Child’s Informed Consent to Medical Intervention – Illusion or Reality? The Estonian Experience

Paron, Kristi

How to cite

PARON, Kristi. Child’s Informed Consent to Medical Intervention – Illusion or Reality? The Estonian Experience. Master of advanced Studies, 2019.

UNIVERSITÉ
DE GENÈVE
CENTRE FOR CHILDREN'S
RIGHTS STUDIES

Master of Advanced Studies in
Children's Rights (2017 – 2018)

Child's Informed Consent to Medical Intervention – Illusion or Reality?

The Estonian Experience

Kristi Paron

Thesis submitted in the framework of the

Master of Advanced Studies in Children's Rights

Sion, 30 September 2018

Tutor: Roberta Ruggiero

Contents

Abbreviations

CRC	The United Nations Convention on the Rights of the Child
CRC Committee	The Committee on the Rights of the Child
FRA	European Union Agency for Fundamental Rights
General Comment	General Comment of the Committee on the Rights of the Child
Guidelines	Council of Europe guidelines on child-friendly health care
Oviedo Convention	The Council of Europe’s Convention for the Protection of Human Rights and Dignity of the Human Being with regard to the Application of Biology and Medicine: Convention on Human Rights and Biomedicine

Introduction

With the adoption of the United Nations Convention on the Rights of the Child (CRC) children were given a voice. Article 12 of the CRC stipulates that "States Parties shall assure to the child who is capable of forming his or her own views the right to express those views freely in all matters affecting the child […]". The coin has another side, however, as the second part of the sentence continues: "the views of the child being given due weight in accordance with the age and maturity of the child". It is an inherent paradox of children's rights that they address subjects "who, on the one hand lack the full autonomy of adults but, on the other, are subjects of rights", as illustrated in a statement of the Committee on the Rights of the Child (CRC Committee)[1] (General Comment No. 12, 2009). The gradual shift towards full autonomy that is conceptualised in the CRC as "evolving capacities" makes it challenge to establish legal norms to address the legal capacity of children in real life situations.

The above may explain why the theories around Article 12 have been conceptualised as "participation", i.e. children participate in decision-making but are often not the decision-makers. According to the CRC Committee, the term participation is "widely used to describe ongoing processes, which include information-sharing and dialogue between children and adults based on mutual respect, and in which children can learn how their views and those of adults are taken into account and shape the outcome of such processes" (General Comment No. 12, 2009). It is also the reason why children's participation has been criticised; children's participation can easily remain in a "virtual box", consisting of activities that run parallel with those of adults (Hart, 2008). "[S]eparate process of representation tends toward tokenism, placing an inherent distance between representation and real power" (Wall, 2011).

This thesis goes beyond participation, as it looks at the autonomous decision-making of the child in health care settings and analyses whether and how the informed consent of child patients is obtained in practice. As contended by Hodgkin and

---

[1] The Committee on the Rights of the Child is a treaty body created pursuant to Article 43 of the CRC. According to rule 73(1) of the "Provisional Rules of Procedure", the Committee may prepare general comments based on the articles and provisions of the convention with a view to promoting its further implementation and assisting States parties in fulfilling their reporting obligations.

Newell, "in a few countries the concept of "evolving capacities" is reflected by a general provision in legislation that once children acquire sufficient maturity or understanding, they may make decisions for themselves …" (Hodgkin and Newell, 2007). Estonia is one of the few countries in Europe where children have been given such decision-making power with regard to health issues by law. This right is included in Subsection 766 of the Law of Obligations Act, which provides for the right of patients to information and to give informed consent to any intervention or treatment. It derives from this rule that the legal representative of a child patient has the right to give informed consent on behalf of the child patient in so far as the patient himself/herself is unable to consider the pros and cons responsibly.

Although the above law has been in effect since 2002, it would seem, at least from the outside, that this principle is not followed in the everyday practice of hospitals and other health care institutions. It would appear that as a general practice, consent forms for treatment of child patients are explained to and signed by parents (or other legal representatives). It is therefore analysed in this thesis whether the concept of child's consent is or is not applied in everyday medical practice.

The right of children to autonomous decision-making in health care has not been publicly debated in Estonia.[2] However, society's views towards children and their competence in general were analysed in a study "Monitoring on children's rights and parenting" published in 2012. According to this study, 65 % of children and 56 % of adults in Estonia think that children are able to make autonomous choices. Further, 96 % of children and 94 % of adults in Estonia agree or rather agree that children have their own opinions and preferences and that it is important to take them into account. What is worrying, however, is that 46 % of adults agree or rather agree that a child may be heard, but the child's view does not have to be considered. There is also a relatively large proportion of adults – approximately 1/3 of respondents - with negative attitudes towards child participation.

---

[2] The right of minors to decide on abortion was debated in 2014/2015 when the law on abortion was reformed. This debate is not brought into this thesis, as it was impacted by another huge philosophical discussion regarding the right to decide on another human being's life and death. The 2014/2015 parliamentary debates are discussed in para 2.1 insofar as they pertained to the general rule as set out in Section 766 of the Law of Obligations Act.

But why is the topic of child's informed consent to medical treatment important? It is vital because it touches upon the very fundamental questions surrounding children's rights: do children have the right to self-determination and autonomy as adults do? And are children competent to decide on their own health and life? According to Farson, "[t]he issue of self-determination is at the heart of children's liberation. It is, in fact, the only issue, a definition of the entire concept. The acceptance of the child's right to self-determination is fundamental to all the rights to which children are entitled" (Archard, p. 71).

The importance of children's participation and autonomy in health care was also emphasised in a recent General Comment of the CRC Committee. General Comment No. 20 (2016) quite strongly states that "the voluntary and informed consent of the adolescent should be obtained whether or not the consent of a parent or guardian is required for any medical treatment or procedure" (para. 39). The Council of Europe Guidelines on child-friendly health care (2011) stress that "[w]hen a child, according to law, is able to consent to an intervention, the intervention may only be carried out after the child has given his or her free and informed consent."

The above is in line with the conclusions of a recent study on children's participation in health care. The Committee on Bioethics of the Council of Europe commissioned a report "Towards a Roadmap to Strengthen Children's Rights in the Era of Biomedicine" (2017), which highlights the need to recognise the principle of children's evolving capacities and their right to participate in decision-making. The report also marks the fact that existing European and international standards overemphasise the child's right to protection. The complexity and challenges of child's informed consent are highlighted among other problems. One of the recommendations of the report is to invest in awareness-raising, information/education and training. This thesis is one small step into this area in Estonia.

Problem statement and research questions

This thesis studies whether the concept of child patients' informed consent, deriving from Subsection 766(4) of the Law of Obligations Act, is applied in everyday medical practice in Estonia. The thesis is based on the hypothesis that the above norm on child patients' informed consent is not applied in practice, and children are not involved in decision-making regarding medical treatment to the degree that the applicable law enables. This assumption is supported by the general practice of hospitals and other health care institutions whereby consent forms are explained to and signed by parents. It is also illustrated by the fact that 46 % of adults in Estonia agree or rather agree that a child may be heard, but the child's view does not have to be taken into consideration.

Against this problem statement, this thesis first analyses the theoretical and normative background of child's consent, both on a national and international level, and also the concept of autonomy in a broader sense. Secondly, the thesis studies the theoretical and empirical aspects of assessment of capacity to give informed consent in medical practice. Thirdly, within a qualitative social study, it is analysed whether children in Estonia are involved in decision-making in health care settings and, more specifically, whether their informed consent is asked for medical interventions and treatment. Within the above main question, the following sub-questions are analysed:

1. Are doctors aware of the provisions of Subsection 766(4) of the Law of Obligations Act with regard to child's informed consent?
2. Are child patients informed and given explanations when health care services are provided to them and if so, how?
3. Do doctors obtain the informed consent of child patients and if so, how?
4. How do or would doctors evaluate a child's competence (according to which criteria)?
5. What happens in practice if a competent child refuses to give consent (and should the same rules be applied as for adult patients)?
6. What is the role of parents in the consent procedure?

7. What happens if a competent child’s will is in contradiction with his/her parents’ will?
8. At what age are children competent to give informed consent?

Methodology

This thesis combines legal and socio-legal studies as its research method. In the framework of legal doctrinal study, the theoretical and normative context of the regulation of child's informed consent is presented. Thereafter, the functioning of this norm in the concrete social context, that is, the application of this norm by individuals in practice, is analysed. Socio-legal studies (interdisciplinary studies)[3] allow us to go beyond classical legal research, to analyse the law (legal phenomenon) and its relationships with the wider society and use methods of sociology for problem analysis. This thesis uses qualitative research, as explained in more detail below.

The study presented in this thesis vividly illustrates the gap between "law in books" and "law in action" (McConville and Chui, 2007), which has given cause to a wider use of interdisciplinary research methods in law. It is also a testimony to "living rights", as worded by Hanson and Nieuwenhuys (2013), "that are an imperfect compromise negotiated at a certain moment in time and in specific contexts by individuals representing different local and organizational interests and possessing different kinds of knowledge, skills and power".

In the first chapter, the thesis starts with an analysis of the theoretical framework of children's competence, based on research of the literature.

The second chapter contains a legal analysis of the laws and treaties that are applicable to child patients' informed consent in Estonia. Within domestic law, the Law of Obligations Act and Child Protection Act are studied, as are two international conventions that have been ratified by the Parliament of Estonia, the CRC and the Oviedo Convention. Soft law in the form of "Council of Europe Guidelines on child-friendly health care" is presented. For a broader perspective of the normative background, a short overview is provided of the rules governing the age of consent in EU countries.

---

[3] McConville and Chui (2007) use both terms for identifying this research method.

In the third chapter, the principles of assessment of a child's competence in medical practice are analysed. Some best practices for guiding such assessment are presented in the form of the consent policies of the United Kingdom and Ireland. Both countries have been active in conceptualising child participation in health care, especially after the famous Gillick case[4], where the House of Lords acknowledged the right of a child to give autonomous consent. The number of examples is limited, as this thesis does not aim to give a comparative overview of practices in different countries.

As the debate over child's competence has generally concentrated on ethical and legal aspects (Hein et al., 2015), empirical studies regarding children's competence were of special interest for this thesis. The results of three empirical studies, carried out in the Netherlands, Canada and USA respectively, are presented in the third chapter. These studies were included as they all focus on children's developmental abilities. Although two of the studies assess the capacity of children to consent to medical research (and not to medical treatment), the methods used for capacity assessment are similar in both fields, and thus the results of the studies are also relevant for this thesis.

The fourth chapter contains a qualitative analysis of the views of children, parents and doctors with regard to children's involvement and decision-making in health care settings. A qualitative research method was preferred (vs quantitative), as this study aims to gain insight into a topic that has not been widely debated in society. The author was interested in the personal experiences and stories of both patients and professionals. A quantitative study would not have enabled such an in-depth analysis of these personal experiences.

Twenty-four children, fifteen parents and eleven doctors were interviewed for this thesis. The interviewees were invited through social media, and children with extensive experience in receiving health care were offered the opportunity to participate through their doctors at Tallinn Children's Hospital. The doctors and other medical professionals were approached through their professional associations.

---

[4] House of Lords, Gillick v West Norfolk and Wisbech AHA [1986] AC 112.

Two focus group interviews were conducted with children, with one group consisting of children between the ages of 7–10 (7 children in total) and the other of children between the ages of 15–17 (9 children in total). Eight individual interviews were conducted with children between the ages of 9–16, of whom 5 had extensive experience with health practitioners and hospitals due to chronic illness or condition, while 4 were interviewed in hospital. Two focus group interviews and two individual interviews were carried out with parents (15 parents in total). Eight individual interviews were held with doctors, involving three paediatricians, two family doctors (GP), a dentist, a child psychiatrist and a paediatric ear-nose-throat specialist. Another focus group interview was conducted with three gynaecologists. The views of the gynaecologists were of special interest for this thesis, as they had been involved in the 2014–2015 law reform regarding the right of adolescents to decide on abortion.

The interviews were semi-structured, concentrating on four thematic blocks that constitute the core of consent issues: (i) communication with the child; (ii) practices of taking the consent of child patients; (iii) capacity of the child to consent; and (iv) the role of parents. In addition, doctors were asked about their knowledge of the law governing consent, since under the law, they are the ones who are obliged to apply these rules in everyday practice. Children were also asked about their general attitudes and expectations with regard to doctors (or medical personnel more generally). This was done in order to allow for the children to open up for the discussion and be ready for more specific questions. The interviews were first audiotaped and thereafter transcribed; a thematic analysis of the transcripts was carried out. Finally, conclusions about the situation in Estonia with regard to child patients' involvement and informed consent were made, and remarks on possible developments and a best practice framework were presented.

The Ethical Research Involving Children (Graham, Powell, Taylor, Anderson and Fitzgerald, 2013) principles were used for guidance in ethical matters. Voluntary participation, informed consent and protection of privacy (confidentiality) were key concerns for the author. All of the interviews were based on the voluntary consent of the interviewee. The adolescents (aged 15–17 years), who participated in the study on their own initiative, consented to the interviews autonomously. For the other children (who were involved in the study through their parents), both the consent of the child and of the parent was acquired. In addition, the approval of the Tallinn Medical Research Ethics Committee was obtained for interviewing children in Tallinn Children's Hospital. The research was explained to the children in an age appropriate way. The children were also assured that they did not have to answer any of the questions they did not want to or share information about their illness or condition. All of the interviewees, both children and adults, were ensured that their responses would be used anonymously and that they would not be identifiable either from the transcripts or from any information that was made public. Consent to record the interview was obtained before the beginning of each interview. Audiotapes of the interviews did not include any reference to the identity of the interviewee and were erased after anonymised transcriptions of the audiotapes had been made.

Due to the small number of interviewees, it is not possible to state that the opinions of the children and adults interviewed represent the wider opinion in each segment. The study made within this thesis can rather be regarded as a problem mapping and a starting point for further, more elaborate research.

Chapter 1. Theoretical framework

In this chapter, the theoretical framework regarding children's autonomy and autonomous decision-making is presented. As the idea of children's active participation in decision-making on an international normative level was first introduced through Article 12 of the CRC, this Article and the idea of a child's right to be heard is introduced in the beginning of the chapter. Thereafter, elements of autonomy are analysed, inspired by Archard's (2015) philosophy of rational autonomy divided into rationality, maturity and independence. These three key elements identified by Archard are supported by other authors' remarks on children's competence. In para. 1.3, the concept of children's evolving capacities is analysed, as the shift towards full autonomy is interpreted in the CRC through this concept. The idea of evolving capacities is a key concept with regard to child patients' autonomous decision-making. Finally, the role of parents as guardians and guides of a child's evolving capacities is analysed in the framework of the CRC.

1.1 Child's right to be heard

"The right of all children to be heard and taken seriously constitutes one of the fundamental values of the Convention" (General Comment No. 12). According to Article 12 of the CRC, "States Parties shall assure to the child who is capable of forming his or her own views the right to express those views freely in all matters affecting the child, the views of the child being given due weight in accordance with the age and maturity of the child." For this purpose, the CRC requires that the child must be heard in any proceedings affecting the child. Article 12 sets out one of the four general principles of the CRC, together with the right to non-discrimination, the right to life and development, and the primary consideration of the child's best interests.

The wording "age and maturity of the child", which is key in judging how much weight the views of the child must be given, is closely related to the concept of evolving capacities (elaborated in more detail in para. 1.3).

As Article 12 refers to the child "who is capable of forming his or her views", it is important to ask whether the wording of the Article limits the scope of its application in saying that such right must be assured (only) to the "capable" child. The CRC Committee has explained that "[t]his phrase should not be seen as a limitation, but rather as an obligation for States parties to assess the capacity of the child to form an autonomous opinion to the greatest extent possible. […] States parties should presume that a child has the capacity to form her or his own views and recognise that she or he has the right to express them […]" (General Comment No. 12, para. 20).

In the context of this thesis, the key part of the Article 12 is how due weight is given to the opinion of the child. According to the Article, age and maturity are the determining factors in giving weight to the opinion of the child. The CRC Committee has explained that age alone cannot determinate the significance of a child's view: "Research has shown that information, experience, environment, social and cultural expectations, and levels of support all contribute to the development of a child's capacities to form a view. For this reason, the views of the child have to be assessed on a case-by-case examination" (General Comment No. 12, para. 29).

The second criterion to be used when assessing what weight to give a child's views is the child's maturity. The concept of maturity is analysed further in para. 1.2. According to the CRC Committee, maturity is the "capacity of a child to express her or his views on issues in a reasonable and independent manner" (General Comment No. 12, para. 30). The CRC Committee acknowledges the challenges that such assessment entails, and therefore expresses the need to develop good practice for assessing the capacity of the child (General Comment No. 12, para. 44).

The key-elements contained in Article 12 of the CRC have been comprehensively presented in Laura Lundy's model for conceptualising the Article (Lundy, 2007). Lundy offers a model of four chronological elements:

Space:	children must be given safe, inclusive opportunity to form and express their views;
Voice:	children must be facilitated to express their view;
Audience:	the view must be listened to;
Influence:	the view must be acted upon, as appropriate.

The above model provides a useful framework for professionals working with children, including health practitioners, to think through the steps that are necessary to enable meaningful child participation.

It is important to stress that Article 12 focuses on the right to express one's views and participate in decision-making, but not on the right to decide. In the framework of Article 12 there is always an adult who decides how much weight the child's view will be given. Therefore, it is hard to fully agree with those authors who contend that Article 12 "expresses true respect for the child as an autonomous person" (Brems, 2007). By criticising the above statement, it is not argued that children should always be given the right to decide regardless of their age, maturity and circumstances. It is argued in this thesis that it is necessary to be precise in the definition of what we mean by autonomy, as the right to participate in decision-making is not the same as the right to decide, and this differentiation has direct legal implications. In the health care systems of those jurisdictions where the child may be deemed capable to decide, once a doctor finds a child capable of forming a rational and weighed opinion about treatment, the doctor is obliged to follow the child's decision. The CRC gives little, if any, guidance on the autonomous decision-making of children. Therefore, a more elaborate analysis of the autonomy of children is given below in para. 1.2.

1.2 Autonomy and competence

The key question in the debate over a child's informed consent to medical intervention or treatment is competence. Autonomy, the precious precondition of human dignity, consists of certain elements, and competence lies at their centre. According to Archard (2015), rational autonomy comprises at least three elements: rationality, maturity and independence. The following discussion of children's competence is based on this division, as it is more elaborate than the classical competent/non-competent discussion.

