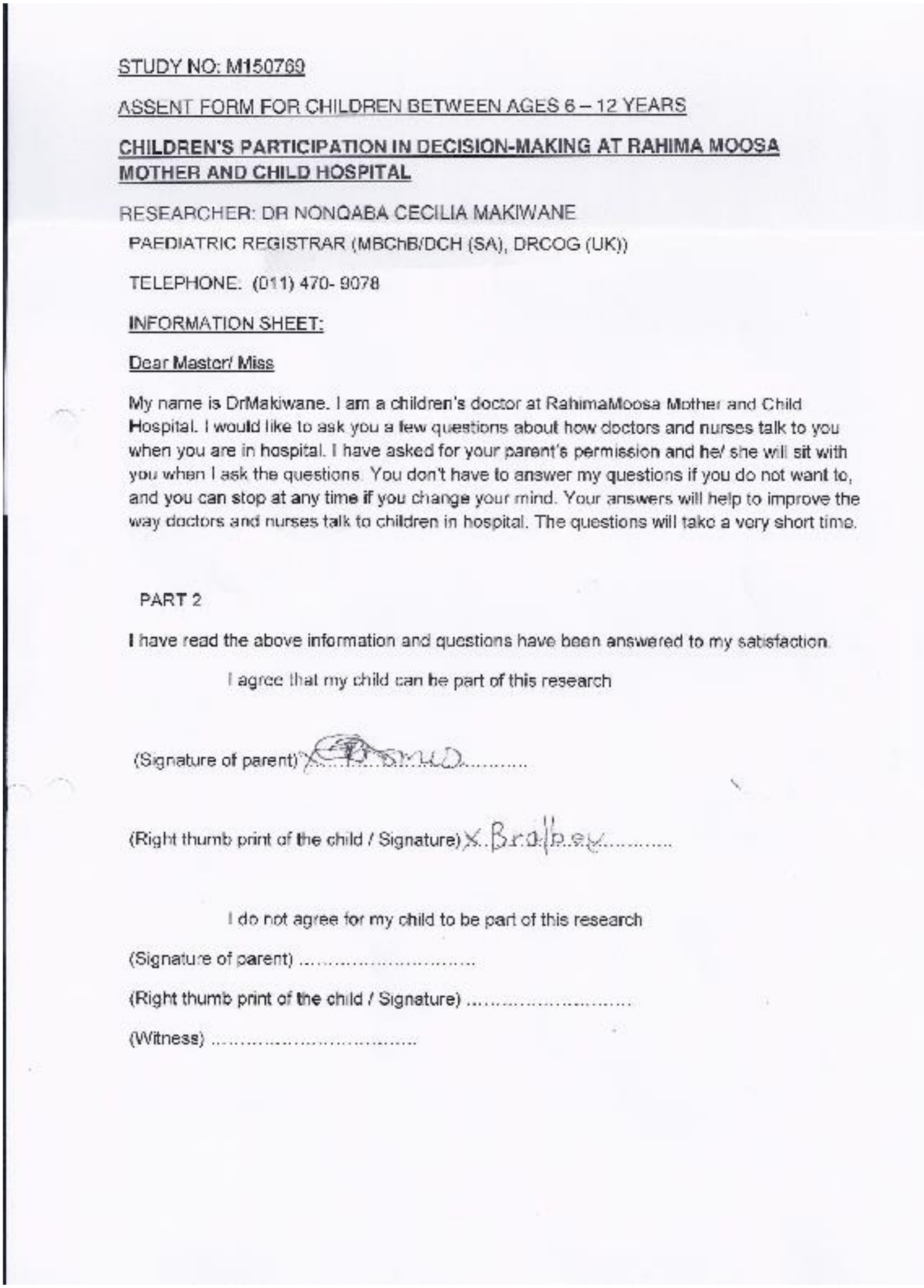
Thank you

Printed name of Interviewer…………………..

Signature of Interviewer…………………………. **Date ……………………….**

Appendix I

Scanned copy of assent form



STUDY NO: M150769

ASSENT FORM FOR CHILDREN BETWEEN AGES 6 – 12 YEARS

CHILDREN'S PARTICIPATION IN DECISION-MAKING AT RAHIMA MOOSA MOTHER AND CHILD HOSPITAL

RESEARCHER: DR NONQABA CECILIA MAKIWANE

PAEDIATRIC REGISTRAR (MBChB/DCH (SA), DRCOG (UK))

TELEPHONE: (011) 470- 9078

INFORMATION SHEET:

Dear Master/ Miss

My name is DrMakiwane. I am a children's doctor at RahimaMoosa Mother and Child Hospital. I would like to ask you a few questions about how doctors and nurses talk to you when you are in hospital. I have asked for your parent's permission and he/ she will sit with you when I ask the questions. You don't have to answer my questions if you do not want to, and you can stop at any time if you change your mind. Your answers will help to improve the way doctors and nurses talk to children in hospital. The questions will take a very short time.

