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## **FACILITATING PARTICIPATION**

**A JOINT USE OF AN INTERACTIVE COMMUNICATION TOOL BY  
CHILDREN AND PROFESSIONALS IN HEALTHCARE SITUATIONS**

**Anna Stålberg**

**2017**



School of Health, Care and Social Welfare

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Anna Stålberg

Akademisk avhandling

som för avläggande av filosofie doktorsexamen i vårdvetenskap vid  
Akademin för hälsa, vård och välfärd kommer att offentligen försvaras  
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Fakultetsopponent: Professor Kerstin Öhrling, Luleå tekniska universitet



Akademin för hälsa, vård och välfärd

## Abstract

Children's right to participation in situations that matter to them is stated in law and convention texts and is emphasized by the children themselves in research studies, too. When actively involved, their perspective is visualized. Children's use of interactive technology has increased considerably during the last decade. The use of applications and web sites are becoming a regular occurrence in paediatric healthcare.

The overall aim was to develop and test, together with children, an interactive communication tool meant to facilitate young children's participation in healthcare situations.

To understand children's varied perceptions of their involvement in healthcare situations, interviews, drawings and vignettes were used in a phenomenographic approach (I). A participatory design iteratively evaluated evolving prototypes of an application (II). Video observations and hermeneutics captured the meanings of the participation cues that the children demonstrated when they used the application in healthcare situations (III). A quantitative approach was used to identify patterns in the children's cue use (IV). In total, 114 children in two clinical settings and in a preschool were involved.

The result showed that the children perceived themselves, their parents and the professionals as actors in a healthcare situation, although all were perceived to act differently (I). The children contributed important information on age-appropriateness, usability and likeability in the iterative evaluating phases that eventually ended up in the application (II). When using the application in healthcare situations, the cues they demonstrated were understood as representing a curious, thoughtful or affirmative meaning (III). Curious cues were demonstrated to the highest extent. The three-year-olds and the children with the least experience of healthcare situations demonstrated the highest numbers of cues (IV).

*Conclusion:* when using the application, the children demonstrated a situated participation which was influenced by their perspective of the situation and their inter-inter-action with the application as well as the health professional. The children's situated participation provided the professionals' with additional ways of guiding the children based on their perspectives.





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*Key words:* children; child's perspective; participation; phenomenography; interactive technology; participatory design approach; application; video observations; cues; hermeneutics

# Svensk sammanfattning

I lag- och konventionstexter, liksom i forskning, som använder barnens egna uttryck betonas deras rättighet att vara delaktiga i situationer av betydelse för dem. Genom att delta kan barnen göra sitt perspektiv synligt. Under det senaste årtiondet har barns användning av interaktiv teknik ökat kraftigt och applikationer och web-sidor används nuförtiden även flitigt inom barnsjukvården.

Avhandlingens övergripande syfte var att utveckla och pröva, tillsammans med barn, ett interaktivt kommunikationsverktyg, avsett att möjliggöra yngre barns delaktighet i vårdssituationer.

Intervjuer, teckningar och vignetter användes för att, fenomenografiskt, förstå barnens uppfattningar av att vara i en vårdssituation (I). En iterativ deltagarbaserad design användes för att utveckla en prototyp av en applikation. En hermeneutisk tolkning av video-observationer fångade meningen i barnens sätt att visa sin delaktighet (hintar) vid användningen av applikationen i vårdssituationer (III). En deduktiv, kvantitativ ansats användes för att identifiera mönster i barnens sätt att visa sin delaktighet när de använde applikationen (IV).

Resultatet visade att barnen uppfattade sig själva, föräldrarna och vårdpersonalen som aktörer i situationen, även om alla uppfattades agera på olika sätt (I). Barnen bidrog med viktig information i den iterativa processen gällande aspekter som åldersanpassning, användbarhet och hur väl den tilltalar dem, vilket slutligen ledde fram till den färdiga applikationen (II). Barnens sätt att visa sin delaktighet när de använde applikationen förstods ha en nyfiken, tankfull och självbekräftande mening (III). Nyfikenheten visades mest vid användningen av applikationen. Treåringarna samt barnen med minst vårderfarenhet använde applikationen i störst utsträckning (IV).

*Sammanfattning:* När applikationen användes i vårdssituationen visade barnen en situerad delaktighet, vilken byggde på deras perspektiv på den aktuella situationen samt på deras inter-aktion med applikationen och vårdpersonalen. Genom detta erbjöds vårdpersonalen ytterligare ett sätt att guida barnet utifrån barnets eget perspektiv.

*Nyckelord:* barn; barnets perspektiv; delaktighet; fenomenografi; interaktiv teknik; deltagarbaserad design; applikation; video-observationer; hint; hermeneutik



***Ur "Till eftertanke"***

*För att hjälpa någon måste jag visserligen förstå mer än vad han gör men först och främst förstå det han förstår. Om jag inte kan det så hjälper det inte att jag kan mer och vet mer.*

*Sören Kirkegaard*



# List of papers

This thesis is based on the following papers, which are referred to in the text by their Roman numerals.

- I Stålberg, A., Sandberg, A. & Söderbäck, M. (2016). Younger children's (three to five years) perceptions of being in a healthcare situation. *Early Child Development & Care*, 186 (5): 832-844.
- II Stålberg, A., Sandberg, A., Söderbäck, M. & Larsson, T. (2016). The child's perspective as a guiding principle: Young children as co-designers in the design of an interactive application meant to facilitate participation in healthcare situations. *Journal of Biomedical Informatics*, 61: 149-158.
- III Stålberg, A., Sandberg, A., Larsson, T., Coyne, I. & Söderbäck, M. (accepted). Curious, Thoughtful and Affirmative – Young Children's Meanings of Participation in Healthcare Situations when using an Interactive Communication Tool. *Journal of Clinical Nursing*.
- IV Stålberg, A., Sandberg, A., Coyne, I., Larsson, T. & Söderbäck, M. Patterns of young children's use of cues when using an interactive communication tool in healthcare situations. (Manuscript).

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# Abbreviations

AI	Active intervention
HCI/CCI	Human-computer interaction/Child-computer interaction
IACTA	Interactive communication tool for activities
PD	Participatory design
PHCC	Primary healthcare clinic
POU	Paediatric outpatient unit
PS	Preschool
UNCRC	United Nations' Convention on the Rights of the Child



# Introduction

Some things in life occur as a result of thorough planning. Others occur randomly. For me, being admitted to the research education represents a mix of these things. After many years of clinical work, I felt ready to take a step into a new world, that of academia. At that time, I had a budding but unformed idea that I one day would undertake a PhD. Randomly, something else happened: soon after I had started work at Mälardalen University, in the early summer of 2011, it was announced that the School of Health, Care and Social Welfare had obtained authorisation to conduct a research education within the area of health and welfare. Everyone rejoiced, and so did I, although my focus at the time was on adapting to the challenges of my new position.

During the autumn term I followed, from a distance, the process and debate about the research education. At the end of the term, the doctoral projects available to apply for were presented. As a children's nurse with long clinical experience, the projects with a child connection caught my interest. From initially viewing the research education as interesting but not something applicable for me at present, I suddenly realized that I was drawn closer to it. I understood that the opportunity to be admitted to the research education and to be part of a child focused project was something too good to overlook and I sent in my application. Eventually I was offered one of the projects. The project was aimed at developing, together with children, an application suitable for tablet use. The application was intended to be used by children and health professionals in healthcare situations, to provide the children, through virtual visual guidance, with an understanding of healthcare-related procedures and, in this way facilitate their participation in these situations in real life.

A sister project focused on preparing the health professionals for their involvement due to the intended joint use of the application (child and professional). Within the sister project, the issues of the child's perspective, a child perspective and a child's rights perspective were discussed. The professionals have been provided with continuous updates on the progression of the application, and a workshop has been conducted focusing on how to include the application in healthcare situations in real-life settings.

The project was a co-production between Mälardalen University, Nobab, an organization that works for children's and youths' rights in healthcare settings, and the County Council of Sörmland with external expertise used with regard to the programming and design of the application. The project was funded by the Inheritance Fund and Mälardalen University. All data, as well

as the application, belong to the project in general and myself as the doctoral student in particular, according to an agreement between the research group and the companies involved, meaning that there was no economic gain for the companies as a result of their involvement in the project, their liability being limited to the development of the application.

# Background

## Perspectives on health and welfare

In this thesis, health, from a healthcare perspective is understood as a multidimensional concept involving physical, psychological and social aspects. Given its multidimensionality, health represents different meanings for different individuals which emphasizes the understanding of it as a self-perceived and self-experienced concept.

Children's perception of health is influenced by their physical condition at the time. Psychological aspects, such as feelings of security or insecurity, anxiety, fear and/or lack of knowledge, also influence this perception. The same goes for social aspects, which are partly linked to the psychological factors, such as the presence of parents, which children describe as important for feeling better (Salmela, Aronen, & Salanterä, 2010; Salmela, Salanterä, Ruotsalainen, & Aronen, 2010). Social aspect external to the family, such as the degree and quality of their interaction with health professionals, also impact children's experience of health. To be involved, listened to and respected in the situation are all central to children's overall experience of health (Coyne & Kirwan, 2012; Gibson, Aldiss, Horstman, Kumpunen, & Richardson, 2010; Schalkers, Dedding, & Bunders, 2015).

Being involved, listened to and respected are all aspects that draw on the rights' perspective of health, too. The right to health is stated in the Universal Declaration of Human Rights (United Nations, 1948) and has been further developed in conventions specifically targeting vulnerable groups (Forman & Bomze, 2012). The Convention on the Rights of the Child [UNCRC] (United Nations, 1989) formulates the child's right to health as: 'States Parties recognise 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' (United Nations, 1989, Article 24). In a Swedish context, the Health Act (SFS 1982:76) states the right to health of everyone, including children, although they are not specifically mentioned.

Welfare is a broad concept involving both individual and societal aspects. Furthermore, welfare could be described as a benefit, as contentment, as thriving or as a state of well-being (Thesaurus.com, 2016) which shows that welfare mediates a favourable state of being. Some of the words are closely linked

to health; health is even mentioned as a synonym of welfare. From the individual's, i.e. the child's perspective, welfare involves physical, psychological and social aspects of health, including a sense of contentment and well-being. From a broader, societal perspective, welfare represents a system, dealing with aspects of life and living from a lifespan perspective. In this thesis, a specific part of the national welfare system is targeted, i.e. the healthcare system in general and two clinical settings in particular providing care at a regional level (Swedish Association of Local Authorities and Regions, n.d.)

In addition, there is a right's perspective linked to the welfare system, which applied to this project has an immediate impact on the children's health and well-being. According to the law, parents have the right to stay at home from work and care for their children when they are ill, while still receiving pay. The same right enables parents to accompany their children when visiting clinical settings, whether for shorter or longer stays (SFS 2010:110). As stated above, the presence of parents when the children are being ill is of importance for their experience of health as well as their feeling of well-being.

## Children's rights in healthcare

The United Nations' Convention on the Rights of the Child [UNCRC] (United Nations, 1989) has proven important for strengthening issues of children's rights. Since its establishment in 1989, there has been a growing interest in questions addressing these rights (Ombudsman for Children, n.d.; United Nations, 2002). Furthermore, the UNCRC has placed a focus on the child's perspective as well as on applications of this perspective (Qvarsell, 2003). Sweden was one of the first countries, in 1990, to ratify the UNCRC but has not yet incorporated the convention in the Swedish legislation. Instead, strategies to strengthen the right of the child have been applied, focusing on issues such as ensuring that Swedish legislation is written according to the UNCRC, that children are treated with respect and are enabled to express their opinions and that children, parents and those working with children are made aware of children's rights (Ministry of Social Affairs, 2010). Work is now being conducted on preparing for the UNCRC to be part of the Swedish legislation, starting from 1<sup>st</sup> January, 2018 (SOU 2016:19).

In this thesis, a healthcare context is of interest. When focusing on children's rights within the field of healthcare, the UNCRC is still applicable, for instance Article 24 that states the child's right to best available healthcare, as well as the fundamental articles, dealing with non-discrimination (Article 2), the child's best interests (Article 3), life and development (Article 6) and participation (Article 12) (United Nations, 1989). From a European perspective, the European Association for Children in Hospitals (EACH) in the late 1980s began their work regarding children's rights in hospitals and created the Charter of the European Association for Children in Hospitals (European

Association for Children in Hospital, 2015). Since then, children's rights in hospital settings have gradually been implemented. The Nordic network for children's rights and needs in healthcare, in association with EACH, has developed a Nordic standard regarding children's rights when they are ill and hospitalized (Nobab, n.d.). From a Swedish perspective, the Health Act (SFS 1982:76) states the right of everyone to healthcare on equal terms. However, this act does not focus specifically on the child as a patient. The Patient Act (SFS 2014:821), which aims to strengthen the rights of the patient, focuses more clearly on the child as a patient, and targets the rights of the child regarding information, consent and shared decision-making. Although the Patient Act is intended to be positive, discouraging results have been reported, involving both children and adults, when evaluating early effects of its implementation. Parents report a decrease rather than an increase, regarding both the information made available to and participation of their children in healthcare situations (Vårdanalys, 2017).

## Theoretical framework

### The child's perspective and a child perspective

The *child's perspective* represents the views, understanding, experiences and perceptions of the individual child in reference to a situation or context. This perspective is influenced by age and earlier experiences, or lack of experience, of similar situations or contexts (Sommer, Pramling Samuelsson, & Hundeide, 2010). A *child perspective* is an adult perspective, or construction, of the child. This perspective combines the adults' knowledge of the demands associated with a certain situation and the understanding of the child's perspective with regard to the same situation. The important distinction between these two perspectives derives from which person formulates it: the child or someone who represents the child (Halldén, 2003).

In all situations involving children, both the child's perspective and a child perspective need to be applied (Coyne, Hallström, & Söderbäck, 2016; Sommer et al., 2010). A child perspective is often referred to as a justification that actions directed to children are automatically positive and beneficial for them. However, careful consideration is needed in all situations to ensure that proposed actions, arising from a child perspective are beneficial from the child's perspective as well (Lindgren & Sparrman, 2003).

In child research, the child's perspective is used when trying to elicit a more diverse knowledge and understanding of a phenomenon (Alanen, 2001; Qvarsell, 2003). There are various methods available for acquiring a better understanding of the child's perspective, although each method needs to be selected with consideration for the specific prerequisites of the participating

children (Clark, 2005). Analysing data eliciting the child's perspective, verbal or non-verbal, is a delicate process which requires adults to be both attentive and sensitive to the child's actual meaning (Söderbäck, Coyne, & Harder, 2011).

## The ecology of human development

The theory of the ecology of human development derives from the assumption that human development, from a life span perspective in general and the early development of children in particular “takes place through processes of progressively more complex reciprocal interaction between an active, evolving biopsychological human organism and the persons, objects, and symbols in its immediate external environment” (Bronfenbrenner & Morris, 2006, p. 797). To be adequate, these processes, understood as the main source for development, need to be continued over an extended period of time and adapted to both individual and contextual aspects.

The ecological theory of Bronfenbrenner (1979) is a systems theory viewed as nested environments involving five systems – *micro*, *meso*, *exo* and *macro* (see Fig. 1). The fifth system, i.e. the outer layer, *chrono*, was added to the theory at a later stage (Bronfenbrenner, 1994). Indefinite ways of interactions occur between the different systems, and the individual both influences and is influenced by aspects involved in each of the systems. The *micro* system involves social face-to-face relationships between the children and people in their immediate environment. These relationships are bidirectional, indicating that the children are involved as active participants (Paat, 2013). As the children grow, the number of micro systems they are part of increases. The interactions and connections between different micro systems form the *meso* system, a system of subsystems. The development that occurs depends on whether, and in what way, the micro systems within the meso system collaborate with or counteract each other (Bronfenbrenner, 1979). Relationships and interactions in the immediate environments exercise a considerable impact on the child development, although remote systems, i.e. the *exo* and *macro* systems, influence and affect this development (Hwang & Nilsson, 2011). The *exo* system involves environments external to the child; for instance the parents' work place and work situation. The *macro* system consists of universal patterns influenced by society, such as politics and the political situation, standard of living, norms, culture values and religion. Despite its remote position, the macro level exercises a significant impact on the inner systems and provides the social context in which the other systems are engaged. The *chronosystem*, the outer layer, represents time and deals with the overarching changes throughout the lifespan, see Fig. 1 (Bronfenbrenner, 1986; Hwang & Nilsson, 2011; Härkönen, 2007).

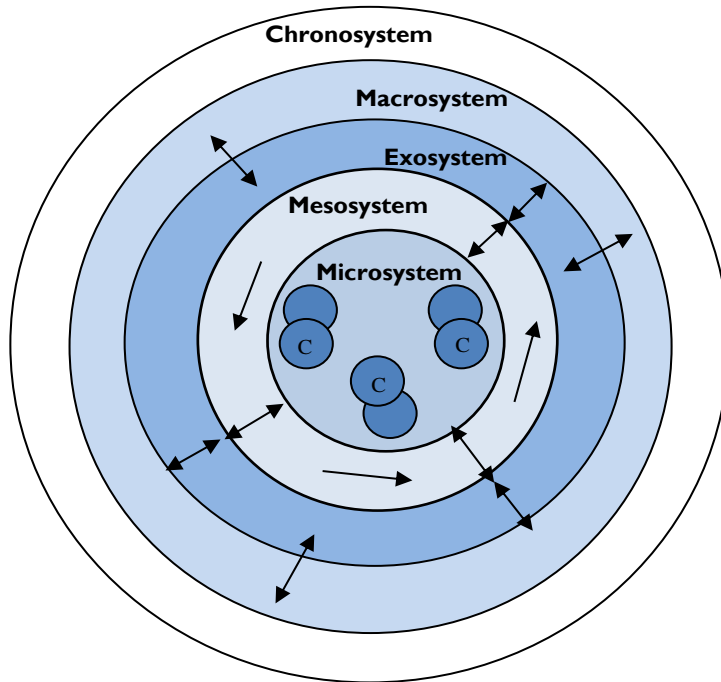


Figure 1. The nested environments, the reciprocal interactions occurring between the different layers and the proximal processes between the child (C) and other persons, objects or symbols in the microsystem (Bronfenbrenner, 1979, 2006).

