AN EXPLORATIVE STUDY:

PARENTAL INVOLVEMENT IN YOUTH HEALTHCARE

MASTER THESIS

Marloes Roerdink

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EXAMINATION COMMITTEE

Dr. Stans Drossaert
Dr. Jörgen Svensson
Drs. Ir. Sander van Loon
Tim Holweg, MSc

MSC HEALTH SCIENCES (2016-201600036)

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UNIVERSITY OF TWENTE.

Preface

This study was carried out from April till October 2017 to complete the Master Health Sciences at the University of Twente. This study took place at Topicus Healthcare B.V. where I had the opportunity to choose my own topic of interest for my master research. During my time at Topicus Healthcare B.V. I learned a lot with the help of my supervisors Sander van Loon and Tim Holweg. I would like to thank them for all their time, help and feedback and for the interesting discussions we had. My thanks also go to the colleagues of Topicus Healthcare B.V. I had a really nice time working on my master thesis.

I would also like to thank my supervisors of the University of Twente, Stans Drossaert and Jörgen Svensson. The meetings of support we had and the inspiring conversations motivated me to improve the quality of my work. I learned a lot from the knowledge they shared with me and the valuable feedback they gave during the process of writing my master thesis.

I could not finish without a word of thanks to all the healthcare professionals and parents for their time, effort and participation in this study. Without them I would not have been able to conduct this study. Besides that, I would like to thank my family and friends for their moral support when I needed it most, they were all valuable motivators in the finishing of my master thesis!

I hope you enjoy reading this thesis.

Marloes Roerdink

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Abstract

Background

Youth health services (YHS) in the Netherlands are the public healthcare organization for children and adolescents between 0 and 18 year. The purpose of YHS is to follow the physical, social, psychological and cognitive development of children and adolescents and to identify disorders by providing interventions at an early stage. YHS in the Netherlands are successful in the preventive care for children, but have to deal with cuts in their budget. More tasks are assigned to healthcare organizations, but there is no increased budget to complete these tasks. To realize provision of high-quality care with diminishing means, it is important to investigate whether co-production is applicable to YHS. If parents can become more involved in the basic tasks of youth healthcare with the help of an online support service, parents become empowered and time and cost savings for YHS can be realized.

Objective

The objective of this study was to investigate to what extent parents who visit youth health services with 0-4 year old children can become involved in basic task of youth healthcare with the help of an online support service.

Methods

An explorative study was conducted consisting of a document analysis and two qualitative studies. In the document analysis policy documents, journal articles, YHS guidelines and legal documents were investigated to explore the limits of parental involvement in YHS. The first qualitative study consisted of interviews with YHS professionals (N=6) to explore their opinion concerning parental involvement. The results of the document analysis and the first qualitative study formed the basis for the second qualitative study. In the latter, parents (N=16) who visit the YHS with their 0-4 year old children were interviewed to explore their opinion towards an online support service and parental involvement in tasks.

Results

The interviews explored that professionals and parents thought that parents can become involved in the healthcare of their child with the help of an online support service. This finding was also supported by the document analysis. It depends on the type of tasks and the kind of information whether parents can become more involved. Parents can become partly involved in the healthcare of their child because they can read standardized information online, they can fill in simple information in an online support service and they can perform some tasks partly themselves at home or at the child consultation clinic. Arguments that were often stated as beneficial for parental involvement were that parents know their child best. Besides that, it is time saving for the professional and parents and parents can also become more empowered. The main argument against parental involvement for certain tasks was parents' lack of expertise. Additionally, professionals and parents had the opinion that the child must stay under control of YHS to monitor the development, to ensure high quality of care and to make sure that no disorders are missed.

Conclusion

It can be concluded that both parents as well as professionals are of opinion that parents could be more involved in certain tasks with the help of an online support service. This finding was also supported by the document analysis. According to YHS professionals and parents, involving parents in youth healthcare could improve empowerment. Empowerment of parents could lead to more effective care and decision making since parents know their child best. Besides that, parental involvement in YHS with the help of an online support service can save time for YHS professionals. This saved time can be invested in high-quality care and more customized and efficient appointments. This study showed that there appears to be an interest in parental involvement via online support service. However, future research should reveal whether parental involvement via an online support service actually lead to empowerment, cost and time savings.

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1. Introduction

1.1 Background

In the Netherlands, youth health services (in Dutch: Jeugdgezondheidszorgorganisaties, YHS) play a major role in healthcare. In 2012 over €83 billion was spent on healthcare in the Netherlands [1]. These high expenditures led to substantial benefits which are attributable to expenditures in both curative and preventive care [2]. Curative care focuses on the healing and treatment of acute and chronic physical diseases and disorders, while the goal of prevention is to ensure that people stay healthy by promoting and protecting their health [3, 4]. YHS are preventive care facilities for children and their parents that are constituted by the government.

YHS are the public healthcare organizations for children and adolescents between 0 and 18 year [5, 6]. The purpose of the YHS is to follow the physical, social, psychological and cognitive development of children and adolescents and to identify disorders by providing interventions at an early stage [7, 8]. The care offered by YHS is legally defined in the Decree on Public Health (in Dutch: Besluit Publieke Gezondheid, DPH) [9]. The aim of the DPH is that all children in the Netherlands receive the same package of care stated in the Basic Tasks Youth Healthcare (in Dutch: Basistakenpakket Jeugdgezondheidszorg, BTYH) [10]. In principle, doctors and nurses provide all care stated in the BTYH to all children in the Netherlands, but it is possible to adapt care in order to meet the specific needs of children and their parents [11]. In this way, it is possible to define a unique, appropriate care pathway, which enables customization to the level of individual children and their environment [12, 13].

All residents of the Netherlands owe on average one year of life in good health to YHS. Additionally, the number of healthy life years gained because of YHS is more than 200,000 years each year in the Netherlands [14]. Moreover, YHS are easily accessible and close to home and have a long experience in the field of care, parenting support and early detection of disorders [15]. Additionally, research into major successes of prevention in the last forty years shows that YHS are very successful [12]. The screening and monitoring of YHS on heart defects, hip disorders, eye problems and hearing impairment prevent twenty deaths annually and ensure that the development of 2,200 children is improved. The vaccinations that YHS give prevent annually 6,000 disease cases and 50 deaths. The heel prick screening detects 200 children per year who would be severely disabled or deceased without treatment, and each year more than 150 children are saved from sudden infant death syndrome [12, 16].

Despite the beneficial results, it is costly to deliver preventive care. In 2012, €2.5 billion was spent on preventive care in the Netherlands [1]. In 2007, costs for YHS were estimated at €433 million per year [12, 17]. Since municipalities became responsible for child healthcare in 2015, there are cuts in youth healthcare to reduce spending [15, 18, 19]. In the case of YHS, more tasks are assigned to healthcare organizations, but there is no increased budget to complete tasks [15, 20]. Consequently, YHS professionals feel that they can deliver less care and less quality of care [15, 18, 21-23]. YHS professionals work under pressure, which is a suboptimal circumstance to identify children at-risk [20, 22, 24]. These professionals play a big role in the detection of children where problems can arise. Therefore, there must be space and time for attention, reflection and consultation instead of rushing to handle the most important tasks within the set time and skipping parts of the BTYH [15, 23, 25]. This

time can be found partly in rearrangement of tasks between disciplines, but also co-production between YHS and parents can provide a solution.

Co-production can reduce the costs and is time saving [26]. Co-production is defined as the presence of a continuous relationship between employees of an organization and individual citizens; the direct and active inputs and efforts of citizens; the voluntary engagement of the citizen and the payment of the employee [27]. Co-production can be a solution for health systems which want to improve the individual experience of care, improve the health of populations and reduce the per capita costs of care [26]. Besides, costs and time savings, co-production can also empower the public [27-30]. In the case of YHS, co-production can contribute to patient engagement and may strengthen the provision of customized care in YHS organizations [31]. Parents might feel more satisfied since they become (more) involved in the healthcare of their child [32]. Parental satisfaction is important because it increases adherence to treatment recommendations, improves well-being and leads to fewer parental feelings of distress and depression [33-35]. Co-production creates a more active role for the public in the functioning of their government [28]. Moreover, there are many other benefits of co-production: it fosters social capital, it strengthens civil society, it produces positive spill-overs by stimulating local activism in other areas and it promotes innovation [36-38].

To realize provision of high-quality care with diminishing means, it is important to investigate whether co-production is applicable to YHS. It is necessary to find out if certain tasks of YHS professionals can be (partly) performed by parents themselves. Since it is probable that parents cannot perform every task, technology can lend a helpful hand. If it is possible for parents to become more involved in the care delivered by YHS and some form of preventive care can be delivered via web-based applications, this can eventually result in a form of co-production between YHS and parents. Parental involvement can lead to time savings for YHS professionals since they have to perform fewer tasks themselves [39-41]. The saved time can be used to focus on relevant issues to ensure a high quality of care [42, 43]. Moreover, co-production can contribute to parental satisfaction and empowerment, which lead to fewer health and development problems for children [34, 35, 44, 45].

1.2 Organization of the youth health services

To investigate whether parental involvement is possible, it is important to get insight into the organization of YHS. Therefore, a description of the services and the way of working by YHS are outlined. The care delivered by YHS organizations is free of charge and voluntary, so parents are not obliged to respond to requests of YHS [46]. On the other hand, article 24 of the Convention on the Rights of the Child (In Dutch: Verdrag inzake de rechten van het kind) states that the child is entitled to the highest possible level of health and facilities for medical care and rehabilitation [47]. This means that YHS have the power to take action to deliver the desired care if parents do not respond to requests of YHS.

When the birth certificate is created for the baby, the child consultation clinic automatically receives a notification and contacts parents to schedule the first appointment at the child consultation clinic (in Dutch: consultatiebureau) [48]. After the first appointment, a new appointment is planned and this process continues till the age of 3.9 years [5]. After that, appointments take place at school. During appointments, a so-called ‘contact moment’ is followed-up which describes aspects that should be

addressed at that moment. The following primary tasks must be carried out during the contact moments to achieve the goal of YHS:

- Monitoring of the growth and development of children;
- Provision of information;
- Advice, instruction and guidance for the healthiest possible development;
- Prevention of risk (primary prevention);
- Early identification of risk factors that threaten functioning, development and health (secondary prevention). [7, 8, 10]

A comprehensive overview of all specific tasks performed during the regular contact moments is described in the report BTYH [10]. The contact moments are designed by the Dutch centre for youth healthcare (In Dutch: Nederlands Centrum Jeugdgezondheidszorg) and based on (key) ages in the development of the child [49]. Because of these (key) ages, contact moments are suitable for the detection of potential developmental delay and the offering of targeted, age-specific information and advice [10]. Tasks carried out in every contact moment are measurement and weighing of the child. Besides that, a general health check is done by a nurse or doctor in every contact moment and physical and mental development of children is always monitored. A brief view of the other important tasks per regular contact moment according to the BTYH is shown in table 1.

Table 1 *Overview of other important basic tasks per contact moment* [10]

Contact moment	Tasks	Location
Week 1	The YHS professional gives the heel prick and performs a hearing test.	Home visit
Week 2	The YHS professional meets the family and tells what to expect of the child consultation clinic. Parents also get the growth booklet that they should bring to all subsequent visits. The YHS professional will first check the baby's health and discuss the pregnancy, childbirth and any abnormalities since this may influence the child's development.	
Week 4	The YHS professional takes time and has attention for the parents and any questions about the baby or parenting.	Child consultation clinic
Week 8	The YHS professional gives the first two vaccinations, one for DKTP (diphtheria, pertussis, tetanus and polio), Hib (haemophilus influenzae type b) and HepB (hepatitis B) and one for Pneu (pneumococci).	
Month 3	The YHS professional gives a second DKTP, Hib and HepB vaccination.	
Month 4	The YHS professional will give the baby the two vaccinations again.	
Month 6	The YHS professional talks about giving supplementary feeding. Parents receive a brochure about safety since the baby will start crawling.	
Month 7.5	The YHS professional looks if the baby is teething and asks how it goes with giving solid foods.	
Month 9	The YHS professional explains the baby's language development. The YHS professional will see if the development of the baby is on schedule and gives tips and advice on promoting language development.	
Month 11	The YHS professional gives again the two vaccinations for DKTP, Hib and HepB and Pneu.	
Month 14	The YHS professional gives the BMR (mumps, measles and rubella) and MenC (meningococci) vaccinations.	
Month 18	The YHS professional plays some games with the child to test the motor skills and knowledge of the child.	
Year 2	The YHS professional discusses toilet training, the twice daily tooth brushing and stopping with the teat and bottle. Another important issue is the language development.	Child consultation clinic
Year 3	The YHS professional is taking an eye test to measure the sharpness of the eyes.	
Year 3.9	Another eye test takes places and a DKTP vaccination is given. This is the last visit to the child consultation clinic.	
Year 5	The YHS professional takes an eye and hearing test, and the language development is monitored.	Primary school
Year 9	The YHS professional gives two vaccinations, DTP and BMR.	*
Year 10	The YHS professional monitors the motor and language development and asks about the behaviour at school. The YHS professional addresses the topics puberty and sexuality.	Primary school
Year 13	The YHS professional pays attention to the sexual development and the use of drugs and alcohol. The YHS professional signals possible psychosocial problems.	High school

* The so-called mass vaccination takes place at different locations.

In each contact moment, the risk factors for children are estimated and information is registered in the child's dossier (In Dutch: Digitaal Dossier Jeugdgezondheidszorg). YHS are legally obliged to make a digital dossier of every child according to the National Public Health Act (In Dutch: Wet publieke gezondheid) [9]. The dossier begins after birth and continues until the child is eighteen year old and has the purpose to follow the growth and development of the child over a longer period [50].

As it can be seen in table 1, the number of contact moments is higher in the first years of a child's life than in following years [10]. This is due to the nature of tasks that are tailored to the child's age. For

example, more vaccinations and screenings are indicated for younger children than for older groups. Also, medical support of parents and children plays an important role in physical and developmental problems in the early years and this gradually decreases over years [12]. This results in the fact that most contact moments happen between 0-4 year. During the remaining four contact moments after four year equal or fewer tasks need to be performed by professionals than in contact moments before the age of four [10]. For these reasons, it is likely that parents can be involved in more tasks in the 0-4 year group compared to groups that are in primary and high school. Therefore, this study focuses on the age group between zero and four year old children.

1.3 Parental involvement in basic tasks of youth healthcare

This study uses the BTYH as a guideline for the tasks YHS professionals must perform. This is because the BTYH is the standard package of care that is delivered to children via YHS [9, 12]. Besides that, the committee evaluation BTYH (In Dutch: Commissie evaluatie basistakenpakket jeugdgezondheidszorg) and other parties evaluated the BTYH and because of this the added value of the BTYH is known [12, 51].

The BTYH consists of many tasks that are summarized in 28 sections. Appendix I shows the sections and describes the involved tasks. The tasks in the sections are all performed by YHS professionals by children of 0-4 year old. It differs per contact moment which sections are discussed by the professional and parents. Examples of sections discussed every contact moment are the general impression of the professional about the child and the measuring of the growth, length, weight and head circumference. There are also sections that are only discussed one or two times during childhood, such as the sections pre-schooling and family composition [10].

Since there is much variety in the kind of tasks per sections, it is chosen to divide the tasks described in the sections into four types of tasks (see table 2). Because the included tasks in one section belong to different types of tasks, it is only possible to divide the tasks in the sections among the four types of tasks instead of dividing the complete sections. The classification into four types of tasks is done to get a better understanding of how parental involvement is possible for certain types of tasks.

Table 2 *Overview of YHS professionals' types of tasks*

Type of tasks	Explanation
Medical procedures	YHS professionals has to perform medical procedures by children (e.g. heel prick and vaccinations)
Obtaining information	YHS professionals get information of parents about many subjects. A distinction can be made between practical information that parents give (e.g. personal data) and important screenings information that YHS professionals observe (e.g. threat from the immediate vicinity).
Providing information	YHS professionals give much information and advice to parents. There is a difference in the practical and standardized information which is shown to parents in folders (e.g. dental care) and the specific and medical information which must be explained comprehensively to parents (e.g. explanation of provided care / treatment).
Monitoring development	YHS professionals monitor the development of the child in different ways during the contact moments (e.g. heart research, eye test).

1.3.1 Parental involvement via internet

The internet has increased opportunities to contribute to parental involvement since internet provides diverse possibilities to involve people in healthcare. An advantage of internet is that it can be used to educate and empower the public. This is done by providing information on health and health services and supporting self-help and patient choice based on the empowerment of patients [52]. Empowerment proposes persons as active participants in their management of illness and health [53]. Increasing empowerment can be created via web-based applications, since it is known that web-based applications have the potential to support the ongoing care needs of people [54-57]. Other advantages of internet are that it is available at any time, that it has a flexible interface and that it is possible to provide information in different ways, for example video, audio and text [58, 59].

Besides that, more and more people have access to web-based applications. In 2015, 92% of the Dutch population used internet and this number will grow in the future [60]. As can be seen in figure 1, the younger the group, the more persons use internet [61]. Most parents fall in de group 25-44 year old, which means that many parents have access to internet and are able to use an online support service [62].

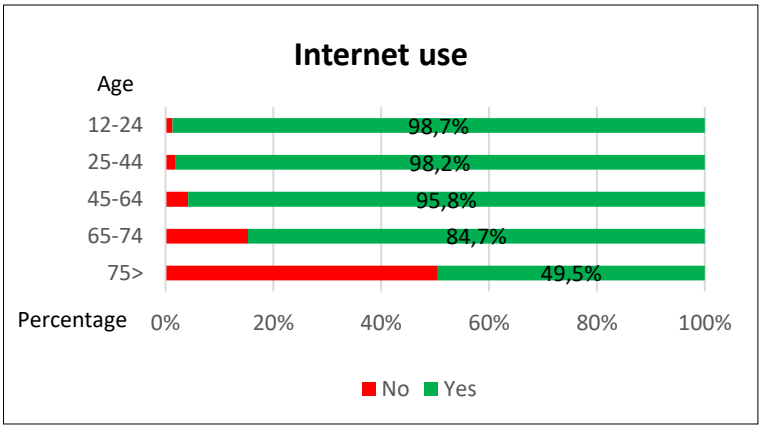

Figure 1 Internet use in the Netherlands in 2015

1.3.2 Different groups of parents

It is conceivable that not all parents are willing to become more involved in youth healthcare with help of an online support service. Maybe parents do not want to be involved because they want the doctor to provide all care. Besides that, not all young people are reached by YHS [18, 63]. This so-called hard-to-reach group does not visit YHS, for several reasons:

- There are parents who do not opt for the care of YHS because:
  - their child receives care elsewhere;
  - they think they do not need YHS care for their child.
- There are parents who will not visit YHS due to major problems in several areas that have higher priority.
- Sometimes it is not clear which YHS organization is responsible for the care of the child.
- Some children are not invited for an appointment because they are not known at YHS organizations because they are not registered at the municipality. [63]

There is also a group of parents that cannot become more involved in YHS because of the lack of medical expertise. In some cases, it is not desirable to involve parents since not all parents can assess the development of their child. Additionally, there are risk groups for which it is not advisable to stimulate parental involvement in the preventive care of their child. Parental involvement in risk groups can increase the risk of later problems [64, 65]. Risk groups are defined as:

- Parents with a non-western background.
- Parents with a low socio-economic status (SES).
- Single parents.
- Parents of children with physical and mental disabilities. [45, 64, 66, 67]

Another reason why parents cannot become involved is illiteracy and a low health literacy. Health literacy means the ability to seek, find, understand, appraise and use health information and communication technologies to improve and/or enable health and healthcare [68, 69]. If parents are illiterate or their health literacy is low, parents are unable to understand the information that is given or asked of them via an online support service.

