Challenges in encouraging and maintaining participation in cervical cancer screening programmes in Romania and Norway

A screening programme will only succeed if it manages to

‘integrate itself into a network of actors who take it up, support it, diffuse it’

(Akrich, Callon, & Latour, 2002, p. 204)

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# Abbreviations

<table>
<thead>
<tr>
<th>Abbreviation</th>
<th>Description</th>
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<tbody>
<tr>
<td>ASCUS</td>
<td>Atypical Squamous Cells of Undetermined Significance</td>
</tr>
<tr>
<td>CBPR</td>
<td>Community-Based Participatory Research</td>
</tr>
<tr>
<td>CE</td>
<td>la Communauté Européenne</td>
</tr>
<tr>
<td>CerCCRom</td>
<td>Cervical Cancer Control for Roma and other disadvantaged groups in North Western Union of Romania</td>
</tr>
<tr>
<td>CI</td>
<td>confidence interval</td>
</tr>
<tr>
<td>CRN</td>
<td>Cancer Registry of Norway</td>
</tr>
<tr>
<td>GAD</td>
<td>Generalised Anxiety Disorder Scale</td>
</tr>
<tr>
<td>HPV</td>
<td>human papillomavirus</td>
</tr>
<tr>
<td>hrHPV</td>
<td>high-risk human papillomavirus</td>
</tr>
<tr>
<td>IOCN</td>
<td>Institute of Oncology of Cluj-Napoca</td>
</tr>
<tr>
<td>LBC</td>
<td>liquid-based cytology</td>
</tr>
<tr>
<td>LSIL</td>
<td>low-grade squamous intraepithelial lesion</td>
</tr>
<tr>
<td>NCCSP</td>
<td>Norwegian Cervical Cancer Screening Programme</td>
</tr>
<tr>
<td>OR</td>
<td>odds ratio</td>
</tr>
<tr>
<td>PHQ</td>
<td>Patient Health Questionnaire</td>
</tr>
<tr>
<td>PVO</td>
<td>Privacy Ombudsman and Data Protection Officer</td>
</tr>
<tr>
<td>REK</td>
<td>Regional Committee for Medical &amp; Health Research Ethics</td>
</tr>
<tr>
<td>RRR</td>
<td>relative risk ratio</td>
</tr>
<tr>
<td>WHO</td>
<td>World Health Organisation</td>
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Acknowledgement

The present thesis is the result of a huge quantity of work that has swallowed (and almost drowned) me over the last 4 years. During 2015 and 2016, I lived in Romania for four months to carry out the first two studies of this thesis (the Romanian studies), which depended heavily on the Roma women and men living there. I was so well received by them. They shared their life, experiences, and wisdom with me; they guided, looked after, and protected me; they showed me a warm hospitality and an eagerness to help with the two studies. This experience was overwhelming, and I will forever be grateful for the way they welcomed me into their communities and their homes.

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Finally thank you to my family, Lasse, Helén, Hanna, and Helma, who have been so understanding and supportive during this long project.
List of Papers


1. Introduction

This thesis deals with participation in the national cervical cancer screening programmes of Romania and Norway. Based on three different studies employing both qualitative and quantitative research methods, the thesis explores the experiences, circumstances, and characteristics that may have an impact on the degree to which women with different backgrounds and in different contexts and countries participate in cervical cancer screening programmes.

While there are many differences in the cervical cancer screening programmes of Romania and Norway, their most basic challenge is identical: How to achieve and maintain high participation among the target population? This fundamental question motivated all three studies on which this thesis is based. It is well documented that cervical cancer screening programmes can significantly decrease the incidence of and mortality from cervical cancer (i.e., Arbyn et al., 2010), but this potential remains unfulfilled if women do not attend.

A complex mix of factors contribute to participation in any health promotion or disease prevention programme. Engel’s biopsychosocial model (Engel, 1978) encourages us to look for such factors and circumstances in the biological, as well as the psychological, social, and cultural domains. To do so, one must have a strong focus on issues of local relevance – i.e., how factors in a given setting shape participation in cervical cancer screening programmes.

So, although this thesis deals with the issue of participation in the cervical cancer screening programmes of Romania and Norway, its specific focus was to address issues that were of contemporary significance to screening, which are very different in the two countries. In the case of Romania, a main contemporary concern is the very low participation rate among Roma women (Todorova, Băban, Alexandrova-Karamanova, & Bradley, 2009), a disadvantaged minority population. As there was almost no previous research in this field, at the time of the fieldwork which this thesis draws on, the research in Romania had to start with a broad exploration, using exploratory qualitative research methods followed by a quantitative questionnaire study. In the case of Norway, a main contemporary concern is the introduction of a new primary screening method, high-risk human papillomavirus (hrHPV) testing, in the Norwegian Cervical Cancer Screening Programme (NCCSP). Previous research has suggested that hrHPV testing could be associated with anxiety and depression among screening participants (i.e., Hendry et al., 2012; McCaffery, Waller, Nazroo, & Wardle, 2006). Apart from the harm that anxiety and depression could represent in and of themselves, an additional concern was that they could lower participation in the NCCSP. Therefore, our aim was immensely narrow and specific: provide and compare levels of anxiety and depression among NCCSP participants receiving either cytology or hrHPV testing as a primary screening method.
2. Background

2.1. Cervical cancer

Cervical cancer is the tenth most commonly diagnosed cancer worldwide, with an estimated 570,000 new cases and 311,000 deaths in 2018 (GLOBOCAN, 2018a). There are large geographical variations in cervical cancer rates worldwide, and almost 90% of all cervical cancer deaths occur in low- and middle-income countries. In Europe, more than 61,000 new cases are diagnosed and almost 26,000 patients die every year (GLOBOCAN, 2018a). In 2018, the estimated crude cervical cancer incidence and mortality rates in Europe were highest in Romania (19.5 and 8.9 per 100,000 women, respectively) and lowest in Finland (4.7 and 0.94 per 100,000 women, respectively). Norway, in comparison, has estimated cervical cancer incidence and mortality rates of 10.7 and 1.7 per 100,000 women, respectively (GLOBOCAN, 2018b) (Figure 1).

The aetiology and pathogenesis of cervical cancer is well understood (de Villiers et al., 1987; Walbloomers et al., 1999) and in 2008, Dr Harald zur Hausen received the Nobel Prize in medicine for linking human papillomavirus (HPV) to the development of cervical cancer. HPV is a DNA virus, and knowledge of its role\(^1\) in cervical cancer aetiology has made it possible to develop two different methods of cervical cancer prevention: primary prevention by HPV vaccination and secondary prevention by cervical cancer screening.

\(^1\)More information about HPV and its link to cervical cancer is given in chapter 12, contextual background information.
Figure 1: Estimated age-standardised cervical cancer incidence and mortality rates per 100,000 European women in 2018 by country, all ages

(based on data from GLOBOCAN, 2018b)
2.2. Principles for screening programmes

National cancer screening programmes have the potential to reduce cancer incidence and mortality rates through early detection (Wilson & Jungner, 1968). Early detection aims to detect precursors of cancer, followed by adequate treatment, thereby avoiding cancer development (Wilson & Jungner, 1968). In cancer screening programmes, large healthy proportions of the at-risk population are examined for the benefit of a small proportion. It is therefore important that certain criteria be met (Bretthauer & Kalager, 2013), and that screening in itself is not associated with too much danger.

Before introducing a cancer screening programme into a healthy population, the challenges of over- and under-treatment (Bretthauer & Kalager, 2013), the potential for psychological distress among participants (Hendry et al., 2012), and the fact that screening can detect precursors that may never develop into cancer within a person’s lifetime (Jorgensen & Gotzsche, 2009) should always be considered. The World Health Organisation (WHO) uses the 10 classic screening criteria of Wilson and Jungner (Wilson & Jungner, 1968), and they recommend these criteria be met before a screening programme is implemented (Table 1).

Table 1: Wilson and Jungner classic screening criteria

<table>
<thead>
<tr>
<th>Criterion</th>
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<tbody>
<tr>
<td>The condition sought should be an important health problem.</td>
</tr>
<tr>
<td>There should be an accepted treatment for patients with recognized disease.</td>
</tr>
<tr>
<td>Facilities for diagnosis and treatment should be available.</td>
</tr>
<tr>
<td>There should be a recognizable latent or early symptomatic stage.</td>
</tr>
<tr>
<td>There should be a suitable test or examination.</td>
</tr>
<tr>
<td>The test should be acceptable to the population.</td>
</tr>
<tr>
<td>The natural history of the condition, including development from latent to declared disease should be adequately understood.</td>
</tr>
<tr>
<td>There should be an agreed policy on whom to treat as patients.</td>
</tr>
<tr>
<td>The cost of case-finding (including diagnosis and treatment of patients diagnosed) should be economically balanced in relation to possible expenditure on medical care as a whole.</td>
</tr>
<tr>
<td>Case-finding should be a continuing process and not a “once and for all” project.</td>
</tr>
</tbody>
</table>

(Wilson & Jungner, 1968)

Based on consensus processes in Europe, in order for any cancer screening programme to be effective in decreasing incidence and mortality rates, they must go beyond the 10 criteria proposed by Wilson and Jungner. In addition to these criteria they must have a population-based approach, a defined screening policy, individual invitations or reminders, high participation rates, and adequate follow-up and treatment of screening-detected abnormalities (Arbyn et al., 2008).
2.3. Cervical cancer screening

It would seem safe to say that cervical cancer screening meets most of the 10 criteria of Wilson and Jungner (1968). Cervical cancer is indeed a serious health problem, and testing and treatment of precancerous lesions is possible without too much discomfort to participating women. The natural history of the disease is well understood, and the disease has a recognisable latent and early symptom stage. The European Guidelines for Quality Assurance in Cervical Cancer Screening (Arbyn et al., 2008) (hereafter referred to as European Guidelines) help determine target populations for national cervical cancer screening programmes, and organised, cytology-based cervical cancer screening is a cost-effective means of preventing the disease (Diaz et al., 2018). In relation to the third criterion (facilities for diagnosis and treatment should be available), different kinds of ‘Communauté Européenne’ (CE)-marked in vitro diagnostic medical devices for cytology and hrHPV testing are currently on the market. However, not all countries offer these tests free of charge, thus women must have the financial resources to undergo cervical cancer screening.

Many other contextual circumstances can also make screening less achievable for women. It is important to pay attention to how a screening programme is offered and experienced in different countries, and to determine whether the programme is serving the interests of the target population. Therefore, the fulfilment of the sixth criterion (the test should be acceptable to the population) cannot be determined in general terms; instead it must be carefully examined in specific contexts. This thesis contributes with just such an examination, as it brings out new information on the acceptance of cytology testing among Roma women in Romania and hrHPV testing among women in Norway.

2.4. Participation in cervical cancer screening programmes in Europe

The beneficial impact of screening on cervical cancer incidence and mortality led most European countries to implement national cervical cancer screening programmes (Arbyn et al., 2008; Arbyn, Raifu, Weiderpass, Bray, & Anttila, 2009). However, there are large geographical variations in how and when these programmes were established and organised, and in the participation rates of the target population (from 10-79% within European Union (EU) member states) (Arbyn et al., 2008). In 2016 in Norway, the attendance rate of the NCCSP was 63% at the recommended 3-year interval, measured after 3.5 years (Cancer Registry of Norway, 2017). Unlike in Norway, where all screening

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1 More information about cervical cancer and cancer development is given in Chapter 12.

2 This label is used on a number of products within the European Economic Area and is intended as information to the authorities that the safety requirements are met. Thus, the product can freely circulate on the market (available in Norwegian language at: https://www.dsb.no/lover/produkter-og-forbrukestjenester/artikler/fakta-om-ce-merking/).
activities are registered by the Cancer Registry of Norway (CRN) (Cancer Registry of Norway, 2001), there is no national registry for the Romanian cervical cancer screening programme (Bastos, Peleteiro, Gouveia, Coleman, & Lunet, 2010); thus participation rates are unknown. However, a study conducted in 2009, before the cervical cancer screening programme became national in 2012, indicated that only 20% of Romanian, and 5% of ethnic minority Roma women living in in the North-Western region of Romania, had ever undergone cervical cancer screening (Todorova et al., 2009). The differences in the organisation of and participation in screening programmes in European countries is partly reflected in variations in observed cervical cancer incidence and mortality rates (Arbyn et al., 2008) (Figure 1).

Participation in cervical cancer screening programmes does not only differ between countries, it also differs between groups of people living within a country, as has been found in numerous studies, i.e., in North America, where Native Americans (Brown et al., 2015), Indian-Americans (Dockery et al., 2018), and Korean-Americans (Lee, 2000) participated more rarely in cervical cancer screening programmes compared to non-Hispanic white women. Studies from England have found that blacks, Asians, women from ethnic minority groups (Marlow, Wardle, & Waller, 2015), Polish, Slovak, and Romanian women (Jackowska et al., 2012) were less likely to attend the cervical cancer screening programme than white British women. In Romania, a study revealed that Roma women participated less frequently in the cervical cancer screening than native Romanian women (Băban et al., 2006), and in Norway, one study found that immigrants had a lower participation rate in the NCCSP than women born in Norway (Leinonen, Campbell, Ursin, Tropé, & Nygård, 2017a) (Figure 2).

**Figure 2: Participation rate in the national cervical cancer screening programmes of Romania and Norway**

<table>
<thead>
<tr>
<th>Norwegian</th>
<th>Immigrants from Nordic countries</th>
<th>Immigrants from Romania</th>
<th>Romanians</th>
<th>Roma</th>
</tr>
</thead>
<tbody>
<tr>
<td>68%</td>
<td>61%</td>
<td>37%</td>
<td>20%</td>
<td>5%</td>
</tr>
</tbody>
</table>

1 Native Romanians=persons born and living in Romania with at least one Romanian parent.
High participation rates are fundamental to successful cervical cancer screening programmes, as those who are either under-screened or do not participate at all are at a much higher risk of developing and dying from cervical cancer when compared to screening participants. A modelling study from 2014 (Vaccarella et al., 2014) indicated that the cervical cancer incidence rate in the Nordic countries between 2006 and 2010 would have been between 3 and 5 times higher in the absence of a national cervical cancer screening programme. Another study (Peto, Gilham, Fletcher, & Matthews, 2004) estimated that, between 1988 and 2004, up to 5000 cervical cancer deaths per year were prevented in England and Wales due to the implementation of their national cervical cancer screening programme. When the differences in screening participation between countries, and between groups of people living within countries, are so large, it is crucial to investigate what specifically affects participation so that targeted measures can be developed to increase it.

European Guidelines (Arbyn et al., 2008), and a report based on screening data from the European Union member states (Anttila, et al., 2010a), offer some general explanations for the large variations in screening participation. These include differences in screening organisation, communication with the target population, screening method, method of invitation, and differences in programme implementation. In addition, an exceedingly large number of studies have investigated screening participation, or lack thereof, in more specific terms (i.e., Blomberg, Ternestedt, Tornberg, & Tishelman, 2008; Camilloni et al., 2013; Chorley, Marlow, Forster, Haddrell, & Waller, 2017; Eardley et al., 1985; Priaulx, de Koning, de Kok, Szeles, & McKee, 2018). Many studies that focused on women’s decision-making processes explained non-participation by the existence of ‘barriers’. For instance, a study from Great Britain (Bennett et al., 2018) found that one barrier to screening participation might be women’s perception that they are not in a high-risk population based on their sexual behaviour, making them see screening as irrelevant. Another study from England (Waller, Bartoszek, Marlow, & Wardle, 2009) reported that embarrassment, intending to go but not getting around to it, fear of pain, and worrying about the screening results, were barriers to screening participation. Yet another study from England detected barriers such as younger age, belonging to an ethnic minority group, and having lower socioeconomic status (Marlow, Chorley, Haddrell, Ferrer, & Waller, 2017). In Serbia, a study found that inadequate public health education and lack of patient-friendly services could act as barriers (Markovic, Kesimal, Topic, & Matejic, 2005). A study from Sweden identified feeling healthy, lack of time, and feelings of discomfort with the gynaecological examination as barriers (Oscarsson, Benzein, & Wijma, 2008). In Norway, a study reported that women’s relationship with their general practitioner could be a barrier to screening, as having a male, a foreign, or a young GP made women reluctant to participate in screening. In addition,
barriers such as being unmarried, having no children, lower socioeconomic status, and area of residence were detected (Leinonen et al., 2017b). Two studies from Romania revealed that Romanian women with a lower education level and lower financial resources, who were unemployed, who resided in rural areas, were single and/or widowed, and Roma women, were underserved with regard to cervical cancer screening. Barriers identified included lack of knowledge, thinking of gynaecological exams as unpleasant, fear of a bad diagnosis, high cost of service, long waiting lines at the doctor’s office, cytology perceived as an unnecessary test, women’s exhaustion, lack of time, doctor’s refusal to examine women, and apprehension of being labelled as a hypochondriac (Băban et al., 2006; Todorova et al., 2009).

Other studies have focused on methods that may explain why women choose to participate in screening. A study from Norway showed that women who received a scheduled appointment had a 1.9-fold increase in screening participation compared to women who received a standard, open reminder letter (Lönnberg et al., 2016). A systematic literature review (Camilloni et al., 2013) of 69 different types of screening programmes supported this result, as they found that invitation letters with scheduled appointments were effective in increasing screening participation, because women did not have to make an appointment on their own, thus making attendance easier. Another systematic review (Chorley et al., 2017) of studies from the United Kingdom, Australia, Sweden, and Korea found that women who chose to participate in screening did so because they considered cervical cancer to be a serious disease that represented a potential threat to their health. The role of education in screening participation was investigated by Willems and Bracke (2018), who studied education inequalities in 9965 women from 27 European countries. The study found that women with a higher education level tended to participate more frequently in cervical cancer screening as compared to women with a lower education level, likely due to the capacity that educated women have to understand screening information accurately, and their ability to consider the advantages and disadvantages of screening participation (Bretthauer & Kalager, 2013; Burger, Nygard, Gyrd-Hansen, Moger, & Kristiansen, 2014). However, women with a lower education level are not necessarily less able to understand the advantages and disadvantages of screening. Instead, a study from the United Kingdom (Eardly et al., 1985) suggested that the health care workers responsible for giving screening information don’t necessarily adapt the information to patients’ needs. Indeed, the study showed that doctors tend to communicate better with more educated women, and that some doctors were less likely to perform screening tests on women from lower socioeconomic groups. Eardly et al. (1985) argued that cervical cancer screening programmes often fail to meet the needs of women, and that there are three possible pathways by which a woman may be screened, a) being screened as part of another medical procedure, b) by the women requiring a screening test or c) by
receiving an screening invitation. Eardley et al. (1985) suggested that an effective cervical cancer screening programme should be provider-initiated and user-oriented in order to meet women's needs, as screening providers must strive to find out "what it is that motivates those they seek to attract" (Eardly et al., 1985, p. 961). Other studies are in line with Eardly at al.(1985) and focused on how important it is that the target population be informed about the screening programme’s existence, understand the possible benefits and harms, and understand the risk factors for the disease to be screened for (Bretthauer & Kalager, 2013). Adequate information is required so that women can make an informed choice about whether or not to participate (Østerlie et al., 2008). One of the key criterion put forth by the European Union for a successful cervical cancer screening programme is to help women understand the rationale for screening (Arbyn et al., 2008).

All of the above-mentioned studies contribute important knowledge about an important issue, how to encourage and maintain participation in cervical cancer screening programmes. Some of these studies suggest targeted measures that, to some extent, can help with this issue. However, the results of most of these studies reflect the time period and circumstances in which they were carried out, and thus the identified barriers to participation and factors that explained participation may be limited to the context in which they were revealed. What remains unanswered is: Which conditions and circumstances play a role in a particular place, at a particular time, and in a particular group of people? Indeed, it is difficult to determine what will lead to screening participation in another country and another group of women based on results from previous studies; this question has to be studied in its actual context. In order to achieve and maintain high participation in any national cervical cancer screening programme, it is essential to pay close attention to the women the programme is targeting and to the entire network in which the programme is situated.

2.5. Cervical cancer screening in Romania
Romania started their national cervical cancer screening programme in 2012 (Ministry of Health, 2015) after piloting cervical cancer screening since 2002 (Nicula et al., 2009). The programme, which offers conventional cytology every 5 years to women aged 25-64 years, is delivered through primary health care services and is financed by the Ministry of Health (Ministry of Health, 2015). Initial cervical cancer screening by cytology is offered free of charge, as is cancer treatment, to all women in the target age range, irrespective of their health insurance status (Government of Romania, 2016-2017; Vlădescu, Scîntee, Olsavszky, Hernández-Quevedo, & Sagan, 2016). However, repeat cytology and follow-up of women with screening-detected precancerous lesions are either covered by private health insurance or the woman must pay for it herself (Governmental Decision, 2016-2017; Vlădescu
et al., 2016). Moreover, before women can participate in the Romanian cervical cancer screening programme, they must be referred by a general practitioner who is registered with the programme. Almost 85% of all general practitioners in Romania are registered with the Romanian cervical cancer screening programme and can make such referrals (Ministry of Health, 2015). As mentioned above, participation in the Romanian cervical cancer screening programme is low compared to that of other countries in Europe, with less than one-fifth of the total target population attending (IOCN personal communication, 2016). In addition, over 50% of all cervical cancer cases in Romania are diagnosed at advanced stages (Socolov et al., 2016), which complicates treatment and reduces survival rates (Arbyn et al., 2011).

2.6. Cervical cancer screening in Norway
Norway started the NCCSP in 1995. The programme is administered by the CRN. Until 2015, the NCCSP recommended that women aged 25-69 years should undergo cervical cancer screening by cytology every 3 years screening (Haldorsen, Skare, Steen, & Thoresen, 2008). From 2005, hrHPV testing has been used as a secondary screening test (a triage test) for following-up women with abnormal, low-grade cytology. Women who participate in the NCCSP have to book an appointment with their doctor every 3 years, or whenever they receive an open reminder letter from the CRN. Participating women must pay 300 NOK (30 EURO) for the doctor’s consultation. The NCCSP has national guidelines that are based on the European Guidelines (Arbyn et al., 2008), a quality manual (Faglig rådgivningsgruppen for Masseundersøkelsen mot livmorhalskreft, 2014), an advisory board, and a Steering Group (Tropè et al., 2017). All screening tests results are registered at the CRN (Cancer Registry of Norway, 2001) unless a woman actively requests that her negative screening results not be recorded, which occurs in 3% of all participating women. Today the screening database contains data from 1.4 million women (Leinonen et al., 2017b).

The NCCSP has been effective in reducing cervical cancer incidence; it has been estimated that since 1996, 600–1200 incident cases yearly have been avoided (Vaccarella et al., 2014). Today, more than 50% of cervical cancer cases arise in the 30% of women who do not attend screening (Lönnberg et al., 2015).

2.7. Knowledge gaps
In this thesis, I examine factors that are important to the participation of Roma women in the Romanian cervical cancer screening programme. Although the participation rate in Romania is generally low, it has been reported to be even lower among Roma women (Băban et al., 2006;
Todorova et al., 2009). This thesis explores screening participation, reasons for low screening participation, and contributes insights into Roma women’s screening engagement in today’s Romania.

This thesis also contributes insight into psychological distress among women in the NCCSP in today’s Norway, where participation rates are relatively high (Cancer Registry of Norway, 2017). However, there are concerns that changes in the primary screening method, from cytology to hrHPV testing, may have negative consequences on the participation rate in the NCCSP.

Thus, the thesis examines key questions regarding screening participation in today’s situation in two different European countries.

2.7.1. Knowledge gap in Romania
Several reports and studies have described the Roma’s health status and situation in Europe and Romania (European Commission, 2014; Sandor et al., 2017; The World Bank Group, 2014; Wamsiedel et al., 2012), drawing a picture of a population without a common motherland, living segregated in many European countries (Fesus, Ostlin, McKee, & Adany, 2012; Hajioff & McKee, 2000). Romania consists of 21 million people, and the Roma are regarded as the largest ethnic minority in the country, with an estimated 2.3 million (Hajioff & McKee, 2000). The Roma population in Romania has increased morbidity from non-communicable diseases compared to Romanian citizens (Masseria, Mladovsky, & Hernandez-Quevedo, 2010), they have 2.5-times higher infant mortality rates, and a life expectancy that is as much as 6 years lower than that of other European Union citizens (The World Bank Group, 2014).

Many studies have linked the Roma’s poor health status to discrimination (i.e., Fox, 2002) and found that Roma in Romania have considerably poorer access to health care services and lower uptake of preventative health care than the majority Romanian population (Hajioff & McKee, 2000). Qualitative research (Wamsiedel et al., 2012) has revealed that discriminatory practices in health facilities, under-the-table payments charged by physicians, the high cost of medical procedures, general practitioners who deny health care enrolment to Roma patients, and use of derogatory language, are obstacles that make health care less available to the Roma when compared to the host population of Romania.

While several reports have described the health status and health care access of the Roma in the general terms described above, we did not find much work related to Roma women’s engagement in cervical cancer screening when this project started in 2014. The two studies by Băban et al. (2006) and Todorova et al. (2009) did offer some insight into cervical cancer screening and participation, but they focused primarily on Romanian women. Only sparse information was given on Roma women
and their engagement with and lack of participation in cervical cancer screening, leaving the field almost completely unexplored.

The knowledge gap is further widened by the fact that there is no national registration or national cancer registry that records screening results or the screening activities of women taking part in the Romanian cervical cancer screening programme. This makes it impossible to collect information on previous screening history, diagnosis, and treatment at a national level. Although there are regional cancer registries (Bastos et al., 2010) in each of Romania’s seven regions, these registries lack screening information, as the reporting of such information is not mandatory (Government of Romania, 2016-2017). This overall sparse registration of screening activities, screening results, follow-up, and treatment at both a national, regional, and individual level makes it impossible, based on this lacking data to understand why Roma women participate so rarely in screening, as some studies have shown.

As the question of cervical cancer screening and participation among Roma women was almost unknown when this project started, broad and flexible exploration was necessary. Thus, Papers I and II of this present thesis contribute knowledge related to this unexplored topic.

2.7.2. Knowledge gap in Norway

2.7.2.1. hrHPV testing in primary screening

Between 2015 and 2018, Norway implemented a pilot project of hrHPV testing in primary screening, in which hrHPV was used as the primary screening method instead of cytology (Andreassen & Vogt, 2014; Tropè et al., 2017). This was done after comprehensive scientific studies (Anttila et al., 2010b; Bulkmans et al., 2007; Ronco et al., 2014) showed that HPV-based screening could lead to better target achievements, reduced cervical cancer mortality, and reduced resource utilisation, and the effect was in reasonable proportion to the costs in terms of increased security, improved quality, and economic efficiency. hrHPV testing was also considered to have a 23-27% higher sensitivity to detect hrHPV than cytology had to detect cytological abnormalities (Ronco et al., 2014). Four counties in Norway (Rogaland, Hordaland, Sør-Trøndelag, and Nord-Trøndelag) participated in the pilot project. Women aged 34-69 years living in these counties who attended routine, triennial cervical cancer screening were randomised (1:1) to receive either hrHPV testing every 5 years or cytology testing every 3 years. Randomisation was based on whether a participant’s date of birth was an even or odd day (Tropé et al., 2017). Women allocated to the hrHPV arm would, if the hrHPV test turned out to be positive, have their samples analysed by cytology as well, in what is called secondary screening.

1 Women aged 25-33 years living in one of these four counties were not part of the pilot project due to high prevalence of hrHPV infections with no clinical relevance in this age category (Ronco et al. 2014). These women are therefore screened every 3 years with cytology.
(meaning the second analysis performed). Conversely, the samples of women with positive cytology in the cytology arm would be used for hrHPV testing in secondary screening. The algorithm for primary screening by cytology and hrHPV testing used during the pilot project (2015-2018) is shown in Figure 3.

Women taking part in the pilot project can, when NCCSP guidelines are followed, receive seven different combinations of screening test results:

**In the cytology arm:**
- I. Cytology normal
- II. ASCUS\(^2\) or LSIL\(^3\) and hrHPV-negative
- III. ASCUS or LSIL and hrHPV-positive
- IV. High-grade cytology

**In the hrHPV arm:**
- V. hrHPV-negative
- VI. hrHPV-positive and normal cytology
- VII. hrHPV-positive and ASCUS or more severe

Based on an early evaluation of the pilot project (Engesæter, Nygård, & Tropé, 2017), it was decided that Norway would implement hrHPV testing within a randomised design to all women aged 34-69 years starting in March 2018, and that this would be expanded to all women aged above 34 years at the end of 2021.

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\(^1\) In addition is it possible to receive unsatisfactory cytology and unsatisfactory hrHPV test results

\(^2\) Atypical Squamous Cells of Undetermined Significance

\(^3\) Low-grade squamous intraepithelial lesion
1. When repeated screening tests are unsuitable for analysis, reference to gynaecologist is recommended.
2. hrHPV analysis is done on a liquid-based primary test. If the primary test is liquid-based cytology (LBC) or for some reason not suitable for hrHPV analysis, a new test for hrHPV and LBC should be taken in 6-12 months.
3. Diagnostic colposcopy with portiobiopsy and endocervical abrasion is performed according to the Guide to Gynaecological Oncology.

2.7.2.2. Psychological effects of cervical cancer screening

The psychological effects of cervical cancer screening was first studied in Rotterdam back in 1984 and showed that most women who attended screening and had normal results did not have any psychological effects associated with screening participation. However, psychological effects did occur in women with positive screening results (Reelick, de Haes, & Schuurman, 1984). Since then, several studies have investigated the psychological effects of participating in cervical cancer screening (i.e., Rask, Swahnberg, Lindell, & Oscarsson, 2017). More recently, studies have focused on anxiety related to hrHPV testing used in national screening programmes (i.e., Hendry et al., 2012; Ngu et al., 2017). However, the literature on anxiety and depression related to hrHPV testing is inconsistent: some studies suggest that there is no negative effect of screening method on anxiety (i.e., Burger et al., 2014; O’Connor et al., 2015), whereas others have reported that there is a negative effect (McCaffery et al., 2004). A systematic review of 17 studies concluded that hrHPV testing could increase anxiety, have an impact on women’s relationships, and provoke fear of stigmatisation (Hendry et al., 2012), as HPV is a sexually transmitted infection (McCaffery et al., 2004). Hence the situation regarding screening method and its impact on anxiety and depression appears unresolved. Nevertheless, it is important that the psychological effect of screening, regardless of the method used, be explored and considered in any country’s screening programme.
2.7.2.3. Anxiety and depression

Anxiety is understood as a natural response in humans and is described by three components: the subjective experience of fear, psychological reactions, and behaviour that aims to avoid the threatening situation (Barlow, 2002). Anxiety is strongly linked to fear, but fear is an emotional response to a present threat, whereas anxiety is the anticipation of a future threat (Barlow, 2000). Anxiety can be experienced and expressed in many ways, from no changes in behaviour to severe disorders and behavioural disturbances. Depression is defined by a depressed mood, loss of interest and enjoyment, as well as reduced energy. In order to diagnose anyone with depression, at least two of these symptoms must be present (World Health Organisation, 1992).

In Norway, about 25% of the adult population will be affected by an anxiety disorder at some time in their life, and around 15% will experience the disorder for over 1 year. About 20% of the adult population in Norway will experience depression at some time in their life, and 10% will be affected for over 1 year. The prevalence of mental disorders in Norway is similar to that in other European countries and the United States (Bang Nes & Clench-Aas, 2011).

In Paper III, we investigated anxiety and depression as measured by the Patient Health Questionnaire (PHQ)-4, a four-itemed, ultra-brief screening scale for anxiety and depression (Kroenke, Spitzer, Williams, & Löwe, 2009). As Norway changes its primary cervical cancer screening method to hrHPV testing for greater accuracy, it is important to investigate whether this shift influences women’s levels of anxiety and depression more than previous cytology method did, and if this change affects screening participation in the target population of the NCCSP.
3. Aims of the three studies

The overall aim of the three studies that comprise this thesis was to develop new knowledge related to the experiences, circumstances, and characteristics that may have an impact on the degree to which women of different backgrounds and in different contexts participate in national cervical cancer screening programmes in Romania and Norway.

In Romania, the main aim was to understand the low participation rate of Roma women in the Romanian cervical cancer screening programme. An additional aim was to explore Roma women’s engagement with, understanding of, and participation or non-participation in the programme.

Against this background, the more specific objectives of the two Romanian studies were:

- to develop insight into experiences and circumstances that encourage and discourage participation in the Romanian cervical cancer screening programme among Roma women;
- to explore Roma women’s engagement and participation in the Romanian cervical cancer screening programme from the perspective of screening providers;
- to explore the association between different factors and participation and non-participation in the Romanian cervical cancer screening programme among Roma in the North-Western region of Romania, using non-Roma women as comparison.

In Norway, the main aim was:

- to learn whether levels of anxiety and depression differed by primary screening method (cytology or hrHPV testing) among NCCSP participants.

An additional, overarching goal was to provide the basis for further research on screening participation and improve screening practices that, in the long run, could contribute to decreasing cervical cancer incidence and mortality rates in Romania and Norway.
4. Methods and fieldwork

The two Romanian studies in this thesis (Papers I and II) were part of a larger study entitled, ‘Cervical cancer control for Roma and other disadvantaged groups in North-Western region of Romania’ (CerCcRom), financed by Norway Grants (Norway Grants 2014) through the European Union (Assessment Record no. 28/10.12.2014, request no. 10988/10.12.2014). CerCcRom was administrated by the Institute of Oncology of Cluj-Napoca (IOCN) in Romania, in collaboration with the CRN. The overall aim of CerCcRom was to detect barriers to screening participation among Roma women living in the North-Western region of Romania and was initially conceptualised by the IOCN. In the two Romanian studies, the empirical material was produced using a combination of qualitative and quantitative research methods.

The Norwegian study (Paper III) was conducted within the framework of the pilot project of hrHPV testing in primary screening (Tropè et al., 2017), in which the primary screening method of the NCCSP was switched from cytology to hrHPV test.

The methods and number of participants in all three studies are summarised in Table 2.

Table 2: Overview of studies, number of participants, and exposures/outcomes in Paper I to III

<table>
<thead>
<tr>
<th>Paper</th>
<th>Study design</th>
<th>Method used</th>
<th>Number of participants in the analysis</th>
<th>Exposure/Outcome</th>
</tr>
</thead>
</table>
| Study 1, from Romania | I | Qualitative, interactive and exploratory design | • Participant observation  
• Qualitative interviews  
• Focus group discussions | • 125 days of participant observation involving 78 study participants,  
• 15 interviews with 11 study participants,  
• 7 focus groups with 57 study participants | Exposure: not applicable in qualitative studies  
Outcome: knowledge that may serve to contextualise and understand screening participation/non-participation |
| Study 2, from Romania | II | Quantitative, cross-sectional design | • Questionnaires | • 980 study participants  
• 588 Roma  
• 392 non-Roma | Exposure: different factors/barriers potentially associated with screening attendance  
Outcome: attendance/non-attendance |
| Study 3, from Norway | III | Quantitative, cross-sectional design | • Questionnaires | • 1008 study participants  
• 521 cytology screened  
• 487 hrHPV test screened | Exposure: screening method and screening results  
Outcome: anxiety & depression/no anxiety & no depression |

4.1. Overall study design - using a combination of complementary methods

Of the three studies in the present thesis one was qualitative with an exploratory design (Paper I) and the others were quantitative with cross-sectional designs (Papers II and III).
The qualitative study (Paper I) used three complementary qualitative methods. The two Romanian studies (Papers I and II) were also complementary in the sense that they addressed the same overall theme: namely, screening participation and non-participation among Romanian women with a specific aim to address minority Roma women. While Paper I identified and described controversies that exist between the national cervical cancer screening programme’s participants and its providers in an effort to understand why so few Roma women participate, Paper II answered quantitative questions related to different factors potentially associated with screening participation or non-participation in Romania. Hence, these two studies did not set out to answer exactly the same research questions, even though they were related.

Since knowledge related to screening participation among Roma women was practically non-existent when this project started, we could not know in advance what questions would be relevant to include in the questionnaire. To conduct the exploratory qualitative study (Paper I) before we carried out the quantitative study (Paper II) was therefore considered necessary. While Paper I was based on extensive field work aiming to answer research questions not previously known, Paper II allowed us to explore factors related to screening participation that needed to be quantified.

The Norwegian study (Paper III) was quantitative with a cross-sectional design and was not directly connected to the Romanian studies. However, the Norwegian study was also related to (potential) challenges by achieving high screening participation. The aim of Paper III was to gain knowledge related to the level of anxiety and depression among screening participants when the primary screening method was changed to hrHPV testing. There was research that had indicated that this shift in primary screening method could lead to lower participation in screening due to more anxiety and depression (i.e., Hendry et al., 2012; McCaffery, Waller, Nazroo, & Wardle, 2006). Still, the Norwegian study had the same broader research theme, namely screening and participation in a national cervical cancer screening programme.

4.2. The qualitative study (Paper I) from Romania

4.2.1. Design and rationale

It seemed clear from the outset that a study regarding screening participation among Roma women living in Romania had to be interactive and exploratory. This was because a literature review (as described in Chapter 2) only revealed two previously published studies (Băban et al., 2006; Todorova et al., 2009) that explored participation in cervical cancer screening in Romania. The barriers to participation described in these two studies were linked to all women living in Romania and did not address minority Roma women in particular. However, what the studies did reveal about Roma
women was important: they were severely underserved with regard to cervical cancer screening. Information from the IOCN supported this impression; they reported that less than 5% of Roma women living in the North-Western region of Romania had ever had a screening test when the research for Paper I started in 2015 (IOCN personal communication). Apart from this, little was known about screening and screening participation from the perspective of Roma women, and an exploratory design was therefore warranted.

An exploratory design is used to discover something which was not previously known. Therefore, this design demands considerable flexibility so that new ideas, theories, and insights can develop (Fagermoen, Nord, Hanestad, & Bjørnsborg, 1998). In an exploratory design, a phenomenon which is currently unknown (such as what contributes to participation and non-participation among Roma women), might be brought to the surface. Qualitative research methods are suitable when exploring a field in which knowledge is lacking (Polit & Beck, 2018).

In Paper I, we used a combination of three qualitative research methods: 1) participant observation, 2) qualitative interviews, and 3) focus group discussions. We used these three qualitative methods in a complementary way, with the aim of strengthening the study’s exploratory potential, as the methods offered support to one another (Polit & Beck, 2018). Moreover, to get a richer understanding of participation in the Romanian cervical cancer screening programme, we (the research team) did not want to narrow our scope to the viewpoint of women from the target population. Indeed, we anticipated that this could make us miss out on valuable insights into other aspects of the screening venture and the social context in which women live their lives. Thus, to broaden the opportunities for insight and understanding, we identified as many actors involved in the screening venture as we could and included them in the study sample. This included non-Roma women, screening providers, policy makers, as well as Roma men. Paper I was an open study, meaning that we were not sure what to expect to come out of it (Polit & Beck, 2018).

The three qualitative research methods we used stood in an ongoing, dynamic relation to one another. The fieldwork for participant observation lasted 125 days, during which both qualitative interviews and focus group discussions were also taking place. However, participant observation produced the initial knowledge needed to perform the interviews and focus group discussions. It was through participant observation we identified whom to recruit for qualitative interviews and focus group discussions.
4.2.2. Fieldwork

The fieldwork was split into three phases: a preparatory phase, a main fieldwork phase and a write-up phase. In all these phases, I spent time in Romania and Norway, and data production was occurring throughout the project.

4.2.2.1. Preparatory phase

The aim of the preparatory phase was to prepare the fieldwork by establishing contact with study participants. Additional aims were to start learning about the North-Western region of Romania, the contexts in which the people lived their lives, and to learn about the cervical cancer screening programme and participation therein from the perspective of both the screening receivers and screening providers.

I had never been to Romania prior to this study. During the preparatory phase, I made three visits to the city of Cluj-Napoca, located in the North-Western region of Romania, lasting for 5, 3, and 7 days, respectively. The IOCN, a regional oncological hospital that is also responsible for the Cluj Regional Cancer Registry, had already made initial contact with the Roma population through a Roma mediator\(^1\) and a Roma leader\(^2\) living in the study area\(^3\). During my first visit, the IOCN arranged two different meetings with Roma communities in Cluj County. During these meetings, the study and its aims, and I as the researcher from Norway, was introduced by the head of the department at the IOCN. I took advantage of this time to talk with as many Roma women and men as I could, and IOCN employees helped me translate these conversations back and forth between English and Romanian.

During the preparatory phase, the IOCN also arranged for an open meeting, to which Roma mediators, Roma leaders, and Roma community members from the North-Western region were invited. The aim of this meeting was to establish contact with four different Roma leaders and 10 different Roma mediators in Cluj County; and to establish contact with regular Roma living in these communities. Approximately 100 Roma men and women participated in the open meeting, during which the IOCN introduced CerCcRom, and discussions took place surrounding themes such as screening, cervical cancer, and Norway’s contribution to CerCcRom. In the first part of the open meeting, mostly IOCN employees, Roma leaders, and Roma mediators took the floor. In the last part

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\(^1\) To improve the Roma’s access to basic health care services, the Ministry of Health in Romania started a national programme in 2002, introducing the concept of a ‘Roma mediator’. A Roma mediator is defined as a respected and trusted Roma community member and is usually a woman. A Roma mediator’s role is to support, and be a bridge between, Roma communities and local facilities; to aid Roma in accessing social services and to enable the delivery of these services to the Roma population (The World Bank Group 2014).

\(^2\) A Roma leader is always a man at the head of the Roma community. Roma leaders are selected within the Roma communities, and unlike Roma mediators, they are not under the administration of the Ministry of Health.

\(^3\) Official Roma leaders and Roma mediators are registered with the Ministry of Health, and the IOCN used this information to make the initial contact with the Roma population living in the North-Western region.
of this meeting, participants were split into different groups to facilitate an atmosphere where both Roma women and men could feel free to voice their opinions. One IOCN employee served as a group leader, and at the end of the day each group leader presented the main discussions in plenum. During these group discussions, Roma women recounted the difficulties they faced when seeking health care, how they struggled due to limited financial resources, and their main health concerns. Throughout the day, IOCN employees translated some of the conversations into English for me.

During the preparatory phase, I was also introduced to two English-speaking Roma women by the IOCN. These women had contacts within Roma communities, and we planned for them to introduce me to these communities when the study began. This phase also included some visits to Roma families who had invited me to their homes, as well as visits to the IOCN, where I learned how the IOCN organises follow-up and treatment of women after cervical cancer screening or after a cervical cancer diagnosis. I was also informed about the organisation of the Cluj Regional Cancer Registry, I was introduced to the Romanian Cancer Society of Cluj-Napoca, and to employees who were performing studies on HPV vaccination coverage in the Roma population at the University of Medicine and Pharmacy ‘Iuliu Hatieganu’ in Cluj-Napoca.

Although I had never been in Romania prior to this study, a subset of the Roma population was somewhat familiar to me, as many Roma men and women are visible in the Oslo cityscape as beggars on street corners or as entertainers in public transportation. Therefore, to start getting to know the Roma population, I started to interact with a Roma woman I passed every day on my way to work in Norway. The woman spoke no Norwegian or English and I spoke no Romanian, so we interacted by signs and non-verbal communication. I realised that my lack of Romanian language skills was a major obstacle for the PhD project, and the professionals at the IOCN informed me that the Roma population in Romania seldom speaks English. They also informed me that Romanes, the Roma population’s mother tongue, is an oral language that Roma are often reluctant to teach to non-Roma. Therefore, I met with a private tutor, 4 hours per week for 6 months to learn basic Romanian, as this was regarded as a language all Roma in Romania could understand and speak (Engebrigtsen, 2007; IOCN personal communication, 2016). As I advanced in my knowledge of the Romanian language, I interacted with the Roma I encountered in Oslo whenever I could. I spoke frequently with around 20 different persons, and I invited four of them to my home from time to time, with the aim of learning as much of the Romanian language as I could before the fieldwork started.

As part of the preparatory phase, I also visited a Roma resource centre in Oslo. The centre offers adult education programmes for Roma children living in Norway. The preparatory phase also involved writing the study protocol; writing applications for ethical approvals; preparing an interview
guide; performing a literature review; and completing some qualitative research courses at the University of Oslo.

The draft interview guide was organised in themes and considered a living document that was periodically updated during the research process (Moen & Middelthon, 2015). The interview guide contained no full sentences as recommended by Moen and Middleton (2015). This was done to make it feasible for conversations to develop freely where “comments, questions and probing are grounded in the experiences, stories and opinions put forward by the study participants” (Moen & Middelthon, 2015, p. 343), and so that the researcher could ask and respond to topics that came up but may not have been predicted in advance. The interview guide used in Paper I is shown in Attachment 1.

The preparatory phase also included writing a dairy about things I wanted to explore when the main field work phase was to begin. I wrote questions to myself and I also wrote down my own thought, feelings and emotions of what I experienced and learned in this early phase of the study.

4.2.3. Main fieldwork phase. Participant observation

Participant observation lasted for 125 days in six different Roma communities, five located in the outskirts of Cluj-Napoca and one in Bucharest, in 2015 and 2016.

Participant observation is a suitable method to use when there is little knowledge related to the task one is studying. Various authors have offered the following definitions of participant observation:

“...a method in which a researcher takes part in daily activities, rituals, interactions, and events of a groups of people as one of the means of learning the explicit and tacit aspect of their life routines and their culture.” (DeWalt & DeWalt, 2011, p. 1).

"[A method in which one] submit(s) oneself on the company of the members to the daily round of petty contingencies to which they are subset.” (Goffman, 1961, p. ix).

"...immersion in a culture (which) helps the researcher internalize the basis beliefs, fears, hopes and expectations of the people under study.” (Fetterman, 2010, p. 37).

In participant observation, researchers become an active instrument to gain insight into the field to be studied. Participant observation is regarded as a beneficial method to use when human behaviour and human interaction with society are to be studied (DeWalt & DeWalt, 2011; Fangen, 2010; Glesne, 1999). The knowledge I strove to gain in this initial phase included the opinions of the Roma population, their living conditions, their everyday activities, as well as their sedentary views and cultural sedentary assumptions. Participant observation was also used to help understand Roma women’s and screening providers’ engagement with, relationship to, and participation in the Romanian cervical cancer screening programme (Kvale & Brinkmann, 2015).
When fieldwork started, I was introduced to the residents of a Roma community in Cluj County by a Roma woman acting as interpreter in this study, and to a Roma community in Bucharest County by a Roma woman working in an organisation for Roma rights. The two women also introduced me to other Roma communities with the help of Roma mediators and Roma leaders. Roma mediators and Roma leaders are regarded as door-openers in Roma communities (Engebrigtsen, 2007), and in order to get access to the people living in “their” communities one first has to get “approval” from them. First, after the study had been accepted by the Roma mediators and Roma leaders, they introduced the study and me to those living in the different Roma communities. In the location where I did most participant observation, the actual Roma leader introduced me to a Roma woman and a Roma man who were not formally designated as mediators or leaders, but who still acted as leading figures in their community. They had both been given the responsibility to maintain a common outhouse and a common meeting room. Both of them spoke English and were very helpful; during the fieldwork phase I got to know them very well. During the main fieldwork phase, I used their houses as bases. Throughout the field work I wrote scratch notes describing things I experienced, events I took part in and conversations I had taken part in or overheard. These notes were written as more coherent and detailed notes called field notes at the end of every day. The field notes were always typed directly to my work computer.