The bio-ecological model, or theory, is an evolution of the ecological systems theory (Bronfenbrenner, 2005; Bronfenbrenner & Ceci, 1994; Bronfenbrenner & Morris, 2006). In this model, Bronfenbrenner and partners keep their view of human development as occurring through bidirectional relationships between the child and its immediate, and more remote, environments. However, instead of stressing the reciprocal interactions within and between different systems, with the interactions in the microsystem as the ‘center of gravity’ (Bronfenbrenner, 2005, p. xvi), Bronfenbrenner and partners, in the bio-ecological model, emphasize proximal processes, as well as genetics, as central to the development of the individual. The effects of these proximal processes vary as a joint function of person, context and time (the PPCT-model). Time and stability over time both regarding processes and context are important factors in relation to development, since an extended time allows for more complex reciprocal interactions to occur (Bronfenbrenner, 1994, 2005; Bronfenbrenner & Morris, 2006)

## The child as a social actor

The traditional understanding of children and childhood, formed by developmental psychology, has long influenced, and still influences the mainstream view of children. According to this, childhood is understood as a time of immaturity, irrationality and incompetence and the children, viewed as ‘becomings’, are transformed through socialization from passive objects to social beings, i.e. adults (James, Jenks, & Prout, 1998).

From the late 1960s onwards, an alternative understanding of children and childhood emerged that challenged the current understanding of the time. The main focus on this novel view, the new sociology of childhood, was on childhood per se, not childhood as a component of a broader context, such as the family or school. Childhood was no longer understood as a biological immaturity, but as a social construction, an idea that strongly contradicted the earlier understanding of the ‘universal child’ and a finite and identifiable childhood. Instead, the idea that there could be a variety of childhoods, each varying according to cultural differences, was discussed. This idea implied that the understanding of children and childhood could vary depending on aspects of time and space. The idea of children as children and competent individuals evolved as a research field (James et al., 1998).

When socialization is understood as a social and active process instead of a transformation of passive objects, children become subjects or agents who are viewed as competent individuals who actively participate in the construction of everyday situations together with other individuals (Alanen, 1988; Prout & James, 1997; Sommer, 2005). The children are important actors in their own development, and they use their motivation to explore and to learn. The information they come across, whether it is provided or self-acquired, is actively processed through guidance and support by sensitive and attentive adults. In this joint process, the information becomes meaningful to the individual child (Sommer, 2005; Woodhead, 2005).

The ideas originally formulated within the area of sociology of childhood, i.e. children as social actors, have now become established and accepted (Halldén, 2005) and are also embraced within other areas of research, which enable an understanding of children and childhood in other situations apart from the commonly described family and school arenas (Prout & James, 1997).

## Participation

Participation is a multi-dimensional and complex concept which is defined in varied ways. Some definitions are broad, opening the way to the involvement of a diversity of aspects. However, broad definitions such as ‘the action of taking part in something’ (Oxford Dictionaries, 2016a) or ‘an individual’s active engagement in a life situation’ (World Health Organization, 2013) carry



the risk of being too vague. Sloper and Franklin (2005) describe participation as a broad continuum of involvement in decision-making processes. Other definitions use a narrower scope, focusing on either the individual's contribution to the situation (Coyne, 2008; Hemingway & Redsell, 2011) or the interaction between individuals and their physical and social contexts (Forsyth & Jarvis, 2002).

Participation is also classified into typologies, by the use of metaphors. Arnstein (1969) understood participation as the cornerstone in a democracy, and she focused her work on citizen participation among the adult population. According to Arnstein, citizen participation equals citizen power. To describe citizen participation, she created an eight-rung-ladder of which each rung corresponded to a certain level of citizen power. Hart (1992) adopted Arnstein's ladder metaphor when describing child participation, a description that was a reaction to the growing awareness and interest in children's rights in the wake of the establishment of the UNCRC, an interest that, according to Hart, lacked a critical perspective. A major theme in both models is that of the individual's differing level of opportunity (low or high) to influence the situation (see Fig. 2).

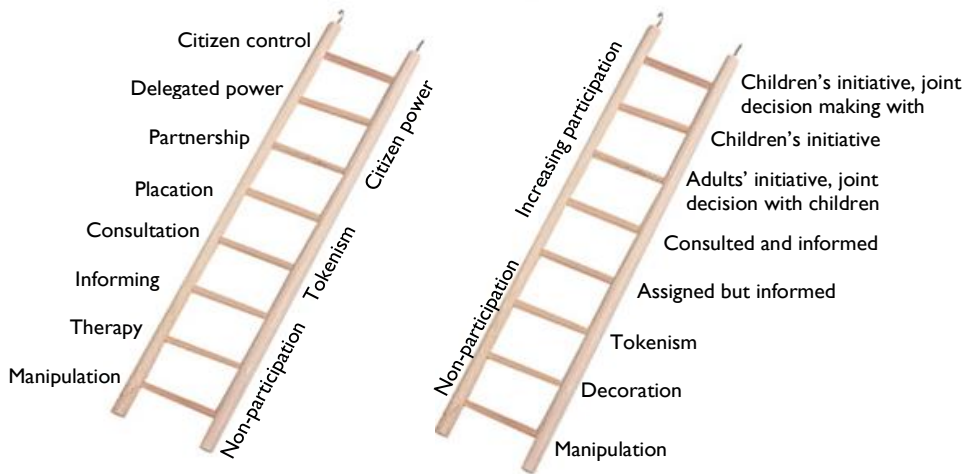


Figure 2. Adaptation of Arnstein's and Hart's ladder metaphors of participation (Arnstein, 1969; Hart, 1992).

Both the Arnstein and Hart models have been criticized. Arnstein's model was criticised for focusing too much on power issues, and critics felt that the ladder metaphor offered a static view of participation, ignoring and undermining the process of user-involvement for which it was initially created (Collins & Ison, 2009; Tritter & McCallum, 2006). Hart himself has criticised, but also defended, his version (Hart, 2008). He admitted that the ladder metaphor is

narrow and can be interpreted as favouring a stepwise climb to the highest rungs, which could be understood as superior to the rungs beneath. Furthermore, Hart pointed out to his critics that the model mostly describes child participation from an adult perspective. However, he insisted that the ladder metaphor had a purpose, bringing a critical perspective into a discussion he thought lacked that dimension. He defended the ladder metaphor and intended it to be understood in the sense of to which degree adults allow and enable children to participate (Hart, 2008).

Shier (2001), also influenced by the growing interest in children's rights, elaborated on Hart's ideas about participation in the model "Pathways to participation", a five-level model describing different aspects of a participatory process. Each level of the pathway includes three stages of adult commitments to child participation: openings (i.e. willingness), opportunities (i.e. ability) and obligations (i.e. rules and regulations). As with Hart's ladder metaphor, the goal of Shier's model is not solely to reach to the top level, but to raise the awareness of which kind of participation children are offered, as well as to find a level of participation that is adequate for the specific situation. With reference to children's rights, in order to meet the UNCRC's requirements, child participation aligning with the third level of the model, i.e. *Children's views are taken into account*, must be reached (Shier, 2001).

Yet another model describing participation from a child's rights perspective has been developed by Lundy (2007). Her work on the model grew from her criticism of the application of Article 12 in the UNCRC describing the child's right to participation (United Nations, 1989), which she meant focused too much on providing the child with 'a voice'. According to Lundy, such a focus narrows the intended scope of this article. Instead, for a successful implementation of child participation, she proposed a model involving *space*, *audience* and *influence* in addition to *voice*, where the internal relationship between the concepts is also of importance (see Fig. 3).

The extensive blend of definitions, descriptions and perspectives of participation that are in existence show that there is a need to clarify which definition should be used in the specific situation in order to avoid misunderstandings or vagueness (McPherson, 2010). The definition of participation used in this thesis is to be understood as, from the child's perspective, an active involvement in the situation (World Health Organization, 2013). Although there is a risk that this could be seen as too vague, this broad description was chosen as to allow the children a variety of ways in which to participate. Accordingly, the degree of involvement or engagement in the situation could vary according to the preferences of the individual child (Söderbäck, 2012) with a state of non-engagement being accepted as the result of an active choice made by the child. Child participation is influenced by in what way adults view and understand children, either as 'becomings/dependent' or 'beings/competent' (Thomas, 2007). The definition used in this thesis understands the child as a competent social actor in his/her own right (Alanen, 1988; Prout & James,

1997). The definition also takes the UNCRC (United Nations, 1989) and the Swedish healthcare legislation (SFS 2014:821) into account. Due to the nature of this thesis, interaction and communication are integrated in the definition as well.

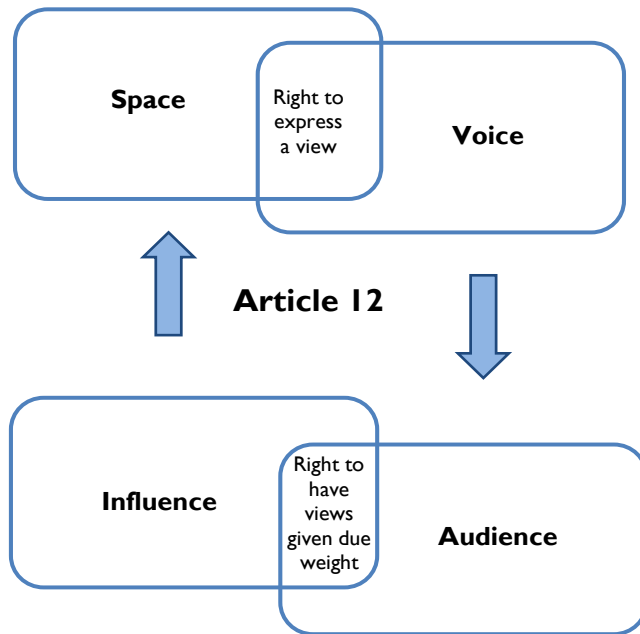


Figure 3. Prerequisites for adequate implementation of article 12, UNCRC (Lundy, 2007).

## Guided participation

Guided participation is a global phenomenon that emphasizes a learning and development process influenced by sociocultural aspects. Within the framework of guided participation, culture has a prominent position. Due to culturally and socially defined development goals, the implementation of guided participation varies between different countries and regions. The implementation process is also influenced by the degree to which children are able to observe or participate in these sociocultural relevant activities (Rogoff, 1990).

Guided participation focuses on a shared activity and a mutual understanding between a child and a more skilled person, and occurs verbally or as a face-to-face interaction. Participation, from the child's perspective, involves either an observational or a hands-on approach (Rogoff, 2008). The mutuality in the situation comes from the fusion of the perspectives of the persons involved. The more skilled person is responsive to the child's perspective, and the child sets the pace of the progression of the situation (Rogoff, 1990). Learning is a transformation of thinking, broadly understood as problem solving. The child is guided, through 'scaffolding', in appropriate ways while

learning how to carry out a task, and the child's participation in the situation subsequently changes and increases. The more skilled person increases the difficulty of the tasks to be performed as the child gains new skills and experiences (Rogoff, 1990). Within this learning process, the child is an active participant, seeking knowledge and demanding guidance in how to approach the situations. Children who prefer to participate by observing the situation are still viewed as active and skilled learners, since guided participation does not regard observation as a passive way of learning. Instead, children who engage in observation are viewed as active when watching (Rogoff, 1990, 2008).

## Aspects of child participation in healthcare situations

Children's actions in healthcare situations, as in others, are intentional, and their engagement is navigated by their perspective on these situations (Harder, Christensson, Coyne, & Söderbäck, 2011; Harder, Christensson, & Söderbäck, 2009, 2013). Söderbäck (2012) describes children's fluctuating engagement when undergoing a venepuncture. Their varied levels of engagement, combined with a preference of using non-verbal expressions, puts emphasis on the professionals' sensitivity and responsiveness to the children's expressions and engagement to guide them in an appropriate way (a.a).

A child's age and maturity are aspects that strongly influence adults' willingness to negotiate the degree of child participation in healthcare situations. Older children and adolescents tend to, or are allowed to, participate to a higher degree than younger children (Kilkelly & Donnelly, 2011; Schalkers, Parsons, Bunders, & Dedding, 2016). However, age and maturity are not always linked to one another (Alderson, 1993). When age is the only aspect used to decide whether children are competent to participate in a certain situation, their actual competence and understanding of the situation may be missed (Alderson, 2007). The competence of the individual child is of importance and should guide the decision of an appropriate level of child participation (Schalkers et al., 2016) and children themselves desire that their age should have less influence when it comes to deciding on their degree of participation (Coyne & Kirwan, 2012; Davies & Randall, 2015).

Given the multidimensional character of participation, various aspects need to be addressed when describing child participation in healthcare situations.

## Information

Information stands out as one of the most important prerequisites for child participation in healthcare situations. Children clearly manifest a wish to get information in and about these situations as it improves their understanding of the illness and treatment and thereby increases their ability to become involved in the situation. Regardless of the situation, whether the illness is acute

or non-acute, or whether the encounter concerns short- or long-term illness, the children require information to enable them to prepare for procedures, examinations or the hospital stay itself (Coyne & Gallagher, 2011; Coyne & Kirwan, 2012; Gibson et al., 2010; Salmela, Aronen, et al., 2010; Schalkers et al., 2015). Information works as a coping strategy (Coyne, 2006) and there is a strong relationship between the receiving of information and reduced levels of fear (Kilkelly & Donnelly, 2011; Salmela, Aronen, et al., 2010).

Young children prefer to be informed by their parents. Older children more often express a wish to be informed directly and not for their parents to be informed in advance (Gibson et al., 2010). However, children do not make up a homogenous group, which implies that there is no common method of information provision that suits all children of a certain age. Instead, an individualized approach is required.

To improve young children's understanding of the information provided to them, the use of a child-friendly language is of importance (Coyne & Kirwan, 2012; Davies & Randall, 2015; Kilkelly & Donnelly, 2011; Schalkers et al., 2016). Older children are reluctant to being informed by professionals who use childish words, although they prefer the language used not be too difficult either (Gibson et al., 2010). Despite the provision of an age-appropriate information, there will still be a group of children who do not understand what they are told, and professionals have to be aware of children's potential need to ask additional questions, as parents not always realise their children's problems of understanding the situation (Schalkers et al., 2015). A facilitating atmosphere enables the children to ask questions, which seems to be of most importance in situations involving children who are unfamiliar with the healthcare context (Gibson et al., 2010; Schalkers et al., 2016). Children who suffer from long-term or chronic diseases tend to ask questions more often (Kilkelly & Donnelly, 2011).

## Decision-making

In healthcare situations involving children, the children perceive that they have a right to be involved in the decision-making process, since everything discussed and decided upon is about them (Coyne & Gallagher, 2011). Their participation in decision-making has an empowering effect, and makes them feel respected and listened to (Davies & Randall, 2015; Moore & Kirk, 2010; Schalkers et al., 2015). Being involved is also of importance for the building of a relationship between the child and the professional (Coyne, Amory, Kiernan, & Gibson, 2014; Soanes, Hargrave, Smith, & Gibson, 2009). If excluded from the decision-making, children describe feelings like anger, frustration, disappointment and a sense of being ignored (Coyne & Kirwan, 2012; Schalkers et al., 2015).

Although children generally want to be involved in decision-making, professionals need to consider when and in what way they want to be involved

(Coyne & Harder, 2011; Hemingway & Redsell, 2011). Young children more often feel satisfied by being involved in minor decisions, mainly in relation to activities of everyday life, but prefer major decisions to be made by their parents and the professionals (Coyne & Gallagher, 2011). Older children more often prefer to be involved also when major decisions are made as well, or at least to be informed before any decision is made. In situations where the children, young and older, have to accept decisions made by professionals and/or their parents, their involvement in other decision-making becomes more important (Coyne et al., 2014).

## The influence of parents and health professionals

Despite the desire expressed by children to participate in healthcare situations, their actual degree of involvement depends on actions taken by their parents and the professionals. Parents who encourage and support their children, and at the same time take a step back themselves, influence their children's participation in a positive way (Davies & Randall, 2015). In other situations, the active presence and closeness of the parents, who provide their children comfort and security, is needed to facilitate the child's participation (Harder, Söderbäck, & Ranheim, 2015). The parents' presence is also of importance in situations where the children choose not to participate because they do not feel ready to face the demands of the specific situation or when they attempt to avoid being exposed to bad news (Coyne & Kirwan, 2012; Davies & Randall, 2015; Kilkelly & Donnelly, 2011). On the other hand, in some situations, the parents' actions, such as interrupting or blocking the child-professional interaction, answering questions meant for the child or telling the child to be quiet can actively hinder the child's participation (Harder, Söderbäck, et al., 2015; Moore & Kirk, 2010). The desire of parents to protect their children in these situations may lead to them trying to hinder the children from being actively involved (Soanes et al., 2009). In other situations, the parents do not actively hinder the participation, but their emotional status makes them incapable of adequately supporting their children (Coyne, 2008). In such situations, parents may request support from the professional. When providing that support, the professionals, at the same time, strengthen the child in the situation (Karlsson, Dalheim Englund, Enskär, & Rydström, 2014).

Health professionals agree on children's right to participate in healthcare situations (Coad & Shaw, 2008; Schalkers et al., 2015) and that their participation can be a coping strategy that helps them to reduce feelings of anxiety and distress. Child participation also provides the professionals with opportunities to capture the child's perspective (Schalkers et al., 2016). Despite their understanding of the importance of child participation, health professionals do not always act in accordance with their beliefs, and as parents, professionals can hinder the children's participation in situations where they perceive that the children are in need of protection (Coyne & Harder, 2011). Aspects of

communication skills influence the child participation as well. Professionals who lack skill of how to communicate with children appropriately rarely invite children into the conversation (Coad & Shaw, 2008).

## Children's use of interactive technology

The use of internet and interactive technology among Swedish children has increased exponentially during the last decade, which is in accordance with a worldwide trend, although the greatest increase is found in the developed countries (Holloway, Green, & Livingstone, 2013; Radesky, Schumacher, & Zuckerman, 2015; Swedish Media Council, 2015). From a Swedish perspective, in 2005, the age of onset of internet was nine years. A decade later, the situation has changed drastically and an internet use among children aged 0-1 years is now a reality. Today, internet use among children 0-1 years old equals the use among 5-and-6-year-olds in 2010 (Swedish Media Council, 2015). In Sweden, video sharing sites like Youtube and SVT Play (Barnkanalen/Bolibompa) are the most popular sites among young children (Swedish Media Council, 2015). Also from an international perspective, young children demonstrate a preference of using video sharing sites.

