Shared Decision Making in Paediatric Oncology

Master Thesis

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Submission Date: 05/08/2021

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Word Count: 15,569

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Preface

This thesis was written as a final stage for graduation obtaining a Master's degree in Health Economics, Policy and Law at Erasmus University, Rotterdam. This process has been a pleasantly educational and exciting stage of the program. To be able to conduct research on my own, I have gained some skills that I will now be able to use in the next phase of my career. It has taught me the importance of perseverance and consistency. Along this journey, there have been a few mishaps. Nevertheless, the main lesson to take away from these setbacks was to keep going regardless of what may. I would therefore like to thank all of the paediatric oncologists in the NHS for their time and input in taking part in this research as without their time and effort this would not have been possible. I would also like to thank my friends and fellow students who have proofread my thesis. Additionally, I would like to thank my supervisor and the reading committee for their useful feedback. Lastly, I would like to thank my family for their continuous support.

I hope this will be an insightful and enjoyable read.

Summary

The prevalence of cancer in children makes shared decision-making now more than ever extremely imperative. Especially during the current global pandemic and scarce resources within the NHS. Shortened length of consultations is only one of many consequences resulting from limited resources available. Over the years, the shared decision-making model has become a popular discussion in health care provision in the United Kingdom. According to existing studies, a number of general impediments were identified that prevents a forward drive in the shared decision-making model. Questions remain whether other obstacles other than resources also contribute to the slow take up of SDM.

In children's cancer services, coming together to decide on the right treatments options is vital as it is often the starting point towards a journey to recovery. The impediments associated with shared decision making is especially crucial during conversations when it is done in collaboration with concerned and distressed parents or guardians who may not fully understand the severity of the chronic conditions and to which extent treatment options may affect their child. Once these impediments are identified using the experiences of those who are at the forefront of the process, only then can solutions be made to improve shared decision making. An improvement in this process strengthens the bond and encourages an open positive dialogue between the doctor and parents in any area where communication plays a key part.

This study is based on the following research question: ***What are the existing impediments experienced by doctors and the potential solutions for successfully implementing SDM in paediatric oncology treatments in the United Kingdom?***

The study found although the paediatric oncologists had some knowledge of the core fundamentals of the shared decision-making process, they also showed a lack of awareness in practice causing a delay in the successful implementation of shared decision making. Their perception of the decision-making process differed. Many of the interviewed doctors mentioned their role was to act as a guide. However, when it came to answering who the actual decision maker was in the shared decision-making process, some doctors proceeded to state they were either indirectly the main cause of influence by coercing parents or directly by stating they perceive themselves as the main influence without taking into account the views of the parents. Resulting in the elimination of the SDM process in clinical practice.

Despite the efforts shown by the doctors in proving that they do take into account SDM during the process of offering treatments, the main obstacles simply narrow down to the necessary resources namely training, policies and procedures not targeting and recognising SDM as a standalone model.

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1.Introduction

Shared decision making (SDM) was first mentioned in the United States in a report by the president's commission (Michigan law review, 1984). Charles et al, (1997) highlighted the theoretical clarity concerning SDM. He expressed the SDM method is most useful during key stages in disease processes where alternative competing treatment options with uncertainty may exist. Some distinctions have been noticed in the way SDM has been defined over the last 30 years (Makoul & Clayman, 2006). In essence, the concept of SDM is easy to comprehend; it is about connecting the patients and doctors in the process of making decisions (Elwyn et al, 2010).

SDM is a key element in any area in the health sector that empowers patient-centred care. The conversation that occurs during SDM unites both the clinical expertise of doctors and patient preferences, values and beliefs (NHS choices, n.d). Patients are encouraged to think about the available screening, treatment and management options. Also, the likely benefits and harms of each treatment option enables patients to communicate their preferences and helps them select the best course of action. In addition, SDM respects and exercises patient autonomy and promotes patient engagement (Elwyn et al, 2010). Despite the many benefits of SDM, a number of challenging encounters and conflicts may arise during SDM conversations (Rapport et al, 2018).

SDM becomes more complex in chronic conditions like cancer. It becomes even more complicated in conversations involving vulnerable children who require urgent treatment in comparison to adult clinical practice (Rapport et al, 2018). One of the main reasons for the increased complexity being the inclusion of multiple stakeholders for instance parents, the patient (child) and healthcare professionals each with their own preferences (Rapport et al, 2018).

The adoption of the SDM model in health care has been fairly slow over the last few years (Maskrey, 2019). This slow progression of SDM is the result of lack of research and education as well as the ineffectiveness of current SDM strategies used in practice. The approach to adopting an effective SDM process in health care often varies between countries and is dependent on numerous factors. One of these factors include the way in which the health care system is set up and the impact of financing healthcare in terms of resource allocation and policy changes. In the United Kingdom (UK), most citizens depend on the National Health Service (NHS) for almost all health care needs. It is largely funded out of taxation with the service covering primary, community and mental health care. Changes within the system largely impact policies within the scope of doctors' work responsibilities on a micro level and national guidelines or requirements on a micro level.

In the UK, SDM is included in the NHS Constitution as a set requirement of the General Medical Council (GMC) who are the regulatory licensing body for doctors. It is also recommended as usual practice by

NHS England (NHS choices, n.d). Likewise, SDM is included in the guidelines set by the National Institute for Health and Care Excellence (NICE). There are number of active research groups that mostly focus on the development of new interventions. A new government in 2010 included SDM as a central policy drive even though limited funding was given to support the work. With this limited funding, the NHS commissioned NHS Direct to host online decision aids as a method of SDM. Decision aids aim to inform and highlight options, risks, benefits and consequences associated to various number of conditions such as prostate cancer (Sepucha et al., 2013). However, questions remain whether decision aids are used in paediatric cancer services and the impacts of the usage of these decision aids are in clinical practice across the NHS (Härter et al., 2011).

The latest statistics on children cancer diagnosis incidences show there are around 1,900 new children's cancer cases in the UK every year. That's around five diagnosed each day during the years 2015-2017 (Cancer research, 2021). The most common type of cancer being Leukaemia (Irvine, 2021).

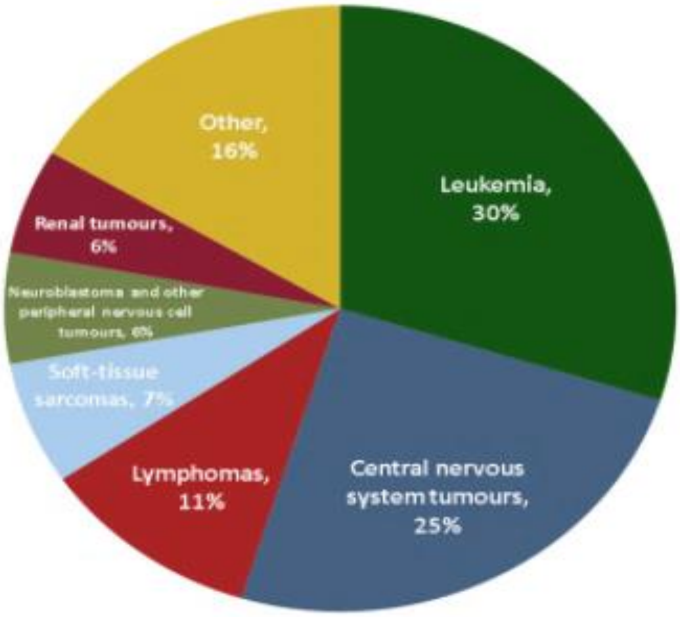

Figure 1. Children cancer types (Irvine, 2021).

In view of these statistics, each incidence of diagnosis involves some parts of SDM. In paediatric oncology many obstacles can arise. The main focus of SDM in paediatric oncology is to have the best interest of the child. This can easily be neglected when miscommunication occurs between the different stakeholders involved. Coulter et al. (2017) reports, despite the prominent interest and progress of implementing SDM across the NHS, many health care professionals still fail to comply with the requirements to inform and involve all of the decisions that may or may not affect their health. Further complexities can arise when a child reaches a certain age with the ability to express their own views on potential treatments (Coyne et al, 2016). This also raises a concern surrounding the benefits and effectiveness of the current SDM method of practice for paediatric oncologists across the NHS. Additionally, it questions whether the model aims to satisfy all agents involved and what interventions are most useful in clinical practice (Coyne et al, 2016). Information and research related to SDM in paediatric oncology is however limited especially within the NHS. With these gaps in research, this study will look to outline the perspectives and experiences of paediatric oncologist in order to form a deeper understanding of the usage and key considerations of the SDM model. The findings in this research will be used to lay the foundations for future policy making and provide recommendations to overcome the impediments identified in the process of conducting this research.

1.1 Societal relevance

In research, it is beneficial to highlight the societal and scientific relevance. Societal relevance refers to the benefits to society as a result of increased understanding i.e., findings of a study (Wilbertz, 2013).

In a society, the need to build a trusting bond between health care providers and patients plays a central theme in SDM. Communication is the centre of good patient centred care (Aiello et al, 2008) and minimises the risk of miscommunication. The Agency for Healthcare Research and Quality (n.d.) mentioned greater consumer involvement in decision making leads to lower demand for health resources. This is deemed beneficial for society as resources in the UK are already scarce. This is especially relevant considering the rising number of childhood cancer diagnosis over the last few years. Thus, this study provides a greater insight on micro and macro level factors such as training programmes offered in the NHS as well as relevant national guidelines followed by an in-depth analysis of how doctors experience SDM and to identify their contributions or restraints to the impediments in the practice of SDM.

