TALLINN UNIVERSITY OF TECHNOLOGY School of Information Technologies Department of Health Technologies

Merilin Varsamaa 192599YVEM

# Preventing cervical cancer: the potential of digital interventions in supporting parents' decision-making for human papillomavirus vaccination

Master's thesis

Supervisor: Kadi Lubi

PhD

TALLINNA TEHNIKAÜLIKOOL Infotehnoloogia teaduskond Tervisetehnoloogiate instituut

Merilin Varsamaa 192599YVEM

# Emakakaelavähi ennetamine: digilahenduste võimekus toetada lapsevanemate vaktsineerimisotsuse kujunemist inimese papilloomviiruse vastasel vaktsineerimisel

Magistritöö

Juhendaja: Kadi Lubi

PhD

## Author's declaration of originality

I hereby certify that I am the sole author of this thesis. All the used materials, references to the literature and the work of others have been referred to. This thesis has not been presented for examination anywhere else.

Author: Merilin Varsamaa

10.05.2021

## Abstract

**Background:** Cervical cancer [CC] is the fourth leading cause of cancer-related death among women, with more than 311,000 people dying of CC worldwide each year. In Estonia, the incidence and mortality rate of CC is one of the highest in Europe. Every year, 186 women in Estonia are diagnosed with CC, and 43% of those diagnosed die. Human papillomavirus [HPV] is the root cause for developing CC. It is recommended that 9-14-year-old girls be vaccinated to prevent CC. The vaccination is conducted primarily at school by a specialized nurse. This thesis aims to analyse parents' perceptions about HPV and CC, including the potential of digital interventions on decision-making for HPV vaccination through increasing awareness. Methods: A qualitative study was conducted, in which focus group interviews were used to obtain parental opinions and the interview method was used to obtain an expert opinion. Inductive coding has been used to analyse the data. The results have been divided into three categories - knowledge of CC and HPV vaccination; vaccination communication and the potential of digital solutions in HPV vaccination decision. As a result, parents were found to not have enough information about CC and HPV vaccination to give consent. The active involvement of health care professionals and school nurses is important to raise parental awareness for informed decision-making. Public discussions with parents and health care professionals are key as they help to share evidence-based information. The parents found that FightHPV and digital solutions can help for informed decision-making. Conclusions: CC prevention is addressed as a wicked problem that requires a holistic approach. A consistent national communication strategy can raise awareness which helps with parents' decision-making. In addition, digital solutions can be useful in automating the vaccination process by storing all information in one place. Different digital solutions help to raise the awareness of parents and children when they are implemented in the school curriculum.

This thesis is written in English and is 61 pages long, including 6 chapters, 5 figures.

## Annotatsioon

Emakakaelavähi ennetamine: digilahenduste võimekus toetada lapsevanemate vaktsineerimisotsuse kujunemist inimese papilloomviiruse vastasel vaktsineerimisel

**Taust:** emakakaelavähk on naiste seas neljas surmavaim vähitüüp ja igal aastal sureb emakakaelavähki enam kui 311 000 inimest üle maailma. Eestis on emakakaelavähi esinemissagedus ja suremus Euroopa üks kõrgemaid. Igal aastal diagnoositakse Eestis 186 naisel emakakaelavähk ning igal aastal sureb 43% diagnoosi saanutest. Inimese papilloomviirus [HPV] on emakakaelavähi peamiseks tekkepõhjuseks. Emakakaelavähi ennetamiseks soovitatakse vaktsineerida 9-14-aastaseid tüdrukuid, keda vaktsineeritakse peamiselt koolis kooliõe poolt. Eesmärk: on analüüsida vanemate hoiakuid HPV ja emakakaelavähi osas ning uurida kuidas digitaalsed lahendused aitaksid tõsta teadlikkust vaktsineerimisega seotud otsuse tegemisel. Metoodika: teostati kvalitatiivne uuring, mille käigus kasutati vanemate arvamuste kogumiseks fookusgrupi intervjuusid ja ekspertarvamuse saamiseks intervjuu meetodit. Andmete analüüsimiseks kasutati induktiivset kodeerimist. Tulemused jagunesid kolme kategooriasse - teadmised HPV-vastase emakakaelavähi ja vaktsineerimise kohta: vaktsineerimisalane kommunikatsioon ja digitaalsete lahenduste potentsiaal **HPV**-vastase vaktsineerimisotsuse tegemisel. Selgus, et vanematel puudub piisav teave nõusoleku andmiseks emakakaelavähi ja HPV-vastase vaktsineerimise osas. Vanemate teadlikkuse tõstmisel on oluline roll tervishoiutöötajate ja kooliõdede aktiivsel kaasamisel. Avalikud arutelud vanemate ja tervishoiutöötajatega on võtmetähtsusega, kuna aitavad jagada tõenduspõhist infot. Vanemad leidsid, et digilahendused, sh FightHPV võivad kaasa aidata otsuste tegemisel. Järeldused: Emakakaelavähi ennetamine on nõiutud probleem ja vajab terviklikku lähenemist. Järjepidev riiklik kommunikatsioonistrateegia võib tõsta teadlikkust aidates vanemaid vaktsineerimisotsuse tegemisel. Digilahendused võivad olla kasulikud vaktsineerimisprotsessi automatiseerimisel, koondades kogu info ühte kohta. Laste ja vanemate teadlikkuse tõstmist toetab erinevate digilahenduste integreerimine õppekavadesse.

Lõputöö on kirjutatud inglise keeles ning sisaldab teksti 61 leheküljel, 6 peatükki, 5 joonist.

## List of abbreviations and terms

ASIR	World age-standardized incidence rate
ASMR	World age-standardized mortality rate
CC	Cervical cancer
ECR	Estonian Cancer Registry
EHB	Estonian Health Board
EHIF	Estonian Health Insurance Fund
ETAIS	Estonian Scientific Computing Infrastructure
EU	European Union
GP	General Practitioner
HIS	Health Information System
HPV	Human Papillomavirus
NCSP	National Cervical Screening Program
NIHD REC	Research Ethics Committee of the National Institute for
	Health Development
PAP test	Papanicolaou's test
TalTech	Tallinn University of Technology
WHO	World Health Organization
WMA	The World Medical Association

## **Table of Contents**

1 Introduction	
2 Literature overview	
2.1 The epidemiology of cervical cancer	12
2.2 Cervical cancer and its prevention	14
2.3 HPV vaccination strategies	15
2.3.1 HPV vaccination in Estonia	17
2.4 Digital interventions for health-related decision making	18
2.5 The concept of wicked problems	19
2.5.1 Wicked problems in healthcare settings	20
3 Methodology	21
3.1 Data collection methods and instruments	21
3.2 Study population	23
3.3 Data analysis methods	24
3.4 Ethical Considerations	25
3.4.1 Ethics in Human Research	
3.4.2 Aspects of data protection	26
4 Results	28
4.1 Knowledge about cervical cancer and HPV vaccination	28
4.2 Communication regarding vaccination	30
4.2.1 Information provision aspects regarding HPV vaccination	
4.2.2 Communication about HPV vaccination at school	32
4.3 The potential of digital solutions in HPV vaccination decision	34
4.3.1 Variety and reliability of digital solutions	
4.3.2 Perceptions of the FightHPV application	
4.3.3 Usability of FightHPV at educational institutions	38
5 Discussion	
5.1 Parents knowledge about HPV vaccination and CC	39

5.2 Vaccination communication	
5.3 The potential of digital solutions in HPV vaccination decision	44
5.4 Main contribution to the core audience	45
5.5 Study limitations	46
5.6 Future research	47
5.7 Final conclusions	48
6 Summary	49
References	50
Appendix 1 – Focus group interview invitation	55
Appendix 2 – Informed consent for signing	56
Appendix 3 – Focus group plan	58
Appendix 4 – FightHPV application	60
Appendix 5 – Structure of the expert interview	61

# List of figures

Figure 1. Worldwide calculations of incidence and mortality rates determining	ASIR and
ASMR per 100,000 women regarding CC in 2018	13
Figure 2. Cervical cancer screening pathway in Estonia	15
Figure 3. 2018-2019 cumulative numbers of HPV vaccinated girls born betw	een 2003-
2007 in Estonia (modified)	17
Figure 4. Screenshots of FightHPV social gaming application	22
Figure 5. Data coding and categorization.	25

## **1** Introduction

Cervical cancer [CC] is diagnosed in Estonia every year among 186 women out of which 80 women die each year due to CC. The primary morbidity and mortality of CC in Estonia is one of the highest in Europe. Vaccinating against CC in the age of 12-14 is the most beneficial method to prevent CC as the vaccine gives total protection against most malignant human papillomavirus [HPV] types. The problem is that in Estonia, HPV vaccination coverage among girls aged 12-14 is below recommended (>70%) target rate and to ensure complete protection, adolescents need to have two doses of vaccine [1].

HPV vaccination is the primary prevention against CC, and WHO guidelines recommend vaccinating girls who are between 9-14 years old [2]. Vaccination is most effective when it is done before starting a sex life. Since 2018, 12-14-year-old girls were vaccinated against HPV in Estonia based on the national immunization plan. Vaccination for girls aged 12-14 was funded by EHIF in the years 2018-2019 and coordinated by EHB. Since January 2020 the funding by EHIF is only available for 12-year-old girls. The vaccination is mostly held in schools by a specialized nurse but can be also performed at GP's office. Vaccination is voluntary and needs a signed consent of the parent [3]. Between the years 2018-2019 vaccination coverage in Estonia for 12-14-year-old girls was 62% for the first dose and 47% for the second dose [4].

There have been multiple researches that indicate digital tools to be cost-effective for raising knowledge on CC and HPV vaccination [5], [6], [7], [8]. National campaigns are efficient in informing people about possible interventions and tools for self-education [6], [8]. It is important to engage health care professionals as this group is trusted by people for asking information and receiving recommendations on HPV vaccination [5], [7]. Future studies are focused on personalized solutions for patient's needs to withdraw the spread of CC [9]. The author found one suitable application FightHPV, which is used globally for increasing knowledge about CC and HPV by combining gaming and social nudging [10]. FightHPV application is introduced in 3.1 and a comprehensive analysis of FightHPV is found in chapters 4.3.2 and 4.3.3.

To the best of the author's knowledge, there have not been any surveys conducted in Estonia regarding parent's perception of HPV vaccination for 12-14-year-old girls. Although a research about parents perceptions and attitudes regarding vaccinating against

the human papillomavirus was defended in 2020 [11], the research is not publicly available to use in this analysis. Currently, there is no information about studies of digital solutions which would help to raise parents' awareness regarding vaccinating against HPV. The current thesis brings novel contributions to the topic of HPV vaccination and observes the effectiveness of digital solutions, which could be implemented in the future to assist parents with informed decision-making on a child's behalf.

**Problem statement:** HPV vaccination is the most beneficial preventive method, but the coverage for girls between the age 12-14 is below recommended (>70%) rate, and the incidence and mortality rate of CC in Estonia is one of the highest in Europe [1], and although the benefit of digital interventions has been shown in other countries [5] - [9], it has not been examined in Estonia.

**This study aims** to examine parents' perceptions regarding CC, HPV and the potential influence of digital solutions on parents' decision-making regarding HPV vaccination through raising awareness.

### **Research questions:**

1. What are the perceptions of parents about CC and HPV vaccination?

2. Which communication strategies or digital tools could be effective, safe and reliable for informed decision making and HPV communication?

3. Could applications like FightHPV help parents in decision making for HPV vaccination and be exploited as a part of the education system/program?

## 2 Literature overview

The following chapter is formed on a literature review, focuses on the introduction of CC and its prevention including CC screening. Furthermore, insights into international HPV vaccination strategies and HPV vaccination in Estonia are given. Additionally, this chapter presents digital interventions for informed decision-making and discussion on wicked problems in healthcare.

## 2.1 The epidemiology of cervical cancer

CC is the fourth deadliest cancer type in women, and in 2018 there were more than half a million new cases worldwide. The global death toll for CC each year is more than 311,000 cases and 85% of cases are diagnosed in middle- and low-income countries [12]. In the EU, there are approximately 34,000 new CC cases and more than 13,000 deaths every year [13]. Very high incidence rates in low- and middle-income countries show the global inequality in the prevention of CC. The risk factors for CC development are HPV type; individual immune system; chronic diseases which may lead to higher exposure to cancer; coinfection of other sexually transmitted determinants; smoking and young age at the time of childbirth [12]. In Estonia, according to the statistics of ECR, in 2018, out of all malignant neoplasms cases in female genital organs 127 (24%) were CC cases, which shows the high prevalence of the disease [14].

