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Containment -  
An examination of Roma health mediation in Romania

Charlotte Sophie Kühlbrandt

Thesis submitted in accordance with the requirements for the degree of Doctor of Philosophy

University of London

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Department of Public Health and Policy  
Faculty of Social and Environmental Health Research  
London School of Hygiene and Tropical Medicine



Funded by an ESRC doctoral research grant

‘I, Charlotte Sophie Kühlbrandt, confirm that the work presented in this thesis is my own. Where information has been derived from other sources, I confirm that this has been indicated in the thesis.’

## Abstract

This thesis critically examines the ways in which “Roma health” is physically and discursively enacted in communities. Following a year of participant observation of the Roma health mediation programme in Romania, I borrow productive elements from post-colonial and intersectional theories to analyse the tensions and ambivalences that arise from interactions between mediators, community members, health professionals, and local authorities. Beginning with the case of a community which was rehoused in shipping containers after being evicted from their homes, the “container” emerges as an apposite metaphor which I have used to structure my thesis. The thesis investigates the “contained” nature of many segregated communities and how this influences their material and health conditions, as well as asking how this affects the construction of “Roma” communities. I analyse attempts at “containing” ethnicity within a categorical binary of “Roma” and “non-Roma”, while observing how the contestation and negotiation of this binary, along with its implicit hierarchies produces “leaky” categories. The thesis attends to the “containment” of health, exploring how in regard to hygiene, vaccination and reproductive health, participants map concepts of “good” and “bad” patients onto Roma ethnicity. In this context mediators are often constructed as actors who transform “bad patients” into “good patients.” I show how mediators use their involvement in creating “good patients” to produce local meanings of “citizenship” and “non-citizenship”, and how people responded by participating, resisting, negotiating, or perpetuating their positions within these classifications. Finally, while acknowledging the important contribution that health mediators bring to accessing health care, I discuss the mediators’ role in promoting a neoliberal approach to governing Roma communities. I suggest that Roma health mediation could learn from dialogical and emancipatory approaches to participatory interventions in health, which aim for transformative encounters between parties while also fostering critical consciousness and aiming to change communities’ structural environment.

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**Abbreviations**

ANR	National Agency for Roma [ <i>Agenția Națională pentru Romi</i> ]
CEU	Central European University
CNP	Personal Registration Number [ <i>Codul Numeric Personal</i> ]
DSP	Public Health Direction [ <i> Direcția de Sănătate Publică</i> ]
ERRC	European Roma Rights Centre
EU	European Union
FGD	Focus Group Discussion
GP	General Practitioner
INSP	National Institute of Public Health [ <i>Institutul Național de Sănătate Publică</i> ]
NGO	Nongovernmental Organisation
OCSE	Organization for Security and Co-operation in Europe
OSF	Open Society Foundation
OSI	Open Society Institute
TB	Tuberculosis
UNDP	United Nations
UNICEF	United Nations Children's Fund
WHO	World Health Organisation



Image 1 - Shipping containers as shelter

## Preface: Shipping Containers

Eight shipping containers in a row, numbered with red paint: one, two, three, four, five, six, seven, eight. Each is twenty feet long, eight feet wide. A couple of paces apart, wires dangling in the space between. The metal is powder-coated in a bright industrial blue that clashes with the browns and greens of the surrounding field. Corrugated steel, forged and galvanised, certified by Germanischer Lloyd. Burning hot in summer, freezing cold in winter. The containers are slightly lifted off the ground, debris caught underneath. Doors and windows wide open because it is summer. A radio blasting out tunes, distorted by poor reception. Inside, fourteen square metres, buzzing with big bottle flies, hundreds of them bombing around, noisily taking off from every surface. Lace curtains hanging from each door and window frame, limp and useless against the flies. Fourteen square metres. A double bed at the far end, more mattresses propped up against the walls. Piles of duvets, blankets, pillows ready to be unfolded for the night. Bags of plastic tautly stuffed with clothes, piled on top of stacked suitcases. Prams and broken toys, children's clothes scattered across the remaining laminated floor. The smell of stewed potatoes and cabbage emanating from an improvised cooker made from breezeblock and wire springs glowing red hot in an S-shaped groove. Hanging on the wall above, a cheerful tapestry depicting a peacock in a lush oriental garden.

Immediately surrounding the containers, earth so dry that it has cracked. In front of the containers a small collection of floor matting, barely visible, encrusted with earth. Ready for when the rain comes, and the cracked earth turns into a sea of mud. Behind the blue containers, two white sanitary containers. Toilets and showers for the 80 people who have been forced to live in these eight containers. A little further, a pile of colourful plastic bottles, waiting to be weighed and exchanged for a couple of lei. All around uncultivated land stretching as far as the eye can see. Pylons and grass. In the distance a few houses: the edge of a small town, itself on the edge of a larger city. A lot of empty land all around the containers, but right in front of the containers: a hole in the landscape. A ten-metre drop down to an area roughly the size of a football pitch, filled with rubble,

unidentified plastic, waste paper. The lighter items blow off into the field. Children playing on the edge of the drop, throwing rocks into the pit.

People packed into shipping containers. The absurd notion that these metal boxes should contain anything other than objects. Fourteen square metres. Families of five or six, sometimes ten people living together in one space.

I was first brought here by an unemployed nurse, who stopped me when we approached the containers: “Come here, stand here, from this angle - what can you see? What you see is one of the sites of the Social Democratic Holocaust! What is missing? Just the Nazi soldiers and the gas chambers!” It was the first time he had been there; until that point he had only heard about the site.

The containers don’t have many visitors: the small trickle of journalists, who used to come when the containers were new, has dried up; every now and again a town hall official comes to tell them their electricity will be switched off if they don’t pay their bills; at other times a woman from the Child Protection services comes to tell them their children will be taken away if they are not treated better; most evenings a police car slowly circles around the containers before disappearing into the distance. People treated as objects: moved out of their houses, packed into containers, where they can be more easily policed, where they are regularly reported on by journalists, occasionally also by academics.

The families used to live half a kilometre away, in a little cluster of houses. In October 2013, the mayor decreed that these houses were illegal constructions on municipal land. The people who had been living there for decades were evicted by armed police and their houses bulldozed. Some of the families have been moved into a crumbling old school building nearby, others have moved back to the place where their houses were demolished and live in temporary structures. Six months after the eviction, the families who were registered as local residents were given new homes by the municipality: these eight shipping containers.

The containers were in Eforie Sud, a small town by the Black Sea, popular with Romanians during the summer season. The containers are invisible from the beach, or from any of the places where a tourist would go; they are on the very edge of the town, in a field, next to a hole in the ground that was used to broaden the beach front, and which now doubles up as an illegal landfill site where construction firms dump their waste.

Although other evicted families in Romania have been provided with equally unsuitable shelters, it is precisely the specificity and materiality of the shipping containers that I am interested in. Because Eforie was not one of my long-term fieldwork sites, because I did not conduct interviews there, and because it was widely covered by the media, it is the only place to which I have not given a pseudonym. I heard about Eforie through the network of Roma activists whom I got to know while I was in Romania, and travelled there several times from Bucharest. The eviction itself, which happened more than a year before I visited the site, had been covered extensively in the Romanian and international press (Moldovan 2014). It was hailed by local and national right wing press outlets as yet another example of Roma families living in an infectious hotspot, which had to be cleared by the authorities (Hulubei and Ionescu 2013). The local and international liberal press, on the other hand, covered it as yet another incident in which Roma families were treated without dignity, and possibly in violation of their human rights (Popescu 2013; Ciorniciuc 2013). By 2013, the narrative was already familiar to activists and journalists alike. In the preceding decade a large number of evictions had already taken place all over the country, largely following the same patterns, and disproportionately affecting Roma families (Lancione 2015). After the economic crisis of 2008-09 and the resulting austerity measures that cut budgets for local councils, municipalities are on the lookout for ways to monetarise their land. In Eforie Sud, the houses of the evicted families were demolished in order to make room for a car park for two blocks of flats that the municipality was developing, ostensibly for social housing. Local rumour has it that all the flats have already been allocated to people who bribed the local authorities, with no plans to provide space for the evicted families. In 2017, four years after their houses were demolished, the residents of the shipping containers still have an excellent view of the

empty concrete shells that mark the unfinished development. The plot where their houses once stood is unused and overgrown with weeds.

The metal containers of Eforie Sud are a striking symbol. The shipping container is perhaps the most emblematic object of contemporary capitalism (Martin 2016). It has changed the world economy because it is “at the core of a highly automated system for moving goods from anywhere, to anywhere, with a minimum of cost and complication on the way” (Levinson 2016, 2). As converted spaces they are equally characteristic of a dual drive for retail space, as well as stop-gap approaches to housing crises. They can be converted into shopping units (Fry 2017) and dystopian shopping malls such as City Container in Rotterdam (Martin 2016), into expensive housing developments (Taylor 2001), schools, studios and residency accommodation (Container City TM 2017), or indeed into social housing (Rippingale 2014). Preserved in their most basic form, in the shape of simple metal boxes such as they are to be found in Eforie Sud and elsewhere (Lancione 2016), they make cheap homeless shelters. They are symbolic of the ways in which local governments no longer strive to provide adequate housing for the most vulnerable populations. In my conversation with the local mayor of Eforie Sud, he presented himself as magnanimous for having provided the families with these eight crowded and badly insulated metal containers on the edge of a landfill.

But aside from this spatial containment, shipping containers are also symbolic of a different, more figurative form of containment. These shipping containers represent the discursive containment of Roma communities not only in Eforie but across Romania and Europe more widely. In contradiction to huge local, national and international variations, “Roma” evokes a set of narrow attributes across a wide set of contexts. Roma are “contained” by stereotypes which typically portray them as poor, uneducated, unemployed, dirty, criminal, lazy and untrustworthy (De Genova et al. 2015; Csepeli and Simon 2004; Schneeweis 2011). “The Roma subject” emerges as a dehumanised Other (Rat 2009; van Baar 2012), who has been defined and discursively contained by all but herself. The community living in the shipping containers is defined as Roma by their material conditions rather than by “essential” features that can be used to clearly mark

them out as belonging to a specific category. Their material condition interacts with the imposed ethnic category. At the intersection of “being poor” and “being Roma,” they have been essentialised, victimised, and vilified. As the archetypal European Other, they had already been placed in multiple, intersecting figurative containers, and now finally they have been made to live in a physical container. Their condition becomes the definition of their status: they live in the containers because they are “Roma,” but they are also commonly identified as “Roma” because they have been evicted, and now live in shipping containers. Perhaps they have also been housed in containers because there they can be more easily policed, both directly (by driving around them in a police car) and discursively (they no longer need to be called by name, they are now simply called “the Roma from the containers”). As I will come to show, the violence of spatial and discursive containment and surveillance reinforce each other in complex ways.

Containment has come at a high price: according to a wide consensus across politicians, scientists, and journalists, the social, political and economic exclusion of Roma communities has led to deprivation and marginalisation in employment, housing, education, and health (Hollo and Quinn 2006; Fésüs 2012; Parliamentary Assembly of the Council of Europe 2010; Parliamentary Assembly of the Council of Europe 2017). Over recent decades, civil society and governments have developed interventions to better connect contained communities with the “outside world.” One of these interventions is the Roma health mediation programme, the focus of this thesis. Health mediators have been employed by local authorities in order to build trusting relationships between Roma communities, health professionals and local authorities. My thesis critically interrogates this relationship, and the ways in which mediators try to improve access to health care for Roma communities.

The container is a useful concept to structure this thesis. Even when turning to other contexts and field sites, it serves as a constant reminder of the shipping containers in Eforie Sud. The shipping containers represent the structural, concrete, and figurative violence (Fanon 2008) involved in putting people in containers where they cannot live except in poverty, thus providing a consistent nudge towards approaching research in an anti-



essentialist way. In their hard rectangularity and with their weighty metal doors, containers are heavy symbols. My contention, however, is that containers are never as sealed as they might first appear. Part of my aim is to attend to the ways in which containers are “leaky” (Bowker and Star 1999; Manning 2009) to observe where the doors might not quite shut, and to examine where these leaks leave room for negotiation and resistance.

# Chapter 1: Introduction

This chapter is divided into three parts. First, I present what has come to be the “consensus narrative” on Roma and Roma health in Eastern Europe. I describe the key elements of this narrative, and show how the Roma health mediation programme has evolved from and is currently understood as part of this narrative. Second, I introduce the Roma health mediation programme as a response to ethnic inequalities in health. I also introduce the concept of participatory health interventions, asking to what extent the Roma health mediation programme may be considered in this light. Third, I consider critiques of the consensus narrative that have emerged over recent years. I outline some of the key theories that have propelled and underpinned my investigation of the Roma health mediation programme. Building on this critical literature, I present the research questions and objectives for this study, which uses the health mediation programme as a case study to re-evaluate some of the more contentious issues of Roma health.

## Part I - Consensus Narratives

Collectively, the summaries given about “the Roma” in the introductions to journal articles about Roma health have produced a kind of consensus narrative that is reinforced through its formulaic repetition. Given the constraints of the word count in many journals, authors often only have space to briefly engage with the setting, the historical background, and contemporary complexities of their subject matter, before focusing on their research question of interest. Below I offer a representative collage of the fairly consistent and stable consensus narrative that has arisen in academic texts on Roma health. I reproduce this narrative in somewhat caricatured form in order to highlight some of the common features that are found not only in the literature on Roma health but across other policy sectors, including education, housing and employment. Furthermore, this narrative is not only reproduced in scientific journals, but is very similar to that commonly found in policy literature, where the same language and story is recycled, for instance in successive World Bank reports about the status of Roma in Central and Eastern Europe (M. Surdu 2016). Policy and academic literature cross-reference each other, which has further stabilised the consensus narrative.

Below are five excerpts from articles on Roma health by four different sets of authors published over the last ten years:

“The Roma, a people who moved from northern India into Europe between the 9th and 14th centuries, number between 5 and 10 million people and are the European Union’s largest minority group. Within the European Union, most of the Roma population lives in the new member states—in particular, Romania, Bulgaria, Hungary, and Slovakia” (Z. Kósa et al. 2007, 853).

“Their history in the region can be described as a combination of peaceful coexistence and blatant discrimination with multiple and complex causes, among which are their remarkably preserved traditions and resistance to assimilation” (Peter Kolarcik et al. 2009, 1279).

“Although the Roma were originally nomadic, today they consist of nomadic, semi-nomadic, and settled groups [...] The Roma have maintained a distinct identity characterized by language, communal solidarity, close extended family bonds, and cultural traditions. Roma have endured centuries of persecution and enforced assimilation, and have faced persistent inequalities, poverty, and social exclusion” (Cook et al. 2013, 1).

“International recognition of their plight led the pre-2004 EU to impose requirements on some of the acceding states to address Roma rights explicitly as a condition of EU membership, while measures to improve their situation received support from several international agencies [...] Yet, despite these various policy initiatives, there has been limited progress in tackling the adverse health and social conditions of the Roma over the past two decades in most countries in Central and South Eastern Europe” (Fésüs et al. 2012, 25).

“Health inequalities experienced by Roma people living in Europe present a persisting challenge for health research and practice. Available literature on Roma and health agrees that: (1) Roma people suffer from poorer health and unhealthier living conditions compared to majority populations, (2) better data are needed to explain the Roma health gap and design better interventions to reduce this gap and (3) the poor health of Roma is closely linked to the social determinants of health” (Földes and Covaci 2012, 37).

A number of points should be highlighted as particularly recurrent. These are: a large and distinct Roma population size; inequalities, poverty, and social exclusion faced by Roma; Roma identity and traditions; the history and ongoing experience of discrimination; the inadequacy of policy to address inequalities and discrimination; and poor health outcomes compared to non-Roma. Below, I summarise the dominant discourse around each of these common themes, with a particular emphasis on the literature about Roma health.

## **Large and distinct Roma population**

Journal articles about Roma health will usually settle on a large but rather vague number to demonstrate the significant size of the population. Roma are seen as a heterogeneous yet distinct group that presents multiple difficulties for census collectors. Nevertheless, authors do not shy away from giving figures for Europe, usually between 5 and 15 million. Roma population size is often cited as a broad range without further explanation as to how this number has been arrived at (Skaric-Juric 2006; Mladovsky 2007; Peter Kolarcik et al. 2009; Kvetoslava 2010; Molnár et al. 2010; Masseria, Mladovsky, and Hernández-Quevedo 2010; Kósa, Darago, and Adany 2011; Colombini, Rechel, and Mayhew 2012; Fésüs 2012; Cook et al. 2013; Kühlbrandt et al. 2014; Silarova et al. 2014; Duval et al. 2016). While many policy makers and analysis seem to be adhering to the motto “we cannot precisely define them – but we all know who they are” (Andrey Ivanov, Kling, and Kagin 2011, 11), most academic authors highlight the difficulty of determining an accurate count for the Roma population (Kósa and Ádány 2007). Authors point to a discrepancy between census data and much larger “expert” estimates (Rughiniş 2010), explained by an “undercount” in census data (Lee et al. 2014) that can be attributed to the “procedural limitations” of data collection, “reluctance of Roma to disclose ethnicity”, or “enumerators’ departures from data-collection rules” (Wamsiedel 2013, 1). In Romania, for example, which has a total population of just over 21 million, the official census is under 620,000 Roma, in contrast to an NGO estimate of 2.2 million (A Abdikeeva, Covaci, and Ezer 2013, 8), while the most commonly cited unofficial estimate is 1.5 million, or 6.7 per cent of the total population (Open Society Foundations 2010b). For quantitative studies, researchers sometimes rely on secondary data (Idzerda et al. 2011; Kühlbrandt et al. 2014; Duval et al. 2016), or they generate their own samples by selecting participants from “Roma settlements”, which are usually not further defined (K. Kósa and Ádány 2007; Vokó et al. 2009; Kelly et al. 2006; Zelko, Švab, and Rotar Pavlič 2015). It is rare for academic articles or policy documents to refer to the “vague” or “fluid nature of Roma identity” (A Ivanov, Kling, and Kagin 2012, 8–11). The heterogeneity and complexity of subgroups among the Roma population is often foregrounded, although having mentioned these, authors continue to make assertions and conclusions based on a

simple binary distinction between “Roma” and “non-Roma” (Ringold 2000; Pavlič et al. 2011; Jarcuska et al. 2013; Bobakova et al. 2015; Watson and Downe 2017; Belak et al. 2017). Although authors tend not to give rationales for this binary, they most likely do this in order to create straightforward data that is legible and actionable by policy makers. A practical alternative for those using ethnically segregated quantitative data is yet to be proposed.

Research projects about Roma communities often take segregated communities as their starting point by selecting participants who come from “Roma settlements”, without further defining what constitutes such a settlement, or how it might be recognisable as such (Vokó et al. 2009; Kaluski et al. 2015). The large and prestigious UNDP/World Bank/EC Regional Roma Survey (2011), for example, based its approach to sampling “Roma” individuals on the idea that it was not possible to accurately determine whether an individual was Roma, but that it was possible definitively to locate “Roma communities”. It was “not practically feasible”, it said, for this large-scale survey to compile individual profiles on “values, behavioural patterns, myths, beliefs, cultural traits, etc.” in order to “conclude whether the person is ‘Roma’ or not” (Andrey Ivanov, Kling, and Kagin 2011, 11). As a result, they decided to use the unit of the settlement as an ethnic descriptor, sampling 9,207 “Roma” individuals, or 41,334 “Roma” household members from “Roma settlements or areas of compact Roma population” (14). The definition of such communities was that “15% or more households [were] Roma households,” (13), as declared in the 2002 census.<sup>1</sup> This means that, for the purposes of the census, up to 85% of the “Roma” community had not declared themselves as such. In spite of such large proportions of self-declared non-Roma ethnicity, enumerators took their respondents to be “Roma” if they lived in these sampled “Roma communities,” and if they gave their “implicit endorsement of the external identification.” The enumerators told respondents: “We are conducting a survey among the Roma population. Would you mind to be

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<sup>1</sup> The report on the methodologies in fact contradicts itself: on p.13 Ivanov et al. say that “The sampling frame for Roma settlements was based on information from the 2002 Population Census, using the enumeration areas with 15% or more households being Roma households.” Later, on p. 21, the same report states that “for the purpose of this survey, a Roma settlement was defined as part of a settlement in which the Roma population represents more than 50% of the total population of that part of the settlement).

interviewed?” and a “willingness to participate in the interview was seen as a tacit endorsement of Roma status” (15). Although the methodological report for the survey claims to recognise Roma ethnicity as a “political construct,” and a “multifaceted category,” the survey nonetheless takes “Roma communities” to be clearly measurable entities which are locatable and visitable.

Even though the abstract notion of community is also a slippery concept (Reynolds 2016), taken together, the notional existence of “Roma communities” goes largely uncriticised amongst those who write about Roma. Without further specifying what makes a “Roma community” or a “Roma settlement” Roma, the idea of ethnic separateness in certain communities is likely to be related to how difference is produced materially and imprinted on the landscape through spatial segregation, which manifests in living conditions, and in everyday absences of employment, education, and health care.

### **Inequalities, poverty and social exclusion**

Articles point to the poverty (Colombini, Rechel, and Mayhew 2012; Fésüs 2012) and inequalities (Földes and Covaci 2012; Mladovsky 2007; Rosicova et al. 2015) experienced by Roma, as well as their social exclusion and marginalisation (Janevic et al. 2011; Fésüs et al. 2012; Silarova et al. 2014; Duval et al. 2016; Belak et al. 2017). The Roma are spotlighted as “Europe’s largest and most vulnerable minority”, an expression coined by a World Bank report, *Roma in an Expanding Europe: Breaking the Poverty Cycle*<sup>2</sup> (Ringold et al. 2006, xiii), which – with small variations – has become a frequently repeated epithet (Stojanovski et al. 2012; Cook et al. 2013; Amir Khanian et al. 2013; Kühlbrandt et al. 2014; Colombini, Rechel, and Mayhew 2012). There is a large debate around the causal mechanisms for this marginality, and no agreement on the extent to which factors explain poor health outcomes (Peter Kolarcik et al. 2009; Masseria, Mladovsky, and Hernández-Quevedo 2010). One Romanian paper cites a history of nomadism as a crude and essentialist explanation for the marginal situation of Roma today (Costachie, Diaconu,

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<sup>2</sup> For further analysis of this and preceding World Bank reports on the Roma, see the analyses by Huub van Baar (2011) and Mihai Surdu (2016).

and Teodorescu 2010). Most articles, however, do not attempt to give direct causal explanations for Roma poverty, instead citing a long history of “persecution, including slavery, genocide, and stigmatization” (Djonic et al. 2013, 235). Poverty among Roma forms a backdrop against which research is conducted although only a relatively small number of articles explicitly test whether poverty or ethnicity is a stronger explanatory factor for inequalities, often finding that adjustments for factors explain only part of the disparities (Kühlbrandt et al. 2014; Duval et al. 2016; Peter Kolarcik et al. 2009; Masseria, Mladovsky, and Hernández-Quevedo 2010; Arora, Kühlbrandt, and McKee 2016).

### **Roma identity and traditions**

Roma identity and traditions are either implicitly or explicitly related to their “nomadic” origins, as well as their roots in India. “The Roma population is a diverse minority group traditionally known for their nomadic lifestyle, though many have settled over time” (Lee et al. 2014, 1), as a recent article about the mental health of Roma children states in its introductory sentence.<sup>3</sup>

“Traditional Roma” beliefs are said to influence the way in which Roma populations engage or fail to engage with health systems.<sup>4</sup> In a paper adapted from a doctoral thesis from the University of Oxford, Dorian Singh (2011) asserts that “prior to Romania’s communist era, Romanian Roma primarily relied upon their traditional medical practices and beliefs, as they were a largely unintegrated, excluded, and nomadic population” (127). Of Romanian Roma, Singh goes on to say that “there are particular health-related beliefs and practices which are more pronounced and apparent within

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<sup>3</sup> He cites an old World Bank report (Ringold 2000) “While Roma in some countries are nomadic, most in Central and Eastern Europe have settled over time, some under Ottoman rule and others more recently under socialism” (xiii).

<sup>4</sup> Following Rat (2013), I maintain that the term “traditional Roma” is a cliché that is simultaneously misleading, and useful. The term is misleading because it does not describe a single or coherent population group. Instead, those described as “traditional Roma” may come from different regions, speak different dialects, and might not think of themselves as having any common features with other so-called “traditional Roma”. The term is useful in that it is a “discursive device” (Rat 2013, nn. 5) that is commonly used to label Roma who speak Romanes, who adhere to certain social practices, lifestyles or professions. I therefore keep the term in quotation marks. I discuss other forms of discursive and enacted distinctions between different groups of Roma throughout the thesis.

Romani groups specifically, and these beliefs and practices are shared and common throughout Romani groups, irrespective of specific clan affiliation.” He highlights practices such as “clipping the hair and fingernails of the ill person and throwing them into a river [to] ward off illness, ...[drinking] a glass of water that has been held up to the moonlight [...], decorating one’s home with quartz crystals and horseshoes [to] stave off headaches” (128). Singh’s findings are extensively quoted in one of the very few Romanian studies on cultural factors influencing access to health care among Roma (Soponaru et al. 2015), which itself asserts that “because the community is nomadic, Roma people’s cultural identity, represented by beliefs, rituals, etc. has been influenced by the peoples among whom they have migrated” (196).

While this may be a particularly ill-informed and generalised example of accounts of Roma health, other authors are also quick to attribute inequalities in Roma health outcomes to specific Roma health beliefs. These are often understood to be related to culturally specific ways of life and Roma values regarding luck, symbolic pollution, communal suffering, and a certain desired number of children (Hulubaş 2011; P Kolarcik et al. 2010; Pavlič et al. 2011; Petek et al. 2006; Schneeweis 2011). For example, a report on the health of the *Roma People in Central and Eastern Europe* (2010) states that “Roma females often bear responsibility for health of children and other family members, but they may neglect their own health. Females are unaware of the importance of preventive, namely prenatal care, during pregnancy. The reasons are mostly cultural and traditional and include also a part of purity and modesty explanation in Roma culture” (47).<sup>5</sup> The report goes into great detail about symbolic and ritual pollution, citing an internet article as their sole source.

Ritual pollution is given particular attention in an article by Vivian and Dundes (2004) about American Romanies, whose purpose is “to increase awareness of the cultural

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<sup>5</sup> The report is simultaneously the “thesis for the habilitation procedure” of the author, Kvetoslava Rimárová, at the University of Kosice in Slovakia and an outcome of a project entitled *Migrant and Ethnic Health Observatory*, a “European network of epidemiological observatories on migrants’ health”, highlighted as “best practice”, and subsidised by the European Commission, see [http://www.migrant-health-europe.org/files/Research%20on%20Migrant%20Health\\_Brief\(1\).pdf](http://www.migrant-health-europe.org/files/Research%20on%20Migrant%20Health_Brief(1).pdf)



differences related to health care that are paramount to providing the Roma with appropriate accommodations and avoiding miscommunications that adversely affect the quality of treatment and care” (86). They introduce the population saying that “health practitioners may know about common risk factors among this population, such as smoking, inbreeding, and a diet heavy in fat”, but state that they want to explain more about aspects of Roma culture that might influence their attitude to health. A large section of the article (based on a “review of literature and personal interviews”) is dedicated to cultural perceptions of “pollution” or “impurity”. I cite from it at length because it is one of the most-cited articles on the link between Roma and health culture (50 citations on Google Scholar on May 1<sup>st</sup>, 2017) despite being based on a population on the other side of the Atlantic, and despite consisting of stupendously sweeping statements, many of which are not backed up by evidence. Vivian and Dundes claim that the importance of cleanliness to Romani culture is “a vestige of their Indian roots.” They go on to explain that the Romani body is divided into a pure upper part and an impure lower part (pollution stemming from urine, faeces and menstruation). This may cause problems in hospital, when they are given only one bar of soap to wash their whole body: “The staff should recognize the importance the Roma place on maintaining the body’s purity. The Roma will become upset if the staff ignore their wishes and contaminate their bodies, violating their deep faith in their traditions” (87). Further, they apparently “detest wearing hospital gowns” and are “uncomfortable in public places where Gadge [non-Roma] (who are less pure) have touched items in their surrounding” (90). The authors provide recommendations to help health professionals not to offend the sensitive Roma. For example, they recommend that “women’s clothing must be washed separately from men’s because of perceived differences in purity. If women are pregnant or menstruating, their clothes must be washed far away from other women’s clothes”. Finally, they comment that “Romani revulsion at what they consider impure practices keep the Roma separate from the Gadge, not only impeding their assimilation and the delivery of health care, but also resulting in exclusion of the Gadge from those whom the Roma might consider potential friends or equals” (90). The importance of pollution rituals to the provision of health care among Roma is also highlighted by reports by the European Commission and UNICEF (2004; 2007). Other authors simply emphasise “cultural barriers, with “traditional” Roma

beliefs about health and disease at odds with western ones as well as continuing belief in the efficacy of alternative treatment methods (Fésüs et al. 2012, 26).<sup>6</sup>

### **A history of discrimination**

Most articles on Roma health place great emphasis on the long-lasting and enduring persecution and discrimination they have faced. While it is rare for authors to make more than a fleeting reference to the history of the Roma in the region, some do make reference to the slavery experienced by Roma in some areas until the mid 19<sup>th</sup> century (Z. Kósa et al. 2007; T Skaric-Juric et al. 2007; Zeman, Depken, and Senchina 2003; Koupilová et al. 2001), or to the mass-murder of Roma during the Holocaust (e.g. Zeman, Depken, and Senchina 2003; Duval et al. 2016). The vast majority of articles make early and emphatic reference to continued cases of discrimination that Roma face within health systems today. Access is also said to be impaired by the discriminatory attitudes of health care staff, as well as institutional racism that sees Roma patients receive degrading or inferior treatment, Roma women segregated in maternity wards, and Roma families refused in emergency departments (Colombini, Rechel, and Mayhew 2012; Peter Kolarcik et al. 2015; L. Surdu and Surdu 2006; Nanu et al. 2008; Open Society Foundations 2013; Wamsiedel 2013; Watson and Downe 2017). There is a marked absence of studies that focus on discriminatory practices among medical staff, and with a few exceptions (Ungureanu, Vicol, and Matei 2013) there is a general paucity of recommendations on how discrimination could be addressed.

### **The inadequacy of policy and interventions**

There is great consensus around the lack of success in the way that policy has tried to address the many challenges of Roma health. Interest in Roma wellbeing was catalysed in part by the launching of the Roma Decade of Inclusion (2005-2015), a framework for action across international organisations and national governments (including Romania)

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<sup>6</sup> They cite the report *Ambulance not on the Way* as a source (Danova-Russinova 2006).

with the aim of improving the situation of the Roma. The Decade was initiated and coordinated by the World Bank and the Open Society Foundations, and brought together the governments of Albania, Bulgaria, Croatia, the Czech Republic, Hungary, Macedonia, Romania, Serbia and Montenegro, Slovakia, Slovenia, the US, and Norway (the latter three as observers), with partnerships from UN agencies and large NGOs such as the Roma Education Fund (Brüggemann and Friedman 2017). The Decade of Roma Inclusion prioritised the four sectors of education, employment, health, and housing (Fésüs et al. 2012), and made explicit that it recognised Roma civil society as an important actor alongside governments, intended to boost Roma participation and act as the bridge between high level policy efforts and grassroots Roma communities. However, the Decade has widely been seen if not as a failure, then as underwhelming in terms of the results at the community level. As Brüggemann and Friedman note, “civil society reports seem to be equally sceptical about the Decade’s achievements, highlighting in particular that national plans have been drafted but not implemented, that Roma participation in policy making has remained superficial and that local communities were largely not aware of the existence of the Decade.” In conclusion, they note that “most observers seem to agree that high expectations have ultimately brought little observable change at the local level” (2017, 5).

### **Poor health outcomes compared to non-Roma**

A whole host of literature on genetic research into the Roma tries to identify ethnically specific genes to explain patterns of ill-health (see for example Agnes, Henriett, and Veronika 2008; Ádány et al. 2014; Pikó et al. 2016; Poveda 2012; Sevilla et al. 2013), which seems to be a persistent feature of research into Roma health (Hajioff and Mckee 2000).

There is also a large literature focusing both on differences in health outcomes between Roma and non-Roma, as well as on the likely causes for these disparities. While studies disagree about whether “Roma” use health care more or less than the general population (Peter Kolarcik et al. 2009; Mihailov 2012), there is a general consensus that they rely more on emergency care than non-Roma (Földes and Covaci 2012). Poor vaccination coverage

is frequently highlighted as a problem among Roma communities (Duval et al. 2016; Kraigher 2006; Stojanovski et al. 2012), as is inadequate access to modern contraception (Colombini, Rechel, and Mayhew 2012; Nikolic and Djikanovic 2015).

Research frequently makes a link between poor health outcomes and social determinants of health. Several barriers to access to care are highlighted, amongst them geographical and financial: Roma settlements are said, on average, to be further away from medical facilities (Mihailov 2012), and some communities have such bad infrastructure that ambulances either cannot, or refuse to reach people at their homes (Danova-Russinova 2006). A number of studies turn their attention to a lack of hygienic conditions in Roma settlements, leading to self-reported ill-health (Cook et al. 2013). Roma families are also said to face greater challenges in covering the cost of transport, as well as the opportunity costs of attending facilities (Rechel et al. 2009).

The report on the UNDP/World Bank/EC Regional Roma Survey (Mihailov 2012) recommends that interventions be refocused. The authors suggest focusing on the inclusiveness of health systems, education and employment, though they also recommend that specific “Roma issues”, namely “educational needs, child vaccinations, and reproductive health” (78) should be addressed through targeted Roma programmes. As I will come to show, the Roma health mediation programme is the main such “targeted Roma programme”, intended specifically to address some of the key areas of inequality highlighted above.

### **Initial remarks on the failures of the consensus narrative**

Do Roma or non-Roma have worse health outcomes, and why? The research that I have reviewed gives the resounding answer that it is Roma who suffer from worse health, because of their marginalisation and because of the mechanisms behind the social determinants of health. In many other ways, what I have termed the consensus narrative on Roma health is of course not a homogenous entity. Many different researchers have considered Roma health from a great number of angles. What unites the narrative that I

have outlined, however, is the absence of critical engagement, first with some of the key assumptions that have gone into its production; second with the process of knowledge production; and third with the politics of knowledge about Roma health.

The two major assumptions that the consensus narrative fails to question are the distinction between Roma and non-Roma, and the assumption that Romani culture is a major influence on health. The duality between Roma and non-Roma is something that only very few researchers interrogate (A Ivanov, Kling, and Kagin 2012), and even when they do, the binary is upheld in order to answer research questions that are posed precisely in terms of a binary distinction. I shall turn to the many ways in which this is problematic in due course. The influence of Romani culture on health and health-seeking behaviours runs through the literature even though there has been very little research on the subject, and what little literature exists is of poor quality (Singh 2011; Vivian and Dundes 2004). Nevertheless, these articles are widely cited to make assertive claims, for example about how Romani culture dictates social norms about the “purity of the body”, “fatalism”, and attitudes to vaccination and surgery (Bobakova et al. 2012; Belák, n.d.; Zelko, Švab, and Rotar Pavliě 2015; Mladovsky 2007). The Roma health mediation programme is in part premised on this assumption.

With the exception of the UNDP/World Bank/EC Regional Roma Survey which dedicates a whole separate report on explaining the process of conducting research in Roma communities (A Ivanov, Kling, and Kagin 2012), researchers tend to show little reflexivity about the way in which they use categories and measurements to generate knowledge about Roma health. This is not just about the unquestioning use of binary distinctions between Roma and non-Roma, it is also about how so-called Roma participants are sampled and selected. According to whom are they Roma? When NGOs are used to identify Roma communities, according to what criteria do they do so? What is the relationship between the organisation and the community, or the individuals that are being selected as participants? When researchers advertise the fact that they have used Roma enumerators to conduct surveys, do they believe that participants will automatically and immediately recognise the enumerator as Roma, and that this immediately increases

levels of trust, independent of differences of class, gender, and education? These questions are important not only for the production of ethical and good quality data, but also to ensure that research is measuring what it is intending to measure. Nevertheless, these questions of social and cultural representation are left unaddressed in the consensus narrative.

Thirdly, with one notable exception (Hajioff and Mckee 2000), the consensus narrative does not interrogate the topics on which it focuses its attention. Looking at reviews of research on Roma health produced over the last two decades (Hajioff and Mckee 2000; Zeman, Depken, and Senchina 2003; Cook et al. 2013), it is clear that the medical gaze is focused on particular issues. Hajioff and McKee (2000) specifically address this point when they point to “problematic issues relating to values underlying the research” on Roma health (868). While other topics such as child health and non-communicable and chronic diseases are now starting to receive more attention, it is worth questioning why a large amount of the literature investigates health topics relating to genetic disorders, reproductive health, and communicable diseases (Hajioff and Mckee 2000). Who prioritises these topics, and according to what rationale? Is the focus a result of previous research that has shown these areas as particularly important (and if so, in what way), or are they based on vague or stereotypical ideas of Roma as having a limited gene pool (based on endogamy and/or their common Indian origins), as particularly prone to bearing children, or as a threat to the health of others (as sources of infectious disease)? Again, the literature on Roma health yields unsatisfactory answers. What is worrying about this is that the particular gaze offered by the academic literature on Roma health reinforces itself: when a large part of the literature focuses on genetics, reproductive health, and infectious diseases, these topics are likely to be seen as “objective” problems in Roma communities. At the same time, nobody seems to be asking Roma communities (however defined) what they see as their own health priorities.

The above explication of the consensus narrative on Roma health also serves as an introduction to the Roma health mediation programme itself. As a community intervention that aims to improve access to health care for marginalised Roma

communities, while also increasing trust between communities, health professionals, and local authorities, the mediation programme necessarily draws on and intersects with the various consensus surrounding Roma health. Thus the programme can be understood on the one hand as a response to some of the issues highlighted in the literature on Roma health, and on the other hand as a programme created by Roma activists for Roma communities; one that has been conceived and assessed in terms of the consensus narrative about Roma health. Below I document the origins, aims, and mechanisms of the Roma health mediation programme, considering it in terms of both the consensus narrative outlined above, the literature that has grown up around the programme, and the programme's own discursive practices.

## **Part II - The Roma health mediation programme: a response to inequalities in health**

This thesis focuses on the Roma health mediation programme in Romania as it is the oldest and largest of its kind and therefore provides a case study of how the programme works. Even though these programmes now employ hundreds of mediators across at least six countries (Bulgaria, Macedonia, Romania, Serbia, Slovakia and Ukraine), very little has been written about how mediation works in practice, what it means to those involved, and how they experience the process.

The idea for the health mediation programme was derived from a community mediation programme, which Roma NGOs put in place as a response to a spate of violence between “Roma” and “non-Roma” citizens. In the early 1990s, violence between neighbours broke out in several villages. Often as a result of one person getting injured in a drunken fight, people set houses alight in revenge. In other cases, families moved out of fear of retribution. Reporting on these incidents emphasised their cultural dimension, calling it “interethnic violence” (Toma 2012). Spontaneous mob violence in Hădăreni (Transylvania) left three men dead and many houses destroyed (Mirga 2009). Against a backdrop of ongoing civil war in Yugoslavia, and rising tensions between Hungarians and

Romanians in Transylvania, Romanian media, NGOs, and government organisations warned about violent ethnic conflict also breaking out in Romania. After 1994, violence decreased, but tensions remained (Toma 2012).<sup>7</sup> A mediation programme was set up to establish peaceful solutions to conflicts between Roma and non-Roma within Romanian communities.

This community mediation programme provided the blueprint for the Roma health mediation programme (Wamsiedel 2013). Its basic premise is to train mediators from Roma communities to act as intermediaries between Roma patients and health professionals and local authorities. The manual for health mediators defines the mediator as “a person who mediates the relationship between the Roma community and the local health authorities” (i.e. doctors and nurses) (Nanu et al. 2008, 28), with the overall aim of increasing trust between them and improving access to health care. “Through their work,” the manual says, “the health mediators contribute to the improved health of Roma communities in Romania” (Nanu et al. 2008, 33). As others point out, the Roma health mediation programme is therefore designed to help Roma “exclusively” (Bejenariu and Mitrut 2014, 8). While the manual does not itself give a more elaborate definition of mediation, Roman et al. refer to Roma health mediation as an act of cultural brokering, “the act of bridging, linking or mediating between groups or persons of differing cultural backgrounds for the purpose of reducing conflict or producing change” (Roman et al. 2013, 3).

The Roma health mediation programme is now part of a range of cross-sectional policies that aim to improve the socioeconomic conditions of Romania’s “Roma” population. Roma health mediators work mainly with “excluded Roma,” on the grounds that “integrated Roma” with adequate housing and access to employment and education do not require mediation (Open Society Foundation 2011). The programme’s origins are in civil society, but it has become appropriated by government and has undergone

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<sup>7</sup> In an act reminiscent of the violence in the 1990s, a house in Harghita county was set on fire as a kind of retribution for a theft in Spring 2017, see <http://www.errc.org/blog/roma-burned-from-their-homes-as-lessons-go-unlearned-in-romania/165>



institutionalisation. The programme was first piloted with 30 women in 1996 by RomaniCRISS, a Romanian NGO that was set up by a new generation of Roma leaders with the aim of protecting the Roma minority. The programme initially had financial backing from the Catholic Committee for Development and against Hunger. In 1999, RomaniCRISS began a training programme for “the improvement of the health situation of Roma communities through the active involvement of health mediators connecting the local authorities and the Roma community” in five Romanian counties (Wamsiedel, Vincze, and Ionescu 2012). In 2002, RomaniCRISS, the Ministry of Health, and the Organisation for Security and Cooperation in Europe signed an agreement that enabled the programme of health mediators to be scaled up in Romania (Open Society Foundation 2011). Through this process, as well as a change in practice, the health mediation programme became institutionalised in government policy and law. As a result, the programme was officially recognised and funded by the Romanian Ministry of Health, and Roma health mediators were listed in the record of recognised professions (Wamsiedel 2013). RomaniCRISS continued to train the mediators, but they were employed by the Ministry of Health (Open Society Foundation 2011). This ultimate institutionalisation was reported as a great triumph for the NGO, attributed to “the result of a particular configuration of factors, including international pressure to improve the situation of Roma, governmental commitment to achieve this goal, proactive involvement of civil society and support from international organisations” (Wamsiedel 2013, 7). This move reflected the government’s support for improving the situation of the Roma in Romania as well as representing governmental backing for a participatory community programme that has been described by scholars as a “bottom-up approach” (Wamsiedel 2013, 18).

The programme grew quickly, and by 2008 the Ministry of Health had employed 600 mediators. In 2008-2009, as a result of the financial crisis, the Romanian government imposed a drastic budget cut and decentralisation process that had major effects on the programme. The organisation of the programme was shifted from county to local authority (municipality) level. Before decentralisation, mediators were employed by the Ministry of Health via county hospitals. Their activities were coordinated by district Public Health Authorities (DSP), to whom they were expected to report on a monthly

basis. In the aftermath of decentralisation, the mediation programme is still supported by the Ministry, but these funds are directly transferred to municipal budgets, making health mediators employees of town halls, paid indirectly by the Ministry of Health (Wamsiedel 2013). This means that local authorities (i.e. municipalities in the form of town halls under the authority of mayors) now have the autonomy to decide whether to keep or cut the position of health mediator (Wamsiedel 2013). This has led to a reduction of the total number of health mediators employed (Wamsiedel 2013), as some mayors have opted not to re-employ mediators who were previously working in their communities (Wamsiedel, Vincze, and Ionescu 2012). It has been estimated that in 2011 there were 380 health mediators working throughout Romania, each nominally serving a community of 500-750 people (Open Society Foundation 2011). A more accurate or up-to-date number of health mediators working in Romania has not been officially published, but since the employment of new mediators has stagnated since decentralisation, it is likely to be less than half of the pre-crisis numbers. There is an ongoing risk that individual positions will not receive funding and will therefore be discontinued (RomaniCRISS 2013). Decentralisation therefore has been a demoralising caesura within the programme's overall success story.

Those mediators that continue to be employed as part of the new, decentralised structure often work closely with the town hall. Some of the literature on the Roma health mediation programme in Romania mentions or bemoans this new relationship, which has led to the abuse of the position by many mayors, who see mediators as an additional labour force at no cost to their own budget. Discriminatory practices have included “abusive dismissals, non-compliance to the job description by the employers, [and] racist language towards the employees” (Wamsiedel, Vincze, and Ionescu 2012, 12). Often this has meant that mediators are shouldered with tasks that lie firmly outside of their job description. They reportedly spend only some of their time carrying out their role as mediator, otherwise filling in staff shortages at the town hall, most often in the domain of social work (Wamsiedel, Vincze, and Ionescu 2012).

These troubles notwithstanding, between 2003 and 2010 Bulgaria, Slovakia, Moldova, Serbia, Macedonia, and Ukraine all introduced similar programmes as a policy to address Roma health inequalities (Bejenariu and Mitrut 2014). The Roma health mediation programme has also been emulated in other parts of the public sector: Romania also has Roma school mediators addressing non-attendance and ethnic segregation in schools (Moisă et al. 2016; National Agency for Roma 2005), and in Hungary and Macedonia Roma legal mediators help poor Roma families take cases of ethnic discrimination to court (Open Society Foundations 2010a).

As the remainder of this thesis concentrates on health mediators and their relationships with community members, health professionals and local authorities, it is worth outlining the programme through which they are employed in some detail. Given my methodology, which uses an in-depth examination of individual relationships to develop theory around social constructions and processes of mediation, I do not aim to make claims about the programme as a whole. Nevertheless, the historical development of the programme, its aims and assumptions, as well as the way in which mediators are embedded in the programme all form the direct background against which the relationships I analyse take place. This section gives the reader the background information they will need to understand the idiosyncrasies of the Romanian health mediation programme. It simultaneously serves as an overview of the literature published on the programme so far, which exhibits a dearth of critical and in-depth engagement with mediation.

In my initial examination of the Romanian Roma health mediation programme below, I broadly follow the structure of my preceding exposition of the consensus narrative on Roma health. My intention is to show how, with a few exceptions, health mediation has been conceived of and understood in terms of this narrative. This analysis is based on the small number of texts that have been published on the Romanian Roma health mediation programme, both in peer-reviewed journals, and in grey policy literature. The most detailed overview of the programme can be found in a report commissioned by the WHO Regional Office for Europe and funded by the Open Society Foundations

(Wamsiedel 2013). It is the first in the Roma Health Case Study Series, and was written by Marius Wamsiedel, who was at the time working for RomaniCRISS, the programme's founding NGO. An extensive unpublished report of the mediation programme was co-authored by Wamsiedel, and feeds into the WHO publication (Wamsiedel, Vincze, and Ionescu 2012). This report was preceded by two multi-country reports (Open Society Institute 2005; Open Society Foundations 2011). The peer-reviewed published literature with an explicit focus on Romanian Roma health mediation is sparse and methodologically limited, as I go on to discuss below. Two articles are based on focus group interviews (Schneeweis 2013; Roman et al. 2013), one on population level data (Bejenariu and Mitrut 2014).<sup>8</sup>

### **The Romanian Roma health mediation programme in academic literature**

None of the peer-reviewed literature engages with health mediation as a process. This is an important limitation because it obscures how mediation is implemented, and therefore cannot comment on why it does or does not achieve the aims it sets itself out to achieve. Adina Schneeweis' publication (2013) is based on only two focus groups (each lasting two hours) with a total of nine mediators from the same region and focuses on women's experience of practicing mediation. She emphasises the hybrid identity of health mediators as sitting squarely between the Roma and the non-Roma world, and pays fleeting attention to the mediators' construction of Roma communities as inferior and in need of assimilation. Mainly, however, her study investigates how mediators' own lives have been affected by the success of health mediation, rather than the process of mediation itself.

Gabriel Roman et al. base their study on three focus group discussions with 30 mediators from two regions, each lasting 60-80 minutes. The authors aim to contribute to "knowledge among health professionals about specific behaviours among Roma patients seeking healthcare" (2013, 6) and what role health mediators play in meeting these needs

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<sup>8</sup> An abstract for a poster presentation entitled "The costs and benefits of Roma Health Mediation in Bulgaria and Romania" gives little information on methods or results (Schaaf et al. 2016).

in Roma communities. The authors make claims about cultural barriers to accessing health care based on these interviews, without acknowledging that their information is derived from interviews rather than observations, and therefore shaped by the way that mediators construct questions of access in communities. One of the major limitations of this study is that it misses out the voices of community members, while still making claims about their behaviours.

The most recent publication by Bejenariu and Mitrut (2014) is an ambitious attempt at evaluating the effectiveness of health mediation. It uses vital statistics data and a registry of health mediators to establish the effect of health mediation on the uptake of prenatal services and child health. The authors' assumptions about how health mediation functions are based on a review of the literature, and logical assumptions rather than observational data or interviews. For example, they rely on self-declaration of ethnicity at birth to establish their Roma population, as well as assuming that all Roma have been visited by, or have spoken to a health mediator. This is a significant assumption, which, if incorrect, would severely impact the validity of the findings. The authors do not critically engage with these assumptions, nor do they give alternative explanations for their findings. Apart from these articles and a number of reports (Cace and Vlădescu 2004; Fleck and Rughiniş 2008; Rădulescu 2014), none of which are based on long-term engagement or participant observation of health mediation as a process, no other published studies have investigated the functioning of the Romanian Roma health mediation programme in any depth. One report (Wamsiedel, Vincze, and Ionescu 2012), based on qualitative interviews and quantitative surveys with community members and health mediators, foreshadows many of my own findings, especially with regard to the priorities in mediators' work, and doctors' perceptions of their patients. However, the report reproduces large amounts of raw data in thematic sections, preceded only by a summary of each. Based on interview and survey data rather than long-term observation, the report is restricted to analysing abstract relationships between doctors, patients, and mediators. It sheds little light on the process of mediation and provides no critical or theoretically driven analysis.

Below I outline the aims and mechanisms of the programme. This is followed by a review of the way in which “culture” is understood to be a key part of the mediation process. Finally, I turn to evaluations of the health mediation programme, showing how both policy makers and scholars have framed the programme as a success story, while also highlighting important limitations.

Before turning to the aims and mechanisms, however, it is important to reiterate the fact that the health mediation programme is an ethnically targeted intervention, and to unpack certain of the assumptions underlying this. Why do Roma need a targeted intervention? On the one hand it is seen as an answer to the inequalities uncovered by the literature and policy reports. The reason for implementing an ethnically targeted programme is that ethnicity is believed to influence health-seeking behaviours. This is evident from the way in which academic studies treat “Roma culture” as a rationale for mediation. Roman et al. observe (in line with previous studies) that the main barriers to access to health care for Roma patients are limited or absent financial resources and health insurance coverage, lack of health literacy and linguistic barriers, and lack of personal hygiene (2013, 14). Bejenariu and Mitrut claim that “most Roma women, especially in rural areas, are housewives with no formal employment and often no identification papers” (2014, 5). “Patients’ cultural values and preferences”, Roman et al. say, “are essential to healthcare in terms of both access and relationship with the healthcare providers [...] ethnic specificities, collectively and simultaneously affect the management of illness in complex ways” (2013, 16). One of these “ethnic specificities” is “the large numbers of those accompanying the Roma patient [*sic*], creating disruption and inconveniences in the hospital” (2013, 12). In a similar vein, the WHO report on mediation by Wamsiedel mentions that since “about one fourth of doctors working with Roma patients mention difficult encounters because of alleged aggressive behaviour, verbal violence, inappropriate behaviour, failure to respect the appointment and low education level,” mediators are employed to act as “liaisons between doctors and Roma patients, trying to reach common ground for the effective delivery of health care” (2013, 14). All in all, health mediators are portrayed as being needed in Roma communities because these communities are often marginalised or socially excluded (this as an implicit

backdrop), and (this more explicitly) because they have worse access to health care, as well as certain behavioural traits that make communication with health professionals difficult.