The easily accessible touchscreen technology used in tablets and smartphones, combined with an ever-growing availability of applications, can explain the rapid increase in children's use of interactive technology (Beschoner & Hutchison, 2013). Young children quickly learn the useful operational skills of how to interact successfully and purposefully with applications and games (Ahearne, Dilwoth, Rollings, Livingstone, & Murray, 2015; Beschoner & Hutchison, 2013; Couse & Chen, 2010; Plowman, Stevenson, Stephen, & McPake, 2012). Even toddlers are able to discover interactive touchscreen features and use them adequately (Ahearne et al., 2015). A growing number of children have access to a tablet at home, either their own or shared with siblings or the rest of the family, and this increase can partly be explained by parents' increasingly positive attitudes towards their children's use of tablets (Nikken & Schols, 2015; Swedish Media Council, 2015).

## Interactive technology in child healthcare contexts

Consistent with the last decade's increase in children's use of interactive technology, there has also been an increase in child-friendly interactive games and applications focusing on the healthcare context (Burbank et al., 2015; Cafazzo, Casselman, Hamming, Katzman, & Palmert, 2012; Fröisland, Årsand, & Skårderud, 2012). Although young children make up a growing group of interactive game users (Holloway et al., 2013; Swedish Media Council, 2015), the development of applications dealing with various

healthcare issues in age-appropriate ways for this group of children is still at a low level (Høiseth, Giannakos, Alsos, Jaccheri, & Asheim, 2013).

A growing field of applications within the field of paediatric healthcare deals with aspects of preparation, either for a hospital stay or focusing on specific procedures (Fernandes, Arriaga, & Esteves, 2015; Tseng, Chuang, Hermann, Koehler, & Do, 2011). Gamification, i.e. applying ideas used when developing interactive games (Markopoulos, Read, MacFarlane, & Hoysniemi, 2008), has been adopted to increase the usability, likeability and age-appropriateness of these applications. Most of them address school-aged children, but Williams and Greene (2015) describe an application developed for preparation of children aged 4-8 for medical imaging procedures.

Other applications already available in the field of paediatric healthcare deal with health education. Blanson Henkemans et al. (2013) describe the use of an interactive, personalised robot that, through a quiz game, contributes to improved knowledge about diabetes among children, aged 8-12, who have been diagnosed with the disease.

SISOM deals with issues of communication (Ruland, Starren, & Vatne, 2008). SISOM has been developed through a participatory design process, with the input of children, for children aged 7-12 with cancer. In the storyboard of the application, the child designs an avatar who goes by boat to different islands. Each island represents different topics like 'in the hospital', 'body' and 'things one can be afraid of'. By interacting with the application the child is enabled to express opinions, thoughts, wishes and worries in reference to these topics. Aside from its use as a communication tool, SISOM is intended to support individually-tailored patient care, from the child's perspective.

Distraction makes up yet another area in which interactive technology is used in the paediatric healthcare context. Miller, Rodger, Bucolo, Greer, and Kimble (2010) describe an interactive multi-modal distraction device for children aged 3-10 years which aims to reduce procedural pain when changing burn wound dressings. The device consists of a hand-held console that provides interactive procedural and distraction stories to be used prior and during the changing of dressings.

As a variation of distraction, Høiseth et al. (2013); Høiseth and Holm Hopperstad (2016) describe one of the few healthcare applications developed for toddlers and aimed at facilitating their nebuliser treatment, provided in situations of acute respiratory distress. Through an interactive story, the children and their parents are informed about treatment procedures. Another interactive story describes a train journey. The story is shown on a screen during the actual treatment period, with the final goal of the train journey being reached as the treatment is finished.

From a Swedish perspective, some of the larger children's hospitals provide web sites involving child-friendly and age-appropriate information about procedures and treatments (Akademiska barnsjukhuset, 2014; Karolinska



sjukhuset, n.d.). Other hospitals refer to 1177 Vårdguiden (n.d.), a web site providing information on health-related issues for all ages. The web site contains a section specifically targeting parents and children, and in which there are short film clips available to watch, dealing with information as preparation for examination, procedures and hospital visits.

## Rationale

The facilitation of child participation in healthcare situations is a complex matter, dealing with issues concerning parents, professionals and the children themselves. Children in general prefer an active involvement in these situations, as it provides them information, which gives a better understanding, potentially reduces fear and can be used as preparation. Child participation opens the way to child-centred care in which the child's perspective in the situation is requested. Furthermore, participation in healthcare situations is a right of the child, both from an international and a Swedish perspective.

Interactive technology use among young children has increased considerably during the last decade. The trend for using this technology has also found its way into the field of paediatric healthcare, where web sites and applications are becoming more common. Many of these health-related interactive solutions address school-aged children and adolescents, although interactive information is provided to younger children via web sites as well. However, this information is meant as a preparation and is not situated in that way.

Gamification is one way of capturing the interest of children and can be used to adapt health-related information in usable and likeable ways. Interactivity and animation link to the children's engagement with computers, smartphones and tablets. Given this, when interacting with these devices, their prerequisites, wishes and needs in a specific situation can influence the events on the screen. How gamification can be applied to facilitate young children's participation in health related examinations or procedures and support their understanding has not yet been investigated.

# Aim

The overall aim is to develop and test, together with children, an interactive communication tool meant to facilitate young children's participation in healthcare situations.

The specific aim of each study was:

- I. To describe how younger children, aged three to five years, perceive to be in a health-care situation.
- II. To describe the systematic participatory design approach used during the development and design process and the particular contributions of the young children – from the child's perspective – in the development of an application.
- III. To describe young children's demonstrated participation in healthcare situations while using an interactive communication tool.
- IV. To investigate similarities and differences in relation to age, setting and examination or procedure in young children's cues when using an interactive communication tool in healthcare situations.

# Method

## Points of departure

### Ontological and epistemological stance

In this thesis, the world is understood as multidimensional and socially constructed, which implies a world view created, perceived and experienced differently by each individual (Schütz, 1999). The world, the person, and in particular the child, is understood as a multidimensional being, a social actor who through thoughts, feelings, perceptions, experiences and understanding participate actively in and contributes to the evolution of a variety of situations. To recognize the child as a social actor emphasizes the child as a subject, and not an object, in the situation.

Alike the ontological stance, knowledge is understood as multidimensional and socially constructed (Schütz, 1999). The thesis focuses on subjective qualitative knowledge, i.e. knowledge from the child's perspective. Deriving from this, knowledge was mostly elicited using an inductive approach, although some areas were also derived deductively. Through induction, generalizations are made from the empirical data. In this subjective, qualitative method of knowledge acquisition, there will always be a lack of objectively, experimentally formed answers or conclusions also described as the 'true truth'. Instead, truth is perceived as relative and variable, in opposition to the objective knowledge gained by deduction (Ladyman, 2007).

### **Doing research with children**

Ethical concerns are complex matters and of importance to consider in all research involving living beings. In research studies where there is a more obvious asymmetry between the participants and the researcher(s), such as in the situation with children, ethical considerations are even more delicate. However, too high a level of concern for and focus on their exposed situation and need for protection does not allow an understanding of children as competent and might result in a situation where children and young people are denied participation in research studies, even in studies aimed at and beneficial to children (Skelton, 2008). [Over]protection of children is not in accordance with Article 12 in the UNCRC, which makes clear children's right to take part freely in all situations that matter to them (United Nations, 1989). The under-

standing of children as competent and active participants in a situation constitutes an important and positive point of departure when involving and listening to them in various occasions (Clark, 2005).

When involving children in qualitative research, substantial physical risks are low. However, potential psychological and/or emotional risks might occur due to their recollection of situations and experiences that have caused discomfort and anxiety. Despite these potential risks, it could still be argued that conducting the research could be beneficial for other children in similar situations (Huang, O'Conner, Ke, & Lee, 2016). Although children lack the knowledge and skills adults have gained through the years, they are part of society, and when children are actively involved in research, they are viewed as beings who have important information to bring into the situation from their own perspective. Children may tell, describe things and behave in different ways compared to adults, but they have to be respected for their way of being and acting in the world (Korczak, 2011). The focus in recent decades on children as competent social actors has resulted in an increased number of research studies conducted *with* rather than *on* children. Additionally, the recent increase of participatory methods has led to research conducted *by* children, either as co-researchers or primary researchers (Clavering & McLaughlin, 2010).

## Methodological stance

The methodology is linked to the ontological and epistemological stance (Ladyman, 2007) as well as to the concerns with regard to conducting research with children (Clavering & McLaughlin, 2010).

In this thesis, a mixed-methods design was used, with an emphasis on the qualitative parts, studies I-III (Andrew & Halcomb, 2009), see Table 1. The qualitative design is flexible and has an inherently open nature in regard to what is being studied. Given that the qualitative studies used an inductive approach, the methodology had to take into account ways of exploring and interpreting perceptions, perspectives and meanings intended by the children involved. Furthermore, the methodology also had to be appropriate for their level of competence and skill, and their prerequisites, so a series of methods, more or less participatory, were used. The quantitative study (study IV) focused on similarities and differences and comparisons of the phenomenon of interest. This knowledge contributed to an improved understanding of the qualitative studies of the project (Andrew & Halcomb, 2009).

## Settings

Throughout the studies, children in two clinical settings have been involved. In the initial studies, children also in a preschool setting were involved as to

enable a variation of experiences. The three settings involved are all areas of the Swedish welfare system and financed mainly by taxation.

The clinical settings of interest in the project belong to the county council organization of Sweden. The county councils provide for healthcare at a regional level (Swedish Association of Local Authorities and Regions, n.d.), and this provision is divided into primary healthcare clinics and hospital settings. Each setting, managed by either the county council itself or by private interests, is regulated by laws; for instance the Health Act and the Patient Act (SFS 1982:76; SFS 2014:821). Primary healthcare clinics have a life-course perspective and treat individuals from birth onwards. They deal with health promotion as well as healthcare and provide a 'first-line' care. When necessary, patients are referred to hospital settings for highly-specialised healthcare. Children attend for primary healthcare when they are suffering from health problems, such as colds, ear aches or sore throat, coughs and minor allergy symptoms. The paediatric outpatient unit is part of a tertiary hospital-based healthcare provided to children 0-17 years old. In this setting, children with a need of specialised paediatric care are investigated and treated. Furthermore, children attend this unit for preparation and premedication for day surgery or advanced X-ray examinations (MRI or CT-scans). Healthcare services for children aged 0-17 years are mainly free of charge, although some county councils charge for visits to the emergency department.

Children's attendance at preschool is voluntary in the educational system in Sweden and children aged 1-5 years old can attend. Although it is voluntary, a majority of children attend this early childhood education (Swedish National Agency for Education, 2013). Preschools, at a municipality level, can be either public, private or run as a parents' cooperative. The activities of the Swedish preschools are regulated by a curriculum (Swedish National Agency for Education, 2010) and the schools are staffed by preschool teachers and child-care attendants. Although tax financed, parents are charged an additional monthly fee, with a maximum level.

## Sample

Prior to the study start, managers within the clinical settings, a primary health care clinic [PHCC] and a paediatric outpatient unit at a tertiary hospital [POU] as well as a preschool [PS], were contacted and informed, since their approval was essential for the studies to take place. Later, the staff in the three settings were contacted. They received information about the aim of the thesis as well as about the data collection procedures. They were then regularly informed about study results during the progression of the project.

Table 1. Overview of the thesis.

Study	Aim	Design	Data collection	Analysis
<b>I</b>	To describe how younger children, aged three to five years, perceive to be in a health-care situation	Descriptive, interpretative	Semi-structured interviews, drawings, vignettes, audio recordings	Phenomenography
<b>II</b>	To describe the systematic participatory design approach used during the development and design process and the particular contributions of the young children – from the child’s perspective – in the development of an application	Descriptive, interpretative	Field notes, structured observations, evaluation protocols, audio recordings	Iterative test-and-evaluation process
<b>III</b>	To describe young children’s demonstrated participation in healthcare situations while using an interactive communication tool	Pilot study, interpretative	Video observations	Hermeneutics
<b>IV</b>	To investigate similarities and differences in relation to age, setting and examination or procedure in young children’s cues when using an interactive communication tool in healthcare situations	Descriptive, explorative	Transcripts of video observations	Quantitative descriptive analysis

The involvement of children from both a PS and clinical settings was chosen to explore the children’s varied experiences of healthcare situations (Bronfenbrenner, 1979; Marton & Booth, 1997). The age of the children, i.e. 3-5 years, was another inclusion criterion, and in addition it was required that they and their parents were able to understand and speak Swedish. However, children from different ethnic origins were included. Children who were severely ill prior to or at the day of their visit to the clinical setting and children or parents who used an interpreter when communicating with the professionals were excluded.

The number of boys and girls included happened to be almost equal (see Table 2), although there was no inclusion criterion for gender. A potential gender difference was not an area of investigation in this thesis, either in relation to perceptions of healthcare situations or in relation to interactive technology use.

In the PS setting, the staff recruited the children by providing the parents with written study information. In the clinical setting, nurses recruited the children when their parents made an appointment. In the POU setting only, some

children who were regular visitors to the unit were recruited when the nurse arranged new appointments for them. Although the same settings were used for data collection in all studies, no child participated more than once. A total of 114 children were involved in the studies: In study I, 49 children were recruited, although six were excluded, either because they chose to withdraw or because their parents interfering to such an extent that the child's perspective was lost. In study II, 51 children were involved in an iterative process. Three additional children were encountered but were excluded due to unwillingness to take part or lack of experience of using tablets and apps. In study III, 20 children in the clinical settings were involved. There were no drop-outs in study III. Study IV was based on the same information as study III, and therefore no more children were added. However, study IV focused on situations, i.e. physical examinations and needle procedures, instead of number of children. Given that one child in study III was involved in two situations, study IV was made up by 21 situations, 13 examinations of chest and ear and eight needle procedures (see Table 2).

Table 2. Overview of study participants.

Study details		Participants (n)	Age (months)	Gender		
				Boys	Girls	
Study I	PS	10	40-70	4	6	
	PHCC	20	37-76	7	13	
	POU	13	39-70	9	4	
Study II	PS	Phase I	9	49-72	2	7
		Phase II	12	37-58	9	3
	PHCC	Phase II	13	36-70	6	7
		Phase III	7	36-72	2	5
	POU	Phase II	8	40-69	4	4
		Phase III	2	71	2	0
Study III	PHCC	15	39-70	11	4	
	POU	5	48-60	2	3	
<b>In total</b>		<b>114</b>	<b>36-76</b>	<b>58</b>	<b>56</b>	

## Ethical considerations

Research requires a proper benefit-and-risk evaluation and approval. This project was approved by the regional vetting board in Uppsala, Sweden, dnr. 2012.489. Prior to the study start, additional approval was gained from managers in the preschool and clinical settings.

In research with children, the building of a relationship between the child and the researcher needs to be emphasized. A relationship based on trust is an important foundation for a successful data collection process (Huang et al.,

2016). In the studies included in this thesis, different approaches were used to enable familiarisation between the children and the researcher. Prior to the study start, the children in the preschool setting were seen several times, and each time they were verbally informed about the study. In the clinical settings it was not possible to use the same relation-building approach. Instead, the children and parents were encountered at their arrival, and were provided verbal information about the study at this time. The children were invited to have a conversation about everyday activities as a way to enable familiarisation. This conversation took place in the waiting room and often involved elements of play.

Parents' presence in research is frequently discussed, since it can both facilitate and hinder the children to express their opinions (Huang et al., 2016). In the clinical settings, because the children were in unfamiliar environments, the parents were present during the data collection session, a presence that was considered as strictly beneficial. On the other hand, in the PS setting, no parents were present, because the PS constitutes the everyday environment for the children, it is a place where they feel safe, and normally no parents are present in that context. Additionally, the children in the preschool setting had had the chance to become familiar with the researcher in a more extensive way than the children in the clinical settings.

Regarding the ethical considerations in this thesis, the guidelines described by the Swedish Research Council were used (Vetenskapsrådet, n.d.). *Information* deals with participants' right to information concerning the aim of the study, as well as on how it will be conducted. Potential gains of the research and hazards related to participation as well as information on the voluntary engagement and the right to withdraw at any stage need to be clarified. When children participate in research, age-appropriate information that meets their prerequisites has to be provided (Allmark, 2003). For that reason, two types of information letters were used, one for the children and one for their parents. The children's information used an easily understandable language to explain the research process. The parental information provided a description which elaborated further on the project. In both letters, information about voluntary participation and the right to withdraw at any stage was provided. In addition to the written information, both children and parents were provided verbal information on their arrival to the clinical setting. Verbal information was also provided to the children in the PS setting prior to the start of the study.

*Consent* involves the right to voluntary engagement in the research study. The signed informed consent of each participant is required to ensure that the participation is a choice of free will. When involving participants such as children, the obtaining of informed consent is a sensitive process. In the literature, there are divergent ideas about children's competence to give informed consent. Some regard young children as lacking the competence to give informed consent but capable of giving assent or dissent (Allmark, 2003; Polit & Beck, 2010). Others consider that children are capable of understanding voluntary



participation and can therefore be asked to give informed consent (Alderson, 2007; Chu, De Prince, & Weinzierl, 2008; Kassam-Adams & Newman, 2005). In the studies included in this thesis, thorough and age-appropriate information has been provided. The children were regarded as social actors in their own right and therefore they were asked to give signed informed consent. The children who could write their names or initial letters were asked to do so and those who could not, were asked to do a drawing instead. Although they had given their signed consent, each participant had the right to decide independently how long and under which conditions he or she would participate, as well as to withdraw at any stage without facing any consequences. Since young children often use non-verbal expressions, attentiveness and sensitivity was necessary in the researcher, in order to be alert to any expressions made by the children that might indicate a wish to withdraw. In the third study, the professionals were asked to sign informed consent, because they performed overtly in video recordings.

Regarding *confidentiality*, when publishing, information needs to be presented in a way that the single participant cannot be identified, and therefore, when publishing data from the studies, fictitious names or simply the child's sex have been used in the quotes in the text. Information on age and setting was added for clarification. The use of audio recordings facilitates the privacy of the participants to a higher degree than video recordings, and when video observations were used, the parents were informed that they could stop the recording if they did not want a specific part of the health visits to be recorded. In this thesis, no register of participants was established.