PART 2

I have read the above information and questions have been answered to my satisfaction.

I agree that my child can be part of this research

(Signature of parent) ....

(Right thumb print of the child / Signature) X Bradley............

I do not agree for my child to be part of this research

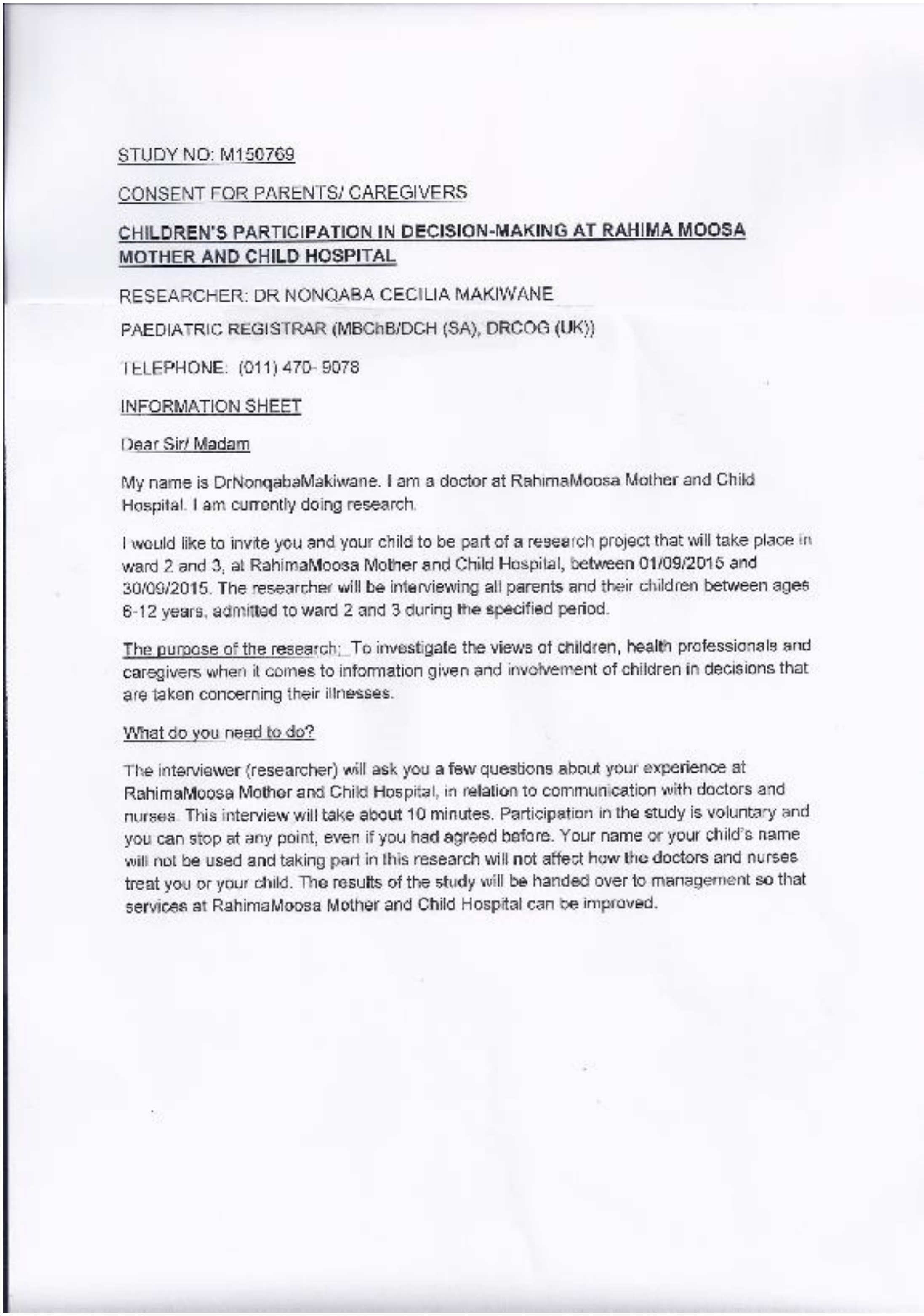
(Signature of parent) ....

(Right thumb print of the child / Signature) ....

(Witness) ....

Appendix J

CONSENT FOR PARENTS



STUDY NO: M150769

CONSENT FOR PARENTS/ CAREGIVERS

CHILDREN'S PARTICIPATION IN DECISION-MAKING AT RAHIMA MOOSA MOTHER AND CHILD HOSPITAL

RESEARCHER: DR NONQABA CECILIA MAKIWANE

PAEDIATRIC REGISTRAR (MBChB/DCH (SA), DRCOG (UK))

TELEPHONE: (011) 470- 9078

INFORMATION SHEET

Dear Sir/ Madam

My name is DrNonqabaMakiwane. I am a doctor at RahimaMoosa Mother and Child Hospital. I am currently doing research.