At first, many of the Roma seemed uninterested in my presence, and very few of them talked to me. The English-speaking Roma woman said that this was because many researchers and politicians tend to come to their community, talk to them, take pictures of them, and then leave. She told me, “We are not animals in a camp you rich people can take pictures of for your own amusement.” (Field notes, June 2015). She also shared with me that many Roma living in that area had told her that they did not trust me because of the notebook I always carried: “You always carry around that book you write in, and it makes them sceptical as to what you might say about us.” (Field notes, June 2015). She said that they were afraid I would make them appear “lazy and dumb” (Field notes, June 2015) as everybody else seemed to do. Therefore, I explained to her the purpose of participant observation and my presence in their community. I also decided to put away my scratch notebook. Instead, I wrote scratch notes immediately upon returning to my hotel room, or if I had some private time in their homes. However, what really made me feel accepted and involved was when, some days later, I was invited to join some of them in a religious service:

“The church is the biggest building in the four camps that make up this Roma community. The ceremony lasted for 3 and 1/2 hours and was an intense experience. The churchgoers switched between wailing and weeping as they prayed and sang with what seemed to be all the air in their lungs. (…) almost like they were shouting, or like I can do at a rock concert. There were many songs, and two middle-aged men used a microphone and sang along really loudly. I was sure they
could hear us all the way in the city. They gave all that they had when they sang. They were
completely into it. It got emotional. I was not used to seeing grown-ups take part in singing or in
a ceremony like that. They sang loudly whether or not they could carry a tune. I could not help
crying in response to it all. When Georgina¹ saw my tears, she hugged me and handed me a
handkerchief. Others who saw it also hugged me and held me in their arms. I was surprised by my
own feelings. I guess I felt sorry for them somehow, for all their hardship, and the suffering I had
started to see around me, and for the strong feeling of affection that filled the church. ‘You are
one of us now,’ Georgina said.” (Summary of field notes, June 2015).

The Roma community where this happened comprised approximately 1800 people and was located
at a garbage dump, where the houses surrounded the dump itself. The houses were made of wood
and/or bricks collected at the garbage dump, the roofs were made of tin or cardboard, and used
mattresses or simple pallets served as a front door. A few houses had electricity, but almost none
had running water. Public water stations were installed in these communities together with some
common outhouses. Most of the people living in these communities worked at the garbage dump,
recycling plastic or selling equipment they found, while others worked in the city, were unemployed,
or were on social welfare (Andreassen et al., 2017).

While doing my participant observation, I took part in the activities of these different communities
with the aim of learning about women’s daily lives and understanding how they discussed,
understood, and engaged with health and illness, and cervical cancer and cervical cancer screening.
In the numerous conversations I had with Roma women, we typically talked about how the Roma
population lived, how they were met by health care staff, and the difficulties many Roma faced when
trying to find regular work. Many Roma also told hurtful stories about discrimination in the school
system and/or in health care settings. On the bright side, I observed a warm, inclusive relationship
between the members of the communities in which I did most of my fieldwork. One Roma woman
described it to me in this way: “You may say many things about us, but there is one thing we have of
great value, and that is that we are never lonely.” (Field notes, August 2015).

Later in the fieldwork, I was invited by the IOCN to be actively involved in the planning and
performance of cervical cancer screening services via IOCN mobile units, which were offered to Roma
women in the communities where I did participant observation. Before the mobile units arrived in
these communities, I served as the link between the Roma communities and the IOCN, and I also
took an active role in informing the Roma women about the Romanian cervical cancer screening
programme and the mobile unit’s appearance, as I was present doing participant observation at that
time.

¹ All names used in field notes and diary summaries are pseudonyms.
I also took part in many social interactions, such as shopping, visiting the doctor, and attending church. I spent a few nights with a family who offered me a couch to sleep on, which was right next to their only family bed. I was invited to take part in birthdays, and one family even invited me to the baptism of their newborn.

In order to learn more about the Romanian cervical cancer screening programme and its organisation, I also did participant observation at the IOCN, where I took part in daily work activities. I spent time at the office where the employees worked, talked with staff involved in cervical cancer screening, and observed them during their daily working hours. I spoke frequently with employees involved in different parts of the cervical cancer screening programme, such as laboratory personnel, and nurses and doctors involved in the follow-up of women diagnosed with precancerous lesions or cervical cancer. IOCN employees also explained how they registered screening results, diagnoses, and treatment. In addition, I often visited their laboratory to learn how they analysed cell samples and to get a first-hand look at their (lack of) resources. Together with IOCN employees, I visited another hospital in order to learn how they related to Roma women and to learn more about screening participation. I joined IOCN employees when they were arranging meetings and seminars, and on one occasion, I joined them for a 1-week workshop at the Black Sea, where national policy makers and decision makers were present. To gain insight into the perspective of general practitioner’s, I visited the office of two of them who were involved in screening. Finally, I interacted with a policymaker at her office in Bucharest. The aim of all this was to get a rich and thorough understanding of screening participation from the perspective of screening providers, doctors, and policymakers.

During the 125 days of participant observation, I made comments, and I took part in small talk, numerous ongoing conversations and discussions, as well as non-verbal communications. I also kept in constant touch with one of my supervisors in Norway, who joined me for a period in the field to help me improve my approach so that I might get as much out of the fieldwork process as possible. During this time my supervisor became acquainted with the people and with the places where I did my fieldwork. The importance of his participation was revealed when we later analysed and wrote Papers I and II.

Before I used information from a conversation and/or from things I had observed or taken part in, I asked the persons concerned to sign an informed consent form. In total, 78 people signed such a consent form, although the actual number of people I met during participant observation was much higher. By the end of the fieldwork, I had a total of 600 pages of field notes, and our (the study team’s) impression was that there were not many new perspectives on screening participation and cervical cancer screening programmes, i.e., that the data material was saturated with respect to these topics.
4.2.3.1. Recruitment of participants for participant observation

In participant observation, the recruitment process often starts with a researcher choosing a suitable study area (Moen & Middelthon, 2015). Once an area is chosen, the researcher is dependent on what happens at this study area at any given time, and recruitment is dependent on people being present in the study area. In my situation the Roma communities in which I did participated observation was chosen by the two Roma women who introduced me to communities in which they already had contact. When I was being present in a study area I recruited the participants by asking them face to face if they wanted to take part in the study. At the start of fieldwork I used an interpreter or the Roma mediators to help me with this matter, but toward the end of fieldwork, as my familiarity with the Romanian language improved, I managed to recruit participants myself.

After being introduced in different Roma communities, I performed participant observation mostly among citizens who were financially poor. I talked to the people I met and started to broaden my circle as I spent more time in Roma communities. To broaden my insight into the life of the Roma, I also performed participant observation among a few Roma women with better socio-economic living conditions (e.g. women living in apartments and/or who had jobs and higher education). I also wanted to get men’s perspective on the life of Roma women and thus included Roma men in the participant observation. I also including Romanians who were not Roma into the study sample, as I joined them when socialising, for example at family dinners and holidays. The non-Roma participants was recruited with the help of my colleagues at IOCN as they introduced me to different persons at meetings, in seminars and when socializing. When I noticed that persons had something to tell about Roma women in context to screening and/or health care, I asked them to take part in the study.

4.2.4. Main fieldwork phase/Qualitative interviews

A semi-structured, qualitative interview allows the interviewer to let the interviewee take the conversation to areas other than those the interviewer may have foreseen or intended, without losing sight of the theme to be studied (Kvale & Brinkmann, 2015). The aim of a qualitative interview is to obtain a description of the interviewee’s life, experiences, and perspectives; and then to interpret the phenomena described (Kvale & Brinkmann, 2015). In qualitative interviews (and also in participant observation and focus group discussions), the data is coproduced, meaning that it is produced jointly by the interviewer and the interviewee (Moen & Middelthon, 2015). As part of the fieldwork in Romania, 11 persons were interviewed; interviewees included Roma women and men, screening providers, and health care professionals. The goal of the interviews was to expand the insight into issues and circumstances that contributed to women’s participation or non-participation in the Romanian cervical cancer screening programme.
As repeat interviews may improve the breadth and depth of the exploration of issues of interest (Moen & Middelthon, 2015), the research team decided to interview as many of the interviewees as possible several times. As a result, I interviewed four of the 11 interviewees on several occasions to give them the opportunity to think about the topic between interviews (Berger, 2015). These repeat interviews also gave me a chance to return to things I had missed in previous interviews (Moen & Middelthon, 2015).

While participant observation entailed numerous conversations with people, the interviews were of a more formal character. In five of these interviews the interviewees spoke English, and I performed the interviews on my own. I wrote notes during the interviews, and in two of them (one with a screening provider and one with a Roma woman), the interview was recorded and later transcribed with the help of a professional translator. In the interviews with women who only spoke Romanian, I used an interpreter: I would ask a question in English, the interpreter would translate it into Romanian for the interviewee, and the interpreter would then translate the answer into English. In these interviews, I wrote down the answers interviewees gave, first as scratch notes before I expanded them into more coherent field notes.

The interviews carried out in English were in many ways the easiest interviews to perform, as I could pose follow-up questions and statements more freely than I could with the use of an interpreter. On the other hand, when I used an interpreter, I could observe the dynamic of the interview more freely and pick up on and note the non-verbal communication, which also enriched the data collection (Chan, 2013). As my Romanian improved, I managed to follow more and more of the conversation in the interviews, making my notes easier to follow when I later analysed what had been said. All interviews lasted from 1 to 1.5 hours.

4.2.4.1. Recruitment of participant to qualitative interviews
Participants for qualitative interviews were recruited during participant observation, using a heterogeneity sampling technique in order to include persons with different perspectives and experiences related to age, socioeconomic background, and area of residence. I asked those taking part in participant observation to take part in the interviews if they had something to say about women’s health and/or screening. All of this was done to get a broader understanding when I later analysed what it means to be a Roma woman living in Romania.
4.2.5. Main fieldwork phase/Focus group discussions

A focus group discussion is a group interview or discussion used to collect qualitative data on a specific theme (Malterud, 2012). The interaction between the participants is central to this method, and the interviews/discussions are conducted in a way that displays the dynamic between participants to reveal insights that might not be gleaned from individual interviews. Focus group discussions can mobilise associations, and participants can trigger each other’s memory to produce more information (Malterud, 2012). In order to explore and discuss the impressions and findings generated during participant observation and qualitative interviews, we conducted focus group discussions with women, screening providers, and healthcare professionals from the North-Western region of Romania and Bucharest County.

The seven focus group discussions were semi-structured, in the sense that the interview guide (Attachment 1) was updated in advance with issues to be clarified. The questions in the interview guide were open, which allowed participants to discuss certain issues broadly. The size of the focus groups ranged from 5 to 12 participants. The participants were mostly Roma women in the target screening age (from 25-64 years old) living in both rural and urban settings. All Roma women who took part in focus group discussions were living in poor Roma settlements.

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**Table 3: Study participants in qualitative interviews**

<table>
<thead>
<tr>
<th>Qualitative interviews</th>
</tr>
</thead>
<tbody>
<tr>
<td>Qualitative interview one</td>
</tr>
<tr>
<td>Roma woman, age 25, living in urban area</td>
</tr>
<tr>
<td>Qualitative interview two</td>
</tr>
<tr>
<td>Roma woman, age 33, living in urban area</td>
</tr>
<tr>
<td>Qualitative interview three</td>
</tr>
<tr>
<td>Roma woman, age 26, living in urban area</td>
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<tr>
<td>Qualitative interview four</td>
</tr>
<tr>
<td>Roma woman, age 35, living in urban area</td>
</tr>
<tr>
<td>Qualitative interview five</td>
</tr>
<tr>
<td>Roma man, age 33, living in urban area</td>
</tr>
<tr>
<td>Qualitative interview six</td>
</tr>
<tr>
<td>Roma woman, age 23, living in urban area</td>
</tr>
<tr>
<td>Qualitative interview seven</td>
</tr>
<tr>
<td>Roma woman, age 55, living in urban area</td>
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<tr>
<td>Qualitative interview eight</td>
</tr>
<tr>
<td>Roma woman, age 34, living in rural area</td>
</tr>
<tr>
<td>Qualitative interview nine</td>
</tr>
<tr>
<td>non-Roma woman, age 50, living in urban area</td>
</tr>
<tr>
<td>Qualitative interview ten</td>
</tr>
<tr>
<td>Roma man, age 42, living in urban area</td>
</tr>
<tr>
<td>Qualitative interview eleven</td>
</tr>
<tr>
<td>non-Roma woman, age 65, living in urban area</td>
</tr>
<tr>
<td>Total</td>
</tr>
<tr>
<td>11 study participants</td>
</tr>
</tbody>
</table>
4.2.5.1. Recruitment of participants to focus group discussions

We performed a purposeful recruitment of participants to the focus group discussions (Sparks & Smith, 2013) to give a complex, nuanced, and contextual description of the theme under exploration (Moen & Middelthon, 2015). The aim was to include a wide and diverse range of people, phenomena, positions, and situations that were relevant to Roma women’s engagement with cervical cancer screening and participation in the Romanian cervical cancer screening programme. Therefore, for all seven focus groups I tried to maximise the variation in perspectives and experiences, age groups, areas of residence (rural/urban), social positions, socioeconomic conditions, and experiences with health and illness, cervical cancer, and cervical cancer screening. When that said, there was not so much variation within each group (at least not with regard to area of residence), but overall the groups represented a span with regard to these things. Participants for focus group discussions were recruited during participant observation; as I met them, I asked them to take part. Screening providers were also included in separate focus groups in order to get the perceptive of heath care professionals. In total, 48 Roma women and nine screening providers took part in focus group discussions.

Table 4: Participants in focus group discussions

<table>
<thead>
<tr>
<th>Focus group discussions</th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>Focus group one</td>
<td>8 Roma women from urban areas</td>
</tr>
<tr>
<td>Focus group two</td>
<td>7 Roma women from urban areas</td>
</tr>
<tr>
<td>Focus group three</td>
<td>12 Roma women from urban areas</td>
</tr>
<tr>
<td>Focus group four</td>
<td>10 Roma women from rural areas</td>
</tr>
<tr>
<td>Focus group five</td>
<td>11 Roma women from rural areas</td>
</tr>
<tr>
<td>Focus group six</td>
<td>5 screening providers</td>
</tr>
<tr>
<td>Focus group seven</td>
<td>4 screening providers</td>
</tr>
<tr>
<td>Total</td>
<td>57 study participants</td>
</tr>
</tbody>
</table>

Focus group discussions lasted between 1 and 1.5 hours, and all but one was conducted in Romanian with the help of a research assistant. All focus group discussions were recorded and transcribed, and then translated into English by a professional translator. During the discussions, I made notes of the groups’ dynamic and non-verbal communication. I also drew the room and the participants to help me remember more details when I analysed the notes later. One of my three supervisors attended two of the focus group discussions.
4.2.6. Research assistants/interpreters
A Roma woman and a non-Roma woman acted both as research assistants and interpreters during the Romanian studies. Both were involved in health care; the Roma woman was a medical student and the non-Roma woman worked with cervical cancer screening at the IOCN. Before fieldwork started, the aim of participant observation was explained to them, and both were trained in conducting qualitative interviews and focus group discussions. Two pilot qualitative interviews and one pilot focus group discussion with Roma women were conducted as part of this training. This research assistance was necessary as I was insufficiently fluent in Romanian to engage in conversations with Roma on my own.

The fact that one of the interpreters was Roma and one was non-Roma seemed to bring out different perspectives on the interactions with study participants. The three of us were engaged in ongoing joint reflections about Roma women and the way they lived their lives, and we frequently discussed what we had experienced and observed. The use of interpreters with different ethnicities seemed to provide contextual information. In addition, both helped me understand what I participated in and observed.

In the early phase of fieldwork, the interpreters were always present, but as time went by, I spent more and more time alone in the field. When I was alone, my communication with Roma people was based on a mix of my limited Romanian, shared capabilities in English, French, or German, as well as extended non-verbal communications. Even though we managed to communicate on some level, my lack of fluent Romanian was a disadvantage, as I could not communicate as freely as I had hoped. However, the use of interpreters was not always ideal, as conversations had to be translated back and forth between us, making the conversations tiresome. However, at the end of the fieldwork period, I spoke more fluently, and understood much more Romanian than I did at the start of fieldwork.

4.2.7. The write-up phase, Paper I
As I started to analyse the data I had collected during field work, I visited Cluj-Napoca five times. During these visits, I reconnected with study participants, but I also used the opportunity to discuss the ongoing analysis (described in detail in Chapter 7) by presenting the preliminary findings to the study participants. This is called member checking (Green & Thorogood, 2014), and means that the researcher presents a tentative analysis to study participants and asks if they find it reasonable. In cases where I was unsure if I had understood them correctly, this phase allowed me to get feedback and get things right. Each of these visits lasted for approximately 3-10 days. I always drove out to the Roma communities to meet with the people I had gotten to know during participant observation.
I also spend time with my colleagues at the IOCN and discussed the findings with them. During this phase of the project, the controversies that existed between the screening providers and the screened population were brought to the surface, as Roma women and the screening providers had very different understandings of and considerable disagreements related to the national cervical cancer screening programme. Discussing these controversies with IOCN colleagues was both challenging and useful, especially because my colleagues at the IOCN had difficulty understanding, justifying or denying some of the findings, i.e., Roma women’s descriptions of the discrimination they had faced from health care providers. They were sometimes unaware of the things I brought to their attention, and they had a hard time believing some of them, i.e., Roma women’s lack of knowledge about the existence of the Romanian cervical cancer screening programme. My IOCN colleagues said they were concerned I did not see the big picture; that I only spoke on behalf of Roma women and did not understand the experiences of screening providers. Discussing the findings with all fieldwork actors gave me valuable insight into different perspectives and was useful in the analytical process. In the end, all the actors said that I presented the data in a way that was meaningful.

4.3. The quantitative study (Paper II) from Romania

4.3.1. Design and rationale
The second Romanian study was a cross-sectional study. Between March and June 2016, 1000 women (60% Roma and 40% non-Roma) answered a structured questionnaire, which was designed based on the experiences I gained during field work and the results of Paper I. The questionnaire was designed in close collaboration with IOCN colleagues, the Romanian Cancer Society, the CRN in Norway, and the University of Oslo.

Participants included both Roma and non-Roma women; the latter were used as a comparison group. This allowed the research team to have a better understanding of the association between screening attendance and different factors (i.e., age, marital status, education level, ethnicity, working situation, living conditions, sexual relationships, knowledge related to cervical cancer, screening, HPV, and participation in the Romanian cervical cancer screening programme) in the entire population of the North-Western region of Romania.

The research for Paper II was dependent on the knowledge gained in Paper I, which allowed us to include relevant questions in the questionnaire. This research could not have been carried out without the results of Paper I, which gave an initial exploration of the field.

1 We excluded 19 women for whom information about screening was missing, and one with missing information about ethnicity, resulting in 980 women.
This study aimed to identify barriers to screening and women’s perceptions of their attendance to cervical cancer screening. It also aimed to quantify findings from Paper I related to discrimination from health care workers towards members of the Roma population, Roma women’s apparent lack of knowledge about the existence of the Romanian cervical cancer screening programme, women’s living conditions, their reluctance to participate in the screening programme, and their actual participation rate in the programme.

Due to the almost non-existent experience of cervical cancer screening among Roma women, we had to develop our own questionnaire that adequately captured the information needed. This requires “a thorough understanding of the questions, the best way to ask them, and the range of possible responses.” (Mack, Woodsong, Macqueen, Guest, & Namey, 2005, p. 3). The knowledge gained from Paper I was of crucial importance when developing this questionnaire, and progressive versions were discussed with the study team until consensus was achieved about which questions to include.

The final questionnaire included 69 questions, which collected information on things like marital status, education level, ethnicity, belonging to a community, working situation, economy and living conditions, sexual relationships, use of contraceptive methods, pregnancies and number of children, use of the health care system, how they perceived and participated in the Romanian cervical cancer screening programme, and their knowledge of and attitudes towards cervical cancer. The questionnaire also included questions related to discrimination that were used in a previous study by Shariff-Marco et al. (2011) (Attachment 2).

A professional interpreter translated different versions of the questionnaire from English to Romanian. As part of quality assurance, the Romanian Cancer Society translated the Romanian version back to English. The final translation of the questionnaire to Romanian was quality assured by the Romanian Cancer Society and the IOCN (attachment 3).

Because many Roma women are unable to read and/or write (European Commission, 2014), we arranged for three pilot questionnaire meetings, one in Oslo with Roma women, and two in Romania with Roma women living in North-Western region. During the meetings, we investigated women’s understanding of the different questions on the questionnaire and evaluated the feasibility of collecting information by reading the questions, as well as the different response options, aloud. We also investigated women’s understanding of the questionnaire by discussing this issue with some of the pilot participants after they had submitted the questionnaire. The pilot participant’s suggestions and input were taken into consideration when constructing the final questionnaire.
At the pilot meeting in Oslo, a professional interpreter and two Romanian female volunteers helped eight Roma women complete the questionnaire. The two pilot questionnaire meetings in Romania were conducted with help of three volunteers, and a total of 25 Roma women participated.

4.3.2.2. Data collectors
Two persons from the Romanian Cancer Society and myself trained 17 individuals (eight Roma mediators who assisted in the recruitment of Roma women, and nine physicians and nurses who assisted in the recruitment of non-Roma women) to assist in data collection (data collectors). The training was done in mini-seminars, during which each data collector was informed of the inclusion criteria\(^1\) for the study and received detailed explanations of each question. The data collectors were trained how to ask the questions in a neutral way.

4.3.2.3. Recruitment of participants
Participants were recruited to questionnaire meetings from Roma communities using the ‘snowball method’: data collectors informed Roma women aged 25 years and older from their communities about the questionnaire meetings, their time and place. As a result, the news about questionnaire meetings was spread by the women themselves, and women who wished to take part attended spontaneously and voluntarily; study participants were not selected randomly. We aimed to recruitment Roma women from both rural and urban areas of the North-Western region of Romania and women of different age within the target age group (25-64 years old). Recruitment lasted 4 months, and according to the data collectors, Roma women were eager to participate. Non-Roma women were recruited at doctors’ offices or other places where women usually received health care. Some non-Roma women answered the questionnaire alone in their doctor’s waiting room; other non-Roma women attended questionnaire meetings arranged by nurses or physicians.

4.3.2.4. Questionnaire meetings
The data collectors arranged 30 questionnaire meetings, during which questionnaire information was collected from 1000 women. In all questionnaire meetings a representative from the Romanian Cancer Society and/or myself were present, observing and assisting the participants if needed. Each meeting lasted between 1 and 1.5 hours and 3-40 women participated. The questionnaire meetings were organised in classrooms or similar rooms, and women were seated at individual desks to ensure privacy. The trained data collectors informed participating women about the study and its aims and let them know that they could ask for help completing the questionnaire. One day, 40 Roma women answered questionnaires, with the help of six data collectors. On other occasions, women answered questionnaires individually without needing any help from data collectors.

\(^1\) The inclusion criteria for the questionnaire survey were age (≥25 years) and residence in Romania.
4.4. The quantitative study (Paper III) from Norway

4.4.1. Design and rationale
Paper III was designed as a cross-sectional study. With the impending change in the primary screening method used in the NCCSP from cytology to hrHPV testing, women will increasingly be informed about their hrHPV test results. Since cervical cancer rarely occurs in the absence of hrHPV infections, a positive cytology result indicates that the woman most likely has, or has had, a hrHPV infection. To what degree women in the general population are aware of this, and how they would react to knowing their HPV status, was unknown when the pilot project of hrHPV testing in primary screening started in 2015. A condition\(^1\) for full-scale implementation of hrHPV testing in primary screening was that the CRN address whether the transition would lead to reduced screening participation or increased anxiety and depression among screening participants. Therefore, the CRN requested that I carry out the research in Paper III to obtain knowledge about women’s anxiety and depression when switching the primary screening method from cytology to hrHPV testing.

4.4.2. Method used, questionnaire survey
We used a questionnaire to measure anxiety and depression in women receiving cytology or hrHPV test as a primary screening method. The questionnaire was specifically designed as part of this PhD project (Chapter 4.4.3).

4.4.2.1. Inclusion and exclusion criteria
The NCCSP database contains screening data from 1.4 million women (Leinonen et al., 2017b). Of these, a total of 168,201 women took part in the pilot project of hrHPV testing in primary screening between February 2015 and September 2016 (Engesæter et al., 2017). Out of this pool of women, we obtained data from 2000 women (Table 5) who had participated in the pilot project between February 2015 and September 2016 (less than 0.1% of women in the four pilot counties choose not to take part in the pilot project of hrHPV testing in primary screening) and were aged 34-69 years. We did not include women who chose not to have personal, identifiable screening results registered at the CRN (less than 3% do so). We then randomly selected 500 women from the cytology screening arm and 500 women from the hrHPV screening arm. In order to measure anxiety and depression among women with an abnormal screening results, we also randomly sampled 500 women with positive cytology results from the cytology screening arm and 500 women with a positive hrHPV test from the hrHPV screening arm (Table 5).

\(^1\) This was a prerequisite from the National Council of Priority Settings (The Norwegian Directorate of Health., 2018).
Table 5: Study sample in the Norwegian study (study III). Random selection of 2000 women among the 168,201 taking part in the pilot project of hrHPV testing in primary screening between February 2015 and September 2016

<table>
<thead>
<tr>
<th>Number of women</th>
<th>Primary screening method</th>
<th>Screening result</th>
</tr>
</thead>
<tbody>
<tr>
<td>500 women</td>
<td>Cytology</td>
<td>Not considered</td>
</tr>
<tr>
<td>500 women</td>
<td>hrHPV test</td>
<td>Not considered</td>
</tr>
<tr>
<td>500 women</td>
<td>Cytology</td>
<td>Positive cytology result</td>
</tr>
<tr>
<td>500 women</td>
<td>hrHPV test</td>
<td>Positive hrHPV test result</td>
</tr>
</tbody>
</table>

4.4.3. The questionnaire

The 2000 selected women received a questionnaire by post. The questionnaire was marked with a unique ID number1, making it possible to later link their completed questionnaire to objective clinical screening data from the CRN. A second mailing of questionnaires was sent to non-responders after 1 month.

The questionnaire used in this study (Attachment 4) was designed partly based on results from other studies (Burger, et al., 2014; McCaffery et al., 2006) and partly on the validated PHQ-4 scale for measuring anxiety and depression (Kroenke et al., 2009; Löwe et al., 2010). The PHQ-4 is a self-reported, brief screening instrument with 4 items. Its aim is to improve physicians’ ability to identify individuals who might need treatment. The PHQ-4 is based on two larger, validated instruments that measure anxiety and depression: the seven-itemed Generalised Anxiety Disorder Scale (GAD)-7, which measures anxiety (Spitzer, Kroenke, Williams, & Löwe, 2006) and the nine-itemed PHQ, which measures depression (Kroenke, Spitzer, & Williams, 2001). These two instruments were shortened into 2-item questionnaires (the PHQ-2 and the GAD-2) that incorporate the core criteria for anxiety and depression (Kroenke et al., 2009; Löwe et al., 2010). The PHQ-2 has been compared to instruments such as the Hospital Anxiety and Depression Scale, the World Health Organisation Five Item Well-Being Index, the Twelve-Item Short Form Health Survey and finally the gold standard, the Structured Clinical Interview for DSM-IV, and it was found to be a validated and practical tool for depression diagnoses (Löwe, Kroenke, & Grafe, 2005). The shortened GAD-2 instrument for anxiety has been validated by standard interviews and was found to be a good criterion for measuring anxiety (Löwe et al., 2010; Spitzer et al., 2006). A meta-analysis (Mitchell & Coyne, 2007) revealed that combining anxiety and depression items into one gave better results than a single-item screening instrument. Thus, the PHQ-4 was made by combining the PHQ-2 and GAD-2. The PHQ-4

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1 Not the social security number given all Norwegian citizens at birth
The PHQ-4 scale is recommended for use in busy medical settings as well as in research studies. We therefore considered it valuable to include in our questionnaire.

The study questionnaire also included questions on age, marital status, and education level. In order to explore women’s understanding of and knowledge acquired from the CRN’s HPV-information strategy, we added some questions related to these issues. We also asked which screening method the women underwent at their last screening visit, and their latest screening results. The questionnaire was piloted among female employees at the CRN and revised based on their feedback.

Of the 2000 women invited, 1008 (521 from the cytology screening arm and 487 from the hrHPV screening arm) completed the questionnaire survey (Figure 4).

Figure 4: (from study III) Flow diagram of study participants and their previous screening results².

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1 Translated into Norwegian by Sverre Urnes Johnson, Asle Hooffart, Pål Ulvenes, Harald Sexton, and Bruce E. Wapold.

2 Nine women with inconclusive screening test results in the cytology arm are excluded from the analysis.
5. Ethical Issues

5.1. Ethical considerations and approvals for the Romanian studies

The IOCN had already received the necessary approvals to conduct the two Romanian studies during the application process for CerCcRom, according to Romania’s legislation. The approval was given by the Ethics Committee of the Institute of Oncology Prof. Dr. Ion Chiricuță (Attachment 5).

Nevertheless, because part of CerCcRom analyses were to be conducted in Norway and because approval is required when Norwegian universities do research abroad, approvals from that country were also necessary. Approval from the Regional Committee for Medical & Health Research Ethics (REK) was sought, but the REK deemed the project to be outside the remit of the Act on Medical and Health Research (2008) (Attachment 6). We therefore applied to the Privacy Ombudsman and Data Protection Officer (PVO) at Oslo University Hospital, which provided a recommendation for the project (Attachment 7).

All participants in Romania signed an informed consent form. The informed consent (Attachment 8) followed a template from REK, and we strove to make the informed consent understandable to lay people. Study participants from health care and governmental positions also signed an informed consent form (Attachment 9) before taking part in participant observation, qualitative interviews and/or focus group discussions.

All scratch notes written during the fieldwork process in Romania were initially written in Norwegian, because it was easier for me to write down thoughts and reflections in Norwegian and because Norwegian notes could not be read by speakers of Romanian. It thereby offered some protection in case I were too lose my scratch notebook (admittedly, the Norwegian language offered only limited protection due to translation programs (e.g. Google Translate) which are easily accessible). During the two Romanian studies, all scratch and field notes were taken as described in the application to the PVO, i.e., I collected the names of people with whom I had repeated interactions, I gave them all a pseudonym which was linked to their real names listed in a separate notebook (called the pseudonym book). The pseudonym book was stored in a safe in my hotel when I was in Cluj-Napoca or Bucharest and locked in a desk at my office at the CRN when I was in Norway. I always used pseudonyms when I wrote down conversations and/or experiences of interest. Interview notes and focus group discussion notes were taken using similar procedures. Since Roma participants lived in certain communities, I did not need to (and I therefore did not) collect their phone numbers in order to stay in touch with them. In cases where study participants could have been recognised based on a story or geographical data, I omitted or altered relevant details in the scratch notebook. When I expanded the scratch notes into more coherent and detailed field notes, I translated them into English, and used only the pseudonyms, which I came to learn very well. The pseudonym book was
destroyed in April 2016. When the scratch notes were expanded into field note I always used my work computer. All field notes were without names, addresses, or dates of birth and since the data also was omitted, they did not contain any indirectly identifying information. My work computer was protected with a username and a password.

A professional translator was used to translate transcripts of the recordings of qualitative interviews and focus group discussions from Romanian into English. A standard agreement form for assistance from consultants (the simple aid agreement - Agency for Public Management and eGovernment) was signed by the CRN and the professional translator. Following the steps of this agreement, the audio tapes and the transcribed material were delivered to the CRN immediately after the translation was completed. The transcribed material was stored on a memory stick. No personal identifying information or indirectly identifying information was collected during these qualitative interviews or focus group discussions, just a number that linked the actual person or focus group to a certain place and the actual date. This linkage list was kept in my pseudonym notebook1. All voice recordings were destroyed in April 2016.

No identifying information was collected in the questionnaire survey. However, it could have been possible to detect a person's identity by summarizing multiple answers from the questionnaire. Paper versions of the completed questionnaires are currently stored in a locked cabinet by the Romanian Cancer Society, as described in the application to the PVO. The questions from the questionnaires and the answers from the study participants were coded and plotted into an excel file by the Romanian Cancer Society. This excel file was stored on a memory stick and delivered to me in person. The codes for the questions and answers were sent to me in a separate email. This code was destroyed 31.12.18. Informed consent forms from study participants answering the questionnaires were kept in locked cabinets at the Romanian Cancer Society. The paper versions of the questionnaires, and the informed consent forms, are stored separately and will be destroyed by the Romanian Cancer Society by 31 March 2023, in accordance with the Data Protection Official provisions.

5.2. Ethical considerations and approval for the Norwegian study
Approval from the REK was sought for the Norwegian study, but they deemed it to be outside the remit of the Act on Medical and Health Research (2008) (Attachment 10). We therefore applied to

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1 The pseudonym notebook was stored in a safe in my hotel when I was in Cluj-Napoca or Bucharest or locked in a desk at my office at the CRN when I was in Norway.
the Data Protection Officer for Research in Norway, which provided a recommendation for the study (Attachment 11). The Data Delivery Department at the CRN also approved the study (Attachment 12) and randomly selected the women to whom we sent questionnaires, based on the inclusion criteria described in Chapter 4.

The 2000 randomly selected women received an information leaflet (Attachment 13) with the questionnaire. This leaflet explained that completing the questionnaire was regarded as sufficient informed consent to take part in the study, and that their questionnaire would be linked to their screening history at the CRN. The questionnaires received a unique serial number from 1 to 2000. A key linking this serial number to the actual women was kept only by the Data Delivery Department at CRN. Completed questionnaires were scanned and plotted into an excel file by an external agency assigned for this task. The external agency signed a standard data processor agreement with the CRN. The excel file was mailed to the Data Delivery Department at CRN and the external agency deleted the material immediately after delivery, in accordance with the data processor agreement. The paper versions of the questionnaires were given to me in person at the CRN and are kept in a locked cabinet in an office at the CRN. The questionnaires will be destroyed by 30th of June 2023 by the leader of the cervical department. A database has been created by the Data Delivery Department, in which study participants’ screening history is linked to their questionnaire. This database is password-protected, and the questions and answers are coded.

The responsibility for the safekeeping and deletion of the study material from Papers II and III has been handed over to the head of the Cervical Department at the CRN, in accordance with the provisions of the Data Protection Official.
6. Reflexivity

The debate on the role of the self in qualitative knowledge production has expanded in academic circles during the last decades. Reflexivity is part of this debate. In qualitative studies, the researcher is central to the production of knowledge, because they influence the research process through their interactions with study participants, their presence in the field, and the analytical explanations they give (Finlay, 2002). Reflexivity refers to self-examination, by which the researcher addresses these influences through a continuous inner dialogue (Berger, 2015).

As preparation for the fieldwork, I engaged in reflexivity as a process of critical self-evaluation of my position as a researcher, as well as an acknowledgement and explicit recognition that this position could affect the research process and outcome (Bradbury-Jones, 2007).

“Reflexivity means turning of the researcher’s lens back onto oneself to recognize and take responsibility for one’s own situatedness within the research and the effect that it may have on the setting and peoples being studies, questions being asked, data being collected and it’s interpretation. As such, the idea of reflexivity challenges the view of knowledge production as independent of the researcher production it and of knowledge as objective.” (Berger, 2015, p. 220).

In qualitative research, reflexivity aims to push the researcher to address and acknowledge the preconceptions they have that may affect the direction and the outcome of a study, thereby facilitating the transparency, accountability, and trustworthiness of the research (Finlay., 2002). In the following, I will start with reflections on my own social background and my interest in humanitarian work and how this might have affected my commitment to this project and influenced the research process in various ways. I will follow by stating how I worked with reflexivity through all phases of the qualitative study in Romania. This is done with the aim of being transparent and giving the reader the possibility to follow and inspect my work from beginning to end.

6.1. Researcher positions

I am trained as an anaesthetic nurse and have worked in the operating theatre and as a transplant coordinator at the Oslo University Hospital for a total of 14 years. I have a Master’s Degree of Nursing Science from the University of Oslo based on the qualitative research method, focus group discussions. As I am not a statistician or an epidemiologist; I had to learn quantitative methods and data analysis and interpretation as part of this PhD project. In order to do so, I took mandatory classes and courses as part of my PhD education at the University of Oslo. I also attended two additional courses in cancer epidemiology organised by the association of Nordic Cancer Registries.
I have always been interested in relief work, and during my time as an anaesthetic nurse, I took some time to serve in Burkina Faso with the Red Cross relief organisation. My background in these surroundings may come to matter in the course of research as I easily felt empathy for the Roma population and as I eager to help them improve their health. To speak on the behalf of the Roma population more than I did for the health care workers, was therefore a possible outcome. To be aware of this fact and try to not make my own position lead the analytical work in any directions was therefore a constant ongoing process.

During the last 12 years, I have been a senior adviser at the Norwegian Directorate of Health on the topic of cervical cancer screening and the organisation of the NCCSP. In the year before I started this PhD project, I worked as a project leader for the pilot project of implementing hrHPV testing in primary screening within the NCCSP at the CRN. When this PhD project turned up, it was interesting to me in several different ways. First, I thought it made good sense to engage in research that could be beneficial to a disenfranchised group of persons, and second, in my previous jobs at the directorate and the CRN, I had learned the importance of cervical cancer screening. Therefore, the theme of the present thesis was an excellent fit for me.

6.2. Preconceptions about Roma

In wrote down my thoughts and feelings throughout my reflexivity work, which was an ongoing process that started 6 months prior to the onset of fieldwork. In retrospect, the preparation phase (Chapter 4.2.2.1) was very useful, as I used these months before fieldwork to become aware of my thoughts and assumptions related to the Roma. There were, and still are, many prejudices against the Roma population in Norwegian society (Engebrectsen, 2012). I, however, tended to regard myself as having few prejudices and started to talk and engage with Roma begging in the street in Oslo. As mentioned earlier, I spoke frequently with many Roma women and men and invited some of them to my home. At one point during this period, my bike was stolen from my garden, and I noticed that, impulsively, I got a nagging suspicion that it might have been one of my new Roma acquaintances. This turned out not to be the case, but nevertheless, it made me aware that I was not as free from prejudice as I had thought. This experience made me realise that I should try to do more work on myself before fieldwork started, so that I could better serve as an active tool in the field to gain an insider perspective (Glesne, 1999) of the experience of Roma women living in Romania. In the time that followed, I examined closely my own prejudices; I wanted to prove to myself that I had changed my own stigmatising views of Roma as untrustworthy. I therefore invited a young Roma couple (a pregnant woman and her husband) to live in my house, and my family and I hosted them for several months. I saw this not only as an opportunity to do my reflexivity work (Finlay, 2002), but also to be
able to practice the Romanian language. I also did this out of a genuine desire to help Roma who were without a regular income and a place to live during the cold winter in Norway. When the pregnant woman was about to deliver, she wanted to go back to her family and her children in Romania. We (my family) paid for her travel back to Romania, but her husband wanted to stay in Norway a bit longer, as they did not manage to save up as much money as they had hoped. In the following weeks, we spoke frequently with his wife in Romania, and we tried to help ‘Tony’ get temporary work in Oslo. It was a terrible shock to us when we came home one day and found that our home had been burgled. When ‘Tony’ later called to confess to and apologise for the robbery, we could simply not believe it.

“The worst thing is not that he stole the jewellery I had inherited from my great grandmother, or the children’s jewellery, or our family’s computers and phones; the worst thing was that he abused the trust and hospitality that my family has shown him all these months. I can actually understand to some extent why he was tempted to steal from us, as he has seen that we (in his eyes) live in luxury and have a house, a cabin, a car, a sailboat, three children, a foster child, a dog, a cat, and electrical equipment many Roma cannot even dream of acquiring themselves. How he must have been tempted to steal from our abundance so that he could go home to his wife, his newborn, and his children in Romania. I understand all that, but still I feel so much betrayed. The worst thing, however, is that I feel so stupid, and I do not look forward to listening to everyone say, ‘I told you so.’ As I intended to show that helping others in need is a good thing, I feel that I have lost twice. It is also difficult to listen to both the police and insurance companies, who said that we had been careless and naive, and that because of this we will receive reduced insurance settlements. How should I now relate to the Roma and the prejudices I have worked to get rid of? Maybe I am and have been naive, or maybe I simply have lost my innocence.”

(summary from my diary, 2015).

This was part of my diary that I wrote during the preparatory phase (4.2.2.1), and I have been worried that including it in this thesis could contribute to further stigmatisation of the Roma as untrustworthy or of myself as naive. However, even today, I consider these diary notes to reflect a very important lesson learned, and a very valuable example of the reflexivity work I did prior to the onset of fieldwork. Even though Norwegian newspapers report that crime perpetrated by Roma and Romanians in Oslo is higher than that perpetrated by the average Norwegian citizen (Mjaaland, 2013), I believe that I cannot draw general conclusions about the Roma based on my single experience. I also think that the over-representation of crime among the Roma must be regarded in the context of how the Roma are treated in Europe, and the discrimination they encounter in society. In many ways, the Roma population faces structural violence in Europe, meaning that the social arrangement they face puts them, both as individuals and as a population, in harm’s way. According to Farmer, Nizeye, Stulac, & Keshavjee (2006), the social arrangement of the Roma is structural because it is embedded in the political and economic organisation of our social world, and this arrangement is violent because it can cause injury to the people it targets. This structural violence is
perpetrated by one or more of the following structures: economic, political, legal, religious and/or cultural (Farmer et al., 2006; Galtung, 1969). Structural violence may cause the Roma population not to reach their full potential. If this short, superficial analysis that I propose of Roma being victims of structural violence is correct, then we as Norwegian citizens are jointly responsible for considerably greater injustices than the one ‘Tony’ committed in my home, or when someone gets their wallet stolen in the streets of Oslo.

In the period that followed, I tried to prepare myself for the fieldwork to come with an open mind. I started by summing up what I already knew about the Roma and participation in cervical cancer screening programmes and tried to put this aside. In addition, I tried to place my experiences with Roma, and in particular with ‘Tony’, in a ‘bracket’. I did this in an effort to go to the field without my biases, which could keep me from seeing the research realities clearly. It is part of my positionality that I am a rather rich person who does research among some of the world’s poorest persons. In some ways, this is a difficult starting point, because I lack the personal background to understand the experiences I try to describe and analyse, and thus I am constantly in danger of a misunderstanding or an incorrect interpretation. On the other hand, to be able to understand the world from the perspective of the other is a general challenge in qualitative research. Something that was helpful to me in this context was that I had a relatively long fieldwork period.

6.3. Reflections regarding participant observation, qualitative interviews, focus group discussions and questionnaire meetings

Also, before I performed qualitative interviews, focus group discussions and questionnaire meetings I worked with self-evaluation of my positions as a researcher. While doing participant observation among the Roma population in very poor parts of Romania, at times I had to look for my inner strength. Indeed, at least in the beginning of fieldwork, I was afraid of the "wild" dogs living in some of the Roma communities, of being robbed, and of being banned from the area where foreigners are not allowed. When going into the field, I never knew what would happen, and this sometimes made me feel unsafe. The fieldwork was also a lonely experience, as I did not always have anyone to discuss my experiences and findings with. Some days I felt sad and angry because of the way the Roma were treated, and I often found myself exhausted at the end of a fieldwork period.

While performing the qualitative interviews and focus group discussions with the Roma, there were a lot of interruptions. Indeed, from participant observation, I had learned that Roma who live in the same community are often very social. In my experience it is considered almost rude when two persons retreat to one house when several were gathered together. I observed that many Roma in
the study area typically spent a lot of time together, and that they often shared food, household
goods, wood, gas, medicine and clothes with one another. I often saw them looking after each
other’s children and helping each other when and if they refurbished or built on to their houses. They
freely expressed their thoughts and opinions; every day, I witnessed arguing and loud voices that
were followed by words of friendship. This compact and intimate way of living in some ways
conflicted with my ideas about how to carry out private qualitative interviews and focus group
discussions. At first, I was very surprised and at some point, even frustrated when neighbours
expected to take part in and listen to a qualitative interview. When I told them that the qualitative
interviews were supposed to be private, they typically responded by staying and listening, but not
speaking, as if simply not interrupting allowed enough privacy. I had to consult with my supervisors in
Norway to get ideas for how to make the Roma I interacted with understand what I meant when I
asked for privacy during an interview. These differences in interview situations were important, even
if they quite frustrated me. They taught me that we had a different understanding of the word
‘privacy’. After some difficulties, I managed, to some degree, to make the interviews more private,
but I never managed to make them totally without interruptions. In focus group discussions, women
typically started to smoke, eat, take a phone call, or even wander around. They could suddenly
disappear and then return. At some point, husbands, children, and even other unknown persons
could appear, and this did not seem to bother the participating women. “They are unruly and
undisciplined in this way” (Field notes, June 2015), a Romanian health care worker told me when I
discussed the matter with her. However, this qualification of the Roma as undisciplined or unruly was
something I seldom experienced; we simply had different understandings and expectations of
interview situations.

Also, when performing questionnaire meeting I was sometimes surprised about the way the Roma
study participants interacted with each other. At times women could ask each other about what they
had answered on a specific question from the questionnaire. For example, did some women at a
questionnaire meeting share how many sex partners they had had and how many induced abortions
they had performed openly. When I told them that this was supposed to be private they stated that
they liked to know and share these issues.

6.4. Reflections regarding the quantitative study from Norway

The Norwegian study was related to the NCCSP, a topic I have worked with since 2009. I was very
familiar with and interested in investigating anxiety and depression among the NCCSP participants
taking part in the pilot project of hrHPV testing in primary screening. I was not sure what the
outcome would be, but I had an idea that women who received hrHPV testing as a primary screening method might be more anxious and depressed than women who received cytology as a primary screening method. This was partly because of the existing literature (i.e. Anhang et al., 2004) and partly because of the concerns raised from the National Council of Priority settings (The Norwegian Directorate of Health., 2018).

My awareness of my own expectations of the study results was also part of my positionality related to the quantitative study III.

6.5. Conclusion
Reflexivity can be understood as self-examination with a continuous inner dialogue, in which the researcher acknowledges that he or she may threaten the accuracy of the study’s results. In order to enhance the trustworthiness, transparency, and accountability of the research process, the researcher must address his or her preconceptions and other conditions that may affect the direction and/or the outcome of the study (Finlay, 2002). However, how one approaches reflexivity and what one seeks to reveal depends on the researcher. In this chapter, I have tried to show how I performed my reflexivity work in all three studies of this thesis, so that the reader can follow and inspect my steps.

I used reflexivity in all three studies, but mostly in the research for Paper I, during which I strove to bring my own positionality to the surface. Reflexivity was also valuable in the planning and performance of the research for Papers II and III. This was indeed a challenging task, because it involved both the data collection and the writing process.

Reflexivity work is easier said than done, but by focusing on this task, I think I was better prepared to go into the field and perform the qualitative and quantitative studies than if I had not done this mental exercise.
7. Qualitative and quantitative data analyses

7.1. Analysing qualitative data from study one – Paper I

Since little previous research had focused on Roma women and their participation in cervical cancer screening, Paper I was an exploratory work which attempted to produce a rich, descriptive account of screening activities and how Roma women engage with cervical cancer screening, and health issues. The aim was to develop an understanding of the different ways in which Roma women live their lives, and their experiences and engagement related to participation in the Romanian cervical cancer screening programme.