This thesis examines these aspects of SDM in the context of paediatric oncology. The results of this study will potentially support policy makers in the NHS and other health providers by providing future policy recommendations used in clinical practice.

1.2 Scientific relevance

Scientific relevance refers to the idea of a study increasing the understanding of a disease or a process (Wilbertz, 2013). In the context of paediatric oncology, the scientific relevance of this thesis aims to increase the understanding of decision processes for treatments in paediatric oncology.

Most existing research is based on general views of SDM impediments yet existing literature on impediments for paediatric oncology specifically are minimal. As a result, this research will support the existing research on paediatric oncology SDM and build upon the gaps to support the progression of implementing SDM as a standard practice across the NHS. A gap in scientific knowledge exists regarding doctor views and the understanding of their own SDM practices. Often chronic conditions require having intense and complicated conversations. Therefore, to bridge the gap between the causes of delay in SDM and the successful implementation that drives SDM forward, it is necessary to start with the most difficult circumstances and areas with those who are at the forefront of SDM.

With the central theme being communication, in cases where more than one party is involved in the process, it is easy to lose sight of the end goal (Aiello et al, 2008). It is therefore advisable to have a structured plan of action. Thus, the research study will dive deeper into the perspective of doctors along with relevant policies and guidelines used in the NHS which will allow the exploration of methods used as well as their pitfalls. To do this, the role of the doctors and their experiences in SDM will be used as a framework in conjunction with references to previous decision-making models.

1.3 Research objectives & question

The core objective of this research is to identify the impediments in SDM in paediatric oncology practice from a doctor's perspective working in the NHS. Moreover, the research sets out to establish three main objectives. These are:

- To identify, understand and analyse the impediments in paediatric oncology using doctor experiences
- To explore the various SDM NHS hospital and national guidelines processes in order to understand the extent to which these are used.
- To provide recommendations and identify practical solutions to the impediments found in the data collected

To meet these three main objectives, some macro (legal, regulatory and national), meso (attitudes and support) and micro (day to day operations) level factors were considered in this research to detect if these contributed to the obstacles based on doctor responses (Sawatzky et al., 2021). Meeting these objectives will assists in potential changes in existing and new policies and procedures followed in clinical practice on both national and organisational levels.

To constructively answer the objectives of this research using the data collection, I formulated a central research question;

What are the existing impediments experienced by doctors and the potential solutions for successfully implementing SDM in paediatric oncology in the United Kingdom?

1.4 Reader’s guide

In the following chapter, the different components of SDM strategies and models are constructively examined as well as existing literature based on SDM in relation to the NHS. Next, in chapter three the methods that were used to obtain the data and perform the empirical analysis are clarified. Consecutively, the main findings of the data collection will be presented in chapter four. Lastly, chapter five and six will gather the findings derived from the results to form conclusions and discuss the potential recommendations for future shared decision policy making.

2. Theoretical framework

The theoretical framework contains all concepts that are relevant to the research question. This section of the thesis expands more precisely on the various dimensions that contribute to the execution and the obstacles that delay the successful SDM implementation. Processes can differ in SDM depending on the relevant context and situation as mentioned in the introduction. However, in this thesis, the focus is on paediatric oncology SDM within the NHS. The following sections will discuss the key models relevant to the research derived from existing literature.

2.1 What is the SDM model?

The SDM model in health care over the years has gained enhanced prominence in health policy (Elwyn & Frosch,2012). The principles that underpin this model are patient autonomy, control and the ability to challenge to physician authority. This is based on the fundamental moral principles of respecting patient autonomy (the ability to make one's own decisions) and the duties for healthcare professionals of beneficence (doing good) and non-maleficence (not doing harm) (Gillon, 1994). It is about decreasing the power asymmetry between doctors and patient through; increase of information available to patients, sense of autonomy and control over treatments decision in line with their patients' rights and doctor boundaries (Emanuel, 1992). Furthermore, it is about changing the narrative and/or nature of medical practice in chronic diseases because in most similar cases physicians tend to build long term relationships with patients. In order to fully grasp the concept of SDM in paediatric oncology it is necessary to understand the full meaning of the process. Therefore, the following definition will be used in this research as it gives a clear and comprehensible view of the model:

"It is the process of converging clinicians and patients to reach an agreement on the best outcome for treatments and care plans based on clinic evidence" **(Desroches, 2010).**

The rising interest in SDM originates from previous models and legal rights, for example informed consent which is now established as an ethical and legal basic patient right. Some level of SDM occurs when informed consent is given. According to Charles et al, SDM involves a number of characteristics:

- At least two participants involved i.e., physician and patient
- Parties should take the necessary steps to participate in the process
- Information sharing is a requirement
- A treatment decision is made and both parties agree

SDM is only one of other former treatment decision models. Other models exist such as the paternalistic model, the informed decision-making model and the professional-as-agent model. Each of these prototype models to a certain extent contain necessary elements that make up the SDM model. This has been explained in depth by Charles et al, (1997). He has clarified that the informed decision-making model and paternalism model closely resonate with the current SDM model used in healthcare practices. SDM is positioned as a balance of both models. Distinctions and similarities of these models will be discussed in the next few paragraphs.

As previously mentioned, informed consent plays a crucial part in SDM. It also forms a fundamental part in the informed decision-making model (Emanuel, 1992). In this model, the power is mainly given to the patient rather than the doctor and often limits their role. In contrast to this, the paternalistic approach limits the role of the patient and allows the doctor to dominate the decision making using his expertise to make the necessary decision in the best interests of the patients (Emanuel, 1992). This makes a fascinating case in this study considering how doctors actually perceive their role and their preferences in decision making power in paediatric oncology.

In contrast, the professional-as-agent model is quite the opposite of the informed decision-making model. The primary goal of this model is to also resolve the information asymmetry between physicians and patients. However, the physician assumes in this case that they hold the responsibilities for guidance of utilities available to the patient (Emanuel, 1992). In essence, the ultimate decision is made by the physician who takes into account the views of the patients based on for example their lifestyle or how they would like to live life in the future (Emanuel, 1992).

In the UK, offering SDM is a legal requirement based on the ruling by the UK Supreme Court in the case of Montgomery versus Lanarkshire Health Board (Sokol 2015). Although this is an obligation to fulfil, research indicates there may be cases where the doctor knows it is illegal to proceed with treatments without consent but still goes ahead and proceeds. In hopes that the patient does not launch a legal suit claiming a breach of their violation of patient rights to informed consent (Emanuel, 1992).

Aspects of these models used in common practice can also be used to explain the reasons behind the slow growth and recognition of SDM in present time.

2.2 SDM in paediatric oncology

In life changing or even life-threatening diseases like cancer that are predominant today in health care, patients and families are left to make difficult decisions that may end up with major mental or physical consequences. Examples of difficult circumstances in paediatric oncology could be where parents with a teenage daughter diagnosed with early phase breast cancer are left faced with a decision to undergo a mastectomy procedure or to remove a lump. Both these choices can leave the child with mental, physical and social scars. Additional decisions may have to be made by the parents to provide further therapy. Decisions such as these should not be delayed further in order to prevent spread of the disease. SDM becomes particularly important when there are a range of treatments available with multiple sub-specialties involved or even during the participation of clinical trials (Boland et al, 2019). The range and complexity of the conversation is automatically increased (Boland et al, 2019). It increases the chances of misunderstanding in connection with communication and conflicting views (Boland et al, 2019). This is not just the parent-doctor conversation but also the views of the patient who may be at an age to make decision based on their developmental context e.g., cognitive, biological and psychosocial factors (Boland et al, 2019). However, at the end, the goal is to achieve the outcome that is in the best interest of the patient (Charles et al, 1997).

Strong literary evidence supporting tools like patient decision aids, education and training are demonstrated much more in adult clinical practice in comparison to paediatric practice. Only a few interventions have been developed and evaluated (Wyatt et al, 2015). This sparks a conversation as to why this is happening considering the complexity of paedology especially in oncology as well as the prevalence of children cancers across the UK where SDM is fundamental. SDM in paediatric oncology is defined as "*the ways in which children can contribute to the decision-making process, independent of who makes the final decision*" (Paediatric Society, 2004). Whether the doctors do actually involve the children is not clear. In the United Kingdom the legal age for a young person to give consent is 16 years old. If the young person does decide to refuse treatment and their life is at risk, doctors may go through the courts to gain consent. In the case parents are present, they also have to power to decide. The legal age to consent may differ between countries.

2.3 The SDM role of a paediatric oncologist

SDM is subject to a respectable conversation (Montori, 2007). It allows a space for health professionals to share and discuss benefits, risks and alternative treatments with patients who also express what their preferences are (Elwyn & Frosch, 2012). These preferences may not always align with those of the doctors. SDM should aim to follow the principles of providing patient centred care and encourage an open discussion and informed consent (Barry & Edgman-Levitan, 2012).

Picone, (2014) suggests that although doctors believe they actively promote SDM, evidence suggests otherwise. He proposes this may be due to misconceptions about the view and nature of SDM, the skills needed to influence SDM and the degree to which stakeholders wish to participate in SDM is often misunderstood.

Each conversation carried out in paediatric oncology is influenced by many factors. These factors include the circumstances of the patient, the medical attention required and the beliefs. These beliefs can include religious views and previous medical perceptions. It stems from what the parents have read as well as personal experiences, information from families and friends and perhaps the media (Agoritsas et al,2015). It is the role of the doctors to therefore offer patients with correct and up to date evidence on the benefits and risks of alternative treatments. To do this, doctors need to have readily available summaries of the latest evidence to share in an approach that supports parents' thoughtful deliberation (Agoritsas et al,2015). This is seen as a current obstacle. Additionally, doctors should make them aware of the likely effect on the outcomes whether positive or negative (Journal of ethics, 2008). Though the complexity of some parents who may choose to ignore the severity of the child's condition, could end up putting doctors in a difficult position.