*Usage* involves the requirement that all data collected in a project is only allowed to be used by people working on the project. All audio and video recordings, as well as interview transcripts, have been transferred to an external hard drive which has been stored in a fireproof cupboard together with the signed consent forms. No one except the members of the research group has had access to the data material. The parents were informed in detail about how the recordings would be used. Three families were asked if the video recording of their child could be used in research presentations; one family approved. Another family approved that a photo of their child was used for publication reasons, and both families were asked to sign a specific informed consent form regarding the use of the visual data of their child.

No reimbursements were given to the children following their involvement in the studies.

## Data collection

When aiming to elicit knowledge from young children in qualitative research, a standard method such as interviewing may not be the best option as it requires certain verbal skills (Bagnoli, 2009). Instead, a variety of methods are

required as they differ in the way they make use of the children’s wide range of competencies and varying verbal skills (Dockett, Main, & Kelly, 2011). The younger the children, the greater is the need to employ participatory methods which enable them to be involved in a way which takes into account their prerequisites and perspectives (White, Bushin, Carpena-Méndez, & Ní Laoire, 2010). Varied methods also provide the children a choice of how to participate in a way that is best for them, so various methods, more or less participatory, were used to elicit the children’s perspective. Each method involved will be presented in association with the study in which it was used.

## Study I

In study I, interviews and two participatory methods were chosen, to enable rich descriptions of the phenomenon of interest. To combine interview sessions with other activities can prove useful when children are involved (Kvale & Brinkmann, 2009). The data were collected over an extended period of time (see Table 3).

Table 3. The data collection process

<b>Study</b>	<b>Setting</b>	<b>Phase</b>	<b>Data collection period</b>
<b>I</b>	PS	Not applicable	December 2012 - April 2013
	PHCC		February - December 2013
	POU		February - December 2013
<b>II</b>	PS	Phase I	March - April 2014
		Phase II	November 2014
	PHCC	Phase II	September - November 2014
		Phase III	March 2015
	POU	Phase II	November 2014
		Phase III	March 2015
<b>III</b>	PHCC	Not applicable	October - November 2015
	POU		October 2015 - March 2016
<b>IV</b>	The same data set as in study III		

In the PS setting, the sessions took place in a separate room in which only the child and the researcher were present. The other children and staff were in a room next door. In all sessions but one, which was conducted with two girls participating together, the children participated alone. In the clinical settings, the sessions were arranged directly after the child had met the doctor or the nurse, and took place in a separate room but still in the clinical setting. All sessions were audio recorded. The children were informed of the purpose of the recorder and it was visible on the table throughout each session.

## **Semi-structured interviews**

A semi-structured interview is more flexible than a structured interview. The questions formulated in the interview guide are open-ended and composed in a way which invite the study participants to speak freely and to elaborate on their answers. Due to the flexible character of the interview, the researcher does not have to follow the interview guide strictly, but can rearrange the questions in accordance with the development of the specific interview (Patton, 2002). The children were asked similar questions, although the exact wording and order differed slightly due to situational aspects in the respective child encounter.

To enable the children to familiarise themselves with the situation as well as the room before the actual data collection procedure started, each session was introduced by a short ‘small talk’ in which the conversation about everyday activities that had been introduced earlier was continued. This introductory phase was used in all settings, although it was of most importance to the children in the clinical settings. After only a few encounters with children in the clinical settings it was apparent that the children were mostly unresponsive. To enable recall of the situation, and in that way facilitate the children to elaborate on their answers in the interview situation (Doverborg & Pramling Samuelsson, 2012; Solberg, 2012), the researcher participated in the doctor or nurse encounters, a presence that was consented to verbally by children, parents and professionals.

## **Vignettes**

A vignette is either a picture or a photo, based on fiction or fact, describing a certain situation and used to elicit verbal responses and to steer the narratives towards a certain topic. When children participate in research studies, the use of a vignette can encourage them to start to talk and to elaborate on their answers, since talking about a situation presented in a picture or a photo is perceived as less frightening than to talk about the real-life situation (Holmsen, 2005, 2007).

Children, if identifying themselves with what is shown in the vignette, usually involve their own experiences in their descriptions. The use of a vignette is therefore a way for children to subjectively re-tell a real-life situation which provide adults with a better and more comprehensive understanding of the children’s world (Holmsen, 2005). Vignettes are also a useful method of enabling children to verbalise situations that otherwise would be difficult for them to talk about. In situations when the child does not want to talk about the vignette situation, a leading story, based on the child’s own history, can be used as encouragement. In vignette use, the children can be asked open-ended questions which facilitate them to tell their stories. These open questions also encourage them to answer in whole sentences and ‘Yes’, ‘No’, ‘Good’ and ‘I do not know’ answers can be avoided. The questions asked are directed to the

person/peoples in the vignette and not to the child him/herself. The naming of the individual(s) in the vignette enables the child to involve him/her/them in a more fruitful way when answering the questions (Holmsen, 2007).

In study I, three vignettes were used, all with painted pictures of animals (mice) describing various healthcare situations. The vignettes were introduced at the same time, and the children were asked to choose the one they preferred to start with. To encourage the children's descriptions, and to elaborations on their answers, each vignette was introduced with a short story in which the mouse was given a name. After this, the children were asked an open question about what was happening in that specific situation. Furthermore, they were encouraged to speak freely about which aspect(s) of the situation they preferred. Follow-up questions were used in accordance with the children's specific descriptions. Prompts or direct questions to encourage, or elaborate on, the conversation were added when needed.

## **Drawings**

Taking into account young children's limited verbal skills, the use of drawings is a common method in research targeting this age group (Bagnoli, 2009; Bradding & Horstman, 1999; Horstman, Aldiss, Richardson, & Gibson, 2008; White et al., 2010). Children, including young children, regard drawing as positive, as it is a familiar activity. Drawings enable a creative, interactive and communicative process, since the children are facilitated to express themselves in ways they might not or cannot do verbally (Driessnack & Furukawa, 2012; Knighting, Rowa-Dewar, Malcolm, Keraney, & Gibson, 2010; White et al., 2010; Wright, 2007). Children's drawings can be used to understand their meaning-making in various situations, as children's drawings are made in a purposeful way and from their perspective (Einarsdottir, Dockett, & Perry, 2009). When children are allowed to decide freely what to draw, they become the expert of the topic, which shifts the power balance between the researcher and the children and empowers them in the situation (Rollins, 2005). Furthermore, their free choice of motifs ensures that the discussion is based on situations, issues and topics relevant for the child. When drawing, the children can focus on the task and can avoid eye contact with the researcher, which might otherwise be perceived as intimidating (Einarsdottir et al., 2009).

A 'draw-and-write' technique is commonly used among school-aged children. In this technique, the children are asked to do a drawing on a specific topic. Although influenced by that request, the children are then free to choose what, how and who they want to draw. Afterwards the children write about their drawings (Matsumori, 2005). The 'draw-and-tell' method is used when the children are too young to write. The method has the same purpose as the 'draw-and write' technique, as it gives young children the opportunity to share their perspective and meaning both verbally and non-verbally (Bradding &

Horstman, 1999). However, when listening to and being involved in the children's storytelling, adults need to consider their role in the discussion carefully, as their presence influences the children's drawings (Wright, 2007).

In study I, the children were asked to do a drawing of a healthcare situation they had been involved in. They could choose freely which situation (present or past) to draw and which aspect(s) of that situation they wanted to focus on. The drawing was discussed either while the child was making it or afterwards, depending on what the individual child preferred. Some children, though, made it clear that they did not wish to say anything about their drawing. Instead they completed the task in silence and handed in the drawing afterwards.

When using drawings in a research study, the focus is not on the child's drawing skills or the aesthetic quality of the drawing. Instead, the emphasis lies on the child's descriptions, interpretations and information about the drawing (Bagnoli, 2009; Driessnack & Furukawa, 2012). However, there are differences in children's ability to do drawings (Bradding & Horstman, 1999). From the age of four and onwards children start to draw motifs involving expressions of joy, happiness, sorrow and anger as well as of fantasy, dreams and expectations (Holmsen, 2007). The children participating in study I, aged 3-5, demonstrated various drawing skills and levels of abilities to focus on the task. The youngest children more often did colourful drawings but without any clear association to what they were asked to draw. However, most children performed the task according to the request, and their drawings revealed various perceptions of being in a healthcare situation. Afterwards, the children were offered a copy of their drawing(s). Two children replied positively and they were given a coloured photocopy to take home.

The data collected from the drawings were used in two ways. Firstly, the audio recorded discussions focusing on the motifs and meanings of the drawings were transcribed and used for analysis in study I. Secondly, the drawings themselves, focusing on the explicit motifs, colours, situations, persons present and their locations in the drawing, were used as guidance when carrying out the initial graphic design of the first prototype of the application.

## Study II

In study II, a participatory design was applied, using an iterative approach (see Table 2 and 3). The data collection was performed in the PS (phase I and II) and in the clinical settings (phase II and III). A new group of children was included in each test phase as to reduce bias and to obtain as many comments as possible (Markopoulos & Bekker, 2003). In phase I, the children tested and evaluated a paper prototype involving a 10-scene-storyboard. In the second phase, the first interactive prototype, involving a 12-scene-storyboard, was tested and evaluated. In the final phase, the children evaluated the second interactive prototype consisting of a 10-scene-storyboard.

In the PS setting, each test session involved one child and the researcher and took place in a separate room next door to where the other children and staff were. In the clinical settings, the prototypes were tested after the children had visited the doctor or the nurse; these sessions were conducted in a separate room. The data were collected from March 2014 to March 2015 (see Table 3).

### **Participatory design and usability testing**

During the latter part of the 20<sup>th</sup> century, large transformations were seen in workplaces. Computerized work related duties were subsequently implemented, a transition that, at least in the beginning, neglected the user perspective. As a reaction to this transformation process lacking user co-operation and user perspective, participatory design [PD], within a Scandinavian context, emerged as a research field (Bödker, Ehn, Sjögren, & Sundblad, 2000; Kensing & Blomberg, 1998). PD is characterized by the involvement of potential end-users of a certain product throughout the entire development process (Markopoulos et al., 2008). The PD approach was later adapted to research within the field of human-computer interaction [HCI]. HCI for children, i.e. child-computer interaction [CCI], was not established as a research field of its own, apart from scattered contributions, until the beginning of the 1990s (Khanum & Trivedi, 2012). Adults continued to evaluate child products, due to the lack of appropriate evaluation methods involving children. Furthermore, child involvement was viewed as too difficult and not necessary (Druin, 2002). Nowadays, child involvement in tests of products intended for children is recognised as central, due to the physical as well as cognitive differences between children and adults. Child involvement also ensures that the content and design truly mirror the users', i.e. the children's, perspective (Brandt, 2006; Bruckman, Bandlow, & Forte, 2002; Hanna, Ridsen, & Alexander, 1997; Markopoulos & Bekker, 2003). The user-friendliness and likeability of a product can only be controlled by the intended users (Zaman, 2006), both important factors to evaluate since they are closely linked to the enjoyment and the usability of the product (Hanna, Ridsen, Czerwinski, & Alexander, 1998).

Usability testing of a product involves an iterative process in which evolving prototypes of a product are tested, re-made and re-tested. Accordingly, the iterative process involves increasingly more advanced prototypes and continues until the final product is reached (Hanna et al., 1998). In an early stage of a usability test, paper prototypes can prove to be useful tools. Although lacking interactivity and animation, tests involving a paper prototype provide an opportunity to reveal major usability problems and loopholes. Without proper usability, a product will not be used in the intended way (Bruckman et al., 2002; Markopoulos & Bekker, 2003; Sim, MacFarlane, & Read, 2006).

In usability tests, child participants are assigned the different roles described in the Onion model by Druin (2002), see Fig 4. Each role influences the development of the product, but in different ways. From the centre to the outer layers of the model, the child's involvement in the design process subsequently increases. The *user* is the traditional child participant, who tests already existing technologies under observation. The *tester* uses evolving prototypes and gives feedback. *Informants* participate in several stages of the development process, where their input is believed to be central for the further development as well as the usability, likeability and graphic design of the product. A *design partner* participates as an equal partner from the planning stage throughout the whole development process (Druin, 2002).

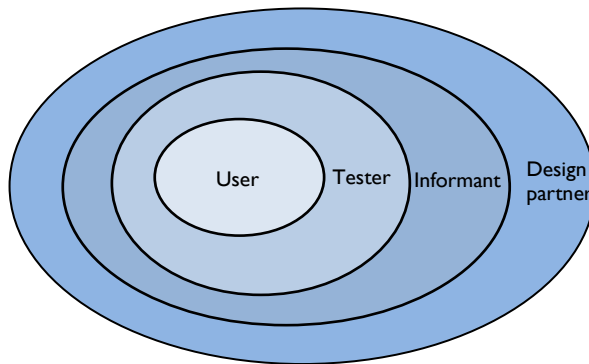


Figure 4. Adaptation of the Onion model (Druin, 2002).

In study II, children participated in all stages of the development process. Initially, the drawings of their perceptions of healthcare situations gave valuable input to the design of the first prototype. When testing and evaluating the prototypes, paper or interactive, the children participated as testers and informants. Due to their age, they could not be included as design partners. However, as a result of their essential contributions, leading to continuous improvements in usability, likeability, age-appropriateness and graphic design, the children were viewed as *co-designers* by the members of the research groups.

Multiple methods were used to collect data from the usability tests performed in this study. According to aspects listed in evaluation protocols, usability, user performance, likeability, age appropriateness and the graphic design were assessed (Markopoulos et al., 2008). The protocols enabled a structured data collection, as all children were asked the same questions and observed according to the same aspects. Audio recordings were used to collect the verbal responses from the children, and field notes were taken for each child and were added to the evaluation protocols. These notes had most importance in phase I, as no evaluation protocols were used because the test included the paper prototype. Structured observations of non-verbal expressions were performed in order to gain additional information. The observations were

carried out by the test facilitator (myself) and an observer (a supervisor). In some situations, the roles of the facilitator and the observer were combined.

In usability tests involving children, both the physical and social context matter (Trivedi & Khanum, 2012). The physical context involves the location where the test is conducted, i.e. in a laboratory setting or in the field (Hanna et al., 1998) as well as the product and technology to be tested (Hanna et al., 1997; Khanum & Trivedi, 2012; Zaman, 2006). The social context includes the people present in the physical context. In addition to the child participant, usability tests involve a facilitator who instructs and talks to the child and a note taker/observer. For the test to be successful, the child needs time to establish a relationship with these people (Khanum & Trivedi, 2012). The parent(s), although external to the test situation, is/are also included in the social context.

In the test sessions, the children were asked questions related to the aspects in the evaluation protocols, based on active intervention [AI] (Markopoulos et al., 2008; van Kesteren, Bekker, Vermeeren, & Lloyd, 2003). AI is a usability evaluation method that uses questions which the children are asked during their task performance. The children are prompted to answer, and verbal as well as non-verbal answers are accepted. The questions are listed in a pre-composed manual, with questions directed at the child's plans for the task performance, as well as their evaluation of the respective task. Due to the use of a paper prototype, the questions asked in phase I of study II were an adaption of an AI-approach.

## Studies III and IV

In the third study children in the clinical settings were observed using the application jointly with the professionals. The children in the PHCC setting used the application in connection with the scenes involving physical examinations (chest: heart and lungs). In the POU setting, the test situations focused on the virtual needle procedures. Video recordings were used to capture these situations. Prior to the start of the study, the professionals participated in workshops which focused on familiarisation with the final version of the application. Furthermore, the professionals tested ways of using the application in potential real-life situations. The fourth study was an evolvement of the third study and used the same data as in study III. The data was collected October 2015 to March 2016 (see Table 3).

### **Video observations**

In research involving children, video observations have advantages compared to audio recordings. Due to young children's limited verbal skills and preferences for using body language (Sommer, 2003), audio recordings give a false picture of children's communication, as their non-verbal expressions cannot be registered. Video observations capture social activities and interactions just



as they are (Flewitt, 2006; Heath, Hindmarsh, & Luff, 2010; Sparrman, 2005) and they allow the child's perspective to be presented (Harder et al., 2009).

Before conducting video recordings, the placement of the camera and microphone(s) needs to be considered carefully, as it decides what will, and can, be observed (Heikkilä & Sahlström, 2003) which implies a need of familiarisation with the research setting prior to the study start (Heath et al., 2010; Sparrman, 2005). Furthermore, consideration is needed about whether to use a single camera or multiple cameras. A single camera, put on a tripod, creates qualitatively good footages although the situations observed tend to be space bound. Furthermore, a single camera use allows the researcher to be an observer of the situation. The use of multiple cameras obtain more data, but this approach requires the researcher's active involvement in the situation, which might interfere with the situation and/or interaction. It might also add to the costs of the project due to the need for more equipment and, possibly, more people operating the different cameras (Heath et al., 2010).

In study III, the situations were to be observed with a single camera, placed on a tripod, focusing on the child and the professional. Prior to the start of the study, the best placement of the camera was discussed with professionals involved. As the room in each setting was rather small, the available options for how to place the camera were limited. As the professional, child and parent would be seated almost next to, instead of opposite, each other, the chosen viewpoint of the camera allowed all participants to be adequately observed. Although the rooms were small, the camera could be moved when needed to better capture footage of the joint use of the application between the child and the professional (see Fig. 5).



Figure 5. The joint use of IACTA by the child and the professional in a healthcare situation. (Photos published after informed consent by parents and professional).

The video observations began when the child and parent(s) entered the room. Children, as well as all other people, have a right to their integrity, and being filmed might risk violating that right (Lindgren & Sparrman, 2003). However, the video recordings used in study III focused on a specific situation known to the child, the parent(s) and the professional on forehand. Before entering the examination or treatment room, the child and parent(s) were once again informed about the presence of the camera and the researcher handling

the camera. The entire visit was recorded, since there was no pattern relating to how, and when the application was used in the situations.

## Analysis

In research involving children, adults mainly perform the interpretation of the data. Delicacy is necessary when trying to understand the meaning of the children's comments as well as their perspective. However, no interpretation process is ever totally neutral, which implies that an adult perspective is inevitable in interpretations of children's data (Dockett, Einarsdottir, & Perry, 2009). In the studies included in this thesis, the analysis of the data was conducted at a detailed level, an approach that was chosen in order to try to come as close as possible to capturing and understanding the meaning expressed by the children. Different data analysis methods have been used, and each method will be presented in reference to the study in which it was applied.

