

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 living 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 gynecologists (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 national screening 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 (Engebriksen 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. T 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 women 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 basis of the results of our qualitative study (Andreassen. T 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 when 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 minutes. The meetings were organized in classroom-like venues, with women were 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 respondent's 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 (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 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 on ethnicity, resulting in 980. Their mean age of the participants 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 behavior from their gynecologist and/or GP during their last health care visit (Table 2).

Table 1 Characteristics of 980 Roma and non-Roma women, living in North-Western region of Romania, 2016-2017

		Groups of ethnicity				Univariate OR	95 % CI
		non-Roma ¹ n= 392 [40 %]		Roma 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 ²	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 2-5 times a week	93	24	209	36	2.22	0.66-2.98

¹ Referring to Romanians, Hungarians or Ukrainians

² i.e: students, retired or unemployed

	Maximun 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 dont know	10	3	102	17	1	
	Yes	382	97	486	83	0.12	0.064-0.24

Table 2: Women's experiences when last visiting health care, by type of doctor:

When you last visited health care, did you experience that they:	Gynaecologist						GP					
	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

Characteristics of screening attenders and non-screening attenders

Dividing the study participants into attender and non-attenders, we found that non-attenders, in addition to being more often Roma, reported more frequent 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 constraints and the distance to the doctor, more frequent than Roma women did (Figure 1).

Table 3: Multivariate analysis with odds ratio for attending cervical cancer screening among Roma and non-Roma women living in North-Western regions of Romania, 2016-2017

		Have you ever taken a screening-test from the cervix?				Multivariate OR	95 % CI
		No		Yes			
		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 ¹	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
	Other possibilities ²	86	19	76	15	1	
What best describes what you do every day?	Mainly employed	96	21	248	48	2.01	1.25–3.24
	Mainly housewife	281	61	193	37	0.90	0.58–1.40
	Every day	217	47	360	70	2.53	1.39–4.62
Approximately, how often do you take a shower or a bath?	Between 2-5 times a week	172	37	131	25	1.75	0.94–3.25
	Maximum once a week	74	16	27	5	1	
	None	11	2	5	1	1	
Number of sex partners	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	Yes	126	27	68	13	1	
	No/I'm not sure	337	73	449	87	1.70	4.14–2.53

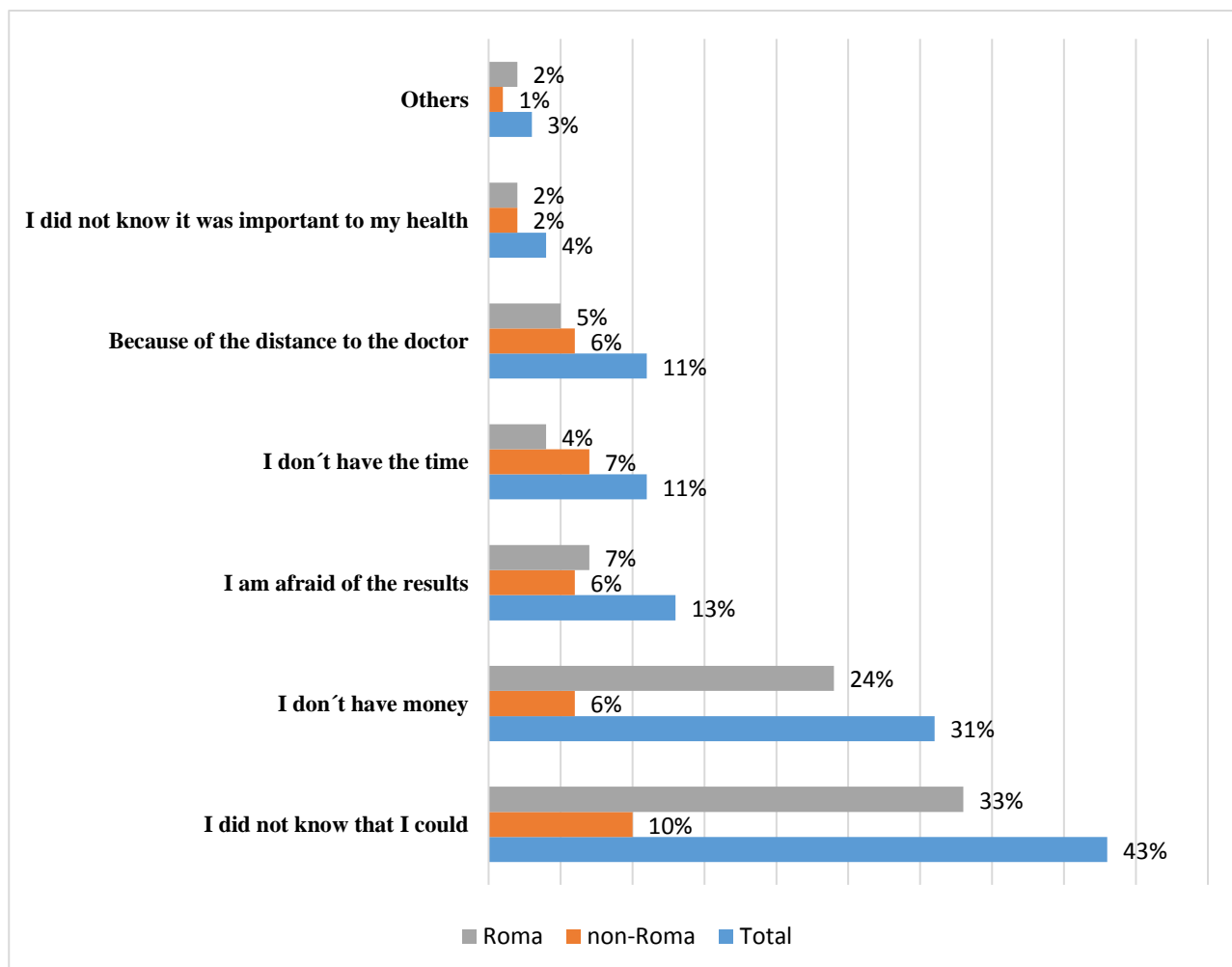
¹ Referring to Romanians, Hungarians or Ukrainians