1.4 Research problem

Although YHS are well organized in the Netherlands in terms of better health for children, cost reductions have a negative impact on the quality of care [15, 18, 21-23]. More tasks are assigned to YHS professionals, but there is no increased budget to complete these tasks [15, 20]. As a result, YHS professionals feel like they can deliver less care and less quality of care [15, 18, 21-23]. It is possible that co-production lead to cost and time savings for YHS professionals [26]. If parts of the preventive care delivered by YHS can be incorporated in an online tool, this saves time for YHS professionals since they do not have to perform all tasks themselves anymore [39-41]. Therefore, more time is available to deliver customized and high-quality care to children and parents. Besides that, parental involvement can lead to more satisfied and empowered parents [70-72]. However, to realize the provision of high quality care with diminishing needs, it must be investigated if parental involvement is possible in YHS professionals' tasks. It is first necessary to explore existing documents about YHS to get insight if there are limits to parental involvement in YHS. Additionally, the opinion of YHS professionals is needed to check whether parents can become more involved in YHS according to the experts in the YHS field. After that, the opinion of the parents is investigated to explore the parents' opinion towards an online support service. Besides that, it is necessary to find out if parents can and are willing to become more involved in the basic tasks of youth healthcare. If this is explored, it is known if parental involvement is possible in basic tasks of youth healthcare.

1.5 Research questions

To realize the provision of high quality care with diminishing needs, it is important to explore if it is possible to involve parents in the tasks of the YHS professional in the preventive care for 0-4 year old children. To date, it is not known if parents can become more involved in the basic tasks of youth healthcare and whether parents are willing to use an online tool for preventive care for their own child. Therefore, the study aims to answer the following research question:

To what extent can parents who visit the youth health services with their 0 to 4 year old child become involved in basic tasks of youth healthcare with the help of an online support service?

Before this research question could be answered, it is important to get an answer on different sub-questions. First of all, it is important to investigate existing documents of YHS to explore if there are limits to parental involvement. This leads to the first sub question:

1. ***What are the limits to parental involvement in basic tasks of youth healthcare in compliance with documents about youth health services?***

YHS professionals might have different opinions than the information found in the documents. Since YHS professionals are the experts in the field, it is important to involve the opinion of the YHS professional about the tasks which can be (partly) performed by parents. This results in the second sub question:

2. ***To what extent is parental involvement possible in the basic tasks of youth healthcare according to youth health services professionals?***

When it is clear in which tasks parents could be more involved according to documents about YHS and YHS professionals' opinions, it is important to find out if parents were willing to use an online support service which could help with the performance of tasks. This is investigated with the third sub question:

3. ***To what extent are parents of 0-4 year old children who visit youth health services willing to use an online support service for the preventive care of their child?***

When it is known if parents are willing to use an online support service, it is important to know if parents can become more involved in YHS in the opinion of parents. This is asked in the fourth question:

4. ***To what extent is parental involvement possible in the basic tasks of youth healthcare according to the parents who visit youth health services with their 0-4 year old children?***

When these questions are answered, it is known to what extent parents can become involved in basic tasks of youth healthcare and if parents are willing to use an online support service. With this information, the research questions can be answered.

2. Methods

An explorative study was conducted to answer the main research question and sub-questions. A short document analysis investigated if there were limits to parental involvement in tasks. Thereafter, two qualitative studies were performed. The first focused on YHS professionals' opinion about parental involvement. The latter investigated parents' opinion towards an online support service and parental involvement.

2.1 Study I: Document analysis

A document analysis was conducted to give answer to the first sub question: *What are the limits to parental involvement in basic tasks of youth healthcare in compliance with documents about youth health services?* Document analysis was used to identify in which tasks parents could not become more involved in. It was chosen to conduct a document analysis because it is an efficient and effective way of gathering data since documents are manageable and practical resources [73]. Moreover, a document analysis combined with other studies can reduce the impact of potential biases that exist in a single study [74]. The four type of tasks YHS professionals have to perform, medical procedures, providing information, obtaining information and monitoring development were used as guide for study I. Based on the type of tasks, different associated documents were inspected. The documents were found in public records about YHS and derived from different databases like Google Scholar and PubMed. Policy documents, journal articles, YHS guidelines and legal documents were investigated to explore the limits of parental involvement in YHS.

2.2 Study II: Professionals' opinions

2.2.1 Design

The goal of study II was to gain insights in the attitude of the YHS professional towards parental involvement in YHS professionals' tasks, focusing on the sub-question: *To what extent is parental involvement possible in the basic tasks of youth healthcare according to youth health services professionals?* Semi-structured interviews were conducted to gain the information of YHS professionals. Semi-structured interviews were chosen to be used because semi-structured interviews provide a clear set of instructions for interviewers and can provide reliable and comparable qualitative data [75, 76].

2.2.2 Participants & procedures

The participants in study II were YHS professionals. Inclusion criteria for the participants in the present study were: speaking Dutch, working for a YHS organization in the Netherlands with 0-4 year old children, having at least one year of work experience in YHS as a nurse or doctor and willing to participate in this interview. Participants who did not work at a child consultation clinic were excluded. The participants were recruited by consultants working at Topicus Healthcare B.V via an informing letter to ask the organizations if they knew YHS professionals who wanted to participate. This informing letter can be found in appendix II. Ten organizations were contacted and eventually six professionals participated in this research of which four were nurses and two were doctors.

The interviews were held over the phone, or face-to-face at the work location of the researcher or the participant. All participants were informed in advance about the interview and they got the

opportunity to ask questions. Prior to the start of the interview, the interviewer introduced the study and explained the goal of the interview. The participants were asked for permission to audio-record the interview and an informed consent form was signed, which can be found in appendix III. The interviews took half an hour to an hour, depending on the participant.

2.2.3 Materials

The interview was conducted consistent with the interview scheme in appendix II. The interview consisted of 33 open questions divided in six parts. The first part of the interview started with general information about the participant and their profession. In the second part, the professionals' opinion was asked about parental involvement in tasks included in the type of task medical procedures. In the third part, the tasks in providing information were described one by one asking the opinion of the participants if parental involvement was possible in the included tasks. The fourth part focused on the type of task obtaining information and the last part on monitoring development. After that, the interviews ended with space for other suggestions and ideas.

2.2.4 Data analyses

Results were anonymously transcribed verbatim leaving out surplus details like pauses, thinking expressions, colloquialism, repetitions and stutter. During this process, only the participant numbers were used to protect the anonymity of the participants. The transcripts were analysed and inductive coding was used. Codes and sub-codes were identified which resulted in a coding scheme per section. If necessary, the codes were evaluated and revised during the transcription process. The coding scheme which is used for analysis can be found in appendix IV. Only one researcher was involved in the coding process. The interview transcripts were coded and analysed in ATLAS.ti to make the analysing process more systemized, ordered and transparent [77, 78]. The sub-codes belonging to the codes of all different tasks were: parental involvement, no parental involvement, partly parental involvement and doubt about parental involvement. The results were compared with the information of study I. Based on the result of study I and II, the study design for study III was conceived.

2.3 Study III: Parents' opinions

2.3.1 Design

When it was known from study I and II what the limits were of parental involvement and what the opinion of the professional was about parental involvement in tasks, the next step was to ask the opinion of the parents. The goal of study III was to get an understanding of parents' attitude towards an online support service and their involvement in tasks. Study III gave answer to the following two sub-questions:

- *To what extent are parents of 0-4 year old children who visit youth health services willing to use an online support service for the preventive care of their child?*
- *To what extent is parental involvement possible in the basic tasks of youth healthcare according to the parents who visit youth health services with their 0-4 year old children?*

Semi-structured face-to-face interviews were held to get understanding of parents' opinions towards parental involvement and an online support service.

2.3.2 Participants & procedures

The participants in study III were parents of children who visited YHS. The first inclusion criteria for the participants was: having at least one child between one and five year old. The child needed to be at least one year old since parents have by then experienced most tasks at least two times. The (youngest) child should be no older than five, since the time between the interview and the last appointment at the child consultation clinic should be relatively short to make sure that the parents give a reliable opinion. Other inclusion criteria were: speaking Dutch or English, going to appointments at the child consultation clinic and willing to participate in the interview. Excluded from this study were parents who did not visit the child consultation clinic. The participants were recruited by relatives and friends of the researcher and consultants of Topicus Healthcare B.V. via an informing letter asking the parents if they wanted to participate. This letter can be found in appendix V. The researcher tried to get a good impression of the population who visit the child consultation clinic. Parents were interviewed until data saturation was reached, which means that there is enough information to replicate the study when the ability to obtain additional new information has been attained, and when further coding is no longer feasible [79]. In total sixteen interviews were conducted, four with men and twelve with women.

The interviews were conducted at the participants' home or work, according to the participant's choice. All participants were informed in advance about the interview and they got the opportunity to ask questions. Prior to the start of the interview, the interviewer gave an introduction and explained the goal of the interview. The participants were asked for permission to audio-record the interview and signed an informed consent form which can be found in appendix III. The interviews took half an hour to an hour, depending on the participant. This study was approved by the ethical committee of the University of Twente under application number 17443.

2.3.3 Materials

The interviews were conducted according to an interview scheme which can be found in appendix V. The interview consisted of 33 open questions divided in six parts. The interview started with general information about the parents and children. Secondly, parents were asked about their daily internet use. In the next part, parents' opinion about the YHS was asked. After that, questions about their attitude towards an online support service were asked. This was asked twice, but the second time with the support of a mock-up that gave an example of an online support service. The mock-up showed a page of "my child's dossier" (in Dutch: Mijn Kinddossier) of Topicus Healthcare B.V. with relevant data of the child. Additionally, a webpage with relevant information for parents about their child was shown. In the last part, tasks in which parents could be more involved were described and parents' opinion was asked about parental involvement in the described tasks. Based on study I and II, the parents' opinion was asked about tasks in nineteen sections. An overview of these nineteen sections is given in paragraph 3.2.3. Thereafter, parents got background questions about their social demographical data. The interviews ended with space for other suggestions and ideas.

2.3.4 Data analyses

Results were anonymously transcribed verbatim leaving out surplus details. Participants were coded under a random numeric code to ensure anonymity. The transcripts were analysed with inductive coding to create a coding scheme. The coding scheme can be found in appendix VI. The codes were revised when necessary. The coding process was performed by only one researcher. ATLAS.ti was used

to analyse the interview transcripts. The results obtained of the interviews with parents are divided into two parts. The first part shows the results of parents' opinion towards an online support service. The other part gives parents' opinion about involvement in tasks.

3. Results

This chapter shows the results from the studies described in chapter two. The results of the document analysis are presented in the first paragraph, the results of the interviews with YHS professionals in de second paragraph and the results of the interviews with parents are given in the third paragraph.

3.1 Results document analysis

The results in this paragraph give answer to the first sub-question: *What are the limits to parental involvement in basic tasks of youth healthcare in compliance with documents about youth health services?* The results are given per type of task.

3.1.1 Parental involvement according to the document analysis

Medical procedures

The first type of task describes the medical procedures which professionals perform. The heel prick and vaccinations are medical procedures in which parents cannot become involved. According to the Occupational Individual Health Act (In Dutch: Wet op de beroepen in de individuele gezondheidszorg, OIHA), the heel prick and vaccinations are reserved actions for professionals stated in the OIHA [80]. A reserved action is a medical procedure that involves unacceptable risks to a patient's health if it is carried out by an inexperienced person. For this reason, it is not permissible that someone else performs these tasks other than professionals.

Obtaining information of parents

Another type of task is that the YHS professional has to obtain information of parents and child. There are some tasks for which the YHS professional must follow guidelines. This is the case for information about the maternity period for which the transfer protocol for maternity and obstetrics to youth healthcare is followed [81, 82]. For the gathering of information of the recurrent child's history, the YHS professional discusses some issues according to YHS guidelines like 'Nutrition of infants and toddlers', 'Overweight' and 'Parental support' [64, 83, 84]. There are also several guidelines that make use of the 'Balansmodel van Bakker' to estimate the ratio of capacity and burden [64, 85, 86]. YHS professionals have knowledge of the risk factors and the protective factors and weigh these up, so it is probable that only YHS professionals can estimate the ratio [87]. The request to parents for permission to carry out tasks (including vaccinations) and to share information with third parties has to be performed by the professional. YHS professionals must comply with the Law for the protection of personal information (In Dutch: Wet bescherming persoonsgegevens) and the Medical Treatment Agreement Act (In Dutch: Wet op de Geneeskundige Behandelings Overeenkomst) [88, 89]. It is conceivable that YHS professionals can still comply with the law when informed consent and the request for permission are organized online.

The literature showed some inconsistency when parents can give the information about certain tasks themselves. YHS professionals register the living situation and details of other family members in the child's dossier. Parents can fill in part of this information online. But if important information is received during a home visit, such as a notification of a dirty or unsafe living environment, YHS professionals need to report it in the dossier. Moreover, threats from the immediate vicinity, like smoking and child abuse or a bad neighbourhood, are described by YHS professionals [81]. The

environment is mainly assessed by YHS professionals during home visits. It is conceivable that parents can be involved in these tasks, but it is uncertain if parents can assess these threats since they are used to the situation and probably do not see any problems. Besides, YHS professionals must screen and monitor proactively according to the law to ensure the highest quality of care for the children [47]. YHS professionals also ask for (hereditary) risk factors. Parents can fill in hereditary disorders and diseases in the biological family online but professionals has to investigate to what extent the child has increased risks and must be alert to symptoms and signs [10].

It is possible to make a distinction between information that is simple and can be given by the parents and information that is more complex. For simple information like personal data, it is conceivable that parents fill in the information online in advance of the appointment. Considering complex information like threats from the immediate vicinity, the monitoring function of YHS professionals plays an important role in detecting problems that cannot be detected if parents give this information themselves. Besides that, YHS professionals have a paternalistic role and monitor peculiarities, like signals of child abuse, without the permission of parents. Therefore, a difference can be made between information that is obtained of parents voluntarily and involuntarily.

Taken the above information into account, there are limits to parental involvement because there are tasks for which YHS professionals' expertise is needed. This expertise is needed to obtain complex information (involuntarily) and follow the guidelines to ensure high quality of care. Nevertheless, parents can fill in simple information themselves.

Providing information to parents

Within the second type of task, professionals share much information with parents. For part of the information that the YHS professional provides, the YHS professional has to follow guidelines. Therefore, parents cannot read this kind of information themselves. This is the case in which YHS professionals discuss information about provided care with parents based on YHS guidelines and expertise [83]. This also accounts partly for the information, advice, instruction and guidance that the YHS professional provides. Guidelines that must be followed by the professional for these tasks, are for example 'Nutrition of infants and toddlers' and 'Cot death prevention' [83, 90]. Professionals have a monitoring function and must handle proactively to make sure that parents receive the information. For this reason, important information and unsolicited advice, for example about provided care, must be given to parents by YHS professionals themselves.

YHS professionals also give standardized, practical information and solicited advice to the parents, like information about dental care or toilet training. Moreover, during many contact moments information is repeated. It is possible to share this kind of information online with parents so this information can always be read by them and does not have to be repeated. According to literature, there is a shift from a more paternalistic approach to a situation where parents have more access to information, are more coached in their situation and are encouraged to intervene and act themselves [64]. Besides that, parents have full right of access to all information in the child's dossier and may request a correction, addition, or removal of data [50]. Therefore, it is possible that information in the child's dossier can be shared with parents online instead of discussing it during an appointment.

The literature was not clear as to whether information about conclusion and follow-up of the appointment can be shared online with parents. If follow-up is necessary and extra monitoring is needed, this must be explained comprehensively during the appointment [10]. But when everything is alright with the child and the parents, it is presumable that information can be shared online with parents.

In short, it is conceivable that there are limits to parental involvement in tasks. Parental involvement is not possible for tasks where guidelines must be followed or for which professional's expertise is necessary. Therefore, unsolicited advice and important information must be given by YHS professionals themselves. However, parents are authorized to have access to the child's dossier and the included information should also be given to parents. Besides that, parental involvement is possible for standardized and more practical information.

Monitoring development

The last type of task that professionals have to perform focuses on monitoring the development of the child. There are a few tasks that must be performed by professionals according to the literature. The first one is the hearing test which is performed by the OAE (Oto Acoustic Emission) screener. This person is authorized to screen the children and must meet different criteria and training requirements, so it is likely that it can only be performed by professionals [91]. Another task that can probably only be assessed by experienced YHS professionals is, on every contact, the registration of information of the child based on a general impression of the professional [10].

There are other tasks for which it is likely that they can only be performed by YHS professionals. For these tasks, the YHS professional's experience is essential to follow the guidelines to guarantee a good quality of care. The first one is the check on diaper rash, eczema, fungal infections, hematomas and other abnormalities during every appointment which is carried out in accordance with the YHS guideline for skin disorders [10, 92]. The second one is the check of the navel, thorax, lungs and groin regions according to several guidelines [10, 85]. The third task is the inspection of the lower extremities, hips and feet and different guidelines are followed to monitor this musculoskeletal development [10, 93-95]. The fourth task is the check on genitalia, YHS screens and is alert on abnormalities based on the YHS guideline for maldescensus testis [10, 96]. Detection of congenital heart defects is performed according to the guideline 'heart defects' and the guideline 'Psychosocial problems' is followed to signal psychosocial problems in youth healthcare [10, 97-100]. During every visit to the child consultation clinic the functioning of the child is evaluated conforming to YHS guidelines [85]. The observation of the shape of the skull and fontanel is evaluated following the guideline preference position and skull distortion [10, 94]. The manual 'Attention points Preventive Dental Care 0-19 year for youth healthcare' is followed to give a dental check-up [101]. However, this last one is not intended as standard care.

For the task of measuring and weighing, the literature was inconsistent if parental involvement was possible. According to the literature, the measurement and weighing of children by parents is unreliable, because the quantifying of the length and weight is not done in the same way, no calibrated measuring instruments are used, and parents are not well trained in performing the measurements [102-105]. Moreover, studies showed that parents tend to report lower weight than children actually have. This would mean that the prevalence of overweight is underestimated [84, 102-105]. However

document analysis showed also some advantages of self-measurement, namely children are measured and weighed in a familiar environment, parents are empowered to measure and weigh their child and the time saved by YHS professionals can be spent on other important business [105]. Altogether, this means that it is unclear whether it is advisable to involve parents in this task.