## Study I

Study I focused on children's varied perceptions of their involvement in a healthcare situation. Thus, a phenomenographic approach was chosen (Marton & Booth, 1997). Phenomenography was developed as a research tradition within the field of pedagogy; the pioneering work was performed by INOM-gruppen at Gothenburg University and this research tradition was initially named by Marton (Marton, 1981; Uljens, 1989). Subsequently, the method has spread into other research disciplines, such as nursing, involving research with both child and adult participants (Harder, Christensson, & Söderbäck, 2015; Johansson-Pajala, Gustafsson, Jorsäter Blomgren, & Fastbom, 2017; Kaminsky, Rosenqvist, & Holmström, 2009).

Phenomenography focuses on the qualitatively different ways a phenomenon is perceived. The *what* and *how* aspects, i.e. what aspects of a phenomenon that are perceived, as well as how they are perceived, are of interest. These aspects form a second-order perspective. That perspective differs from the first-order perspective, which instead focuses on what the phenomenon *is* (Marton & Booth, 1997; Trigwell, 2006). What a phenomenon and how it is perceived by an individual person is influenced by earlier experiences and perceptions, and depends on which aspects that are derived from the phenomenon. Perception of a phenomenon is influenced by external factors. The relation between the individual and the world is flexible, which means that experience or knowledge is not static but is constantly changing (Marton & Booth, 1997; Svensson, 1997).

Within a phenomenographic analysis, descriptive categories are formed. Similar qualitative ways of perceiving the phenomenon, or common themes of meaning, are grouped together (Marton & Booth, 1997; Svensson, 1997;

Trigwell, 2006). The number of descriptive categories is kept low to enable a critical variation to be presented (Trigwell, 2006). An outcome space reveals the result of the analysis and describes the internal relation between the descriptive categories. These are often formed hierarchically, indicating a subsequently more complex way of perceiving a phenomenon (Marton & Booth, 1997). However, the outcome space can also be displayed horizontally, indicating that no category is more complex, or superior, than the others (O’Gorman, 2007; Uljens, 1989).

The phenomenographic analysis of study I was inspired by the approach described by Dahlgren and Fallsberg (1991). Initially, all transcripts were read and re-read to get an overall understanding of the children’s narratives. In an inductive approach utterances demonstrating aspects of *what* children perceived when involved in a healthcare situation and *how* they perceived the same situation were identified. These utterances were decontextualized and put in a separate document for further analysis. In the next step of the analysis, a computerized system (NVivo, n.d.) was used to facilitate the coding process. The utterances were initially preliminary categorised according to similarities and differences. Through a process, involving the members of the research group, the preliminary categorisations were repeatedly discussed and changed. Eventually a first draft of mutually-exclusive descriptive categories was constructed. The discussions within the research team continued, which resulted in a second and subsequently third construction of the descriptive categories. The descriptive categories constituted a non-hierarchical outcome space including: *‘myself’ as actor, the parents as actors and the professionals as actors*. Although a hierarchical relation was missing, there was an internal relation between the categories. The children’s relationships with their parents were stronger and closer than their relationships with the professionals. The relationships between the parents and the professionals was perceived by the children as being on an equal level.

## Study II

In study II the children tested and evaluated evolving prototypes of the application and were assessed and observed according to evaluation protocols which enabled, in combination with the audio recordings and field notes taken, a systematic and continuous process of analysis of the data. After each iterative phase, all information was summarized. Aspects of usability and user performance were analysed from the children’s answers and the actions observed when they engaged with the different tasks from the storyboard. Engagement with and verbal or non-verbal expressions of approval or dislike were used to assess the likeability of the prototype. Age appropriateness was assessed by observing motor skills of the children as well as their understanding of how to carry out the tasks (Hanna et al., 1997).

Initially, in the pre-phase, data from the drawings made in study I were used to obtain knowledge of how to develop the graphic design in the first, i.e. the paper prototype. No picture analysis of the drawings was conducted (Holmsen, 2007). Instead, the drawings were used to obtain knowledge and ideas about how to create the graphic design, with reference to preferred colours, placement of the participating individuals and the level of detail present in each scene. In phase I, the paper prototype was tested and evaluated. Each scene was represented on a single piece of paper, and the children were shown one scene at the time. These tests focused on major aspects relating to age-appropriateness and graphic design, although the questions provided the children also touched upon aspects of usability and user performance. The children either answered the questions verbally or 'interacted' with the paper scenes, and in this way showed their user performance. In phase II, the first interactive prototype was used and tested. Its content, tasks and graphic design were the result of modifications made from the feedback provided by the children who had participated in phase I. The summary of the evaluations protocols in phase II indicated that the storyboard, i.e. the content, tasks and graphic design, reflected neither the child's perspective nor the understanding, demands and needs of children of this age, and there was a need for extensive changes to be made in the further development of the prototype. Due to these results, the prototype went through drastic but vital changes in respect to the graphic design as well as the tasks in the examination and treatment scenes. In phase III, however a new graphic design, the content of each scene was similar to earlier iterations due to the fact that the situations of interest, i.e. examinations and procedures, had not been altered. The summary of the evaluation protocols after phase III showed only minor usability problems which were modified in the final version of the prototype, also called IACTA (interactive communication tool for activities).

The intention is that IACTA should be used in healthcare situations in real life, and will be there to provide visual guidance about examinations and procedures to the children. The joint interaction (child + professional) with the application facilitates a mutual understanding of the situation, which can direct the professionals to use verbal guidance in an appropriate and individualised way. The guidance provided by the professionals, combined with the opportunity for the child to try out the situations in a hands-on manner, means that educational content is woven into the interaction with the application (Berkman, Davis, & McCormack, 2010; Borzekowski, 2009; Lave & Wenger, 1991).

Prior to the start of the study, the research group presented the company that initially programmed and designed the software a framework regarding the content and design. A discussion followed and based on that, the paper prototype was developed. Between each iterative test phase, I, partly together with the research team, worked closely with the companies involved. In these discussions, we used our respective areas of knowledge and I/we was/were

presented suggestions on how to develop and design the software further. The way we worked changed according to the development process and the demands of each situation. In some situations, a ‘side-by-side’ approach was convenient in order to enable an easy and efficient discussion based on the hands-on development of the prototype. In other situations, Skype, e-mail or phone were used for contact. This close co-operation throughout the development process was a necessity, firstly as I lack knowledge of how to develop and design interactive and animated software, and secondly, to ensure that the child’s perspective remained the guiding principle. During these iterative phases, T Larsson, the supervisor in the research team who possesses a high level of knowledge regarding HCI, was another important source of knowledge and support.

### Study III

In the third study, the video recordings were analysed hermeneutically. A person acts intentionally, implying that there is a specific meaning behind actions and expressions, a meaning that is mirrored by how that person perceives and understands the situation. Given this, actions and expressions should be interpreted within the situation in which they are performed. A hermeneutic analysis deals with the interpretation of meanings (Sjöström, 1994; Ödman, 2007).

A hermeneutic study is metaphorically compared to a puzzle where each part is as important as the whole picture. In the interpretations, there is an ongoing movement in which meanings of the parts are tested against the whole, and the parts, if agreed to subsequently construct an understanding of the whole (Ödman, 2004). The ongoing movement between parts and whole and their interdependence is described as the hermeneutic circle, or spiral which represents a more dynamic metaphor. The spiral indicates the ongoing change and expansion of the hermeneutic process (Ödman, 2007). According to Radnitsky in Ödman (2007, p. 105), the spiral is viewed as ‘the fruitful, open circle’.

Some situations do not require interpretations. Instead, there is an intersubjective understanding of the phenomenon, i.e. a well-known interpretation. Without intersubjectivity, interpretations are needed to reach a common understanding, but interpretations are made from a subjective standpoint, which implies that a phenomenon could be understood in other ways (Ödman, 2007). Situations with possibly competing interpretations place focus on the preunderstanding of the interpreter. A person’s preunderstanding is developed from his/her earlier experience and understanding of similar situations. The preunderstanding influences how the person understands something *as* something (Ödman, 2007). My preunderstanding of the situations focused on in this study is based on my work experience as a children’s nurse in an emergency department for children and within the primary child healthcare. As a nurse, I have

met children in all ages, although the vast majority have been of preschool age. Since the other members of the research team contributed to the interpretation process, their preunderstanding was of interest as well. M Söderbäck and I Coyne are children's nurses with experience of clinical paediatric nursing, as well as being experienced researchers within the field of child healthcare. A Sandberg is an experienced preschool teacher, and has long researched the field of early childhood education. T Larsson is an experienced researcher within computer science. Although he possesses no work experience with young children, he is the father of three children.

The hermeneutic analysis of the third study was conducted systematically (Ödman, 2007). To get an overall understanding of the data, the video recordings were watched and re-watched in detail. When an understanding of the whole was gained, the focus turned to the episodes that met to the aim of the study. This initial familiarisation with the data enabled an awareness of details in the child-IACTA-professional interaction and made up a central part of the analytic process (Heath et al., 2010). The selected parts of each recording were transcribed into text, with each transcript made on a detailed level, and as a result of this, verbal communication and non-verbal expressions were noticed following the development of the situation. The detailed level of descriptions was chosen in order to minimize the risk of interpretations being made while transcribing. However, it is impossible to totally avoid interpretations while transcribing the course of events. Deriving from the aim of the study, participation cues were identified in each transcript and decontextualized for analytical purpose. A cue was understood as a 'thing said or done that serves as a signal to an actor or other performer to enter or to begin their speech or performance' (Oxford Dictionaries, 2016b) or as a verbal or non-verbal hint (Zimmermann et al., 2011). Similarities and differences among the cues were identified. Groups of cues were created and described in an abstract way, related to how the cues were understood. The movement between the parts (interpretations of the cues) and the whole (the transcripts) formed the hermeneutic interpretation and was conducted repeatedly. Within this process, individual and situational aspects influenced how the cues, although similar, were understood, i.e. which meaning they presented. The analysis revealed that the cues represented three meanings of participation: *curious*, *thoughtful* and *affirmative*.

## Study IV

The fourth study used a secondary analysis approach (Carter & Lubinsky, 2016). The participation cues identified in a previous study (study III), were re-analysed to identify potential patterns in the children's use of these cues. Altogether, 53 cues were identified and understood as representing either a curious (17 cues), thoughtful (25 cues) or affirmative (11 cues) meaning of participation. Due to the large number of cues and to enable a more adequate

focus on patterns, the *total* cue use on each meaning of participation was summarized per age, setting and examination or procedure and used for analysis.

Before the analysis started, an adaptation of the summarised number of cue use was conducted in order to remove differences related to group sizes. The adaptation of the cue use provided two results, the average cue use and a number for comparison.

The average cue use, calculated by dividing the cue use for each age group with the number of situations in which the cues were expressed, provided an overview of which age group(s) that used the cues to a high or low degree and which cues were used more or less by the children in the different situations.

The number of comparison was the result of dividing the average cue use of two groups, with the result shown as a percentage. The higher or lower the percentage, the stronger or weaker was the tendency shown by a certain age group towards using those specific cues more or less than the group they were compared to. A number of comparison equaling, or approaching 100 (%) indicated an even, or similar, cue use between the groups compared. Accordingly, although not showing statistical significance, the average cue use and the number for comparison showed similarities as well as differences in the children's cue use in relation to age, setting and examination or procedure.

# Results

In this section, the results are presented in two parts. Initially, all studies involved in the thesis are briefly presented. A more comprehensive description of the study results can be found in the respective articles. After this, a synthesis of the results is presented.

## Summary of the study results

### Younger children's (three to five years) perceptions of being in a health-care situation (study I)

In the text below, the results are presented as descriptive categories (in bold) and as sub-categories (in italics).

**Myself as actor** involved the individual child's, i.e. 'myself', perceptions of being the *main* and/or *the co-actor* in a healthcare situation. As the main actor, the children preferred to be actively involved in the situations, receiving and providing information, and to make decisions based on their own preferences relating to the specific situation. As the co-actor, while still actively involved in the situation, the children preferred to interact with someone else; a parent or a cuddly toy. The children also perceived various *feelings in the situations*: negative feelings were emphasized, although positive feelings were also described. **Parents as actors** were perceived as acting practically, such as *being present* and emotionally, such as *being close*. **Professionals as actors** were perceived as directing different actions towards 'myself', for instance in examinations and treatments. The professionals were also perceived as being of different types, with these descriptions focusing on negative perceptions, although positive descriptions were also revealed.

In conclusion, an understanding of how young children perceived their involvement in healthcare situations provides professionals with knowledge that can both support and challenge their interaction with children. When children participate actively in these situations and are enabled to provide their own perspective, a child's rights perspective is involved. The results were used in study II.



The child's perspective as a guiding principle: Young children as co-designers in the design of an interactive application meant to facilitate participation in healthcare situations (study II)

In an iterative process, involving three phases, children tested and evaluated evolving prototypes of the application. The children's active involvement in the developing process, contributing from their perspectives, resulted in aspects of age-appropriateness, usability and likeability of the content and the graphic design being repeatedly processed until the final version of the application, IACTA, was reached.

Conclusively, in a participatory design, potential end-users contribute with valuable feedback throughout the entire development process. In this study, the active involvement of children as co-designers enabled their perspective to be visualized and heard. Given that the child's perspective reflects better than an adult's child perspective which aspects of the content and graphic design require improvement, the participation of children was of importance for the quality of the end-product.

Curious, Thoughtful and Affirmative – Young Children's Meanings of Participation in Healthcare Situations when using an Interactive Communication Tool (study III)

In their joint use of IACTA with professionals in healthcare situations in real life, the children demonstrated cues which were understood as having different meanings related to their participation in the encounter. Below, each meaning is presented in bold text.

Cues of **curious meaning of participation** were demonstrated in a series of situations, such as when IACTA was introduced/re-introduced in the situations, the scenes changed or when something unexpected, but fun, happened on the screen. **Thoughtful meaning of participation** was demonstrated by cues which slowed down the progression of the situation. Cues understood as thoughtful were also demonstrated in situations when the children needed support or guidance, either from the professional or a parent. Cues of **affirmative meaning of participation** were demonstrated during or after a task performance, especially when the children felt satisfied with the outcome. These cues were also shown when the children had understood how to perform a procedure.

In this study, an innovative area of health technology was illustrated. By the use of an interactive communication tool in healthcare situations, and by their understanding of these situations, the children demonstrated cues which were understood as representing a curious, thoughtful or affirmative meaning. Depending which cues were used, the situations either could proceed according to plan or be delayed due to the children's demonstrated need for time, support and guidance. The children's use of IACTA provided professionals

with additional ways of being attentive and sensitive to the children's expressions.

### Patterns of young children's use of cues when using an interactive communication tool in healthcare situations (study IV)

The children expressed, altogether, 53 cues understood as having either a curious (17 cues), thoughtful (25 cues) or affirmative meaning (11) of participation. These cues were, in total, expressed 2167 times in 21 video recorded situations. Curious cues were used to the highest extent, representing almost 2/3 (66 %) of all cues that were expressed. Cues of thoughtful and affirmative meaning were used in a more restricted way, 28 % and 6 % respectively. The youngest children appeared to use a higher number of cues. A similar tendency was shown among the children in the PHCC setting, who generally demonstrated a higher cue use, regardless of age, than the children in the POU setting.

The results of this study showed that IACTA seemed to be used in the most intense way by the children who had the least experience of being in healthcare situations. The children's eagerness and positive attitude in their interaction with IACTA pointed to the potential of using interactive elements as tools in healthcare situations, both for a present and future perspective. Although the positive results of the innovative use of the application in these situations, the children demonstrated a willingness, and a desire, for a human-human-interaction.

## Synthesis of the result

The synthesised interpretation of the results showed a situated participation deriving from a process of *learning from* as well as *developing and testing together with* children. Additional, aspects of an *inter-inter-action*, and a *guidance* from the professionals' perspective both influenced and contributed to the understanding of a situated participation (see Fig. 6).

### Situated participation

Throughout the studies, the child's perspective has been involved and contributed valuable and varied knowledge.

Initially, the child's perspective was used when *learning from* the children how they perceived their involvement in healthcare situations (study I). Information was gained about all the actors present in the situations: including the children, the parents and the professionals, all of whom acted differently, but intentionally, depending on the person and situation. Furthermore, knowledge from the child's perspective provided an understanding of how the children

perceived the placement of people and things present in the situation, as well as of preferred colours and levels of detail.

The knowledge gained from the children’s perceptions of their involvement in healthcare situations was adapted and used as follows: In an iterative *development* process, children were actively involved in all phases of evaluation of the evolving prototypes of the application (study II) which enabled the child’s perspective to be visualized in a series of situations. As a result of this, each scene was repeatedly reworked in order to arrive at the final version, which was age-appropriate, usable and likeable.

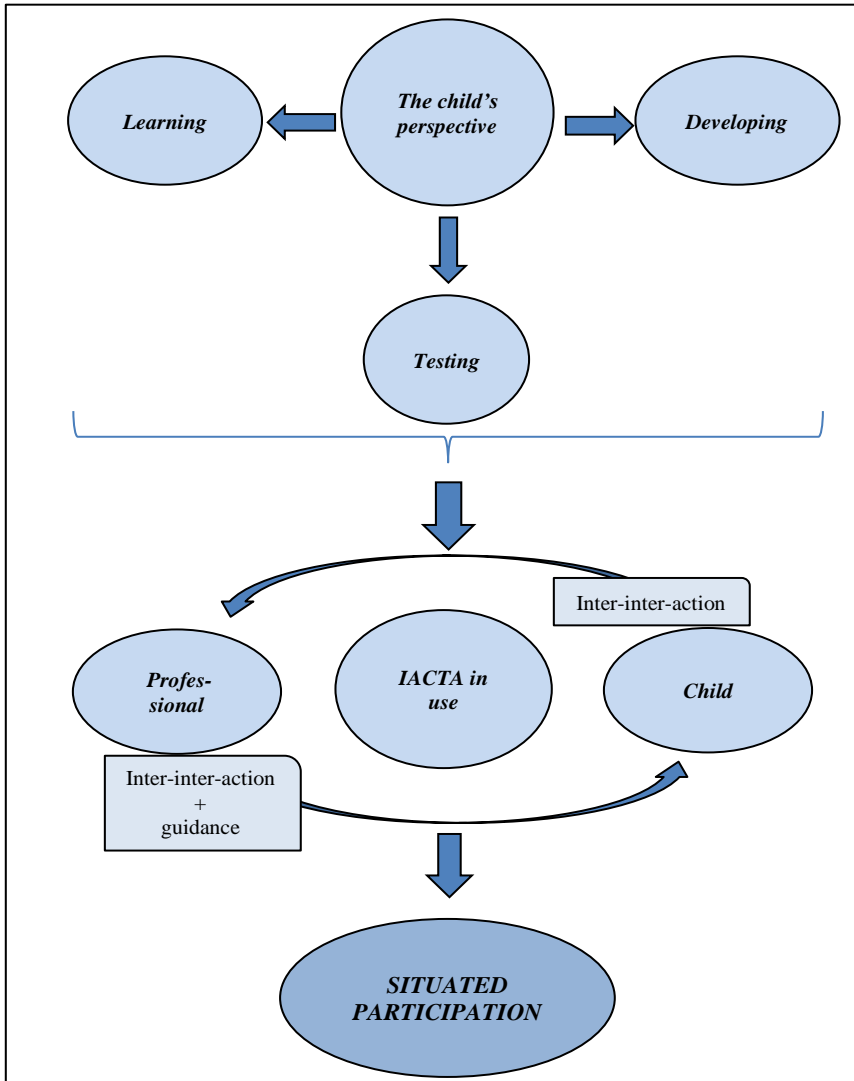


Figure 6. The synthesised understanding of the result.