In the analytical part of the qualitative study, we were inspired by Coffey and Atkinson (1996) and Moen and Middleton (2015). Their recommendation is to make the qualitative analysis an integral and ongoing part of the research process, which includes methodological considerations, data production, analytical work, and theorising. The analytical work has thereby been an interactive process that started with the planning of the study reported in Paper I.

The three qualitative research methods (participant observation, qualitative interviews, and focus group discussions) used in this study were done during the main fieldwork phase, allowing for an ongoing interaction between these methods (Maxwell, 2012). Issues or themes that emerged during one method could thereby be explored further with one of the other methods. For instance, things I observed during participant observation were often further investigated in qualitative interviews and focus group discussions. Conversely, issues that emerged during qualitative interviews or focus group discussions could be explored further during participant observation.

The data material collected using these three different qualitative methods included transcribed interviews, diary notes, scratch notes, and field notes. At the end of the study, I had 600 pages of data material and my engagement with it formed part of my everyday life. The hand-written scratch notes I took throughout every fieldwork day had to be expanded into more coherent, digitised field notes. Thus, the scratch notes represented the starting point of the analytical process, as I had to think through what I had heard, observed, and experienced in order to get things right, and I could not include everything. I had to reflect on what to include and what to not include; what I wanted and what I needed to include in the field notes. This process was considered part of the tentative analytical process, as it made me go back to the experiences I had during each fieldwork day, and this brought to the foreground issues that needed further clarification or inquiry. The analytical work continued when different parts of the scratch notes and field notes were re-read, for example when I prepared for qualitative interviews and focus group discussions.
When the audio recordings from qualitative interviews and focus group discussions were transcribed, they changed form from oral to written data. This transformation also contributed to the analytical work, as written data may offer an overview of the material that oral records do not give, and thereby increase a researcher’s familiarity with the data (Kvale & Brinkmann, 2015). Since the data were transcribed by a professional translator, I read the transcript several times to become more familiar with it.

The analytical process also involved the study participants through member checking where the researcher presents a tentative analysis to study participants and asks for their comments and whether they found it reasonable. During the main fieldwork phase, but also in the write-up phase, I asked many of the Roma women I interacted with if the analyses that gradually evolved made sense to them. The women contributed by clearing up issues I felt unsure of, and they sometimes brought themes to the surface that needed further clarification. In such cases, any ambiguity was further discussed and explored with the study participants.

The research teams from Norway and Romania were also included in the analytical process. I discussed preliminary findings and regularly shared field notes with them; this material and resultant discussions formed part of the joint analytical work. In addition, I had parallel discussions with the supervisor who joined me for a period in the field (as explained in Chapter 4.3.2). This supervisor knew the data material very well, and the two of us had many intense discussions about the material and the analytical work.

During the analytical process I had to deal with a large amount of textual data. In order to work with it all, I started to look for different ways to categorise the material while I read it. I initially used open coding (Dahlgren, Emmelin, & Winkvist, 2004), meaning that codes were derived from the data material; for example: health issues, discrimination, financial resources, and health insurance. The use of codes allowed me to consider thematically-related data in conjunction. Text that fitted within these codes was shortened by meaning condensation, i.e., removing reluctant words, half sentences, digressions and repetitions, and statements not found to influence the content or the main issues (Kvale & Brinkmann, 2015). During this process the material was reduced to less than one-fourth of the original number of pages. In the following analyses, data that pertained to certain characteristics were identified, and the different codes were replaced with categories. The new categories were more detailed than the original codes, e.g., lack of health insurance, access to care, perspectives on screening, being unaware of the existence of the Romanian cervical cancer screening programme, having no or very few financial recourses, feelings of discrimination from health care professionals, and screening providers stating that Roma are uninterested in cervical cancer screening. The
identification of categories made it possible to examine material that was related or had something in common and separate it from the rest.

Early in the analytical process, we (the research team) became aware of a considerable disagreement that seemed to exist between women in the target age group for the Romanian cervical cancer screening programme and screening providers. Indeed, they differed substantially in how they reported their own, and the other’s engagement with screening and screening participation. We often found that the screening providers understanding of the screening programme and women’s access to the programme were at odds with each other. Therefore, in this part of the analytical process, we drew inspiration from Latour’s (2007) recommendation to learn from the controversies that exist between different actors when trying to understand the social world. This approach is beneficial because the different viewpoints and perspectives are activated, articulated, and amplified, and thereby made visible (Venturini, 2010). We started by searching through the different categories to identify issues of major controversy between screening providers and women in the target screening age group. When looking at the material within this theoretical framework, we found that the controversies surrounding the Romanian cervical cancer screening programme were not only plentiful, they also pertained to fundamental questions related to the programme: who was the target population, did women in Romania have equal access to screening, and what was the outcome if one were to participate in screening? At the end of the analytical process, we ended up with four questions that engendered considerable controversy: 1) does the national screening programme exist?; 2) does the programme apply to Roma women?; 3) do Roma women want to take part?; and 4) does screening change anything?

With this theoretical framework, we tried to understand the data both from the perspective of women in the target population and screening providers.

The results from the analysis of qualitative data made us better equipped to understand participation and non-participation in the Romanian cervical cancer screening programme among Roma women, and was a necessary step to understand what shaped Roma women’s screening attendance. This was then further measured and explored in Paper II.

7.2. Quantitative data analyses – Papers II and III
In Papers II and III, the chi-square test was applied for comparison between two categorical outcomes at baseline. For the continuous variable; age, independent t-tests was used.
7.2.1. Paper II
In Paper II we analysed the association between variables from the questionnaire (exposure) and screening participation (outcome). Data were analysed using logistic regression, reporting odds ratios (ORs) of screening participation and respective 95% confidence intervals (CIs). We selected the following potential confounding variables \textit{a priori}: age (continuous variable), education level (0-4 years, 5-9 years, >9 years), number of sexual partners (none, 1, 2, ≥3 partners, I am not sure, I don’t want to answer), and previous screening attendance (no, yes). In addition to these variables, we included other variables that were statistically significant (p<0.05) in a univariate analysis in a forward stepwise process. We only kept those variables that were statistically significant (p<0.05) in the final multivariate model. These were: ethnicity (non-Roma, Roma), marital status (single, cohabiting, married, divorced/separated, widow), daily activity (student/retired/unemployed, mainly employed, mainly housewife), access to bath facilities (every day, 2-5 times a week, maximum once a week), having ever heard of cervical cancer screening /Pap-smear (no/I’m not sure, yes), knowledge of the screening programme’s existence (no/I’m not sure, yes), needing permission from someone else to undergo screening (yes, no/I’m not sure), wanting to take a screening test this year (no/I’m not sure, yes), time constraints (yes, no/ I’m not sure), believing they would receive free treatment of diagnosed cancer (no/I’m not sure, yes), and area of residence (rural, urban). The goodness of fit of the final multivariate model was checked using the Hosmer and Lemeshow test (Hosmer & Lemeshow, 2000).

The null hypothesis in this study were that there were \textbf{no} associations between screening attendance and ethnicity.

7.2.2. Paper III
In Paper III, we examined the association between primary screening methods and screening results on anxiety and depression scores. The primary screening methods (cytology and hrHPV testing) and screening results \textsuperscript{1}(normal cytology; atypical squamous cells of undetermined significance (ASCUS)/low-grade squamous intraepithelial lesions (LSIL) and HPV-negative; ASCUS/LSIL and HPV-positive; high-grade cytology; hrHPV-negative; hrHPV-positive and normal cytology; hrHPV-positive and high-grade cytology) represented the exposures.

Combined anxiety and depression scores were the outcomes and were categorised as normal (values ≤2), mild (values 3-5), or moderate/severe (values >5). These outcomes were compared between the hrHPV and the cytology screening arm and between women with the seven different screening test results. Analyses were done for all women combined and for women with different screening arm

\textsuperscript{1} Also shown in chapter 2.7.2.1
and screening results as described above. We compared women with mild anxiety and depression scores to those with normal anxiety and depression scores and those with moderate/severe anxiety and depression scores to those with normal anxiety and depression scores.

The association between the two screening arms and anxiety and depression scores; and between specific screening results and anxiety and depression scores, were estimated in two separate multinomial logistic regression models, which were used to report relative risk ratios (RRRs) of anxiety and depression scores with 95% CIs. We adjusted for the potential confounding variables marital status (married/cohabiting, single/divorced/widowed) and place of birth (Norway, all other countries), as these two demographic characteristics were statistically significantly different between women in the two screening arms (Table 1, Paper III), and as we assumed that they also could be risk factors for anxiety and depression scores. We also adjusted for the variables age (34-44, 45-54, ≥55 years) and education level (≤13, >13 years) based on findings from prior studies on the association between these variables and both screening method and psychological distress (Burger et al., 2014; Idestöm, Milsom & Andersson-Ellstrom, 2002; Anhang, Goodman, & Goldie, 2004). The goodness of fit of the two multinomial models was evaluated by testing the goodness of fit in the two corresponding logistic regression models for mild vs normal and moderate/severe vs normal scores of anxiety and depression, using the Hosmer and Lemeshow test (Hosmer & Lemeshow, 2000).

The null hypothesis was that there was no difference between anxiety and depression scores and screening arm or between anxiety and depression scores and screening results.

RRR is a ratio of two relative risks: the relative risk of the exposed divided by the relative risk of the unexposed (Gurierrez, 2005). The relative risk is defined as the probability of, for example, mild anxiety and depression scores divided by the likelihood of normal anxiety and depression scores. The following equation illustrates how RRR is calculated:

\[
\frac{\text{Probability of exposed and mild anxiety and depression}}{\text{Probability of exposed and normal anxiety and depression}} / \frac{\text{Probability of unexposed and mild anxiety and depression}}{\text{Probability of unexposed and normal anxiety and depression}}
\]

### 7.3. Sample size in Papers II and III

Statistical power is the probability that a statistical test correctly rejects the null hypothesis of no difference (Cohen, 1988). This ability increases with the sample size and the strength of the association.
In Paper II, data on cervical cancer screening attenders vs non-attenders were used as estimates for different factors that influence screening participation. With 80% power, a 5% significance level, and using the estimated proportion of the different factors mentioned above, we calculated that we would need 400 participants in each screening arm to be able to detect a 10% difference between attenders and non-attenders.

In Paper III, we assumed that approximately 25% of women with positive cytology would experience some kind of anxiety (Cotton et al., 2015). We calculated that with 80% power and a 5% significance level, we would need 400 participants in the cytology and hrHPV arm, respectively. We (the research team) expected a response rate to the questionnaire of at least 20%. We also estimated that by sending out 2000 questionnaires to women, oversampled with positive tests results in each screening arm, we would be able to detect a 10% increase in perceived anxiety and depression after receiving a positive hrHPV test result, compared with positive cytology.

All tests in both studies were two-sided with a 5% significance level. Statistical analyses were performed using the Stata statistical software package (version 14.2).

7.4. Missing data

Paper II: A total of 29 variables had missing values, ranging from 2 to 47 (Table 6). We handled missing data using a multiple imputation technique (Cummings, 2013). After checking the type of missing data in the dataset, we imputed all missing data based on multiple study variables.

The imputation allowed us to include all women with information on screening attendance, reducing any bias due to missing data. However, our estimate of the association between screening attendance and all variables included in the final multivariate model could still be biased if missing data depended not only in the variable we used to impute missing values, but also on the missing values themselves.
Table 6: Missing data for all variables used in Paper II

<table>
<thead>
<tr>
<th>Variables</th>
<th>Missing</th>
</tr>
</thead>
<tbody>
<tr>
<td>Marital status</td>
<td>4</td>
</tr>
<tr>
<td>What district are you from?</td>
<td>14</td>
</tr>
<tr>
<td>Age</td>
<td>2</td>
</tr>
<tr>
<td>Years of schooling</td>
<td>3</td>
</tr>
<tr>
<td>Do you have health insurance?</td>
<td>8</td>
</tr>
<tr>
<td>How many people do you live together with?</td>
<td>16</td>
</tr>
<tr>
<td>If you live in a house or flat: How many rooms does it have?</td>
<td>14</td>
</tr>
<tr>
<td>Approximately how often do you take a shower or a bath?</td>
<td>17</td>
</tr>
<tr>
<td>Have you ever had sexual intercourse?</td>
<td>24</td>
</tr>
<tr>
<td>How many partners have you had sexual intercourse with?</td>
<td>26</td>
</tr>
<tr>
<td>Use of contraceptive</td>
<td>18</td>
</tr>
<tr>
<td>How many induced abortions you have had?</td>
<td>47</td>
</tr>
<tr>
<td>Do you have a general practitioner?</td>
<td>6</td>
</tr>
<tr>
<td>Do you think that cervical cancer is curable?</td>
<td>36</td>
</tr>
<tr>
<td>Have you ever heard of cervical cancer screening / Pap-smear?</td>
<td>30</td>
</tr>
<tr>
<td>Do you believe there is a national cervical cancer preventing programme in Romania?</td>
<td>35</td>
</tr>
<tr>
<td>Have you ever heard about human papillomavirus, HPV?</td>
<td>34</td>
</tr>
<tr>
<td>Do you think it is embarrassing to take a screening-test?</td>
<td>35</td>
</tr>
<tr>
<td>Do you think it is painful to take a screening-test?</td>
<td>38</td>
</tr>
<tr>
<td>Do you think that to take a screening-test would leads to worries?</td>
<td>37</td>
</tr>
<tr>
<td>Do you think that it is only necessary to take a screening-test if you have symptoms from the womb?</td>
<td>40</td>
</tr>
<tr>
<td>Would you like to take a screening-test this year?</td>
<td>40</td>
</tr>
<tr>
<td>Is it difficult for you to find the time to take a screening-test?</td>
<td>13</td>
</tr>
<tr>
<td>Is it expensive for you to take a screening-test?</td>
<td>17</td>
</tr>
<tr>
<td>Do you think that you would receive free-of-charge treatment if you had cervical cancer?</td>
<td>21</td>
</tr>
<tr>
<td>Do you have faith in the health care system?</td>
<td>13</td>
</tr>
<tr>
<td>Do you care about your health?</td>
<td>12</td>
</tr>
</tbody>
</table>

**Paper III:** Participants who did not answer all four questions in the PHQ-4 were excluded from all analyses. Women with inconclusive cytology and hrHPV test results were also excluded from the final multinominal logistic regression analyses. No missing data imputation technique was used for excluded participants.
8. Findings from the three studies

8.1. Paper I

Controversies about cervical cancer screening: A qualitative study of Roma women’s (non)participation in cervical cancer screening in Romania.

The main aim of Paper I was to understand why Roma women participate so rarely in cervical cancer screening, as previous research had suggested (Băban et al., 2006; Todorova et al., 2009). In order to find answers to this important question, we started with exploratory research to get an awareness of Roma women’s engagement and experiences with health issues, cervical cancer, and cervical cancer screening. While searching for explanations for the low participation rate, we identified some basic disagreements between Roma women and screening providers, including disagreement on the very existence of the Romanian cervical cancer screening programme. In the light of this, we searched for controversies that existed between Roma women and screening providers and health care workers.

Many of the Roma women I interacted with had never heard of any national cervical cancer screening programme that offered screening tests free-of-charge to women aged 25-65 years. Most study participants from Paper I had not only never heard of the Romanian cervical cancer screening programme, they also doubted that screening was offered for free. In their experience, they always had to pay for their health care, either as legal charges or as an under-the-table payment. After being informed about the screening programme’s existence, one woman I met during participant observation said, “There is no such things as a free-of-charge screening programme in Romania.” (From field notes, August 2015). On the other hand, screening providers and health care workers had no doubt about the screening programme’s existence, as the programme was outlined in a national guideline (Ministry of Health, 2015), and there were number of screening test taken every year as part of this programme. In addition, screening providers used much of their time and expertise trying to make more women, including Roma women, participate in the programme. This was the first controversy identified.

The second controversy was about whether the Romanian cervical cancer screening programme was meant to include Roma women. Indeed, there were disagreements surrounding Roma women and whether they were entitled to health care in Romania at all. Many Roma women said that they did not have health insurance, and thus they believed they could not receive any kind of free health care. The screening providers, on the other hand, said that women could simply sign-up for health insurance, even if they were unemployed, and get access to free health care and/or free cervical cancer screening. The Roma women I interacted with had no knowledge of this possibility. Some Roma women also said that they felt stigmatised as dirty, smelly, and lazy by both health care workers and other authorities. Many Roma women also spoke of experiences of discrimination and
rejection in health care settings and reasoned that they did not want to seek help from a system they felt was against them.

The third controversy entailed whether Roma women wanted to take part in cervical cancer screening. Most Roma women I interacted with welcomed a free-of-charge screening programme after being informed of its existence. Screening providers, on the other hand, often said that the Roma population did not seem to understand the benefits of screening. During participant observation, in qualitative interviews, and in focus group discussions, screening providers expressed that Roma women were not “sensible” enough to participate in screening.

Finally, Paper I revealed that Roma women and screening providers disagreed on whether participating in the screening programme would improve women’s health. Part of this was because the Romanian cervical cancer screening programme did not offer free-of-charge follow-up of precancerous lesions. Therefore, Roma women feared that screening participation could result in detection of disease that needed treatment they simply could not afford. Roma women also pointed out that, even if they did get health insurance, there was still an expectation that they should pay money under-the-table. Screening providers and health workers, in turn, indicated that citizens of Romania could simply register themselves as unemployed and thus gain access to health care services.

By discussing the identified controversies, Paper I develop ideas about how to encourage more Roma women to participate in the Romanian cervical cancer screening programme. When Roma women did not participate in screening, it was linked to not believing that the screening programme was meant not to include them, either because screening would not be affordable or due to discriminatory behaviour among providers. The study suggests that a process that builds contact, interaction, and cooperation between the screening programme and its potential Roma participants is warranted to encourage more women to attend. Paper I further suggest that user involvement, i.e., having women as active partners in the planning, implementation, and evaluation of the screening programme, could be a part of this process.
8.2. Paper II
Attendance to cervical cancer screening among Roma and non-Roma women living in North-Western region of Romania

Paper II included 980 Roma and non-Roma women living in the North-Western region of Romania who completed a structured questionnaire, which collected information on participants’ background, working situation, economy and living conditions, sexual relationships and contraception use, number of pregnancies and children, experiences with their general practitioner and gynaecologist, knowledge of cervical cancer and cervical cancer screening, and screening attendance. Women’s participation in cervical cancer screening was quantified and compared between Roma and non-Roma women. The associations between screening attendance and different factors were explored. Although the research questions in Paper II were developed based on findings from Paper I, Paper II had a different aim (Chapter 3).

Before the study started, our hypothesis, based on the existing literature (Băban et al., 2006; Todorova et al., 2009) and information from the Romanian cervical cancer screening programme in Cluj-Napoca, was that Roma women would participate statistically significantly more rarely in cervical cancer screening compared to non-Roma women. Admittedly, we did find a lower participation rate among Roma women than non-Roma women (46% vs 63%, respectively; OR 0.49, 95% CI 0.38-0.64) (Table 1, Paper II). We also found that 35% of both Roma women and non-Roma women reported to have undergone screening only once in their lifetime; 9% of Roma and 14% of non-Roma, reported to have undergone screening twice (OR 0.68, 95% CI 0.44-1.04), and 3% of Roma and 9% of non-Roma, reported to have undergone screening more than five times (OR 0.38, 95% CI 0.21-0.69) (Supplementary Table 1, Paper II). However, logistic regression analyses showed that ethnicity was not associated with screening attendance (OR 0.89, 95% CI 0.58-1.35) (Table 3, Paper II). Thus, other factors and their associations with screening attendance, non-attendance were examined.

Instead of ethnicity, Paper II revealed that screening participation was associated with having three or more sexual partners (OR 5.99, 95% CI 1.71 -21.04), having ever heard of cervical cancer screening (OR 5.90, 95% CI 3.76-9.27), urban area of residence (OR 3.12, 95% CI 2.21-4.39), being able to bathe daily (OR 2.53, 95% CI 1.39-4.62), not having time constraints (OR 2.20, 95% CI 1.47-3.30), being married (OR 2.07, 95% CI 1.17-3.65), being able to decide for one’s self whether to take attend screening (OR 1.70, 95% CI 1.14-2.53)\(^1\), believing the existence of the Romanian cervical cancer screening programme (OR 1.55, 95% CI 1.10-2.18), and finally, thinking that one would receive

\(^1\) Typographic error discovered, in Table 3, Paper II. The 95% CI was stated as 4.14-2.53 this should be 95% CI 1.14-2.53. An Errata is sent to the Journal.
treatment free-of-charge if diagnosed with cervical cancer (OR 1.52, 95% CI 1.07-2.16) (Table 3, Paper II). All these factors were associated with higher odds of previous screening attendance. These findings help to close a knowledge gap regarding contextual circumstances associated with screening attendance among Roma and non-Roma women living in the North-Western region of Romania.

Paper II also contributed new knowledge, as it included information on barriers to screening from 463 women who had never been screened. These barriers were that the women did not know that they could take a screening test (43%), that women lacked the money to participate in screening (30%), that women were afraid of the screening results (13%), that they lacked time (11%), and that they had to travel too far to see a doctor (6%) (Figure 5). These findings corresponded well with many of the findings from Paper I.

The knowledge related to travel distances from women’s homes to their gynaecologists revealed in the quantitative Romania study was also valuable. In an effort to understand the low participation rate, we compared women living in rural and urban areas (Table 7). We found that 22% of women living in rural areas and 51% living in urban areas travelled for up to 30 minutes to see their gynaecologist; 47% and 30% travelled for between 30 minutes and 1 hour; 26% and 18% travelled between 1 and 2 hours; and 5% and 1% had to travel between 2 and 4 hours to visit their gynaecologist (p>0.001) (data not shown in Paper II).

When asking the study women about their knowledge of cervical cancer, we found that 67% of Roma women and 92% of non-Roma women had knowledge about cervical cancer and cytology (p<0.001); 37% and 55% believed that cervical cancer was curable (p<0.001); and finally, 30% and 65% (p<0.001) had ever heard of HPV. We also asked women if they believed that a Romanian cervical cancer screening programme existed and found that 62% of Roma and 36% of non-Roma (p>0.001) did not believe that it did (data not shown in Paper II). When asked about their experiences with information delivery the last time they visited their general practitioner (Table 8), 81% of Roma women and 64% of non-Roma women reported that their doctors did not talk to them about cervical cancer screening (>0.001); 87% and 81% reported that their general practitioner did not offer them a referral to a gynaecologist for screening (p=0.014); 95% and 93% reported that their general practitioner did not offer them a screening test at their last visit (p=0.107); and 93% and 90% (p=0.059) reported that their general practitioner did not offer them a flyer (Table 8, also shown in Supplementary Table 1; Paper II).
Figure 5: Barriers to screening participation among 463 never attending Roma and non-Roma women living in the North-Western region of Romania in 2016-2017.

Table 7: Women’s travel time to their gynaecologist

<table>
<thead>
<tr>
<th>Travel Time</th>
<th>Women living in rural areas</th>
<th>Women living in urban areas</th>
<th>p-value</th>
</tr>
</thead>
<tbody>
<tr>
<td>&gt;30 minutes</td>
<td>22%</td>
<td>51%</td>
<td>p&gt;0.001</td>
</tr>
<tr>
<td>30 minutes - 1 hour</td>
<td>47%</td>
<td>30%</td>
<td></td>
</tr>
<tr>
<td>1-2 hours</td>
<td>26%</td>
<td>18%</td>
<td></td>
</tr>
<tr>
<td>2-4 hours</td>
<td>5%</td>
<td>1%</td>
<td></td>
</tr>
</tbody>
</table>
### Table 8: Women’s experiences when last visiting their general practitioner

<table>
<thead>
<tr>
<th>The last time you visited your general practitioner, did anyone at the clinic?</th>
<th>Roma n=588 / (%)</th>
<th>non-Roma n=392 / (%)</th>
<th>p-value</th>
</tr>
</thead>
<tbody>
<tr>
<td>Talk to you about cervical cancer screening?</td>
<td>Yes 112 / (19%)</td>
<td>140 / (36%)</td>
<td>&gt;0.001</td>
</tr>
<tr>
<td></td>
<td>No 476 / (81%)</td>
<td>252 / (64%)</td>
<td></td>
</tr>
<tr>
<td>Offer you a referral to a gynaecologist?</td>
<td>Yes 77 / (13%)</td>
<td>74 / (19%)</td>
<td>0.014</td>
</tr>
<tr>
<td></td>
<td>No 511 / (87%)</td>
<td>318 / (81%)</td>
<td></td>
</tr>
<tr>
<td>Offer you a screening test?</td>
<td>Yes 29 / (5%)</td>
<td>29 / (7%)</td>
<td>0.107</td>
</tr>
<tr>
<td></td>
<td>No 599 / (95%)</td>
<td>363 / (93%)</td>
<td></td>
</tr>
<tr>
<td>Offer you a flyer about cervical cancer screening?</td>
<td>Yes 39 / (7%)</td>
<td>39 / (10%)</td>
<td>0.059</td>
</tr>
<tr>
<td></td>
<td>No 549 / (93%)</td>
<td>353 / (90%)</td>
<td></td>
</tr>
</tbody>
</table>

Paper II also revealed that women reported perceived discriminatory behaviour from their general practitioners and/or gynaecologists. As much as 10% and 8% of Roma women, compared to 5% and 6% of non-Roma women, reported that their gynaecologist and general practitioner, respectively, had hinted that they were dishonest. Nine percent and 8% of Roma, compared to 8% and 6% of non-Roma, reported that their gynaecologist and general practitioner, respectively, had called them bad names. Eleven percent and 8% of Roma women, compared to 2% and 3% of non-Roma women, reported that their gynaecologist and general practitioner, respectively, had hinted that they were stupid. Finally, 9% and 6% of Roma, compared to 2% and 2% of non-Roma, reported that their gynaecologist and general practitioner, respectively, had hinted that they were dirty or smelly at their last health care visit (Table 2, Paper II). These findings matched those from Paper I, in which many of the Roma women I interacted with described experiences of a discriminatory nature in health care settings.

In Paper II, we concluded that information about the existence of the Romanian cervical cancer screening programme and its rationale did not seem to sufficiently reach women in the target population. We argue that user involvement that aims to build contact, interaction, and cooperation between the screening programme and its potential participants is warranted in order to increase participation in the Romanian cervical cancer screening programme.
8.3. Paper III
Psychological effect of cervical cancer screening when changing primary screening method from cytology to hrHPV testing

In Paper III, all 1008 women who took part in the study had previously attended the NCCSP. Paper III attempted to learn more about women’s experiences of anxiety and depression when the primary screening method in the NCCSP was changed from cytology to hrHPV testing. The study also tried to determine whether the hrHPV testing had negative consequences on screening participation due to mental distress. The screening programme in Norway is basically well functioning, and participation is relatively high (Cancer Registry of Norway, 2017); it was therefore considered important to know if a change in primary screening method would harm this successful programme. We found no differences in anxiety and depression scores among women in the hrHPV and cytology screening arm, nor among women with different screening results.

As much as 73% of all women in both the hrHPV and cytology screening arm had normal anxiety and depression scores. The remaining 27% had either mild (22% and 21% in the cytology and the hrHPV screening arms, respectively) or moderate/severe (5 and 6% in the cytology and the hrHPV screening arms, respectively) anxiety and depression scores (Figure 3A, Paper III). Few women had moderate/severe anxiety and depression scores. Analysis of variance revealed that the only women with an anxiety and depression score other than normal were those in the hrHPV arm who were hrHPV-positive and had high-grade cytology. These women had a mean anxiety and depression score of 2.1, indicating mild anxiety and depression (Table 9). There were only 84 women who were both hrHPV-positive and had high-grade cytology (Figure 2, Paper III), thus the analysis of variance finding was not statistically significantly different from that found among women with other screening results (p=0.575) (Table 9). All women with other screening results had mean values below 2, meaning that they had normal anxiety and depression scores (data not shown in Paper III).
Table 9: Mean anxiety and depression scores among women with different screening results taking part in the pilot project of hrHPV testing in primary screening

<table>
<thead>
<tr>
<th>Screening results</th>
<th>One-way analysis of variance, Mean (standard deviation)</th>
<th>p-value difference between groups</th>
</tr>
</thead>
<tbody>
<tr>
<td>Cytology normal</td>
<td>1.8 (2.4)</td>
<td>0.575</td>
</tr>
<tr>
<td>ASCUS/LSIL &amp; hrHPV-negative</td>
<td>1.7 (2.0)</td>
<td></td>
</tr>
<tr>
<td>ASCUS/LSIL &amp; hrHPV-positive</td>
<td>1.6 (1.8)</td>
<td></td>
</tr>
<tr>
<td>High-grade cytology</td>
<td>1.7 (1.9)</td>
<td></td>
</tr>
<tr>
<td>hrHPV-negative</td>
<td>1.4 (2.1)</td>
<td></td>
</tr>
<tr>
<td>hrHPV-positive/cytology normal</td>
<td>1.7 (1.9)</td>
<td></td>
</tr>
<tr>
<td>hrHPV-positive &amp; high-grade cytology</td>
<td>2.1 (2.6)</td>
<td></td>
</tr>
</tbody>
</table>

Normal anxiety and depression scores: 0-2, mild anxiety and depression scores: 2-5, moderate/severe anxiety and depression scores: 5-12.

We also compared women with correct knowledge about the primary screening method used (37%) at their last screening visit and those with either incorrect or no knowledge about the method used (63%) (Table 1, Paper III) and compared their anxiety and depression scores. This revealed that knowing the primary screening method did not play a role in anxiety and depression scores (p=0.887). Twenty-two percent of women who had this knowledge and 21% of those who did not, had mild anxiety and depression scores, and 5% of women with and without this knowledge had moderate/severe anxiety and depression scores (p=0.908) (data not shown in Paper III).

When we compared women with and without knowledge of their last screening results, we found that 74% of the women with and 75% of women without this knowledge had normal anxiety and depression scores, 21% and 20% had mild anxiety and depression scores, and 5% and 6% had moderate/severe anxiety and depression scores (p=0.877) (data not shown in Paper III).

The scores of women who answered the questionnaire 4 months to 2 years after receiving their last screening results were considered long-term anxiety and depression scores. We found no association between time since receiving last screening results and long-term scores of anxiety and depression (Supplementary table 1, Paper III).

In the final multinomial logistic regression models, screening arms did not affect anxiety and depression scores. This is shown in Table 2 in Paper III, were no differences in univariate and multivariate models respectively is revealed, between screening arms and women with mild vs. normal anxiety and depression scores [RRR 0.95, 95% CI 0.70–1.30; RRR 0.96, 95% CI 0.70–1.31] and between screening arms and women with moderate/ severe vs. normal anxiety and depression [RRR 1.11, 95% CI 0.64–1.94; RRR 1.14, 95% CI 0.65–2.02]. Neither did we find and differences in mild vs.
normal anxiety and depression scores and moderate/ severe vs. normal anxiety and depression and the seven different screening test results (as described in Chapter 2.7.2) in univariate nor multivariate models respectively (Table 2, Paper III).

However, we did find that women aged 35-44 years were more likely of having mild vs normal anxiety and depression scores as compared to older women (RRR 2.07 95% CI 1.37-3.12). Women who were single/divorced/widowed were also more likely to have moderate/severe vs normal anxiety and depression scores as compared to married women (RRR 2.06 95% CI 1.06-4.01). Finally, women with less than 13 years of education were more likely to have mild vs normal anxiety and depression scores as compared to women with more than 14 years of education (RRR 1.42 95% CI 1.02-1.97) (Table 10) (data not shown in Paper III).
Table 10: Multinomial logistic regression for anxiety and depression scores among women with different screening results

<table>
<thead>
<tr>
<th>Anxiety and depression scores:</th>
<th>Normal</th>
<th>Mild</th>
<th>Moderate/severe</th>
<th>RRR</th>
<th>95% CI</th>
<th>RRR</th>
<th>95% CI</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>n=716</td>
<td>n=206</td>
<td>n=53</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Age</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>55 years and older (n=343)</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>45-54 years (n=334)</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>35-44 years (n=298)</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Screening results</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Cytology normal (n=232)</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>ASC-US/HPV- (n=160)</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>ASC-US/HPV+ (n=53)</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Cytology High grade (n=51)</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>HPV- (n=222)</td>
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<td>HPV+/High grade (n=80)</td>
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<td>Single/divorced/widow(n=168)</td>
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<td>More than 14 years (n=568)</td>
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<td>Less than 13 years (n=402)</td>
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9. Methodological considerations

As the selection of a study method can affect the study’s results, the methods used in the present thesis are addressed before the results are interpreted. Methodological considerations are discussed in the order in which they were performed.

9.1. The trustworthiness of the qualitative study (Paper I)

Lincoln and Guba (1985) refer to trustworthiness and discuss the methods used when a study’s results are evaluated. Trustworthiness refers to objectivity, i.e., to what degree the study’s results reflect the characteristics of the study participants instead of those of the researcher’s biases (Polit & Beck, 2018). Polit and Beck (2018) lean on Lincoln and Guba (1985) and set four main criteria to achieve trustworthiness of qualitative data: credibility, dependability, conformability, and transferability (Table 11).

Table 11: Assessment of proving trustworthiness in qualitative data. Based on Polit and Beck’s (2018) four criteria

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<td><strong>Credibility</strong></td>
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<td>• Inquiry audit</td>
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<td><strong>Conformability</strong></td>
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<td><strong>Transferability</strong></td>
<td>• Generalizability</td>
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9.1.1. Credibility

Credibility is considered the overriding criterion to establish trustworthiness (Lincoln & Guba, 1985; Polit & Beck, 2018; Whittemore, Chase, & Lynn Mandle, 2001) and refers to “confidence in the truth of the data and interpretation of them.” (Polit & Beck, 2018, p. 430). Credibility consists of two aspects: first, that the study is carried out in a way that enhances the believability of the findings; and second, that the study takes steps to demonstrate credibility to the readers and users of its findings (Polit and Beck, 2018). There are many ways in which credibility in qualitative research may be achieved (Table 11, first column).

The first step to achieving credibility is ‘prolonged engagement’, meaning that the researcher took enough time to collect data and to build trust with study participants. This should be done in order to achieve a thorough understanding of the topic being investigated. In the qualitative Romanian study, I performed 125 days of participant observation, as well as qualitative interviews and focus group discussions. I also spent time in Cluj County during the preparatory phase, the write-up phase, and while collecting data on and preparing for the research for Paper II. During all these periods, I spent time with and among Roma and non-Roma women and men, screening providers, and policy makers. This prolonged engagement contributed to my learning and understanding, and one can argue that 4 months is a rather long time to live with and among study participants, giving any researcher the opportunity to gather thorough data. I also ended up with 600 pages of data material, which is undoubtedly a lot. However, some researchers have spent as much as 15 months (Moen, Aggleton, Leshabari, & Middelthon, 2012) and even years (Fangen, 2010) doing participant observation with and among study participants to collect as many aspects and views of the phenomena under study as possible. That said, there have also been studies with shorter periods of participant observation than I did for study one; in one study from Swaziland (Malambo & Erikson, 2018), participant observation lasted for 3 months. What is important in participant observation is that one invests the time to try and observe as many different perspectives and views on the phenomena under study as possible (Moen & Middelthon, 2015). Since social learning requires that one develop familiarity and insight into the complexities of a sociocultural system, it usually demands a considerable amount of time (Moen & Middelthon, 2015). The 4 months of fieldwork I did in Romania were limited by the time I had available in my PhD project. If more time had been available for fieldwork, obviously more information of relevance could have been learned to understand the health conditions of the Roma population and their access to and use of preventive health services like cervical cancer screening. At the same time, the research team’s impression was that I ended up with rich, nuanced material about many aspects that played a role in how Roma women perceived, thought, and felt about cervical cancer screening. I also got a nuanced insight into how health care workers saw these
phenomena, and I was continuously in contact with individuals who had a health care background. At the same time, the data collection among health care workers was not as extensive as it was among Roma women.

Another aspect of credibility is **persistent observation**, meaning that it is important to focus in depth on different characteristics or aspects of a situation or conversation that are relevant to the phenomena being studied (Polit & Beck 2018). In Paper I, I considered it important to have discussions and engage myself in aspects of life other than those pertaining to the phenomena under study, especially since this was an exploratory study. However, even if I did explore broadly, I always tried, along with my supervisors and colleagues in the field, to reminded myself of the aim of the study, which was to understand participation in the Romanian cervical cancer screening programme from the perspective of Roma women and screening providers. This motivated most of the conversations and situations in which I was involved. For example, when we introduced mobile units in some Roma communities, I used the opportunity to talk to women about their present and past experiences related to screening and screening participation. At the end of each fieldwork day, all of my experiences and observations were placed in the context of the phenomena under study when I transformed my scratch notes into field notes.

**Triangulation** is also used to enhance credibility in a qualitative study and aims to overcome bias that may occur in single-method studies (Polit & Beck 2018). Polit and Beck (1985) identified seven types of triangulations (Table 11) that can be used to strengthen the truth of findings from a qualitative study. **Data triangulation** refers to time-, space-, and person-triangulation and involves multiple data sources. **Time triangulation** refers to the collection of data at different times of the day or year, with the aim to develop knowledge on the phenomena being studies across time. **Space- and person-triangulations** refers to investigating the phenomena at different sites and among different groups and collectives receptively, aiming to provide multiple perspectives. In study one, I used many different sites and stayed in different Roma communities in both rural and urban areas. I also spent time with non-Roma men and women at work, during holidays, at workshops, and when socialising. This allowed for time-, person-, and space- triangulation, as I was present at different times, at different places, and among different people in the communities where I did fieldwork. However, it must be considered that I did most of the fieldwork with and among Roma women in one urban Roma community. The study might have been strengthened if I had done participant observation in other communities with other persons in Romania, or if I had done participant observation in other health care settings. The choice not to do this was related to this PhD project, i.e., a single project that used complementary methods (qualitative and quantitative) within a timeframe of 3 years. Nevertheless, the study participants in Paper I represented quite a diverse group of ages,
socioeconomic statuses, living areas, and ethnicities. Study participants also varied in their engagement with health, cervical cancer, and screening. This allowed a rich and different understanding of the topic under study and may strengthen the plausibility of the data analyses.

**Investigator triangulation** refers to the use of more than one researcher to analyse and interpret the data. In Paper I, one of my supervisors was very involved in the data analysis. Often, I would present possible or early finding to him and show him certain parts of the data that I felt were interesting or incomplete. I also presented data analysis and early findings to my colleagues at IOCN. Through collaboration, a complementary blend of skills and expertise was brought to the surface and reduced the chances for a biased interpretation of the data (Polit & Beck, 2018).

**Theory triangulation** is another way to achieve credibility. It means that complementary hypotheses, and even theories, are used when the data is being analysed. With theory triangulation, the researcher can avoid developing premature concepts, as the flexible design makes it possible to redirect the position of the study. When we first started to analyse the data collected in Paper I, we started to search for barriers that could act as explanation for the low screening participation rate in Romania’s screening programme. When we tried to look at the material in other ways we identified the many different views acting between the screening providers and the screening takers. In a way, the four controversies identified in Paper I can be explained by theory triangulation, as they were revealed following the first search for barriers to screening participation. Without the theory triangulation, we might have ended up identifying the same barriers as so many other studies before ours (i.e., Anttila et al., 2010a; Bennett et al., 2018).

**Method triangulation** was fulfilled in Paper I by the combination of the three qualitative methods used. The data material collected was of different quality to me, as my familiarisation with the material, and thereby my knowledge of its content, varied. This was because I made scratch notes myself and translated them into field notes at the end of every fieldwork day. This made me very familiar with this data, and also trigged memories of what I had experienced (Moen & Middelthon, 2015). On the other hand, qualitative interviews and focus group discussions were mostly performed by the interpreter in the Romanian language, with me as an observer, and this data was thus not equally familiar to me as the field notes came to be. The use of the three different qualitative methods to study the same phenomena was a definite advantage, as uncertainties and issues of interest discovered by one method could be further investigated with one or both of the complementary methods. This was valuable when answering research questions and in order to reinforce the findings (Kvale & Brinkmann, 2015).
Member checking is another validation criterion and was done face to face with the study participants from Paper I, as presented in the emerging data and interpretations. This gave participants the opportunity to give feedback and comment on the findings and whether they made sense to them. However, when doing member checking, it is important to be aware that study participants might confirm a possible phenomenon based on a belief that the researchers are wiser than they are. I kept this in mind when I presented the four controversies to some study participants and they recognised the main content and/or gave nuanced considerations. The additional information given by some was considered to strengthen the trustworthiness of the presented controversies. The fact that my field observation included several discussions with study participants, and that qualitative interviews were performed with the same people at several occasions, ensured that the findings were open to revision and clarification by the study participants. This is another technique that can establish the credibility of a qualitative study (Lincoln & Guba, 1985; Polit & Beck, 2018).

Yet another credibility aspect is researcher credibility, where the researcher him or herself is being evaluated (Polit & Beck 2018). In qualitative research, the researchers are the data collection instruments and are also responsible for the analytical process, albeit with input and contributions from the study participants. Because of this, the researcher needs to address his or her own qualifications and experiences, to determine how he or she may have influenced the research process. Reflexivity is a process in which the researcher has to understand his or her own position, and how it may influence the research (Berger, 2015), and it is one of the key strategies by which a researcher can address his or her qualifications and experiences. Because researchers are active instruments in the qualitative research process, especially in participant observation (Glesne, 1999), they risk interpreting the data based on personal experiences, professional experiences, and political beliefs. Another risk is that the researcher might understand the research process based on his or her own proprietary prejudices or already acquired knowledge. To avoid this, researchers must reflect on their own status quo and on themselves in order to minimise bias, and they should report any personal and professional information that might have affected the data collection or the analytical process so that the reader can assess the study’s quality. I have done this and explain it in detail (Chapter 6).

9.1.2. Dependability and conformability
According to Polit and Beck (2018), dependability and conformability are the second and third steps to attaining trustworthiness in qualitative research. Dependability means that the evidence is consistent and stable over time and conditions (Lincoln & Guba, 1985), whereas conformability refers to the objectivity and/or the neutrality of the data and to the congruence of the data’s accuracy,
relevance, and meaning between two or more independent researchers. In order to achieve dependability, Polit and Beck (2018) recommend that researchers undertake a stepwise replication. For example, two research teams are presented with the same dataset, but the interpretation and analyses are done separately before they are compared. In order to achieve dependability, Polit and Beck (2018) recommend performing an inquiry audit, a technique where an external reviewer scrutinises the dataset and other relevant reports and documents. Inquiry audits can also be used to prove the conformability of the data (Polit & Beck 2018), but for this, an audit trail needs to be performed to prove congruence between researchers. Although it would have strengthened the trustworthiness of the results, this was not done in Paper I due to a lack of resources and time. Nevertheless, in the absence of these measures to achieve trustworthiness, the dataset was discussed at repeated occasions within the research team in an effort to agree on its interpretation.

9.1.3. Transferability
The trustworthiness of a qualitative study must also consider whether the findings are transferable beyond the context in which the study was conducted, and whether the study’s findings are of any relevance (Polit & Beck, 2018). This requires that the researcher provide a thorough description of the research setting and context, and of the interpretation of the data, so that the reader can evaluate the applicability of the data to other contexts. The knowledge gained in study I could in fact travel to other context were screening and screening participation among minority women is on the agenda (Moen & Middelthon, 2015). Indeed, the insight gained in study I can form part of the repertoire of phenomena the screening providers at IOCN consider in encounters with Roma women and the Romanian cervical cancer screening programme. The controversies revealed can as a result be addressed and amended. By including user involvement and patient-centred care, as suggested in Paper I, women and screening providers can create a joint measure to make the Romanian cervical cancer screening programme more successful in its target population. The findings might also offer some valuable knowledge that will increase participation in cervical cancer screening by Roma women in other countries.

9.2. Validity and reliability of the quantitative studies – Papers II and III
In epidemiological studies, validity and reliability are essential. Validity indicates the precision and accuracy of all parts of the research process and whether the method used really measures what it purports to measure (Kelsey & Bernstein, 1996; Rothman, 2012). Validity is categorised into internal and external validities. Internal validity is how accurately the measures obtained from the research actually quantify what it was designed to measure (Rothman, Greenland, & Lash, 2012b), e.g., when asking how many times a women has undergone cervical cancer screening, the correct number is
measured. The internal validity of a questionnaire can be examined by comparing the obtained measurement with a reference instrument. If the two measures obtain the same results, the internal validity of the questionnaire is said to be good (Rothman et al., 2012b). When validating a questionnaire, it is crucial that the two methods used to measure the outcome/exposure do not have the same measurement errors (Kirkwood & Sterne, 2006).

External validity is defined as generalisability (Rothman et al., 2012b), i.e., is whether it is possible to generalise the results of the study beyond the study population to other populations or settings (Polit & Beck, 2018; Rothman et al., 2012b). External validity is dependent on the internal validity (Grimes & Schulz, 2002).

Reliability is related to whether the same results would have been obtained if the study was to be repeated. Reliability is said to be high if a replication study produces similar results (Rothman et al., 2012b). The reliability of a measurement instrument is said to be high if, for instance, a person’s height was found to be the same with the use of two different instruments, or if a questionnaire produces the same results when repeated. Reliability pertains to scores and not people. The reliability related to a questionnaire measuring scores of clinical symptoms such as anxiety and depression (as in Paper III) would be high if it showed very consistent scores over time (Bolarinwa, 2015).

9.2.1. Bias

Bias is defined as systematic errors (Rothman, 2012). It is important to address different biases when evaluating the validity of a study. Bias may threaten or even undermine the validity of the study by skewing the results. There are three main types of biases: selection bias, information bias and confounding (Grimes & Schulz, 2002).

Selection bias can occur if the study sample is not representative of the target population. If selection bias is present in a study, it may create a systematic difference in the characteristics between study participants and non-study participants or between cases and controls. In order for selection bias to happen, the differences in characteristics have to be related to the exposure and/or the outcome (Grimes & Schulz, 2002).

Information bias can be due to measurement error or the incorrect registration of data (Grimes & Schulz, 2002; Rothman, 2012). This may happen if there is a systematic difference in the method used to collect exposure information between individuals with and without the outcome of interest (Grimes and Schulz 2002). For instance, if information is gathered in a screening clinic for cases, and it is gathered by telephone for controls. If data is registered incorrectly, it may cause systematic differences between the groups studied (Grimes & Schulz, 2002; Rothman, 2012).
Confounding is a systematic error and is defined as a confusion of effects (Rothman, 2012). Confounding may appear when variables that may affect the outcome are not equally distributed between the groups the study is comparing. The outcome can, as a result, be confounded with the effect of the variables (Kelsey & Bernstein, 1996). Confounding may occur if a true association between an exposure and an outcome is hidden by other variables associated with both the exposure and the outcome. Confounding may disturb the validity of the study’s results (Rothman, 2012). Confounding can be handled by measuring the cofounders and adjusting for the confounding variables in statistical models. Confounding can also be handled by pairwise matching on a specific factor, stratification by levels of confounding factors, or by restricting the analyses (Rothman, 2012).

When and if information on the confounding variable is not available, if the information on the confounding variable is of poor quality, or if modelling does not appropriately handle the confounding effect, then residual confounding may still occur (Grimes & Schulz, 2002; Rothman, 2012). For instance, residual confounding may be present in a study if the measurement of a confounder (e.g., a questionnaire) is of poor quality.