(a) Rationality

Archard (2015) defines rationality as the ability to form generally reliable beliefs about the world, and this requires cognitive competence. The inability to form reliable beliefs or take well-founded decisions has been “the most fundamental, recurring argument against autonomous rights for children” (Verhellen, 2015, p. 51). Cognitive competence, necessary for “well-founded” or “generally reliable” decision-making, may be one of the most challenging factors in assessing a person's rational autonomy or competence in the broader sense. One of the most influential experts in child cognitive development, Jean Piaget, attributed certain levels of cognitive competence to certain developmental stages, and saw children’s intellectual development as “progression through a series of qualitatively distinct stages of intellectual ability” (Corsaro, 2011, p. 12). “According to Piaget's findings, children would be capable only from around 12 years old as this is the age at which they attend the concrete operative stage where they have the cognitive competence to make their own rational and moral judgements” (Hanson, 2012, p. 67). However, we now have enough evidence that children's competence does not depend only on their physical (biological) development but may depend just as much on the characteristics of the adults living and working with them, such as e.g. the adults’ competence, training, support, willingness and generosity (Hanson, 2012, p. 68; Alderson, 2007, p. 2277).

As rationality is connected with knowledge and experience, and both must be acquired, it can be concluded that rationality increases with age (Archard, 2015, p. 89). Therefore, age may be one of the many criteria by which a child's competence can be assessed.

Rationality comes under close scrutiny in the topic of informed consent in health care. A child's decision is often assessed through the lens of rationality: is the child's decision rational in the eyes of others (doctor, parents) or is it irrational in the eyes of others and therefore not “well-founded”?

(b) Maturity

Archard (2015) talks about maturity borrowing from the theory of John Stuart Mill, who probably means by maturity "fully developed, where this implies settled and unlikely significantly to change". He also refers to maturity as emotionally balanced (Archard 2015, p. 89). This is probably the most common approach to maturity, as we often hear that someone is mature because he or she does not make decisions in the heat of emotions. Small children are known for not being fully able to separate themselves from their emotions and letting emotions guide their decisions.

Maturity is often related to rationality, especially in the process of decision-making in health care settings. A child's decision is generally assessed through the perspective of whether this decision is rational (see para 3.2 and 3.3). In the context of this thesis, it is important to refer to maturity in the sense of gathered life experience. As research shows, children's understanding of their health and treatment issues depends far more on their experience than their age or ability (Alderson, 2007; Hein et al., 2015). The Ethics Working Group of the Confederation of European Specialists in Paediatrics notes that "[c]ompetence has often been associated with cognitive capacity, rationality and age. However, it is now regarded to be also a function of a child's experience of the illness in question." (De Lourdes Levy et al., 2003, p. 631). Alderson (2007, p. 2277) brings an example where a child's long-term condition may give them "maturity" with regard to their health at a very early age: "Everyday evidence of children aged 3 and 4 years, with such conditions as cystic fibrosis or type 1 diabetes, shows how responsible they can be when adults are not present. For example, children with diabetes refuse sweets, which their friends enjoy, and cope in sophisticated ways with being different yet sustaining friendships."

The above shows the danger of treating children solely on the general scale of mature-immature. Therefore, it is hard to fully agree with Woodhead (2009, p. 56) who states that "[y]et, immaturity remains one of the most distinctive features of the young of the human species (Bruner, 1972), whether constructed in terms of nurturance and vulnerability, teaching and learning, socialization and development or respect for their rights." Since maturity is connected with life experience, a child with a long-term health condition and related experience may be much more mature with regard to his/her health issues than an adult who has only little or no experience with the same.

Maturity is also a central term in the CRC. As one of the four general principles of the CRC, Article 12 states that the views of the child must be given due weight according to his/her age and maturity. As Freeman (2009, p. 386) rightly points out, "the Convention gives no indication as to how to judge the maturity, or indeed what is meant by maturity." As noted above, the CRC Committee has explained the concept of maturity in its General Comment No. 12 as the "capacity of a child to express her or his views on issues in a reasonable and independent manner" (para. 30). Here we see that the CRC Committee links maturity with reasonability or rationality and independence, which are both key concepts used by Archard (2015).

(c) Independence

Archard (2015) states on the basis of Kantian philosophy that "the strongest sense of independence or 'self-maintenance' is self-sufficiency, that is an ability to sustain oneself physically by providing for one's own food, clothing and shelter." Archard of course accepts that in modern societies this definition is inapplicable, as societies and economies are much more complex than in Kantian times. Archard therefore concludes that "[a] broader interpretation of self-maintenance is that people are self-maintaining when they can actually act out their choices." It is here that one of the main challenges of child-participation and implementation of children's rights is best reflected:

> "Presumed unable to do something, children may simply not be allowed to show that in fact they can. More subtly, it may be the case that a competence can only be acquired in the exercise of the appropriate activity. A child may display incompetence just because she has been prevented from doing what would give her the ability" (Archard, 2015, p. 91).

Allowing children to practice independence/independent decision-making and thereby autonomy is key to more meaningful and effective implementation of children's rights. Of course, this practice cannot happen overnight, and independence and autonomy should be acquired gradually. Freeman (2009, p. 387) agrees with Virginia Morrow who explains that autonomy requires "not the straightforward delegation of decision-making to children, but rather enabling children to make decisions in controlled conditions, the overall intention being to enhance their capacities for mature well-founded choices". Freeman (2009, p. 387) also cites John Eekelaar who defines the same process of gradual maturation as "dynamic self-determinism", the goal of which is "to bring a child to the threshold of adulthood with the maximum opportunities to form and pursue life-goals which reflect as closely as possible an autonomous choice".

Independence could be also viewed as physical autonomy or freedom. With regard to this type of independence, a big contrast can be seen between the children of the Global South and the Global North. As Lancy (2012, p. 6) puts it, in the Global South children are granted a lot of agency in the form of physical autonomy but little efficacy, meaning effect on others and responsiveness from adults. In the Global North, it is vice versa: children are granted little physical autonomy but a lot of efficacy. This illustrates how independence, as a component of autonomy, depends on the context.

To conclude on competence, the competence of a child depends on many factors and there is no universal criterion to determine whether a person is competent to decide on a certain matter or not. The complexity of the issues related to competence are well summarised by De Lourdes Levy, Larcher and Kurz (2003, p. 631):

> "Competence depends on the context which may involve the physical surroundings of the child. It also depends on the relationship between the child, the parents and the health professionals and must be seen within the child's experience of their illness. Competence also varies over time and with the state of the illness. For example a child who is in severe pain may not be competent to make decisions which they could otherwise make. […] There is a complex relationship between competence and information. It would be difficult for a child to be competent if they had not been adequately informed."

However, there is a position among many child rights specialists that the competence of children must be presumed, not vice versa, and the burden of proof lies on those who wish to deny rights to children (Freeman, 2009; Verhellen, 2015; Hanson, 2012). It is the position of the author of this thesis that competence could be presumed from a certain age, based on empirical evidence (a more elaborate discussion is found in para. 3.6). Setting a fair and balanced rule for determining competence remains a challenge for legislators. "If, as seems reasonable, children cannot be thought of as legal agents in the same way as adults, then it is up to the law to draw the required distinction" (Archard, 2015, p. 36).

1.3 Evolving capacities

All three elements - rationality, maturity and independence are closely linked to the concept of evolving capacities, provided in Article 5 of the CRC. Article 5 of the CRC stipulates a right and duty of a parent to provide appropriate direction and guidance to the child, in a manner consistent with the evolving capacities of the child. The concept of evolving capacities is also mentioned in Article 14 of the CRC in the context of parental responsibility with regard to the freedom of thought of the child. Parents have to provide direction to the child, in the exercise of his/her right to freedom of thought, in a manner that is consistent with the evolving capacities of the child.

The CRC Committee has defined the concept of evolving capacities in its general comments as follows:

> "The Committee defines evolving capacities as an enabling principle that addresses the process of maturation and learning through which children progressively acquire competencies, understanding and increasing levels of agency to take responsibility and exercise their rights." (General Comment No. 20, para. 18). "The more the child himself or herself knows, has experienced and understands, the more the parent, legal guardian or other persons legally responsible for the child have to transform direction and guidance into reminders and advice and later to an exchange on an equal footing. This transformation will not take place at a fixed point in a child's development, but will steadily increase as the child is encouraged to contribute her or his views." (General Comment No. 12, para. 84).

The principle of evolving capacities is closely interlinked with the best interests principle (Van Bueren, 2007) deriving from Article 3 of the CRC, which requires that in any action or decision concerning the child, the child's best interests must be a primary consideration. Both principles target the fact that the child, although given certain autonomy by the Convention, cannot carry out his/her rights autonomously, and there is a need for protection and guidance that depends on the age and maturity of the child. Thus, on one hand the Convention encourages the emancipation of children (Articles 12-17), hand in hand with their optimum development (Article 6). On the other hand, however, it requires their protection (Articles 19 and following), to be guaranteed primarily by their parents (Article 18).

The above is also reflected in Lansdown's (2005) three dimensions of the concept of evolving capacities: (i) a developmental concept, emphasising the child's right to development; (ii) a participatory or emancipatory concept focusing on the shift of transferring rights from adults to the child; and (iii) a protective concept acknowledging the child's right to protection while the capacities of the child are still evolving.

Thus, the concept of evolving capacities addresses the gradual shift from dependence to independence/autonomy, and parents (or other legal guardians, as the case may be) have a crucial role in enabling the capacities of their children to evolve. Therefore, the role of parents is elaborated in more detail in the following paragraph.

1.4 The role of parents

As the rights of the child are generally performed through or with the assistance of the parents (or other caretakers)[5], the role of parents in the consent procedure is of fundamental importance. Coyne, Hallström and Söderbäck (2016) note that "[c]hildren's participation in decision-making in healthcare is frequently more dependent on parents' and health professionals' attitudes rather than on their actual

---

[5] There can be another caretaker other than a parent who has the right of legal representation of the child. For the sake of simplicity, the term "parent" is used throughout this thesis.

competence". The versatile and important role of parents was also mentioned by the doctors and parents in the interviews conducted for this thesis (see Chapter IV).

Article 18, together with Articles 3 and 5 of the CRC acknowledge that parents or, as the case may be, legal guardians, have the primary responsibility for the upbringing and development of the child, and that the best interests of the child will be their basic concern.

No law, including the CRC, provides for a parenting standard or norms about what good parenting means in the framework of parental responsibility for the upbringing of a child. However, the CRC gives some guiding principles for framing the scope of parental responsibilities. Namely, Article 27(2) of the CRC entails an obligation of parents, stating clearly that "parent(s) or others responsible for the child have the primary responsibility to secure, within their abilities and financial capacities, the conditions of living necessary for the child's development."

As Ruggiero, Volonakis and Hanson (2017, p. 74) state on the scope of parental responsibilities within the framework of the CRC:

> "Parents are endowed with a spectrum of rights, duties and/or responsibilities for the fulfilment of two aims: first, to secure the child's well-being through the purveyance of protection and care (Articles 3(2) and 18) and, secondly, to provide evolving and age-appropriate guidance to the child in the child's exercise of his or her rights (Article 5)."

The CRC Committee stresses the requirement to act in the child's best interests as the main content of parental responsibility (General Comment No. 7, para. 16). In a later General Comment, the CRC Committee emphasises the role of parents in providing security, emotional stability, encouragement and protection to children (General Comment No. 20, para. 50).

In the context of this thesis, the question of the role of parents in child autonomous decision-making arises. As described earlier in this thesis, Estonian law enables autonomous decision-making by the child in the form of informed consent, provided that the child is, in the health practitioner's opinion, competent to do so. However, this does not mean that parents have no role to play once the child is regarded as competent. Regardless of whether the child is competent or not, the parents have the duty to give appropriate direction and guidance to their child (Article 5 of the CRC).

1.5 Conclusion

Article 12 of the CRC forms the basis for child participation – the child who is capable of forming his or her own views must be given the opportunity to express those views. However, Article 12 gives the child the right to participate in decision-making, but not the right to decide. This is also a reason why neither the CRC nor the CRC Committee give guidance on the principles of child's autonomous decision-making, and other theoretical materials must be explored. As shown in this chapter, autonomy can be conceptualised through rationality, maturity and independence (Archard, 2015). A rational person is able to form generally reliable beliefs about the world. A mature person should be emotionally balanced and not let emotions lead his/her decisions. Instead, his/her life experience and value system should help him/her to form decisions. Independence refers to self-maintenance, the ability to act based on one's own choices. These three concepts can guide assessment of children's competence. Of course, all of these qualities are acquired gradually, and therefore it is important to understand and support a child's evolving capacities and to enable the child to practice decision-making.

Parents and other adults, i.e. health practitioners in the context of this thesis, are the key players in allowing children's capacities to evolve and letting children become autonomous individuals. In order to become autonomous, children must be given opportunities to practice decision-making and weighing different options. When giving consent to medical treatment on behalf of their child, if the child herself or himself is not capable of giving consent, and also when guiding and advising their child who is capable of giving consent autonomously, parents must:

(1) try to see the situation through their child's eyes in order to guarantee that the best interests of their child and not their own interests is a primary consideration for them;

(2) encourage the maximum development of their child and enable autonomous decision-making as much as possible in accordance with the maturity of their child.

The child is a unique individual with his/her own thoughts, ideas and life goals. The obligation of parents to proceed from their child's best interests as a primary consideration assumes that parents accept their child's own path and do not force the child to follow theirs.

Chapter 2. Normative framework

The aim of this thesis is to analyse how the legal norm on child patients' informed consent to medical intervention and treatment is applied in practice in Estonia. Thus, an overview of the relevant Estonian law is given in the first paragraph of this Chapter. Thereafter, in the second paragraph, an overview of the relevant international conventions ratified by the Republic of Estonia is presented. In the third paragraph, soft law, in the form of "Council of Europe guidelines on child-friendly health care" is explained. Finally, a short overview of the normative framework of other EU countries with regard to minimum age requirements in health care is given, in order to view the Estonian regulation in a wider perspective.

2.1 Estonian law

In Estonia, the contractual issues related to health care services, such as the duty to inform the patient and acquire the patient's consent, are regulated by contract law in the Law of Obligations Act, which has been in force since 2002. Subsection 766(4) of the Law of Obligations Act provides:

> "[I]n the case of a patient with restricted active legal capacity, the legal representative of the patient has the rights specified in subsections (1) and (3) of this section[6] in so far as the patient is unable to consider the pros and cons responsibly. If the decision of the legal representative appears to harm the interests of the patient, the provider of health care services shall not comply with the decision. The patient shall be given information required by law and shall be informed of the decisions made to a reasonable extent."

The above means that the competence of child patients (as persons with restricted legal capacity) has to be decided on a case-by-case basis, whereas the law gives one criterion for assessing competence: the ability to consider the pros and cons responsibly. It is also important to note that Subsection 766(4) covers two rights of a child patient, the right to information and the right to consent. Although the law does

---

[6] Subsections (1) and (3) regulate the patient's right to information and the right to give informed consent.

not specify who must make the decision on a child's competence or capacity, it derives from a systematic analysis of the law that it is the health care service provider who is obliged to assess the child's capacity.

Another essential question is the form of consent. Estonian law does not require written consent, which means that consent can be given orally. This makes it more difficult to study how consent is taken from patients, as oral practices may not be documented and not perceived by patients as clearly as in case of written consent being taken.

There is no soft law in the form of recommendations or guidelines regarding the right of patients, including child patients, to information or their right to consent. The Doctors' Code of Ethics (para. 2(2)) provides only generally that the doctor shall explain to the patient his/her health condition and shall acquire the voluntary and informed consent of the patient for necessary interventions and treatment.

Unfortunately, there is no explanatory memorandum nor minutes of parliamentary debates regarding patients' rights from the time of the adoption of the Law of Obligations Act in 2001. This is perhaps explained by the fact that at the time of its adoption, the Law of Obligations Act was one of the most extensive laws that had ever been passed, as it reformed the entirety of contract law and covered more than one thousand sections. This was quite a challenge for the Estonian legal system at that time.

Some clarification was given to the context of child patients' rights during the debates in Parliament in 2014/2015 when the law governing abortion was changed so that minors could decide autonomously on abortion on the same terms as generally provided for in the Law of Obligations Act. The chairman of the Social Affairs Committee of the Parliament (which was responsible for the draft law) explained to Parliament on 28 January 2015:

> "A patient with restricted active legal capacity is offered health care services based on his/her consent in so far as the patient is able to weigh the pros and cons responsibly. This is said in Section 766(4). Health practitioners are obliged to assess whether a person with restricted capacity is sufficiently responsible to give informed consent for abortion. If a person with restricted capacity is able to give

> informed consent for abortion, it is not justified to request the consent of their legal representative in addition. This is the general rule for health care services.

Etti Kagarov, a member of the Social Affairs Committee explained that "[i]f a young person and her legal representative disagree and the doctor has assessed that this young person is able to weigh all of the pros and cons responsibly, in such case the opinion of the minor shall be taken into account."

As the proposed draft law (on abortion) was based on the general rules in the Law of Obligations Act, the above statement reflects the will of the legislator that Subsection 766(4) would leave the final say to the child if the child and the parent(s) disagreed, provided that the child was, in the health practitioner's view, competent according to Subsection 766(4).

The Supreme Court of Estonia issued a decision on 11 May 2011 in a case regarding consent for abortion. Although the legal requirements for abortion were regulated by a specific law and at the time of the decision the law regarding abortion had not yet been harmonised with the Law of Obligations Act, the court also reflected on the general conditions of informed consent. The court found that "[t]o offer health care services to a patient with restricted active legal capacity, there must be, as a general rule, the consent of his/her legal representative". As this case was based primarily on the law on abortion, no further elaboration on the content of Subsection 766(4) of the Law of Obligations Act was given, which left many relevant issues unanswered.

In the light of the parliamentary debates in 2014/2015, the view of the Supreme Court may seem superficial and may therefore mislead health care practitioners. It is true, as will be elaborated in more detail in Chapter 4, that children generally visit health practitioners with their parents and, as a general rule, a child and his/her parent(s) agree on the child's health issues, which means that the question of who precisely gives consent may not arise. This is particularly true when one takes into account that the law allows for consent to be given orally. However, the true essence of Subsection 766(4) will be tested in situations where a child's will is contrary to his/her parents will and/or the health practitioner's will. Such situations are elaborated in more detail in Chapters 3 and 4. As reflected above, the parliamentary debates in 2014/2015 suggested that the child's opinion would be decisive in such situations, provided that the health practitioner found the child to be competent in the meaning of Subsection 766(4).