CC has most likely no symptoms at the early stage of cancer development. If cancer proliferates, women may have abnormal vaginal bleeding. This can happen during menstrual periods, after intercourse or after menopause. Additional symptoms include pain during intercourse, pain in the pelvic area or increased vaginal discharge. CC is with slow progression, and any changes which may lead to CC can be detected with the PAP test [15]. The main cause for CC is HPV, which is a set of different viruses. There are more than 100 types of HPV, and out of all types of HPVs approximately 15% are of high risk and the root cause for developing cancer. HPV is a virus causing an infection in the reproductive area and people who are sexually active are likely to catch the virus. The most common HPV related illness is CC, but HPV may cause cancer of other organs, like the vagina, penis, vulva, anus and oropharynx. The high-risk HPV types which are

identified as cancerous are 16, 18, 31, 33, 35, 39, 45, 51, 52, 56, 58 [16]. Two HPV types, 16 and 18 are connected with 71% of CC cases worldwide [13].

The methods for preventing other HPV related cancers can be prevented in the same methods used for CC (see chapter 2.2). Usually, HPV infections clear up naturally, yet there is still a threat to the immune system, and in some cases, the infection can become chronic and progress to CC. This type of cancer may develop in 15-20 years although manifestation is dependent on the person's immune system [12].

A worldwide analysis conducted in 2018 about the calculations of incidence and death rate of CC compared countries with the highest and lowest incidence rate of CC. The highest incidence rate for CC was in most parts of Africa, except in Northern Africa, as seen from figure 1.

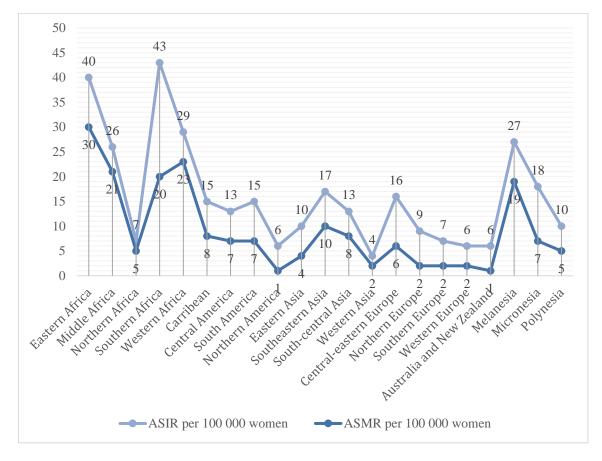


Figure 1. Worldwide calculations of incidence and mortality rates determining ASIR and ASMR per 100,000 women regarding CC in 2018 [17].

In Eastern Africa, there were 40 CC cases per 100,000 women, whereas the mortality rate for 100,000 was 30 cases (75%). Low incidence and mortality rate was shown in Australia and New Zealand. This analysis showed that the average age at the time of diagnosis for

CC was 53, the global average age of mortality of CC was 59 [17]. Estonia is located in central-eastern Europe, which shows the highest incidence and mortality rate in Europe, per 100,000 women ASIR was 16 and ASMR was 6 as seen in figure 1.

## 2.2 Cervical cancer and its prevention

Effective measures for preventing CC are going for regular screenings and vaccinating against HPV. Screening helps to detect any conditions which may lead to cancer development, whereas the HPV vaccine gives full protection against malignant HPV types [18]. Restricting exposure to HPV helps to prevent receiving HPV, as it is transferred from one individual to another during skin-to-skin contact by an infected body part. Using a condom may protect against HPV, but does not fully avoid the infection, as it does not fully cover HPV infected part of the body, but it is effective in the protection against other sexually transmitted diseases [12].

The global strategy for CC prevention has three directions. The first prevention starts with vaccination against HPV including girls and boys at the age of 9-14 before their active sex life. The next stage for preventing CC is directed to women at the age of 30 and older to participate in CC screening regularly. The frequency depends on the screening method. The screening contains the examination of pre-cancer or cancerous signs, as it enables to discover cancer at an early stage. Providing treatment at an early stage is likely to be successful. If there are any signs of changed cells or abnormality, the treatment should follow immediately. Tertiary prevention targets all women as malignant CC requires a treatment plan e.g. radiotherapy, chemotherapy, surgery or palliative care [12].

In Estonia, the target group for screening are women between the age 30-65 and screening interval is five years. Estonian Cancer Screening Registry provides the information and communication for participants via e-mail or the national e-booking system and sends the invitation to the person's registered postal address. In addition, the digital prescription is available to the person in HIS [19]. The screening pathway for CC used in Estonia is shown in figure 2.

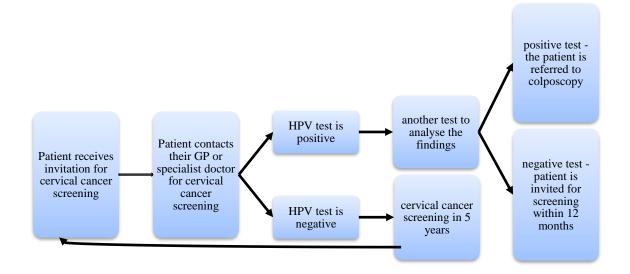


Figure 2. Cervical cancer screening pathway in Estonia [19].

An invitation is a basis for the women to contact their family doctor or gynaecologist to proceed with the PAP test. If the test reveals that a person is HPV positive, another test in the lab is conducted. If the test is negative, then the person is invited for screening in 12 months. In the case of the intraepithelial lesion, the procedure of colposcopy has to be performed [19].

The participation rate of CC screening has been low in Estonia when comparing it with EU standards. In 2019, from all women who were invited for CC screening, only 46,1% participated. When comparing numbers between the years 2015-2016, the participation rate of CC screening has remained the same [20]. WHO strategy encourages the use of digital technologies to improve CC screening efficiency and promote responsibility among individuals [2].

## **2.3 HPV vaccination strategies**

Vaccination against HPV is the primary measure in preventing CC and the vaccine can protect against most malignant HPV types [12]. Clear strategies for HPV vaccination and frequent screening for HPV detection in high-income countries indicates its efficiency in preventing mortality and lowering incidence rates for CC [5]. HPV vaccination among adolescents is a priority to protect future generations against malignant HPV types [21].

In most countries, adolescent girls and boys need their parents' or legal representative's permission for HPV vaccination up to the legal age of 18 [22].

Between 2006-2014 there were HPV immunization plans set up in 64 countries nationwide. Tracking HPV vaccination coverage is essential to evaluate the implementation of vaccination plans and to find out the possible effects of HPV vaccines regarding diseases connected to HPV. The target group for HPV vaccines are adolescent girls at the age of 10-14. Vaccination plans differ by target groups and HPV vaccine introduction year varies in different nations and program delivery policies. Globally, the target group between the years 2006-2014 were 118 million women. Females from high-income countries were mostly targeted, and the vaccination rate was 68%. From low-income and lower-middle-income countries, only 1.4 million women were vaccinated against HPV, which was 7% of the total number [23].

Australia set an example as being one of the first countries for setting up an HPV vaccination program in 2007 and targets both sexes. The incidence and mortality rate of CC in Australia is globally the lowest, seven cases per 100,000 females. Australia has set a goal to eliminate CC among Australian women within the next 20 years. Through NCSP in Australia, HPV screening is performed in every 5 years for females at the age between 25-69 and exit screening for females at the age between 70-74. In 2017, from all 12-year-old girls, 82% received the HPV vaccine and from all 12-year-old boys, 76% were vaccinated against HPV [24].

In Europe, Germany, France and Spain were the first countries to implement national HPV vaccination strategies in 2007. In Germany, HPV vaccination is for 9-14-year-old boys and girls as an obligatory benefit of legislative health insurance. France offers HPV vaccination only to 11-14-year-old girls as a part of the vaccination program. Only nine countries in Europe provide HPV vaccination as a part of the immunization plan also to boys; the target age varies in each country. In the United Kingdom, girls who fail the chance for the HPV vaccination can receive a catch-up HPV vaccine up to the age of 18. In Poland, the HPV vaccination is not included in the national immunization program; however, it is recommended for 13-18-year-old girls [13].

#### 2.3.1 HPV vaccination in Estonia

In 2018, the HPV vaccination in Estonia was included in the national immunization plan for girls [13]. The Estonian cancer prevention action plan aims to widen HPV vaccination for boys within the next years. The main expectation is to increase vaccination coverage within the country for the next nine years [21]. The combined use of screening and HPV vaccination would result in higher prevention methods of CC. Vaccinating girls at the age of 12 is cost-efficient as health gains are high, and vaccination protects from the most malignant HPV types 16 and 18 as presumed to show 98,4% and 98,8% of efficiency [25]. In the years 2018-2019, the target group for the HPV vaccination were girls born in 2003-2007 as shown in figure 3.

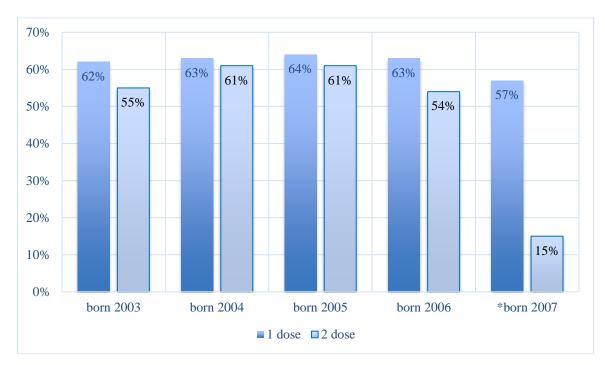


Figure 3. 2018-2019 cumulative numbers of HPV vaccinated girls born between 2003-2007 in Estonia (modified) [26]. \*born 2007 does not indicate full coverage, vaccination continued in 2020.

62% of girls born between 2003-2007 received the first vaccination dose from total girls born in the same years. The second dose was received only by 47% of all girls born between 2003-2007. The biggest difference for receiving two doses of vaccination was for the youngest girls born in 2007 – the first HPV vaccination dose was 57% from all girls, whereas the second HPV vaccination dose was done only for 15% of the girls. Statistical numbers of 2007 may be misleading due to the lack of data in 2020, at the time of writing the thesis. It is likely that the part of girls born in 2007 received both of their HPV vaccination dosages in 2020. The estimated age of girls born in 2006-2007 was 12

which is the target group for HPV vaccination since 2020 [26]. The protection from cancerous HPV types is most efficient when the person receiving the vaccine follows vaccination guidelines. When comparing vaccination years, the total number of vaccinations between years 2008-2017 was 10,364 and among girls at the age of 9-14, the vaccination rate was 14% from the total vaccination number [3]. In 2018-2019 there were 16,537 vaccinations done, which was significantly higher when comparing nine years of vaccination with the past two years. Of all vaccinated individuals between the years 2018-2019, 80% accounted for kids at the age of 9-14. When comparing the statistics of years 2008-2017 and years 2018-2019 the vaccination rate for adolescents (age 15-17) slightly increased in the past two years [26]. The increased vaccination being funded for 12-14-year-old girls by EHIF [3]. However, according to EHIF statistics from 2019, it showed that 22 schools did not have a school health care service provider, which resulted in unvaccinated children against HPV or vaccination lagging [26].

## 2.4 Digital interventions for health-related decision making

In 2019, a survey among 210 students in North Florida was conducted to find out what are the perceptions of HPV vaccination. Students who used different technological solutions were selected for the study (messaging, email, social media). The study tested the potential of technological solutions to increase informed decision-making. As a result, the recommendations of health care professionals were the biggest factors to support the decision for HPV vaccination [5].

In 2020, a cross-sectional survey was conducted among adults in Wales and England about parental awareness of HPV vaccination for young girls and boys. As a result, 55% of the respondents knew about HPV and after a short introduction of HPV vaccination program 62% would agree to vaccinate their child against CC. However, 54% of respondents wanted more information to make a vaccination decision. Awareness-raising campaigns addressing key parental issues and concerns are important to ensure HPV vaccination for both girls and boys [6].

A study aimed to utilize mHealth technology to increase HPV knowledge and HPV vaccine uptake in adolescents was conducted in 2018. It was found that using mobile information methods, helps to raise awareness about HPV and HPV vaccination among

young people between the age of 18-25. Respondents were found to be more responsive to text messages and applications that help to raise health awareness, especially when sent by a health care professional [7].

In Estonia, a research is underway on smart and personalized screening solutions for the elimination of CC. Researchers hope to develop user-friendly digital solutions which could be implemented in common practice, based on interventions tailored specifically to individual's needs, accessible and understandable to physicians and patients, according to their risk level [9].