Another task that must be carried out by professionals are the eye tests [10]. These tests are taken based on the YHS guideline for 'Detection of visual disorders' [106]. But it may be possible to provide an accurate eye test online in advance [107]. Besides that, it is conceivable that taking an eye test during the appointment will go smoother if parents practice the eye test at home in advance.

Medical knowledge and skills are required for the complete execution and interpretation of the 'Van Wiechenonderzoek'. The Dutch Centre for Youth and Family (In Dutch: Nederlands Centrum voor Jeugd en Gezin), the Van Wiechen Research Development Foundation (In Dutch: Stichting Van Wiechen Ontwikkelingsonderzoek) and the Netherlands organization for applied scientific research (TNO) have established expertise requirements to carry out the research. Specific training is required to obtain the essential skills for performing the research [108-110]. However, to get a good view of the child's development, the opinion and observation of parents is also of importance [10]. Some parts may even be carried out with the help of an online tool; an example is the part in which the child must stack blocks, it is conceivable that this action can be recorded on video by parents and uploaded online [111]. In this way, it is imaginable that parts of the van Wiechenonderzoek can be performed by parents.

Looking at all the different tasks involved in monitoring development, there are limits to parental involvement in this type of task. Parent cannot be involved in tasks for which professionals' expertise is needed to follow the guidelines. However, it is possible that parents become partly involved to support the YHS professional with measuring and weighing, the eye test and the 'Van Wiechenonderzoek'.

3.1.2 Summary of parental involvement according to the document analysis

Table 3 summarizes the previous sub-paragraphs and describes per type of task what the limits are of parental involvement in youth healthcare with the help of an online support service according to the document analysis.

Table 3 *Summary of parental involvement in type of tasks according to document analysis*

Type of task	Parental involvement possible?
Medical procedures	It is not desirable to involve parents in the medical procedures related to the heel prick and vaccinations since these are reserved actions.
Obtaining information	It is possible that YHS professionals receive simple information of the parents via an online support service. E.g. personal data, family composition and pre-schooling. However, this is not possible for all sections, since the expertise of YHS professionals is needed to follow guidelines to discuss complex information about e.g. the maternity period, recurrent history and data transfer. There is some doubt if parents can be involved in assessing the living situation of the child and if they can estimate the ratio of capacity and burden.
Providing information	Parents can be partly involved because many practical and standardized information can be read online by the parents. E.g. information about the purpose and methods of YHS and information about privacy. But there is more complex information, advice, instruction and guidance, like information about provided care / treatment plan, for which the guidelines must be followed by YHS professionals. It is unclear whether information given in the conclusion and follow-up can be given to parents online.
Monitoring development	The hearing test and the general impression of YHS professionals cannot be done online since the professionals' expertise is needed for this. Guidelines must be followed for many other monitoring tasks, e.g. monitoring of the skin, locomotor apparatus, genitalia and heart defects. It is uncertain whether parents can become involved in the measuring and weighing of the child, the execution of the eye test and the performance of the 'Van Wiechenonderzoek'.

The main reason why parents cannot be involved in certain sections is because YHS professionals must follow the YHS guidelines to guarantee good quality of care. The health inspection (In Dutch: Inspectie voor de Gezondheidszorg) uses the YHS guidelines as professional standards and tests the quality of provided care based on these [12, 85]. It is possible that an online tool can enforce parents in such a way that the guidelines are followed without the need of the professionals' expertise. The protocols of certain guidelines are already automated to involve parents without YHS professionals' support, for example the Strengths and Difficulties Questionnaire (SDQ) that is available online for parents [112]. This means that YHS guidelines are not necessarily a reason why parental involvement is not possible. If this is the case, parents can be involved in more tasks with remaining quality of care. Besides, it should be noted that the documents do not give a well-founded reason for every task whether parents could be more involved with the help of an online support service or not. It is important to take the goals of YHS into account, which means that it is of importance that YHS professionals keep seeing the child and parents [7, 8, 10]. Therefore, it is not desirable that the parents take over all tasks in such a way that an appointment at the child consultation clinic is not necessary anymore, since monitoring and prevention and detection of risks is going to be difficult for YHS professionals without seeing the child. However, it is up to the parents themselves whether they want to carry out tasks since the care delivered by YHS is not mandatory [46]. If parents do not feel comfortable about it, it is likely that YHS professionals keeps performing the tasks instead of parents.

3.2 Results interviews with professionals

3.2.1 Study population

Six YHS professionals were interviewed in this research: four nurses and two doctors. The participants were from different YHS organizations in the Netherlands: one small (< 10,000 children between 0-4), two middle (10,000-20,000) and two large (20,000 >) organizations. Two participants, a nurse and a doctor, were from the same (middle) organization. The participants were active in the YHS field for between 8 and 35 years (mean=18).

3.2.2 Parental involvement according to professionals

The second sub-question is answered in this paragraph: *To what extent is parental involvement possible in the basic tasks of youth healthcare according to youth health services professionals?* The results are given per type of task. An elaboration of the results per section can be found in appendix VII.

Medical procedures

The arguments why tasks under medical procedures had to be carried out by YHS professionals can be found in table 4. All six participants agreed that the heel prick and vaccinations must be performed by the YHS professional. Two professionals thought parental involvement could be possible in the future, this can be derived from this citation: *"Currently not, as we give vaccinations through injections. These are all reserved actions. But there might be a time when vaccinations become patches or drops and then I can imagine that people could do it themselves."*

Table 4 *Professionals' arguments for parental involvement in medical procedures*

Motives pro	Motives con	Preconditions / requirements / opportunities
	- It is unnatural to hurt your own child - It is a medical act	- Parents might do it if vaccinations become patches or drops

Obtaining information of parents

In the type of task obtaining information, the YHS professional has to obtain information of parents and children. The arguments for (no) parental involvement are summarized in table 5.

Table 5 *Professionals' arguments for parental involvement in obtaining information of parents*

Motives pro	Motives con	Preconditions / requirements / opportunities

- Parents can give certain information easily themselves
- Parents know their child best
- It is time saving for the professional
- Professionals do not know all information
- Online because:
  o It is easier for professionals and parents
  o Parents can prepare for the appointment
	- Parents are too busy
	- Not all parents can fill the information in
	- Gut-feeling of the professional is necessary
	- In conversation because:
	  o It is easier for parents
	  o More information can be derived
	  o Personal attention
		- Parents can add/change/check information
		- Questions can be clarified with an I (I for information ed.)
		- Checkboxes / a list with all factors can help parents to give the right information to professionals

There is much information that can be filled in online by the parents according to the YHS professionals. A remarkable point was that professionals had some doubt if they could obtain the information concerning threats from the immediate vicinity of parents. Three professionals had some doubt whether they can assess it themselves and whether parents give this information to them. This is shown in a citation: *"That's a difficult one. I find it a bit dubious. We do not see everything, but parents do not fill them in."* The other three professionals had the opinion that parents cannot fill the information in, since parents cannot assess that themselves and professionals really need a home visit to observe this. Another noteworthy point was shown with hereditary risk factors, there was one professional who disagreed with the others and thought that parents cannot be involved: "*I think that you don't really want to have parents to tell themselves that they have psychiatric problems for example. That is not desirable, so then I think that it's better that we fill in that part."*

With the estimation of the ratio of capacity and burden it was striking that two professionals thought that parents can be involved. The other four professionals had the opinion that parents cannot provide this information to the professional. The main reason for this was that the professionals have a gut-feeling for certain situations: *"We have many radars, radar to parents, radar on how do parents interact with each other, how does the child respond to his parents and how does the child respond to me. That's all apart from the actual conversation and for that part you really need someone. You cannot digitize that."* The last notable point is that only one professional thought that parents cannot give the information about the maternity period themselves to the YHS professional: *"Only the question is always, you know there is so much happening at that moment, so can they see that? And are parents looking for that? And then I think it's good that this stays with us. Yes, I think that it just has to stay with us."* The other five thought parents can give the information themselves.

Since there were many arguments pro and con parental involvement, it is not clear whether it is a good idea to involve parents. It is conceivable that a distinction can be made between information that parents can fill in easily and information that is complex. Information like contact moment, personal data and general practitioner can be registered easily by parents. Information like threat from the immediate vicinity and the ratio of capacity and burden requires skills of parents and it may be wise that the professional obtains this information during an appointment.

Providing information to parents

All professionals had the opinion that parents can become partly involved in the type of task providing information where the professional provide the information to parents (see table 6).

Table 6 *Professionals' arguments for parental involvement in providing information to parents*

Motives pro	Motives con	Preconditions / requirements / opportunities

- Parents can read information themselves easily
- Parents will become more involved
- Parents know their child best
- It is time saving for professionals
- Appointments are more to-the-point
- Online because:
  o Information is always accessible
  o It is easier for professionals and parents
  o Many ways to provide information
	- Parents do not know which information they miss
	- Parents cannot assess all information
	- Professional is needed for specific information
	- In conversation because:
	  o Not every parent can read the information
	  o A good relationship / mutual trust can be realized
		- Conversation about risk factors is needed
		- Combination of a personal story and rereading online
		- Discuss together with parents
		- Online is only suitable for standardized information

The reasons why parental involvement is somewhat unwise, were also important to take into account. The main reason why professionals wanted to give the information themselves instead of online was because they have the knowledge and experience. It may be wise to discuss important information, like information about treatment and provided care, together with parents because the power of persuasion is missing online. Professionals are needed for this kind of specific information to convince parents. Basic information, such as information about toilet training or education, can be given to parents online instead of telling it during an appointment. One professional gave a good summary of different arguments: *"We have popular topics that many parents have questions about and where kind of standard answers can be given (…) Only in the case of an educational question very often come the feelings of the family situation and context in which the child grows, apparent."* Another professional thought that parents can read much information online except for important specific information: *"Yes, I think that parents can do themselves 80-85%, but I think that that little specific part lies with us."*

Monitoring development

In the type of task where YHS professionals monitor the development of the child, the different arguments for parental involvement are shown in table 7.

Table 7 *Professionals' arguments for parental involvement in monitoring development*

Motives pro	Motives con	Preconditions / requirements / opportunities
- Parents know their child best - Parents are able to monitor their child - Parent can practice / prepare things at home easily - Videos give good insight in the development - It does not have to happen in the appointment / live	- Parents do not want to monitor their child - Parents cannot assess the development of their child - Professionals' expertise is needed - It is a medical evaluation	- Children can be measured when they are bigger - Combination of parents' and professionals' observation - Questionnaires help parents with monitoring - An interactive video helps parents with monitoring - The research setting must be right for examination

The professionals agreed that parents cannot become involved in most tasks because professional expertise was needed: *"That's a medical evaluation. That's why you really need doctors/nurses."* However, all professionals thought that parents can be partly involved in measuring and weighing of the child, as can be derived from the citation: *"Measuring of the length of children who should be measured lying flat is also quite difficult. But if children are bigger and able to stand under a measuring stick parents can do that."*

Two professionals disagreed with the other four and stated that professionals have to monitor the physical, psychological, emotional and social functioning: *You want to see a child walking, you want to see how it develops. In the case of limp children, you want to feel them. (…) But you also want to see how the interaction is between mother and child."* Whether parents can monitor the head/neck area, resulted also in a disagreement between the professionals. Two professionals had the opinion that an experienced professional had to perform this task. The other four professionals thought that there are ways in which parents can become partly involved: *"So, I think that an interactive video certainly contributes to it. But still, we also ask for the use of teat/bottle and the consequences of it. You should also offer customized care."* Another professional showed some doubt whether parents could monitor the psychological, cognitive, motor and speech and language development and stated: *"Yes, that is possible, but that are quite strict instructions of how to do it and what you may or may not say or can or cannot show the child (…) Then parents must be able to film the action very well before it is of added value."* The other five professionals thought that parents are able to be partly involved in the monitoring of the development: *"Parents provide the information, the child shows something and I conclude whether it is all right or not."*

About the eye research was also disagreement among the professionals if parents can become more involved or not. Three professionals stated that the eye test must be performed by professionals because of their expertise: *"It must be with both eyes separately and you have to make sure that the other eye cannot see anything. If you want to be sure, the professional must do that."* The other three professionals thought that parents can become involved in the eye test or can practice the eye test at home: *"Parents can be able to perform the eye test, but then the research situation should also be conforming the guidelines."* and *"…then they really have to perform it correctly, otherwise it is useless. Then they can better not do it. So, practising at home, please do, that really helps us. But performing, no, I'm against that."*

There were many arguments pro and against parental involvement in monitoring of development. The most important reason why parents cannot be involved was because the professional's expertise was needed. There were also reasons why parents can monitor the development of their child, but it is important to realize that parental involvement in the monitoring of the development can influence the quality of care. It may be wise to involve parents only partly in monitoring tasks and that YHS professionals still control parents and children and monitors the important aspects.

3.2.3 Summary of results study I & II

Of the 28 sections in the Basic Tasks Youth Healthcare, both the document analysis and the interviews with YHS professionals showed that parents cannot be involved in the following sections: Heel prick, National immunization program, Hearing test, General impression, Skin/Hair/Nails, Torso, Genitalia and Heart research. These eight sections were all excluded from study III because the professionals' expertise was necessary for the included tasks. All tasks were medical examinations in which parents cannot be involved to guarantee the quality of care. Since the section locomotor apparatus is not presented to the professionals, it is decided to also exclude this section from study III because the document analysis showed that this cannot be performed by parents.

Based on the results of study I and II, nineteen sections remain of interest for study III. These nineteen sections include the sections where parents can be completely or partly involved in and where there was doubt and disagreement among the results of the document analysis and the interviews with YHS professionals. The sections where there was doubt and disagreement were also included, because the opinion of the parents could give arguments for decision-making if parental involvement is possible. The following nineteen sections, in which parental involvement was possible according the document analysis and / or the YHS professionals, were relevant for study III:

- Conclusion and follow-up
- Contact moment
- Determining delivered care
- Estimating the ratio of capacity and burden
- Eye research
- Family composition
- General practitioner
- Growth, length, weight, head circumference
- Head/neck
- Hereditary risk factors
- Information about process YHS, Civil code, Law on Medical Treatment Agreement, Law for the protection of personal information
- Information, advice, instruction and guidance
- Personal data
- Physical, psychological, emotional and social functioning
- Pregnancy, delivery, newborn, first weeks
- Pre-schooling
- Psychosocial and cognitive development, motor development, speech and language development
- Recurrent history
- Threat from the immediate vicinity

3.3 Results interviews with parents

3.3.1 Study population

Sixteen parents were interviewed in this study, of which four men and twelve women. Appendix VIII shows an overview of the demographic data of the interviewed persons. The parents had on average two children. Of all parents, seven finished secondary vocational education (in Dutch: mbo), seven had followed higher professional education (in Dutch: hbo) and two parents had finished university (in Dutch: wo). All parents had access to a laptop, mobile phone and sometimes also a tablet and they all used internet every day.

3.3.2 Parents' opinion towards an online support service

This paragraph give answer to the third sub-question: *To what extent are parents of 0-4 year old children who visit youth health services willing to use an online support service for the preventive care of their child?*

All participants used internet frequently and saw themselves as experienced users, as can be seen in the following quotation: *"Yes, I use it daily. Actually, I do everything with it nowadays."*. Seven parents already used something similar to an online support service, namely the 'Mijn Kinddossier' of Topicus Healthcare B.V. Parents were all satisfied about the 'Mijn Kinddossier', but it was mainly interesting when children were younger: *"Yes, I think is very useful. I'm glad that you can change appointments. It is also nice that the professional can also see this information, so if you have questions this is the basic system where you can find the right information. If they register something, then you don't have the information but now you can look online and read it whenever you want. Especially when the children are younger is this really helpful."* Eight parents who had not used 'Mijn Kinddossier' were positive concerning the use of an online support service: *"Yes, I'm in favour of digitizing on all levels. The growth booklet is still a book which is easily damaged if you for example drop a cup of coffee on it. And such an online tool, that's super! Looks really good. Also, that you can rely on that instead of being dependent on a doctor. In this overview, you see at a glance what your child had done or does."* One parent said that she only wanted to use it if it works properly and if privacy was guaranteed: *"If it works properly, I think it's useful. It's just quite hard to make this really work properly. (…) And then I do not see the added value of it if you have the growth booklet. The booklet contains all the information and it's a lot more fun to read the book than to browse such a site and to click around a hundred times before you find something relevant. And all information is kept online, then security is also of importance."*

It is shown that, in principle, all parents wanted to use an online support service for the healthcare of their child. Table 8 gives an overview of the functionalities that the parents wanted to have in an online support service if they were going to use it. All parents wanted to have a functionality in which they can make or change appointments online. The visual display of the growth chart was also mentioned often by the parents.

Table 8 *Preferred functionalities in an online support service according to parents*

Functionalities	Example quotation (N)
Appointment	*"…making appointments online is very useful."* (16)
Growth chart	*"Yes, I think the growth charts are important…"* (12)
General information	*"…all information that you need about chilrend in a nutshell."* (9)
Vaccinations	*"…it would also be nice if you can see the information about vaccinations online and in which appointment they are."* (8)
Register information (diary)	*"It can be nice to have some sort of diary, that you can register information about you child."* (7)
Contact with YHS	*"…direct contact after login, I think this could be of added value for many people."* (6)
Advice of professional	*"…also useful if the professional can give advice."* (6)
Medical data of child	*"… the professionals fill in a form every appointment, that you have insight in that, the child's dossier."* (4)
Background information / dossier of parents	*"…also medical information of the parents can be important."* (2)
Questionnaires	*"Yes, questionnaires are certainly useful if you need to fill them in…"* (2)
Comparison between own children	*"I like it if you can compare between your children, that one was so big and this one is smaller…"* (1)

3.3.3 Parental involvement according to parents

The fourth sub-question is answered in this paragraph: *To what extent is parental involvement possible in the basic tasks of youth healthcare according to the parents who visit youth health services with their 0-4 year old children?* The results are given per type of task. The type of task medical procedures is not shown in this paragraph since the underlying tasks were excluded from study III. An elaboration of the results per section can be found in appendix IX.

Obtaining information of parents

Table 9 gives an overview of the reasons why parents can or cannot become involved in the type of task obtaining information.

Table 9 *Parents' arguments for parental involvement in obtaining information of parents*

Motives pro	Motives con	Preconditions / requirements / opportunities

- Parents will fill in the information
- Parents know certain information better
- Parents can assess the needed information
- Parents can prepare for the appointments
- It is time saving for professionals
- Online because:
  o Parents are not looking forward to a visit
  o It is easier for professionals and parents
  o The information is always accessible
	- Parents do not want to fill in the information
	- Parents forget to fill it in
	- Not every parent can assess everything
	- Professionals' expertise is needed
	- Social desirable answers can be given online
	- Emotions cannot be conveyed online
	- In conversation because:
	  o Parents get personal attention
	  o Parents find it nice
		- Transfer the information from organizations
		- Fill in the information online before childbirth
		- Reminder parents that the information can be filled in online
		- Professional can check/correct information afterwards
		- Combination of information online and conversation about relevant things
		- If a list with a good explanation of the information YHS want is given online, parents can give the information

In general, parents want to provide the information online to professionals. This is especially the case if the information contains data that can easily be given, like information about personal data, who the general practitioner of the child is, when parents want to make a new appointment et cetera: *"That's not so complicated. I would like to fill that in myself."* Parents were not looking forward to providing professionals with more complex information, like threats from the immediate vicinity and the ratio of capacity and burden. Parents thought that they were not able to assess all things and to give reliable information to the professional: *"Because you're just part of the situation and they come from the outside and therefore can estimate things better. I think they should do that. People can say that they belong to the good part while they are completely on the other side."* However, one parent thought that parents can provide the professional with all information: *"I find it ridiculous that they check it that way, so patronizing. I can estimate whether the environment is safe. You are nine months pregnant, you can prepare for it all that time."*

Providing information to parents

The results regarding the type of task providing information are shown in table 10.