As Estonian law is quite laconic on child patients' rights, the CRC (which has been ratified by Estonia) should be used as guidance when interpreting the law. Article18, together with Articles 3 and 5 of the CRC, give guidance with regard to the scope of parental duties, as was discussed in para. 1.4, and proposed in para. 1.5 of this thesis. With regard to a child's right to information that is an important prerequisite for informed consent, guidance can be taken from Article 17 of the CRC (see para. 2.2.2).

In addition to the principles of the Law of Obligations Act, professionals working with children, including health practitioners, have to follow the requirements of the Child Protection Act. All general principles of the CRC (Articles 2, 3, 6 and 12) have been transposed into the Child Protection Act. Article 21 of the Child Protection Act obliges professionals who make decisions with regard to children to follow from the child's best interests as a primary consideration and to give the child's views due weight in accordance with the age and maturity of the child.

2.2 International conventions

According to Article 123(2) of the Constitution of the Republic of Estonia, international treaty norms have precedence over domestic norms in case of conflict between them. In academic literature, this Article has most commonly been regarded as an expression of a monist legal system (Mälksoo et al., 2017). Norms of international treaties that have been ratified by Parliament are directly applicable in Estonia without the need to transpose them into domestic law. This principle does not, however, prohibit the transposition of international treaty norms into domestic law. This has been done for example in the case of the CRC, the general principles of which (Articles 2, 3, 6 and 12) have been transposed into the Child Protection Act, as explained in para. 2.1.

2.2.1 Oviedo Convention

The Republic of Estonia ratified the Council of Europe's 1997 Convention for the Protection of Human Rights and Dignity of the Human Being with regard to the Application of Biology and Medicine: Convention on Human Rights and Biomedicine (Oviedo Convention), which is the only binding international legal instrument on the subject of bioethics (www.coe.int/bioethics), in 2002. Since the Law of Obligations Act, including patient's rights, was adopted before the ratification of the Oviedo Convention, the ratification did not have an impact on the drafting of the rules that are studied in this thesis. A more elaborate analysis of the impact of ratification of the Oviedo Convention, e.g. on principles governing consent in clinical trials of medicinal products that are included in the Medicinal Products Act, would fall beyond the scope of this thesis.

The ability to give free and informed consent to medical treatment and intervention is one of the most fundamental rights of a patient. This principle is anchored in Article 5 of the Oviedo Convention. Article 5 provides that an intervention in the health field may only be carried out after the person concerned has given free and informed consent.

Article 6 of the Oviedo Convention addresses those persons who are not able to consent, including children, stipulating that where, according to law, a minor does not have the capacity to consent to an intervention, the intervention may only be carried out with the authorisation of his or her representative or an authority or a person or body provided by law. The opinion of the minor shall be taken into consideration as an increasingly determining factor in proportion to his or her age and degree of maturity.

2.2.2 CRC

The Republic of Estonia ratified the CRC, which gives children the right to be heard in Article 12, in 1991. The theoretical context of this Article was discussed in para. 1.1 of the thesis. This paragraph concentrates on the right to be heard in a health care context and analyses other Articles of the CRC, namely Articles 17 and 24, that are relevant to child patients' informed consent in health care.

(i) Right to be heard

The CRC does not address the issue of children's autonomous decision-making in health care directly. Article 12 of the CRC ensures the child the right to express his/her views in any matter concerning him/her. There is no doubt that medical decisions with regard to the child's health belong to matters covered under Article 12.

With specific regard to the child's right to be heard in health care, the CRC Committee (General Comment No. 12, 2009) has expressed the need to:

1. include young children in decision-making processes (para. 100);
2. introduce legislation to ensure that children have access to confidential medical counselling and advice without parental consent (para .101);
3. provide clear and accessible information to children (para. 103);
4. introduce measures enabling children to contribute their views and experiences to the planning and programming of health services (para.104).

Most importantly, in the context of this thesis, the CRC Committee (General Comment No. 12, 2009) has welcomed the introduction in some countries of a fixed age at which the right to consent transfers to the child, and encourages other states to introduce such legislation but at the same time to ensure that a child younger than this age limit could demonstrate capacity to express an informed view.

In a later General Comment No. 20 (2016), the CRC Committee is more precise on the topic of children's autonomy in health care. The CRC Committee invites states to "review or introduce legislation recognizing the right of adolescents to take increasing responsibility for decisions affecting their lives." It also recommends that states introduce minimum legal age limits that "recognize the right to make decisions in respect of health services or treatment". The CRC Committee states that "voluntary and informed consent of the adolescent should be obtained whether or not the consent of a parent or guardian is required for any medical treatment or procedure."

An adolescent, in the meaning of the General Comment No. 20, is a child between the ages of 10 and 18 (para. 5), and therefore it could be argued that in the eyes of the CRC Committee, a child of at least 10 years of age should generally be able to consent to medical treatment. It must be borne in mind, however, that the CRC Committee does not state this explicitly.

The CRC Committee also finds that "consideration should also be given to the introduction of a legal presumption that adolescents are competent to seek and have access to confidential medical counselling and advice without the consent of a parent or guardian, irrespective of age, if they so wish." (para. 39, General Comment No. 20).

The child's right to express his/her views as protected under Article 12 is closely related to the child's right to freedom of thought provided under Article 14. Article 14(2) emphasises the role of parents in guiding and instructing the child in the exercise of his/her right. Such guidance must be consistent with the evolving capacities of the child, as was discussed in para. 1.3.

(ii) Right to information

With regard to consent in a health care context, the provision of information to child patients is key. "It would be difficult for a child to be competent if they had not been adequately informed" (De Lourdes Levy et al., 2003, p. 631). It will be elaborated further in Chapter 3 that for consent to be valid, it must be informed.

The CRC stipulates the right of the child to information in Article 17, whereby "States Parties recognise the important function performed by the mass media and shall ensure that the child has access to information and material from a diversity of national and international sources, especially those aimed at the promotion of his or her social, spiritual and moral well-being and physical and mental health." It can be seen from the text of the norm that special emphasis is put on the importance of information aimed at the promotion of the child's physical and mental health. The CRC Committee has stressed (General Comment No. 4, para. 10) that:

> "The right of adolescents to access appropriate information is crucial if States parties are to promote cost-effective measures, including through laws, policies and programmes, with regard to numerous health-related situations, including those covered in articles 24 and 33 such as family planning, prevention of accidents, protection from harmful traditional practices, including early marriages and female genital mutilation, and the abuse of alcohol, tobacco and other harmful substances."

(iii) Right to health

Another relevant norm in the CRC is set out in Article 24 which recognises the right of children to health. According to Article 24, "States Parties recognize the right of the child to the enjoyment of the highest attainable standard of health and to facilities for the treatment of illness and rehabilitation of health. States Parties shall strive to ensure that no child is deprived of his or her right of access to such health care services." Article 24 touches upon the quality of health services. The procedures for informing child patients and taking a child patient's informed consent are without a doubt one aspect of the quality of health care services.

The CRC Committee has emphasised in its General Comment No. 15 (2013) that children's right to health contains freedoms "which are of increasing importance in accordance with growing capacity and maturity, include the right to control one's health and body, including sexual and reproductive freedom to make responsible choices."

The CRC Committee has also explained the connection between children's autonomy in health issues and children's evolving capacities (General Comment No. 15, 2013, para. 21):

> "The Committee recognizes that children's evolving capacities have a bearing on their independent decision-making on their health issues. It also notes that there are often serious discrepancies regarding such autonomous decision-making, with children who are particularly vulnerable to discrimination often less able to exercise this autonomy. It is therefore essential that supportive policies

> are in place and that children, parents and health workers have adequate rights-based guidance on consent, assent and confidentiality."

Thus, the child's right to self-determination with regard to his/her body is an integral part of the child's right to health.

2.3 Council of Europe Guidelines on child-friendly health care

The Council of Europe, of which Estonia is a member, adopted guidelines on child-friendly health care (hereinafter "Guidelines") in 2011. Although these Guidelines are non-binding, they help and guide the medical profession in introducing child-friendly practices. The Guidelines build upon five keywords: participation, promotion, protection, prevention and provision. The rights of the child, with the right to be heard and the best interests' principle on the frontline, are at the core of the Guidelines.

The Guidelines take an integrated approach to child health care, which according to para. 2 "places children's rights, needs and resources at the centre of health care activities, taking into account their family and social environment. It promotes policies to deliver child-oriented services based on child-specific developmental needs and evolving capacities, ensuring children's participation at every level of decision making, in accordance with their age and degree of maturity."

According to para. 3 of the Guidelines, "'child-friendly health care' refers to health care policy and practice that are centred on children's rights, needs, characteristics, assets and evolving capacities, taking into account their own opinion." Para. 33 of the Guidelines also emphasises that "[t]he child-friendly health care approach recognises that interventions should focus not only on managing the child's health condition, but also on their physical or social environment, thus avoiding the medicalisation of social problems. It includes addressing environmental issues (air and water quality, sanitation), socio-economic problems (poverty, social exclusion, poor housing and nutrition), access to education, or parental issues (parenting skills, parents' mental health, domestic violence or substance abuse)."

For the purposes of this thesis, para. 12.(i) of the Guidelines is of greatest relevance. It states that "[w]hen a child, according to law, is able to consent to an intervention, the intervention may only be carried out after the child has given his or her free and informed consent. When, according to law, the child does not have the capacity to consent to an intervention, the opinion of the child shall be taken into account as an increasingly determining factor in proportion to his or her age and degree of maturity. Children should be given appropriate information beforehand."

2.4 Normative background in individual EU countries

Although a comparative study is not the aim of this thesis, a short overview of the normative framework of other EU countries with regard to minimum age requirements in health care is given below. This overview puts the Estonian context in a wider European perspective.

In 2017, the European Union Agency for Fundamental Rights (FRA) published a mapping of the minimum age requirements concerning the rights of the child in the EU (FRA mapping). The objective of FRA's activity was to assist EU Member States in addressing these issues and to facilitate the EU in exercising its competence to support and coordinate Member States' actions related to children and youth, as there are inconsistencies, protection gaps and restrictions deriving from different age thresholds (FRA website). One of the areas where age limits were analysed was health care.

The FRA mapping gives a unique and practical opportunity to compare how different countries have regulated the issue of consent in their domestic law. Both the Oviedo Convention and the CRC leave countries the freedom to regulate the age of majority in different areas.

According to the FRA mapping (FRA website):

- In ten Member States (Bulgaria, Cyprus, Finland, France, Greece, Hungary, Italy, Malta, Romania and Slovakia), children do not have the right to make autonomous decisions about their medical treatments until they reach the age of majority, meaning that parents must always give their consent. In some cases – for example in France – the parents' final decision must take into account the opinion of the child, if the child is able to express his/her will.
- In Ireland, Lithuania, the Netherlands, Poland, Portugal, Spain and the United Kingdom, the minimum age at which children can consent to medical treatments without parental approval is 16 years. In Croatia, the minimum age for this is also 16 years. However, where a medical intervention carries a high risk of adverse consequences on the physical or psychological health of a child who is older than 16, the parents' written consent is required in addition to the child's consent.
- In Denmark and Slovenia, the minimum age is set at 15 years. However, in Denmark, whether or not patients aged 15–17 years can consent to medical treatments without parental consent depends on their maturity, assessed on a case-by-case basis. Latvia has set the lowest minimum age in the EU for children's autonomous consent to medical treatment at 14 years. In the United Kingdom, the age can be younger than 16 years in cases where the individual patient can appreciate the nature and implications of the treatment or diagnosis.
- In Austria, Belgium, the Czech Republic, Estonia, Germany, Luxembourg and Sweden, there is no fixed minimum age requirement for consent to medical treatments. Instead, each situation is treated individually depending on the maturity of the child.

For illustration of the above data, a map of EU countries has been composed for this thesis with references to age limits ("NL" refers to "no age limit"):

According to the FRA mapping, there may be different rules regarding the minimum age at which children can seek medical advice and/or treatment without parental consent and with no information being disclosed to the parents. Some Member States assess the maturity of the child before allowing them to seek medical advice and/or treatment independently, while others always keep parents informed about a child's health issues.

2.5 Conclusion

According to Estonian law, a child may have the right to consent to medical treatment and intervention if he or she is able to consider the pros and cons responsibly. A child's capacity to consider the pros and cons responsibly must be assessed on a case-by-case basis. This is in line with Article 6 of the Oviedo Convention, which requires that the opinion of a minor should be taken into consideration as an increasingly determining factor in proportion to his or her age and degree of maturity. The same principle derives from Article 12 of the CRC, which stipulates that the child who is capable of forming his or her own views must be assured the right to express those views freely in all matters affecting the child, the views of the child being given due weight in accordance with the age and maturity of the child.

As shown by the FRA mapping, the model where there is no fixed minimum age requirement in law for consent to medical treatments is applied only in seven EU countries, with Estonia being one of them. This model is in line with the CRC Committee recommendations given in the General Comments. In General Comment No. 12 (2009), the CRC Committee invites parties to the CRC to lower the age limits at which the right to consent transfers to the child but at the same time to ensure that a child younger than this age limit can demonstrate capacity to express an informed view. In General Comment No. 20 (2016), the CRC Committee has elaborated its view further, stating that voluntary and informed consent of the adolescent[7] should be obtained whether or not the consent of a parent or guardian is required for any medical treatment or procedure.

---

[7] According to para. 5, when talking about adolescence the General Comment focuses on the period of childhood from 10 years until the 18th birthday of the child.

Chapter 3. Assessment of capacity to give informed consent in medical practice

The current chapter analyses the principles of and guidelines for assessing capacity to give informed consent. The biggest challenge posed by the children's rights approach where the acquisition of rights depends on the competence of each individual child, is that is encompasses a serious administrative burden since the competence of the child must be individually assessed every time a relevant decision must be made. Practical guidelines on how to assess capacity to consent are therefore of utmost importance. In para. 3.1, the content and purpose of informed consent are introduced. Thereafter, in para. 3.2, the general principles of assessing capacity to consent are discussed. In para. 3.3 it is analysed whether the assessment of children's capacity differs from that of adults. Further, in para. 3.4, the question of a child's right to refuse treatment is discussed, as a child deemed competent to give consent should in principle also be deemed competent to refuse treatment. The involvement of a child who has been deemed not capable to give autonomous consent is discussed briefly thereafter in para. 3.5. Finally, empirical evidence on children's capacity to consent is studied in para. 3.6 of this chapter.

3.1 Content and purpose of informed consent in medical practice

“The legal purpose of consent of the patient is to safeguard his or her autonomy or right to self-determination but it also gives licence for the physician and others to do things to patients which would otherwise be illegal.” (De Lourdes Levy, et al., 2003, p. 629).

The Ethics Working Group of the Confederation of European Specialists in Paediatrics brings out four main aspects or aims of informed consent that together foster the doctor-patient relationship, and create mutual trust and understanding (De Lourdes Levy, et al., 2003, p. 630):

- respecting patients’ autonomy (patients should be entitled to decide what is best for them);
- treating patients justly;

- protecting patients from the possible harm the treatment may cause;
- allowing patients to benefit from involvement and participation.

Procedurally, giving informed consent involves several steps: first, the doctor must give information to the patient. Secondly, the patient has to understand the information given and finally, the patient has to give his/her consent (form an opinion) based on that information. In short, for consent to be valid, it must be given voluntarily by an informed person who has the capacity to consent (Oviedo Convention, Art. 5).

3.2 Assessing capacity to consent in medical practice, general principles

In clinical practice, competence is generally addressed as decision-making capacity. (Hein et al., 2015). In adults, the generally accepted reference standard for competence assessment by clinicians revolves around four relevant criteria: the ability (i) to communicate a choice; (ii) to understand the relevant information; (iii) to appreciate the medical consequences of the situation; and (iv) to reason about treatment choices (Hein).

Alderson (2007), who is one of the leading researchers of children's rights in health care, points out that "four standards of mental competence are commonly assessed [in the UK] in the person giving consent. Are they sufficiently able to: understand the relevant information; weigh the information in order to make a reasoned choice; and make voluntary and autonomous decisions? Two other standards are the ability to communicate the decision, and the ability 'to believe the information' (Mental Capacity Act, 2005)".

Morreim (1993) emphasises the role of the assessor in the competence assessment procedure. He differentiates between the substantial and procedural aspects of decision-making: substantively we ask what would be the best decision for a particular patient in a particular situation, while procedurally we ask who should make the decision. As decision-making on a substantive level includes assessment of what is in the best interests of a particular patient, it contains rationalising the decision against a certain system of values. As Morreim notes, the patient should be able "to draw inferences from the information with reasonable rationality, to hold some sort of value framework sufficient to guide his choice, and to make an actual decision on the basis of those values" (Morreim, 1993, p. 295). Thus, the value framework is one of the key factors in the light of which capacity is assessed. Some authors contend that "children may differ from adults by not having developed yet stable long term goals and values in life, meaning that children may procedurally be classified as competent although their decisions are based on values that might change. This could imply that later on they might regret decisions based on those early-life values" (Hein et al., 2015, p. 3). But the above may very well happen to adults also: it is quite common that later in life people regret things they did when they were younger, even though they were adults in legal terms. The author of this thesis would therefore not consider the aspect of set values as a criterion that is specific to children.

Morreim (1993, p. 301) then moves beyond the assessor (of competence) in saying that "we need to rewrite the traditional view's simplistic formulations of the substantive and procedural questions." He proposes that instead of "who should decide?" the correct procedural question should be "how should the decision be made?" Morreim then finds that "the physician should get to know the patient as best he can, should put that person at ease so that he can learn what sort of life the patient lives and what is important to him in the wider world outside the office or hospital room. […] In this sense, the physician's central obligation is to take the patient seriously as an individual."

The challenging part of assessing capacity is that the assessor (health practitioner) judges the decision through the lens of his/her own value framework. If the doctor finds the patient to be capable to make the decision, the doctor has to honour the decision however irrational it may seem to the doctor according to his own views and values. "If we are to honor autonomy, we cannot say, 'We will honor your decision, but only if it's the right one.' Only if someone is not competent can we override his expressed decision and appoint someone else to choose for him." (Morreim, 1993, p. 295). "Capacity should not be confused with a healthcare professional's assessment of the reasonableness of the person's decision. (UK "Reference guide to consent for examination or treatment", 2009, para. 6).

One important aspect of capacity assessment is that the patient must be capable in the matter in question, that is, the doctor does not have to evaluate the overall competence of the patient (Morreim, 1993, p. 295). The Irish "National Consent Policy" (2013, para. 5.1) states that "best practice favours a 'functional' or decision-specific approach to defining decision-making capacity: that capacity is to be judged in relation to a particular decision to be made, at the time it is to be made – in other words it should be issue specific and time specific – and depends upon the ability to an individual to comprehend, reason with and express a choice with regard to information about the specific decision." The policy also states that "the fact that a service user has been found to lack capacity to make a decision on a particular occasion does not mean that they lack capacity to make any decisions at all, or that they will not be able to make similar or other decisions in the future." (para. 5.3, p. 30). The above principle is a relevant aspect when we talk about children's competence, as this means that they do not have to prove their overall competence, but only competence for the matter in question.