The Norwegian Cancer Registry has developed a free educational game FightHPV for women aged 25-69 to raise awareness of CC and HPV by increasing prevention through the use of social games as a digital way of communication. The game consists of 60 different levels where the player learns about the different forms of HPV, HPV vaccination, the treatment and the screening process [10]. In 2019, the FightHPV application feedback study was conducted and 26 players participated in it. 22 players at the age between 16-18 and 4 players at the age between 40-50 participated in the study. As a result, focus group discussions helped to improve the user experience and pathways of improving the application. The participants agreed that FightHPV is an attractive educational instrument and there was an increase in HPV awareness among players. FightHPV has been downloaded for more than 12,000 times in 45 countries. The application was created in the Norwegian context but can be easily modified for other countries, however, an overview of the context is needed by the local health authorities [8].

Although there is an action plan stating that its goal for years 2021-2030 is to improve data structure and quality by using possible digital tools for inviting target groups to cancer screening [21], there are currently no digital tools or applications developed or used in Estonia as part of national vaccination plan for educational purposes regarding HPV vaccination or CC prevention.

## 2.5 The concept of wicked problems

The wicked problem originates from complex theory and is described as problems that are difficult to explain. An explanation of a problem can develop new problems as each of the issues is unique on its own, and the solution provided previously may not be thoroughly suitable when new issues arise. When tackling wicked problems, the choice of a solution method may be very hard as stakeholders and participants have different needs. The consequences for solving these problems are unpredictable as each possible solution method may cause new wicked matters. These problems are intertwined, difficult to structure and complex as consequences may be global and result in a poor healthcare system and pose health risks for people [27].

#### 2.5.1 Wicked problems in healthcare settings

Wicked problems in social care and health care can be coped with when the network and co-operational governance is the centre and leadership together with hierarchies are set aside. Government representatives should realize that sorting out wicked problems requires the participation of different stakeholders with new skills regarding the joint operation on governance. As the world grows and develops new systems and information flow, the complexity of problems as called the wicked problems rise significantly [28].

A growing number of chronic diseases constitutes the challenges of management structure. The evolution in healthcare is overshadowed by the general approach in healthcare by setting the perspective of professions higher from the person's needs. The beneficial part for examining complex problems in healthcare is to underline the importance of free-flowing design training. The idea of a free-flow design is that the problem and solution run hand-in-hand. The process for tackling complex problems has to be based on a logical model. Free-flow design is founded on the approach of design abduction, justifying the result is permitted to shift. This approach may be a prerequisite for radical innovation in healthcare by averting less intense issues [29].

By analysing the beforementioned concept of wicked problems, the theory of digital tools and solutions improving healthcare may be a wicked problem and needs to be handled by addressing the core issue of the topic and setting the focus on sub-topics aside.

## **3 Methodology**

This section provides detailed information about the study methodology. For collecting data for this study, different qualitative methods were used. The study period was October 2020 – March 2021. This study is a qualitative research using two methods - focus group interviews with parents of 12-14-year-old girls and an expert interview with an expert working in the area of health communication in a governmental institution.

## **3.1 Data collection methods and instruments**

The method of this study was a focus group interview. Focus group interview is one of the main techniques for qualitative research and used for data collection [30]. The qualitative research method using focus group interviews was used due to its variety of advantages – getting in detail regarding communication issues and social pressure when the topic is sensitive. A focus group interview is a cost-effective measure and a great alternative for understanding the distinct worldviews of participants. Online focus group interviews are more beneficial as participants are more engaging as there is no usual face-to-face pressure when doing physical focus group interviews [31]. The obstacles for conducting focus group interviews online may be poor internet connection or other technical problems as weak video connection or loss of microphone which leads to failure in catching non-verbal information [31]. To mitigate risks posed by COVID-19, a comfortable online environment using MS Teams was created for focus group participants to create a productive discussion that includes teamwork and testing the application.

During focus group interviews, interviewees were asked about their knowledge about CC and HPV vaccination as well as the perceptions of their family or friends regarding the topic. In addition to this, the participants were asked about current information sources of HPV vaccination and what perceptions they have about information received from the school and EHB. Furthermore, they were asked whether the information was considered to be sufficient to make an informed decision about vaccinating their daughter with the HPV vaccine or deciding not to allow it. A discussion about possible digital interventions was addressed. The focus group agenda is found in Appendix 3.

As a part of focus group interviews, FightHPV application usage and design was introduced and participants were instructed on how to use the application. Downloading the application was voluntary, and the focus group moderator introduced the application and its potential via application screenshots (Figure 4 and Appendix 4). During the group work, the moderator asked for feedback about the FightHPV application.



Figure 4. Screenshots of FightHPV social gaming application [10].

The application FightHPV is used for increasing awareness about CC and HPV vaccination among adolescents and parents. The FightHPV application was selected for this study due to its wide user population and evidence-based reliable content. The FightHPV was composed in cooperation between Cancer Registry of Norway and Simula Research Laboratory [10]. After the introduction of the FightHPV application, participants discussed the application, its content and potential suitability in the Estonian context.

An expert interview was conducted with an expert working in the area of health communication in a public institution. The interview was performed virtually using Microsoft Teams environment on 26<sup>th</sup> February 2021 and the duration was approximately 45 minutes. The expert interview was chosen for this study as it helps to collect new information from the individual who has the competence in a certain field of action [32]. During the interview, the FightHPV application was introduced and the expert's

perception of the application was collected. The expert shared the expertise in the area of health communication. The structure of the expert interview is seen in Appendix 5.

## **3.2 Study population**

The primary selection of participants was made using a snowball sampling method through the social media channel *Facebook*. The Snowball method was used due to its efficiency in catching some cases to stimulate the participation of others. This method is useful as it contributes to engaging small target groups [33].

Study participants were found during period 12.01.2021-27.01.2021. Firstly, the mass posting was conducted on the author's social media page. Some candidates showed interest in participating in the study, but the number of participants showing interest was not sufficient to conduct focus group interviews. Therefore, as the next step in sample formation the convenience sample was used through *Facebook*. The author of the study directly wrote to possible candidates who could fit into the study target group. A convenience sample was applied due to its capability to approach target groups directly, as friends and family are often comfortably available. This approach regularly helps to overcome the burden of limitations connected with the survey [33].

Focus group interviews with complex topics and more questions should be conducted with fewer participants because it allows profound understanding participants experiences and allows everyone to share their experience of the subject. The preferred size of a focus group is stated to be mostly between five and eight people [34]. However, the preferred size for conducting online focus group interviews is 3-6 people [35], to include everyone in the active discussion. The target group and criteria for inclusion in the study were parents who have a 12-14-year-old daughter, who has not yet received HPV vaccination, but who has received a notification from the EHB via school nurse. Finding participants taking part in focus group interviews was challenging and therefore the study population was widened. Five parents, who had daughters at the age of 11 were also included as the girls were to turn 12 later that year. The objective was to have 15 parents participants who agreed to participate in the focus group interviews declined at the last minute due to unsuitable time. The mean age of girls was 12 years. The subjects were included by the author of this study. An informed consent (Appendix 2) was sent to

participants via e-mail, which was digitally signed by both parties. Data collection aspects regarding personal data are presented in detail in chapter 3.4.2.

Before the inclusion in the study, the investigator informed subjects of their right to participate in the study as well as the possibility to withdraw their consent at any time without any need to explain the decision. It was explained that in case of withdrawal of the consent, the data already collected would be used for further data analysis.

The subjects were divided into three different groups on a random basis, mostly depending on the suitable time, and the interviews took place in groups at different timeslots in the Microsoft Teams web environment. The Microsoft Teams online platform was used because Office365 is a cloud-based service, and it is an institutional environment for TalTech for saving documents, sending e-mails and conducting interviews or participating in lectures. There were 4 participants in the first and second group, and the third group had 5 participants. The interviews were held on 28<sup>th</sup> and 29<sup>th</sup> January, the duration of each focus group interview was approximately 1,5 hours. Each participant felt comfortable switching on video during the interview, which ensured better communication between participants and the moderator of the interviews. Focus group interviews were introduced as parents' meetings to make participants feel more comfortable and engaging in discussions.

Participants against vaccination were not the target group of this study for avoiding bias for determining real causes. Still, it appeared during the first focus group interview that one participant mentioned herself to be against vaccination in general (see chapter 5.3. "Study Limitations" for details).

## **3.3 Data analysis methods**

Thematic textual analysis was performed and inductive methods were used. Data was coded and categorized according to the focus group plan. Inductive coding was chosen as a coding method to understand the worldviews and experiences of the participants. This method allows studying the data more comprehensively. For applying inductive coding, the text was marked with different colours according to the topics shown in figure 5. After that primary codes were formed and grouped into larger thematic categories [36]. Recorded video files were transcribed using web-based speech recognition [37].

Transcripts were copied into Microsoft Word to regulate analysis and coding. Collected data passed thematic textual analysis and coding logic is explained in chapter 3.4.2 and seen in figure 5. Interview topics were divided into three main categories.

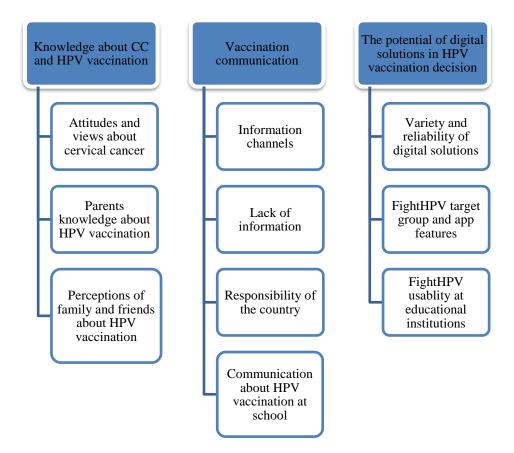


Figure 5. Data coding and categorization.

Recurring thoughts of the participants were added under each topic, and only the key citations in the results were selected.

## **3.4 Ethical Considerations**

Approval for this research was granted on December 1st, 2020 by NIHD REC (research no 2185 and decision no 560).

## 3.4.1 Ethics in Human Research

WMA Declaration of Helsinki states the ethical principles for medical research which include human participants. The goal of medical research is to obtain new information on a specific topic, but the goal can never overshadow the interests and rights of the participants [38]. Scientific research which involves human subjects has to respect the personal autonomy, human dignity and privacy of the subject, avoiding any harm to them. Preserving human dignity means that each individual has their interests that need to be considered when aiming for higher insight into the research for contributing to society [39]. Privacy, autonomy and well-being of the subject are connected to individuals' personal data. The data subject has the right to withdraw consent at any time as participating in a research is purely voluntary. When processing participants personal data, it has to be done according to the law and for specific purpose; data needs to be held in a secure location to avoid misuse, destruction or leakage to unauthorized parties. The processing and use of personal data have to be in accordance with Personal Data Protection Act [40]. The principles for respecting participants equally includes non-discrimination based on age, gender, race, religion, beliefs, education, socio-economic status and disability. The rights of participants have to be protected and respected to ensure both the mental and physical well-being of individuals taking part in focus group interviews [41].

As the study deals with the matter of health topic, it was expected that participants may reveal health data during the research. Therefore, before the focus group interview, it was agreed with the participants that the ideas and information published in the group will not be disclosed outside the focus group. At the same time, it was also considered that the subjects might come up with questions that the researcher cannot answer, and in this case, it was recommended to visit the informative website <u>www.vaktsineeri.ee</u> or contact the school nurse/family doctor to find additional information.

The participation in the study was considered to be useful for the participants, as via focus group interviews they were able to discuss the pros and cons of HPV vaccination and CC, talk about the fears of vaccination in an open environment and how to alleviate them.

#### 3.4.2 Aspects of data protection

The collection of personalized data (name of the participant, gender, e-mail, child's age) was necessary because answering questions anonymously online would not have given deep details about parents' perceptions about the potential of digital interventions. The used method helps to provide detailed insights into parents' perceptions of digital solutions and their knowledge about CC and HPV vaccination.

Participants personal data, together with the recording, was stored in a passwordprotected document folder on the OneDrive cloud server of TalTech. These documents are accessible only to the author of this study and to the author's supervisor. The signed consent forms were destroyed at the end of the data analysis (March 2021). The focus group conversation was recorded and used only to document the data analysis accurately. The recorded conversation was only available to the author of this study and the author's supervisor, and auto-recordings were deleted after transcribing. Analysis files with pseudonymized data will be deleted no later than two years after the defence of the study (May 2023) to allow publication of the data in a scientific article.