### **The aims of health mediation**

Apart from the broad definition given above, there is generally a lack of consensus in the literature about the exact aims of health mediation. The aims stated in publications on Romanian Roma health mediation are imputed from a combination of existing publications, reports, and interviews with mediators themselves. Schneeweis says that mediators' "work has targeted child vaccination, pre- and postnatal care, contraception, and family planning," without further explanation (2013, 170), while Bejenariu and Mitrut observe that "the main aim of RHM was to improve the health status of pregnant and postpartum Roma women, infants and children by providing basic health education and better communication between the Roma ethnics [*sic*] and healthcare practitioners" (2014, 2). On top of this, they add, mediators inform women about their rights regarding health insurance and free preventive and emergency care. One of the Roma health mediators' key tasks is to tackle the inequality in insurance status, to help people obtain the documents that are required for health insurance (Open Society Foundation 2011; Wamsiedel 2013). Furthermore, to promote better access to care, "mediators act as liaisons between doctors and Roma patients, trying to reach common ground for the effective delivery of health care" (Wamsiedel 2013, 14). Similarly, the *Health Mediator's Manual* (Nanu et al. 2008) points out that "communication is the mediator's main tool. A successful health mediator must develop her skills to correctly use this tool, because her work basically needs to build trust between two different worlds, i.e. the Roma community members and the medical staff" (9). At the same time the programme is considered "an empowering tool for Roma" (European Public Health Alliance 2016, 4). This is reflected in Romani CRISS' overall objectives for the programme, which are quoted by the WHO report as being "civic and social mobilization, by involving local communities in the programme's implementation; facilitation of communication between Roma communities and local medical providers; facilitation of access of Roma to health care services; increased stock of knowledge pertaining to health among Roma communities; and

empowerment of Roma women” (Wamsiedel 2013, 8–9). Health mediators’ main aims, it can be surmised, are to improve access and education in specific domains that are of particular concern (vaccination, reproductive, and child health), obtain documents for members of Roma communities, and facilitate communication between communities and health professionals. The programme aims to mobilise, involve, and empower Roma communities, though it is unclear what kind of mobilisation, involvement and empowerment the designers of the programme are referring to, nor what people should be empowered to be able to do (Cornish 2006). This leaves room for ambiguity about whether the programme aims for a utilitarian approach to mediation in which mobilisation aims for compliance with top-down regulations, or whether it sets out to fundamentally challenge and change the living conditions for communities. I discuss the theoretical distinction between these different approaches below, and return to them throughout the thesis.

### **The mechanisms of health mediation**

Given the multiple aims of health mediation, often vaguely defined, it is perhaps not surprising that scholars looking at the programme have struggled to succinctly capture how these are to be achieved. While the WHO report describes the programme as a “bottom-up” approach there is not much emphasis on the mechanisms through which the mobilisation, involvement and empowerment of local communities should be achieved. By design, health mediators come from the communities for whom they mediate. Eligible candidates are Roma women who have at least eight years of school education. Candidates who have children and who have a high social standing within the community are considered to be at an advantage. Candidates are put forward by community leaders, and selected by the organising NGO for a three-day training course in Bucharest. The core training modules include communication (non-verbal language, planning change, conflict resolution, community relationships); methods and techniques of mediation (social and medical activities, writing reports); health promotion (hygiene and infectious diseases, healthy lifestyle); community and family health education (reproductive health, sexually transmitted diseases, mother and child care, family planning); and legislation



(health insurance, patient rights, discrimination) (Nanu et al. 2008). Before receiving their contract, mediators have to pass an exam set by the NGO in charge of monitoring and evaluating the programme (Wamsiedel 2013).

According to the literature about mediation, the programme includes health promotion, and enrolling patients with health insurance. The WHO report says that mediators are involved in four of the five areas of service coverage: “accessibility, acceptability, contact and effectiveness,” (Wamsiedel 2013, 12–13) while the fifth, availability, lies outside their responsibility.<sup>9</sup> According to the report, health mediator activities include:

- ❖ “serving as a liaison between communities and health care practitioners”, i.e. “increasing mutual trust and improving communication between members of the community and medical personnel”;
- ❖ “collecting data on the health situation in the community”, i.e. “on pregnant and recently confined women, the infant population of the community and immunization and check-ups of children aged 0 to 7”;
- ❖ “increasing Roma access to health care”, i.e. “enrol new-borns with family doctors and explain the advantages of being medically insured and the procedures for obtaining insurance coverage” including “helping people who do not have birth certificates or identification cards complete the process of obtaining them” (13);
- ❖ “providing health education” i.e. “raising awareness on family planning, child health care, nutrition, breastfeeding and hygiene”;

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<sup>9</sup> The report defines each of these terms as following: “Availability refers to the existence of resources necessary for the provision of the service (such as staff and medicines). Accessibility refers to “the number of people who can reach and use it”. Acceptability comprises both affordability of the service and people’s willingness to use it. Contact refers to the actual use of the service, whereas effectiveness refers to users’ satisfaction with the services they received” (Wamsiedel 2013, 12–13).

- ❖ participating in public health interventions” i.e. “mobilizing community members to take part in health campaigns (on vaccination or chronic diseases for example), identifying cases of TB [tuberculosis] and transmittable diseases and informing medical practitioners about the occurrence of particular problems within the community, such as transmittable disease foci and intoxications” (Wamsiedel 2013, 9).

In this respect, the topics of health mediation (including during the training) focus fairly closely on those topics foregrounded by the literature on Roma health.

Given that the practice of mediation has largely gone unobserved, however, the ways in which mediators achieve these tasks remain a matter largely of conjecture or of relying on mediators’ own reports. Wamsiedel points out that mediators receive initial training, as well as continuous training on topics including TB, rights, communication, and bureaucratic procedures for obtaining papers (Wamsiedel 2013, 7). One document comments that mediators “frequently engage in activities related to health literacy and hygiene, which provide effective peer education related to health” (European Public Health Alliance 2016, 5). According to others, mediators conduct home visits and accompany people to the doctor, facilitate their interactions with health professionals, and explain appointments and elements of care (Bejenariu and Mitrut 2014). In short, no one can agree on quite what health mediation looks like or how it works in practice.

### **Mediation as a culturally sensitive answer to a cultural problem**

In most settings, the main rationale for employing any kind of mediator is the need to accommodate cultural difference in a multicultural society (Miklavcic 2015). Nevertheless, “culture” does not feature much in the official literature on health mediation. The WHO report concentrates mainly on lack of insurance, health education and discrimination from health professionals, and barriers to care that may be interpreted as stemming from social exclusion, which may or may not be related to cultural difference. The text seems almost careful not to attribute any of these barriers to Roma culture *per se*.

The same cannot be said for scholarly engagements with the mediation programme, where the specifics of “Roma culture” play a prominent role. Bejenariu and Mitrut point out that there is often a linguistic barrier to accessing and receiving health care, because “a considerable share of Roma ethnics [*sic*] speak only Romani *chib* [Romanes], the traditional language, unrelated to the official Romanian language spoken by family physicians” (5n5). Roman et al. highlight mediators’ abilities to “adapt their way of communication according to the patient’s cultural norms” (Roman et al. 2013, 15). They speak of Roma “beliefs and practices” (1) and Roma groups who preserve “ethnic traditions including the perception of illness and patient care” (4). One of these, Roman et al. find from their study, is that illness is kept secret, a finding which they say is confirmed by data in the literature “which show that according to Roma culture, it is not appropriate to disclose personal failures or illness” (17). While pointing to cultural heterogeneity between different Roma sub-groups, Bejenariu and Mitrut also mention that among “some Romani castes a woman is considered impure during pregnancy and up to two months after birth and is forbidden to undertake a wide range of activities, including leaving the house because of the shame produced by her condition” (2014, 42n27).

Given these “cultural norms”, it follows that mediators should belong to the same group that observes these norms, speaks the language and appreciates Roma traditions: “Knowing the cultural environment of the Roma and the majority, HMs [health mediators] are helpful in a physician’s activity and can mediate tense situations, guiding and advising the Roma patients to comply with the rules they should follow when seeking medical services” (Roman et al. 2013, 12). Other studies highlight the need for mediators who match the target population in ethnicity and gender, given certain “strong social norms.” (Bejenariu and Mitrut 2014, 5n4). Employing a Roma woman, according to this logic, would “increase her acceptability and effectiveness through a higher level of trust toward the mediator and an in-depth knowledge of the mediator about specific local social norms, culture and circumstances” (5).

At the same time, these studies point to the fact that cultural norms vary locally, and between different social groups. They warn against essentialisms, such as the presumption that patients from certain groups share the beliefs and values of that community (Roman et al. 2013). Schneeweis, while listing the ways in which “Romani customs” influence gender roles (respect, eating habits, decision-making in the family) is sure to assert that, depending on the degree of integration into broader society, these traditions vary enormously across Romania (Schneeweis 2013).

The guide for health mediators makes a number of references to Roma culture and traditions, at times in a fairly essentialist manner. For example, it states that “Roma culture especially favours cleanliness. The problems occur when people are forced to move from the traditional community, to live on the periphery of cities, and in time they forget what they have learnt from their elderly” (Nanu et al. 2008, 65); or that reproductive health is a “quite delicate matter with Roma communities” (72). For the most part, however, the manual speaks merely of the necessity for mediators to be acquainted with the “traditional cultural environment of the Roma communities” without further specifying what this might be (9). A mediator “must help the doctor understand the basic elements of Roma culture and traditions, so that she prevents the unpleasant situations that may arise between the doctor and her Roma patients” (34).

For this reason, the manual is unequivocal about mediators needing to come from the communities for which they mediate. Thus, the manual states that the criteria for being an efficient health mediator are “to be a woman” who is “recognised by the Roma community she belongs to”. More than that, she must live there and “come from that community.” This is “so she will know and understand the community’s issues, as well as know the particularities of the community so she will not have communication problems” (30). This implies that discrimination against Roma communities has led to distrust, which can only be addressed through a participatory programme run by fellow Roma.

## **Evaluations of health mediation**

Health mediation has been the main policy response to inequalities in Roma health. Despite this, there is no clear sense in the literature about how or even whether the policy has been effective in achieving its (many, vague) aims. Indeed, as indicated above, since the research, reports, and evaluations that exist are based on interviews with mediators, little is known about how mediation works in practice. Schneeweis, for example, says that “the program has been deemed a success by officials, practitioners, and Roma patients alike” (2013, 163), but does not specify how this success was defined or how it was measured.

The study by Bejenariu and Mitrut reports positive findings based on a number of assumptions about mediation (discussed above) and their analysis of population level data. They find that “the program had a very large impact on the take-up of prenatal care services, but this improvement was not reflected in the health outcomes at birth of Roma children” (2014, 1). Their results also indicate a decrease in stillbirths and infant deaths after health mediation was introduced. The WHO report does not cite any specific positive outcomes, but still reports positively on the programme overall. It celebrates the process of institutionalisation as a success in itself and estimates that around 660,000 Roma have been served by health mediators at some point. This, the report says, represents “between one third and one fourth of the total number of Roma in Romania according to independent estimates, and more than the official number of Roma living in the country according to the most recent census” (Wamsiedel 2013, 15). Other strong points of the programme, according to the report, are “its focus on preventive, instead of curative care, its contribution to knowledge pertaining to health among Roma, and the assistance provided to some of the most vulnerable categories of Roma, particularly persons lacking identity documents” (viii). Furthermore, it states that “raising awareness on issues such as family planning and contraception, vaccination, hygiene and a healthy lifestyle is likely to have contributed at least to a reconsideration of behaviour related to health” and that mediators have increased access to care “by helping Roma obtain identity documents, acquire health insurance and enrol with family doctors” (16).

Schneeweis is generally positive about the programme, and finds that mediators have benefited from forms of social emancipation. According to her interpretation, mediators had risen above their class and gender status through gaining knowledge as well as the trust of “both” genders, different generations, and “traditional” and “modernized” Roma. She reports mediators’ pride in having relationships with medical staff as well as community links (2013, 178). In other words, Schneeweis finds that mediators are genuine bridges between cultures. Alongside her favourable estimation of the programme itself, Schneeweis also uses her analysis of discourse and language to question the mediators’ desire to assimilate Roma communities in their quest to demonstrate their own journey towards emancipation.

With a few exceptions (in which the author questions the construction of Roma by mediators, as well as the homogeneity of Roma as an ethnic group (Schneeweis 2013)), the academic literature on health mediation relies on unquestioned assumptions about a natural distinction between Roma and non-Roma. The literature lacks in-depth engagement with key assumptions that are made about “the Roma” as a large, marginalised, poor, culturally distinct, group, about whom it is possible to speak as though they were a largely homogenous group.

In terms of critical accounts of the programme, only one study (a published abstract for a conference poster that does not justify its conclusions) condemns the programme entirely, claiming that health mediation was “ineffective on a population level in Romania” for the period 2007-2013, and that “the current number of mediators employed (about 380) is unlikely to be adequate to ensure population level impact” (Schaaf et al. 2016). The WHO report does highlight a number of shortcomings. These are: a shortage of mediators (only 2.05 mediators per 10 000 Roma) (31), lack of supervision and feedback, poor use of data collected, inadequate transparency of funding, limited continuous training, and “difficult working conditions (lack of an office, low wages, insecure employment)” (11). Wamsiedel recommends giving medical staff training on cultural diversity to “increase their cultural sensitivity” and “make them aware of cultural

differences that might otherwise be mistakenly interpreted as signs of disrespect for their authority and professional competence” (19). In spite of these shortcomings and challenges, health mediation in Romania has been reviewed positively and continues to be supported by the Romanian Ministry of Health as the main policy for improving access to care for Roma communities. It has also been used as a blueprint for other mediation programmes, which constitute the main and sometimes sole response to inequalities in health in other countries.

The way in which mediation is conceptually designed, as well as the literature that describes it, gives the impression that “the Roma” are defined mainly by their cultural norms and social exclusion, which are portrayed as obstacles to good quality health care. Mediators are employed on the one hand to provide health education to this population, which is shown to display low levels of health literacy. On the other hand, mediators are to facilitate access to health care by obtaining documents for a population said to be lacking them. Mediators accompany patients in order to provide language and cultural translation services because – much of the literature has the reader believe – people either do not speak the same language as doctors, or because they display behavioural problems that need to be managed in encounters with health professionals.

Handbooks on mediation and reports on the programme pay particular attention to hygiene and infectious diseases, reproductive health, sexually transmitted diseases, mother and childcare, and family planning. Scholars have focused on problematic encounters between Roma patients and health professionals (Roman et al. 2013) and reproductive health (Bejenariu and Mitrut 2014). Again, this begs the question: why these topics? Who decided on these as priorities for health mediation? The literature on health mediation does not provide any clues.

There is no questioning of the way in which this programme, which calls itself a “bottom-up” approach to health inequalities, may be legitimately considered a participatory initiative, nor whether it serves the emancipation of communities themselves. The published literature crucially relies entirely on the reported processes of

mediation through the eyes of mediators (with the exception of one report that also interviews patients and doctors) (Wamsiedel, Vincze, and Ionescu 2012). As a result, more than 20 years after it was first piloted, and after the employment of many hundreds of mediators in as many districts, health mediation remains a largely opaque process.

### **The figure and position of the mediator**

One way to approach this opacity may be to consider the figure of the mediator herself – her positionality, expectations, and responsibilities.<sup>10</sup> What is a mediator? What should a mediator be? For whom are they acting, and for whom are they supposed to act? Depending on the context, mediators may be referred to in the literature as “cultural mediators” (Gobbo 2004; Minervino and Martin 2007), “cultural brokers” (Geertz 1960; Kaufert and Koolage 1984; Barbee 1987), “culture brokers” (Miklavcic and LeBlanc 2014), “intercultural mediators” (Agusti-Panareda 2006), or “community mediators” (Mulcahy 2000), each of which refer to slight variations in the lived experience of Roma health mediators themselves. Mediation, in the sense that is relevant to Roma health mediation, occurs in contexts of tension or conflict between parties who come into contact not so much by choice as by necessity. The mediator can help both patients and health professionals to negotiate each other’s hybrid realities (Miklavcic and LeBlanc 2014, 120), a role that may be “particularly relevant in situations of conflict arising from divergent views of health and healing, which bring to the forefront the incommensurability of cultural values” (119). Mediators should be able to speak different languages and navigate between the two, as well as being able to project different identities. This, however, may not always be the case. Mediators or culture brokers have been categorised into three broad groups, (1) those who work on behalf of public authorities; (2) those who work as advocates on behalf of the minority group; and (3) those who strive to navigate “neutrally” between the two positions (Agusti-Panareda 2006; Miklavcic and LeBlanc 2014).

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<sup>10</sup> Most treatments of mediation are found in the legal literature, where mediation refers to solving a legal dispute out of court. In the legal literature it may also refer to community mediation, which is closer to what the Roma health mediation programme represents (Mulcahy 2000). Within the health literature there is a small body of literature that concerns itself with health mediation, mostly focusing on “culture brokers” or cultural translators in hospitals for migrants (Barbee 1987; Agusti-Panareda 2006).



As outlined by the WHO report on Roma health mediation in Romania (Wamsiedel 2013), mediators are charged with “serving as a liaison between communities and health care practitioners; collecting data on the health situation in the community; increasing Roma access to health care; providing health education; and participating in public health interventions” (9). Based on this definition, it is unclear whether the objective is for mediators to fulfil this role on behalf of authorities, as allies for Roma communities or as neutral navigators. This relates to the complexities involved in the relationship between mediators being seen as part of an ethnic group – and therefore representing them – and simultaneously being part of the state system, by being paid by the state and needing to conform to its demands and ways of operating. The lack of clarity on this question points, perhaps, to the fact that such questions of allegiance were not necessarily given adequate consideration in the initial design of the programme.

Scholars of mediation in other contexts have noted mediators’ tendency to regard the law as a “fixed, instead of a fluid, entity,” (Agusti-Panareda 2006, 247) which meant that instead of approaching problems in a creative way and alongside the patient, they appeared to embody the law in front of the patient. In the case of Roma health mediation, however, this is not only a question of how mediators interpret the law, but also a question of how they position and represent themselves with regard to whether or not they are primarily part of the “community” or part of the state apparatus, or both.

In practice, mediators are often constrained by power asymmetries that may not have been considered in the original conceptualisation of health mediation. As Agusti-Panareda (2006) and Miklavcic and LeBlanc (2014) point out, health mediation has the potential to contribute to a patient-centred approach to health care for minority groups and migrants, but a number of hurdles often prevent mediation from being to the advantage of these groups. First, they say, culture is often seen as fixed, rather than as a relational, and fluid process (which can lead to stereotyping and the inability to engage with individuals on their own terms); second, institutional power dynamics and mediators’ own social

insecurities mean mediators often form an alliance with the authorities or health professionals, even when they are explicitly encouraged to side with patients.

Because of existing power dynamics, mediators therefore often fall into normative frameworks, and consequently they work towards the assimilation of minorities rather than being able to neutrally translate, or even advocate for them (Agusti-Panareda 2006). In this way, mediators have been portrayed as aspects of “normalising intervention” (420), operating in a framework of biopower in the interest of “the welfare of the population, the improvement of its condition, the increase of its wealth, longevity, health, etc.” (Foucault 2006, 140). Mediators may be seen as operating under the guise of neutrality and health, while simultaneously promoting discipline and control over a population that would otherwise be hard to reach (Agusti-Panareda 2006). Clifford Geertz (1960), in his study of what he calls “cultural brokers” in Indonesia, focuses explicitly on their role as builders of the nation-state, actors in a “desperate attempt to build up an effective communication network between leaders and led in such a socially and culturally heterogeneous country as Indonesia” (249). In the chapters that follow I interrogate to what extent Roma health mediators are also contributing to political projects that are much broader than their immediate remit on health.

### **Health mediation as community participation in health**

Across a number of health domains, but especially when so-called marginalised groups are concerned, the participation of communities in health care provision has become an “article of faith” (Cornish and Campbell 2009, 3) in many areas of global health policy. Proponents of participatory interventions argue that these are especially important for marginalised groups, whose voices, health beliefs, and wider life conditions tend to be ignored (Campbell and Jovchelovitch 2000; Howarth, Foster, and Dorrer 2004; Campbell and Cornish 2011). Participation can take different forms, with people being involved at different levels: it may involve peers who promote healthy behaviours and aim to influence neighbourhood conditions. Other approaches include involving communities in decision-making about health service improvements, or the planning of services and programmes.

Participatory interventions often aim to increase “trust, mutual support and high levels of involvement in local community projects of mutual interest” (Campbell and Jovchelovitch 2000, 256).

According to its own methods and aims (inasmuch as these are nominally defined), the Roma health mediation programme can be thought of as a participatory community intervention, even if it does not advertise itself as such. Technically speaking, the programme fits the WHO definition of “community involvement in health”: a process which “actively promotes people’s involvement and encourages them to take an interest in, to contribute to and take some responsibility for the provision of services to promote health” (Marston et al. 2013, 2). Seen in this light, the literature on community participation in health interventions raises important questions about what kind of participation the health mediation programme pursues and what purpose participation from Roma communities in the delivery of health care serves. Approaches to participatory health interventions recur throughout my discussions of the Roma health mediation programme. With this in mind, I lay out here the core theoretical premises behind diverging approaches to participatory interventions, and describe in more detail the ways in which the specific example of the Roma health mediation programme can be said to correspond to or deviate from these premises.

At this point, it is important to emphasise that there are different approaches to participatory health interventions: broadly speaking, they may emerge either from a utilitarian perspective, or from the desire to empower communities to change the circumstances of their lives (Marston et al. 2013; Morgan 2001). The utilitarian or instrumental approach to participatory health interventions has been criticised for seeking simply to transfer technical information and skills (Oakley, Bichmann, and Rifkin 1999). Critics argue that it has a biomedical outlook on health at the cost of ignoring the underlying community contexts and processes that contribute to inequalities (Rifkin 1986; Rifkin 1996). The “empowerment approach”, on the other hand, seeks to address precisely these contextual factors of ill-health through social and political transformations, which are seen as part of a long-term process (Guareschi and Jovchelovitch 2004). While

it often remains unclear what exactly is meant by the “participation” of communities in the context of empowerment based health interventions, it may be broadly understood as “redistributing decision making power from professionals to community members” (Cornish 2006, 303). This devolution of powers aims at the empowerment of communities. But, as Cornish (2006) points out, empowerment is all too often used in vague terms. Instead, when talking about somebody being empowered, it is important to “say what action it is that the person is empowered to take” (Cornish 2006, 304). In successful participatory approaches to health, the aim of empowerment is for communities to be empowered to participate in the implementation of strategies that aim to change the economic, social, political, and psychological conditions that influence their health (Marston et al. 2013; N. Nelson and Wright 1995).

The empowerment approach to participation has been conceptualised using social representations theory (Campbell and Jovchelovitch 2000; Guareschi and Jovchelovitch 2004; Renedo and Marston 2015a). Before turning to a more detailed account of how empowerment of communities is thought to be achieved through participation, it is therefore worth outlining its basic premises. Social representations theory tries to contribute to an understanding of how shared views of the world (such as health beliefs) come about within communities, and how these shared views can also contain diverging knowledge about the surrounding world and peoples. Social representations are systems of practices, ideas, and values that allow people to orientate themselves in the social and material world, and to make communication between community members possible (Moscovici 1988). Social representations theory employs the notion of “social knowledges”, which “are not only lay knowledge ‘about something’, they are also expressive of how communities hand down, sustain and negotiate their cultural identities, ways of life and strategies for survival and living” (Campbell and Jovchelovitch 2000, 265). Social representations reflect the culture, the living conditions and the history of the communities that hold them (Jovchelovitch 2007) and form the backdrop against which health and illness are understood and “socially negotiated” (Campbell and MacPhail 2002, 333) by members of a group. This theory acknowledges that group identities are rarely homogeneous, and that overlapping and simultaneous membership in several social

groups leads to hybrid representations (that is, more plural forms of knowledge) and struggles over social identity (Renedo 2010; Guareschi and Jovchelovitch 2004).

In the context of health, social knowledge relates to the ways in which people think of health or make sense of the world in which illness exists. They often refer to lay or “local” understandings of health and illness, which are put into conversation with technical – often biomedical – forms of knowledge (Gervais and Jovchelovitch 1998). Campbell and Jovchelovitch (2000) propose that successful and sustainable empowerment approaches to participation in health have to engage in dialogical relationships between different groups of people and their different forms of knowledge. In these relationships, knowledge that is not “technical”, but rather based in people’s lived experiences, is recognised and not dismissed as illegitimate. Dialogical relationships aim for a “politicised process, through which marginalised groups develop critical understandings of the political and economic roots of their vulnerability to ill-health, and the confidence and strategies for tackling them” (Campbell and Cornish 2013, 848).

Influenced by the radical philosopher of critical pedagogy Paolo Freire, social psychological scholars of community participation distinguish between dialogical and monological relationships (Aveling 2011). While dialogical relationships encourage critical consciousness about how conditions of living lead to ill health, in monological relationships one form of local, non-technical knowledge is seen as less valid or inferior to technical knowledge, and is subsumed as a consequence (Jovchelovitch 2007). In contrast dialogical relationships value the knowledge of the other and engaged with it on equal footing. Empowerment approaches to participation promote dialogical above monological relationships because they have the potential to transform the knowledge that is held by both parties. This is important because it takes into account the context of knowledge production, that is, the social and material conditions in which knowledge is acquired. Scholars of empowerment based participation argue that dialogical relationships have a positive impact on health (Campbell and Jovchelovitch 2000; Kaseje et al. 2010; Marston et al. 2013). Programmes that engage with local knowledge about health, and which allow community members to be involved in decision making processes about health priorities

or how the programme is implemented, are more likely to lead to community members adopting changes. This is because interventions are put forward by community members themselves, rather than being based on externally imposed technical knowledge. Such programmes are more likely to generate successful and sustainable interventions (Campbell and Jovchelovitch 2000).

Dialogue is also important because it can lead to co-conscientisation, a process through which people are helped to gain awareness of the socioeconomic, political and cultural injustices that make their lives worse (Ledwith 2011). The process of developing critical thinking or “conscientisation” is a key part of Freire’s pedagogy (1974). Community participation for better health should involve a political process of building such critical consciousness in communities. Such participation is transformative in that it allows people to see the connection between their own problems and larger political determinants of their health. In the effort to improve health, it is important to build critical awareness about the conditions that may prevent people from engaging in healthy behaviours. Only then is it possible to envisage collective action that empowers community members to change these conditions of living (Campbell and Cornish 2013).

Utilitarian approaches to participation may instead facilitate monologising encounters, in which (most often) local knowledge is subsumed by biomedical knowledge, and the social and material context of the people who hold non-technical knowledge is not taken into account (Aveling 2011). In this way, utilitarian approaches often fail to take into account the wider determinants of health. The potential for a figure such as the mediator to contribute to this process should be clear: they can promote monologising or dialogical relationships between groups, depending on how they conceptualise and engage with the knowledge held by community members, health professionals, policy makers, and local authorities.

In the context of participatory interventions, dialogical relationships are important because they may also lead to improved relationships of trust (Stern and Green 2008). As others have emphasised, trusting relationships between patients and providers are said to

make health care not only more accessible, but also more acceptable (Gilson, Palmer, and Schneider 2005). Trust has been described as a mediator between patient and physician (Green 2004) and as a means for “smoothing the progress of communication” in order to improve the exchange of information and ultimately also access to care (Thiede 2005, 1453).

Returning to Romania, the political and socioeconomic context of Roma communities has often been highlighted by scholars and policy makers as a cause for poor health outcomes. Health mediation could contribute to co-conscientisation by engaging in dialogue, not only about health, but also about the context in which community members live. An empowerment approach to participation would give communities the critical consciousness about the connection between their environment and their health or access to health care, as well as collectively developing a plan on how this might be achieved at the community level.

According to Freire, transformation and conscientisation can only be achieved through “dialogical and participatory relationships” (Campbell and Jovchelovitch 2000, 260). Dialogue inevitably involves a process of knowledge brokering, something that mediators may be involved with, for example when they conduct health promotion activities, or in their interactions with community members and health professionals. If, as discussed above, social representations are expressions of group belongings, and groups are associated with different knowledge systems, then power relations may be analysed by exploring “which representations, associated with which groups, are privileged, [...] suppressed or hybridised” (Aveling 2011, 98) in the interaction with other groups (Jovchelovitch 2007). Knowledge brokering may therefore contribute to the reproduction or transformation of power relations. Theorists who argue for a more dialogical, empowerment based approach to participation maintain that successful community participation does not try to suppress social knowledges or representations (as might be the case in utilitarian approaches to participation) but instead engages with them and strives for transformation which can result in more plural forms of knowledge (Aveling 2011; Jovchelovitch 2007). Here the figure of the mediator has a potential role to play in

this process of brokering of social representations and facilitating dialogical relationships between the parties among whom they mediate, namely community members and health professionals.

To render all of these concepts slightly less abstract, let me briefly outline two projects, one that has been seen as a fruitful and sustainable participatory health intervention, and one that has been described as instrumental, and which was therefore unable to alter the context of participants' lives or lead to dialogical relationships that improved the health or wellbeing of its participants. Campbell and Cornish (2013) give accounts of two HIV/AIDS management projects, one in South Africa and one in India. The South African project involved peer educators to train volunteers who were already providing home assistance to people dying of AIDS, but without training, payment, or recognition. The project gave women technical skills and knowledge for the support they provided to community members. However, it did not manage to act as a catalyst for the empowerment of volunteers to change the way in which they were being materially supported. As a result, the project was not sustainable and did not survive beyond its initial 3 years of external funding. The Indian project, on the other hand, which promoted HIV prevention among sex workers in a Kolkata red light district, empowered sex workers to be in control of the project themselves, as well as engaging in the wider context of their lives. For example, sex workers not only took on leadership roles in the health intervention, they also formed a collective organisation through which they united to fight for their collective rights and negotiated with more powerful groups. Gradually, the project turned to interventions that lay outside of the health domain, for example by ensuring that sex workers had a secure place to save their money by establishing a co-operative bank. The project is now not only sustainable, it has also increased condom use and led to decreases in sexually transmitted diseases. In this example, workers participated in peer education about condom use, but they were also empowered to make decisions about how the project should be run. This in turn led to the empowerment of other sex workers to take up non-stigmatising health services, and as a result of their savings through the co-operative bank, to enforce condom use, since their improved financial security allowed them to turn away clients that refused condoms. The success of the Kolkata project is built



on dialogue in which the social knowledge of sex workers about their environment was not seen as less valid than biomedical knowledge about the transmission of disease. Instead, the project showed that it took sex workers' knowledge and experience seriously by giving them roles of responsibility and leadership, which ultimately led to a more politicised engagement with the social and material structures that influence people's health.

As Cornish and Campbell (2009) emphasise, implementing successful and sustainable participatory interventions is neither cheap nor quick. "Participation is not simply a thing to achieve, but a complex activity to be provided for by building the necessary resources" (Cornish, 2006). Working towards empowerment through participatory health intervention is an extremely challenging task, especially in historically marginalised and disempowered areas and populations. Participation requires resources and time, a large amount of support for engaging with all involved parties, as well as the willingness to involve participants in the design and running of the intervention itself.

With the above theoretical perspectives in mind, it is clear that participatory approaches to community involvement in health are potentially highly relevant to Roma health mediation. Part of mediators' official job description is to build trust, as well as contribute to the empowerment of communities (Nanu et al. 2008; Wamsiedel 2013). Roma health mediators are so-called because they address conflict and power imbalances between two groups. In the literature about mediation the groups that mediators deal with are mainly defined as "Roma communities" and "health professionals". A third (though vaguely defined) group of interest are "local authorities". Mediators are employed precisely in order to negotiate encounters between Roma communities and health professionals/local authorities. These different groups can be seen as inhabiting different social representations and forms of knowledge about health, and the mediators' task can be seen as facilitating encounters between them. Part of my aim in this thesis, then, is to investigate how mediators negotiate the relationships between community members, health professionals, and local authorities.

The literature on participatory health interventions is useful when thinking practically about the way in which mediators interact with different groups. It provides a critical backdrop to examining where the programme sits on the spectrum between utilitarian and empowerment approaches to participation. It helps to think about what kind of encounters mediators promote between communities and health professionals/local authorities – whether these tend to be monologising or dialogical. Do certain forms of knowledge tend to be subsumed by other forms of knowledge, are there instances in which knowledge is transformed? Are they able to improve relationships of trust? How much attention can mediators pay to their social, economic, and political environment? Are they able to foster the empowerment of communities to change their environment? A critical approach to participation can help to question the extent to which mediators are able to think critically about their own position, and promote critical thinking in the groups with whom they are working.

### **Part III - Destabilising the consensus narrative**

The consensus narrative has increasingly come under criticism from scholars building on critical theory. I will introduce these relatively new lines of enquiry by reviewing the ways in which critical theory has been used to understand the position of Roma in Eastern Europe today. Following this review, I point to health as an area that has received less critical attention, as well as touching on the methodological limitations of some of these studies. This will lead me directly to the presentation of my own research questions, which use critical theory to investigate mediation as a Roma health intervention. This thesis builds directly on existing critiques, while also hoping to contribute new empirical data providing ground for further theorisation.

The following review focuses on the work of a fairly small number of scholars who have been at the forefront of a new wave of critical approaches to discourses about Roma in Eastern Europe. It touches on the work of, amongst others, Angela Kóczé, Joanna Kostka, Martin Kovats, Margareta Matache, Alexandra Oprea, Cristina Rat, Nando Sigona, Mihai Surdu, Nidhi Trehan, Hub van Baar, Peter Vermeersch, and Enikő Vincze.

This kind of review is necessarily selective. The above are all scholars who have written extensively and critically about the way in which Roma are framed in European or Romanian policy and academic discourses. There are many others whose work I do not cover (for instance, Thomas Acton, Nicolae Gheorghe, Will Guy, Tina Magazzini, Aidan McGarry, Katrin Simhandl), mainly because their contributions are either less recent or because they do not directly speak to issues or the region covered in this thesis.

This body of literature produced by these critical scholars, which I refer to as “the critical literature on Roma”, covers social constructions of and knowledge production about Roma. In this brief review of the literature I cannot claim comprehensiveness. I have chosen to include texts that speak to similar themes, and which use interrelated theoretical approaches. Although the texts themselves often do not make mutual reference I try to put their themes and approaches in conversation with each other. This is not an attempt to form a coherent theoretical “story”, but rather an attempt to show that there is a wave of scholars, influenced by critical theory, whose work destabilises the consensus narrative about Roma, and opens up new lines of enquiry, many of which are still fundamentally underexplored. The review first outlines the theoretical premise of constructionism and the postcolonial critique of development that these scholars broadly share. It then turns to explanations of when, how and why the Roma have been constructed as a “problem” population by the consensus narrative. Lastly, the review gives an overview of how scholars have understood current policies to address the “Roma problem” and the ways in which these are lacking.

While many of the scholars mentioned above differ on important theoretical (and ultimately political) questions, they largely share a constructivist approach to ethnicity. This means that they see “ethnic groups as socially constructed and ethnicity as contextual, situational, performative and fluid,” rather than as “objective, stable and independent of socio-political and economic contexts” (M. Surdu and Kovats 2015a, 7). Many also share a frame of reference deriving from critical and postcolonial studies, making references to the works of, amongst others, Homi Bhabha, Frantz Fanon, Michel Foucault, Stuart Hall, Edward Said, and Gayatri Spivak. They draw on these theorists with reference to the

importance of how people are discursively constructed; that is, how academic and broader public conversations frame particular groups of people, while paying attention to the wider power dynamics that underlie this framing.

### **The construction of Roma as a problem population**

How is it that the Roma are now widely seen as a largely homogenous population that constitutes a “problem”, or a “European problem” (van Baar 2011, 204) that has to be solved? Vermeersch (2006), Surdu (2016) and van Baar (van Baar 2011) build on the work of historians (Lucassen, Willems, and Cottaar 1998) who show how the emergence of nation-states brought about the framing of heterogeneous itinerant groups as a homogenous Romani group, who were believed to share historical, cultural and linguistic roots in India (van Baar 2012). The point is not so much the veracity of this Indian origin (for an extensive debate on this, see Matras 2004), but rather the way in which it instigated the stigmatisation of a group seen as fundamentally un-European. Critical scholars build on the idea that ethnicity (including Roma ethnicity) is in itself an unstable category. The grand narrative of a group who originally migrated from India overrides observations that the boundaries of “Roma-hood” have always been porous. At the time of slavery, for example, in Walachia and Moldavia, the Southern and Eastern parts of what is now Romania, in order to better organise taxation “gypsies” were understood to represent an economic rather than a cultural group (M. Surdu and Kovats 2015b). It is likely that during this time many different groups who had little in common except for their enslavement also became known as “gypsies”, even though they did not speak Romanes, did not come from India, and did not share any other cultural traits. People could be bought out of slavery just as free people could fall into servitude. As Viorel Achim remarks, “in the seventeenth and eighteenth centuries, enslavement as a result of marriage was a relatively common phenomenon” (2004, 32). Inter-marriage, the cross-over between occupational groups and economic classes, produced a hybridity that escapes easy or binary classification. While scholarship about Roma health often touches upon heterogeneity among Roma, and in some cases even acknowledges the constructed nature of ethnicity (for instance, in Ivanov, Kling, and Kagin 2011) it nevertheless tends to fall

back on a binary distinction between Roma and non-Roma in order to measure differences between them (e.g. Mihailov 2012).

The exoticisation of Roma, both historically and contemporaneously, is analysed by Trehan and Kóczé (2011; 2009) as the starting point for their postcolonial critique of the way in which Roma (or, as in this case, Roma activists) have been framed. They make the argument that within the European political institutions Romani activism is treated with neo-colonial attitude, referencing both existing “asymmetrical relations of economic and political power”, and Said’s description of *Orientalism* as a “variety of strategies whose common factor is the resultant position of superiority for westerners vis-a-vis the ‘Orient’” (Trehan and Kóczé 2009, 57).

The orientalist gaze on Eastern Europe at the heart of this symbolic binary between “Eastern other” and “Western normality” was put forward most notably by Maria Todorova, (2009), who, drawing on Said (1978), writes about how, in contrast to Western Europeans, “those who reside in Southeastern Europe, are framed as people suffering from an atavistic ‘backwardness’” (Kóczé 2011, 34). Todorova terms the gaze of Westerners upon this region “Balkanism” (2009). Within this East-West hierarchy of cultures (Chakrabarty 2009), Roma are seen as occupying a rung below the Balkans, inscribed with even more “otherness” and “backwardness”, especially given the emphasis on their Indian origins. “Gypsies”, Kóczé notes, “have become the colonized groups [...] the ‘primitives’ of modern Europe” (2011, 99). Accompanying this notion of backwardness is a psychological dimension of objectification. Drawing a parallel to Fanon’s account of the French treatment of the colonised Algerian population in Algeria (Fanon 1963), Trehan and Kóczé argue that the Roma are infantilised and denigrated in academic and policy discourses, where they are treated as children who are yet to fully develop, and assumed to be “defective” (2009, 59).

Trehan and Kóczé (2009) argue that “colonialism” can refer not only to historical cases of imperial colonisation, but also to relationships that describe more generally the economic and political power of stronger groups over weaker ones. A number of critics

have taken on this postcolonial reading of Eastern Europe. Some critics have come to speak of the Roma as “subaltern”. The term was coined by Antonio Gramsci (1971) in the 1930s to describe rural labourers, the proletariat, and other people who found themselves excluded from formal political structures. Since then the term has been used widely in postcolonial studies, notably by Spivak. Spivak (1988) uses the subaltern to theorise internal differences within colonised groups. On the one hand, she argues, colonised groups include educated elites who participate in conversations and (albeit antagonised) negotiations with the coloniser. On the other hand there is an illiterate, disempowered – often female – underclass: “the lowest strata of the urban subproletariat” (283), the subaltern. These are the people at the foot of the “international division of labour” (283). All too often the struggles of the subaltern to emancipate themselves are taken on by spokespersons from local (or Western) academic elites. As a result of being spoken for, the subaltern, who have vastly differing concerns and values, are presented as a homogenous group. Being spoken for by an elite, Spivak argues, reinforces their subordinate position in society, and leaves them continuously open to capitalist exploitation.

Trehan and Kóczé (2009) build on Spivak’s work in analysing the relationship between Roma “elites” and the Roma “subaltern”, understood as a class within the “colony” of contemporary Eastern European Roma, itself “internal to the state” (57). Surdu and Kovats (2015b) reference the work of Spivak, Bourdieu, Callon, and Latour to talk about the way in which scientists and experts instrumentalise the voice of the subaltern, becoming spokespersons and “assuming the role of representing oppressed groups” (M. Surdu and Kovats 2015a, 7).

The various processes outlined by these critical and postcolonial theorists and their acolytes combine to “construct” the conditions of Roma-hood as it is framed by the consensus narrative. Homogenisation of the Roma creates the impression of an a priori group; their exoticisation reinforces the idea of the Roma as a marginal people who do not belong; and their objectification justifies the idea that they need to be developed or improved upon by more civilised (read Western) influences. These are all markers of a

racialised (essentialist, ethnocentric) approach to the Roma, in which they are seen neither in terms of their internal differences nor their structural positioning (in relation, for instance, to the economy or their built environment), but in the intrinsic terms of their ethnicity. In health, this means that even when it is acknowledged that broader structural causes (such as poverty or lack of education and employment) are the cause of disparities in health outcomes, the problem is still framed in ethnic rather than in structural terms.

A small number of scholars (in particular Kóczé and Oprea (Kóczé 2011; 2012)) have drawn on intersectional theory to highlight internal divisions and differences among the Roma. The term “intersectionality” was coined by black feminists to describe the intersecting experiences of oppression on the basis of race as well as gender (Crenshaw 1991; Patricia Hill Collins 1986). Intersectional theorists demonstrate the absurdity of treating oppressed groups as homogenous. They show how different forms of oppressions (based on ethnicity, gender, sexual orientation, class etc.) often work together. They argue that these should not be treated in isolation, and that studies focusing on oppressed social groups should pay attention to how multiple forms of oppression often intersect, creating new forms of oppression that cannot be tackled in isolation. Kóczé (2011), for example, looks into different understandings of gendered oppression amongst women from the Romani elite and women from the lower classes. Oprea (2005) focuses on Romani feminism, arguing that Roma culture is essentially constructed as chauvinistic, while Roma women are seen as universally oppressed. Her intersectional analysis recognises that many Romani women are struggling for a specifically Romani form of feminism that does not force them to choose between being a “non-Roma feminist” or an “oppressed Roma woman”.

### **Critical views on Roma politics and policy**

The above theoretical approaches to the general category of “Roma” inform and produce critical policy analyses and suggestions. A perspective informed by critical theory allows scholars to ask: what does contemporary policy offer to address this problem, and in what ways is it lacking? This is perhaps the key question for practically-minded critical thinkers.

Their analysis of current policy builds on a critique of the ways in which Roma are framed as homogenous, other, and deficient in the first place. The most important tenet in this, taken from the postcolonial critique of development (van Baar 2011), is that current policy proceeds from the basis that Roma can or should be corrected, rather than addressing the structures that surround them. This correction, it has been argued, can be interpreted as a “civilising mission.” Scholars draw parallels between EU policy today and imperial policy toward colonised people in the 19th and 20th century. Citing Spivak (Spivak 1988) and Mohanty (1991), Kóczé speaks of a “Western urge to civilize the ‘savage’ population (here Romas), while the interested party pursues its own economic and political interests” (2011, 52). Trehan and Kóczé (2009) call attention to the civilising missions directed at the Roma population of the Habsburg Empire under Empress Maria Therese and her son, Emperor Joseph II. These included forbidding people from wearing traditional dress, using Romani language, travelling across lands, or practicing a number of traditional professions, and separating children from their parents in order for them to be brought up in “non-Roma” households (Achim 2004). Such policies, they argue, bear strong resemblance to policies in the United States or in Australia, where “indigenous children underwent forcible removal from their families and were placed in foster care [...] for the express purpose of ‘becoming civilized’” (2009, 53). They argue that these Habsburg policies, though largely unsuccessful, reflected a “pervasive belief in Romani ‘deviance’ and ‘inferiority’ within the Austro-Hungarian society, a belief that continues to have repercussions for Romani communities as pernicious narratives of ‘Gypsy otherness’ reproduce themselves in contemporary European society” (53).

In “contemporary European society,” as seen in the above overview of the consensus narrative, the emphasis of Roma policy has been placed on integration, especially in education, health, employment, and housing. What this means in practice, and how it may be achieved, has been a matter of great debate. Over the past decade or so, a consensus seems to have built that it is necessary to gather data (for monitoring and evaluation) (Open Society Foundations 2010b) and to “ensure participation” (Ringold et al. 2006, xxv). Both of these approaches entail political, conceptual, and methodological conundrums, which in turn have attracted attention from critical scholars.



Gathering data about Roma does allow monitoring for change (that is, an improvement or worsening in their situation), but it also requires enumerators to classify their objects of enquiry as either Roma and non-Roma, which involves defining either explicitly or implicitly in the first instance what “Roma” means. In this context, the fluidity and ambiguity of Roma identity, which might previously have been acknowledged, fall by the wayside of binary distinctions. The way in which Roma are classified as Roma, the underlying assumptions that these classifications involve, as well as the way in which they build on historical classifications is the subject of Surdu’s recent book *Those Who Count: Expert Practices of Roma Classification* (2016). Surdu’s central contention is that systems of ethnic classification are neither objective nor politically neutral. Rather they serve a purpose, one which is usually defined by those who classify rather than those being classified. Knowledge about Roma is produced not by Roma themselves, but by experts in the academy and in policy, who base their classification on vague and sometimes dubious assumptions or previous research. One such example is the way in which population estimates have been based on historical files, originally drawn up by the police force, and later used to identify Roma for the purpose of deportation. Surdu shows how contemporary classification systems are based on orientalist, exoticising and othering discourses, and how – by conflating definitions of Roma with poverty and marginality – these classification systems in fact perpetuate such discourses. Above all, Surdu shows how the classification of Roma is a top-down process eliding self-definition and local knowledge in favour of external – ostensibly “expert” – forms of knowledge.

The idea that Roma should be involved in policies that are designed to improve their condition would seem to be based on a different kind of logic to that outlined by Surdu. Roma involvement here suggests a bottom-up, emancipatory approach that aims to challenge classical models of external development. The empowerment of Roma through participation has been explicitly on the policy agenda of organisations that have taken on leading roles in promoting Roma equality. The World Bank report (Ringold et al. 2006) states that “community and group empowerment have become increasingly viewed as essential ingredients for improving the welfare of the poor” (19). Empowerment in this

context refers to the capacity of the poor to “participate in, negotiate with, influence, control and hold accountable institutions that affect their lives” (Ringold et al. 2006, 19). In its concluding remarks to the report on public policies for Roma in Romania, the National Roma Agency in Romania stated in 2005 that it was “placing a great emphasis on empowering Roma communities” (2005, 38).

When asking how the empowerment of Roma communities can be promoted (and by whom), however, it should be emphasised that this idea of empowerment through involvement is situated within the political economy of development and policy. The amount of interest in the Roma cause at international level, and the funding that accompanies it has led to what Martin Kovats calls a “phenomenal quantitative expansion of Roma organisations” (2003, 3), a grouping which has collectively become to be known as “Roma civil society” (Kovats 2003, 3; Kóczé 2011, 20; Földes and Covaci 2012, 38). The Open Society Foundations specify that they have supported the health mediation programme precisely as part of its mission to “advance the health and human rights of Roma people by building the capacity of Roma civil society leaders and organizations and advocating for accountability and a strong civil society role in the design, implementation, and monitoring of policies and practices that most impact the health of Roma” (2011, 7).

Trehan and Kóczé call this sudden expansion of Roma civil society the “NGOisation” of Roma politics (Trehan and Kóczé 2009), which they believe to be constitutive of a hegemonic neoliberal order, of which the co-option of Roma activists is an intrinsic part (van Baar 2012). This forms part of their wider argument that contemporary eastern Europe still forms a “colonised space marked by the profound influence of global capitalist forces based in western capitals, and by the academic and institutional hegemony of the West” (Trehan and Kóczé 2009, 53), a phenomenon that they find reflected in Roma civil society. Further to this, they claim that the hold of Western neoliberalism over Eastern Europe constitutes a form of neo-colonialism, which they say is characterised by the appearance of sovereignty, while economic and political systems are controlled by external forces – in this case, Western capital.

Critics have argued that part of the motivation for encouraging – or “creating” – this Roma civil society has been to provide “‘negotiating partners’ for the state and other institutions” (Kovats 2003, 3). These “Roma representatives” serve a particular function at meetings in Budapest, Brussels, and New York, where legitimacy from “official Roma leaders” is needed to demonstrate that Roma policies led by international actors are, indeed, bottom-up and participatory. At home, it is argued, leaders have little political weight in their own communities, meaning that local authorities are not compelled to take notice of them. “Rather than being the means by which the demands of Roma people can be transmitted ‘up’ to those in power, the structure and agenda of Roma politics is determined by external funders, for whom Roma organisations provide the vehicle by which they can communicate their interests to Roma people,” as Kovats contends (2003, 3).

Critical scholars have questioned both the intentions and the outcomes of the involvement of trans-governmental actors in promoting Roma equality. In his study of international Roma representation, van Baar (2011) argues that the leading international organisations seeking to address Roma inequalities are promoting neoliberal policies through the mobilisation of human and social capital while using the language of participation and empowerment. He shows how Roma inclusion policies are often based on technologies of “activating” citizens, a process intended to transform “passive welfare subjects” into “freely choosing and responsible agents” who fully participate in the market economy (202). This “activation” is neoliberal not only because it stresses participation in capitalist markets, but also because it conceptualises the problem as well as the solution to social exclusion and poverty on an individual rather than a collective level, thus “shifting responsibilities toward the private person” (202). At the same time, the discourse of “activation” shies away from concepts of “power, poverty, domination, equality and exploitation” (203). Within the neoliberal discourse, poverty and inequalities become depoliticised.

Van Baar’s analysis of international Roma representations and politics draws heavily on Foucault’s theory of governmentality and biopolitics. Governmentality is the idea that

technologies of state governance are linked to certain modes of thinking (governmentality is a composite noun formed from “govern” and “mentality”). Van Baar understands governmentality first as a conceptual analysis of historically specific ways of governing; second, a process of strategies, technologies, and rationalities of governing; and third, a form of power through which “government is consolidated” (2011, 43). Governmentality allows for the conceptualisation of state institutions not as natural formations, but as “temporal, unstable, and contestable effects of various technologies of power and their dissemination through the social body” (49). One technology of governmentality is biopolitics, which specifically refers to strategies for the regulation of populations. Foucault (2008) uses the term to describe strategies for dealing with intractable problems such as “health, hygiene, birth-rate, life expectancy, race.” (218). Biopolitics describes the effort of the state apparatus to subject life-styles to medical intervention, as well as the integration of medical practice into the social and economic management of a population. By emphasising hygiene and the ethics of good health, medicine becomes an instrument of social control (Macey 2001).

Van Baar (2011) understands the Roma as a case study for examining the influence of various forms of European governmentality. He relates contemporary “Romani minority governance” to an ongoing legacy of bio-political regulation of populations. Practices and discourses emanating from state institutions and the academy have impacted on the marginalisation of Roma groups. The fall of communism has brought about a new form of Roma governmentality, presented as focusing on the inclusion of Roma “on their own terms”, including their development, empowerment and emancipation of Roma, instead of past forms of “disciplining, controlling, policing or simply excluding the Roma” (189). He proposes that this break needs to be understood not merely in terms of a progressive agenda, but in the context of the neoliberal forms of governmentality that have simultaneously emerged across Europe. Neoliberal technologies of Roma inclusion, van Baar argues, depoliticise questions of inequality and poverty in that they render them “politically neutral and technically governable problems” (268). Van Baar particularly focuses on workfare as an activation programme that supposedly enhances the employability of Roma individuals, showing how – actually – it fulfils the role of

“ethnicity-based governmentality” (202) aiming for socio-cultural assimilation. He argues that “governmentalization” has brought about new spaces for participation and resistance “between state, market, and civil society,” through the act of claiming rights as equal citizens. He sees this in the form of a network of European, traveling activists. He thinks of these not in terms of traditional “mass mobilization” form of transformative politics, but instead as “hybrid” and “ambiguous” that may bring about “new forms of agency” that may also contribute to “transformative participation.” (268-269).