To conclude on the assessment of capacity to consent to medical intervention, it is a process with different stages that happens between a person who has to give or refuse to give consent (a patient) and an assessor, who by law or other rules has been given the power to decide on the capacity of that person (usually a health practitioner). First, the assessor has to give the patient information that is relevant for the decision. The patient has to understand the information and then weigh/analyse such information in the framework of his/her value system. At the same time, the patient must satisfy the assessor that he/she understands what is explained to him/her. Based on the information, the patient has to form an opinion/make a choice and be able to (a) communicate and (b) reason that choice to the assessor. It is important to emphasise a principle that is usually not mentioned with regard to consent, which is that the doctor also has to understand the information and reasons given by the patient, as otherwise it is not possible for the doctor to weigh them. As Morreim (1993) contends, the doctor has to get to know the patient as best as he can.

3.3 Is children's capacity assessment different from that of adults?

All the above general principles of assessing capacity to consent are also valid in relation to child patients. The author did not find any arguments in the course of her research that would support the view that those principles should not apply to children. There is no methodological difference between assessing the capacity of an adult and the capacity of a minor.

The consent policies of the United Kingdom and Ireland are analysed in this thesis as best practice examples with regard to guidance on the capacity assessment. Both countries have been active in conceptualising child participation in health care, especially after the famous Gillick case[8], where the court acknowledged the right of a child to give autonomous consent.

In the United Kingdom and Ireland, the child of at least 16 years of age is regarded as capable to consent to medical treatment. Thus, there are different rules for children under 16 and for children aged 16-18. However, since the landmark Gillick case in 1985, doctors in the United Kingdom are allowed to judge the capacity of children under 16, and if they consider a child capable to consent (called "Gillick competent"), the consent of the parents is not necessary.

According to the UK "Reference guide to consent for examination or treatment" (2009) "If the child is Gillick competent and is able to give voluntary consent after receiving appropriate information, that consent will be valid and additional consent by a person with parental responsibility will not be required. It is however, good practice to involve the child's family in the decision-making process, if the child consents to their information being shared." The guide also emphasises that consent must be given voluntarily, and consent is invalid, if it is not given voluntarily (para. 12). The guide explains that "[c]hildren and young people may be subject to undue influence by their parent(s), other carers or a sexual partner (current or potential), and it is important to establish that the decision is that of the individual him or herself." (para. 12).

---

[8] House of Lords, Gillick v West Norfolk and Wisbech AHA [1986] AC 112.

In the Gillick judgment, Lord Fraser concluded that in a case where the child (in this case a girl) refused to inform her parents, the doctor would be justified to proceed without the girl's parents' consent, if the doctor was "satisfied on the following matters: (1) that the girl … will understand his advice (2) that he cannot persuade her to inform her parents or allow him to inform the parents that she is seeking contraceptive advice (3) that she is very likely to begin or to continue having sexual intercourse with or without contraceptive treatment (4) that unless she receives contraceptive advice or treatment her physical or mental health or both are likely to suffer (5) that her best interests require him to give her contraceptive advice, treatment or both without the parental consent."

The judgment gives only little guidance on what criteria should be used to assess a child's capacity to consent. Lord Scarman notes that "a minor's capacity to make his or her own decision depends on the minor having sufficient understanding and intelligence to make the decision." It is the reading of the author of this thesis of the Gillick judgment that the court trusted that doctors would be sufficiently qualified and able to assess the capacity of a child.

In Ireland, the general rule applies that children are capable to consent, if they are at least 16 years of age. However, the Irish National Consent Policy (2013) acknowledges the right of the child under 16, in exceptional circumstances, to consent to medical treatment without the parents' or legal guardian's consent and knowledge (p. 54). In those circumstances, an assessment must be made as to whether:

- the minor has sufficient maturity to understand the information relevant to making the decision and to appreciate its potential consequences;
- the minor's views are stable and a true reflection of his or her core values and beliefs, taking into account his or her physical and mental health and any other factors that affect his or her ability to exercise independent judgement;
- the nature, purpose and usefulness of the treatment or social care intervention;
- the risks and benefits involved in the treatment or social care intervention, and
- any other specific welfare, protection or public health considerations.

Thus, in addition to an understanding of the relevant information, the Irish National Consent policy puts emphasis on the nature and purpose of the treatment as well as the risks and benefits thereof, and on the assessment of child's own value system – an element which other authors (Morreim, 1993) have outlined as a fundamental component of assessment procedure.

The UK and Irish examples and experiences could be used in the development of guidelines on child patient's consent in other countries, including Estonia.

One important criterion for assessing the child's capacity to consent should be, in the opinion of the author of this thesis, the child's own assessment/opinion whether he/she feels capable to decide autonomously. If the child says that he/she does not feel capable of making decisions autonomously, this should be decisive. As described in Chapter IV, some of the children interviewed said they would be afraid to decide themselves and that they would want to ask their parents' advice or to make the decision together with their parents. This shows that children's own opinion about their competence should also be trusted, and it should not be presumed that children want to make autonomous decisions once they are given the opportunity to do so.

The above should not be confused with the common interpretation of Article 12 of the CRC that the child should be given an opportunity to express her or his views in the matter affecting her or him. In the literature explored for this thesis, the above principle was interpreted in the context of the child's view on the medical intervention itself and not in the context of child's view on whether she or he feels capable to consent to the medical intervention.

To conclude on assessment of children's capacity to consent, it does not differ methodologically from assessing adults' capacity. The main difference is in the approach: in the case of adults, competence is presumed, whereas in the case of children it is generally the other way around. This is where a change in attitudes is necessary, as proposed by many authors (Freeman, 2009, p. 387; Verhellen, 2015, p. 55; Hanson, 2012, p. 69). The competence of children should be presumed, not their incompetence, and the burden of proof should lie on those who wish to deny rights to children. The author contends that competence/capacity could be presumed from a certain age, based on empirical evidence, as elaborated in para. 3.6. Some argue that children differ from adults because they have not yet developed long term goals and values in life. However, as the empirical evidence presented in para. 3.6 shows, even if the above is true to a certain extent, it does not render children, as of a certain age, less competent than adults to explain and reason their choices. When assessing children's capacity to consent, it is also important to ask children whether they are capable to do so in their own eyes. Children should not be forced to make decisions if they do not feel able to do so, even if an assessor finds them capable.

3.4 Is capable to consent also capable to refuse treatment?

As discussed above, according to the principles of medical ethics, consent has to safeguard the individual's autonomy or right to self-determination. Without informed consent, medical intervention is not allowed as a general rule. This would inevitably mean that if a patient does not consent, he/she may not be treated. Thus, a patient may refuse treatment, at least this is the case for competent adult patients. The right of a competent child patient to refuse treatment remains sensitive and controversial. In principle, a child who is regarded capable to give consent should also be regarded as capable to refuse treatment, as the whole concept behind consent is the choice to accept treatment or not. However, both in academic literature and sometimes in the domestic law of different states, the right of the child to refuse treatment is separated from the concept of consent.

De Lourdes Levy, et. al. (2003, p. 632 - 633) state in the Statement of the Ethics Working Group of Confederation of European Specialists in Paediatrics that "[c]hildren may (*only*) refuse treatment or procedures which are not necessary to save their lives or prevent serious harm, e.g. blood tests or minor dental procedures. … Where treatment is necessary to save life or prevent harm, the doctor has a duty to act in the best interest of the child. In these circumstances the consent of the parents is usually obtained and in law this is often regarded as sufficient".

Freeman (2009, p. 381) refers to an English case where the child's will to refuse a heart transplant was not accepted by the judges who found that "a competent child can consent to a treatment but cannot refuse it."

The UK Reference Guide states that where a child competent by law (i.e. over 16) or a Gillick competent child under 16 refuses treatment, "it is possible that such a refusal could be overruled if it would in all probability lead to the death of the child/young person or to severe permanent injury." (para. 13, p. 34 of the Reference Guide).

In Estonia, the law does not differentiate between the right to consent and the right to refuse, and there have also been no related court cases. As there has been no legal debate on the issue of child patients' consent in Estonia, it is very hard to predict what the courts' position might be with regard to a child's right to refuse treatment. The majority of doctors interviewed tended to adhere to the principle obligation of doctors to do good, which if the treatment in question were recommendable would probably mean treating the child (see Chapter IV). Two doctors (of 11) contended that a competent child's decision to refuse treatment should have the same value (consequences) as that of an adult.

3.5 The involvement of the child who has been deemed not capable to consent

Even if a child is deemed not capable to give informed consent autonomously, any medical intervention or treatment must be done with the maximum participation of the child. Therefore, the conclusion that a child is incapable to give autonomous consent should not be the end of the participation process. As analysed in paragraphs 1.1 and 2.2.2, the child's right to be heard, deriving from Article 12 of the CRC, is one of the four general principles of the CRC and guides the interpretation of all other articles.

The Council of Europe Guidelines on child-friendly health care (2011) emphasise two stages of participation: when a child is deemed capable to give informed consent by law, medical intervention may be carried out only after such consent has been given; when, according to law, the child does not have such capacity, the opinion of the child must be taken into account. The rules, deriving from the CRC, that are applicable to the process of giving weight to the child's opinion are the child's age and maturity (Article 12), the child's evolving capacities (Articles 5 and 14) and the child's best interests (Article 3). The content of those Articles has been elaborated in more detail in paragraphs 1.1 and 2.2.2.

3.6 Empirical evidence on children's capacity to consent

For the purpose of this thesis, the author had a special interest in empirical evidence regarding children's capacity to give informed consent. The results of three empirical studies, carried out in the Netherlands, Canada and USA, are presented in the thesis. The most recent by Hein et. al. (2015) was carried out in the Netherlands. The second by Ondrusek, Abramovitch, Pencharz and Koren (1998) was conducted in Canada and the third by Weithorn and Campbell (1982) was completed in the US. These studies are presented as they all focus on children's developmental abilities which is a key issue with regard to child patient's consent. Two of the studies addressed consent to medical research and one examined consent to medical treatment. Although two of the studies focused on consent to clinical research, they are relevant in the context of medical treatment, as assessing competence is similar in both contexts.[9] The main conclusions of these three studies are introduced below.

According to the study by Hein et al. (2015, p. 2):

> "Age limits for children to be deemed competent to decide on research participation were estimated: children of 11.2 years and above generally appeared to be competent, while children of 9.6 years and younger were not. Children between 9.6 and 11.2 years were in a transition period; they develop important capacities but their maturity is not pervasive. Furthermore age turned out to be the factor that explains most of the variance in children's competence to consent, followed by intelligence. Theoretical assumptions that risk and

---

[9] Hein et. al. (2015) note that the MacArthur Competence Assessment Tool for Clinical Research (MacCAT-CR) was used in the study. As stated by the authors, the MacCAT-CR measures the same four aspects of decision-making capacities as the MacCAT-T, which is an instrument for assessing patients' competence to consent in a treatment setting (Hein et al., 2015, p. 5). It is also noted that „[i]n a pilot study, use of the MacCAT-T proved feasible in a population of children between 8 and 17 years of age who had to decide on predictive genetic testing for cardiac diseases. Although sample-size was small (N=17) and conclusions premature, all participating children above the age of 12 years were judged to be competent to decide on this treatment option."

> complexity of the decision would be related to a competence classification could not be confirmed with empirical data. This demonstrated that more radical decisions, requiring a higher level of competence, could possibly made by children as young as the group of children who were able to make lower impact decisions. An explanation might be that children at a certain age have the required capacities, and competent decision-making is possible when information provision is of good quality. For other potential determining factors for competence, like gender, systemic influences, disease experience, ethnicity and socio-economic status, no clear relationship with a competence classification could be demonstrated either."

Finally, Hein et. al. (2015) conclude with regard to children's consent that "the age limit that presents closest accordance with children's competence is eleven or twelve years".

Ondrusek et. al. (1998, p. 163) find in their study that:

> "Two interesting trends regarding understanding and age of participants emerged: 1) Understanding of several aspects of the study, namely: purpose, potential harms (for those taking part in the long study), right to withdraw, and potential benefits, showed a definite age-related pattern, whereas understanding of other types of information, such as procedures, did not appear related to age. 2) For all the areas where there was an age-related pattern in the response, 9 years of age seemed a changing point – the majority of those 9 years of age and younger did not understand those elements of the study, while the majority of those over 9 years of age did appear to understand the same elements. […] The fact that older children were able to understand information that the younger children were not able to understand, and the fact that in all cases the change in understanding occurred about 9 years of age, indicates that there is a developmental difference in understanding information."

Weithorn and Campbell (1980, p. 1589) conclude in their study, which was the only study that directly tested developmental differences in competency to make informed treatment decisions:

> "Overall, 14-year-olds did not differ from adults. 9-year-olds appeared less competent than adults with respect to their ability to reason about and understand the treatment information provided in the dilemmas. However, they did not differ from older subjects in their expression of reasonable preferences regarding treatment. It is concluded that the findings do not support the denial of the right of self-determination to adolescents in health-care situations on the basis of a presumption of incapacity. Further, children as young as 9 appear able to participate meaningfully in personal health-care decision making."

It could be concluded on the basis of the results of these three studies that the age of 9 seems to be a turning point in the development of children, and that from age 9 upwards, children are able to understand information they are given and base their choices and/or decisions on that information. There can be differences between the ages of 9–11.2, where children are in a so-called "transition period" (Hein et. al., 2015). The age limit that presents closest accordance with children's competence to consent to medical research is 11 or 12 years. By the age of 14, children acquire competence equal to that of adults when it comes to consenting to medical treatment.

Although the above three studies were carried out in different geographical contexts – Europe, USA and Canada – it is interesting to note that they all came to similar conclusions about children's competence. This may indicate that geographically there are no relevant differences in children's capacity to consent, at least within the Western cultural context.

3.7 Conclusion

The competence of children should be assessed based on the same principles as that of adults, and there is no methodological difference in assessing competence in children and adults.

In adults, the generally accepted reference standard for competence assessment by clinicians revolves around four relevant criteria: the ability (i) to communicate a choice; (ii) to understand the relevant information; (iii) to appreciate the medical consequences of the situation; and (iv) to reason about treatment choices (Hein, 2015). The assessment must be made with regard to the specific situation and specific treatment the patient is facing. In that sense, assessment of capacity to consent is issue specific and time specific. A lack of competence in relation to one specific issue does not render the patient incapable for all other issues. It is also important not to confuse a judgement on the competence of a person with a judgement on the reasonableness of that person. What may seem unreasonable to a doctor may seem completely reasonable to a patient. Therefore, it is important to assess a patient's competence through the lens of his/her value system. A patient should be able "to draw inferences from the information with reasonable rationality, to hold some sort of value framework sufficient to guide his choice, and to make an actual decision on the basis of those values." (Morreim, 1993, p. 295).

According to empirical studies, from age 9, children are able to understand information they are given and base their choices and/or decisions on that information. There can be differences between the ages of 9–11.2 when children are in a so-called "transition period". The age limit that presents closest accordance with children's competence to consent to medical research is 11 or 12 years. By the age of 14, children acquire competence equal to that of adults when it comes to consenting to medical treatment.

Chapter 4. The Estonian context. Experiences of doctors, children and parents

In this chapter, a qualitative analysis of the views of doctors, children and parents with regard to children's involvement and decision-making in health care settings is presented. In total, 24 children, 15 parents and 11 doctors were interviewed. The interviews were semi-structured and concentrated around four thematic blocks that constitute a core of consent issues: (i) communication with the child; (ii) practices of taking consent from child patients; (iii) capacity of the child to consent; and (iv) the role of parents. In addition, doctors were also asked about their knowledge of the rules regarding child patients' consent, since according to the law, they assess a child's capacity to consent. Children were also asked about their general attitudes and expectations with regard to doctors.

4.1 Experiences of doctors

4.1.1 Knowledge about the law governing informed consent of child patients

The doctors interviewed were well aware of the ethical principles of informed consent. However, they were not aware of the content of Estonian law regarding child patients' consent. Most of the doctors interviewed did not know that Subsection 766(4) of the Law of Obligations Act enables them to weigh the capacity of the child to give informed consent and, if they deem the child capable, the legal right to give consent could belong to the child. An interesting trend could be seen with regard to the views of the gynaecologists in the study. When compared to other doctors, they were more aware of the law relating to child patients' informed consent. This can be explained by the fact that sexual health issues are regarded as matters belonging to the private sphere of a person, even if that person is a minor. It may be also be related to the reform in 2014–2015 of the law governing a minor's right to abortion. Before 2015, a minor had the right to an abortion only with the consent of her legal representative, i.e. her parent or legal guardian. The Gynaecologists' Union was in favour of changing the law on abortion so that a minor would have the right to decide on abortion without permission of a legal representative, if the minor was able to weigh the pros and cons responsibly. The law was amended in 2015. Since 2015, the general rule of child patients' informed consent set out in the Law of Obligations Act applies also to a minor's decision on abortion. This means that if the gynaecologist finds the minor capable to weigh all the pros and cons responsibly, the minor may decide on abortion.

All the doctors interviewed found that they had received either insufficient training with regard to child patients' informed consent or no training at all. Most of the doctors had studied medicine before the Law of Obligations Act came into force (in 2002). They found that materials explaining the content of the law and best practices would be helpful.

One of the doctors also stated that doctors should receive basic training in psychology.

4.1.2 Communication with the child

All of the doctors interviewed explained that they communicated with children directly. What kind of explanations they gave and the proportion of communication with the child compared with communication with the parent depended on the age and maturity of the child. There was no pattern revealed how doctors made those adjustments in communication.

One family practitioner explained that as soon as a child is able to communicate, they communicate with the child: "*Even with babies – I communicate with the baby directly, not only with the parents*". The same doctor also contended that direct communication with the child provides a lot of information that has medical relevance. For example, family doctors have to assess the school readiness of children. It is impossible to do so if a parent does not let his/her child talk to the doctor.

One gynaecologist pointed out that: "*It is essential that you communicate with the child directly and not with the parent, even if the parent sits there. You have to look at the child and talk to the child directly.*"

Some doctors pointed out that they explicitly ask children whether they have any questions. As one of the gynaecologists pointed out: "*We try to reflect back to the* *child what she understood. We ask questions. And if the child does not ask any questions, it is important to say "do you have questions?"*.