The following personal data was collected from participants: participant's name, gender and e-mail, including the age of the child. From this data, the gender and age of the participant were used to generate the code of the participant. The name was reflected in the consent form and was also known during the online focus group interview, but was not used for data analysis or subsequent interpretation of the results. Each participant was given a study code to ensure anonymity. Codes were formed based on participants gender (M for man and F for female), the age of the daughter and the study number (1, 2, 3 up to 13). According to this coding scheme, the first female participant with the daughter aged 12 received a code 1-F-12. The opinion and perceptions of the expert are shown as code E.

## **4 Results**

This chapter gives an analysed overview of parents' perceptions discussed in focus group interviews and the expert's opinions about the topics. Interview topics were separated into three categories – knowledge about CC and HPV vaccination; vaccination communication and the potential of digital solutions for informed decision-making.

## 4.1 Knowledge about cervical cancer and HPV vaccination

Knowledge category includes codes regarding attitudes and views about CC, participants knowledge about HPV vaccination and perceptions of family and friends about HPV vaccination.

Participants associated CC with disease prevention related testing and pre-cancerous conditions:

"When I think about the word CC, I've had pre-conditions of CC, and therefore previously for many years I had to do PAP tests every year." (7-F-11)

As the quotation indicates, personal perception arises from personal experiences and may materialize not as a disease (e.g., CC), but rather means individual actions in the context of CC. Therefore, it may be that people without personal experience do not understand the nature of the disease, and the participants outlined the lack of awareness about CC among the general public:

"I think people who are not health care professionals don't know the prevalence rate of CC, how CC develops and spreads." (7-F-11)

As the excerpt indicates, the rates to take preventive actions might be related to a potential lack of knowledge about CC as an illness, i.e. its prevalence, epidemiology and aetiology. Participants analysed discussing HPV vaccination with others:

"There has been no discussion at school or with other parents/.../ but we've discussed this with our family." (12-F-12)

As seen from this excerpt, the HPV vaccination is spoken within the family circle and not with others as the information may not be as understandable and acceptable to speak about publicly. Another participant stated that HPV vaccination is considered to be "*a sensitive topic, therefore I haven't had discussions with my friends /…/ it is like intruding into people's values and their decision*" (3-F-12) and this situation may increase the lack of

information. The issue is more complex due to various opinions among specialists as well, which might increase the confusion for the parent in the decision-making:

"I spoke with my gynaecologist /.../ recommended the vaccination for the child when the menstruation cycle has been developed. It seemed like a good argument for me." (3-F-12)

As the excerpt indicates, parents asked for advice from medical professionals, who explained their views according to their practice. The participants felt that the information given was trustworthy and considered it when deciding on behalf of their child. Another participant underlined that she "*trust(s) medical specialists and doctors, perhaps too much*" (9-F-13); however, the participant also outlined that when a doctor recommends something "*I won't question specialists' opinions*." (9-F-13). In terms of trustworthy sources, the phenomenon of vaccine hesitancy was discussed, and in order to mitigate these hesitations, there is the need to provide information through scientific resources to decrease the influence of anti-vaccine views on parents' decision-making:

"I think it is important to fight disbelief against vaccination and give information about possible side-effects of vaccinations through reliable resources." (2-F-14)

As this excerpt indicates, it is important to provide information about possible vaccination side-effects on websites managed by health organizations to reduce superstition among parents.

The role of previously acquired habits to discuss health-related issues might also influence the current behaviour:

"I've grown up in this society where talking about vaccines was a taboo subject /.../ now I'm facing with the consequences which could have been prevented in the past." (3-F-12)

The quotation specifies in detail the participant's experience of not receiving enough information about HPV vaccination and CC to take preventive actions towards her health from an early age.

To sum up, the participants linked CC directly with prevention for going for regular health check-ups. HPV vaccination brought up confusing feelings as participants mentioned their lack of knowledge. Health care professionals' opinion is important for the participants as it helps to form their understanding and make decisions based on specialists' knowledge.

## 4.2 Communication regarding vaccination

#### 4.2.1 Information provision aspects regarding HPV vaccination

The vaccination communication category included the following codes – information channels; lack of information; responsibility of the country; communication about HPV vaccination at school.

Participants expressed their feelings about vaccinating their child, that it should be a shared liability between the country and the parent:

"It is the state's role to share necessary information about CC. I feel powerless as a woman that there are so many diseases which I don't know about that could be prevented. The information provided has to be crystal clear, whom it endangers, how it spreads and why vaccination is important." (13-F-13)

According to the quote, parents need clear guidance and knowledge by the public institutions to make an informed decision and collect enough information to make a vaccination decision on behalf of their child. Another participant outlined that child's vaccination "*should be a shared responsibility*" (9-F-13) between the parent and the state. Participants debated that there is an abundance of information about HPV and CC, therefore it is hard to find evidence-based knowledge and discard misinformation:

"I have received information about CC and HPV vaccination in doctors' waiting room by reading brochures. /.../ there is so much information, and it is hard to separate evidence-based information from false one /.../ CC has a negative tone, and perhaps there should be campaigns with famous people aimed at target groups to stand out from all the information one receives on a daily basis." (6-F-12)

As the quote states, there is a lot of information to process and memorize, therefore important topics should stand out from others to raise awareness and help to prevent illnesses in the early stages. It was mentioned that campaigns with well-known people may be beneficial for guiding people to find evidence-based information. The expert addressed the downsides of involving famous people in public campaigns:

"It is difficult to find a famous individual who has been vaccinated against HPV. This person has to have knowledge about CC and HPV vaccination/.../ campaigns with idols have to be well elaborated for the public health to benefit /.../ there have been downfalls as a person who promotes alcohol-free life, on the contrary, is an active consumer which shows the controversy of these campaigns." (E)

This quote demonstrates the need for well-thought campaigns. The spokesperson needs to have the competence on these topics to be profitable for the society. Poorly planned campaigns can have negative effects on HPV vaccination and can backfire preventive methods. Participants mentioned that EHIF screening campaigns are prominent:

*"EHIF campaigns about breast cancer screening, prostate cancer screening, CC screening have caught my eye the most as they are for target groups."* (8-F-11)

This excerpt indicates that campaigns developed and delivered by public health organizations should be more prioritized as this information is reliable and can reach target groups. The expert emphasized the need for creating a holistic patient experience:

"Designing the service pathway is crucial to create a person-centred approach.

If a vaccination has side effects this has to be communicated as well." (E)

This quote underlines the importance of the comprehensiveness of the patient journey, for the people to collect and understand the information. Informing people has to include information about vaccine contraindications, long-term benefits and importance for their child's health. It was indicated by the participants that "doctor Google gives tasteful solutions for everyone" (8-F-11), however, they discussed that "it should be overlooked with a critical point of view and multiple articles should be sought for" (8-F-11) to find information from different resources which could confirm the authenticity of the information. The expert highlighted that "people tend to use Google, and the information found there may not be adequate and can draw negative understandings of the topics" (E) as Google influences the opinions more than reading medical literature. It may be that medical wording can hamper the susceptibility of information as "medical terminology is hard to understand for people not of the medical field" (E) and it can jeopardize parents' decision-making on behalf of their child's health. The participants highlighted the importance of group discussions when addressing child vaccination topics:

"I think taking part in these kinds of group meetings as if they were parents meetings is essential." (1-F-11)

As stated by the quotation these meetings help parents' to fill the information gaps. It is mentioned that information shortage is a problem and increases confusion among parents.

In conclusion, from the parents' perspective, the information about CC and HPV vaccination is scattered on the internet and the research is time consuming. Parents agreed

that group discussions and public campaigns are crucial for addressing vaccination concerns and increase awareness among parents.

#### 4.2.2 Communication about HPV vaccination at school

Participants pointed out that the school provided only the consent letter which did not serve its purpose for supporting the decision-making process:

"I don't remember that we've had a meeting with the class or school regarding the HPV vaccine /.../ the consent letter had a reference to the webpage <u>www.vaktsineeri.ee</u>, which in my opinion was not sufficient." (1-F-11)

This excerpt demonstrates the participant's description of their experience with the information channel which for them was not effective for finding solid information. A participant emphasized, "*that some parents declined to sign the consent paper as there was very little information and they felt scared for their child*" (3-F-12) which resulted in parents' action not to give their consent. The information given by the school or by the organization which coordinates public health communication for delivering a national immunization plan seems to be ineffective. The interviewees expressed their concerns about not knowing about alternative choices for their child:

"I had no information about alternative choices, can my child be vaccinated at family doctor's office or how long can I postpone my decision on vaccinating my child. Do I need to pay for the vaccine?" (2-F-14)

This quotation shows that participants experienced that there was no substantive information provided by the school. The only form given before vaccinating their child was a short consent form and parents may have questions regarding the HPV vaccine which have been unanswered. An additional aspect to note is the matter of unequal responsibility as one participant underlined *"I read that in Australia also boys are vaccinated which makes it* (preventing cancer) *a shared responsibility"* (2-F-14) which shows that while parents of girls have to contribute, the parents of boys do not have the possibility. HPV vaccination should be performed on boys as well as HPV affects both boys' and girls' health. The participants discussed that engaging methods at schools are essential for raising health awareness:

"I was invited to a school seminar moderated by a psychologist about CC and HPV vaccine and other relevant topics regarding children's health, and my child was informed about this vaccine. /.../ the seminar was well organized, and the

interest in this was enormous. I believe addressing different topics about children's health invited a lot of participants." (13-F-13)

This quote shows how a school solved communication issues by sharing HPV vaccination and CC information. The participants mentioned that seminars which address multiple topics about a child's health are beneficial for the parents to gather information and ask questions from the experts. The expert agreed that "short seminars before signing the consent form can address and solve questions that parents may have" (E). Moreover, the excerpt indicated the importance of health care organizations as "EHB could address parent's concerns and perhaps develop a vaccination calendar with references to information channels" (E) to increase the communication flow. Therefore, the expert underlined good collaboration between involved health care parties and mentioned that /.../ school healthcare guidelines could include information about HPV vaccination and CC by providing leaflets and information in collaboration between different organizations" (E) to build a strong foundation for increasing health awareness among parents. A participant described the inefficiency of informative tools and the problem of not receiving the second dose due to COVID-19:

"At first I was unable to sign the consent form, as it was in between the child's notebook /.../ there was no information about this. Next year, a new consent form with informative booklet came, and I signed it." (11-F-14)

As the quote indicates, the participant discussed the defaults of receiving vaccine the first year although the information flow on the second year through e-school improved. An additional dimension is related to the public health emergency, and the participant indicated that "*due to COVID-19 the child has been unable to receive the second dose, and the school does not provide any information about this*" (11-F-14), which shows the increased information chaos questioning the arrangement of strategic planning for HPV vaccination.

In conclusion, educational institutions should integrate knowledge about HPV vaccination and CC into school programs as it helps to raise awareness among parents and their children. It was mentioned that an informed consent form is not enough to give information to the parent for making an informed decision.

## 4.3 The potential of digital solutions in HPV vaccination decision

#### 4.3.1 Variety and reliability of digital solutions

This category included codes about the variety and reliability of applications, FightHPV application features and target group, FightHPV usability at educational institutions. The participants discussed the importance of digital tools for transmitting information and filling consent forms electronically:

"Digital channels seem suitable choices for handing out information, consent forms should also be signed digitally /.../ it could send automatic information or reminders." (9-F-13)

This quote shows that participants value the power of digital tools and emphasize the importance of filling and signing vaccination consent electronically. The expert emphasized the relevance of HIS to attract the user:

"If a person visits HIS for the first time, it is very difficult to find any information /.../ there is a lot to adjust in HIS; it should be user friendly and easy for the person to find relevant topics." (E)

This quote demonstrates that systems need to be designed to attract the user and increase awareness about a person's health data. Using HIS would engage patients to actively take action on their health, raise knowledge, arrange doctor's visits and give feedback to the service provider by improving the overall quality. Innovative technological solutions for receiving information may be beneficial as discussed by the parents:

"I think digital interventions like health information robot would be ideal to ask questions in real time and receive answers." (12-F-12)

This quotation shows the need for digital solutions, like developing a health robot for an evidence-based health website to provide real-time information. Parents underlined the importance to receive information in a form of questions-answers and "a *webpage with frequently asked questions section would be very informative*" (1-F-11) to make the information consuming easier and "to find answers on what are the malignant types of *HPV*" (1-F-11). Participants emphasized that "the information which is sent to my e-mail is easily accessible and I can analyse the information there" (8-F-11) which shows the importance of electronic mail for communication. Parents highlighted that the credibility of a tool depends on where the information was collected:

"The reliability of a tool depends on where I have received the information, when EHB supports and promotes this intervention, I would certainly use it." (13-F-13) This excerpt shows that digital tools which have been approved by national health institutions would increase the reliability and usage of technological interventions. A participant described that she doesn't "know(s) if the information provided in an application or at a site is precise; perhaps it is due to how the tool is designed and how the text is written" (12-F-12) in order the application to be trustworthy. During the discussion it was described the significance of digital tools in future prospective:

"I haven't changed my view on this topic, but it gave me trust that these issues are dealt with /.../ I think digital solutions will be more suitable for our children, and from the future perspective it is a good approach." (6-F-12)

This quote demonstrates the support from parents when addressing HPV vaccination and CC topics among children, and this shows the importance of innovative interventions for future generations. The expert emphasized the need for coherent collaboration between organizations who are responsible for improving public health:

"There are a lot of confounding factors, like bureaucracy. One institution gives a lot of time for research to analyse the problem in the society. When a problem occurs /.../ the research can be done in parallel. Of course, another issue is the lack of human resources and experts. I think the key is prioritizing tasks, and then it is vital for one party to take the responsibility and the leading role." (E)

This excerpt underlines the problems of communication and cooperation. In order the public health to improve, empower citizens and increase overall health, it is crucial for different health institutions to cooperate. A wholesome approach can provide the solution to current problems of decreasing communication issues.