I would like to invite you and your child to be part of a research project that will take place in ward 2 and 3, at RahimaMoosa Mother and Child Hospital, between 01/09/2015 and 30/09/2015. The researcher will be interviewing all parents and their children between ages 6-12 years, admitted to ward 2 and 3 during the specified period.

The purpose of the research: To investigate the views of children, health professionals and caregivers when it comes to information given and involvement of children in decisions that are taken concerning their illnesses.

What do you need to do?

The interviewer (researcher) will ask you a few questions about your experience at RahimaMoosa Mother and Child Hospital, in relation to communication with doctors and nurses. This interview will take about 10 minutes. Participation in the study is voluntary and you can stop at any point, even if you had agreed before. Your name or your child's name will not be used and taking part in this research will not affect how the doctors and nurses treat you or your child. The results of the study will be handed over to management so that services at RahimaMoosa Mother and Child Hospital can be improved.

PART 2

I have read the above information and questions have been answered to my satisfaction.

I agree to be part of this research

……………………………………………………………………………

(Signature of parent)

I do not agree to be part of this research

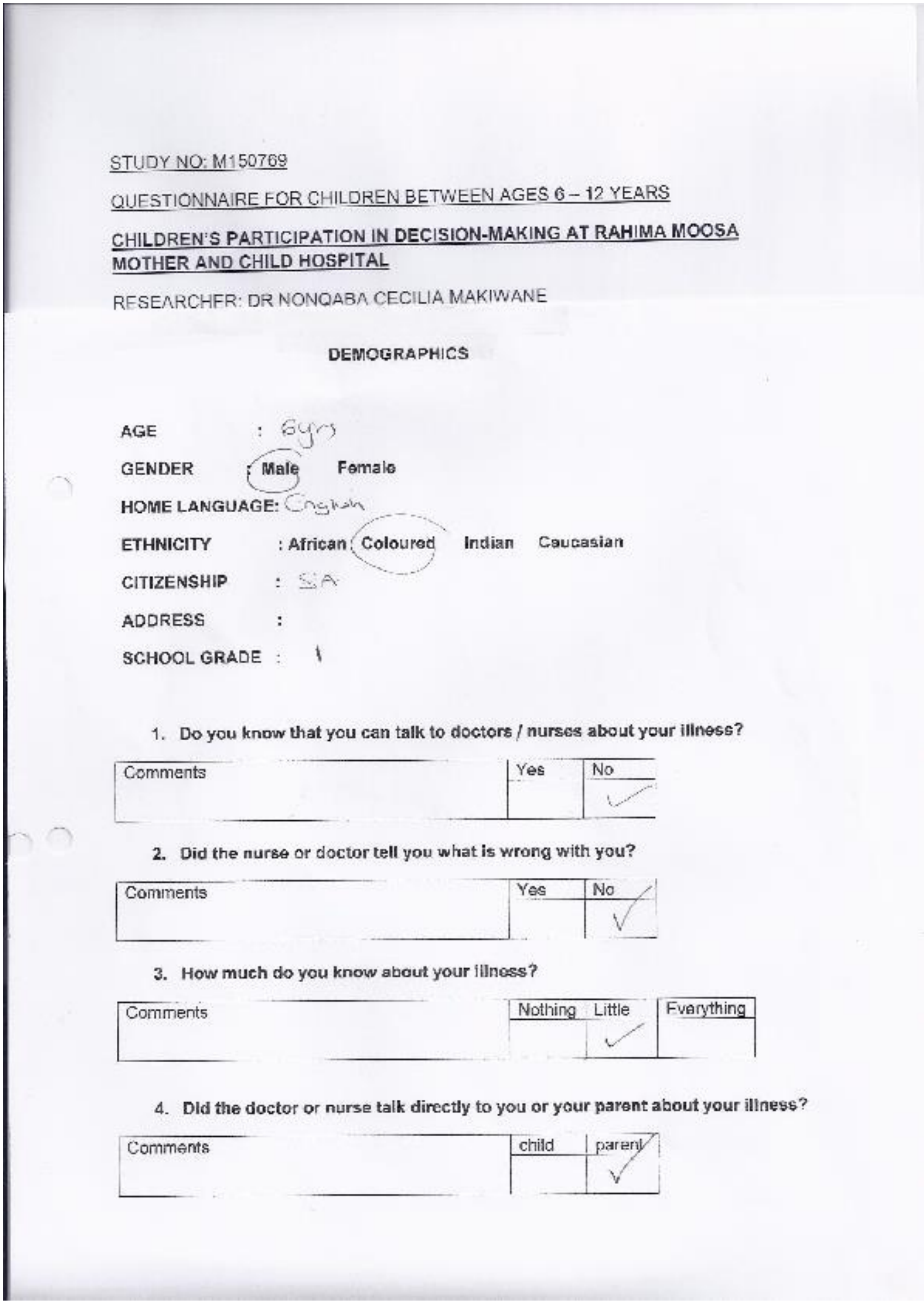
……………………………………………………………………………

(Signature of parent)