² Referring to students, retired, unemployed

were to take a screening-test (Pap-smear/HPV-test)?

Would you like to take a screening-test this year?	No/I'm 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'm 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

Fig. 1 Barriers for screening participation among 463 never attending Roma and non-Roma women living in the North-Western region of Romania in 2016-2017



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 in 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 they would 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 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 the 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 taken 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 statistically significantly associated with screening attendance (Table 3), in contrast to studies on ethnicity, education and 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 a 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 not in itself explain their attendance rate. Instead, several social and economic factors contributed to the lower rate of screening participation rate 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 emphasise the need to wash up before a doctor's visit (Andreassen et al, 2017).

Some women in our 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 care. Women feeling discriminated are less likely to use health care service 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 GP's seldom provided information about or offered women screening may partially explain these low rates. Moreover, the cervical cancer screening programme in Romania is organized in a complex way, requiring women 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 insurance status, is clearly not sufficient to enable and motivate uninsured women to attend screening.

Strength's and limitations

This study has several strengths, including its large sample size and the inclusion of women with different ethnic background. 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 of women; 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 resonated 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 program 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 and C. 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 program in Romania, with increased attendance as one outcome.

Moreover, for the screening program 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 diagnosis 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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Supplementary Table 1: Characteristic of 980 Roma and non-Roma living in North-Western region of Romania, 2016-2017

		Groups of ethnicity				Univariate OR	95% Confidence interval
		non-Roma ¹		Roma			
		n =392	[40%]	n= 588	[60%]		
During the last 10 years, how many times have you had a screening test taken?	Once	136	35%	204	35%	1	
	Twice	55	14%	56	9%	0.68	0.44-1.04
	Three times	30	7%	21	4%	0.47	0.26-0.85
	Four times	13	3%	7	1%	0.36	0.14-0.92
	Five times	4	2%	6	1%	1.00	0.28-3.61
	More than five times	35	9%	20	3%	0.38	0.21-0.69
	<i>Missing</i>	<i>119</i>	<i>30%</i>	<i>274</i>	<i>47%</i>		
Whom took your last screening-test?	Gynaecologist	216	55%	116	20%	1	
	GP	8	2%	10	2%	2.33	0.89-6.06
	Mobil unit	5	1%	6	1%	2.23	0.67-7.48
	I don't remember	13	4%	107	18%	15.32	8.26-28.44
	<i>Missing</i>	<i>150</i>	<i>38%</i>	<i>349</i>	<i>59%</i>		
If I take a screening test the doctor need to be:	A man	11	3%	14	2%	1	
	A woman	134	34%	299	51%	0.75	0.76-3.96
	I don't care	239	61%	262	45%	0.87	0.73-1.93
	<i>Missing</i>	<i>8</i>	<i>2%</i>	<i>13</i>	<i>2%</i>		
Do you need permission to take a screening-test?	No/I'm not sure	360	92%	426	72%	1	
	Yes	32	8%	162	28%	4.28	2.86-6.41
Did you have to pay for the test the last time?	No	132	34%	233	40%	1	
	Yes	123	31%	59	10%	2.71	0.19-0.40
	I don't remember	35	9%	48	8%	0.75	1.48-1.26
	<i>Missing</i>	<i>102</i>	<i>26%</i>	<i>248</i>	<i>42%</i>		
The last time you visited your GP did any at the clinic: ²							
Talk to you about cervical cancer screening?	No	252	64%	476	81%	1	
	Yes	140	36%	112	19%	0.42	0.32-0.57
Offer you a referral to the gynaecologist for screening?	No	318	81%	511	87%	1	
	Yes	74	19%	77	13%	0.65	9.46-0.92
Offer you to take a screening test?	No	363	93%	559	95%	1	
	Yes	29	7%	29	5%	0.65	0.38-1.10
	No	353	90%	549	93%	1	

¹ Referring to Romanians, Hungarians or Ukrainians

² Multiple choice question

Offer you flyers about cervical cancer screening?	Yes	39	10%	39	7%	0.64	0.40-1.01
	No	48	12%	105	18%	1	
Is your GP in the national screening programme?	Yes	147	38%	125	21%	0.39	0.26-0.59
	I don't know	173	44%	253	43%	0.66	0.44-0.97
	Missing	24	6%	105	18%		

Supplementary Table 2: Missing data information for all variables used in the study regarding Roma and non-Roma women living in North-Western region of Romania, 2016-2017

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