To sum up, the participants thought that digital solutions could improve information transmission, by having up to date and real time information. To increase the usage of these tools among the participants, digital interventions should be approved by national health institutions. The parents presumed that digital applications could be suitable for adolescents as their interests and digital skills are constantly improving.

### 4.3.2 Perceptions of the FightHPV application

The participants pointed out that it was difficult to identify themselves with the target group:

"I don't understand the target group of this application /.../ it seems like it is aimed for teenagers to whom it may be exciting /.../ I would like to receive adequate and fast information." (3-F-12)

This quote demonstrated parents' thoughts that the application was not clearly positioned and contained very different content (heavy text vs game). Parents can be involved in a discussion with the child afterwards. On the other hand, for parents, it is important to receive information directly not through playing games. The expert demonstrated the need for a general application to gather all health information and indicated that /.../ *gamification is secondary as evidence-based information is the key*." (E). The expert agreed with the parents' opinion that FightHPV appears to be directed for adolescents as seen from the context and design. Although the first impression was gaming, the information provided tended to be too difficult to understand. The participants stated that *"the information provided in the application is too serious and not understandable"* (6-F-12) therefore parent's intervention is needed to explain the importance of the topic as the parents stated that *"I don't feel my child would try this game on her own."* (6-F-12). The parents analysed that the game can be useful for the child for collecting information about CC and HPV:

"I would let my child surf in that game if she is interested. If she wants to receive the HPV vaccine then I would approve her decision, but before we would have a discussion to understand where her point of view comes from." (4-F-14)

As the quote shows, the participants assessed that this application could be an efficient tool for the child to raise awareness about CC and HPV. The FightHPV may increase knowledge among children with added playfulness for educational purposes. The participants mentioned adding the questions and answers feature to the game as it would make it more educationally engaging:

"My child is very curious about digital solutions, and she would definitely like the game /.../ it should provide questions the children could answer to be more challenging and engaging. I would be willing to play that game with my child /.../ gaming functionality gives interest." (13-F-13)

As the quote stated, technological solutions and applications are available on the internet, and children have the curiosity to try new gadgets. By combining social gaming and answering questions, it could benefit the child to gain new information. The interviewees analysed that the application had abundance of text which decreased the readability: "/.../ it should include bullet points to make it easier to read; also, the appearance of the images raises questions as they may be frightening for the children." (10-F-11)

As stated in the quote, children's imagination should be considered when images are designed to prevent intimidation and the context should be well-thought for the readers/players to engage. The expert demonstrated the importance of the application to nudge and therefore engage the player:

"Vaccination time and introduction of this kind of app (FightHPV) need to be synchronized. /.../ the application should also send notifications and reminders to parents and their children to be informed ahead of vaccination." (E)

This quote indicates that similar applications should, in addition to providing information, raise awareness, and these propositions should be considered when developing future applications. Gamification, providing information on CC, HPV and HPV vaccination including live reminders and notifications is important to alert the user before HPV vaccination. Moreover, the participants described different functions which could be added to increase the usage of the game like *"search engine, so I could type my question, and the answer would pop up."* (10-F-11). Nevertheless, the participants pointed out that one tool is not enough as *"it is not possible to make a decision based on one application"* (6-F-12) which indicates the wickedness of the problem – while previously it was mentioned the abundance of and clear connection with authoritative institution to provide the information, it is still considered that one source (although reliable) is not enough to make an informed decision. The expert analysed the need to create an application focused on multiple health topics:

# "An application should include different health topics which address the user /.../ then the spectrum is wider and more beneficial for the user." (E)

This quote shows the need to include a variety of health topics into one application. In this case, all the information and data is held in one place and more convenient for the user.

In conclusion, parents agreed that the application is mostly aimed for the child as the gaming and learning functionality is combined, however, adults should explain the purpose of the game to ensure safety for the children.

## 4.3.3 Usability of FightHPV at educational institutions

The participants discussed using the application in school programs as a part of educational courses:

"The game should be integrated into school curriculum /.../ children can play together and afterwards ask additional questions from the school nurse or the teacher. The game should be presented before HPV vaccination at school." (8-F-11)

This quote indicates that HPV vaccination at schools should be linked with providing an introduction of the application to use as a part of the decision-making process. The participants deliberated that introducing the application by the school nurse/teacher helps the children to understand the purpose of the application better. The expert agreed with this opinion and found it also relevant to integrate this tool into the regular teaching process.

The participants discussed about specialists who should be involved in preventive actions and provide information at schools:

"I think doctors are too busy to find the time for educating parents and our children/.../school nurse is a reliable specialist who has the knowledge to answer any questions related to health." (1-F-11)

This quote underlines the importance of the school nurse as being the first contact for the children and parents to improve health education at schools and increase prevention regarding the knowledge about vaccination. The participants described the need of providing a QR code of the game to the information leaflet:

"The game has to be easily accessible, it should be a part of the educational leaflet as a QR code provides easy downloading." (9-F-13)

As the quote underlines, the participants gave ideas on how to make the application more attractive and increase the use of application to draw attention to the prevention of CC.

In conclusion, the parents found that the school nurse could be a trustworthy specialist to provide preventive communication and knowledge on HPV vaccination and CC. The application could be most useful when integrated into school programs and introduced before vaccination to raise awareness and help in vaccination decision-making.

## **5** Discussion

This section provides a profound overview of the discussion on the results, previous studies and tries to answer study questions. Furthermore, the main contributors of this study are upbrought and limitations of this study are examined. Future research including the next steps and conclusions sums up this chapter.

## 5.1 Parents knowledge about HPV vaccination and CC

The results of this study brought up the complexity of this topic due to different understandings about the illness and vaccination. It was stated in this study that parents, who have had exposure to HPV, are more aware of the risks and consequences the diagnosis brings. Therefore, these parents are more informed when deciding on behalf of their child to receive HPV vaccination in order to prevent the development of CC in the future although there seems to be a strong relationship regarding parents' decisionmaking depending upon the information source. The finding is confirmed by a previous study which showed that parents' who sought information on the internet were more often to decline the vaccine whereas parents who reached out to GP's or obtained the information from health organizations were more likely to accept the vaccination [42].

The findings of this study confirmed HPV vaccination to be a fragile topic that is discussed rather within the family circle than with friends and other people. The reason is that talking about vaccination used to be a so-called banned action. It is possible that parents' previous view of not speaking publicly about HPV vaccination reflects the current situation, and perhaps it is an acquired habit not to discuss HPV vaccination. This may be one of the reasons for the lack of information as there is no discussion on a public or broader level. Previous finding has shown that vaccination is a sensitive topic and a wicked problem because it covers the areas of public health, ethical and law fields. It may be that people do not apprehend the impact of vaccine-preventable illnesses and whether the probability of contracting a disease is explicitly understood [43].

As stated by the participants of this research, one of the pinpoints for not vaccinating their child may be due to the gynaecologist's opinion for recommending to vaccinate when their child is older. The information differences from different health care professionals

due to their attitudes and knowledge confuses and increases misapprehension among people. However, a previous study stated that there is not enough time for the doctor to consult with the parent during the visit, and the topic caused inconvenience among the parents [44]. This finding confirms the complexity of this topic as, additionally, health care professionals lack time to provide information on preventive methods during the consultation. The participants of this study indicated that health care professionals are believed to be trustworthy contributors to health prevention by presenting evidence-based information for parents and their children. Therefore, physicians with more experience in this field could be great advocates for contributing to HPV vaccination programs and spreading communication among the society as they were mentioned to be reliable. The previous finding confirmed the importance of health care professionals in sharing knowledge about HPV vaccination with parents, as physicians with longer practice had broader expertise of the topic, and the majority (61%) of GP's demonstrated good knowledge of CC [44]. However, most of the physicians recommended HPV vaccine to adolescents at the age of 16-26 [44] which might be another barrier as it is recommended by WHO to vaccinate adolescents between the age of 9-14 when the vaccine is most effective [2]. Perhaps different perceptions among health care professionals increase the misunderstanding of when to perform HPV vaccination for adolescents. Therefore, it is easier for the parents to postpone the vaccination for their children, which may lead to negative outcomes in the future.

In conclusion, the parents who took part of the interviews seemed to have their understanding of what is HPV, CC and how to prevent it. People with different perceptions challenge to develop a solution fit-for-all. Therefore, perhaps the general prospect of health care professionals should be agreed on regarding recent studies, current statistics and other information on HPV, related vaccination and CC.

## **5.2 Vaccination communication**

The results of this study showed that parents lack evidence-based information to decide on behalf of their child; however, in some cases, there seems to be too much information. A previous finding has shown that parents who refused their children of receiving the HPV vaccine were likely to decline past childhood vaccinations, and most of the parents were not aware of the linkage between HPV and CC, and this outcome was among all parents [45].

As current research shows, the information sources that are used by the parents are strongly correlated with their decision to give vaccination consent or not. Mass media consumption helps with state-of-the-art information but may be detrimental when information is not from a reliable source, and as an outcome can harm one's child. Previous research about parents' perceptions and attitudes about HPV vaccination conducted in Estonia states that parents evaluated themselves to have some knowledge about HPV, but they require additional information to make a vaccination decision on behalf of their child [11]. However, another finding clearly states that the obstacles for adapting HPV vaccination, according to GP's, were that parental knowledge is poor [44]. Furthermore, this finding may be due to the content of information as parents of this study stated that they would like to access evidence-based knowledge about the statistics of CC and HPV vaccination. The previous finding highlighted that the main questions parents want answers to are - the cost of the vaccine, when the child should be vaccinated and what side effects the vaccine has [46]. Therefore, information sheets should be based on the information parents require and can make a decision upon. These questions which are crucial for the parents could be communicated through health organizations and initially through the school nurse to receive information from and have a discussion on their children's health. Furthermore, the participants outlined the incomprehensibility of medical terminology, which perhaps directs people to find information from other sources with clear messages and understandable vocabulary. This might influence parents to seek information from Google as was stated by the interviewees of this study. However, the information found in Google should always be overlooked with other information sources which are scientific or presented by health organizations.

The findings of this study emphasized the need for the development of clear communication strategies to battle with vaccine-hesitant people, who may influence others with decision-making on HPV vaccination through social media and therefore reach a broader audience. A previous study has shown that designing national communication strategies help to combat the spread of misinformation through reliable tools and personalized information, has shown benefits for developing good health behaviours [47]. Another study highlighted the influence of media on HPV vaccination,

and due to media promoting anti-vaccine movements because of few adverse events, vaccination coverage has rapidly decreased since 2013 in Japan, from 70% in 2012 to few per cent by 2014 among 12-16-year-old girls [48]. As these findings show, by influencing parents, the mainstream media influences mostly children's uptake on the HPV vaccine. If clear national communication strategies are not composed, the HPV vaccination coverage will drastically decrease and the probability of CC incidences may increase. In order to solve this problem, public debates and open discussions should be performed to raise awareness on the HPV vaccination and CC and by that reduce the spread of false information. From the future perspective, national HPV communication plan should clearly present the risks and benefits for every age group specifically, and possible crisis scenarios should be considered. Clearly designed analysis with scenarios addresses the audience and helps to understand the context.