Mostly, children visit doctors with a parent (or parents). Doctors must therefore communicate both with the child and the parents. A pattern emerged from the interviews that approximately from the age of puberty, the doctors encouraged children to enter the examination room alone and asked parents to wait outside. This was practiced by family doctors and gynaecologists. Both of the family doctors interviewed said that the age from which they encouraged children to enter the examination room alone was around 12. The gynaecologists contended that in their field, there is a huge difference whether a medical examination takes place before or after puberty; in their words, everything depends on this. A family doctor explained her practice as follows: *"When a teenager comes with a parent, and the parent walks into the room, and when I want to talk to the teenager about alcohol, tobacco, drugs, sexual health or psychological problems, I ask the child – is it okay that your mum/dad is here in the room. If the child says it's okay, I'll talk to the child in the presence of the parent, if the child says it's not okay, I ask the parent to wait outside. … When I come to a topic where I see the young person is not responding honestly, I quite confidently ask the parent to wait outside. … I have never had any problems with that. I'm quite a direct doctor in that sense. … "*

There seems to be no common practice for informing parents when children visit doctors alone. Some doctors will contact a parent and some not. A family doctor pointed out: *"If a child comes to me alone, I normally ask whether he/she wants me to call his/her parents. If the child finds it unnecessary, I will not contact the parents."* A dentist explained: *"Normally I will contact the parents. Or the whole family visits me regularly and it is agreed beforehand that the child will come alone*." One family doctor remembered a couple of cases where teenage girls (14-15) had complained that she had informed their parents and not the girls themselves about the results of blood tests. The health centre apologised to the girls and marked in their medical records that the patients wanted to be informed directly and not through their parents. Generally, the doctors assumed that if a child visits the doctor alone, it is agreed within the family. It may be generalised from the doctors' answers that if a doctor knows the family of the child well, he/she is more comfortable with taking decisions on treatment without the parents' participation. With some families, family doctors have an agreement that the child visits the doctor alone. This may be a good practice to avoid later misunderstandings.

In response to the question of what inhibits communication with and involvement of the child, some doctors answered that there are time constraints. As the dentist pointed out: "*There is a time-constraint that inhibits giving explanations to the child and convincing him/her. If you need too much time, there will be no time left for the treatment.*"

4.1.3 Capacity of the child to consent

During the interviews the doctors were asked whether there is a specific age as of which children are capable to give informed consent, i.e. weigh the pros and cons responsibly as stipulated by the Law of Obligations Act. Most of the doctors agreed that it is very hard to specify one particular age from which children are capable to weigh the pros and cons responsibly. The most common answer was 16:

"Maybe this age is 16, when they start to grow out of puberty. However, there may be exceptions. I have some 7-8-year-old patients who have clear values and understand that it is their own health and it is only they themselves who can take responsibility for their health. And sometimes children have a better grasp than their parents. In such cases, it may become a hindrance if you have to confirm everything with the parent."

"A 16-year-old is definitely capable of weighing the pros and cons responsibly. I would communicate with him/her like I do with an adult patient."

"There is no such age limit. Everything depends on the nature and seriousness of the procedure or intervention in question. What is the relation between harm and benefit? And whether the young person understands it."

"I think the capacity to think autonomously starts already at a pre-school age. A 6-year-old is able to think about something together with you, and you can discuss things with him/her. Of course, there are exceptions. But the capacity to weigh the pros and cons responsibly, I would say at the age of 14 to 15, and a 16-year-old is definitely able to do so."

"In my opinion the capacity to decide autonomously develops at the age of 11–13."

"When the child comes alone to the doctor, often he/she is capable."

An interesting pattern could be drawn from the interviews. Some of the doctors who answered that 16 is the age at which a child is capable of weighing the pros and cons responsibly had actually treated children as their own agents from a much earlier age. For example, one of them had consulted younger adolescents independently or honoured their request not to involve parents, and had encouraged children of around 12 years to enter the examination room alone. Another had treated children from about the age of 7 as decision-makers together with their parents. This may reflect an understanding that informed consent is a legal concept, which therefore sets, in doctors' opinions, a higher standard for children's understanding than "ordinary" everyday participation in decision-making. It may also be that legal aspects are intimidating to non-lawyers and that doctors are more conservative in their answers when directly asked about such topics.

It also emerged from the interviews that as a general rule, from puberty on children are reasonable and understand that treatment or procedures are in their own interests. As one paediatrician with 30 years of experience said: *"I do not recall a case where a teenager has walked away (from treatment)."* A dentist who had practiced for 25 years recalled 15 child patients who had refused treatment, of whom most were younger children (under 7).

Based on the interviews, it can be concluded that the main criteria according to which doctors assess children's capacity to consent is their understanding, i.e. whether they understand the information given to them and whether they understand their situation.

According to the doctors, judging the capacity of the child depends significantly on whether they have contact with a patient on one occasion or the doctor knows the patient over a longer period of time. Many doctors contended that it was easier to assess the capacity of a child who is known to the doctor for a longer time. As one of the doctors put it, *"with child patients that regularly visit me, I know whether they are able to weigh the pros and cons responsibly"*. If a doctor only has contact with a child once, it is very hard to judge the capacity of the child. Some doctors mentioned that one of the obstacles to judging the capacity of a child is the limited time they can dedicate to a patient.

One gynaecologist contended that it had become evident from the abortion debate in 2014/2015 that doctors do not know how to evaluate the capacity/competence of children.

As contended in para. 3.3, one important aspect when judging a child's capability is the child's own opinion of whether he/she is capable. The fact that a child visits a doctor alone may be a strong indication that the child is capable to weigh the pros and cons him/herself, as one of the doctors pointed out. Some doctors pointed out that it is very rare for children to visit doctors alone and those who do, vary a lot in age. As one family doctor noted, some children visit doctors alone already at the age of 10, and many come with a parent even when they are 18.

The doctors were also asked whether a child who is capable to consent should also be able to refuse treatment. For the doctors, there seemed to be an ethical challenge to accepting a child's refusal of a treatment, where the treatment is necessary in the doctor's view, especially if a life-saving treatment is involved. As one family doctor contended: "*In making such a decision (accepting a child's refusal), it's very important what is at stake – do we only gain a couple of months extra time or the child has the chance to become an adult. … Of course in some cases you must override an adolescent's wishes – for example in the case of eating disorders, because these may be fatal. At the same time there are no good tools how to do it – there's only psychological work with the child and the family.*" Doctors' ethics require them to do good, which may be behind the tendency not to accept a child's refusal. As a gynaecologist worded it: "*My answer to whether we have to treat a child patient and an adult patient differently is a definite "No". However, doctors have the obligation to do good. And if the patient is a child, then somehow doctors instinctively start to behave differently – they think they have to help the child. If the patient is an adult, then it's said an adult person knows what he/she does.*"

Two doctors explicitly stated that a competent child-patient's decision to refuse treatment should have the same meaning as that of an adult.

4.1.4 Practices of taking children's consent

None of the doctors interviewed said that they explicitly took informed consent from children for a treatment or procedure. They all claimed that as a general rule, children come to the doctor with a parent and consent was not an issue. They assumed that parents are the ones who give consent for the treatment of a child who is under 18 or that coming to the doctor demonstrates tacit consent. One family doctor pointed out that *"It (the consent giving) is a shared process. Both (child and parent) should agree."* However, upon listening to their practices it became evident that in practice they sought the acceptance or assent of the child for any procedure. Even if the doctors did not take a minor's consent consciously, there was a general approach whereby the child was involved as much as possible and the child was respected as a patient. As one family doctor stated: *"I'll put the child on that chair in front of me, because the child is my patient (not the parent). I'll interview the child. If the parent starts to talk on behalf of the child, I'll also ask the child. I want the child to speak in his or her own words. I'll never base a diagnosis solely on a parent's explanations."*

A positive initiative was found to be in place in the Children's Mental Health Centre, which is part of Tallinn Children's Hospital, where from the age of 10 children sign health service contracts together with a parent. According to the specialists of the centre, this empowers children and helps them to understand that they are patients, not their parents, and it is also their own responsibility to take care of their health.

According to the interviews, as a general rule, children are not treated and procedures are not performed on them against their will. As the dentist put it: *"I haven't treated any child against his or her will. It's not possible to work in this practice like that. You have to build trust with the child."* A family doctor stated: *"If a procedure can be postponed, we postpone it. We don't want for a child to have a traumatic experience or to remember it every time, he/she sees a doctor. …. The art of convincing is our main tool here."* Another family doctor found that *"[w]hen I have a good relationship with the family, then the parent agrees to convince the child about the necessity of the procedure. I convince the parent and the parent convinces the child. ... I cannot risk the doctor-patient relationship of trust by forcefully doing something to a child."* The ear-nose-throat specialist contended that: *"It cannot be only a parent's decision* *to have a painful procedure where the child is already at the age where they leave kindergarten and start school*[10]*. The child has to know what awaits him/her and must agree to it. There should not be a presumption of incompetence of the child in that sense."*

Some of the doctors pointed out that a child who does not agree to a procedure in the presence of a parent may be more cooperative when the parent is sent out of the room. The fear and anxiousness of a parent may be transmitted to the child in such cases and therefore the presence of the parent is unhelpful. The interviewed dentist pointed out that sometimes a child who opposes a procedure may behave differently if he comes with the other parent or a relative (e.g. a grandparent). She has therefore used the tactic of suggesting that the child come again with the other parent, which has given good results. She has also in some cases recommended to the parents that they try with another doctor, as sometimes a child may have a better rapport with another doctor.

Some of the doctors explained that they give children who oppose a procedure (e.g. at the dentist for taking a blood sample) the chance to come back. This may mean a couple of "empty" visits, but ultimately the child will agree to the procedure. The dentist who was interviewed had witnessed a pattern during her 25 years of practice that it takes three visits to obtain a child's consent. Even the most stubborn child patients who had been afraid of the dentist had agreed to the procedure after a maximum of three visits.

A more autonomy-orientated approach could be seen among the gynaecologists. All of them were of the opinion that they followed the ethical code for doctors and they would follow a minor's will if the minor were capable to consent. As one of the gynaecologists pointed out, *"[c]hildren usually come with their parents. But we have to take into account the child's best interests. Even if the mother brings the adolescent to the doctor and we see that the mother's interest differs from the child's interest, we will take the child's interest into account."* At the same time, they pointed out that they did not want there to be any conflict between the child and the parent.

---

[10] In Estonia, the compulsory school age is 7.

A young gynaecologist who consults child patients every week contended: *"If the child does not agree, she does not agree. We cannot examine her. Sometimes a child will visit me several times before she is ready for an examination. She gets used to me and consents to the procedure. I never examine children against their will. Some parents offer to hold their child by force for the examination. I never allow that, except for babies, who may otherwise fall off the examination table."*

There also seems to be a difference in the practice relating to consent procedures in general medical care (family doctors) and specialised medical care that is provided in the form of in-patient care in hospitals.[11] In hospitals, there is a general practice for in-patient care, mostly surgeries, that a written consent form must be signed by a parent or other legal representative of the child before treatment/surgery. Children and young people are therefore not able to go to hospital for in-patient care alone or give independent consent for such treatment. The doctors who worked in hospitals contended that they could not treat (operate on) a child without a parent's consent, as the formal procedures in the hospital require the signature of a parent on a consent form. Conversely, both of the family doctors interviewed said that they had offered health services to children independently, whereby they had accepted the child's independent consent. In one case a family doctor had referred a suicidal child to a psychiatrist without informing the parents because this was the child's explicit request. In another case, a family doctor had consulted a minor about sexual health and had prescribed contraceptives. There was also a case where the family doctor had vaccinated an adolescent approaching adulthood, who explicitly requested vaccination, although his parents were against vaccination. Thus, formalities and not only the doctors' knowledge or attitudes also seem to hinder the giving of autonomous consent by an adolescent. On the other hand, it is obvious that in the case of in-patient care in hospital, the medical intervention is generally more invasive and carries more risks. The family doctors also mentioned that they normally do not have to

---

[11] In Estonia, health services are divided into general medical care and specialised medical care (Health Services Organisation Act). General medical care means out-patient health services which are provided by family physicians. Specialised medical care means out-patient or in-patient health services which are provided by medical specialists or dentists and health care professionals working together with them. As a general rule, specialised medical care is provided in hospitals. In-patient health services are health services for the provision of which a person needs to stay in hospital twenty-four hours a day, and out-patient health services are health services for the provision of which a person does not need to stay in hospital twenty-four hours a day.

provide invasive treatment and that makes their "life easier" when compared to doctors providing treatment in hospital.

Based on the interviews, it can be concluded that in Estonia the approach of doctors is mainly based on a parent's consent on behalf of his/her child and the child's assent/acceptance. However, in cases where the child's will had been contrary to the parent's will or the child had explicitly asked the doctor not to consult with his/her parents, family doctors had based treatment on the child's informed consent, since they had found the child capable of weighing the pros and cons responsibly. In hospitals, the formalities and not the doctors' attitudes seem to inhibit the possibility of taking informed consent from a child independently.

4.1.5 The role of parents

All of the doctors interviewed emphasised the role of parents with regard to their child's health and attitudes towards doctors and treatment. They found that it is mainly up to the parents to convince a child who opposes medical intervention. Parents have to explain to the child that it is his/her health which she/he has to take care of. As the dentist noted with regard to getting a child's assent to procedures: *"It depends a lot on how it has been explained at home to the child. … Parents can explain to their child and get the child's assent with different methods …. It is much easier to cooperate with children who come from families with good mental health. If the child has to face fears at home, it effects his/her behaviour in the examination room. … Some parents are not able to convince their child."*

One family doctor explained that with some parents you can see that the parent has no authority and that this is the reason why the child does not agree to anything. *"If the parents are very 'weak', we sometimes ask them to wait outside and we tell them we will do this ourselves."*

One doctor explained that children have to know and understand what will happen to them. According to this doctor, some parents lie to their children (especially with younger children) when painful procedures are involved (e.g. the removal of tonsils) in order to convince them. They tell the child that nothing will happen, the doctor will only look at your throat. The doctor found this to be unacceptable, and that children should not be lied to.

The dentist who was interviewed contended that it is easier to deal with children who respect adults and adult professionals. She found that *"The parents' role is huge … It is very complicated if they have not been raised well. They (children) hit their parents and you see that the parent is helpless. In such cases I have talked to the parents and have explained them that something more has to be done. Sometimes I have proposed that the child come back with another parent or a grandparent, and then the situation has been totally different."*

In the interviews the doctors were asked how they would solve a situation where a child's will was contrary to his/her parents' will. The prevailing thought expressed by the doctors was that there should be cooperation between the child and parents, and conflicts should be avoided as much as possible:

"If the 'home' doesn't know what we do here, it's hard to work. There must be cooperation with the child's home."
"I think it is necessary to take these decisions within the family."

"It is very hard to proceed with medical intervention, if the child knows that his parents do not support him in the decision-making and afterwards in executing the decisions."

As a general rule, children cannot be treated forcefully, and therefore practical problems may arise mainly in situations where a child wants treatment but the parents oppose it. Such dilemmas may arise with regard to vaccination, prescribed medications (e.g. antibiotics), a tonsillectomy or the like. The doctors were very careful and diplomatic in their answers. Most of them said that if a child wanted treatment that they found necessary, they would try to convince the parents. However, some of them, especially the family doctors and gynaecologists, were more open to a solution whereby they would respect the child's will in such a situation. One family doctor explained: *"If a girl came for an appointment and wanted an HPV-vaccination, I would do it, even if the parents were against it … If a young person is sexually active and asks for contraceptives, I will prescribe them, I will not consult the parent. I would* *rather discuss with the young person whether she knows what she is doing, whether she has a steady partner and whether there is a mutual agreement on having sex."* Another family doctor had also prescribed contraceptives to adolescents without the parents' involvement. The gynaecologists had also consulted adolescents on sexual health and prescribed contraceptives without the parents' involvement.

In cases involving life-saving treatment, there was a clear understanding among the doctors interviewed that they would have to treat the child, regardless of the parents' will. This is also required by law. The issue is more complicated when it comes to treatment or operations that are necessary but can be postponed. Two of the doctors remembered cases where the child had come back to them for surgery that was opposed by the parents as soon as the child became an adult. One was a case where the doctor had recommended a tonsillectomy and the child agreed but the parents had opposed the operation, and the other was a case where reconstructive surgery had been recommended to a 17-year-old girl who did not have a uterus or vagina, but which the mother opposed.

4.1.6 Conclusion

Most of the doctors interviewed did not know that Subsection 766(4) of the Law of Obligations Act enables them to weigh the capacity of the child to give informed consent and if they deem the child capable, the legal right to consent could belong to the child. The doctors also found that they had received insufficient training with regard to child patients' informed consent or no training at all. Nevertheless, everyday practices in health care settings target the child's acceptance and involvement as much as possible. Based on the interviews, it can be concluded that in Estonia the approach of doctors is mainly based on a parent's consent on behalf of his/her child and a child's assent/acceptance. However, in some cases where an adolescent's will had been contrary to his/her parent's will or the adolescent had explicitly asked the doctor not to consult with his/her parents, the family doctors had based treatment on the child's informed consent since they had found the child capable to weigh pros and cons responsibly. In hospitals, the formalities and not the doctors' attitudes seem to inhibit the possibility of taking informed consent from a child independently.

It is encouraging that some of the doctors with long experience considered it possible to convince children to understand the need for and accept treatment. The parents' role is of utmost importance. The doctors stated that it is mainly up to the parents to convince a child who opposes medical intervention. Parents have to explain to the child that it is his/her health which she/he has to take care of. The doctors also held that children and parents should try to reach a consensus, as it is hard for an adolescent to undergo treatment where there is no support from his/her family.

Most of the doctors were reluctant to specify an age as of which children are capable to weigh the pros and cons responsibly. The most common answer was 16. It emerged from the interviews, however, that in their everyday practice, doctors treated their child patients as partners from a much earlier age. Some of them considered children from about the age of six to be able to discuss things and understand the necessity of medical intervention. Even if they accepted a child's capacity and competence, it remained an ethical challenge for doctors to accept a child's refusal of a treatment, where the doctor considered the treatment to be necessary, especially if the treatment was life-saving. Only two doctors explicitly contended that a competent child patient's decision to refuse treatment should have the same meaning as that of an adult.

All of doctors who were interviewed explained that they communicated with children directly. What kind of explanations they give and what proportion of communication is with the child and what proportion is with the parent depends on the age of the child.

4.2 Experiences of children

4.2.1 What children expect from doctors/nurses[12]

All of the children who were interviewed emphasised that doctors should be nice to them. When asked what nice means, they said it means friendly and not angry

---

[12] When talking about their experiences, the children did not differentiate between doctors, nurses or other health practitioners. For them, they were all health personnel. Therefore the word "doctors" is used in the text for the sake of simplicity. It could, however, mean any health practitioner.