……………………………………………………………………………

(Witness)

Questionnaire for Children



STUDY NO: M150769

QUESTIONNAIRE FOR CHILDREN BETWEEN AGES 6 – 12 YEARS

CHILDREN'S PARTICIPATION IN DECISION-MAKING AT RAHIMA MOOSA MOTHER AND CHILD HOSPITAL

RESEARCHER: DR NONQABA CECILIA MAKIWANE

DEMOGRAPHICS

AGE : 6yrs

GENDER : [✓ Male] Female

HOME LANGUAGE: English

ETHNICITY : African [✓ Coloured] Indian Caucasian

CITIZENSHIP : SA

ADDRESS :

SCHOOL GRADE : 1

1. **Do you know that you can talk to doctors / nurses about your illness?**

Comments	Yes	No
		✓

2. **Did the nurse or doctor tell you what is wrong with you?**

Comments	Yes	No
		✓

3. **How much do you know about your illness?**

Comments	Nothing	Little	Everything
		✓	

4. **Did the doctor or nurse talk directly to you or your parent about your illness?**

Comments	child	parent
		✓

5. **Did the doctor/ nurse tell you what they will do to you to make you better; and what medication you need to take to make you better?**

Comments	Yes	No
		✓

6. **Did you ask questions or tell the doctor /nurse how you felt?**

Comments	Yes	No
		✓

7. **Do you feel you can talk to the doctors and nurses about your illness?**

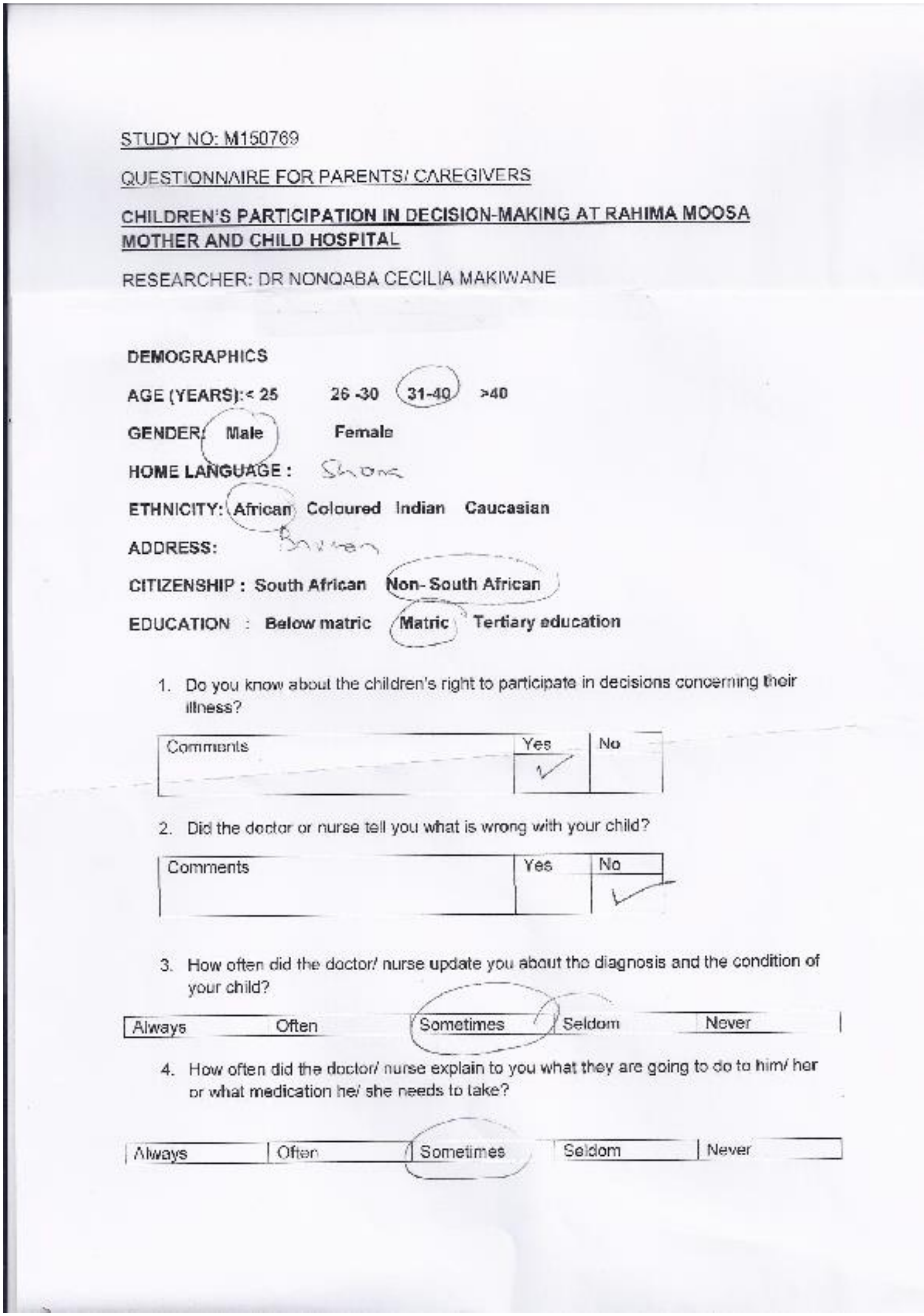
Comments	Yes	No
	✓	

Thank you

Printed name of Interviewer...D.T. Makuwane.........