The results of this study show the benefits of EHIF campaigns, which were mentioned by the parents as a striking way of increasing awareness about CC screening. Therefore, national campaigns about the importance of HPV vaccination should be addressed to increase the importance of CC prevention. This finding was confirmed by a study, which analysed the cost-effectiveness of HPV vaccination campaigns and indicated that campaigns should be conducted in every three years and should target a broader target group. Moreover, a comparison with a regular HPV vaccination strategy was drawn and the limitations of a routine strategy were that the information is at certain sites which limits the information spread among target groups [49]. As stated by WHO, the HPV vaccination strategy should be communicated as a "cancer vaccine" as it increases the interest and draws more attention due to cancer being a feared health outcome and reduces HPV vaccine connection with increased sexual activity. WHO strategic planning on HPV vaccination gives very clear recommendations on how to communicate, collaborate and deliver clear information to people [50]. Every word has to be well thought as perceptions among people are different as was outlined during the focus group interviews. The wicked concept follows the HPV vaccine communication as the study [43] mentioned new approaches of empowering local authorities to impact individuals health behaviour.

Previous studies have shown that school nurses play a crucial role in participating in national immunization strategies by supporting and helping parents to make an informed decision [51]. On the other hand, school nurses need support and necessary training to

provide latest information and support to the parents and their children regarding HPV vaccination. A previous study about the perceptions of school nurses in Sweden indicated that there was little knowledge about HPV vaccine side effects and more than half of the school nurses admitted that they needed more education about HPV vaccination [52]. This finding is confirmed by another study conducted in Norway which highlighted that less than half of the public health nurses and GP's had an understanding of HPV being the cause of CC [53]. On the other hand, the findings of this study referred to health care professionals as a reliable resource, but the reality is controversial, as previous studies [52], [53], show that medical professionals do not have an understanding of the connection between CC and HPV vaccination. However, the main problem of not receiving the HPV vaccine for the adolescent lies within the requirement of the parent's written consent. The findings of this study outlined that a consent letter was not enough for the parents, to make a decision upon. This results in not being able to take the time to acknowledge the topic or contact a health care professional which may put parents under pressure to make the decision without knowing further information about HPV and CC. As seen from parents' opinions, HPV vaccination at school poses multiple challenges, the main one of them is fighting with misinformation found on the internet and media which increases the fear about HPV vaccination.

Clearly, as EHIF statistics [26] indicate, there is a lack of school nurses which may lead to adolescents' health risks. However, the responsibility may lie within the school management to engage teachers and school board for providing strategic approach and communication by performing lectures engaging parents, children and health care professionals. School seminars about children's health and wellbeing are necessary to conduct, as questions can be asked by the participants and answered by health care professionals. This finding was confirmed by a previous study which stated that strong collaboration between school teachers, health care professionals and the community is the key element for educating parents' and increase vaccination uptake among children [50]. Therefore, schools should pay attention to increasing health and sexual education among adolescents and provide necessary information about CC and HPV vaccination to make an informed decision.

In conclusion, school nurses are valued in the context of public health, therefore training and guidelines for school nurses should be provided to give information about different health topics. From just providing vaccinations in the past, school nurses should be implemented into interventions aimed at increasing health awareness at schools for different classes and different ages.

#### **5.3** The potential of digital solutions in HPV vaccination decision

During the interviews of this study, the topic of reliability of applications and digital interventions arose. It was mentioned that when a public health organization promotes a solution, then it would increase the trust of intervention and urge people to use this technology. The findings of this study indicated that the FightHPV application could be useful and educational to use; on the other hand, the information provided in the application was confusing for the parents. Furthermore, digitally more advanced parents found that this tool was not aimed at them for informed decision-making. For educating children, parents acknowledged the application, but perhaps the Estonian system will not support the solution due to text heaviness and the Norwegian approach which may differ from the Estonian cancer prevention action plan. Due to the increase of technology and children living in an environment where technology plays a crucial role, a game might be a supporting tool for health education as it connects education and fun. Therefore the FightHPV application could be a beneficial solution, but introduction needs parents' or teachers' guidance. Another issue, as stated in chapter 5.2, is that text should be simplified for people with non-medical background to attract a parent to gain knowledge. In order to make safer and healthier choices for one's child, the information has to be overlooked and controlled through different evidence-based resources.

The participants mentioned different digital tools to increase information gaining and automatization of the consent process. The previous finding showed an intervention conducted in London as parents described e-system simple to access and exploit although some parents expressed their dissatisfaction due to language barriers and some parents were not on the list of school mail system [54]. Therefore, new digital interventions need time to adapt as a transition from paper consent letter is transferred into a digital platform and takes time to get used to for all parties. One of the main opinions of the parents from this study was that health information should be gathered into one platform or application, e.g. to HIS. Using HIS helps to increase reliability and information consumption as everything is gathered in one place. A previous research that evaluated the management

of public HIS in primary care, with its wide variety of functions, found benefits of providing knowledge through the system which can help in health prevention [55]. This finding indicates that HIS allows better use of health data and storage for continuity of care and data exchange between the providers. Although providing just information is not enough, systematic reminders including health and vaccination plan help the parent to be up-to-date with the information and ease the remembering of crucial knowledge. This finding was confirmed by a research that showed that using reminders through HIS is strongly connected with HPV vaccination rates, especially among the male population [56]. Another important aspect is to schedule the introduction of the application and can help to make an informed decision. On the other hand, when developing an HPV vaccination strategy one should not rule out the power of e-mail, to receive, send and learn new information as mentioned by the interviewees of this study.

To sum up, digital solutions can simplify the process of gaining health knowledge on the matter of CC and HPV vaccination and automate the process of asking and giving consent. Applications, like FightHPV, could be beneficial to use in the school curriculum, but when implementing solutions from other countries, the content should be adjusted and introduced beforehand.

## 5.4 Main contribution to the core audience

The author contributes to CC prevention regarding HPV vaccination addressed as wicked problems in healthcare, that do not have a single functional nor universal solution. The barriers for not giving consent for HPV vaccination are that the decision-making process is different for everyone, starting from lack of information, different information provided by the health care professionals up to abundance of information, that hinders processing and selecting crucial information. The study highlighted that tackling the previous issue creates a problem in another field when thinking about possible solutions. HPV vaccination is directly linked with lowering CC cases when performed for adolescents between recommended ages according to WHO [2]. However, HPV vaccination is performed for adolescents only through parental consent, therefore parents are an important link for deciding on their children's health. Before giving consent, parents need information about CC, HPV vaccination and why it is needed for their child. As seen

above, trying to solve one problem leads to another three or more problems. The findings of this study address the areas of improvement in communication strategies aimed at parents to analyse if digital solutions could be beneficial for raising awareness about CC and help with informed decision-making on HPV vaccination. Furthermore, as analysed, technological interventions could help to ease the burden of sending and receiving consent letters, while it is important to deliver pre-communication about HPV vaccination and CC. Digital solutions, like the application FightHPV, which was introduced during this study, could draw attention to HPV vaccination and CC through mixed methods by combining gaming and educational aspects. This approach could be concluded in future interventions aimed at parents and their children to provide evidence-based education on CC and HPV vaccine to highlight the prevention in early ages.

## 5.5 Study limitations

This study had some limitations to address. The participants of focus group studies were digitally more advanced and were more susceptible to taking part in online interviews. The cohort of this study was restricted as people who participated were engaging in social media and had access to technology. It may be possible that due to the technical competence of the participants, this study attracted active participants with higher technical skills and digital literacy.

The participants of the three focus groups were different from each other due to participants' background, knowledge and personal experience regarding HPV. The author of this study made a decision to involve parents of 11-year-old girls as these girls would be 12 later that year, and who proactively provide an important input.

The invitation for taking part in the study included information about the suitable target group although a public invitation did not include specific requirements for the participants; nonetheless, the author informed each possible participant specifically about target group requirements for excluding people against vaccination. During a focus group interview, one participant who was against vaccination took part in the study and her opinions which were related to being against vaccination were not included in the final results. The opinion of this participant was included in this study when the feedback of the FightHPV application was asked.

The first choice of selecting a suitable expert for conducting an interview was from EHB, but due to COVID-19 and the overwhelming workload, there was no feedback. As the aim of the interview was to analyse the role of digital interventions in raising parent's health awareness about HPV vaccination and CC, to critically analyse the overall composition of national strategic health communication not the national vaccination strategy, another expert in the field of public health communication was interviewed.

The methods of this study ensured data saturation, which is for calculating and determining sample sizes for qualitative research. Reaching data saturation means that additional data collection produce no extra information for the objectives of this study [57]. The author of this study believes that despite the limitations mentioned above, the overall value of the study results is beneficial and the research provides essential insights about the topic.

### **5.6 Future research**

For future steps, the author advises to examine the potential of digital interventions of implementing in educational institutions. Furthermore, to conduct a research focused on communication and collaboration between the public, private and the third sector regarding HPV vaccination among adolescents. As the results and discussion showed, a study regarding the perceptions of health care professionals on HPV vaccination for adolescents should be conducted to understand the readiness to educate people about the risks of HPV and provide support when making a decision regarding HPV vaccination. Immunization strategies of some countries for HPV vaccination include vaccination for adolescent boys; therefore, it should be researched in Estonia whether parents are willing to vaccinate their boys and what their knowledge on the topic is. Discussion with EHIF on this matter should be held to include vaccinating boys against HPV into national immunization strategy. The author of this study plans to present the results of this study to Estonian health care organizations to have an open discussion about improvements and cooperation in the field of HPV vaccination and health promotion conducted at schools. Furthermore, as the participants of this study indicated, possible digital tools will be introduced and described to give ideas of future technological improvements for increasing efficiency of parental consent and communication among and at schools.

## **5.7 Final conclusions**

Following conclusions based on study findings can be drawn:

- 1. HPV vaccination is a wicked problem in health care and when planning communication strategies, stakeholders should develop an immunization strategy that is aimed at a variety of target groups.
- Drawing direct links between the HPV vaccine and its purpose should be established to increase the understanding of the HPV vaccine and vaccination coverage to prevent CC.
- 3. Health care professionals are a reliable resource to provide knowledge to parents and have a discussion on HPV vaccination and CC and addressing questions when to vaccinate, why to vaccinate and what the contraindications of the vaccine are.
- 4. Public discussions including seminars, meetings with health care professionals and other parents or teachers are crucial to exchange questions and receive answers.
- 5. Clear and consistent communication strategies have to be elaborated with media, health care organizations and the government to rule out the spread of false information or spread of single injuries, which outweigh the benefits of the HPV vaccine.
- 6. Digital consent letters may be beneficial for improving the vaccination process as digital platforms can include knowledge about HPV vaccination and CC with indicating sources to address the benefits and risks.
- Digital interventions as FightHPV could be implemented into school programs before the vaccination process, but the intervention of teacher or parent is necessary to educate children about CC and HPV vaccination to minimize risks.
- 8. Applications like FightHPV could be beneficial in future settings when adapting time is applied, the system is designed as secure, easy to use and provides information that parents' need.
- One solution or intervention does not ease the decision process; parents require information from multiple sources – from their GP, school nurse, health organization websites and evidence-based sources.

## **6** Summary

The aim of this thesis was to analyse parents' perceptions about CC and HPV and the potential of digital interventions on raising awareness for parents' decision-making process regarding HPV vaccination. The author of this thesis conducted focus group interviews with parents and with the expert in the field of health communication to get insights of problems and possible solutions regarding HPV vaccination among adolescents to implement in future settings.

Firstly, the interviews with parents gave valuable insights into their perceptions on CC and HPV vaccination. Most parents mentioned their lack of knowledge and inability to distinguish superficial information found in the media from evidence-based sources.

Secondly, a medical specialist should be involved in preventive actions aimed at HPV vaccination and CC; therefore, parents and their children should be consulted beforehand on the vaccination process. However, educating parents should be a collaboration between the school nurse, teachers and medical professionals to gain information from different sources.

Thirdly, HPV vaccination is a matter of public health, therefore the state should take the responsibility to provide necessary tools, interventions and solutions for the parent to make their decision upon. Furthermore, public health campaigns addressing target groups about CC and HPV vaccination need to be conducted consistently to reduce CC incidence and mortality rates in Estonia. Therefore, communications strategies need to be collaborated between all stakeholders.

Digital interventions, including applications, like FightHPV which combine gaming and education can be used in school programs to provide an effective approach when increasing awareness among adolescents and their parents.

To sum up, as the concept of wicked problems is addressed, multiple problems arise when trying to tackle a single problem. Therefore, one channel nor application is not enough for the parents to make a decision upon. Therefore, for increasing awareness, a set of different tools should be used – reminders and knowledge through HIS, education during school programs and seminars, conducting public meetings to have an open argument about the advantages and disadvantages of HPV vaccination among adolescents.