Previous studies have found an improved adherence to recommendations when patients are encouraged by the doctors to play an active role in consultations and decision making (Brom et al, 2015. This is dependent on the effectiveness and the encouragement to use the policies and procedures available as well as the steps in the process of SDM.

2.4 NICE guidance and NHS long term plan framework

NICE guidance

The National institute of Health and Care Excellence (NICE) is an institute designed to improve the outcomes for patients who use the public health services such as the NHS as well as other social care services. To achieve this, the institute produces evidence-based documents and develops quality standards and performance indicators as well as providing information services to providers. (NICE, n.d). The NHS litigation authority strongly encourages health care providers to follow the NICE guidelines and implement them in their policies (NHS, 2019). Similarly, NICE expects health care organisation to make use of evidence-based guidance (NICE, 2019).

Much like other SDM definitions, NICE recognises similar components like the involvement of more than one party and treatment options. However, it also adds that SDM is not only the exchange of information but it also takes into account the two main tasks in SDM derived from Elwyn et al, (2012).

It is cited in the NICE document for SDM, the purpose of SDM is to ensure individuals are not making decisions in the face of preventable ignorance and to support patients to deliberate about their options by exploring their reactions to information (NICE, 2019). The first task is about patients that tend to underestimate the seriousness of the potential harms of treatment and even overestimate the benefits. In some cases, doctors are also likely to do the same (Hoffman, Bennet & Del Mar, 2017). The second task emphasises the importance of supporting patients who feel rather unsettled and overwhelmed by the offers of a range of treatments and the uncertainty of the outcomes of each.

Furthermore, NICE notes there is a significant difference between what patients want and what healthcare professionals think they want. In paediatric oncology the doctors may seem to only think about the medical side of the disease rather than what parents may think about the effects of treatments on the child's future (NICE, 2019). This document is set as a proposal until an official NICE guidance on SDM is published in the coming months.

NHS framework

Whilst the NHS is certainly an immense achievement, according to the NHS England report there has also been a fundamental cultural division between the professional and the patient (NHS England, 2019). The NHS operates under a standard model to formulate personalised plans with the help of the Clinical Commissioning Groups (CCGs) as well as other organisations. Together they assist to provide a guide for improvement with minimum expected standards that need to be met (NHS England, 2019). These collaborations resulted NHS England to produce a long-term comprehensive plan using the standard model. The comprehensive plan aims to shift towards a more personalised approach where individuals have the same control over their health and treatments as they do in other aspects of their life.

Figure 2. NHS England SDM implementation framework (NHS England, 2019)

SDM is one of six components of the comprehensive model for personalised care. Some of the criteria's included in the model relevant to SDM are; information on patients' legal rights to choose are accessible, publicised and promoted (NHS England, 2019). Regular feedback to comprehend these measures are put in place in the NHS. Further points raised in the NHS England report, also include a number of proposed expectations to be met over the year 2021. If SDM is accomplished according to this standard model, the NHS predictive expectation is that

- *90% of clinicians involved in decision making with people have had access to accredited personalised care training, which includes shared decision making*
- *By 2020/21, implement a framework of approved training providers for shared decision making*
- *by 2023/24 SDM will be embedded in 30 high-value clinical situations in primary care, secondary care*

(NHS England, 2019)

The goals for the years 2019/20 was to expand the SDM program by developing more decisions tools and online learning resources to embed SDM. It also finds 30 specific clinical situations whereby SDM will improve evidence base treatments. The clinical situations are unknown. To reach these goals, the NHS will work in collaboration with NICE to develop a decision support tool as well as work with Health Education England (HEE) and the Academy of Medical Royal Colleges to ensure that e-learning resources are available to all staff (NHS England, 2019).

2.5 SDM strategies used in clinical practice

A widely used SDM intervention are decision aids that have been developed in the form of videos/DVD and computer programmes to support patient decisions. These decisions aids are created using evidence-based information. Decision aids are used when uncertainty occurs about what the best possible treatment are (Coulter, 2017). "*Decision aids can improve knowledge, reduce decisional conflict, improve patients' perceptions of risk, and increase patient participation in the decision-making process*" (Spiegle et al., 2012). They provide the patient with detailed information about treatment choices, outcomes, the probability of these outcomes and quality of life associated with each outcome. Treatment decision aids are a form of educational intervention. However, these traditional decision aids are frequently not grounded on current evidence or seem to be rapidly outdated. This does somewhat contradict the evidence-based approach to SDM set out by the NICE. Furthermore, there is uncertainty whether these decision aids aim to take into account those who are not able to communicate based on other factors such as language barriers, scientific terminology that is difficult to understand etc (Agoritsas et al,2015). This is often due to limitations in funding after the launch of these tools (Montori, 2007). In cases like these, the decision aids cause more harm than good. Again, this could put more pressure on the doctors especially with the scarcity in the NHS.

According to the International Patient Decision Aids Standards (IPDAS) decision aids are used for complex decisions that require more information and careful consideration (IPDAS, n.d), This casts some doubt on reasons why in paediatric oncology decision aids are underdeveloped or not developed at all. A pilot study testing the first ever decision aid in paediatric oncology with a focus on preventing malnutrition in children with cancer has recently surfaced (Sajeev et al, 2016). The results of the study showed decision aids were indeed acceptable for use by the target population. With regards to the doctors, they positively rated the development process, usefulness to parents, and content and format of the decision aid and reported that it actually saved them time. They provide a way of structuring the decision-making process, and breaking it down into a number of specific and chronological steps.

A comprehensible description of a decision aid is one derived from an article by Stacey et al 2017 stating "*A distinguishing feature of a decision aid is the inclusion of exercises designed to promote clarification of the patient's values regarding what is at stake and what it is that he or she is trying to achieve as a result of treatment*". Figure 3 exemplifies the process of the use of decision aids based on the definitions and features.

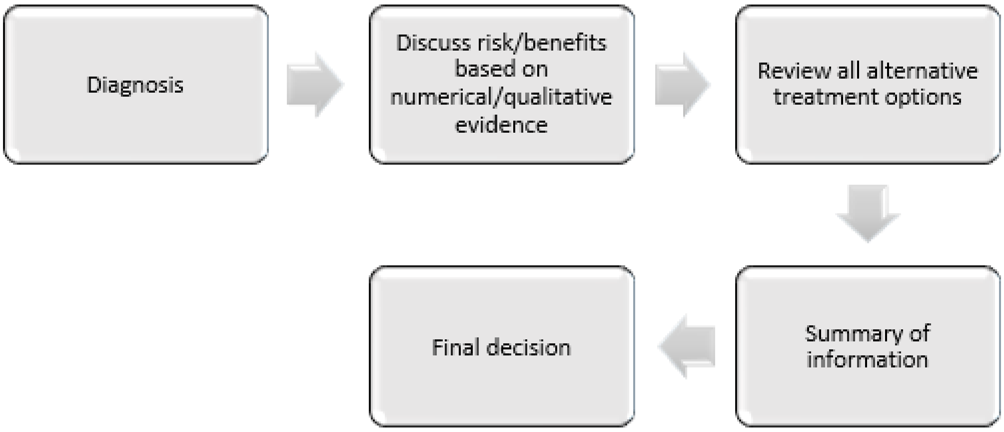

Figure 3. Decision Aid process

A major challenge in the NHS is to guarantee that decision aid resources are accessible to both the patients/ parents and doctors. Familiarising tools rather than reinventing would be ideal for the NHS given the time and scarce resources (Clarke & Fletcher, 2003).

2.6 Existing impediments of SDM based on literature

Although SDM has been getting more notice over the past few years, it is still experiencing delays in relation to effective implementation. According to an article based on the MAGIC program, there are a number of challenges the NHS faces (The British Medical Journal, 2017). These impediments are based on general SDM obstacles across the NHS and are not specific to paediatric oncology. As mentioned in the previous sections, most literature is based on SDM in all disciplines of healthcare. At the end of this thesis, the impediments on paediatric oncology will be made clear using the data collected. The literature discussed in this section will be used to find out if these obstacles are present in paediatric oncologic practice.

Attitudes and perceptions - doctors

The first challenge identified by the magic program is one which is *"we do it already"* attitude which is almost seen as a dismissal on the model (The British Medical Journal, 2017). This shows not much attention is put on SDM rather it is seen as something that a doctor does without putting a label on it. Having this attitude especially in settings like chronic care treatments can have a negative effect on patient experience. It clearly diminishes the personalised aspect of what the NHS mentioned in the NHS England framework report. This is why it makes an interesting find whether oncologists in paediatric settings within the NHS share similar views.

System level impediments

The second challenge identified is that the tools necessary are not available. Physicians often believe that decision aid tools will in itself allow SDM and that decisions are purely made in assistance with those tools. The magic program provided key learning points one of which was that tools are only effective when the doctor communication skills are effective and that these skills are gained with the right attitudes (The British Medical Journal, 2017). According to their results, there will almost never be decision support tools for every decision; nor will patients ever find them as a sole tool to help. The skills to have different types of conversations with patients are principal whether it is with the assistance of a tool or not. In reference to the availability of resources in the NHS, scarcity is predominant and the aging population is growing (The Kings Fund, 2017). This impacts the quality of the NHS as it pressurizes the NHS staff and enables more room for clinical mishaps. This obstacle then turns into another challenge whereby the priorities of the doctors exceed what is practical and feasible. Consequently, time spend on patients is limited e.g., for cancer treatment time targets and treatment delays especially now during the current pandemic (The Guardian,2021). This impediment puts an emphasis on restricted time to treatment but patients may prioritise time to make the decision instead of rushing to make a decision.