Signature of Interviewer.................................... **Date** ...02/09/15.........

Questionnaire for Parents/Caregivers



STUDY NO: M150769

QUESTIONNAIRE FOR PARENTS/ CAREGIVERS

CHILDREN'S PARTICIPATION IN DECISION-MAKING AT RAHIMA MOOSA MOTHER AND CHILD HOSPITAL

RESEARCHER: DR NONQABA CECILIA MAKIWANE

DEMOGRAPHICS

AGE (YEARS): < 25 26 -30 [✓ 31-40] >40

GENDER: [✓ Male] Female

HOME LANGUAGE : Shona

ETHNICITY: [✓ African] Coloured Indian Caucasian

ADDRESS: Brixton

CITIZENSHIP : South African [✓ Non- South African]

EDUCATION : Below matric [✓ Matric] Tertiary education

1. Do you know about the children's right to participate in decisions concerning their illness?

Comments	Yes ✓	No

2. Did the doctor or nurse tell you what is wrong with your child?

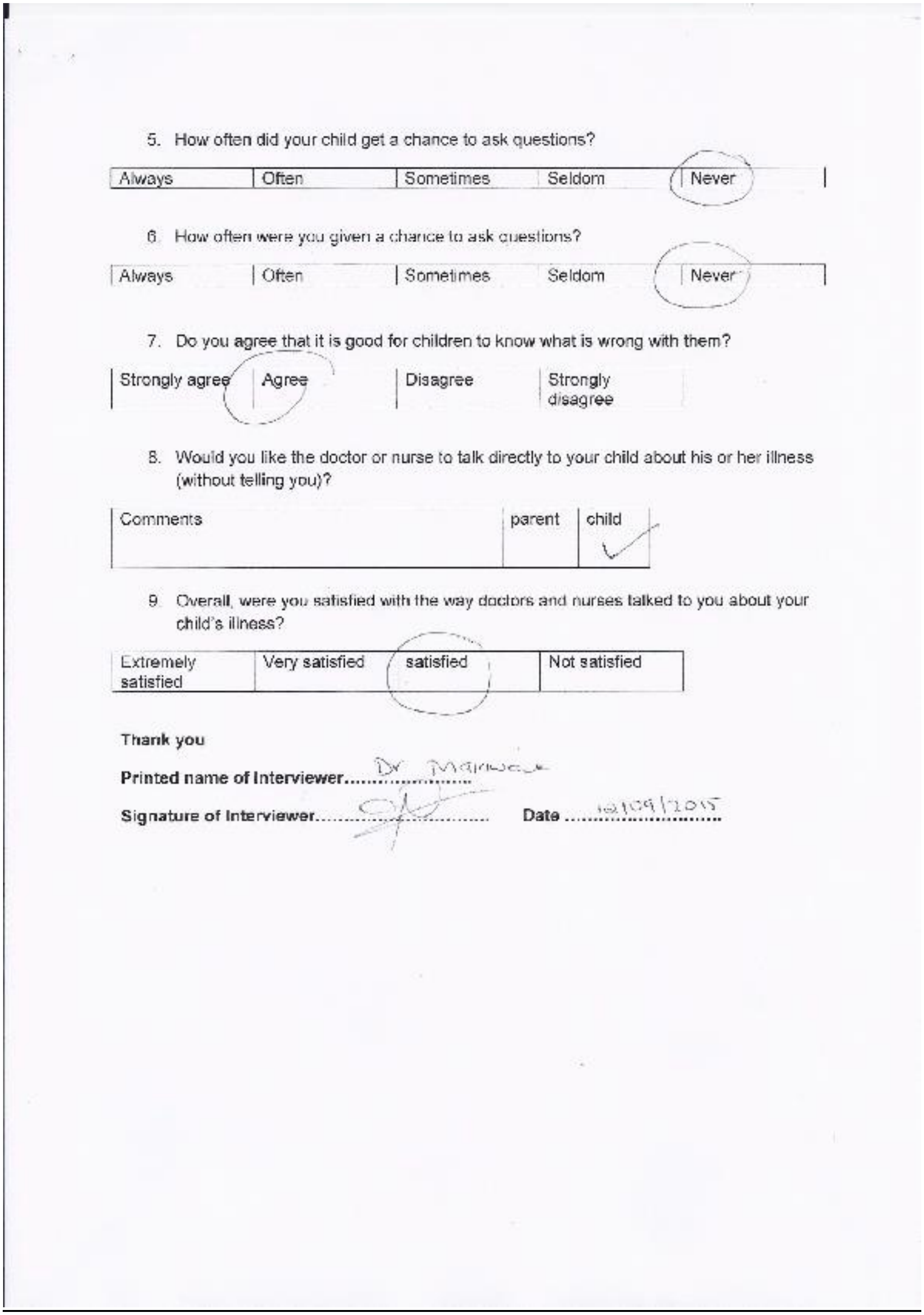
Comments	Yes	No ✓

3. How often did the doctor/ nurse update you about the diagnosis and the condition of your child?