# References

- J.-J. Oidermaa, "Eesti Rahvusringhääling," 2017. [Online]. Available: https://novaator.err.ee/644507/hpv-vaktsiinist-ausalt-ja-emotsioonideta. [Accessed 12 October 2020].
- [2] World Health Organization, "Global strategy to accelerate the elimination of cervical cancer as a public health problem," 2020. [Online]. Available: https://www.who.int/publications/i/item/9789240014107. [Accessed 4 January 2021].
- [3] Terviseamet, "Lapsevanematele oluline teave: kuidas toimub HPV vastu vaktsineerimine?,"
  2019. [Online]. Available: https://www.vaktsineeri.ee/uudised/lapsevanematele-oluline-teave-kuidas-toimub-hpv-vastu-vaktsineerimine. [Accessed 4 December 2020].
- [4] Estonian Health Board, "Request for Information about Cervical Cancer Vaccination among 12-14 year old girls.," 2020.
- [5] V. Johnson-Mallard, G. Darville, R. Mercado, C. Anderson-Lewis and J. MacInnes, "How Health Care Providers Can Use Digital Health Technologies to Inform Human Papillomavirus (HPV) Decision Making and Promote the HPV Vaccine Uptake Among Adolescents and Young Adults," *Biores Open Access*, vol. 8, no. 1, pp. 84-93, 2019.
- [6] J. Waller, A. Forster, M. Ryan, R. Richards, H. Bedford and L. Marlow, "Decision-making about HPV vaccination in parents of boys and girls: A population-based survey in England and Wales," *Vaccine*, vol. 38, no. 5, pp. 1040-1047, 2020.
- [7] G. C. Darville, C. Anderson-Lewis, R. Mercado, J. Ma and J. MacInnes, "Utilizing mHealth technology to increase HPV knowledge and HPV vaccine uptake in adolescents: A qualitative study," *Journal of Adolescent and Family Health*, vol. 9, no. 1, p. Article 9, 2018.
- [8] T. Ruiz-Lopez, S. Sen, E. Jakobsen, A. Trope, P. E. Castle, B. T. Hansen and M. Nygard, "FightHPV: Design and Evaluation of a Mobile Game to Raise Awareness About Human Papillomavirus and Nudge People to Take Action Against Cervical Cancer," *JMIR Serious Games*, vol. 7, no. 2, p. e8540, 2019.
- [9] A. Uusküla, "Towards elimination of cervical cancer: intelligent and personalised solutions for cancer screening," Start date 1.02.2020 - End date 31.07.2023. [Online]. Available: https://www.etis.ee/Portal/Projects/Display/3c444dd4-aa24-4cbd-9cdb-762bf313c9b6?lang=ENG. [Accessed 6 November 2020].
- [10] International Papillomavirus Society, "Fight HPV a free social gaming app," 2017. [Online]. Available: https://ipvsoc.org/news/fight-hpv-free-social-gaming-app/. [Accessed 14 October 2020].
- [11] Virtuaalkliinik, "Nooremad emad suhtuvad vaktsineerimisse positiivsemalt," 12 May 2020.
  [Online]. Available: https://www.virtuaalkliinik.ee/uudised/2020/05/12/nooremad-emad-suhtuvad-vaktsineerimisse-positiivsemalt. [Accessed 17 April 2021].
- [12] World Health Organization, "Human papillomavirus (HPV) and cervical cancer," 2020.
  [Online]. Available: https://www.who.int/news-room/fact-sheets/detail/human-papillomavirus-(hpv)-and-cervical-cancer. [Accessed 6 December 2020].
- [13] European Centre for Disease Prevention and Control, "Guidance on HPV vaccination in EU countries: focus on boys, people living with HIV and 9-valent HPV vaccine introduction, 2020.," Stockholm: ECDC; 2020..
- [14] Health Statistics and Health Research Database, "PK10: New cases of malignant neoplasms by specified site, sex and age group (2014-2018)," [Online]. Available:

https://statistika.tai.ee/pxweb/en/Andmebaas/Andmebaas\_02Haigestumus\_04Pahaloom ulisedKasvajad/PK10.px/. [Accessed 11 January 2021].

- [15] The James. The Ohio State University.. [Online]. Available: https://cancer.osu.edu/forpatients-and-caregivers/learn-about-cancers-and-treatments/cancers-conditions-andtreatment/cancer-types/cervical-cancer. [Accessed 11 December 2020].
- [16] B. Owsianka and M. Ganczak, "Evaluation of human papilloma virus (HPV) vaccination strategies and vaccination coverage in adolescent girls worldwide," *Przegl Epidemiol.*, vol. 69(1), no. 53-8, pp. 151-5, 2015.
- [17] M. Arbyn, E. Weiderpass, L. Bruni, S. Sanjose, M. Saraiya, J. Ferlay and F. Bray, "Estimates of incidence and mortality of cervical cancer in 2018: a worldwide analysis," *The Lancet Healthy Longevity*, vol. 8, no. 2, pp. E191-E203, 2020.
- [18] American Cancer Society, "Can Cervical Cancer Be Prevented?," [Online]. Available: https://www.cancer.org/cancer/cervical-cancer/causes-risks-prevention/prevention.html. [Accessed 14 January 2021].
- [19] Eesti Haigekassa, "Emakakaelavähi sõeluuring. Tegevusjuhend.," Eesti Haigekassa 2020., 2020.
- [20] Tervise Arengu Instituut, "Vähi sõeluuringutel osalemine on kasvanud," 2020. [Online]. Available: https://www.tai.ee/et/instituut/pressile/uudised/4814-vaehi-soeluuringutelosalemine-on-kasvanud. [Accessed 14 January 2021].
- [21] Tervise Arengu Instituut and Sotsiaalministeerium, "Vähitõrje tegevuskava 2021–2030. Tööversioon avalikuks kaasamiseks.," 2021.
- [22] "Considerations regarding consent in vaccinating children and adolescents between 6 and 17 years old," World Health Organization, 2014. [Online]. Available: https://www.who.int/immunization/programmes\_systems/policies\_strategies/consent\_note \_en.pdf. [Accessed 19 April 2021].
- [23] L. Bruni, M. Diaz, L. Barrionuevo-Rosas, R. Herrero, F. Bray, F. X. Bosch, S. d. Sanjose and X. Castellsague, "Global estimates of human papillomavirus vaccination coverage by region and income level: a pooled analysis," *The Lancet Global Health*, vol. 4, no. 7, pp. E453-E463, 2016.
- [24] M. T. Hall, K. T. Simms, J.-B. Lew, M. A. Smith, J. M. Brotherton, M. Saville, I. H. Frazer and K. Canfell, "The projected timeframe until cervical cancer elimination in Australia: a modelling study," *The Lancet Public Health*, vol. 4, no. 1, pp. E19-E27, 2019.
- [25] A. Uusküla, A. Müürsepp, K. Kawai, M. Raag, M. Jürisson and M. Pillsbury, "The epidemiological and economic impact of a quadrivalent human papillomavirus (hpv) vaccine in Estonia," *BMC Infect Dis*, vol. 13, no. 304, 2013.
- [26] Estonian Health Insurance Fund, "Request for Information about Cervical Cancer Vaccination among 12-14 year old girls.," 2020.
- [27] Tartu Ülikool, "Kuidas parandada maailma? Kommunikatsioon sotsiaalsete muutuste kujundamisel. 3.2.1. Taltsad ja nõiutud probleemid," [Online]. Available: https://sisu.ut.ee/kommunikatsioon/32-kuidas-probleem-üles-leida. [Accessed 13 February 2021].
- [28] H. Raisio, A. Puustinen and P. Vartiainen, "The Concept of wicked problems : improving the understanding of managing problem wickedness in health and social care," Vaasan yliopisto, OSUVA Open Science, 2018. [Online]. Available: https://osuva.uwasa.fi/bitstream/handle/10024/10236/Osuva\_Raisio\_Puustinen\_Vartiainen \_2018.pdf?sequence=2&isAllowed=y. [Accessed 12 February 2021].

- [29] A. Thies, "Understanding Complex Problems in Healthcare By Applying a Free-Flowing Design Practice," 2016. [Online]. Available: https://su.divaportal.org/smash/get/diva2:923909/FULLTEXT03.pdf. [Accessed 18 February 2021].
- [30] R. Barbour, Doing Focus Groups, The Safe Qualitative Research Kit 2nd edition, 2018.
- [31] T. O. Nyumba, K. Wilson, C. J. Derrick and N. Mukherjee, "The use of focus group discussion methodology: Insights from two decades of application in conservation," *Methods in Ecology and Evolution*, vol. 9, no. 1, pp. 20-32, 2018.
- [32] S. Döringer, "The problem-centred expert interview'. Combining qualitative interviewing approaches for investigating implicit expert knowledge," *International Journal of Social Research Methodology*, p. https://doi.org/10.1080/13645579.2020.1766777, 2020.
- [33] H. Taherdoost, "Sampling Methods in Research Methodology; How to Choose a Sampling Technique for Research," *SSRN Electronic Journal*, vol. 5, no. 2, pp. 18-27, 2016.
- [34] S. P. Inc., "Participants in a Focus Group 4.," [Online]. Available: https://www.sagepub.com/sites/default/files/upm-binaries/24056\_Chapter4.pdf. [Accessed 29 January 2021].
- [35] I. R. LLC, "Online versus In-Person Focus Groups," GreenBook Directory, [Online]. Available: https://www.greenbook.org/marketing-research/Online-Versus-In-Person. [Accessed 26 April 2021].
- [36] V. Kalmus, A. Masso and M. Linno, "Kvalitatiivne sisuanalüüs," *Tartu Ülikool. Sotsiaalse analüüsi meetodite ja metodoloogia õpibaas*, 2015.
- [37] T. Alumäe, O. Tilk and Asadullah, "Advanced Rich Transcription System for Estonian Speech," Baltic HLT, 2018.
- [38] World Medical Association, "WMA DECLARATION OF HELSINKI ETHICAL PRINCIPLES FOR MEDICAL RESEARCH INVOLVING HUMAN SUBJECTS," 2018. [Online]. Available: https://www.wma.net/policies-post/wma-declaration-of-helsinkiethical-principles-for-medical-research-involving-human-subjects/. [Accessed 9 February 2021].
- [39] The Norwegian National Research Ethics Committees, "Guidelines for Research Ethics in the Social Sciences, Humanities, Law and Theology," 2019. [Online]. Available: https://www.forskningsetikk.no/en/guidelines/social-sciences-humanities-law-andtheology/guidelines-for-research-ethics-in-the-social-sciences-humanities-law-andtheology/. [Accessed 12 February 2021].
- [40] "Personal Data Protection Act," 2019. [Online]. Available: https://www.riigiteataja.ee/en/eli/ee/523012019001/consolide. [Accessed 15 February 2021].
- [41] "Code of Human Research Ethics," The British Psychological Society, Leicester, 2014.
- [42] A. Baumann, B. Andersen, L. Østergaard and M. B. Larsen, "Sense & sensibility: Decisionmaking and sources of information in mothers who decline HPV vaccination of their adolescent daughters," *Vaccine X*, vol. 2, no. 100020, 2019.
- [43] A. K. Shen, "Finding a way to address a wicked problem: vaccines, vaccination, and a shared understanding," *Hum Vaccin Immunother*, vol. 16, no. (5), pp. 1030-1033, 2020.
- [44] S. Almazrou, B. Saddik and H. Jradi, "Knowledge, attitudes, and practices of Saudi physicians regarding cervical cancer and the human papilloma virus vaccine," *Journal of Infection and Public Health*, vol. 13, no. 4, pp. 584-590, 2020.
- [45] M. Grandahl, T. Tyden, R. Westerling, T. Neveus, A. Rosenblad, E. Hedin and M. Oscarsson, "To Consent or Decline HPV Vaccination: A Pilot Study at the Start of the

National School-Based Vaccination Program in Sweden," *J Sch Health*, vol. 87, no. (1), pp. 62-70, 2017.