Table 10 *Parents' arguments for parental involvement in providing information to parents*

Motives pro	Motives con	Preconditions / requirements / opportunities

- Parents get insight into professionals' opinion
- Fewer appointments necessary
- Online because:
  o Parents read the information that is relevant for them
  o It is easier for professionals and parents
  o Information is always accessible
  o More comprehensive information can be given
	- Parents will not read it
	- Parents cannot assess the information
	- Professionals' expertise is needed
	- In conversation because:
	  o It is easier for parents
	  o Parents get personal attention
	  o Parents find it nice
		- Transfer the information from organizations
		- Mention it in appointment, but give the information online
		- Discuss questions and relevant things during appointments
		- Combination of information online and conversation about it
		- In conversation with the first child and after that online
		- Only information online that is understandable for parents
		- Reminder parents that the information is online

Parents were not sure if all the information that the YHS professional gives can be given online, because they cannot assess all information. In general, it can be said that parents wanted to read more general and simple information online, like information about toilet training. A parent stated: *"One environment that contains all information, I think it's a very welcome feature. In the form of an app or an online environment."* If the information is more complex or personal, such as information about provided care, parents liked to have a conversation about it. An important argument for this is: *"Yes, I know how it works and I know what to do. But I can imagine that I do not see things or miss things or things that can be easier or better or smarter. And therefore, you need the professionals' advice."* One parent had the opinion that everything can be put online after the first child: *"With the first child it is important information, but with the second or third you already know this. So, the first conversation person to person and then they can put it online so I can read it if I don't know it anymore."*

Monitoring development

Table 11 gives an overview of the arguments why parental involvement is (not) possible in the type of task monitoring development.

Table 11 *Parents' arguments for parental involvement in monitoring development*

Motives pro	Motives con	Preconditions / requirements / opportunities

- Parents can monitor in their own time
- Parents will monitor their child
- Parents are not dependent on the actions of their child at the child consultation clinic
	- Professionals' expertise is needed
	- It is more efficient if the professional does this
	- Not all parents are capable of monitoring their child
	- Parents forget it
	- Parents do not want to put effort in it
	- It is an important checkpoint
	- No child is the same
	- In conversation because:
	  o Professionals can assess this better in an appointment
	  o Parents find it nice to discuss this in personal
		- Combination of information online and conversation about relevant things
		- Actions explained in consult but the rest online
		- Reminder parents that things need to be done
		- Parents can perform tasks at the child consultation clinic with the right research setting
		- Parents want perform monitoring tests if the child does not succeed during the appointment
		- Parents do not want to film things structurally, only if it is necessary
		- Parents want instruction of the professional
		- In conversation with the first child and after that online

There are many different tasks included in this type of task. Most parents thought that they can monitor the development of the child partly. Parents can find information about monitoring online and wanted to perform certain tasks themselves with professionals' help: *"I would not have much trouble doing that myself. If they just tell you how to do that, you can do it."* Parents also wanted to film the development if the child does not succeed with the actions during the appointment: *"Yes, if they say that it doesn't work during the appointment and it works at home and they ask me if I want to film it, that's not a problem for me. I want to do that."* Additionally, parents stated that it depends on the child: *"Some children are shy and don't dare to do anything. If I can do anything that helps, I would do that."* However, parents also saw problems if parents became involved in the monitoring task of the professional since the professionals' expertise is needed: *"Yes, I think that these are tasks for the child consultation clinic. I have more things to do. I really think it's a checkpoint, you cannot depend on the parent's trustworthiness."* It is conceivable that a distinction should be made between monitoring parts that parents can do themselves with the help of a professional and monitoring parts for which the professionals' expertise is needed.

4. Discussion

4.1 Answering the research question

With the results of the document analysis and the interviews with professionals and parents, the four sub-questions can be answered. An explanation if parents can become more involved in the tasks of YHS professionals is given in the next paragraphs per type of task based on the results the document analysis revealed and the arguments that the professionals and parents gave. Thereafter, the main research question is answered.

Medical procedures

According to the document analysis and the professionals' opinion, parental involvement is not possible in the medical procedures that YHS professionals must perform. As long as medical procedures are reserved actions, parents are not allowed to become involved.

Obtaining information

The results from the document analysis and interviews with both professionals and parents showed that YHS professionals can obtain information of parents and children via an online support service. Parents can and want to fill in simple information, like personal data, via an online support service to become more empowered. It is helpful to ask for this kind of information in a questionnaire to make sure that parents do not forget any relevant information. It should be noted that parents liked to get a reminder to make sure that they do not forget to fill in this information online. Professionals and parents found it important that relevant issues based on the information that parents gave should be discussed in the appointment. Moreover, parents should not provide complex important information, such as information about threats from the vicinity, via an online support service. Professionals have to ask for complex and important information to make sure that parents understand it and that all information is gathered.

Providing information

The results of the document analysis and interviews with professionals and parents agreed that professionals do not have to share all information with parents during appointments. Parents can and want to read standardized information, like information about toilet training and dental care, themselves via an online support service. This can make parents more empowered in the healthcare of their child. It is important that YHS professionals tell relevant information during the appointment and make sure that parents know where to find the information. Since parents cannot assess all information themselves, important and complex information, about for example treatment and provided care, must be shared with parents during an appointment besides putting it only online. Additionally, it is necessary to discuss information in the appointment if parents have questions concerning certain information.

Monitoring development

Professionals and parents thought that parents can be partly involved in the monitoring of the development. Parents can and want to measure and weigh their child themselves at the child consultation clinic. Additionally, if professionals cannot evaluate whether the child can perform certain actions, parents can film this themselves and upload it in an online support service. It is conceivable that simple tasks can be performed by parents, like practicing the eye test at home. Besides that,

parents can inform the professional on development since they know their child best. However, both professionals and parents thought that the development is a medical evaluation of YHS professionals. This means that it is important that the child stays under control of YHS to ensure high quality of care and to make sure that no disorders are missed.

Now is known to what extent parental involvement is possible, the main research question can be answered: *"To what extent can parents who visit the youth health services with their 0 to 4 year old child become involved in basic tasks of youth healthcare with the help of an online support service?"* Parents can become involved in the basic tasks of youth healthcare for which no professional expertise is needed. It was also shown that parents wanted to use an online support service to perform simple tasks themselves. Parents can become partly involved with the help of an online support service because they can read standardized information online, they can fill in simple information online and they can perform certain tasks at home or at the child consultation clinic.

4.2 Explanation of results & comparison with literature

The most interesting findings of this study are described below. These findings are compared with results of other studies and recommendations are given.

First of all, the results of the interviews with professionals and parents showed certain basic tasks of youth healthcare for which parental involvement is not recommended. The main argument for this is parents' lack of expertise. This is in line with the document analysis and literature that showed that the YHS professionals' expertise is needed to ensure the highest possible level of health and facilities for medical care and rehabilitation [9, 12, 47, 113].

A notable difference was that the document analysis showed less sections in which parental involvement was possible than the interviews results showed. An explanation for this difference is that the document analysis' results gave YHS guidelines and Dutch laws often as an important reason why parents cannot become involved. Neither professionals nor parents named the guidelines and laws as a reason against parental involvement. The most likely explanation is that the guidelines and laws already play an important role in YHS professionals' tasks. This was also shown in the document analysis, since parts of the guidelines were already implemented online for parental involvement [112]. This means that YHS professionals argued from their expertise with the documents that parents can become involved in tasks. Moreover, a too strict interpretation of the documents in the document analysis might have caused the different results. This means that parental involvement might be possible in tasks were guidelines must be followed. Therefore, it is recommended to investigate if it is possible to implement other requirements of YHS guidelines and Dutch laws in an online support service.

Another striking point was that parents wanted to become involved in fewer tasks than professionals thought parents could become involved in. This was especially the case for the type of task monitoring development. Most professionals were optimistic about parental involvement and thought that parents were able to perform tasks themselves. On the other hand, the parents did not want to be more involved in certain tasks because they thought they were not capable enough. This result contradicts the findings in previous studies that showed that healthcare providers underestimate patients' capabilities [114, 115]. The contradictory results may be caused by the difference between

curative and preventive healthcare. However, YHS professionals should be attentive to this difference because YHS professionals may have unrealistic expectations of parent's capabilities. Another explanation why professionals were more positive about the capabilities of parents than parents were themselves, could be that parents have a lack of self-esteem. It became clear that parents were more concerned about development at the first child than with the second and third child. This is also scientifically underpinned, because research findings showed that parents with the first child felt overwhelmed by the new situation and had a need for help from their partner, their own network and YHS professionals [116, 117]. If new parents get training about how to perform tasks or how to use an online support service, it is presumable that this will lead to more self-confident parents who want to and can become more empowered [118-121].

Another reason why parents did not want to be involved in certain tasks, is because parents want the advice of the professional face-to-face. This applies in particular to the type of task obtaining information. Parents liked the fact that they can share their story in person during appointments instead of via an online support service. This finding is in line with the literature, because an online support service cannot replace the patient-provider relationship which can offer personal interaction and customized advice [122]. In addition, participants found it important that YHS professionals keep a monitoring function. This is in accordance with the results from the document analysis and the goal of the YHS, because parents cannot monitor everything themselves [7, 8]. For the above reasons, it is important that the YHS professional sees the child on a regular basis. But there are other more efficient ways how YHS professionals can see children on a regular basis to ensure supervision and control. Studies showed that the need for appointments can decrease with the use of an online support tool or video conferencing tools like Skype [123-125]. It could be interesting to look at the option to include video conferencing in an online support service. Moreover, it is recommended to investigate if group meetings with parents and children and professionals can be implemented. In group meetings, professionals can observe the children and it is more efficient since parents can learn from each other and the YHS professional at the same time [121, 126, 127]. It is conceivable that group meetings and video conferencing tools may address the parents' needs.

There are also certain tasks parents do want to become involved in. This is an expected result since there is a shift from a paternalistic approach to more patient-centred care [128, 129] Besides that, studies showed that patients want to become more empowered via online tools because online tools have the potential to improve patients' access to information, engagement in care, and health outcomes [32, 130-132]. By involving parents in YHS, parents can become more active participants in their child's healthcare and this could improve empowerment. But whether parental involvement is actually possible and will lead to empowerment, needs to be examined in future research. It is recommended to set-up an experimental study where parents actually become involved in YHS to investigate the effects of parental involvement on parents and professionals. With a pilot experiment feasibility, time, cost and adverse events can be evaluated of parental involvement.

Another expected result was that parents were positive towards the use of an online support service for youth healthcare of their child. This is not surprisingly since other studies showed that internet use for health purposes is growing in all age groups [133-135]. Studies showed an increase in internet use, which makes it conceivable that in the future almost all parents have internet access and can make use of an online support service [60, 61]. Therefore, it is recommended to find out if and how online

support services can be implemented in YHS. However, parents with a low eHealth literacy or illiteracy have difficulties with the use of an online support service. Yet, an online support service can be tailored to fit different users [136]. A literature study demonstrates that efforts in the content, design, and ease of use of health information on the internet can contribute in such a way that also people low in eHealth literacy may make fuller use of digital resources [137]. The way in which an online support service is designed for parents, is essential for the capability of parents to assess things. It is important to involve parents' input for the realization and further development since they are the end-users of the tool. Besides that, it is important to take into account the ease of learning a new technology for professionals as an important factor in the acceptance and adoption of an online support service [123, 138]. Nevertheless, this study showed that not all parents can assess all things themselves. Therefore, it should be noted that there are still parents who do not want to or are not able to use an online support service. For these parents, it is important that care is provided offline.

A drawback of an online support service which has to be taken into account is that it cannot provide persuasive power to parents. An important aspect of the appointments is that YHS professionals can convince parents to do things for the child's best health, an online support service lacks this convincing power. A positive point of an online support service is on the other hand that the provision of information can be realized via different ways. Studies showed that repetition of information via different communication channels has a positive influence on the recall of health-related information and health outcomes [139, 140]. This means that an online support service can help parents by showing information in different ways to improve recall of important information. Professionals and parents named more beneficial aspects of parental involvement via an online support service. The contact moments can be carried out more efficiently since the YHS professional knows what issues should be addressed in advance. Moreover, the length of appointments can be adjusted to concerns parents want to address. Research showed that there is an increasing request for a demand-orientated and demand-driven approach in health care [141, 142]. Since the focus of YHS can become more demand-orientated and customized with the help of an online support service, parents are probably more satisfied about YHS.

Since parents wanted to use an online support service for their child's healthcare, this can lead to time savings for YHS professionals. Studies showed that eHealth can be time saving when it for example helps avoiding time consuming face-to-face consultations [39-41]. Moreover, parents can perform certain tasks which will also save time since YHS professionals have to perform fewer tasks. It is likely that YHS professionals' time is spent differently and more efficiently when an online support service is used and parental involvement is possible. On the other hand, the YHS professional has to invest time in an online support service as well [138]. It is the question whether this will save time for the YHS professional eventually. To get to know if parental involvement is time saving and how much time can be saved, it is recommended to explore how often tasks are performed and how long it takes professionals to perform them. In this way, it can be investigated which tasks could generate the most time savings for professionals if parents become involved. Next to that it is interesting to investigate how much time it costs for YHS professionals to use an online support service. This can create an overview of saved time because of parental involvement in tasks of the YHS.

4.3 Strengths & limitations

To the best of the researcher's knowledge, this is the first study that investigated the possibilities of parental involvement in YHS with the help of an online support service. A strong point is that this study included a document analysis and interviews with professionals as well as parents which gave an understanding of parental involvement from different perspectives. Nevertheless, there are also some limitations which should be taken into account by the interpretation of the results.

Although the number of interviews is limited, the researcher was convinced that data saturation was achieved. However, a first limitation is that further research is necessary to draw conclusions concerning parental involvement since the number of participants is too low to generalize the results for YHS in the Netherlands.

A second limitation is that the recruiting of participants can cause selection bias. The participants in study I were approached via YHS managers and in study II via the researcher and consultants at Topicus Healthcare B.V. In addition, all participants volunteered in the interviews which can also create selection bias.

It is important to note that professionals' and parents' opinions were asked about abstract situations, which can lead to different interpretations. Therefore, a degree of caution is necessary in drawing conclusions from this study. Only when parents actually become involved in YHS, it can be explored how participants react. Further research in conducting an experiment that can investigate the real effects of parental involvement on parents and professionals can overcome the foregoing limitation.

A qualitative study was suitable for this study since it was an explorative study. However, only one researcher interpreted all data which can cause subjectivity and interpretation mistakes. To minimize the influence of the researcher, two supervisors assisted with analysis of the results.

4.4 Recommendations

The previous paragraphs already pointed out several recommendations, which are summarized in table 12.

Table 12 *Overview of recommendations for YHS and further research*

Recommendations	
Practical recommendations	
Online support service	1. Find out if and how online support services can be implemented in YHS. a. Investigate if it is possible to implement requirements of YHS guidelines and Dutch laws in an online support service. b. Involve professionals and parents' input for the realization and further development of an online support service. c. Investigate if it is beneficial to implement a video conferencing tool in an online support service.
Parental involvement tasks	2. YHS professionals should keep performing tasks for which their expertise is necessary. 3. Investigate if group meetings with parents and children and professionals can be implemented. 4. Give training to new parents to improve self-esteem and empower them. 5. Care must also be delivered offline for parents who cannot use an online support service.
Recommendations for further research	
Experimental study	6. Set-up an experimental study to evaluate the feasibility, time, cost and adverse events of parental involvement.
Time saving study	7. Explore how often tasks are performed by YHS professionals and how long it takes to perform them. 8. Investigate how much time it costs for YHS professionals to use an online support service.

4.4.1 Practical recommendations

Recommendations for an online support service were already outlined in the previous paragraph. In line with this, it is first recommended to create an implementation plan for parental involvement in YHS via an online support service. The results of this study gave starting points about how parental involvement is possible via an online support service. In appendix X is outlined which parts can be implemented in an online support service for parents in YHS.

There are other recommendations that can be implemented in an online support service, but an online support service is not necessary needed to adhere to these recommendations. The first recommendation is that YHS must organize the current contact moments more flexibly to meet the parents' wishes. Parents appreciate demand-oriented care instead of a standard approach. Secondly, it is recommended that it is important that YHS give parents the possibility to become involved in their child's healthcare. Starting with simple tasks where YHS professionals obtain information of parents via for example a questionnaire and increase involvement slowly if this is successful.

4.4.2 Recommendations for further research

A recommendation that was outlined in the previous paragraph was to set-up an experimental pilot. When an online support services is developed, it is possible to start an experimental pilot to investigate whether parental involvement is actually possible in YHS. But before an experimental study is conducted, a recommendation is to perform a quantitative study first to get a better understanding of

the opinions of professionals and parents. The information gathered in this study provides interesting background information that can be useful for the design of a quantitative study.

This study took the BTYH as the basis for YHS professionals, but it is conceivable that there are other ways to get insight into parental involvement because the BTYH is not strictly followed in a contact moment. For this reason, it is important for further research to look at other ways to describe the tasks performed by the YHS professionals, for example the basic dataset YHS (In Dutch: Basisdataset Jeugdgezondheidszorg) [87].

The last recommendation is that it can be interesting to zoom in on specific groups, like parents of risk groups, because it is possible that different groups have different opinions. Besides that, if it is possible to reach parents that do not visit YHS, it can be interesting to investigate whether these parents are willing to use an online support service since this is easier accessible than going to appointments [55, 56, 143, 144].

4.5 Conclusion

It can be concluded that both parents as well as professionals share the opinion that parents could be more involved in certain tasks with the help of an online support service. This finding was also supported by the document analysis. According to the results of the document analysis and the interviews with YHS professionals and parents, involving parents in youth healthcare could improve empowerment. Empowerment of parents could lead to more effective care and decision making since parents know their child best. Besides that, parental involvement in tasks can save time for YHS professionals who have to perform fewer tasks. This time can lead to shorter appointment durations and cost savings or can be invested in more customized care to improve te quality of care. Whether parental involvement will actually lead to empowerment, improved care or reduced costs needs to be examined in future research.