The instrumentalisation of Roma representatives by neoliberal discourses and organisations has also been noted by Trehan and Kóczé, who claim that since Roma NGOs have little political or representational legitimacy within communities, they do not challenge but rather contribute to maintaining the neoliberal status quo (Trehan and Kóczé 2009; van Baar 2011; van Baar 2012). As such, these Romani activists or spokespersons have been co-opted within participatory spaces. Van Baar (2012) proposes that within “neoliberal discourses, the co-option of Romani activists in participatory spaces” (292) is not a by-product, but an intrinsic part of such new forms of minority governance.

A related critique of how ethnicity is constructed and exploited is offered by the Romanian scholar Enikő Vincze. Building on a Marxist critique of the contemporary neoliberal order in Romania, she highlights the ways in which the racialisation and precariatization of Roma are interlinked. Roma’s construction as “other” pushes them into physical and social spaces of insecurity; they are portrayed as “redundant” members of society on the one hand, while on the other hand they are “needed by the system as a reserve army and/or as a cheap, easily exploitable labour force both in the formal and informal economy” (2015, 16). She draws attention to the way in which this racialisation and precaritization is “sustained by a political economy of space and development” that represents the very same forces that have shaped Romania since the end of the Ceausescu regime, namely: neoliberalism. In this context, racialisation is used as a justification for the “neglect of residential areas inhabited by ‘undeserving Roma’ who supposedly ‘like living in poverty’ (without water, electricity etc.) or in ‘dangerous areas’ (such as landfills,

polluted environments, water treatment plants)” (2015, 21). In other words, it is “post-socialist neoliberal economic restructuring” that has led to the formation of “the underprivileged Roma, racialized both by the majority and by the better-off Roma groups as the ‘inferior, undeserving population’ with whom nobody wants to mingle” (Vincze and Rat 2013, 6).

Although critical theories about Roma activism and representation diverge on the role and importance of neoliberalism, as well as the possibilities of resistance with this political economy, the authors reviewed above seem to broadly agree that the amalgamation of participatory democratic projects with the solidification of the neoliberal order in Eastern Europe means that the Romani movement cannot be interpreted straightforwardly as one that is leading to emancipation and empowerment (van Baar 2011).

### **Shortcomings of Roma-focused critical theory**

The body of critical literature that I have presented above is not in direct conversation with the consensus narrative on Roma health, but it speaks to the much broader and dominant discourse about Roma that underlies it. It provides much needed critical angles that help to highlight the ways in which Roma have come to be portrayed and discussed not only in public, but also in academic and policy perspectives. The theoretical approaches used by authors to interrogate prevalent discourses also inform my own study of health mediation. These critical authors have addressed some of the questions that have arisen as part of my research, but they also leave a number of areas unaddressed.

First and foremost, the question of health is hardly mooted. Scholars have mainly addressed the knotty problems of Romani politics, activism, and governance at national and international levels. They have focused on female empowerment (Kóczé 2011), policies to address unemployment (van Baar 2011), and scientific discourses of constructing, classifying, and counting Roma (M. Surdu 2016; M. Surdu and Kovats 2015b). They have focused on questions of housing (Vincze 2015; Vincze, Bartha, and Virág 2015; Vincze and Rat 2013) and welfare provisions (Rat 2005; Rat 2012).

Sometimes, questions of health are addressed at the margins of these studies, but there is still a remarkable paucity of critical investigation into Roma-related policies targeting health. This also means that the question of how Roma health priorities are determined has not received any significant attention.

Another shortcoming of current critical approaches to Roma inclusion policies is that – to date – they tend to address themselves to discourses at the national and transnational level. Apart from Angéla Kóczé's (2011) doctoral thesis (in which she combined local observations and interviews with perspectives at the national Hungarian level), authors largely use published literature and policy reports and documents, sometimes in combination with interviews with people at the policy level either within a country, or they concentrate mainly on international actors (Trehan 2009; van Baar 2011; M. Surdu 2016). As such, the local – that is the material, social, and economic – context into which these policies are supposed to feed cannot be taken into account. With the exception of studies on housing (e.g. Vincze and Rat 2013), critical scholars have tended not to use observation as part of their methodology, and are therefore unable to investigate how discourses feed into practice and vice versa at the local level. This is why little is known about how Roma are classified “locally” by regional NGO employees working to international agendas, by frontline social workers, or “small bureaucrats” working in remote town halls. Even though there have been calls to “widen and deepen ethnographic analyses” (van Baar 2011, 278), there has not been much insight into everyday practices of constructing and enacting either Roma culture, or ethnicity, poverty, and marginality within local machineries of Roma inclusion. There has been, for that matter, very little attention paid to how so-called participatory interventions that aim for Roma inclusion are conceived of in terms of their perceived successes and failures, nor to how people attempt to translate them into practice. The shortcomings of the critical literature on Roma inclusion is thus tied to questions of methodology and scale; this thesis seeks to address these lacunae through observation and analysis of precisely those mutually constitutive, local discourses and practices which are elided in critical scholarship in their political and theoretical contexts.

## **A critical approach to health mediation**

This thesis builds on and adds to the critiques that I have outlined. I take Roma health mediation as a case to focus specifically at the local level of discourse and enactment. I look at how concepts and categories translate into local conversations and practices. Through the case study of the Roma health mediation programme in Romania, this thesis asks:

*How are Roma locally defined and classified in the context of health mediation?*

- How are ethnicity, poverty and marginality constructed and enacted?
- How is Roma culture constructed?

*How is knowledge about Roma health constructed and enacted in local practice?*

- How are health priorities defined and enacted?
- How is health knowledge translated or transmitted between participants?

*How does health mediation as a participatory intervention translate into practice?*

- How does the social and material context shape health mediation?
- How do participants negotiate relationships between each other?

By asking these questions, I hope to destabilise the consensus narrative that has built around Roma health mediation, while providing new theoretical insights into how interventions for the inclusion of so-called marginal populations are put into practice. Hopefully this will be useful not only for rethinking the way Roma health mediation is practiced in Romania, it could also yield insights that will be relevant to interventions in different sectors, in different regions, and relevant to different groups.

My research objectives are:

- To examine the social and material context of health mediation
- To examine how health mediation is locally practiced
- To deconstruct underlying assumptions of success in health mediation
- To identify participants' practices of ethnic categorisation
- To take intersectional relationships between participants into account



## **Thesis outline**

This thesis shows how health mediation was about more than enabling access to health care for marginalised Roma communities. While nominally addressing the causes and mechanisms behind health inequalities, mediators were entangled in a much broader, political process of shaping and policing how “Roma health” was perceived and enacted. I address the context, content and processes of health mediation, bringing in the perspectives of health mediators, community members and health professionals.

Chapter 2 outlines my methodology and data collection methods. It introduces my first encounter with the topic of Roma health mediation, my methodological approach and the data collection methods that allowed me to answer my research questions. It gives a chronological overview of the research process, and details how I selected my fieldsites for participant observation and interviews. It considers the process of leaving fieldwork behind, the progression of my analysis, and finally the writing process.

Chapter 3 (*Containers*) addresses the context of health mediation, and interrogates how participants construct the notion of contained, locatable “Roma communities”. The chapter’s account of containerisation and locatability shifts between my own experiences of the material and structural environment of health mediation, and those voiced by participants, including health mediators, community members and health professionals. It looks at participants’ understandings of the historical origins of Roma communities, as well as at eviction and intentional segregation practices that are currently directed at Roma communities. I build on my own observations of poor, segregated, and containerised communities in contemporary Romania to show how social and material conditions contribute to negative social determinants of health. Throughout the chapter I question the ubiquitous practice of labelling such communities as “Roma”, which can contribute to the conflation of marginality, poverty and ethnicity. I interrogate the role of the Roma health mediation programme in addressing material and structural conditions as well as the danger of contributing to ethnocentric and essentialised understandings of

such communities. Finally, I show how these communities were more fluid or “leaky” than they are commonly presented by participants.

Chapter 4 (*Containment*) turns to constructions and enactments of “health” as the subject of Roma health mediation. I question who gets to define health priorities for Roma communities and focus on the three topics that were most salient throughout my fieldsites: hygiene, vaccination and contraception. The chapter contrasts the perspectives of health professionals with those of community members, and explores how mediators themselves enacted each of these health concerns. I pay special attention to the ways in which “Roma culture” is invoked to explain or justify enactments of medical interventions. Finally, the chapter turns to broader notions of patient attitudes and behaviours, looking at how participants enacted “patienthood” (that is, the state of being a patient) in discourse and in practice. The chapter ultimately argues that Roma health intervention contributes to the “containment” of certain dangers that are perceived to emanate from Roma communities.

In the fifth chapter (*Paper Containers*) I address a phenomenon that I did not set out to study, namely the paperwork that turned out to be a major part of health mediation. Instead of spending time in Roma communities, most of mediators’ daily routine was taken up by dealing with the bureaucratic and paper-heavy process of obtaining documents for community members who did not have fully documented citizenship, thereby essentially “creating citizens”. The chapter starts by outlining why undocumented citizenship is perceived to disproportionately affect Roma communities. It turns to explaining what hurdles community members need to overcome in order to fully documented. By helping people with this process, mediators aided those who – lacking the appropriate documents – did not have access to health care. All through the chapter I interrogate how participants, especially mediators, constructed “citizenship” in relation to Roma communities, and how it tied in with previously discussed notions of patienthood. Finally, I examine mediators’ role in how community members enacted citizenship.

At the end of each of the three chapters outlined above – *Containers*, *Containment* and *Paper Containers* – I briefly discuss the data in light of theories presented at the outset of this thesis. In Chapter 6 (*Discussion*), I bring together the strands from each chapter to form a more holistic understanding of my findings. After outlining the limitations of this study, I return to my overall research questions. Combining elements from dialogical, postcolonial and intersectional theories, the main body of this chapter offers a more in-depth discussion of the research questions. I begin by asking how health mediation contributes to the definition and classification of Roma, showing how in discourse and practice they do not challenge, but instead contribute to an essentialised and otherised understanding of Roma culture and Roma communities that conflates ethnicity with poverty and marginality. Second, I discuss the production of knowledge about Roma health, highlighting mediators’ monological engagements with communities which are premised on top-down conceptualisations of health, and which lead to a disciplinary approach to health mediation. Third, looking at how health mediation translates into practice, I interrogate the links between constructions and enactments of “patienthood” and “citizenship”. Acknowledging the important contribution that health mediators bring to accessing health care and the acquisition of identity documents without which certain community members cannot access their rights, I draw attention to role that mediators play in a promoting a neoliberal approach to governing Roma communities.

Finally, in *Conclusions* I offer some implications and policy recommendations that emerge from my research, both in terms of practical improvements that could make the Roma health mediation programme more effective, and in terms of a future research agenda on Roma health and more broadly on inequalities in health.

## Chapter 2: Methods

This chapter introduces the mode of production behind this thesis, investigating its motivations and processes. It also provides the ontological, epistemological, and theoretical backdrop to my research. My intention is not to simply lay before the reader a rough methodological grid to demonstrate that I have followed basic disciplinary, methodological, and ethical protocols. While discussing ethical considerations and approaches throughout, including questions of positionality, power dynamics between myself as researcher and participants, and issues of knowledge production about Roma, I delve into some of the tensions and ambiguities that were part of this process. I pause on the logistic and affective elements of ethnographic knowledge production, in the hope of grasping the nature of research as “mobile, creative, messy, sensory or affective, open-ended and changing” (Bakko and Merz 2015, 9). I do so with reference to my understanding of the production of knowledge about the world as constantly evolving rather than linear and bounded. At the same time, this chapter serves as an introduction to the participants who populate the pages that follow, the setting against which this research took place, as well as to myself as a researcher.

In this chapter I also reflect on the tensions between ethnography and evaluation that I experienced while doing fieldwork. It shows how I was expected (by participants, key informants, and other academics) to adopt an evaluative framework, and how I tried to steer away from this and towards different questions about the context, constructed nature, and underlying assumptions of health mediation. I also wanted to find out what the implications were for how “Roma health” is produced through the health mediation programme. I discuss this process because the question of whether or not my research was evaluative permeated my thoughts and relationships throughout the research process: from developing the initial idea, to meeting gatekeepers, participants, and policy makers, and deciding which fieldsites to sample. The question of whether to evaluate or not was essentially also an epistemological and ontological question: how do I know what I know, and what counts as valid knowledge in this context?

I begin by outlining the genesis and rationale for embarking on the project, and then trace the journey from the initial idea to fieldwork, and finally the composition of the thesis. The chapter is thus structured according to the journey that my research took. In the spirit of decolonising methodologies (Smith 1999), aspiring to clarity regarding who produces research, how, and with what qualifications, I foreground not only the research process, but also myself as the person behind that process. After all, the main research instrument of participant observation is the researcher herself (Scheper-Hughes 1993, 28).

The first thing I should say about myself is that before beginning this research, I was familiar with neither the Romanian context, nor the Romanian language, nor the method that I ended up pursuing. I came to studying “Roma health” not as an anthropologist of Romani culture,<sup>11</sup> nor as a scholar of Romania. Instead, I had previously studied post-socialist and post-Soviet literature, history, and public health. I had perceived research on “Roma health” as a kind of comparative litmus test for the performance of health systems: if a health system was struggling to deliver services to the most vulnerable members of society, it was likely to have shortcomings in other areas. With this in mind, I had published on the disparity in health insurance coverage between Roma and non-Roma populations in Central and Eastern Europe (Kühlbrandt et al. 2014; Arora, Kühlbrandt, and McKee 2016), using data collected by the UNDP/World Bank/EC Regional Roma Survey (A Ivanov, Kling, and Kagin 2012). While I was working with this data, I did not thoroughly question the binary distinction between Roma and non-Roma that the Regional Roma Survey data sets out.<sup>12</sup>

It was in the course of this research that I first came across the health mediation programme. I knew from the outset that I did not want to conduct an evaluation of it. Instead, my aim was to clarify the previously implicit and opaque assumptions about how health mediation works in practice, and to question what effective mediation meant. I

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<sup>11</sup> The field of Romani Studies, which while criticising homogenising notions and aiming to dispel stereotypes about Roma, has arguably also been instrumental in “building up and sustaining an image of the ‘true Gypsy’ through the continuing circulation of false or exaggerated representations” (Tremlett 2014, 3).

wanted to engage more critically with the programme, its context, its actors and their histories. I was interested in theoretical questions about trust, knowledge, and power. As a former student of literature and history, I was familiar with constructivism as a philosophical concept. Up to this point I had not been forced to outline my own thinking in epistemological or ontological terms. I positioned myself as a constructivist, taking a dialogical approach to research (Gillespie and Cornish 2010; Aveling, Gillespie, and Cornish 2014), acknowledging both that as a researcher I bring my own life-world to the sphere I research and that I am likely to influence the life-worlds and relations of participants (Jovchelovitch 2007). On the other hand, I would also be influenced by the field, which would shape my previous assumptions and hypotheses. This dialogical engagement with research would produce readjustments in both myself as the researcher and the researched (Jovchelovitch 2007).

In my upgrading proposal, the research proposal developed during the first year of PhD (Kühlbrandt 2014), I argued that the fundamental position of relational ontology is that relationships between subjects are ontologically more important than the subjects themselves (Gergen 2009). This meant that an analysis of individuals would be more fruitful when their relational context was taken into account. Social constructivism recognises that knowledge is co-constructed in relations between individuals and their surroundings (Gergen 2009). Social, economic, cultural, and political structures shape the way individuals relate to the world and their agency to act within it, while at the same time, people produce the social, economic, and political structures that surround them (Butler 1997; Fraser 1998; Fraser 2000). It would therefore be important to employ methods, I argued, that would allow for the observations of dialogue in context. Following a Bakhtinian approach, I conceptualised dialogue as including relationships, not only communication. This would allow me to contextualise both external dialogues (such as those between mediators, health professionals, and patients), and internal dialogues (with imagined others) (Renedo 2010; Aveling, Gillespie, and Cornish 2014; Renedo, Komporozos-Athanasidou, and Marston 2017). Only through a combination of prolonged ethnographic fieldwork, participant observation, in-depth interviews, and focus-group discussions would I gain sufficient depth and insight to understand trust, knowledge, and

power dynamics between health mediators, the Roma community, and health professionals in their relational and lived-out context.

I share a constructionist and interpretivist epistemology with many anthropologists, and I draw on anthropological theory and ethnographies throughout my research. My methodology borrows extensively from ethnography, including the methods of participant observation, writing fieldnotes, long-term engagement in a place, and in-depth interviewing. Nevertheless, this study is not an ethnography. I say this mainly because, with my background in literature, history, and health systems research, I have had no training in anthropology, nor was my research supervised by an anthropologist. I consider myself an anthropologist in training, and this thesis has been a large step in learning this craft. For now, at the end of this research project, I still consider myself an interdisciplinary qualitative researcher, and because this is an ontologically and epistemologically murky territory, it is perhaps worth spelling out my criteria for good quality research.

The quality of a study based on participant observation and in-depth interviews cannot be demonstrated or measured according to conventional positivist measures of validity, generalisability, and reliability. How to determine “good” qualitative research has been the subject of much debate and depends largely on researchers’ epistemological outlook (Reynolds et al. 2011). Broadly speaking, the kind of research that I am interested in producing strives to develop theory, show consistency between theoretical claims and empirical data, and demonstrate credibility and reflexivity of the research process (Mays and Pope 2000). Research based on participant observation should be able to describe context in a holistic way, as well as having the capacity to switch between emic and etic perspectives; that is, to construct an analysis that incorporates the perspectives both of participants and of the researcher as an outsider (Boyle 1994). This reflects my position that there is no reality out there waiting to be captured by researchers, but that instead “knowledge is constructed through the research process and interpreted through the researcher’s own values and assumptions” (Reynolds et al. 2011, 4). In this sense, the quality of research should be judged by its process as much as its outcome. The purpose of this chapter is to reflect this process, on the way in which I attempted to design, conduct

and analyse my research in a systematic way while simultaneously dealing with the stumbling blocks and complexities of life in the “real world”. I hope to show how my own position as a young, female, white, non-Romanian, and non-Roma researcher impacted on some of the decisions I made, as well as how this positionality of mine affected my relationships with participants, and how it influenced the production of knowledge in this thesis as a whole. In the words of Nancy Scheper-Hughes:

The anthropologist is an instrument of cultural translation that is necessarily flawed and biased. We cannot rid ourselves of the cultural self we bring with us into the field any more than we can disown the eyes, ears, and skin through which we take in our intuitive perceptions about the new and strange world which we have entered. Nonetheless, like every other master artisan (and I dare say that at our best we are this), we struggle to do the best we can with the limited resources we have at hand – our ability to listen and observe carefully, empathetically, and compassionately (1993, 28).

## Preparing

As I have outlined, the literature on health mediation consists mainly of reports which were structured according to evaluation-type questions (Wamsiedel 2013; Open Society Foundation 2011). Policy makers and civil society organisations seem interested to find out whether or not health mediation “works”, especially since few alternatives for improving Roma health have been proposed. The main questions that were being pursued in the literature therefore seemed to relate to the question of whether the programme worked, for whom, and in what context, following a broadly “realist evaluation” perspective (Pawson and Tilley 1997). In conducting my research, I wanted to provide a piece of research that would be practically useful for the health mediation programme and its users, a question to which I return to in the *Discussion Chapter*. On the other hand, I was interested in pursuing a number of theoretical questions that arose from this particular context. I was interested in trust, knowledge, and power encounters between Roma populations and the health system in Romania. This led to an epistemological dilemma about what knowledge I was aiming to pursue. While I did not resolve the question at this early stage of my research, I resolved to benefit users and providers of health mediation



by providing recommendations on how to improve dialogue and relations of trust. By contributing to theories of trust and “knowledge encounters” (Jovchelovitch 2007), conceptualised as encounters between different systems of values and beliefs, I also hoped to offer an in-depth understanding of the processes and concepts that underpin health mediation. These knowledge encounters are also relevant to other situations in which third parties are introduced to patient-provider relationships, such as can be found in a large number of cultural brokering or patient translation services (Miklavcic and LeBlanc 2014; Faouzi 2010; Grall et al. 2012; Gobbo 2004; Jackson-Carroll, Elinor, and Jackson 1998; Minervino and Martin 2007).

At this point, I defined “Roma” as a heterogeneous population including different groups, such as Sinti, Căldărari, Boyash, Lovari, Ursari, and so on. I emphasised that the Romanian Roma population is socially, culturally, and economically diverse, ranging from poor, segregated, and “traditional” communities to wealthy property owners and urban intellectual figures. I did not dwell on these differences, arguing that distinctions between different Roma groups as well as power dynamics within Roma populations would become relevant during data collection and would play a central role during analysis. Instead of making generalisations before fieldwork, they would be analysed on a “community-by-community” basis (Oprea 2005, 138). In a footnote of my upgrading document I argued “the most important distinction at this stage is between Roma and non-Roma, as the encounter between these two groups is the central subject of my thesis.” All the same, I warned that “ignoring social constructions and cultural context risks essentialising Roma knowledge systems” (Kühlbrandt 2014, 6). As a result of this warning, which was purely theoretical at that point, I committed myself to being attentive to the social constructions of trust, knowledge, and power, and how they change through relationships and dialogues. At the same time, I paid little attention to the social construction of ethnic categories themselves. Based on what I had read, I assumed health mediators to be unambiguously identifiable as Roma within their own context, as well as that they provided services for their own communities, i.e. the place where they had grown up or called home.

Mediators are distributed across Romania and are allocated to a specific community or county (Open Society Institute 2005; Open Society Foundation 2011).<sup>13</sup> Since comparison is what drives qualitative data analysis (Green and Thorogood 2009), I aimed to make comparisons within the case studies, and enrich this by comparing sites in order to gain a greater contextual understanding of how mediation works in different contexts. I planned to conduct ethnographic fieldwork in three main case sites in Romania where a health mediator worked. In addition to this, I planned to visit a number of other sites for shorter periods, offering different social, cultural, economic, and political contexts. Through comparison I aimed to look for regularities and exceptions, and refine and amend emerging theory (Charmaz 2014). In each site I was to engage in participant observation and in-depth interviews with members of each group of participants (mediators, patients, and health professionals).

Rather than conducting what has been termed a “multi-sited ethnography” analysing connected but spatially distant systems (Marcus 1995), I was planning to follow a “case study logic,” whereby “the first unit or case yields a set of findings and a set of questions that inform the next case” and “each case provides an increasingly accurate understanding of the question at hand” (Small 2009, 24–25). Instead of seeking empirical generalisability from these successive and comparative cases, I sought to build theory that would speak to, capture, or explain some of the “tensions between the general and the particular” instances of health mediation in practice (Yates-Doerr and Labuski 2015). However, before and during fieldwork, my plans for how many cases to select and on what basis changed a number of times, reflecting how fieldwork based on participant observation is and should be an iterative process (Green and Thorogood 2009). Initially, I had planned for three sites at three months each. Following advice from senior colleagues, I changed this plan to favour depth of interaction, which would have seen me spending six months in one site, followed by several shorter visits to other sites. After the first few months in Bucharest, the majority of key informants and gatekeepers advised me that it would be difficult to find a mediator who would agree to a six-month visit, and so I resorted back to

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<sup>13</sup> Romania is administratively split into communes, towns and counties. There are 41 counties and one city, Bucharest (Vlădescu et al. 2008).

finding three sites, and using my shorter scoping visits as comparative instances where I would conduct interviews with mediators, health professionals, and where possible and appropriate, community members. The study received ethical approval from the London School of Hygiene and Tropical Medicine, as well as local approval from the Romanian Institute for Research on National Minorities.

## **Arriving**

### **Language**

Because social groups do not necessarily share understandings and meanings of language, communication between researcher and researched is always a site of contention even when researcher and participants share the same native language (Winchatz 2006). When I arrived in Bucharest in November 2014, I had been learning Romanian in London in one-on-one classes for more than one year. During my time in Bucharest I continued Romanian lessons. Having previously learnt Latin, French, and Russian proved to be an advantage, since Romanian is a Romance language, with a Latinate grammatical structure, and some Slavic inflections to its vocabulary (Gönczöl-Davies and Deletant 2002). My spoken Romanian was initially poor, although it improved rapidly with immersion. During the first few months I conducted key informant interviews in English. By the time I began doing fieldwork, I was able to conduct document reviews, conversations, interviews, and focus group discussions on my own in Romanian.<sup>14</sup> Despite my initial shortcomings, being a non-native speaker in Romanian conferred some advantages, such as my ability to be more inclined to question the taken-for-granted (within and beyond linguistic issues), as well as a more acute sensitivity to non-verbal interaction.

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<sup>14</sup> I also took elementary lessons in Romani at the University of Bucharest, though not aiming for any level of fluency, since I relied on documentation that showed that in Romania most Romani families speak only Romanian or are bilingual in Romani and Romanian (A Ivanov, Kling, and Kagin 2012; Brüggemann 2012). Although a better comprehension of Romani would have been useful for understanding informal conversations in a small number of situations, all Romani speakers I met also spoke fluent Romanian.

### **Selecting cases**

No form of participant observation could ethically take place without the mediators' full agreement. Preliminary sampling criteria therefore centred on questions of gaining informed consent, cooperation, and the availability of health mediators. Since I was interested in the dynamics not only between the community and the mediator, but also between mediator and health professionals, mediators were to have an active working relationship with local health professionals. After scoping an initial selection of possible locations, a number of pragmatic criteria were added that I had not previously considered. These included the availability of appropriate accommodation in the vicinity, as well as the ability to gain cooperation and consent from people who lived and worked in the mediators' environment, including colleagues, family members, and liaising health professionals. At the sampling stage I was again confronted with the tension between the methodologies of in-depth ethnographic research, which may purposefully sample for diversity, and the methodology of evaluation, which would more fruitfully look for a "typical" health mediation context. Because there was a large amount of variation between the different kinds of employment status and contractual arrangements that mediators were under, no two working conditions of mediators were alike. Nevertheless, I discounted situations in which I realised that mediators worked under very unusual contractual obligations (such as if they were part of a pilot project for a new kind of health mediation) so as to allow this research to contribute to debates about health mediators more generally.

### **Gatekeepers**

For a number of reasons, fieldsites had to be identified via gatekeepers, whom I introduce below. First, there was no publicly available list of mediators in Romania, so it was impossible to know in which communities they were active. Second, I assumed that there would only be a small minority of mediators who would be prepared to have their work observed for an extended period of time. Third, I quickly discovered that people were distrustful if I contacted them without first having been introduced by somebody they

knew. For example, before arriving in Romania, I tried in vain to get in touch with the Roma health mediator association, Zurale Romnia, through whom I reasoned I would be able to side-step gatekeepers at higher levels.

My main contacts during the first months were, then, two NGOs that had been involved in establishing and running the health mediation programme. Through them I became acquainted with policy makers in a number of government institutions. In order to inform my fieldwork and to gain a better understanding of the programme and its context, I had informal conversations (plus four key informant interviews) with people I met in this way. Many of these key informants subsequently became gatekeepers for fieldsites, since they had close ties to health mediators, as well as an overview of the different contexts in which mediators were operating. In short, they had a sense of which mediators might be willing to be involved in the research project.

While their detailed knowledge of the health mediation programme made these contacts excellent gatekeepers, there were a number of other reasons why they were problematic as go-betweens between myself and the mediators. First, although not formally their employers, these NGOs and policy makers were nevertheless thought of as holding positions of power with regards to the mediators' themselves. Especially since the decentralisation process in 2009, when mediators started to be employed through local authorities, many mediators were at risk of not having their contracts renewed. They hoped that if their jobs were at risk, the NGOs and policy makers would step in to defend them and use their contacts to lobby for the mediators' re-employment. Thus, mediators had an interest in maintaining good working relationships with their advocates in Bucharest. I was concerned that mediators might feel pressured into taking part in my research project if these gatekeepers put them in touch with me. While I was in no position to eliminate these concerns with certainty, I was able to take steps in order to mitigate their effects, which I describe below.

An additional source of concern was whether it would be possible to conduct open-ended research, as opposed to the evaluative frameworks that I was toying with both under

my own pressure and under that of others. One of the principal gatekeepers was a woman whom people called “the mother of health mediators,” apparently because of her key involvement in setting up the programme. She told me that she thought my study would be a valuable contribution for her and for other organisations because I was an “objective” outsider. She expressed her concern about my plans to use ethnographic methods; she thought I would become “too attached to the mediators,” with the implication that I would be biased. External objectivity, she said, was useful, because being Roma herself, her judgement counted very little among more important policy makers. At the Ministry of Health, she told me, people assumed that she lacked objectivity about the health mediation programme because of her ethnicity. The “mother of health mediators” hoped that my research would endorse the programme, but she also knew that my report could not be used to lobby the Ministry unless it read as a neutral evaluation. Her notion that I might be able to produce what she believed others to think of as neutral evidence was bound up with her view of my identity as a Western, non-Roma researcher.

Previous research on health mediation in Romania has always contained at least some evaluative element (Wamsiedel, Vincze, and Ionescu 2012). Due to the precarious future status of the programme, I gathered from key informants that a lot of the existing research has mainly been generated and used in order to secure continued support and funding. In this context, no previous research has sought explicitly to be open-ended or theoretically driven. Because I was relying on gatekeepers’ help to identify participants, I repeatedly stressed the fact that I was not conducting an evaluation of the programme. Nevertheless, gatekeepers wanted to put me in touch with their “favourite” mediators. Perhaps these were women who had been part of the programme as mediators for a long time, whom they had personally met, whom they liked as individuals, and whom they believed were engaged in good work with their communities. Although they did not say this, I suspected that this was so that I would gain a positive impression of the programme, and would therefore positively “evaluate” it. Initially I tried to resist such recommendations, but I soon realised that my own reasoning had also become tainted by ideas of “neutral evaluation.” If I was to only observe the “best” mediators, I thought, how would I know whether the mediation programme worked? Even though I was aware of this “evaluative

trap” in my own thinking (after all, I was interested in different, more theoretical questions), I sometimes subsequently caught myself being driven by the pursuit for an “objective truth” on which I would consequently be able to report. In the end, I spent time both with mediators who were favoured by gatekeepers, as well as those whom I identified without the recommendations of gatekeepers.

Evaluative knowledge pertains to the value of something. It is created to satisfy the needs of programme implementers, such as state or non-governmental institutions, usually in order to analyse effectiveness or cost-effectiveness. The questions that evaluations ask are a variation on a theme: “Does it work? Why does it work? Why doesn’t it work?” Evaluations are based on the assumption that there are lessons to be learnt from current programme implementation. Based on these lessons, implementation may be adjusted to make programmes more effective (Crain and Tashima 2005). Indeed, many of the benefits of the health mediation programme could be easily captured in evaluative quantitative data (for instance, newly insured patients, patients newly registered with GP, patients successfully referred to specialists, number of newly vaccinated children, number of pre-natal check-ups, increase in contraceptive uptake). In addition to these quantitative data, a qualitative evaluation may be able to give insight into the process or patient experience of health mediation, questions of stigma and discrimination, and provide recommendations about how to amend the program so as to improve outcomes, how to smooth the processes and make them more “effective.”

Similar to ethnographic accounts, evaluations are stories, written by those performing the evaluation. Evaluations are also shaped by their methodological approaches, and the data that are produced and reproduced as part of them is constructed at every stage. Evaluators come with their own values which determine the way they see what is before them and privilege some forms of knowledge over others (Phillips and Edwards 2000; Mosse 2006). Evaluations are therefore political texts in themselves, often disguised as neutral, depoliticised accounts.

Anthropologists are in the privileged position, inasmuch as they can use theoretical perspectives precisely in order to uncover the politics and power dynamics underlying policy implementation. Ethnography allows for political positioning, because there is room for making partisanship explicit. Because they are not limited by pre-established protocols, the stories resulting from ethnographic fieldwork need not feed into incremental programme improvements (even when the whole programme might be based on false or ideologically laden assumptions), and they need not maintain inoffensive neutrality. Instead, anthropology's impact on health policy should be to provide a critical analysis of what is happening at various levels of policy implementation, and to use detailed knowledge of the field to link it to the wider structural, historical, and political context in which it is embedded. In this sense, it has the potential to contribute to more radical critiques, explaining not the failings of one programme in particular, but "general and inherent features of the system" (Mosse 2006, 940) on which the programme is based. I follow Mosse in arguing that ethnographic enquiry leads not to answers about whether or not a programme or intervention is successful, but "how 'success' is socially produced or constructed" (2006, 940). Perhaps research that resists evaluation is therefore in a better position to invite critical discussion. In my case, I hope to set in motion an analytical debate about Roma inclusion policies, their underlying assumptions, definitions about their effectiveness and impact, and, most of all, the question of whom they benefit.

In my relationships with key informants, as well as other participants, ethical and political questions arose about how legitimate it was for a non-Roma, Western European researcher to publicly critique a programme that has been designed, maintained, and fought for by Roma for Roma under the Roma inclusion slogan "nothing about us without us" (Ryder, Rostas, and Taba 2014). The way that my position as a researcher was constructed gave me a high status as a producer of knowledge, making my research a potentially valuable product for interested parties, but only if it reflected positively on the programme, as well as functioning as a kind of objective evaluation. Throughout the production of this thesis I have questioned my own sense of legitimacy, as well as the legitimacy that has been projected onto me by others, as to my ability to make assertions about the health mediation programme based on my research, and, more problematically,



based on my position as a Western outsider. I have also wondered about the potential implications that such assertions may have on those dependent on the programme for their livelihoods. All this brings up questions of intersectionality: not only in the subject matter of my research, but also in the need to heed intersectional power asymmetries in the course of the research process. Ultimately, I hope to be able to contribute to a productive debate about the merits and challenges of the health mediation programme. I hope that my contribution will be read not as a “neutral evaluation,” but as a product of highly situated, relational, and experiential knowledge. For this reason, I will not confine reflexive considerations to this chapter: instead they are written into the relevant parts of every chapter.

Throughout the production of my thesis – that is, in the mutually overlapping cycles of preparation, fieldwork, and analysis – I have followed a dialogical and relational ontology. Evidence cannot be seen as “external to the context of the situation” (Hastrup 2004, 455). Instead, I see knowledge as a result of collaboration, dialogue, and as a product of relationships. In this, part of the enquiry is directed not only at the participants, but also at the relationship between myself as a researcher and the participants as objects of my enquiry (Hastrup 2004; Mosse 2006). Knowledge about these relationships “emerges within a dialogical field” (Hastrup 2004, 456). This means that I recognise my own participation in the production of knowledge, the effect of my presence on people’s utterances, relationships and behaviours. A part of this acknowledgement also pertains to the power inequalities that exist between researcher and researched, which can appear in multiple and sometimes surprisingly reciprocal ways. Regarding the production of truth or evidence, as Hastrup (2004) and Mosse (2006) point out, researchers working with a relational and dialogical ontology “can never actually prove the rightness of their generalizations with reference to evidence or experience (‘as an independent measure of validity’), since these are neither separate from, nor prior to, [their] own frame of interpretation, the pre-existing scheme of objectification that transforms facts into ‘evidence’ or imputes causation.” Therefore “rightness” is an “epistemological awareness not an ontological certainty” (Mosse 2006, 949–50).

Before selecting my two main fieldsites, I visited each mediator twice, and each time I spoke to them at length in order to establish their willingness to participate in the study. In several open conversations with the mediators, I stressed my own independence as a researcher (that is, with no ties to the gatekeepers, local authorities, or any other Romanian institution), the purpose of my research (to understand how mediation worked in practice rather than an evaluation of mediators' work), and that any data I would gather would be reproduced anonymously. Analogously, all transcripts and fieldnotes have been anonymised. Throughout the thesis I use pseudonyms for the names of places and individuals. Because of the relatively small number of mediators in Romania, and because most villages, towns, and cities only employ one mediator, I have changed attributes of both people and places where disclosing these might compromise anonymity. All pseudonyms and changes to attributes (such as distances or local specificities) are marked by an asterisk when they are first mentioned.

### **Gaining access**

Before I finally found these mediators, I spent six months scouting for appropriate fieldsites. I travelled to six counties across Romania's three historical regions (Wallachia, Moldova and Transylvania), and visited mediators for periods of 1-6 days in three towns, which I have given the pseudonyms Tabăra\*, Stăvilă\*, and Movilă\*. Independently of whether they were appropriate as long-term fieldsites, I conducted interviews in each of the locations I visited as part of my scouting activities. These visits were therefore not fruitless, since I used the interviews and informal observations as data for my analysis. I used the preliminary work to refine my topic guide questions, becoming more aware of the relevance not only of mediators' relationships with doctors and communities, but also the way in which they were often caught between different interest in their jobs, such as whether to prioritise the needs of health professionals or local authorities.

The aim of extended visits to sites that looked like possible long-term fieldsites was to establish what kind of relationship I would be able to build over the course of several days, and whether the dynamic between the mediator and myself would allow for longer-term

participant observation. These initial impressions were often influenced by relatively intangible concerns, such as whether I felt we were compatible on a personal level, whether it felt like we could bridge – or at least work with – the uncomfortable dynamic afforded by the researcher-participant relationship. These visits and decisions were not always easy, in part because they were under constant scrutiny for whether they were suited to a future projected visit, in part because they involved a substantial amount of emotional labour (Spencer 2010). To illustrate this, I briefly discuss my time with Inna\*, the mediator in Movilă.

Inna and I got on well for the week that I stayed with her. In fact, she was urging me to come back and stay longer. On paper, the community fulfilled the criteria for a fieldsite: Inna was highly involved in her work as mediator; she appeared to know most people in her neighbourhood; she seemed to have good working relations with at least one GP; and her whole family had welcomed me into their house. She was proud to show me her work and introduce me to all her neighbours. Nevertheless, a number of complications arose. First, I was never sure to what extent she felt obliged to tolerate my presence because one of the gatekeepers had referred me to her. In any given situation I relied not only on written or verbal assurances that I was welcome; I would also try to ascertain and act according to how I thought people felt towards my presence through body language, tone of voice, and the ways in which people included or excluded me from their activities. Nevertheless, I will ultimately never know for sure to what extent I was truly welcome in any given field site. Second, I had very little privacy while staying with her. Inna told me that she considered it a matter of great honour that I should stay at her house and seemed offended at my suggestion of staying elsewhere. It being winter, during which the family only heated one room in the house, this meant sharing a bed with Inna, which was in the same room as her ageing mother. Inna also insisted that it was dangerous for me to go out alone, and not wanting to cause her concern I spent almost a full week not leaving her side. While this was a trying situation on a personal level, it also meant that I had nowhere to write up fieldnotes, and as a consequence I wrote them up after I left. Third, I suspected that Inna also had material reasons for wanting me to stay. Not only was I a paying guest in her home (a pre-arranged fee of £5/night), but whenever she took me shopping to the

local market she would tell me she had run out of money and urged me to pay for food, cigarettes, and drinks. On one occasion she suggested I should fund a family outing to the local baths. I declined, but perceived our relationship with increasing ambivalence: on the one hand, I was bound by ethical agreement not to offer informants payment. On the other hand, her family was hosting me, so I felt duty-bound to contribute to the household, particularly in light of the discrepancy between the family's standing, her salary (£190/month), and my student stipend (£1300/month). While a small contribution as a guest in Inna's house seemed entirely appropriate, yielding to her growing demands did not. I understood Inna's requests for money, but in context they progressively eroded away my feeling that we were building an open, trusting, and cooperative relationship. While my dialogical approach acknowledges that there are no firm boundaries between the researcher in their professional capacity and the researcher as a private individual, I felt that my interactions with Inna made it difficult to judge the most ethical line of action at any given time.<sup>15</sup> Only in hindsight did I realise that withdrawing from Movilă as a long-term fieldsite was a good decision. While I was grateful for the week I spent there, for the observations I had made and the interviews I had conducted (all of which have informed my analysis), I was able to concentrate on identifying other fieldsites in which I would be less involved in mediators' familial and private lives, engendering a greater distance between private and professional spheres which were already fluid enough as they were.

Even though it is generally assumed that “the healthy person is self-contained and clearly bounded,” (Blackman 2008, 26), it is also the case that “affect can be passed and transmitted between people.” Blackman, following Latour (2004), suggests that this is in part because bodies are “always in the process of becoming.” This was certainly the case in each of the fieldsite locations I visited or stayed for longer periods. Each physical arrival in a new place was also a “process of becoming.” I was constantly in the process of

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<sup>15</sup> In fact, this line continued to be blurry, even after I decided not to return to Movilă. A week after I left Movilă, I received a phone call from Inna's sister. She asked whether her son-in-law (whom I had not met) could stay with my family in London. He had only just arrived, but he was homeless and sleeping rough in Hyde Park because he had no job, no money, no accommodation, and spoke no English. In a different context I would have tried to find a place for him to stay, but in these circumstances, the boundaries between me as a researcher, and me as a personal social and financial resource for the extended family had to be made clear. I directed Inna's sister's son-in-law to organisations and centres who would provide him with free food, shelter, and Romanian-speaking advice.

adjusting, realigning, and becoming new versions of myself. Depending on the situation and the people I was surrounded by, I was simultaneously several versions of the inquisitive student and researcher, the silent observer, the naïve but entertaining foreigner, the confident expert, the politically astute activist, and so on. This realisation also played into my observations of others' multiple and overlapping identities, as well as the way that affect translated between participants and myself during the process of research.

Besides this, Movilă also highlighted for me several other considerations in selecting fieldwork sites for ethnographic research. First, even when selection criteria are officially met, contextual circumstances may prevent a site from being appropriate for long-term engagement. Second, particularly in iterative and ethnographic research, ethical judgement has to be relational and contextual rather than rigid and prescriptive (Riessman and Mattingly 2005). Third, conducting research in severely economically deprived communities requires sensitive, contextual, and relational processes of negotiation between the researcher and participants (Kingori 2013). Furthermore, gaining access to economically deprived communities through figures of authority may bring with it a real or imagined possibility of gain and/or obligation on the part of community members, and therefore calls for particular attention to relationships of power. Through dialogue, it may be possible to bridge social, cultural, material, or political differences between researcher and researched. As this did not seem possible, I saw it as my responsibility to withdraw from this and other prospective sites.

Comparatively, selecting Dacia City\* as a first fieldsite was a straightforward process. When I visited the mediator, Viorica\*, for the first time, she was open and friendly, and seemed more acquainted with the concept of research than other mediators I had met. Viorica was also “recommended” to me as an engaged and committed mediator by one of the gatekeepers, but instead of relying on a direct introduction, I contacted Viorica independently. When I first visited her, she showed me her office and introduced me to her colleagues, as well as giving me a tour of the hospital and the town centre. She was open, talkative, and seemed proud to share her experiences as a mediator with a researcher from abroad. I visited her again two weeks later. She organised an excursion in order to

meet mediators from neighbouring villages and towns for the occasion. After long conversations and an in-depth explanation of my project, she agreed that I could come for two months. I found a flat share that afforded independence from the mediator outside of her working hours, and moved there for two months.

In order to avoid relying only on “recommended” mediators, it was important to identify the second fieldsite independently, without the endorsement of Roma organisations and NGOs. I found Colină\*, the second fieldsite, through private contacts: in spring I had visited a priest with whom I was distantly acquainted in a Transylvanian village. It turned out that the municipality of Colină employed a health mediator, Roberta\*. I organised an interview with her during my first visit to Colină, and found her to be open and willing to demonstrate her work as a mediator. When I visited for the second time, I explained the purpose of my project to Roberta, and she agreed for me to stay for a longer period of time.

In Colină and in Dacia I had found two communities in which it was feasible to conduct participant observations while maintaining clearer boundaries between myself as a researcher and the mediators. This was important both for my own well-being (Wray, Markovic, and Manderson 2007) and for the quality of the data that I was producing.

## **Being there**

### **Participant observation**

In Dacia City and in Colină I had already interviewed Viorica and Roberta during the course of my initial visits in order to get to know them and to gain information about the scope of their practice. This simultaneously allowed them to become acquainted with me and the purpose of my project. On my second visit, I spoke to them at length but informally, after which they indicated their verbal consent to a prolonged stay. In order to pre-empt a sense of premature commitment on their behalf, I was also in regular telephone contact with them before my arrival to confirm their continuous support for

being involved in the project. We discussed their participation again when I arrived for my two-month stay. Only then did I present them with the consent form for participant observation. I furthermore received informed consent for participant observation from the mediators' colleagues with whom they shared an office. I informed other staff, or community members whom I observed in the mediator's office, about myself and the research project as and when I came into contact with them, and when the moment was appropriate. Negotiating this moment was often a matter of delicate judgement, and I attempted to be contextually sensitive. For example, it was not appropriate to take up the time of community members who visited the mediator in a hurry. During my observations I took notes on verbal, non-verbal, relational, spatial, and emotional aspects of the interactions and activities that I observed, such as facial expressions, tones of voice, body language, and seating and standing arrangements within a room. I later wrote these notes up into long-form texts. In Dacia, I delineated my observations by accompanying participants throughout their working day. In Colină, I also spent time with GPs and community members.

Mediators vacillated between periods of inactivity and intense activity. Where appropriate, I helped with tasks such as photocopying documents, getting coffee, cold drinks or lunch provisions, or staying in the office when people went on short errands. I helped Viorica translate e-mails to and from English, and on one occasion, I offered my native German as a form of assistance to a survivor of the Second World War who was applying for a German pension on the grounds that he had been deported as part of the Roma Holocaust. For the most part, however, there were not many ways in which I could appropriately contribute to "mediation." Mediators conducted some of their duties outside of their offices, such as visiting families, accompanying people to hospital, or negotiating with local authorities. Sometimes they indicated that they preferred to go alone, other times they offered me to come along. With Viorica I went to the town hall, to the hospital, to conferences held by NGOs, and events put on by the municipality. In these moments, as well as during the times in which we simply sat and talked in the office, I gained insights into the everyday lives and concerns of mediators and their colleagues. They spoke about their work, but also their lives outside of work, their families or current

affairs. When they interacted with community members, or more rarely with health professionals, social services, and local authorities, I made note of these exchanges and their context.

In Colină I observed Roberta, the mediator, at work. For the most part, this involved work at a computer or completing paperwork in the town hall. More rarely, Roberta asked me to accompany her on one of her “fieldwork days,” which – to my knowledge – occurred only sporadically. This involved visiting families in their homes, as well as supervising community members who were performing workfare in order to receive their social allowance. In addition to my observations of the mediators’ work, I focused on the relationship between community members and the three GPs working in the village. Being less bound to the mediator, and living in a small village offered plenty of opportunities for getting to know people and having conversations with them independently of their relationship to either the GPs or the mediator.

In my first encounters with mediators I realised that they seemed to be doing very little “mediating”: at least, what they were doing did not match my expectations, nor was it always congruent with the programme’s official aims. They were not spending time in their community or talking to people there, nor were they accompanying them to the hospital or the family doctor in the manner I had expected. They were sitting behind desks, photocopying documents, and taking them from one authority to the next. Even though I knew I was not there to evaluate their work, I soon became embroiled in evaluation-type questions: What if this mediation process does not work at all, I asked myself. What impact is it having on Roma communities? I fell into the pattern of trying to count the number of days mediators had not visited communities, or had not spoken to a single health care practitioner. This led to further epistemological tension: I was eager to know the “truth” about how much time mediators spent in communities (I often felt they were telling me one thing, and doing another), while also being aware that mediators were co-producing this knowledge, and that I only had access to the “truths” that participants constructed.



As discussed in my outline of relational ontology, scientific knowledge is neither a detached nor a politically neutral reflection of reality. Constructivist approaches to research recognise that knowledge is co-produced, as a “collaborative endeavour of academic and non-academic actors” (Pohl et al. 2010, 269). This perspective acknowledges that representations of the world cannot be separated from the ways in which we inhabit it. Scientific knowledge “embeds and is embedded in social practices, identities, norms, conventions, discourses, instruments and institutions – in short, in all the building blocks of what we term the *social*.” (Jasanoff 2004, 2). In this way, acknowledging the co-production of knowledge is simultaneously a critique of realist ideologies that attempt to separate “the domains of nature, facts, objectivity, reason and policy from those of culture, values, subjectivity, emotion and politics” (3). Recognising these domains as co-constituent and that knowledge is contextual and situated requires the researcher to bring the context of knowledge into focus (Edwards and Holland 2013). One way of establishing such contextualisation is by “being there,” by focusing on the social relations between researcher and participant (Strathern 1996) that generate ethnographic knowledge (Reynolds 2016).

As the first few months of fieldwork went by, I came to terms with what I had known long before, namely that the kind of data I was collecting through participant observation and interviews would not lead to a satisfactory answer to the question, “does this work?” Simplistic as this line of questioning was, I was interested in such questions, which were also what I felt gatekeepers wanted to know from my study. I also realised that there were more interesting processes at work, processes that transcended this simple evaluative framework. This involved questioning what mediation really was and the assumptions that underlie Roma health mediation: assumptions about efficiency and its meanings, but also about ethnic differences, about approaches to inequality as well as intersectional links between health, housing, work, and education, and the role of the state in addressing inequalities. The main question I became interested in was: who actually benefits from health mediation? Had I gone further down the evaluative line of enquiry, I might not have spent time questioning why mediators frequently operated outside of their official brief and what effect this produced on the institutions and communities with which they

worked. I had initially been interested in trust and relationships between mediators, community members and health professionals, but realised during the course of fieldwork that this triangular relationship played a more minor role than I had expected, since health mediators spent little time with either doctors or communities.

## **Interviews**

People were sceptical of being interviewed unless I had been introduced to them by somebody they already knew well. This created a methodological dilemma. In Dacia, for example, at first my only contact was the mediator. While people who had never had contact with a health mediator were easy to find, and I had numerous conversations with people who had never heard of this role, the purpose of my interviews was to explore the relationship between community members and health mediators; interviewees had to have had at least some interactions with the mediator. Since Dacia City was a city in which relatively few people came into contact with the mediator, it was therefore not possible for me to identify interviewees independently of their relationships with her. This meant that the data I was generating were being co-produced by the mediator: when I interviewed people about their relationships with Viorica, she could potentially influence how she was being represented, even when she was not physically present (a relation that was worth considering in the analysis). I was aware of this, and at times sought to avoid it. This initially led to several interviews with people (both community members and health professionals) who knew Viorica well, and who appreciated her work. During the course of an interview with a paediatrician, for example, it transpired that the two women had been neighbours in the past, and that the doctor knew Viorica less in a professional than in a personal capacity. After this interview, I made efforts to make an independent sample: for example, I recruited Dr Florian\*, a gynaecologist, whom I met through Viorica, but only when I had accompanied her as she was bringing a patient to see him. On the one hand, I saw through their interactions that they were familiar with each other; on the other, Viorica had not recommended me to talk to him. In a similar vein, it was only towards the end of my two-month visit that I was able to identify and interview community

members who had regular contact with the mediator without going through the mediator herself.

The way in which participants are connected to each other is particularly relevant when interviews cover these relationships. Rather than pretend that people exist as independent monads, I acknowledge that people influence each other in complex and sometimes ambiguous ways. Recognising interrelationships as part of a relational ontology not only helps with the theoretical sampling of participants, it also adds depth to analysis for these relationships and power dynamics to be taken into account. The methodological dilemma was whether to accept “recommendations” for interviews (a form of snowball sampling), even if this was likely to substantially influence the interviewee’s perspective on the subjects to be discussed (Small 2009). From a constructivist perspective, however, no interview takes place in a neutral context. Instead, researchers build relationships with participants whom they encounter, and when the research concerns relationships, it is likely that interviewees will have relationships amongst each other. In this way it is not only the participants who are co-producing data, but also the researcher, by way of asking questions in certain manners, or writing up fieldnotes in a necessarily partial way.