Attitudes and perceptions - patients

Another challenge is the perception of "*patients do not want shared decision making*" (The British Medical Journal, 2017). Doctors often report that patients rely on the doctor to make the right decision on their behalf. This is mostly common in the older age group derived from many experiences of paternalistic approach mentioned previously in this section of the paper. Furthermore, a number of patients feel that they need to be "good" and this overrides their desire to be involved because they do not want to ruin the doctor-patient relationship in fear of receiving satisfactory care (The British Medical Journal, 2017). This questions whether parents have the same attitude or perhaps have the opposite view. This may sometimes be mistaken for a lack of interest. However, this is when the role of a doctor comes into effect to make the patients feel included and respected. Although this could be the opposite for paediatric oncology because parents want to know every detail. Alternatively, parents could perhaps have the opposite view where they challenge the doctors but because research in this field is limited this remains unknown. This research took this into account. Involving patients can increase the likelihood of enabling meaningful conversation as well as getting to know the patients and what they believe in which in turn helps steer a natural conversation into a mutual agreement.

With the impediments derived from literature, the information is used in this thesis to identify whether paediatric oncologists in the NHS face similar obstacles and challenges as well as what support they would like to be available to them and further solutions. Furthermore, regarding data collection, it helped formulate the right interview questions to ask respondents.

2.7 Theoretically informed sub-questions

Following the theoretical background, to help answer the central research question I have developed five sub-questions. These sub-questions will be answered using the qualitative empirical data collected in this study in the discussion chapter. These questions are:

- **Sub question** 1 – What is shared decision making and what is its value in paediatric oncology treatments?
- **Sub question 2** - What is the role of the doctor in SDM and what do they expect from parents?
- **Sub question 3** - What are the obstacles in the process/models of shared decision making within the NHS?
- **Sub question 4** - To what extent is shared decision making practiced in paediatric oncology treatments?
- **Sub question 5** - What can be learned from these impediments and how can it be used to remove obstacles?

3. Methodology

This chapter of the thesis focuses on the methodology used to answer the sub-questions as a clear outline to the main research question. Moreover, it elaborates on the design of the study along with the process of data collection as well as a description and justification of data analysis. Lastly, the importance of reliability and validity will be highlighted in broader contexts relating to this research.

3.1 Study design

The study design chosen and deemed appropriate for this study was a qualitative research. In general, this particular type of research is beneficial when the research phenomena cannot be quantified (BMJ, 2017). Often in healthcare, many comprehensive papers exist as qualitative research (BMJ, 2017).

According to Al-Busaidi (2008), qualitative research is now increasingly used in health care research with social and cultural dimensions taken into account and a more in depth understanding through real life experiences and views of participants. Therefore, the main pinnacle of qualitive research is to comprehend people's experiences on an individual level (Jackson, Drummond, & Camara, 2007). Alternatively, quantitative research in healthcare tends to focus more on the trends of the phenomenon being studied.

Since the focus of this research was to identify the impediments and solutions to SDM, the most appropriate qualitative method was to carry out semi structured interviews to gain a clear insight of doctor experiences and the tools available to enforce effective implementation of SDM.

3.1.1 Qualitative research

Semi-structured interviews were well suited to this task for several reasons. First, they allow for an in-depth exploration and an increased understanding of the SDM processes (DeJonckheere & Vaughn, 2019). Semi structured interviews are appropriate to use when the researcher wants to collect qualitative, open-ended information; explore participant thoughts, feelings and beliefs about a particular topic and to delve deeper into personal and sensitive issues (DeJonckheere & Vaughn, 2019). Hence, this was the reason for the use of semi-structured interviews for this research. It allowed to address all relevant topics related to the research questions without leaving out any unexpected findings.

During the process of carrying out the semi-structured interviews, respondents were able to freely express their opinions, concerns, personal and past experiences. Interviews are more so about positive interactions between respondents and interviewers in natural conversations rather than a formal conversation. Prior to the interviews, I set out a number of questions covering topics that were created using the theoretical background and applicable to paediatric oncologists. However, a few of these were often subject to change based on the direction of the flow of conversation. Furthermore, the respondents were able to express themselves without being restricted to stick to certain topics of discussion. Making sure to control the conversation in order to prevent deviation from the key research question was also a pivotal part.

3.1.2 Research setting

I worked on this thesis from start to finish, formulating the research question to finding participants and carrying out the interviews. The respondents included in this study were paediatric oncologists working in different disciplines like radiology and surgery working for the NHS in United Kingdom. Taking note of the current COVID pandemic, unfortunately the interviews were not taken face to face. I am based in the Netherlands and the research was based on interviewing respondents in the UK.

The respondents were approached and invited for interviews through virtual calls. I presented the option to have a phone call or a face-to-face call depending on the respondent's comfort. Although a face-to-face call was the desired method in terms of building a rapport and being able to better understand facial expressions, only one respondent agreed to have their camera on despite all being informed about their information being kept confidential. The number of respondents needed for meaningful findings are a minimum of ten to thirteen respondents. This is based on the numbers reported by Francis et al. (2010) and Marshall (1996) based on research on medical leaders, practitioners and patients' relatives. However, it is vital to account for any withdrawals in research. Therefore, a possible two respondent dropouts were taken into consideration. Due to the short time frame of the research, I took into account Francis et al, 2010's proposal to start off with eight to ten interviews as a guide followed by any extra interviews to verify the data. At the end, a total of eight interviews were taken.

3.2 Data collection methods

The forms of data collection for this research were interviews, official NICE guidance and framework documents. Prior to the research, I set out to find a policymaker within the NHS. For this research, this meant data on the hospital level relating to the financing and hospital policies in procedures were not attainable for use. Unfortunately, despite my effort, they were difficult to get into contact with and there was limited time to carry on the search.

The interviews explored the scope of doctor experiences. It also looked at a wider understanding of the doctor's perspectives and expectations in the implementation of SDM.

3.2.1 The first stages

After the thesis proposal was accepted in March 2021, it was time to find respondents to contact. This was done through a number of ways using an online search as a first step. The NHS website often provides information about doctors and secretaries. In the case where I was unable to find any details for contact, LinkedIn was used to gather the names. This helped with contacting hospitals and obtaining their email addresses and contact numbers. One of the respondents helped with recommending other consultants to take part. This helped tremendously as it was a challenge to make the connections.

Once I had good number of potential respondents across the country, I then proceeded with sending emails and making telephone calls with invitations and the scheduling of interviews in accordance with the respondents' availabilities. Arranging calendars seemed difficult at first instance but we were able to align and agree pre-scheduled slots.

Out of the twenty-nine potential interviewees I contacted, eleven answered and accepted the invite. Towards the end of the interview stage, two of the respondents who were scheduled for an interview were a no-show. Unfortunately, after several attempts of contacting them, one of the secretaries expressed that one of the consultants were away on emergency leave. The other reason for the second participant is yet unknown. The third participant who opted out mid-interview had to tend to a personal matter and when I asked to reschedule, I received no response. At this stage, it was too late in the research to find new participants. In light of the current pandemic and time restrictions, I did not proceed to recontact them a third time.

3.2.2 Interviews

I completed and conducted eight interviews. The respondents worked across four NHS trusts in the UK. The names of the trusts will not be mentioned in this thesis. Interviewing more than two trusts was an advantage because it gave an insight of the differences in how hospitals operate. The respondents differed in age, sex and clinical background. To protect their identity this information will also be kept confidential.

3.3 Data analysis

In this section, I will describe the foundations of the analysis in this research namely transcribing, coding and analysis. The purpose of this section is to show transparency and to identify the gaps in research.

3.3.1Transcription and Coding

Transcribing interviews is a central part of accuracy in qualitative research (Davison, 2009). At the end of each interview, I transcribed the recorded audio verbatim. The use of interview transcripts enabled the ability to use good qualitative analysis methods showing a more accurate view of the interviews (Burnard, 1991). All transcripts of the interviews can be found in a separate document.

There are numerous ways to analyse phenomena. The data analysis conducted included transcriptions coded into categories. The analysis type used for this study was an abductive qualitative analysis. This type of analysis assumes prior knowledge and theories exists about the concept, which is the case for SDM (Seale, n.d). The abductive approach is a combination of inductive and deductive approach. An inductive perspective involves researchers using empirical cases to recognise a pattern from which a general statement can be made. A deductive approach starts with a specific theory and examines the raw data to support the theory. The definition of abductive approach varies between authors, one of them being "*qualitative researchers use a selective and creative process to examine how the data support existing theories as well as how the data may call for modifications in existing understandings*" (Thornberg, 2012). The interview findings will be analysed in the discussion section using the concepts gathered in the theoretical framework. Throughout the research, I was open to new relevant theories to avoid missed findings (Nicolini,2009).

The purpose of coding in qualitative research is described in three ways: data reduction, organisation and the creation of searching aids and analysis (Cope, 2020). To categorise the data collected and to reach saturation, "trigger words" were used based on different themes of answers e.g., "difficulty understanding" would be placed into a communication category (Cope, 2020). The type of category was presented using grounded theory. Saturation has become a commonly used methodological principle in qualitative research. It is used to indicate that on the basis of the data collection analysed up till now, further data collection is unnecessary because new data is not found (Saunders et al., 2017). Although interviews were cancelled in this present study, the data collected did show signs of saturation through common responses and phrases in the responses given.