9.3. Discussion on the validity of Papers II and III

In cross-sectional studies, information on the exposure and the outcome are usually collected at the same point in time. Such studies are suitable to calculate the occurrence, or prevalence, of a state (Rothman, 2012). Cross-sectional studies are economical, easy to conduct, and are useful when the exposures are fixed characteristics such as age, marital status, and ethnicity. Data collected from a cross-sectional study can, for example, explore the health care needs of a population.

To understand the causes of a disease, it is important to know if the exposure precedes or follows the outcome (Rothman, 2012). Cross-sectional studies cannot prove causation, because they have no direct information on temporality.

9.3.1. Paper II

In Paper II, the initial exposures were different factors associated with screening attendance, and the outcome was attendance/non-attendance in the Romanian cervical cancer screening programme. Previous screening non-attenders (n=463) were used as a control group to screening attenders (n=517). The aim was to compare screening attenders and non-attenders in Romania, and these groups were not randomly created.

Selection bias: could be present in Paper II if individuals who had positive screening experiences were more likely to participate in our study, i.e., to complete the questionnaire (Rothman et al., 2012b) compared to women with previous negative screening experiences or women lacking screening
experiences. If this were true, it could affect the study’s outcome; women’s likelihood to attend in screening. If women with positive screening experiences were oversampled in our study it could also result in a higher participation rate than reality.

Generalisability: Less representable participant could also decrease the external validity of the study, threatening its generalisability. However, the study had a relatively large sample size (n=980), including different ethnic groups living in Romania, which should increase the overall generalisability of the study’s results.

Information bias: could be present in Paper II if women with positive screening experiences answered in favour of screening. Information bias cold also be present if the questions in the questionnaire were of poor quality. The fact that we did not use a validated questionnaire is a potential weakness of Paper II, as some questions might have been leading, causing information bias among study participants. The questionnaire study was not replicated, thus there is a lack of knowledge related to the reliability of the study results. However, this choice was based on the knowledge obtained from Paper I, which revealed low levels of literacy and limited screening experience among Roma women. We considered that the validated questionnaires used in other settings to assess the likelihood of screening attendance would not capture circumstantial factors associated with screening attendance in our target population. However, we carefully designed the questionnaire based on the results of Paper I, and we performed three pilot questionnaire meetings, where we tested different versions of the questionnaire. These meetings were followed by discussions among the participants, in which each question from the questionnaire, as well as the logical order of the questions, was evaluated in detail. Thus, we believe that the final questionnaire was clear enough for our target women to understand and answer, and that the questions were culturally and linguistically well-adapted. For example, it became clear in the pilot questionnaire meetings that women had difficulties distinguishing between words such as ‘little’ and ‘quite’ and in placing their answers on a scale. We therefore changed the response options to ‘yes’, ‘no’, and ‘I don’t know’. With these three pilot questionnaire meetings, we also explored if Roma were offended by questions related to discrimination, personal hygiene habits, number of sexual partners, and possible induced abortions, which was not the case. This was important to investigate, as it could have resulted in information bias, and in particular, social desirability bias (Rothman, Greenland, & Lash, 2012a). The discussions that followed each pilot questionnaire meeting were also meant to increase the relevance of the questionnaire, and were used to thoroughly discuss the participant’s experiences when completing the questionnaire. In short, the consensus in the three pilot questionnaire meetings was that women did not feel offended by any of the questions, but said they were glad – and even honoured – that
their voices were being heard. The questionnaire was changed according to the feedback the research team received from these women.

Confounding: We attempted to measure and adjust for all confounding variables in Paper II by this general approach: first we defined confounders \textit{a priori}, meaning that we used the literature to identify confounders that were both connected with the exposure and were risk factors for the outcome (attendance/non-attendance), while not being a result of the exposure or the outcome (Rothman, 2012). There were a number of variables whose status as confounders was uncertain, as we did not know their relationship to the outcome (attendance/non-attendance). These were variables like number of induced abortions, health insurance status, having a general practitioner who was registered with the Romanian cervical cancer screening programme, and ever having had sexual intercourse. We therefore performed a stepwise logistic regression analysis to identify the risk factor for the outcome, and adjusted for these variables.

The goal of Paper II was to quantify the findings from Paper I as well as quantify the participation rate to the cervical cancer screening programme. The questionnaire used in Paper II included 69 questions. Long questionnaires can decrease the quality of the data recorded, as it might be difficult for study participants to complete (Rolstad, Adler, & Rydén, 2011). However, during the pilot questionnaire meetings, participants did not consider the number of questions or the questionnaire length to be problematic. On the contrary, they expressed gratitude that we were taking them seriously, and that they had the chance to speak out. However, because of the questionnaire’s length, we cannot rule out that questions towards the end of the questionnaire may have less accurate responses, as the participants may have been too tired to answer correctly (Rolstad et al., 2011).

9.3.2. Paper III

Paper III included a random selection of 1008 women who had previously attended the NCCSP. In this study, we compared the long-term anxiety and depression scores of women who underwent primary screening with cytology and those who underwent primary screening with hrHPV testing. We also compared anxiety and depression scores between women with different screening results. Anxiety and depression were measured between 4 months up to 2 years after women were informed about their last screening results.

Selection bias: women taking part in the pilot project of hrHPV testing in primary screening in the NCCSP were randomly selected based on their date of birth. From this cohort, we randomly selected women from the cytology and hrHPV screening arms, and oversampled women with positive screening results at their last screening visit. However, the response rate was only 50%, and although
we did not explain the exact hypothesis to the participants, we cannot exclude the possibility that the 1008 women who chose to answer the study questionnaire may differ from non-responders. It is possible that study participants differed from non-study participants in terms of lifestyle, education level, anxiety and depression, knowledge related to screening and its rationale, and previous experiences with and participation in cervical cancer screening. Another study has shown that individuals with mental distress are less likely to respond to psychological questionnaires (Lundberg, Damstrom Thakker, Hallstrom, & Forsell, 2005). If this were true in our study, study participants might have had lower anxiety and depression scores than non-responders. However, it is not unlikely that non-responders in the two screening arms (hrHPV and cytology) differed, as knowledge related to HPV was considered to be low among women in the counties where the pilot project was carried out (Nilsen, Aasland, & Klouman, 2017). Neither was there any media interest related to the pilot project of hrHPV testing in primary screening when the research for Paper III started.

Intern validity: Although we think the participants may have been a select population, this should not have threatened the internal validity of the study due to the randomisation to the two screening arms. Further, the lifetime occurrence of anxiety and depression among study participants was similar to that found in the general female population of Norway (Reneflot et al., 2018).

Information bias: We designed the questionnaire used in the study to include questions on experiences with receiving different kinds of letters from the CRN, knowledge related to cervical cancer and HPV, last screening results, and the type of screening method used at last screening attendance, as well as the validated PHQ-4 scale on symptoms of anxiety and depression (Kroenke et al., 2009; Löwe et al., 2010). The PHQ-4 scale is an instrument used for measuring anxiety and depression among persons in the general population (Kroenke et al., 2009; Löwe et al., 2010) and is not specifically validated for measuring anxiety and depression related to screening. Women answered the questionnaire up to 2 years after receiving their last screening results, and any anxiety and depression they might have felt closer to their screening participation could have faded by the time they answered the questionnaire. This could be a limitation of the study. We did not, however, find any statistically significant influence on time as a factor, which reduces the chances that women were reporting their experiences wrongly. Nevertheless, any short-term anxiety and depression women might have felt closer in time to screening participation could have been forgotten when they answered the questionnaire. Thus, the answers we collected are unlikely to differ between screening arms, and thereby represent no threat of information bias.

We did not find any significant association between the exposure of interest and outcomes in the study. However, we cannot entirely rule out that the lack of statistically significant associations
between screening arms or screening results and anxiety and depression scores may be due to measurement error. Also, we had limited power for subgroup analyses, as some screening result groups involved a low number of women. Reassuringly, our results were very consistent across various sensitivity analyses, such as among subgroups of screening results.
10. Discussion of main results and further directions

10.1. Romania

10.1.1. Cervical cancer screening is wanted
As we have seen earlier, the participation rate in the Romanian cervical cancer screening programme is low, especially among minority Roma women. Among explanations offered by health care workers and screening providers were that Roma women do not take good care of themselves and that they are not “sensible enough” to understand why they should participate in screening. "They don’t care about their own health" and "They don’t understand what’s in their best interest." was the consensus in a focus group discussion performed with health care workers and screening providers as part of Paper I. However, these explanations were in conflict with reflections Roma women shared in qualitative interviews, as they expressed that if the programme really was free and was meant to include them, then they wanted to take part. Let me mention that there was also ongoing activism among Roma women to support screening attendance. One of the Roma interviewees shared how she had decided to promote screening attendance. Through a grassroots organisation, she informed and mobilised Roma women to go and see their general practitioner in order to obtain referrals to a gynaecologist for examination and cytology testing.

It was important to understand whether or not Roma women wanted cervical cancer screening, as the answer to this question would play a role in deliberations about the measures that need to be taken in order to make screening participation more attractive to women. We therefore quantified this question in Paper II and found that 76% of the Roma study participants wanted to undergo screening that year.\(^1\)

In sum, the two Romanian studies revealed that Roma women living in Romania did not oppose the idea of screening; they overwhelmingly supported it.

10.1.2. Attendance to cervical cancer screening among Roma women appears to have increased in recent years
Even though the coverage of the Romanian cervical cancer screening programme is low, as explained in the previous section, results from Paper II showed that more Roma women participated in screening in Cluj County in 2016 (46% had ever attended cervical cancer screening) than had been reported in previous studies (5%) (Băban et al., 2006; Todorova et al., 2009) and in unpublished data from the Romanian Cancer Registry (<5%). If these findings are accurate, there has been an increase

\(^1\) This was not very different from other women in Romania; we found that 79% of the non-Roma study participants reported the same. The difference in wanting to take a screening test that year between Roma and non-Roma women was not statistically significant (p=0.221)(not shown in tables).
in cervical cancer screening participation among Roma women in recent years. However, one must take into consideration that the questionnaire was distributed to a convenience sample of women in a specific geographical area. One must also take into consideration that the 46% participation rate was found after I had carried out a user-oriented intervention in the communities where women lived, which offered free-of-charge cervical cancer screening in a mobile unit. Through this intervention, women were invited to take part in the planning and roll out of the screening offered, and this resulted in a higher participation rate in the study area than we had observed when we offered screening without this intervention (as explained in Paper I). Then again, in Paper II we also found that only 1%\(^1\) of the Roma study participants had their last screening test taken at a mobile unit, so the aforementioned intervention cannot fully explanation the increase in screening attendance. Nevertheless, we cannot rule out that the two Romanian studies, and my presence as a researcher (and screening promoter), might have led to a higher participation rate in the study area than elsewhere, as women might have been motivated to seek screening on their own from their general practitioner or gynaecologist. In addition, one must also consider the possibility that the relatively high participation rate found in Paper II could reflect social desirability bias. One of the women I interacted with in Paper I, for example, told me that many Roma women used to tell researchers (such as myself) and authorities what they thought the researchers wanted to hear. This was done, according to my informant, in order to decrease the stigma the Roma women felt they suffered in Romanian society, namely as persons who were lazy and untrustworthy. If this is the case, we cannot rule out that social desirability bias is present in Paper II, as women might have answered inaccurately on the question about screening participation in order to appear more in favour of screening than they actually were. As we do not know whether information bias is present, and as we are unsure of the influence that the two studies and the user-oriented intervention had on screening participation, we must take this uncertainty into consideration when interpreting the results from Paper II.

Nevertheless, and even though a 46% participation rate is much better than the previous rate reported (around 5%), the participation rate is still too low. The European Guidelines for Quality Assurance in Cervical Cancer Screening (Arbyn et al., 2008) recommend that participation be as high as possible, and many countries in the European Union have a coverage close to 70% (Arbyn et al., 2008). Measures to improve the participation rate are therefore still clearly warranted and will be discussed later in this chapter.

\(^1\) This is shown in Supplementary table 1 of Paper II.
10.1.3. There is deficient knowledge about the Romanian cervical cancer screening programme

In Paper II, we found that 62% of Roma study participants\(^1\) did not know of the existence of the Romanian cervical cancer screening programme. Thus, the low participation rate in the programme could, to a large extent, be explained by this fact. The lack of knowledge about the existence of the national cervical cancer programme must be understood in light of the newness of the screening programme, which has only been implemented since 2012 (Government of Romania 2016-2017). In addition, very little information work, information strategies, or public awareness campaigns (IOCN personal communication 2016) had been carried out by the Romanian government or by the screening programme providers in order to get women, and especially Roma women, interested in participating. In addition, the programme does not send information letters, invitations, or reminders to its target population (Government of Romania, 2016-2017), and this likely contributes to a low awareness of the programme’s existence, and in turn, a low participation rate. In an effort to learn more about the information work related to the Romanian cervical cancer screening programme, in study two, we asked participants if they had received information about the programme from their general practitioner: 81% of Roma women said they had not\(^2\) (Table 8).

Few interventions to inform the target population about the screening programme had been carried out in Romania. This is important knowledge, as strengthened information work can thereby be addressed. Awareness campaigns, information letters, invitations, and/or reminders can be used as measures to inform women about screening (Arbyn et al., 2008). In Paper II, we also found that women who had ever heard about cervical cancer screening and/or Pap smear were six times more likely to participate than women lacking this information. On the other hand, based on findings from Paper I, factual information alone may be insufficient to increase screening attendance in Romania. Indeed, there was an idea circulating among Roma women that doctors did not really want to provide screening to them. They felt that the health care system was not fair, and they did not trust that it fully welcomed them. It would seem entirely unrealistic to expect that this basic lack of trust, which exists in the backdrop of a long history of discrimination against the Roma people in Europe (Hajioff & McKee, 2000) and the ongoing marginalisation of this population in Romania (Fesus et al., 2012; Fox, 2002), could be fully mended through a simple information campaign. Indeed, it is very important to find creative ways of engaging with these complex issues. A possible place to start could be a community-based participatory research (CBPR) project which would involve Roma women in

\(^1\) 36% of non-Roma women did not know of the existence of the Romanian cervical cancer screening programme. The difference between Roma and non-Roma women was statistically significant (p>0.001) (data not shown in tables).

\(^2\) 64% of non-Roma participants reported the same. The difference between Roma and non-Roma women was statistically significant (p>0.001).
the development of better service delivery (Christopher, Watts, McCormick, & Young, 2008). With a CBPR approach, screening providers would engage in a partnership with screening attenders, starting with a partnership where everyone involved defined health needs before developing a project. In relation to cervical cancer screening, this would mean implementing screening in a way that benefits all parties. In a CBPR project, all partners contribute their expertise and share decision making and ownership. Central in such an approach is trust, which must be established early in project development. This all seems very easy to achieve; however, I must point out that trust is not something that can simply be implemented – it is something that the involved partners need to develop together. One might even say that aiming to build trust is risky; one may fail. Christopher et al. (2008) suggest that trust can be built in five steps, starting with the researchers - and in the case of cervical cancer screening, the providers - acknowledging and working with their own perceptions to understand how their history affects their work. In a second step, researchers or screening providers must strive to understand the history of the community members and of the community in which they are working. In the third step, the researcher and screening providers should be present in the community and listen to the community members, aiming to show them a broad and genuine interest. Acknowledging the expertise that exists among targeted women and being upfront about all partners’ expectations and intentions are the fourth and fifth steps of building trust. Building trust is the very key to success, and this trust must be engendered and maintained from the very start to the very end (Christopher et al., 2008). It is therefore necessary to build trust between Roma women and health care workers/screening providers. Thus, I argue that, without building trust between the different partners in the screening venture, the participation rate will likely stay low. This was indeed what we experienced when we first offered screening to Roma women through a mobile unit without their involvement as part of Paper I. As a result, many women missed out on that first screening opportunity. However, when we stepped back and planned a user-oriented intervention in which we aimed to build trust and cooperation between all partners by involving women from one community in the planning and roll-out of the screening offer, the participation rate increased enormously, from only a handful of women at our first visit, to 158 women after the user-oriented intervention.

10.1.4. A higher number of sexual partners is associated with cervical cancer screening participation

The factor most strongly associated with women’s participation in screening was having a lifetime number of sexual partners of three or more, which increased the odds of participating by six times (Table 3, Paper II). This is an encouraging finding, as a higher lifetime number of sexual partners increases the risk of acquiring HPV and thereby the risk of developing cervical cancer (Arbyn et al., 2008). The association between the lifetime number of sexual partners and screening participation
might be that women with multiple sexual partners are more aware of the risk of sexually transmitted infections, and because of this increased risk they attend screening (Lim & Sasieni, 2015).

A focus on sexual health in general seems to be important among Roma women. Paper II revealed that Roma women had more induced abortions, had given birth to more children, had an earlier age at sexual debut, and more seldom used contraception when compared to non-Roma women\(^1\). This suggests the need for further studies investigating why this is so, which may guide future interventions.

10.1.5. Urban residence is associated with participation in the Romanian cervical cancer screening programme

Another strong association in Paper II was that women living in urban areas were three times more likely to participate in the Romanian cervical cancer screening programme than women living in rural areas. This might be explained by the better availability of gynaecologists and general practitioners in urban compared to rural settings (Vlădescu et al., 2016), and by the fact that 90% of public hospitals are located in urban areas (Ibid). In addition, more than half of Roma mediators (56.1%) are located in urban settings (Wamsiedel et al., 2012). As Roma mediators are regarded as a support and a connection between Roma women and health care services (The World Bank Group, 2014), their presence may also be important to help Roma women attend the screening programme.

People living in rural areas in Romania often have to travel long distances, sometimes on twisted, difficult roads, to reach their general practitioners and/or specialist health care services (Vlădescu et al., 2016). In Paper II, we found that women living in rural areas had to travel statistically significantly longer distances to their gynaecologist than women living in the urban areas. While most women in urban areas travelled for under 30 minutes to their gynaecologist, most women living in rural areas travelled between 30 minutes and 1 hour, and for some women (5%) this time reached 4 hours (Table 7). Transportation costs can be high, and can further compromise accessibility to health care in rural areas (Vlădescu et al., 2016). The long travel distances, together with lower access to health care services and Roma mediators, might explain why women in urban settings had higher odds for screening attendance as compared to women living in rural areas.

10.1.6. Worries about costs and lack of health insurance

Romanian health care is built on a private health insurance system, in which insured people have access to the same health care benefits regardless of their socioeconomic situation (Vlădescu et al., 2016). The health insurance premiums of the employed are generally covered by the taxes they pay (Ibid), but people can also pay the premiums themselves if they prefer. Pensioners, people receiving

\(^1\) Data not shown in Paper II
social assistance, the registered unemployed, conscripted soldiers, people in custody or under arrest, children up to 18 years of age, disabled people, war veterans with no income, and the dependants of all insured people (spouses, parents, and grandparents) are included in the health insurance system, but do not pay premiums. Therefore, those without health insurance are mostly students and members of the Roma population who lack the identity cards and documentation that would enable them to enrol (Vlădescu et al., 2016).

Individuals not enrolled in the health insurance system in Romania still have access to what is called a ‘minimum package’ of benefits, which covers life-threatening emergencies, epidemic diseases, and antenatal and delivery care (Vlădescu et al., 2016). As from 2012, initial cervical cancer screening and cervical cancer treatment were included in the minimum package (Government of Romania, 2016-2017). In order to get access to testing, women have to be part of the target population (aged 25-64 years) and have a referral to her gynaecologist from general practitioner that is registered with the Romanian cervical cancer screening programme (Government of Romania, 2016-2017). However, follow-up and treatment of precancerous lesions are not covered by the minimum package, which means that women without health insurance must pay for these services on their own. Screening providers and policy makers explained that this did not really represent a problem, because all citizens in Romania could sign up for health insurance, even the unemployed (as mentioned above), and thereby get access to free medical help.

This was not an experience Roma woman commonly shared. When Roma women were asked about their health insurance status in focus group discussions, some explained that they did not have any and how this excluded them from receiving health care services: “No, I don’t have health insurance, so if I go, he [the general practitioner] won’t do anything.”(Roma women from focus group discussion, June 2015).

Some Roma women explained that they did not sign up for health insurance because they did not have time; others said they did not know how to sign up:

"Even if I manage to find the right building downtown...how am I going to find my way there? I cannot read or write. How can I find the right floor? How can I fill in the right forms? ...How? I am sure that they [the employees] don’t want me there...they might ask me to leave.”
(Summary of conversation with a Roma woman during participant observation, September 2015).
According to Roma women, it was not easy to get health insurance. Therefore, in Paper II we quantified women’s health insurance status and found that 32% of the Roma study participants had none (Table 1, Study II). In addition, 17% of all Roma women reported they did not have a general practitioner (Table 1, Study II), and as much as 43% of Roma women reported that they did not know if their general practitioner was registered with the screening programme (Supplementary Table 1, Paper II).

We suggest that in order to make screening attendance more attainable for Roma women, follow-up and treatment of precancerous lesions should be free-of-charge and included in the minimum package of health benefits. This would be in line with the third criterion by Wilson and Jungner (1968) stating the "facilities for diagnosis and treatment should be available" which is not achieved if women cannot afford necessary follow-up and treatment. Indeed, women who participate in screening must be assured that any necessary follow-up and treatment will be without costs. We also suggest that information about the screening programme and its costs must be delivered to the target population using a CBPR approach that aims to build trust and interaction between screening providers and screening attenders.

10.1.7. Screening in the context of under-the-table payments
When Roma women expressed concerns about the affordability of screening, it was because they were convinced it would not be free in practice, as they had either been charged official fees or had been asked for under-the-table payments. As a result, Roma women distrusted that the screening programme would lead to improved health, and they assumed that taking part might instead lead to worries about results, about their health, or about how to afford required treatments. One Roma woman said in a focus group discussion, “I think it is very good that we can do that [take part in screening], but I do not understand why Roma women are charged a fee for this (...)” (focus group discussion, June 2015). Many women told stories about being asked for under-the-table payments to take part in screening. One Roma woman said it this way, “No, the test is not free, not even for those who have insurance. One has to pay.” (focus group discussion, June 2015).

In Paper II, we found that 10% of Roma women had experienced having to pay for screening (Supplementary Table 1, Paper II). This could be because they lacked the necessary referral from their general practitioner, or it could be due to demands for under-the-table payments. Such illegal payments have been suggested to comprise almost one-fifth of the total health care expenditure in Romania (Vlădescu et al., 2016). It has been argued that the high prevalence of such payments is a
major reason for the health care problems in Romania (Vlădescu, et al., 2016) because many cannot afford to pay (Wamsiedel et al., 2012).

10.1.8. The role of perceived discrimination in screening participation

In qualitative interviews and focus group discussions, health care providers said that they saw Roma women differently from themselves. They noted that Roma people had “their own character”, were “louder than Romanians”, and that many people did not trust the Roma because most of them “are beggars or thieves”. One person mentioned that “stealing and being false is in the Roma peoples’ character” because “they once were slaves and during that time had to steal in order to survive.” One of the focus group participants alluded to how frequent these impressions are in Europe, explaining that she was afraid of being taken for a Roma when travelling abroad:

“When you go, for example, to France or Germany or Spain. I don’t know, sometimes you feel ashamed to say you are Romanian because of the bad publicity they [Roma] have, you know? Because they steal a lot, they are begging, they are not working, they are living from social insurance... and they are doing a lot of bad things.” (Screening providers from focus group discussion, October 2015).

When we discussed Roma women’s lack of participation in screening, one non-Roma physician explained in this way: “They don’t know practically how to do anything.” and “We know this because we have lived with them [Roma] for decades.” Health care providers often referred to Roma women’s lack of capacity and competence when the low participation rate was discussed.

As for the Roma women, they said that they often felt that they were being discriminated against by health care workers and screening providers. The examples they gave included having to wait longer in line than non-Roma patients, or being referred to as lazy, dirty, and untrustworthy.

Roma women explained that they were often perceived as unclean by health care workers, and many women told stories where their so-called uncleanness led to discrimination. One woman explained that she was not afraid of discrimination because she always took great care to wash herself and dress nicely before visiting health care services. When her daughter was hospitalised, the doctor could not believe that they were Roma because both the mother and daughter were so clean. The doctor said that most women from Roma communities did not take good care of their children, and that they never washed themselves.

Roma women answered questions about stigma and discrimination in Paper II, where 9% reported that their gynaecologist, and 6% reported that their general practitioner, had hinted that they were dirty and smelly at their last visit. Further, 11% and 8% reported that their gynaecologist and general practitioner, respectively, had hinted that they were stupid; 10% and 8% reported that their gynaecologist and general practitioner, respectively, had hinted that they were dishonest; and 9%
and 8% reported at their gynaecologist and general practitioner, respectively, had called them bad names (Table 2. Paper II).

It seems clear that experiences of stigma and discrimination might also contribute to explain the low participation rate among Roma women in the Romanian cervical cancer screening programme. Many women would be reluctant to undergo a gynaecological exam (or seek health care in the first place) if it was administered by someone they felt disliked or disrespected them.

10.1.9. What can be done to increase participation in cervical cancer screening among Roma women?

Previous research from many parts of the world has indicated that communities and individuals are more likely to participate in and make use of health interventions and programmes that are developed and implemented in genuine partnership with the community and its members (i.e., Christopher et al., 2008; Eardly et al., 1985). At the core of such approaches stands the idea that community members are recognised as subjects with agency, insight, and resources. Contrary to more top-down styles, community-based approaches build on the principle of collaboration between experts of different kinds. Community members are recognised as the true experts on their own lives and the overall situation in their community, whereas health care professionals have technical insights into issues that could potentially benefit the health of community members. The aim in such approaches is to bring these different types of expertise together through conversations and discussions, so that a mutual understanding of the issues at hand can be developed, and collaborative action can be taken (Christopher et al., 2008).

This kind of approach was explored through fieldwork and described briefly in Paper I. As part of the fieldwork, I spent time in two different Roma communities prior to the arrival of the mobile unit. During this time, I engaged in conversations about cervical cancer and screening, provided information about the mobile unit, and arranged for meetings to which all women living in these communities were invited. Many women participated in these meetings, and they were encouraged to speak freely about their own health and their main health problems. A medical student presented information about cervical cancer and HPV, and the local women took part in the planning of health care delivery. The day the mobile unit arrived, there was considerable conviviality among the residents, and the willingness and eagerness to attend was remarkable. Women got up earlier than usual to wash and dress in preparation for a gynaecological exam. In one of the camps, they arranged for shower facilities that enabled women to go straight from the shower into the waiting line in front of the mobile unit. After spending time with Roma women and discussing screening and its importance, the situation did seem to have changed considerably. After speaking with those involved and bringing them into the planning and implementation process, attendance increased. When
women were treated and acknowledged as equal partners that also had their own will and agenda, trust was fostered.

Let me also mention that the most basic factor for screening success among Roma women living in Romania may already have been achieved, as cervical cancer screening is wanted by the target population. One important reason why women did not participate was that they did not know about the programme’s existence, but there were other important explanations: women did not trust, and felt discrimination from, health care workers and screening providers. Therefore, in order to achieve higher participation among Roma women in the Romanian cervical cancer screening programme, I propose that the programme address the knowledge gap and acknowledge the stigma Roma women feel that they suffer when meeting with health care professionals. Discriminatory behaviour must be highlighted, recognised, and eliminated. One way to start might be to arrange for a work-shop or similar events were screening providers are encouraged to discuss the stigma and discrimination that seems to be existing towards the Roma population in Romanian health care. An aim with this event could be to make screening providers aware of the existence of discrimination behaviour and then find measure to fight it. Another measure might be to include Roma women in the planning and design of interventions that encourage women to participate in screening. This includes making women aware of the screening programme’s existence, the fact that the programme is free-of-charge, and that Roma women are welcomed and wanted in the programme. For this, it will be important to give Roma women a clear voice and to use a CBPR approach to build trust between screening providers and screening attenders. By involving Roma women in the planning and implementation of the programme, they can advance their own views and make clear how they desire the programme to be. An explanation of the health insurance sign-up process, which would give women access to free follow-up and care, must be highlighted. The controversies that exist between screening providers and the target population should also be addressed, and the people involved must find ways to amend them together. A CBPR approach, in which all those involved are encouraged to speak their mind, is warranted. Involvement of the local target population should also be included, so that women’s differing needs can be addressed.

10.2. Norway

10.2.1. hrHPV testing did not increase anxiety and depression scores
In Norway, as in Romania, the overall aim of the NCCSP is to decrease the overall burden of cervical cancer through early detection and treatment. While Romania continues to strive to get more women participate, in Norway, the challenge was to improve the NCCSP. Large international randomised trials (i.e., Ronco et al., 2014) proposed that this goal could be accomplished by changing
primary screening methods to the more sensitive hrHPV test. In Norway, the government (The Norwegian Directorate of Health, 2018) decided that the implementation of hrHPV testing in primary screening among women aged 34-69 years should be done in a controlled, randomised, and gradual manner. This was done in order to have control over the effect the new screening method had on follow-up, on detected precancerous lesions, on conisations, and on the work load in the laboratories, in addition to allowing researchers to investigate if this new screening method affected attendance rates and/or women’s anxiety and depression scores. Therefore, it was reassuring that Paper III did not find any differences in anxiety and depression scores between women who received primary cytology screening and women who received primary hrHPV screening. No statistically significant differences in anxiety and depression scores between the cytology and hrHPV screening arms were observed.

All the women taking part in Paper III received the result of their last screening test between 4 months and 2 years prior to receiving the study questionnaire, thus we considered the anxiety and depression scores we observed to be ‘long-term’ scores. We did not find any statistically significant differences in anxiety or depression scores when comparing women who received their last screening results between 4 months and 1 year before completing the questionnaire vs those who completed it 1-2 years after they received their last screening results (supplementary Table 2, Paper III).

Thus, Paper III suggested that a change in primary screening method to hrHPV testing for women aged 34-69 years is not likely to increase anxiety and depression scores among NCCSP participants.

10.2.2. Anxiety and depression did not increase with the severity of screening result

Anxiety and depression scores were also compared among women who received different screening results (Chapter 2.7.2). Paper III found that anxiety and depression scores did not increase in a statistically significant manner with the severity of the screening results. However, women in the hrHPV screening arm who were hrHPV-positive and had high-grade cytology had slightly elevated anxiety and depression scores (mean score 2.1) (Table 9), whereas women with other screening results had normal anxiety and depression scores (mean score <2). Even though the mean values between women with different screening results were not statistically significant different, we cannot ignore the finding that double positive results in the hrHPV screening arm were associated with mild anxiety and depression scores. It is understandable that women with these particular screening results feel anxious, as this particular diagnostic combination requires serious attention. Women with these results are sent straight to follow-up with colposcopy and biopsy (Figure 3). Women in the hrHPV screening arm also had a non-significant 14% increased risk of moderate/severe anxiety and depression scores as compared to women in the cytology screening arm (Table 2, Paper
III). Due to a limited number of study participants in some of the screening result groups, our statistical power was limited. However, we could not rule out that a difference exists. This finding should probably be examined in future studies with a higher number of women to ensure sufficient power to detect statistically significant results.

10.2.3. New subset of women
With the implementation of hrHPV testing in primary screening, a new subset of women was identified, namely women in the hrHPV arm who were hrHPV-positive with normal cytology (Figure 3). This group of women would not have been identified in a cytology-based screening programme, as their primary test, cytology, would have been normal. However, as they were in the hrHPV-arm, those who are hrHPV-positive will have cytology as secondary screening. If their cytology results are normal, according to the current screening algorithm (Figure 3) they are advised to wait 12 months before taking a follow-up hrHPV test. The likelihood of this subset of women developing cervical cancer in the interim period is extremely low (Arbyn et al., 2010; Ronco et al., 2014), but it was still important to explore if they reported significant anxiety and depression in the 12-month interim period. In Paper III, there were 168 study participants who were hrHPV-positive with normal cytology; 70% had normal, 25% had mild, and 5% had moderate/severe anxiety and depression scores (Table 10). The mean score of anxiety and depression was 1.7, in other words normal (Table 9). Hence, Paper III suggested that hrHPV testing in primary screening is not likely to increase anxiety and depression scores in this particular subgroup of women.

10.2.4. Deficient knowledge related to screening method and results
Paper III identified a knowledge gap among study participants. This was not related to knowledge about cervical cancer and HPV, as almost all participating women had knowledge about the preventive effect of screening on cervical cancer (98%) and the link between HPV and cervical cancer (69%). Instead, the knowledge gap was related to the primary screening method used (cytology or hrHPV testing) when women last participated in screening. A striking finding was that 63% of all study participants were unable to identify the primary screening method used at their last screening visit (Table 1, Paper III). This was a bit surprising, because information campaigns had been carried out in the study area prior to the initiation of the pilot project of hrHPV testing in primary screening. These included advertisements and information sheets in the newspapers with the highest circulation in the four counties included in the pilot project. In addition, all health care centres in these counties had been given informational posters to hang in their waiting rooms. All general practitioners and gynaecologists had also been given informational brochures to hand out to women when they underwent cervical cancer screening. All these elements included information about hrHPV and cytology screening, and the randomisation between women born on even and odd days (Chapter 2).
An information letter was also sent from CRN to all women in the hrHPV screening arm who tested negative. The letter had information about the test results and the extended screening interval that follows hrHPV testing (Tropé et al., 2017; Engesæter et al., 2017).

The fact that most of our study participants did not know which primary screening method was used at their last screening visit indicates that the information campaign was not entirely successful. This is important to know, because of the extended screening interval (from 3 to 5 years) that follows hrHPV testing when used in primary screening. It is also considered important that women know the method used, as they will be better prepared to understand the screening results. The lack of knowledge revealed in Paper III should be taken into consideration for future screening strategies, particularly as hrHPV testing in primary screening is now (between 2019 and 2022) being implemented nationwide among women aged 34-69 years in Norway (Ibid).

The knowledge gap related to primary screening method used at women’s last screening visit did not influence their anxiety and depression scores; the scores of anxiety and depression among women who did and did not have this knowledge did not differ (p=0.908) (not shown in tables).

Knowledge of last screening results was higher than knowledge of the primary screening method used. It is obviously more important for a woman to know the results of her testing than the method used, as the former may influence her health more than the latter. Still the knowledge women had about their last screening results was not that high, as one-third (34%) of women in the cytology screening arm and one-fifth (18%) in the hrHPV screening arm were not able to state if their last screening results was normal or abnormal (Table 1, Paper III). Nevertheless, it is interesting that women in the hrHPV screening arm had significantly more knowledge about their screening results (normal or abnormal), compared to women in the cytology screening arm (82% in the hrHPV and 66% in the cytology screening arm answered this question correctly, p<0.001) (Table 1, Paper III). A possible explanation might be the extra information letter that was sent to hrHPV-negative women. Another explanation might be that women who are tested with hrHPV and women who are hrHPV-positive tend to seek information about screening results more often than do women who are tested with cytology (Hendry et al., 2012; O’Connor et al., 2014). This may also indicate that the information women received about screening results raised their awareness of screening procedures and outcomes. The role that knowledge of last screening result played in anxiety and depression scores did not seem to differ between those who knew their last screening results and those who did not (p=0.877) (not shown in tables).
10.2.5. Education level and age was associated with anxiety and depression scores
In our study, we found that lower education level (OR 1.42; 95% CI 1.02-1.97) and younger age (OR 2.07; 95% CI 1.37-3.12) were associated with a higher risk of mild vs normal anxiety and depression scores (Table 10). This finding is in line with that of other studies (Maissi et al., 2004; Sheikh, 2017), which have found that younger age and lower education level predict higher anxiety and depression scores among women participating in screening. It has been suggested that the association between lower education level and anxiety and depression is due to difficulty in understanding the information related to screening and screening results (Burger et al., 2014; Jayathunge, Bowanwatanuwong, Maek, & Pitisuttithum, 2010). Another possible explanation could be that health care workers do not sufficiently adapt the information to patients’ needs and preconceptions (Eardley, 1985). Conversations between a physician and patient that are responsive to the patient’s understanding and concerns can reduce negative psychological outcomes (O’Connor et al., 2015; Rosen et al., 2010; Williams-Piehota et al., 2015). This should be taken into consideration when screening information is presented. Providers should tailor the information to match the individual patient’s needs (Befring, 2004).

10.2.6. Marital status is associated with anxiety and depression scores
A study (Klugel et al., 2017) among women diagnosed with cervical cancer found that being single was correlated with an increased risk of anxiety and depression, while being married or having a partner offered protection. This is in line with our study, in which married women had a lower risk of moderate/severe anxiety and depression scores than single/divorced/widowed women (Table 10). However, this stands in contrast to the role marriage seemed to play in anxiety and depression before and after treatment for breast cancer. Villar et al. (2017) found that married women had a 2.28 times higher risk of anxiety than single women in connection with such treatment. This finding was linked to married women’s concerns about their families, which functioned as a stress-generating variable.

While our study participants were not diagnosed with cancer, it might not be surprising that being in a relationship can be a benefit in connection with screening-associated distress, at least if the relationship is perceived as good and supportive.

10.2.7. What can be done to improve information delivery?
Overall, the women who received hrHPV testing in primary screening showed no statistically significant increase in anxiety and depression scores as compared to women who received a cytology test. However, the information campaign related to the pilot project did not succeed in informing women about the screening method used. There were also many women who did not know their
own screening results. Many women (56%) also reported that they would seek screening more often than the recommend screening interval when hrHPV testing is implemented nation-wide (Table 1, Paper III), which is the main reason why women need to be aware of what screening method they are offered. This may indicate that women don’t trust or are unaware that the 5-year screening interval with hrHPV testing is considered safer that the 3-year interval with cytology (Arbyn et al., 2010; Ronco et al., 2014).

An interesting question is whether CBPR projects (Chapter 10.1.3), which aim to reorient health care towards approaches that understand, respect, and empower patients through collaboration and partnership, could play a role in an organised screening setting such as the NCCSP. In a CBPR approach, the patient’s perspective and interest take central stage, and a principle aim is to provide understandable information (Christopher et al., 2008). In the pilot project of hrHPV testing in primary screening, the NCCSP created standardised information letters to all women in the target age group. This was done after arranging focus group discussions among women before and after the information material was finalised (Engesæter, et al., 2017). This was a good start to disseminating high-quality information. However, as Paper III revealed that women did not fully understand the screening method used or their screening results, I suggest that this be considered when it comes time to make new information packets.

The study women in Paper III received the questionnaire between 4 months and 2 years after their last screening results, and any anxiety they might have felt closer in time to the screening itself could have faded by this time. Future studies could include short-term anxiety and depression scores, as it would be interesting and valuable to know if women are psychologically distressed soon after the testing procedure. It would also be interesting to know if anxiety and depression appear after 2 years, and this could be included in future studies.

To sum up, our findings of no statistically significant differences in the anxiety and depression scores of women in the two screening arms or among women with different screening results, are useful. First, is it reassuring for the ongoing implementation of hrHPV testing in primary screening in Norway, and second, if the new screening method does not lead to increases anxiety and depression scores, it will likely not reduce the participation rate in the NCCSP due to mental distress. This study may also offer knowledge that can benefit other countries wishing to implement hrHPV testing in primary screening.
11. Conclusion

The overall aim of this thesis was to create new insight into experiences, circumstances, and characteristics that might have an impact on the degree to which women with different backgrounds and in different contexts and two different countries participate in national cervical cancer screening programmes.

The thesis consists of a Romanian part and a Norwegian part, including three Papers. The first paper (Paper I) contribute with knowledge related to understand the low participation rate in Romania’s cervical cancer screening programme from the perspective of Roma women and screening providers. Roma women were found to have an almost no knowledge about the existence of the Romanian cervical cancer screening programme, and few of them had previous screening experiences. The women also had a hard time believing that the programme was free-of-charge for all women, irrespective of their health insurance status. This was partly linked to their previous experiences of having to pay for all heath care services they received, either as official fees or as under-the-table payments, and partly due to experiences of stigmatisation and discrimination. Many Roma women also doubted that screening would lead to better health, as follow-up and treatment of precancerous lesions is not included in the screening programme or in the minimum package of insurance. Many of the women from the Roma minority population also lacked health insurance. Health care workers and screening providers had a different understanding of the screening programme and argued that the programme was really free-of-charge and that uninsured women could simply register as unemployed and get free medical help.

In the qualitative study (Paper II), we developed new knowledge related to experiences and circumstances that encourage and discourage participation among Roma women in the Romanian cervical cancer screening programme. Although the participation rate in the cervical cancer programme in the North-Western region of Romania, was higher than we had anticipated, it was still low in 2016 when compared to other European countries. Ethnicity was not found to be associated with screening attendance, but other factors were associated, and women with a higher lifetime number of sexual partners, who had heard about a screening opportunity, and who lived in urban areas had highest likelihood for having screening experiences.

Based on the results from the two studies in Romania, I will argue that further research on screening participation should include Roma women. Approaches could investigate if involvement of Roma women in the planning, mobilisation, and enrolment of the screening programme will increase screening participation in the country.
In the Norwegian study (Paper III), the main aim was to learn whether levels of anxiety and depression differed among NCCSP participants who received either cytology or hrHPV testing as a primary screening method.

No increase in long-term anxiety and depression scores were observed among women aged 34 years and older who received hrHPV testing as compared to women receiving cytology in primary screening in four Norwegian counties between 2016 and 2018. Neither did anxiety and depression scores seem to increase with the severity of screening results. Thus, there are no indications that screening participation will be adversely affected by anxiety and depression, nor that hrHPV testing in primary screening will make women more anxious and/or depressed than cytology screening. This is reassuring, as hrHPV testing is more sensitive to detect the hrHPV types included in the HPV test than cytology is to detect precancerous lesions (Ronco et al., 2014). It would have reduced the benefits of hrHPV testing in primary screening if its implementation increased psychological distress among NCCSP participants. Further studies could investigate if the new screening method (hrHPV testing in primary screening) increases anxiety and depression scores in a longer time perspective than we investigated in Paper III. These results from the Norwegian study also support further research on short-term anxiety and depression scores among women who receive hrHPV testing in primary screening and its possible impact on screening participation. Whether this has negative effects on screening participation should also be investigated in the years to come.

The study showed that a large proportion of women did not know which screening method was used at their last screening visit. In addition, many women did not know the results of their last screening test. This suggests that informing participating women about these issues is challenging. In the study, we propose that information to women may be improved by following the principles of CBPR, where the patient’s assumptions about screening, screening participation, and screening results are in focus.
12. Contextual background information

12.1. Anatomy of the cervix

Cervix is a Latin word that means the neck of the uterus. The cervix is also called ‘the uterus port’; it is circa 2-3 cm long, with a cylindrical shape formed as a canal. The uterus connects the uterine cavity with the lumen of the vagina (Singer, Monaghan, Quek, & Deery, 2000). The female reproductive system is covered by secreting mucosa; squamous epithelial cells are located above, while columnar epithelial cells are located below the portal in the cervical canal. The space where the squamous epithelial cells and the columnar epithelial cells meet is called the squamous columnar junction (SCJ). In young girls, the SCJ is visible at the endocervical canal, but as oestrogen levels rise during puberty, the columnar epithelium is exposed in the vagina, and is partly replaced by squamous epithelium. This process is called metaplasia, during which a new SCJ is made further down in the cervix. The place between the old and the new SCJ is called the transformation zone (TZ) (Singer et al., 2000).

The majority of cervical cancer cases are carcinomas that originate in squamous cells and the glandular epithelium. When women participate in screening, cells from the TZ must be harvested (Bray et al., 2005) in order to detect precancerous lesions that can be removed to avoid progression to cancer.

Figure 6: The female reproductive system

12.2. Cervical abnormalities and cervical cancer

Cancer is a term used to describe a group of diseases characterised by a number of processes, including uncontrolled cell division, where mutated cells invade other healthy cells (Hanahan & Weinberg, 2011). According to one theory (Pitot, 1993), there are three stages in the development of solid cancers: the initiation stage, when changes happen in the cell’s DNA, the promotion stage,
when the development of tumours and genetic changes (potential reversible stage) take place, and **the progression stage**, when the cancer progresses with irreversible growth of altered cells and potentially also metastasis (Pitot, 1993).

In 99% of all cases, the cervical cancer development is initiated by infection with hrHPV types (Walbloomers et al., 1999). HPV is a DNA virus from the papovavirdae family, and 200 different genotypes have been identified so far. Around 40 of these genotypes are sexually transmitted and may cause symptomless infections in the human mucosa. hrHPV infections are common, with 75% of all sexually active men and women being infected with one or multiple hrHPV types once or several times during their lifetime (Rodriguez et al., 2010; Winer et al., 2006). hrHPV infections are regarded as the most common sexual transmitted infection and condom use provides only partial protection against genital HPV infections (Winer et al., 2006).

Most of the 200 identified HPV types have low carcinogenic potential and are known as low-risk (lrHPV). The most common lrHPV types are HPV6 and 11, which are linked to genital warts (condylomas) (Munoz et al., 2010). Condylomas can cause clinical symptoms such as itching, burning, bleeding, pain (Kjaer et al., 2007), and fluid wounds (Camargo, D'Elia, & Miot, 2017). There are 16 identified hrHPV types that have been associated with cervical cancer. These are HPV16, 18, 31, 33, 35, 39, 45, 51, 52, 56, 58, 59, 66, 68, 73, and 82 (Munoz et al., 2003). HPV16 and 18 cause over 70% of all cervical cancer cases (de Sanjose et al., 2010; Zandberg, Bhargava, Badin, & Cullen, 2013). Over the past few decades, hrHPV has also been associated with anogenital cancers, head and neck cancers, and cancers of the vulva and vagina (de Martel et al., 2012). About 5% of all cancers are caused by infection with hrHPV (Parkin & Bray, 2006).

**Figure 7: Illustration of HPV**

hrHPV infections are asymptomatic. Over half of them clear spontaneously within 6 months, and as much as 90% clear after a few years without leading to any clinical disease (Rodriguez et al., 2010;
Winer et al., 2006). However, in a minority of women, persistent hrHPV infection triggers cellular changes that can lead to cancer. In these cases, hrHPV takes control of the cell cycle in infected cells by the inhibitory cellular tumour suppressor genes, p53 and Rb. This leads to a modified proliferation and differentiation pattern in infected cells, especially those in the TZ (zur Hausen, 2000). This happens in the **initial stage** of cancer development described above. As a result of this process, cervical cells can become immortalised and divide abnormally, ultimately developing into neoplasia (zur Hausen, 2000, 2002) in the so-called **promotion stage** (Pitot, 1993). Cervical cancer can occur in the squamous epithelium (Schiffman, Castle, Jeronimo, Rodriguez, & Wacholder, 2007) and develops through the precursor cervical intraepithelial neoplasia (CIN), which is classified into grades 1 to 3. Gland cells of the cervix can also be affected by hrHPV infections and develop into adenocarcinoma through adeno carcinomas *in situ* (Schiffman et al., 2007). The third stage of cancer development is known as the **progression stage** (Pitot, 1993).

