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ORIGINAL ARTICLE

# 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 that 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

**Electronic supplementary material** The online version of this article (https://doi.org/10.1007/s00038-018-1107-5) contains supplementary material, which is available to authorized users.

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## 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 (Engebrigtsen 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 Chiricuţă" 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 (CerCcRom)—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

(version 14.2). 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).

### Factors that predicted women's willingness to attend screening

In a final fitted multivariate model, screening attendance was associated with being married (OR 2.07, 95% CI 1.17–3.65, as compared to being single), being employed (2.01, 1.25–3.24, as compared to being unemployed, a student or retired), taking a shower or bath daily (2.53, 1.39–4.62, as compared to maximum once a week), having 3 or more sex partners (5.99 1.71–21.04 as compared to none), having ever heard of cervical cancer screening (5.90, 3.76–9.27, as compared to not having heard of it), believing there is a national cervical cancer screening programme in Romania (1.55, 1.10–2.18, as compared to not believing this) and thinking that one would receive treatment free of charge if diagnosed with cervical cancer (1.52, 1.07–2.16, as compared to not thinking so). Women without time constraints (2.20, 1.47–3.30, as compared to women with time constraints), who could decide for themselves whether to take a screening test (1.70, 4.14–2.53, as compared to those needing to have someone else's permission), and who lived in urban areas (3.12, 2.21–4.39, as compared to rural areas) had higher odds of having attended screening. Women's ethnicity and educational level were not associated with screening attendance (Table 3).

## 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

| | Groups of ethnicity | | | | | |
|---|---|---|---|---|---|---|
| | Non-Roma | | Roma | | Univariate OR | 95% CI |
| | *n* = 392 [40%] | | *n* = 588 [60%] | | | |
| Age | | | | | | |
| Mean (standard deviation) | 45.6 (10.4) | | 38.0 (9.6) | | | |
| Marital status | | | | | | |
| Single | 28 | 7 | 62 | 11 | 1 | |
| Cohabiting | 55 | 14 | 210 | 36 | 1.72 | 1.01–2.95 |
| Married | 273 | 70 | 261 | 44 | 0.43 | 0.27–0.70 |
| Divorced/separated | 25 | 6 | 20 | 3 | 0.36 | 0.17.0.76 |
| Widow | 11 | 3 | 35 | 6 | 1.44 | 0.64–3.23 |
| Attained education | | | | | | |
| 0–4 years | 8 | 2 | 315 | 54 | 1 | |
| 5–8 years | 88 | 22 | 196 | 33 | 0.57 | 0.27–0.12 |
| 9 or more years | 296 | 76 | 77 | 13 | 0.01 | 0.00–0.01 |
| Do you have health insurance? | | | | | | |
| No/I do not know | 61 | 16 | 191 | 32 | 1 | |
| Yes | 331 | 84 | 397 | 68 | 0.38 | 0.28–0.53 |
| Have you ever taken a screening-test from the cervix? | | | | | | |
| No | 144 | 37 | 319 | 54 | 1 | |
| Yes | 248 | 63 | 269 | 46 | 0.49 | 0.38–0.64 |
| What best describes what you do every day? (regrouped) | | | | | | |
| Employed | 239 | 61 | 105 | 18 | 1 | |
| Housewife | 92 | 23 | 382 | 65 | 9.45 | 6.84–13.06 |
| Others[b] | 61 | 16 | 101 | 17 | 3.77 | 2.55–5.58 |
| How many people do you live together with? | | | | | | |
| 0–2 people | 146 | 37 | 95 | 16 | 1 | |
| 3 people | 104 | 27 | 105 | 18 | 1.55 | 1.07–2.26 |
| 4–5 people | 104 | 27 | 217 | 37 | 3.21 | 2.26–4.54 |
| 6 or more people | 38 | 10 | 171 | 29 | 6.92 | 4.45–10.70 |
| If you live in a house or flat: How many rooms does it have? | | | | | | |
| 1 room | 19 | 5 | 143 | 24 | 1 | |
| 2 rooms | 79 | 20 | 246 | 42 | 0.41 | 0.24–0.71 |
| 3–4 rooms | 154 | 39 | 164 | 28 | 0.14 | 0.08–0.24 |
| 5 or more rooms | 140 | 36 | 35 | 6 | 0.33 | 0.02–0.06 |
| Approximately, how often do you take a shower or a bath? | | | | | | |
| Every day | 287 | 73 | 290 | 49 | 1 | |
| Between 2 and 5 times a week | 93 | 24 | 209 | 36 | 2.22 | 0.66–2.98 |
| Maximum once a week | 12 | 3 | 89 | 15 | 7.33 | 3.93–13.71 |
| Have you ever had sexual intercourse? | | | | | | |
| No | 11 | 3 | 12 | 2 | 1 | |
| Yes | 381 | 97 | 576 | 98 | 1.39 | 0.61.3.17 |
| Do you have a GP? | | | | | | |
| No + I do not know | 10 | 3 | 102 | 17 | 1 | |
| Yes | 382 | 97 | 486 | 83 | 0.12 | 0.064–0.24 |