Always	Often	[✓ Sometimes]	Seldom	Never

4. How often did the doctor/ nurse explain to you what they are going to do to him/ her or what medication he/ she needs to take?

Always	Often	[✓ Sometimes]	Seldom	Never



5. How often did your child get a chance to ask questions?

Always	Often	Sometimes	Seldom	[✓ Never]

6. How often were you given a chance to ask questions?

Always	Often	Sometimes	Seldom	[✓ Never]

7. Do you agree that it is good for children to know what is wrong with them?

Strongly agree	[✓ Agree]	Disagree	Strongly disagree

8. Would you like the doctor or nurse to talk directly to your child about his or her illness (without telling you)?

Comments	parent	child ✓

9. Overall, were you satisfied with the way doctors and nurses talked to you about your child's illness?

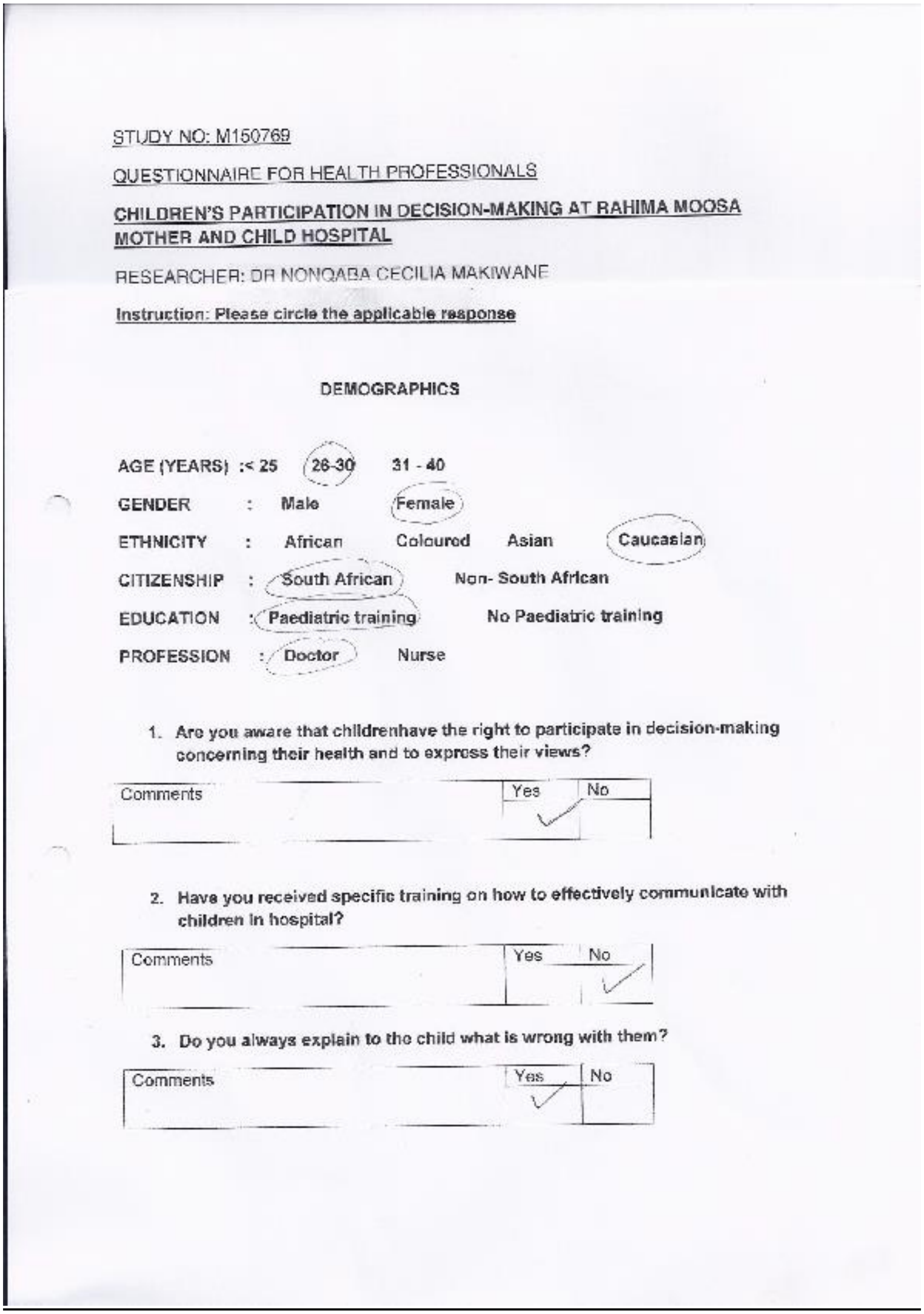
Extremely satisfied	Very satisfied	[✓ satisfied]	Not satisfied

Thank you

Printed name of Interviewer......Dr Mainwa......