**Figure 8: Stepwise cancer development from normal cells through CIN1, 2, and 3 to cervical cancer. Cervical pre-cancer and cancer progression**

(O’Leary et al., 2018)

This stepwise cancer development (Figure 8) is described by progressively more pronounced changes in the cervical mucosa, such as CIN1, 2, and 3. Approximately 99% of all CIN1 cases disappear by themselves after 6 to 24 months (Moscicki et al., 2012; Schiffman, Clifford, & Buonaguro, 2009) while only 20-30% of all in CIN 2 and 3 disappear by themselves. Consequently, the risk of developing invasive cervical cancer increases with the degree of dysplasia (McCredie et al., 2008; Ostor, 1993). Medical recommendations indicate that all women with CIN2 and 3 should be treated in order to
stop cancer development (Arbyn et al., 2008). Usually progression from hrHPV infection to CIN2 or worse takes at least 10-15 years, and progression to cervical cancer takes on average 20-25 years (Moscicki et al., 2012; Schiffman et al., 2009).

12.3. **Cytology screening**

The technique of analysing cervical cells to detect precancerous lesions was developed by the Greek-American doctor, Georgi Papanikolaou (Nygård et al., 2012) and the Romanian doctor Babes Papanicolaou in the 1930s (Badulescu et al., 2011; Şuteu, Nicula, Coza, & Lupşa, 2002). The technique became commonly used in Europe from the 1950s (Andreassen & Vogt, 2014; Haldorsen et al., 2008). With cytology screening, cells are harvested from a woman’s cervix with a small brush and/or a spatula before they are fixed on a slide (conventional cytology) or shaken into a fixation fluid (LBC) before the cells are analysed (Nygård et al., 2013). The harvested cells are generally taken by a general practitioner, a gynaecologist, or a midwife before being analysed at a laboratory.

Normal cells require no follow-up, while high-grade cytological changes require immediate follow-up and/or treatment. If results from the cell sample are inconclusive, unsafe or low-grade cellular changes (ASCUS/LSIL\(^1\)), European Guidelines (Arbyn et al., 2008) recommend that the woman be sent to follow-up.

The European Guidelines for Quality Assurance in Cervical Cancer Screening were first published in 1993 (Coleman et al., 1993) and later updated (Arbyn et al., 2010). The guidelines recommend that countries offer national cervical cancer screening programmes to women aged 20-30 years until 60-65 years, with cytology as a standard screening test with a 3-5-year interval.

12.4. **hrHPV screening**

hrHPV testing has been implemented as an additional screening test in many European countries since the beginning of the year 2000. Cells used for hrHPV analysis are harvested using the same method as LBC (Nygård et al., 2013). Women who participate in screening will not notice any difference in the way cells are harvested for the two methods. The difference between the two methods is the way the cell sample is analysed.

hrHPV testing was initially used for further clarification if a women had inconclusive cytology results, such as ASCUS or LSIL (Arbyn et al., 2010). This use of hrHPV testing after a primary cytology

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\(^1\) ASC-US = Atypical Squamous Cells of Undetermined Significance, LSIL= Low-grade Squamous Intraepithelial Lesion
screening is often referred to as ‘triage’ or ‘secondary screening’. hrHPV testing was implemented as a triage test in the NSSCP in 2005 (Nygård et al., 2013), but it has not, as of yet, been implemented as a routine test in the Romanian cervical cancer screening programme, which offers only repeated cytology (Government of Romania, 2016-2017).

In countries using hrHPV testing in secondary screening, women are divided into different follow-up courses based on their cytology results. European Guidelines (Arbyn et al., 2008) recommend the use of hrHPV testing as triage among screened women and also suggest how these women should be followed-up.

In 2014, a large randomised trial (Ronco et al., 2014) showed that screening programmes based on hrHPV testing in primary screening provided 60-70% greater protection against invasive cervical carcinoma compared to cytology-based screening programmes. As a result, several countries, including Norway, are changing their national screening programme to integrate hrHPV testing in primary screening (Andreassen & Vogt, 2014). The third study in the present PhD thesis is based on this change in the NSSCP.
13. References


O’Connor, M., Costello, L., Murphy, J., Prendiville, W., Martin, C. M., O’Leary, J. J., & Sharp, L. (2014). ‘I don’t care whether it’s HPV or ABC, I just want to know if I have cancer.’ Factors influencing women’s emotional responses to undergoing human papillomavirus testing in routine management in cervical screening: a qualitative study. BJOG, 121(11), 1421-1429. doi:10.1111/1471-0528.12741


Priaulx, J., de Koning, H. J., de Kok, I., Szèles, G., & McKee, M. (2018). Identifying the barriers to effective breast, cervical and colorectal cancer screening in thirty one European countries using the Barriers to Effective Screening Tool (BEST). Health Policy, 122(11), 1190-1197. doi:10.1016/j.healthpol.2018.08.004


Personal communication. Dr. Ofelia Suteu, IOCN (05.09.2016).
Attachment 1
This interview guide provides an overview of topics to be covered under different forms of qualitative interventions such as participant observation, qualitative interviews and focus group discussions. The conversations, interviews, and discussions will be semi-structured in character, where there will be plenty of room for the various conversations to develop during the interventions.

Interview guide

**Being invited to participate:**
How was it?
Thoughts?
Feelings?
Barriers?
Decision to participate?

**Background:**
Age?
Where are you from?
Education?
Work?
For those who have a job, what kind of job?
Is the job regular?
For those who don’t, would you like to have?
Why do you think you don’t have a job?
Do your husband/partner have a job?
Do anyone else in your household have a job?

**Family situation:**
Are you married/living with a man?
children?
Have you ever been divorced?
Whom do you live together with?
Do everybody have their own bed?

**GP:**
Do you have a GP?
How long have you had one?
If no, can you tell why?

If no, can you explain/discuss if you would like to have one?
Have your children any GP?
Do anyone in your household have a GP? How often do you visit your GP or the hospital? Do you have health insurance? Do you feel stigmatized or discriminated against when you go to the GP/Hospital?
If yes, in what way?
Have you ever experienced being/not being discriminated when visiting the GP?

**Cervical cancer:**
What is cervical cancer?
Who can get cervical cancer?
How can you get cervical cancer?
What is HPV?
Is HPV related to cervical cancer?

**Screening:**
What do you know about cervical screening?
Thoughts about screening and testing?
Is screening intended for you?
Is screening available for you?
What is positive regarding screening?
What is negative about screening?
Is there a national screening programme in Romania?
For whom is this screening programme?
Who can perform screening, The GP or the Gynaecologist?
Participation:
Would you like to attend to a national screening programme?
Are you afraid of being discriminated if you are going to take a smear? Are there any available screening stations near your home?
Can you decide for yourself if you like to attend screening?
If no, who will decide this?
Will you get free from work to take a smear?
Can you afford to take a smear? Do you have any thoughts about the results of the smear?
Do you fear the result?
Do you fear the examination will be painful?
Do you fear the examination will be embarrassing?
Do you fear anyone else will look different at you if you take a smear? Do you have any thought regarding HPV-testing?
Is it any difference in testing for HPV compared with cytology? Do you prefer your gynaecologist to be a specific gender?
Would you discuss screening attendance with your husband/your mother/ the health mediator/ your friends/ others? Would you discuss screening results with your husband/your mother/ the health mediator/ your friends/ others?

Lifestyle and Health:
How would you describe your own health?
What do you do, if you feel sick? Have you ever been feeling sick and not contacted a GP/the ambulance?
What did you do instead?
Are you often feeling sick?
Do you feel that you have access to health services?

Conclusion:
Thoughts you get during this conversation?
Questions?
Comments?
How to get others to participate in this study?
SURVEY ABOUT WOMEN’S HEALTH
The main purpose of this project is to study whether or not women in Romania will attend to a national cervical cancer-screening programme. In order to find answer to this question we need to understand women’s life as is it lived, and how women think regarding their own health, illness, cancer and screening.

You will see that some questions in this questionnaire are personal and some questions may be difficult to answer exactly, such as how old you were when certain events happen in your life. Other questions are regarding your background and experiences you have gain during your life. If you are unsure, please estimate as best you can in your answer. You have the right to refrain from answering any questions in this questionnaire. However, we hope that you will answer all the questions, as your answers are important in efforts to prevent cervical cancer.

Answer the questions on behalf of yourself. Your answers will be treated anonymously, which means that no one can connect your answers to you as a person. When you fill out this questionnaire please remember that it is no “right” or “wrong” answers. It is VERY important that you answer each question as accurate and honest as possible.

Fill in the boxes as follows:

◊ Check the box that best fits your situation, as follows: ✗

◊ If you select the wrong box, please fill the box completely as follow: ☐
and set a new cross in the appropriate box.

THANK YOU FOR YOUR HELP
**BACKGROUND QUESTIONS**

Questions 1 – 6 are regarding your background

1. **What year were you born?**
   - 19 [ ] [ ]

2. **What is your marital status today?**
   - Single [ ]
   - Cohabiting [ ]
   - Married [ ]
   - Divorced / separated [ ]
   - Widow [ ]

3. **How many years of schooling do you have?**
   - None [ ]
   - 1 - 4 years [ ]
   - 5 - 8 years [ ]
   - 9 - 12 years [ ]
   - More than 12 years [ ]

4. **How would you define your ethnicity? (Answer on behalf of yourself, not on behalf of your parents or other family members)**
   - Romanian [ ]
   - Moldovan [ ]
   - Hungarian [ ]
   - German [ ]
   - Ukrainian [ ]
   - Roma [ ]
   - Russian [ ]
   - Slovakian [ ]
   - Other [ ]
   - Is there a Roma-mediator in your community?
     - Yes [ ]
     - No [ ]
     - I don’t know [ ]

5. **What is your mother tongue? (Check all that apply)**
   - Romanian [ ]
   - Roma [ ]
   - Hungarian [ ]
   - German [ ]
   - Ukrainian [ ]
   - Moldovan [ ]
   - Russian [ ]
   - Slovakian [ ]
   - Other [ ]

6. **How well do you speak romanian?**
   - Very well [ ]
   - Well [ ]
   - Badly [ ]
   - Not at all [ ]
YOUR COMMUNITY

Questions 7 – 11 are regarding your community (the place where you live and the people you live together with: friends, families and neighbors).

<table>
<thead>
<tr>
<th></th>
<th>7. Do you feel that you are part of a community?</th>
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<tbody>
<tr>
<td></td>
<td>☐ Yes ☐ No ☐ I don’t know</td>
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<tr>
<th></th>
<th>8. Is it important for you to be part of this community?</th>
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<td></td>
<td>☐ Yes ☐ No ☐ I don’t know</td>
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<tr>
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<th>9. Will members of your community take care of each other’s children, for example if some of us need to run errands or visit the GP</th>
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<tbody>
<tr>
<td></td>
<td>☐ Yes ☐ No ☐ I don’t know</td>
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<th></th>
<th>10. If you don’t have enough food to eat, will your community help you?</th>
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<tr>
<td></td>
<td>☐ Yes ☐ No ☐ I don’t know</td>
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<th>11. If you have questions related to your health, with whom would you discuss these issues (Check all that apply)?</th>
</tr>
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<tbody>
<tr>
<td></td>
<td>☐ My family ☐ My friends ☐ Roma leaders ☐ Roma mediators ☐ Health personnel</td>
</tr>
<tr>
<td></td>
<td>☐ Others</td>
</tr>
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WORK SITUATION

Questions 12 – 14 are regarding your daily activities/working situation

<table>
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<tr>
<th></th>
<th>12. What best describes what you do every day?</th>
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<tr>
<td></td>
<td>☐ I am employed ☐ I am self-employed ☐ I am studying / undergoing training</td>
</tr>
<tr>
<td></td>
<td>☐ Work at home ☐ Housewife ☐ I am retired ☐ I do not work</td>
</tr>
<tr>
<td></td>
<td>☐ Others</td>
</tr>
</tbody>
</table>
13. **Approximately how many hours do you work every week, outside the home?**

- [ ] Less than 10 hours
- [ ] Between 11 and 20 hours
- [ ] Between 21 and 30 hours
- [ ] More than 30 hours
- [ ] It varies

14. **What of the following best describes the type of work you do?**

- [ ] Cleaning
- [ ] Farming
- [ ] Sales
- [ ] Service
- [ ] Health services
- [ ] School system
- [ ] Office work
- [ ] Garbage and refuse collection
- [ ] Other

**ECONOMY AND LIVING CONDITIONS**

Questions 15-21 are regarding your socioeconomic status

15. **Do you have health insurance?**

- [ ] Yes
- [ ] No
- [ ] I am not sure
- [ ] I do not know what health insurance is

16. **How many people do you live together with?**

- [ ] People

17. **If you live in a house or flat: How many rooms does it have? (Include all rooms)**

- [ ] Room(s)

18. **In what ways do you usually wash yourselves? (Check all that apply)**

- [ ] I take a shower in a bathroom
- [ ] I take a bath in a bathtub
- [ ] I wash myself in a sink
- [ ] I wash myself using a basin
- [ ] I wash myself in a river, pond or lake
- [ ] I wash myself in public baths
## 19. Approximately how often do you take a shower or a bath?

- [ ] Every day
- [ ] Between 2 and 5 times a week
- [ ] Once a week
- [ ] Once every 14 day
- [ ] Once a month
- [ ] Less than once a month

## 20. Indicate what of the following you own (Check all that apply)

- [ ] Clothes to use for all seasons
- [ ] A mobile phone
- [ ] TV
- [ ] PC
- [ ] A refrigerator
- [ ] A bed
- [ ] A car
- [ ] A flat
- [ ] A house

## 21. Overall, how would you rate your own health?

- [ ] Excellent
- [ ] Very good
- [ ] Good
- [ ] Satisfactory
- [ ] Poor
- [ ] I don’t know

### SEXUAL RELATIONS AND CONTRACEPTION

Questions 22 - 27 are regarding sexual relationships and contraception

## 22. Have you ever had sexual intercourse?

- [ ] Yes
- [ ] No

## 23. If yes, what was your age when you had your first sexual intercourse?

I was [ ] [ ] years

- [ ] I am not sure

## 24. What was the age of the partner you had your first sexual intercourse with?

He/she was [ ] [ ] years

- [ ] I am not sure
25. What kind of contraceptive method have you used (Check all that apply)?

- [ ] Condom
- [ ] Birth control pills
- [ ] IUD
- [ ] Secure periods (calendar method)
- [ ] Coitus interrupts / withdrawal
- [ ] Sterilization
- [ ] Injections
- [ ] Other
- [ ] None

26. When you think back on your life, how many partners have you had sexual intercourse with?

- [ ] Sexual partners
- [ ] I am not sure
- [ ] I don’t want to answer this question

27. How many partners had you had sexual intercourse with before you turned 18 years old?

- [ ] Sexual partners
- [ ] I am not sure
- [ ] I don’t want to answer this question

PREGNANCIES AND CHILDREN

Questions 28 – 29 are regarding pregnancies and children.

28. How many children alive or dead do you have? (Enter 0 if none)

- [ ] Children alive
- [ ] Children dead

29. How many induced abortions you have had? (Enter 0 if none)

- [ ] Induced abortions

HEALTHCARE SYSTEM

Questions 30 - 51 are regarding your experiences with your general practitioner (GP) and gynecologist.
30. Do you have a GP?

☐ Yes  ☐ No  ☐ I am not sure

↓

Is your GP in the national screening programme?

☐ Yes  ☐ No  ☐ I don’t know

31. When you visited your GP, did any at the office (Check all that apply):

☐ Talk to you about cervical cancer screening?

☐ Offered to give you a referral to the gynecologist for screening?

☐ Offered you to have a screening test at the clinic?

☐ Offered you a flyer about cervical cancer screening?

☐ None of the above

32. Have you ever taken a screening-test (Pap-smear/HPV-test) from the cervix?

☐ No

↓

Why have you never taken a screening-test?

☐ Because I did not know that I could

☐ Because I did not know it was important to my health

☐ Because of the distance to the doctor

☐ Because it takes to long time to first travel to the GP and get a referral and then travel to the gynecologist

☐ Because I don’t have the time

☐ Because I don’t have money

☐ Because I am afraid of the results

☐ Because I don’t trust the Healthcare system

☐ Others

↓

Who took your last screening-test?

☐ Yes  ☐ I don’t know

☐ Gynecologist

☐ GP

☐ Mobil unit

☐ I don’t remember
33. Whom do you prefer to take your screening test?

- I prefer my GP from my community
- I prefer another GP
- I prefer to receive a referral from my GP and take the screening test at a gynecologist
- I prefer to take a screening test by mobil unit
- Others

34. If I take a screening test (Pap-smear/HPV test) from my cervix, the doctor needs to be:

- A man
- A woman
- I don’t care if the doctor is a man or a women

35. During the last 10 years approximately how many times have you taken a screening-test (Pap-smear/HPV test)?

- Once
- Twice
- Three times
- Four times
- Five times
- More than five times

36. Did you have to pay for the test, last time you took a screening-test?

- Yes
- No
- I don’t remember

37. What kind of transport do you typically use when you are going to:

**The gynecologist:**

- I walk
- I ride a bicycle
- I take a bus or train
- I go by car
- I use other transport

**The GP:**

- I walk
- I ride a bicycle
- I take a bus or train
- I go by car
- I use other transport
38. How long time does it take to travel from your home to the:

**The gynecologist:**
- [ ] Hours
- [ ] Minutes

**The GP:**
- [ ] Hours
- [ ] Minutes

39. Thinking of the last time you visited the gynecologist/GP: how long time did you have to wait before you were attended to by:

**The gynecologist:**
- [ ] Under 30 minutes
- [ ] Between 30 and 60 minutes
- [ ] Between 1 and 2 hours
- [ ] Between 2 and 3 hours
- [ ] More than 3 hours

**The GP:**
- [ ] Under 30 minutes
- [ ] Between 30 and 60 minutes
- [ ] Between 1 and 2 hours
- [ ] Between 2 and 3 hours
- [ ] More than 3 hours

40. The last time you visited the health care professional. Did you experience that he/she/they made you feel good about yourself?

**The gynecologist:**
- [ ] Yes
- [ ] No
- [ ] I don’t know

**The GP:**
- [ ] Yes
- [ ] No
- [ ] I don’t know

41. The last time you visited the health care professional. Did you experience that he/she/they respected you?

**The gynecologist:**
- [ ] Yes
- [ ] No
- [ ] I don’t know

**The GP:**
- [ ] Yes
- [ ] No
- [ ] I don’t know
<table>
<thead>
<tr>
<th>Question</th>
<th>The gynecologist</th>
<th>The GP</th>
</tr>
</thead>
<tbody>
<tr>
<td>42. The last time you visited the health care professional. Did you experience that he/she/they called you bad names?</td>
<td></td>
<td></td>
</tr>
<tr>
<td>□ Yes</td>
<td>■ Yes</td>
<td></td>
</tr>
<tr>
<td>□ No</td>
<td>■ No</td>
<td></td>
</tr>
<tr>
<td>□ I don’t know</td>
<td>■ I don’t know</td>
<td></td>
</tr>
<tr>
<td>43. The last time you visited the health care professional. Did you experience that he/she/they hinted you were dishonest?</td>
<td></td>
<td></td>
</tr>
<tr>
<td>□ Yes</td>
<td>■ Yes</td>
<td></td>
</tr>
<tr>
<td>□ No</td>
<td>■ No</td>
<td></td>
</tr>
<tr>
<td>□ I don’t know</td>
<td>■ I don’t know</td>
<td></td>
</tr>
<tr>
<td>44. The last time you visited the health care professional. Did you experience that he/she/they were good to speak to?</td>
<td></td>
<td></td>
</tr>
<tr>
<td>□ Yes</td>
<td>■ Yes</td>
<td></td>
</tr>
<tr>
<td>□ No</td>
<td>■ No</td>
<td></td>
</tr>
<tr>
<td>□ I don’t know</td>
<td>■ I don’t know</td>
<td></td>
</tr>
<tr>
<td>45. The last time you visited the health care professional. Did you experience that he/she/they hinted you are stupid?</td>
<td></td>
<td></td>
</tr>
<tr>
<td>□ Yes</td>
<td>■ Yes</td>
<td></td>
</tr>
<tr>
<td>□ No</td>
<td>■ No</td>
<td></td>
</tr>
<tr>
<td>□ I don’t know</td>
<td>■ I don’t know</td>
<td></td>
</tr>
</tbody>
</table>
46. The last time you visited the health care professional. Did you experience that he/she/they cared about you?

**The gynecologist:**
- [ ] Yes
- [ ] No
- [ ] I don’t know

**The GP:**
- [ ] Yes
- [ ] No
- [ ] I don’t know

47. The last time you visited the health care professional. Did you experience that he/she/they took you seriously?

**The gynecologist:**
- [ ] Yes
- [ ] No
- [ ] I don’t know

**The GP:**
- [ ] Yes
- [ ] No
- [ ] I don’t know

48. The last time you visited the health care professional. Did you experience that he/she/they examined you in a gentle manner?

**The gynecologist:**
- [ ] Yes
- [ ] No
- [ ] I don’t know

**The GP:**
- [ ] Yes
- [ ] No
- [ ] I don’t know

49. The last time you visited the health care professional. Did you experience that he/she/they hinted you were dirty or smelly?

**The gynecologist:**
- [ ] Yes
- [ ] No
- [ ] I don’t know

**The GP:**
- [ ] Yes
- [ ] No
- [ ] I don’t know
50. The last time you visited the health care professional. Did you experience that he/she/they informed you about your health in an understandable way?

**The gynecologist:**
- □ Yes
- □ No
- □ I don’t know

**The GP:**
- □ Yes
- □ No
- □ I don’t know

51. The last time you visited the health care professional. Did you experience that he/she/they had time to listen to what you had to say?

**The gynecologist:**
- □ Yes
- □ No
- □ I don’t know

**The GP:**
- □ Yes
- □ No
- □ I don’t know

---

**CERVICAL CANCER**
Questions 52-69 are regarding cervical cancer and screening

52. What do you believe about your own risk of developing cervical cancer?

- □ I believe I have no risk
- □ I believe I have little risk
- □ I believe I have medium risk
- □ I believe I have high risk
- □ I don’t know

53. Do you think that cervical cancer is curable?

- □ Yes
- □ No
- □ I am not sure
54. Have you ever heard of cervical cancer screening / Pap-smear?

☐ Yes  ☐ No  ☐ I am not sure

If yes, by whom have you hear about cervical cancer screening? (Check all that apply)

☐ From TV  ☐ From radio  ☐ From school  ☐ From friends

☐ From family  ☐ From health personnel  ☐ From others

55. Do you believe there is a national cervical cancer preventing programme in Romania?

☐ Yes  ☐ No  ☐ I am not sure

56. Have you ever heard about human papillomavirus, HPV?

☐ Yes  ☐ No  ☐ I am not sure

57. Do you need permission from someone else if you were to take a screening-test (Pap-smear/HPV-test)?

☐ Yes  ☐ No  ☐ I don’t know

If yes, from whom do you need permission? (Check all that apply)

☐ My husband  ☐ My mother  ☐ My mother in law  ☐ My father

☐ Other family member  ☐ The Roma mediator  ☐ The Roma leader  ☐ Others

58. Do you think it is embarrassing to take a screening-test?

☐ Yes  ☐ No  ☐ I don’t know

59. Do you think it is painful to take a screening-test?

☐ Yes  ☐ No  ☐ I don’t know
<table>
<thead>
<tr>
<th>Question</th>
<th>Option 1</th>
<th>Option 2</th>
<th>Option 3</th>
<th>Option 4</th>
</tr>
</thead>
<tbody>
<tr>
<td>60. Do you think that to take a screening-test would leads to worriers?</td>
<td>Yes</td>
<td>No</td>
<td>I don’t know</td>
<td></td>
</tr>
<tr>
<td>61. Do you think that it is only necessary to take a screening-test if you have symptoms from the womb?</td>
<td>Yes</td>
<td>No</td>
<td>I don’t know</td>
<td></td>
</tr>
<tr>
<td>62. Would you like to take a screening-test this year?</td>
<td>Yes</td>
<td>No</td>
<td>I don’t know</td>
<td></td>
</tr>
<tr>
<td>Why would you not like to take a screening-test the year? (Check all that apply)</td>
<td>Because I put my life in Gods hands</td>
<td>Because I believe that what happens happens</td>
<td>Because I just took a screening-test</td>
<td>Because I don’t care if I live or die</td>
</tr>
<tr>
<td>63. Is it difficult for you to find the time to take a screening-test?</td>
<td>Yes</td>
<td>No</td>
<td>I don’t know</td>
<td></td>
</tr>
<tr>
<td>64. Is it expensive for you to take a screening-test?</td>
<td>Yes</td>
<td>No</td>
<td>I don’t know</td>
<td></td>
</tr>
<tr>
<td>65. Do you think that you would receive free of charge treatment if you had cervical cancer?</td>
<td>Yes</td>
<td>No</td>
<td>I don’t know</td>
<td></td>
</tr>
<tr>
<td>66. Do you have faith in the health care system?</td>
<td>Yes</td>
<td>No</td>
<td>I don’t know</td>
<td></td>
</tr>
<tr>
<td>67. Do you care about your health?</td>
<td>Yes</td>
<td>No</td>
<td>I don’t know</td>
<td></td>
</tr>
<tr>
<td>Who has filled out this questionnaire?</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>---------------------------------------</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Self</td>
<td>Assistant</td>
<td>Others</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>What district are you from</th>
</tr>
</thead>
<tbody>
<tr>
<td>Urban</td>
</tr>
</tbody>
</table>
Attachment 3
CHESTIONAR PRIVIND SĂNĂTATEA FEMEILOR
CHESTIONAR PRIVIND SĂNĂTATEA FEMEILOR

Scopul principal al acestui proiect este să studieze dacă femeile din România vor participa la un program național de screening pentru cancerul de col uterin. Pentru a afla răspunsul la această întrebare trebuie să înțelegem viața femeilor așa cum este trăită de ele și ce gândesc femeile legat de sănătatea lor, boală, cancer și programul de screening.

Veți vedea că unele dintre întrebările din acest chestionar sunt personale. La altele poate fi dificil să dați un răspuns exact, de exemplu să spuneți vârsta la care vi s-au întâmplat anumite lucruri. Alte întrebări se referă la mediul și la experiențele dumneavoastră de viață. Dacă nu puteți răspunde exact la o întrebare, vă rugăm să approximați cât de bine posibil. Aveți dreptul să nu răspundeți la întrebările la care nu doriți să răspundeți, totuși sperăm că veți răspunde la toate întrebările pentru că răspunsurile dumneavoastră sunt importante în efortul de a preveni cancerul de col uterin.

Vă rugăm să răspundeți la întrebări în numele dumneavoastră. Răspunsurile vor rămâne anonime. Asta înseamnă că nimeni nu va putea face legătura între dumneavoastră și răspunsurile pe care le dați.

Când completați chestionarul, vă rugăm să nu uitați că nu există răspunsuri “corecte” și răspunsuri “greșite”. Este FOARTE important să răspundeți cât mai exact și mai sincer, la fiecare întrebare.

◇ Marcați cu X răspunsul corect pentru situația dvs: ☒

◇ Dacă bifați o căsuță greșită, vă rugăm să o colorați în întregime, astfel: apoi să marcați cu X căsuța corectă.

VĂ MULȚUMIM PENTRU AJUTOR
# ÎNTREBĂRI LEGATE DE DATELE DUMNEAVOASTĂ PERSONALE

Întrebările 1 – 6 privesc istoria dumneavoastră personală.

1. În ce an v-ați născut?

<p>| | |</p>
<table>
<thead>
<tr>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>19</td>
<td></td>
</tr>
</tbody>
</table>

2. În acest moment, care este starea dumneavoastră civilă?

- [ ] Singură
- [ ] Concubinaj
- [ ] Căsătorită
- [ ] Divorțată / separată
- [ ] Văduvă

3. Câți ani de școală aveți?

- [ ] Niciunul
- [ ] 1 - 4 ani
- [ ] 5 - 8 ani
- [ ] 9 - 12 ani
- [ ] peste 12 ani (studii superioare)

4. Cărui grup etnic considerați dumneavoastră că aparțineți? (Răspundeți în numele dumneavoastră, nu a părinților sau a altor membri ai familiei):

- [ ] Român
- [ ] Maghiar
- [ ] German
- [ ] Ucrainean
- [ ] Roma
- [ ] Rus
- [ ] Slovac
- [ ] Altul

**In comunitatea voastră exista mediator sanitar?**

- [ ] Da
- [ ] Nu
- [ ] Nu știu

5. Care este limba dumneavoastră maternă? (limba vorbită acasă în copilărie)

- [ ] Română
- [ ] Maghiară
- [ ] Germană
- [ ] Ucrainiană
- [ ] Romanes
- [ ] Rusă
- [ ] Slovacă
- [ ] Alta

6. Cât de bine vorbiți românește:

- [ ] Foarte bine
- [ ] Bine
- [ ] Râu
- [ ] Deloc
COMUNITATEA DIN CARE FACEȚI PARTE

Întrebările 7-11 se referă la comunitatea din care faceți parte (locul și oamenii alături de care trăiți).

7. Considerați că faceți parte dintr-o comunitate?
- Da
- Nu
- Nu știu

8. Faptul că faceți parte din această comunitate este important pentru dumneavoastră?
- Da
- Nu
- Nu știu

9. Membrii acestei comunități au grijă unii de copii altora, de exemplu când unii dintre voi trebuie să mergeți în oraș cu treburi sau la doctorul de familie?
- Da
- Nu
- Nu știu

10. Dacă nu aveți suficientă mâncare, comunitatea vă ajută?
- Da
- Nu
- Nu știu

11. Cu cine discutați dacă aveți întrebări legate de starea dumneavoastră de sănătate?
- Cu familia mea
- Cu prietenii mei
- Cu liderii comunității roma
- Cu mediatorii roma
- Cu personalul medical
- Cu alții

OCUPAȚIA DUMNEAVOASTRĂ

Întrebările 12 – 14 privesc activitățile dumneavoastră zilnice/ocupația dumneavoastră.

12. Care dintre afirmațiile de mai jos descrie cel mai bine ceea ce faceți zi de zi? (un singur răspuns care descrie cel mai bine ce ocupație aveți)
- Angajată
- Liber profesionist
- Studiez/Sunt în practică
- Munca la domiciliu
- Casnică
- Sunt pensionară
- Nu lucrez
- Altceva
13. Aproximativ câte ore lucrați pe săptămână, în afara casei?

☐ Mai puțin de 10 ore  ☐ Între 11 și 20 de ore  ☐ Între 21 și 30 de ore

☐ Mai mult de 30 de ore  ☐ Depinde de la săptămână la săptămână

14. Care dintre afirmațiile de mai jos decrie cel mai bine ceea ce faceți?

☐ Curățenie  ☐ Muncă agricolă  ☐ Vânzări  ☐ Servicii  ☐ Cabinet medical

☐ Invatamant  ☐ Muncă la birou  ☐ Colectarea de gunoi și materiale reciclabile

☐ Altceva

SITUAȚIA FINANCIARĂ ȘI CONDIȚII DE VIAȚĂ

Întrebările 15 – 21 privesc situația dumneavoastră socio-economică:

15. Aveți asigurare de sănătate?

☐ Da  ☐ Nu  ☐ Nu sunt sigură  ☐ Nu știu ce înseamnă “asigurare de sănătate”

16. Împreună cu câte alte persoane locuiți?

☐ ☐ Persoane

17. Dacă locuiți într-o casă sau un apartament, câte încăperi are aceasta/aceasta? (includeți toate încăperile inclusiv baia și bucătăria)

☐ ☐ Camere

18. Cum vă spălați de obicei? (Bifați toate afirmațiile corecte în cazul dumneavoastră)

☐ Fac duș în baie  ☐ Fac baie în cadă  ☐ Mă spăl la chiuvetă

☐ Mă spăl în lighean/vană  ☐ Mă spăl în râu, iaz sau lac

☐ Mă spăl la baia publică
19. Aproximativ cât de des faceți duș sau baie?

☐ În fiecare zi    ☐ Între 2 și 5 ori pe săptămână    ☐ O dată pe săptămână
☐ O dată la 14 zile    ☐ O dată pe lună    ☐ Mai rar de o dată pe lună

20. Ce aveți dintre cele de mai jos? (bifați toate răspunsurile corecte în cazul dumneavoastră):

☐ Haine potrivite pentru toate anotimpurile    ☐ Telefon mobil    ☐ Televizor
☐ Calculator    ☐ Frigider    ☐ Pat    ☐ Mașină    ☐ Apartament    ☐ Casă

21. Cum ați descrie starea dumneavoastră de sănătate?

☐ Excelentă    ☐ Foarte bună    ☐ Bună    ☐ Satisfăcătoare
☐ Proastă    ☐ Nu știu

RELĂȚII SEXUALE ȘI METODE CONTRACEPTIVE

Întrebările 22 –27 privesc relațiile sexuale și metodele contraceptive.

22. Ați avut relații sexuale?

☐ Da    ☐ Nu

23. Dacă da, la ce vârstă ați avut primul contact sexual?

Avem ☐ ☐ ani    ☐ Nu sunt sigură

24. Ce vârstă avea partenerul cu care ați avut primul contact sexual?

El/ea avea ☐ ☐ ani    ☐ Nu sunt sigură
25. Ce fel de metode contraceptive ați folosit? (Puteți bifa mai multe căsuțe)

☐ Prezervativ  ☐ Pilula contraceptive  ☐ Dispozitiv intrauterin (sterilet)
☐ Metoda calendarului (zilele sigure)  ☐ Coitus interrupts / retragere  ☐ Sterilizare
☐ Injecții  ☐ Altele  ☐ Nimic

26. Câți parteneri sexauli ați avut de când v-ați început viața sexuală și până acum?

☐ ☐ ☐ Parteneri sexauli  ☐ Nu știu
☐ Nu doresc să răspund la această întrebare

27. Câți parteneri sexauli ați avut înainte de a împlini vârsta de 18 ani?

☐ ☐ ☐ Parteneri sexauli înainte să împlinesc 18 ani  ☐ I am not sure
☐ Nu doresc să răspund la această întrebare

SARCINI ȘI COPII

Întrebările 28 – 29 privesc sarcinile avute și copiii:

28. Câți copii aveți (în viață sau decedați)? Scrieți 0 dacă nu aveți

☐ ☐ Copii în viață  ☐ ☐ Copii decedați

29. Câte avorturi la cerere ați făcut?

☐ ☐ Scrieți 0 dacă nu ați făcut

SISTEMUL DE SANATATE

Întrebările 30– 51 privesc experiențele dumneavoastră cu medicul de familie și medicul ginecolog
30. Aveți medic de familie?

☐ Da  ☐ Nu  ☐ Nu sunt sigură

↓

Medicul de familie face parte din programul național de screening pentru depistarea cancerului de col uterin?

☐ Da  ☐ Nu  ☐ Nu stiu

31. La cabinetul medicului de familie, medicul/asistenta:

☐ V-a vorbit despre screening pentru depistarea cancerului de col uterin?
☐ V-a oferit o trimitere catre medicul ginecolog pentru screening?
☐ V-a oferit sa va recolteze testul la cabinet?
☐ V-a oferit pliante informative cu privire la screeningul?
☐ Nimic

32. Vi s-au recoltat vreodată testul pentru screening (test Papanicolaou sau HPV) din colul uterin?

☐ Nu  ☐ Da  ☐ Nu stiu

↓

Dacă ați răspuns ‘NU’, bifați căsuțele care explică de ce nu ați făcut niciodată acest fel de test. (Puteți bifa mai multe căsuțe.)

☐ Pentru că nu am știut că pot
☐ Pentru că nu cred că e important pentru sănătatea mea
☐ Pentru că distanța până la medic e prea mare
☐ Pentru ca mi se pare mult sa trebuiască merg la medicul de familie pentru formular si sa merg apoi si la ginecolog
☐ Pentru că nu am timp
☐ Pentru că nu am bani
☐ Pentru că mi-e frică de rezultate
☐ Pentru că nu-mi pasă dacă trăiesc sau nu
☐ Pentru că nu am încredere în sistemul de sănătate
☐ Altele, vă rugăm să le scrieți în căsuța alaturata

↓

Dacă da: Cine v-a recoltat ultimul test?

☐ Medicul ginecolog
☐ Medicul de familie
☐ Nu mai stiu
☐ Unitatea mobila
33. Cine ați prefera să vă recolteze testul screening pentru depistarea cancerului de col uterin?

- [ ] Medicul dumneavoastră de familie
- [ ] Un alt medic de familie în comunitatea dumneavoastră
- [ ] Să cereti de la medicul dumneavoastră de familie o trimitere și să mergeți apoi la un medic ginecolog
- [ ] Unitatea mobilă de recoltare atunci când vine la dumneavoastră în comunitate
- [ ] Altceva, vă rugăm să le scrieți în căsuța de mai jos

34. Dacă participați la un test screening pentru depistarea cancerului de colului uterin (test Papanicolaou sau HPV), medicul trebuie să fie:

- [ ] Bărbat
- [ ] Femeie
- [ ] Nu contează dacă e bărbat sau femeie

35. De câte ori în cursul vieții vi s-a recoltat testul pentru screening?

- [ ] O dată
- [ ] De două ori
- [ ] De trei ori
- [ ] De 4 ori
- [ ] De 5 ori
- [ ] De mai mult de 5 ori

36. Ultima oară când vi s-a recoltat testul a trebuit să plătiți?

- [ ] Da
- [ ] Nu
- [ ] Nu mai știu
37. Cu ce mijloc de transport ajungeți de obicei la cabinetul medicului ginecolog?

<table>
<thead>
<tr>
<th>Medic Ginecolog</th>
<th>Medic de familie</th>
</tr>
</thead>
<tbody>
<tr>
<td>□ Merg pe jos</td>
<td>□ Merg pe jos</td>
</tr>
<tr>
<td>□ Cu bicicleta</td>
<td>□ Cu bicicleta</td>
</tr>
<tr>
<td>□ Cu autobuzul sau trenul</td>
<td>□ Cu autobuzul sau trenul</td>
</tr>
<tr>
<td>□ Cu mașina</td>
<td>□ Cu mașina</td>
</tr>
<tr>
<td>□ Cu alt mijloc de transport</td>
<td>□ Cu alt mijloc de transport</td>
</tr>
</tbody>
</table>

38. Cât timp faceți de acasă până la cabinet?

<table>
<thead>
<tr>
<th>Medic Ginecolog</th>
<th>Medic de familie</th>
</tr>
</thead>
<tbody>
<tr>
<td>□ Ore</td>
<td>□ Ore</td>
</tr>
<tr>
<td>□ □ Minute</td>
<td>□ □ Minute</td>
</tr>
</tbody>
</table>

39. Ultima dată când ați fost la cabinetul medicului ginecolog, cât timp a trebuit să așteptați până să fiți consultată?

<table>
<thead>
<tr>
<th>Medic Ginecolog</th>
<th>Medic de familie</th>
</tr>
</thead>
<tbody>
<tr>
<td>□ Mai puțin de 30 de minute</td>
<td>□ Mai puțin de 30 de minute</td>
</tr>
<tr>
<td>□ între 30 și 60 de minute</td>
<td>□ între 30 și 60 de minute</td>
</tr>
<tr>
<td>□ între 1 și 2 ore</td>
<td>□ între 1 și 2 ore</td>
</tr>
<tr>
<td>□ între 2 și 3 ore</td>
<td>□ între 2 și 3 ore</td>
</tr>
<tr>
<td>□ Mai mult de 3 ore</td>
<td>□ Mai mult de 3 ore</td>
</tr>
</tbody>
</table>

Mai jos sunt mai multe afirmații legate de ultimul contact pe care l-ați avut cu sistemul de sănătate. Vă rugăm să bifați dacă sunteți de acord cu acestea sau nu.
<table>
<thead>
<tr>
<th>40. Ultima dată când ați fost la medic, v-ați simțit în largul dumneavoastră?</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Medic Ginecolog</strong></td>
</tr>
<tr>
<td>□ Da</td>
</tr>
<tr>
<td>□ Nu</td>
</tr>
<tr>
<td>□ Nu știu</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>41. Ultima dată când ați fost la medic v-au tratat cu respect?</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Medic Ginecolog</strong></td>
</tr>
<tr>
<td>□ Da</td>
</tr>
<tr>
<td>□ Nu</td>
</tr>
<tr>
<td>□ Nu știu</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>42. Ultima dată când ați fost la medic, v-au insultat?</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Medic Ginecolog</strong></td>
</tr>
<tr>
<td>□ Da</td>
</tr>
<tr>
<td>□ Nu</td>
</tr>
<tr>
<td>□ Nu știu</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>43. Ultima dată când ați fost la medic, v-au făcut să vă simțiți ca și cum v-ar considera necinstită/nedemnă de încredere?</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Medic Ginecolog</strong></td>
</tr>
<tr>
<td>□ Da</td>
</tr>
<tr>
<td>□ Nu</td>
</tr>
<tr>
<td>□ Nu știu</td>
</tr>
<tr>
<td>44. Ultima dată când ați fost la medic, v-au ascultat?</td>
</tr>
<tr>
<td>---------------------------------------------------</td>
</tr>
<tr>
<td><strong>Medic Ginecolog</strong></td>
</tr>
<tr>
<td>Da</td>
</tr>
<tr>
<td>Nu</td>
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<tr>
<td>Nu știu</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>45. Ultima dată când ați fost la medic, v-au făcut să vă simțiți ca și cum v-ar considera prost/proastă?</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Medic Ginecolog</strong></td>
</tr>
<tr>
<td>Da</td>
</tr>
<tr>
<td>Nu</td>
</tr>
<tr>
<td>Nu știu</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>46. Ultima dată când ați fost la medic, le-a păsat de dumneavoastră?</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Medic Ginecolog</strong></td>
</tr>
<tr>
<td>Da</td>
</tr>
<tr>
<td>Nu</td>
</tr>
<tr>
<td>Nu știu</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>47. Ultima dată când ați fost la medic, v-au luat în serios?</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Medic Ginecolog</strong></td>
</tr>
<tr>
<td>Da</td>
</tr>
<tr>
<td>Nu</td>
</tr>
<tr>
<td>Nu știu</td>
</tr>
</tbody>
</table>
48. Ultima dată când ați fost la medic, v-au consultat cu blândețe?

<table>
<thead>
<tr>
<th>Medic Ginecolog</th>
<th>Medic de familie</th>
</tr>
</thead>
<tbody>
<tr>
<td>Da</td>
<td>Da</td>
</tr>
<tr>
<td>Nu</td>
<td>Nu</td>
</tr>
<tr>
<td>Nu știu</td>
<td>Nu știu</td>
</tr>
</tbody>
</table>

49. Ultima dată când ați fost la medic, v-au făcut să vă simțiți ca și cum v-ar considera murdară?

<table>
<thead>
<tr>
<th>Medic Ginecolog</th>
<th>Medic de familie</th>
</tr>
</thead>
<tbody>
<tr>
<td>Da</td>
<td>Da</td>
</tr>
<tr>
<td>Nu</td>
<td>Nu</td>
</tr>
<tr>
<td>Nu știu</td>
<td>Nu știu</td>
</tr>
</tbody>
</table>

50. Ultima dată când ați fost la medic, v-au explicat pe înțelesul dumneavoastră problemele de sănătate pe care le aveți?

<table>
<thead>
<tr>
<th>Medic Ginecolog</th>
<th>Medic de familie</th>
</tr>
</thead>
<tbody>
<tr>
<td>Da</td>
<td>Da</td>
</tr>
<tr>
<td>Nu</td>
<td>Nu</td>
</tr>
<tr>
<td>Nu știu</td>
<td>Nu știu</td>
</tr>
</tbody>
</table>

51. Ultima dată când ați fost la medic, au avut timp să asculte tot ce ați vrut să le spuneți?

<table>
<thead>
<tr>
<th>Medic Ginecolog</th>
<th>Medic de familie</th>
</tr>
</thead>
<tbody>
<tr>
<td>Da</td>
<td>Da</td>
</tr>
<tr>
<td>Nu</td>
<td>Nu</td>
</tr>
<tr>
<td>Nu știu</td>
<td>Nu știu</td>
</tr>
</tbody>
</table>
**PREVENIREA CANCERULUI DE COL UTERIN**

Întrebările 52 - 69 se referă la cancerul de col uterin și la screeningul pentru depistarea precoce.

<table>
<thead>
<tr>
<th>52. Credeți că dumneavoastră ați putea face cancer de col uterin?</th>
</tr>
</thead>
<tbody>
<tr>
<td>□ Nu, cred că nu există acest risc   □ Cred că există un risc mic</td>
</tr>
<tr>
<td>□ Cred că există un risc mediu   □ Cred că riscul este mare   □ Nu știu</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>53. Credeți că e posibil să te vindeci de cancer de col uterin?</th>
</tr>
</thead>
<tbody>
<tr>
<td>□ Da   □ Nu   □ Nu sunt sigură</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>54. Ați auzit vreodată de examenul Babeș-Papanicolaou/testul pentru depistarea cancerului de col?</th>
</tr>
</thead>
<tbody>
<tr>
<td>□ Da   □ Nu   □ Nu sunt sigură</td>
</tr>
</tbody>
</table>

**Daca “DA”, de unde ați auzit de examenul Babeș-Papanicolaou/testul pentru depistarea cancerului de col?**

| □ TV   □ Radio   □ Scoală   □ Prietenii |
|-----|--------|-----|-----|
| □ Familie   □ Personal din sănătate (medic, asistentă)   □ Altele |

<table>
<thead>
<tr>
<th>55. Există în România program național de screening pentru cancer de col uterin?</th>
</tr>
</thead>
<tbody>
<tr>
<td>□ Da   □ Nu   □ Nu sunt sigură</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>56. Ați auzit vreodată de virusul papilloma uman, HPV?</th>
</tr>
</thead>
<tbody>
<tr>
<td>□ Da   □ Nu   □ Nu sunt sigură</td>
</tr>
</tbody>
</table>
57. Trebuie să ceri voie de la cineva pentru a putea participa la un test de screening (test Papanicolaou sau HPV)?

- □ Da
- □ Nu
- □ Nu ştiu

**Dacă da, cu cine trebuie să îi ceri voie?** Marcați cu X toate căsuțele care vi se potrivesc:

- □ Soțului meu
- □ Mamei mele
- □ Soarei mele
- □ Tatălui meu
- □ Altui membru al familiei
- □ Mediatorului romă
- □ Leaderului romă
- □ Altcuiva

58. Credeți că efectuarea testului este jenanta/ruşinoasă?

- □ Da
- □ Nu
- □ Nu ştiu

59. Credeți că procedura de recoltare este dureroasă?

- □ Da
- □ Nu
- □ Nu ştiu

60. V-ar fi frică de rezultat?

- □ Da
- □ Nu
- □ Nu ştiu

61. Credeți că trebuie să faceți testul doar dacă aveți simptome (dacă aveți manifestări neplăcute)?

- □ Da
- □ Nu
- □ Nu ştiu

62. Doriți să faceți testul anul acesta?

- □ Da
- □ Nu
- □ Nu ştiu

**Nu doriți să faceți testul anul acesta pentru că:**

- □ Pentru că mă las în voia Domnului
- □ Pentru că merg pe mâna destinului
- □ Pentru că tocmai a făcut testul
- □ Pentru că nu imi pasa daca traiesc sau mor
- □ Alt motiv
63. E greu să găsiți timp pentru a participa la programul de recoltare?