According to Strauss and Corbin, (1990) grounded theory provides a set of methods to support the data collection. Grounded theory is used to help research related to a phenomenon that lacks a solid theoretical foundation. One particular type is the use of open codes where the data is divided into smaller parts for deeper analysis. For this research, the codes were developed in vivo. These codes derive directly from the statements made by respondents or these codes can also be common phrases found in the transcripts being examined (Strauss and Corbin, 1990). In vivo, codes are beneficial when the study is designed to be exploratory (Strauss and Corbin, 1990). The codes used in this study were directly derived from the interviews.

Prior to the interviews, I made a list of potentially relevant codes which made it easier for me to spot common themes, developed a set of codes to simplify the search for meaningful findings to present in the results section. These first set of codes are called analytical codes and are usually assembled at the start of the coding process and embedded in the research questions with connections to the theoretical framework. A brief example part of this research would be "obstacles" as an analytical code and "language barrier" as a descriptive code that falls under the former category. These codes were regularly reviewed and added during the process of interviews. The more interviews that were carried out, the fewer codes that emerged increasing saturation. To spot the themes in the interview transcripts, each category was assigned a colour and was used to highlight relevant parts in the transcripts (See appendix 2).

3.3.3 Ethical reflections

Each respondent was informed about the purpose of the research prior to the interview as well as reminded on the day with additional information on what will be asked and the confidentiality concerning their answers. They were fully informed about their right to withdraw their consent at any time. Informed oral consent was given for both privacy and ethical perspectives in line with the Erasmus University ethical review guidelines (Erasmus, n.d).

Interviews were carried out through Zoom which is a virtual call conference program and in some cases over telephone. Respondents did show discomfort when asked if they would be willing to turn on their cameras while recording, however I reassured them that it is entirely their choice and most opted to keep it off. For the purpose of the research, I did not push for it as I wanted to make them feel comfortable to answer without distractions. Additionally, private records were kept to demonstrate the inability to trace. Any indicator of what could potentially identify the respondents has been removed throughout this research. Respondents were made aware about their data only being used for the purpose of this research.

3.4 Validity and reliability

Reliability

Reliability refers to the extent results are consistent over showing an accurate representation of the total sample used in the study (Joppe, 2000). Embodied in this definition is the idea of replicability of results which means if the same approach was used it would always result in the same exact outcome. The notion of consistency in reliability can be a slight challenge in qualitative research. For example, in interviews, if the study were to be repeated twice, participants would be unlikely to give the same response each time (Joppe, 2000). This was evident in this research as open-ended answers from doctors who work in different disciplines were unlikely to replicate the same answers.

It was vital in this research to acknowledge the data collected would most likely not be replicated in the exact same way. However, some reliability and saturation were detected through the use of common words in the interview responses despite being from different clinical backgrounds. During the interviews, I kept track of these words using the coding schemes in the same way as using a topic list to ensure some reliability. This helped spot any major changes in trends within the responses that may question the reliability of the study.

Validity

Some qualitative researchers have argued that the term validity is not applicable to qualitative research. Validity is determined based on whether the research is a true measure of how truthful the results are based on what was intended for measure (Lincoln and Guba, 1985). Validity means appropriateness and whether the research question formulated, methodology, study design, analysis, results and recommendations are valid for the desired outcome (Leung, 2015).

The validity of this research was constantly measured by identifying any inconsistencies during the data analysis as a measure of ensuring that the methods used were appropriate to find the right set of results to answer the research question. Also, as an attempt to strengthen validity in this study, I planned to interview doctors from various levels so that I could understand their level of practice of SDM and to account for any biases that may have influenced the responses given.

Achieving a complete objective overview in this study was not attainable because conducting observations as a third method of data collection would have further strengthened the validity of this research.

3.5 Triangulation

Mathison (1988) states “*Triangulation has risen an important methodological issue in naturalistic and qualitative approaches to evaluation [in order to] control bias and establishing valid propositions because traditional scientific techniques are incompatible with this alternate epistemology*”. In order to guarantee the validity and reliability of this study, data triangulation was used.

Data triangulation is the*” use of a variety of data sources, including time, space, persons in a study*”. This interprets to using at least more than one use of a data method. This is so that any missing data can be compensated by the strengths of another set of data thereby increasing the validity of the findings (Hales, 2010).

In this research, data triangulation was particularly useful for connecting the gap between the existing data and new data for meaningful findings to overcoming impediments in the SDM model in paediatric oncology. Both Interviews and document analysis have been used to support the credibility and validity by providing a cross verification of the two methods. The responses received in the interviews were analysed using document analysis to present the results. The results showed there were some discrepancies in the responses given and the proposed plans set by the NHS. For example, the proposed SDM training programs set to be provided by the NHS for health care professionals during the years 2019-2021, show no current signs of execution. These new findings increase validity by corroborating the weaknesses in both data sources.

Often in qualitative research, data triangulation includes the use of three data methods. Unfortunately, due to circumstances a third preferred method like carrying out observation was not feasible at the time. This does limit the findings in terms of behavioural and observational contexts that could potentially add other dimensions to the findings. Observations would distinguish between doctors saying they actively practice SDM as a “natural organic” and the interview response possibly showing a gap between behaviour and response. This is because observations would teach us that doctors might actually say they are doing it but in reality, it would show the opposite.

3.6 Self reflection

As revealed, the three elements for quality are not all fit for qualitative research as it is often difficult to measure. During the interviews, the respondents’ answers generated some bias into the conversation and results. Throughout the data collection I was inclined to accept the doctor views on the impediments based on the individual patient level but noticed that this is a biased view. Based on the existing literature, doctors themselves can be portrayed as impediments depending on the context of the situation. It was easy to get immersed in the responses given since highly experienced doctors were answering questions using their expertise and reasoning.

Having read the literature prior to the interviews and understanding the general obstacles of SDM in health care, I had a perception of receiving similar responses but soon found out this was not the case. As a result, during the process of this research it was imperative for me to constantly reflect and detect any bias and document this throughout the thesis. The discussion section will explain this in more detail.

3.7 Audit trail

An audit trail enables to show transparency in the steps that were taken in the process of carrying out the qualitative research. It allows a person who is not familiar with this topic to follow and comprehend what was done in each step of this research. This is strengthened and obtainable in the methodology. In the same way, it is evident in the transcripts and coding schemes found in the appendix. Any gaps in the research that hindered the research has also been highlighted in the methodology and reported in the limitations.

In regards to ensuring the achievement of validity and reliability, I constantly reflected on the process and tried to identify any missing components as well as diversify respondents to avoid any detrimental gaps in this research. In addition, I kept track of interviews to improve the type of questions asked as part of the interviews to avoid leaving out any stimulating findings. An example is, if one doctor raised an important and relevant point, I then brought it up in my next interview to see if this was common practice.

4.Results

This chapter of the thesis will include a presentation of the data collected and a description of the findings. The results will be guided using the first four sub-questions in theoretical framework to reduce the data to central topics that make up the research question. This is illustrated in Figure 4. The fifth sub-question is more relevant in the last section of this thesis. Thus, the data will be interpreted and discussed further in an in-depth analysis in the discussion chapter.

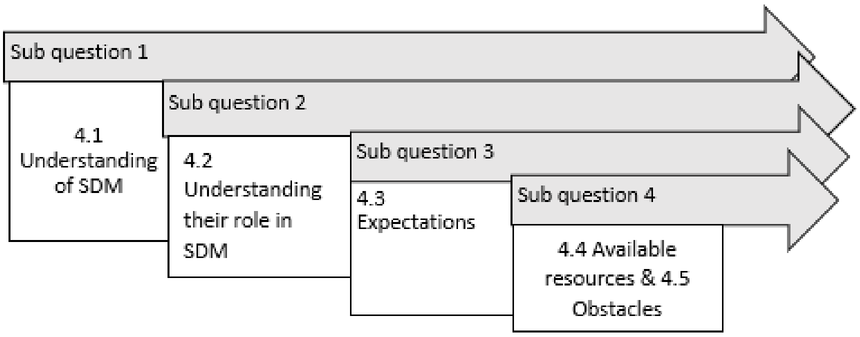

Figure 4. Mapping the results

The data collected and the findings related more to micro level views focusing more on doctor perceptions and day to day practices within the NHS hospitals. Some national level responses based on frameworks and guidelines were given by the respondents but these were not consistent throughout the results.

4.1 Understanding of SDM

This section will present findings based on the perception of the respondents and their understanding of SDM. Majority of the respondents gave similar and very general definitions of SDM. A general understanding of SDM meant they had good foundation of what the process of SDM involves at a micro level. On the contrary, a lack of understanding in the responses would solidify SDM is not something that is practiced and discouraged within the NHS.

Defining SDM

The following quotations show interesting responses, each respondent working in four different NHS trusts for a fair representation. The responses were based on what SDM means to them in paediatric oncology services.

> *"Something we practice every day, we may as a result of multidisciplinary discussions have decided what treatment Is appropriate, we may have come up with a range of possible options but in my view multidisciplinary teams don't make decisions. They consider the*

> *options and then inform the decision makers. The decision making is between the consultant or more than one with the family" (*respondent 1)

> *"My role is to make sure that I say what is in the best interest of the patient irrespective of what the parents may want and whatever the outcome*" (respondent 2)

Although majority of the respondents said SDM is about coming together to reach a mutual agreement. In the statement made by respondent 2, the "*irrespective*" aspect of this response shows a clear dismissal of the views of parents and validates the perception of doctors knowing what is best in decision making eliminating the practice of SDM and contradicting previous statements above. This also serves as a clear SDM impediment as it fails to meet the fundamental basics of SDM.

