Summary

Introduction
In the Netherlands, each year more than one million children (0-18 years) visit a hospital for outpatient treatment, day treatment or admission. Children are not just small adults; they need to be diagnosed and treated in the context of their rapid growth and development, a context that has no counterpart in adults. Other important differences between children and adults as patients include children’s dependence on adults for access to the medical system, their different types, expression and severity of illnesses and their different responses to treatment. Furthermore, hospitalization is generally a stressful experience for children, not only due to their medical condition, but also because they are in a completely unfamiliar environment.

These differential characteristics shape the way quality care for children needs to be organized. The approach of child and family-centred care is considered to be the standard of paediatric healthcare by providers in many countries, including the Netherlands. This approach to healthcare recognizes the importance of meeting the child’s unique physical, mental and developmental needs. Furthermore, it recognizes that patients and family are integral partners with the healthcare team, demanding that children’s and parents’ experiential knowledge – acquired though their daily personal experience with the condition and the healthcare system – and the professional’s medical knowledge are complementary at all levels of decision-making. The increasing recognition that children are not only objects of care but knowledgeable social actors who have their own unique perspectives on issues that affect them, has been stimulated by the adoption of the children’s rights agenda, the reconceptualization of children within the social study of childhood and the growing influence of patients as consumers. Nonetheless, there remains a gap between legal regulations on children’s rights to participate in healthcare and the actual fulfilment of these rights in practice.

The challenge of closing the implementation gap is particularly complex for a number of reasons, including that children’s experiential knowledge generally has a low status compared to that of the parents and physicians, and that there is little experience with how to involve children in hospital care, especially how to do so in a way that befits the competences and needs of children, and brings about changes that matter to them. Further, the respect for a child’s right to participation is largely dependent on the attitudes and approaches of healthcare professionals, but their perspectives on children’s participation in hospital care remain largely unexplored. Previous research suggests that professionals might have difficulty in facilitating or supporting child participation, due, among other things, to protective attitudes toward children, doubts about the competence of children to participate and assumptions about a child’s age and maturity.

This thesis research addresses the challenges mentioned above, in order to ensure that children and young people can participate more effectively at all levels of healthcare decision-making. Good quality hospital care for children is only possible if children’s views, needs and wishes are structurally taken into account. This will result in much richer perspectives, allow an understanding of how children experience their hospitalization, what they consider important and how to align this with hospital policies and daily care practice, with the ultimate goal of improving health outcomes.

Theoretical background and study objectives
Several key international organisations, including the World Health Organisation (WHO), the Council of Europe (CoE) and the European Association for Children in Hospital (EACH) have already addressed the question of what actually constitutes high quality care centred around children’s and young people’s needs, and they have made recommendations to guide policy-making, planning and delivery of services. Relevant concepts from these policy frameworks are brought together in a
conceptual framework that takes into account that the participation of children is crucial to the realization of high quality care that places children and their families at the centre of healthcare practice. Three levels of participation are distinguished:

- **Micro level**: participation in individual decision-making, whether this be lifestyle choices or involvement in medical decision-making.
- **Meso level**: children should be given the opportunity to provide feedback on their experience after they have used services.
- **Macro level**: with increasing maturity and capacity, children should be involved in the policy/planning process for the services they use.

Furthermore, the conceptual framework recognizes that the attitudes and practices of healthcare professionals as well as parents largely contribute to the delivery of child-and family-centred care. They are the ones to provide children with appropriate care and support, but they also have significant influence in the process of child participation. Obviously, there are many more factors influencing the implementation of child-and family-centred care, such as appealing hospital environments, understandable information for patients and the availability of necessary equipment and supplies. In this study, I specifically focus on the question of how the participation of children and parents can contribute to strengthening the quality of child-and family-centred hospital care, taking into account that paediatric healthcare is grounded in a three-way relationship, involving the child, the child’s parent(s) and the healthcare professional. Three study objectives have been formulated:

1. To understand what children and parents regard as good-quality hospital care and how their perspectives correspond with existing policy frameworks for child-and family-centred care.
2. To understand health professionals’ perspectives on child participation in paediatric hospital care.
3. To understand what methods are appropriate for facilitating meaningful participation of children at different levels of healthcare decision-making (micro, meso, macro).