In light of my relational ontology my aim was not to find “neutral” participants, but to keep a balance between participants who tended towards a positive view of the mediator and those who had more ambivalent experiences. For this reason, I identified interviewees both through the mediator, and independently from her. Nevertheless, I saw how data was co-produced by the different contexts of the interviews. For example, I interviewed one woman twice, once before and once after she had seen me in the mediator’s office. During the second interview, her interaction with me differed from the first interview, as did the way she spoke about the mediator: she portrayed her relationship with the mediator as being closer and friendlier than she had done in the first interview. On a different occasion, I interviewed the vice mayor of Eforie, who agreed to speak to me, but in front of whom I could not embody the position of neutral researcher, since he had previously seen me with a group of journalists and activists who had come to his office to protest a second eviction. Instead, our interaction was confrontational: I challenged

what I believed to be his openly racist views, while he mockingly humoured my position as an enraged outsider who in his view was unable to grasp the logic behind his actions.

I received written consent from everybody whom I interviewed. Although I was already well acquainted with most of the participants before interviewing them, I re-introduced myself and the project before every interview, gave participants an information sheet and the consent form, discussed it with them (going through it in simplified language for participants who lacked the literacy to read and fully understand the form). I only asked for participants' signature after the end of the interview, in case they felt uncomfortable with anything they had said. In this manner I ensured that the consent process was not merely a single event that precluded a change of heart. Instead, this more fluid approach paid continuous attention to whether participants felt comfortable taking part in the study.

Interviews followed a topic guide that I developed at the outset of fieldwork, iteratively adapted during the time of my study, and which I tailored to each participant. I listened back to previous interviews and began analysing them before conducting the next, which informed refinements of the topic guide. Interviews were held like open conversations, where every question was adjusted to the respondent, the context, and data that I had gathered up to that point. In general, interviews covered open-ended questions about participants' perceptions of the aims and scope of health mediation, the relationships between mediators and communities, as well as relationships between mediators and health professionals. As I progressed with interviewing I added personalised questions and follow-up questions. While conducting interviews I also took note of the participants' interactions with their environment, for example where they lived, and of evident family or neighbourhood constellations. In total, I conducted 40 interviews and three focus group discussions (FGD) in nine locations: three focus groups with health mediators (one with six, and two with four mediators), 13 individual interviews with health mediators, 11 with health professionals (seven doctors and four nurses), six with community members, six with key informants (NGO workers, Roma health mediation programme designers and implementers), and four with other participants (two town hall officials, a school mediator

and a priest). The total number of interviews does not include second interviews, which I conducted with Viorica and Roberta, the mediators in the two main field sites, whom I interviewed both at the beginning and at the end of my stay. The interviews and focus groups lasted approximately an hour, sometimes less, sometimes up to two hours. All interviews were audio-recorded (except one doctor who did not give consent for recording). The focus groups were held on occasions when mediators were already gathering for a different purpose (for training and for a group meeting). Interviews with health mediators and health professionals took place in people's place of work. Interviews with community members usually took place at people's homes, where participants were more relaxed and spoke less formally. At times it was difficult to speak uninterrupted with mothers who were looking after their children and would have to tend to them simultaneously. However, I preferred to contend with these interruptions while interviewing people at home, not least because some of them did not have alternative child care arrangements that they could fall back on.

## **Leaving**

Counter to plans and expectations, I did not conduct research in a third main fieldsite. Because finding a third site had been part of my plan for conducting a comparative, multi-sited study, the decision to stop after spending 11 months of fieldwork (including two months of 24/7 fieldwork in each of the two main fieldsites) deserves some illumination. Far from reaching the elusive point of "data saturation," (Small 2009) the combination of participant observation and interviews instead brought me closer to a point of "researcher saturation," which Wray et al. (2007) describe as an outcome of qualitative research into emotionally distressing subjects. In addition to the often unsettling content of interviews and interviewees' living conditions, the scoping and confirmation of fieldsites had required frequent and often long train and bus journeys covering large distances between different cities, towns, and villages, often at very short notice. These involved intricate planning and required flexibility on my part. At the same time some fieldsites required a great deal of emotional labour, as discussed above.

After leaving Colină, several factors constrained the possibility of finding a third site: the first of these was time. In total, I had planned for 12 months of fieldwork, in order to allow for the writing up of my data in the final year of the study. Because it took six months to begin participant observation (instead of the three months I had originally planned for), I was left with two months to identify a third site and conduct participant observation. Because Colină was situated in a remote part of Romania, and since I was living there full-time, I could not scout for a third site while living in Colină.

When I returned to Bucharest from Colină, I attended a mediator training, with the possible prospect of recruiting a mediator for the study. The gatekeepers also played a role in co-producing the knowledge I gathered by recommending certain mediators or sites to me. They proposed that I should identify a “traditional” community among the mediators who were being trained in order for my study to be more comprehensive. Throughout fieldwork, in conversations and in interviews, I heard such communities referred to as the “real” Roma: those who spoke Romani, upheld customs, and dressed in “traditional” ways. Recommendations to spend time with such communities were accompanied with an implication of authenticity. Since I was new to the context, I did not immediately question this categorisation into “assimilated” and “real” / “traditional” Roma. I contacted two mediators, Amalia\* and Marta\*, both from so-called “traditional” Căldărari communities. The gatekeepers told me they admired the work of both mediators, especially since they were negotiating relationships with communities who in Bucharest were considered “hard-to-reach.”

I spent four days with Amalia, and two days in Marta’s town. Neither turned out to be appropriate as fieldsites. Although Amalia had presented herself as open and welcoming prior to my arrival, she immediately expressed a profound suspicion not only of the project and of research more broadly, but also towards me personally.<sup>16</sup> While we became

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<sup>16</sup> At the end of my stay, when we had got to know each other better, she told me that (apparently based on a previous experience) she had suspected me to be an undercover journalist whose aim was to besmirch the reputation of her community. More than that, she told me three days into my visit that during the first night of my stay she had believed that I might assassinate her while we had been sharing a bedroom. The family insisted that I should stay at their house, but the mediator’s fear of me was so great that she kept the light and the television on at night so that she would not fall asleep. By the time I left she seemed to have

amicable towards the end of my stay, I was aware that I had caused distress, and I sensed that she did not fully trust me to not cause harm in her community. For these reasons, I cut my stay short and left to visit Marta's community. Here, the main challenge was not trust (both Marta and her family welcomed me with open arms), but space: people lived in self-built shacks made of breezeblock, often without windows, and a great number of people to each room. Since each house was already over-crowded, there was no place for me to stay within the community, and so for the three days I spent there, I paid for a room at the nearest hotel. Because of the geographic distance, as well as the obvious material contrast between our different accommodations, it did not seem ethical or practically feasible to stay in order to build a trusting relationship.

The distribution of fieldwork among two main sites and the insights I gained while scoping in seven other locations allowed me to capture diversity. A third site would have been a valuable source of further comparison, but the notion (held, amongst others, by the gatekeepers) that my study would have been incomplete without having conducted extended research in a "traditional community" was based on a categorising "typology" of communities which by this time I was already beginning to question and deconstruct. At the end of my visit to Marta's community I decided to desist from trying to identify a third "authentic" community, and instead to devote my time fully to the analysis of the data I had collected up to this point, which I had already begun by writing memos, coding interviews, and analysing fieldnotes, especially during a one-month fieldwork break around Easter 2015.

It dawned on me that I had not only been sampling theoretically, to maximise variation between mediators and their working practices: I had also, at least subconsciously, been seeking a certain kind of representativeness for my sample. This representativeness, a senseless pursuit from many perspectives (given my study objectives and given the small sample size), was influenced by my desire to be able to contribute some kind of evaluation of the health mediation programme, an impulse which had already led to epistemological

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warmed towards me and were both able to laugh about her initial trepidations, but the experience left me with the uncomfortable feeling of having intruded on her life and so I was also glad to leave.

tensions that I have outlined above. I was driven, on the one hand, by the wish to “give back” something that would be useful in improving the programme. On the other hand, I still experienced an epistemological tension, in search of a “truth” which I imagined to be lying somewhere between or behind what I had observed and what participants had told me in interviews. Once I was back in London, analysing material and feeling progressively more removed from the direct experiences of fieldwork, and seeing how different constructions of health and mediation appeared on the page, the desire to speak in terms of a representative sample waned.

## **Processing**

I received funds from the ESRC to pay a Romanian researcher – Alina Huzui – to transcribe and translate the interviews as I collected them. I asked Alina to transcribe the interviews verbatim, including my mistakes in Romanian, which she at first tried to graciously correct. For the sake of speed, I read through interviews and coded them in English, cross-checking key sections and words in the Romanian transcription. Where I reproduce quotes in the thesis, I have re-translated them from the Romanian for clarity and comprehension. Throughout, I have stayed close to the original, and any mistakes or inaccuracies in the translation are my responsibility alone.

I began the process of coding data during the course of doing fieldwork, beginning with line by line coding and memo-writing of three interviews (Charmaz 2014). During the process of open coding and continued memo-writing, I developed a coding framework in discussion with my primary supervisor, Alicia Renedo. Coding proved to be useful not only because it removed me further from an evaluative framework and towards abstraction and theoretical questions, but also for engaging with the interviews in-depth, reading them repeatedly and closely, focusing my attention more narrowly on emerging themes. Nevertheless, I found that coding flattened the conversations, imposing a straitjacket of gerunds on fluid processes that were sometimes difficult to grasp: language, non-verbal interactions, emotions. The codes did not feel like they did justice to the complexity and ambiguity of what I had experienced. Reading through my fieldnotes with an open



approach helped to open up my overall analysis, and generated new ideas, which I cross-referenced with the interview data. In this way, my coding of interviews and my analysis of fieldnotes mutually influenced each other, adding three-dimensionality to the writing.

By coding interview data and reading through fieldnotes, my analysis slowly started to centre around a number of overarching themes: “encountering the ‘other’”, “governing and regulating Roma communities”, “navigating networks of power”, “working as part of the system”, and “resisting.” These themes were in part influenced by the theoretical questions about knowledge, trust, and power with which I had begun the study, as well as theoretical texts to which I intermittently returned before, during, and after fieldwork. As a consequence, my engagements with theoretical and historical texts influenced my gaze, but my experiences also influenced my readings of the texts. I developed a dialogical relationship with these texts, constantly moving between theory and data. After returning from Romania, I revisited the authors I had been reading in my first year (Bakhtin 1981; Biko 2015; Freire 1974; Hook 2005). While I was in Romania, I read about the history of Romania, and the history of Roma in Romania (Achim 2004) and in Eastern Europe (Marushiakova, Popov, and Reyniers 2007). When I returned, I read more of the works of critical and postcolonial theorists, (Hall and Du Gay 1996; Spivak 1988; Spivak 2006; Foucault and Rabinow 1984; Patricia Hill Collins 1986; Mbembe 2001; Crenshaw 1991). My thinking was shaped in conversation with these texts. Theories not only help to delineate areas of research for more in-depth analysis and prevent the researcher being lost in a sea of data and impressions, they do the same at the stage of data analysis. These texts encouraged me to investigate alignments of power, not only in terms of direct forms of oppression but also in more complex, multi-directional, capillary, and intersectional ways: not only how “Roma” and “non-Roma” spoke about and behaved around each other, but also how those who were non-Roma spoke about each other or how people who self-defined as “Roma” spoke about others whom they defined as Roma. I paid attention to expressions of language in enacted relationships, as well as to silences and what went unsaid. I moved away from my initial interest in knowledge and trust. The theoretical texts pushed me to question categorisations which were being taken for granted. Most of all, however, it was through engagement with critical theory that the data, flattened through

coding and repeated reading in my London office, was given a fresh breath of life and regained its multi-dimensionality for me. It was through the engagement with this theory that I started imagining the thesis as it is now structured: as a contemplation on different forms of containers, containing, and containment.

## Chapter 3: Containers

In this chapter I talk about the interaction between the spatial and the nominative or classificatory “containment” of Roma in the context of the health mediation programme. In this analysis, the “container” refers less to the physical constraints within which communities live than to the confluence of discursive and enacted divisions that sees certain people labelled as “Roma” or not. In this way, for example, an ethnic categorisation as “Roma” is understood precisely as a “container” for its object. While some social scientists and ethnographers typically work towards refuting fixed binaries, and instead emphasise the invented, hybrid, fluid, and negotiated nature of categories, or see things in terms of a continuum (e.g. Bowker and Star 1999; Mbembe 2001; Blackman 2012), such refutations are not always foregrounded in writings about health in Roma communities. Even when scholars do not directly assert the existence of clear-cut binaries, these often persist as a background assumption “containing” the objects of their research within predetermined discursive boundaries (e.g. Sedlecky and Rašević 2015; Cook et al. 2013; Fésüs et al. 2012). It is rarer for scholars writing about Roma health to question to what extent such binaries are meaningful to those people who are constantly confronted with them in their everyday lives, or how people respond to being placed in the quasi-abstracted “container” of this or that ethnic category.

There is still a lot of work to be done to show who benefits from categorisation, as well as asking who is involved in attempts to uphold, police, or reject ethnic “containers” in everyday life. These are questions with material, political consequences. As Bowker and Star (1999) point out, “things perceived as real are real in their consequences ... even when people take classifications to be purely mental, or purely formal, they also mould their behaviour to fit those conceptions [...] They often come to be considered as natural, and no one is able completely to disregard or escape them” (53). This chapter shows how practices of ethnic classification and the spatial context of poverty and marginality co-exist and mutually influence each other. I interrogate how participants construct and perform

“containing” categories of ethnicity, asking what role Roma health mediators play in negotiating, shaping, and reproducing classifications.

The “nature” of Roma ethnicity is fiercely contested, and in the critical literature it is acknowledged to be a constructed, fluid and situational identity (e.g. Tremlett 2014; Surdu 2016). In the policy-oriented literature, it now seems widely accepted that it is difficult to classify individuals according to their Roma or non-Roma ethnicity, and that any attempt to do so will raise a large number of conceptual, epistemological, and ontological problems (Ladányi and Szelényi 2005; M. Surdu 2016; Andrey Ivanov, Kling, and Kagin 2011). Perhaps in an attempt to avoid such conceptual complexities, individual classification seems to have given way to the practice of collective and spatial classification: both in research, as outlined in the *Introduction*, and – as this chapter shows – in the daily practice of health mediation.

I did not begin my research with a clear idea of how I myself defined “Roma communities”. During the process of fieldwork, I could not formulate a clearer definition because – as I go on to illustrate – I found that “the Roma community” was neither bounded, nor locatable. Instead it was dispersed and hybrid, with highly uncertain demarcation lines. Often it appeared to exist as an abstract construct. I therefore use the word “community” mainly as a reflection of how others talked about it. When writing about individuals, I use the term “community member” mainly to distinguish them from mediators, health professionals, local authorities, and other “professional” groups. Given my focus on Roma health mediation, the community members I write about were more often than not either defined by others as Roma, or defined themselves as Roma. Since I do not aspire to a binary categorisation of people, I do not refer to individuals as “Roma/Romanian community members” unless they explicitly identified themselves as such in conversation with me.

## Community as container

I begin with an example of an incident from my fieldwork that underscored for me the significance of questions of spatiality and classification, and the way that the Roma “community” functioned within this. In the final week of my stay in Dacia, Viorica took me to what she called one of the “Roma communities” in town. On a hot summer’s day, we took the bus to a neighbourhood on the edge of Dacia City. Several pre-fabricated housing blocks had been constructed for people who had been evicted from nationalised property in the old town a number of years ago. The streets were clean, and had a sanitised feel to them. Later, I saw that local newspapers described the neighbourhood as a Roma ghetto, with frequent reference to its high level of crime.

We paced the streets, with Viorica looking for people to talk to. She approached a family sitting outside the front entrance, one of whom – a boy – was in a wheelchair. She asked them whether the children had all received their vaccinations. One of the older women looked at Viorica inquisitively and politely answered that yes, the children had received all their vaccinations. “Good, good,” Viorica said, smiled, and indicated to me that we should move on. A young woman stood in the entrance hall of a building in the middle of the locality, cradling an infant in her arms while settling her bills with a cashier behind a glass window. Viorica had spotted her, and waited for her to conclude business with the cashier and then walked up to her directly. “I see you have recently given birth. Is this your first child?” Slightly puzzled, the young woman replied that, yes, it was her first. “Then it is very important that you breastfeed the child, do you know how to do this?” Viorica asked her. The young woman pulled the infant closer to her chest, and, still puzzled about why she had been approached, replied that, yes, she did indeed know how to breastfeed. Undeterred, Viorica continued her inquiry: “And has your child been vaccinated?” — “Yes,” the woman answered, “but he had a cold when the last vaccine was due, so I have to go back to get his latest vaccine done.” “Good,” Viorica replied, “take him to the doctor, these vaccinations are very important, especially when they are this young.” Still perplexed, the woman left the entrance hall, and though I might have imagined it, it seemed she was shaking her head ever so slightly. Viorica straightened her

dress, and looked at me, part triumphant, part expectant of my approval. I winced with embarrassment. She had not paused to introduce herself to the young woman (nor to the family on the pavement), and had instead launched straight into unsolicited recommendations about child health. To me, this seemed inappropriate and invasive, a far cry from how I had imagined “community engagement”.

When I first met her, Viorica had told me about how much she enjoyed going to communities and talking to people about their problems. She told me with enthusiasm that she would introduce me to all the different Roma communities in Dacia City. “*Mergem la comunitate*,” [“we’ll go to the community”], she had told me, “*să vezi și tu cum e acolo*” [“so that you too can see what it’s like there”]. To be quite honest, her enthusiasm for “*muncă de teren*” [fieldwork], as it is called in health mediator-speak, and the prospect of spending time with her in Roma communities were among the main reasons I settled for Dacia as my first long-term fieldsite. Once in Dacia, I eagerly awaited the first day that we would go to the community. But whenever she voiced plans to “go to the community,” some other problem arose, which meant she had to stay in the office. And so our visit to the community was perpetually postponed. As the days and weeks went by, I became more frustrated at observing Viorica spending time in her office. I was confused because of what she had previously told me about her love of spending time with communities, and because I knew that visits to the community were an important part of her job description. On top of which, Viorica had been “recommended” to me for being one of the most engaged Roma health mediators in Romania.

On occasion Viorica apologised to me disarmingly, saying that if I wanted, we could go any time. I did not quite know how to negotiate my conflicting feelings about these proposals: on the one hand I was compelled not to influence the course of events, not to impact on the way Viorica practiced health mediation. On the other hand, I asked myself, had I not come to Dacia especially in order to bear witness to these elusive engagements between mediators and Roma communities? Had I not waited for this moment for weeks already? In spite of my craving for some out-of-office activity, the non-interventionist in me prevailed, and I reassured her, saying that she should not go to the community for my

sake. Despite my efforts to not let it show, Viorica may have sensed my impatience. In my final week with her she announced that she would take me to the community; I did not protest, but neither was I sure that she was, in fact, going for her own sake.

My own frustration and impatience was not the only reason that the interaction between Viorica and the young woman with the infant seemed clumsy, even performative. In preparation for fieldwork I had studied Bakhtin (Bakhtin 1981), and I was ready to analyse the extent to which her interaction with “the community” was monological or dialogical – who was being heard, and whose knowledge was being subsumed (Jovchelovitch 2007; Aveling 2011). Viorica’s interaction with the family and with the young mother had only been fleeting, but it was all I had to go by. It seemed staged and monological. Instead of finding out what people’s concerns were, instead of starting a conversation with people, she had imposed her own knowledge of health (breastfeeding, vaccinations) on them, in a technical way that did not leave room for social knowledge (Jovchelovitch 2007). At the time, I found it difficult to get beyond the notion that Viorica was not doing her job very well, and that I would find it difficult to write about it, especially since I had relied on her generosity in allowing me to observe her work for two months.

I should add that not all the “community interactions” had the same monological, staged feel. As we continued walking through the streets of the neighbourhood, we encountered a woman whom Viorica already knew. Although I noticed that she asked Viorica why it had been such a long time since she had come to see them, they had what seemed like a heartfelt exchange, and as they talked to each other more and more women gathered around, each bringing forward a request for Viorica: one of the women wanted to get her son into higher education, and asked Viorica how he might get a Roma scholarship. Another woman had recently been evicted from her apartment (along with her whole family including a new-born baby) and was now sleeping in the streets. She wanted to know whether Viorica could help her get her apartment back. Another woman was disabled, and Viorica gave her carer advice on claiming disability benefits.

As Viorica stood there surrounded by women, pen in hand, notebook resting on her arm, fragments of stories accumulating on its pages, I realised that this was, in fact, more like what I had imagined “mediation” to be. Yet much of it did not appear to directly concern “health,” and was instead about the wider context in which people found themselves: access to education, housing, and social benefits. After talking to the group of women Viorica appeared exhausted, and having given out a few addresses where she said people could turn to with their concerns, she told the women that if they had any more worries, they could come see her in her office. She did not promise that she would return, and judging by the weeks I had spent in her office, I did not think that she would come back any time soon. If people wanted her assistance, they would have to come to her.

The different ways in which health was produced is one of the main subjects of this thesis. In my next chapter, *Containment*, I focus on how community members, health mediators, and also health professionals relate to “Roma health”. However, before I do so, I want to focus on the material conditions in which health was being produced and the spatial context in which health mediation was enacted. This is the focus of this chapter.

As Viorica entered “the community”, that is, the geographically bounded space that constituted what she (and others) spoke of as one of the “Roma neighbourhoods” in Dacia, her behaviour changed: she enacted the role of the mediator by approaching a family and a young woman whom she had never previously met, and who did not know why they had been approached. Viorica seemed proud after so many hours in which I had observed her in her office (during which she was mainly dealing with paperwork) to be doing fieldwork, speaking to a real community member about real issues of health. She seemed less excited about her engagement with the group of women, and even though she could answer their questions, and knew where to direct them, these questions were similar to the kind of issues she dealt with in her office. There, the majority of people’s concerns were related to missing documents and to making appointments at the hospital. She always listened to people’s concerns and usually responded by finding ways to solve them, whether this meant directing them elsewhere, making a phone call to the hospital or chasing various papers all over the city. These were issues that she knew about, but they



were not what she seemed to think of as “fieldwork”. In contrast, she seemed to relish giving direct instructions on how to breastfeed, and when to vaccinate children. This was directly about health, not about the social context of health.

The way in which Viorica enacted mediation, both during visits to the community and in her office, was related to the space around her. In order to gain a better understanding of how health mediation is enacted more generally, it is necessary to take into account the space in which mediation takes place. In the first part of this chapter, I show how communities are constructed as homogeneous, or “containerised” Roma settlements. In the second part, I focus on how health mediators interacted and negotiated their role with regards to these containerised communities. In the final part, I focus on the conceptual and political problems that accompany the containerisation of Roma communities, showing how community members themselves use spatial binaries to participate and perpetuate the notion of “them” and “us”, but also how people negotiate and challenge these binaries. Ultimately, I hope to reveal how discursive and enacted divisions between Roma and non-Roma become politically instrumentalised. Spatial segregation and containerisation mutually interact with already existing ethnocentric notions of “the Roma” as a natural and given category about whom it is possible to collect “expert knowledge”. The Roma are seen simultaneously as homogenous, poor, and marginal to Romanian society. This is the foundation upon which “Roma” is constructed as a problem category, itself laying the ground for a discourse that stresses the need for corrective intervention. Since the discourse and enactment of intervention is one of the main subjects of this thesis as a whole, it is worth pausing on the premise of the argument first.

In the months leading up to our trip to the Roma neighbourhood, I was frustrated: I imagined community engagement to involve mediators physically “going to the Roma community”. This idea was based not only on what I had previously read about health mediation, but also on the way in which gatekeepers and mediators themselves talked about it. “Going to Roma communities” was, as I understood it, an important part of health mediation. How else were mediators supposed to engage in dialogue with people?

How else would they find out about people's health concerns, how would they know about the conditions in which people lived? Only much later did it occur to me that "going to Roma communities" implied that there were "Roma communities" to go to. This notion itself carried the assumption that communities were both bounded and locatable. To a large extent, this assumption was further solidified through the conversations I had throughout the period of my fieldwork. Wherever I went, people would talk to me about certain "Roma communities". Whether people identified as Roma or not, they seemed to be able to clearly identify the "Roma neighbourhood(s)" in their city, town, or village. This unambiguous identification of communities as being "Roma" (or otherwise) is perhaps most poignantly illustrated by the many cases of evictions that have taken place over the last few decades. Roma ethnicity is one of the main features foregrounded in the public discourse about these evictions.

International organisations cite evictions as one of the main problems for Roma in Romania (Amnesty International 2011; Amnesty International 2013). In doing so they also attribute ethnicity to those suffering evictions. In Uscat\*, where I witnessed an eviction as part of my fieldwork, the mayor explicitly spoke to me about the people who were being evicted on his orders as being "of Roma ethnicity". When I spoke to the evicted families, they seemed to largely agree with this assessment: they spoke of themselves as having been the victims of an ethnically-targeted state intervention. Many of these evictions have taken place from housing stock, which was nationalised to provide living quarters for poor families during the communist period.

There have been well-documented cases of Roma evictions across the country, in Cluj-Napoca, Baia Mare, Eforie Sud, Piatra Neamţ, Caracal, and Tulcea. Many of these evictions have led to the containerisation of communities in temporary shelters. In Cluj-Napoca approximately 300 people were evicted from their houses in the city centre and provided with inadequate accommodation on the outskirts of the city, next to a waste dump (European Roma Rights Centre 2013). In Baia Mare, the town hall evicted a whole community from their houses in the centre of the city and provided them with accommodation in a contaminated industrial estate. In Miercurea Ciuc about 100 people

were evicted from the town centre and rehoused in metal cabins on the outskirts of the town next to the sewage plant, where they have been living since 2004 (Amnesty International 2011). In Stradă Vulturilor, a street in central Bucharest, the houses of more than 100 people were bulldozed, and they were subsequently left homeless on the streets where they built themselves box-like shacks on the pavement, without electricity or light (Lancione 2017b). In none of these cases has there been any doubt raised about the ethnicity of those affected: across the board they are talked, written, and agonised about as “Roma communities.”

While a UNDP report cautions that “social scientists should be wary of perpetuating stereotypes by conflating Roma ethnicity with economic hardship and discrimination, thereby inadvertently compounding their stigmatization,” (UNDP 2002, 24; Lindner 2012, 114), this is precisely what happens every day at the level of discourse. Ethnicity, materiality, and space are constantly presumed to correlate. Of course the wider public has pre-existing notions about the Roma identity of those who are evicted. This is, as Lancione (2017b) argues, because the “evicted Roma body” is familiar in the Romanian context: it is a common sight because Roma are “disproportionately affected” by forced evictions (Amnesty International 2011, 2). Evictions usually affect poor communities, for reasons including the allocation mechanisms of nationalised housing stock and its restitution to private owners in recent years. Evictions are most visible when the people who were evicted have nowhere to go because they lack the means to rent on the private market. People are often evicted because they do not have the means to bring legal charges against private owners who claim that they have been living in their homes illegally. At the same time, the poorer an individual or a community is, and the more they are seen as causing a problem or breaking the law, the more likely they seem to be identified as Roma. People are not given the chance to clarify their ethnic identity – it is simply presumed by the public discourse, precisely because they are poor, because evictions cause a nuisance, and because – seen from the perspective of those doing the evicting – the evicted families are often seen to be on the wrong side of the law. The practice of eviction itself produces material destitution, which is also associated with being Roma. In this way discourse and enacted practice of evictions produces highly visible, precisely locatable, and ethnically

unambiguous “familiar Roma bodies” or communities (Lancione 2017b, 8) marked out as being poor, marginal, deviant, and a nuisance to the wider public.

But it is not only evictions that contribute to the creation of “familiar Roma bodies”. Other forms of discriminatory spatial practices that have been recorded in Romania have had similar effects. The mayor of Baia Mare, for example, built a wall around apartment blocks said to house approximately 1000 people, allegedly to prevent traffic accidents (Estrin 2012). The wall was widely decried as an act of racial segregation, rendering the walled-in community visibly “Roma.” The mayor of Piatra Neamț publicly voiced plans to forcibly move several families to a former chicken farm outside of town, which he intended to surround with barbed wire and have patrolled by community police and dogs (European Roma Rights Centre 2001). Given the clear connotations with Nazi concentration camps, the community was subsequently reported on as victims of racial discrimination. Nor are such phenomena unique to Romania: similar practices of building walls around communities have been documented in Slovakia and the Czech Republic (BBC 1999), with each incident being noted as a case of discrimination against Roma. Again, this discourse and practice of segregation stresses the poverty and the precariously marginal status of Roma in Romanian society.

This discrimination assumes material forms, and can have grave repercussions on the material circumstances of affected families: their ability to be employed, healthy, and give their children an education. People are pushed into material living conditions in which it is extremely difficult to uphold basic hygiene. These practices of eviction and segregation feed into the way in which evicted and segregated communities are perceived (as Roma), while they also contribute to the way in which Roma are perceived as a broad category (as poor and precariously marginal to Romanian society). The “familiar Roma body” is therefore the product of an essentialising and homogenising view of the Roma, a perspective that does not recognise intersectionality, and which instead conflates the most visible and locatable Roma with the concept of “all Roma”. It is not my aim to challenge whether or not people who were evicted actually identified themselves as Roma (and in any case, it would be difficult to do so in a systematic way), but to point to the unquestioned

assumptions that supported their presumed ethnic affiliation in the public discourse. Similar assumptions seemed at play when I was guided to other “Roma communities”.

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The places presented to me as “Roma communities” all shared the characteristic of visual poverty, and/or spatial segregation.<sup>17</sup> The houses in these “Roma communities” were smaller and less well-built than in other parts of town. Often the roads were unpaved, sometimes there was no running electricity or water. The “Roma community” was often located in a geographically undesirable location, at the bottom of a slope or a hill where the ground was damper and more prone to flooding. The spatial aspects of difference were entwined with the material differences that sprung from the landscape and the infrastructure embedded within it.

The mediators I encountered were also all able to pinpoint, without ambiguity, the “Roma settlement” in their village, town, or city. In Dacia, for example, when Viorica and I were filling in a questionnaire about the Roma population, she immediately reeled off the names of five “Roma neighbourhoods”. In some cases these communities were spatially isolated from the administrative centre, forming a unit of their own. In other cases, they were neighbourhoods, sometimes in the very centre of town, sometimes on the periphery. Often there was more than one “Roma settlement”. Usually (with one exception in Padureă\*, which the mediator told me included a neighbourhood of “wealthy Roma”) these were the poorest neighbourhoods, with poor infrastructure, and poor access to public services. In this way, many such areas experienced elements of physical as well as discursive containment, as “Roma settlements”.

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<sup>17</sup> In Romanian vernacular, the distinction between “a group of Roma people” and the settlement in which these people live is arguably as blurred as in the common understanding of “Roma settlements.” A commonly used term for “Roma settlement” is “*țigănie*,” derived from “*țigan*” the derogatory Romanian word for “gypsy.” “*Țigănie*” is defined in the Romanian dictionary as either “the sum total of gypsies who live in a collective, or a large number of gypsies, [*țiganime*],” or as “a settlement or local neighbourhood populated with gypsies,” or, figuratively, “a deed, misbehaviour; excessive bargaining; noise, pandemonium, uproar.” (Dex Online: Definition Of “*țigănie*” 2017)

In Tabăra, for example, there was a “Roma settlement” that bore little spatial relationship to Tabăra itself, beyond inclusion within the village’s municipal boundary. The Roma settlement was 15 kilometres\* from Tabăra. It had a population of roughly 1000 (a substantial part of the total population of 5000), was known by a different name, and was not served by any public transport links to Tabăra itself. In Bucharest, Ferentarii is widely known as “the Roma neighbourhood,” often also referred to as the “Roma ghetto” (Berescu 2011), where many houses are not connected to electricity, water, or central heating. In Stăvilă the mediators told me that 4000 people, the entirety of the town’s estimated Roma population, lived down in the floodplains next to a river that regularly burst its banks. When the mediators took me on a “tour” of the neighbourhood, they showed me how people lived in half-built breezeblock houses, where, despite temperatures well below zero, sheets of plastic flapped in the wind where roofs and windows should have been. In Coliță, the “Roma settlement” was also down by the stream,<sup>18</sup> where people lived in huts built of mud vulnerable to floods, in some cases without running water or electricity.

In some cases, such as in Tabăra and in Uscat, it was difficult to get to these communities, and difficult to leave, due to their relative remoteness: since there were no municipal or health facilities in these communities, and because they were not connected by public transport, with few car owners, this meant that every interaction with health professionals or with the local authorities necessitated walking or hitching a ride to the nearest administrative centre. The GP in Tabăra told me that people came to her practice in horse and carts, because the 1500 inhabitants of the village only had two cars between them. This was fine in summer, she said, but in winter it was difficult because of bad weather and low temperatures. In Uscat there were no paved roads, and the inhabitants told me that in bad weather ambulances refused to drive all the way up to the shacks, for fear of getting stuck in the muddy field. This form of spatial isolation acted as spatial

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<sup>18</sup> The priest’s appellation for these families, “our brown brothers from down by the stream,” was, I believe, used less in Christian compassion or in mockery of the people themselves, and more with the added aim of provoking reactions of righteous indignation by politically correct foreigners like myself.

containment: communities were not integrated, but separated from the rest of the population.

While the historical emergence of such communities cannot be explored in detail within the frame of this thesis, it is important to note that these segregated communities are produced and reproduced through enacted construction in everyday life. In these localities ethnicity and space co-construct each other; spatial and symbolic dimensions of ethnicity mutually constitute each other. The settlements are constructed as “Roma,” and therefore the people living in these settlements are constantly produced and re-produced as “Roma.” At the same time, people did respond, to this production of ethnicity: as I will show below, they participated, resisted, negotiated and perpetuated their positions within these neatly containerised classifications. For now, however, I shall focus on how people living in a given settlement are constructed as Roma. It is presumed that what makes a settlement “Roma” is that “Roma” people live there, but the reverse would be just as accurate. People are not innately “Roma:” they *become* “Roma,” they are seen as “Roma” if they are born into a “Roma community,” or if they live there. These overlaps in meaning between ethnicity and space remain almost wholly unspoken.

In my experience, the poverty found in such settlements was taken for granted. It fitted too well with the assumption that Roma were poor (Gupta 1984). Poverty in Roma communities did not need to be discussed, and it did not provoke a sense of injustice in the people I spoke to, whether they self-identified as Roma or not. As a result, there was scant reflection on how they came into being. For the most part, the existence of these poor communities is subsumed under the assumption that “Roma” are poor, and therefore “Roma communities” must be poor. Discourse and material circumstance are combined into a containing and mutually-perpetuating categorisation.

### **Discourse of historical continuity in containerised Roma communities**

This intersection between ethnicity, materiality, and space is one that has evolved historically. While any detailed enquiry into the ways in which these communities have

evolved in terms of their spatial manifestations and locations goes far beyond the scope of this thesis, I would nevertheless like to pause here on the ways that my informants related the stories of how these “Roma communities” were created. Paying attention to the telling of these stories may contribute to a better understanding of how constructions of “Roma communities” both reach into the past and have a hold in the present, how history is told, enacted, and materialised. By analysing underlying assumptions and silences about “Roma history” which I observed during fieldwork, it is possible to better understand the construction of “Roma communities” today. In each of the examples, political understandings of the past and the present are in dialogue with one another: present understandings of Romanian society influence how the past is constructed, while beliefs about the past come to bear on understandings of the present. At the same time, these socio-historical constructions of “Roma” have led to a situation in which the idea of “Roma communities” has become closely tied to the locality of such communities in spatial terms.

At the outset of my research, I understood the history of Roma slavery and the mass deportation of Roma (Achim 2004) as “context” for my enquiry into interpersonal communication and access to health care. More and more, however, I started questioning how much these historical episodes were also part of a silent backdrop against which participants established their constructions of “the Roma” in relation to their own identities, as well as their relationship with state institutions. Four examples show how themes of otherness, inferiority, and contemporary stereotyping run through narrative constructions and historical explanations of why segregation exists today; that is, there is an underexamined historical aspect to the “containing” of categorisation and segregation.

The first time I encountered historical narratives about spatial segregation was in Stăvilar, one of the first places I visited. It was also the first time I witnessed segregation between the “poor Roma settlement” in the floodplains, and the town further up. “Why are they living here and why is there this big segregation between the town and this site where they are living?” I asked the mediator, who had grown up in the floodplains, but who had since moved to a house in the “other” part of town. “Because they settled here



right from the beginning, as soon as they arrived,” she told me. Curious about this historicisation of the “Roma settlement,” I asked her more about it. “I don’t know too much about their arrival in Stăvilar, it was a very small group at first [...] They arrived and had children who had children in their turn, and more children, so they spread. They weren’t taken and put there. No, no. They had children and gathered there. No one forced them to settle there, at the town edge, they weren’t segregated. No.” I asked her whether she could imagine a scenario in which there was no more segregation, and she told me that she thought, “Roma people are fine with living here. They are not bothered because they are satisfied [...] probably they don’t pay taxes, they’ve built wherever they wanted and they are fine living here. They wanted to live here.” This notion of intentional segregation surprised me. “But without sewerage, without running water?” I enquired. She assured me that “in time they will have sewerage, some already have running water and even electric power. [...] we already have a few paved streets that will soon have sewerage.” One of the main problems, she said, was that people did not have documents to prove their ownership of property, the very reason that many of the communities mentioned above had been evicted from their houses. But despite this, the notion prevailed that it was neither by accident nor by force that the community lived where it did; rather it was a matter of choice, and in fact these people did not mind living without basic infrastructure or legal housing.

The second example refers to Tabăra, the village in which a “Roma community” lived 15 kilometres down the road, entirely cut off from public services. The local GP, Dr Mirea\*, told me that the people living in the “Roma settlement” outside the village had been brought there. “Our Roma people [...] were brought here as early as 1500 I think, 1600, more recently by King Michael, no it was 1800. King Michael had an estate here.” The doctor was vague both about the historical period in which “the Roma” arrived, as well as for what purpose.<sup>19</sup> Dr Mirea conveyed with certainty only that the community had been brought there: even after centuries of living there, in her description they still came across as alien. “They are darker skinned and most of them have these gorgeous

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<sup>19</sup> The unspoken, perhaps unknown part of the narrative might have been that the community was brought there as slaves who belonged either to the king or the church, in order to work on land.

eyes which I like a lot, I admit it! Their eyes are always black, round, and happy. Their expression is joyful, it's beautiful and warm." She described to me how she used to visit the settlement as a child: "their customs were also different. Truthfully they were an oddity for me." The historical narrative of having been "brought" into the territory from outside underlined the description of the "Roma community" as an "oddity", and as essentially foreign or "Other."

My third example, is my second long-term fieldsite, Coli $\ddot{a}$ , where I spent two months walking the streets of the small, wondering how it had assumed its current spatial layout. The main street was lined with wealthy-looking houses, now mainly occupied by those commonly referred to as "Romanians," while the street on which I lived was a mixture of simpler and more affluent-looking houses. The houses on the other side of the village, where the "Roma" were said to live, became less and less formal as they descended down towards the stream, leading up to those at the very bottom of the hill, which were dilapidated and built from mud. When I started asking people how the village had evolved in this way, I was surprised to find a large degree of narrative overlap among residents. The woman I was staying with, the priest, and the mayor, as well as Adela\*, one of the women in the village who was commonly referred to as being "Roma," all told similar versions of the same story. Regarding the "Roma population," all four agreed that they had been there for a long time, perhaps since the 18<sup>th</sup> century, but in any case, during the reign of the Habsburg Empire over Transylvania.

During this time, a part of the population had been held as serfs, and — so the narrative went — at least some of the Roma living in the village today were the direct descendants of those serfs. Adela told me that her "grandparents worked as serfs for the Saxons." The priest assured me that "every Saxon peasant family had its *tigan* family." The mayor and the priest both told me how the serfs had lived in an "isolated colony." Each year, the Saxons would come to destroy the shacks, leaving the serfs to retreat to the forest, as Adela told me, "where the poor people starved, because Saxons refused to give them anything. You see? This is what our elders and grandparents used to say." When I spoke to the mayor, he claimed that this ritual had continued until the 1960s. Only over

the last 50 years, he claimed, had these former serfs been allowed to live in the village. As the Saxons left the village, the more affluent “Romanian residents” bought and moved into the grand Saxon farmhouses. At the same time, the “*țigani*” who could afford it purchased houses on the street on which I lived, as well as on the upper side of the valley, while others, presumably those who had no resources to buy houses, built shacks on the edges of the village. And this was where, so people told me, they still lived to this day.

The way in which this narrative established continuity between present inhabitants and the people who were once serfs, whose houses were demolished each year by those who had the power to do so, and its emphasis on the recentness of this history contributes to a construction of the current “Roma population” as socially inferior. The fact that they still lived in the valley down by the stream was used as evidence that they had not risen above their historical standing. This narrative was carried forward not only by those who had a high standing in the community (such as the priest and the mayor), but also by those who were themselves spoken about as “Roma.” This narrative, then, connects to present day spatial enactments of both superiority and inferiority amongst the inhabitants of Coliță.

The priest, like so many others I encountered, divided the group whom he firmly called “*țigani*” into two groups: the ones who lived in Coliță, in his valley, and the ones whom he called the “real *țigani*”, of whom there were none in the village, but whom he had seen elsewhere and on television. The “*țigani*” from down by the river in his village, he said, lived off child benefits, explaining why they had so many children. They did not work, only watched television, smoke, and drink coffee. “The moment you have a society which is based on the fact that every citizen is valued according to how they represent themselves through work, and how they contribute to the greater good, then it is also about your own decision ... you have to acquire a skill for a job, you need to be able to calculate, to write, you need to use your head and your hands. You cannot just sit in your mud hut in front of your black-and-white TV, right? ... You cannot get ahead in life if you beat your children if they want to go to school.” The *țigani* from the valley, he said, lived in appalling conditions, “eleven people and four generations to a room.” They were

part of the majority of Romanian *țigani*, of which there were “legions and millions”. They were *țigani*, he said, but they also constituted a social class, “or a social ill”.

And then there were the “real *țigani*”, the ones who “still speak Romanes, where the grandmothers plait their grey hair and decorate them with Austro-Hungarian gold coins, they smoke their pipes, and build palaces for themselves like in the Arabian Nights, they are the ones who drive to the town hall in their Mercedes to pick up their social benefits, and they are probably also those who organise those enormous begging groups abroad.” The priest made a distinction between those whom he saw as an unemployed, lazy underclass, and those whom he saw as exotic and deviant. In his view of the world, where humans had to prove their worth through their work, and everyone had to take individual responsibility for their welfare, both groups (and therefore all *țigani*) clearly constituted a social problem. Those who were wealthier did not earn their money through honest labour but through crime or defrauding of the social care system. While the “real *țigani*” were exotic and culturally Other, the “majority” of *țigani* were merely lazy and irresponsible and therefore inferior. The priest’s verbal onslaught stands collectively for a pervasive discourse that resonates through the Romanian press and television, and conversations overheard on trains and buses, but which I also encountered (in varied forms) in many of my conversations with doctors, nurses, town hall officials, taxi drivers *et cetera*.

My fourth and final example relating to historical constructions relates not to remembering, but to the capacity to forget explanatory narratives. A school teacher in Pârâu\* told me she had been taught Roma history as part of a sociology degree at university, but that she could not remember a thing about it. Conversations about Roma slavery and the Roma Holocaust seem to take place among intellectuals or not at all. Elsewhere, these stories have been all but forgotten. Having become more interested in historical narratives of the Roma, I confronted Otilia\*, the community health nurse in Padureă, with my understanding of the “Roma history” in Romania. “Do you know about their history?” I asked her. “No, I don’t,” she replied. My own growing exasperation at

Otilia's declaration of ignorance on the subject comes through in the transcript of the interview:

CK: And at school, did you learn about the history of the Roma?

Otilia: No, I didn't learn anything about the history of the Roma at school. In fact, I think it would be a good idea if it were taught in schools. So that they are not perceived like that.

CK: And the fact that they were slaves, [...] here in this region\*, did you know about that?

Otilia: I don't know whether they were slaves, exactly. But, personally, I don't think... some of them don't want to work. In order to be a slave, you would have to know how to work. But they refuse to work. There are others who steal. Who ask for a lot more money for a day's work than Romanians do, they don't want to work honestly. [...]

CK: So you don't believe that they were slaves here in this region\*?

Otilia: No, I don't think so. I don't think they were slaves. Because here in this region\*, the majority is equal. That's how I perceive the population.

CK: And about the deportations, have you heard something about that?

Otilia: No, I haven't heard.

CK: That they were deported during the world war.

Otilia: Probably.

CK: They were deported to camps.

Otilia: Yes, camps, yes, yes.

CK: And treated very badly there.

Otilia: Well yes, usually people in camps are treated very badly. I don't know whether people necessarily took notice of the fact that they were Roma, Romanians, or Hungarian, or what they were. So, the time that they spent in the camps, it was a terrible life. I mean, the behaviour of those who were in charge of the camps, with slaves, was super drastic.

CK: But they were deported because they were Roma, I mean, the Roma specifically were deported because of their ethnicity.

Otilia: I don't think it was because of their ethnicity. I think at the time of the war, everyone was deported who didn't obey the laws of the time. The people who were against our laws. That's something different."

Throughout our conversation, Otilia shielded herself from engagement with my statements about "Roma history." Instead, she transposed both her contemporary understanding of Romanian society (a just and equal society), as well as her judgement of Roma (as lazy, dishonest, and mercenary) into the past. She evaluated the idea that Roma might have been used as slaves against this transposed idea of history, dismissing it on account of a combination of contemporary ideology and stereotyping. In a just society, adversity makes sense only if it is self-inflicted. If their position of inferiority and powerlessness was deserved in the past, why would it not continue to be so today? In a just

society, only the deserving do well for themselves, while the undeserving face challenges and hardship. These challenges and hardships were expressed spatially within Padureă, on the edges of the town, where the poorest Roma lived.

Each of these examples shows how constructions of ethnicity, poverty, and space co-produce one another. While these narratives came from a different part of Romania, they each reflect complimentary elements of a broader historical construction of “Roma communities” that I encountered everywhere. This included an emphasis on Otherness through constant re-assertion of the external origins of “Roma communities” (brought to the village by a King); the foregrounding of inferiority by linking current conditions to the historical origins of “Roma communities” in serfdom or slavery; and a simultaneous shying away from questions of the material gain that might have resulted from such conditions of subjugation. Last, and perhaps most pervasive, was the question of responsibility, which was seen to lie with individuals as well as communities. This projection of responsibility produced a political imagination in which groups of people experienced conditions of poverty, hardship, and destitution as the result not of hegemonic structures and powerful oppression, but of individualised characteristics such as laziness and dishonesty. As a result, the conditions in which “Roma communities” found themselves today were seen not only as just, but also in some case altogether deserved.

Historical assumptions chime with notions of responsibility and self-inflicted inequality, producing the discourse of self-segregation, of being wilfully Other, of not wanting to be more integrated, not making an effort to be integrated. The spatial containment of “Roma communities” that is found in so many villages, towns and cities today has, in this way, been rendered historically coherent with notions of responsibility, otherness, and deliberate separation.

## **Health mediators among the containers**

The spatial and discursive “containment” or segregation of “Roma communities” – as well as the historical explanations or justifications in place to maintain them – should in

theory represent the terrain against which the health mediator works. However, I found that far from simply defining the task at hand for mediators, these intersecting spatial and discursive “containers” were constitutive of the concept of “mediation” *per se*. After all, inherent to the very idea of health mediation is the notion of a dichotomous world, where “the Roma community” is somehow separate from the rest of society. As one of the manuals for health mediators puts it, “a successful health mediator must develop her skills to correctly use [communication as a] tool, because her work basically needs to build trust *between two different worlds*, i.e. the Roma community members and the medical staff” (Nanu et al. 2008, 9 emphasis added). The mediators’ contract states explicitly that health mediators are to foster reciprocal relations of trust between local authorities and “the community of which they are a part” [*comunitatea din care face parte*], and to “facilitate communication between community members and medical professionals” [*faciliteaza comunicarea dintre membrii comunitatii si personalui medico-sanitar*]. Inna, the mediator from Movilă said as a mediator, she represented the “linking bridge”.

The Roma health mediation programme does not explicitly state that it targets segregated Roma communities, but by emphasising the necessity for working “in the community,” it singles out those spaces that are discursively, spatially, and materially identifiable as “Roma communities.” Indeed, the UNDP/World Bank/EC Regional Roma Survey (2011), which – as discussed – sampled precisely from these kind of locatable communities, suggests that health outcomes are relatively poor precisely here. Previous research has highlighted the need for improving financial, geographical, and bureaucratic access to health care in such communities (i.e. having the right identification documents, insurance etc.) (Kühlbrandt et al. 2014; Arora, Kühlbrandt, and McKee 2016). While this need no doubt exists, it is also instrumentalised by NGOs who emphasise (possibly over-emphasise) the “neediness” (Timmer 2010) of such communities in order to improve their chances of receiving funding for their projects to alleviate the need. This adds yet another layer to the construction of “Roma communities” as poor and disadvantaged.

While not always explicit about the mechanisms by which it hopes to achieve improved health outcomes in Roma communities, the mediation programme has clear

criteria for those it employs. By design, health mediators come from the communities for whom they mediate. Eligible candidates are “Roma” women who have at least eight years of school education. Candidates who have children and who have a high social standing within the community are considered to be at an advantage. Candidates are put forward by “community leaders,” and selected by the organising NGO for a short course of training. Before receiving their contract, mediators have to pass an exam set by one of the NGOs, who are in charge of monitoring and evaluating the programme.

In this way, “the Roma community” was not specifically conceptualised as geographically bounded. Nevertheless, the mediators’ contract also stated that they were to create *catagrafiere*, “a systematic administrative register” of the children, pregnant and breast-feeding women in the community. The handbook describes this activity as making an inventory:

The first thing a health mediator does in her first month of activity is to identify the problems the community she serves faces. This inventory is done by means of mapping (registration of all the beneficiaries and inventorying the problems the people face). Without knowing the problems the members of the community are up against, the health mediator won’t be able to work efficiently and won’t be able to respond to the needs of the community. (Nanu et al. 2008, 31)

In practice, mediators told me, this meant that when they first started their job, they would go door-to-door in their community, thereby spatially delineating and identifying it.

Ideally, health mediators worked in close physical proximity to “the community.” In Bucharest, for example, the health mediator was based not in the centre of town, but in Ferentarii, the semi-segregated neighbourhood that is commonly referred to as the “Roma ghetto.” Such an explicit spatial positioning of the mediator was based on limited resources that only allowed for one mediator for the whole of Bucharest, but it arguably disregarded the needs of the Roma in Bucharest who live in less confined “Roma communities” (possibly also a large proportion of self-declared Roma) in favour of a



specific, highly visible, and locatable notion of “Roma community,” thus constituting another way in which the programme conflated materiality, ethnicity, and space.

Within spatially locatable communities, the programme often did not attempt to challenge essentialising notions of socio-cultural homogeneity among Roma. Arguably because it locked itself into a vague but spatially delineated idea of “Roma community,” while simultaneously making no effort to emphasise the heterogeneity within Roma populations, it perpetuated the already prevalent understanding of Roma as a monolithic group. This made it seem plausible to one of the doctors whom I spoke to in Dacia that Viorica could be responsible for, or even representative of, all Roma in the city. When I asked her about Viorica’s relationship to “the Roma community,” she told me that she thought she the mediator was “an important part of the community.”

