



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

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