Signature of Interviewer.............................. **Date** ....10/09/2015....

Questionnaire for Health professionals



STUDY NO: M150769

QUESTIONNAIRE FOR HEALTH PROFESSIONALS

CHILDREN'S PARTICIPATION IN DECISION-MAKING AT RAHIMA MOOSA MOTHER AND CHILD HOSPITAL

RESEARCHER: DR NONQABA CECILIA MAKIWANE

Instruction: Please circle the applicable response

DEMOGRAPHICS

AGE (YEARS) :< 25 [✓ 26-30] 31 - 40

GENDER : Male [✓ Female]

ETHNICITY : African Coloured Asian [✓ Caucasian]

CITIZENSHIP : [✓ South African] Non- South African

EDUCATION : [✓ Paediatric training] No Paediatric training

PROFESSION : [✓ Doctor] Nurse

1. **Are you aware that childrenhave the right to participate in decision-making concerning their health and to express their views?**

Comments	Yes	No
	✓	

2. **Have you received specific training on how to effectively communicate with children in hospital?**

Comments	Yes	No
		✓

3. **Do you always explain to the child what is wrong with them?**

Comments	Yes	No
	✓	

4. **How often do you explain procedures and treatment to children?**

[✓ Always]	Often	Sometimes	Seldom	Never

5. **How often do you speak to the child directly between the ages 6-9 years?**

[✓ Always]	Often	Sometimes	Seldom	Never

6. **How often do you speak to the child directly between the ages 10 -12 years?**

[✓ Always]	Often	Sometimes	Seldom	Never

7. **How often to you give children a chance to ask questions?**

[✓ Always]	Often	Sometimes	Seldom	Never

8. **How often do you give the parent a chance to ask questions?**

[✓ Always]	Often	Sometimes	Seldom	Never

9. **How often does the hospital provide you with age appropriate information (e.g. handouts) to hand over to children about their illness?**

Always	Often	Sometimes	Seldom	[✓ Never]

10. **Do you agree that it is important to involve children when making decisions about their illness?**

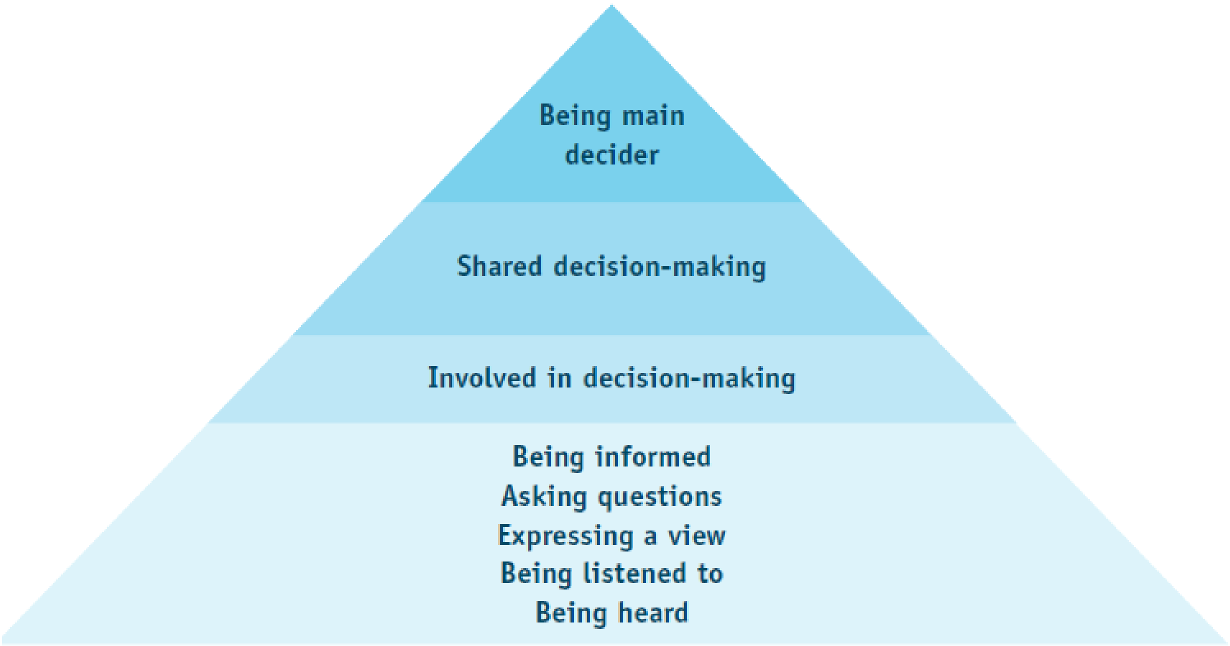
[✓ Strongly agree]	Agree	Disagree	Strongly Disagree