When IACTA was *tested* in healthcare situations in real life, the child's perspective directed the understanding of the meaning of their interaction with the application (study III). The way the children interacted with IACTA improved the understanding of the ways in which their interaction was influenced by aspects such as age and setting, or by which examinations or procedures they were about to undergo (study IV).

Using the knowledge and understanding gained in studies I and II, but focusing on the results in studies III and IV, the synthesis showed a situated participation. The *inter-inter-action* shown by the children as well as the professionals in regard to the application was a prerequisite for the understanding of the situated participation. However, the inter-inter-action was reciprocal, meaning that the professionals demonstrated an interaction with the child and the application as well. Accordingly, the professionals' inter-inter-action was of importance, and influenced the way the children expressed their situated participation. Additionally, the children's situated participation was influenced by the *guidance* provided by the professionals.

# Discussion

## Is it possible to capture the child's perspective?

The child's perspective has been sought and used as the guiding principle in this thesis, and has been understood as the individual child's perceptions, experiences and understanding of a situation, a perspective influenced by aspects such as age and earlier experiences (Sommer et al., 2010). Accordingly, the child's perspective is a subjective perspective. Given this, is it possible to truly capture the child's perspective and if so, has this been achieved in this thesis?

A prerequisite for trying to capture the child's perspective is children's active involvement as actors in their own right in situations of interest (Alanen, 1988; James et al., 1998). Furthermore, there have to be opportunities for the children to express their thoughts, and for these to be listened to and taken into account. When expressing oneself, language is of importance. Children, especially young children, have varying communication and language skills and young children prefer to add a large number of non-verbal expressions, such as body language, gazes and facial expressions, in their communication (Bjar & Liberg, 2010; Iversen & Goldin-Meadow, 2005). Given this, when asking children to tell a story on a certain matter, methods are required which allow also the non-verbal expressions to be noticed and heard. In research with young children, as a way of allowing them to use their bodies and varied competences when expressing themselves, participatory methods are used, either alone or combined with traditional methods such as interviews (White et al., 2010). In this thesis, different methods, traditional as well as participatory, were included in order to invite the children to express their perspectives in ways and forms they found most beneficial.

Drawings, as a well-known and appreciated activity among children (Driessnack & Furukawa, 2012; Knighting et al., 2010; White et al., 2010; Wright, 2007), led the children to engage actively with the task, and elicited their perspectives in various ways, either focusing on an overall description or on a detailed level of the situation of interest. While drawing, most children seemed to open up towards the task as well as the researcher in other ways than they did when being interviewed. This was most evident among the children in the clinical settings, who were mostly rather unresponsive in the interview sessions. The vignette use, although relying on verbal communication, also seemed to make the story-telling easier for them. Some children chose to adapt their stories about the child figure (a mouse) in the vignette to the short

story they were told as an introduction. Other children preferred to construct a totally new story. Regardless of which was used, self-experienced situations were more or less explicitly added to their narratives, which enabled their own perspectives on these situations to be elicited.

As to involve a variety of perspectives early in the participatory design process, children from three settings were included (Marton & Booth, 1997), and due to their varied experiences, they focused on different aspects in the scenes (Bronfenbrenner, 1979). In the final phases, the perspectives of the potential end-users were specifically sought, and the tests included only children in the clinical settings (Brandt, 2006; Bruckman et al., 2002; Hanna et al., 1997; Markopoulos & Bekker, 2003). In these test situations, questions were used which attempted to elicit the children's thoughts and opinions on issues such as content, tasks and graphic design. However, most children preferred, for different reasons, to interact with the prototypes without answering any questions. In these situations, the placement of the researcher next to the children allowed their actions and interactions with IACTA to be followed closely. Additionally, observational protocols, listing issues of importance for understanding aspects of age-appropriateness, usability and likeability, enabled the child's perspective to be visualised despite limited verbal comments. Observations, although not a participatory method from the child's perspective, are required when trying to capture the child's perspective, given that children, specifically young children, use non-verbal communication to a great extent.

When trying to interpret expressions representing the child's perspective, be they narratives or observations, there is a risk that the child's perspective vanishes and that the adult's child perspective becomes too powerful and misleads the analysis (Söderbäck et al., 2011). The difference between the child's perspective and a child perspective became evident in the iterative design process. Although focusing closely on non-verbal as well as verbal perceptions, actions and remarks made by the children, the re-designed prototypes did not fully meet the child's perspective when re-tested and re-evaluated by a new group of children. Given this, it was clear that the adult interpretation sometimes failed to reveal the true aspects of the child's perspective. Leaving out the active involvement of children during this process, or involving them as users (Druin, 2002), could have risked that these aspects were overlooked. Such a scenario could mean that the final version of the application would fail to meet the requirements of children in the target age, in respect of usability and likeability. To further strive to capture and use the child's perspective, analyses of all studies were conducted and described at a detailed level. This enabled a closeness to the actual expressions, verbal as well as non-verbal, made by the children, which reduced the risk of applying a child perspective instead of allowing the child's perspective to be visible.

This reasoning draws us back to the questions posted in the beginning of the section, i.e. is it possible to truly capture the child's perspective, and if so, has it been achieved in this thesis? Given the subjective character of the child's

perspective, the short answer to the questions would be ‘No’. However, methods that in appropriate, favourable and age-appropriate ways enable children to express themselves verbally or non-verbally as well as to use their utterances in a detailed way, have been used in an attempt to come as close to the child’s perspective as possible.

## Situated participation

In their interaction with IACTA, the children, depending on individual and situational aspects, demonstrated varied participation cues. These cues were understood as representing different meanings for the children, depending on the situation in which they were used and the way in which they were expressed. The progression of the situation was influenced by the way the child interacted with IACTA. Furthermore, the cues the children demonstrated directed the professionals’ understanding of how to provide appropriate guidance. The use of a thoughtful cue, often interrupting the continuance of the situation, required one method of guidance. In situations where curious or affirmative cues were expressed, the guidance needed was provided in other guises. Guided participation is a creative and supportive way of providing a situated knowledge and skills (Rogoff, 1990). The children’s interaction with IACTA indicated that the application has the potential to provide a situated understanding and skills (Lave & Wenger, 1991; Lieberman, 2006; Wouters, van Nimwegen, van Oostendorp, & van der Spek, 2013) since a mutual understanding between the child and a more skilled person, in these situations a health professional, is a prerequisite for appropriate guidance (Rogoff, 1990).

Hart (1992) and Shier (2001) describe different levels of child participation, using metaphors (a ladder and a pathway). Although both metaphors can be seen as favouring the highest levels, describing shared decision-making between children and adults, neither Hart nor Shier meant that these levels should be the ultimate goal to strive towards. Instead, their intention was to place focus on the fact that child participation can occur in different ways according to what is most appropriate in the situation. Accordingly, participation to a lesser degree is not a failure, but rather an adaptation to both individual and situational requirements (Thomas, 2007). However, according to Hart and Shier, a change of level of participation requires active contributions from adults. The use of IACTA in a healthcare situation could enable the children themselves to influence their level of participation, according to their situated preferences, and by this reduce their dependence on adults’ actions.

When using IACTA in healthcare situations in real-life, the children demonstrated a large number of cues in relation to the situations in which they were expressed. A majority of the cues were understood as showing a curious meaning, which could be linked to the extensive interest among young children in the use of interactive technology (Holloway et al., 2013; Radesky et

al., 2015; Swedish Media Council, 2015). If so, IACTA would provide yet another opportunity for the children to use the technology. However, another explanation could be related to children's desire to be actively involved in healthcare situations and to obtain information related to them (Coyne & Kirwan, 2012; Davies & Randall, 2015; Gibson et al., 2010; Schalkers et al., 2015). When the children were aware that IACTA provided information on examinations and procedures in an appealing way, their extensive use of curious cues could be understood as a response to their interest in and eagerness to acquire information and an improved understanding.

The cue use demonstrated by the children showed both similarities and differences. The main differences were related to age and setting. The youngest children, i.e. the three-year-olds, showed the highest cue use (overall). A majority of their expressed cues were non-verbal, which could be one reason why they engaged so extensively with the application. IACTA, as a communication tool, also facilitates non-verbal communication. Owing to its visual content, important information cannot only be gained by interacting with the application, but also produced, from the child's perspective. Yet another explanation for the extensive cue use among the three-year-olds could relate to an ecological perspective. Due to their age, the youngest children, theoretically, have had fewer opportunities than the older children to engage in healthcare situations. The higher cue use in the PHCC setting compared to the POU setting could be explained similarly. These children had limited or no experience of healthcare situations, whereas the opposite was the case for the children in the POU setting. The children's previous experience or lack of it meant that they entered the health visits with diverse prerequisites (Bronfenbrenner & Morris, 2006). According to Bronfenbrenner (1979), children's increased knowledge is gained through participation in relationships with others, starting with immediate family relationships. Subsequently, the number and complexity of the relationships increases. Depending on with whom and in which relations the children participate, the knowledge and competences they gain follow different trajectories. This implies that children develop differently depending on which situations and relationships they have been and are still part of (a.a.). Lack of or limited experience and knowledge could therefore be a motivating factor for the children in the PHCC setting to interact with IACTA. Likewise, as most children in the POU setting had already gained a more adequate situated knowledge by being involved in healthcare situations for an extended period of time, their more limited use could be explained by their having lower motivation to engage with the situations presented on the screen.



## A child's rights perspective on the IACTA use

Various questions have been raised concerning the necessity for addressing child participation, and the reasons have been summarised as either emancipatory or democracy strengthening (Thomas, 2007). What purpose lies behind the interest in facilitating child participation in healthcare situations? Children themselves describe their participation in these situations, although in different ways, as important for both their present and future situations. They view their participation as something which should be self-evident, as the situation is about them. However, child participation in healthcare situations, especially those involving young children, depends on adults' actions (Coyne et al., 2016). This thesis raises the questions of the child's rights perspective in such situations.

IACTA was intended to facilitate young children's participation in healthcare situations and the application could be understood as *one* attempt to implement a child's rights perspective in such a situation. Child participation is a human right for children, according to the UNCRC (United Nations, 1989), but despite an obligation for adults to implement this right, the way in which this is done may not always be adequate if viewed from the child's perspective. Lundy (2007) argues that the implementation of Article 12 of the UNCRC, dealing with the child's right to participation, focuses too much, or exclusively, on actions which allow the child's voice to be heard. According to Lundy (a.a.), *voice* alone is not enough, with *space*, *audience* and *influence* being equally important prerequisites. Lundy's model is an interesting one for adaption to the use of IACTA. The application is to be used as a communication tool, which implies that it could provide the children with a voice; either verbal or non-verbal. Space could, in regard to the use of IACTA, be understood in two ways: firstly, IACTA provides a virtual environment where the children can watch examinations and procedure and try them out in a way that suits them best. Secondly, space could be understood as time, meaning that the children are enabled, when interacting with IACTA, to indicate in which situations they need less or more time to adapt to what is happening. Aspects of audience and influence are associated with to what extent the children's voices are given due weight. If no one listens to them, their voices will remain unheard and their efforts to put into practice their right to participation risk to be of no avail. The joint use of IACTA strengthens the children's position in the situation because their interactions are noticed and can be reacted to and acted upon. There is a distinction between activities controlled by children and activities initiated by children. Each healthcare situation has its specific purpose, and because of this, there is a pre-decided agenda that the professionals need to follow and which the children cannot change. However, when interacting with IACTA and the professional, the children are facilitated to influence the situations, and in this way initiate certain activities which are advantageous from their perspective. In other words, the influence of the use of

IACTA is not intended to focus on *what* is to be done, but rather on *how* it is done.

From a Swedish perspective, the Patient Act (SFS 2014:821) was intended to strengthen the rights of the patient. Children, as patients, are mentioned specifically in it, which was not the case in the Health Act (SFS 1982:76). However, despite promising expectations, an evaluation of the early implementation of the act shows discouraging results (Vårdanalys, 2017). Nevertheless, regardless of these negative results, an obligation remains for adults to act upon ensuring children's rights in healthcare situations. The use of IACTA in healthcare situations will not tackle all problems caused by health professionals not complying with the Patient Act regarding child information and participation, but it is *one* way of facilitating young children's participation as well as *one* way for professionals to capture and act upon the child's perspective.

## Concluding remarks

A majority of research studies describing development or implementation of interactive technology in paediatric healthcare contexts present a positive attitude towards the technology use. So does the IACTA-project. The technology possesses important attributes, such as being easy to learn and to handle, and enabling elements of education, information and preparation to be provided in ways that are appealing for children (Fernandes et al., 2015; Michael Cohen Group LLC, 2011; Tseng et al., 2011; Williams & Greene, 2015). However, there are always two sides of the coin. Interactive technology used in paediatric healthcare contexts may not be suitable for all children, although a majority seem to engage gladly and well with the technology. For the children who are not used to the technology, or who find the proposed interactive 'games' boring, this approach might be confusing, unhelpful or even frustrating (Michael Cohen Group LLC, 2011). Høiseth et al. (2013) emphasize that human interaction is always of importance, and that both children and their parents ask for and need human contact when being involved in healthcare situations. When testing IACTA in healthcare situations in real life the children, although interested in the application, nevertheless demonstrated in various ways, verbal or non-verbal, that they wanted and needed a human-human interaction. Eye contact, for instance, seemed to be of importance for them, and was understood as having either a curious, thoughtful or affirmative meaning. Regardless of cause, the children sought eye contact with the professional for aspects like confirmation, guidance and approval. Accordingly, when implementing child participation in healthcare situations, with or without virtuality, the child's perspective in all guises is required to be sought, heard and acted upon.

# Methodological strengths and limitations

## Complexity of co-production

This project represents a co-production between Mälardalen University, the healthcare sector, a preschool and the business sector. The university views co-production as a prioritised area of interest and co-production is found to be of mutual use for all partners involved (Mälardalen University, n.d.), but however useful, it also involves complexities, partly deriving from the partners having different agendas. In co-production, a common point of departure in relation to central issues of the project is a requirement. In this project, which clearly emphasises the importance of including and acting upon the child's perspective, there have been some disagreements between the partners, despite repeated discussions on the matter, over how to put this perspective into practice. From the business sector, an adult-centeredness was partly preferred over the main focus on the project, i.e. the contributions from the children.

Although the partners in the healthcare sector were devoted to the project, the co-operation presented obstacles. In Sweden, the healthcare sector is in a strained situation due to shortage of staff, a growing and ageing population and high costs (Swedish Association of Local Authorities and Regions, n.d.; The National Board of Health and Welfare, n.d.). In the studies included in this thesis, nurses in each setting were engaged as gatekeepers, and due to their strained work situation, the recruiting of children was a less-prioritized task, which was one reason to the extended data collection periods.

The PS setting, although also an arena battling against a strained work situation and large groups of children, the situations ran more smoothly (Swedish Association of Local Authorities and Regions, n.d.). The staff at the PS provided study information to the parents, collected consent forms and organised suitable spaces for the data collection sessions. The availability of the same group of children was another advantage to being in the preschool setting, and because it was easy to meet the same children at each visit prior to the start of the study, a kind of familiarity was established between the children and the researcher which proved beneficial.

Apart from the co-production with external partners, the project also included an internal co-production. The constellation of supervisors included representatives from three schools of the university and involved expertise in children's nursing, early childhood education and human-computer interaction. The various forms of knowledge and preunderstandings were an asset, and directed as well as challenged the discussions.

## Sample and settings

Children aged 3-5 were involved in the four studies. This specific age range was chosen because there is a deficit of studies on preschool-aged children's own perspective on issues associated with the healthcare context. Instead, the vast majority of studies focusing on children's perspective and perceptions in this context involve school aged children and youths (Coyne, 2006; Lambert, Glacken, & McCarron, 2010; Runeson, Mårtenson, & Enskär, 2007). When research studies focus on young children in healthcare situations, their perspective is instead described by observations or through interviews with adults, i.e. parents or professionals (Hallström & Elander, 2004; Harder et al., 2011; Harder et al., 2009, 2013; Meltzer et al., 2008; Söderbäck, 2012), although exceptions are found, for instance in research conducted by Salmela and partners (2010; 2009; 2010) and Korttesluoma and Nikkonen (2006).

In a quantitative study, the power calculation is decisive regarding the sample size. In qualitative research, saturation of data is often mistakenly referred to when discussing the sample size of a study (Malterud, Siersma, & Guassora, 2016), and instead of saturation, Malterud et al. (2016) propose that the information power of a sample should guide how many participants to include. The information power consists of five items: study aim, sample specificity, use of established theory, the quality of dialogue and analysis strategy. According to a model, each item is presented on a continuum along which the researcher can position the study in order to guide the assessment of a preliminary sample size. In study I, the information power of the sample was low which explained the large number of participants ( $n = 43$ ). In study III, the information power within the sample was higher which explained the lower number of participants ( $n = 20$ ). The lower and higher levels of information power in the studies was determined by the same items: the aim, the specificity of the children, the quality of dialogue and analysis strategy. In study I, the aim was broad and the analysis was planned to cover a variation of the studied phenomenon. The specificity of knowledge and experience of the children varied. The children's varied verbal skills and to a certain extent their unfamiliarity with the situation affected the communication. The researcher was a novice in such situations. Due to these factors, the quality of the dialogue was low. In study III, the aim was narrower and an in-depth analysis was planned. The specificity of the children was higher, although it still varied. The dialogue was represented of the communication of the children and the professionals. Due to this, most children engaged in the situation to a high degree, verbally and/or non-verbally, and the quality of the dialogue was considered satisfactory. The use of established theory was the same in both studies and had the same impact on the information power.

