



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

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communication, 2016). 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 (Engebriksen, 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. 4.9/100 000, 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-screener 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 (2010) 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 Bucharest 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

Table 1
Number of study participants interacted with in various components of fieldwork. The reported number of persons encountered during participant observation includes persons the researchers interacted with more extensively (the total number of persons met was higher). Abbreviations: RW: Roma woman/women, NW: non-Roma woman/women.

Qualitative Interviews (QI)		Participant Observation (PO)		Focus Group Discussions (FGD)	
QI#1	RW, 25, urban	PO#1-21	Roma community, urban	FGD#1-8	8 RW, urban
QI#2	RW, 33, urban	PO#22-34	Roma community, urban	FGD#9-15	7 RW, urban
QI#3	RW, 26, urban	PO#35-42	Roma community, rural	FGD#16-27	12 RW, urban
QI#4	RW, 35, urban	PO#43-51	Screening providers	FGD#28-37	10 RW, rural
QI#5	RW, 23, urban	PO#52-58	Hospitals, institutes	FGD#38-48	11 RW, rural
QI#6	RW, 55, urban	PO#59-63	Doctors' offices	FGD#49-53	5 screening specialists
QI#7	RW, 34, rural	PO#64-72	Meetings/seminars	FGD#54-57	4 screening specialists
QI#8	NW, 50, urban	PO#73-78	NGOs	57 study participants	
QI#9	NW, 65, rural	78 study participants		Total: 144 study participants	
9 study participants					

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 Middelthun, 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 based on impressions and experiences arising in the participant observation part of the study. During interviews, scratch notes were taken, and these were expanded afterwards.

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 works 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 Chiricuța" (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 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 (QI#2) 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 (PO#43) 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. FGD#16-27), 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.” (FGD#27)

Table 2
Demographic characteristics of participating Roma women.

Age	
Below screening age	4%
In screening age	91%
Above screening age	5%
Residence	
Urban	66%
Rural	34%
Married	59%
Employed	34%
Health insurance	52%
Having a GP	65%

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.” (QI#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 disapproving 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 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. Behbakht 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 a widely agreed-upon basic 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 their aftermath. What this may suggest is that the screening 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, and could not fathom that women would want to miss out on them. To do so was straightforwardly irrational in their conceptualization. Yet, women did not really overlook 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.

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