**Methodology**

I mainly used a qualitative research approach, combining **participatory data collection methods** and **traditional qualitative research methods**. Participatory data collection methods have their roots in collaborative or partnership methodologies. Collaborative research adopts an epistemological position that not only acknowledges children’s agency, but aims to facilitate their voices being heard in research affecting their lives. It appeals for consistent collaboration with children in some or all stages of a research project. In this study, participatory research methods were used to evaluate the quality of hospital care from children’s perspectives (first research objective) and to consider the appropriateness of such methods for facilitating meaningful participation of children at different levels of healthcare decisions-making (third research objective). Qualitative research methods, including semi-structured interviews and focus group discussions, were used to address the second aim of this study because these methods are particularly suited to gain insight into the experiences, meanings and views of individuals in relation to the complex circumstances of illness, treatment and hospitalization.

**Results**

**Children’s and parents’ perspectives on quality hospital care**

By focusing on what children and parents have to say instead of solely what researchers want to know, this study has identified those aspects of hospital care that are most important to children, young people and their families. We identified **six domains** that stand out as central to children’s and parents’ experience of healthcare. The **first** domain reflects hospital staff’s attitudes, such as respect, attention and friendliness. Participants emphasized that doctors, nurses and other hospital staff need to
show technical expertise and professionalism without losing sight of the humanity of healthcare. When the balance between ‘heart, head and hands’ is missing, experiences are mainly negative. In such cases, professionals displayed little empathy for patients’ feelings, took decisions without consulting children and families, did not listen to their opinions and acted hurried or carelessly. The second domain reflects children’s desire for effective communication, including being well-informed, healthcare professionals speaking directly to children, and good collaboration and communication between all persons involved in the care of children, including professionals outside of the paediatric unit, such as anaesthesiologists, surgeons and emergency physicians. The third domain relates to children’s need for support and distraction provided by nurses and hospital play specialists during stressful medical procedures, such as taking a blood sample, inserting a drip, receiving injections and induction of general anaesthesia. Particularly outside of the children’s ward, including in the surgery and Accident & Emergency (A&E) department, preparation and support are not as extensive as patients would prefer. The fourth domain reflects child-friendly hospital environments. Participants’ comments focused specifically on recreational facilities, poor hospital food, the furnishings and decorations of the paediatric department, and lack of privacy. The fifth domain is about maintaining contacts with parents, family and friends. Children frequently mentioned that they were happy when parents could stay the night and when they received visits from family members and peers. Adolescents, in particular, also highlighted the need for electronic communication with people outside the hospital using mobile phones and the Internet. The sixth domain, being listened to and having a say in healthcare, touches upon the core objective of this thesis. Even though the principle of listening to and engaging children and parents is highly supported by current policy framework on child- and family-centred care, in this study, children, as well as parents, frequently expressed the wish that their experiential knowledge should be more valued and taken into account by healthcare professionals, claiming that nobody knows about the issues of hospitalized children better than the children and parents themselves.

Health professionals’ perspectives on child participation in paediatric hospital care
Health professionals, together with parents, have significant influence in the process of child participation. Our results demonstrate that participation is not a term that is frequently used by professionals; however, they feel familiar with the ideas underlying the term, and it is perceived as being at the core of their work. For interviewees, the essence of child participation is to actively involve children as much as possible in individual decision-making about their treatment and their hospital stays. Professionals believe that high levels of participation are possible in ‘minor’ decisions that have a relatively low impact on the child’s health, including decisions about the child’s basic care and choices about care delivery (micro level). Participation in medical decision-making is considered to be more complex and subject to a number of reservations and restrictions because of the implications of such decisions on the child’s health and wellbeing.

With two exceptions, professionals said that they are not accustomed to inviting children to evaluate their hospital stays (meso level), nor do they involve them in policy-making processes (macro level). Professionals recognize the lack of specific evaluation strategies for children as a shortcoming because they feel that children often perceive things differently than their parents or focus on other aspects of care. The participants expressed a strong need for age-appropriate methods for evaluating paediatric hospital care from children’s and adolescents’ perspectives. Furthermore, they voiced the need to increase the respect for and understanding of the rights of children to participate outside of the paediatric unit, including in the surgery and emergency departments.

Methods for facilitating meaningful participation of children
This study generated knowledge of appropriate methods for facilitating child participation at different
levels of healthcare decision-making (micro, meso, macro). We identified a number of strategies and tools that doctors, nurses and hospital play specialists have developed to ensure that children can participate in the clinical encounter (micro level). Play specialists mentioned several methods of supporting children in expressing their views. These methods varied from asking children general questions, such as “Is there anything you need?”, to specially designed “pain passports”, in which children can write down personal rituals, special wishes and coping strategies they have developed over time in painful situations. Interviewees said that they often allow children to have input in how and when particular procedures are carried out. They provide alternative options, for example, whether the child would prefer to be anaesthetized using a mask or injection, and they often give children the opportunity to postpone or determine the timing of invasive procedures, and for example, decide who should accompany them.