Dr Avram\*: I think the community, when they have problems, they go to her.

CK: And which community?

Dr Avram: No, all, I don’t specify, in general, I am saying, in general.

CK: In general, the Roma community?

Dr Avram: The Roma community.

CK: Okay, because there are many different there are many different Roma communities, there’s a non-Romanian speaking\*, there’s the căldărari, there’s the rudari, there’s the ursari, lots of different...

Dr Avram: I know, I know, but in general, all the communities trust her.

Despite being from the communities they served, mediators were expected to spend several days a week doing “fieldwork” [*muncă de teren*] within them. Given how the assumption of closeness between mediator and community was built into the programme’s idea, the choice of the term “fieldwork” surprised me. To me, “doing fieldwork” had connotations of foreignness and exoticism similar to my own “fieldwork.” Instead of emphasising familiarity and belonging that was at the heart of the selection criteria for mediators, this term implied observing “natives” in their natural habitat. It implied that mediators were not, after all, entirely “naturalised” (Bowker and Star 1999) within their communities.

What this ambiguity demonstrates is that the Roma health mediation programme at a fundamental conceptual level harboured the very spatial logic that I have outlined in this chapter. In practice, health mediators were confronted with the messiness of an extremely heterogeneous and spatially divergent population. Because the design of the programme did not take such realities into consideration, this led to tensions between mediators and “community members” in ways that I outline below.

Geographical containment, then, affected both communities and the mediators. Communities struggled to access services because of poor and expensive transport links and long distances. Mediators, whose transport costs were officially covered by municipalities, but rarely reimbursed in practice, also struggled to reach communities. Viorica and other mediators rarely actually physically went to communities to scout out what kind of problems people were facing. If people needed help, with health-related problems or anything else, they had to come to the mediator’s office.

### **Unhealthy containers for unhealthy communities**

Spatial containment and the inadequacy of immediate physical infrastructure took their toll on the health of the residents I encountered during fieldwork. Many suffered accidents, disease, and distress as direct consequences of their physical surroundings. The environmental conditions faced by communities impacted gravely on their social determinants of health (Dahlgren and Whitehead 1991). To give only a few examples: due to regular flooding in Stăvilă, the GP serving the “Roma” community, Dr Naum\*, told me the community faced problems with nitrate poisoning from the surface water in the wells that people used to get drinking water. In Tabăra, the GP told me it was not good for sick infants to travel in an open horse and cart, exposed to the elements, especially in winter. In Uscat, evicted community members told me that the housing with which the municipality had finally provided them after intense negotiations was thoroughly damp, causing the children to get asthma. In fact, the condition of the house in which they were living was so fragile that part of the floor had collapsed in one room and fallen into the inhabited room below. Some of the inhabitants had their belongings packed into bags.

They told me that their concerns were two-fold: on the one hand they were worried about another impending eviction. On the other hand, they believed the house to be in such a state of disrepair that it might start to collapse on them at any moment. One mother in Uscat told me that the children in the community had already been deeply distressed by the last eviction, during which the children had experienced them and their parents being dragged out of their houses by armed police, and then watched as bulldozers ran over their homes. The parents wanted to prevent them experiencing another eviction.

The links between the community's environment and ill health were, for the most part, cumulative and opaque, relating to low but persistent levels of dampness, stress, and malnutrition. Several instances, however, came to my attention that highlighted how directly the forms of containment described above could lead to ill health.

Community members were legitimately concerned about their children's wellbeing in the decaying house in which they lived: shortly after the community's eviction from their houses one of the children had, in fact, had a disabling accident. The community members had called in the council to deal with an infestation of rats, after which the pest controllers had carelessly left rat poison in the house. One of the toddlers swallowed some of this caustic substance, which scoured the inside of her oesophagus and prevented her from eating. She now had to be fed through a tube and was awaiting multiple surgeries in order to ensure her survival.

It is important to note that "Roma communities" were often claimed by local authorities and in the media to be the cause of infectious outbreaks of disease. This notion is explored in detail in the next chapter, *Containment*. Suffice to say here that there was an obvious connection between spatial containment causing bad health, and the idea that "Roma" themselves are inseparable from disease. To contain Roma communities, was – following this argument – also a way of containing disease.

## **Responses to containerisation: participation, negotiation, resistance?**

Containment or “segregation”, then, is the contextual and constitutive basis of health mediation. How communities and mediators respond to this, however, is a different matter also worthy of consideration. Crudely speaking, it could be said that containment or segregation is both the structural cause and the nominal effect of health mediation. Whether or not (and why) mediators and communities seek – either consciously or not – to participate in, negotiate around, or actively resist containment thus explains much about how each side of the binary of mediation approaches the process.

It is, I would argue, perfectly possible to live in Romania without being faced with many challenges to the established Manichaeic view clearly dividing Roma and non-Roma communities or settlements. This is because these divisions are not only discursively produced in constructions of the present and the past: they are enacted in practice. These enactments, however, are not straightforward. In this chapter I have shown how people participate in and perpetuate the semblance of clear-cut boundaries, which helped to further seal the discursive and spatial containerisation of ethnicity. However, people also negotiated and resisted being placed in containers. These acts create “leaks in the containers” which are often overlooked by those in search of more clear-cut distinctions.

Discursive “participation” in containerisation, however, was certainly prevalent across the sites I visited. Sometimes those who are classified as being part of “Roma communities” are not only seen as “bound” and “locatable” by outsiders, they may see themselves as such. When I asked Isabella\*, a nurse from a GP practice about different Roma communities in Padureă, she was quick to refer to a specific community, whom she described both in terms of the space that they occupied, and in terms of their poverty: “Somewhere on the edge of the village we have these ... [she laughs] right before you leave the village... and they are deplorable. They walk around barefoot, naked, in shabby clothing.” Sonia\*, one of the women who lived on the outskirts of the village did not refute the idea that there was a clearly defined “Roma community”. She told me that “only

*țigani*” inhabited the few houses that formed the cluster in which she lived. “Everyone grew up here,” she said “they know each other, they live with their parents. We also grew up here. I’m from across the street and my husband grew up here. Basically I crossed the street to his place. That’s our custom. We don’t move and we don’t separate from each other, from our *țigani* ... we go into the village to sell oil, sugar, and [...] whatever we can get, whatever we can work with.”

Miriam\* in Coliță also told me that her village was “divided” into the “Romanian” and the “*țigan*” part. The binary expressed a relationship that was simultaneously expressed in the material conditions that she witnessed. “If I need money and a job to be paid and to buy bread, then I got to work for [the Romanians] and they say ‘the *țigancă* is coming to work.’... They are a bit wealthier. They have large houses, land properties, animals, things they gathered through theft. You work all day long for them, from morning at 7 o’clock until 8 in the evening, you have to work all the time and you get only half an hour to eat in the afternoon ... the *țigani* are poorer. They don’t have jobs and they came from poorer families, like ours. People who do daily chores. We never had land, my family never had property and that’s why we’re stuck in this little house.”

Sonia and Miriam enacted “bounded communities”, but they were both relational and functional: the division between communities described their relationship with other people in the village, while also reinforcing the containerisation of the village, the division between the poor part and the wealthier part, between “us” and “them”. The material basis for these kinds of “participation” in (self-)containerisation should not be neglected. For many of the people I spoke to during fieldwork, this division between “us” and “them” was explicitly not a cultural, but a material one. This was expressed particularly poignantly by Adela in Coliță, who said she could not consider herself “Romanian” because she was poorer than “them”: “They are a bit wealthier and they’re different from us. ... that’s all, that’s all. ... we wear the same clothes; we dress the same way ... We don’t wear long *țigani* robes. And we don’t dance like *țigani* on the hill. We don’t dance. Or if we dance, we dance to ‘manele’ songs, for instance these kind of dances, like Romanians. We don’t know *țigani* dances, nice *țigani* dances, we can’t dance.” This differentiation on grounds between

“Romanians” and “*țigani*”, and the cultural differentiation between “assimilated” and “real *țigani*” were common distinctions that I encountered.

The self-understanding and self-definition of “Roma communities” is an extremely complex matter rarely given sufficient thought, and I cannot claim to address it in full here. However, I take it into consideration here precisely in order to demonstrate distancing to containerisation. “Roma communities” self-definition is more fluid and plural than can be expressed through a binary distinction. As is shown at various points throughout this thesis, people take different identity positions at different points, depending on the context. At the same time, difference is also produced materially and spatially, in a way that is not fixed in perpetuity, but is produced by long-term conditions that are difficult to challenge or change. Not only in policy and health contexts have “being poor” and “being Roma” come to be used synonymously.

As I have shown, ethnic difference is produced and reproduced both by experts, and by participants themselves, to explain and perhaps even to justify the persistence of these differences. In short, the enumerators for UNDP/World Bank/EC Regional Roma Survey are not the only ones to containerise people into “Roma” and “non-Roma” depending on whether they live in what looks like a “Roma” or a “non-Roma” settlement. These assumptions are ubiquitous, and constantly reproduced, not only by the “experts”. But where does this containerisation come from, and are there “leaks” in the containers?

## **Leaking containers**

This chapter seeks to defamiliarise readers with the “naturalness” of the binary Roma/non-Roma distinction. Having given a large amount of attention to the social construction of spatial segregation and binaries between “Roma” and “non-Roma” communities, I now turn to the fault lines that are produced by attempts to force the “messiness” of ethnic difference into neatly spatialised forms of containment.

Spatial binaries create conceptual homogeneity. Superficially, it seems to serve those with classificatory agency to see society in terms of clear social and spatial categories, rather than as an entangled network of heterogeneous people living convivially side by side (Mbembe 2001; Bowker and Star 1999). Instead of allowing for the complexities and leaks that permeate the spatial boundaries which are discursively and materially placed between different “communities,” the use of external, binary spatial classification is a mechanism depriving people of the ability to self-define within their locality, to be seen in terms of their cultural, social, or economic heterogeneity. Instead it essentialises residents under one all-encompassing and much-maligned category.

Talking to people in different localities, however, reveals how such binary categories are not in fact reflected so clearly in spatial terms, and that heterogeneity persists despite efforts to police binary categories: the notion of a single category of “Roma” does not hold up to the experience of individuals, in ethnic or spatial terms. This complicates the idea that “Roma communities” might, in fact, be spatially locatable. Simultaneously, the system of binary classification is often used and subverted by people themselves as a way to align themselves with the category that best serves their interest at any given time, as I will illustrate. In this way, the spatial division into “Roma” and “non-Roma” settlements does not hold up to scrutiny.

“Community members,” mediators, health professionals, and local authorities displayed different ways of dealing with the complexity of “ethnic belonging.” They policed borders of ethnicity, both from outside and from within. Often, however, boundaries that seemed rigid and impermeable crumbled under closer scrutiny. On the one hand, people maintained boundaries, constructed categories, and placed ethnicities and their sub-groups in a hierarchical order. Community members and health mediators emphasised the significance of difference between different “Roma groups”, pointing to boundaries of language, dialect, religion, trade professions, or tradition. Health professionals and local bureaucrats, on the other hand, to whom such sub-groups seemed largely invisible, discursively subsumed all of them under the umbrella term “Roma.”

The discrepancy between discursive and enacted forms of spatial categorisation often played out in problematic ways. Generally, ethnicity was externally assumed rather than interrogated, and it was assumed in binary terms: “Roma,” or “Romanian.” Those external to communities applied such descriptors with apparent certainty. But despite the frequency of its discursive invocation, ethnic homogeneity is an implausible concept to apply either to “Roma” or to “non-Roma communities.” Mediators talked about how these distinctions used to make sense (at an unspecified point in the past), but that they had become eroded over time. The boundaries that had been drawn by history could now be permeated by inter-marriage. “It’s an extraordinary mixture, you see?” Amalia said of the “Roma community” in her village.

The evicted community of Uscat provides a good example of this discrepancy. Local authorities, NGOs, and journalists reporting on the eviction referred to those who had been evicted as either “people of Roma ethnicity”, or simply as “the Roma”. At the same time, I met several families who had been evicted, but who did not fit into this binary of “Roma” or “non-Roma” communities. One of the women, who told me she was Romanian, not Roma, said that she had come to live in the community because her sister-in-law had been struggling to take care of her niece on her own. She had moved in with her in order to help with the child’s upbringing. While this particular woman did not seem to mind being “mis-classified” in the racialised discourse that surrounded the eviction, another family was at pains to state that they were not Roma, but respectable Romanians who had fallen on hard times. The mother told me that she and her family had moved into the building before the others had been moved there, but now that they all shared the same building, and faced the same threat of being evicted once more, her family was assumed to belong to the “Roma community.” In this way, the spatiality of housing was being mapped onto the homogeneity of ethnic distinction in ways that did not correspond to the self-definition of people inhabiting that space.

Reading my transcripts, I see how I too imposed a binary understanding of ethnicity onto people, particularly in early interviews. But in conversation and in interviews, people often deconstructed or rejected the categories within which I tried discursively to contain



them. To give an example: when I asked Anita\* in Uscat whether she identified as “Roma” or “Romanian,” she told me she identified with neither: in her words she was a mixture between a “*țiganka*” and one of Romania’s other nineteen minorities. She explained that she could not fully consider herself “a *țiganka*” because she did not speak “the language.” Nevertheless, the doctors and staff at the hospital still referred to her as a “*țiganka*.” She said she did not like this expression, but at the same time she did not feel she could intervene: “I stay quiet. What can I tell them? I shut up because I want to see my child recovering. Nothing to be done.” Anita had multiple, overlapping identities, but she was also accustomed to not challenging externally attributed identities. Thus, she revealed how layered and complex her positioning in fact was. Regardless of the spatial conditions and locations in which she lived, “Roma-ness” remained a complex and multifaceted identity.

It is possible to get a sense of the ways in which spatial segregation does not translate into clear-cut ethnic distinction by considering the cases of several inhabitants of Coliță. When I first scouted Coliță as one of my potential field sites, the priest told me that 95 per cent of the population were “*țigani*.” When I spoke to the mediator, she also estimated the proportion at around 80-90 per cent. Much later, when I was already settled in the village, I interviewed the mayor, who said he could not say that any large part of the village was “Roma” or “*țigani*” because fewer than 5% of the population had officially declared themselves as “Roma” in the census of 2011. Moreover, he said that since “this group of people don’t have traditional customs, church, or a different language than the Romanian language [it] would be unfair for me and anyone else to call them anything other than Romanians.” Amongst the small handful of people who “officially” declared themselves Roma, I was acquainted with Anna\* and Maria\*. Both of them were part of the priest’s larger entourage. Maria was his housekeeper, and Anna was one of the priest’s many protégées whose education he sponsored and whom he regularly invited to his house for lunch and study time. In the time I spent at his house, I witnessed him constantly speaking to them as “*țigani*” from down by the stream, where the Roma community lived. He told me that he had encouraged Maria and Anna to register as “Roma,” both in their passports and during the census, since they were clearly not “Romanian”, and so it was only right

that their passports should not state otherwise. He was appalled that the other 95 per cent of the village had “gotten away” with being “Romanian”.

Adela, Anna’s mother, was one of the 95 per cent of the village population who had registered as “Romanian” during the census. Doctors, people in the town hall, and (of course) the priest, all spoke of her as “one of the *țigani* living in the valley.” When I talked to her, she simultaneously employed and rejected the categories of “Roma” and “*țigan*” to her own ends. She was enlisted as a member of the Roma Party, but only, she told me, because she might get some material benefits out of her membership, in the form of food donations or building materials. On the other hand, she told me that since she neither dressed like a Roma woman, nor did she speak Romanes, she could not possibly consider herself “Roma.” She preferred to think of herself as a “*țigancă*,” not because of her personal attributes, but because of her relative socio-cultural and economic situation in comparison to the “Romanians” of Colină: “We curse a lot. And we’re poorer, miserable, and different.” On paper, however, she remained “Romanian,” because, I presumed, there was apparently nothing material or social to gain from officially declaring herself as “Roma.”

Roberta, the health mediator of Colină, maintained that ethnic identification overrode spatial segregation. Being “Roma” or a “*țigan*,” she declared, was a trait you were born with, and in order to self-define as such, a genealogical justification was required: “being part of the Roma community, the gypsy community, means sharing a history, having a gypsy ancestor in your family.” Roberta believed that she was a better judge of whether or not people should be considered “Roma” than they were themselves: “80 per cent of the population in Colină is Roma – even if they don’t admit it.” In positioning herself as an expert and arbiter of ethnic classification, she aligned herself with the priest. Her claim, however, was contrary to the priest’s other assertion, which was that the Roma community lived down by the stream. Since the village of Colină was not, in fact, built down by the stream, and therefore most houses had been built much further up on the hill, it was illogical to claim that “all Roma” – 80 to 95 per cent of the population – lived by the stream. Even though evidently contradictory, both the priest and the health mediator were

able to hold both of these convictions simultaneously. Their capacity to do so, however, does not alter the fact that the notion of bounded “Roma communities” in Coli na was problematic to say the least.

For Viorica in Dacia, the “Roma community” was not a monolithic group. Viorica talked about complexity among “the Roma” in a way that “Romanian” people I spoke to generally did not. She emphasised the many sub-categories, and when she spoke to me about the Roma community of Dacia City, she would usually specify whether she was referring to “*C ld rari*,” “*Rudari*” or “*Ursari*” Roma. In this, however, she was not averse to a degree of discursive containerisation: she placed these sub-groups within a clear hierarchy, and in order to do so, she spoke of the sub-groups as though they were bounded and internally homogenous. “The ‘Rudari’ are superior to the ‘C ld rari’ in terms of education. [...] But in terms of welfare, the ‘C ld rari’ are superior to the ‘Rudari’. [...] The ‘C ld rari’ are rich. But uneducated.” In this, Viorica was typical; such distinctions were frequently enumerated by health mediators. They would tell me in great detail about the differences between each of the sub-groups, where each of them lived, how I should think of them hierarchically in terms of education and status.

As for health professionals, they often seemed to struggle with the concept of heterogeneity among the Roma population. Sometimes this produced confusion, such as in Padure , where the nurse seemed baffled at the characteristics that her “Roma patients” displayed: “they are well educated, they have a proper vocabulary, they are respectful and you can’t tell whether they are real gypsies.” She seemingly could not work out whether she should consider these particular patients to be Roma or not, since they did not display the traits that she expected of Roma patients who came from the “Roma community”.

Thus the various groups implicated in the health mediation process – Roma, mediators, and health professionals – reacted in varying and contextualised ways to the disjuncture between presumptions of definitive containerisation and the messier realities

of lived experience. Spatial and ethnic categorisations cannot easily be mapped onto one another in cases in which “Roma communities” have nominally been firmly identified.

This observation, however, itself disregards another singularly important point, one that in the literature is usually made only in passing (Timmer 2010) if at all. A vast number – possibly even a large majority<sup>20</sup> – of those who self-identify as Roma in census surveys simply do not live in the kind of segregated conditions that draw the attention of NGOs, journalists, politicians, or researchers like myself. The “integrated Roma,” as they are commonly known, generate little attention, precisely because they live convivially, residing in the same streets or housing blocks as “non-Roma”, working the same kinds of jobs, and sending their children to the same schools. Amongst those that I met, were a number of those who could be described as belonging to a small “Roma elite:” NGO workers, Roma doctors, and politicians. In many ways, these individuals are indistinguishable from the rest of (“Romanian”) society. In spatial terms, they do not constitute a “Roma community.” Even disregarding the messy boundaries between different “Roma communities,” and the presence of “non-Roma” within segregated “Roma communities,” these cases of conviviality should shatter the notion of a clear Roma/non-Roma binary. Conviviality should be an incentive to start thinking of intervention in terms of intersecting identities (most notably class, in this case) and the role they play in the production and reproduction of space and health. When discussing discursive and enacted segregation, the failed mapping of ethnicity onto spatiality, or the participation, negotiation, or resistance of mediators and community members to the project of containerisation, one should bear in mind the integrated Roma and their demonstration of the presumptions undergirding our thinking and practice.

### **Enacting community membership**

Recall Viorica and her interaction with “the community” with which I opened this chapter. I am now in a position to ask how Viorica’s own messy and ambiguous identity might refine my initial reading of the situation. How did health mediators understand and

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<sup>20</sup> A hypothesis on which, to the best of my knowledge, there has not been any research.

enact their membership of a given, nominally bounded community within the context of their professional activity? I remember one occasion on which Viorica had sent me to interview a paediatrician, with whom she said she had a good relationship. Indeed, the doctor spoke highly of her, and told me that she and Viorica had a close relationship, despite ethnic differences. This, I gathered, was not primarily on account of her efforts as a mediator, but based on an already existing relationship between the women, when she was Viorica's neighbour and had treated her children as patients. I recalled another instance, in which a "non-Roma" woman came to enquire with Viorica whether she could train as a Roma health mediator. Initially, Viorica greeted her question with some hostility, telling her that the job was strictly reserved for Roma women, who were better able to communicate with "Roma communities" on account of their cultural knowledge. Just then, the two women recognised each other as having been classmates at school, and almost in an instant they seemed to establish a more intimate and trusting relationship than I had seen with most other "Roma community members" who came through Viorica's door.

Viorica inhabited a number of worlds simultaneously. She had – as per her job description – eight years of schooling and had gone to a regular Romanian school, growing up in the old town of Dacia, a fairly mixed neighbourhood in terms of social status in the communist period. Part of her family, she said, was Romanian. At the same time, she identified as "Rudari Roma". She was careful which clothes she wore on what day. Sometimes she would wear a dress that she thought a bit risqué, and commented that she wore it because she knew she did not have any meetings with Roma men set up for the day. She was interested and involved in local Roma politics: she was close friends with the founders of a number of Roma NGOs, and was on first name terms with all the most important figures in the local Roma Party [*Partida Romilor*], some of whom were based in local authorities. She toyed with the idea of getting involved in Roma NGO work and politics herself. She was always full of plans as to what she wanted to do for "the Roma" in Dacia, but by this she also meant the poorest members of society. When I met her again almost a year after I had spent two months with her, she told me that she wanted to build a social and educational centre for deprived Roma children, and take them on a summer

camp. She also told me, rather proudly, that she had been asked to be more heavily involved in Roma politics. She seemed to think that she would be well suited, not so much because she was Roma herself, but because she had already gathered experience with Roma communities in her capacity as health mediator (“I’ve been there, I’ve talked to the people”). In the end, she could not garner the support that she would have needed to become more involved, a fact she downplayed, but which evidently caused her some upset. She told me that “they” – and by this she meant the Roma of Dacia on whose behalf she would have been involved – were “ungrateful.”

Viorica’s experiences indicated how space influenced the forms and possibilities of social relationships in health mediation. While living in a relatively mixed neighbourhood, Viorica had formed close ties that defied the boundaries of ethnicity that were writ so large in the imagination of spatially bounded, homogenous “Roma communities.” Viorica, who identified as a “Rudari Roma,” told me that she had been afraid of the “Căldărari Roma” when she had started her job as a mediator. At that point, she had never come into contact with them except for one “bad experience,” when a “Căldărița” woman had tried to steal her wedding ring, and she had maintained her suspicions ever since. Over the two months I spent with her, however, I saw many times that she was at ease with “Căldărari Roma,” forming a close relationship with a number of families. In part, I felt that she retained a sense of awe towards these “traditional communities,” respecting them at the same time as she exoticised them. The leaders of the Căldărari Roma communities (the *bulibași*) in and around Dacia city came to her for help, and she treated them with great reverence, telling me that they were illiterate but that they were driven by chauffeurs. She was always friendly towards them, and went out of her way to help them with paperwork. The Căldărari women read people’s fortunes and, she told me – somewhat scandalised – did not know that it was proper to wear underwear. I witnessed a number of interactions between Viorica and the women whom she called Căldărari. One family in particular (mother and daughter) seemed to rely heavily on Viorica for access to the health and social care system. They would come by her office before going to any appointment at the hospital or the Child Protection Office, and they would ask – sometimes beg – her to accompany them to the appointment. In the time that I spent in her office, Viorica

consented more often with this particular family than with any other community members.

Perhaps her interaction with the young mother in the “Roma neighbourhood” which we visited seemed performative precisely because it was. It was a performance for my benefit, to show me that she was doing her job correctly. But it was perhaps also a performance for the benefit of the young mother, and maybe even for herself. She seemed to be performing an idea of health mediation. In the same way that I had preconceived assumptions about what health mediation looked like, Viorica had her own. I had pictured Viorica spending her days in the community, chatting to familiar faces, finding out about people’s concerns. When I had first met her, Viorica had encouraged me to think that this was an accurate picture by emphasising just how much she enjoyed spending time with “her communities”, where, she said, everyone knew her. And this was the image she was projecting when – finally – we went to the community: the mediator *in* the community, the mediator going *to* the community. By approaching the young woman without hesitation or introduction, she seemed to be demonstrating to me, to the young mother and to herself that she, as a Roma health mediator, could inhabit this “Roma space.” Had we not been “in the Roma community,” it is unlikely that she would have approached a young mother with such intimate questions about her child and in such a direct manner. Because we were “in a Roma community,” however, she granted herself the permission to treat all “Roma,” or all “presumed Roma” as potential health mediation subjects, whether they solicited her help or not. Based on *where* the interaction was taking place, Viorica treated the young woman as “Roma,” and therefore as her client. More than that, she treated her as a “Roma” woman *in need* of intervention. This interaction fitted into the common pattern found in the literature about Roma health whereby Roma communities are essentialised as needy. The interaction felt uncomfortable because it was unsolicited advice, because it was performative, but also because Viorica conflated locality, ethnicity, and need for intervention in order – so it seemed to me – to aggrandise her own role in the community.

Following her encounter with the young mother, Viorica came across a woman with whom she was familiar. Later, Viorica explained to me that she and the woman had been neighbours when they had lived in the old town of Dacia. They had known each other for decades, and even if they had not seen each other in years, the two women had a bond that transcended the role of mediator and community member. This bond had formed on account of spatial vicinity.

When a group of women gathered spontaneously around her after the encounter had ended, however, her behaviour changed. People came to Viorica with their concerns, and she pointed them in a direction that might take them further towards a solution. Her membership of this contained community that we were visiting was clearly disputable, and it was certainly expressed in spatially contingent ways.

Both Viorica's interaction with the young mother, and her interaction with the familiar women may have been performances, but they were performances of different kinds of affiliations: while the first was based on presumed ethnic affiliation, the second was built on the actual experience of spatialised affiliation based on a shared history and social interactions as neighbours. Each relationship was therefore determined by space, in the former case based on her role as a mediator in what she saw as "a Roma community", and in the latter case based on a shared neighbourhood in the past, but neither was straightforwardly built on the fact that she was "Roma". These relationships were highly contingent, based on historical social connections rather than essential characteristics. My initial reactions to Viorica's actions "in the community" on that day were understandable inasmuch as they were in keeping with a system of discursive and enacted containerisation. It was only later that I recognised that I had been given an example of the messiness of enacted community membership that resulted inevitably from the differentiated social relationships at play in the maintenance and provision for "bounded" communities.



### **Messy “filiations” to Roma communities**

Relationships do not function straight-forwardly along ethnic lines. Two given “Roma” women may not be able to build a stronger bond on account of their shared ethnicity than any other two women, especially if there are other identities, such as class or locality, that separate them. Bowker and Star (1999) use the term “filiation [...] – related via Latin to the French ‘fil’ for thread – as a thread that goes from a category to a person” (314), as a metaphor that allows for a “rich examination of the architecture of the multiple categories that touch people's lives. Threads,” they say, “carry a variety of textural qualities that are often applied to human interactions: tension, knottiness or smoothness, bundling, proximity, and thickness” (315). This chapter has examined the influence of ethnicity, material circumstances, and space on discursively constructed and enacted relationships. Ethnicity, material circumstances, and space are all filiations, each of which may have a different and unpredictably messy hold on individuals or communities and their relationships to each other.

Despite the vast differences in the constellation of space/materiality/ethnicity, I found that in conversation with health mediators they often employed a similar conflation of these factors as that found in NGO policies, or implicit in practices of local authorities. Amongst a myriad of examples of ethnic, spatial, and material filiations in health mediation, I draw on only a few. I do so in order to show how mediation provokes tensions when it is conducted in communities that are constructed as bounded and locatable, but which are in fact spatially tangled and interwoven with the rest of the world.

There was little uniformity to the spatial and ethnic constellations found in the different locations in which I visited mediators. In Colină, for example, the Roma identity of Roberta, the health mediator, was questioned – and with it the very premise on which her job was based. Whenever I spoke to people in Colină about Roberta as the “Roma health mediator,” people seemed confused: “Roberta is not Roma,” they would say. Roberta did not live in the “Roma neighbourhood,” she had an education and employment, she did not appear “Roma” on account of her light skin, she had moved to

Colină from a different region only relatively recently, and spoke with an accent that was markedly un-Transylvanian. Indeed, people in Colină identified her as being from a different region, rather than specifying her ethnicity. Despite her own claims, people seemed reticent to believe that she really was “Roma.” In contrast, there never seemed to be any doubt from community members or health professionals about Viorica’s ethnicity (possibly on account of her darker appearance), despite her not living in a Roma community, not speaking Romanes, and having an education and a job. Nevertheless, as we have seen, this did not grant her unfettered access to “all Roma communities,” as Dr Avram imagined.

In the majority of places that I visited, mediators did not serve the actual locality in which they lived or in which they had grown up. In Padureă, the mediator had to travel several dozen kilometres to reach a community that had been entirely unknown to her prior to starting her job as mediator. When I asked a young woman what she thought of the mediator, she told me, “she seems to be Romanian, actually people say she’s Romanian, but she’s also like us.” From my limited observations, I gathered that people in the community were only just getting to know her, and that they found it difficult to “place” her since she was from a different Roma sub-group than they were, and occupied a different class status. In Stăvilă, although the mediator had grown up in the floodplains, she was the daughter of the “community leader” and so had been able to afford to move to a bigger house in a different part of town some years prior to beginning work as a mediator. The material disparity between her lifestyle and that of people living in the floodplains was evident in the way she dressed and carried herself, and it is difficult to imagine that this would not have brought about tensions in encounters between her and other community members, even if they had once grown up together.

In a few communities, mediators practiced mediation from home. In Movilă, for example, the mediator had an official office, but she largely worked from the house in which she had grown up as part of an extended “Căldărari” community. While the neighbourhood was not obviously segregated, there were many “Căldărari Roma” in the neighbourhood, and it was their houses she walked freely in and out of, as she had

presumably done all her life; community members also came to see her in her house. It was as if the whole neighbourhood were not a series of flats and houses but one large house with interconnecting rooms. (Even in this scenario, where the mediator formed an integral part of one given community, divisions remained: she told me that she was afraid to visit the “poor Roma,” who, according to her, lived in a ghetto on the outskirts of town.)

In fact, given that the boundaries of “Roma communities” were in fact messy and intersectional, and given that – with the exception of segregated communities – people tended to live convivially amongst a broader mix of ethnicities and identities than was commonly acknowledged, it was often difficult to tell whether mediators could be considered to be part of any given “community” or not. Their status as insider or outsider was therefore ambiguous both within and without “the community.” Local authority officials and health professionals, who were for the most part clearly situated outside “Roma communities,” were more likely to understand mediators as members of given “Roma communities” than the members of that community themselves. For “Roma community” members, the figure of the mediator had the potential to be useful, but this was not necessarily the result of any ethnic affiliation. Rather it was because their own classification as “Roma” rendered them eligible for the help of a Roma health mediator. If community members found a mediator helpful, as the Căldărari family did with Viorica, then they would return frequently. If they did not, as was the case with Adela in Colină, or Anita and Olga\* in Uscat, they would not.

Above, I stated that the very concept of “mediation” contains within it the notion of bounded and immutable identities that must be bridged. As I have shown throughout this chapter, the “containerisation”/segregation/delimitation of ethnicity and other identities is both constitutive to the Roma health mediation programme and “Roma”/“non-Roma” relations in general, and constantly disrupted by the “leakiness” or “messiness” of nominal boundaries. As such, it should not be surprising that mediators were ultimately judged by the community members they worked with not on any essential aspect of their profession – their Roma-hood, their community membership, their locality – but on their functional usefulness or otherwise in a given context. Indeed, in its exploration of discursive and

enacted practices of disease “containment,” the final *Discussion* explores in more detail whether mediators can therefore be said to be truly “liminal” or “marginal persons,” defined “not in the sense of centre-margin or centre-periphery” but as “having more than one identity to negotiate” (Bowker and Star 1999, 302).

## **Discussion: from containers to conviviality**

Most “Roma” development projects, including Roma health mediation, take segregated Roma communities as their starting point, and they do so for a reason. The image of the segregated community is powerful because it reifies the distinction between Roma and non-Roma. Clear-cut categories may not accurately reflect the messy filiations that surround us, but they fulfil a functional purpose. The binary between Roma and non-Roma represents an essentialising distinction in a way that is easy to comprehend and intervene in, precisely because it is binary: Roma are perceived to live inside their segregated communities, whereas non-Roma are believed to live more freely and unbounded. Furthermore, representations of segregated communities solidify the stereotypical image of “Roma” as being both alien and inferior; this separation confirms extant notions of “Roma” as living a different lifestyle, often dominated by poverty, which itself can be used to justify their social and economic domination by non-Roma hegemonic powers. Within the individualistic discourse of neoliberal politics, Roma communities are constructed as deserving of this inferior status, a discourse fed by ahistorical understandings of communities’ “choice” to live in conditions of poverty and segregation.

Where they do exist, segregated communities should instead be understood in their historical context, with attention paid to how material circumstances can be read as manifestations of colonial/post-colonial power relations. For the most part, container-communities arose not out of “choice”, but through external imposition, sometimes through brutal physical exclusion, and underpinned (as in the case of Eforie Sud or Stradă Vulturilor) by a rationale for separation based on the exploitation of “Roma” labour. Segregation is not only historically produced, but also constantly re-produced through contemporary practices. Today some of the poorest and most vulnerable people are still

being pushed into segregation through practices of eviction. People can become trapped by the lack of basic infrastructure such as sanitation, transport, education, and employment. These factors add to these communities' intensifying containment. By attending to the ways in which the distribution of resources is taken for granted in such settings, it is possible to make hegemonic power relations visible: they play out not merely through discourse, but are present in the very materials that surround communities in their everyday lives. It is these material surroundings that arguably play the largest role in the ill-health that is so commonly ascribed to Roma communities.

Since Roma health mediation, almost by definition, does not include the possibility of addressing the material surroundings of communities, it may be perceived as a misguided approach when it comes to improving health outcomes. Health mediation proposes better communication between and education of Roma and non-Roma communities as an achievable response to discrimination. In order to achieve this, health mediation has to take the bounded nature of "Roma" communities as its starting point: in order to mediate, there need to be two distinct parties. Mediators themselves appear to subscribe to this rhetoric when they emphasise the importance of their doing fieldwork inside "the community" or describe themselves as the "linking bridge" between Roma communities and local authorities. This kind of language is based on an essentialising idea of Roma as a bounded, homogenous group sharing a single set of problems.

This approach, however, avoids a more pluralistic, intersectional understanding of Roma communities. A large part of those who are commonly identified as "Roma" do not live in such segregated circumstances. Instead, many people live convivially (Mbembe 2001), in the midst of a diverse society. Despite self-defining as Roma, many may live in entirely different social, economic, and cultural circumstances than the inhabitants of the more visible container-communities, meaning they may not share any of the same concerns.

Being "Roma" is clearly a relational category, enacted in the context of current and past power dynamics (Zentai 2014). Both in the past and in the present, people are

considered Roma based on their social position in relation to others, as much as any characteristics that are intrinsic to them. But this is not how it is spoken about. Instead, a person may be “Roma” or “Romanian”, they may be “Roma” or a “*țigan*”, they may be “Ursari Roma” or “Căldărari Roma”. Much discursive and enacted work has gone into containing people within discrete categories with precise outlines. Seldom is it acknowledged that within these binaries people might be both, or neither, or something in between. Hints of a continuum rather than a binary go unseen or unheard. Having clear boundaries between categories, it seems, makes it easier to understand people as part of a homogenous “other”. In the case of the “Roma,” the production of a “hierarchised other” is not merely discursive, but acted upon, and enacted in ways that are problematic for the health mediation programme.

An intersectional understanding of the relationship between Roma and non-Roma communities would be characterised not by binary opposition and impermeable boundaries, but rather by a rejection of clear oppositions and “absolute domination.” Instead, power relations should be understood to work in many directions, and not just “between” binaries (Foucault and Rabinow 1984). Particular attention should be paid when binaries are constructed (as is so often the case) for the purpose of maintaining a dominant, hegemonic position over a constructed, inferior “other.” Relevant to the context of this thesis, examples of such dominant positions include the unequal distribution of positions of power in the medical profession, or in local authorities and higher positions of government. More widely, however, such positions of power are unequally distributed across social, cultural and economic spheres. An intersectional understanding of oppression leaves little possibility for outright resistance. In the analysis of the “convivial” situation, it is necessary “to move beyond the idea of binary oppositional mode and embrace a more complex model in which the forces of oppressive power (...) are revealed as symbolic languages, fetishized in a variety of daily rituals” (Ashcroft, Griffiths, and Tiffin 2013, 177). This is the objective of the chapter that follows.

## Chapter 4: Containment

When I visited the settlement in Eforie which had been bulldozed, and whose residents had been re-housed in shipping containers, I was given a large folder of documents by the vice-mayor. I was part of a group of journalists and activists who had come to his office to protest the second eviction of a group of people who had been housed in a crumbling school building after their houses had been bulldozed. The vice-mayor presented the folder almost ceremoniously, saying it would give us a better understanding of why the municipality had decided to raze the settlement to the ground. The folder contained mainly copies of people's identity documents (arranged by family), a letter of complaint from the neighbours about how they did not feel secure in the neighbourhood, and pages and pages of fines – issued to residents of the settlement for the unlicensed selling of bottled therapeutic mud from a nearby lake for 2 lei (£0.50) to tourists who came to visit the beach during the short summer holiday season. Within the folder I also found a letter, sent by the mayor to the county prefect, justifying the first round of evictions that had led to the rehousing. This is an extract:

This letter aims to inform you about the enforcement during [Day/Month/Year] of the mayor's decision no. xxxxxxxxx to demolish through administrative procedures some shacks that were built without permit on both public and private parcels within Eforie town, XXX street, considering that this measure became compulsory in order to clear up the area that was occupied by 65 persons, out of which 35 grown-ups and 33 children, being a measure of sanitation [...] Following the decision to clear and sanitize the area, more than 600 tons of waste were moved out up to this moment, it is estimated that 2000 tons of waste will be collected by the end. The appalling situation encountered in the area was brought to attention several times as a result of the inspections carried out by observers from the Municipality and the Environment Patrol.

According to the evaluation, an area of almost 3000 sq. meters was occupied by mixed waste, including plastic, PET, glass, textiles, construction material and other elements, thus forming an infectious hotspot. In order to mitigate health problems and to reduce the discomfort felt by neighbouring people, a situation perpetuated by the persistence of this hotbed of infection, the Municipality of Eforie was spending annually almost 100000-150000 lei to sanitise the area.

Since the end of 2001, the secretary of Eforie Municipality has registered up to present 30 petitions filed by townspeople related to criminal acts, especially thefts or attempted thefts of personal belongings or metal values from the yards/surroundings in which had engaged

various groups or people of Roma ethnicity living without legal papers on XXX Street.

The petitions point to a state of insecurity that was created in time, the citizens feeling threatened, while the living context has become dreadful, not to mention that during summertime the situation on XXX Street is truly a menace for the wellbeing of tourists. The situation encountered in this case forced the Local Police Service in Eforie to request the intervention of the [...] County Police Inspectorate through proper actions and measures to bring under justice, dissolve and clear this group of persons due to which permanently settled locals are under threat of becoming victims.

The municipality of Eforie used sanitisation, hygiene, and health as justifications for the demolition of the houses of around 100 people who were explicitly referred to as being “of Roma ethnicity”. This speaks to the municipality’s concern, not for the evicted people who were living in the “infectious hotspot,” but for their neighbours, who were not Roma, and whose health and security was said to be in danger. This framing of the problem lays the blame for “the appalling situation” not on infrastructural challenges such as a lack of sewage or rubbish collection, but on the Roma families themselves. This framing of responsibility was brought into even sharper relief by the fact that the municipality decided to solve the problem of the “infectious hotspot” by physically removing (“dissolve and clear”) the families and their houses from this spot of land, with no option to return. According to this line of thought, it is the people themselves, their bodies, which are presented as problematic. Such a framing takes no account of what surrounds the bodies in material terms, nor how bodies became embedded in their material environment. This framing is not only individualising; it draws a close association between Roma bodies and dirt, infection, and ill health. By doing so, it pathologises “the Roma community” as the source of disease and bad hygiene, thereby justifying its removal.

Far from empowering communities to recognise their own societal oppression, or helping to give people a voice and the means to challenge their circumstances, the health mediation programme has been instrumentalised by health professionals and local authorities who aim to employ top-down methods for governing the “problematic” Roma population. This chapter addresses ways in which the Roma health mediation programme has become co-opted to address constructed dangers posed by “Roma communities” as sources of ill-health. This instrumentalisation contributes to a discourse and practice of containment that is particularly apparent in key areas of health mediation, including



vaccination, hygiene, and family planning. It is striking how patterned the pathologisation of “the Roma” and how similar the concomitant proposed solutions were, not only across health topics, but also across the field sites I visited in Romania. I begin by outlining the general pattern that these discourses and enactments tended to follow. I then address the specific health challenges of vaccination, hygiene, and contraception, each of which speaks to different issues concerning the wider construction of “the Roma” as both inferior and dangerous. To conclude, I describe how Roma were imagined within Romanian health care to be “bad patients,” and how mediators were made complicit in teaching “the Roma” to become “good patients”. This provides a link to questions of the production and negotiation of citizenship that are explored in the following chapter.

### **Patterns of containment through health**

Health professionals constructed “Roma communities” as being defective in their approach to questions of health; as a result, these communities were seen as being in need of intervention. Individual behaviour, knowledge, and cultural attitudes were posited as more central to the problematisation of health in Roma communities than their economic position or material surroundings. As is evident from the material I present below, health care professionals tended to portray Roma patients as irresponsible and lacking the relevant knowledge to address health problems within the Roma community. Without taking account of material circumstances, and without reflecting on their own relationship with their patients, health professionals imagined that the mediator’s role was to make patients more conscientious about their health, and to convey knowledge about how to become better patients. This construction of Roma patients as irresponsible and lacking knowledge about important health concerns was almost diametrically opposed to my experience of how people spoke about their own health. In this chapter I show how community members were in fact deeply concerned and often highly informed about the health topics I discussed with them, and how their enactment of such knowledge was often hampered by their environment and their poverty. Mediators were more aware than health professionals of the material circumstances of Roma communities, but instead of amplifying community concerns amongst health professionals, they amplified health

professionals' constructions of the community in their own discourse about Roma communities, portraying them as irresponsible and lacking health knowledge. Mediators described their own role as one of teaching patients, and bestowing knowledge upon communities, in order to improve the minds and bodies of community members. However, as I will go on to show, there seemed to be a discrepancy between the way in which mediators spoke about their didactic relationships with communities, and the ways in which these relationships were enacted. Enacted relationships with individuals often shied away from explicitly didactic interactions, focusing instead on the bureaucracy of accessing health care.

## **Containment through hygiene**

“Focar de infecție” was the Romanian term used by the mayor of Eforie to describe the conditions in which a number of families were living, and to justify their eviction. It translates into English roughly as “hotbed of infection”. In the Romanian dictionary it is defined as: “the centre of an inflammatory process”; “a place collecting pus”; “a place where germs spread, causing infection” (Dex Online: Definition Of “focar” 2017). In other words, a hotbed of infection is a dangerous as well as a repulsive place. Comparing Roma communities to “hotbeds of infection,” as the mayor did, seems to be a fairly common trope in Romanian local media and politics. On Stradă Vulturilor in central Bucharest, several families lived in shacks that they had erected as a protest camp outside the property from which they had been evicted. On 17<sup>th</sup> July 2016, after the shacks had been cleared, the mayor of Sector 3, Robert Negoită, posted a message on his Facebook page: “It’s quiet and clean on Vulturilor Street! #iLoveS3 The area had become a hotspot of infection. [...] Now, Vulturilor street has been given back to people with common sense, who love safety and cleanliness and who contribute to maintaining the calm of Sector 3!” (Lancione 2017a). In his message, the mayor contrasts “disease” with “cleanliness”, while “calm”, “common sense”, and “safety” are used to elevate the non-Roma residents, in contrast to their unspoken counterparts: “noise”, “madness”, and “danger”. The reader is able to make the link between these invoked traits and the evicted families without Negoită having to spell it out, especially since these attributes are part of a common frame

of reference in racist portrayals of Roma communities.

How commonly this link is made can be gleaned from a short search on Google for the terms “romi” and “focar de infecție,” which brings up dozens of online news articles (see for example Ștefan 2012; Adevarul 2017; Stan 2015; Deaconescu 2016), mostly from local press, relating to neighbours complaining about “Roma squats” or “illegal settlements,” which, they say, constitute a real “hotbed of infection.” One of these articles reports a hepatitis A outbreak in a “Roma ghetto” in Botoșani (Botoșani Necenzurat 2016). After the outbreak, children and parents from the area were lectured in schools about hygiene for two weeks. The county prefect is quoted in the piece, saying: “it might be better to move them [the ‘ghetto residents’].” Below the article, a reader has commented: “The city hall must move them, or take them home with them, if you do not understand that these gypsies need to be moved outside the city. What lectures on hygiene, these people don’t want to wash after a 1000 years of your hygiene lectures. Gypsies will be gypsies. We will all get ill, just because of some disgusting gypsies whom the town hall keeps under their wing. Shame on you.” Such a comment might be easily dismissed as vitriolic internet racism, if not for the fact that the reader is demanding (or perhaps foreshadowing) what in fact happened in Eforie, Vulturilor, and possibly in a number of other locations throughout Romania. Again: a spoken/written verbal discourse produces enacted practice, and enacted practice produces verbal discourse. Both are permeated by symbolic constructions and representations of what it means to be Roma. Discourse about Roma and enactments of how those perceived to be Roma are treated are in constant dialogue with each other.

The common practice of evicting Roma families has so far been considered from legal-activist (Amnesty International 2011), historico-economic (Lancione 2015), and critical geographical perspectives (Lancione 2017b). What seems to have gone uncommented about this troubling procedure is the sinister discourse of “cleansing” areas of their Roma populations, and what role “public health” and “hygiene” are afforded as a part of this discourse. In the cases recounted above “health” is used as a justification, both discursively and in enacted forms, to brutally remove families from their homes. The discursive link

that is drawn between “Roma” and “disease” therefore merits greater attention, both in terms of its everyday usage, and in terms of the enacted practices that such discourses generate or encourage. Both discourse and practice may be well-intentioned, but when they can also be instrumentalised in the name of violence against people, any professed innocence deserves to be thoroughly interrogated.

With this in mind, it should be emphasised that similar — albeit milder — forms of discourse about hygiene in Roma communities were deployed by health professionals and, as I will show below, by Roma health mediators themselves. Doctors and nurses lamented the lack of hygiene in Roma communities. They sometimes directly attributed a number of health problems to poor hygiene. For example, Otilia, the nurse in Padureă, who had been employed as part of the health mediation programme to work together with the mediator, told me that, “basically, they still don’t really know anything about hygiene.” This, she said, could lead to “diseases” such as “tuberculosis, intoxications, hepatitis.” Dr Naum told me about a hepatitis outbreak which he had treated in Stăvilă, which he saw as a direct consequence of the unhygienic conditions of the segregated, flood-plain dwellings in which people lived. Even when communities lived without basic infrastructure, their “lack of hygiene” was framed as lack of knowledge, or as unwillingness to conform. Note how Otilia said they “*still*” did not know anything about hygiene. In her framing of the problem, this lack of knowledge was a form of underdevelopment, and hence inferiority. Otilia’s proposed solution to the lack of hygiene (which was also part of her job as a community health nurse) was not to improve the community’s infrastructure, but to conduct “information sessions,” so that people would know what it was to be hygienic, or to set an example, so that people could be persuaded, almost unconsciously, that it was better to be “clean.” She did not seem to consider that some people, especially those living in “containerised” communities, lived in conditions in which it would have been difficult to uphold basic standards of hygiene.

Local authority officials and doctors spoke about mediators as people whose task was to encourage their communities to be more “hygienic.” When I interviewed Mr Vânturel\*, a town hall official in Uscat, I asked him what he thought the duties of a health

mediator were. “They probably guide them on hygiene issues and other aspects related to this matter, right?” Dr Naum told me that it was the responsibility of the mediator to show people how to prepare food hygienically. On top of this, they should teach them about vectors of disease, such as how to avoid getting rabies from dogs on the street. When I asked Dr Stoica\* from Coli n  what she thought the mediators’ role was, she went a step further: she said she expected Roberta to prepare patients when they came to her practice. The mediator, she said, “must visit each house and teach them to wash themselves, to remove their lice, to brush their teeth, to — what can I say — to teach them various important things, first of all the Roma people, because they need it.” Health mediation should contribute to the containment of dirt not just in the public domain, but also within the domestic sphere of individuals.

What did it mean to be clean? Hygiene was framed in a highly individualised way, foregrounding the role of knowledge and choice over structural or material factors. As Otilia, the nurse in Padure , said of her efforts to improve hygiene in the community, “we’ll go into the community, and we’ll have some training sessions, in order to acknowledge the importance of hygiene. And it is left up to their awareness whether they want to change their lifestyle or not.” Smell was part of the containerised discourse around hygiene. Otilia told me: “they don’t wash, they don’t use deodorants and all of this, not even water.” But, she said, “these things can be set right [...] through a strict programme.” Including bodily odours in the discourse about hygiene perhaps reveals that “hygiene” may be something that benefits not only the person who is hygienic themselves, but also innocent bystanders. The standards of hygiene that doctors expected their patients to adhere to were evidently their own; they did not consider the standards of cleanliness which other people held, nor what was preventing people from “being clean.” The standards were set by health professionals, and they were therefore also the arbiters over which patients’ standards were below par. Dr Naum told me that he was “demanding” of his patients. He said he had wanted to persuade his patients that going to the doctor was like going to church: “you have to be clean.” “I set basic personal hygiene rules, of cleanliness, of cooperation [...] Many of them have embraced them, but equally as many have chosen another practitioner. [...] One who is more indulgent, who accepts them just

the way they are. [...] Maybe I was more authoritarian.” By not “accepting patients as they were,” the GP exerted considerable power over the community, especially since people with an address in the segregated area might have found it difficult to register with a different GP, in particular if the other GP also considered them to be “lacking hygiene.” Dr Naum seemed to think that his “authoritarian” methods were successful, since, he said, “they come to me quite a lot and I’m satisfied with them and with our cooperation.” It seemed to be commonly accepted that doctors could refuse patients on grounds of their poor hygiene. Roberta portrayed Dr Trifa\* as exceedingly generous for not discriminating between “clean” and “unclean” patients: “She never dwells on the reason for which you haven’t washed, perhaps you’ve worked and transpired, so she’ll never comment or offend you. She’s a patient woman and she works a lot. That’s why they prefer her.” Here, Roberta implied that “they” preferred Dr Trifa not because she was a better doctor, or because they found her more sympathetic, but because she was more tolerant of dirt. Before I return to mediators’ portrayal of community hygiene, I want to briefly turn to patients’ own ways of talking about hygiene, both in bio-medical terms, and in terms of social knowledge (Jovchelovitch 2007), or, more specifically, culturally “Roma” terms. One productive way of doing so is to consider hygiene in gendered terms.