Study II differed from studies I and III in its approach. Because of this, the information power was not used as the determinant of the sample size. Instead, the large sample ( $n = 53$ ) was partly due to the iterative approach involving a

new group of children in each phase. However, there was a difference in group sizes, where the number of children participating in the second phase stands out. In the first phase, children in a preschool participated, and given the recruiting problems in this phase, children from more units were invited to participate in phase II. A larger number of children than expected consented to participate and they were all invited to do so, although not all of them were required for the study. A high number of test situations is time-consuming. However, the children were easily accessible, given that they all went to the same preschool. No time was lost on travel and the PS setting was optimal for the test sessions as well. In phase II, children from the clinical settings also were involved which added the number of participants. For testing the very first version of the interactive prototype, a larger group of children was considered appropriate in order to obtain as many comments as possible, as they provided important and valuable knowledge for the forthcoming development process. However, in usability testing, such a large group of participants is rarely seen (Markopoulos et al., 2008).

Three settings consisting of two clinical settings and a preschool have been involved. Given the overall aim of the thesis, the inclusion of the clinical settings was understandable. The children in these settings could contribute their perspective on the situation they had just been involved in, based on that experience or on a more extensive period of experiences. The PS setting was included in order to involve children representing as broad a range of perceptions and perspectives of healthcare situations as possible (Marton & Booth, 1997), and this setting was useful as the group of children was constant, which enabled all repeated visits to focus on the same group of children. The preschool setting also represents more routine bound activities than is possible in the clinical settings which facilitated the planning of the visits.

## Participatory methods used

The younger the children, the greater were the challenges to find suitable research methods (White et al., 2010). Children differ from adults, and traditional research methods might be less applicable to young children (Bagnoli, 2009). Participatory research methods allow children to use competences and skills other than verbal language (Dockett et al., 2011). Within this thesis, a variety of participatory methods was used and they worked well, regardless of setting. The children could engage with most methods either non-verbally or verbally.

Drawings was a popular method and an activity that both the talkative and taciturn children engaged with. Their way of carrying out the task differed with some children preferring to express an overall perspective of the situation, while others chose to include more detail. As they could choose freely which aspects they wanted to draw, a variety of drawings arose. Although the

drawing task was perceived as positive, it was also a time-consuming act, as it was hard to interrupt when the children had started to do their drawing.

The vignette use demanded more from the children regarding language skills, as well as their willingness to tell stories. However, the vignettes seemed to appeal to the children, and they told stories freely or answered questions in a different, less embarrassed, way than they did in the interview sessions. Regarding the interviews, a difference was apparent between the children in the PS setting compared to the children in the clinical settings when it came to willingness to tell stories and the content of those that were told. The children in the PS setting were more relaxed when telling their stories and they elaborated more easily on their answers. Some reasons for this difference were believed to derive from the fact that the children in the PS setting were encountered in a well-known and safe environment, and that they had had the chance to be familiar with the researcher before the interview sessions started. However, individual differences were noted. To enable the interview situation in the clinical setting, the researcher was present as an observer in the doctor/nurse encounters. This approach enabled the asking of relevant and situated questions afterwards if needed, which gained some positive results, although the interview situation remained somewhat problematic.

The influence of myself as a researcher/interviewer also has to be discussed. As a children's nurse, I have met and spoken to many children within the target age of this thesis, speaking to them in my role as a nurse, which was a well-known situation for me. When the project started, I had no experience of asking questions in the role of a researcher, which influenced the situation and the quality of the conversation as I was not, at least not in the beginning, comfortable with the situation.

The iterative design process gave valuable information. The inclusion of children in different phases gave important feedback and knowledge, both to be used when developing the prototype further and to better understand from the child's perspective which aspects were usable and likeable and which were not. Most children engaged well with the prototype and the tasks. Some children preferred to use the application as a game instead of a tool and in these situations, they went through the storyboard too quickly, so that there was not enough time to adequately observe their interaction with the tasks or to ask questions related to each task or scene. The first interactive version lacked a rewind-arrow, which made it impossible to go backwards, and therefore in some test situations, parts of the storyboard therefore had to be tested twice. Despite a bit annoyance, the children did not seem to be bothered, and it did not seem to affect their willingness to interact with the application.

Video recordings enable observations of what happens in a situation. The result of the recordings is influenced depending on the placement of the camera and the number of cameras used (Heath et al., 2010; Heikkilä & Sahlström, 2003). In study III, a single camera put on a tripod was used which reduced the possibility of moving around easily and following the development of the

situation. However, the placement of the camera was discussed with professionals prior to the start of the study. Because most situations were rather space-bound, an angle was chosen which captured most of the situations. When needed, the camera could be moved, although such an approach risked drawing too much attention away from the situations of interest.

When introducing a camera to a situation, children react differently to its presence. Some children forget it is there, others try to act in companionship with it or to challenge it (Lindgren & Sparrman, 2003). In study III, the children rarely noticed the camera, although some of them occasionally looked at it and smiled. These short interruptions did not interfere with the main focus of the recordings, namely their inter-inter-action with IACTA and the professional. Nowadays, children are used to being video recorded, which could be a possible explanation for why they largely ignored the camera and engaged with the situation instead (Cromdal, 2000).

In study IV a quantification was made of how many times the children used each participation cue. The approach was facilitated by the identification of the cues already being made (study III). A limitation to this approach was that it represented a secondary analysis of a data set collected for another reason. Other limitations were the small sample size (21 situations) and the inclusion of only two settings.

## Trustworthiness of the thesis

According to Lincoln and Guba (1985), the rigour of a qualitative study is referred to as its trustworthiness, which is made up by four criteria: credibility, transferability, dependability and confirmability. As one of the studies used a quantitative design, issues concerning validity and reliability will be discussed as well.

### **Credibility**

The credibility of qualitative data, as well as the interpretations drawn from these data, comes from how the study was carried out and the way in which the findings of the study are reported (Lincoln & Guba, 1985).

This thesis has stated that the child's perspective was of paramount interest and that it was sought throughout the studies. To enhance the credibility of the involvement of the child's perspective, methods suitable for capturing that perspective were chosen. The age of the study participants corresponded well to the inclusion criterion for age, i.e. 3-5 years, which made the result based on information from children representing the whole age range. Because the thesis aimed to facilitate participation in healthcare situations, the credibility of the result was improved by the fact that information was sought from children who were currently involved in such situations. However, in study I, variations were sought and the inclusion of preschool children enabled a broader variety of perceptions to be recorded as the children talked about earlier si-

tuations, which enabled them to reflect on the situations in other ways than the children in the clinical settings did. To further strengthen the credibility when testing IACTA in real-life healthcare situations, the children tested the situations that were of interest for their specific visit, meaning that they did not randomly use or test scenes from the storyboard.

Building trust, although slightly different from the description by Lincoln and Guba (1985), was a prioritised task, although performed differently in each setting. Prior to the start of the study, the children in the PS setting participated in a series of visits to enable familiarisation. In the clinical settings, the familiarisation process was less lengthy, but still emphasized.

The data collection was conducted by one person, enabling consistency in the organisation of each situation as well as the encounters with the study participants. The preliminary interpretations were made by one person, the novice researcher, and later questioned and discussed within the research group. This approach enabled a probability check of the interpretations.

The individual articles reporting on the studies have presented thorough descriptions of the method used and the process of analysis. Quotes and/or detailed descriptions deriving from the data were presented to provide the reader with information from the children's perspective.

### **Transferability**

The results of qualitative studies are not generalizable in the way quantitative results are. Instead, a transferability of the study results is discussed. According to Lincoln and Guba (1985), transferability, from the researcher's perspective, is impossible to discuss. Instead, they propose that as rich descriptions of a study as possible are made, including all areas, to provide a basis for others to judge whether they consider the results to be transferable to another context.

The involvement of a large study sample meant that the child's perspective was illuminated from a variety of angles which increased the probability of the transferability of the results. However, the inclusion of solely a Swedish context might limit the transferability, perhaps not in a European or Western perspective, but in a global one.

Given that the articles reporting on the studies presented extensive descriptive data, including method and analysis, individuals external to the studies are enabled to evaluate the applicability of using the results in other settings or contexts.

### **Dependability**

Validity and reliability are linked to each other, as are credibility and dependability. Dependability deals with stability over time, i.e. if the study result could be replicated.

Lincoln and Guba (1985) place a focus on the difficulties of trying to replicate a naturalistic study. Due to the qualitative nature of the majority of the



studies in this thesis, replicated studies including the same sample would probably not render the same result as the children continue to grow and gain new experiences and knowledge. Given this, there is a potential risk that in a replicated study, they would react differently to the situations and questions of interest differently. However, the use of interactive technology is now seen among even younger children, who are skilled users of applications from a very early age (Swedish Media Council, 2015). This situation increases the possibility, when including a group of children recruited in similar contexts and with similar previous experiences, that similar contributions could be made. Instead of replicating a previous study, Lincoln and Guba (1985) propose an external audit of the research process as well as the result. In studies I and III, inter-rater tests were conducted. Independent research assistants, coming from another field of nursing and thereby having a different pre-understanding, organized utterances and cues into a pre-established matrix. The tests showed satisfactory agreements.

### **Confirmability**

The level of a study's dependability may be essential to the confirmability of the study as well, as confirmability deals with objectivity (Lincoln & Guba, 1985). The interpretation of data should be independent and represent the participants' views and not the understanding of the researcher. Throughout the studies, the preliminary interpretations were reviewed and discussed by all members in the research group. In studies III and IV an additional researcher joined the research group and was involved in the review and discussion process. To enhance the conformability of interpretations, the pre-understanding of the person performing them needed to be mentioned, as that influences in what way data was understood (Ödman, 2007).

### **Validity and reliability**

Aspects of validity and reliability are often discussed regarding the use of a certain instrument, focusing on how reliable and valid measurements of that instrument are (Bryman, 2016).

In study IV, a quantitative approach was used, although without the use of an instrument. Instead, a secondary analysis (Carter & Lubinsky, 2016) was used on a qualitatively gathered data set in which cues of participation had been identified. To ensure the validity of the identification process, clear definitions of the core concepts, i.e. participation and cue, were required, especially regarding participation, due to its multidimensional character. A definition specifically composed to fit the project was used. To further enhance the validity of each demonstrated participation cue, the identification process was conducted in two steps. The initial identification was followed by a discussion and verification of the cues within the research group. The reliability of the cue identification was enhanced by the fact that an inter-rater test regarding

the evaluation of cue identification and organization of the cues had been conducted with satisfactory agreement.

## Ethical discussion

All research involving living beings calls for deliberate ethical considerations. When conducting research with children, the ethical stakes are viewed as higher, due to their need of protection (Huang et al., 2016). Sometimes children are denied involvement, or this is considerably restricted, owing to their age (Tates, Meeuwesen, Elbers, & Bensing, 2002). However, the overprotecting of children involves a risk of denying them the right to have their perspective heard. Denying children participation is a violation against the UNCRC (United Nations, 1989), in which Article 12 states that children have the right to participate in all situations that matter to them, a wording implying that children's contributions are important.

In this thesis, the children were understood as social actors in their own right, who contributed to and constructed situations with others (Alanen, 1988; Prout & James, 1997). Given that, their active involvement was never questioned, although there was an awareness of children having different prerequisites from adults when participating in research studies. Study information, which is a requirement in all research, was adapted in order to be age-appropriate (Alderson, 2004). This information, apart from telling about the study, emphasised their right to withdraw at any stage, a right that was also provided verbally during each child encounter. Regardless of the information, the children were observed carefully in order to notice any signs that could be understood as a desire to stop. If signs were noticed, the child was asked if he/she wanted to end the session. If the answer was yes, the session was terminated immediately. If the answer was no, the process continued but the child was still attentively observed for any other signs.

In all settings, gatekeepers contributed to the recruiting of children and provision of study information. In the PS setting, the staff in each unit helped out. In the clinical settings, either a tele nurse or the nurses on the ward acted as gatekeepers. When I initially met the children and their parents, they had already consented to their participation and I avoided the risk that my presence had a persuasive effect on their decisions.

When the healthcare situations were video recorded, the parents were told about their right to refuse the recording of specific sequences. No parents expressed such a refusal. However, one situation, when a child was partly undressed, was stopped by the researcher. The parent and the professional were informed about the interruption, and the information was repeated when the recording was re-started.

It is advantageous for children who are involved in research to become used to the study environment and the person(s) who are to be present prior to the

start of the study (Jones, 2004). In the PS setting I had the opportunity to visit the children several times before the study start. During these visits, the children familiarised themselves with me, and they were repeatedly provided with information on the reason that I was attending their group. In the clinical settings, I had to become familiar with the children in other ways. The verbal study information was provided at the same time as I tried to familiarise myself with the child. Unfortunately, the time for getting to know each other was sometimes short and I learnt that the best way to come closer to the children, if possible, was through play. In the encounters, when the initial time had been too limited for the children to familiarise themselves with me and the situation, the data collection session started with a more extensive period of 'small talk'.

The written study information for the parents contained my contact details and they were encouraged to get in touch if they had any questions which arose later, or if they wished to withdraw their child's participation. No such questions or requests were reported.

All data collected in the project have only been handled within the research group. In the articles reporting data from the studies, child confidentiality was secured by the use of fictitious names or letters indicating whether the quote was from a girl or a boy. Information on age and setting was added to the quotes which nevertheless did not mean that there was a risk of the children being identified. Video recordings have an inherent problem when it comes to ensuring the respondent's confidentiality, and the study information clearly emphasised that no one except the members of the research group would have access to the recordings. Three families were therefore explicitly asked if they would allow the recording of their child to be viewed in front of a larger audience, although kept to a minimum and only in situations associated with research. One family replied positively and another family replied positively to allowing a photo of their child engaging with IACTA to be used in similar situations.

## Conclusion and future research

The overall aim was to develop and test, together with children, an interactive communication tool meant to facilitate young children's participation in healthcare situations. The synthesised result described the situated participation of the children when they used the communication tool jointly with professionals in healthcare situations in real life. The situated participation was a result of the individual child's perspective on the situation which influenced the inter-inter-action, verbal or non-verbal according to the preferences of the child, with IACTA and the professional. The way the child interacted with IACTA as well as with the professional, provided the doctor or the nurse with an additional understanding of the child's perspective of that specific situation. This understanding enabled them, in their mirrored inter-inter-action with IACTA, to respond to and guide the child in an individualized way.

Apart from the knowledge gained from the children's use of IACTA, the thesis contributed with knowledge regarding how young children perceive their involvement in a healthcare situation. Their perception of themselves as actors who want to participate alone, as co-actor or both, adds to the professionals' understanding of how to approach and encounter young children in these situations. Likewise, the thesis illustrated the existing differences between the child's perspective and an adult child perspective which emphasises the importance of actively involving children and seeking their perspective when researching areas that are of importance for the children themselves.

Proposals for future research include a continuation of the IACTA-project, involving a further refinement of the application by adding more virtual examinations and procedures, as well as testing the tool in a larger sample to validate outcomes when using it in healthcare situations.

IACTA was developed and designed in a Western context, adopting Western ideas about content, graphic design and relationships between the child and the professional. As Sweden represents a multicultural society, it would be of interest to investigate if IACTA is a cultural neutral tool or if culturally specific issues influence the relevance of its use for children having other cultural backgrounds.

The three-year-olds seemed to gain most from IACTA use in the situation. Based on this, the inclusion of even younger children would be of interest in order to investigate whether the tool is suitable to use also for children younger than three years. Additionally, children with less experience of healthcare situations seemed to engage to a greater extent with IACTA. In the future, it

would be of interest to focus more on which situations are adequate for them to encounter virtually. Likewise, there is an interest in investigating the ways in which a tool like IACTA could be useful for children who have an extensive experience of healthcare situations.

Given the intention of joint use involving the child and the professional it would also be of interest to investigate the professionals' perspective on the use of an application or interactive communication tool such as IACTA.

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# Appendix





# Study information parents preschool, study I

***IACTA-projektet - att möjliggöra yngre barns (3-5 år) delaktighet i vårdssituationer genom användning av interaktiv teknik (IACTA = Inter-Active Communication Tool for Activities)***

Jag heter Anna Stålberg. Jag är barnsjuksköterska och doktorand vid Mälardalens högskola, Västerås. Jag genomför ett forskningsprojekt som tar sin utgångspunkt i konventionen om barns rättigheter. Artikel 3 berör att vuxna ska se till barns bästa, och artikel 12 berör barns rätt att komma till tals i frågor som berör dem och att bli lyssnade till. Dessa rättigheter utgör möjligheter för ett barn att kunna påverka sin situation. Det finns få studier gjorda med barn i förskoleåldern om deras erfarenheter av vårdssituationer. Det här forskningsprojektet vill utöka kunskap från *barnens* egna erfarenheter.

Den första studien inom projektet utgår från samtal med barn som besöker en vårdcentral eller en sjukhusansluten dagvårdsavdelning kring vårdssituationer som kroppsundersökning eller sticksituationer (som exempelvis blodprov). I den andra studien, utifrån den kunskap som erhållits om barns erfarenheter av vårdssituationer, fortsätter projektet sedan med att utveckla ett interaktivt kommunikationsprogram (applikation) tänkt att användas i en läsplatta. I utvecklingsarbetet samarbetar vi med ett app-utvecklingsföretag. I den tredje studien kommer app-en att testas i verkliga vårdssituationer. Applikationen är tänkt att möjliggöra för yngre barn att bli mer delaktiga i vårdssituationen och även kunna delge sina erfarenheter. Användningen av applikationen skulle även kunna underlätta för vårdpersonal att anpassa sitt bemötande och sin vägledning utifrån det enskilda barnets behov i samband med förberedelser och genomförande av exempelvis undersökningar och provtagningar.