(mean)[13]. Many children associated friendly with comforting, and said that a friendly doctor comforts them or knows how to do it. This was mainly emphasised by the younger children (10 and below), which strongly indicates that younger children need more comforting compared to older ones. When asked what "angry" doctors do differently, the children could not explain, rather they just felt that they were angry or nervous. A 9-year-old boy said about other doctors who are not nice: *"They are not impolite, these others, they are just ordinary."* A 16-year-old girl explained that doctors should be more modern, like young people and not old-fashioned so they could better communicate with young people. Another 16-year-old girl said she liked doctors who make you feel equal with them and that they should not be too official. A 13-year-old girl said doctors should be understanding and not judgemental. Most of the children liked it when doctors took an interest in their lives and asked for example about their school and hobbies. Many children also pointed out that the doctors whom they visit regularly, like family doctors or dentists, are friendlier and take a greater interest in them compared to other doctors. This is understandable, as children have time to build relationships with such doctors. It is also an indication that in specialised medical care doctors have to put more effort into being friendly with children and taking a genuine interest in them.

One thing that is important to adolescents is privacy. Two girls mentioned that they could not talk openly to their family doctors, as the doctors knew their parents well. Most of the adolescent girls also felt that doctors should understand what issues young people do not want to discuss in the presence of their parents. One 17-year-old girl said: *"When I was fifteen, I visited a gynaecologist with my mum and the doctor asked about my sex life. I did not want to answer this in front of my mum."* Two girls had had experiences where a male doctor had examined them whereas they would have preferred a female doctor.

4.2.2 Communication with the child

Most of the children who were interviewed liked when doctors talked to them directly. They wanted doctors to talk to them in a friendly way and so that they understood what they were talking about. When asked what such communication normally looks

---

[13] There is no exact equivalent in English for the Estonian word "*kuri*" used by the children. It is somewhere between angry and mean.

like, most of them said that doctors talked both to them and their parent(s). Some of them mentioned that they wanted doctors to talk more to them than to their parents.

The children over 15 mostly visited doctors alone, which means that the doctors communicated only with them. Some had visited doctors with their parent(s), but wanted to feel in charge. As a 15-year-old girl put it: *"I like it when I sit in front of the doctor and my mum sits a little bit further."* A 16-year-old girl who visited doctors with her mum said: *"Now I start to talk first and then the doctor talks to me."* Another 16-year-old girl said: *"When I started to visit doctors alone, they started to see me as a child. When I visited with my mum, they were more official."*

A 16-year-old girl had had an experience where the doctor had asked her questions and her mum had always wanted to answer. Finally the doctor had said that she had to let her child talk or wait outside. When asked about whether he liked for doctors to talk to him or to his parents, one 9-year-old boy said: *"I like it better when doctors talk to my mum or dad. I cannot answer their* (doctors') *questions."* A 12-year-old girl who had stayed in hospital for 8 months and had been compelled to lie in bed the entire time said that it depended on her mood and health whether she wanted to talk or not, and sometimes she did not want to talk to doctors.

Many children said that doctors do not explain things enough. This was the prevailing feeling among older children (from 15 upwards). Most of them had had such an experience:

A 15-year-old girl: *"When I was twelve I had to go to the EMO[14] with a stomach ache. I had to wait for two hours without any explanations at all about what was happening or what they suspected."*
A 15-year-old girl: *"I had to receive orthopaedic soles. The appointment lasted only 3 minutes, nobody explained anything to me."*
A 17-year-old girl: *"You have the feeling that doctors have no time to communicate with you."*
A 15-year-old girl: *"I visited a doctor and she prescribed medicine without explaining what kind of medicine it was or how it worked."*

---

[14] Emergency health care unit.

A 10-year-old boy: *"I like doctors who communicate with children, who talk to them and make jokes. I don't like my family doctor because he does not talk to me at all, he only looks at his computer. ... Once I had surgery and they had to put me under anaesthesia. I wanted to ask all kinds of questions about the procedure, but they did not let me, they just put the mask on my face. I panicked."*
A 13-year-old girl: *"I visited an eye doctor. She put some drops into my eyes and did not explain that afterwards my sight might be blurred for a while."*

It can be concluded on the basis of the interviews that a lack of explanations is a bigger problem in the EMO or emergency health care unit than in other types of health care. As one 15-year-old girl put it: *"They seem to be somehow outdated in the EMO. They never ask anything, they just do things."* One 16-year-old girl said that it seemed as if they were always in such a hurry in the EMO.

Many of the children interviewed and all of the children in the younger children's focus group (aged 7-10) said that they sometimes had not understood what doctors had told them and that they had had to ask their parents afterwards. Interestingly, many children mentioned their dentists when talking about positive examples of doctors giving explanations and talking to them. A 9-year-old boy: *"When I first visited my dentist, she explained all the tools she uses to me."* A 7-year-old girl: *"I like my dentist, she explains things to me and tells me to say "Aaaa" when it hurts. Then she stops and comforts me."* A 17-year-old girl: *"I have braces and I have to visit the dentist often. There they take an interest in me, they ask me how I'm doing in school and sports."*

Remarkably, a 16-year-old girl with a unique diagnosis due to which she has had to visit hospital regularly since birth, said that doctors used too many foreign words and that she has had to ask her mother afterwards what it all meant. This was one of the reasons why she wanted to visit the doctor always with her mother.

4.2.3 Capacity of the child to consent

A child's capacity to consent was discussed during the group interview with older children (aged 15–17). The children were asked their opinion on the age at what children are able to decide independently on their health issues.

A 17-year-old girl: *"Maybe from the age of 10 a child is able to think it through, but regardless, the doctor should assess in each individual case whether the child is able to decide."*
A 15-year-old girl: *"There should not be any specific age. It depends on the child whether he/she is able to decide."*
A 16-year-old boy: *"From the age of 14 a child is able to decide independently, but not in matters of life and death."*
A 17-year-old girl: *"A twelve year old might refuse surgery only because of fear. Then it's not a weighed decision."*
A 15-year-old girl: *"It depends a lot on the experiences the child has had, how much contact he/she has had with doctors and hospitals, whether he/she is able to decide. It can be seen from the medical records of that child how much experience the child has had and based on that, the doctor can assess it."*
A 15-year-old girl: *"I think in my case from the age 14-15 I got the feeling that I'm able to decide alone."*
A 16-year-old girl: *"A 12-year-old thinks already and participates in the discussion, but he/she should not decide alone. A 16-year-old should be able to decide alone."*

During the discussion, some of the adolescents expressed doubt whether young people should always be able to decide autonomously. The adolescents were more conservative in their answers when the topic was discussed on an abstract level. However, when asked about themselves – whether they should be allowed to decide independently about their health and treatment – all of them said they should be allowed to decide independently. They also found unanimously that they should have the right to refuse treatment even if their parents were opposed. Only one girl, aged 15, doubted whether she could decide independently. She was sure that even if she wanted something else, her parents would convince her to do what they thought was right.

The majority of the adolescents found that doctors would be able to assess the capacity of a child to decide independently only if they took time to communicate with the child and got to know the child. They emphasised that it is not possible to assess competence on the basis of formal interaction.

4.2.4 Practices of taking child's consent

None of the children remembered if anyone had asked for their consent. This does not, however, mean that doctors in general do not seek children's acceptance for what they intend to do. Children may not interpret negotiations with them as asking for their consent. Some children talked about cases where they had not agreed to a procedure (vein puncture or injection) and had had time to think it through. They had gone out of the room and discussed the procedure with their parent(s) until they were ready to go back and undergo it. This allows for the conclusion that sometimes children are asked for consent, even if not explicitly.

When asked what should be done if a child does not agree to something, even younger children said: *"If it is a situation that is not so bad, then they should postpone it. But if it's something that definitely must be done, then they have to do it"* (10-year-old girl) or *"If it's an important thing and makes your life better, you have to do it, then the child cannot decide"* (7-year-old girl). This shows that children around 7-10 may have quite reasonable and responsible views on whether and in which cases children should be able to decide.

A 10-year-old boy who has a fear of needles and medical procedures said: *"I think what's the point of asking for my consent, they would not take it into account anyway. I never want do have anything (medical treatment/procedures)"*. However, the same boy added that his mum and dad could talk to him in such a way that he would agree to a procedure or treatment.

A 10-year-old girl: *"When they had to puncture my vein in hospital, they asked for my consent. I said I didn't want it, but they did it anyway. My answer would not mean anything."*

The above illustrates that it is important to children, already from a young age, that adults are honest with them. Children do not want "fake" consent procedures.

4.2.5 The role of parents

Parents have an important role to play with regard to the experiences children have with doctors and health services.

From the interviews with younger children, aged of 7–11, it became evident that their experiences depended to a large degree on their parents. All of them wanted to visit the doctor with a parent and their biggest fears were connected to being left alone, especially for those who had stayed in hospital. Most of the younger children mentioned parents holding their hand during a procedure, comforting them and being able to convince them to agree to painful procedures. Some adolescents also felt more secure visiting a doctor with a parent. A 16-year-old girl with a chronic disease and long medical history recalled that her most awful experience had been when she had had to stay in hospital without her mum. Two 15-year-old girls remembered cases from when they were 9 and 12 and had had to have surgery without their parent(s) being present, which had been frightening for them.

The adolescents who seemed to have a good relationship with their parents were more eager to discuss things with them, even if they wanted to take the final decision autonomously and visit the doctor alone. It seems to be a good practice in the eyes of adolescents that adolescents visit doctors with their parent(s) but that the parents stay in the background and do not intervene in the communication between the doctor and the child, or they wait outside.

Parents also have an important role, in the eyes of children, in explaining things to their children that remain unclear after the child has talked to a doctor.

4.2.6 Conclusion

For children, it is most important that health practitioners are friendly towards them. Children want doctors to talk to them in a friendly way and with a good sense of humour. They want doctors to take a genuine interest in them, and to ask how they are doing in school or what their hobbies are. For younger children, it is important that health practitioners comfort them, while adolescents want to be treated as equal partners and they want doctors to know how to talk to young people. Thus, it may be concluded that the experiences of children in health care settings depend significantly on the personal qualities and social skills of the health practitioners.

For adolescents, privacy is important, and they do not want to discuss certain matters in the presence of their parents. Most children, both younger children and adolescents, want doctors to talk to them directly. They are more eager to communicate with doctors if they understand what is explained to them. Unfortunately, children quite often experience that little or no explanations are given to them. Some of them have experienced that the explanations have been too complicated and they have had to ask their parents for clarification afterwards.

None of the children could recall that anyone had explicitly asked for their consent. It may be, however, that children do not regard negotiations with them as asking for their consent. Some of them, especially younger children, remembered cases where they had not wanted to undergo a procedure and had been given a chance to think about it until they were ready. Some younger children felt that there was no point asking for their consent if it would not be taken into account anyway. This is a clear indication that for children it is important that adults are honest with them, and they do not want “fake” consent procedures. Children can generally understand if something needs to be done for the sake of their health and there is no point in refusing treatment.

The adolescents (15–17) contended that they were able and should be allowed to decide on their health issues independently. They held that doctors may be able to assess the capacity of a child to decide independently only if they take time to communicate with the child and get to know the child.

Parents have an important role in the eyes of the children. The younger children wanted to visit doctors with their parents, and they also mentioned that they had needed explanations and clarifications from their parents. The adolescents had needed their parents’ guidance but often wanted to be independent in the doctor-patient relationship.

4.3 Experiences of parents

4.3.1 Communication with the child

The experiences of the parents regarding how doctors communicated with their children varied. Some had experienced that doctors communicated more with the child directly, and some that doctors communicated more with them:

"I have very positive experiences from the Children's Hospital. They talk to children and give them explanations."
"I remember the last time I visited our family doctor with my 14-year-old. There was a new young doctor who communicated directly with the child, and I was not given any attention. It was so cool. They managed everything between themselves. I was not needed. I had not experienced such a thing before."
"I have been in hospitals with my child often. Nothing has been done by force to him, however little has been explained. For example, they gave him a pill and did not say anything about what the pill was for."
"I visit a doctor often for my child's allergy. She communicates only a little with the child directly. I'm satisfied, but when I asked my 8-year-old recently, she said that doctors only do things and explain nothing."
"Our family doctor talks more to me than to my child. Maybe when the child gets older, let's say 10, she will start to communicate more with the child. I have the impression that with the younger ones, they don't consider them as independent."

One mother had changed both her family doctor and dentist explicitly because of a lack of communication. She contended: "*How little effort is actually needed to explain things to a child. A child feels like an object if everybody around him is doing something and nobody explains anything."*

The proportion of communication between the doctor and the child clearly depends on which role the parent takes in this process. As one mother of a 15-year-old girl contended: *"We have it this way that the doctor talks to the child and I sit further away. If the doctor begins to communicate more with me, I indicate that he should communicate directly with the child. Three years ago one doctor hinted to me that a* *child should say what is bothering her herself. Before that, I was always the one who talked."*

It must be kept in mind that many of the adolescents visited doctors alone (especially their family doctor or dentist), and therefore the parents' complaints about a lack of communication with the child may be more relevant in the case of younger children.

The parents had had more positive experiences with the family doctors. The same pattern emerged from the interviews with children. There may be several reasons for this. One is the long-term relationship, as normally a child has the same family doctor from birth and can build a relationship with that doctor. It is also in the interest of a family doctor to maintain good relations with the families in his/her list.[15]

It can be concluded that all of the parents interviewed wanted the maximum involvement of their children from an early age. They wanted doctors to communicate directly to the child, and to explain to the child everything that is being done.

4.3.2 Capacity of the child to consent

If the parents were very open to their child's involvement and maximum participation in the process of medical consultation, they were more conservative when it came to the child's capacity to consent or decide independently over his/her health issues. The parents wanted to be involved in the decision-making together with their adolescent children and found that such decisions impact the whole family. As one father worded it: *"I cannot draw the line between a child patient and an adult patient on this issue. It must be a family decision, as it impacts many people directly and they have to participate in the decision-making. Whether it is an adult patient or a child patient."* A mother also contended: *"Children are very different. They must be allowed to participate as soon as they are able to. Whether their opinion should be the decisive one is another matter. I also think it must be a family decision."*

The parents saw their adolescent children more as partners in decision-making. A mother explained: *"Let's say my child wants to be vaccinated and I'm against*

---

[15] In Estonia, every person has to be assigned to a family doctor. Ideally, one could have the same family doctor for a lifetime. There is a limit set by law for how many patients one family doctor may have.

vaccinations. Let's say the child is 14. If I saw that she has her own opinion and wants to be vaccinated not only for the reason that it's cool or that her friends are doing it, I think I would let her decide. But I would show her materials I've read and explain my position. As for a 10-year-old, I don't think she would be ready to analyse all the aspects in a way that she could make a decision." However, it could be seen from the interviews that the parents did not think that it was necessary to have the consent or assent of younger children for a medical intervention. A mother contended: *"If you asked a three-year-old 'do you agree that we pull out your tooth?', there is no way he would agree. Somehow you have to be rational."* A father explained: *"I don' think a 2- year-old should be asked for consent. Or a 4-year-old. There are things that need to be done anyway…. Of course, there needs to be some kind of cooperation."* At the same time, most of the parents were not in favour of doing things against a child's will/using force, rather they mainly had a different attitude towards the value and meaning of consent in the case of younger children.

Most parents felt that it was their job to convince the child to agree to a medical intervention. As expressed by one mother: *"When I think of my 12-year-old, would he ever agree, if I did not work on it before? It's easier for him to say no to everything that hurts or is unpleasant, why should he agree? I think that if I did not work on that, he would not agree. Maybe only if it's an issue that impacts his appearance, then it's a different story, then he feels the consequences directly. I think that a child's consent depends on the parent."* Another mother also emphasised the importance of convincing the child: *"I don't think that it should be allowed for things to be done forcefully to a child of any age. It should not be done. I believe it's always possible to convince the child. There are all kinds of things you can do."*

Many parents doubted whether children are reasonable in taking decisions about medical treatment. They believed that children's decision-making capacity may be hindered by fear. As one mother explained: *"I think the main factor that makes a child refuse is fear of the unknown. It must be well explained and reasoned to the child."* This is coherent with the outcomes of the interviews conducted with the children. The adolescents were quite explicit in saying that small children say no to things out of fear.

Parents were asked whether there is a specific age from which children are capable to give informed consent by weighing the pros and cons responsibly. Most of the parents were reluctant to state a specific age, and they said that each child and each situation is unique. Those who did, specified an age between 14–16. One father said: *"I think a 14-15-year-old must be allowed to decide independently on certain issues and should be able to seek help privately. A parent may be present."* Two mothers contended that a 16-year-old should be able to decide independently.

A father of two daughters who both wear glasses explained: *"I think the problem arises only if there is a procedure that does not necessarily need to be done. If you have severe appendicitis, there is no point in refusing surgery. Another matter is whether it's necessary to perform an eye operation on a child, so she doesn't need to wear glasses anymore. If my daughter came to me when she was 13 and wanted to do that, I would not allow her to. I would tell her it's too risky, think about it when you are 18. … At the same time, I can't imagine I would forbid a procedure if I could not explain to the child what's bad about it or what bad consequences it could have."*

Another father contended: *"There is this criterion in law, whether the child is objectively capable, whether he/she understands the risks. And this may be very different in different children. There are adults who do not have a grasp of things. But what has surprised me with my own son, aged 11, is how he can control himself about his diet. He cannot eat milk products. We have not imposed a harsh diet on him, we have explained a lot, what he has to follow when he eats outside of home. And it is surprising how well he is able to control himself. Therefore, if I were to base my opinion on his example, I could say that an 11-year-old can weigh matters responsibly."*

A mother explained: *"If you ask me from what age a child is capable of giving consent, I think, is it really consent that is needed? I think it is important that they know and understand. As a parent, you should not oppose your child. You have to work with your child until he or she accepts the solution you are offering him or her. You have to maintain trust with your child."*

However, there were also parents who allowed their children to decide. One mother gave an example of how her daughter, aged 12, had come home from school with a consent form that parents had to sign for an HPV-vaccination[16]: *"We read the information with my husband and then my daughter came and said she thought it needed to be done. I asked "it seems you are quite sure of that?", she said "if you want, we can discuss it a bit". Then I signed the consent form and forgot about it. After a while I asked about the HPV-vaccination and she said the vaccination had been done the following day after I had signed the consent form."*

Many parents also allowed their adolescent children to visit doctors alone, which may be a sign of trusting their ability to make reasonable decisions independently. As discussed before, the age from which children are ready to visit doctors alone may be one indication that they are mature enough to weigh the pros and cons responsibly. This age varies considerably. According to the parents, some children visited doctors alone already when they were 10, while some wanted their parent(s) to be present until adulthood. It was interesting to see that children from the same family may become independent on this issue at different ages. One mother said that her 12-year-old daughter had visited doctors alone from the age of 10 and that this had happened on her own initiative. Her other daughter who was 20 years old had wanted her parents to accompany her until she was an adult.