### **Women’s experiences of hygiene**

The “Romani women” I spoke to were concerned about hygiene. Two encounters, each interesting in its own way, expressly highlighted this. Both subvert the medical professionals’ definition of hygiene. Here, the women portray themselves as the arbiters of proper hygiene, and claim that it is others, including non-Roma and medical staff, who are unhygienic. Miriam\* was scandalised by the fact that Dr Trifa would often refuse to have her practice cleaned. Miriam knew this because she was friends with the person who cleaned the GP’s practice. “Frankly speaking,” Miriam said, “it is not right for this to happen in a medical office.” She complained that there were spiders, and that the place was messy. She also disapproved of the clothes that Dr Trifa wore, telling me that other doctors looked “more stylish and hygienic.” She worried that people who were treated by Dr Trifa might get “ill and infected with hepatitis and with lice.” As a result, Miriam chose

to be seen by a different GP in the village. Here, it was “the Roma patient” who had a voice in defining and enacting their own standards of hygiene. While Miriam’s definition of hygiene (related to mess, cleaning and disease) did not substantially divert from the definitions of the medical professionals I spoke to, its directionality was subversive (patient-defined rather than doctor-defined). In the context of the way in which Roma were spoken about as being unhygienic themselves, this subversion may be thought of in terms of a “leakiness”: Miriam’s understanding of who was being dirty or hygienic did not conform to the way in which Roma community members’ relationship to hygiene was constructed by those external to communities themselves.

Amalia, who described her community as “Căldărări,” related a culturally different understanding of hygiene. When I asked Amalia to tell me what the positive aspects of Căldărări customs were, she told me that women washed their underwear and other clothing separately, and never together with their husbands’ clothing. She described customs that conformed to practices of ritual cleanliness and pollution that I had read about prior to beginning fieldwork. Those families who could afford it would buy two washing machines in order to be able to maintain this separation. Those who could not would wash their underwear separately, by hand. Amalia told me that this was a good thing, that it prevented the spreading of bacteria. She emphasised that this was something that the wider population should adopt, not just the Căldărări Roma. “It has a good effect on people’s health because it helps them maintain some hygiene, you see?” Amalia specifically pointed to this custom as a positive aspect of Căldărări culture. A few days later I spoke to Isabella, the nurse in the GP practice with whom Amalia worked most closely. Isabella told me that “they” (by which she meant the “traditional Roma”) were only allowed to use their own car, for fear of spreading viruses and bacteria. They also did not drink water from glasses, using their hands instead. Probably, Isabella said, this was “to prevent getting a shameful disease.” She called these customs “crazy things” and shook her head in disapproval when she was telling me about them. In this instance, then, both Amalia and the nurse understood Căldărări Roma custom to be calling for much more stringent hygiene criteria than any bio-medical concept. Instead of allowing this to subvert or dispel stereotypes of Roma as dirty, the nurse dismissed this form of social knowledge

as “crazy,” thereby pathologising unorthodox understandings of hygiene.

“Pollution rituals” observed by some Roma have been the subject of extensive anthropological analysis (Stewart 1997). As highlighted in the *Introduction*, pollution rituals are often invoked as a potential cultural barrier between Roma patients and health professionals (Vivian and Dundes 2004; Singh 2011; Kvetoslava 2010; European Commission 2004; UNICEF CEE/CIS 2007). Based on my own observations, it is unlikely that this is a common phenomenon except in a small number of communities, and it would be misguided to assume that this is important for “all Roma.” Nevertheless, many authors (perhaps especially those who have not spent time with the people they write about in participant observation) claim that such customs are pervasive. Pollution rituals are written about as if they could be applied to what seems a homogenous understanding of “the Roma.” This essentialising approach to cultural customs is simultaneously accompanied by barely concealed wonder at their exoticism, not dissimilar in tone to the way in which Isabella spoke about them. Since I had read these articles prior to my fieldwork, I had presumed at the outset of my study that mediators would be enlisted to act in precisely these kind of situation as cultural interpreters, to explain to doctors and nurses what kind of practices their communities observed, especially if these were relevant to health. This kind of “cultural mediation,” however, was never mentioned: neither by mediators, health professionals, nor patients themselves. This is because, as will become evident, the mediators’ designated role was one of transmitting top-down knowledge: they were supposed to convey what the doctor pronounced to “the community,” to make them understand what good bio-medical practice was. The Roma health mediation programme did not call for any reverse transmission of knowledge, and, at least in my experience, mediators did not usually take the initiative when it came to inverting the top-down flow of information and “knowledge.” In other words, the health mediation programme was, both in design and in its enactment, a practice that was based on monological rather than dialogical relationships between health professionals and mediators, mediators and “communities.” As outlined in the *Introduction*, if mediation constituted a dialogical relationship it would be able to facilitate a process in which health professionals took the concerns of community members seriously. It was monological because biomedical



knowledge is seen as superior and more valid. Even with the involvement of the mediator, the relationship between health professionals and community members tended to not allow for the mutual transformation of knowledge held by health professionals and community members. Instead, the concerns of community members were subsumed under the knowledge and requirements of the health system.

### **Mediating hygiene**

Mediators themselves saw “hygiene” as one of their key responsibilities. “It’s our role to teach them about hygiene,” Dorina\* said in one of the focus groups (FGD02). It seemed to go almost unquestioned that Roma did not wash themselves “correctly,” and that this was something that they needed to change. Roberta, speaking about her predecessor’s tasks, told me that “she used to visit poor families and taught them, ‘look, you need to bathe your children better, you should keep the house cleaner, you should wash the dishes this way, and don’t let the flies come in’, basically things related to sanitary hygiene. Of course this is the health mediator’s job. Primarily to promote sanitary hygiene.” Speaking about her own, very poor community, Marta told me: “I’ve noticed they have problems with their nails, they don’t cut or clean their nails, neither on the hands or their toes. Right, and [um] the head hair, you see? They don’t wash their hair properly.” Here too, it seemed that hygiene was less about health than it was about the containment of visible dirt, about appearing clean, and thereby not drawing the unfavourable attention of others.

Only rarely did mediators speak of hygiene as being related to poor infrastructure in the community. In Stăvilă, a large part of the neighbourhood had recently flooded due to its close proximity to the riverbed, and the doctor told me the community had problems with nitrate poisoning from the wells that people used to get fresh water. Cosmina\*, one of the mediators in Stăvilă, told me that the lack of running water for people to wash themselves had led to health concerns, such as “breathing problems, coughs, they have eye disorders, all due to hygiene.” Independent of the causal mechanism that mediators believed to be behind this connection between lack of infrastructure, hygiene, and health problems, it was surprising to me how little they made – in common with the health professionals I spoke to – of the fact that the poorest and most segregated communities

with the least amount of infrastructure were often unable to maintain basic levels of hygiene. This was especially the case for people who, like a number of families I met in Uscat, earned a living by searching for scrap metal or plastic bottles in waste deposits that others left behind in bins or landfills. In their resettled homes they had inadequate cleaning facilities for their bodies or washing facilities for their clothes. Furthermore, these homes were located in an area that turned into a field of mud during heavy rain. Adela picked and sold fruit and berries in the summer, and worked people's land whenever she had the chance. She struggled to keep her seven children clean: "I actually wash their clothes with my hands and it's not a burden for me", she told me. "I like washing their clothes even if I don't have a washing machine, because I can't afford to buy a machine. I wash the poop off their clothes because I don't have money for pampers, and I only buy 2-10 pampers when I have money, otherwise I can't afford to buy pampers." These kinds of considerations were not expressed by health professionals or by the mediators who, coming from Roma communities themselves, might be expected to appreciate the conditions in which people lived. As outlined in the previous chapter, however, even when mediators did live in the same community they served, they often occupied a social position above the poorest members of that community, and discursively and practically distanced themselves from others in that community. A true, lived connection between a mediator and the community they served was something I rarely observed.

The necessity of keeping children clean was also important for community members because of its association with the threat of having them taken away. Miriam told me that the police had threatened to take her neighbour's children away: "If they see them unclean they will try again to take them to the Child Protection. They will probably will be taken to a foster care centre [...] The cop said it's better for them to go there." Miriam had also had dealings with the Child Protection Agency because a different neighbour had reported her: "a woman from here who talks with [a local government official] from the city hall, she said 'look, Miriam leaves the child with her father-in-law in order to go to work, and with her sisters, so she doesn't care for him.' And Child Protection came to see what happened. And I told them 'I won't give my child away whatever happens you can have him only if I want to give him to you.' [...] 'Now he's dirty because he plays everywhere

like any child but then he was a baby and he was clean, no reason to be taken away. I refused to give him, not even to someone from Bucharest. And here he is now.” Although I did not speak to an affected family myself, I heard of many other families who were not able to negotiate their position as clearly as Miriam, and whose children were indeed taken into care. It seemed to be a constant threat to families who brought up their children in circumstances of material deprivation. And while lack of cleanliness was unlikely to be the only reason for children being taken from their families, it was an emotive, evocative, and visible sign of the poverty, against which parents, mediators, and state officials measured levels of care. Considering Miriam’s account, it is likely that not only health professionals but other state institutions (for instance the Child Protection Agency) were involved in the containment of Roma through the promotion of hygiene and the condemnation of dirt. In the chapter that follows, *Paper Containers*, I return to this threat of removing children from their families, considering it as part of a larger movement to govern Roma and the “rights and obligations” that were attached to their citizenship. For now, let me come back to the subject of hygiene and mediators’ role in promoting cleanliness among Roma communities.

Mediators emphasised that they should exercise delicacy when approaching the topic of how to keep children and households clean. Better hygiene, they told me, could not simply be demanded. Instead, it had to be more subtly engineered. It could take the shape of leading by example, or inventing strategies by which “cleanliness” could be introduced into communities. Lidia\* and Dorina\* explained to me in a focus group how, as mediators, they acted as a positive example for their communities; how they did not need to give direct instructions on how to keep children clean, nor tell people that it was “dangerous to have dirty nails.” Cleanliness improved, they said, merely by visiting people. “When we visit them they can see that we’re clean, we wear washed clothes, so when you return they are changed.” Roberta also told me that she preferred not to let people know directly that their houses were “dirty,” that it was better to point them towards “good” examples, such as their neighbours’ households. She spoke about volition: people would want to change their habits. Later on she clarified that in some cases more direct intervention was needed: “We have families where the mothers have children and they don’t take care of them.

They are dirty, full of snot, full of dirt, poor things. So we bring them to counselling and we talk to them explaining why it's important to be clean, why they need to be washed. How to clean up." Amalia told me of a clever ruse she had thought of to disguise "health mediation" as a beauty session. She had wanted to gain the trust of the community, and she thought if she won over younger girls, she might eventually also gain the trust of their mothers. Amalia told me how she had booked a classroom in a school one afternoon, and invited some girls to shape their eyebrows. She framed this as a double intervention: as well as wanting to gain their trust, she wanted to correct their thick eyebrows, which she said were in need of shaping. She wanted to "make them beautiful." Amalia told me that her plan had worked out. Word got around, until everyone wanted her advice and even the mothers wanted their eyebrows shaped. Eventually she felt comfortable enough to start doing health mediation. She said she organised a session "to inform them [...] So I got them all in one place and trained them." Not only did they come, Amalia related to me proudly, they came out of pleasure rather than obligation.

Each of these mediators spoke of bringing hygiene to communities as though they were introducing a new religion, a different kind of faith. The way in which Amalia dressed it up as a make-up session, the way in which mediators talked about the need for careful persuasion suggests that they believed their message had to be subliminal, or else they might be rejected out of hand. The implication behind all this, namely that communities were *unwilling* to be clean, that they *believed* in dirt, that they did not *want* to be beautiful, was rather astonishing.

Perhaps mediators bought into this discourse, and reproduced it with proselytising overtones, because they themselves had been exposed to it all their lives (more than that: for generations). Amalia, for example, told me that she thought the very word "*tigan*" meant "dirt." She said she was not sure of the origin, or how the meaning had been derived, but she told me, "It means a dirty, miserable, a worthless person." She told me that, since it was such a "bad word," communities should be educated not to use "*tigan*" to describe themselves.

As well as worrying about the way in which the word “Roma” seemed to be associated with the concept of “dirt,” she seemed even more concerned that it was somehow intrinsically part of the very being of “Roma people.” When she was a girl, she told me, she thought she “carried some odour despite washing.” Nowadays, she said, people commonly did not perceive her as being “Roma.” She described the surprised reactions she received from others who were confused to find out that she was “Roma,” even though she was not “dirty.” She thought this was because she had the advantage of being tall and thin, and she made an effort to make her hair look nice. On her first day as a health mediator, she said, “a secretary came and said ‘what a beautiful *țigăncă!* And you’re clean!’ To me, she added, with some disdain, “It’s like you’ve been filthy until then but now you’ve washed yourself, and now you’re a beautiful *țigăncă.*” On the one hand, Amalia battled with the idea that she might herself be perceived as “dirty,” while on the other hand she was employed to teach whole communities how to be “clean” in the name of hygiene and health.

The imagery of “dirt” deeply penetrated the social imagination of what it meant to be “Roma.” Metaphors carried a great deal of weight, and were reflected in a materiality that demanded action. The figurative association of “dirt” turned into the literal imperative to be “clean.” But if “being dirty” meant “being Roma,” did “being less dirty” not also mean being “less Roma?” This logic points to issues that lie beyond health and hygiene. The discursive connection that participants made between “Roma-ness” and “dirt”, combined with the emphasis on being “clean” links to a more widespread desire for the cultural assimilation of the Roma population. This, I propose, is an attempt at the “containment” of a population that is seen either as exotic and different, or as poor and inferior. It is linked to the idea that if Roma want to be part of Romanian society, they cannot do so on their own terms. Instead, they must tone down their difference and make their Roma-ness imperceptible.

## **Containment through vaccination**

Concerning vaccination, health professionals spoke of Roma patients' unwillingness to have their children immunised. They attributed this mainly to a lack of knowledge about the benefits of vaccination, as well as to cultural traits that they saw as specific to Roma communities. Across field sites, doctors talked about how they struggled to get children from Roma communities immunised, and many told me that this was their greatest concern in their work with "Roma communities." Doctors feared infectious outbreaks: one of the GPs in Colină told me about a "measles epidemic" that had occurred as a result of refusal to vaccinate children in a part of the town that was known to have a large Roma population. Others mentioned previous experiences of tuberculosis outbreaks in Roma communities. Dr Avram, a GP in Dacia, told me she thought the unvaccinated children (whom she implied were Roma) were lucky, because other children (whom she implied were non-Roma) were immunised and thereby gave herd immunity to Roma children. The contrast drawn was between responsible and irresponsible families and implied an ethnically structured pattern. "What about this reticence regarding vaccinations?" I asked Dr Avram. "It's not reticence," she answered. "They simply don't come. I think it's something like complacency, and perhaps a fear of injections, but... they don't think like the others, like us, for instance. In the Romanian population there is also widespread reticence about vaccination. Concerning rubella, and measles, concerning the link to autism, there's widespread reticence. They don't know about this. [...] They don't not come because they are afraid of a particular reaction, no, they don't consider the problem like this. They simply don't come, because they've forgotten, that's the most common reason, that they didn't have clothes to dress their child, or that the clothes are still drying, so for reasons that aren't reasons at all." Dr Avram contrasted the legitimate reasons for which Romanians did not come to vaccinations, based on biomedical, or at least pseudo biomedical knowledge (McMurray et al. 2004; Hilton, Petticrew, and Hunt 2007; Stanescu et al. 2011), with the illegitimate reasons of Roma families (forgetfulness, poverty). While she considered the material conditions of Roma families as a possible reason for low uptake, she dismissed it out of hand as being, in fact, "no reason at all," and emphasised instead that they seemed unable to grasp bio-medical considerations. It

should be mentioned that like all GPs, Dr Avram had her own interest in increasing the vaccination coverage among her registered patients. She told me that she feared being penalised for low immunisation coverage: “frankly speaking if I am to be investigated by Sanepid [public health authorities] on the vaccination matter, it will be a disaster!”

Dr Avram constructed the most explicit ethnocentric link between ethnicity and attitudes to vaccination. Almost all the doctors and nurses I spoke to, however, told me that they struggled to increase uptake of vaccinations in Roma communities. Dr Naum from Stăvilăra told me that he spent much of his time persuading parents that vaccines were beneficial to their children, implying that the problem was one of insufficient information. Unlike Dr Avram, he stressed the need for a conversation about vaccines. In the 1980s, he said, he was responsible for the health of the Roma community in Stăvilăra.

Dr Naum: The vaccination had to be kept to a precise schedule. Yet they refused to take part in the vaccination, therefore we had to go on the field and to make them

CK: And why did they refuse to take part in the programme?

Dr Naum: Because of their cultural level, the side effects were most frightening to them. There were some – how to say this – with big side effects. Yeah, accompanied by fever, they had even convulsions

CK: So it's understandable why they would refuse

Dr Naum: Yeah. And we helped them to get over these moments and we didn't encounter problems with post-vaccination incidents in the case of children. But it required more discussion, the possibility of having a detailed discussion, more with them. And more time, patience.

Dr Naum said more patience was needed with people in this community because they had low levels of education, itself a fact that he attributed to “their cultural level”, “their custom” of leaving school when they were aged 13-14. While I did not observe interactions between Dr Naum and his patients, his own account of his relationship was rare in that he stressed the importance of dialogue rather than simply wanting to teach communities the “correct” approach.

Other health professionals, too, perceived themselves as having had some success in changing vaccination uptake. Dr Radu\* in Colină, for example, told me that while she had struggled when she started working in the village, over time she had managed to

persuade “them” to have their children vaccinated. One of the strategies that health professionals used in order to improve uptake was to send out practice nurses to identify patients who had not received immunisation. This was resource intensive work, however, which deprived doctors of assistance while nurses were in the community. Another way in which they hoped to capture children was to vaccinate them in schools, which had previously been national policy. Recently, however, vaccinations in schools had been outlawed, meaning that it was now the responsibility of parents to bring their children to the doctor individually. Several of the doctors were worried that fewer children would be covered under this new policy. Because of these policy changes, because of their own self-interest in increasing immunisation rates, and because they were reluctant to use their own resources to do so, doctors were eager to receive help from health mediators on the vaccination front. Inevitably, when I talked to health professionals about what they thought the mediators’ main tasks were, vaccination campaigns were among the first things they mentioned. Even doctors who were on the whole sceptical about the benefits of having a health mediator in the community were keen to deploy them in their recruitment of unvaccinated community members.

### **Women’s experience of vaccination**

The resistance to vaccination portrayed by doctors was generally not borne out in the conversations I had with women about vaccinating their children. They did not oppose vaccination, and often used biomedical reasoning to justify their decision to have their children immunised. Sonia\* in Padureă, who had two children and could neither read nor write, told me that she had both of them vaccinated. “Vaccines are good,” she said: they would help them grow, and they would be less sensitive, and not “catch a cold so quickly.” She told me babies should not be immunised when they were sick, and said she was waiting for her youngest child to get over a cold before she took her for her next set of jabs. Miriam from Colină, who also had two children, told me that she completely agreed with all the vaccines. “Why shouldn’t I?” she asked, “They [the children] won’t die from a little sting.” Bianca\*, who described herself as a “Căldărari Roma,” told me she agreed with vaccines in principle, but she had refused for her youngest to be immunised when



she found out that “they vaccinated children in the head.” She was outraged by what she considered to be bad medical practice. She said it was not “normal” to inject into the head, that the doctor must have lost his mind if he was not injecting into the arm or the leg. Independently of whether or not doctors were vaccinating children in the head, her refusal of vaccinations was unlikely to be related to lack of knowledge, nor an inherent distrust of vaccines, since she had already had her older children vaccinated. More likely, this story was related to a distrust of medical practice, rather than a biomedical approach to medical practice. Collectively, these conversations attest to Romani women who were both accepting and knowledgeable about the benefits of child immunisation.

### **Mediating vaccination**

Regardless, Roma health mediators were tasked with compiling “inventories” (*catagrafiere*) of children “in the community,” and announcing to them in person when they were due for their next round of immunisation, based on their children’s age and the Romanian National Immunisation plan (Haverkate et al. 2012). The mediators I spoke to accepted this role and positioned themselves in opposition to people they encountered who refused vaccination. They readily displayed their biomedical knowledge about vaccination in conversations with me, telling me proudly of their cooperation with GPs to “announce vaccinations.” Inna\* from Movilă, for example, told me that this was her duty since she was the “connecting bridge” for the community. But far from this bridge being one that allowed two-way traffic, information flowed predominantly in one direction only: from doctor to mediator and then to community members. It was Inna’s responsibility to distribute information and to “mobilise” mothers and children for vaccination. She was given a list by the general practitioner, and then she would go and check on the “Roma children” who were due for vaccines that month. Since she lived in the middle of town, she knew the families well, and it was easy to imagine that her announcements would be more convincing to her neighbours than those of GP nurses. Elena\*, a newly employed mediator, told me that the GP in her village dispatched her to “the community” or to individual households, where she was to identify individual vaccination refusers, and to gently persuade them that vaccinations were beneficial for their children. She said they

would have a discussion, which touched on the risks, but in which she would conclude that immunisation was a “good thing.” As discussed below, the rounding up of community members who had missed their immunisation appointments may be read as another form of containment.

Mediators showed themselves to be committed and proud of their ability to improve vaccination rates in Roma communities. Adriana\* from Stăvilăru told me that due to her persuasion skills, there were now fewer unvaccinated children. As a health mediator, she said, it was sometimes even necessary to accompany mothers to the GP, “in order to be sure that the child really received the vaccine.” A number of mediators talked about doubting whether people told them “the truth” about their children’s immunisation status. Emilia\* from Tabăra, for example, told me that she thought one of the mothers had lied to her. The mother had told her that her child was immunised, when in fact Emilia knew this not to be the case. In another example of distrust toward community members, Elena told me that, as a mediator, she had the right to request to see children’s vaccination booklets in order to check whether parents were revealing the truth about their children’s immunisation status. Furthermore, another mediator told me about an instance in which she had actively intervened. Flavia\* in Dacia had identified the houses of children who had refused immunisation at the GP practice, and had given them the vaccine on the spot. “It’s not proper to vaccinate them at home,” she said, “but we did it.” Apart from Flavia, who was aware of having overstepped the mark, the mediators I spoke to did not seem to question where the boundary of their work lay. They saw their involvement and their gentle persuasion skills as a form of “mediation” that was beneficial to patients, as well as to doctors. In this, they did not seem to mind positioning themselves as “community monitors” in addition to, or sometimes instead of “community mediators.” I did not witness or hear mediators speak about listening to or attempting to address people’s concerns about vaccination processes, including the logistical problem of getting young children to the doctor, and the practice of vaccination itself; mediators placed more emphasis on carrying out doctors’ orders.

What little literature there is on vaccination in Roma populations points to a gap

between Roma and non-Roma vaccination rates, based on the UNDP/World Bank/EC Regional Roma Survey (Duval et al. 2016). However, as I have outlined in the *Introduction*, the methods for identifying “Roma” as part of this Regional Roma Survey should give food for thought about whether differences can, in fact, be attributed to ethnicity. Primarily the survey indicates that those living in communities that are externally identified as “Roma” have lower vaccination rates than people living in areas that do not appear to be so. Duval et al. indicate that the likelihood of children being vaccinated was also attributable to characteristics not directly linked to ethnicity (such as “possession of a birth certificate and the carer’s age, education, asset index and living in a town”; “carer being single, a homemaker or not working” (5527)). The authors point to an intersectional understanding of this data, in which ethnicity and other factors such as class interact to create a difference in health outcomes. It is possible that class and spatial segregation play a larger role than can be captured by the survey data, considering its neighbourhood-focused methodology that conflates “being Roma” with living in a Roma neighbourhood. While Duval et al. do stress structural factors such as poverty, lack of infrastructure, and affordability of health insurance for the undocumented, researchers could do more to foster non-essentialist approaches by taking structural factors rather than ethnicity as their main research target, or by stressing that due to badly run vaccination campaigns, lack of dialogue, and high-handed publicity, mistrust of immunisation is common across the region, and not just among Roma (UNICEF 2013). The emphasis on ethnicity in differences of vaccine uptake is an inevitable outcome of a research approach that takes it as its key explanatory factor. This plays into the dangerous dynamic that I witnessed in the language and practices used by health professionals in Romania: namely of essentialising, othering, and demonising Roma as being the cause of their own problems.

What this literature on vaccination among Roma does not mention is that most common immunisations are already mandatory in Romania and many other Eastern European countries where the survey was conducted (Haverkate et al. 2012). During fieldwork nobody mentioned that vaccines were compulsory. While the ethics of making such a decision compulsory are murky at best (Salmon et al. 2006), and while it is unclear what penalisation awaits non-compliant parents or medical practitioners, this obligation

to get their patients vaccinated may explain the sense of urgency and impatience displayed in my conversations with health professionals. Their attempts to increase (or maintain) vaccination rates among their patients is understandable, particularly in light of the pressure they themselves are presumably under, but the approach they adopted leaves a lot to be desired. With the exception of Dr Naum, health professionals did not appear to be trying to engage in a dialogue with patients who were hesitant, reticent, or refused vaccinations. Health professionals did not take seriously people's motivations for missing vaccines and instead dismissed them as being irrational ("they are afraid") or invalid ("no reason at all"). To my surprise, mediators did not appear to take on this perspective. They could, for example, initiate two-way conversations between doctors and patients like Bianca, who had reasons to be hesitant about vaccination that were not related to laziness or to lack of knowledge or affordability, but, it seemed, to a generalised mistrust of the medical profession (they might vaccinate her child in the wrong way).

Considering this gap in communication and the sense of mistrust, mediators could play an important role in trying to find out about concerns in the community, and engage in a dialogue that could transform not only the opinions of community members but also the practice and discourse of health professionals. Instead, however, mediators tended to defer to the very health professionals who co-opted them into transmitting information to community members in a directive, top-down manner. This resulted in mediators essentially persuading community members to accept immunisation without listening to their objections. In doing so, they also perpetuated the discourse used by health professionals, which promoted a sense of individualised blame, as well as the idea that Roma individuals or even whole communities refused vaccination and therefore constituted a threat to the health of society more widely. Forcing vaccination on these individuals and communities while disregarding whether or not they had in fact refused and the reasons they may have had for doing so is a way of containing this threat. It is the containment of infectious diseases, perceived to emanate from this already threateningly "different" or "exotic" part of the population.

## Containment through contraception

As well as being seen as unhygienic and unwilling to have their children vaccinated, Roma families were spoken about as wanting and having an unreasonably large number of children, a phenomenon that needed to be curtailed. This constituted a different form of containment: governing and policing the fertility and reproduction of the Roma population. Similar to the discourse about hygiene and vaccinations, the health professionals I spoke to framed women's reproductive decisions as a question of knowledge, individual choice, cultural practice, or a combination of the above. It could not be for financial reasons, they argued, because contraception was provided to women for free. "Roma families have more children in comparison to the Romanian families who don't have [as many] children. One child, or two children at most. But the others have five or six [...] Even if somebody suggested some contraception methods in order not to, they don't accept them," Dr Radu told me. Doctors' understanding of the issue included the assumption that Romani women were under cultural pressure to conceive. But they also said that Romani women did not care about contraception, implying a recklessness not found in non-Romani women. About her young Roma female patients, Dr Radu told me, "they don't care about living standards, nor their responsibilities, nor nothing. No, usually [they get pregnant] after finishing eighth grade." Dr Stoica\*, also in Coliină, emphasised that girls as young as 13 or 14 became pregnant: "I was shocked [...] I'd never encountered anything like it... By the time they turn 20, they already have five children... These are their customs."

Both doctors emphasised that they had already done everything in their power to increase the uptake of contraception among teenage girls. "It is in vain that I explain protection measures, birth control measures, condoms, it just goes in one ear and out the other," Dr Radu said. A number of years ago, she had organised an educational workshop. When she did not see any results from the workshop, she gave up. "We were explaining contraceptive methods and what they should do, that they can receive contraceptives at no cost, and girls got pregnant a year later. But it was their will to get pregnant. So they wanted — it's the reality — they were children caring for other children."

CK: and why do you think this happens?

Dr Radu: um, phua, (she laughs) it's an ugly reason and I don't want to comment it.

CK: An ugly reason?

Dr Radu: Yeah, I don't find it right to use the child's allowance for the parent's interest. It's true, basically they spend the child's allowance 3 months in advance. It's the reality.

What Dr Radu was saying was similar to what the priest had told me before: people had children so that they could then live from the child benefits (see *Containers*). These benefits used to amount to as little as €10/month, although now the sum had “doubled” to €18, the priest had said, smiling at the idea of bringing a child into the world for the sake of such a small sum of money. He and many others – including Dr Radu – seemed to believe that this was genuinely the motivation behind having children. Dr Florian\*, a hospital specialist of obstetrics and gynaecology used similar language and logic. Dr Radu seemed less concerned about families being able to maintain standards of living, and more concerned about an increased birth rate among the Roma population affecting the demographic fabric of Romanian society. When I interviewed him, he drew me a pie chart with which he wanted to demonstrate that the Roma population would soon overtake the Romanian population in terms of its size.

Dr Florian: At the time of the Revolution, I don't know, there were about half a million gypsies and now I think there are two (he scribbles on a piece of paper). Two million right now [...] because they have four, five or six or however many children they can. [...] It will become a problem for Romania, because (he pauses) this, um...

CK: Why will it be a problem?

Dr Florian: Because there are, um, I think in fifty years from now they will become the majority here in Romania.

CK: And how do you imagine that society to be?

Dr Florian: A jungle (he laughs) a jungle!

CK: A jungle?

Dr Florian: [...] If communism couldn't integrate, [...] half a million gypsies [...] during the totalitarian regime, in democracy [um] they are growing fast and [...] we have reached the critical point. [...] the critical point means that the population, if there are three, four or five million, they can't be integrated. They start shifting the integration, we as the majority, we will have to start integrating with them.

Dr Florian's language was objectifying in that the way he spoke was reminiscent of

how someone might talk about a threatening epidemic (“a problem for Romania”; “growing fast”; “the critical point”). His use of “they” was homogenising in that it paid no heed to differences within this large and heterogenous group, and he bluntly portrayed the Roma population as a problem for Romanian society, undesirably deviant and Other. His proposed solution was to stop paying families child allowance after their third child, and to further promote free contraception. This narrative of fear, the open anxiety of a shifting demographic pattern is widespread in Romania, and has been well documented and analysed by Enikő Vincze (2006; 2008; 2009; 2013). In conversations and interviews, however, people seemed to be more careful about the ways in which they expressed themselves, and perhaps as a result of this I rarely heard this sentiment voiced in such a direct way. Only the GP in Pârâu, with whom Marta worked most closely, was even more explicit in her utter disgust at the way she saw demographics in Romania evolving. In the very brief conversation we had when I came to request an interview with her (which she declined), she told me that she thought there were too many “gypsies” in Romania, that sure, Hitler had killed some, but that now again they were “multiplying.” While I do not wish to imply that this kind of neo-fascist discourse was lurking behind the comments made by other health professionals, the extreme positions that I did encounter suffice to demonstrate how dangerously close these discourses are to an undisguised eugenic desire. It is against this background, and against the historical examples of enacted eugenics during the Holocaust and forced sterilisation during and after the Second World War, that any policy regarding Romani women’s contraceptive choices must be understood. A politics of population containment may be outrightly fascist and eugenicist, but it may also take subtler forms; on occasion it may be disguised in the language of progressive liberalism.

### **Women’s experiences of contraception**

Health professionals’ reasoning as to why there was low contraceptive uptake among women did not on the whole resonate with the conversations I had with women about past, present and future family planning decisions.

Anita in Uscat had five children, the oldest of which cannot have been much older than twelve. They all shared one of the small shacks to which they had been moved after their eviction. Anita told me that she had conceived the last child only because she had no longer been receiving the contraceptive “vaccine every three months.” She told me she had been receiving her contraceptive injections from the Child Protection Agency, a non-medical government institution that was apparently targeting poor Romani women like Anita with its offers of free contraception. While I did not ask Anita whether she had planned to have five children, she said that now she did not want any more, and the Child Protection Agency was no longer offering free contraception. What would she do instead, I asked her. “I’ll see the general practitioner and ask her to vaccinate me every three months.”

I spoke to many women, across different parts of Romania, who told me that the expense of contraception prevented them from using it. In some cases, this was more a matter of being informed about ways of accessing free contraception, rather than free contraception being unavailable *per se*.<sup>21</sup> Sonia in Padureă, for example, was now taking the pill. She told me that her GP had tried to charge her for contraception, and if she had known earlier that she could get it free from the family planning clinic, she would have been able to prevent her last pregnancy.

I saw community members make fun of women whom they saw as being too fertile. While I was shadowing Dr Trifa in Colină, I saw how patients and nurses teased Adela in the waiting room. She was in her mid-thirties and had seven children. “How many more children do you want? Will you ever stop?” they taunted her. Her reply came quick, and with a twinkle in her eye, as though she was well used to the gibes: “I won’t stop till I’ve had 14, that’s a good number.” She knew how to self-ironise the dominant discourse about Roma fertility, and used it in her defence. When I spoke to her at her house, with one child breastfeeding on her arm, and the others whizzing every which way and demanding

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<sup>21</sup> In Romania, family planning is nominally included under a package of free treatment, both for insured and uninsured patients (Vlădescu et al. 2016). In practice, however, treatment is often subject to informal payments. When women referred to the cost of contraception in conversation with me, it was not always clear whether they were referring to official or informal charges.



her attention every few minutes, she told me that she did not, in fact, want more children. The two of us were crouching on a log behind her house, out of earshot from her partner, about whom she had few favourable things to say. She thanked the Lord for giving her so many children, because she loved them all dearly, but she had never intended to have this many. She had trouble doing all the washing by hand, she had a painful leg, and she could no longer move freely. The whole family shared a single room, but it was not her house she lived in; it was her partner's. "I cannot leave him," she whispered to me, "because I have nowhere to go." She said that when she gave birth to her sixth child, she had started taking contraceptive pills, but one month she had not been able to afford them, in which she had gotten pregnant immediately. Prior to that, she had gone for three-monthly injections at the GP for four years, during which she had not fallen pregnant once. But then they stopped offering the injections for free, and so she had another child. Now, she said, she wanted to get the coil, but she struggled to save up the money: 250 lei for the coil, 10 lei for the trip, and 300 lei for the cost of the examination: almost 600 lei (£120), she calculated. She said it was not feasible for her at the moment, since whenever she got her hands on 50 lei, she would buy food for the family. But, she sighed, she could also not afford to have another child; she could barely manage the seven she already had. For now, Adela said, she would continue with the pills, even though they made her feel dizzy.

These women were not choosing or planning to have as many children as they did, and in many cases they fell pregnant despite their intention not to have any more. This was not because they lacked knowledge about different forms of contraception: on the contrary, they knew what was on offer, but perceived it to be financially unaffordable.

### **Mediating contraception**

Following the pattern of health mediation's role in promoting hygiene and vaccines, mediators were tasked with gently *persuading* Romani women to take contraception. "The community has difficulties accepting contraceptive methods, there's a lot of work to be done [...] it's sensitive," Flavia said in one of the focus groups in Dacia County. The other mediators in the group nodded in agreement. Regarding contraception, mediators were

in a difficult position, especially in light of nefarious historical precedents around sterilisation. Based on the conversations I had with mediators, it seemed that for them contraception was indeed a sensitive issue, one that was more complex to negotiate, and which involved many more uncertainty than either hygiene or vaccination, both of which they were able to frame as unambiguously “good things.”

In conversations with me, mediators spoke about the multiple and conflicting reproductive pressures on Romani women, often nuanced, and sometimes contradictory. As mediators, they had overlapping forms of “expertise:” on the one hand they were frequently exposed to the kind of anti-natalist discourses presented above, while, as Romani women, they also knew about the kind of financial and cultural pressures facing Roma communities. They spoke of the organisational challenges (registering with a GP), as well as the often hidden and prohibitive costs of contraception (paying for a referral for a gynaecological examination). They also spoke of a different kind of knowledge – the kind of social knowledge that pertained to customs of “traditional Romani women,” whom they said wanted to “have as many children as possible.” They told me about the pressures that women experienced from their husbands, and how men were entitled to leave their wives if they did not bear children soon after their wedding. They also spoke of the changing attitudes towards contraception, saying that women now knew that they should not have too many children. The mediators generally spoke out in favour of contraception, and told me that they saw it as their responsibility to encourage women to use it.

From the programme’s perspective they were under strict instructions not to give direct advice on contraceptive methods, but rather to refer women to the appropriate medical facility (Nanu et al. 2008). Despite this, mediators portrayed themselves as key figures in women’s contraceptive choices. Given my observations of examples of health mediation in practice in which mediators had little contact with community members outside of their office, and where people largely came with bureaucratic requests, mediators were unlikely to play a significant role in the contraceptive choices of very many women. Mediators’ portrayal of their role as family planning advisor to the community was nevertheless significant, inasmuch as it indicated to me the kind of role they felt they

should be enacting, and pointed to the kind of discourses that they might reproduce in conversations with community members. Marta told me about information sessions which she organised with a small group of women in the community, answering questions like, “what am I supposed to do not to get pregnant again?” or “what can I do to keep it a secret?” The mediators in one of the focus groups said they discussed the “advantages and disadvantages” of different types of contraception. On occasion, they said, they would accompany women to family planning services, “because they don’t know how to get there,” and would sometimes even pay the cost of women’s transport. Mediators had different ways of promoting contraception. Some did so by presenting themselves as a positive example of family planning practices, while others intervened more directly by distributing contraception to women. Others still devised elaborate strategies through which they hoped they could influence family planning decisions.

Marta presented herself as a kind of avant-garde of family planning in the community. She spoke of herself as a role-model for other women, both in terms of the values she believed in, and the contraceptive methods she promoted that would enable women to live according to those values. Marta told me that the women in her settlement would ask her: “how come you haven’t gotten pregnant again?” She would tell them that she used the intrauterine coil, and that if she could live her life again, she would have made different choices: “I wouldn’t have married so young, I wouldn’t have had children at such an early age, I would have attended school, I would have prioritised the need to go to school, to have a job, my own house, my own salary. Or to afford looking after my children, to invest in their future, to allow them to evolve in life. To avoid them having the same life as mine, not to go to school, to starve.” She told me with apparent pride that now at least twelve other women in her settlement also used intrauterine coils. Marta framed contraceptive use in terms of female empowerment and developmental progress, hoping that by setting a positive example, she could change important reproductive dynamics in her settlement. Sometimes it was the men who needed more persuasion than the women. Nell\*, who was part of one of the focus groups, recounted the elaborate story of how she had persuaded a husband that it would be in his favour to allow his wife to use contraception. She had invited him to her house under the pretence of getting him to wash her windows, and had

used this as an opportunity to persuade him that his wife would have more time for him (“to kiss” and “to talk”) if they did not have any more children. Other mediators contributed in more direct ways. In Podgorie\*, for example, Silvia\* the mediator told me that she had on occasion personally provided contraception to women in her town. “The GP gave me the prescribed contraceptive for young mothers [...] and I would do the fieldwork of injecting them.” Silvia said she did this only when women could not go to the GP themselves, because they were “too busy or didn’t have enough time.”

Independently of how well intentioned such forms of subtle persuasions or direct distribution were, they cannot be extracted from the generalised climate of continued suspicion towards external interventions in the reproductive decisions of Romani women. I heard reports of recent cases in which patients had accused doctors of unlawfully performing sterilisations without their consent. A number of years ago, Viorica told me, one woman had officially reported that her daughter had been sterilised against her will. She had come to hospital to give birth, Viorica told me, and had needed a caesarean section.

The practitioner who had been assigned to operate had fallen asleep and left the resident [alone]. The resident panicked, and he didn’t clean the girl properly and two days later [...] she got septicaemia. When the family came to visit, she wasn’t in the room because they urgently operated on her again, in order to clean her better. But they cleared everything, because they sterilised her. She was 22 years old! And without her consent, without calling the family to say ‘Sir, something came up, look! It’s a medical error, something happened! I need your signature so I can remove everything from her, otherwise she’ll die.’ Right? They didn’t announce it to the family, no, nothing. They couldn’t get her to sign because she was already very sick and she couldn’t sign. And they sterilised her at 22 without her consent, nor the family’s. [...] When I returned [from annual leave], this had already happened, it had happened a week before. They found me and we talked. God, what could I have done, I worked here. You can imagine that I didn’t want to lose my job. I asked around, who was there, what did he do, who was on guard duty, who was operating, I don’t know. [...] Because by getting too involved, [...] I could have lost my job. They could have created all sort of obstacles, problems to dismiss me. Right? [...] And there was another problem. I was afraid that if [the doctors] would find out about my work, I wouldn’t be able to identify other cases, you see? But they found out. Because, it was revealed who I was, and my role.

When we spoke about this incident another time, when I was not recording, she told

me that she did not want to pursue the complaint because she was worried she could lose her job, and because it might have repercussions on the way that her and her family would be treated by hospital staff. Viorica thought that this was not an isolated case, but part of a larger pattern. She told me that a few years ago, there had been a number of cases in which women had had their “uterine tubes tied without their knowledge.” She apparently also did not believe that this was simply a medical error. Instead, she tied this incidence to an ethnically targeted anger towards Roma on behalf of medical practitioners. “It was a difficult period. Practitioners were bitter about gypsies, girls, women, and sterilised them.” She had wanted to support the women in making a complaint, but she told me that they had been “afraid of the doctors.” When she had offered her help, these women had said, “No, because I’ll give birth again and I don’t want trouble in the hospital. [...] My child will give birth, and her sister and she too will give birth, and I don’t want any trouble.” Because of her position within the local administration, directly answerable to the town hall, which could block the renewal of her contract, Viorica was even less likely to intervene.

Viorica’s retelling of the story shows that mediators perceived their practices with regard to family planning as being under multiple pressures. Most egregiously, there were cases of potentially unlawful medical practice that obstructed Romani women’s fertility against their choice. It was perhaps revealing that apart from in this incidence, mediators did not touch on eugenicist discourses or the historical or contemporary infringements on women’s reproductive rights. Instead, they focused on the emancipatory potential of contraception. They portrayed it as a rung on the developmental ladder upon which Roma communities found themselves, their responsibility to help women to gain more knowledge about and access to forms of contraception. Mediators’ practice of promoting contraception was therefore contiguous with their discourse. But it is still possible that they contributed to the “containment” of Roma populations, even as they benefitted those women whom they helped to acquire contraception. Judging by the conversations I had with women, lacking access to contraception was less a question of knowledge and the power of persuasion than of financial inaccessibility of appropriate and acceptable methods. Neither health professionals nor mediators acknowledged the salience of this

barrier, nor did health mediation contain the mechanisms to address it. The discourse of these women thus substantially departed from that of health professionals, whose interest sometimes veered into Malthusian or even openly eugenicist territory. With these tendencies in mind, and despite the frequently beneficial outcomes of health mediators' work regarding contraception, it is worth questioning the extent to which enacted health mediation was complicit in a project that saw as its aim the "containment" of the Roma part of the Romanian population.

Who benefits from health mediation? With regards to hygiene, vaccination, and contraception, this is a complex and knotted question. It is especially difficult to answer this question, considering that I did not observe mediators enact many of the things they talked to me about. Nevertheless, an analysis of the way in which they spoke about their practice reveals the kind of assumptions that they were based on and gives an indication of how they saw patients and how they believed patients should behave. I explore these expectations in the next section, turning to discursive constructions of the "patient" more generally in order to interrogate whether these assumptions were specific to key health mediation topics, or whether they were related to broader assumptions about Roma patients.

## **Containment through assimilation and subordination**

"Roma" often fell short of doctors' understanding of how patienthood should be enacted. Medical professionals frequently implied that "Roma" patients were simply not equipped to correctly perform the role of the patient: they were constructed as "bad patients." The health professionals I spoke to painted a picture of the Roma patient as impolite, impatient, and aggressive. As Isabella\*, the GP nurse in Padureă said, "Roma patients" were "aggressive, not like they will start kicking you, it's more like a verbal aggression." Dr Trifa in Colină also complained that patients were unwilling to take doctors' advice: "They simply don't listen. [...] they prefer their traditions, 'don't worry, I'll cook some

hot polenta and put it on his belly,' this is what I've heard them say. And in [the city] it was the same, 'I can handle it, I don't need Paracetamol, I don't need it.' And they encounter extreme situations and when they can't deal with it anymore, they run to the nearest emergency service [...], where the entire tribe meets to solve this acute situation and they wonder what to do." Her description was typical of the kind of things I heard all over: Roma patients did not use medicine or medical service correctly, or at the right time. When they did come to hospital, they would usually come in the wrong way: in large numbers, bringing their entire extended family along with them. This, it was strongly implied, was also not correct patient behaviour.

A "good patient," it transpired from my conversations with health professionals and mediators, was a patient who listened to and followed the doctor's advice. A "good patient" (and this, I expect, might well be a more global phenomenon) was someone who neither overused nor underused health care resources, somebody who accessed the health system at the "correct" point. A "good patient" was moreover somebody who kept appointments, arrived on time, and waited silently to be seen. A "good patient" was one who regularly went to preventive check-ups, who went to the GP in a timely manner, and who did not resort to emergency care, home remedies, or traditional medicine when it was not indicated. The categories of "bad patient" and "Roma patient" were so closely mapped on to one another that if a patient behaved like a "good patient," they were sometimes no longer considered to be a "Roma patient." Sometimes this produced confusion, such as in Padureă, where the nurse seemed baffled at the characteristics that her "Roma patients" displayed: "they are well educated, they have a proper vocabulary, they are respectful and you can't tell whether they are real gypsies."

On occasion, doctors seemed to understand where "differences" in patient behaviour came from. Dr Mirea\*, the GP who treated patients from the isolated community 12 kilometres outside Tabăra, laughed heartily when she told me about her patients' impatience when they came to visit her at her practice.

Inevitably they take what they can to come here, with carts or cars when people stop and help them. [...] And then, of course, since they are hurried by the driver who brought them in,

especially during bad weather (it's different when it's nice outside, in spring or summer, they come in with the carts) but when the weather is unpleasant and someone hurries them, then it's true that they step in front of the line and they don't understand that you need an appointment before entering the practice. I need to examine their condition, and they don't care that I have 20 other medical examinations and that I can't take him anymore. Or whatever. For them it's like: he's here and it's his right to be examined. And so I've tried to explain them: 'well you must understand that you don't have an appointment. I will try to examine you also, but next time you should get an appointment.' – 'Fine Madam, I will make an appointment!' The next time it's the same: 'What did we say? I told you to' – 'Yes Madam, but I don't have money for a phone card!' So they invent excuses.

Dr Mirea's own account of her good-natured approach towards these demanding patients was accompanied by self-admiration for how she dealt with people as equals ("I talk with them from equal to equal, it means a lot for them"). She went the extra mile in learning some Romanes, and knew how to tell children: "'open your mouth', 'breath out', 'don't be afraid, come to me'". She did not allow herself to look down on people, she said, but at the same time she had to retain the ability to communicate well with all manner of people, independent of their age or level of education, because "basically we are not all smart". She was unusual amongst the health professionals I spoke to in explaining the structural pressures that her patients were under. I thought her accounts of her interactions with the patients from the Roma settlement (which, being one of my short term field sites, I did not witness myself) nevertheless had a rather patronising undertone, as though she was speaking about endearingly dim or renegade children. Doctors seemed to either condemn Roma patient behaviour as aggressive and inconvenient, or indulge it as exotically charming. Dr Mirea belonged to the second group. She was the same doctor who had told me that she liked her Roma patients because of their "black, round, and happy" eyes, whose expression was "joyful, beautiful, and warm" (see *Containers*).

### **Mediating patienthood**

By now it should come as no surprise that mediators spoke about their role in the community partly as one of reforming Roma and teaching them to become "good patients." Mediators presented themselves as being willing to shape patients in a way that would conform to the expectations of health professionals. They seemed to agree with some of the health professionals' assessments of Roma as being "bad patients," framing



people's behaviour in moral terms. Flavia and Alexandra\*, both mediators I interviewed as part of a focus group in Dacia, agreed that "Roma patients" were "very vulgar" and "rude."

Flavia: They insult the general practitioner, they demand treatment whenever they want it and whatever they want. Things can't be this way.

Alexandra: People scream sometimes

Flavia: Yeah, it's true that it's quite difficult to work with them sometimes

The implication was that they needed to be disciplined. As was the case here, mediators often seemed to adopt the perspective of the health professional. Sometimes, however, they were able to consider both the doctor's and the patients' perspectives simultaneously. Emilia, for example, who was the mediator for the isolated Roma community outside Tabăra, told me that she did not think it was a "good thing" that families did not take their children to the doctor when they were ill, trying to describe symptoms rather than allowing the doctor to physically examine the patient, allowing for a more precise diagnosis. On the other hand, Emilia clearly recognised why patients chose not to bring their children: they had to make the journey in an open horse-drawn cart, and were worried that the child's condition might worsen during the journey.

In some ways, mediators presented their role in instructing patients' behaviour as a pragmatic response that would facilitate their access to health care when they needed it. They spoke of adjusting "Roma customs" as a way of preventing discriminatory behaviour from medical professionals, and seemed proud when they had managed to change the behaviour of individuals. One of the mediators from the Dacia County group discussion told me that she had managed to get her community to make appointments before going to the doctor. She "had to visit the community in order to explain the situation to each one and to keep order in the medical office." Before, she said, they would turn up and expect to be seen immediately. If they had to wait, they would "cause disturbances [*fac scandal*] with the general practitioner," whereas now they were "polite, and make appointments, they got used to the rules." She had disciplined them by giving them a warning: "I told them 'if you don't listen to me, they'll remove you from the registration list and no other practitioner will ever see you.' It happened in the case of a family, they

were removed from the registration list and it set an example for all of them.” As a mediator, she may have been backing the wellbeing of patients, but the way in which she attempted to protect them was by disciplining them so that they would not cause trouble to doctors.

Marta, the mediator from a “traditional” community in Pârâu, told me about how she negotiated between a large Căldărari family and the staff of the local hospital. This episode is one of the only times I heard mediators talking about direct conflict mediation. It centred on clashing conceptualisations of patienthood:

This *țiganka* was sick, she had cancer, [...] so she wanted to go to the emergency room, to have a perfusion. She has eight children. [...]. They are all married. So should you count all of them, you get 16 [...] So as soon as 16 gypsies, boys and girls come with their relatives, they started to curse the entire medical staff! And their manner of speaking like gypsies bothered the staff. That woman felt some, a stomach pain. She kept asking for medication. She went to the hospital like twice each [um] night. She asked for a drip during the day. But doctors don't like having so many gypsies gathered around, and it's actually not nice to have so many.

She understood why they had come as a large group. This was what people in her settlement did: it was “the *țigani* way of being.” People looked out for each other, and being ill was a communal, not an individual affair: “It's like one for all and all for one.” She gave me another example to highlight the consistency of this custom: when her daughter-in-law gave birth, she said, “the entire *țigani* neighbourhood followed me that night.” But she also understood the perspective of the doctors, for whom the individual patient rather than the whole family was the point of focus. This meant that Marta did not think it wholly unjustified that the doctors refused to see the woman unless she came alone. She was called in to mediate between the family and the hospital staff. First, she spoke to the family, and told them “not to gather so many from then on. Perhaps two or maximum five of them were enough. To wait outside of the hospital's gate, and there should be only two people inside. So one could stay for half an hour, then the second one and so on.” Only after that did she return to the doctors. She said she “managed to cut a deal, for [the woman] to receive a drip each time it was necessary.” Unlike many of the other mediators, Marta described how she tried to change behaviours on both sides, to engender transformation

not just among her own community but among health professionals as well. Yet ultimately this meant trying to suppress – to contain – what she herself described as “the *țigani* way of life,” in order to negotiate access to care. In the end, it meant conforming to forms of behaviour that doctors deemed good and proper.