> *"I believe it helps my patients understand their health conditions, what they need to do and agree on a plan" (*respondent 3)

The aspect of teaching about health conditions comes into play here where the patients/parents are informed about their health conditions in order to come to decision. This view implies the doctor prioritises getting patients to understand and ensure a joint decision is made. The perceived process of SDM varies, some respondents see it as a decision point and some see it as a process and based on this view, this is also deemed an impediment.

> *"...I mean it speaks for itself doesn't it... it's about sharing and informing parents of possible treatments, offering a listening ear and to just be there when there is any slight uncertainty on their end" (*respondent 8)

The respondents placed a high importance on offering treatments that are available to them and emphasising what the best treatment for the child is at the time. Furthermore, some of the respondent's mention coming together in a multidisciplinary team (MDT) meeting where all who are involved including doctors, nurses and other consultants join to discuss what the best possible treatments are for the child. The information is then relayed to the parents who are lawfully the decision makers. With this statement, it can be assumed some doctors to perceive themselves as actors that conduct and encourage an open dialogue between themselves and the parents.

Respondent 8 as an additional point raised in the interview the elimination of "*uncertainty*" and "*offering a listening ear*" bringing some value to SDM in paediatric oncology. Respondent 2 also mentioned the primary goal of the use of any *"a patient-centred approach*" in SDM which is a key element of the NHS personalised framework.

4.2 Understanding the role of the paediatric oncologist

To understand their role meant they understood what it takes to implement SDM in clinical practice. Almost all respondents mentioned acting as a *"guide*". In other words, the respondents described themselves as a person who leads parents and families into making the right decisions. Prior to the interview, I asked the respondents to give a brief introduction of their subspecialties and therefore, some of these responses are in the context of these areas but this may not be clear in their statements due to data protection. Below are some of the responses that stood out.

> **"**It *is relatively clear cut I would meet with the family I would discuss with the patient and why the proposed treatment is the best way forward, I would discuss the practicalities of the treatment side effects and if it was a straightforward one where radiotherapy treatment is indicated. At this point parents would agree but rarely do, they disagree"* (respondent 1)

Respondent 1 is a well experienced oncology who leads the oncology radiotherapy sessions. Their stance was to emphasise the effects of the treatments based on the fact of how much the cancer had spread focusing more on the biological aspect of treatments rather than other aspects that also make up SDM such as the mental health effects.

> *"I believe I am the main influence when it comes to decision making"* (respondent 3*).*

> "*Some doctors do prefer to in some cases limit patient treatment choices and they do tend to (…) I wouldn't want to say push but persuade them a whole lot to go for the one particular treatment that they deem necessary*" (respondent 5)

The statement from respondent 3 also comes from well experienced oncologist who has been in the field for over 20 years. The respondent went on to express that their role in SDM is substantial and that parents should understand the necessary steps to take to create a positive relationship. An opposing statement from Respondent 5, said that some doctors actually put some form of pressure in order to get them to choose the option that is presented to them. This was an intriguing point raised as it can be assumed parents are being coerced into choosing the respondents choice and giving all the power to them resembling the paternalistic model of decision making (Emanuel, 1992).

I therefore proceeded to ask whether they kept any of the information on the risks of treatments. Their answer was that they do not put much emphasis on the negatives and that parents often make emotional decisions rather balanced decisions. This did go against what was stated in the Journal of ethics referenced in the theoretical framework where positives and negatives should be discussed at all times to avoid unethical decision making. It challenges autonomy which is also a fundamental element of SDM that encourages the individuals to exercise their rights.

4.3 What did respondents expect from the parents/families in SDM?

To fulfil the requirements of the role of the doctors in the SDM, it is necessary to understand what needs to be done by the caretakers. The following statements extracted from the transcripts has identified that although the doctors can have the main influence as mentioned in the previous sections, a lot of the responsibilities are on the parents and/or families. This steers away from the collaborative effort in decision making,

".. we do expect them to go over everything" (respondent 1)

Respondent 1 states once the information is passed onto the patient and family, they expect them to process the information rather than just listen and make an uninformed decision. However, some patients may feel they need to agree and this dominates their desire to be involved which

Again, this particular statement assigns the SDM to the parents rather than a joint participation clearly emphasizing that doctors have assigned all the power to the parents.

"It has to be in the best interests of the patient at the end of the day (..) also parents have to be open to hear about all possibilities" (respondent 5)

Respondent 5 has added an additional valuable point stating they need to be able to keep an open mind when discussing the possibilities of treatments. The advantage of this is to always expect the unexpected based on the risks and benefits of each treatment.

".. family processes the information until they have made up their mind" (respondent 6)

"One size doesn't fit all different people like a mother and father can be in consultation with one doctor (…) they will hang onto different bits of the message (…) two people hearing the same message can take it in different" (respondent 1)

Respondent 6 emphasises the reaching of an agreement until every piece of information has been comprehended by the family as one of the steps to SDM. It demonstrates the respondents do not proceed with any treatment until they have been given the go-ahead. SDM can be hindered when both parents are not on the same page because they have processed and comprehended the information in different ways as mentioned by respondent 1. The notion of mixed messages received also serves an impediment.

4.4 Impediments

The impediments extracted from the data collected are central to the research question. These impediments are based on doctor experiences, perceptions and resources available both organisation and national level.

Impediments resulting from communication problems

Some of the general responses mentioned by the majority was the communication issue experienced due to language problems. Although interpreters are provided by the NHS, "*it is rarely as a good as having a direct conversation" (*respondent 1). Again, the following statements express the obstacles that stood out from the general responses experienced by the respondents.

> "*Distress and worry can also be one of the difficulties, it is not the lack of understanding but when people think they understand it but they actually misunderstand it, they do have a knowledge base but it is wrong and that can be a little awkward"* (respondent 1)

This particular statement emphasises the mental wellbeing side of SDM which had not been mentioned in the literature found. The distress and worry are specified to be one of the main difficulties for respondent 1 which leads to a misunderstanding. Patients do not always have the cognitive or emotional capabilities of digesting the information to make a shared decision and these feelings are not necessarily an impediment rather the after effects and results of these feelings are what serve as impediments. The reasons behind these misunderstandings occur when parents believe they understand the current situation regarding their child when in fact they actually do not understand the information was provided. Furthermore, as mentioned in the previous section, some parents take in pieces of information and interpret it in different ways.

Another respondent declared although this may not always happen due to feasibility, some doctors set parents up in meetings with other families who are able to sympathize and share their experiences which in turns helps parents and families' cope.

Impediments resulting from parent and doctor relationships

> *"…problems can arise when parents are at a different stage of the acceptance, other feels child has been through enough and the other is hopeful that the treatment will work"* (respondent 1*)*

> "*I think perception is probably the only main one I can think of now(...) some perceive things in a way other don't, it is either that they are optimistic or that they totally feel negative towards a treatment option*" (respondent 4)

This view was one directed towards the parents and their relationship in regards to them coming to an agreement which in turn compromises the position of the consultant in SDM when a conflict occurs. This delay caused by negative perception can in some cases be detrimental to a child's diagnosis or treatment. Furthermore, the answer given by respondent 4 makes a remark on patients requiring an individualised approach as no one parent is the same.

> *"...having to take in a lot of information especially as parent and this is also dependent on time restrictions"* (respondent 5)

From this statement, time restrictions serve as an obstacle especially when there is not much time left to treat the child. Understandably, this is an impediment in SDM in any discipline but one that remains as an important one especially during current unprecedented times battling COVID. It also indicates the SDM process requires more time. However, this does also mean consultation length times will add further costs. This does not necessarily mean it is an obstacle that will remain. It may be the case the lengthier consultations will eventually lead to shorter consultations in the long term because of the improved parent-doctor relationship and information asymmetry.

> *"The fact parents are now informed much more than they used to be because of the internet and the access to information (…) ... this can sometimes be good and bad but for parents it means they almost get to challenge us*" (respondent 6)

This obstacle could also be interpreted as a positive but for this consultant it was deemed as an obstacle because it compromises and challenges their role as the informer and the guide in the process. As the researcher, from this statement an assumption can be made regarding informed parents being the impediment whereby perhaps parents have read the wrong pieces of information that delays the process. However, from the respondent's view, the impediment is the challenge symbolising this as more of a personal problem. This statement undermines the idea of doctors encouraging an open dialogue that promotes parents to present their knowledge on what they already know about the conditions.

> *"Sometimes we refuse treatments on the basis that it simply is not funded and this does take its toll on the family. Some are not aware of these treatments but for those that have done their research this can be a disappointment"* (respondent 2)

Respondent 2 refers to the funding in the NHS. Obstacles arise when parents are aware of potential treatments that may be beneficial for their child but because they may not fit a certain criterion for the treatment or it is simply not funded, this becomes an obstacle for the oncologists putting a strain of the relationship between themselves and the parents. It is evident that the element of SDM is not present because it removes the idea of negotiating. Furthermore, when this happens, the parents have to seek advice for alternative treatment that they may not be happy with.

SDM tools

In any field, to successfully execute a process, the necessary resources need to be available. In the theoretical framework, I mentioned a widely used SDM treatment tools named decision aids, the NHS framework and the NICE guidance. Some of the answers were based on these tools and documents and its uses in paediatric oncology. The common responses are highlighted in the following quotations.