<table>
<thead>
<tr>
<th></th>
<th>Da</th>
<th>Nu</th>
<th>Nu știu</th>
</tr>
</thead>
</table>

64. Este scump să participați la programul de recoltare?

<table>
<thead>
<tr>
<th></th>
<th>Da</th>
<th>Nu</th>
<th>Nu știu</th>
</tr>
</thead>
</table>

65. Credeți că dacă v-ați îmbolnăvi de cancer de col uterin, ați primi tratamentul necesar gratuit?

<table>
<thead>
<tr>
<th></th>
<th>Da</th>
<th>Nu</th>
<th>Nu știu</th>
</tr>
</thead>
</table>

66. Aveți încredere în sistemul de sănătate?

<table>
<thead>
<tr>
<th></th>
<th>Da</th>
<th>Nu</th>
<th>Nu știu</th>
</tr>
</thead>
</table>

67. Vă pasă de pasă de sănătatea dumneavoastră?

<table>
<thead>
<tr>
<th></th>
<th>Da</th>
<th>Nu</th>
<th>Nu știu</th>
</tr>
</thead>
</table>

Cine a completat acest chestionar?

<table>
<thead>
<tr>
<th></th>
<th>Eu</th>
<th>Un asistent</th>
<th>Altcineva</th>
</tr>
</thead>
</table>

Locuți în: județ

<table>
<thead>
<tr>
<th></th>
<th>Urban</th>
<th>Rural</th>
</tr>
</thead>
</table>
Attachment 4
Kvinner erfaringer med screening mot livmorhalskreft

Vennligst svar ved å krysse av ☒ for de/det mest passende svaret.
Vi håper du vil besvare alle spørsmålene, også de av personlig karakter. Vi ønsker svar fra deg om du har tatt livmorhalsprøve eller ikke. Dine svar er viktige i arbeidet med å forebygge livmorhalskreft.

BAKGRUNN

1. Hvilket år ble du født? 19 ☒ ☐

2. Hva er din sivilstatus i dag?
☐ Gift/samboer/partnerskap
☐ Har kjæreste, men vi bor ikke sammen
☐ Singel
☐ Skilt/separert
☐ Enke

3. Hvor mange års skolegang har du fullført (inkludert teoretiske studier og yrkesutdanning; rund av til nærmeste hele år)?
☐ Mindre enn 10 år
☐ 11-13 år
☐ 14-17 år
☐ Mer enn 17 år

4. Hvor er du født?
☐ Norge
☐ Europa (unntatt Norge)
☐ Afrika
☐ Amerika
☐ Asia
☐ Oseania

5. Hvor mange år har du bodd i Norge (rund av til nærmeste hele år)?
☐ 0 - 1 år
☐ 2-5 år
☐ 6-10 år
☐ 11-20 år
☐ 21 år eller mer
☐ Hele livet
HELSE

6. Stort sett, vil du si at din fysiske helse er:
   [ ] Utmerket
   [ ] Meget god
   [ ] God
   [ ] Nokså god
   [ ] Dårlig

7. I løpet av de siste to ukene, hvor ofte har du vært plaget av de følgende problemene? (For hver rad, sett ett kryss i den ruta som passer best)

<table>
<thead>
<tr>
<th></th>
<th>Ikke i det hele tatt</th>
<th>Noen dager</th>
<th>Mer enn halvparten av dagene</th>
<th>Nesten hver dag</th>
</tr>
</thead>
<tbody>
<tr>
<td>Følt deg nervøs, engstelig eller på tuppa...</td>
<td>[ ]</td>
<td>[ ]</td>
<td>[ ]</td>
<td>[ ]</td>
</tr>
<tr>
<td>Ikke klart å stoppe eller kontrollere bekymringene dine.</td>
<td>[ ]</td>
<td>[ ]</td>
<td>[ ]</td>
<td>[ ]</td>
</tr>
<tr>
<td>Følt deg nedfor, deprimert eller fylt av håpløshet...</td>
<td>[ ]</td>
<td>[ ]</td>
<td>[ ]</td>
<td>[ ]</td>
</tr>
<tr>
<td>Følt liten interesse eller glede av å gjøre ting...</td>
<td>[ ]</td>
<td>[ ]</td>
<td>[ ]</td>
<td>[ ]</td>
</tr>
</tbody>
</table>

SCREENING MOT LIVMORHALSKREFT

8. Før du leste vedlagte informasjon, visste du da at en livmorhalsprøve kan avdekke celleforandringer som ubehandlet kan føre til livmorhalskreft?
   [ ] Ja
   [ ] Nei
   [ ] Vet ikke

9. Hvis du svarte «ja» på det forrige spørsmålet, kan du huske hvor du fikk denne kunnskapen fra? (Det er mulig å sette flere kryss)
   [ ] Påminnelsebrev fra Kreftregisteret
   [ ] Fastlegen
   [ ] Gynekologen
   [ ] Annet helsepersonell
   [ ] Internett
   [ ] Media
   [ ] Familie/venner
   [ ] Helsestasjon
   [ ] Annet, spesifisér
   [ ] Husker ikke

10. Har du noen gang mottatt brev fra Kreftregisteret med påminnelse om å ta livmorhalsprøve?
    [ ] Ja
    [ ] Nei
    [ ] Vet ikke
11. Hvis du svarte «ja» på det forrige spørsmålet, hvordan reagerte du på dette brevet? (For hver rad, sett kryss i den ruta som passer best)

<table>
<thead>
<tr>
<th>Stemmer</th>
<th>Stemmer</th>
<th>Stemmer</th>
<th>Stemmer</th>
</tr>
</thead>
<tbody>
<tr>
<td>ikke</td>
<td>litt</td>
<td>ganske</td>
<td>helt</td>
</tr>
</tbody>
</table>

- Jeg leste brevet .......................................................................................................................... 
- Jeg forstod brevet .......................................................................................................................... 
- Jeg bestilte time for celleprøvetakning ..................................................................................... 
- Brevet irriterte meg ....................................................................................................................... 
- Jeg ble bekymret ............................................................................................................................ 
- Jeg følte at noen «passer på» meg (positivt) ................................................................................. 
- Jeg følte meg overvåket (negativt) ................................................................................................. 
- Jeg reagerte ikke i det hele tatt ..................................................................................................... 
- Jeg husker ikke .............................................................................................................................. 

12. Hvor ofte pleier du å ta livmorhalsprøve?

- Oftere enn hvert tredje år
- Sjeldnere enn hvert tredje år
- Når jeg får påminnelsesbrev
- Jeg pleier ikke å ta livmorhalsprøve

13. Livmorhalsprogrammet vil øke anbefalt tidsintervall mellom hver livmorhalsprøve til hvert femte år. Hvordan vil du forholde deg til dette?

- Jeg kommer til å ta livmorhalsprøve oftere enn hvert femte år
- Jeg kommer til å ta livmorhalsprøve sjeldnere enn hvert femte år
- Jeg kommer til å ta livmorhalsprøve når jeg får påminnelsesbrev
- Jeg kommer ikke til å ta livmorhalsprøve
- Jeg vet ikke

14. Hva er det som påvirker når du pleier å ta livmorhalsprøve? (Det er mulig å sette flere kryss)

- Påminnelsesbrevet jeg får fra livmorhalsprogrammet får meg til å ta en livmorhalsprøve
- Legen min minner meg på det
- Jeg tar livmorhalsprøve på eget initiativ
- Etter å ha lest om det, hørt om det og/eller snakket med venner om det, tar jeg livmorhalsprøve
- Annet, spesifiser

15. Hvordan opplever du tiden fra du tar en livmorhalsprøve til du får resultatet?

- Jeg tenker ikke på hva resultatet av livmorhalsprøven vil bli
- Jeg tenker på hva resultatet av livmorhalsprøven vil bli, men det bekymrer meg ikke
- Jeg bekymrer meg over hva resultatet av livmorhalsprøven vil bli
- Jeg har aldri tatt livmorhalsprøve
- Jeg vet ikke
16. Hva var resultatet av din siste livmorhalsprøve?
- Normalt
- Unormalt
- Vet ikke
- Jeg forstod ikke resultatet

17. Dersom din siste livmorhalsprøve var unormal, hvordan opplevde du dette? (For hver rad, sett kryss i den ruta som passer best)

<table>
<thead>
<tr>
<th>Stemmer</th>
<th>Stemmer</th>
<th>Stemmer</th>
<th>Stemmer</th>
<th>Ikke</th>
</tr>
</thead>
<tbody>
<tr>
<td>Ikke</td>
<td>litt</td>
<td>ganske</td>
<td>helt</td>
<td>aktuelt</td>
</tr>
<tr>
<td>Jeg fikk god informasjon om videre oppfølging...</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
</tr>
<tr>
<td>Jeg ble bekymret for min fremtidige helse...</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
</tr>
<tr>
<td>Jeg snakket om prøveresultatet med min partner</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
</tr>
<tr>
<td>Jeg snakket om prøveresultatet med mine nære venner</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
</tr>
<tr>
<td>Det føltes vanskelig å informere partnerekken</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
</tr>
<tr>
<td>Jeg snakket om prøveresultatet med mine nære venner</td>
<td>☐</td>
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<tr>
<td>Jeg snakket om prøveresultatet med mine nære venner</td>
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<tr>
<td>Jeg snakket om prøveresultatet med mine nære venner</td>
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<tr>
<td>Jeg snakket om prøveresultatet med mine nære venner</td>
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<tr>
<td>Jeg snakket om prøveresultatet med mine nære venner</td>
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<tr>
<td>Jeg snakket om prøveresultatet med mine nære venner</td>
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<tr>
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<tr>
<td>Jeg snakket om prøveresultatet med mine nære venner</td>
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<td>☐</td>
</tr>
<tr>
<td>Jeg snakket om prøveresultatet med mine nære venner</td>
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<td>☐</td>
<td>☐</td>
<td>☐</td>
</tr>
</tbody>
</table>

18. Hvilken metode ble din siste livmorhalsprøve testet med?
- Cytologisk celleanalyse
- HPV-test
- Både med cytologisk celleanalyse og HPV-test
- Vet ikke

19. Før du leste om humant papillomavirus (HPV) i vedlagte informasjon, hadde du noen gang hørt at HPV kan forårsake kreft?
- Ja
- Nei
- Vet ikke

Du er nå ferdig med spørreskjemaet. Takk for dine svar! Vennligst returner det utfylte skjemaet ved å legge det i vedlagte ferdigutfylte og frankerte svarkonvolutt
Attachment 5
Assessment Record no. 27/10.12.2014
(request no. 10989/10.12.2014)

Drafted today, the 10th December 2014, during the meeting of the Ethics Committee, assigned to manage the research and development activities and quality assessment of clinical trials within the Oncology Institute “Ion Chiricuță” in Cluj-Napoca.

The project in question „Control of cervical cancer within Roma population and other disadvantaged groups from the North-Western region of Romania (CerCeRom)” is submitted by Florian Nicula, MD, as project manager, primary physician within the Oncology Institute in Cluj-Napoca.

The project is a EEA Grants project in collaboration with the Ministry of National Education.

The project is situated within the theme „health and food safety” and is aimed to promote activities for the improvement of life standard and women welfare within the Roma population and other disadvantaged groups from the population at risk of cervical cancer. The project shall be implemented within the North-Western Region of Romania by the Centre of Excellence in Cancer Control and Prevention within the Oncology Institute of Cluj-Napoca, in collaboration with the Cancer Registry of Norway (Universitetssykehus HF / Kreftrегистret, Oslo).

The Ethics Committee approves with majority of votes the implementation of the CerCeRom project according to enclosed research protocol.

During the study taking place within the Oncology Institute, the following medical ethics criteria shall be respected:

- all individual rights shall be respected and personal data security is to be guaranteed;
- the informed consent of all patients will be obtained prior to the investigation within the project.
The members of the Ethics Committee are:

Anca Bojan, MD, PhD, Assoc. Prof., President

Ioana Neagoe, MD, PhD, Assist. Prof., Member

Doina Piciu, MD, PhD, Member

Bogdan Fetica, MD, PhD, Member

Ovidiu Coza, MD, PhD, Assist. Prof., Member

Florian Nicula, MD, Member

Liliana Policiuc, Member

Monica Groza, MD, PhD, Secretary
Attachment 6
To whom it may concern,

**Re: REC Letter of Exemption**

I am writing in reference to a request from Trude Andreassen via e-mail dated 15th of December 2016, regarding a Letter of Exemption in English.

**Review**
The Chairperson for the Regional Committee for Medical & Health Research Ethics, Section A, South East Norway, reviewed the Remit Assessment Form received on the 11th March 2015 for the Research Project “Barriers to cervical cancer screening in Romania” (Norwegian title: Barrierer mot livmørhalskreft screening i Romania). The Project Manager is Trude Andreassen and the Institution Responsible for Research is CANCER registry of Norway. The Review was carried out on behalf of the Committee on the 18th of March 2015.

The application was assessed accordance with the Norwegian Research Ethics Act (2006) and Act on Medical and Health Research (2008).

**The Decision**
The Chairperson for the Regional Committee for Medical & Health Research Ethics, Section A, South East Norway, found the Research Project to be outside the remit of the Act on Medical and Health Research (2008) and therefore can be implemented without its approval.

**Ethics Committee System**
The Ethics Committee System in Norway consists of seven Independent Regional Committees with authority to either approve or disapprove Medical Research Studies conducted within Norway, or by Norwegian Institutions, in accordance with the Act on Medical and Health Research (2008).

Please do not hesitate to contact the Regional Committee for Medical and Health Research Ethics Section South East A (REK Sør-Øst A) if further information is required, as we are happy to be of assistance.

Yours faithfully,

Knut Engedal
Chair of the Regional Committee for Medical & Health Research Ethics of South East Norway,
Section A

Anne Schiøtz Kavli
Senior Executive Officer
Attachment 7
The Privacy Ombudsman's recommendation in processing personal data or health information

“Barriers to cervical cancer screening in Romania”

We refer to Your submitted notification form of 21th of Mach 2015, regarding processing health information in medical research. The following is the privacy recommendation of the project.

Pursuant to the Personal Data Regulations § 7-12, cf. Health Register Act § 5, the Norwegian Data Inspectorate, by the appointment of a Data Protection Officer, exempt the hospital from the obligation to report to the Data Inspectorate. Processing and delivery of personal data and health information shall therefore be reported to the hospital Protection Officer.

Data Processing satisfies the conditions for notification issued Personal Data Regulations § 7-27 and is therefore exempt license.

The Privacy Ombudsman recommends that the project is carried out under the assumption of the following:
1. The Data controller is the Cancer Registry, represented by the CEO.
2. Processing of personal data in the project is in accordance with and within the purposes specified in the notification form.
3. Data is stored as specified in the notification.
4. Documents linking de-identified data with personal data shall be stored as indicated in the notification form.
5. The study is based on each participants consent.
6. Data shall be deleted or anonymised at project completion by cross-deleted list and any other identification possibilities in the database are removed.
7. When the purpose of the register is fulfilled, a notification shall be sent the Protection Officer to confirm deletion.

The project is registered in the list of recommendations for the hospital. The list is publicly available

Best regards

Privacy Ombudsman and Data Protection Officer
Oslo University Hospital

Privacy and Data Protection Adviser
Oslo University Hospital
Staff Patient Safety and Quality
Section of privacy and information security

Epost: personvern@oslo-universitetssykehus.no
Web: www.oslo-universitetssykehus.no/personvern
Attachment 8
Request for participation in a research project

A study about women’s health, illness and cervical cancer

Background and purpose
This is a request for you to participate in a study about women’s health issues. The study will focus on many aspects of how women experience health and illness, and it will have a particular focus on issues related to cervical cancer. This is a type of cancer that can occur in women’s wombs (in a place in the womb that is known as the cervix in medical language). While this type of cancer is fairly common among women, it can often be successfully treated if it is detected early. For this reason, doctors recommend that women go for regular testing for this kind of cancer so that those who are affected can get the necessary treatment in time.

In this study, we hope to find out whether this kind of testing is something that women in Romania would like. At the moment, testing is supposed to be available in Romania, but very few women are actually going for tests regularly. We wonder why this is so. In order to find out more about this, we are planning to talk to many people and learn from them about the health issues among women.

The Institute of Oncology in Cluj-Napoca (IOCN) is in charge of this study in cooperation with the Cancer Registry of Norway.

What does the study entail?
The aim of the study is to learn about people's everyday lives and health through becoming familiar with the place and the people who live in the North Western region of Romania. Four different types of methods will be conducted between 2015 and 2016 to fulfil the studies aim:

1. Participant observation
2. Quality interviews
3. Focus group interviews and
4. Questionnaire survey

The different types of methods will be explained below:

Participant observation: A researcher from Norway (who speak a little Romanian), will spend time together with, and take part in the daily activities of Roma women in the North Western region of Romania. When a researcher is living together with a population, this is called fieldwork. This particular fieldwork will last for 100 days during 2015. The researcher will ask if she can spend time with the Roma women on a daily basis, and live one or more shorter periods together with one or two Roma families. During participant observation, the aim will be to become part of and take part in life as it is lived. The researcher will have a particular focus on the life of women and will seek to take part in women’s activities at home, in the family, in various social contexts, at work, when visiting the doctor, and so forth. The life of Roma men will also be studied as he is part of the community, but the focus will be on the women. The aim will be to understand women’s thoughts about health and illness, cancer and screening. A translator from IOCN will sometimes take part in the fieldwork.

Qualitative interviews is best explained as a conversation between two persons where one is a scientist and the other is a person possessing knowledge that the scientist would like to learn about. In this study the Norwegian researcher would like to interview Roma women and women from rural areas in order to expand the insight into women’s life as it is lived as well as the researcher would like to learn about the women’s thoughts about health, illness and cervical cancer. The interviews will be conducted while the researcher is doing the fieldwork in the spring and in the autumn of 2015. The researcher from Norway with help of an interpreter from IOCN will conduct the interviews.
Focus group interviews is a kind of a group-interview where a scientist will have a conversation with approximately 6 – 10 participants. The conversation will be regarding a special issue as witch the scientist would like to learn more about. In this study, the focus groups will be regarding women’s thoughts about health, illness, cervical cancer and screening. The focus groups will be conducted during autumn 2015. In the focus groups, the participants will be asked to discuss certain issues presented as health, illness, cancer and screening. A translator will be conducting the interviews in Romanian, while the Norwegian researcher will be participating in the interviews having an observation role.

Questionnaires: There will also be arranged questionnaire meetings where women will be asked to fill out questionnaires jointly. The questions will be regarding the same issues, health, illness, cancer and screening. The answers will be submitted anonymously, which means that the information given from the women cannot be linked to any individual persons. There will be separate meetings in which a translator will read the questions aloud in Romanian and explain what the different boxes represent. A translator will be conducting the interview in Romanian while the researcher from Norway will be participating in the questionnaire meeting having an observation role.

Potential advantages and disadvantages
The aim of this study is to develop better insight into health issues, including cancer-related health issues, and to use this insight to improve health and health care. This is the most important potential advantage of the study. If you participate in the study, you will give an important contribution to this process. Other than that, there may perhaps not be any advantages to you as an individual, but hopefully we will learn from each other and have interesting conversation as we spend time together.

What will happen to the information about you?
All information collected about you will only be used in accordance with the purpose of the study as described above. The researcher will write notes about observations and learnings made during visitation and conversations. The researcher is subject to confidentiality so that names of people will not be listed. Instead, a code number links you to your data through a list of names. This means that the information is de-identified. Details that indirectly could lead to recognition will be changed so that, nobody later could recognize the stories of individuals. Only the researcher will have access to the list of names and be able to identify you.

The results of the study will be published in such a manner that your identity is not recognized.

Voluntary participation
Participation in the study is voluntary. You can withdraw your consent to participate in the study at any time and without stating any particular reason. This will not have any consequences for you. If you wish to participate, sign the declaration of consent on the final page. If you later on wish to withdraw your consent or have questions concerning the study, you may contact Andreea Itu, at: itu.andreea@yahoo.com or Trude Andreassen at: trude.andreassen@kreftregisteret.no and mobile: +47 99265740

Further information on the study can be found in Chapter A – Further elaboration of what the study entails.

Further information about privacy can be found in Chapter B – Privacy and funding.

The declaration of consent follows Chapter B.
Chapter A – Further elaboration of what the study entails

- **Criteria’s for participation in participant observation**
  - Women and men in all ages from Roma population in the North Western region of Romania (NW Region).

- **Criteria’s for quantitative interviews, focus group interviews and questionnaires**
  - Women from Roma population and women from rural areas in NW region.
  - Women in the age group 25-64

- **Background information about the study**
  Cervical cancer represents a major health problem in Romania. 4,300 women are diagnosed with cervical cancer each year, and 1,900 cervical cancer-related deaths occur annually.

  In 2002, a cervical cancer-screening programme was starting in Cluj-Napoca in the Northern Western Region, targeting women in the age range from 25 to 64 years. The programme, which offers traditional pap smears every 5 years, is organized by the Centre of Excellence in Cancer Control and Prevention at the Oncology Institute in Cluj-Napoca (IOCN). Screening is offered free of charge, also for women without health insurance.

  NW Region has a population of 2.7 million, and 470 cases (11%) of all new cervical cancer cases occur in this region. Data from the Cancer Registry in Cluj, shows that screening covers rural areas insufficiently. In 2012, the Roma population made up 3.3% of the population of Romania. Out of these, only 2.4% attends cervical cancer screening.

- **Schedule – what happens and when does it happen?**
  The different interventions described above will be conducted in 2015 and 2016.
  - Participant observations and in depth interviews will be conducted during the months Mai, June, August and September 2015.
  - The focus group interviews will be conducted in October, November and December 2015.
  - The Questionnaire meetings will be conducted in early 2016.

- **Compensation and reimbursement of expenses for the participants**
  For participation in the observation part of the study, each family as the researcher will live together with will receive a compensation of 50 lei per day. The amount will be paid out at the end of every day the researcher lives together with a family.

  For participation in, in-depth interview, each participant will be offered a snack and drink, and travel expenses will be reimbursed.

  For participation in the focus group interviews and questionnaire meetings, each participant will receive a compensation of 15 lei provided the form is properly filled in. The amounts to be paid, is due to an agreement between the Association of the Roma people in Transylvania and IOCN.
Chapter B – Privacy and funding

Privacy
Information that is registered about you, is related to what emerges from observations, from the different types of interviews and from the received questionnaires. Only the researcher from Norway will have access to your name, address and telephone number collected before participant observation and in-depth interviews. The raw material from this part of the study is only available for the researcher. The focus group interviews will be taped before it will be transcribed and translated to English by a co-researcher from IOCN. All the data collected from participant observation, in depth-interviews and focus groups will be analysed by the Cancer Registry in Norway, where the researcher from Norway is engaged. The questionnaires will be analysed both in Norway and at IOCN.

IOCN will have the right to access to relevant parts of the information collected from participant observation and in-depth interviews after anonymously. They will also have right to information collected from focus groups and questionnaires. This for improving their screening programme. Anyone who has access to the information is bound to secrecy.

IOCN in Romania and The Cancer Registry in Norway represented by its supreme leaders, are responsible for the data.

Funding
The study is funded by EEA Norway-grants.

Consent for participation in the study

I am willing to participate in the study.

(Signed by the project participant, date)

Proxy consent when this is warranted, either in addition to or in place of the participant’s consent.

(Signed by representative, date)

I confirm that I have given information about the study.

(Signed, role in the study, date)
Attachment 9
Request for participation in a research project

Identify barriers to participation in the cervical cancer-screening programme of Roma and women from rural areas in North Western region of Romania

Background and purpose
This is a request for you to participate in a research study that intends to study barriers to cervical cancer screening among Roma women and women from rural areas in Romania. The aim with this study is to seek a rich understanding of the complexities that influence women’s participation in cervical cancer screening.

Cervical cancer represents an important health problem in Romania, which has the highest rate of incidence and mortality of cervical cancer in Europe. Women without health insurance, women from rural and remote or isolated areas, and women belonging to ethnic minorities such as Roma women, seldom attend the screening programme in the North Western (NW) region. Since a large majority of women do not attend screening, they have increased risk for cervical cancer and a greater prevalence of dysplasia, with higher mortality due to late detection.

The Institute of Oncology in Cluj-Napoca (IOCN) is in charge of this study in cooperation with the Cancer Registry of Norway.

What does the study entail?
Four different sources will be conducted to gain information regarding women perspective of participation in screening towards cervical cancer. These sources are: participant observation, qualitative interviews, focus groups and questionnaires.

You are asked to participate in a questionnaire survey addressing cervical cancer screening in conjunction with Roma women and women from rural areas of Northern Western region of Romania.

Potential advantages and disadvantages
The aim of this study is to develop better insight into health issues, including cancer-related health issues, and to use this insight to improve health and health care. This is the most important potential advantage of the study. If you participate in the study, you will give an important contribution to this process. Other than that, there may perhaps not be any advantages to you as an individual.

What will happen to the information about you?
All information collected about you will only be used in accordance with the purpose of the study as described above. All the information will be processed without name, or other characteristics serving to identify a person.

Only specially authorised persons from IOCN and the Cancer Registry of Norway involved in the project will have access to the received questionnaires.

The results of the study will be published in such a manner that the participants’ identity is not disclosed.
Voluntary participation
Participation in the study is voluntary. You can withdraw your consent to participate in the study at any time and without stating any particular reason. This will not have any consequences for you. If you wish to participate, sign the declaration of consent on the final page. If you later on wish to withdraw your consent or have questions concerning the study, you may contact Andreea Itu, at: itu.andrea@yahoo.com or Trude Andreassen at: trude.andreassen@kreftregisteret.no and mobil +47 99265740

Further information on the study can be found in Chapter A – Further elaboration of what the study entails.

Further information about privacy and fundings can be found in Chapter B – Privacy and fundings.

The declaration of consent follows in Chapter B.
Chapter A – Further elaboration of what the study entails

- **Criteria’s for questionnaire for medical providers**
  - Women and men working with the issues cervical cancer and/or screening in NW region of Romania

- **Background information about the study**
  Cervical cancer represents a major health problem in Romania. As many as 4,300 women are diagnosed with cervical cancer each year, and 1,900 cervical cancer-related deaths occur annually.

  In 2002, a cervical cancer screening programme was started in Cluj-Napoca in the NW Region, targeting women in the age range from 25 to 64 years. The programme, which offers traditional pap smears every 5 years, is organized by the Center of Excellence in Cancer Control and Prevention at the Oncology Institute in Cluj-Napoca (IOCN). Screening is offered free of charge, also for women without health insurance.

  NW Region has a population of 2.7 million, and 11% of all new cervical cancer cases in Romania occur in this region (470 cases per year). In Cluj-Napoca, the target female population for cervical cancer screening consists of 228,700 women. Data from the Cancer Registry in Cluj shows that screening covers rural areas insufficiently, and these are areas where as much as 30% of the target population lives. In 2012, the Roma population made up 3.3% of the population of Romania. Out of these, only 2.4% attends cervical cancer screening in NW Region.

- **Schedule – what happens and when does it happen?**
  The different interventions described above will be conducted in 2015 and 2016.
  - Participant observations and in depth interviews will be conducted during the months Mai, June, August and September 2015.
  - The focus group interviews will be conducted in October, November and December 2015.
  - The Questionnaire meetings will be conducted in early 2016.

Chapter B – Privacy, funding and insurance

**Privacy**
Information that is registered about you is related to what emerges out of the received questionnaires. The questionnaires will be analysed both in Norway and at IOCN.

IOCN will have the right to access to relevant parts of the information collected for improving their screening programme. Anyone who has access to the information is bound to secrecy.

IOCN in Romania and The Cancer Registry in Norway represented by its supreme leaders, are responsible for the data.

**Funding**
The study is funded by EEA Norway-grants.
Consent for participation in the study

I am willing to participate in the study.

(Signed by the project participant, date)

I confirm that I have given information about the study.

(Signed, role in the study, date)
Attachment 10
To whom it may concern,

**Re: REC Letter of Exemption**

I am writing in reference to a request from Trude Andreassen via e-mail dated 2th of April 2018, regarding a Letter of Exemption in English.

**Review**

The Regional Committee for Medical & Health Research Ethics, Section D, South East Norway, reviewed the Research Project “Barrierer mot livmorhalskreftscreening i Romania og i Norge” at its Committee Review Meeting on the 19th of August 2015. The Project Manager is Elisabete Weiderpass and the Institution Responsible for Research is Kreftregisteret.

The application was assessed accordance with the Norwegian Research Ethics Act (2006) and Act on Medical and Health Research (2008).

**The Committee’s Decision**

The Regional Committee for Medical & Health Research Ethics, Section D, South East Norway, found the Research Project to be outside the remit of the Act on Medical and Health Research (2008) and therefore can be implemented without its approval.

**Ethics Committee System**

The Ethics Committee System in Norway consists of seven Independent Regional Committees with authority to either approve or disapprove Medical Research Studies conducted within Norway, or by Norwegian Institutions, in accordance with the Act on Medical and Health Research (2008).

Please do not hesitate to contact the Regional Committee for Medical and Health Research Ethics Section South East D (REK Sør-Øst D) if further information is required, as we are happy to be of assistance.

Yours faithfully,

Finn Wisløff
Chair of the Regional Committee for Medical & Health Research Ethics of South East Norway, Section D

Nora Eikeland
Executive Officer
Attachment 11
The Privacy Ombudsman's recommendation in processing personal data or health information

Women's experience with the cervical program on transition from cytology-based screening to HPV-based screening

Period: 01.11.2016-31.06.2023

We refer to Your submitted notification form, regarding processing health information in medical research. The following is the privacy recommendation of the project.

Pursuant to the Personal Data Regulations § 7-12, cf. Health Register Act § 5, the Norwegian Data Inspectorate, by the appointment of a Data Protection Officer, exempt the hospital from the obligation to report to the Data Inspectorate. Processing and delivery of personal data and health information shall therefore be reported to the hospital Protection Officer.

Data Processing satisfies the conditions for notification issued Personal Data Regulations § 7-27 and is therefore exempt license.
The Privacy Ombudsman recommends that the project is carried out under the assumption of the following:

1. The Data controller is the Cancer Registry, represented by the CEO.
2. Processing of personal data in the project is in accordance with and within the purposes specified in the notification form.
3. Data is stored as specified in the notification.
4. Documents linking de-identified data with personal data shall be stored as indicated in the notification form.
5. The study is based on each participant's consent.
6. Data shall be deleted or anonymised at project completion by cross-deleted list and any other identification possibilities in the database are removed.
7. When the purpose of the register is fulfilled, a notification shall be sent to the Protection Officer to confirm deletion.

The project is registered in the list of recommendations for the hospital. The list is publicly available.

Best regards

Tor Åsmund Martinsen
Privacy and Data Protection Adviser

Oslo University Hospital
Staff Patient Safety and Quality
Section of privacy and information security

Epost: personvern@oslo-universitetssykehus.no
Web: www.oslo-universitetssykehus.no/personvern
Attachment 12
Psychological Effect of Cervical Cancer Screening When Changing Primary Screening Method From Cytology to hrHPV testing

Application for data to the above-mentioned project (Project Investigator: Trude Andreassen, Institution: Kreftregisteret) was approved in the Cancer Registry of Norway 2016-11-02.

Best regards

Edrun Andrea Schnell
Advisor
Data Delivery Unit
Cancer Registry of Norway
P.O. Box 5313 Majorstuen
0304 Oslo
Tel.: 22 92 88 13
Attachment 13
Forespørsel om deltagelse i studie
om kvinners erfaringer med screening mot livmorhalskreft

Dette er en invitasjon til deg om å delta i en kort spørreundersøkelse om dine erfaringer med Livmorhalsprogrammet. Programmet organiserer screeningen mot livmorhalskreft i Norge, og ledes av Kreftregisteret.

I 2015 startet innføringen av en ny testmetode i Livmorhalsprogrammet, kalt «HPV-test». Du som får dette brevet, har enten fått tilbud om HPV-test eller vanlig cytologisk celleprøve. Alle som mottar dette brevet, er invitert til å delta i studien, uavhengig av om du har møtt opp til screening eller hvilken type livmorhalstest du har tatt.

Kreftregisteret ønsker med denne studien å kartlegge kvinners erfaringer med Livmorhalsprogrammet, og med innføringen av den nye testmetoden. Mer utfyllende informasjon om studien finner du på neste side.

Hva innebærer deltagelse i studien for deg?

Ved å svare på spørreskjemaet, og returnere det til Kreftregisteret, samtykker du i at dine svar kan kobles til data som allerede er lagret om deg i Livmorhalsprogrammet. Alle opplysninger vil bli behandlet strengt konfidensielt, og det vil ikke være mulig å gjenkjenne noen av deltakere i studiens resultater.

Å svare på spørreskjemaet vil ikke innebære noen fordeler eller ulemper for deg personlig. Resultater fra studien skal brukes til å forbedre Livmorhalsprogrammet, noe som kommer kvinner i målgruppen for screening til gode.

Hvis du senere skulle ombestemme deg, kan du når som helst, og uten å oppgi grunn, trekke deg fra videre deltagelse i studien.

Dersom du har spørsmål om studien, kan du kontakte prosjektleder Trude Andreassen på telefon 99265740, eller på epost: trude.andreassen@kreftregisteret.no

Med vennlig hilsen

Trude Andreassen
Prosjektleder
Kreftregisteret
**Mer informasjon om studien**


Studien er finansiert av Kreftregisteret, og Kreftregisterets direktør, Giske Ursin, er forskningsansvarlig for studien.

**Hvem kan delta**

Kvinner som inviteres til deltakelse i studien er i alderen 34-49 år, og bor i Rogaland, Hordaland, Nord- eller Sør-Trøndelag. Alle som mottar invitasjon kan delta i studien, uavhengig av eget oppmøte til screening og hvilken type test en har tatt. Kvinner som ikke mottar egen invitasjon skal ikke delta i studien.

**Personvern**

Ved å svare på spørreskjemaet og returnere det til Kreftregisteret samtykker du i at dine svar, kan kobles til data som allerede er lagret om deg i Livmorhalsprogrammet. Programmet har informasjon om blant annet datoer, diagnoser og test-type for hver enkelt livmorhaltest du eventuelt har tatt.


**Informasjon om utfallet av studien**

Deltakerne i studien har rett til å få informasjon om resultater av studien. Det kan du få ved henvendelse til Kreftregisteret ved prosjektleder, Trude Andreassen, på e-post trude.andreassen@kreftregisteret.no. Offentliggjøring av resultater fra studien forventes i 2019.

Takk for at du tok deg tid til å lese denne informasjonen.
Errata
Errata

Name of candidate: Trude Andreassen

Title of thesis: Challenges in encouraging and maintaining participation in cervical cancer screening programmes in Romania and Norway

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Original Figure 5, with orthographic error:

I didn’t know that I could
I am afraid of the results
Because of the distance to the doctor
I don’t have the time
I don’t have the money
I did not know it was important to my health

Other

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<td>I did not know that I could</td>
<td>33%</td>
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Other: 2% Roma, 5% non-Roma, 3% Total.
Paper I-III
Controversies about cervical cancer screening: A qualitative study of Roma women's (non)participation in cervical cancer screening in Romania

Trude Andreassen a, b, *, Elisabete Weiderpass a, c, d, e, Florian Nicula f, Ofelia Suteu f, g, Andreea Itu f, Minodora Bumbu f, Aida Tincu g, Giske Ursin a, b, Kåre Moen b

a Cancer Registry of Norway, Oslo, Norway
b Institute of Health and Society, University of Oslo, Norway
c Department of Community Medicine, Faculty of Health Sciences, University of Tromsø, The Arctic University of Norway, Tromsø, Norway
d Department of Medical Epidemiology and Biostatistics, Karolinska Institute, Stockholm, Sweden
e Genetic Epidemiology Group, Folkhälsoan Research Center, Helsinki, Finland
f The Oncology Institute "Prof. Dr. Ion Chirică" of Cluj-Napoca, Romania
g "Iuliu Hațieganu", University of Medicine and Pharmacy, Cluj-Napoca, Romania
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ABSTRACT

Romania has Europe's highest incidence and mortality of cervical cancer. While a free national cervical cancer-screening programme has been in operation since 2012, participation in the programme is low, particularly in minority populations. The aim of this study was to explore Roma women's (non)participation in the programme from women's own perspectives and those of healthcare providers and policy makers. We carried out fieldwork for a period of 125 days in 2015/16 involving 144 study participants in Cluj and Bucharest counties. Fieldwork entailed participant observation, qualitative interviewing and focus group discussions. A striking finding was that screening providers and Roma women had highly different takes on the national screening programme. We identified four fundamental questions about which there was considerable disagreement between them: whether a free national screening programme existed in the first place, whether Roma women were meant to be included in the programme if it did, whether Roma women wanted to take part in screening, and to what degree screening participation would really benefit women's health. On the background of insights from actor-network theory, the article discusses to what degree the programme could be said to speak to the interest of its intended Roma public, and considers the controversies in light of the literature on patient centred care and user involvement in health care. The paper contributes to the understanding of the health and health-related circumstances of the largest minority in Europe. It also problematizes the use of the concept of "barriers" in research into participation in cancer screening, and exemplifies how user involvement can potentially help transform and improve screening programmes.

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1. Introduction

Romania has had the highest incidence and mortality of cervical cancer in Europe over the past few decades, with incidence and mortality rates reaching 28.6 and 10.8, respectively, per 100,000 population in 2012 (Ferlay et al., 2015). In response, a national cervical cancer-screening programme was started in 2012, targeting women aged from 25 to 64 years with free-of-charge conventional Pap smears every five years. There is as of yet no available statistics on nationwide programme attendance, but data from Cluj County indicate that around 20% of targeted women are taking part overall (CerCcRom personal communication, 2016) whereas participation is significantly lower in minority strata of the population. Among Roma women, only 4% in the targeted age range have so far participated in the programme (CerCcRom personal...
In this article, we explore the question of why so few Roma women in Romania attend screening.

The Roma constitute the largest ethnic minority in Europe (Fesus et al., 2012). Compared to national averages on the continent, Roma have significantly higher morbidity from both communicable and non-communicable diseases (Fesus et al., 2012; Parekh and Rose, 2011), twice as high infant mortality rates, and up to 20 years shorter life expectancy (European Commission, 2014). Roma are often discriminated against (Fesus et al., 2012; Fox, 2001) and have poorer access to health services, and lower uptake of preventative health care, than non-Roma (European Commission, 2014; Hajioff and McKee, 2000; Parekh and Rose, 2011).

In Romania, Roma are officially reported to make up 3.3% of the total population, equivalent to about 700,000 persons (Ministry of Health, 2012). However, many Roma are without citizenship, and the actual number is therefore likely higher, with some estimating that there are around 2.3 million Roma in Romania (Hajioff and McKee, 2000). Although Roma are found in all socio-economic groups, and in both rural and urban areas of the country, the majority lives in poor conditions, often in settlements segregated from the rest of the population (Engbergtsen, 2007).

Romania lags behind European Union (EU) averages with regard to many health indicators. Life expectancy at birth is 5 years lower than in EU (75.1 vs. 80.9 years) (Vladescu et al., 2016), whereas infant and maternal mortality rates are considerably higher (8.8 vs. 3.8/100 000 and 13 vs. 4.5/100 000, respectively). For all of these indicators, the Roma population is worse off than non-Roma, with six years lower life expectancy (The World Bank Group, 2014) and 2.5 times higher infant mortality (Sepkowitz, 2006). Many obstacles contribute to render health services less available for Roma, including the cost of medical care and the existence of discriminatory practices in health-care settings (Wamsiedel et al., 2012). Only 50% have health insurance (Kuhlbrandt et al., 2014) (80% among non-Roma), 9% do not have a general practitioner (GP) (4.5% among non-Roma) (European Commission, 2014), and only 10% have ever had a mammography (European Commission, 2014).

Screening for precancerous lesions can radically reduce the incidence and mortality of cervical cancer (Ferlay et al., 2010), and under-screeners and non-participants in screening programmes are at much higher risk of developing and dying from cervical cancer than screening attenders are. In the Nordic countries, Vaccarella et al. (2014) have projected that the incidence of cervical cancer in the absence of screening would have been 3 to 5 times higher than observed rates. From this perspective, the low screening participation rates amongst Roma women are of considerable concern.

In what follows, we will compare Roma women’s perspectives on cervical cancer screening and the Romanian screening programme with the perspectives prevailing among the providers and owners of screening. We do this in order to identify differences in perceptions and understandings between lay and professional actors in the screening venture. These differences will be treated and referred to as disagreements and controversies. Indeed, inspired by Latour (2005), our aim is to let these variously positioned actors “deploy the full range of controversies in which they are immersed” (p. 23). As Venturini (2012) argued, tracing controversies is beneficial for anyone observing the social world. In controversies viewpoints and perspectives are activated, articulated and amplified and thereby made more easily visible. Tracing controversies may be of particular benefit when the aim is to bring to the fore viewpoints of minority groups – such as Roma women – since it is always “disagreeing minorities who bring controversies into existence by refusing to settle with the mainstream” (Venturini, 2012, p. 798).

In the discussion section, we will consider the identified controversies, and the widely lacking uptake to cervical cancer-screening among Roma women, in light of Akrich, Callon and Latour’s (2002) work on success in innovation processes. They emphasized that the potential take-up of any novelty is completely in the hands of its intended users, leaving innovators with no choice but to become artisans of interessement; i.e. to engage in the art of discovering how an innovation can speak to the interests of its intended public. To achieve this, we will argue, requires interaction and collaboration, and we will therefore also consider the controversies about the cervical cancer-screening programme in light of the literature on patient-centred care (e.g. Morgan and Yoder, 2012) and user involvement in healthcare (e.g. Greenhalgh et al., 2010) in which the focus is exactly on how the health services may treat its users as partners in the planning, development and monitoring of care.

2. Methods

This paper is based on research carried out in the Cluj and Bucuresti counties of Romania in 2015 and 2016. The first author conducted the fieldwork and employed a mix of qualitative research methods: participant observation, qualitative interviewing, and focus group discussions. The study design was interactive and explorative, and the three research methods stood in a dynamic relation to one another. Fieldwork lasted for 125 days, during which the researcher interacted and communicated with approximately 144 variously positioned actors, including Roma women, health care providers, screening specialists and health policy makers (Table 1). When we refer to these persons collectively as ‘actors’, it is to highlight the understanding that they are people who need to act together if a well-functioning screening programme is to emerge.

2.1. Study setting

The Roma communities where the first author spent most time formed a cluster of settlements located on and around a large garbage dump outside the city of Cluj. They had a combined population of approximately 1800 people. Residents lived in temporary shelters or small houses built from wood or bricks collected at the garbage dump, with roofs made from straightened tin containers or cardboard. There was electricity in most houses, but almost none had piped water. Instead, common water stations were located in most of the “camps” along with shared outhouse toilets. Many people earned a living from canvassing the dump, whereas others had temporary work in the city or were unemployed and/or lived on social welfare. Fieldwork was also conducted in Roma communities in urban and rural locations elsewhere in the North-Western region and in Bucharest, and in settings where health workers, cancer-screening specialists and policy makers, respectively, worked and met (Table 1).

2.2. Participant observation

Participant observation entailed taking part in daily activities with the study participants. Among other things, the first author spent time with Roma women in their homes and joined them when they socialised, went shopping, visited the doctor, attended church, and celebrated birthdays. She spent time at an oncological institute where she became part of the professional milieu and took part in daily work life, she visited hospitals and doctors’ offices, and she took part in meetings and seminars with screening providers and policy makers. In the course of fieldwork, she also took part in situations where screening providers and Roma women interacted, including when the local oncological institute started offering...
mobile cervical screening in the study area. As we will return to, when attendance rates turned out to be dismal, she joined the screening providers in trying out an approach to service delivery that aimed at greater user orientation and involvement.

Throughout each fieldwork day, scratch notes were taken on experiences, events and conversations. These were written out as detailed field notes at the end of the day.

2.3. Qualitative interviews

While participant observation entailed numerous conversations with a large number of people, nine persons also took part in more formal interviews. The interviewees included Roma women as well as professionals involved in different aspects of the cervical cancer-screening programme (Table 1). Interviewees were recruited in the course of participant observation using a maximum heterogeneity sampling technique approach where the aim was to include people with different perspectives and experiences with respect to residence, age, and socio-economic background. Most interviews lasted from 60 to 90 min. To understand their points of view better (Moen and Middelthon, 2015), four persons were interviewed on several occasions. Four interviewees spoke English and were interviewed by the first author alone whereas the others were interviewed in Romanian with interpretation assistance from a research assistant. An interview guide had been prepared in advance. All discussions were tape-recorded. A research assistant facilitated discussions conducted in Romanian while the first author otherwise might not have had access to. Also, each team member seemed to help bring out different perspectives.

2.4. Focus group discussions

To further explore and discuss impressions and findings generated during participant observation and qualitative interviewing, seven focus group discussions were conducted; five with women and two with health professionals (Table 1). The focus groups consisted of from six to twelve participants and lasted from one to two hours. The selection of group participants aimed to maximize variation in perspectives and experiences within groups, see Table 1. Discussions were semi-structured in the sense that a topic guide had been prepared in advance. All discussions were tape-recorded. A research assistant facilitated discussions conducted in Romanian while the first author was taking notes and observing the participants and group dynamics. These discussions were translated into English by a professional translator. Discussions with health care workers were conducted in English by the first author.

In the latter part of fieldwork, our impression was that conversations, interviews and discussions brought out few new perspectives on participation in cervical cancer-screening, and that the data material was therefore relatively "saturated".

2.5. The first author's position

The first author had previous experience with cancer-screening in Norway where she had worked as a secretary for the steering group of the National Cervical Cancer-Screening Programme. In preparation for fieldwork, she learned basic Romanian and visited several Roma communities in Norway and Romania.

2.6. Research assistants/interpreters

One Roma and one non-Roma woman served as research assistants and interpreters in the field. The use of interpreters was necessary because the first author was insufficiently fluent in Romanian and Romani to engage in in-depth conversations on her own. To rely on interpretation was associated with disadvantages, for example that comments at times were omitted from translation, and it was sometimes difficult to be spontaneous in conversations. On the other hand, the first author and the assistants came to constitute a fieldwork team that engaged in ongoing reflection about women's circumstances and narratives. Since the assistants were Romanian, they were able to provide contextual information that the first author otherwise might not have had access to. Also, each team member seemed to help bring out different perspectives in interactions with study participants.

2.7. Ethical considerations

Before fieldwork started, and on repeated occasions later, the aims and methods of the study were explained to study participants by the fieldwork team, and it was emphasised that participation was voluntary and that participants could withdraw at any time and for whatever reason. Everyone who was asked to participate agreed to take part. Participants in interviews and group discussions signed a written informed consent form. Directly person identifying information was omitted when data was computerized and biographical and other details were modified if necessary to secure the confidentiality of individuals. The key linking data files to actual names has been securely stored separate from the data material and will be deleted at the end of the project.

The study was approved in Romania by the Ethics Committee of the Institute of Oncology "Prof. Dr. Ion Chiricuţa" (IOCN) as part of its overall assessment of the project entitled "Cervical Cancer control among Roma and other disadvantaged groups of women" (CerCcrRoma); Assessment Report no. 28/10.12.2014, request no. 10988/10.12.2014. The study was also recommended by the Data Protection Official of the Cancer Registry of Norway (case number 2015/4787).

An ongoing challenge in connection with this study was the question of how to engage with situations in which minorities are...
marginalised from and experience disparities in healthcare. This is a topic that we will have to address in more detail elsewhere, but let us mention that there has been ongoing discussion with screening providers and policy makers in the study period and that we expect this conversation to continue into the future on the basis of this and other publications.