Lavinia\* from Movilă was the only mediator I met who explicitly stated that it was her job to educate doctors about the socio-cultural context of people’s behaviour: “the practitioners we are working with, they must know some problems, some things about our culture.” She proposed a dialogue with health professionals, where they could voice their grievances about patients, but where the mediator could respond with explanations that might transform the way health professionals viewed their patients. Apart from performing the “*țigani* way of life,” as Marta put it, there may be other reasons why patients, especially from poor “Roma” communities, come to hospital in groups, or raised their voices. Lavinia said people feared they might not be heard unless they spoke loudly. She explained this in terms of Roma communities’ history of being ignored: “They talk louder with the practitioner because they have never been heard by anyone.” By the same token, it might have been the case that “Roma patients” preferred to come to the hospital as a group because they were afraid that not only would they not be heard, but also they might be overlooked by the hospital staff. Most other mediators seemed to accept that doctors were within their rights not to tolerate culturally specific behaviour from Roma patients. It was patients, not health professionals, who were expected to adjust their behaviour.

### **Leaving discriminatory practices unaddressed**

An important corollary of this expectation to adjust and contain was that discriminatory behaviour on the part of doctors was left largely unaddressed, revealing how interactions between doctors, health mediators, and patients were based on a fundamentally unequal power dynamic. Whether or not patients could be contained within a specific, constructed form of patienthood sometimes directly influenced whether they were included or excluded from health care provisions. I often heard that doctors used their “discretion” in

making access to health services for “Roma patients” conditional upon the fulfilment of “patient obligations.” Failure to comply could lead to punishment. Some doctors, Lavinia told me, were well known for selecting only “good patients” (“People who sit quietly in the queue, people without special problems.”) Health mediation did little to address notions of “acceptable” ways of behaving as a doctor. Only some mediators – like Lavinia – perceived their role to be one in which they would lead an open a dialogue with practitioners. In this context they might convey to doctors why it was difficult to “contain” patients according to their professional expectations, and which “cultural” and economic factors might lead “Roma” patients to behave differently. Lavinia’s unusual stance, I suggest, may plausibly have been related to her position in the community: she was part of and lived in the middle of a close-knit Căldărari community in Movilă. She and her extended family experienced the same conditions and had grown up within the same cultural context as their immediate neighbours. It was telling that she spoke in derogatory terms of a different Roma community who did not live in central Movilă, but on the outskirts, in the area she called the “ghetto”. She told me that she was so afraid of the people who lived there that she refused to go there without being accompanied by one of the community nurses. When explaining the “unusual” behaviour patterns of patients, she spoke from the perspective of her own specific, small community, and spoke about their social knowledge without claiming that it extended to a wider, homogenous Roma population group with whom she had no interaction and with whom she felt no connection. As I have outlined, such a perspective seemed rare, since most mediators spoke about Roma in more generalised and essentialised terms.

Instead of helping patients to make official complaints regarding physicians’ behaviour, mediators tried to adjust patient behaviour so that doctors would have no reason to discriminate. I witnessed exceptions to this pattern: one day, for example, Viorica tried to make a complaint on behalf of several families who had been taken off their GP’s list because of their behaviour. The doctor claimed the family had spat at him during a consultation. Viorica and I went together to the local public health authority, where she brought up the case with an official at the DSP. The woman was understanding, but told Viorica that there was nothing that could be done about the case; since GP

practices operated as de-facto private entities, they were free to choose their patients, and were under no obligation to keep patients on their list. Instead, it was the responsibility of the affected families to find another GP practice. As far as I was aware, Viorica did not pursue the case any further. Just as when we went to the Roma community outside Dacia, I was left with the uneasy feeling that she may have been performing this quest for justice for my benefit, to show me that she was being a good mediator.

A GP taking a family off their list, or the cases of suspected sterilisation discussed earlier represented explicit forms of discrimination. There were also much subtler manifestations of health professional behaviour that highlighted the asymmetrical power dynamic involved in treatment, as well as health mediation's inability to advocate convincingly on the part of the patient. Here, I am thinking of Dr Trifa. As a doctor and as an individual she was a complex character. She was an eccentric, who had her own way of running her family medicine practice. In the same way that she did not seem to believe in having her office cleaned on a regular basis, she also did not believe in the necessity of appointments or patient confidentiality. I spent several days in her practice, and witnessed the chaos that resulted from her unorthodox management. Usually, she was one or two hours late according to the schedule that was pinned up outside the practice. By the time she arrived, a large queue of patients would already have formed in the corridor outside. At the beginning of the day, she would call in patients individually, but as the day progressed, and as the corridor became more crowded, people would start letting themselves into her office, interrupting on-going consultations. Instead of sending them back outside, Dr Trifa would ask them to wait inside her office. Before the morning was over, her whole office was filled with up to half a dozen patients, some sitting, others standing, but all observing the consultations of the others. Only when somebody needed physical examination would she take them into a different room. Apart from that, she would conduct her consultations almost collectively, flitting from one case to the other, while the assisting nurse filled in the paperwork. Patients discussed their pains and illnesses with each other, and despite a low level of irritation at Dr Trifa's combination of calm and chaos the atmosphere was jovial.

The more educated and economically well-off people in the village, such as the

mayor's wife or the priest, openly made fun of Dr Trifa, saying that they would not dream of seeing her as a doctor: although she was medically competent, they would not want all the *tigani* to know about their health problems. When I spoke to Dr Trifa, she maintained that her method was a better way of treating patients, that it made her more approachable, especially to the less educated people in the village: "They usually come in [without waiting], you've seen what they do [she laughs]. But I'm fond of this trait and I understand it. If someone is in a hurry, I'd rather let him in and solve his problem than to hear him complaining and return ten times." Like Dr Mirea, she found her patients' unorthodox behaviour endearing, seemingly because it suited her own rather unusual character. Many of the people I spoke to indeed seemed proud to be her patient. Others, however, complained that they would prefer her to go about her business in a more orderly way that respected patient confidentiality. Roberta the mediator, however, supported the doctor's point of view. She laughed off patient's complaints, implying that if they were bothered by this kind of behaviour, they should sign up to a different GP. I should mention that even during the short two months I spent in the village, I witnessed several patients requesting a transfer to one of the other two doctors. Clearly not all the patients condoned her practices. Some may have endured them begrudgingly (one of my neighbours told me she was unhappy about the whole village knowing about her medical problems after a visit to Dr Trifa). But others took the situation into their own hands, and simply had themselves transferred. The peculiarity of Dr Trifa's work derived from the way in which she actively discouraged containment of patients both physically (they crowded together in her office) and discursively (medical issues were discussed openly). In this instance, however, and without the intervention of the health mediator, some Roma patients themselves chose to reintroduce a degree of containment by isolating themselves from the practice at hand. Health professionals and mediators may largely have operated as if health and hygiene were unilaterally distributed qualities that necessitated containment, but the case of Dr Trifa indicates that containment itself was potentially as much the province of patients as of professionals.

## **Discussion: classifications, hierarchies, containment**

What constituted good health and good patient behaviour was defined top-down by health professionals. In most of the situations which I have described, the performance of patienthood as a set of unwritten rules and obligations was evaluated by those who had the power to admit or reject patients, and this notion was endorsed, and sometimes reinforced or even policed by health mediators. Excluding people from the category of patienthood can be a way to exclude people from health services, or make access difficult. This is an aspect of “access to care” that has not been well described in previous discussions about Roma health, which have tended to focus on open discrimination, lack of documents, or geographical and financial exclusion.

For the most part, doctors made their own attempts at moulding patients in the image of the “good patient”. Presented with the opportunity, however, they gladly accepted the assistance of health mediators, even when they were not generally convinced that these were needed. Mediators tended to take on this role with apparent enthusiasm. They also commonly presented Roma patients as lacking knowledge about relevant health issues, and making “bad” individual choices as a result.

Narratives of deviance and otherness were not borne out by the discourse of Roma patients themselves, who presented themselves as normative in their desire for cleanliness in their houses, immunisation for their children, and affordable contraception. Rather than focusing on Roma culture or their personal choices, patients spoke about the structural barriers that prevented them from attaining good health, such as their physical surroundings, or a lack of financial resources. On the whole they seemed to conform with top-down definitions of “good patients”, and they strove to fulfil that role. This overlap in how patienthood was understood both by patients and by health professionals reveals the fault lines of ethnically grounded stereotyping that were at the heart of the portrayal of Roma patients. Health professionals seemed to relate their experience of patients to pre-

established notions of ethnicity. Mediators who, as part of their programme, were expected to facilitate trust between community members and health professionals did not offer a counter-narrative to the kind of discourses that were perpetuated by health professionals. Instead of prizing open the categories by questioning dominant discourses, and revealing the ways in which dominant ideas of Roma did not match their own experience as community members; instead of engaging in dialogue with health professionals about the structural constraints that community members faced; and instead of encouraging an understanding of locally specific social knowledge in the communities they worked with, mediators promoted discourses and practices that called for further categorical containment. They acted in a way that promoted disciplining people into a particular form of patienthood. They appeared to be willing partners in the project of containing dirt, disease, and the growth of a population that was seen by health professionals as “other” and threatening. Some of the dynamics described above, in particular the ways in which Roma patients were portrayed by health professionals and the role that mediators had in shaping patienthood, may be understood more productively through the prism of pre-existing bodies of critical theory.

From the perspective of dialogical theory, what becomes immediately apparent is that mediators are not really, as one might have imagined, facilitating a dialogue between patients and health professionals. Instead, they generally take on the perspective of health professionals and communicate these interests to communities. They echo certain “expert knowledge” about the needs of Roma communities that is not necessarily reflected in their own experience of being Roma. This knowledge takes a distinctly technical form, focusing on physician-led notions of hygiene, disease prevention, and family planning. Mediators do not – as they perhaps could – pay due attention to the needs of communities, as they themselves voice them. As a result, they are unable to serve as an amplifier (or indeed as a mediator) for communicating such needs to health professionals. The two mediators who did talk to me about community needs and perception of health issues (about hygiene and pollution, conception, communal notions of care and so on) did not sense the need to communicate these to health professionals. Lavinia, who explicitly told me that it was a mediator’s duty to transmit knowledge to health professionals as well as to communities,



was an exception to this pattern. On the whole, the social knowledge specific to the communities they were working with was something that mediators kept to themselves. If they were to transmit it, they would be in the unique position of being able to work towards a better understanding of locally specific practices or needs, thereby helping to challenge views of Roma communities as homogenous. When mediators did have locally specific social knowledge about communities this was useful to them only in so far as that it meant that they had a better understanding of the community, and were therefore able to better tailor top-down, physician-led instruction. Rather than being instrumental to building a dialogue between communities and health professionals, mediators thus seem to act mainly as instruments of containment.

From the standpoint of intersectional theory, it is notable that the perceived need to contain Roma communities is based on dubious, homogenising notions of Roma as having certain behavioural traits (unhygienic, difficult to vaccinate, unwilling to use contraception). Health professionals spoke in generalised terms about Roma communities, most often using the unspecific collective pronoun “them”. This might have been done to avoid making a distinction between the two politically fraught terms *romi* and *ṭigani*, but it also fed into the hazy approach commonly found among policy makers who assert simultaneously the indefinability of Roma *and* their delimitation nonetheless (“we cannot precisely define them – but we all know who they are” (Andrey Ivanov, Kling, and Kagin 2011, 11)). Only rarely did health professionals make distinctions between different groups, and when they did, it was usually to differentiate between the “real *ṭigani*” and the others, the “assimilated ones”. (It went unremarked that these were apparently not “assimilated enough”, or else how would health professionals still be able to identify them as “other”?) Roma “realness”, it seems, was mainly identified by material destitution, though the economic identifier was not usually recognised as such. Instead, people who were destitute were in fact seen as part of a “culturally different group”, who were constructed by health professionals as being wilfully different, rather than the result of their social and structural circumstances. In other words, health professionals lacked any kind of intersectional understanding of Roma communities.

Post-colonial theory has contributed to a politicised understanding of how power dynamics affect the construction of ethnic and material difference; that is to say, why it serves the powerful to conflate concepts or attributes of poverty, difference, and inferiority. Post-colonial theory emphasises the importance of discourse in establishing and maintaining power over representation and communication (Hall 1997). Top-down definitions of health and good patient behaviour have the ability to affirm power over the representation of and communication about Roma patients. As this chapter has shown, the classification of people into “patients” and “non-patients” was not random, but followed perceived ethnic differentiation between Roma and non-Roma. Doctors, nurses, and mediators tended to speak about patients as being Roma only when they behaved in a way that constituted a problem. When doctors questioned patients’ qualification to perform patienthood correctly, citing those who were obstinate or “lazy” about vaccinations, those who had many children despite clinical advice, and those who would not queue, or listen, or behave the way the doctor wanted them to behave – in short, all those who were somehow “other” – were identifiable as Roma patients. There was an analogy between the way in which certain spaces (those that were poor, segregated, or had been the site of an eviction) were seen as Roma (see *Containers*), and the way that certain patient behaviours were understood to be Roma. Roma were constructed as either exotic and charming (beautiful eyes; strange pollution rituals), or threatening, deviant, and inferior (unhygienic; aggressive; not obeying the rules; demographically threatening; scrounging off child benefits). Nobody spoke of Roma patients who behaved “normally”.

This links to what Macey (2001) describes as Nietzsche’s theory of a “master morality”, recognisable in the way Romanian doctors speak about Roma patients. It “is generated by dominant groups which have acquired power and project their own values as ‘the good’. In projecting their own sense of the good, they eventually come to see the dominated group as ‘bad’ rather than simply as inferior. [...] Conceptions of morality do not originate in abstract notions of good and evil, but in the impersonal structures of power that impose standards in the name of the will to power” (275). In other words, doctors project their own values and ideal forms of behaviour as necessarily “good”. Patients who do not conform to these values or behaviours are not only seen as different and inferior;

they are understood to be morally “bad”. The “master morality” serves to solidify and maintain positions of hegemony, especially in situations of gross power differential, or amongst those who feel their superiority is threatened. Such a sense of threat was evident, for example, in the gynaecologist’s projection into a future in which the Roma population would become the majority. Classifying people into bad patients and good patients, into Roma and non-Roma, reinforces a hierarchical social order that provides the justification for intervention, for the containment of behaviours seen as “other”.

Fanon (2008) describes how in dominated groups, this sense of moral inferiority can become internalised. Building on Fanon, Biko (2015) emphasises the need for dominated groups to break out of such internalised thought patterns, and to build critical consciousness about the social and economic positions in which they find themselves. Health mediators display many of the signs of internalised moral inferiority, with few examples of critically conscious mentality. For the most part, mediators were not instrumental in building critical consciousness, but rather themselves became instrumentalised within the project of turning “bad patients” “good”. This may be interpreted as a kind of civilising mission towards the Roma, who find themselves on a developmentally lower rung than their Romanian neighbours, in the “waiting room of history” (Chakrabarty 2009), ready to be transformed.

The most symbolically striking iteration of the civilising mission came when health professionals and mediators talked about being “clean” or “dirty”. Mary Douglas’ (2003) foundational work on rituals of pollution and taboo, *Purity and Danger*, introduces the idea of maintaining symbolic boundaries through differentiated rules of hygiene. My research does not address “Roma understandings” about health and hygiene directly. Instead, it investigates constructions about Roma understandings of health and hygiene, and how they impact on relationships with health professionals. I therefore do not attempt to provide an analysis of Romani pollution rituals *per se*. Health professionals seem to use their own notion of “hygiene” as a way to place boundaries that enforce a binary between Roma and non-Roma. Marginalisation through hygienist discourses can become a tool to re-affirm a nascent or unstable mainstream identity (Downs 2012). This is not only a

feature of contemporary Romania. Defining what counts as “hygienic” or “pathological” has been used as a mechanism for ideological state-building exercises throughout the 20th century. In South-Eastern Europe, for example, health and hygiene were instrumentalised by nationalist discourses in an effort to enact “population hygiene” (i.e., eugenics) both before and during the Second World War, when ideologies of the nation-state were in the process of emerging (Promitzer, Troumpeta, and Turda 2011). On the other hand, the Western orientalist imagination of Eastern Europe as “backwards” and “intrinsically diseased” (Promitzer, Troumpeta, and Turda 2011, 2:5) has given outsiders grounds for intervening in health and hygiene. In the context of European colonialism, Stuart Hall (1997) describes the symbolic power that soap holds over the post-colonial subject: “In its capacity to cleanse and purify, soap acquired in the fantasy world of imperial advertising the quality of the fetish-object. It apparently had the power to wash black skin white as well as being capable of washing off the soot, grime and dirt of the industrial slums and their inhabitants — the unwashed poor — at home, while at the same time keeping the imperial body clean and pure in the racially polluted contact zones ‘out there’ in the Empire” (241). The idea of washing black skin white is reminiscent of Amalia’s associating being Roma and being considered unclean, and of her poignant childhood memory of thinking that on account of her being Roma she “carried some odour despite washing.” The constant emphasis on washing, and the mediators’ role in promoting ways to keep households clean is indicative not only of symbolic boundaries, but also of how mediation attempts to penetrate into people’s private, domestic spheres.

As discussed, discourses about health, hygiene and cleanliness have a long history of contributing and perpetuating the racialisation of certain groups, and the maintenance of power over them. These discourses and enactments, their symbolic representations, practices, and behaviours, represented ways of pathologising Roma bodies, marking them out as ab-normal. Health mediation may therefore be seen as an attempt at containing those aspects of Roma-hood that are constructed as “pathological”.

Relationships of power may be enacted by occupying the position that is able to control the definition of what counts as “normal” (Foucault 1977; Foucault 1998).

Mediators participate in the powerful act of defining what counts as “normal” in terms of dirt, disease, fertility, and patienthood. In this way they also contribute to definitions of “deviance” and hence the targets of containment. The next chapter focuses on the technologies of governmentality (outlined in the *Introduction*) and modes of regulating the Roma “Other” beyond the relationship of doctors, patients, and medical professionals, thereby exploring the wider political context in which attempts at containment take place. Highlighting the context in which mediators operate also serves to show how mediators themselves are not to blame for the way in which they relate to community members, and that this relationship must instead be understood as part of a wider political dynamic between state institutions and marginalised communities.

*Image 2 - patient files in a hospital corridor*



## Chapter 5: Paper containers

Viorica and I were walking through Dacia City together when we bumped into a woman who recognised her. “This is Tania\*,” Viorica introduced her to me with enthusiasm, “I met her when she was 40 years old, and at that time, *nici nu exista* [she didn’t even exist]! So, of course, we sorted things out, we got her a birth certificate and now she even has an identity card, and so does her daughter, imagine!” Tania stood by, nodding in agreement, and muttering her gratitude while Viorica told me how she had made Tania into a citizen. Viorica often talked about people “not existing,” and by this she meant that they had no papers, that they were not official citizens. At first this struck me as an odd phrase, since Viorica came into contact with these “cases” as people, standing, alive, in front of her. But as I encountered more such cases during my stay in Dacia, I realised that she was ventriloquising the state’s perspective: since they were not registered, since they were *de facto* stateless, these people did not “exist” in the eyes of the state.

The title of the chapter, *Paper Containers*, is a reference to the filing cabinets, folders and notebooks that dominated the mediators’ working lives. The title is also a reflection of the way in which legal statuses determined by this or that piece of paper can impact people’s ability to access health care, as well as other rights, such as the right to education and even the right to free movement. I did not come to Romania looking for paper containers. But in one of my first encounters with a health mediator, in Movilă, where I observed Inna working for a week, I wrote in my notebook:

It’s strange being thrown into a life that I spent so much of the last two years trying to imagine. I think I’ve spent a lot of time persuading myself that things would be different from what I kind of guessed they would be like. I thought the mediator would be this intermediary figure, human and in the community. In fact, she’s entirely wrapped up in the whole bureaucratic nightmare of post-socialist workfare. She spends her day running between institutions to chase bits of paper. From my perspective right now the problem [with accessing health care] doesn’t seem to be inter-human relationships – it’s this paper labyrinth that is intrinsically exclusive for the poor and uneducated. The irony is that Inna is very attached to these papers and

doesn't see them as the enemy. They seem to be the things by which she measures her success - they seem to demonstrate her worth as a mediator.

In conversations, mediators spoke about their engagements with communities, the interactions they had with community members, and the education sessions that they had organised around health topics. When I observed them at their work, what they actually did on a daily basis mostly revolved around paperwork. No matter in which part of Romania I found myself, when mediators encountered a "community member," the first thing they would do was ask them for their papers: birth certificates, temporary identity cards, permanent identity cards, marriage certificates, divorce certificates, death certificates. If they could, mediators would photocopy them and place them in a file, which was their way of organising community members' paper incarnations. It was a routinised practice; people did not need to be asked for their papers. In most meetings with mediators, they would come carrying their papers – sometimes in a special folder, sometimes laminated, sometimes loose in a plastic bag – different containers for the precious papers that proved they existed, that they were citizens, and therefore entitled to certain rights. Among them was the right to be treated as patients. Even when people could not read or write, they came to the mediator bearing their lives in their hands in the form of official documents. This paperwork and bureaucracy became one of the most salient themes during the course of my fieldwork. Paper mediated interactions between institutions, but also between people.

This chapter shows how people's lives were contained within these pieces of paper, and how this paper had the ability to constrict people's field of action, both as citizens and as patients. It explores how paper produced and reproduced certain forms of citizenship, which in turn set limits on who did or did not have the right to be a patient. I aim to explore underlying assumptions behind, and processes of negotiation involved in mediators' "creating citizens." Analogously to their role in teaching people how to become good patients, mediators were tasked with the additional role of teaching people how to become "good citizens". Mediators promoted and facilitated a particular type of citizenship, namely a paper-based, documented form, as evidenced by the discourses and enacted practices that I encountered as part of my fieldwork. These amounted to yet



another form of “containment”, within which people were categorised as either deserving or undeserving of rights equated with documented citizenship. I illustrate how mediators promoted an individualist or neoliberal version of citizenship, focused on individual attributes, responsibilities and rights (similar to the forms of patienthood they promoted), while neglecting relational dimensions of citizenship, as well as the potential for negotiating rights and responsibilities.

The kind of effects that owning or not owning the “correct” paperwork can have on the lives of those perceived as Roma has attracted some scholarly attention. In a recent article, Ioana Vrăbiescu (2017) points to the ways in which state institutions can deny people their rights by not registering them at birth, or deregistering them on account of certain behaviours that do not conform with dominant ideas of citizenship. Cristina Rat (2013) shows how state-issued temporary ID cards create suspicious categories of citizenship that *de facto* deprive people of the possibility of employment and other subsistence-level requirements. Vrăbiescu touches on the Romanian state’s abdication of responsibility towards its non-citizens, noting that the registering or reregistering of citizens has fallen to third sector institutions. This fits with my observations of the Roma health mediation programme, which – being run by community members but through contracts issued by local and central state authorities – sat uncomfortably between state and third sector institutions. Building on my own observations, as well as the categories employed by Vrăbiescu, this chapter distinguishes three different categories of citizenship: documented citizenship (pertaining to those with permanent ID cards), conditional citizenship (those with temporary ID cards), and non-citizenship (those without identity documents), and looks at how citizenship is performed and negotiated in the context of Roma health mediation. Both Vrăbiescu and Rat mention that a lack of documented citizenship deprives people of access to health care except in emergencies. There has been little interrogation, however, of how “non-citizens” become conditional or full citizens. I investigate the kinds of assumptions that structure whether or not people are seen as deserving of such citizenship and the rights that accompany it, including access to free health care.

## **Mediation and documentation**

Since health care in Romania is funded through “mandatory” health insurance, those who do not have health insurance do not receive free treatment except in emergencies. A few exceptions are made for those who are deemed deserving of free health care even when they do not have health insurance: these include children under 18 and certain people with infectious or chronic diseases (HIV, TB, diabetes). In order to be covered by health insurance, people must either have an employer who contributes to social insurance (Vlădescu et al. 2008), be self-employed (in which case they must pay a monthly contribution to insurance out of their own pocket), or be officially unemployed. Official unemployment registration comes with a long list of conditions regarding, amongst other things, employment history; other forms of income; ownership of property, land, livestock, and commodities; travel restrictions; and periodic re-registration. In addition, those receiving unemployment benefits have to carry out a number of hours of community work (referred to henceforth as “workfare”) commensurate with the monthly allowance allocated to their family. In other words, there are many situations in which health insurance is practically unobtainable, even for documented citizens. In the case of non-citizens, however, the registration for citizenship was the first in a long list of procedures required to access free health care.

Because of this link between health insurance and citizenship, it became part of mediators’ tasks to sort out documents for non-citizens. Often this meant that mediators took on roles that are usually the responsibility of social workers. This fusion of their tasks as mediators and as social workers was often materialised in a spatial context, since their offices were often located in the town hall, and on a day-to-day basis many mediators had more direct contact with the mayor and other town hall officials than with any health professionals or public health authority. Mediators encouraged the attainment of documented citizenship among “Roma communities.”

To begin with, it is important to reiterate that the discourse and practice of health mediation is governed by the context in which it is forced to operate. The transition to

capitalism has long since introduced neoliberal modes of governance to Romania. The decentralisation process that accompanied the austerity measures introduced after the economic crisis of 2008/9 led to a monumental upheaval in the way in which the Romanian government was structured. As outlined in the *Introduction*, the Roma health mediation programme was majorly affected by this decentralisation process, as it had been a centrally financed health intervention. Decentralisation substantially increased the power of municipalities over the daily running of the programme, including their ability to hire and fire mediators, who have therefore become much more beholden to the whims of mayors or the departments they are attached to in the town hall's organisational structure. At the same time, austerity has reinforced neoliberal discourses and practices of governance: more suspicion towards the poor, more stringent checks on claimants, more cuts to benefits.

Roberta's position within the town hall was clearly demonstrated to me when I was observing her work one day and a community member from the village walked in, irate, complaining that his benefits had been cut. Roberta explained to him that this was because the office for revenues and taxes had found out that he had sold a piece of land, and that he thereby no longer qualified for the benefits he had been receiving. The next day, Roberta was called into the mayor's office. A day later, the claimant came back to hand in his claims for benefits again, and this time Roberta accepted them with gritted teeth. She later told me that the man had sold his land to the mayor, with whom he had a "special agreement". While it was not clear what this agreement was, the mayor had requested that the man's claims to be accepted and processed. Roberta was visibly downcast about the situation, and told me something along the lines of: "I know it's not right, but what else can I do? I might lose my job if I don't do what he tells me." Not all the mediators had such a direct relationship with the mayor. Viorica, for example, who was a mediator in a larger city, never had any direct contact with the mayor during my stay. She did, however, feel she might lose her job if she did not consent to those more powerful than her, as was demonstrated in her response to the cases of alleged sterilisation. The looming threat of being fired as a mediator is important to bear in mind when discussing health mediators' roles in paper containment.

## Hurdles to documented citizenship

In Romania, paper-based or documented citizenship is transmitted from one generation to another.<sup>22</sup> When a child is born, the mother is required to show her ID card before a birth certificate is issued for the child. If the child is to carry the father's name, the father also has to provide his ID card. The child's birth certificate serves as its official proof of documented citizenship until the age of 14. It gives people a CNP, or personal registration number, which is used as the basis for all interactions with the state. Without a CNP people are refused access to health insurance, official employment, all recourse to public funds (child allowances, heating subsidies, pensions, and so on), and sometimes even access to state schools. People without a CNP cannot legally cross borders, nor be registered as residents of a particular locality, as is also required by law. Even though everyone over the age of 14 is required by law to carry an official ID card, not everyone has one (Vrăbiescu 2017). These regulations, of course, apply to the whole population, not just the Roma. But lack of documented citizenship has been widely reported as an issue that disproportionately affects Roma communities (Council of Europe 2003; OSCE 2003; National Agency for Roma 2005; K. Kósa and Adany 2007; Colombini, Rechel, and Mayhew 2012; Wamsiedel 2013; Alphia Abdikeeva 2013). Below I indicate why this might be the case; however, in taking a non-essentialist and intersectional perspective it should be noted that this by no means affects all Roma. Mainly it is the poorest part of the population that is affected – those who are most likely to be categorised as Roma regardless. This is why the Roma health mediation programme has always charged mediators with obtaining documents.

Romanian governance, as is the case in many post-socialist states, is particularly meticulous regarding the number of documents that are required in order to receive official citizenship. Vrăbiescu (2017) suggests that this may have been inherited from a

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<sup>22</sup> In Romania (as in many other East-Central European countries), citizenship is generally acquired by the principle of *jus sanguinis*, that is, upon proof that at least one parent is a Romanian national. This is in contrast to *jus soli*, the principle according to which citizens become nationals when born within the nation's borders. For an extensive historical overview of how citizenship has developed in Romania see (Iordachi 2002), and for current laws on citizenship see ('Romanian Citizenship Law' 2010).

paranoid socialist surveillance apparatus that obsessively collected data on its subjects. Now that the responsibility for collecting these data no longer lies with the state, the demand to supply it has been transferred to individuals, independent of whether they have the means to provide the kind of evidence that is required by law. There were two principle reasons that people became non-citizens: the first was when somebody had lost their citizenship documents or status, and was unable to renew it. The second was when a person had never been registered at birth. In order to renew or reregister documented citizenship, one of the documents required is proof of address. This immediately makes it harder for communities who have less than stable accommodation, or those who live without documentary proof of residency (e.g. land titles, utility bills as proof of address etc.) to prove their citizenship (Amnesty International 2011). As discussed in *Containers*, this situation disproportionately affects “Roma communities,” especially those who have been evicted from nationalised housing stock, or those who live in informal settlements. In cases of late registration – a year or more after the birth – the process of receiving a birth certificate is arduous and expensive: it requires finding a record of the birth in the hospital, as well as the involvement of the police and a court hearing in which two witnesses testify to the person’s identity. If a child was not born in hospital (for instance, in an ambulance or at home), there would be no official record of the child’s birth, generating a whole host of complications that required more time and more money to overcome.

In Dacia City, I met two women, Mariela\* and Ioana\*, who highlighted the intergenerational nature of citizenship. Mariela was Ioana’s niece. Mariela had an identity card, whereas Ioana did not. Mariela had twelve children, all of whom had birth certificates, while Ioana had three children, none of whom had a birth certificate. Ioana’s mother, Mariela’s sister, did not have any identifying documents when Ioana was born. “How come,” I asked Mariela, “you have an identity card, whereas your sister doesn’t?” Mariela told me that she was the youngest of six children, and when her mother gave birth to her, she had the possibility to register the child; her older siblings had been born in a field next to a horse and cart, and nobody had ever asked their mother to register them. Thus, Ioana’s mother’s undocumented citizenship not only affected her, but was also

transmitted to her children, as well as her grandchildren, resulting in three generations of undocumented citizens.

What was it about poor Roma communities that meant that they were more likely to lack documented citizenship, or birth certificates? Mediators told me about incidents in which people lost all their possessions due to flooding or fires, including their birth certificates. Registrations of births were often delayed because the family wanted the child to carry the father's name, and the father was abroad for seasonal work, picking asparagus, strawberries, fruit and olives for Western European consumption. Families would wait until the father's return, which sometimes took longer than a year. One of the mediators told me about a case in which the father had pawned his identity card to somebody who had lent him money, and this led to his child never being registered. In this way, non-citizenship as well as documented citizenship is transmitted from one generation to the next.

Theoretically, it was possible for most of these undocumented citizens to become documented citizens. In practice, this transition cost both time and money (see Vrăbiescu 2017). The hurdles to becoming a documented citizen were granular, but they disproportionately affected those who experienced them as insurmountably large. One of these people was Anita. Anita had recently given birth to a boy, who was six weeks old. At home, she already had three daughters and a son. When I visited her in the small shack that the town hall had allocated to her and her husband after they had been evicted, she told me that she had not yet got around to naming her new-born boy. For the time being he had the same name as his brother: Anton. "They have forced me to give him a name so I can find him in the hospital, because he doesn't have papers." She would have to get him a birth certificate eventually, she said, because she would need it if ever he got ill. In order for him to be seen by a doctor, she would have to present her own identity card, along with the boy's certificate. "They can't help you without the proper documents, they say that the child isn't registered," she explained. But she could not register him, she told me, because her identity card had expired. The officials at the town hall refused to renew it without her first paying the mandatory fee of 6 lei (£1.20). She would have to get new

passport photos, which cost 15 lei (£3). On top of this, in order to get the boy's birth certificate, she had to go to the hospital to get his proof of birth from the maternity ward, before going to the town hall itself. The bus ride into Dacia City was 7 lei (£1.40) each way, meaning that the whole procedure would cost her at least 35 lei (£7). She did not have money for these small fees since, as she told me, if she got her hands on a 10 lei note she would use it to buy food for the family. Even if she had paid all these fees, it was unclear whether the municipality would issue her a contract to say that she was living in the small shack that she had been allocated after her eviction. In the face of her poverty, as well as the uncertainties surrounding her residency, it seemed unlikely that she would have Anton registered before his first birthday. Without this registration, he may be unable to attend school; certainly he would not find official employment without his CNP.

## **Producing and reproducing documented citizenship**

Identifying undocumented citizens and providing them with an official identity was one of the tasks that mediators took most seriously. Mediators spoke of this task as complex and often arduous, but also honourable. They sounded excited when they talked about it. At least some of this energy might have come from the fact that unlike many of their other tasks, creating documented citizens was a discreet, quantifiable action with an immediate, potentially transformative outcome for community members. On another level, however, this was a task through which the mediators aligned themselves with the state. In addition to their task of creating “good patients” (as discussed in *Containment*), mediators were involved in “creating citizens,” which – analogously – involved teaching non-citizens to become “good citizens”. Often this meant making sure that community members fulfilled their social responsibilities toward the state.

Mediators identified “non-existing” people, those who had never been registered with the state, and guided them through the processes that would lead them to becoming citizens. Many of these cases were infants or children who had missed the registration

window of one year, but, as in the case of Tania, mediators occasionally also identified adult non-citizens. This was one of the purposes of *catagrafiere*, where – as discussed in *Containers* – mediators established an “inventory” of their area by going from house to house, asking people about their health, but also their status with regards to documented citizenship. Aside from this process, the identification of undocumented citizens was an ad-hoc affair, as I demonstrate below. Mediators did not actively seek cases, but would often come across them in their daily activities. I witnessed one of these occasions when I was having lunch with Viorica in a fast-food stall outside the train station. We were approached by a young woman with a baby in her arms, asking for spare change. “*N-am bani*,” (I don’t have any money), Viorica told the woman, quite brusquely. “*N-am bani*,” I repeated after her, trying not to meet the woman’s eyes. But just as the young woman was withdrawing, Viorica called her back. The girl reversed and stood by our table, expectantly. “What’s your name? Where are you from? What are you doing here?” Viorica fired the questions at the young mother, who answered obediently. “Do you have an identity card?” Viorica asked. “No.” And your little boy there, does he have a birth certificate?” - “No.” - “And your mother, does she have an identity card?”- “No, she doesn’t either.” - “*Aoleo!* (oh dear!)” Viorica exclaimed, clasping her hands over her head, and meeting my eyes. “You see, here’s a case, a person without documents.” Viorica had an entire folder in her office of cases like this, waiting to go to court, in order to receive an “official identity.” But being the third generation without official documents meant that it would be very hard to turn the people stood before her into citizens.

With her Schnitzel sandwich half finished, Viorica got out one of her many notebooks from her handbag, and started writing. “What’s your date of birth?” - “1989.” - “Where were you born?” - “In the hospital of X.” - “How many children do you have?” - “Four.” - “What are their dates of birth?” - “One is four, one is two and a half, one is one and a half, and this one is eleven months old.” The young mother couldn’t remember their exact dates of birth. “*Aoleo!*” Viorica exclaimed. For Viorica, “*aoleo!*” seemed to be an expression of mixed feelings – on the one hand she was aghast that this woman did not have papers and did not know her children’s birthdays. On the other hand, I felt a certain excitement in her exclamation: she had identified a case, her role as a mediator was



validated and important. She scribbled down the information in her notebook. The young woman was from a different town, one that had its own mediator. Viorica wrote down the name of the mediator, tore the page out of her notebook and handed it to the young woman. “Listen,” she said, “When you get home, go to the town hall, and ask for this woman. But go with your mother, it’s very important that you go with your mother, do you hear? And it’s very urgent, you need to go sort out your papers immediately.”

This encounter highlights several aspects of how mediators participate in the production and reproduction of documented citizenship. It shows the chance nature of the incident. Normally, Viorica spent her days in her office. People like this young mother did not know that there was a designated Roma health mediator who could help her not only with questions of health, but with her and her children “becoming citizens,” and thereby attaining health insurance. Viorica’s initial reaction to the woman made me question whether she would have called her back if I had not been there. It was as though she had forgotten her role as a health mediator, and joined the other people in the café in gesturing to her to leave us alone. Only when she looked back at me, and remembered that I was there to observe her in her capacity of health mediator, did she call back the girl. Although I evidently cannot say for certain, I had the feeling that had she been alone, she would not have called her back. As a mediator she did not leave the office much. People outside of her office did not know about her existence. This meant that the meeting of mediator and non-citizens seemed to rely either on referrals, or on complete accidents such as this. Viorica focused immediately on the young woman’s citizenship status. During their whole interaction, she did not introduce herself as the health mediator, she did not enquire about her health, or her children’s health, or any other aspect of her wellbeing. First and foremost, she was interested in whether or not she had valid papers. She did not explain why it was so urgent for her to sort out her papers, or invite any questions about the process. Even though she could have explained that there were pragmatic reasons why she should become a documented citizen, for example to get health insurance, child allowances, or unemployment benefits, she did not. Instead, she presented the need to become a documented citizen as an imperative, whilst presenting citizenship solely in its paper incarnation.

The interaction speaks to a more general discourse on citizenship that I frequently encountered. Mediators appeared to be more concerned with people owning the right piece of paper than with what the piece of paper would do for people once they owned it. In their interactions with community members they promoted a normative idea of what it meant to be a documented citizen, one that emphasised compliance with institutional expectations over the enactment of citizens' rights.

It was this paper form of citizenship that mediators not only discursively promoted, but helped to enforce. In a mediator training session that I observed, a group was presented with the case of an individual, who, for some reason or other, lacked one of the required pieces of paper to register or renew their citizenship or health insurance. Mediators were then tested on their knowledge about how to negotiate the bureaucratic pathways to obtaining citizenship or health insurance. The teacher (an experienced mediator) located the problem of citizenship at the level of the individual, and so mediators were taught to approach the solution at the level of the individual. At no point during this training day did the mediators or the trainers depart from this individualist approach to the production and reproduction of citizenship. While on the one hand this meant that mediators could focus on the specifics of each case, it also conditioned their understanding of citizenship as something determined by a piece of paper, detached from the human being in question. In conversations with me, mediators did not express criticism about the rules that made it disproportionately difficult for poor people to attain the paper that proved their citizenship, nor did they encourage those who were affected to question these rules. On the contrary, by aligning themselves with institutional discourses, mediators formed a part of the state apparatus that normalised these procedures. As I show below, mediators reprimanded those who were not compliant. In addition to normalising the convoluted and often repressive mechanism of exclusion from citizenship, they fulfilled a moralistic role within the discourse around paper containment. As the example below illustrates, if someone was a non-citizen, or if somebody did not have health insurance, it was not only their fault: it was their fault because they had behaved incorrectly, or because they were a bad person.

Unsurprisingly – given their training – when I asked mediators about why they supposed some people struggled to have their papers in order, they gave answers that assigned blame to individuals. In Colină, I spoke to Nina\*, who used to be the mediator before Roberta took over the position. She came from an educated family, and was the only person in the village who spoke Romanes. She herself identified as Roma. She also told me that in her experience, it was only Roma families that did not manage to get their papers in order. She said it was because they were “very sluggish.”

I never understood it. They tried to explain it to me, but I simply think that they are lazy. Because during the first days after delivery, the second or the third day you must find time to take the papers from the hospital and to come here to the city hall. No, they postpone, and they keep on postponing, until they run out of time. [...] When you return with the child from the hospital, you need the child’s certificate, and your identity card for the town hall in the village, or for social assistance in order to receive the allowance offered by the Romanian state to children, this is a guaranteed right. As a parent you haven’t been sufficiently conscious of why it’s compulsory to do this, and you’ve destroyed the child’s right even from birth.

Not only did Nina consider individuals at fault for not sorting their papers on time, she thought it their fault for not being “sufficiently conscious” of the consequences this would have for the child. She talked of this as an act of “destroying” the child’s potential future rights. Instead of holding the state accountable for not guaranteeing rights to a child that was born within its national boundaries, she blamed the parents.

My observations of health mediation in practice suggest that mediators saw the framework for obtaining citizenship as rigid and impossible to challenge. They did not see the system as being in need of correction. Instead, they tried to make people comply with this specific formation of citizenship. This dynamic was highlighted to me in an encounter I witnessed between Viorica and the family of a 15-year old girl, who had given birth prematurely, and whose baby died when it was just two days old. The hospital was refusing to release the body of the baby, until the right paperwork had been filled out. The hospital staff sent the family to Viorica, with the expectation that she would help them.

The young mother's own mother came into Viorica and explained her situation. Viorica slowly lifted her body off her chair. "Aoleo!" she exclaimed characteristically, slapping her hand on her forehead. Without being asked, the woman dug out a card and a folded piece of paper from a crumpled plastic bag, and handed them over to Viorica. She examined them briefly and then put them under her new photocopier, a gift from one of the big Roma NGOs. The card was the woman's identity card. The other piece of paper was her daughter's birth certificate, folded and unfolded so many times that only a few fibres prevented it from falling apart entirely. "I also need a copy of your daughter's identity card," Viorica said, hand outstretched. "She doesn't have one," the woman replied. "How old is she?" - "Fifteen" - "She should have one, all children above the age of 14 should have an identity card," Viorica said with her back turned to the woman, fiddling with the photocopier. "You should have sorted her documents by now, you know," Viorica told her.

The hospital would not release the body without a death certificate, and the office responsible for issuing the death certificate would not issue that without a birth certificate. The baby had not been given a birth certificate because the mother did not have an identity card when she had given birth. Viorica sent the family to the hospital birth register, to get a copy to prove that the baby had been born in Dacia City hospital. But, as it turned out, the young mother had given birth not in the maternity ward but in the ambulance, without a doctor present. Viorica sent them to the neo-natal department, which the mother had visited since giving birth, but there the doctors refused to write a note, since they had not witnessed the birth with their own eyes. Next, Viorica sent the family to the police station, to make a declaration, so that they would issue a temporary ID card for the mother, and make a statement about the child's birth and death. They should then take this to the morgue, where the forensic doctors would issue a document certifying the child's death. They would then have to take all these documents to the registry at the town hall, which would issue a formal death certificate. This should be brought to the staff of the morgue, who would release the body. The interaction illustrates on the one hand the lack of trust on the side of state institutions towards non-citizens. They did not receive proof of birth of a new-born child, or proof of death, the child then

died. It was not enough for the young woman to give birth on her way to the hospital, and lose the child while she was physically in hospital. As a non-citizen who had not given birth within the institution of the hospital, both her and her deceased child were denied their rights as citizens.

Viorica took the institution's point of view: instead of pointing to the absurdity of the situation and seeking a pragmatic solution, she turned on the family, reprimanding them for falling short of their responsibility to sort their daughter's identity documents after she got married. But as well as reprimanding them, she also paved the way for them to "correct" their behaviour: she gave them precise instructions that would lead to the family complying with state expectations regarding the ownership of documentation, pushing them towards the citizenship of the documented, traceable individual. This form of individual blame did not take into account what the value of citizenship might be, beyond the fact that it was a legal requirement. Presuming that the body was eventually released – which I never found out since the family did not return – this interaction had a positive outcome for the family. The mediator helped them to overcome hurdles that the hospital administration was unwilling to traverse. However, there was no in-depth engagement between the mediator and the family. Viorica did not initiate a dialogue between the hospital administration and this family who were evidently both confused and in shock. Viorica's interaction was monological. She did not, for example, negotiate with the hospital staff directly, trying to get them to change the way they managed the case. Instead, she portrayed the family, rather than hospital rules, as the problem, and communicated to them how they should comply with the regulations.

What Nina ascribed to individual "laziness" was, as I have shown, often the result of institutions' refusal to issue the necessary documents. It is true, though, that at other points it may have been related to a reticence on the part of individuals to go to the effort of filling in the enormous quantity of forms, and taking all the right documents to the right place at the right time. People of whom this was demanded recognised that even those people around them who were documented citizens did not necessarily have access to housing, employment, education, or health care. I wondered whether people asked

themselves what difference there was between being given nothing as a documented citizen, or being offered nothing as a non-citizen. If the difference between the category of documented and undocumented citizen was not tangible to the individual to whom it was being applied, what would be their motivation to go to the effort of complying? Perhaps community members engaged passively with the practicalities of gaining paper citizenship because what they gained from documented citizenship did not seem worth more than the piece of paper it was written on. Documented citizenship did not guarantee the things that mediators used to advertise it: health insurance, social benefits, and child allowances all remained elusive for many of the people I met, despite having citizenship in paper form.

Never was this made clearer to me than in the cases of those people who had been evicted from their homes. The people in Eforie who had been moved into shipping containers, for instance, were Romanian citizens, many of them with valid and permanent identity cards. Their children had birth certificates, and they themselves had a house; many of them even had jobs (as street cleaners, for example, employed by the municipality). Their citizenship did not protect them from waking up one morning to the sound of bulldozers crushing their houses. In other words, it did not offer protection from hardship, and it did not protect from state-sponsored violence. What was documented citizenship worth, if it could not even do that?

## **Policing the boundaries of documented citizenship**

The way that mediators promoted, enacted, and policed citizenship was intimately connected with the ways in which “Roma communities” were spoken about more generally by mediators, health professionals, and community members. People made cultural rather than structural arguments about why Roma did not have identity documents. They linked the absence of papers to cultural traits of carelessness and laziness, rather than connecting it to questions of economic and social precarity. Such undesirable attributes, along with similarly problematic constructions of Roma as “dirty,” “diseased,” and “overly fertile” were mapped onto the very notion of what it meant to be

Roma. They were seen as undesirable and in need of correction and containment not only as patients (see chapter on *Containment*), but as citizens.

“Roma communities” were often constructed by health professionals as falling short of the ability to be “good citizens.” As shown in the previous chapter, mediators taught people how to become “good patients”. The mediators’ role in creating citizenship was comparable: they were tasked with the role of teaching people how to become “good citizens.” In some instances, this involved not only registering them with the state for the first time, but actively policing their behaviour as citizens, for example by ensuring that they performed work in exchange for social benefits, or by personally trying to get them into forms of employment.

Not only were mediators’ perspective often aligned with local authorities, mediators were often also spatially associated with state authorities. Many of the mediators’ offices were physically located in the town hall, which they would sometimes share with social workers. In Coli n , Roberta not only shared an office with the village social worker, she also took on tasks associated with social work for the majority of her working day. This was not unusual: I heard reports of this happening in many places. Roberta did not volunteer for this role; she had been pressured into it by the mayor, who saw in her a useful additional worker whom he did not have to pay from the municipal budget since her salary was paid for by the Ministry of Health. When I spoke to the mayor, he was not particularly interested in the *Roma* aspect of Roberta’s job, especially since from his perspective there were only a handful of people in the village who he could legitimately call “Roma” (see *Containers*).

Instead of highlighting the discrepancy between her supposed role as a health mediator and her actual role as a social worker and workfare enforcement officer, Roberta embraced the two, and – at least in my interactions with her – she maintained that they were compatible with each other. As a social worker, she spent her days helping people make claims for benefits that they were entitled to. In this capacity she was facilitating a certain form of citizenship, since the process mainly involved checking that people had no

undeclared income, that they had filled in the right form at the right time, evaluating them and calculating how much money they would get for the month. In this sense, she was enabling people's access to their "rights" as documented citizens within the weak net of Romanian social security. But her job exceeded this, inasmuch as she was also involved in policing the boundaries of this citizenship by making sure that people in fact were deserving of the benefits they received. Calculating benefits also involved calculating the number of "workfare" hours that their benefits would translate into. In addition to this, Roberta was occasionally charged with "monitoring" people during their workfare. In Coli n , workfare took the shape of clearing ditches with scythes, cutting grass in communal areas, or clearing litter. If people were found not to be working, they would lose access to their benefits. If somebody failed to meet the conditions of "citizenship" set out by the town hall, they were seen as undeserving of their "citizen's rights."

Whenever I questioned Roberta on this aspect of her work, she defended it – sometimes, I felt, with pride. For her, I sensed, this was her way of teaching people how to be good citizens. Roberta justified her policing of the community, saying it was just as well that 80-90 per cent of the people doing workfare were "Roma," because in this way she could spend the whole day with them, which gave her the opportunity to do health mediation in a way for which she did not otherwise have time. I asked to join Roberta on one of these "workfare" days. I was curious to see how she combined the tasks of community "policewoman" and community "mediator," two roles which, to me, seemed mutually exclusive. It was a scorching hot day, and, to my surprise, the people who turned up were mostly teenagers who were performing the required "workfare" labour in place of their parents, their uncles and aunts, or grandparents. A few mothers showed up with their young children. They arrived with their own scythes, and one man had brought his horse and cart to pull the hay down the road as they proceeded. They worked from ten till three, at a consistent but leisurely pace, chattering and joking while swinging their scythes from side to side, clearing the ditches on the side of the road to make way for a new concrete gutter, sweat dripping from their brows.



Roberta's role in monitoring people during this "workfare" was to give instructions as to which sections of the road needed clearing, and to stand next to them while they were performing their labour – in order, she said, to prevent accidents, but also to check whether everybody on her list had been physically present until the end of the day. She did not trust these people: if nobody monitored them throughout the day, she explained to me, people would just sign the register in the morning and in the evening without having done any work in the meantime. I asked what she did when people did not turn up, and she said that "unfortunately" she had to register them as absent, even if that meant that they would not receive their social allowance for the month: "That's the law." As to her task as a mediator, this seemed performative on the day. Roberta would go up to individual people, nudge them my way, and tell them to speak to me about their concerns. When they did, they told me about their inadequate houses, about the lack of employment in the village. They spoke of Roberta as a good person, someone they could turn to. Meanwhile, Roberta glanced over in our direction every so often and I could not help thinking that my interlocutors were just as aware of her gaze. Ultimately, I cannot say whether the people performing "workfare" on that day saw Roberta more as a "policewoman" or as a "mediator." I had not previously met any of them, and because I arrived at the site on the back of Roberta's scooter (visually indicating a closeness in our relationship), and because when she introduced me she did not specify what my relationship to her was (she merely told people that I was a student from England), it did not seem like the right context to gauge people's honest thoughts on Roberta's role in their lives.

On a different occasion, however, I was talking to Adela about Roberta's role in the village. Adela and I had become acquainted independently: she was the mother of a friend of mine. Since she associated me with her daughter rather than with the town hall, and since she generally displayed an irreverent character, I felt that she was upfront with me about how she felt about various people in the village. She spoke about Roberta in hostile tones. She called her "a devil," "a thief" and "a rascal." She said she only came to people's houses to announce that they had to go to workfare, or when their social benefits were ready for collection. Otherwise, Adela said, Roberta just sat in the municipal office "like

a bear.” Although I was not exactly sure what she meant by this, it was not meant to be flattering. Most of the other people I spoke to, including Maria and Ana, also thought of Roberta as a social worker and knew nothing of her job as a Roma health mediator. In short, there was little to suggest that Roberta’s role as mediator was perceived as compatible with that of “workfare enforcement officer.”

Roberta’s role was ambiguous. Because she spent her days at the town hall, the cost of this spatial conflation was that community members identified her with the state powers. They saw her as somebody who was not there to help, but to enforce the rules of the state: if necessary, against their will. Citizens’ right to social assistance was conditional on the performance of certain responsibilities (i.e. workfare), whose enactment was policed not just discursively, but physically by Roberta, even though she was appointed specifically to be a mediator between authorities and the community. Roberta’s role in Colină was simultaneously to serve the community’s interest, and to embody the law and act as an “informant” for state authorities. The former served – at least nominally – to empower the community, while the latter served to disempower them. The two roles could not convincingly be contained within the same body. The one that carried greater weight with the mayor, namely that of social worker/ “workfare enforcer” prevailed over that of health mediator. It was up to her whether people would continue to receive social benefits, or whether they would be cut loose. She thereby not only policed people’s enactment of “good citizenship,” but also the access to people’s livelihoods. What was particularly surprising to me was that when she was told to do so by the mayor, Roberta approached this task not with ambiguity, but as her moral duty. Considering Roberta’s position on citizenship, it came as no particular surprise that people in the village like Adela did not feel like they could trust her.