Professionals indicated that they still rely on parents for feedback on the quality of paediatric hospital care and services (meso level). This study identified a number of methods/instruments that are appropriate for gaining meaningful feedback from children (and parents) on their experiences of hospitalization. These methods include Photovoice, online/face-to-face interviews, children writing a letter to the chief executive of the hospital and the Experience Monitor. The methods studied have in common that they enable children to express their views in a manner that suits their capabilities and preferences, and assists them in telling their stories from their own perspectives. In addition, Photovoice is able to provide visual metaphors of what the children want to tell; hereby generating more empathy than words alone. However, in terms of outcomes, the methods differ in the degree to which in-depth and contextualized insights into children’s lifeworlds were obtained, the extent to which the process contributed to the empowerment of children and the extent to which children’s ideas were acted upon.

The participation of children at higher levels of decision-making, including research agenda setting and clinical guideline development (macro level), has been endorsed by international bodies like the WHO and UNICEF. However, our findings indicate that in practice children hardly participate in the planning/policy process for the services they use. For example, in the Netherlands, facilitating the participation of children and young people in guideline development is still in its infancy, although it is becoming increasingly common for adult patients. Many guideline developers perceived children’s participation in guideline development as a challenge, and had doubts and questions about children’s abilities to participate, such as: Do children have the right skills to participate? From what age can they be involved? Is it not too demanding for them? How to organise it? These questions have not yet been solved for adults but are paramount for facilitating children’s participation. Despite all the questions and difficulties, participants recognized the importance and benefits of children’s involvement and welcome further exploration of its possibility in guideline development.

Discussion and Conclusion
Over the last three decades it has been increasingly accepted that paediatric patients are not only objects of care, but knowledgeable social actors who should be enabled to have a say in healthcare decisions that relate to them. However, facilitating meaningful participation of children and adolescents in daily paediatric practice is complex. The present study aimed to better understand how participation of children and their parents can contribute to strengthening the quality of child-and family-centred hospital care.

Evaluating the quality of paediatric hospital care from the perspectives of children and families increases awareness and understanding of their daily realities and experiences. The lessons that we
distilled from these experiences are immediately relevant to clinical practice. Some of the domains identified by children and parents support current good practices, such as unrestricted visiting hours, the possibility for parents to room-in and the crucial work done by hospital play specialists. Some other quality indicators recognized by the participants in this study are applicable to interventions that better orient hospital care to children’s and young people’s needs. Many of the areas for improvement identified during this study were acted upon by the hospitals. Examples include blinding of doors and windows so that children have more privacy, and developing child-friendly menus that have been tasted and assessed by a specially established team. Other action points could not be addressed immediately but are now receiving attention or have been placed high on the agenda. This demonstrates that participatory methods are not merely tools to gather children’s views but can serve as vehicles for making changes that matter.

From a theoretical point of view, children’s and parents’ perceptions of quality healthcare can complement existing policy standards and frameworks. A few of the criteria identified by the participants of this study point to domains that are absent in some or all of the existing standards that were described as theoretical context for the current study. For example, the importance of support and distraction during invasive medical procedures was repeatedly mentioned by both children and parents, but this quality criterion is not explicitly captured in any of the three frameworks. In addition, children’s perceptions of quality healthcare are helpful in refining and operationalizing existing quality standards and frameworks. For instance, where it is generally accepted that paediatric patients deserve ‘child-friendly’ hospital environments, children and young people in this study specified that this implies colourful rooms and corridors, a range of recreational activities and being able to sleep well.

Finally, children’s and parents’ perceptions of ‘good care’ highly support the recognition of the inclusion of patient experiences as one of the central pillars of quality in healthcare. Except for ‘hospital environments’ the domains that children and parents identified as central to the delivery of good hospital care, typically relate to ‘relational’ aspects of care (e.g. attitudes of hospital staff and communication with staff), rather than ‘functional’ aspects such as continuity, accessibility and evidence-based care. Accepting that good quality care is more than just technical care supports broader definitions and measures of quality, acknowledging that nobody can judge the quality of relational aspects better than the patients themselves. In this context, the quality of paediatric hospital care may be substantially improved by adopting participatory evaluation measures, taking into account the fact that quality of care cannot be measured by numbers alone and needs to reflect actual experiences.