> *"I have heard of decision aids used in other practice but not for paediatric oncology"*
> (respondent 2)

All of the respondents had similar answers affirming decision aids are not used for paediatric oncology. This was an engaging find and the reason why decision aids are not a tool used in paediatric oncology is explained in the following response.

> *"But I think the sort of (…) if you like mathematical calculations are particularly not appropriate because percentages are relevant to a population and not to individuals"*
> (respondent 1)

On the contrary, the respondent proceeds to mention that for women with breast cancer decision aids are used by an input of specific characteristics and the survival rates are calculated. This does raise the question of why it is appropriate for breast cancer and not for paediatric oncology. For the purpose of this research, I did not ask further questions on this matter because it would move away from the central research question and put more focus on breast cancer.

Policies and training

Guidelines and policies ranging from hospital level trainings, national and organisational level guidelines that guide the process of SDM. Collecting data based on the SDM policies in the NHS was also one of the main parts of this research because it would solidify the effectiveness of SDM and indicate how serious this phenomenon has been taken over the years in the NHS. The respondents were asked whether SDM policies in the NHS existed and whether they were up to date. Surprisingly, all respondents expressed there was no specific policy in effect and that SDM was somehow embedded in other policies. Respondent 1 articulated it is a "*natural organic*" and SDM only becomes a factor in disagreements and that is when the approach to SDM needs a personalised change. From a researcher's perspective, this statement gives the assumption that SDM is not as vital in normal conversations but rather only if the need arises during more complicated conversations. It is apparent that respondents use their own techniques to encourage SDM without using a tool or process provided by the NHS. This has also been confirmed by other respondents.

> *"…Not one created by the NHS, but personally I use my own initiative and ask questions back to the parents/families to see if they have understood what is being said, you pick up these techniques once you're in the conversation*" (respondent 4)

> *"…*I *have come across some tools on the NHS England website (…) like a guide to the process, as far as I am aware I have not seen this being actively used by doctors. Usually, we make use and refer back to SOPs to see if all is going correctly"* (respondent 5)

SOP's is an abbreviation used for standard operational procedures. One of the respondents got into contact with me after the interview regarding the name of the SOP that included elements of SDM. Luckily this was open to the public and I was able to have a thorough read. The respondent made a brief comment and said "*having read the informed consent SOP, there is a very thin line between informed consent and SDM*" indicating informed consent and SDM are almost the same concept. From a researcher's point of view and in theory there are clear distinctions between the two. SDM is most appropriate in situations of uncertainty where the patient cannot be empowered to make choices. In contrast, informed consent does not require the presence of clinical choice; it is appropriate for all decisions of significant risk, even if there is only one option. As a result, the view and attitude of both concepts being similar to the doctors is an impediment in itself and shows a weak fundamental basic understanding.

When asked whether the respondents had taken SDM training, all respondents answered the training provided in the NHS did not include SDM as one training topic. They stated further that SDM is mentioned under other training topics like the mental health training. Much like the policies, this does also serve as an impediment.

> "*No, I have not, if there is one that I'm not aware of (…) it's definitely not mandatory"* (respondent 1).

Not all impediments were extracted from the one specific question regarding impediments experienced by the respondents. Some of the impediments were actually covertly mentioned as a response to other interview questions for example, the statement given by respondent 2 about dismissing the views of the parents shows a clear removal of the views of parents and validates the perception and attitude of doctors knowing what is best on a micro level. This shows a clear impediment in SDM practicing paternalism which interferes with a person's autonomy moving away from the personalised approach promoted by the NHS.

From a researcher's perspective, the answers received from the respondents seemed biased. The majority of the impediments mentioned refer to the patients not successfully fulfilling their role in the SDM for example parents not communicating and coming to an agreement amongst each other putting the consultants in a difficult position. However, an impediment supporting the patient's perspective would be not enough information was given to both parents to fully comprehend the risks and benefits of treatments.

A previous statement mentioned in section 4.1 which sets out as a positive statement could also be translated as a negative. The statement referred to coming together in a multidisciplinary meeting which in hindsight is seen as a positive collaboration and discussion. Yet, this may not always be the case because what is not mentioned are any impediments that may come from these meetings such as conflicting views of medical treatments or which treatment to prioritise. Again, this shows a common behaviour amongst the doctors focusing on the patient level impediments rather at doctor level.

4.6 Are the consultants satisfied with the current state of SDM?

In order to find the right solutions to the obstacles mentioned above, it was necessary to ask whether they were satisfied with the current handling of SDM and if there were any specific aspects, they would like changed such as a new NHS policy or model that breaks SDM process into stages. Many of the respondents said they were satisfied with the current system indicating a slight reluctancy to change. Still, they would like to see some awareness made as a reminder of the importance of SDM even though, the popular tools like decision aids were not used. Others based their answers on their experience and stated "*I'm not sure if it would be beneficial for me because I'm experienced but it may be useful for junior doctors and other allied health professionals*" (respondent 1). They also mentioned it would be useful to have tool to deal with SDM during the early stages of diagnosis which is often the most important time when it comes to creating treatment plans. This will be further discussed in the following chapters.

5. Discussion and Conclusion

Along with the guidance set out by NICE and the NHS Framework for SDM, this chapter of the thesis will set to answer if the existing literature and new data collected align as well as discuss new findings in the new data that fill the gaps in existing research mentioned in the introduction using the theoretically formed sub-questions as a structure. Subsequently, this will also help identify the gaps in the implementation of SDM in the NHS.

5.1 Answering the theoretical sub-questions

1. **What is shared decision making and what is its value in paediatric oncology treatments?**

Sub-question 1 referred to the understanding on SDM in paediatric oncology. From the research conducted and the existing literature, it is evident that SDM in paediatric oncology is perceived as the coming together of two or more parties to reach a mutual treatment decision on the basis that it is purely decided in the interest of the child. This has been validated using the existing literature as well as the data collected in this research (Rapport et al, 2018). This fundamental understanding of the process of SDM shows no concerns. Even though, there is strong evidence to support that, respondent 8 discussed SDM to be an elimination of "*uncertainty*" whereas respondent 1 said the element of uncertainty will always be there. This displays a part misunderstanding of one of the goals of SDM. Furthermore, when some were asked what their role was in SDM and their expectations of parents as part of sub-question 2, some of the findings highlighted in the results section exposed a slight flaw.

2. **What is the role of the doctor in SDM and what do they expect from parents?**

As per the citations in the results section, some perceived their role to be the key influence as the decision maker which resembles the former paternalistic model possessing a dominant attitude (Emanuel, 1992). It indicates there is some level of superiority of the doctor which ultimately steers away from the concept of SDM. The achievement of SDM is dependent on a balanced argument rather than dominance over another. The expectation they have of the parent is to listen to what they are offering and ultimately accept the treatment irrespective of what their concerns. This was a view popular amongst the respondents with more experience. Those who were experienced said a new process would be beneficial for entry-level doctors and not so much for them because they deem SDM to be "*clear cut*" and a straightforward process. At this point, the "*we do it already*" attitude referenced in the Magic program emphasised in the theoretical framework, comes into effect. From this, one can comprehend the hindrance mentioned in the program is clearly evident and occurring in paediatric oncology. This view takes away the ability to learn and improve SDM because it implies SDM is a "*natural organic*" (respondent 1) rather than a taught skill. In an opposite viewpoint, the respondents who had less experience responded in an optimistic manner asserting that this would be beneficial.

3. **What are the obstacles in the process/models of shared decision making within the NHS?**
4. **To what extent is shared decision making practiced in paediatric oncology treatments?**

Collectively, this adds to the impediments of SDM in accordance to sub-question 3. This view gradually moves towards the technique used by some doctors where they almost push decision makers towards the one option that they believe is the right treatment for the patient. On the other hand, this defeats the purpose of SDM where in any discipline, the decision maker should make a decision purely based on what they deem necessary without any coercion. This is also in relation to the former informed model of decision making where informed decision is made after the decision makers have been given all the right information. Nevertheless, in the results, a respondent mentioned withholding certain pieces of information that may result in a parent to refuse a treatment on the basis of the risks involved. Again, this shows signs of a violation of informed consent and an insight on the extent to which SDM is practiced in paediatric oncology. Thus, answering sub-question 4. Emanuel (1992) stated SDM is closely linked to some fundamentals of the informed decision-making and paternalism models nonetheless from the data collected it is apparent the core foundations of both these models is not practiced to its full potential.

On the contrary, one can argue that according to the findings of the data collected, the tools to successful implementation of SDM is simply not available. The respondents were asked whether they were aware and used the popular SDM tool, decision aids. Though awareness of the tool was detailed, there was no evidence to suggest forms of decision aids catered to paediatric oncology.

The NHS plan 2019-2021 proposed accredited training for health professionals. It was apparent, specific SDM training was not provided up to date. Although the year is yet to conclude, there is no indication so far to suggest whether there will be a training program solely targeting SDM in the near future. Furthermore, the proposed NHS plan set out to expand the SDM program by developing more decisions tools and online learning resources to embed SDM. From the interviews some respondents did mention part of SDM mentioned in other trainings when discussing personalised care plans and taking into consideration the preferences of others, however the processes used for example refusal of treatment which was one of the interview questions, the respondents used their own initiatives. They said standard operational procedures would in cases like this be used but for SDM this was not available.

While respondents did say there were tools out there to help such as SDM checklists provided by NHS, they still seemed very open to the idea to other forms of tools. Again, some respondents said the current system works for them and any new tool would be beneficial for other consultants who were less experienced. However, the same respondents who said the current system works were those who actually showed a flaw in understanding the basic goals of SDM indicating signs of contradiction in their answers.