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6. Appendices

Appendix I – Explanation of sections in the BTYH

Table 13 *Description of basic tasks of youth healthcare included in the sections*

Sections	Explanation of tasks
Newborn heel prick	In the first week after birth, a few drops of blood will be taken from a child's heel. In a laboratory, the blood is examined for several serious rare infectious diseases [145].
Hearing test	In the first few weeks after birth, a child will have a hearing test. This test will measure whether children hear enough to learn to speak.
Personal data	When a baby is two weeks old, data like name, address, date of birth, citizen service number (In Dutch: Burgerservicenummer) of the child based on Municipal Personal Records Database (In Dutch: Gemeentelijke Basisadministratie Persoonsgegevens) and additional information of the child is filled in by the YHS professional in the child's dossier.
General practitioner	In the second week, the name of the GP and location of the GP's office is questioned by the YHS professional.
Family composition	If the child is two weeks old, the YHS professional registers the living situation, family composition and details of other family members in the child's dossier.
Hereditary risk factors	The YHS professional describes the risk factors when the baby is two or four weeks old. Hereditary risk factors from parents and family members are also filled in in the child's dossier.
Pregnancy, delivery, newborn, first weeks	In the second week, the information from obstetrics and the maternity period is filled in by the YHS professional.
Threat from the immediate vicinity	Threats from the immediate vicinity, first and second environment, are described by the YHS professional in the second week. The first environment is based on the family of the child. The housing, schools, playgrounds, traffic safety, environment et cetera are called the second environment of the child. These environments are mainly assessed by the YHS professional during a home visit.
Information about process YHS, Civil code, Law on Medical Treatment Agreement, Law for the protection of personal information	The YHS professional gives information during the second week and the last appointment at the child consultation clinic at 3.9 years. The professional provides information about the purpose and methods of the YHS, requests permission for the performance of activities (including vaccinations) and discusses privacy and data transfer. Permission is also asked for the sharing of information to third parties. Besides that, the YHS professional gives folders about privacy, complaints and vaccinations.
Pre-schooling	When the child is three months old, the YHS professional asks the parent about pre-school and if the child goes to a pre-school the professional wants to know what type of pre-school and how many parts of the day.
Contact moment	At every visit to the child consultation clinic the following information needs to be filled in by the YHS professional in the child's dossier: date, child's age at contact moment (in weeks and days), child's supervisor and professional during contact moment.
Recurrent history	The recurrent child's history is assessed during every appointment at the child consultation clinic. It is dependent on the child's age what information is needed, but in general are the following issues discussed: parent's experience of child's health and diseases, sleeping, milk formula, nutrition, use of vitamins/medicines, striking details of previous vaccination and physical exercise.
General impression	The YHS professional reports information of the child every contact moment at the child consultation clinic based on a general impression. The received information is about: interaction parent/child, interaction child/YHS professional, care/hygiene, preference position, impression of illness, skin colour, fatigue and perspiration.
Psychological, emotional and social functioning	During every visit at the child consultation clinic the functioning of the child is evaluated. The YHS professional focuses in general on the following topics: sleeping, eating, urination/secretion/toilet training, adaptation/social behaviour/personality,

	parent/child relationship, behaviour/temperament, exploring drift, understanding and relation with brother/sister/peers.
Skin/hair/nails	Till the contact moment at nine months old, the YHS professional needs to check the children on diaper rash, eczema, fungal infections, hematomas and other abnormalities during every appointment. In the contact moments after nine months, the professional only checks for particularities.
Head/neck	During the first seven appointments at the child consultation clinic the YHS professional observes the shape of the skull and fontanel and determines if the head has a forced position. When the child gets teeth, a dental check-up is given.
Torso	In the first five contact moments at the child consultation clinic, the navel, thorax, lungs and groin regions of the child are checked.
Locomotor apparatus	The lower extremities, hips and feet are inspected by the YHS professional several times during childhood.
Genitalia	The YHS professional checks the genitalia of the child several times, the YHS screens for maldescensus testis and is alert on abnormalities.
Growth, length, weight, head circumference	The child is measured and weighed during every appointment with the YHS professional.
Psychosocial and cognitive development, motor development, speech and language development	In eleven contact moments till 3.9 years old the 'Van Wiechenonderzoek' is performed which is an important tool to systematically monitor the development of babies and toddlers [111]. Besides that, the YHS professional signals psychosocial problems.
Estimating the ratio of capacity and burden	The YHS professional estimates the ratio of capacity and burden during every contact moment, based on the 'Balansmodel van bakker'. This model summarizes the combination of protective and risk factors for the development of a child [146].
Determining delivered care	During every appointment at the child consultation clinic, received care is determined based on the current present problems.
Eye research	The YHS professional performs eye tests in six contact moments during childhood.
Heart research	During every contact moment, the YHS professional focuses on the detection of congenital heart defects.
National immunization program	The YHS professional gives information about the immunization program and asks for permission when the child is four weeks old, after that the child is vaccinated six times at the child consultation clinic.
Information, advice, instruction and guidance	At every appointment, the YHS professional gives information, advice, instruction and guidance to the parents of a child. The topic of information differs per contact moment, e.g. safety, breast feeding, nutrition, health risks and education.
Conclusion and follow-up	After each appointment, the YHS professional evaluates the appointment, gives a conclusion and describes possible follow-up steps. Besides that, there are also two evaluation moments planned with the parents.

Appendix II - Interview YHS professionals

Interview scheme

Voorbereiding:
Informatiebrief opsturen
Printen:
- *Interview*
- *Interview schema*
- *Excelsheet Basistakenpakket JGZ*
- *Toestemmingsverklaring*

Meenemen:
- *Opnameapparatuur*
- *Telefoon*
- *Opladers*
- *Interview*
- *Interview schema*
- *Toestemmingsverklaring*
- *Pen en papier*

Introductie:
Voorstellen: Afstudeeronderzoek voor de master Gezondheidswetenschappen aan de Universiteit Twente, namens Topicus Healthcare B.V.
Doel: Onderzoeken of ouders bepaalde taken uit het basistakenpakket over zouden kunnen nemen van de professional, zodat de professional meer tijd over houdt voor andere taken.
Procedure: Het interview zal 30-45 minuten in beslag nemen.
Geluidsopname: Toestemming vragen voor geluidsopname.
Toestemmingsverklaring: Toestemmingsverklaring tekenen.
Vragen: Mogelijkheid om vooraf vragen te stellen.

Interview:
Onderdelen:
- *Algemene gegevens*
- *Toelichting geven op taken onder categorie 'Medical procedures'*
- *Toelichting geven op taken onder categorie 'Providing information'*
- *Toelichting geven op taken onder categorie 'Obtaining information'*
- *Toelichting geven op taken onder categorie 'Monitoring development'*

Afsluiting:
Vragen naar overige vragen en interesse in resultaten
Bedanken voor medewerking

Information letter

Informatiebrief professional

Beste meneer/mevrouw,

Ik wil u middels deze brief graag informeren over mijn onderzoek bij Topicus Healthcare B.V. Mijn naam is Marloes Roerdink en om mijn master Gezondheidswetenschappen aan de Universiteit Twente af te ronden, doe ik een afstudeeronderzoek waarbij ik mij richt op de wensen en behoeften van ouders met kinderen tussen de 0 en 4 jaar oud.

Hierbij focus ik mij op de behoefte en wensen van ouders om meer regie te krijgen over de preventieve zorg van hun kind in de hoop meer inzicht te krijgen in de wensen van ouders omtrent de huidige contactmoment met de jeugdartsen en verpleegkundigen in de leeftijd van 0 tot 4 jaar. Voordat ik interviews met ouders ga afnamen, wil ik graag de mening van jeugdartsen en jeugdverpleegkundigen in kaart brengen. Om deze informatie te verzamelen wil ik een semigestructureerde interviews afnemen waarin u uw mening geeft over de activiteiten uit de basisdataset Jeugdgezondheidszorg. Het interview zal 30-45 minuten duren.

De antwoorden die voortkomen uit dit interview zullen worden gebruikt voor de beantwoording van de onderzoeksvragen. Wanneer de ingevulde antwoorden worden gebruikt in het onderzoek, zullen persoonlijke gegevens (zoals naam, organisatie etc.) worden geanonimiseerd. Op deze manier is niet terug te leiden van welke persoon welke antwoorden afkomstig zijn. Deze gegevens zullen nooit aan derden zonder uw toestemming worden verstrekt. Tijdens het interview kunt u altijd besluiten om te stoppen zonder dat dit voor u consequenties heeft. U hoeft geen reden aan te geven waarom u wilt stoppen. Tot 24 uur na het onderzoek kunt u besluiten dat uw gegevens niet verder mee worden genomen in het onderzoek. Na afloop van het volledige onderzoek kunt u, indien u dat wenst, over de verkregen resultaten op de hoogte worden gesteld via de e-mail.

U zou mij ontzettend helpen als u mee wilt werken aan dit interview. Als u na deze brief nog vragen heeft, neem dan gerust contact met mij op.

Met vriendelijke groet,

Marloes Roerdink

Email: m.roerdink@student.utwente.nl
Tel: 06-57824360

Interview

Interview professionals

Datum: Tijd: Locatie: Interview nummer:

Deel 1: Algemene gegevens

1) Wat is uw functie?

2) Hoelang bent u al werkzaam in dit vakgebied?

3) Hoelang bent u al werkzaam voor deze organisatie?

Indien data wordt verkregen van de desbetreffende organisatie, vraag 3a) Op welke manier worden taken geregistreerd in het dossier?

Deel 2: Taken onder categorie 'Medical procedures'

Zouden ouders de volgende taken kunnen uitvoeren?

4) Hielprik pasgeborene: waarom wel/niet, suggesties

5) Rijksvaccinatieprogramma: waarom wel/niet, suggesties

Deel 3) Taken onder categorie 'Providing information'

Zouden ouders de volgende taken kunnen uitvoeren?

6) Zwangerschap, bevalling, pasgeborene, eerste levensweken: waarom wel/niet, suggesties

7) Informatie over werkwijze JGZ, burgerlijk wetboek, WGBO, Wet Bescherming Persoonsgegevens: waarom wel/niet, suggesties

8) Bepalen ontvangen zorg: waarom wel/niet, suggesties

9) Voorlichting, advies, instructie en begeleiding: waarom wel/niet, suggesties

10) Conclusie en vervolgstap(pen): waarom wel/niet, suggesties

Deel 4) Taken onder categorie 'Obtaining information'

Zouden ouders de volgende taken kunnen uitvoeren?

11) Persoonsgegevens: waarom wel/niet, suggesties

12) Huisarts: waarom wel/niet, suggesties

13) Gezinssamenstelling: waarom wel/niet, suggesties

14) Erfelijke belasting en risicofactoren: waarom wel/niet, suggesties

15) Voorschoolse voorziening: waarom wel/niet, suggesties

16) Bedreigingen uit de directe omgeving: waarom wel/niet, suggesties

17) Contactmoment: waarom wel/niet, suggesties

18) Terugkerende anamnese: waarom wel/niet, suggesties

19) Inschatten verhouding draaglast/draagkracht: waarom wel/niet, suggesties

Deel 5) Taken onder categorie 'Monitoring development'

Zouden ouders de volgende taken kunnen uitvoeren?

20) Gehooronderzoek: waarom wel/niet, suggesties

21) Algemene indruk: waarom wel/niet, suggesties

22) Functioneren: Lichamelijk, psychisch, emotioneel en sociaal functioneren: waarom wel/niet, suggesties

23) Huid/haar/nagels: waarom wel/niet, suggesties

24) Hoofd/hals: waarom wel/niet, suggesties

25) Romp: waarom wel/niet, suggesties

26) Locomotor apparatus: waarom wel/niet, suggesties

27) Genitalia: waarom wel/niet, suggesties

28) Groei: lengte naar leeftijd, gewicht naar leeftijd, hoofdomtrek: waarom wel/niet, suggesties

29) Psychosociale en cognitieve ontwikkeling, motorische ontwikkeling, spraak en taalontwikkeling: waarom wel/niet, suggesties

30) Oogonderzoek: waarom wel/niet, suggesties

31) Hartonderzoek: waarom wel/niet, suggesties

Deel 6) Afsluiting

32) Heeft u nog verdere vragen/aanvullingen/ideeën of suggesties?

33) Heeft u interesse in de onderzoeksresultaten? Ja/Nee

Appendix III - Informed consent form

Toestemmingsverklaringformulier

Titel onderzoek: More control for parents of 0-4 years old children in the youth healthcare.
Verantwoordelijke onderzoeker: Marloes Roerdink

In te vullen door de deelnemer

Ik verklaar op een voor mij duidelijke wijze te zijn ingelicht over de aard, methode en doel van het onderzoek. Ik weet dat de gegevens en resultaten van het onderzoek alleen anoniem en vertrouwelijk aan derden bekend gemaakt zullen worden. Mijn vragen zijn naar tevredenheid beantwoord.

Ik begrijp dat de geluidsopnames tijdens het interview uitsluitend voor analyse gebruikt zullen worden.

Ik stem geheel vrijwillig in met deelname aan dit onderzoek. Ik behoud me daarbij het recht voor om op elk moment zonder opgaaf van redenen mijn deelname aan dit onderzoek te beëindigen.

Naam deelnemer: …….

Datum: …-…-…. Handtekening deelnemer: …….

In te vullen door de uitvoerende onderzoeker

Ik heb een mondelinge en schriftelijke toelichting gegeven op het onderzoek. Ik zal resterende vragen over het onderzoek naar vermogen beantwoorden. De deelnemer zal van een eventuele voortijdige beëindiging van deelname aan dit onderzoek geen nadelige gevolgen ondervinden.

Naam onderzoeker: …….

Datum: …-…-…. Handtekening onderzoeker: …….

Appendix IV - Coding scheme interview YHS professionals

Algemene gegevens		
Hoofdcode	**Beschrijving**	**Subcode(s)**
Functie werkzaam	Respondent benoemt de functie die ze heeft	Jeugdverpleegkundige
		Jeugdarts
Tijd werkzaam	Respondent benoemt het aantal jaar dat ze werkzaam is in de functie	
Organisatie werkzaam	Respondent benoemt het aantal jaar dat ze voor de organisatie werkt	
Sections		
Hoofdcode	**Beschrijving**	**Subcode(s)**
Hielprik	Respondent benoemt of de taak vervangen kan worden	Vervangen
		Niet vervangen
		Twijfel
		Gedeeltelijk
Rijksvaccinatieprogramma	Respondent benoemt of de taak vervangen kan worden	Vervangen
		Niet vervangen
		Twijfel
		Gedeeltelijk
Zwangerschap, bevalling, pasgeborene en eerste levensweken	Respondent benoemt of de taken vervangen kunnen worden	Vervangen
		Niet vervangen
		Twijfel
		Gedeeltelijk
Informatie over werkwijze JGZ, burgerlijk wetboek, WGBO, Wet Bescherming Persoonsgegevens	Respondent benoemt of de taken vervangen kunnen worden	Vervangen
		Niet vervangen
		Twijfel
		Gedeeltelijk
Bepalen ontvangen zorg	Respondent benoemt of de taak vervangen kan worden	Vervangen
		Niet vervangen
		Twijfel
		Gedeeltelijk
Voorlichting, advies, instructie en begeleiding	Respondent benoemt of de taken vervangen kunnen worden	Vervangen
		Niet vervangen
		Twijfel
		Gedeeltelijk
Conclusie en vervolgstap(pen)	Respondent benoemt of de taken vervangen kunnen worden	Vervangen
		Niet vervangen
		Twijfel
		Gedeeltelijk
Persoonsgegevens	Respondent benoemt of de taak vervangen kan worden	Vervangen
		Niet vervangen
		Twijfel
		Gedeeltelijk
Huisarts	Respondent benoemt of de taak vervangen kan worden	Vervangen
		Niet vervangen
		Twijfel
		Gedeeltelijk
Gezinssamenstelling	Respondent benoemt of de taak vervangen kan worden	Vervangen
		Niet vervangen
		Twijfel
		Gedeeltelijk
Erfelijke belasting en risicofactoren	Respondent benoemt of de taken vervangen kunnen worden	Vervangen
		Niet vervangen
		Twijfel

		Gedeeltelijk
Voorschoolse voorziening	Respondent benoemt of de taak vervangen kan worden	Vervangen
		Niet vervangen
		Twijfel
		Gedeeltelijk
Bedreigingen uit de directe omgeving	Respondent benoemt of de taak vervangen kan worden	Vervangen
		Niet vervangen
		Twijfel
		Gedeeltelijk
Contactmoment	Respondent benoemt of de taak vervangen kan worden	Vervangen
		Niet vervangen
		Twijfel
		Gedeeltelijk
Terugkerende anamnese	Respondent benoemt of de taak vervangen kan worden	Vervangen
		Niet vervangen
		Twijfel
		Gedeeltelijk
Inschatten verhouding draaglast/draagkracht	Respondent benoemt of de taak vervangen kan worden	Vervangen
		Niet vervangen
		Twijfel
		Gedeeltelijk
Gehooronderzoek	Respondent benoemt of de taak vervangen kan worden	Vervangen
		Niet vervangen
		Twijfel
		Gedeeltelijk
Algemene indruk	Respondent benoemt of de taak vervangen kan worden	Vervangen
		Niet vervangen
		Twijfel
		Gedeeltelijk
Functioneren: Lichamelijk, psychisch, emotioneel en sociaal functioneren	Respondent benoemt of de taken vervangen kunnen worden	Vervangen
		Niet vervangen
		Twijfel
		Gedeeltelijk
Huid/haar/nagels	Respondent benoemt of de taken vervangen kunnen worden	Vervangen
		Niet vervangen
		Twijfel
		Gedeeltelijk
Hoofd/hals	Respondent benoemt of de taken vervangen kunnen worden	Vervangen
		Niet vervangen
		Twijfel
		Gedeeltelijk
Romp	Respondent benoemt of de taak vervangen kan worden	Vervangen
		Niet vervangen
		Twijfel
		Gedeeltelijk
Genitalia	Respondent benoemt of de taak vervangen kan worden	Vervangen
		Niet vervangen
		Twijfel
		Gedeeltelijk
Groei: lengte naar leeftijd, gewicht naar leeftijd, hoofdomtrek	Respondent benoemt of de taken vervangen kunnen worden	Vervangen
		Niet vervangen
		Twijfel
		Gedeeltelijk
Psychosociale en cognitieve ontwikkeling, motorische	Respondent benoemt of de taken vervangen kunnen worden	Vervangen
		Niet vervangen

ontwikkeling, spraak en taalontwikkeling		Twijfel
		Gedeeltelijk
Oogonderzoek	Respondent benoemt of de taak vervangen kan worden	Vervangen
		Niet vervangen
		Twijfel
		Gedeeltelijk
Hartonderzoek	Respondent benoemt of de taak vervangen kan worden	Vervangen
		Niet vervangen
		Twijfel
		Gedeeltelijk

Appendix V - Interview parents

Interview scheme

Voorbereiding:
Informatiebrief opsturen
Printen:
- *Interview*
- *Interview schema*
- *Toestemmingsverklaring*

Meenemen:
- *Opnameapparatuur*
- *Telefoon*
- *Opladers*
- *Interview*
- *Interview schema*
- *Toestemmingsverklaring*
- *Pen en papier*

Introductie:
Voorstellen: Afstudeeronderzoek voor de master Gezondheidswetenschappen aan de Universiteit Twente, namens Topicus Healthcare B.V.
Doel: Onderzoeken of ouders bepaalde taken uit het basistakenpakket over zouden willen nemen van de professional en gebruik zouden willen maken van een online tool.
Procedure: Het interview zal 45-60 minuten in beslag nemen.
Geluidsopname: Toestemming vragen voor geluidsopname.
Toestemmingsverklaring: Toestemmingsverklaring tekenen.
Vragen: Mogelijkheid om vooraf vragen te stellen.