2.8. Data analysis

Analysis was an integral and constantly ongoing part of the research process, where methodological considerations, data production, analytical work, and theorizing were mutually constituting elements (Coffey and Atkinson, 1996). In order to develop knowledge of and familiarization with field and interview notes, the material was read through several times. It was thereafter coded so that thematically related portions of the data could be considered in conjunction. Initially, open coding was used (Dahlgren et al., 2004), i.e. emergent codes were derived from field notes and transcripts. Codes that were related to each other were thereafter subsumed under broader code categories, such as “access to care”, “perspectives on screening” and “discrimination”. In a final step in the preparation of this article, inspired by Latour’s (2005) previously-mentioned recommendation to trace controversies, we searched through the coded material to identify issues about which there was major disagreement between actors.

Let us mention here that we earlier on in the analytical process had tried to understand women’s (non)participation in screening in terms of “barriers” that might explain their choices. However, in the course of the analytical process, we grew increasingly concerned that this concept might have limited analytical utility. As a metaphor, “barrier” draws explanatory meaning from barriers in the physical world. A typical example would be a roadblock; a static and clearly circumscribed object which obstructs road passage until it is removed. However, as long as you have the right lifting equipment, a roadblock can be removed in a single operation, and access and passage is then immediately re-established. Mostly, we find, this does not mirror the complex web of discourses and disagreements in which the cervical screening programme was wound up.

3. Findings

In what follows, we will present and discuss four questions pertaining to the screening programme about which there was considerable disagreement between Roma women, health care providers, cancer-screening specialists and health policy makers. In their discursive engagement with the screening programme, they sometimes agreed, but often their takes were at odds with each other. Below, we have grouped these controversies into four main categories. At times, they emerged as explicit disputes between the actors, but they were more often implicitly at work between them.

3.1. First controversy: does the national screening programme exist?

The most basic controversy encountered was whether a free national screening programme existed in the first place. As a matter of indisputable fact, the programme did exist in the form of national guidelines for screening (Ministry of Health, 2015). It also existed in the form of work tasks for health personnel and administrators, and in the form of a considerable number of screening tests performed every year.

On the other hand, the programme hardly existed as an experienced entity in the lives of most Roma women we interacted with. Indeed, almost none had heard of the programme before the fieldwork team told them about it. This pertained to women who had never had a Pap smear taken, but also to those who had. Many in the latter group also wondered whether their doctors could know about the programme since they had not offered them Pap smears for free, or whether they perhaps did not want them to know. As an example, a woman (Q182) who had been referred by her GP to a gynaecologist for Pap smears every year for the past 7 years had always paid for her tests.

Even when women were informed about the free-of-charge screening programme, many were in doubt about its factuality. They explained that in their experience, medical services supposed to be free rarely turned out to be so in practice. This was because under-the-table payments were often expected. Plentiful stories emphasized this point. For example, a woman who worked in the health sector herself (PO43) explained how patients had to pay an unofficial fee to get services even if they had health insurance entitling them to free care, and in focus group discussions (e.g. FGD16-27), participants explained how one would wait in line for a long time if one did not pay extras, and they were of the impression that the services one would get would be of inferior quality.

Many women expressed an understanding for the habit of informal payments. They reasoned that health workers were not at all well-paid, and empathized with their need for extra income. The point in the context of cervical screening, however, was that the idea that there existed a programme that was more than nominally free-of-charge was perceived as unrealistic. “Free” screening was anticipated to involve some payment.

3.2. Second controversy: does the programme apply to Roma women?

While there were doubts among Roma women about whether a screening programme existed at all, and especially whether there existed a free-of-charge screening programme, a set of additional controversies emerged when the existence of the programme had been asserted. Among these was the question of whether or not the programme was pertaining to Roma women. On the one hand, the programme document clearly stated that the programme was targeting all women living in Romania in the age range between 25 and 64 years (Ministry of Health, 2015). Those who were working in the programme, moreover, were in no doubt about the validity of these inclusion criteria. Indeed, they spent much of their time considering how to best reach and include more Roma women into screening.

Several Roma women, on the other hand, were not confident that they were meant to be included in the programme. Their doubts were rooted in two different concerns, one pertaining to insurance issues and the other to experiences of discrimination.

A common anticipation among women was that one would at the very least need to have health insurance to qualify for participation in the programme, a requirement that, if it was accurate, would exclude half of those who took part in this study (Table 2). The idea that insurance was needed resonated with the crucial link that existed between health insurance and health services in general. Among those who illustrated this point was a woman who had been denied care in an emergency room because she did not have her insurance documents available:

“If you don’t have all the papers, they cannot give you the injection. The doctors at the hospital asked us to wait. We said ‘We came in the ambulance, what you mean wait?’ […] I had to call home to ask them to come with the papers. So, one can die there waiting for the papers to arrive.” (FGD27)
While all women were meant to receive free Pap smears irrespective of insurance status, most Roma women did not know this. They argued that they could not access free services because they had no health insurance – either because they were unemployed, worked without legal contracts, or did not have Romanian identity cards.

The doubts Roma women had about their entitlement to take part in the programme were also intertwined in wider tensions in the relations between Roma and the majority population. Before we describe some of these, it is important to say that women’s stories did not add up to one uniform picture. Indeed, some study participants experienced clearly agreeable relations with healthcare workers. One woman illustrated this by explaining how much her family appreciated their GP:

“Everyone in our family likes him very much. He treats us nicely. I don’t feel discriminated by him, as he is not a racist.” (QI#2)

A different body of stories, however, emphasized considerable tensions between Roma and healthcare workers. For example, Roma women often said that they tended to be perceived as untrustworthy in healthcare settings. One woman who illustrated this (QI#3) explained how health personnel had not believed her even when she provided trivial information about where she had had an abortion performed. Another common expectation among Roma was that they were perceived as unclean by non-Roma, and plentiful stories linked their perceived uncleanliness to experiences of discrimination and rejection in health care settings (e.g. QI#4).

Others suggested that their skin colour was the basis for discriminatory practices, as exemplified by these two quotes:

“They see your skin is a bit darker and they tell you to wait. First the ones with a […] lighter skin tone.” (FGD#16)

“[…] That’s how it is. We wait. Especially us, the gypsies.” (FGD#24)

Imposed waiting was the topic in several women’s portrayals of unfairness in health care facilities. Some had experienced to be waiting in line an entire day before receiving the service they had come for. One interpretation of this was that some doctors would rather not want to see Roma patients:

“Some of them hope that if they neglect Roma people enough, they will get sick and tired of waiting and they will go home, so they will not have to deal with Roma people.” (FGD#5)

Perceived differences between Roma and non-Roma were also articulated by healthcare workers and screening providers. In a focus group discussion, they highlighted Roma as significantly different from themselves in rather disapproving ways. Among the characteristics provided was that Roma had “their own character” (FGD#49), were “louder than Romanians” (FGD#50), did not “know practically how to do anything” (FGD#51), could not be trusted because they “are beggars or thieves” (FGD#54), and that “stealing and being false is in the Roma people’s character.” (FGD#54).

3.3. Third controversy: do Roma women want to take part?

Health care professionals often expressed a clear sense of pessimism regarding the prospects of driving up attendance rates among Roma. Many thought it would be immensely hard to achieve this. A recurring question was “but why don’t they want to participate?” (e.g. PO#46). Confronted with something they did not understand, but tried to make sense of, their explanations varied. Among proposals put forward was that Roma women did not really understand what was best for their own health. In a focus group with healthcare workers, one participant described the situation as “hopeless” (FGD#50). Another participant was marginally more optimistic and responded, “I don’t think it is hopeless, really, but I think it is a very slow walk” (FGD#51). Some were of the opinion that Roma women were “fatalistic” and did “not really care whether they lived or died” (FGD#48), and some wondered whether Roma women might need permission from their husbands to take part in screening (e.g. FGD#53).

Most of these proposals were rather different from the viewpoints encountered among Roma women themselves. Indeed, only a handful of the women encountered in the course of fieldwork said they needed permission from their husband to take a screening test, and very few indicated that they were opposed to cervical cancer-screening. On the contrary, most said they were very much in favour of screening. The latter was not so because most women had a particularly detailed level of insight into medical perspectives on cervical cancer. Most did not. When we asked direct questions about what women took cervical cancer to be, they typically gave short, vague responses and often seemed to be guessing. Among the proposed explanations were that cervical cancer “is race depending” (FGD#2), “represents a malformation” (FGD#6), is caused by “stress”, and may start as “a cold down there” (FGD#15). Nobody knew about human papillomavirus (HPV) or that HPV is a sexually transmitted virus that can cause cervical cancer.

Yet, almost all women were aware that cervical cancer was a potentially serious disease. The word cancer signified gravity, and some knew of women who had died from cervical cancer. When asked, women were overwhelmingly positive to the idea of measures that could contribute to prevention, and almost everyone said that free screening would be a very good thing, indeed. If people knew about it and it was really for free, everyone would participate, was the consensus in one focus group discussion (FGD#28–37).

Notwithstanding this, the turnout was decidedly poor when the local oncological institute started to make cervical cancer-screening available through a mobile testing unit visiting local Roma communities in the study area. After participating in such an event, the first author recorded the following impressions in her field notes:

“We arrived unannounced and started walking from house to house to tell people about the opportunity to get tested. The camp was crowded, and we spoke to as many women as we could, but only a handful agreed to take part. The screening staff was really disappointed, and had lots of disappointing comments. Clara said that Roma women did not seem to understand what was in their own best interest, and Georgina that their unwillingness to participate showed what Roma women are really like.” (Based on field notes; PO#35–42)

Among the criticisms voiced by Roma women in conversations after the mobile unit had left, was that the visit had been
unannounced. Until the van appeared, the women had not heard about the visit itself, the rationale for screening, or the procedures involved in testing. Moreover, they had had no chance to wash up and change clothes before a procedure that would involve a gynaecological exam. This was considered important, not the least given the reputation the Roma women felt they had as dirty and smelly. Since most women lived in houses without piped water, taking a shower was not something they could do in the wink of an eye, and many felt that it was strange to expect them to take part in screening without time to prepare.

The outcome of the just-mentioned episode stands in contrast to what happened when the mobile service was introduced in a different manner. As part of fieldwork, the first author and some of the screening providers spent time in local communities prior to screening events. They engaged in conversations with women about cervical cancer and screening, and arranged for meetings during which women took part in the planning for the mobile unit’s visit. The day the vehicle arrived, the willingness and eagerness to attend was remarkable:

“The vehicle arrived early in the morning. I had stayed over at Ginel’s and Aida’s place and went outside to wait for the van to arrive together with them and a few other women. More and more people arrived, and finally almost everyone seemed to be there. I was surprised to see so many women. Adina told me that everyone had gotten up earlier than usual to wash and dress before the gynaecological exam. And Raluca had arranged for the common shower to be open for everyone to use.” (Based on field notes; PO#1-21)

Throughout the day, there were long lines until almost all women in the two camps had taken part in screening.

3.4. Fourth controversy: does screening change anything?

The fourth issue over which there was diverging opinions, was to what degree screening attendance would be of actual benefit to women’s health. On the one hand, the Romanian screening programme had been founded on the basis of the considerable evidence that cervical cancer-screening can indeed prevent morbidity and mortality through early detection of precancerous lesions (Jordan et al., 2008). Importantly, however, if screening is to have a rationale, early detection must be accompanied by early treatment when precancerous lesions are detected. Many Roma women were in doubt whether they could take this latter requirement for granted. On the contrary, they feared that screening might discover conditions they would not get help to cure. Among those who drew attention to this concern was a woman encountered during mobile testing in one of the Roma settlements just mentioned:

“We walked over to a woman who may have been in her 40ies. She was sitting in front of her house selling vegetables. When Ana asked her if she would like to take a screening test, she yelled, “Why should I take a test?” Ana explained her that testing was free and could prevent cervical cancer. Irritated, the woman responded: “I already have hypertension, diabetes and low metabolism and am getting no help with any of that. If I take the test, I am sure I have cancer, too. So what are you going to do about that?” (Based on field notes; PO#1-21).

A positive test in this woman’s imagination would not only add to her burden of illness, but also to the burden of disease she feared she could do nothing about. When she asked what the screeners would do to help her, her fury seemed to indicate that she thought she knew the answer. Nothing at all.

4. Discussion

The Roma population in Romania carries a highly disproportionate overall burden of disease (Fesus et al., 2012). As long as only a small proportion of Roma women participate in the national screening programme, cervical cancer will continue to contribute to this status quo. While this perspective was widely appreciated by healthcare workers and screening providers in the study area, they often suggested that the main explanation for the low screening coverage was to be found among the Roma women themselves. In so doing, they echoed a perspective that can be traced in much research into (non)participation in cervical cancer-screening worldwide. Frequently, such research has aimed to identify “barriers” that work to prevent screening attendance, and such barriers have often been located in or among the women to be screened, and including women’s “lack of knowledge” (e.g. Ekechi et al., 2014), “misconceptions” (e.g. Johnson et al., 2008), “negligence” (e.g. Todorova et al., 2006), “fatalistic views” (e.g. Austin et al., 2002; Johnson et al., 2008), “denial” (e.g. Lee, 2000), incorrect “health beliefs” (e.g. Markovic et al., 2005), and “low level of education” (e.g. Behbakhht et al., 2004).

While we cannot exclude that “individual barriers” may have played some role for screening attendance in the study area, the findings of this study do not support an image of Roma women as subjects who did not want to get tested, were without concern for what was in the best interest of their health, or did not care whether they lived or died, as the professional actors often argued. As Eardley et al. (1985) have noted from work elsewhere, such proposals in effect blame dismal screening coverage on the women who do not attend screening, while failing to consider the role of the screening system itself.

The main “barrier” in the study area, we suggest, was that the implementation of the screening programme had been conceptualised along the lines of what Akrich, Callon and Latour (2002) have referred to as a “model of diffusion” (p. 203). In such models, innovators expect that the technical superiority of an innovation is sufficient to ensure its diffusion into the populations where it is meant to serve a purpose. However, even the most perfect technical solution will hardly ever translate from potential into practice unless it is adapted to the needs and viewpoints of its intended users (Akrich, Callon and Latour, 2002). The take-up of any novelty is entirely in the hands of the users: it depends on their expectation, their interests, on the problems which they raise” (Akrich, Callon and Latour, 2002, p. 202). Successful implementation therefore requires that models of diffusion be replaced with models of interessement, i.e. approaches that speak to the interests of their users and take into full consideration the characteristics of the social environments in which transformation is intended to spread and have effect (Akrich, Callon and Latour, 2002).

“Patient-centred care” (PCC) is a conceptual framework that builds on, and aims to exploit, this insight in the context of healthcare (Bensing, 2000). In PCC, patients’ perspectives and interests take centre stage, and a principal aim is to reorient services so that providers strive to understand, respect and empower them (Morgan and Yoder, 2012). PCC thus entails a relative shift in the focus of service delivery away from biomedical emphasis and towards approaches that consider users more holistically (Bensing, 2000; Morgan and Yoder, 2012).

How could the screening programme be reoriented to conform better to such principles? A basic modification would have been to ensure that Roma women had knowledge of the programme, including the fact that screening (and cancer treatment) was free of
charge. As long as this remained unclear, cancer-screening entered into women’s considerations about what they could afford. A large proportion was poor in terms of financial resources, and it was uncommon for many to visit a doctor unless there was a medical emergency. Even in such situations, Roma women were typically dependent on raising money from family and friends. Understandably, to spend money on screening for cervical cancer was something few had considered.

Related to this, a PCC approach would also promote engagement with the concerns uninsured women had about the affordability of follow-up for precancerous lesions. While the programme provided treatment of cancer for free (Ministry of Health, 2015), it did not cover follow-up of precancerous lesions (Government of Romania, 2016–2017), and such lesions therefore required that women had health insurance or other ways of raising funds. Only around half of the Roma women participating in this study had insurance a proportion closely resembling insurance coverage rates reported by others (e.g., European Commission, 2014; Kuhlbrandt et al., 2014). In effect, therefore, many women were faced with a cervical cancer-screening programme that could come to detect pathology they did not have the means to get treatment for. To ensure access to follow-up for precancerous lesions is widely agreed upon as the basis principle for screening (Arbyn et al., 2010; Wilson and Jungner, 1968) and an aspect of the Romanian screening programme that might seem to require re-evaluation.

Finally, a PCC approach might also have mandated screening providers to engage with the impression many Roma women had about the health services as unwelcoming towards them. Women’s narratives often elaborated experiences of disrespect and discrimination in healthcare settings (as in society more generally), and many found it difficult to believe that they were actually entitled to free-of-charge cancer-screening. Also, women did notice that their interests tended to be relegated into the background when mobile screening services were first introduced. They had not been informed about the visits ahead of time, nor about the screening procedure or its rationale, and there had been no time set aside for them to prepare for gynaecological exams.

In order to practice PCC, providers have a need to become familiar with and understand user’s perspectives and needs, and “user involvement” is therefore recommended when services are planned (Hickey and Kipping, 1998). User involvement entails that service users take part in the design, production and/or leadership of healthcare undertakings. The degree to which users are involved varies along a “participation continuum” ranging from “information sharing” (users have access to knowledge and explanations) via “consultation” (users’ views are heard) to “partnership” and “user control” (users take part in or control decision making) (Hickey and Kipping, 1998).

While Roma women in the study area had not been extensively involved in the planning of the screening programme from the outset, an interesting try-out of user involvement was undertaken in connection with this study. When the local oncological institute and the first author worked jointly with Roma women about the planning and implementation of mobile screening services in their local communities. The interest for and participation in these collaborative activities was high, and screening participation rose substantially in the ensuing months. What this may suggest is that the programme could have much to gain from drawing more extensively on user involvement strategies. There is now a rich literature on the experiences with such approaches that the programme could take advantage of (e.g., Bensing, 2000; de Freitas and Martin, 2015; Hickey and Kipping, 1998; Morgan and Yoder, 2012). Among important questions to take into consideration are how to ensure that user involvement becomes more than tokenistic (Crawford et al., 2003), and how to provide support to members of marginalised populations so that they build confidence to speak their minds in collaborative spaces (de Freitas and Martin, 2015).

5. Conclusion

Cervical cancer-screening may be understood as an actor-network (Callon, 1986) consisting of both human and non-human actors, including women in a certain age range, appropriate testing equipment, and professionals performing a set of testing procedures. For this actor-network to be activated, i.e. for a screening programme to be in active existence, all of these actors must be assembled and act together. In the study area, there had been very little contact and inter-action between screening providers and Roma women. Thus, the screening actor-network had not been activated to any considerable degree, and the human actors involved in that network had not had the opportunity to develop anything close to a common “take” on the screening programme. On the one hand, providers highlighted the health benefits of screening. When they did not participate, it was ultimately because they could not believe that the screening programme was meant for them, or – if it was – that they would nonetheless come to be excluded from it, either because screening would not be affordable or due to discriminatory attitudes and acts among providers. If the programme is to interest Roma women, we suggest, it is this set of concerns that must be addressed through a process that builds contact, interaction and cooperation between the programme and its potential Roma participants. The intervention that was conducted in the course of this study suggests that this can be achieved if women are involved as active partners in planning, implementation and evaluation of the programme, through a genuine and accommodating process of user involvement.

Acknowledgements

This study was conducted as part of a project called CerCcRom (cervical cancer among Roma and other disadvantage groups of women in Romania) funded through the European Economic Area (EEA) Financial Mechanism 2009–2014 under Project Contract no 6SEE/30.06.2014. We thank the Oncology Institute “Prof.Dr. Ion Chiricuta” of Cluj-Napoca, Romania and the Cancer Registry of Norway for making this study possible. Most of all we thank those who participated in the study; including many Roma women, men and healthcare providers. Special thanks go to those who received the first author so warmly in their communities and let her take part in their daily lives.

References


Attendance to cervical cancer screening among Roma and non-Roma women living in North-Western region of Romania

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Abstract

Objectives Romania has Europe’s highest incidence and mortality rates of cervical cancer. Participation in the national cervical cancer-screening programme is low, especially among minority Roma women.

Methods We conducted a cross-sectional study, using a structured questionnaire aiming to quantify reasons for screening attendance among women in North-Western region of Romania.

Results 980 women were enrolled in this study. Data were analysed using logistic regression, estimating odds ratios (OR) and 95% confidence intervals (CI). This study revealed that Roma women (46%) attended screening less frequently than non-Roma women (63%); however, ethnicity in itself was not associated with screening attendance. Instead we found that attendance to the cervical cancer screening programme was determined by having ever heard about a screening opportunity (OR 5.90, 95% CI 3.76–9.27) and having three or more sex partners (OR 5.99, 95% CI 1.71–21.04).

Conclusions We concluded that information about the screening programme’s existence and its rationale does not reach the women targeted for screening sufficiently and argue that a process of user involvement aiming to build contact, interaction and cooperation between the programme and its potential participants is warranted.

Keywords Cervical cancer screening attendance · Minority Roma women · Discrimination · Access to health · Health insurance · Odds ratio
Introduction

Cervical cancer is the fourth most common cancer among women worldwide, responsible for around half a million new cases and 270,000 deaths per year (Ferlay et al. 2015). Screening for precancerous lesions can reduce the incidence and mortality of cervical cancer since detected precancerous lesions can be surgically removed. Invasive cervical cancer is strongly linked to socioeconomic, geographic and ethnic disparities and more than 80% of all new cervical cancer cases occur in developing countries (Ferlay et al. 2015). According to the European Guidelines for quality assurance in cervical cancer screening, optimal screening programmes require a population-based approach, a defined screening policy, individual invitation of members in the targeted population and follow-up and treatment of women with screening-detected abnormalities (Ferlay et al. 2015).

Cervical cancer screening in Romania

For decades, Romania has carried Europe’s heaviest burden of cervical cancer with incidence and mortality rates reaching 28.6 and 10.8 per 100,000 population, respectively, in 2012 (Ferlay et al. 2015). 11% (470 per year) of all new cervical cancer cases occur in the North-Western Region of Romania (IOCN 2017). A national cervical cancer screening programme was established in 2012 (Ministry of Health 2015) offering Pap-smears every 5 years for women aged 25–64 years. Primary sample takers are gynaecologists (66%) and general practitioners (GPs) (34%) (Ministry of Health 2015). When referred from a programme-registered GP, testing is free of charge for all women in the targeted age group, as is treatment if cancer is diagnosed. Re-testing and follow-up of detected precancerous lesions are, however, only covered for women with health insurance (Government of Romania 2016–2017; Ministry of Health 2015). Participation in the national screening programme is low (European Commission 2014) and a study conducted before the programme was established showed that only 20% of Romanian women overall, and 5% of Roma women had ever been screened (Todorova et al. 2009). In addition over 50% of cervical cancers in Romania are diagnosed in advanced stages (Socolov et al. 2016), which complicates treatment and reduces the chances of survival.

The population of Romania

There are 21 million inhabitants in Romania, and in 2011, the Roma population was reported to be the third largest minority in the country with 600,000 people (National Institute of Statistics 2011). There are, however, sources reporting that there are many Roma without legal citizenship and that the Roma in fact make up the largest minority in the country with an estimated 2.3 million inhabitants (Hajioff and McKee 2000).

Cervical cancer is not the only health indicator according to which Romania lags behind other European Union (EU) countries, as life expectancy at birth is 5 years lower than EU averages (Vladescu et al. 2016) and the infant mortality rate 2.3 times higher (The World Bank Group 2014). Roma are worse off than other Romanians, with higher morbidity from both non-communicable and communicable diseases, and 6 years lower life expectancy (The World Bank Group 2014). Many Roma are in addition economically disadvantaged, live segregated in communities in the outskirts of large cities (Engebretsen 2007), often in simple houses without piped water and electricity (Masseria et al. 2010). 25% of the Roma in Romania are illiterate (European Commission 2014) and 64% are without regular employment (The World Bank Group 2014). The Roma population is reported to have poorer access to health services and lower uptake of preventative care (Hajioff and McKee 2000; Wamsiedel et al. 2012) than other citizens. Half of the Roma population (vs. 20% of the overall population) is without health insurance (European Commission 2014; Kuhlbrandt et al. 2014).

Screening attendance

Previous studies have identified barriers to screening attendance among Romanian women (Baban et al. 2006; Todorova et al. 2009). These include fear of a cancer diagnosis, lack of information about cervical cancer screening, high costs, long waiting time at doctors’ offices and that some doctors refuse to examine women. We have previously conducted a qualitative study exploring Roma women’s (non-)attendance in cervical cancer screening in Cluj and Bucharest counties (Andreassen et al. 2017). We found that many did not know about the screening programme’s existence. Doubt endured as to whether it was meant to include Roma women if the programme did exist, and to what degree it would be free of charge in practice. Many were also unsure whether attending screening would lead to improvement of their health.

We decided to follow up on our qualitative study with a cross-sectional study. Our aim was to quantify reasons for Roma and non-Roma women’s attendance in the national screening programme in the North-Western Region of Romania.
Methods

This study includes a convenience sample of 1000 women with Roma and non-Roma backgrounds (the latter category includes women of Romanian, Hungarian and Ukrainian backgrounds), aged between 25 and 65 years, and living in the North-Western Region of Romania. Roma are purposely overrepresented in the sample. A questionnaire, designed on the basis of the results of our qualitative study (Andreassen et al. 2017) was used.

Piloting the questionnaire

The questionnaire was piloted amongst Roma women in Oslo, Norway and in the North-Western Region of Romania. This piloting demonstrated that some questions were difficult to understand and that some women had limited literacy skills and needed help filling in the forms. As a result, some questions were simplified, and it was decided to administer the questionnaire during ‘questionnaire-meetings’ where assistance would be available for the study participants. 17 data collectors were trained by the Romanian Cancer Society and the first author to provide such assistance. The data collectors consisted of 8 Roma mediators (for recruiting Roma women), and 9 were majors, GPs or nurses (for recruiting non-Roma women). They were trained to ask questions in a standardized fashion and provided with detailed written instructions about each question in the questionnaire. The data collectors were compensated with 15 RON (3 Euro) for each woman they assisted in completing the questionnaire. Between April and July 2016 the data collectors conducted 30 questionnaire-meetings for women recruited from the data collector’s communities.

Questionnaire-meetings

Women who attended the questionnaire-meetings were offered snacks and information flyers about the national screening programme. Between 3 and 10 women participated in each meeting, which lasted from 60 to 90 min. The meetings were organized in classroom-like venues, with women seated at individual desks, to ensure their privacy. The data collectors started the meeting by informing the participating women about the study and that they could be contacted if something was unclear or if help was needed, when filling in the questionnaire.

Questionnaire

The questionnaire contained 69 questions regarding year of birth, marital status, attained education, ethnicity, country of birth, language spoken at home, living and working situation, number of sex partners, use of contraception, pregnancies and childbirths, experiences with health care services, feeling of discrimination, knowledge of, and attitudes towards cervical cancer and screening, knowledge about human papillomavirus (HPV) and previous attendance in cervical cancer screening (Supplementary material 1). No personal identifying information was written on the questionnaires. We checked whether any women had attended twice (none had), using a list of previous respondents names. This list was deleted after the checking was completed. No records were kept by the trained operators.

Approvals

The study was reviewed and approved in Romania by the Ethics Committee for the Institute of Oncology Prof. Dr. Ion Chiricuță” in Cluj-Napoca (IOCN) as part of its overall assessment of the project entitled Cervical Cancer control among Roma and other disadvantaged groups of women (CertCcRom)—Assessment Record no. 28/10.12.2014, request no. 10988/10.12.2014. The study was recommended by the Data Protection Official for Research in Norway (case number 2015/4787).

Statistical analysis

Statistical differences between women who had and had not attended screening were assessed using Student’s t test for the continuous outcome, age. The association between two categorical variables was estimated through univariate odds ratios (OR) and 95% confidence intervals (CI). A multivariate model adjusted for the following potential confounders: age, education level, number of sex partners and cervical screening attendance, was estimated through OR and 95% CI by logistic regression. In this multivariate model, all variables that were found to be statistically significant in univariate analyses were assessed one by one in order to identify potential factors that could influence cervical screening attendance. The strength of the final multivariate model was checked using the Hosmer and Lemeshow test (Hosmer and Lemeshow 2000).

Missing data were treated using multiple imputation technique (Cummings. 2013). The estimation for imputed data was based on all other variables used in the study (all variables with missing data are presented in Supplementary Table 2). The imputation allowed us to include all women with information on attendance in screening avoiding bias in the final analyses (Li et al. 2015b).

All statistical analyses and multiple imputation methods were conducted using the Stata statistical software package.
We used a two-sided 5% significance level for all analyses.

Results

Women’s characteristics

A total of 1000 women were enrolled into the study. We excluded 19 women from whom information about screening was missing, and one with missing information about ethnicity, resulting in 980 women. Their mean age was 39 (± 10) years. Women described themselves as Roma (60%), Romanians (35%), Hungarians (4.7%) and Ukrainian (0.3%). We divided ethnicity into two categories, i.e. Roma and non-Roma (with the latter category encompassing all but those self-identifying as Roma).

Characteristics of participating women by ethnicity

Non-Roma women were older and more often married and employed than Roma women and had longer education and more rooms in their houses (Table 1). Roma women were more often single or cohabiting, had considerably shorter education and reported to live in smaller houses and together with more people compared to non-Roma women. Roma women also reported to take a shower or bath less often than non-Roma and were less likely to have a GP and health insurance. Far more Roma women (54%) reported to never have taken a cervical cancer screening test than non-Roma women (37%) (Table 1). Roma women reported more frequently than non-Roma women to have experienced discriminatory behaviour from their gynaecologist and/or GP during their last health care visit (Table 2).

Characteristics of screening attenders and non-screening attenders

Dividing the study participants into attenders and non-attenders, we found that non-attenders, in addition to being more often Roma, reported more frequently to have less than 5 years of education (41 vs 26%), being single (11 vs 7%) or co-habiting (30 vs 25%), working at home as a housewife (61 vs 37%), living in a rural (70 vs 51%) as opposed to an urban area. Non-attenders were also more likely than attenders to take a shower or bath maximum once a week (16 vs 5%). These proportions and corresponding multivariate ORs are reported in Table 3.

The most frequent barrier for non-attendance among never-attenders was lack of awareness about the programme’s existence (43%), lack of money (31%), being afraid of the results (13%) lack of time (11%) and the distance to the doctor (11%). Roma women reported the three most frequent barriers (lacking awareness about the programme, lack of money and being afraid of results) more often than non-Roma women did. Non-Roma women, on the other hand, reported the barriers, time contains and the distance to the doctor, more frequently than Roma women did (Fig. 1).

Discussion

In this cross-sectional study in Romania, having three or more lifelong sex partners and having ever heard about cervical cancer screening were associated with higher odds of attending screening. That women with more lifelong sex partners are more likely to attend screening has been reported in studies elsewhere. For instance, in Northern Ethiopia (Bayu et al. 2016) and Australia (Smith et al. 2011), women with multiple sex partners had 1.6 and 1.06 higher odds of attending screening, respectively, than women without multiple sex partners. This may be explained by the fact that cervical cancer is mainly caused by a sexually transmitted virus, HPV. Women knowing about this link might seek screening more often if they consider their own cancer risk as higher when having multiple sex partners. The fact that only 44% of the women, taking part in our study, had knowledge about HPV could counter-argue this hypothesis. However, while the link between sexual activity and cervical cancer may be
### Table 1 Characteristics of 980 Roma and non-Roma women, living in North-Western region of Romania, 2016-2017

<table>
<thead>
<tr>
<th>Group of ethnicity</th>
<th>Non-Roma</th>
<th>Roma</th>
<th>Univariate OR</th>
<th>95% CI</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Age</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Mean (standard deviation)</td>
<td>45.6 (10.4)</td>
<td>38.0 (9.6)</td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>Marital status</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Single</td>
<td>28</td>
<td>7</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Cohabiting</td>
<td>55</td>
<td>14</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Married</td>
<td>273</td>
<td>70</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Divorced/separated</td>
<td>25</td>
<td>6</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Widow</td>
<td>11</td>
<td>3</td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>Attained education</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>0–4 years</td>
<td>8</td>
<td>2</td>
<td></td>
<td></td>
</tr>
<tr>
<td>5–8 years</td>
<td>88</td>
<td>22</td>
<td></td>
<td></td>
</tr>
<tr>
<td>9 or more years</td>
<td>296</td>
<td>76</td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>Do you have health insurance?</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>No/I do not know</td>
<td>61</td>
<td>16</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Yes</td>
<td>331</td>
<td>84</td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>Have you ever taken a screening-test from the cervix?</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>No</td>
<td>144</td>
<td>37</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Yes</td>
<td>248</td>
<td>63</td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>What best describes what you do every day? (regrouped)</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Employed</td>
<td>239</td>
<td>61</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Housewife</td>
<td>92</td>
<td>23</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Others$^b$</td>
<td>61</td>
<td>16</td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>How many people do you live together with?</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>0–2 people</td>
<td>146</td>
<td>37</td>
<td></td>
<td></td>
</tr>
<tr>
<td>3 people</td>
<td>104</td>
<td>27</td>
<td></td>
<td></td>
</tr>
<tr>
<td>4–5 people</td>
<td>104</td>
<td>27</td>
<td></td>
<td></td>
</tr>
<tr>
<td>6 or more people</td>
<td>38</td>
<td>10</td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>If you live in a house or flat: How many rooms does it have?</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>1 room</td>
<td>19</td>
<td>5</td>
<td></td>
<td></td>
</tr>
<tr>
<td>2 rooms</td>
<td>79</td>
<td>20</td>
<td></td>
<td></td>
</tr>
<tr>
<td>3–4 rooms</td>
<td>154</td>
<td>39</td>
<td></td>
<td></td>
</tr>
<tr>
<td>5 or more rooms</td>
<td>140</td>
<td>36</td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>Approximately, how often do you take a shower or a bath?</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Every day</td>
<td>287</td>
<td>73</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Between 2 and 5 times a week</td>
<td>93</td>
<td>24</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Maximum once a week</td>
<td>12</td>
<td>3</td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>Have you ever had sexual intercourse?</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>No</td>
<td>11</td>
<td>3</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Yes</td>
<td>381</td>
<td>97</td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>Do you have a GP?</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>No + I do not know</td>
<td>10</td>
<td>3</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Yes</td>
<td>382</td>
<td>97</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

$^a$Referring to Romanians, Hungarians or Ukrainians

$^b$i.e., students, retired or unemployed
known to women, the role of HPV in cancer development is usually unknown. Women with multiple sex partners may, therefore, look upon their own chances for cervical cancer development regardless of their HPV knowledge. The link between number of sex partners and screening may also be understood in conjunction with other sexually transmitted infections, as a higher number of sex partners increases the risks of developing symptoms, which again may lead women to seek medical help and thereby attend screening. Several studies (Lim and Sasieni 2015; Mutyaba et al. 2007; Ogunwale et al. 2016) have shown that women who seek health care for purposes other than screening are more likely to take a screening-test. This is because as soon as contact between health care and women is established, screening becomes more available and thereby more achievable.

It is well established that balanced and targeted information to women in screening age can improve uptake of screening (i.e. Chorley et al. 2017; Ferlay et al. 2015; Jepson et al. 2007). Our findings support this, as women who had ever heard of cervical cancer screening and Pap-smears had 6 times higher odds of attending screening compared to women who had not. The low attendance in Romania’s national screening programme may, in fact, be explained at least partly by an information deficit, as evidenced in our study: only 48% of the women believed that a national cervical cancer screening programme existed. Our previous qualitative study also supports this as only a handful of women we interviewed had ever heard of the national screening programme before we told them about it (Andreassen et al. 2017). Very few women in the present study had experienced that their GP had talked to them about cervical cancer screening (26%), or offered them screening referral (15%) or a screening test during their last doctor’s visit (6%) (The total not shown in tables). Thus, information about the programme’s existence and rationale does not reach the women targeted for screening sufficiently.

In our study, education level, as an indicator of socioeconomic status, was not significantly associated with screening attendance (Table 3), in contrast to studies on ethnicity, education and cervical cancer screening attendance elsewhere (i.e. Behbakht et al. 2004; Ekechi et al. 2014). Instead, our study indicated that women’s knowledge about cancer and screening played a more important role than education level.

Married women had higher screening attendance rate than women who were single, cohabiting, divorced or widowed. This finding is similar to a study reporting on associations between male partners wanting women to receive regular screening and women’s likeliness to participate (Ogunwale et al. 2016). Women who needed someone else’s permission to attend screening were less likely to attend screening than women who did not. This has also been reported elsewhere (e.g. Byrd et al. 2007; Mutyaba et al. 2007; Ogunwale et al. 2016). That 28% of Roma women and 8% of non-Roma women needed permission to attend screening (Supplementary Table 1) suggests that an information strategy that includes men could potentially be useful.

Other studies in this field have suggested that ethnicity is associated with uptake for different types of cancer screening (i.e. Ekechi et al. 2014; Gimeno Garcia 2012; Marlow et al. 2015; Moser et al. 2009). This stands in contrast to our findings, although Roma women attended screening less often than non-Roma women, ethnicity did
Table 3: Multivariate analysis with odds ratio for attending cervical cancer screening among Roma and non-Roma women living in North-Western region of Romania, 2016–2017

<table>
<thead>
<tr>
<th>Have you ever taken a screening-test from the cervix?</th>
<th>No</th>
<th>Yes</th>
<th>Multivariate odds ratio</th>
<th>95% confidence interval</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>n = 463 [47%]</td>
<td>n = 517 [53%]</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Age</td>
<td>38.8 (10.4)</td>
<td>39.3 (9.8)</td>
<td>1.00</td>
<td>0.98–1.02</td>
</tr>
<tr>
<td>Ethnicity</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Non-Romaa</td>
<td>144</td>
<td>31</td>
<td>248</td>
<td>48</td>
</tr>
<tr>
<td>Roma</td>
<td>319</td>
<td>69</td>
<td>269</td>
<td>52</td>
</tr>
<tr>
<td>Marital status</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Single</td>
<td>53</td>
<td>11</td>
<td>37</td>
<td>7</td>
</tr>
<tr>
<td>Cohabiting</td>
<td>137</td>
<td>30</td>
<td>128</td>
<td>25</td>
</tr>
<tr>
<td>Married</td>
<td>233</td>
<td>50</td>
<td>301</td>
<td>58</td>
</tr>
<tr>
<td>Divorced/ Separated</td>
<td>17</td>
<td>4</td>
<td>28</td>
<td>5</td>
</tr>
<tr>
<td>Widow</td>
<td>23</td>
<td>5</td>
<td>23</td>
<td>4</td>
</tr>
<tr>
<td>Attained education</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>0–4 years</td>
<td>188</td>
<td>41</td>
<td>135</td>
<td>26</td>
</tr>
<tr>
<td>5–9 years</td>
<td>135</td>
<td>29</td>
<td>147</td>
<td>29</td>
</tr>
<tr>
<td>More than 9 years</td>
<td>140</td>
<td>30</td>
<td>233</td>
<td>45</td>
</tr>
<tr>
<td>What best describes what you do every day?</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Other possibilitiesb</td>
<td>86</td>
<td>19</td>
<td>76</td>
<td>15</td>
</tr>
<tr>
<td>Mainly employed</td>
<td>96</td>
<td>21</td>
<td>248</td>
<td>48</td>
</tr>
<tr>
<td>Mainly housewife</td>
<td>281</td>
<td>61</td>
<td>193</td>
<td>37</td>
</tr>
<tr>
<td>Approximately, how often do you take a shower or a bath?</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Every day</td>
<td>217</td>
<td>47</td>
<td>360</td>
<td>70</td>
</tr>
<tr>
<td>Between 2 and 5 times a week</td>
<td>172</td>
<td>37</td>
<td>131</td>
<td>25</td>
</tr>
<tr>
<td>Maximum once a week</td>
<td>74</td>
<td>16</td>
<td>27</td>
<td>5</td>
</tr>
<tr>
<td>Number of sex partners</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>None</td>
<td>11</td>
<td>2</td>
<td>5</td>
<td>1</td>
</tr>
<tr>
<td>1 Partner</td>
<td>160</td>
<td>35</td>
<td>197</td>
<td>38</td>
</tr>
<tr>
<td>2 Partners</td>
<td>79</td>
<td>17</td>
<td>87</td>
<td>17</td>
</tr>
<tr>
<td>3 Partners or more</td>
<td>75</td>
<td>16</td>
<td>82</td>
<td>16</td>
</tr>
<tr>
<td>I am not sure</td>
<td>27</td>
<td>6</td>
<td>17</td>
<td>3</td>
</tr>
<tr>
<td>Did not want to answer</td>
<td>111</td>
<td>24</td>
<td>129</td>
<td>25</td>
</tr>
<tr>
<td>Have you ever heard of cervical cancer screening/Pap-smear?</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>No/I’m not sure</td>
<td>185</td>
<td>40</td>
<td>40</td>
<td>8</td>
</tr>
<tr>
<td>Yes</td>
<td>278</td>
<td>60</td>
<td>477</td>
<td>92</td>
</tr>
<tr>
<td>Do you believe there is a national cervical cancer-preventing programme in Romania?</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>No/I’m not sure</td>
<td>296</td>
<td>64</td>
<td>210</td>
<td>41</td>
</tr>
<tr>
<td>Yes</td>
<td>167</td>
<td>36</td>
<td>307</td>
<td>59</td>
</tr>
<tr>
<td>Do you need permission from someone else if you were to take a screening-test (Pap-smear/HPV-test)?</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Yes</td>
<td>126</td>
<td>27</td>
<td>68</td>
<td>13</td>
</tr>
<tr>
<td>No/I am not sure</td>
<td>337</td>
<td>73</td>
<td>449</td>
<td>87</td>
</tr>
</tbody>
</table>
not in itself explain their attendance rates. Instead, several socio and economic factors contributed to the lower screening participation rates among Roma women (Table 3). Specifically, compared to non-Roma women, Roma women were less often married, employed, living in urban areas, free to attend screening without someone’s permission, believing that there existed a cervical cancer screening programme and having daily access to a shower or bath. Our previous qualitative study of Roma women demonstrated how access to bath facilities might play a role for screening attendance. Women often feared that their health providers perceived of them as ‘dirty’ or ‘smelly’ (sic) and emphasised the need to wash up before a doctor’s visit (Andreassen et al. 2017).

Some women in this study reported feeling discriminated against by health care professionals (most commonly Roma women). We have previously referred to Roma women’s stories about experiences of stigma (Andreassen et al. 2017) and how these were entangled with a sense of reluctance to seek medical health care. Women feeling discriminated are less likely to use health care services than others (de Freitas and Martin 2015). Conversely, in a user-oriented system where women’s views are ascertained, a greater proportion of women would be expected to attend screening if/when it is offered (Eardley et al. 1985). A systematic review (Escriba-Aguir et al. 2016) has shown that targeted patient interventions such as education, media interventions and reminders can reduce racial and ethnic inequalities in access and uptake to cervical cancer screening programmes.

Overall, we found higher cervical cancer screening attendance (53%) than reported by older studies from Romania (circa 20%) (Baban et al. 2006; Todorova et al. 2009). Still, the overall attendance rate was low. That GPs seldom provided information about or offered screening may partially explain these low rates. Moreover, the cervical cancer screening programme in Romania is organized in a complex way, requiring women to consult a GP who is registered by the screening programme, who either provides the test or refers women to a programme-registered gynaecologist. Also, there are no personal invitations or reminders given to women targeted by the programme. GPs or gynaecologists do not have any obligation to report positive or opportunistic screening results (Ministry of Health 2015). This certainly leads to under-registration of positive screening results. Importantly, follow-up of women with pre-cancerous lesions is neither free of charge nor systematic, and consequently, many women without health insurance with suspicious or positive lesions at screening, are not provided adequate diagnosis and care (Government of Romania 2016–2017). As much as 31% of women who never had attended screening considered lack of money a barrier to screening attendance. Including follow-up and retesting in the free programme seems important to increase participation rates. Having cancer treatment free of charge for all women, irrespective of health

<table>
<thead>
<tr>
<th>Table 3 (continued)</th>
<th>Have you ever taken a screening-test from the cervix?</th>
<th>No</th>
<th>Yes</th>
<th>Multivariate odds ratio</th>
<th>95% confidence interval</th>
</tr>
</thead>
<tbody>
<tr>
<td>n = 463 [47%]</td>
<td>n = 517 [53%]</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Would you like to take a screening-test this year?</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>No/I am not sure</td>
<td>130 28 87 17 1</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Yes</td>
<td>333 72 430 83 1.64 1.12–2.40</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Is it difficult for you to find the time to take a screening-test?</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Yes</td>
<td>114 25 68 13 1</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>No/I’m not sure</td>
<td>349 75 449 87 2.20 1.47–3.30</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Do you think that you would receive free of charge treatment if you had cervical cancer?</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>No/I am not sure</td>
<td>367 79 352 68 1</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Yes</td>
<td>96 21 165 32 1.52 1.07–2.16</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>From what district are you?</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Rural</td>
<td>324 70 262 51 1</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Urban</td>
<td>139 30 255 49 3.12 2.21–4.39</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

*Referring to Romanians, Hungarians or Ukrainians

*Referring to students, retired, unemployed
insurance status, is clearly not sufficient to enable and motivate uninsured women to attend screening.

**Strengths and limitations**

This study has several strengths, including its large sample size and the inclusion of women with different ethnic backgrounds. To our knowledge this is the first study to explore participation in the cervical cancer screening programme using a structured questionnaire, with focus on differences between Roma and non-Roma women. Our questionnaire was developed based on our recent qualitative study in Romania (Andreassen et al. 2017) and was, therefore, particularly well attuned to the local circumstances. It has been extensively pilot tested before being administered in the field. By using questionnaire-meetings and trained data collectors, we ensured that information was collected in a standardized way and with ongoing quality assurance.

This study also has several limitations. The main weakness is that we used a convenience sample; thus, the results can only be considered representative of the women in the specific area studied. This was a choice by design, aiming to include a large proportion of Roma women. Roma mediators were seen as the best alternative for data collection among Roma women, being the link between the Roma population and the local health care. As Roma women have a high degree of illiteracy, it was impossible to use other means of data collection. Moreover, the number of women attending screening in Romania is low and this could have led to selection bias, as previous screening attenders and women with history of dysplasia and/or cervical cancer could have been especially motivated to participate in this study. Finally some of the questions in the questionnaire were of a type that could be perceived as sensitive (e.g. questions regarding number of sex partners, induced abortions and personal hygiene); thus we cannot rule out information bias, as there is always a possibility that not all participants have responded...
accurately. However, findings from the questions related to personal hygiene resonate well with our qualitative study findings in the same population (Andreassen et al. 2017).

### Conclusion

In conclusion, our study suggested that women’s cervical cancer attendance in North West Romania is low, and associated with having three or more sex partners and having ever heard about cervical cancer screening and Pap smears. The most important barriers to screening participation were lack of knowledge about the programme’s existence and lack of money (Fig. 1).

Without high coverage, the screening programme is expected to have very limited impact on cervical cancer incidence and mortality, if any. Coverage can be improved by addressing the barriers identified in our study.

The lacking information about the national cervical cancer screening programme amongst the women it targets needs to be addressed conscientiously. If the cervical cancer screening programme is to interest women, it is essential to embark on a process that aims to build contact, interaction and cooperation with them. User involvement has emerged as an approach that aims to invite service users to take part in the decision-making processes affecting their own health (Hickey 1998) and to address and amend their needs and wishes (Li et al. 2015a; Rutter et al. 2004). We propose that an approach along these lines could help re-shape the cervical cancer screening programme in Romania, with increased attendance as one outcome.