Thank you

Date 18/9/15

Appendix N

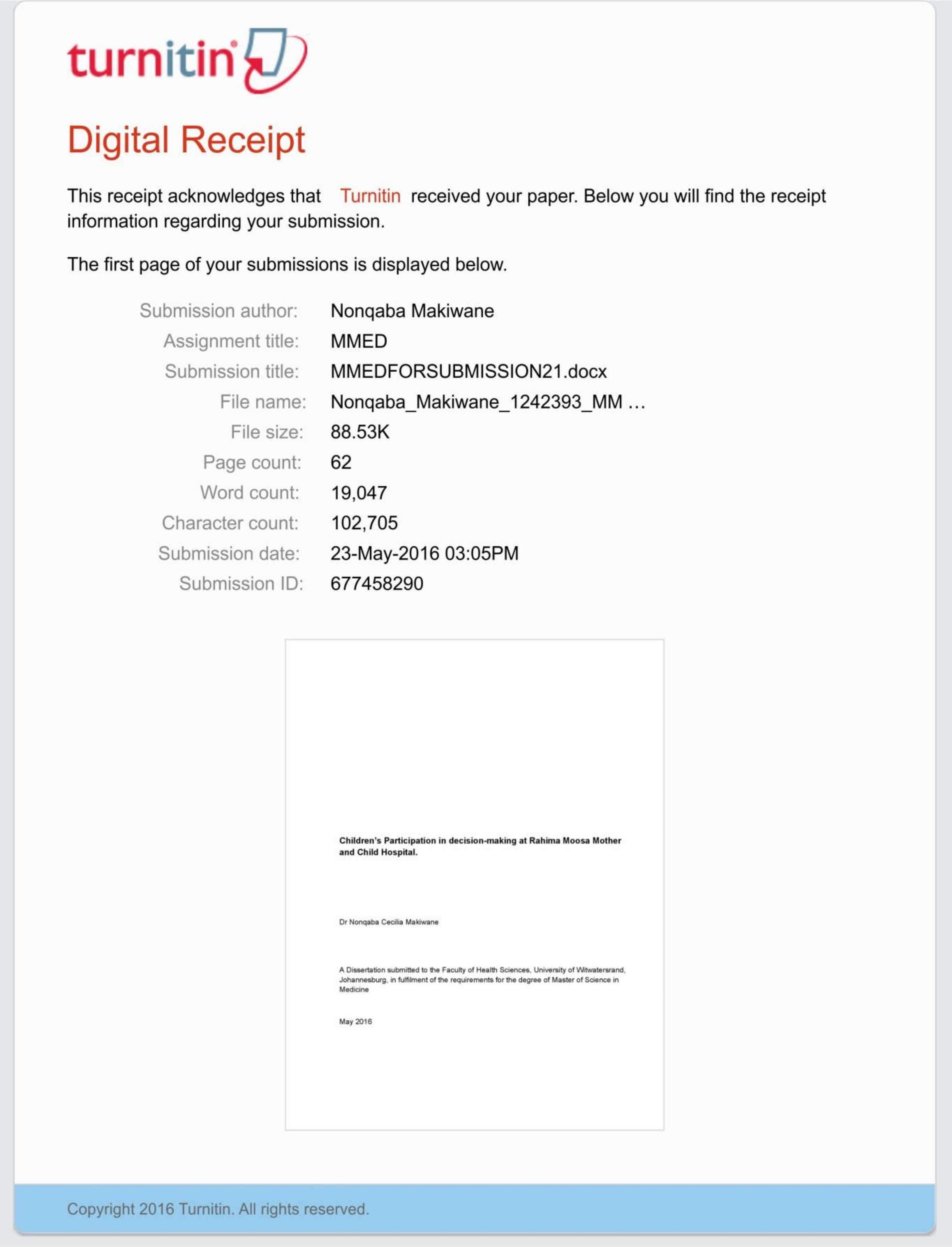
Participation Framework



Source: Coyne et al. 2006. Giving Children a Voice. The National Children’s Strategy Research series.

Appendix O

Turnitin Report



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Children's Participation in decision-making at Rahima Moosa Mother and Child Hospital.

Dr Nonqaba Cecilia Makiwane

A Dissertation submitted to the Faculty of Health Sciences, University of Witwatersrand, Johannesburg, in fulfilment of the requirements for the degree of Master of Science in Medicine

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