Interview:
Onderdelen:
- *Algemene gegevens*
- *Internet gebruik*
- *Jeugdgezondheidszorg*
- *Online omgeving*
- *Uitvoering van taken*

Afsluiting:
Vragen naar overige algemene gegevens
Vragen naar overige vragen
Vragen naar interesse in resultaten
Bedanken voor medewerking

Information letter

Informatiebrief ouders

Beste ouder,

Ik wil u via brief graag informeren over mijn afstudeeronderzoek bij Topicus Healthcare B.V. Mijn naam is Marloes Roerdink en om mijn master Gezondheidswetenschappen aan de Universiteit Twente af te ronden doe ik een onderzoek. Hierbij richt ik mij op wat ouders graag zouden willen zien of ervaren in de jeugdgezondheidszorg voor hun kinderen.

Ik ben vooral benieuwd of ouders meer zeggenschap willen krijgen over de zorg die hun kind ontvangt. Op deze manier hoop ik meer inzicht te krijgen in de wensen van ouders over de huidige contactmomenten met de jeugdartsen en verpleegkundigen in de leeftijd van 0 tot 4 jaar. Om deze informatie te verzamelen wil ik een interview afnemen. Het interview zal ongeveer één uur duren.

De antwoorden die gegeven worden zullen worden gebruikt voor de beantwoording van de onderzoeksvragen. Wanneer de antwoorden worden gebruikt in het onderzoek, zullen persoonlijke gegevens (zoals naam, opleiding etc.) worden geanonimiseerd. Op deze manier is niet terug te leiden van welke ouder welke antwoorden komen. Deze gegevens zullen nooit aan anderen worden gegeven zonder uw toestemming. Tijdens het interview kunt u altijd besluiten om te stoppen zonder dat dit gevolgen heeft. U hoeft geen reden aan te geven waarom u wilt stoppen. Tot 24 uur na het onderzoek kunt u besluiten dat uw gegevens niet verder mee worden genomen in het onderzoek. Na afloop van het volledige onderzoek kunt u, indien u dat wenst, verkregen resultaten inzien via de e-mail.

U zou mij ontzettend helpen als u mee wilt werken aan dit interview. Als u na deze brief nog vragen heeft, neem dan gerust contact met mij op.

Met vriendelijke groet,

Marloes Roerdink

Email: marloes.roerdink@topicus.nl
Tel: 06-57824360

Interview

Interview ouders

Datum: Tijd: Locatie: Interview nummer:

Deel 1: Algemene gegevens

Algemene gegevens:

Geslacht	Man/Vrouw
Leeftijd	
Aantal kinderen	
Leeftijd kind(eren)	
Jeugdgezondheidszorgorganisatie consultatiebureau	

Deel 2: Internet gebruik

Inleiding over internet gebruik.

1) Hoe vaak maakt u gebruik van het internet (dagelijks, wekelijks, maandelijks, nooit), waarom (goed mee overweg)?

2) Op welk internetapparaat werkt u het meest? (Computer, tablet, mobiele telefoon)

Deel 3: Jeugdgezondheidszorg

Inleiding over jeugdgezondheidszorg. Kinderen worden elk jaar een paar keer opgeroepen voor een afspraak op het consultatiebureau. Er komen nu wat vragen over het consultatiebureau.

3) Gaat u mee naar de afspraken op het consultatiebureau (altijd/regelmatig/zelden)?

_____

4) Waarom gaat u naar het consultatiebureau?

_____

5) Wat vindt u goed en slecht aan de zorg/afspraken op het consultatiebureau?

_____

6) Zou u meer invloed willen hebben op hetgeen dat besproken wordt tijdens de afspraken op het consultatiebureau?

_____

7) Op welke manier zou u het liefst contact willen hebben met een jeugdarts/jeugdverpleegkundige naast de huidige afspraken op het consultatiebureau? (E-mail/telefoon/chatten)

_____

8) Op welke manier ontvangt u het liefst informatie over uw kind (App, face-to-face, sms, e-mail, portal)?

_____

Deel 4: Online omgeving

Inleiding over de online omgeving. Tegenwoordig kan veel meer informatie digitaal worden gegeven en worden opgezocht. Het is ook mogelijk dat informatie over uw kind online met u wordt gedeeld.

9) Zoekt u weleens online informatie op over de gezondheid van uw kind? Zo ja, wat voor informatie?

_____

10) Zou u online gezondheidszaken willen regelen voor je kind / via een online omgeving inzicht in de gezondheid van uw kind willen krijgen / gebruik willen maken van zo'n online omgeving, waarom wel/niet?

_____

11) Welke functionaliteiten zou u graag willen hebben in een online omgeving (informatie over ziekte/behandeling, informatie over zorg en ondersteuning, e-consulatie, peer communicatie, toegang tot medisch dossier)?

_____

Deel 5: Uitvoering van taken

Inleiding over het basistakenpakket. Tijdens de afspraken op het consultatiebureau voert de jeugdarts/jeugdverpleegkundigen een aantal taken uit bij uw kind. Het is te denken dat uzelf sommige taken ook gedeeltelijk bij uw kind zou kunnen uitvoeren. Deze taken ga ik nu aan uw voorleggen.

Toen uw kindje twee weken oud was, kwam er iemand van het consultatiebureau bij u thuis. U heeft toen antwoord gegeven op veel vragen. Deze ga ik nu aan u voorleggen met de vraag daarbij of u denkt dat u het antwoord op bepaalde vragen ook zelf had kunnen invullen in een online omgeving.

12) Zou u de persoonsgegevens (roepnaam) van uw kind zelf willen invullen in een online omgeving in plaats van dat de jeugdarts/jeugdverpleegkundige dit uitvraagt (voordelen/nadelen/randvoorwaarden)?

_____

13) Zou u de gegevens van de huisarts van uw kind zelf willen invullen in een online omgeving in plaats van dat de jeugdarts/jeugdverpleegkundige dit uitvraagt (voordelen/nadelen/randvoorwaarden)?

_____

14) Zou u informatie over uw gezinssamenstelling (broertjes, zusjes, aangetrouwd) zelf willen invullen in een online omgeving in plaats van dat de jeugdarts/jeugdverpleegkundige dit uitvraagt (voordelen/nadelen/randvoorwaarden)?

_____

15) Zou u informatie over voorschoolse voorzieningen zoals de crèche of peuterspeelzaal zelf willen invullen in een online omgeving in plaats van dat de jeugdarts/jeugdverpleegkundige dit uitvraagt (voordelen/nadelen/randvoorwaarden)?

_____

16) Zou u informatie over erfelijke belasting (met een i'tje voor uitleg) en risicofactoren (roken, psychische problemen) zelf willen invullen in een online omgeving in plaats van dat de jeugdarts/jeugdverpleegkundige dit uitvraagt (voordelen/nadelen/randvoorwaarden)?

_____

17) Zou u informatie over hoe uw zwangerschap en bevalling zijn verlopen, en hoe het ging met de baby vlak na de geboorte en in de eerste weken zelf willen invullen in een online omgeving in plaats van dat de jeugdarts/jeugdverpleegkundige dit uitvraagt (voordelen/nadelen/randvoorwaarden)?

_____

18) Zou u de informatie over de werkwijze op het consultatiebureau, over uw rechten en plichten als ouder zijnde en over toestemming voor gegevensoverdracht die u krijgt van de jeugdarts/jeugdverpleegkundige via een online omgeving willen ontvangen in plaats van dat de jeugdarts/jeugdverpleegkundige dit uitlegt (voordelen/nadelen/randvoorwaarden)?

_____

19) Zou u zelf willen invullen in een online omgeving welke mogelijke bedreigingen er zijn in de omgeving van uw kind (goede buurt, sociaal vangnet, speelruimte, leefomgeving) in plaats van dat de jeugdarts/jeugdverpleegkundige dit observeert (voordelen/nadelen/randvoorwaarden)?

_____

De volgende afspraken met de jeugdarts/jeugdverpleegkundige vonden plaats op het consultatiebureau zelf. De taken die tijdens deze afspraken worden uitgevoerd zal ik nu aan u voorleggen. Hierbij de vraag of u denkt dat u bepaalde taken ook zelf had kunnen invullen of uitvoeren.

20) Zou u informatie over het contactmoment (zoals datum, leeftijd van uw kind, degene die mee gaat naar de afspraak) zelf willen invullen in een online omgeving in plaats van dat de assistente of jeugdarts/jeugdverpleegkundige dit uitvraagt (voordelen/nadelen/randvoorwaarden)?

_____

21) Zou u informatie over de gezondheid van uw kind (over slapen, voeding, vitamines/medicijnen, belangrijke gebeurtenissen, ziektes) zelf willen invullen in een online omgeving in plaats van dat de jeugdarts/jeugdverpleegkundige dit uitvraagt (voordelen/nadelen/randvoorwaarden)?

_____

22) Zou u de informatie over de hoofd en hals (schedelafplatting en voorkeurshouding) en mondverzorging (tandenpoetsen, gebitsreiniging) die u krijgt van de jeugdarts/jeugdverpleegkundige via een online omgeving willen ontvangen (voordelen/nadelen/suggesties)?

_____

23) Zou u informatie over het lichamelijk, psychisch, emotioneel en sociaal functioneren (zoals slapen/waken, hechting, huilen, motoriek) van uw kind zelf willen invullen in een online omgeving in plaats van dat de jeugdarts/jeugdverpleegkundige dit uitvraagt (voordelen/nadelen/randvoorwaarden)?

_____

24) Zou u uw kind zelf willen wegen en meten (voordelen/nadelen/randvoorwaarden)?

_____

25) Zou u zelf de draaglast/draagkracht (risicofactoren: roken vs. beschermende factoren: stabiel gezin) in kunnen schatten en kunnen invullen een online omgeving in plaats van dat de jeugdarts/jeugdverpleegkundige dit uitvraagt (voordelen/nadelen/randvoorwaarden)?

_____

26) Zou u willen bepalen welke zorg uw kind ontvangt (voordelen/nadelen/randvoorwaarden)?

_____

27) Zou u de voorlichting, het advies, de instructie en de begeleiding (bij voeding, slapen, vitamines, voorkeurshouding etc.) die u krijgt van de jeugdarts/jeugdverpleegkundige via een online omgeving willen ontvangen (voordelen/nadelen/suggesties)?

_____

28) Zou u de conclusie en vervolgstap(pen) (die de jeugdarts/jeugdverpleegkundige heeft vermeld over uw kind) van een afspraak op het consultatiebureau via een online omgeving willen inzien (voordelen/nadelen/suggesties)?

_____

29) Zou u informatie over vaccinaties die u krijgt van de jeugdarts/jeugdverpleegkundige via een online omgeving willen ontvangen (voordelen/nadelen/suggesties)?

_____

In meerdere consulten wordt de ontwikkeling van uw kind gemonitord. Hierbij wordt gelet op de psychosociale en cognitieve ontwikkeling (of uw kind snel boos wordt of juist erg verlegen is, of uw kind u goed begrijpt, welke emoties uw kind toont etc.), op de motorische ontwikkeling (kan uw kind blokjes stapelen, een lijntje tekenen, springen etc.) en de spraak en taalontwikkeling (zegt uw kind al twee woordjes, maakt uw kind al drie-woordzinnen etc.). De jeugdarts/jeugdverpleegkundige probeert de ontwikkeling iedere afspraak weer in kaart te brengen door uw kind te observeren en bepaalde handelingen te laten doen. Hierbij ook de vraag of u denkt dat u bepaalde taken hierin ook zelf had kunnen invullen of uitvoeren.

30) Zou u informatie over de ontwikkeling van uw kind zelf willen toevoegen aan een online omgeving (bijvoorbeeld via filmpjes) in plaats van dat de jeugdarts/jeugdverpleegkundige dit uitvraagt of onderzoekt (voordelen/nadelen/randvoorwaarden)?

_____

Verder wordt op latere leeftijd nog een ogentest gedaan. Hierbij ook de vraag of u denkt dat u bepaalde taken bij de ogentest zelf had kunnen uitvoeren.

31) Zou u (gedeeltes: oefenen van tevoren, plaatjestest) het oogonderzoek zelf willen en kunnen uitvoeren bij uw kind (voordelen/nadelen/randvoorwaarden)?

_____

Deel 6: Afsluiting

*Overig algemeen (*doel: goede afspiegeling van de Nederlandse bevolking)*:*

Getrouwd	Ja/Nee
Geboorteland*	
Geboorteland echtgenoot (indien van toepassing)	
Geboorteland kind(eren)	
Moedertaal	
Spreektaal met kinderen	
Opleidingsniveau (laatst behaalde diploma)	
Beroep (evt. aantal uur/week)	

*Wanneer ouder van niet-Nederlandse afkomst is:

a. Heeft u moeite met het lezen en/of schrijven van de Nederlandse taal?

_____

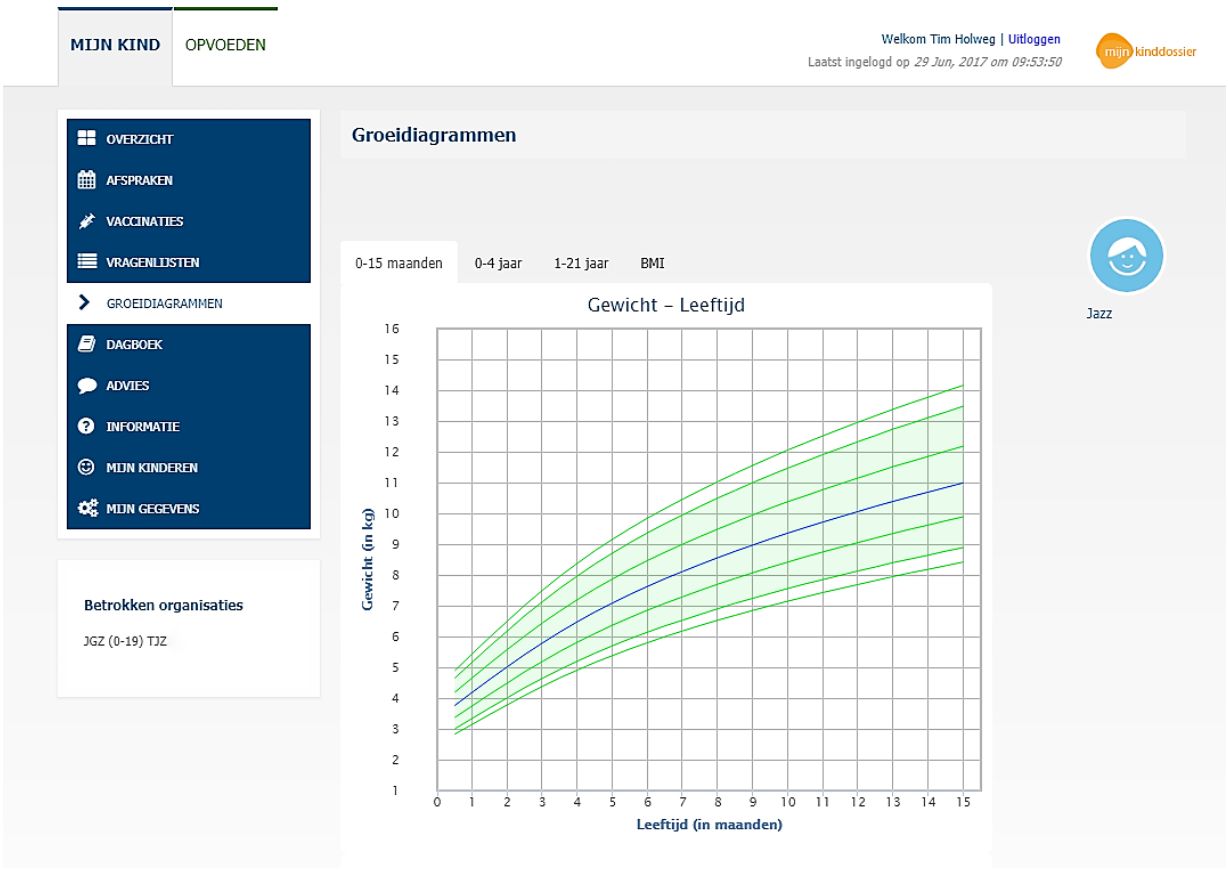
32) Heeft u nog verdere vragen/aanvullingen/ideeën of suggesties?