[a]Referring to Romanians, Hungarians or Ukrainians

[b]i.e., students, retired or unemployed

**Table 2** Roma and non-Roma women living in North-Western region of Romania in 2016–2017 and experiences when last visiting health care, by type of doctor

| When you last visited health care did you experience that they | Gynaecologist | | | | | | General practitioner | | | | | |
|---|---|---|---|---|---|---|---|---|---|---|---|---|
| | Non-Roma | | | Roma | | | Non-Roma | | | Roma | | |
| | *n* | % | Total | *n* | % | Total | *n* | % | Total | *n* | % | Total |
| Made you feel good about yourself? | 285 | 77 | 368 | 306 | 62 | 493 | 336 | 90 | 374 | 372 | 74 | 502 |
| Respected you? | 354 | 96 | 368 | 412 | 83 | 495 | 359 | 96 | 374 | 444 | 88 | 505 |
| Called you bad names? | 28 | 8 | 370 | 46 | 9 | 493 | 24 | 6 | 376 | 41 | 8 | 505 |
| Hinted you were dishonest? | 18 | 5 | 367 | 50 | 10 | 492 | 22 | 6 | 376 | 39 | 8 | 506 |
| Was good to speak to? | 351 | 95 | 366 | 405 | 82 | 493 | 363 | 96 | 377 | 450 | 89 | 504 |
| Hinted you are stupid? | 9 | 2 | 368 | 54 | 11 | 492 | 13 | 3 | 376 | 41 | 8 | 503 |
| Cared about you? | 232 | 88 | 367 | 321 | 66 | 488 | 336 | 89 | 377 | 358 | 72 | 498 |
| Took you seriously? | 337 | 92 | 367 | 345 | 71 | 488 | 296 | 74 | 398 | 443 | 74 | 595 |
| Examined you in a gentle manner? | 345 | 94 | 367 | 400 | 82 | 490 | 360 | 97 | 271 | 441 | 88 | 499 |
| Hinted you were dirty or smelly? | 7 | 2 | 367 | 42 | 9 | 485 | 9 | 2 | 375 | 30 | 6 | 499 |
| Informed you about your health in an understandable way? | 328 | 90 | 365 | 324 | 67 | 485 | 349 | 93 | 375 | 382 | 77 | 498 |

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 programmés 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 elsés 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

| | Have you ever taken a screening-test from the cervix? | | | | | |
|---|---|---|---|---|---|---|
| | No | | Yes | | Multivariate odds ratio | 95% confidence interval |
| | *n* = 463 | [47%] | *n* = 517 | [53%] | | |
| Age | | | | | | |
| Mean (standard deviation) | 38.8 (10.4) | 39.3 (9.8) | | | 1.00 | 0.98–1.02 |
| Ethnicity | | | | | | |
| Non-Roma[a] | 144 | 31 | 248 | 48 | 1 | |
| Roma | 319 | 69 | 269 | 52 | 0.89 | 0.58–1.35 |
| Marital status | | | | | | |
| Single | 53 | 11 | 37 | 7 | 1 | |
| Cohabiting | 137 | 30 | 128 | 25 | 1.34 | 0.75–2.37 |
| Married | 233 | 50 | 301 | 58 | 2.07 | 1.17–3.65 |
| Divorced/separated | 17 | 4 | 28 | 5 | 2.40 | 0.98–5.91 |
| Widow | 23 | 5 | 23 | 4 | 1.59 | 0.65–3.84 |
| Attained education | | | | | | |
| 0–4 years | 188 | 41 | 135 | 26 | 1.38 | 0.91–2.10 |
| 5–9 years | 135 | 29 | 147 | 29 | 1 | |
| More than 9 years | 140 | 30 | 233 | 45 | 0.77 | 0.50–1.17 |
| What best describes what you do every day? | | | | | | |
| Other possibilities[b] | 86 | 19 | 76 | 15 | 1 | |
| Mainly employed | 96 | 21 | 248 | 48 | 2.01 | 1.25–3.24 |
| Mainly housewife | 281 | 61 | 193 | 37 | 0.90 | 0.58–1.40 |
| Approximately, how often do you take a shower or a bath? | | | | | | |
| Every day | 217 | 47 | 360 | 70 | 2.53 | 1.39–4.62 |
| Between 2 and 5 times a week | 172 | 37 | 131 | 25 | 1.75 | 0.94–3.25 |
| Maximum once a week | 74 | 16 | 27 | 5 | 1 | |
| Number of sex partners | | | | | | |
| None | 11 | 2 | 5 | 1 | 1 | |
| 1 Partner | 160 | 35 | 197 | 38 | 4.02 | 1.20–13.41 |
| 2 Partners | 79 | 17 | 87 | 17 | 4.31 | 1.25–14.91 |
| 3 Partners or more | 75 | 16 | 82 | 16 | 5.99 | 1.71–21.04 |
| I am not sure | 27 | 6 | 17 | 3 | 2.51 | 0.63–10.06 |
| Did not want to answer | 111 | 24 | 129 | 25 | 3.88 | 1.15–13.09 |
| Have you ever heard of cervical cancer screening/Pap-smear? | | | | | | |
| No/I'm not sure | 185 | 40 | 40 | 8 | 1.00 | |
| Yes | 278 | 60 | 477 | 92 | 5.90 | 3.76–9.27 |
| Do you believe there is a national cervical cancer-preventing programme in Romania? | | | | | | |
| No/I'm not sure | 296 | 64 | 210 | 41 | 1 | |
| Yes | 167 | 36 | 307 | 59 | 1.55 | 1.10–2.18 |
| Do you need permission from someone else if you were to take a screening-test (Pap-smear/HPV-test)? | | | | | | |
| Yes | 126 | 27 | 68 | 13 | 1 | |
| No/I am not sure | 337 | 73 | 449 | 87 | 1.70 | 4.14–2.53 |