Moreover, for the screening programme to have greater impact on women’s health, it should provide a continuum of care for screened positives. It would seem essential to establish a clear referral pathway and make information easily accessible and comprehensible to women in the target population. Adequate follow-up of all women with a positive (i.e. abnormal screen) test for confirmation of diagnostic and treatment should be free of charge for every woman in the target population, including those who are uninsured.

### Acknowledgements

This study was conducted as part of CerCcRom project (Cervical Cancer among Roma and other disadvantage groups of women in Romania) with funding from the European Economic Area (EEA) Financial Mechanism 2009–2014 under Project Contract no 6SEE/30.06.2014.

### Compliance with ethical standards

This study was funded by the European Economic Area (EEA) Financial Mechanism 2009–2014 under Project Contract no 6SEE/30.06.2014. All authors declare that they have no conflict of interest. All procedures performed in this study involving human participants were in accordance with the ethical standards of the institutional and national research committee and with the 1964 Helsinki declaration and its later amendments or comparable ethical standards. Informed consent was obtained from all individual participants included in the study.

### Conflict of Interest

The authors declare that they have no conflict of interest.

### References


Supplementary material

Paper II
International Journal of Public Health: Attendance to cervical cancer screening among Roma and non-Roma women living in the North-Western region of Romania

Supplementary Table 1: Characteristic of 980 Roma and non-Roma women living in the North-Western region of Romania, 2026-2017

<table>
<thead>
<tr>
<th>Groups of ethnicity</th>
<th>non-Roma</th>
<th>Roma</th>
<th>Univariate OR</th>
<th>95% Confidence interval</th>
</tr>
</thead>
<tbody>
<tr>
<td>During the last 10 years, how many times have you had a screening test taken?</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Once</td>
<td>136 [35%]</td>
<td>204 [35%]</td>
<td>1</td>
<td></td>
</tr>
<tr>
<td>Twice</td>
<td>55 [14%]</td>
<td>56 [9%]</td>
<td>0.68</td>
<td>0.44-1.04</td>
</tr>
<tr>
<td>Three times</td>
<td>30 [7%]</td>
<td>21 [4%]</td>
<td>0.47</td>
<td>0.26-0.85</td>
</tr>
<tr>
<td>Four times</td>
<td>13 [3%]</td>
<td>7 [1%]</td>
<td>0.36</td>
<td>0.14-0.92</td>
</tr>
<tr>
<td>Five times</td>
<td>4 [2%]</td>
<td>6 [1%]</td>
<td>1.00</td>
<td>0.28-3.61</td>
</tr>
<tr>
<td>More than five times</td>
<td>35 [9%]</td>
<td>20 [3%]</td>
<td>0.38</td>
<td>0.21-0.69</td>
</tr>
<tr>
<td>Missing</td>
<td>119 [30%]</td>
<td>274 [47%]</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Whom took your last screening-test?</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Gynaecologist</td>
<td>216 [55%]</td>
<td>116 [20%]</td>
<td>1</td>
<td></td>
</tr>
<tr>
<td>GP</td>
<td>8 [2%]</td>
<td>10 [2%]</td>
<td>2.33</td>
<td>0.89-6.06</td>
</tr>
<tr>
<td>Mobil unit</td>
<td>5 [1%]</td>
<td>6 [1%]</td>
<td>2.23</td>
<td>0.67-7.48</td>
</tr>
<tr>
<td>I don't remember</td>
<td>13 [4%]</td>
<td>107 [18%]</td>
<td>15.32</td>
<td>8.26-28.44</td>
</tr>
<tr>
<td>Missing</td>
<td>150 [38%]</td>
<td>349 [59%]</td>
<td></td>
<td></td>
</tr>
<tr>
<td>If I take a screening test the doctor need to be:</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>A man</td>
<td>11 [3%]</td>
<td>14 [2%]</td>
<td>1</td>
<td></td>
</tr>
<tr>
<td>A women</td>
<td>134 [34%]</td>
<td>299 [51%]</td>
<td>0.75</td>
<td>0.76-3.96</td>
</tr>
<tr>
<td>I don't care</td>
<td>239 [61%]</td>
<td>262 [45%]</td>
<td>0.87</td>
<td>0.73-1.93</td>
</tr>
<tr>
<td>Missing</td>
<td>8 [2%]</td>
<td>13 [2%]</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Do you need permission to take a screening-test?</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>No/I'm not sure</td>
<td>360 [92%]</td>
<td>426 [72%]</td>
<td>1</td>
<td></td>
</tr>
<tr>
<td>Yes</td>
<td>32 [8%]</td>
<td>162 [28%]</td>
<td>4.28</td>
<td>2.86-6.41</td>
</tr>
<tr>
<td>Did you have to pay for the test the last time?</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>No</td>
<td>132 [34%]</td>
<td>233 [40%]</td>
<td>1</td>
<td></td>
</tr>
<tr>
<td>Yes</td>
<td>123 [31%]</td>
<td>59 [10%]</td>
<td>2.71</td>
<td>0.19-0.40</td>
</tr>
<tr>
<td>I don't remember</td>
<td>35 [9%]</td>
<td>48 [8%]</td>
<td>0.75</td>
<td>1.48-1.26</td>
</tr>
<tr>
<td>Missing</td>
<td>102 [26%]</td>
<td>248 [42%]</td>
<td></td>
<td></td>
</tr>
<tr>
<td>The last time you visited your GP did any at the clinic:</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Talk to you about cervical cancer screening?</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>No</td>
<td>252 [64%]</td>
<td>476 [81%]</td>
<td>1</td>
<td></td>
</tr>
<tr>
<td>Yes</td>
<td>140 [36%]</td>
<td>112 [19%]</td>
<td>0.42</td>
<td>0.32-0.57</td>
</tr>
<tr>
<td>Offer you a referral to the gynaecologist for screening?</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>No</td>
<td>318 [81%]</td>
<td>511 [87%]</td>
<td>1</td>
<td></td>
</tr>
<tr>
<td>Yes</td>
<td>74 [19%]</td>
<td>77 [13%]</td>
<td>0.65</td>
<td>9.46-0.92</td>
</tr>
<tr>
<td>Offer you to take a screening test?</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>No</td>
<td>363 [93%]</td>
<td>559 [95%]</td>
<td>1</td>
<td></td>
</tr>
<tr>
<td>Yes</td>
<td>29 [7%]</td>
<td>29 [5%]</td>
<td>0.65</td>
<td>0.38-1.10</td>
</tr>
<tr>
<td>Offer you flyers about cervical cancer screening?</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>No</td>
<td>353 [90%]</td>
<td>549 [93%]</td>
<td>1</td>
<td></td>
</tr>
<tr>
<td>Yes</td>
<td>39 [10%]</td>
<td>39 [7%]</td>
<td>0.64</td>
<td>0.40-1.01</td>
</tr>
<tr>
<td>Is your GP in the national screening programme?</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>No</td>
<td>48 [12%]</td>
<td>105 [18%]</td>
<td>1</td>
<td></td>
</tr>
<tr>
<td>Yes</td>
<td>147 [38%]</td>
<td>125 [21%]</td>
<td>0.39</td>
<td>0.26-0.59</td>
</tr>
<tr>
<td>I don't know</td>
<td>173 [44%]</td>
<td>253 [43%]</td>
<td>0.66</td>
<td>0.44-0.97</td>
</tr>
<tr>
<td>Missing</td>
<td>24 [6%]</td>
<td>105 [18%]</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

1 Referring to Romanians, Hungarians or Ukrainians
2 Multiple choice question
Psychological effect of cervical cancer screening when changing primary screening method from cytology to high-risk human papilloma virus testing

Trude Andreassen, Bo T. Hansen, Birgit Engesæter, Dana Hashim, Nathalie C. Steer, Ameli Tropé, Kåre Moen, Giske Ursin and Elisabete Weiderpass

Introduction
The Norwegian Cervical Cancer Screening Programme (NCCSP) has been national since 1995. It is managed by the Cancer Registry of Norway—Institute of Population based Cancer Research (CRN), which reminds women aged 25–69 years to have a cervical cytology taken every 3 years.1 From 2005, high-risk human papilloma virus (hrHPV) testing has been used as a triage test in the screening process. Since 2015, hrHPV testing has been used as the primary screening method. Women aged 34–69 years, living in four counties, have been pseudo-randomly assigned (1:1 randomization) to either hrHPV testing every 5 years (followed by cytology if hrHPV is positive), or cytology testing every 3 years (followed by hrHPV testing if low-grade cytology is detected). We compared anxiety and depression scores among participants by screening arm and results. In total, 1,008 women answered a structured questionnaire that included the validated Patient Health Questionnaire-4 (PHQ-4). The Relative Risk Ratio (RRR) of mild vs. normal anxiety and depression scores, and moderate/severe vs. normal anxiety and depression scores, were estimated by multinomial logistic regression with 95% confidence intervals (95% CIs). Compared to women who were screened with cytology, women randomized to hrHPV testing were not more likely to have mild anxiety and depression scores (RRR 0.96, CI 0.70–1.31) nor more likely to have moderate/severe anxiety and depression scores (RRR 1.14, CI 0.65–2.02). Women with five different combinations of abnormal screening test results were not more likely to have mild or moderate/severe vs. normal anxiety and depression scores than women with normal screening results. The likelihood of having abnormal long-term (4–24 months after the screening) anxiety or depression scores among women 34 years and older was not affected by screening method or screening results. The results of our study suggest that a change to hrHPV testing in primary screening would not increase psychological distress among participants.

Key words: cervical cancer screening, high-risk human papilloma virus testing, HPV, cancer registry, anxiety and depression, epidemiology, cancer, women, health-care system, prevention, Norway, Scandinavia

Abbreviations: NCCSP: The Norwegian Cervical Cancer Screening Programme; CRN: Cancer Registry of Norway—Institute of Population based Cancer Research; hrHPV: high-risk human papilloma virus; ASC-US: atypical squamous cells of undetermined significance; LSIL: low-grade squamous intraepithelial lesion; AGUS: atypical glandular cells of undetermined significance; ASC-H: atypical squamous cells—cannot exclude HSIL; HSIL: high-grade squamous intraepithelial lesion; ACIS: adeno carcinoma in situ; Ca: cancer; HG: high grade; RRR: Relative risk ratio; CI: Confidence interval

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programme as part of follow-up among women with abnormal low-grade cytology.2

Between 2015 and 2018, a national project implemented hrHPV testing in primary screening1 (i.e. as the first screening test taken) among women in four counties (Rogaland, Hordaland, Sør-Trøndelag, and Nord-Trøndelag). A prerequisite from the National Council for Priority Setting prior to the introduction of the implementation project was that hrHPV testing would not lead to increased anxiety and depression among screening participants.3 The most common mental health conditions in the general population are anxiety and depression.5,6 The prevalence of these conditions in Norway is similar to other countries in Europe and the United States8 about 25% of the Norwegian women will be affected by an anxiety disorder at some point in life,9 and around 20% will experience depression.8 Women may experience increased anxiety and depression at the time of any cervical examination,10 but it is unknown whether a change from cytology to hrHPV testing in primary screening will increase anxiety and depression levels among screening participants.

A study conducted in Norway prior to the implementation project indicated that a switch to hrHPV testing was unlikely to affect women’s anxiety nor to reduce their participation in NCCSP.11 A limitation of the study was that it was not carried out in a real-life situation but merely asked participants how they assumed they would experience the two different screening methods. Research carried out in Ireland12 found that the emotional impact of hrHPV testing in screening participants was modest and that women’s concerns were related to screening test results more than to the screening method used. Yet, the conclusion drawn by these two studies are at odds with those drawn by other researchers, suggesting that hrHPV-based screening programmes may be associated with increased anxiety and stress and to increased concerns about having a sexually transmitted infection.13,14 Hence, the relationship between hrHPV testing in primary screening and women’s mental health is unresolved. Moreover, the majority of studies addressing this issue have been performed in the setting of secondary hrHPV testing (the second test taken after cytology).15,16 We took advantage of the ongoing implementation project in the NCCSP to perform a cross-sectional study comparing anxiety and depression scores among women screened with hrHPV testing or cytology in primary screening.

Objectives
Our objectives were to compare long-term (4–24 months after the screening) anxiety and depression scores between women allocated to the two screening arms, cytology or hrHPV test.

Subjects and Methods
The implementation project of hrHPV testing in primary screening
The implementation project of hrHPV testing in primary screening is pseudo-randomized, that is, allocation to screening method is decided by the participant’s date of birth being an odd or an even day. Women aged 34–69 years living in one of the four implementation counties were allocated either to (i) hrHPV testing with a 5-year screening interval (followed by cytology if hrHPV positive) or to (ii) cytology with a 3-year screening interval (followed by hrHPV testing in case of low-grade cytology).3,17 hrHPV testing was performed on liquid-based cytology samples. Figure 1 summarizes the algorithm for hrHPV and cytology screening used in the implementation project. Women with a negative hrHPV test in the hrHPV arm, received an additional letter from the NCCSP with information about the extended screening interval that followed a hrHPV negative test result. Women aged 25–33 years were not included in the implementation project but continued to be screened with cytology every 3 years due to the generally high hrHPV prevalence with no clinical relevance in this age category.18

Study population
As of September 2017, 168,201 women had participated in the implementation project according to the Cancer Registry of Norway, which records all screening tests taken as part of the NCCSP unless participating women have actively objected to their screening data being registered.19 Among these, we identified women who had undergone cervical cancer screening between February 15, 2015 and September 15, 2016 and randomly sampled 500 women from the cytology arm and 500 women from the hrHPV arm. In addition, we randomly oversampled 500 women who had had a positive cytology in the cytology arm, and 500 women who had had a positive hrHPV test in the hrHPV arm. We did so to compare anxiety and depression scores among women with positive screening test results in the two arms. Thus, a total of 2,000 women were sampled for our study (Fig. 2).

These women received a structured questionnaire by postal mail in January or February 2017, 4–24 months after they had been informed about their last screening test result. An information leaflet and a prepaid return envelope were enclosed with the questionnaire. The initial response rate was 39% (n = 789). The questionnaire was resent to nonresponders after one month, resulting in a total response rate of 51%
We excluded six women who had answered the same questionnaire twice with dissimilar answers, leading to a 50% response rate (n = 1,008). Nine women with unsatisfactory cytology results in the cytology arm were also excluded from the analysis (Fig. 2). The registration of screening activity and screening results in the NCCSP made it feasible to link completed questionnaires to objective data on screening test results.

**Questionnaire**

The questionnaire (in Norwegian language [shown in the Supporting Information 1]) included the Patient Health Questionnaire-4 (PHQ-4) for anxiety and depression. The PHQ-4 has been developed from two larger and validated anxiety and depression measure instruments: the 7-itemed GAD-7 measuring anxiety, and the 9-itemed PHQ-9 measuring depression. PHQ-4 incorporates the core criteria for anxiety and depression from these instruments and has been validated for use as a screening tool. A meta-analysis has found that combining anxiety and depression items into one tool gives better results than single-item screening tools. The PHQ-4 consists of two questions regarding anxiety and two regarding depression. It asks: “Over the last two weeks, how often have you been bothered by the following problems” and then specifies these as “feeling nervous, anxious, or on the edge,” “not being able to stop control worrying,” “feeling down, depressed or hopeless” and “having little interest or pleasure in doing things.” For each of these items, responses were scored as: 0 (“not at all”), 1 (“several days”), 2 (“more than half the days”) or 3 (“nearly every day”), with a total score range from 0 to 12. Anxiety and depression was graded as none (total score from 0 to 2), mild (3–5), moderate (6–8) and severe (9–12).

The questionnaire also asked about age, marital status and educational level. In addition, nonvalidated questions were asked about the study participants’ experience with the NCCSP (e.g. have you ever received a letter from the Cancer Registry reminding you to take a screening test?), knowledge related to cervical cancer (e.g. before reading the attached information letter, did you know that a cervical cytology test...
can reveal cellular changes that untreated can lead to cervical cancer? knowledge related to HPV (e.g., before you read about human papillomavirus (HPV) in the attached information letter, did you know that HPV can cause cancer?), their last screening test results (e.g., what was the result of your last screening test?), and the type of screening method that had been used at their last screening attendance (e.g., what screening method was used when your last screening test was taken?) The questionnaire was piloted in two rounds in 2016 among women working at CRN.

**Ethical considerations**

The Privacy Ombudsman and Data Protection Officer at Oslo University Hospital in Norway, assessed and recommended the study (case number 2016/15743). The information leaflet explained the study, including the registry linkages that would take place, and that answering and returning the questionnaire would be considered informed consent to participate in the study. Each questionnaire was assigned a unique ID number*, from 1 to 2000, and was linked to the objective clinical screening data at the NCCSP.

**Statistical analysis**

Statistical differences between women in the two screening arms (cytology and hrHPV) were assessed using χ² test for categorical outcomes and Student’s t-test for the continuous variable, age. Anxiety and depression scores were categorized as normal (values ≤2), mild (values 3–5), or moderate/severe (values >5), and compared between the two screening arms and among persons with different screening test results. We estimated the relative risk ratio (RRR) of scoring (a) mild vs.

*In Norway, all citizens are given a unique personal identification number when born. To ensure the anonymity of the study participants, we did not use this personal identification number on the questionnaires, rather a unique ID number.

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**Figure 2. Flow diagram of study participants and their previous screening results.** We identified women from the pilot project with the following strata: 500 women from the cytology arm, 500 women from the hrHPV arm, 500 with a positive cytology results from the cytology arm and 500 women with a positive hrHPV test results from the hrHPV arm. Total 2000 women: **nine women with inconclusive screening test results in the cytology arm are excluded from the analysis. [Color figure can be viewed at wileyonlinelibrary.com]**
normal and (b) moderate/severe vs. normal on anxiety and depression by multinomial logistic regression with 95% confidence intervals (95% CI).

The association between the two screening arms and between the specific screening results and anxiety and depression were estimated in two separate models. These models were adjusted for demographic characteristics that differed between women in the two screening arms (Table 1): marital status (married/cohabiting, single/divorced/widowed) and place of birth (Norway, all other countries). Based on findings of prior studies of the association between screening method and psychological distress,\textsuperscript{11,24,25} we also included age group (34–44, 45–54, ≥55) and educational level (≤13 years, >13 years) as covariates in the two multinomial logistic regression models. The goodness of fit of the multinomial crude models was evaluated by testing the goodness of fit in the two corresponding logistic regression models for mild vs. normal and moderate/severe vs. normal using the Hosmer and Lemeshow tests.\textsuperscript{26}

The elapsed time from information about screening results to answering the questionnaire was categorized (4 months to 1 year, 1–2 years). We tested for interactions between the elapsed time and the two screening arms and between elapsed time and the specific screening results by including interaction term in the models, in addition to performing stratified analyses.

The sample in the univariate and multivariate analyses vary from 966 to 1,008 women, due to missing values. All tests were two-sided with a 5% significance level. All statistical analyses were conducted using the Stata statistical software package (version 14.2).

**Definitions of cervical cancer screening test results**

Women taking part in the implementation project can, when the NCCSP’s guidelines\textsuperscript{27} are followed, receive seven different combinations of screening test results:

*In the cytology arm:*
  1. Cytology normal
  2. ASC-US\textsuperscript{5} or LSIL\textsuperscript{6} and hrHPV negative
  3. ASC-US or LSIL and hrHPV positive
  4. High-grade cytology

*In the hrHPV arm:*
  1. hrHPV negative
  2. hrHPV positive and normal cytology
  3. hrHPV positive and ASC-US or more severe

**Results**

Among the 1,008 women who answered the questionnaire, 521 (52%) were from the cytology arm and 487 (48%) from the hrHPV arm. The mean age was 50.5 years (SD ± 9.7) in the cytology arm and 51.2 years (SD ± 10.1) in the hrHPV arm. The frequency of abnormal primary cytology and positive primary hrHPV tests results were 54% and 53%,\textsuperscript{**} respectively (Table 1).

Age, attained education, duration of residency in Norway, previous screening test results and the time that had elapsed from a woman received her last screening test result until she answered the questionnaire, were similar in the two arms (Table 1). However, women in the hrHPV arm were significantly more often single/divorced/widowed (p = 0.04) and more often born in Norway (p = 0.05) than women in the cytology arm.

The knowledge that participation in screening can detect precancerous lesions and prevent cervical cancer was similar and very high in both study arms (97% and 98% of women in the cytology and the hrHPV arm, respectively [p = 0.30]). Fewer (66%) in the cytology arm than in the hrHPV arm (72%) knew that an hrHPV infection can cause cervical cancer (p = 0.02). When women were asked what screening-method had been used the last time they were screened, the answers differed by arms: 35% of those in the cytology arm, and 39% of those in the hrHPV arm, answered correctly, whereas 4% in the cytology arm and 20% in the hrHPV arm answered this question incorrectly (p < 0.0001). Hence, the majority of women were unable to identify the analysis method used the last time they were screened (61% in women in the cytology arm and 41% in the hrHPV arm [p < 0.0001]). When asked about the results of their last screening test, fewer in the cytology arm (66%) reported this correctly than in the hrHPV arm (82%) (p < 0.0001). 53% of women in the cytology arm and 58% of women in the hrHPV arm indicated that they would have had a screening test performed on their own initiative if the screening interval were to be expanded from 3 to 5 years (p = 0.29) (Table 1).

**Anxiety and depression.** The distribution of PHQ-4 scores for anxiety and depression were nearly identical in the cytology and the hrHPV arm: 73% had normal scores, 22% and 21% had mild scores and 5% and 6% had moderate/severe scores, respectively (Fig. 3a). Furthermore, the distribution of anxiety and depression scores among women with different diagnoses is shown in Figure 3b. Most women with normal anxiety and depression scores were to be found among women with normal cytology in the cytology arm (34%) and among women with negative hrHPV test in the hrHPV arm (36%). Anxiety and depression scores among women testing positive on the primary screening test but negative on the second screening test were similar in the two screening arms (women in the cytology arm having ASC-US or LSIL but being hrHPV negative, and women in the hrHPV arm being hrHPV positive but having normal cytology: 23%–25% had

\textsuperscript{**}The high percentage of abnormal screening results is due to oversampling women with positive test results in the study cohort.
normal scores, 7%–9% had mild scores and 2%–1% had moderate/severe anxiety and depression scores, respectively). Anxiety and depression among women being double positive were also similar in the two screening arms (women in the cytology arm having ASC-US or LSIL and being hrHPV positive, and women in the hrHPV arm being hrHPV positive in addition to having ASC-US or more severe cytological diagnoses: 8%–12% had normal scores, 3%–4% had mild scores, and 1%–2% had moderate/severe anxiety and depression scores, respectively) (Fig. 3b).

Two final multivariate logistic regression models confirmed the results from Figure 3a,b with crude percentage

<table>
<thead>
<tr>
<th>Table 1. Characteristics of 1,008 women participating in the study</th>
<th>Total</th>
<th>Cytology</th>
<th>hrHPV</th>
<th>P-values by χ²</th>
</tr>
</thead>
<tbody>
<tr>
<td>Age</td>
<td>34–44 years</td>
<td>301 (30%)</td>
<td>159 (30%)</td>
<td>142 (29%)</td>
</tr>
<tr>
<td></td>
<td>45–54 years</td>
<td>343 (34%)</td>
<td>185 (36%)</td>
<td>158 (32%)</td>
</tr>
<tr>
<td></td>
<td>55 years and older</td>
<td>364 (36%)</td>
<td>177 (34%)</td>
<td>187 (39%)</td>
</tr>
<tr>
<td>Marital status</td>
<td>Married/Cohabiting/Single/divorced/widow</td>
<td>830 (82%)</td>
<td>441 (85%)</td>
<td>389 (80%)</td>
</tr>
<tr>
<td></td>
<td>Up to 13 years</td>
<td>421 (42%)</td>
<td>210 (40%)</td>
<td>211 (43%)</td>
</tr>
<tr>
<td></td>
<td>More than 13 years</td>
<td>582 (58%)</td>
<td>308 (60%)</td>
<td>274 (57%)</td>
</tr>
<tr>
<td>Attained education</td>
<td>Less than all life</td>
<td>148 (15%)</td>
<td>83 (16%)</td>
<td>65 (13%)</td>
</tr>
<tr>
<td></td>
<td>All life</td>
<td>858 (85%)</td>
<td>437 (84%)</td>
<td>421 (87%)</td>
</tr>
<tr>
<td>Birthplace</td>
<td>Norway</td>
<td>917 (91%)</td>
<td>465 (89%)</td>
<td>452 (93%)</td>
</tr>
<tr>
<td></td>
<td>Other countries</td>
<td>91 (9%)</td>
<td>56 (11%)</td>
<td>35 (7%)</td>
</tr>
<tr>
<td>Screening results</td>
<td>Normal screen results</td>
<td>468 (52%)</td>
<td>240 (46%)</td>
<td>228 (47%)</td>
</tr>
<tr>
<td></td>
<td>Abnormal screen results</td>
<td>540 (48%)</td>
<td>281 (54%)</td>
<td>259 (53%)</td>
</tr>
<tr>
<td>Anxiety and depression</td>
<td>Normal scores</td>
<td>716 (73%)</td>
<td>370 (73%)</td>
<td>346 (73%)</td>
</tr>
<tr>
<td></td>
<td>Mild scores</td>
<td>206 (21%)</td>
<td>109 (22%)</td>
<td>97 (21%)</td>
</tr>
<tr>
<td></td>
<td>Moderate/severe scores</td>
<td>53 (6%)</td>
<td>26 (5%)</td>
<td>27 (6%)</td>
</tr>
<tr>
<td>Time between screening and answering questionnaire</td>
<td>4 months to 1 year</td>
<td>521 (52%)</td>
<td>216 (41%)</td>
<td>227 (47%)</td>
</tr>
<tr>
<td></td>
<td>1–2 years</td>
<td>487 (48%)</td>
<td>305 (59%)</td>
<td>260 (53%)</td>
</tr>
<tr>
<td>Knowledge that screening can prevent cervical cancer</td>
<td>Yes</td>
<td>980 (98%)</td>
<td>503 (97%)</td>
<td>477 (98%)</td>
</tr>
<tr>
<td></td>
<td>No</td>
<td>19 (2%)</td>
<td>16 (3%)</td>
<td>10 (2%)</td>
</tr>
<tr>
<td>Knowledge of the link between hrHPV and cervical cancer</td>
<td>Yes</td>
<td>695 (69%)</td>
<td>342 (66%)</td>
<td>353 (72%)</td>
</tr>
<tr>
<td></td>
<td>No</td>
<td>313 (31%)</td>
<td>179 (34%)</td>
<td>134 (28%)</td>
</tr>
<tr>
<td>Knowledge related to last screening method used</td>
<td>Correct</td>
<td>364 (37%)</td>
<td>181 (35%)</td>
<td>183 (39%)</td>
</tr>
<tr>
<td></td>
<td>Not correct</td>
<td>112 (12%)</td>
<td>18 (4%)</td>
<td>94 (20%)</td>
</tr>
<tr>
<td></td>
<td>I do not know</td>
<td>502 (51%)</td>
<td>307 (61%)</td>
<td>195 (41%)</td>
</tr>
<tr>
<td>Knowledge related to last screening test results</td>
<td>Correct</td>
<td>698 (74%)</td>
<td>316 (66%)</td>
<td>382 (82%)</td>
</tr>
<tr>
<td></td>
<td>Not correct</td>
<td>251 (26%)</td>
<td>166 (34%)</td>
<td>85 (18%)</td>
</tr>
<tr>
<td>If the screening interval is extended from 3 to 5 years, I would take an additional screening test on my own initiative</td>
<td>More often (&gt;5 years)</td>
<td>557 (56%)</td>
<td>277 (53%)</td>
<td>280 (58%)</td>
</tr>
<tr>
<td></td>
<td>Rarer (&lt;5 years)</td>
<td>15 (1%)</td>
<td>6 (1%)</td>
<td>9 (2%)</td>
</tr>
<tr>
<td></td>
<td>When reminder from CRN</td>
<td>352 (35%)</td>
<td>189 (36%)</td>
<td>163 (33%)</td>
</tr>
<tr>
<td></td>
<td>Never or not sure</td>
<td>84 (8%)</td>
<td>49 (10%)</td>
<td>35 (7%)</td>
</tr>
</tbody>
</table>

Abbreviations: CRN: Cancer Registry of Norway; hrHPV: high-risk human papilloma virus.
distribution of anxiety and depression scores being similar between screening arms and between screening outcomes (Table 2). Univariate models showed no difference in anxiety and depression scores between women in the cytology arm and women in the hrHPV arm (mild vs. normal anxiety and depression scores [RRR 0.95, 95% CI 0.70–1.30] and moderate/severe vs. normal anxiety and depression [1.11, 0.64–1.94]). Adjustment for age, marital status, education level and birthplace, gave virtually identical results (mild vs. normal anxiety and depression scores [0.96, 0.70–1.31] and moderate/severe vs. normal anxiety and depression scores [1.14, 0.65–2.02]), that is, there were no differences in anxiety and depression scores and screening arms. When we compared the different screening test outcomes with normal cytology (being the most common screening test results in NCCSP), we found no statistically significant differences neither in univariate nor in multivariate models between any screening test results and mild vs. normal anxiety depression scores nor between moderate/severe vs. normal anxiety and depression scores. Women in the cytology arm having the diagnosis ASC-US and in addition being hrHPV negative had results in univariate models and multivariate models, respectively: (mild vs. normal anxiety and depression scores [1.11, 0.68–1.81; 1.05, 0.64–2.02] and moderate/severe vs. normal anxiety and depression scores [1.11, 0.68–1.81; 1.05, 0.64–2.02].

![Figure 3. Scores of anxiety and depression among 966 women with different screening test results (496 from the cytology arm and 470 from the hrHPV arm) (a) Grouped presentation of anxiety and depression scores between screening arm (b) Distribution of anxiety and depression scores between seven different screening diagnoses and between comparable diagnosis in the cytology and the hrHPV arm respectively. The percentage are calculated in the cytology and the hrHPV arm, respectively, *HG = high-grade cytology. [Color figure can be viewed at wileyonlinelibrary.com]
Table 2. Multinomial logistic regression for anxiety and depression scores among 966 women (496 in the cytology and 470 in the hrHPV arm) with different screening test results, reporting RRRs

<table>
<thead>
<tr>
<th>Anxiety and depression scores</th>
<th>Univariate</th>
<th>Multivariable</th>
<th>Univariate</th>
<th>Multivariable</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Normal</td>
<td>Mild</td>
<td>Moderate/severe</td>
<td>Normal</td>
</tr>
<tr>
<td>Screening arm</td>
<td></td>
<td>RRR 95% CI</td>
<td>RRR 95% CI</td>
<td></td>
</tr>
<tr>
<td>Cytology arm</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Screening results I. Cytology</td>
<td></td>
<td>1.11 (0.70–1.30)</td>
<td>0.96 (0.70–1.30)</td>
<td>1.11 (0.70–1.31)</td>
</tr>
<tr>
<td>II. ASC-US/hrHPV</td>
<td>1.11 (0.70–1.30)</td>
<td>0.96 (0.70–1.30)</td>
<td>1.11 (0.70–1.31)</td>
<td>1.11 (0.70–1.31)</td>
</tr>
<tr>
<td>III. ASC-US/hrHPV+</td>
<td>1.11 (0.70–1.30)</td>
<td>0.96 (0.70–1.30)</td>
<td>1.11 (0.70–1.31)</td>
<td>1.11 (0.70–1.31)</td>
</tr>
<tr>
<td>IV. High-grade</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>v. hrHPV−</td>
<td>1.11 (0.70–1.30)</td>
<td>0.96 (0.70–1.30)</td>
<td>1.11 (0.70–1.31)</td>
<td>1.11 (0.70–1.31)</td>
</tr>
<tr>
<td>VI. hrHPV+/Cytology−</td>
<td>1.11 (0.70–1.30)</td>
<td>0.96 (0.70–1.30)</td>
<td>1.11 (0.70–1.31)</td>
<td>1.11 (0.70–1.31)</td>
</tr>
<tr>
<td>VII. hrHPV+/High-grade</td>
<td>1.11 (0.70–1.30)</td>
<td>0.96 (0.70–1.30)</td>
<td>1.11 (0.70–1.31)</td>
<td>1.11 (0.70–1.31)</td>
</tr>
</tbody>
</table>

Abbreviations: RRR: relative risk ratio; hrHPV: high risk human papilloma virus; ASC-US: Atypical squamous cells of undetermined significance.

[0.91, 0.36–2.26; 0.93, 0.37–2.38]). Women in the cytology arm having the diagnosis ASC-US and in addition being hrHPV positive had in univariate and multivariate models results, respectively: (mild vs. normal anxiety and depression scores [1.22, 0.60–2.47; 1.10, 0.53–2.25] and moderate/severe vs. normal anxiety and depression scores [0.69, 0.15–3.20; 0.62 0.13–2.94]). Women in the cytology arm having a high-grade cytology had in the univariate and multivariate models, respectively (mild vs. normal anxiety and depression scores, (9.74, 0.44–2.02; 0.73, 0.33–1.60) and moderate/severe vs. normal anxiety and depression scores (1.04, 0.28–3.82; 0.95, 0.25–3.63)). Women in the hrHPV arm being hrHPV negative had in univariate and multivariate models, respectively (mild vs. normal anxiety and depression scores [0.77, 0.48–1.24; 0.79, 0.48–1.28] and moderate/severe vs. normal anxiety and depression scores [0.99, 0.45–2.21; 1.07, 0.47–2.43]). Women in the hrHPV arm being hrHPV positive and having normal cytology had results in univariate and multivariate models, respectively (mild vs. normal anxiety and depression scores [1.27, 0.79–2.04; 1.15, 0.70–1.87] and moderate/severe vs. normal anxiety and depression scores [1.28, 0.79–2.43]). Finally, women in the hrHPV arm being hrHPV positive and having ASC-US or more severe cytology diagnoses had in univariate and multivariate models, respectively: (mild vs. normal anxiety and depression scores [1.28, 0.79–2.43; 1.07, 0.47–2.43]). Women in the hrHPV arm being hrHPV positive and having normal cytology had results in univariate and multivariate models, respectively (mild vs. normal anxiety and depression scores [1.27, 0.79–2.04; 1.15, 0.70–1.87] and moderate/severe vs. normal anxiety and depression scores [1.28, 0.79–2.43]). To sum up, we found no difference in anxiety and depression scores neither between women in the two screening arms nor between women with different screening diagnosis.

We performed stratified analyses to further investigate whether anxiety and depression scores were associated with time elapsed between when the women were informed about their last screening test results and when they answered the questionnaire. There was no interaction between elapsed time and screening arm (p = 0.39). Stratified analyses by elapsed time can be found in the Supporting Information Table S1.

Separate analyses of the anxiety and the depression dimensions of the PHQ-4 score showed no difference by screening arm or by screening test result on anxiety scores, or on depression scores (Supporting Information Table S2).

Discussion

In this cross-sectional study, we compared mild vs. normal anxiety and depression scores as well as moderate/severe anxiety and depression scores vs. normal, among women, 34 years and older, tested by cytology or hrHPV in primary screening. We found no difference in long-term (4–24 months after the screening) anxiety and depression scores as measured by the PHQ-4 scale between the two groups. Seven different combinations of screening test results were possible outcomes in the implementation project. There were no statistically significant
differences in long-term anxiety and depression scores between women receiving each of these different screening results.

A concern when changing test method in a screening programme is whether the new test could influence screening participation negatively and psychological distress might potentially lead to reduced participation.\(^{28}\) The literature is inconsistent regarding anxiety and depression related to hrHPV testing in cervical cancer screening and its impact on screening participation. The results from our study are coinciding with a large randomized trial from Manchester in 2008 enrolling 24,510 women. Our study found no adverse significant psychological effect on routine hrHPV screening as compared to cytology screening.\(^{29}\) This lack of association between HPV screening and psychological distress might be explained by what is found in three other studies\(^{30–32}\) showing that anxiety and depression is first and foremost linked to having abnormal screening results and not to the screening method used. In contrast to this, a systematic review of 17 studies in 2012 concluded that hrHPV testing could indeed increase anxiety, impact relationships and provoke fear of stigmatization.\(^{33}\) This review and several other studies have linked women’s experiences of anxiety to reflections around stigma as HPV infections are sexually transmitted.\(^{13,34}\) In concordance to our study, where hrHPV was the primary screening test, the women in the above-mentioned studies\(^{13,34}\) knew that they had an abnormal cytology, and the hrHPV test was part of follow-up.

The vast majority of women taking part in our study knew that screening can prevent—and that an HPV infection can cause—cervical cancer. However, most women did not know which method was used in their last screening test. This was the case even though information campaigns in mass media and at health centers had been carried out prior to the initiation of the implementation project of hrHPV as primary screening method, suggesting that the information strategy did not fully succeed in enlightening the women targeted for screening. This should be taken into consideration when interpreting these results.

Half of the participants in the present study said they would seek screening tests more often than ever year if the programme’s screening interval were to be expanded from 3 to 5 years. This may reflect women’s fear that a 5-year interval might be unsafe. However, to expand the screening interval from 3 to 5 years using hrHPV testing in primary screening is considered safer than a 3-year interval with conventional primary cytology screening according to different studies.\(^{18,35}\) However, this fact is not currently known among women targeted by the national cervical cancer screening programme in Norway. Our findings are in line with those from a modeling study in Australia. \(^{36}\) The Australian study indicated that extended screening intervals when adopting hrHPV testing as primary screening method is expected to lead to fluctuation in screening participation of about ±50% in the first 5-year period. A screening programme where over half of the women seek opportunistic screening would entail unnecessary use of healthcare services and costs. Therefore, further efforts are needed to provide women with accurate and understandable information about the HPV infection and the safety of expanding screening intervals with the introduction of hrHPV testing in primary screening.\(^{18,25}\) Information must necessarily be tailored to match women’s needs to be effective.\(^{37}\) Moreover, knowledge has the potential to reduce negative psychological outcomes.\(^{38–40}\) Interestingly, in our study women in the hrHPV arm had significantly more knowledge about their own screening test results than women in the cytology arm. This may be because women in the hrHPV arm who were hrHPV negative received an additional information letter from the CRN,\(^{28}\) including information about the method used and the extended screening interval. The difference in knowledge could also be because women who are tested with hrHPV and who are hrHPV positive tend to seek information about screening test results more actively than women who are tested with cytology.\(^{12,33}\) This may also indicate that the information given related to screening test results raised awareness about the screening procedures and outcomes.

**Strengths and limitations**

Our study has several limitations. The PHQ-4 scale is a general tool for detecting symptoms of anxiety and depression; as such it does not include questions related to cervical cancer screening or its procedures. Women answered the questionnaire 4 months to 2 years after receiving their last screening result, and any anxiety and depression they might have felt closer in time to screening participation could have faded by the time they took part in the study. Another possible limitation in our study is non-response bias, as individuals who chose to answer the questionnaire may differ from non-responders. Nonresponse is unlikely to differ between arms but may have reduced the representability of the study’s sample.

We did not find any significant associations in the study, but some RRR’s were somewhat elevated for example, women in the hrHPV arm had a nonsignificant 14% increased risk of experiencing moderate/severe anxiety and depression scores as compared to women in the cytology arm (Table 2). Due to the limited number of study participants, we cannot entirely rule out that a difference exists but was not revealed due to lack of statistical power.

The entire questionnaire was piloted only among women working at the CRN, a select group likely more aware of health-related issues than the general population. However, the women involved in the pilot were asked to try to look at the questionnaire as if they did not have their professional knowledge, and many good suggestions and subsequent changes were made as a result of this piloting process. Thus, we do not know whether some of the questions were difficult to understand among other women. The PHQ-4 score was, however, a validated screening tool for measuring anxiety and depression.
Despite randomization, there were some differences between screening arms regarding marital status and birthplace, and these differences were therefore adjusted for in the two multinomial logistic regression models. Finally, the survey questionnaire was answered at a single point in time, and any changes in anxiety and depression over time were not assessed.

Prior to the onset of the hrHPV pilot project, information campaigns regarding HPV had been delivered in mass media and at doctors’ offices, and additional information was delivered from the CRN to women randomized into the hrHPV testing arm only. This may have contributed to raise the level of knowledge among women in the hrHPV testing arm, thus making these women more prepared to deal with an abnormal screening test result than women in the cytology arm. This might at least partially explain the difference in knowledge we found between arms in our study.

The study also has several strengths. It was conducted on a large sample, and anxiety and depression scores were measured in a real-life situation (and not only hypothetically as in the previously published study). Women with positive screening results were oversampled by design, which might at least partially explain the difference in knowledge we found between arms in our study.

Conclusions

In our study, we have compared long-term (4–24 months after the screening) anxiety and depression scores between women 34 years and older undergoing primary cervical cancer screening with cytology and hrHPV testing. We found no differences in anxiety and depression scores between the two groups measured from 4 months to 2 years after women had received their last screening test result. We conclude that there are no indications that screening participation will be adversely affected by anxiety and depression nor that hrHPV testing in primary screening would make women have more anxious and/or depressed symptoms than conventional cytology screening.

Acknowledgements

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References

25. Anhang R, Goodman A, Golde SJ. HPV communication: review of existing research and
Supplementary material

Paper III
Supplementary Table 1 Multinomial logistic regression for anxiety and depression scores among 966 women (496 in the cytology and 470 in the hrHPV arm) with different screening test results, measured between 4 months and 1 year and between 1 and 2 years since women had received their last screening test results. Reporting Relative Risk Ratios (RRR)

<table>
<thead>
<tr>
<th>Anxiety and depression scores measured:</th>
<th>Univariate</th>
<th>Multivariable*</th>
<th>Univariate</th>
<th>Multivariable*</th>
</tr>
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<td>RRR</td>
<td>95% CI</td>
<td>RRR</td>
<td>95% CI</td>
</tr>
<tr>
<td></td>
<td>Mild vs. normal</td>
<td>Moderate/severe vs. normal</td>
<td></td>
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<td></td>
<td></td>
<td></td>
<td></td>
</tr>
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<td>1</td>
<td>1</td>
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<td>1</td>
<td>1</td>
</tr>
<tr>
<td></td>
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<td>1</td>
<td>1</td>
</tr>
<tr>
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<td>II. ASC-US/hrHPV-</td>
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<td>0.49-1.79</td>
<td>0.91</td>
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<td>1.08</td>
<td>0.47-2.45</td>
<td>1.04</td>
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</table>

* Adjusted for age, marital status, education level, place of birth and time elapsed from being informed about last screening test results and answering questionnaire.

**No women with these screening test results were reporting moderate/severe anxiety and depression scores.
Supplementary Table 2. Multinomial logistic regression for anxiety scores only and depression scores only among 966 women (496 in the cytology arm and 470 in the hrHPV arm) with different screening test results, reporting Relative Risk Ratios (RRR)

<table>
<thead>
<tr>
<th>Anxiety scores</th>
<th>Screening arm</th>
<th>Univariate</th>
<th>Multivariable*</th>
<th>Univariate</th>
<th>Multivariable*</th>
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<tr>
<td></td>
<td></td>
<td>RRR</td>
<td>95% CI</td>
<td>RRR</td>
<td>95% CI</td>
</tr>
<tr>
<td></td>
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<td>Moderate/severe</td>
<td>Mild vs normal</td>
<td>Moderate/severe vs normal</td>
<td></td>
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<td>Normal</td>
<td>Cytology arm</td>
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<td>82 (16%)</td>
<td>34 (7%)</td>
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<td>hrHPV arm</td>
<td>361 (77%)</td>
<td>75 (16%)</td>
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<td>0.96</td>
</tr>
<tr>
<td></td>
<td></td>
<td>1 (1%)</td>
<td>1</td>
<td>1</td>
<td>1.08</td>
</tr>
<tr>
<td>Mild</td>
<td>I. Cytology-</td>
<td>177 (76%)</td>
<td>40 (17%)</td>
<td>17 (7%)</td>
<td>1</td>
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<tr>
<td></td>
<td>II. ASC-US/hrHPV-</td>
<td>125 (78%)</td>
<td>24 (15%)</td>
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<td>0.84</td>
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<tr>
<td></td>
<td>III. ASC-US/hrHPV+</td>
<td>41 (77%)</td>
<td>10 (19%)</td>
<td>2 (4%)</td>
<td>1.07</td>
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<tr>
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<td>IV. High-grade</td>
<td>39 (76%)</td>
<td>8 (16%)</td>
<td>4 (8%)</td>
<td>0.90</td>
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<td>V. hrHPV-</td>
<td>175 (79%)</td>
<td>32 (14%)</td>
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<td>0.80</td>
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<td>129 (77%)</td>
<td>29 (17%)</td>
<td>10 (6%)</td>
<td>0.99</td>
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<td>VII. hrHPV+/ASC-US+</td>
<td>57 (71%)</td>
<td>14 (18%)</td>
<td>9 (11%)</td>
<td>1.08</td>
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<tr>
<td>Moderate</td>
<td>I. Cytology-</td>
<td>166 (71%)</td>
<td>50 (22%)</td>
<td>17 (7%)</td>
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<tr>
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<td>II. ASC-US/hrHPV-</td>
<td>110 (68%)</td>
<td>43 (26%)</td>
<td>10 (6%)</td>
<td>1.29</td>
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<td>III. ASC-US/hrHPV+</td>
<td>37 (70%)</td>
<td>11 (21%)</td>
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<td></td>
<td>IV. High-grade</td>
<td>35 (67%)</td>
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<td>severe</td>
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<td>VI. hrHPV+/Cytology-</td>
<td>121 (71%)</td>
<td>40 (24%)</td>
<td>9 (5%)</td>
<td>1.09</td>
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<tr>
<td></td>
<td>VII. hrHPV+/ASC-US+</td>
<td>56 (70%)</td>
<td>17 (21%)</td>
<td>7 (9%)</td>
<td>1.00</td>
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<tr>
<td>Depression</td>
<td>Screening arm</td>
<td>Cytology arm</td>
<td>348 (69%)</td>
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<td>33 (7%)</td>
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<tr>
<td></td>
<td>hrHPV arm</td>
<td>353 (75%)</td>
<td>95 (20%)</td>
<td>25 (5%)</td>
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<tr>
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<td>1</td>
<td>1</td>
<td>0.75</td>
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<tr>
<td>I. Cytology-</td>
<td></td>
<td>166 (71%)</td>
<td>50 (22%)</td>
<td>17 (7%)</td>
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</tr>
<tr>
<td>II. ASC-US/hrHPV-</td>
<td>110 (68%)</td>
<td>43 (26%)</td>
<td>10 (6%)</td>
<td>1.29</td>
<td>0.80-2.08</td>
</tr>
<tr>
<td>III. ASC-US/hrHPV+</td>
<td>37 (70%)</td>
<td>11 (21%)</td>
<td>5 (9%)</td>
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<tr>
<td>IV. High-grade</td>
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<td>16 (31%)</td>
<td>1 (2%)</td>
<td>1.51</td>
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<tr>
<td>V. hrHPV-</td>
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<td>176 (79%)</td>
<td>38 (17%)</td>
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<tr>
<td>VI. hrHPV+/Cytology-</td>
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<td>40 (24%)</td>
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<tr>
<td>VII. hrHPV+/ASC-US+</td>
<td>56 (70%)</td>
<td>17 (21%)</td>
<td>7 (9%)</td>
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<td>0.53-1.88</td>
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* Adjusted for age, marital status, education level and place of birth