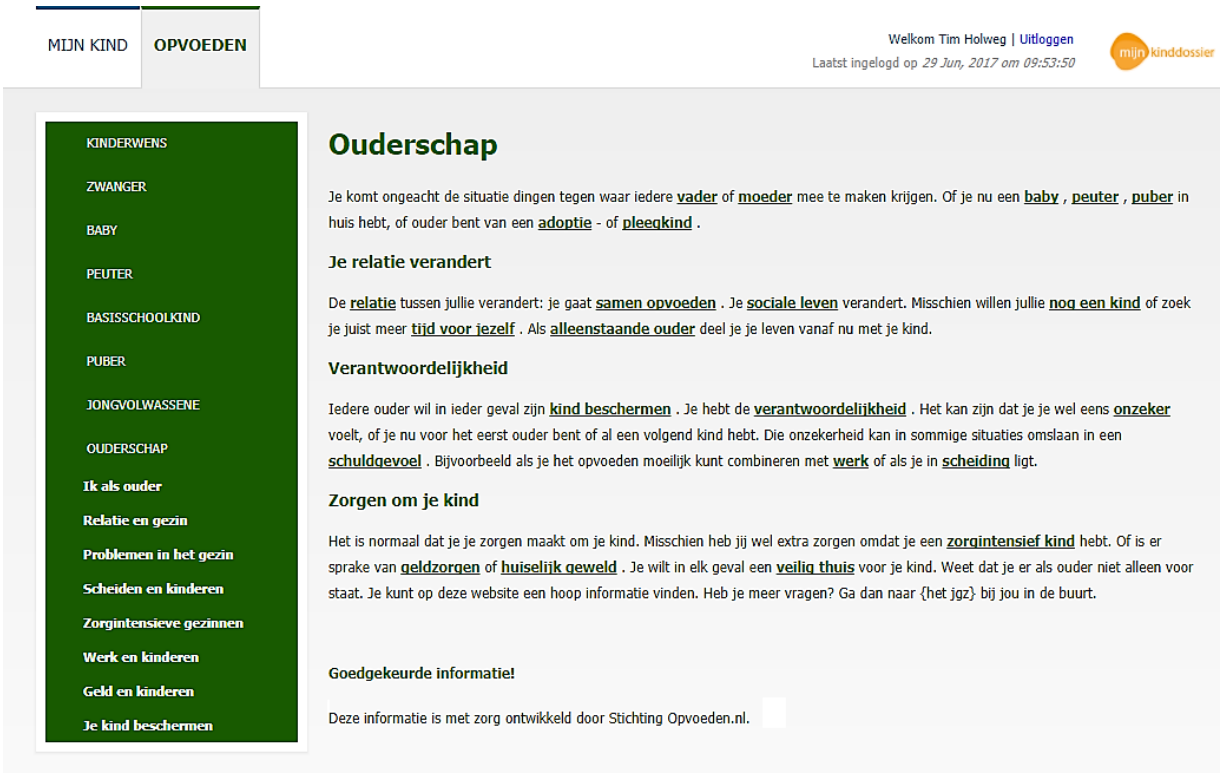
_____

33) Heeft u interesse in de onderzoeksresultaten? Ja/Nee

_____

Mock-up


MIJN KIND
OPVOEDEN
Welkom Tim Holweg | Uitloggen
Laatst ingelogd op 29 Jun, 2017 om 09:53:50
mijn kinddossier
OVERZICHT
AFSPRAKEN
VACCINATIES
VRAGENLIJSTEN
GROEIDIAGRAMMEN
DAGBOEK
ADVIES
INFORMATIE
MIJN KINDEREN
MIJN GEGEVENS
Groeidiagrammen
0-15 maanden
0-4 jaar
1-21 jaar
BMI
Gewicht – Leeftijd
Gewicht (in kg)
Leeftijd (in maanden)
Jazz
Betrokken organisaties
JGZ (0-19) TJZ


MIJN KIND
OPVOEDEN
Welkom Tim Holweg | Uitloggen
Laatst ingelogd op 29 Jun, 2017 om 09:53:50
mijn kinddossier
KINDERWENS
ZWANGER
BABY
PEUTER
BASISSCHOOLKIND
PUBER
JONGVOLWASSENE
OUDERSCHAP
Ik als ouder
Relatie en gezin
Problemen in het gezin
Scheiden en kinderen
Zorgintensieve gezinnen
Werk en kinderen
Geld en kinderen
Je kind beschermen
Ouderschap
Je komt ongeacht de situatie dingen tegen waar iedere vader of moeder mee te maken krijgen. Of je nu een baby , peuter , puber in huis hebt, of ouder bent van een adoptie - of pleegkind .
Je relatie verandert
De relatie tussen jullie verandert: je gaat samen opvoeden . Je sociale leven verandert. Misschien willen jullie nog een kind of zoek je juist meer tijd voor jezelf . Als alleenstaande ouder deel je je leven vanaf nu met je kind.
Verantwoordelijkheid
Iedere ouder wil in ieder geval zijn kind beschermen . Je hebt de verantwoordelijkheid . Het kan zijn dat je je wel eens onzeker voelt, of je nu voor het eerst ouder bent of al een volgend kind hebt. Die onzekerheid kan in sommige situaties omslaan in een schuldgevoel . Bijvoorbeeld als je het opvoeden moeilijk kunt combineren met werk of als je in scheiding ligt.
Zorgen om je kind
Het is normaal dat je je zorgen maakt om je kind. Misschien heb jij wel extra zorgen omdat je een zorgintensief kind hebt. Of is er sprake van geldzorgen of huiselijk geweld . Je wilt in elk geval een veilig thuis voor je kind. Weet dat je er als ouder niet alleen voor staat. Je kunt op deze website een hoop informatie vinden. Heb je meer vragen? Ga dan naar {het jgz} bij jou in de buurt.
Goedgekeurde informatie!
Deze informatie is met zorg ontwikkeld door Stichting Opvoeden.nl.

Appendix VI - Coding scheme interview parents

Persoonlijke gegevens		
Hoofdcode	**Beschrijving**	**Subcode(s)**
Geslacht	Respondent benoemt het geslacht van zichzelf	Vrouw
		Man
Leeftijd	Respondent benoemt de leeftijd van zichzelf	
Aantal kinderen	Respondent benoemt het aantal kinderen dat ze heeft	1
		2
		3
Relatiestatus	Respondent benoemt de relatiestatus	Relatie
		Getrouwd
		Gescheiden – nieuwe partner
Afkomst		
Hoofdcode	**Beschrijving**	**Subcode(s)**
Geboorteland	Respondent benoemt het land waarin diegene geboren is	NL
		TR
		ID
Geboorteland echtgenoot	Respondent benoemt het land waar de partner geboren is	NL
		US
		TH
Geboorteland kind(eren)	Respondent benoemt het land waar de kinderen geboren zijn	NL
Moedertaal	Respondent benoemt de moedertaal	NL
		TR
Spreektaal met kinderen	Respondent benoemt de spreektaal met de kinderen	NL
		SY
		TH
		US
Opleiding/werk		
Hoofdcode	**Beschrijving**	**Subcode(s)**
Opleidingsniveau (laatst behaalde diploma)	Respondent beschrijft het opleidingsniveau	MBO
		HBO
		WO
Beroep + aantal uur/week	Respondent beschrijft het beroep en het aantal uur per week werkzaam	Beroep
		Aantaluur
Internetgebruik		
Hoofdcode	**Beschrijving**	**Subcode(s)**
Vaak internet	Respondent beschrijft hoe vaak diegene internet gebruikt	Internetgebruik
Overweg internet	Respondent beschrijft hoe goed diegene met internet overweg kan	Ervaring
Internetapparaten		Computer/Laptop
		Tablet/IPad
		Mobiele telefoon
Jeugdgezondheidszorg		
Hoofdcode	**Beschrijving**	**Subcode(s)**
Afspraakbezoek	Respondent geeft aan of diegene de afspraken op het consultatiebureau bezoekt	Altijd
		Soms
Waarom cb	Respondent beschrijft waarom diegene naar het consultatiebureau gaat	Inentingen
		Check
		Advies

		Standaard
Mening cb	Respondent geeft mening over het consultatiebureau	Goed
		Slecht
		Afspraak
		Druk
		Gestandaardiseerd
		Online
		Personeel
Contact JA/JVK buiten consult	Respondent geeft aan of diegene contact wil met het consultatiebureau buiten de afspraken om	E-mail
		Telefoon
		WhatsApp
		Chat
		Nee
Invloed op gespreksonderwerp	Respondent geeft aan of diegene invloed wil hebben op hetgeen dat besproken wordt in de afspraak	Ja
		Nee
		Neutraal
Informatie over kind	Respondent geeft aan of diegene informatie over het kind wilt ontvangen buiten de afspraken om	Face-to-face
		Sms
		E-mail
		Online
		Bellen
Online support service		
Hoofdcode	**Beschrijving**	**Subcode(s)**
Online zoeken	Respondent beschrijft of diegene online zoekt naar informatie over de gezondheid van het kind	Positief
		Negatief
Online zaken regelen	Respondent beschrijft of diegene online gezondheidszaken voor het kind wilt regelen	Positief
		Negatief
Functionaliteiten	Respondent geeft aan welke functionaliteiten diegene terug wilt zien in een online support service	Vragenlijst
		Vergelijking tussen kinderen
		Vaccinaties
		Medische gegevens ouders
		Medische gegevens kind
		Informatie krijgen
		Informatie ingeven (dagboek)
		Groeidiagram
		Contactmogelijkheid
		Afspraken
		Advies
Uitvoering van taken		
Hoofdcode	**Beschrijving**	**Subcode(s)**
Persoonsgegevens	Respondent geeft aan of diegene betrokken wil worden bij de taak	In gesprek
		Online
Huisarts	Respondent geeft aan of diegene betrokken wil worden bij de taak	In gesprek
		Online
Gezinssamenstelling	Respondent geeft aan of diegene betrokken wil worden bij de taak	In gesprek
		Online
		Combinatie
Voorschoolse voorzieningen	Respondent geeft aan of diegene betrokken wil worden bij de taak	In gesprek
		Online
Contactmoment	Respondent geeft aan of diegene betrokken wil worden bij de taak	Tijdens afspraak
		Online
		Online wijzigen
		In gesprek

Erfelijke belasting en risicofactoren	Respondent geeft aan of diegene betrokken wil worden bij de taak	Online
		Combinatie
Zwangerschap bevalling, eerste weken	Respondent geeft aan of diegene betrokken wil worden bij de taak	In gesprek
		Online
Werkwijze consultatiebureau, rechten en plichten, toestemming gegevensoverdracht	Respondent geeft aan of diegene betrokken wil worden bij de taak	In gesprek
		Online
		Combinatie
Bedreigingen in de omgeving	Respondent geeft aan of diegene betrokken wil worden bij de taak	Huisbezoek is verstandig
		In gesprek met professional
		Overbodig
Gezondheid kind	Respondent geeft aan of diegene betrokken wil worden bij de taak	In gesprek
		Online
		Combinatie
Draaglast/draagkracht	Respondent geeft aan of diegene betrokken wil worden bij de taak	In gesprek
		Online
		Combinatie
Hoofd/hals en mondverzorging	Respondent geeft aan of diegene betrokken wil worden bij de taak	In gesprek
		Online
		Combinatie
Lichamelijk, psychisch, emotioneel en sociaal functioneren	Respondent geeft aan of diegene betrokken wil worden bij de taak	In gesprek
		Combinatie
Voorlichting, advies, instructie en begeleiding	Respondent geeft aan of diegene betrokken wil worden bij de taak	In gesprek
		Online
		Combinatie
Conclusie en vervolgstappen consult	Respondent geeft aan of diegene betrokken wil worden bij de taak	Online
		Combinatie
Vaccinaties	Respondent geeft aan of diegene betrokken wil worden bij de taak	In gesprek
		Online
		Combinatie
Wegen/meten	Respondent geeft aan of diegene betrokken wil worden bij de taak	Door professional
		Thuis uitvoeren
		Uitvoeren met hulp
Bepalen zorgplan	Respondent geeft aan of diegene betrokken wil worden bij de taak	Professional geeft advies, ik maak de keuze
		In samenspraak
Ontwikkeling kind monitoren	Respondent geeft aan of diegene betrokken wil worden bij de taak	Door professional
		Filmen
		Filmen bij gegronde redenen
Ogentest	Respondent geeft aan of diegene betrokken wil worden bij de taak	Oefenen, evt. helpen bij uitvoeren
Afsluiting		
Hoofdcode	**Beschrijving**	**Subcode(s)**
Overig	Respondent benoemt overige zaken	Eén omgeving met alle informatie is welkom
		Gegevens overnemen uit dossiers is makkelijker
		Gegevens voor de bevalling invullen
		Werkwijze doorlezen tegelijkertijd met invullen persoonsgegevens
		Zorg is te gestandaardiseerd

Appendix VII - Elaboration interview YHS professionals

Looking at table 14, the column 'Label (N)' shows the code label and the number of respondents per label (N). Quotes are added in the last column to show the opinions of the professional about the same section. Quotes were added per section until no new information was given. In this way, all reasons for (no) involvement of parents are presented in the table. The researcher had unintentionally not asked the professionals about their opinion on the section Locomotor apparatus and therefore, no results are derived on this section.

Table 14 *Professionals' opinion towards parental involvement per section*

Section	Label (N)	Example quotations
Heel prick	No involvement (6)	*"I also don't think that you should ask parents to do that. You have to inject your own child, which I think is a too excessive burden for parents."* *"It is a medical act and I think it's an unnatural thing to hurt your own child"*
National immunization program	No involvement (6)	*"Currently not, as we give vaccinations through injections. These are all reserved actions. But there might be a time when vaccinations become patches or drops and then I can imagine that people could do it themselves."* *"You have to make sure there is a distance between the child and the person who gives the vaccination. You just have to know what you are doing. That's the same BIG (OIHA ed.) story, parents are not even allowed.*
Information about process YHS, Civil code, Law on Medical Treatment Agreement, Law for the protection of personal information	Partial involvement (6)	*"You can inform them about their rights and obligations, but it is our job to report it the moment we want to transfer information."* *"I do not think that this should be said verbally. But I do think that it sometimes makes sense to say it verbally, especially if you want to hear it back when parents are not satisfied. If you have a personal relationship with them, you can write it somewhere in a folder, but it feels totally different when someone really tells you: if there is anything, let me know."* *"Parents can easily look up all of that, I think. But I think that it is important to talk about it in the context of building a good relationship and mutual trust."* *"Yes, we can read that and decide if we agree or not. But there will always be a group of people to which you really should address the topic and explain it."* *"I always say, we're just sharing this with comply with the law. We do not spend much more attention on it. I think that parents can be more involved in this. It is also a bit of responsibility."*
Determining delivered care	Partial involvement (6)	*"I also think that nowadays we do not decide what parents should pay attention to, but they should think about that themselves as well. And they therefore often need support and help to formulate it or to set up a plan. But you're supposed to do that with the parents together."* *"I think the parents in general know very well if something is wrong with their child. Whether they can fully determine what care is appropriate, no I don't think so. Then you really need to know the development of the child, the social area, the possibilities and combine these."* *"I do not think it (the input field in child dossier ed.) is being used. Not even for children at risk. Everything is being registered neatly, but a care plan is not really made. But if you create one, you should do that together with the parents."* *"Look, I'm convinced that when you've got a good relationship with the parents, and you've been involved from the start and parents have*

		regularly seen you, you build an equivalent relationship in a certain way. And I think you can let the parents go, because I think parents have confidence in you and will find you when they need you."
Information, advice, instruction and guidance	Partial involvement (6)	*"Yes, I think that parents can do 80-85% themselves, but I think that that little specific part lies with us."* *"We have popular topics that many parents ask about and where kind of standard answers can be given (…) I also think that for some educational questions. Only in the case of an educational question very often come the feelings of the family situation and context in which the child grows, apparent."* *"I think that it could be a great combination of a personal story and the rereading of how was it."* *"A folder can be supportive and can provide clarification, but often not when a problem occurs. Like a folder over preference position, it can work preventively and alert them. But still we see many preference positions. So, it still occurs because of the hustle and bustle of the day. Then, they also need more specific information from me."* *"It is always because of the visit of the child consultation clinic by the parent. So, I already gave a customized advice and then you still have the support of the folder to reread it."*
Conclusion and follow-up	Partial involvement (6)	*"Yes, those parents are often a step ahead of us. Those who say we have already been there or who have already visited an osteopath for example. But when you have a follow-up, I think of speech therapy for example, that follow-up step is often not done by parents themselves. That part is with us. So, that's also a little customization and seeing what you need for a child."* *"The conclusion must actually be a logical consequence of the whole appointment. That's a thing we always discuss together with the follow-up steps. But that's because we work fully demand-oriented. So, we really ask parents every time when they want to come back. There is also a nuance in this, because we are not this easy with children at risk. There is more pressure behind those situations. The children of who we think that they are ok, the 85% is just doing fine, the parents can indicate themselves what they want from our care."* *"I think of all those questions there is much more to do and to register in consultation with the parents. And that parents can, through a parent portal, also have access to it, read it or check it again. That fits this modern time a lot more."* *"I actually always fill this in when parents are already gone. But when we've talked about something sensitive, I discuss with the parents what I put in the dossier or not. At this moment, parents cannot see the content of the dossier. But if they would want to, they are allowed to see it."*
Pregnancy, delivery, newborn, first weeks	No involvement (1)	*"Only the question is always, you know there is so much happening at that moment, so can they see that? And are parents looking forward to that? And then I think it's good that this stays with us. Yes, I think that it just has to stay with us."*
	Partial involvement (5)	*"So, I think that some kind of more technical-like things can be filled in by parents. (...) And I think if you're talking about risk factors/protecting factors, even if parents fill in things, I think you need to talk about it as a professional to know what it means."* *"Well, yes, I think parents cannot inform themselves in the way of not knowing what information they miss. On the other hand, I don't think that it should always be performed by a professional. I think there are also steps in-between. I think of digital possibilities, web lectures, folders of course, people who can actually read something, but also be more interactive. Looking for information or proactively offering*

		something and videos. I think there are a lot of other ways than me telling that to parents." *"There is of course also a group of parents who have a quick search for that data and fill it in very quickly. Those are there too, so it is possible. But there is also a group that never could."*
Personal data	Involvement (6)	*"They can fill in their profession themselves or their level of education. Whether they say it to me or write it down, I'm dependent on what they say and just write it down."* *"I think so, it's only the question if it's not on a stack with too many things to be done? From my own experience, that kind of thing was not necessarily a thing I was looking forward to. I think that many parents find it practical that we do it."* *"Yes, I have no objection to that. These are their children, their data. They can change it If they find that somethings wrong about their name for example."*
General practitioner	Involvement (6)	*"Yes, that's possible yes. In fact, it is now the case that the nurse asks a lot of those things and has to type it all in KD+ (child dossier ed.)."* *"Yes of course can they change that themselves. Yes, they can, just why not? We are happy with every GP we find out that parents have. So, if people change that information, I'm glad that they change it in our dossier."*
Family composition	Partial involvement (1)	*"I want to ask it and fill it in. I would not mind if they could add something in the dossier. I would not have a problem with that. (…) But I'd like to ask it myself too, because then you can have a fair and open conversation about it."*
	Involvement (5)	*"I think parents are able to do that themselves. (…) The normal, average parent, yes."* *"Whether there is a divorce or not, I don't know if parents fill that in easily. But of course, it would be possible. I don't see any objection for that."* *"The parent who has the authority should actually be allowed to delete that information. I can imagine that. Therefore, you have childhood authority."*
Hereditary risk factors	No involvement (1)	*"Risk factors in the sense of single parent or fired parent or parents with psychiatric problems and so on. I think that you don't really want to have parents to tell themselves that they have psychiatric problems for example. That is not desirable, so then I think that it's better that we fill in that part."*
	Partial involvement (4)	*"Well, look, the hereditary factors they can fill in themselves. But you also ask the parents what it is exactly and in particular if it also has consequences for the child and if I have to give other care to the child."* *"I think we should be open to this kind of stuff, we can fill it in and they check or add information."* *"I can imagine that parents can really fill in a lot themselves and that you take that information as a guide to home visits. So, it's possible to win some time. But you have to know parents well, what are things you want to talk about because maybe there's more behind it. (…) Because you notice that with risk factors, parents do not really understand the reason why we ask or view these things. I wonder if you can give this information on paper or digitally why we ask for those things."*
	Involvement (1)	*"Sickle-cell anemia for example is in it, almost nobody knows what it is. Then you have to explain it, but it is possible to do that with an I (for information ed.)."*
Pre-schooling	Involvement (6)	*"Yes, of course they can fill that in themselves."*