**Table 3** (continued)

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

[a]Referring to Romanians, Hungarians or Ukrainians

[b]Referring to students, retired, unemployed

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´dirtý or´smellý (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 refereed 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 ethnical 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

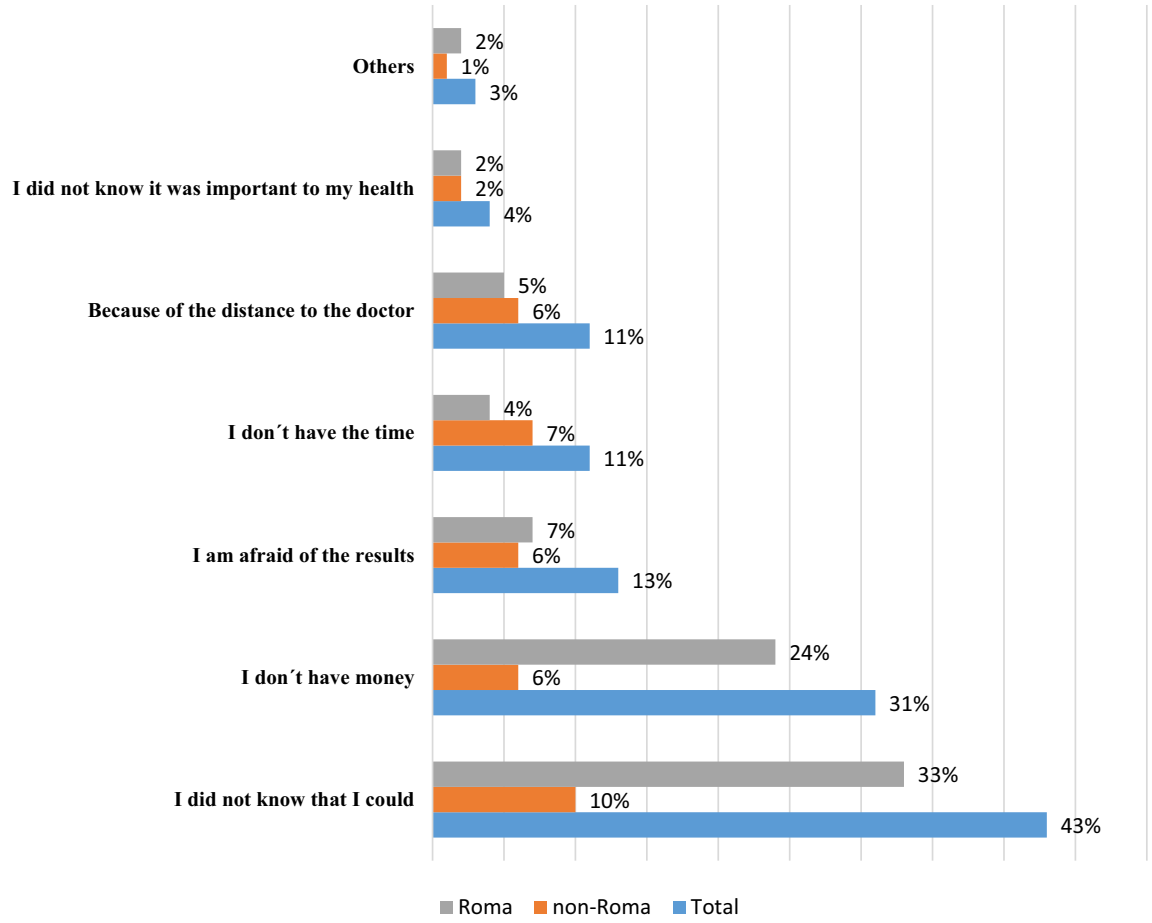


**Fig. 1** Barriers for screening participation among 464 never attending Roma and non-Roma women living in North-Western region of Romania in 2016–2017

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 womeńs 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 womeńs 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.

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## 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.

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