To conclude this section, every component discussed is interlinked. It hinders both the successful implementation and delays the development of practicing SDM to its full extent.

5.2 Answering the research question

What are the existing impediments experienced by doctors and the potential solutions for successfully implementing SDM in paediatric oncology treatments in the United Kingdom?

Now that the first four sub-questions are answered, the discussed points can be used to answer the above research question. The question was the pivotal point of this research. The purpose was to include all aspects involved in the process of SDM.

To summarise, the findings have confirmed the necessary resources are indeed, not available across the NHS leaving the doctors having to fill in those gaps on their own using their own skills. This is especially more complicated for those who are still in training or have just started. However, without the proper training, those skills are purely based on the perception and character of the doctor. These perceptions have shown to be different for each respondent therefore the style is not the same across the board resulting in inconsistencies in clinical practice. Although, each approach for each patient is not necessarily the same, certain criteria should be practiced and these criteria should ideally be presented in the form of a policy. The following section will present some recommendations in light of the findings.

5.3 How did this research contribute to existing literature?

One of the main reasons for conducting this research was to add to existing literature so that policy makers have evidence in a number of different areas where SDM is critical. This research reconfirmed some of the existing impediments identified in literature and identified further areas for research and study. One of the main areas is the lack of effective policies that encourage SDM in the NHS. Although a NICE guidance is set to be released, the fact that NHS framework includes a plan of execution without an established guidance to follow makes it difficult for policy makers within the NHS to create SDM policies and procedures.

5.4 Limitations and recommendations for future research

With research it is vital to recognize limitations. One of the many reasons is to strengthen the credibility and validity of the study. The first limitation acknowledged is the lack of previous studies based on the focus of this research. Literature review on paediatric oncology treatments in the UK in relation to SDM was limited. The SDM phenomenon is still an area yet to be explored. Hence the intention to study this area of research.

Despite, the insightful findings in the data collection, one of the main limitations as mentioned previously in the methodology section, was the unforeseen circumstance of my last two absentee respondents along with one mid-interview withdrawal all beyond my control. After several attempts of recontacting, at this point time was limited. In light of this, the number of interviewees used in this research are in line with theories discussed in the methodology section. The validity of the study did show clear signs of meaningful findings and reaching saturation.

In general, because the respondents were of high calibre and a representative of the focus of the study, it limited the number of participants that were available to interview. Ideally, an additional benefit to this study would have been to expand the scope of research by finding policy makers, who would also benefit from the findings. This would have strengthened the validity of the study. Although, this study did intend to include a national view of policies set out by government organisations such as the NICE it was difficult to recruit policy makers working for both NHS and NICE due to accessibility and time restrictions.

Another limitation was to have a larger sample size. This would have generated more findings but the respondents did consist of a varied group that came within range to successfully answer the research question and objectives. In regards to generalisability which is about whether a study can be used to apply to other contexts, groups and countries in the same way (Tracy, 2013). A large sample size would have to be used. However, in this study it would not be the appropriate to generalise. The reason for this is because this study was specific to the SDM in children's cancer within the NHS in the United Kingdom operating under specific health, financial and national systems. Therefore, the context of this study was aimed at specific target groups and systems that were most suitable to answer the research and cannot be generalised in other contexts. With each research, there is always room for improvement. From this experience, potential recommendations can be made for future research.

Recommendations for future research

A recommendation for future research would be to study more perspectives rather than one for a more balanced argument. In this research, it would have been stimulating to include the perspectives of parents. Unfortunately, the difficulty of approaching parents was due to inaccessibility and data protection reasons, no interviews with parents could be conducted. As a result, the perspectives and beliefs of the parents could not be fully explored. Hence, allowing more room for biased assumptions and views. The view of parents would fill the gaps in research that lacks the perception of what parents require in SDM. Moreover, it would explore what they would like to include in decision making tools and what would benefit them in the process.

Secondly, another recommendation would be to use observations, for example observing a decision-making consultation between the consultants and parents as an additional method of data collection would greatly benefit the research. Currently, a complete objective overview of the data collected was not achieved because several areas were not included in the study. Some of these areas would allow to observe the interaction and in person experience first-hand rather than only going by the experiences of doctors. Adding observations as a third method would also contribute to triangulation and therefore increase validity in this study.

5.5 Practical recommendations

The fifth sub-question reads "What can be learnt from these impediments and how can it be used to remove obstacles?". The removal of obstacles refers to the practical solutions that initiate from the use of the new findings in the data collected in the interviews as well as the existing literature. Some of these recommendations have come from myself and some have been suggested by the respondents themselves in their answers.

Can the elimination of uncertainty be accomplished?

The elimination of uncertainty will most likely not be completely eliminated; still, a practical solution would be to have a meeting whereby not the parents ask questions to the doctor rather the doctor asks the parents questions to check their understanding of treatment options before consent is given. This will ensure legal obligations in the context of informed consent are fulfilled. This way, it also eliminates doctors withholding information because it is now written in clear and comprehensible terms for parents to understand. For those who cannot speak English, then these checklists would have to be translated in various languages.

In order for these checklists to actually work, having a policy that sets out to establish this should be standard procedure. This would hold doctors accountable for the day-to-day operations and ensure compliance is achieved as well as provide guidance for the process of SDM.

Measuring the quality of SDM

It was stated in this thesis, each treatment decision making cases differs, therefore the quality of SDM is difficult to measure. To determine the success of SDM, the measurement of quality is necessary. It is difficult to improve a process without knowing the root of the cause. Most of the respondent thought the current system worked fine however the impediments show otherwise. In order to make sure SDM is adhered to, a form of risk assessment would be beneficial for both doctors and the NHS as an organisation. The NHS has actually provided a specification for this but from the findings it was apparent only one respondent was aware of its publication. The checklist is available on NHS website and accessible to the public. A recommendation would be to have a specific checklist designed for paediatric oncology. Nonetheless, these checklists could also be altered for use in other disciplines. This particular tool would serve as evidence to aid in continuous improvement in children's cancer services.

How can attitudes and perceptions be changed?

Perception of the doctors was also one of the main key findings in this research. The notion of reluctancy to practice SDM due to high level experience could also be tackled by introducing a cultural change management model incorporating SDM. The value of this would be to upkeep quality while keeping track of day-to-day operations and changing the organisational culture that dismisses the practice of SDM for those who are far more experienced than those who are not. This creates a homogenous culture throughout the organisation regardless of experience.

Easily accessible information and resources on SDM

Many of the responses suggested additional tools such as a decision aid would be helpful. Decision aids have proven to be successful in other countries as mentioned in this thesis. Like the breast cancer aids, it would beneficial to have one that supports parents in the paediatric oncology. Granted, this may be difficult to execute due to the nature of the information that needs to be included. The idea is if somehow both percentages and analytical aspects can be incorporated into a decision aid.

Some also thought having specific processes in place would remind doctors of SDM. Furthermore, one respondent mentioned they would set up meetings so parents could discuss with others who were in the same predicament. This is a great initiative and to add to this, a recommendation would be to have an information centre or helpline for those who have further questions or simply need an offering ear to listen. It does not necessarily have to be an actual centre to attend because funding that could be extra financing for the NHS instead it could be set up as a virtual program.

5.6 Conclusion

Overall, in this thesis some thought-provoking insights about the perception and attitudes of paediatric oncologists and the current state of SDM have been identified. SDM is at a stage where although some progress is being made in proposed NHS plans and NICE guidelines, SDM has not morphed into its own process rather it is still used as the former prototype models more so the paternalistic model. The main impediment that originates from all of the findings is that until the inconsistencies in personal perception is removed, change in attitude of SDM is achieved and a clear SDM policies are introduced within the NHS and national system; SDM will continue to be an ambiguous concept.

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8. Appendices

8.1 Appendix 1 List of fixed set of questions

Now that I have given you a short introduction of the purpose of this research, what does shared decision making mean to you as a paediatric oncologist?

What is your role in the process?

What are the obstacles you experience during the process of SDM with parents within the NHS?

Are there any specific models/strategies that are formed in the NHS that you use for SDM?

In the case where the parents refuse treatment what happens then?

Do these obstacles add to your workload?

How do you deal with that?

Have you had a particular training designed for shared decision making over the last 5 years?

Within the NHS, is there a specific policy used?

Would you like to see a model developed that can be used that breaks the process in stages?

Are you familiar with decision aids?

Ideally would it be helpful to have decision aids designed for use in paediatric oncology?

8.2 Appendix 2 Coding scheme

	Analytical codes	**Descriptive codes**
Shared decision Making definition	- Understanding - definition	- Treatment options - Decision making

	Analytical codes	**Descriptive codes**
The role of the doctor	- **Role**	- Guidance - Coming together - Information sharing - Communication - Discussion - Meeting - Multidisciplinary team/ mdt

	Analytical codes	**Descriptive codes**
Obstacles/ Impediments	- Obstacles - impediments	- Too much information out there - Not much information out there - Limited time - Language issue - No issues - Lack of prior knowledge - Extra work load - Pressure - Outdated information - Parent preferences - Beliefs - Opinions - Challenging - Parents taking control - No training/policy

	Analytical codes	**Descriptive codes**
Resources, policies, strategies & models	- Policies - Resources - Strategy/ Methods	- No tools - Information services - Decision aids - Outdated - Regular meetings - Second opinion - No policy

	Analytical codes	Descriptive codes
Recommendations	Suggestions	- Junior doctors - Skills training - Less experience - Information centres - Decision Aids