Threat from the immediate vicinity	Doubt (3)	*"You can think that this might be a somewhat lesser neighbourhood, but the social control and atmosphere may be so good that it's a good living environment for that family. I find it difficult to estimate that."* *"I do not want to say that they cannot fill it in, because they can. But I don't think that it is helpful. Whether a child experiences the environment as safe or unsafe or if the child is hampered in his development because he cannot play outside... That depends on so many things, especially when care is insufficient, you talk about it when there is a possible form of child abuse. A parent will never fill that in! That's a conclusion from a professional and I know that our professionals find it very difficult to register it as a conclusion. Because it is stated very unsubtle."* *"That's a difficult one. I find it a bit dubious. We do not see everything, but parents do not fill them in."*
	No involvement (3)	*"You cannot leave that to another and you cannot develop it digitally. You really need to be in the environment, at the home visit and how someone answers often says a lot of things on which I decide to ask further or not since it is so convincing. I think that really requires a professional assessment. Especially for that gut-feeling you have."* *"I must honestly say that I do not actually perform this task during a home visit. When there is an appointment or appointment on indication or a home visit on indication and I notice things, then I fill it in. But you cannot expect from parents to do that themselves."* *"I don't think that you must let parents fill that in. I think that's only possible with an observation during a home visit."*
Contact moment	Involvement (6)	*"That can parents do themselves."* *"They could do that, but I wonder if it's beneficial."* *"You expect from the parents that they fill in some type of questionnaire beforehand, that will be the future, fill in who will visit the appointment with the child. They can do that in my opinion. It's now administrative unnecessary complicated."*
Recurrent history	Partial Involvement (6)	*"Yes, then they can already think about which items are being appointed. So, that can certainly be helpful. That you can estimate a bit better in advance that I have to spend more time on this and maybe skip other parts."* *"But generally, they can always fill in something. And nutrition is a lot more a topic of discussion I think than to fill in in the dossier. Because there are almost every appointment questions about it and you have to customize the advice. For example, our sprouts do not eat vegetables and what do I do about it? That's something that you can't replace with a digital thing because it's a customized advice that you give. When it comes to actually obtaining information about breastfeeding or bottle feeding, yes that can they easily fill in themselves."* *"I think parents can do that, but they will need some kind of push in the right direction about what is meant with recurrent et cetera. Those checkboxes which they can tick for example."* *"We have also such a questionnaire if the children are two, three or four. Then the parents receive such a list in advance. Does not always work. They fill in general things about their child, about what has happened lately, if the child has been ill, if there were major changes in the family like divorces or whatever, an accident. And also, if they have questions they want to discuss. So yes, I think it is useful."*
Estimating the ratio of capacity and burden	No involvement (4)	*"A risk factor in itself does not say so much, the whole story around it is important. You must always have a good picture of the situation and that's what the professional needs to do in my opinion."* *"We have many radars, radar to parents, radar on how do parents interact with each other, how does the child respond to his parents and*

		how does the child respond to me. That's all apart from the actual conversation and for that part you really need someone. You can nog digitize that." *"No. There will also be parents who would be honest. But I do not think that's something that you ask the parents themselves. It can be asked in a conversation, but not online. I do think so for the ratio of capacity and burden. You must do that in a conversation."*
	Partial involvement (2)	*"If it is purely the feeling if I can handle this, then of course parents are the ones who can fill in. But in that case, you have to check a list with all factors, then that list should be added."* *"Well, that a part is able to do this. But there's also a big group that, I think, is less capable of doing that."*
Hearing test	No involvement (6)	*"That's a technical examination. You have to be trained for that, I cannot even do that."* *"I think it's also something medical that you have to do with your child which is only 4/5 days old. Are you going to fit those caps in the right way or is it a little bit scary? You must be able to guarantee the quality of course."*
General impression	No involvement (6)	*"In fact, that's the impression of a professional from the YHS. So, I do not think that parents can fill that in."* *"Yes, that's the gut feeling again. And the attachment of the child to other persons, yes it's not possible to digitalize it."* *"Yes, that is exactly my job, my impression of the child at this moment. I will not let the parents do that."*
Physical, psychological, emotional and social functioning	No involvement (2)	*"You want to see a child walking, you want to see how it develops. In the case of limp children, you want to feel them. What do you feel and what's the problem and is it still ok or need it support from a physiotherapist or so? But you also want to see how the interaction is between mother and child."*
	Partial involvement (4)	*"It is looking at the development of a child together with the parents, with the parents looking as parent and the professional as a professional and the professional is also needed to form a conclusion derived from that information."* *"You would have options to involve parents in physical functioning. Emotional and social, well that is also really based on interaction."* *"Then you have to do it in a completely different wording. Then it's more like a questionnaire that parents fill in, like the way they do it at our organization right now."* *"That's something that we ask parents, whether the child is feeling well, so parents are already involved. (…) And next to that I'll put my observation*."
Skin/hair/nails	No involvement (6)	*"That's a medical evaluation. That's why you really need doctors/nurses."* *"A parent does not see that."*
Head/neck	No involvement (2)	*"No, that's for the professional."* *"But we have, and I agree with it, head/neck and heart and everything after that (in the dossier ed.) that belongs to physical research, that's for the professional."*
	Partial involvement (4)	*"So, I think that an interactive video certainly contributes to it. But still, we also ask for the use of teat/bottle and the consequences of it. You should also offer customized care."* *"Yes, with the help of folders and videos, that can be explained very well. Yes, here is it also depending on whether parents consider dental care as important."*
Torso	No involvement (6)	*"The majority of the children has a healthy life. But it's important that you filter those little ones who have something visible or invisible. And*

		when parents can do everything themselves, I don't think that parents know how pectus carinatum looks or pectus excavatum. I do not think so." *"That's basically the physical research, that's what doctors do and the findings do you register as a professional."*
Genitalia	No involvement (6)	*"Yes, I want to see it. (…) Otherwise you will miss out on things."* *"That has to stay with us."*
Growth, length, weight, head circumference	Partial involvement (6)	*"People can do it in principle, weighing and measuring is not that difficult. I think the head circumference is difficult because it has to be exactly on a certain line above the ears and eyebrows. Is it feasible that parents do that?"* *"Measuring of the length of children who should be measured lying flat is also quite difficult. But if children are bigger and able to stand under a measuring stick parents can do that."* *"But parents should be able to measure the length and weight of toddlers. With babies, certainly the head circumference, I do not think so. Just leave that to us and especially the interpreting of the results. Growth is not just filling in and measuring, but also interpreting the results."*
Psychosocial and cognitive development, motor development, speech and language development	Doubt (1)	*"Yes, that is possible, but that are quite strict instructions of how to do it and what you may or may not say or can or cannot show the child (…) Then parents must be able to film the action very well before it is of added value."*
	Partial involvement (5)	*"It does not necessarily have to happen live, so I think there are many ways to get input from parents. But the evaluation of it is really a professional thing."* *"Yes, if I can visualize it on a video and I hear a child making two/three word sentences and it has the interactions that it should have at that age. (…) Do you want to perform the van Wiechen correctly, then there are many conditions for it. So with a video, you are reviewing the motor skills but not on the basis of van Wiechen. It's with good reason that we get education in van Wiechen from time to time."* *"You never get everything you see at an appointment from a movie, but it's a very big part what you can get. And then I think that I would like to use it since it is better than having nothing at all."* *"Parents provide the information, the child shows something and I conclude whether it is all right or not."*
Eye research	No involvement (3)	*"That is very standardized. It must be with both eyes separately and you have to make sure that the other eye cannot see anything. If you want to be sure, the professional must do that."* *"If I see how much children we detect. And still the parents who say that everything is okay… The most important thing of the eye test is looking with one eye and to tape the other, parents cannot do that."*
	Partial involvement (3)	*"The eye examination, which the doctor performs, VOV (early detection of visual disorders ed.) and all the other things, parents are not able to do that. A nurse cannot even do that. But parents can be able to perform the eye test, but then the research situation should also be conforming the guidelines."* *"Same as for van Wiechen, then they really have to perform it correctly, otherwise it is useless. Then they can better not do it. So, practising at home, please do, that really helps us. But performing, no, I'm against that."*
Heart research	No involvement (6)	*"Yes, I absolutely do not think that parents can do that. (…) I really think that it's a medical thing."*

Appendix VIII - Demographic data of interviewed parents

Table 15 *Overview of demographic data of interviewed parents*

M/F*	Age	Country of birth*	Age children	Married	YHS	Spoken language*
F	33	NL	0.5, 4 and 6 year	Yes	Icare en GGD Drenthe	NL
F	32	TR	1.9 and 3.5 year	Yes	GGD Twente	NL, SY
F	36	NL	3.5 and 9 year	Yes	CJG Apeldoorn	NL
F	25	NL	1 year	Yes	CJG Apeldoorn	NL
M	33	ID	1.5 and 5 year	Yes	GGD NOG	NL
F	32	NL	2 and 4 year	Yes	GGD Twente	NL
F	28	NL	1 year	Divorced, new partner	Vérian en CJG Apeldoorn	NL
F	28	NL	9 months and 4.5 year	No, relationship	GGD Twente	NL, TH
F	31	NL	13 months	Yes	CJG Apeldoorn	NL
F	40	NL	3 and 5 year	Yes	GGD Utrecht	NL, US
F	31	NL	2 year	Yes	GGD Hart voor Brabant	NL
M	38	NL	3 and 6 year	Divorced, new partner	GGD Kennemerland	NL
M	32	NL	9 months and 2 year	Yes	GGD Twente	NL
M	31	NL	2 year	Yes	Vérian en CJG Apeldoorn	NL
F	26	NL	15 months	Yes	CJG Apeldoorn	NL
F	35	NL	2, 4 and 6 year	Yes	GGD Gelderland-Midden en Yunio	NL

*M=Male; F=Female; NL=The Netherlands; TR=Turkey; ID=Indonesia; SY=Syria; TH=Thailand; US=Amerika

Appendix IX - Elaboration interview parents

In table 16, the column 'Label (N)' shows the code label and the number of respondents per label (N). Quotes are added in the last column to show the opinions of the parents about parental involvement per section and per label.

Table 16 *Parents' opinion towards parental involvement per section*

Section	Label (N)	Example quotations
Persoonsgegevens	In gesprek (5)	*"…dus uitvragen is toch wel fijner denk ik als je net bent bevallen."*
	Online (11)	*"…ik kan het sneller volgens mij zelf invullen."*
Huisarts	In gesprek (5)	*"Ja dat moeten ze dan maar gewoon uitvragen."*
	Online (11)	*"Ja al die gegevens kan je gewoon prima invullen."*
Gezinssamenstelling	In gesprek (4)	*"Ja doe maar bij de professional."*
	Online (11)	*"Zo lang alles goed gaat, kan het wel online."*
	Combinatie (1)	*"Ja dat is prima online en dan op het gesprek erop ingaan."*
Voorschoolse voorzieningen	In gesprek (3)	*"Dat komt wel in een afspraak, dat is wel fijner dan online."*
	Online (13)	*"…tegen die tijd kan je het net zo goed zelf even invullen dan dat hij of zij het weer vraagt."*
Contactmoment	Tijdens afspraak (1)	*"Ja ik vind het wel makkelijk tijdens de afspraak. Online hoeft niet van mij."*
	Online (11)	*"Dat vind ik wel fijn dat ik dat zelf kan."*
	Online wijzigen (4)	*"…dus je moet het online wijzigen maar dat gebeurt eigenlijk nooit, maar ik zou dat wel prima willen doen."*
Erfelijke belasting en risicofactoren	In gesprek (2)	*"Nee dat weet ik zelf niet, doe dat maar face-to-face."*
	Online (2)	*"…dan wil ik ze wel online aangeven als er een reminder is."*
	Combinatie (12)	*"Ja ik kan dat wel inschatten van mijzelf. Daarbij kun je bijvoorbeeld ook een vakje toevoegen met 'weet ik niet, later nog bespreken'."*
Zwangerschap, bevalling, eerste weken	In gesprek (14)	*"…dat het gewoon face-to-face kan zodat ze ook kan inhaken op de dingen die besproken worden."*
	Online (2)	*"Ik had dat prima in kunnen vullen. Voor degene die dat dan niet online willen invullen kunnen ze dat alsnog bespreken tijdens een consult thuis."*
Werkwijze consultatiebureau, rechten en plichten, toestemming gegevensoverdracht	In gesprek (6)	*"Ik denk wel dat ik het fijn vind dat ze het toelichten. Want ik denk online zou het niet iets zijn wat je interesseert…"*
	Online (7)	*"Dat lees ik allemaal wel online."*
	Combinatie (3)	*"Ik vind het belangrijk dat het wel in zo'n gesprek wordt gedaan omdat je dan extra vragen kan stellen. Ik vind het ook wel handig dat je het op een app online neer kan zetten. Dat je een combinatie hebt."*
Bedreigingen in de omgeving	Huisbezoek is verstandig (10)	*"…dat zie je niet eens. Nee, ik denk dat daar juist zo'n huisbezoek goed voor is."*
	In gesprek met professional (2)	*"…maar ook wel in zo'n gesprek. Want je kan zelf ook wel dingen over het hoofd zien."*
	Overbodig (4)	*"Dat vind ik belachelijk eigenlijk dat ze dat zo checken, zo betuttelend. (…) …wat mij betreft hoeft dit echt niet hoor."*
Gezondheid kind	In gesprek (4)	*"Nee dat vind ik in gesprek wel fijn. Dan kan je er meteen op inhaken."*

	Online (1)	*"Dat wil ik graag online invullen. Dan kan ik gewoon mijn verhaal kwijt. (…) …ik krijg liever dan feedback daarop online. Dat is veel makkelijker."*
	Combinatie (11)	*"Als ik mij zorgen maak wil ik het online kunnen aangeven in het dossier en ik wil het kunnen toelichten tijdens het gesprek."*
Draaglast/draagkracht	In gesprek (9)	*"Dat denk ik niet dat ik dat zelf in kan schatten. Ik denk dat zij dat beter kunnen doen."*
	Online (5)	*"Ja dat zou ik wel online even kunnen doen. Dat is voor mij geen probleem."*
	Combinatie (2)	*"Kijk je kan het aangeven online en vervolgens ga je in gesprek erover."*
Hoofd/hals en mondverzorging	In gesprek (4)	*"Nee online kijk ik daar echt niet naar. Ik vind het wel fijn dat dat gewoon verteld wordt."*
	Online (7)	*"Het zou handig zijn als het online komt te staan."*
	Combinatie (5)	*"Ik denk dat de combinatie tussen de app en het consultatiebureau heel sterk kan worden."*
Lichamelijk, psychisch, emotioneel en sociaal functioneren	In gesprek (3)	*"Ik denk dat het goed is dat dat in gesprek gebeurt. Omdat geen kind hetzelfde is."*
	Combinatie (13)	*"…dan staan hier de folders in een online omgeving en kom je daar dan niet uit, dat je dan ook de mogelijkheid hebt om contact op te nemen zonder dat je moet wachten totdat je een consult hebt."*
Voorlichting, advies, instructie en begeleiding	In gesprek (3)	*"Nee doe dat ook maar een op een. Ook omdat je situatie per kind natuurlijk wel kan veranderen…"*
	Online (3)	*"Dat soort informatie kan je voor mij prima online zetten."*
	Combinatie (10)	*"Ik denk dat dat ook tweeledig is. Wij hebben zelf ook een aantal dingen uitgezocht, maar toch vraag je even ter controle in het gesprek ook na of het klopt."*
Conclusie en vervolgstappen consult	Online (8)	*"Ja dat vind ik wel fijn als ik dat kan inzien online."*
	Combinatie (8)	*"Ik zou wel terug willen lezen wat besproken is in de samenvatting en de conclusie."*
Informatie over vaccinaties	In gesprek (2)	*"Doe dat maar in consult, anders lees ik het toch niet."*
	Online (11)	*"Ja dat vind ik wel fijn dat ik dat online kan lezen."*
	Combinatie (3)	*"Ja, zet het online maar benadruk wel even dat ze er ziek van kan worden."*
Wegen/meten	Door professional (3)	*"Nee want ik vind dat het echt bij hun ligt."*
	Thuis uitvoeren (2)	*"Dat zal ik thuis ook wel willen doen ja."*
	Uitvoeren met hulp (11)	*"Als ze gewoon aangeven hoe je dat moet doen kan dat wel."*
Bepalen zorgplan	Professional geeft advies, ik maak de keuze (9)	*"Ik wil zelf de regie houden en zij hebben voor mij een adviserende rol."*
	In samenspraak (7)	*"Dat zou ik wel liever in overleg doen omdat zij gewoon meer ervaring hebben daarmee."*
Ontwikkeling kind monitoren	Door professional (4)	*"Dat mogen ze wel daar doen. Die mensen zijn wat objectiever. Bij een vreemde presteert een kind misschien wel anders dan bij hun thuis."*
	Filmen (3)	*"Ja ze mogen het wel skippen en maak ik er wel een filmpje van. Dat hoeft niet per se daar te gebeuren."*
	Filmen bij gegronde redenen (9)	*"…tenzij het niet wil of zo, de volgende keer dat je het dan thuis filmt en op stuurt om te laten zien dat ze het thuis wel kan."*
Ogentest	Oefenen, evt. helpen bij uitvoeren (16)	*"Ja hoor. Dat kan wel. Als de arts zegt wat ik moet doen, dan wil ik dat best wel."*

Appendix X - Starting points for parental involvement via an online support service

Parental involvement can be possible via an online support service. An overview is given how parents can become involved with the help of an online support service per type of task and per section according to the interviews with YHS professionals and parents.

Obtaining information

Parents can fill in information about themselves and their child. There are nine sections in which parental involvement is possible (table 17).

Table 17 *Parental involvement via an online support service for obtaining information*

Section	Parental involvement
Family composition	Parents fill in the family composition.
General practitioner	Parents fill in who the child's general practitioner is.
Personal data	Parents fill in the personal data of themselves and their child.
Hereditary risk factors	Parents fill in a questionnaire about the hereditary risk factors in their family.
Information about process YHS, Civil code, Law on Medical Treatment Agreement, Law for the protection of personal information	Parents give (no) permission for data transfer of the child's dossier and for vaccinations.
Physical, psychological, emotional and social functioning	Parents fill in a questionnaire that describes the functioning of their child.
Pre-schooling	Parents fill in if their child goes to pre-school or not.
Recurrent history	Parents describe the time with their child prior to the appointment.
Contact moment	Parents plan and change appointments at the child consultation clinic.

Providing information

YHS professional can provide information to parents. There are six sections in which parental involvement is possible (table 18).

Table 18 *Parental involvement via an online support service for providing information*

Section	Parental involvement
Conclusion and follow-up	Professionals provide insight in the conclusion and follow-up of an appointment to the parents.
Head / neck	Professionals give information about preference position and dental care.
Hereditary risk factors	Professionals give information about the hereditary risk factors of a child
Information about process YHS, Civil code, Law on Medical Treatment Agreement, Law for the protection of personal information	Professionals provide parents with information about YHS and relevant laws.
Information, advice, instruction and guidance	Professionals provide general information and solicited advice to parents.
National immunization program	Professionals provide information about vaccinations.

Monitoring development

Parents can help YHS professionals by the monitoring of the child's development via an online support service. This is the case for one section (table 19).

Table 19 *Parental involvement via an online support service for monitoring development.*

Section	Parental involvement
Psychosocial and cognitive development, motor development, speech and language development	Parents follow the 'Van Wiechenonderzoek' to monitor the development of their child, parents film and upload actions of their child to assess their development.

Other:

Other ways of parental involvement via an online support service that were mentioned in the interviews are described in table 20.

Table 20 *Other ways of parental involvement via an online support service.*

Part	Parental involvement
Child's dossier	Parents get access to the child's file.
Contact	Parents get in contact with YHS professionals.