It can be concluded from the interviews that the parents put more emphasis on informing the child and involving the child as much as possible, and less on having the child's consent as such. This is coherent with the position of most parents that a child can be convinced, and it is the parents' job to convince the child about the necessity of a treatment/procedure.

4.3.3 Practices of taking child's consent

Most of the parents had rarely experienced that consent had been taken from their children, either explicitly or indirectly. Some positive experiences were shared, however, where children had been given a choice:

"I had this experience with vaccination. The doctor asked my child whether she was ready for it that day or needed more time."

---

[16] In Estonia, children are vaccinated with parental consent by school nurses within the school health framework. Only vaccinations that are part of the state immunisation plan are administered in schools. Other vaccinations may be done at the family doctor or private health care institutions. The HPV-vaccination for girls aged 12 was introduced into the state immunisation plan in 2018.

"We are really lucky to have our family doctor. She communicates with the child and explains what needs to be done. For blood tests, the nurses ask the children how they want it done – either from the vein or from the fingertip."

"We had this experience in a small hospital. Our child fell and had a wound on her head. We went to the hospital and there they explained that there were two options – either they would sew it or fix it with tape. The child of course did not want to have stitches and we chose closing the wound with tape."

More negative examples were given about obtaining a child's approval for a procedure or treatment:

"One of my son's baby teeth was not getting loose and needed to be pulled out. We went to the dentist and the first thing my son saw was a needle, the doctor wanted to inject an anaesthetic without any explanation. He just ran off and did not allow anything to be done after that."

"Last year I happened to be in the emergency room of the Children's Hospital with my three-year-old. I felt like I was there with a doll. Nobody communicated with the child, not once, they even did not ask how she felt and did not show any empathy. Not to mention explaining anything to the child about what was being done. The entire communication was based on instructions – "open your mouth", "give me your hand".

"My son was approximately 3 years old when they had to take a blood sample. The nurse just held the child by force and took the blood. The child screamed the entire time. She could have just explained to the child."

"My 9-year-old son had to have an x-ray taken. They put a heavy vest on the child. My son started to cry because he was scared. No explanations were given as to why this vest was needed. Or once at the doctor, the doctor checked his ears and had to play sounds in his ears. The child instinctively pulled his head away so they just held his head."

"My child fell and had a wound that needed to be stitched. She was a little bit older than three. We were first sent back home because we had to return with an empty stomach for anaesthesia. We went back. I was told that I had to stay outside and the doctor said to the child in a sharp tone "come, sit here". The child got really scared and did not want to enter the room. I started to explain to my child why it was necessary. The doctor got angry and left without a word. By the time I got the child to

agree and she sat on the chair, the doctor had left. We had to wait for the new shift. When the new shift came, it was like night and day. Two ladies started to talk to the child, asked how she was doing and how old she was. They said – 'come here, we will show you, here you can smell flowers and then you'll fall asleep.'"

The above example is a vivid illustration of how patients' experiences in health care settings depend on the personal qualities and social skills of the health practitioners.

4.3.4 The role of parents

The parents clearly felt that they are the main bearers of responsibility in the doctor-child relationship. As one mother put it: *"I think up to a certain age it is more a doctor-parent relationship, because the responsibility lies completely with the parents. The more a parent and a doctor are able to involve a child, the more probable it is that the child will start at a certain point to give his/her opinion. And you must give the child opportunities to do so."* Another mother, when asked about the parent's role in this process, said that parent-doctor cooperation is key.

One father contended: *"I understand that there are movements towards increasing the autonomy and independent decision-making of children. But from the aspect of how societies are constructed, I would be rather conservative. The role of raising children has been given to parents. This role of a small unit in society is the most important. It starts with the responsibility of the parents. We should not demolish it."*

The parents also felt that they have to protect their children, because the relationship between the child and the doctor is not one between equals. A father contended: *"Even if the child understands everything very well, you cannot leave him one-to-one in a relationship with a doctor or a hospital, because it's an unequal relationship. A doctor or a hospital is in a power position. You are a child and it's not likely that you would oppose something. It's the responsibility of a parent to guarantee balance in this relationship."* When asked "what's most important for child patients", one mother responded that the most important thing is for children to stand up for themselves and how parents can teach this to their children.

Based on the interviews, parents have a huge role in preparing their children to become, step-by-step, independent and autonomous when using health services. It was mentioned earlier that a mother had encouraged her daughter to talk to doctors herself and that she had adopted this model after a doctor had hinted to her that she should allow her child to talk. This story illustrates how doctors can delicately direct parents towards allowing for their child's independence as a patient. Parents understand the role of doctors as educators in that sense, and as one mother worded it: *"Doctors have a huge role in educating parents. Some parents don't understand their role in this process. Doctors have a big opportunity to educate such parents. We cannot expect that all parents are well informed and responsible. Usually, the most conscientious parents educate themselves."*

4.3.5 Conclusion

The parents had had many positive experiences with how health practitioners communicated with their children and how they gave explanations. However, they had also had many negative experiences where children had not been given any explanations or had been treated as objects. The parents would like health practitioners to communicate directly with their children, and the older the child gets, the more communication should transfer from the parents to the child.

Most of the parents had rarely experienced that consent had been taken from their children, either explicitly or indirectly. Even though most parents did not think consent should be asked from very young children, they were not in favour of medical intervention against a child's will. Most of them found that it is always possible to convince a child and it is their job to do so. The parents saw adolescent children more as partners in decision-making. However, a number of parents contended that a child's health issues impacted the whole family and should therefore be decided by the family.

Many parents allowed and encouraged their adolescent children to visit doctors (mainly family doctors or dentists) alone. The age from which children did so varied considerably. According to the parents interviewed, some children visited doctors alone already from the age of 10, while some wanted their parents to accompany them until adulthood.

The parents felt that they have to protect their children, as the relationship between a child and the doctor/hospital is not one between equals. They also wanted to teach their children to stand up for themselves.

It can be concluded from the interviews that the parents put more emphasis on informing the child and involving the child as much as possible, and less on obtaining the child's consent as such.

Chapter 5. Conclusions and remarks on further developments and possible best practices

5.1 Theoretical and normative context

With the adoption of the CRC, especially Article 12, a whole new approach evolved, promoting children's participation and the right of children to be heard. From the 1990s, within this participation framework, a step-by-step movement towards recognising the autonomy of children, from a certain age and maturity, can be seen. In the context of this thesis, the above process is illustrated by the change in the CRC Committee's General Comments over time towards accepting adolescents' full autonomy in health care. As was discussed in para 2.2.2., in 2009 the Committee had expressed the need to include children in decision-making processes in health care, whereas in 2016 the Committee invited states to introduce minimum age limits that "recognize the right to make decisions in respect of health services or treatment" and emphasised that "voluntary and informed consent of adolescent should be obtained whether or not the consent of a parent or guardian is required for any medical treatment or procedure."

Even though the CRC Committee, in its current interpretations of the Convention, recognises the adolescent's autonomous right to make decisions (without specifying from what age), it clearly accepts the need to assess the maturity of the child in question. In para. 44 of General Comment No. 12, the Committee refers to the need to develop good practice for assessing the capacity of the child to form his/her own views.

There is not much theory in the CRC or in the General Comments of the CRC Committee about the criteria for regarding a child as competent for autonomous decision-making. Nor does the Oviedo Convention give any clarification, stating only in Article 6 that "where according to law, a minor does not have the capacity to consent to an intervention, the intervention may only be carried out with the authorisation of his or her representative or an authority or a person or body provided by law."

Both the CRC and the Oviedo Convention leave it open to the member states to specify the age from which children should be able to make decisions in respect of health services or treatment.

The theoretical background presented in para. 1.2 of this thesis regards three main elements of autonomy – rationality, maturity and independence (Archard 2015). A rational person is able to form generally reliable beliefs about the world. Someone who is mature should not let emotions lead his/her decisions; instead, his/her life experience and value system will help him/her to form decisions. Independence refers to self-maintenance, the ability to act out of one's own choices. These three elements could guide health practitioners who need to assess the capacity of a child to consent.

It was shown in para 3.2 of the thesis that in medical practice, decision-making capacity should be assessed through the ability of a patient to: (i) communicate a choice; (ii) understand the relevant information; (iii) appreciate the medical consequences of the situation; and (iv) reason about treatment choices. The assessment must be made with regard to the specific situation and specific treatment the patient is facing. In that sense, assessment of capacity to consent is issue specific and time specific. A lack of competence in relation to one specific issue does not render the patient incapable in relation to all other issues. It is also important not to confuse a judgement on the competence of a person with a judgement on the reasonableness of that person. What may seem unreasonable to a doctor may seem completely reasonable to the patient. Therefore, it is important to assess a patient's competence through the lens of his/her value system.

What makes introducing specific age limits as recommended by the CRC Committee a challenge is the fact that children do not become autonomous overnight. It is a gradual process that is emphasised in the concept of evolving capacities, provided in Article 5 of the CRC. The concept of evolving capacities addresses the gradual shift from dependence towards independence/autonomy, and parents have to guide their children through that process. "The more the child himself or herself knows, has experienced and understands, the more the parent, legal guardian or other persons legally responsible for the child have to transform direction and guidance into reminders and advice and later to an exchange on an equal footing." (General Comment No. 12).

This is why some countries[17] have introduced legislation without fixed age limits and the law enables each situation to be treated individually according to the maturity of the child. Estonia is one of the countries where the law allows for such assessment. Subsection 766(4) of the Law of Obligations Act stipulates that in the case of a patient with restricted active legal capacity, the legal representative of the patient has the rights related to informed consent in so far as the patient is unable to consider the pros and cons responsibly. This means that health practitioners have to weigh, when necessary, the capacity of a child patient to consider all pros and cons responsibly in order to assess whether the right to consent belongs to the child or to his/her parents. It was analysed in this thesis whether doctors in Estonia apply the above norm in practice and whether they obtain autonomous consent from a minor if they find that he/she is able to weigh the pros and cons responsibly.

5.2 The Estonian context

As a general rule, children visit doctors with parents, and they are in agreement about what needs to be done and jointly consent (either explicitly or indirectly) to treatment. In such situations, there is no need for health practitioners to assess whether the child is capable to consent independently. This may also be the reason why doctors are not fully aware of the content of the law governing child's consent, as was shown by the interviews. In everyday practice, the issue of a child's independent consent rarely arises. The approach of doctors in Estonia is mainly based on a parent's consent on behalf of his/her child and the child's assent/acceptance. Such practice is in accordance with international and domestic norms, provided that the child is involved, he/she is given information and explanations and his/her views are given due weight in accordance with his/her age and maturity.

However, problems arise in situations where doctors refuse to assess a young person's capacity to consent although it is needed. The need to assess a child's capacity to

---

[17] According to FRA, those countries are Austria, Belgium, Czech Republic, Estonia, Germany, Luxembourg and Sweden.

consent may arise primarily in two types of situations: first, in situations where a child visits a doctor alone and the parents are not available; secondly, in situations where a child's will is contrary to the parents' will and/or the child explicitly asks the doctor not to inform his/her parents. In such situations Subsection 766(4) of the Law of Obligations Act allows for medical intervention to be based on the child's consent, provided that the health practitioner finds the child capable to weigh the pros and cons responsibly. Another rule that helps health practitioners in such situations is stipulated in the same Section, which provides that a health practitioner is not allowed to follow the decision of a parent (or other legal representative) if such decision appears to harm the interests of the patient.

However, it emerged from the interviews that most of the doctors had never had to assess the capacity of a child to give informed consent. The family doctors and gynaecologists who were interviewed had had some cases where they had based consultation or treatment solely on an adolescent's autonomous decision. The main reason for such autonomous consultation or treatment, especially in sexual health matters, had been the young person's wish for privacy. This was confirmed by the interviews, both with the doctors and with the adolescents. The main criteria by which doctors had assessed adolescents' capacity for autonomous decision-making in such cases seems to be their ability to understand – first the situation they are in and also the information they are given.

As health practitioners rarely come across situations where they have to assess children's capacity to consent or where they need to base their treatment or intervention on a child's autonomous decision, it is clear that they need more information and training about the concept of a child patient's informed consent and about how to assess a child's capacity to consent when necessary. The results of empirical studies on children's competence could be used in such training. The international studies presented in this thesis show that children from the age of 9 are able to understand information they are given and to base their choices and/or decisions on that information. By the age of 14, children acquire competence equal to that of adults when it comes to consenting to medical treatment. According to the social study made within this thesis, the experiences of doctors, parents and children themselves confirm that by the age of 16 at the latest, children are able to make decision autonomously. Regardless of the general evidence we have about children's competence, capacity to consent must be assessed on a case-by-case basis.

It is important that health care institutions develop their own protocols and guidelines on consent procedures. Once a certain way of doing things becomes routine, it takes less time and is less cumbersome for health practitioners. A best practice recommendation on the general framework for a consent procedure is offered in para 5.3. below.

One of the most challenging aspects of children's autonomous decision-making in health care is the parents' role and responsibility. The aim of encouraging young people's agency and autonomy is not to exclude parents and families. How to find the right balance between the parents' involvement where a child is capable to weigh the pros and cons responsibly remains to be decided by the health practitioners. An adolescent's wish for confidentiality must be honoured. However, as emphasised by the doctors interviewed, it may be crucial for a child, including one approaching adulthood, if he or she does not have the support of his/her family in his/her health situation. The interviews with doctors and parents confirmed that parents have a decisive role in the consent procedure: in the case of younger children by convincing them about the necessity of a treatment or intervention and in the case of adolescents by encouraging and guiding them to become independent and supporting them in decision-making. The children also contended that parents are the ones who know how to talk them into agreeing to treatment and unpleasant procedures. The biggest risk group, therefore, are children from disadvantaged families or of parents with insufficient parenting skills. Such children may not get the treatment they need because their parents cannot manage to convince them to undergo it (in the case of younger children) or, if such children are trusted to be capable to decide, they may not undertake necessary treatment without the support of their parents. It is therefore crucial that health practitioners notice such situations and if possible educate and encourage the parents. Health practitioners may also have a role, wanted or unwanted, as a mediator between an adolescent and his/her parents. Family doctors seem to accept and assume this role, and such approach could be applied by other health practitioners. Understandably, the limited time allotted for a consultation per patient makes it a challenge for doctors to devote extra time to child patients.

As concluded in Chapter 4, there seems to be a difference in practice with regard to consent procedures in general medical care (family doctors) and specialised medical care that is provided in the form of in-patient care in hospitals. In hospitals, in in-patient care, mostly for surgery, the practice is that a written consent form must be signed by a parent or other legal representative of the child before treatment/surgery. Consequently, children and young people are not able to go to hospital for in-patient care alone or give independent consent for such treatment. Some of the doctors working in hospitals contended that they could not treat (operate on) a child without a parent's consent, as the formal procedures in the hospital require the signature of a parent on a consent form. Thus, also formalities and not only doctors' knowledge or attitudes seem to be a hindrance to autonomous decision-making by adolescents, where an adolescent is capable in the meaning of Subsection 766(4). Health institutions should analyse their protocols in this regard to ensure that an adolescent who is capable to give informed consent in the meaning of Subsection 766(4) of the Law of Obligations Act can do so.

5.3 Best practice proposal

Based on the conclusions of this thesis and the results of the interviews, the following general framework for a consent procedure in medical practice is proposed.

Information and communication:

- Children should be involved in communication and discussions as much as possible, taking into account their age and maturity, and their preferences.
- Health practitioners should communicate directly with children. Parents should be encouraged to let their children communicate directly with health practitioners where appropriate.
- Communication with children should be friendly, honest and age-appropriate. Children like it when a genuine interest is taken in them, when they are asked about their kindergarten, school and hobbies so they feel at ease.

- Children should be given explanations about what is going to be done to them and they need time to prepare. The younger the child, the more time he/she may need.
- Children should be encouraged and allowed to ask questions and left time to do so. It is recommended that the child be asked explicitly whether he/she has any questions.

Consent:

- For any treatment or medical intervention, the assent/acceptance of the child should be sought, regardless of whether the child has the right to consent or not.
- For babies and younger children, parents should give consent after having convinced and prepared the child.
- From a certain age when the child is able to participate in discussions but is not able to decide autonomously, the child and the parent(s) should give joint consent. The older the child, the greater the weight that should be given to his/her opinion. According to some empirical studies, children from the age 9 are able to understand information they are given and base their choices and/or decisions on that information.
- At a certain age, adolescent children become able to consent autonomously. According to some empirical studies, the age limit which most validly reflects children's competence to consent to medical research is 11 or 12 years and by the age of 14, children acquire competence equal to that of adults when it comes to consenting to medical treatment.
- Capacity to consent, i.e. the ability to weigh the pros and cons responsibly (Subsection 766(4) of the Law of Obligations Act) should be assessed on a case-by-case basis.
- The ability of the child to consent autonomously should not mean that parents are excluded. The involvement of the parents of an autonomous child should be decided by the health practitioner based on the situation. There may be cases were parental involvement is not in the best interests of the child, especially when issues relating to sexual or mental health are concerned.

- Even if a child is not able to give consent, the child should be given, if possible, different options for how to proceed, e.g. whether the child prefers a blood sample to be taken from his/her fingertip or vein, whether they want to sit on a parent's lap, etc.
- It is important to avoid giving a false impression that the consent or assent/approval of a child is being taken where the child in fact has no possibility to refuse.

5.4 Interdisciplinary cooperation between specialists

To assure more meaningful participation and decision-making by children in healthcare settings, better cooperation is needed between specialists from different fields, foremost health practitioners, lawyers and child psychologists/psychiatrists who are experts in child development. Such cooperation needs to be based on openness and empathy that increases and creates knowledge. As worded by Darbellay (2015): "Capacity for empathy is one of the conditions for the successful shift from multidisciplinary communication … to a dialogic interdisciplinarity that sets out to exceed and integrate knowledge."

Within the social study carried out in the framework of this thesis, the author had enriching experiences of mutual learning between the fields of law and medicine. This gives hope that even more emphatic cooperation will be the best way to advance children's rights and children's wellbeing in health care settings. This thesis is only a first step; the topic of child patients' informed consent should be further analysed within the framework of interdisciplinary cooperation.