**Det är i samband med den första studien som jag önskar få samtala med ditt/ert barn om besöket.**

Samtalen kommer att ske med barn, enskilt eller i en grupp med andra barn, i förskolegruppen. Samtalsbilder kommer att användas i samtalet och barnet kommer även att erbjudas att rita en teckning utifrån sina erfarenheter. Samtalen beräknas pågå cirka 15-30 minuter. Ljudinspelning av samtalet kommer att göras och den kommer enbart att användas inom forskningsprojektet. Du/ni får gärna ta del av vad ditt/ert barn berättar. Alla uppgifter om ditt/ert barn som kommer mig till del kommer att behandlas på ett sådant sätt att inga obehöriga får del av dem.

Hör gärna av dig/er med frågor.

Om du/ni medger att ditt/ert barn får delta i samtal önskar jag att du/ni skriver under samtyckesblanketten. Även barnet ombeds signera sitt samtycke, se medföljande blankett.

*Anna Stålberg*

x.x@x.se alternativt XXX - XX XX XX

Huvudman för projektet är Mälardalens högskola. Huvudansvarig för studien är Maja Söderbäck, docent vid Akademin för Hälsa, vård och välfärd, Mälardalens högskola, x.x@x.se alternativt XXX - XX XX XX

# Informed consent parents preschool, study I

*IACTA-projektet - att möjliggöra yngre barns (3-5 år) delaktighet i vårdssituationer genom användning av interaktiv teknik (IACTA = Inter-Active Communication Tool for Activities)*

Jag/vi har tagit del av information om forskningsprojektet, fått möjlighet att ställa frågor och få dem besvarade och jag/vi **samtycker** till att mitt/vårt barn medverkar i samtalet/studien.

**Samtyckesblanketten lämnas till personalen på förskolan.**

.....  
Ort, datum

.....  
Namnteckning

.....  
Namnteckning

.....  
Barnets namn

.....  
Förskoleavdelning

# Study information and informed consent, children preschool, study I

*Hej!*

Jag heter Anna.

Jag tycker att det är viktigt att barn får berätta hur de känner och tänker när de träffar doktorn eller sjuksköterskan eller är på sjukhus. Jag tycker också att det är viktigt att lyssna på barn som vill berätta vad de varit med om och tankar och känslor kring det.

För att ta reda på hur du tänker kring att vara hos doktorn/sjuksköterskan eller på sjukhus skulle jag vilja prata med dig. Men bara om du vill själv förstås. När vi ses kommer du också att få rita en teckning och vi kommer att titta på bilder tillsammans.

Jag kommer att spela in vad vi säger. Om du vill kan vi lyssna på inspelningen tillsammans efteråt.

Jag svarar gärna på dina frågor.

Skriv eller rita något här nedanför om du vill prata med mig.

Kom ihåg! Du har alltid rätt att säga till när du inte vill prata längre.

*Anna*

# Interview guide, study I

- Hur tyckte du det var det att gå till doktorn/sjuksköterskan?
- Har du varit hos doktorn/sjuksköterskan någon annan gång?
- Vad tycker du känns bra när du träffar doktorn/sjuksköterskan/är på sjukhus?
- Vad tycker du känns dåligt/otäckt när du träffar doktorn/sjuksköterskan/är på sjukhus?
- Hur skulle du vilja att det är när du träffar doktorn/sjuksköterskan/är på sjukhus?
- Hur skulle du vilja att det inte är när du träffar doktorn/sjuksköterskan/är på sjukhus?
- Frågade du doktorn/sjuksköterskan om något?
- Var det något du hade velat fråga doktorn/sjuksköterskan om?
- Fanns det något du inte ville/kunde fråga doktorn/sjuksköterskan om?
- Om du blir sjuk igen, hur skulle det då vara att gå till doktorn/sjukhuset?
- Fanns det något som var bra med att ta blodprov/få en spruta?
- Fanns det något som var svårt/dåligt/otäckt med att ta blodprov/få en spruta?
- Vad vill du veta innan sjuksköterskan tar blodprovet/ger sprutan?
- Finns det något du inte vill att sjuksköterskan ska berätta för dig innan blodprovet/sprutan?
- Vad fick du bestämma om när du tog blodprov/fick sprutan?
- Vad skulle du vilja bestämma om?
- Vad vill du inte bestämma om?
- Finns det något du skulle vilja ändra på om du ska ta blodprov/ta en spruta igen?
- Vad tycker du doktorn/sjuksköterskan ska tänka på när du ska träffa dem?

## Study information parents preschool, study II

*IACTA-projektet - att möjliggöra yngre barns (3-5 år) delaktighet i vårdssituationer genom användning av interaktiv teknik (IACTA = Inter-Active Communication Tool for Activities)*

Jag heter Anna Stålberg. Jag är barnsjuksköterska och doktorand vid Mälardalens högskola, Västerås.

Jag genomför ett forskningsprojekt som tar sin utgångspunkt i konventionen om barns rättigheter. Artikel 3 berör att vuxna ska se till barns bästa, och artikel 12 berör barns rätt att komma till tals i frågor som berör dem och att bli lyssnade till. Dessa rättigheter utgör möjligheter för ett barn att kunna påverka sin situation. Det finns få studier gjorda med barn i förskoleåldern om deras erfarenheter av vårdssituationer. Det här forskningsprojektet vill utöka kunskap från *barnens* egna erfarenheter.

I den första delen av projektet intervjuades barn om sin förståelse för och uppfattning av olika vårdssituationer. Erfarenheterna som barnen bidragit med utgör, tillsammans med kunskap från tidigare forskning kring yngre barn, grunden för framtagandet av ett interaktivt kommunikationsverktyg, IACTA, i form av en applikation anpassad för en läsplatta. I den andra studien kommer barn i åldersgruppen 3-5 år att delta i utprovningen av programmet för att på så sätt kunna anpassa det till det yngre barnets förutsättningar. Barnet kommer att få prova programmet och delge sina tankar, förståelse och hantering av design och innehåll.

### **Det är i denna utprovning ditt/ert barn nu tillfrågas att delta.**

Barnet kommer få information om vad utprovningen handlar om och att deltagandet är frivilligt. Barnet ska själv avgöra om det vill delta. Barnet kan också när som helst avbryta sitt deltagande. Utprovningen med barnet beräknas pågå 15-20 minuter. Ljudinspelning kommer att ske. Du/ni har naturligtvis möjlighet att ta del av inspelningen i efterhand om så önskas. Alla uppgifter om ditt/ert barn som kommer oss till del kommer att behandlas på ett sådant sätt att inga obehöriga får del av dem. Vid utprovningen deltar ytterligare en person från forskargruppen som observatör.

Hör gärna av dig/er med funderingar.

Om du/ni **samtycker** till ditt/ert barns deltagande önskar jag att du/ni skriver under medföljande blankett. **Även barnet ombeds skriva under** (med namn eller valfri ritad bild) **sin samtyckesblankett.**

*Anna Stålberg*

x.x@x.se alternativt XXX- XX XX XX

Du/ni kan även kontakta huvudansvarig forskare för projektet: Maja Söderbäck, docent vid Akademin för Hälsa, vård och välfärd, Mälardalens högskola, x.x@x.se alternativt XXX - XX XX XX.

# Informed consent parents preschool, study II

*IACTA-projektet - att möjliggöra yngre barns (3-5 år) delaktighet i vård situationer genom användning av interaktiv teknik (IACTA = Inter-Active Communication Tool for Activities)*

Jag/vi har tagit del av information om forskningsprojektet, fått möjlighet att ställa frågor och få dem besvarade och jag/vi **samtycker** till att mitt/vårt barn medverkar i utprovningen av kommunikationsverktyget.

**Samtyckesblanketten lämnas till personalen på förskolan.**

.....  
Ort, datum

.....  
Namnteckning

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Namnteckning

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Barnets namn

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Förskoleavdelning

# Study information and informed consent children preschool, study II

*Hej!*

Jag heter Anna.

Förra året var jag på förskolan och träffade barn som berättade vad de tänker och känner när de träffar doktorn eller sjuksköterskan. Jag tycker att det är viktigt att barn får möjlighet att förstå vad som händer hos doktorn eller sjuksköterskan och att ni barn kan vara delaktiga i de situationerna.

Jag har utvecklat ett spel utifrån vad barnen berättade för mig. Nu vill jag gå vidare och prova det här spelet på en läsplatta. För att ta reda på vad du tycker vill jag gärna att du provar spelet. Jag kommer att ställa några frågor till dig under tiden som du provar spelet.

Under tiden som du provar spelet kommer jag att spela in vad vi pratar om. Om du vill kan vi lyssna på inspelningen efteråt.

Jag svarar gärna på dina frågor.

Skriv eller rita något här nedan om du vill testa det här spelet tillsammans med mig.

Kom ihåg! Du har alltid rätt att säga till om du inte vill berätta eller använda spelet mer.

*Anna*

## Interview guide, test phase I and II in study II

### Avatar ansikte

Vad kan man göra/välja på den här bilden? Vem vill du vara? Hur skulle du göra för att välja honom/henne om spelet var på en dator eller Ipad? Vad var det som gjorde att du valde den figuren? Finns det någon figur du inte skulle välja? Om du själv fick bestämma hur en av figurerna såg ut, hur skulle den se ut då?

### Avatar kläder

Vad kan man göra/välja på den här bilden? Vilka kläder vill du ha? Hur skulle du göra för att välja de kläderna? Vad var det som gjorde att du valde de kläderna? Om du fick bestämma helt själv, hur skulle dina kläder då se ut?

### Väntrum

Vad är det här för ett rum? Vad kan man göra här? Hur gör du för att välja vad du vill leka med? Finns det något annat du skulle vilja leka med?

### Undersöknings-/behandlingsrum

I vilket rum är vi nu? Vilka personer är med på bilden? Hur vet du det? Var tycker du att din figur ska sitta? Hur kan du flytta den dit? Om du var hos doktorn, var skulle du vilja sitta då? Finns det något annat ställe du skulle vilja sitta på?

### Sticksituation

Vad händer på den här bilden? Hur ska man göra för att ge sprutan?

### Utvärderingsscen

Vad visar de olika ansiktena? Hur man kan se det?

### Kroppspusselscen

Vad är de blå, gröna och röda sakerna för något? Vad och hur kan man göra med dem?

### Slutscen

Vad händer på den här bilden? Hur ser du att spelet är slut? Vilken belöning tycker du är bra? Vad är det som gör att den är bra? Finns det någon belöning som du inte tycker är bra? Vad tycker du är ett roligt slut på ett spel? Vad tycker du är ett tråkigt slut på ett spel?



## Interview guide, test phase III in study II

### Avatar ansikte

Vad kan man göra/välja på den här bilden? Vem vill du vara? Hur gör du för att välja honom/henne? Vad var det som gjorde att du valde det ansiktet? Finns det något ansikte du inte skulle välja? Om du själv fick bestämma hur ett ansikte såg ut, hur skulle det se ut då?

### Avatar kläder

Vad kan man göra/välja på den här bilden? Vilka kläder vill du välja? Hur gör du för att välja de kläderna? Vad var det som gjorde att du valde de kläderna? Om du fick bestämma helt själv, hur skulle de kläder du vill välja se ut?

### Medföljande

Vem/vilka är det här? Vilken väljer du?

### Väntrum

Vad är det här för ett rum? Vad kan man göra här? Hur gör du för att välja vad du vill leka med? Finns det något annat du skulle vilja leka med?

### Undersöknings-/behandlingsrum

I vilket rum är vi nu? Vilka personer är med på bilden? Hur vet du det? Var tycker du att din figur ska sitta? Hur kan du flytta den dit? Om du var hos doktorn, var skulle du vilja sitta då? Finns det något annat ställe du skulle vilja sitta på?

### Sticksituation

Hur ska man göra för att ta blodprovet?

### Hjärt-/lung-undersökning

Vad visas på den här bilden (hjärta/lungor)? Hur gör man för att med stetoskopet? Vart ska det? Vad är det som hörs?

### Utvärderingsscen

Vad visar de olika ansiktena? Hur man kan se det?

## Observation protocol, study II

Användbarhetstest	Avklarad uppgift		Behov av guidning i interaktionen med applikationen	
	Ja	Nej	Ja	Nej
Väljer ansikte till avataren				
Väljer kläder				
Förstår att använda pilen för att byta sida				
Hittar interaktiva element i bilden				
Förstår hur leka med de interaktiva leksakerna				
Känner igen väntrummet				
Uppfattar den medföljande personen som en föräldrar				
Känner igen undersökningsrummet				
Känner igen doktorn/sjuksköterskan				
Identifierar var avataren kan sitta				
Förstår hur hantera sticksituationen				
Förstår hur hantera "kroppsdelspusslet/lyssna på hjärta och lungor				
Ser skillnader i ansiktsuttryck i utvärderingsscenen				

## Observation protocol II, study II

Faktorer gällande åldersanpassning och likeability	Avklarad uppgift		Behov av guidning i interaktionen med applikationen	
	Ja	Nej	Ja	Nej
Har tillräckliga motoriska kunskaper för att kunna trycka				
Har tillräckliga motoriska kunskaper för att kunna dra				
Har tillräckliga kunskaper för att kunna hantera applikationen på egen hand				
Behöver stöd att använda applikationen				
Saknar förmåga att använda applikationen				
Visar nyfikenhet och vill testa applikationen				
Är fokuserad/tittar uppmärksamt på applikationen				
Uttrycker intresse för uppgiften genom att trycka och dra (interagera)				
Ler och/eller skrattar				
Vänder sig mot läsplattan				
Suckar				
Vänder sig från läsplattan				
Visar genom kroppsspråk ovilja att använda applikationen				

## Study information parents clinical setting, study III

### *IACTA-projektet - att möjliggöra yngre barns (3-5 år) delaktighet i vårdssituationer genom användning av interaktiv teknik (IACTA = Inter-Active Communication Tool for Activities)*

Jag heter Anna Stålberg. Jag är barnsjuksköterska och doktorand vid Mälardalens högskola, Västerås.

Jag genomför ett forskningsprojekt som syftar till att möjliggöra det yngre barnets delaktighet i olika vårdssituationer med hjälp av interaktiv teknik. Projektet tar sin utgångspunkt i Barnkonventionen i vilken artikel 3 tar upp vuxnas skyldighet att se till barnets bästa. Artikel 12 belyser barns rätt att få komma till tals i frågor som berör dem och att bli lyssnade på. Dessa rättigheter utgör möjligheter för ett barn att kunna påverka sin situation. Det finns få studier gjorda kring förskolebarns erfarenheter av vårdssituationer. Det här forskningsprojektet vill utöka kunskap från *barnens* egna erfarenheter, det vill säga från deras eget perspektiv.

I tidigare delar av projektet har jag samtalat med barn om deras uppfattningar av vårdssituationer. Utifrån dessa uppfattningar påbörjades utvecklingen av en applikation. Den färdiga applikationen, tänkt för en läsplatta, ska användas av både barn och vårdpersonal i olika vårdssituationer. Genom innehållet i applikationen, samt genom verbal ledning av vårdpersonalen, ges barnet en möjlighet att få en bättre förståelse för situationen vilket i sin tur möjliggör dess delaktighet utifrån sitt eget perspektiv.

Barn i åldern 3-5 år har deltagit i framtagandet av applikationen som nu ska prövas i verkliga vårdssituationer. De vårdssituationer då applikationen prövas kommer att videoinspelas.

#### **Det är i denna studie som ditt/ert barn nu tillfrågas om att delta.**

Barnet kommer att få information om vad som händer under vårdssituationen samt att det kommer att finnas en kamera i rummet. Deltagandet är frivilligt. Barnet ska själv avgöra om det vill delta. Barnet kan också när som helst avbryta sitt deltagande. Prövningssituationen sker i samband med läkar- eller sjuksköterskebesöket. Ljud- och bildinspelningen kommer enbart att användas inom forskningsprojektet.

Hör gärna av dig/er med frågor.

Om du/ni **samtycker** till att ditt/ert barn deltar i prövningen önskar jag att du/ni skriver under medföljande blankett. Även barnet ombeds **signera sin samtyckesblankett**, antingen med namn, initial eller en bild.

*Anna Stålberg*

x.x@x.se alternativt XXX - XX XX XX

Du/ni kan även kontakta min handledare Maja Söderbäck, docent vid Akademin för Hälsa, vård och välfärd, Mälardalens högskola, x.x@x.se alternativt XXX - XX XX XX.

# Informed consent parents clinical settings, study III

*IACTA-projektet - att möjliggöra yngre barns (3-5 år) delaktighet i vårdssituationer genom användning av interaktiv teknik (IACTA = Inter-Active Communication Tool for Activities)*

Jag/vi har tagit del av information om forskningsprojektet, fått möjlighet att ställa frågor och få dem besvarade och jag/vi **samtycker** till att mitt/vårt barn medverkar i prövningen av applikationen samt till den videoinspelning som sker av situationen.

.....  
Ort, datum

.....  
Namnteckning

.....  
Namnteckning

.....  
Barnets förnamn

## Study information and informed consent children clinical setting, study III

*Hej!*

Jag heter Anna.

Jag tycker att det är viktigt att barn får möjlighet att förstå vad som händer hos sjuksköterskan och att barn kan vara delaktiga i besöket.

Tidigare har jag pratat med barn som berättat hur de tycker att det är att träffa doktorn/sjuksköterskan eller att vara på sjukhus. Barnens berättelser har jag använt för att skapa ett material på en läsplatta. Det ska användas av både barn och vårdpersonal tillsammans.

Nu skulle jag vilja filma när du och doktorn/sjuksköterskan använder läsplattan tillsammans.

Om du vill kan vi titta på inspelningen efteråt.

Mamma och/eller pappa kommer att vara med dig.

Jag svarar gärna på dina frågor.

Skriv eller rita något om det är OKEJ att vi pratar tillsammans.

Kom ihåg! Du har alltid rätt att tala om ifall du inte vill använda läsplattan eller berätta mer.

*Anna*

## Informed consent professionals, study III

*IACTA-projektet - att möjliggöra yngre barns (3-5 år) delaktighet i vårdssituationer genom användning av interaktiv teknik (IACTA = Inter-Active Communication Tool for Activities)*

Jag har tagit del av information om forskningsprojektet, fått möjlighet att ställa frågor och få dem besvarade och jag **samtycker** till att medverka i prövningen av applikationen och till den videoinspelning som sker av situationen.

.....  
Ort, datum

.....  
Namnteckning