- [46] M. Highet, G. Jessiman-Perreault, E. Hilton, G. Law and L. Allen-Scott, "Understanding the decision to immunize: insights into the information needs and priorities of people who have utilized and online human papillomavirus (HPV) vaccine decision aid tool," *Can J Public Health*, vol. 112, no. (2), pp. 191-198, 2021.
- [47] J. P. Stahl, R. Cohen, F. Denis, J. Gaudelus, A. Martinot, T. Lery and H. Lepetit, "The impact of the web and social networks on vaccination. New challenges and opportunities offered to fight against vaccine hesitancy," *Médecine et Maladies Infectieuses*, vol. 46, no. 3, pp. 117-122, 2016.
- [48] T. Okuhara, H. Ishikawa, M. Okada, M. Kato and T. Kiuchi, "Newspaper coverage before and after the HPV vaccination crisis began in Japan: a text mining analysis," *BMC Public Health*, vol. 19, no. 770, 2019.
- [49] A. Portnoy, N. G. Campos, S. Sy, E. A. Burger, J. Cohen, C. Regan and J. J. Kim, "Impact and Cost-Effectiveness of Human Papillomavirus Vaccination Campaigns," *Cancer Epidemiology, Biomarkers & Prevention*, vol. 29, no. 1, 2020.
- [50] "HPV Vaccine Communication. Special considerations for a unique vaccine. 2016 update.,"
  World Health Organization, 2017. [Online]. Available: https://apps.who.int/iris/bitstream/handle/10665/250279/WHO-IVB-16.02-eng.pdf. [Accessed 19 April 2021].
- [51] E. Dube, D. Gagnon, P. Clement, J. A. Bettinger, J. L. Comeau, S. Deeks, M. Guay, S. MacDonald, N. E. MacDonald, H. Mijovic, J. Paragg, C. Rubincam, C. Sauvageau, A. Steenbeck and S. Wilson, "Challenges and opportunities of school-based HPV vaccination in Canada," *Hum Vaccin Immunother*, vol. 15, no. (7-8), pp. 1650-1655, 2019.
- [52] M. Grandahl, M. Larsson, T. Tyden and C. Stenhammar, "School nurses' attitudes towards and experiences of the Swedish school-based HPV vaccination programme A repeated cross sectional study," *PLOS ONE*, vol. 12, no. (4), p. e0175883, 2017.
- [53] K. Nilsen, O. G. Aasland and E. Klouman, "The HPV vaccine: knowledge and attitudes among public health nurses and general practitioners in Northern Norway after introduction of the vaccine in the school-based vaccination programme," *Scand J Prim Health Care*, vol. 35, no. (4), pp. 387-395, 2017.
- [54] T. Chantler, E. Pringle, S. Bell, R. Cooper, E. Edmundson, H. Nielsen, S. Roberts, M. Edelstein and S. Mounier-Jack, "Does electronic consent improve the logistics and uptake of HPV vaccination in adolescent girls? A mixed-methods theory informed evaluation of a pilot intervention," *BMJ Open*, vol. 10, no. (11), p. e038963, 2020.
- [55] Y. Zhao, L. Liu, Y. Qi, J. Zhang and W. Ma, "Evaluation and design of public health information management system for primary health care units based on medical and health information," *Journal of Infection and Public Health*, vol. 13, no. 4, pp. 491-496, 2020.
- [56] J. Bae, E. W. Ford, S. Wu and T. Huerta, "Electronic Reminder's Role in Promoting Human Papillomavirus Vaccine Use," *The American Journal of Managed Care*, vol. 23, no. 11, 2017.
- [57] G. Guest, E. Namey and M. Chen, "A simple method to assess and report thematic saturation in qualitative research," *PloS ONE*, vol. 15, no. 5, p. e0232076, 2020.

# Appendix 1 – Focus group interview invitation

Dear parent of a 12-14-year-old daughter!

We invite you to participate in a survey aimed at researching parents' opinions and awareness of vaccinating 12-14-year-old girls against cervical cancer. The target group of the study are parents of 12-14-year-old girls, who have received a Health Board leaflet from a school nurse and whose daughter has not been vaccinated with a HPV vaccine. In addition, this study examines how parents perceive their awareness of the issue and whether and how digital solutions would help influence vaccination decision.

We kindly ask you to participate in a focus group interview to discuss about vaccination against cervical cancer and during the interview group work will be conducted. As a part of the group work, an application (FightHPV) which is used worldwide is tested and your opinion is asked about it. Your opinion is important and can contribute to the development of digital solutions in Estonia, i.e. whether and what solutions could be implemented in Estonia to help parents make a more informed decision regarding the vaccination of their daughter. The focus group interview takes approximately 1.5h-2h and takes place in a web environment; this information is sent after signing the informed consent. The participation in the study is voluntary.

The study will be completed as a master's thesis in health technology at Tallinn University of Technology.

If you have further questions, please contact: Merilin Varsamaa, mevars@ttu.ee

## **Appendix 2 – Informed consent for signing**

Dear parent,

We invite you to participate in a survey aimed at researching parents' opinions and awareness of vaccinating 12-14-year-old girls against cervical cancer, as well as how their awareness of the issue is perceived and whether and how digital solutions would help to influence vaccination rates. As a result of the study, a master's thesis in health technology will be completed at Tallinn University of Technology.

During the study, we ask you to participate in a focus group interview with other parents who have a 12-14-years-old daughter, who has not been vaccinated against cervical cancer, but who has received a leaflet from the Health Board through the school nurse. The focus group interview lasts for 1.5h-2h depending on the volume of the answers. We have received the consent of the Ethics Committee for Human Research of the Institute for Health Development to conduct the study. The participation in the study is voluntary for you, and you can opt out any time. All data we have collected up to your opt-out decision will be used for further analysis. If you agree to participate in the study, you can give your consent to participate digitally (by digitally signing the consent form); the consent forms are stored on the Tallinn University of Technology OneDrive cloud server, which is password protected and accessible only to the researcher and supervisor of this study. At the end of the data collection (March 2021), the signed consent forms will be destroyed (deleted). We use the data already collected in the analysis impersonally, i.e. we do not use your name anywhere, but give your interview a code that includes the interview sequence number, the gender of the parent (M-man or F-woman) and the age of the child, so the first participant of a 12-year-old girl would have the code 1-F-12. The impersonated data is used in the analysis phase of the research data and in the master's thesis and publications prepared on the basis of it.

All interviews are recorded and transcribed verbatim. The full texts of the interviews are not used in any material and neither the recordings nor the full texts are published on the internet. When analysing the data, your full thoughts are extracted from the full texts, but not the whole text of the interview. The study summaries only use the thoughts you say as quotes. The results of the study are presented only in a generalized form and in a collection of completed scientific publications and master's thesis. All collected data and analysis files are stored on the Onedrive cloud server of Tallinn University of Technology, which is password-protected and access is granted only to the principal researcher and supervisor of this study (May 2021). The data will not be transferred to third countries, nor will they be uploaded to databases. Analysis files may be issued if required by reviewers during the publishing process, but files will not be proactively shared and, if necessary, shared files will be forwarded through a password-protected cloud server and only with prior personal contact.

The full texts of the interviews will be kept for up to 2 years after the end of the survey (May 2023) to allow the data to be published, after which they will be deleted. For the time being, the data will be stored on the personal password-protected Onedrive cloud server of Tallinn University of Technology, to which only the principal researcher and supervisor of the study will have access.

### **Consent form**

I have been informed of the above study, and I am aware of the purpose of the research and the methodology of the study and confirm my consent to participate in it and to process my personal data with a digital signature. I know that I will receive the additional information I need from the researcher about the issues and possible problems that arise during the research: Merilin Varsamaa, mevars@ttu.ee

# Appendix 3 – Focus group plan

1. Self-introduction. (Introduction by the researcher, then group participants introduce themselves, by the first name and specify the age of their daughter)

2. Informing subjects that the study will be recorded to better analyse the results.

3. Describing the purpose and the methods of this study.

4. Speaking about the duration and topics of the study (The approximate duration of the study is 1.5h-2h)

5. The subjects will be asked about their knowledge about cervical cancer:

- When I say cervical cancer, what are the first keywords or links that you remember? Why?

- When I say vaccination against cervical cancer, what are the first keywords or connections you remember?

- Why are there such links to the HPV vaccine?

- How do your family, friends and acquaintances view vaccination?

- What would you like to know more about the HPV vaccine?

- Do you feel that the leaflet for the HPV vaccine given at school

is enough for vaccination decision? Yes / No, what could be done in this communication differently / better?

- Have you visited <u>www.vaktsineeri.ee</u> to gather information?

- Has the school made an informative meeting for parents or an hour to talk about

HPV vaccine and cervical cancer? If not, do you feel that such an intervention is necessary? Justify.

- At what age would you be willing to vaccinate your child? Justify.

6. Subjects can try the digital game FightHPV. <u>https://play.google.com/store/apps/details?id=no.cancerregistry.fighthpv</u> <u>https://itunes.apple.com/us/app/fight-hpv/id1091559571</u>

Now, I will introduce you to the game FightHPV, where the player learns different forms of HPV, vaccination, treatment and screening process. Try it for 10 minutes and then we discuss about it.

- What did you like/dislike about this game? Why?

- Who do you think this game is aimed at?

• If children, ask further questions in the children's context.

- Whether/how the existence of such a tool as a parent would affect your child's vaccination decision making?

- If not, would any instrument be affected at all? Which one? Why?

- When and how should such a game reach you/your child?

- What digital interventions would help to make better decisions about vaccinating a child?

• Text messages by the Health Board or a family doctor?

• Vaccination social media campaigns?

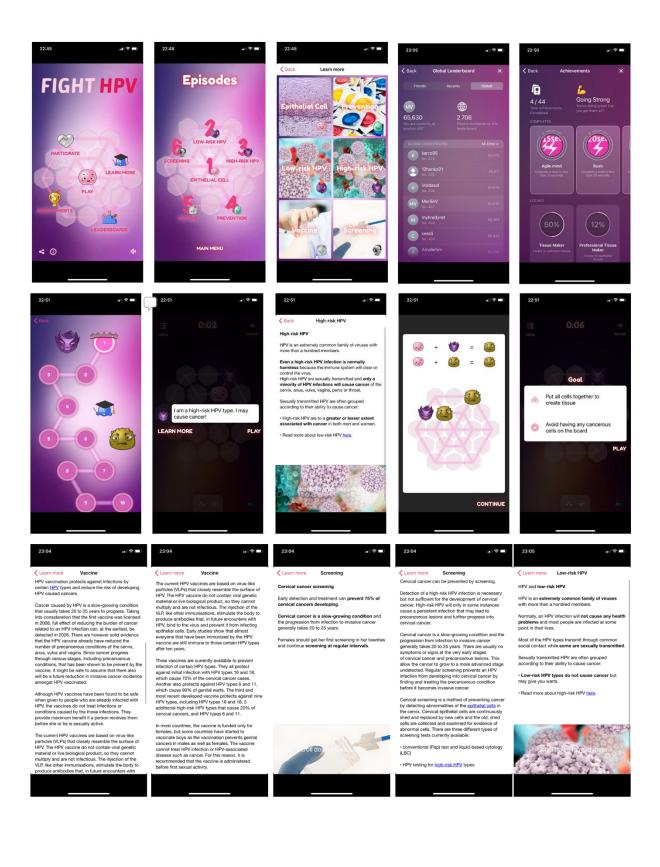
• Applications?

7. At the end of the interview, feedback is requested.

- If you think about your knowledge before today's meeting and now, do you think something has changed? What? How/in what direction?

8. If you want to say something else about the topic that we have not covered so far, it is now the time. Thanking the participants.

# **Appendix 4 – FightHPV application**



# Appendix 5 – Structure of the expert interview

1. Self-introduction.

2. Notification of recording the study.

3. Introduction of the aim and methodology of the study and the duration of the study.

4. Organizing public health campaigns:

- What are important features for making public health campaigns successful? (aimed at prevention)

- What have been your biggest setbacks that could not have been foreseen? (in theory, the campaign seemed fierce, but the feedback/results did not confirm it)

- What should be considered when developing social campaigns or messages/approaches for boosting health behaviour and what have been your biggest lessons?

5. Presentation of the FightHPV application.

Experts feedback:

- What did you like/what didn't you like about this game? Why? Do you agree with the parents' opinions? (quote)

- Who do you think FightHPV is aimed at? Do you agree with the parents' opinions? (quote)

- Would the existence of such an application affect the parents'/child's vaccination decision and how? Do you agree with the parents' opinions? (quote)

- If not, what digital interventions would help the parent to make an informed decision about vaccinating their child? Do you agree with the parents' opinions? (quote)

- When and how should such a game reach the parent/child? Do you agree with the parents' opinions? (quote)

- Does this solution seem safe and reliable to use? Do you agree with the parents' opinions? (quote)

- Would such games be beneficial in the education system? Justify. Do you agree with the parents' opinions? (quote)

6. What communication strategies or (digital) tools could be effective in raising parents' health awareness?

7. How do you assess the information transmission methods applied in Estonia? Do you agree with the parents' opinions?

Expert's sayings about uncovered topics. Thanking the expert.

60