Executive summary

This thesis studies whether the concept of child patients' informed consent, deriving from Subsection 766(4) of the Estonian Law of Obligations Act, is applied in everyday medical practice in Estonia. It explores how doctors, children and parents conceptualise child's consent and what their experiences are in this regard. For a better understanding of the concept of child's informed consent, the thesis analyses the theoretical and normative background of children's consent and autonomy in a broader meaning. The thesis also presents a short overview of empirical evidence with regard to children's capacity to consent to clinical research and treatment.

(i) Methodology

The thesis combines legal and socio-legal studies as its research method. In the framework of legal doctrinal study, the theoretical and normative context of the regulation of child's informed consent is presented. Thereafter, the functioning of this norm in the concrete social context, that is, the application of this norm by individuals in practice, is analysed. Socio-legal studies allow us to go beyond classical legal research, to analyse the law (legal phenomenon) and its relationships with the wider society and use methods of sociology for problem analysis. This thesis uses qualitative research, analysing the experiences of doctors, children and parents with regard to informed consent.

(ii) Theoretical framework of child's consent

The first chapter of the thesis analysis the roots of the concept of child participation, seeded in Article 12 of the CRC, which provides that the child who is capable of forming his or her own views has the right to express those views freely in all matters affecting the child. It was noted that Article 12 focuses on the right of the child to express his/her views and participate in decision-making, but not on the right to decide. The CRC and CRC Committee's General Comments give little guidance on autonomous decision-making by children.

The key question in the debate over children's informed consent to medical intervention is competence. Competence was analysed in the thesis through the lens of Archard's (2015) division of rational autonomy into rationality, maturity and independence. These three are also key words used by the CRC Committee when talking about children's competence. All three qualities – rationality, maturity and independence – are acquired by children gradually. This is why the concept of evolving capacities, introduced in Article 5 of the CRC, is important. It is a right and duty of parents to provide appropriate direction and guidance to a child, in a manner consistent with the evolving capacities of the child. It was noted in the thesis that the concept of evolving capacities addresses the gradual shift from dependence to independence/autonomy and parents (or other guardians) have a crucial role in enabling the capacities of their children to evolve. It is important that children be given opportunities to practice decision-making and weighing different options so they will eventually become autonomous.

(iii) Normative framework

In Estonia, the contractual issues related to health care services, like the duty to inform the patient and acquire the patient's consent for treatment, are regulated by contract law in the Law of Obligations Act. The Law of Obligations Act does not set an age from which children are competent to consent to treatment. The law provides that in the case of a child, as in the case of any other patient with restricted legal capacity, his/her legal representative has the right to give consent in so far as the child is unable to consider the pros and cons responsibly. This means that health practitioners are left to assess, whether a child is competent or not. It was noted that there is no soft law in the form of recommendations or guidelines regarding patients' rights. The Doctors' Code of Ethics provides only a general rule that a doctor shall explain to the patient his/her health condition and shall acquire the patient's voluntary and informed consent for necessary interventions and treatment.

The thesis also analyses two international treaties relevant to child patients' consent ratified by the Republic of Estonia, the CRC and the Oviedo Convention. Both Conventions allow the member states to specify the age from which children should be able to make decisions in respect of health services. However, they both emphasise that the opinion of the child shall be taken into consideration according (in the Oviedo Convention "in proportion") to his/her age and maturity.

It was shown in the thesis that in addition to the general principles of child participation, the CRC Committee has opined on the topic of child's consent in medical practice. It has stated that young children should be involved in decision-making processes and in the case of adolescents, voluntary and informed consent should be obtained whether or not the consent of a parent or guardian is required for any medical treatment or procedure.

It was noted in the thesis that from the perspective of child's consent to medical intervention, Articles 17 (the right to information) and 24 (the right to health) of the CRC are also relevant.

Soft law in the form of the Council of Europe Guidelines on child-friendly health care (2011) was analysed. According to para. 3 of the guidelines, "child-friendly health care refers to health care policy and practice that are centred on children's rights, needs, characteristics, assets and evolving capacities, taking into account their own opinion".

(iv) Assessment of capacity to give informed consent in medical practice

It was of special interest in this thesis to analyse the empirical aspects of competence assessment and find empirical evidence on children's capacity to consent to medical intervention. It was contended that capacity assessment encompasses a serious administrative burden, as the competence of the child must be individually assessed every time a relevant decision must be made. Practical guidelines and elaborative materials would therefore be of utmost importance for health practitioners.

It was noted that for adults, the generally accepted reference standard for competence assessment by clinicians revolves around four relevant criteria, i.e. the ability: (i) to communicate a choice; (ii) to understand the relevant information; (ii) to appreciate the medical consequences of the situation; and (iv) to reason about the choice (Hein, et al., 2015). It was contended in the thesis that assessment of children's competence/capacity to consent does not differ methodologically from assessing the competence of adults. The main difference is in the approach – in the case of adults, competence is presumed, whereas in the case of children it is generally the other way around. It was concluded by the author that the competence of children should be presumed from a certain age, based on empirical evidence. The empirical evidence that was studied in the thesis shows that the age of 9 seems to be a turning point in the development of children, and from that age children are generally able to understand information they are given and base their choices on that information. There can be differences between the ages of 9–11.2 when children are in a so-called "transition period". The age limit that presents closest accordance with children's competence to consent to medical research is 11 or 12 years. By the age of 14, children acquire competence equal to that of adults when it comes to consenting to medical treatment.

It was shown in the thesis that even when accepting a child's right to consent to medical intervention, the child's right to refuse medical intervention remains a sensitive and controversial topic. De Lourdes Levy et al. (2003) note in the Statement of the Ethics Working Group of Confederation of European Specialists in Paediatrics that "[c]hildren may refuse treatment or procedures which are not necessary to save their lives or prevent serious harm, e.g. blood tests or minor dental procedures."

(v) Experiences of doctors, children and parents in Estonia

As one of the aims of the thesis was to study whether and how the concept of child patients' informed consent is applied in everyday medical practice, interviews were conducted with doctors, children and parents; a total of 24 children, 15 parents and 11 doctors were interviewed.

Doctors' interviews

Most of the doctors interviewed did not know that Subsection 766(4) of the Law of Obligations Act enables them to weigh the capacity of a child to give informed consent to medical intervention and, if they deem a child capable, the right to consent could belong to the child. Nevertheless, the everyday practices of doctors seem to target the child's acceptance and involvement as much as possible. It was shown in the thesis that the approach of doctors is mainly based on parental consent and the child's assent/acceptance. However, there were cases where family doctors had based treatment on the child's informed consent as they had found the child capable to weigh the pros and cons responsibly. In hospitals, formalities and not only doctors' knowledge and attitudes also seem to inhibit the possibility of obtaining informed consent from a child independently. The doctors found that it is primarily up to the parents to convince a child to agree to a medical intervention. They also stressed the importance of children and parents finding a consensus. Most of the doctors were reluctant to specify an age from which children are capable to weigh the pros and cons responsibly (the assessment criterion in the law). The most common answer was 16. It emerged from the interviews, however, that some of the doctors may have treated their child patients as partners or agents from a much earlier age. Some spoke of children of 7 years of age with whom they had discussed different options and decided on the way to proceed.

Children's interviews

A child's experience in a health care setting depends significantly on the personal qualities and social skills of the health practitioner attending to him/her. For the children, it was most important that health practitioners be friendly towards them. The children wanted health practitioners to talk to them in a friendly and understandable way and with a good sense of humour. They also wanted for a genuine interest to be taken in them and their activities. Unfortunately, the children had quite often experienced that little or no explanations were given to them or that the explanations were too complicated.

None of the children interviewed could recall that they had explicitly been asked for their consent. However, some younger children remembered cases were they had not wanted to undergo a procedure and had been given a chance to think about it until they were ready. It is important for children that adults be honest with them, and children do not want "fake" or illusionary consent procedures where they actually have no option to refuse. The adolescents (15-17) contended that they were able and should be allowed to decide independently on their health issues. The adolescents also felt that doctors would be able to assess the capacity of a child to decide independently on health issues only if they took time to communicate with the child and got to know the child. They emphasised that it is not possible to assess competence on the basis of formal interaction.

Parents have an important role in the eyes of the children with regard to their experiences in health care settings, especially for the younger children, all of whom wanted to visit doctors with their parents. Some adolescents also wanted their parents to be present when they visited doctors.

Parents' interviews

The parents had had both positive and negative experiences when visiting health practitioners with their children. Most of the parents had rarely experienced that consent, either explicitly or indirectly, had been taken from their children. Even though most parents did not think consent should be asked from very young children, they were not in favour of medical intervention against a child's will. Most of them found that it is always possible to convince a child and it is their job to do so. Parents saw adolescent children more as partners in decision-making. However, many parents found that a child's health issues impacted the whole family and should therefore be decided by the family. Many parents allowed and encouraged their adolescent children to visit doctors alone. The age from which children did so varied significantly. According to the parents, some of their children had visited doctors alone already from the age of 10, while some had wanted their parents to accompany them until adulthood. Many parents also felt that they had to protect their children, as the relationship between the child and the doctor/health care institution is not one between equals. It was concluded in the thesis that the parents put more emphasis on informing the child and involving the child as much as possible, and less on obtaining the child's consent as such.

(vi) Conclusions and remarks on further developments and possible best practices

The interviews revealed that as a general rule, the children visited doctors with parents, they were in agreement about what needs to be done and jointly consented (either explicitly or indirectly) to treatment. The author contends that in such situations there is no need for health practitioners to assess whether the child would be capable to consent independently. It was also concluded that this may be a reason why doctors are not fully aware of the content of the law governing child's consent. In everyday medical practice, the issue of child's autonomous consent rarely arises. Problems arise in situations where doctors refuse to assess a young person's capacity to consent although it is needed. The need to assess a child's capacity to consent mainly arises in two types of situations: first, in situations where a child visits a doctor alone and the parents are not available; secondly, in situations where the child's will is contrary to the parents' will and/or the child explicitly asks the health practitioner not to involve his/her parents. In such situations Subsection 766(4) of the Law of Obligations Act allows medical intervention to be based on the child's consent, provided that the health practitioner finds the child capable to weigh the pros and cons responsibly. However, it emerged from the interviews that most of the doctors had never had to assess the capacity of a child in the meaning of Subsection 766(4) of the Law of Obligations Act. It was concluded in the thesis that health practitioners need more information and training about the concept of child patients' informed consent and about how to assess a child's capacity to consent. The results of empirical studies on children's competence could be used in such training. It was also recommended that health care institutions develop their own protocols and guidelines on consent procedures. Best practice proposals in this regard are presented in the thesis.

It was one of the findings of the thesis that better and more meaningful cooperation is needed between specialists from different fields, foremost between health practitioners, lawyers and child psychologists/psychiatrists who are experts in child development. Such cooperation needs to be based on openness and empathy that increases and creates knowledge.

List of references

1. Alderson, P. (2007). Competent children? Minor's consent to health care treatment and research. *Social Science and Medicine*. Vol. 65(11), pp. 2272–2283.
2. Archard, D. (2015). Children: Rights and Childhood (3rd ed). London: Routledge.
3. Brems, E. (2007). Children's rights and universality. In J.C.M. Willems (Ed.), Developmental and autonomy rights of children. Empowering children, caregivers and communities (2nd ed., pp. 11-37). Antwerp: Intersentia.
4. Corsaro, W. (2011). The Sociology of Childhood 3rd ed. (pp. 1-30). Sage.
5. Coyne, I, Hallström, I. & Söderbäck, M. (2016). Reframing the focus from a family-centred to a child-centred care approach for children's healthcare. *Journal of Child Health Care*. Vol. 20(4), pp. 494–502.
6. Committee of Ministers of the Council of Europe (2011). Council of Europe Guidelines on child-friendly health care. Retrieved August 23, 2018, from: https://rm.coe.int/guidelines-of-the-committee-of-ministers-of-the-council-of-europe-on-c/16808c3a9f
7. CRC Committee, General Comment No. 4: adolescent health and development in the context of the Convention on the Rights of the Child (UN Doc CRC/C/GC/4, 2003).
8. CRC Committee, General Comment No. 7: implementing child rights in early childhood (UN Doc CRC/C/GC/7/Rev.1, 2005).
9. CRC Committee, General Comment No. 12: the right of the child to be heard (UN Doc CRC/C/GC/12, 2009).
10. CRC Committee, General Comment No. 14: on the right of the child to have his or her best interests taken as a primary consideration (UN Doc CRC/C/GC/14, 2013).
11. CRC Committee, General Comment No. 15: on the right of the child to the enjoyment of the highest attainable standard of health (UN Doc CRC/C/GC/15, 2013)
12. CRC Committee, General Comment No. 20: on the implementation of the rights of the child during adolescence (UN Doc CRC/C/GC/20, 2016).

13. Darbellay, F. (2015). The Gift of Interdisciplinarity: Towards an Ability to Think across Disciplines. In *International Journal for Talent Development and Creativity*, 3(2), pp. 201-211.
14. De Lourdes Levy, M., Larcher, V., Kurz, R. (2003). Informed consent/assent in children. Statement of the Ethics Working Group of the Confederation of European Specialists in Paediatrics. *European Journal of Paediatrics*, 162(9), pp. 629-633.
15. Freeman, M. (2009). Children's rights as human rights: Reading the UNCRC. In J. Qvortrup, W.A. Corsaro and M.-S. Honig (Eds.), The Palgrave Handbook of Childhood Studies (pp. 377–393). Basingstoke: Palgrave Macmillan.
16. European Union Agency for Fundamental Rights. Mapping minimum age requirements concerning the rights of the child in the EU, retrieved August 23, 2018 from: http://fra.europa.eu/en/publication/2017/mapping-minimum-age-requirements-concerning-rights-child-eu
17. Graham, A., Powell, M., Taylor, N., Anderson, D. & Fitzgerald, R. (2013). Ethical Research Involving Children. Florence: UNICEF Office of Research-Innocenti.
18. Hanson, K. (2012). Schools of thought in children's rights. In M. Liebel (Ed.), Children's Rights from Below. Cross-Cultural Perspectives (pp. 63-79). Palgrave Macmillan.
19. Hanson, K. and Nieuwenhuys, O. (2013). Living rights, social justice, translations. In K. Hanson & O. Nieuwenhuys (Eds.) Reconceptualizing Children's Rights in International development. Living Rights, Social Justice, Translations (pp. 3-25), Cambridge: University Press.
20. Hart, J. (2008). Children's Participation and International Development: Attending to the Political. International Journal of Children's Rights 16, 407-418.
21. Hein, I.M., Troost, P.W., Broersma, A., de Vires, M.C, Daams, J.G. and Lindauer, R.J.L. (2015). Why is it hard to make progress in assessing children's decision-making competence. BMC Medical Ethics.
22. Hodgkin, R. and Newel, P. (2007), Implementation Handbook for the Convention on the Rights of the Child. United Nations Publications.
23. James, A. (2009). Agency. In J. Qvortrup, W.A. Corsaro and M.-S. Honig (Eds.), The Palgrave Handbook of Childhood Studies (pp. 34-45). Basingstoke: Palgrave Macmillian.

24. Lancy, D.F. (2012). Unmasking children's agency. In AnthropoChildren, 1(2), pp. 1-20.
25. Lansdown, G. (2005). The evolving capacities of the child. UNICEF Innocenti Research Centre. United Nations Children's Fund (UNICEF).
26. Lundy, L. (2007). Voice is not enough: conceptualising article 12 of the United Nations Convention on the Rights of the Child. *British Educational Research Journal*. 33:6, 927-942.
27. McConville, M. and Chui, W. H. (2007). Research Methods for Law. Edinburgh University Press.
28. Morreim, E. H. (1993). Impairments and Impediments in Patients' Decision Making: Reframing the Competence Question. The Journal of Clinical Ethics, 294 – 307.
29. Mälksoo, L., Land, K., Lindpere, H., Madise, L., Pedak, P., Pisuke, H. (2017) Eesti Vabariigi Põhiseadus. Kommenteeritud väljaanne. (*in English: Constitution of the Republic of Estonia. Commentary.*). Retrieved August 23, 2018, from: http://www.pohiseadus.ee/
30. National Consent Policy (2013). Quality and Patient Safety Division (Ireland). Retrieved August 23, 2018, from: https://www.hse.ie/eng/about/who/qid/other-quality-improvement-programmes/consent/national-consent-policy-august-2017.pdf
31. Ondrusek, N., Abramovich, R., Pencharz, P., Koren, G. (1998). Empirical examination of the ability of children to consent to clinical research. Journal of Medical Ethics 24, pp. 158 - 165.
32. Praxis (2012). Lapse õiguste ja vanemluse monitooring. Laste ja täiskasvanute küsitluse kokkuvõte. (*in English: Monitoring of the Rights of the Child and Parenting. Summary of interviews with children and adults.*). Retrieved August 23, 2018, from: http://www.oiguskantsler.ee/sites/default/files/lapse_oiguste_ja_vanemluse_monitooringu_kokkuvote.pdf
33. Reference guide to consent for examination or treatment, second edition 2009. Department of Health (United Kingdom). Retrieved August 23, 2018, from: https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/138296/dh_103653__1_.pdf
34. Ruggiero, R., Volonakis, D., Hanson, K. (2017). The inclusion of "third parties": the status of parenthood in the Convention on the Rights of the Child. In Brems, E.,

Desmet, E. and Vandenhole, W. (Eds.), Children's Rights Law in the Global Human Rights Landscape. Isolation, Inspiration, Integration? (pp. 71–89). London: Routledge.

35. Van Bueren, G. (2007). Chapter 1. The fundamental legal principles of interpretation found in European constitutional and international case law. In G. Van Bueren, *Child rights in Europe. Convergence and divergence in judicial protection* (pp. 15-50). Strasbourg: Council of Europe publishing.
36. Verhellen, E. (2015). The Convention on the Rights of the Child. Reflections from a historical, social policy and educational perspective, Routledge International Handbook of Children's Rights Studies (pp. 43-59). Routledge (in press).
37. Wall, J. (2011). Can democracy represent children? Toward a politics of difference. In Childhood 19(1), pp. 86-100.
38. Weithorn, L.A. and Campbell, S.B. (1982). The Competency of Children and Adolescents to Make Informed Treatment Decisions. Child Development, Vol. 53, No 6, pp 1589 – 1598.
39. Woodhead, M. (2009). Child development and development of childhood. In J. Qvortrup, W.A. Corsaro and M.-S. Honig (Eds.), The Palgrave Handbook of Childhood Studies (pp. 46 - 61). Basingstoke: Palgrave Macmillan.
40. Council of Europe Guidelines on child-friendly health care (2011).