Having said this, I should also emphasise that not all mediators had the same draconian approach to social benefits. Inna from Movilă, for example, spent much of the days in which I accompanied her taking pieces of paper from one authority to the next, ensuring that people received the benefits to which they were entitled. With a twinkle in her eye, she told me she was thoroughly prepared to bend the rules:

If we stick to the job description we will never finish [helping people]. Yeah! We can't finish. Never. You see, it says: 'this is what the law demands.' If we work by the law, we can never solve [our cases]. I can tell this from my own experience. Even I, sometimes you have to lie to them in order to solve the poor man's problem. Yeah! This is how I am.

She told me proudly about the clever ways in which she had managed to get the local authorities to retrospectively sign a dead man up to social benefits on account of the chronic illness from which he had died, so that his family would receive a “funeral allowance” to bury the man. On a small scale, and given the overall discourse that prevailed in health mediation, this achievement (and perhaps many others of this kind) seemed to be an important act of counter-conduct: while still operating within the existing state framework, Inna exploited it to suit community members rather than the state. Amongst the mediators I spoke to, however, this approach remained an exception.

### **Paper citizenship, rights, and obligations**

The way in which mediators interpreted citizenship was important, given that their interactions with community members focused so heavily on the process of “creating citizens.” Recalling Viorica's interaction with the woman we met outside the fast food stall, her interpretation of “citizenship” was narrow, focusing on the piece of paper. I have demonstrated how this concept of citizenship-as-documentation created a series of “paper containers” that delimited the social possibilities (including access to health care) of Roma communities ill-equipped to respond to institutional demands. However, this paper fixation also played into another aspect of mediators' conceptualisation of citizenship. Through our conversations and other interactions with people who came to her for help, I saw how Viorica applied an idea of citizenship that focused on broader questions of “rights and obligations.” This focus was promoted in mediators' training, but it also seemed to be a part of a much broader discourse, repeated refrain-like by mediators, health professionals, and community members alike.

In a focus group discussion, a couple of mediators complained about a particularly marginalised Roma community they were working with. “They believe they have only

rights, never any obligations” – “no obligations,” another mediator chimed in. This neoliberal narrative was related to the question of what could be reasonably expected from citizenship, and consequently in what capacity they were able to enact “correct” forms of patienthood: no access to rights without first fulfilling obligations. What were these rights and obligations, and what do they say about the kind of citizenship that was being advocated? How does it relate to the way that health was being constructed, and the kind of patienthood that was being promoted or excluded?

In my conversations with them, both Viorica and Roberta spoke about something that went far beyond their remit as health mediators. Rather than talking about “health” *per se*, they were in fact addressing the question of “how to be a good citizen.” Their notion of citizenship was derived from neoliberal premises: citizens were individually responsible for their rights, which were granted on condition of performing certain obligations within a system that valued human and social capital. Obligations included working, paying taxes, and being good parents by sending children to school. Analogously, Viorica told me that patients had certain rights: “the right to life, the right to health, the right to education, the right to protection, the right to anything.” But, she countered, they also had certain responsibilities: “towards the family, the authorities [...] they must pay taxes [...] to take the children to school, to look after their health and education, right? They have the right to work, but they also have the obligation to work.” This perspective on citizenship seemed to be more closely aligned with state-level concern with activating parts of the population in the name of the economy than with empowering community members to actively take part in political processes.

In a strikingly similar discourse, Roberta reasoned that “Roma” were currently not seen to be legitimate members of this society because they were not complying with their responsibilities as citizens. Too many of them, she said, were unemployed, not paying taxes, and not bringing up their children correctly: if people expected public institutions to help them, she said, they had to comply with the law. She argued along homogenising and essentialising lines, emphasising the cultural uniqueness of the Roma: she thought “they” (by which she meant “the Roma”) “aren’t used to this. They are used to being free.

Without laws, they don't comply with anything. Hence, as mediator you have to teach them, to get to the phase where they all have identity cards, and certificates, to have a job, and access to education." Roberta not only linked lawlessness with "the Roma," she also suggested that there was a developmental hierarchy, that the Roma had not "yet" reached the phase in which they knew how to be "good citizens," they were "still" in the phase of being "free," which in this context had connotations of being primitive. Roberta saw it as her job to improve the situation of "the Roma" in Coli n . One of the ways she said she could do this was to go about finding work for people herself: another example of how she tried to construct citizens from within the population that she was serving. She told me that she had personally found work for 300 people. "I managed to convince them that it's not good to depend on social allowance," she said, and now some had even built their own houses.

As well as attempting to promote a certain type of citizenship, as in the example above, part of a mediator's role was also to chart the boundaries of health by delineating who did and who did not have the right to be a patient, a categorisation closely linked to people's citizenship status. One day, a woman came to Viorica's office in Dacia, asking for advice about having an abortion. She was from Uscat\*, facing her third eviction in the space of a short number of years. On the surface, their interaction was about accessing health care. Underlying it, however, were Viorica's presumptions about the responsibilities that a citizen had to fulfil in order to qualify for (or even deserve) access to free health care. The woman had nine children and was eleven weeks pregnant. "I don't have health insurance, and I am not registered with a GP," she told Viorica. "And why don't you have health insurance, or a GP, it will be very difficult without being registered with a GP. You will need to see a private doctor for the abortion." "How are we going to pay for that," the woman implored? "Does your husband work?" "No, he doesn't" "Do your children go to school?" "No, they don't." "That's against the law," Viorica told her, "they could send you to prison for that. Why aren't they at school?" "Because nobody came to get them..." Viorica indicated that it was because of the family's own failings that they were uninsured (they would have been, if the husband had been employed). Perhaps as a result of this, she did not show the pregnant woman much sympathy. It would cost 2,500 lei, Viorica told

her, and gave her the name of a private doctor to call. As the woman left, Viorica turned to me, with a remark along the lines of: “why, when the woman knew that she might be facing eviction, and when she already had nine children, why would she do something so stupid as to get pregnant again?” I indicated that I thought it might be related to access to contraception. She countered, saying, yes, it was about access, but that the problem was that she had not registered with a GP, or else she would have access to free contraception. The interaction started as one about obtaining access to health care. It ended up being about correcting the woman and her husband’s behaviour as citizens.

I asked one of the people who was involved in the foundation of the Roma health mediation programme, and consequently in the training of mediators, why they thought the “majority population” did not have a mediation programme. Their answer strongly suggested that the “majority” did not need mediators because they already knew how to be “good patients” and “good citizens”:

When you [...] receive an early education, and step into the labour market, then you get a job, I don’t know, you attend college, anything. The system teaches you, [...] how to see the practitioner, what to do when you have a medical problem, how to pay taxes, how to pay your contributions. What you need to do in order to be equal to the other. In fact, we are speaking about civic culture, right? A citizen’s culture. How you must behave, what are your rights and your obligations, as citizen.

There is no way of knowing whether mediators had similar attitudes towards “civic culture” before they completed their training, or whether this kind of discourse of citizenship “responsibilisation” (van Baar 2011, 173) filtered down through their training. Either way, it was so commonly recited by mediators as to be one of their main mantras. Lavinia in Movilă neatly summed up the role of health mediators in the transformation of people: “Me, as a health mediator, I need to change something in the collective mentality, to bring them to a common ground, [regarding] the national regulations and to their civil rights and obligations relating to any problem.” As I have shown throughout this chapter, the first step in this process was often the acquisition of the correct, legitimising pieces of paper – the willing entrance into the world of paper containment.

### **Child protection as policing of citizenship: an example**

One of the national regulations that mediators were peripherally involved in related to child protection. Two incidents occurred during fieldwork that suggested health mediators' involvement in "policing citizenship" extended into active involvement in decisions about who was and who was not fit to be a parent. The first of these incidents was an allegation by a community member towards Viorica, one which I was unable to confirm or disprove, but which stood out painfully as a display of distrust towards mediators and their alignment with state authorities perceived as direct threats by vulnerable community members. When I spoke to Aurelia\* from the evicted community in Uscat about Viorica, she immediately expressed her violent dislike of her ("I don't even want to hear about her again, she is an unbearable woman"). When I asked her why she thought this, she said: "She makes me fucking laugh. She comes here, she goes to the city hall, and she calls the Child Protection without our knowledge, but she's lucky to have stayed away from us otherwise I would have broken her neck." The Child Protection Agency had come to her house and threatened to take her children into state care. She firmly believed that the Child Protection Agency had been sent by Viorica, apparently because the person who had come told her that the mediator had sent her. As a result, she wanted nothing to do with her, not even to hear her name pronounced.

While it is hard to tell how much her interpretation of events corresponded to what had actually happened, I witnessed a very similar incident first hand in another case involving Roberta. In Coliță, one of the families living on my street had caught Roberta's attention. She told me that she had found the mother drunk, and unable to take care of her children, who were being neglected as a result. Roberta thought the children to be in immediate danger and asked Child Protection to urgently intervene and place the children in state care. I accompanied her on a visit she made to their house after she had issued a warning to tell them that their children may be taken away. On our way there she dropped

by the local police station to ask for back-up. The officer on duty said he was busy, so we went to the family's house without the police escorting us. The family hesitantly opened the door and Roberta let herself into their yard. They were neither hostile nor aggressive. Later, I asked her why she had felt the need to bring a police officer to the meeting.

Roberta: I need the police intervention in addition to my involvement because they have to arrive on site, representing the institution that can issue a fine or can start a crime investigation or other things [...] related to misconducts. It's a crime to hit your child. It's unlawful to hit your child and so on. It's also an offence to get drunk and start making noise because you have disturbed the public order. It's misconduct. So there are some things that I can't do, but the police can. Therefore I go to the police and ask for their support.[...]

CK: And what would the police have done?

Roberta: They would have gone there and forced her to stick to her business, to stop consuming alcohol, but no one can be forced. But they would have prevented her from interacting with the children through a criminal investigation. And this would have helped me a lot.

CK: So the police's role is to frighten them.

Roberta: To scare them and to act in case they're not impressed. [...] it would be impossible without the police involvement because they aren't scared of anything. It's easy to imagine that I don't have any means of kicking some sense into them or to do something else. I do, talk with them, and in case, anyway, even if I talked with them and they understood by committing to take some measures, still I have to send the police over because it has a double effect on them and they finally understand that it's not something to mock [me] about.

In short, Roberta sought the help of the police to reinforce her own messages in the community and to scare people. She thought the police could help create order in the community. She seemed to think of the police force as her allies, an authority that she could rely on to increase her power in a chain-of-command structure that saw the community members at the bottom, her above them, and the police and the law at the top.

Both of these incidents were shocking to me, because they were the exact opposite of how I had imagined the health mediation programme to work. While I do not wish to make any claims about whether or not Viorica was in fact involved in Aurelia's case, the mere perception that she could be speaks volumes about how she was generally perceived, not as an ally of the community, but as closely bound up with state institutions that they feared. In the case of Roberta, her heavy-handed approach to conflict resolution, and her



readiness to involve the police in a matter that she could have approached by herself further clarified to me why somebody such as Adela (who had previously denounced Roberta as a “bear”) would have a healthy amount of suspicion towards her.

Mediators’ endorsement and encouragement of documented citizenship had the aim of helping “Roma communities” to integrate into Romanian society, as well as enabling them to attain the “rights” they were entitled to. This in itself must be framed as an intentional improvement on the lives of those who are often denied rights (including access to health care) because they do not have the correct documents. However, because mediators tended to focus on rules and regulations, they understood citizenship remotely from its wider political context. Because of their endorsement of the (paper) conditionalities that were attached to citizenship, mediators were involved in the production and reproduction of a particular, neoliberal type of citizenship and hence patienthood. They worked with categorisations that were neither emancipatory nor politicising, but derived from an instrumentalist perspective that served the purposes of health professionals and local state authorities. An unintended consequence of health mediation was therefore the reinforcement of conceptual overlaps between “being Roma” and a number of socially undesirable attributes. Many mediators did not challenge, but instead promoted the idea of Roma as a natural and given category of people who constituted a problem for Romanian society because they were “bad patients” and “bad citizens”. This is dangerous in that it stabilises, perpetuates, and entrenches the position of “Roma communities” at the margins of Romanian society.

Given their position within the political structure of local authorities and in the health system, mediators did not have much choice in the kind of work they were tasked with. Equally, the way in which they approached their tasks was structured by wider neoliberal discourses and enacted practices. As I shall discuss below, the mode of health mediation that involved correcting and disciplining community members into certain behaviours as patients and as citizens has to be understood as part of this wider political context. This includes mediators’ immediate working surroundings (town halls, local authorities, hospitals, GP practices), the way in which the programme was designed and is currently

managed, as well as broader national and international discourses about the kind of position that is desired for Roma populations (and ethnic minorities more broadly). Having portrayed mediators as “informants,” “policemen,” and enforcers of neoliberal notions of patienthood and citizenship, it is important to emphasise that the mediators themselves are as little to blame for their enacted practice as individual community members are to blame for their position in society. In order to underscore this assertion, let me consider their role, once more, from a theoretical perspective.

## **Discussion: unpacking paper containers**

When I began my fieldwork, I did not expect to find mediators so embroiled in paperwork. To begin with, I thought of these acts of carrying around scraps of paper as something that was intimately linked with mediators’ role in facilitating access to health care for community members. In a narrow sense, that is what they were. But in a broader sense, these pieces of paper are connected to the task of setting limits on who does and does not have the right to be a citizen. Mediators were often co-opted into this discursive and enacted task, one that lay outside of their official remit. Nevertheless, as this chapter has sought to underline, who counts and who does not count as a patient is closely intermeshed with who does or does not count as a citizen. Similarly, how to be a “good patient” is interlinked with how to be a “good citizen”. Mediators’ interpretation of citizenship was important because – unlike what I had expected prior to fieldwork – so many of their interactions with community members revolved around the processes of “creating patients” and “creating citizens”. As such, every comment or observation on citizenship is necessarily also a reference back to the figure of the vaunted, socially legitimising paper that came to govern interactions between mediators and communities and between communities and the state.

### **Bringing an intersectional understanding to documentation**

The connection between being Roma and not having documents is an easy one to make. As I have shown, the literature – both consensus narrative and more critical approaches

– is replete with assertions to this effect (Vrăbiescu 2017; Cook et al. 2013; Duval et al. 2016; European Public Health Alliance 2016; Danova-Russinova 2006; Mladovsky 2007; Singh 2011; Paunescu 2010). However, what is sorely missing from these claims is an intersectional approach that recognises how, for people who lack documents, or who are trying to obtain them, class and ethnicity collide and reinforce one another, forming often insurmountable hurdles that ultimately keep them in the category of undocumented citizens unable to enact their rights. No doubt ethnicity is an important factor, and it is easy to imagine that people are discriminated against by whomever is making decisions about their claim to citizenship on account of their skin colour, their name, or any other external marker that may point to their “Roma ethnicity”. Indeed, plenty such cases have been documented elsewhere (Danova-Russinova 2006; Colombini, Rechel, and Mayhew 2012). However, during the year I spent doing fieldwork, I did not witness this as the dominant mode of exclusion. The people who were excluded from citizenship who I encountered were referred to by mediators and others as Roma, but they also shared another characteristic, which was not voiced in the same way: they were poor, some of them only just surviving, many of them illiterate and homeless, or in danger of losing their homes. They were excluded not because of some obvious case of discrimination against them, but on account of the fact that they could not afford the granular cost (in terms of money but also time and energy) that was needed to overcome the hurdles to documented citizenship. The reasons for their poverty (which lie beyond the scope of this thesis) in themselves must also be understood in intersectional terms: they were tied to complex historical processes, related to occupation, right to land and property, state policies towards the working class during state communism, and many other matters that cannot be clearly delineated pertinent solely to ethnicity or class.

What mediators, health professionals, local authorities, and – I should be open about this – my own questions to them perpetually emphasised was not this evident intersectional problem, but the ethnic dimension of the problem. Such an ethnocentric approach allowed people like Nina to say that Roma do not have documents because they are disorganised or “lazy”; it allowed people like Roberta to say that they had a culturally different approach to citizenship and documentation because they were a lawless people,

used to being “free”. Such universalising claims were no doubt reinforced by already existing notions, expressed in different contexts, of the Roma as deviant and inferior.

A complicating factor is that non-citizenship pushes people who are already destitute into further destitution and precarity, since it prevents them from working with contracts, from attaining or keeping their housing, and – most relevant to this study – from accessing health care. As outlined in this chapter, this can lead to situations in which women might be unable to afford an abortion, leaving them with an additional child who they struggle to feed. It prevents people from obtaining any kind of health care that might enable them to work again or to look after their children. Without identity documents people are vulnerable to being exploited by an economic system that sees them as redundant, even as it relies upon them for cheap labour (Vincze 2015).

Mediation helps to alleviate this situation inasmuch as it provides an avenue for undocumented citizens to become registered, for unregistered children to receive a CNP, and for people with temporary ID cards to receive permanent ones. It is understandable that mediators feel great pride in the task of “creating citizens”, since “becoming a citizen” could indeed be a life-changing process for affected individuals. It is important not to diminish the importance of this task. It is equally important, however, not to disengage critical capacities when thinking about this process. The way in which the process of “creating citizens” is enacted has not been given adequate attention thus far.

### **Mediating citizenship from a dialogical perspective**

From a dialogical perspective, it is striking how monologically most of the mediators I met approached their job. Thinking back to the way Viorica spoke to the woman we met on the street, she told them how to initiate the process of obtaining documents without even mentioning why this might be important for them: this was purely technical knowledge. Viorica also communicated state interests to community members, often without feeding back the needs of community members to state institutions. This occurred for example in the case of the family trying to obtain a death certificate for their deceased infant son.

Lastly, when she was advising the woman seeking an abortion, she directly linked her misdemeanour as a citizen with her status as a non-patient, implying that it was her fault she did not have health insurance, and therefore also her fault that she would have to pay for the abortion in a private clinic. Obtaining citizenship is essentially a technical and bureaucratic field, so there is perhaps a more limited role for engaging in social knowledge or the wider socio-economic context. Nevertheless, there are ways of engaging with community members in dialogue and recognising their knowledge and concerns about documentation as legitimate (Jovchelovitch 2007), thereby fostering a more collective approach and help build a critical voice among undocumented citizens, who together may be able to bargain for an increase in their rights, or a facilitated process of obtaining citizenship.

Instead, many of the mediators I encountered approach this task from a moralistic standpoint. “Creating citizens” becomes a civilising mission (Trehan and Kóczé 2009), in which – similar to the way in which mediators taught patients how to behave as good patients – they taught citizens to become “good citizens”. The definition of a “good citizen” was shaped by the state’s idea of people who contributed to the market economy, and who would not be a drain on the public budget: someone with a job who owned a house, paid taxes, and sent their child to school. Mediators spoke about their duty to change the collective civic mentality of the Roma community, but not of the civic rights that accompanied citizenship: the right to political representation, to influence the broader political landscape within the framework of participatory parliamentary democracy or local elections.

### **Creating citizens, disciplining citizens**

A different aspect of health mediators’ involvement in creating, shaping and policing the boundaries of citizenship was the way in which mediators’ perspectives seemed to be co-opted by that of state authorities. In its more benign form this presented itself in the way that mediators’ vocabulary and point of view seemed more aligned with that of local authorities than with their role as community members. This was apparent, for example,

when Viorica (and other mediators) spoke about undocumented citizens “not existing”. During the training session that I witnessed I saw how mediators were schooled to think of their task in a highly individualised way, without heed to the bigger picture that engendered the kind of scenarios they were confronted with every day. This atomised approach to community members facilitated their role in governing and regulating people. Ultimately mediators participated in setting limits on who had the right to be a citizen, who could be trusted to be a parent, who deserved to be a patient. They did this often unwittingly and involuntarily; Roberta, for instance, was strong-armed by the mayor into calculating the number of workfare hours people owed the state for receiving benefits, rounding people up for workfare, policing their attendance, and cutting people off benefits if they failed to stick to the rules.

None of this should ever have been part of health mediators’ job, but the way in which the programme was organisationally structured meant that it was easy for local authorities to exploit them for their own purposes, and – given the obviously unequal power dynamic – difficult for mediators to extract themselves from jobs they were unwilling to perform. Roberta may have been the exception in that she seemed to relish many of the tasks that she approached with the clear perspective of the state. She was not coerced into taking such a heavy-handed approach when she approached the family whom she threatened with the removal of their children. Nor was she pressured into reciting essentially neoliberal perspectives on the deserving and the undeserving citizens in her village in her interviews with me. Roberta was noticeably proud of her role in correcting their behaviour, both as citizens, and as patients. This neoliberal, biopolitical governance of the population she was serving surprised me, especially given the setting: a small village in the hills of Transylvania, so far from the kind of international bodies (the International Monetary Fund, the World Bank) or national governments commonly associated with such discourse about the role of the individual in society (Castree 2006; Larner 2000). Governmentality traditionally describes the state institutions’ repertoire of technologies for governing a population. This was governmentality, not practiced by the state itself, but through a more capillary form: exerted not by government forces “from above”, but more horizontally, through community intervention. When community members are targeted

by non-governmental institutions or programmes such as the Roma health mediation programme (run by community members for community members), community members are both subject and object of governmentality. This dynamic has been described as a form of neoliberal governmentality, where the “hollowed-out” nation state devolves the responsibility for regulating its populations to non-state actors (Ferguson and Gupta 2002; Jessop 2013).

It was mediators’ job to help Roma communities to understand top-down definitions of patienthood and citizenship, and then to shape an unwilling and rebellious Roma community so that they fit these definitions. They did this by filing documents into paper containers, thereby delineating who was deserving and who was not deserving of being treated as a citizen, or as a patient. In this way health mediation became an extension of the state’s attempt to regulate its population. Through their participation in governing and disciplining “the Roma community”, mediators became involved – especially when seen from a distance – in much broader political projects such as the mobilisation of human and social capital through the maintenance of cheap workforce (van Baar 2011; Vincze 2015), and, broader still, nation-building (Isin and Turner 2007; Isin 2012).

There were also cracks and leaks in the ways that mediators operated: small acts of counter-conduct, such as Inna, who would bend the rules for the benefit of the community. More importantly, many of the community members I spoke to were unimpressed and to a large extent untouched by the mediators’ activities. Some of them, such as Aurelia and Adela, maintained a healthy suspicion of potential meddling in their lives.

Most of my data speaks to attempts (of mediators, doctors, local authorities) to contain Roma communities in various ways. How successful was health mediation at achieving its aims? In the next chapter – the *Discussion* – I consider this question in detail, both from the perspective of participants themselves, and from broader theoretical angles.

## Chapter 6: Discussion

In this thesis I have examined ways in which Roma health is materially and discursively enacted in communities. I have done so by analysing the practice of health mediation, exploring how it is practiced and conceptualised by health mediators themselves, but also by community members and health professionals. My understanding of the material I gathered through interviews and participant observation was influenced by a number of theoretical considerations that I outlined at the outset of this thesis. The first of these is a dialogical appreciation of the benefits that participatory health interventions may bring to communities. Second, the interpretation of my data has been influenced by a number of postcolonial and intersectional theorists, who offer a critical understanding of how the practical consequences of constructing certain groups as homogenous, Other and deficient justify interventions that aim to correct their behaviour, contributing to the hegemonic control of minorities through biopolitical regulations, on which I will elaborate below. Third, I have built on the related literature concerning neoliberal governmentality to understand the unexpected salience of health mediators' involvement in producing, reproducing and policing the boundaries of citizenship. By examining my data in light of intersectional, postcolonial and biopolitical theories, and by employing the extended metaphor of "containment", I have aimed to expose and destabilise a consensus narrative in the discourse around Roma integration and policy efforts to improve Roma health.

The *Discussion* returns to my original research questions, aiming to draw together the different strands of argument that run through the preceding chapters. I begin by summarising the ways in which the container has been a productive metaphor in structuring this thesis, and how it may be understood to represent different forms of power. Next, I turn to three subsets of questions posed at the outset of this thesis. The first broadly concerns the local definition and classification of Roma population, the second discusses the production and enactment of knowledge about Roma health, and the third aims to understand how Roma health mediation may be productively understood as a participatory intervention. I conclude the chapter with an examination of "leaks in the container" as a counterpart to my initial arguments, and as an examination of the



possibilities for resistance and counter-conduct. This leads into an exploration of the limitations of this study.

## Containers

The Container, as I hastened to point out in the *Preface*, is a heavy metaphor. I have tried to use it only where it is productive. Throughout the thesis, my use of the container, containment or containing often relates to enactments of power. I propose that two different kinds of power have been at play: direct power, exercised from above, and a more diffuse form of multidirectional power, manifested in “capillary” forms. Both forms of power directed participants’ actions, from the town hall officials, to the health professionals, the mediators and community members.

Direct and overtly oppressive forms of power manifested themselves, for example, in the way that austerity measures cut budgets: as a result, town halls scrambled for finances elsewhere, motivating them to repurpose municipal land, and ultimately to bulldoze a large number of family homes. It showed in the way that health professionals had certain vaccination quota to fulfil, or else be sanctioned by the local Public Health Authorities. Direct forms of power substantially influenced mediators’ range of action, in that their new town hall-issued contracts made them accountable to the personal whims of the mayor. Direct forms of power were also often visible in the bureaucratic obligations that community members faced: if they did not have the correct piece of paper to show that they were legitimately inhabiting the place in which they lived, they risked being evicted or even having their houses bulldozed. Another form of direct oppression is the material surroundings into which some of the most marginalised communities that I encountered have been compressed, severely restricting their chances in life. This form of overt power considerably constrained, or “contained” all participants’ possible range of actions.

But there were also other, softer forms of power that constrained participants. Here, I am thinking of the age-old attempt to maintain conceptual boundaries around amorphous groups: boundaries that enclose the idea of “the Roma”; the discursive layering of

attributes such as Other, inferior or bad, onto an artificially constructed group; the language and practices of Roma health mediation, which participates in portraying this group as diseased, dirty and undesirably fecund; the top-down communication of health and citizenship-related norms and behaviours, contributing to the discursive delineation of what counts as “normal” for the communities in which they mediate. In these ways, the container becomes synonymous with acts of disciplining people into various forms of ethnicity, patienthood, and citizenship. This happens via a number of diffuse and soft power mechanisms, such as the framing of material deprivation and community members’ inability to uphold basic forms of hygiene as a choice of lifestyle; the way in which patients are told to smell, dress, queue, speak, and listen in a certain fashion; the way in which vaccination, contraception, cleanliness, work, education, and tax are presented as questions of morality; doctors’ and mediators’ ability to insinuate that if people fail to conform to certain expectations, they risk losing their status as patient or citizen entirely.

All these are forms of conceptual and “lifestyle” containment, pushing people into particular forms of living through the use of forms of discipline, which are not always straightforward or visible. However, as I have shown throughout, these can only ever be attempts at containment. The resulting tension that arises from such attempts becomes synonymous with the “leak” in the container, to which I return in this chapter’s final section.

## **Local classifications and constructions**

### **How were Roma locally defined and classified in the context of health mediation?**

The question of whether ethnicity is an “ontologically valid concept” (Back and Solomos 2000, 21) is not what this thesis has investigated. Instead I have aimed to pursue questions as to why certain racialised subjectivities or social representations are seen as problematic, and in what context such problematisation occurs. I have tried to trace not only the stories of racialised subjects but also those of perpetrators of racialisation, thereby focusing my gaze not only on the ethnicised object but also on the ethnicising subject, “the described

and imagined” and the “describers and imaginers” (Morrison 1992, 90). At the same time, I have shown how on occasion ethnicised subjects may also perpetuate ethnocentric notions of social grouping, behaviour, and spatiality.

As I have shown throughout this thesis, two types of classification dominated the way in which Roma were locally defined. The first was spatial, the second largely based on appearance; combined, they served to produce a category known as the “traditional Roma”. In both cases, Roma were classified as such when they were perceived as highly visible and Other. My experience of how people perceived their own identity was in keeping with the fluidity and constructed nature of ethnic boundaries and groups highlighted in critical literature on ethnicity and race (Back and Solomos 2000; Back and Solomos 2002). My conversations with Adela and Anita specifically showed how, as individuals, they elided straightforward definition, how they had multiple and overlapping identities, but chose to employ ethnic classifications to their own advantage. The complicated ways in which their families – as well as those of many other participants – were structured, through migration, intermarriage, and (usually downward) class mobility highlighted the absurdity of trying to fit the binary straightjacket of “Roma” and “non-Roma” onto complex social representations. This was further corroborated by the many middle-class Roma intellectuals I met who were not recognised as Roma through their appearance, class, or the space that they inhabited, but who nevertheless self-defined as Roma. Ethnicity, as I have shown, cannot easily be contained: it is “leaky” in the extreme.

In contrast to this leakiness, and possibly as a result of it, methods of hetero-classification tended to strain for clear ethnic boundaries, seeing ethnicity as natural, given, and measurable. Ethnicity may be constructed and fluid, but hegemonic practices of inscription and social relations within society limit this fluidity (Alonso 1994) by constantly trying to contain it. The difficulty of doing so was underscored, for instance, by the disparity between census counts and different people’s experience of how many Roma were in any given place. Thus, in Colină, for example, the mayor went along with the official count of 5 per cent, while the priest claimed that 95 per cent, and the mediator 80-

90 per cent of the village were Roma. For Roberta and many others, Roma ethnicity was something you were born with, and could not be exchanged for any other identity. While most mediators did not pronounce on this so definitively, overall, neither health mediators nor documents pertaining to the Roma health mediation programme (such as manuals for mediators, the training course or evaluations) showed any propensity towards engaging critically with ethnic definitions and classification. Instead of challenging binaries, they showed a tendency to use and reproduce them, and thereby contributed to the foundations of a homogenising discourse.

The homogenising discourse about Roma, seen for example in the way health professionals spoke about an undefined “them”, or the way in which Dr Avram in Dacia believed Viorica to be the natural point of contact for all Roma communities despite evident substantial differences between groups of Roma even within Dacia, served to draw clearer boundaries between the binary categories of “them” and “us”, and minimised ambiguity. Those described by others as Roma also participated in this drawing of boundaries. Sonia, for example, had a clear idea of where the boundary between *țigani* and Romanians ran in her village. Mediators, too, contributed to the homogenising discourse, also by speaking in nondescript ways, attributing various characteristics to “the Roma” even as their work exposed them to people with no shared external appearance. Why was it that local actors still grouped individuals under the umbrella term “Roma”? Even when mediators specified which particular group they were talking about, they applied a homogenising discourse to subgroups such as the Rudari or the Căldărari Roma. Why was it that even when an incredible diversity is staring people in the face, people elide complex social structures through binary assertions? Derrida (1981) points to the structure of binary categories as a fundamental characteristic of Western philosophy. He points to dichotomies such as “good” and “evil”, “being” and “nothingness”, “mind” and “matter”, “man” and “woman”, and so on. Heterogeneity is often seen as an accident or an exception (Bowker and Star 1999). The intersectional theorist Kimberle Crenshaw (2000) shows how these polar opposites are rarely equal pairs, and instead manifest a hierarchical order. This hierarchy is at the centre of the next research question.

### **How were ethnicity, poverty, and marginality constructed and enacted?**

Achille Mbembe (2001) criticises historians, anthropologists, and feminist writers who “problematise everything in terms of how identities are ‘invented,’ ‘hybrid,’ ‘fluid’ and ‘negotiated’” (5). He is concerned that critics who have been inspired by neo-Gramscian and Foucauldian theory reduce complex questions of power and the state to “representations” and “discourses” while forgetting about the materiality that underpins them. He bemoans the out-dated Marxist notion that material and economic conditions automatically reflect on and express themselves in individuals’ consciousness. “There persists the false dichotomy between the objectivity of structures and the subjectivity of representations,” he writes, “a distinction allowing all that is cultural and symbolic to be put on one side, all that is economic and material to be put on the other” (6).

In this thesis I have attempted to understand how cultural, symbolic subjectivities and economic, material structures interact. The negative framing of Roma ethnicity was produced, I argue, precisely through the confluence of ethnicity, poverty, and spatial marginality. Each element was seen as mutually constitutive of the others: poor, marginal population groups were seen as Roma, while Roma were seen as poor or marginal, for instance. I contend that in this sense ethnicity is “an ideological effect, a mask that hides real economic relationships” (Back and Solomos 2000, 7). Social relations are re-defined as ethnic relations under the conditions of unequal access to resources and power. This can be seen in the way in which ethnicity is assumed to correlate with space. All these material constellations have affected the subjective representations of Roma. In Coliñă, for example, the complex historical narratives of how different parts of the village assumed their ethnic identities, and how different inhabitants of these areas assumed complex (and hybrid) identities are precisely related to the material and economic conditions that the structure of the village has produced and reproduced over centuries. This production and reproduction of ethnicity through spatial precarisation is still visible today in the practice of forced evictions, physical segregation through walls, and material segregation – such as the cases in Eforie Sud, in Uscat, in Bucharest, and elsewhere. It is also visible in the neglect of spaces nominally labelled as Roma, as has been discussed in detail elsewhere (Pop and Vincze 2016; Vincze and Rat 2013). In all of these examples, processes of

racialisation via the political economy of space are painfully tangible. Moreover, exclusion from documented citizenship represents a key mechanism through which the Roma are “sorted” or contained. These policies render undocumented citizens as inferior subjects. At the same time, they cannot be individually identified as citizens, which hinders or denies their protection by the “surveillant welfare state” (Rat 2013, 156).

In Romania, there is no formal inequality between Roma and non-Roma; there are no official policies of apartheid. Why, then, is there such a large overlap between Roma ethnicity and Roma poverty? I have argued that Roma are seen as Roma (a cultural attribute) through their material and spatial position in society, a condition described by Crenshaw as “material subordination” (2000, 552), in which spatial segregation restricts access to adequate housing, where anxiety, poverty, and poor care lead to poor health. This material subordination, experienced by many of the communities I visited, prompts people to assume the existence of ethnic differentiation. To Crenshaw’s definition of material subordination, I would add the absence of identity documents, which is intimately related to poverty. Lack of identity documents itself can exacerbate spatial marginality because it is interconnected with issues around documents proving home ownership, making undocumented citizens easier targets for evictions and thereby rendering their lives even more precarious. As I have shown throughout this thesis, the product of conflating cultural and symbolic subjectivities with economic material structures is the “familiar Roma body” (Lancione 2017b): one containerised by poverty and spatial marginality.

Racialised poverty, I propose, was framed in ideological terms that enabled its depoliticisation. The critical literature on Roma has pointed to the simultaneous racialisation and depoliticisation of poverty within the context of a neoliberal restructuring of state apparatuses since the fall of communism (van Baar 2011; Vincze 2015; Rat 2013). Collective responsibility and solidarity with the poor have been substituted for a discourse and enacted practice of individual responsibility. This was something I encountered again and again during fieldwork: people talking in terms of “desire”, “will”, or “choice” to have a good life. As I have shown, much of the discourse used by medical professionals and

health mediators revolved around the sense of a necessity to educate people into wanting a different, healthier life, rather than taking into consideration the structures that prevented healthy lives in the first place. I was surprised by the extent to which town hall officials and mediators produced and reproduced a language of citizenship that evolved around neoliberal tenets of individual obligation to work and pay taxes. As Loïc Wacquant writes, “actually existing neoliberalism” is “liberal at the top and paternalistic at the bottom”, meaning that the state only “practices *laissez faire et laissez passer* toward corporations and the upper class” while being “fiercely interventionist and authoritarian when it comes to dealing with the destructive consequences of economic deregulation for those at the lower end of the class and status spectrum” (2012, 2). Consistent with this logic, health professionals generally showed themselves to be suspicious towards Roma welfare recipients (for example, accusing poor Roma women of having children for the benefit of additional child care allowance). Mediators were generally less damning of welfare recipients but nevertheless tended to contrast poor, uneducated, unemployed Roma community members with the ideal neoliberal citizen who was willing to work for their living, who chose education for themselves and their children, and who was able to contribute their fair share by paying taxes. These discourses demonstrate how poverty and inequalities become racialised and depoliticised, and the Roma constructed as inferior members of Romanian society.

Such classifications and discursive productions of Roma, Spivak (1988) would argue, constitute acts of epistemic violence, damage to the possibilities of self-articulation. Material neglect and segregation are enacted forms of structural violence (Farmer 2005), typical of the relationship of the coloniser towards the colonised. In this thesis I have argued that it is productive to approach health mediation through an understanding of Roma as a colonised minority. In my view, many of the tenets proposed by postcolonial scholars to define colonial relations seem to so aptly describe the relationship between Roma and non-Roma: one in which the colonisers are fundamentally segregated from the colonised, in which the colonised are dehumanised, in which domination is “held together by violence” (Burawoy and Holdt 2012, 78–79), and which builds violence into its structures and institutions (Mbembe 2001, 175).

In the chapter on *Containers* I show how – put simply – unaddressed forms of socio-economic oppression of poor communities constituted a perpetuation of the hegemonic order. Any attempt to empower communities would have to engage in their socio-economic context. I would like to stress that the health mediators that I encountered were extremely constrained when it came to addressing the structural or material problems that clearly contributed to ill health in the communities for which they mediated (including nitrate poisoning of drinking water, travelling with patients in open horse and carts, rat infestations, and poisoning in damp and inadequate housing). In some cases, mediators did their best to engage in the community members' struggles against the limitations of their socio-economic context. For example, when Viorica went to the community she was surrounded by women who questioned her not on matters of health, but on housing, education, and disability allowances. She listened, and pointed them in directions where they might find help. This was, however, an ad hoc and short-term approach. Had she come again the next day, different (or perhaps even the same) people would have approached her with different problems. The mediators I encountered did not have the means to address any of these issues in any more radical way, nor did they seem to be involved in trying to promote community members' own capacity to change their environment in a fundamental way. This was rooted first in their own precarious employment and accountability to the town hall, and second, in the value that was placed on technical or biomedical knowledge over social knowledge or the lived experience of mediators and community members about the circumstances that influenced their health. As such, mediators were also victims of their own circumstances, the neoliberal context in which they worked, their own positions as outsiders (sometimes both in public institutions and in communities), and their desire to align themselves with powerful institutions to maximise their own security within a precarious system of employment. In this way, they did not only bring neoliberal understandings of the individual's role in society closer to community members, their position as mediator within the municipal authorities meant that the neoliberal state had direct control over their life conditions. For the most part, mediators seemed to have grown inured to gross socio-economic inequalities that formed the everyday backdrop against which they practiced their profession. Health mediators



did, however, have the capacity to intervene in the epistemic discourses on Roma. This was fundamentally linked to the ways in which mediators positioned themselves in relation to how Roma culture was constructed.

### **How was Roma culture constructed?**

While I have aimed to avoid essentialised narratives about the ways in which “Roma culture” is enacted by Roma themselves, I have paid attention to the ways in which “Roma culture” was constructed by others, including health professionals and health mediators.

A strikingly common exception to the classification of Roma along economic or segregational lines was the recognition of a group of people referred to as the “traditional Roma”. They were identified by their appearance and observations of (or projected ideas about) their behaviour. Unlike other Roma, “traditional Roma” could be wealthy or educated and still be recognised as Roma, as long as they displayed obvious external markers, such as a certain way of dressing, or speaking Romanes. It was these “traditional Roma” who were most commonly exoticised.

In the colony, Mbembe writes, “violence insinuates itself into the economy, domestic life, language, consciousness. It does more than penetrate every space: it pursues the colonized even in sleep and dream. It produces a culture; it is a cultural practice” (175). Mediators sometimes participated in the construction of “traditional Roma” as exotic and Other. Conversely, mediators from so-called traditional families would portray other Roma as dangerous – such as when Inna swore she would not go to the Roma ghetto on the outskirts of Movilă on her own. When Amalia from Padureă told me she thought the word *figan*, with which she identified her own community, meant a “dirty, miserable, worthless person”, it struck me that this was the kind of instance in which violence was pursuing her: she was Othering even herself, her family and her wider community. Such cases of internalised stigma, alongside my analysis of the socio-economic containerisation of Roma communities, resonate with Fanon’s observation that racial identity is “primarily socio-political, and only subsequently – once such effects have been internalised

– psychological” (Hook 2004, 89–90). This was evident also in the way that Amalia told me how, as a girl, she had believed that she “carried some odour despite washing”. The damage done to people as a result of internalised oppressive stereotypes that are the product of structural inequalities of power has been termed “symbolic violence” (Mosse 2007, 30), forming an important backdrop against which much of the practice of health mediation occurs, and to which I return below.

But, as I have indicated, Roma were not only constructed as exotic and inferior: they were constructed as a “problem”. In this thesis I have extensively analysed how unequal relationships of power between doctors and patients, between majority and (constructed) minority led to a construction of “normality” which saw Roma patients as “bad patients” and Roma citizens as “bad citizens”. I have also discussed how health mediators were accorded the role of containing those aspects of Roma-hood that were constructed as “pathological” or “uncivilised”; or, in the terms of Maria Todorova (2009), as suffering from atavistic backwardness. Here, the distinction between “traditional” and “assimilated” Roma seemed to vanish. In many conversations I had during fieldwork, but also in interviews with health professionals, mediators, and community members, it was not always evident whether people were speaking about Roma or “traditional Roma”. Together, racialised precaritisation and the Othering of Roma communities brings to mind the figure of the subaltern, who sits at the foot of the “international division of labour” (Spivak 1988).

As I have indicated throughout the thesis, “Roma culture” was homogenously constructed as backward and Other. Such a construction can productively be understood as both a symptom and a result of the unequal power dynamics between the Roma as a minority and those in more powerful positions, embedded over many centuries. In this way, the treatment of Roma as an oppressed minority is comparable to the way in which Fanon describes colonial subjects in North Africa being treated by the French occupying forces, namely as children: defective, and yet to fully develop (Trehan and Kóczé 2009). One of the reasons that such definitions, classifications, and constructions persist is that that “the advantaged are those whose place in a set of classification systems is a powerful one”

(Bowker and Star 1999, 225). At the same time, classifying certain population groups as defective justifies intervention, and thereby plays a part in the biopolitical regulation of populations by turning to medicine as a form of social control. Others have drawn attention to the “murderous consequences of the fascist construction of the Jews as a ‘degenerate race’” (Back and Solomos 2000, 11). Recent bouts of violence against Roma, such as those in Harghita county (highlighted in the *Introduction*) should serve as a reminder that the murderous consequences of racialised constructions are certainly tangible. What is disconcerting, however, is when well-meaning interventions such as the Roma health mediation programme, put in place as a response to such violence, shares and even perpetuates the kinds of constructions that lead to violence in the first place.

## **Constructions and transmissions of knowledge**

### **How was knowledge about Roma health constructed and enacted in local practice?**

In health mediation “the word ‘culture’ is useful as a less threatening term to stand in for the real problems of poverty, marginalization, and racism, which are more fundamental social causes of health disparities” (Miklavcic and LeBlanc 2014, 16). Cultural approaches to health may often mask deep, underlying economic asymmetries. Culturally centred approaches, such as the health mediation programme, are not well equipped to address the economic situation of whole communities. They may not even be appropriate to address cultural differences. Any attempt at answering this question must first define what is meant by “Roma culture”. At the outset of this study I had initially conceptualised Roma health knowledge as an inherently different form of social knowledge to its non-Roma equivalent, with the mediator acting as go-between. Certain authors writing about Roma health were keen to emphasise magic, crystals, moonlight, and elaborate rituals of purity as part of Roma health practices (Singh 2011; Vivian and Dundes 2004). While these accounts were more exoticising than most, the consensus narrative about Roma health also displayed a tendency to make culturalist assumptions about the connection between

measured inequalities in health and Roma ethnicity, understood – as I have outlined – in largely homogenous ways. It is presumed, and sometimes scientifically asserted (via regression analyses that try to adjust for factors other than ethnicity - (Mihailov 2012)) that there is *something* inherent to the Roma – in other words something about *Roma culture* – that is connected to poorer health or poorer access to health.

Some health professionals with whom I spoke pointed to Roma cultural practices as problematic. One of the nurses spoke about “crazy” pollution rituals, while a number of others emphasised Roma communities’ reversion to traditional remedies such as placing warm polenta on an upset stomach. The manual for health mediators stressed certain Roma cultural practices, such as a desire for cleanliness, or social embarrassment at speaking about contraception (Nanu et al. 2008). According to the manual, it was mediators’ task to “help doctor understand the basic elements of Roma culture and traditions” (34); in other words, forms of social knowledge.

As indicated in the *Introduction*, participatory health interventions with and for marginalised communities are said to be especially appropriate for dealing with cultural differences as regards health services, and difficulty with communication (Campbell and Jovchelovitch 2000). I have outlined how Cornish and Campbell (2009; 2013) suggest a theoretical distinction between utilitarian and empowerment approaches to community participation in health, based on whether they engage in transformative dialogue, take social knowledge seriously, and aim to change the wider social and material structures that influence health. Community empowerment, it has been said, can be defined as the capacity of the poor to negotiate with, participate in, control, influence, and hold accountable those institutions that govern people’s lives (Ringold et al. 2006). Others have categorised the different ways in which mediation may be practiced into three broad terms: mediation on behalf of local authorities, mediation as advocacy for minority groups, and mediation as a neutral navigation between authorities and communities (Agusti-Panareda 2006; Miklavcic and LeBlanc 2014). While I return to the question of how the Roma health mediation programme should be thought of in terms of these different approaches, it should be apparent by now that Roma health mediation tended towards a

utilitarian approach to participation that promoted technical over social knowledge of health, and which mediated largely on behalf of authorities. It is nevertheless worth revisiting ways in which mediators can or cannot be said to have promoted health professionals' engagement with social knowledge of and about communities.

Some doctors seemed to pride themselves on understanding and engaging with the “social knowledge” of Roma communities, such as Dr Naum, who said it was important to know “their customs” and to speak on “their level”; or Dr Mirea, who told me that she had learned basic Romanes so that she could communicate better with the children. Since I did not observe any of their interactions with patients, it was not possible for me to gauge what kind of relationship they in fact had with them. I did observe the interactions between Dr Trifa, who also took great satisfaction in her professed ability to communicate well with her Roma patients, and while the way she ran her practice was unconventional, patients generally seemed to like and trust her both as a person and as a medic. According to doctors' own narrative, the knowledge that they had acquired about the communities they worked with came from their own engagement, often over decades, and not as a result of having been taught by Roma health mediators, with whom in any case they had varying degrees of interaction. Their knowledge of the communities they worked with, I would suggest, was not so much based on knowledge of Roma health or beliefs, but resulted from dialogically engaged interactions with the community, meaning that they listen to people's concerns and took their knowledge seriously, for example about why they might reject contraception, vaccination, or why their social conditions might not allow patients to wash before attending their consultation. I should add that both Dr Naum and Dr Trifa were doctors who had volunteered to take part in a project that aimed at improving Roma health, and were therefore likely to be positively disposed towards a more in-depth form of interaction with the communities they treated.

Judging by my observations and conversations, cultural practices such as those highlighted in the literature or by health professionals did not seem relevant to the vast majority of people. I only occasionally came across overtly “traditional” influences on health practices, mostly in the “traditional Roma communities”, where social knowledge about

pollution, child bearing, or group visits to the hospital were emphasised. Mediators spoke about these kind of practices (Amalia about pollution rituals, Marta about large group visits to the hospital, and other mediators about the pressure on Roma women to have children) in regard to life in the community. They did not emphasise these “traditional” influences on health beliefs when talking about their work as mediators. As a result of these conversations, however, I have come to the conclusion that just as it is difficult and politically counterproductive to insist on ethnic boundaries between population groups, is it likewise with nominal boundaries between kinds of health beliefs. Where differences do exist, they are highly locally specific and not necessarily defined along ethnic lines.

### **How were health priorities defined and enacted?**

Raj Bhopal (1997) warns that “racial prejudice is fuelled by research portraying ethnic minorities as inferior to the majority. Infectious diseases, population growth, and culture are common foci for publicity.” (1754). Not coincidentally, these are precisely the themes that are at the centre of the agenda on Roma health: The UNDP/World Bank/EC Regional Roma Survey (Mihailov 2012), for example, calls for targeted interventions in health education, vaccines, and reproductive health. It was unclear whether or not the Roma health mediation programme was designed in response to the consensus literature on Roma health. Either way, the main health topics covered by health mediation training (such as hygiene, vaccination, and family planning) were strikingly similar to those highlighted by the literature. The curriculum for health mediators also seemed remarkably similar to the kind of topics that used to be covered by health education for ethnic minorities in America: child care, birth control, and lice (Bhopal 1997). Not only do these topics chime with the discourse of Roma as a dangerous or problematic population (based on infections outbreaks and/or demographic shifts), they also dominate at the expense of other health topics such as chronic diseases, which have been covered by the consensus literature on Roma health (Cook et al. 2013).

During my fieldwork it emerged that mediators tended to adhere to a surprising extent to the themes outlined in their training. While this might have indicated that mediators were theoretically fulfilling their jobs, it also meant that they were led by top-down, predefined

notions of community health priorities. In addition to this, mediators seemed to bow to health professionals' assessments of how health was defined.

It is striking both in the literature on Roma health, and in the enactment of Roma health by mediators, that very little attention was paid to the ways in which communities themselves defined health, based on locally specific and experiential categories incorporating "social knowledge" (Jovchelovitch 2007). This could include experiential knowledge, and – where relevant – locally specific cultural and traditional beliefs and practices. Instead, I found that health was overwhelmingly conceptualised in terms of "technical knowledge", the kind of "objective" knowledge that is taught in the academy, and about which doctors and the highly educated are thought to know best. This was the kind of knowledge that doctors and mediators spoke about when referring to "gaps" in the health knowledge of Roma communities: for example, when they said community members did not know about hygiene, vaccination, or contraception. Health professionals were the arbiters of what counted as "clean", as well as how to behave correctly as a patient. The locally specific social knowledge of communities they worked with was generally ignored. The priority of "technical knowledge" is not surprising from a postcolonial and critical theoretical perspective that notes the "hegemony of some forms of knowledge" over delegitimised others (Carter 2006, 680). To the advantaged, in this case Romanian health professionals, their own hierarchies of knowledge may appear natural. This allows them to operate smoothly within the infrastructure of knowledge that creates and supports their positions as doctors (Bowker and Star 1999, 225).

Health mediators occasionally spoke about the needs of their communities as expressed by community members (rather than what they had learnt in training or what the health professionals prioritised). For example, when Marta was called into the hospital to negotiate with health professionals who were not allowing a patient's family to visit in large numbers, she quite clearly told me that it was the community's need to see their relative in hospital that was in effect.

### **What was health mediators' role in translating and transmitting knowledge between the health system and Roma communities?**

As I established in the *Introduction*, the Roma health mediation programme was conceived as a response to violent clashes between Roma and non-Roma. Health mediators were by extension conceptualised as mediators between two clashing worlds. Initially I thought of mediators as navigating between two conflicting systems of knowledge: local and biomedical health knowledge. While I do not wish to contribute to an essentialist discourse about Roma health knowledge, the conceptual framework of social knowledge is nonetheless useful to understand bio-medical or technical forms of knowledge against other forms of knowledge; it is not necessary to revert to cultural essentialism if social knowledge is defined not as *Roma* but as heterogeneous and locally specific. Effective participatory interventions should engage with social knowledge (Cornish and Campbell 2009; Campbell and Cornish 2013). If mediators are to contribute to better relationships, communications, and trust between community members and health professionals, they should be comfortable in both of these systems of knowledge, and be able to navigate between the two. This important not only for the improvement of relationships of trust, but also for establishing ways in which health interventions can be made locally meaningful, thereby increasing the likelihood that it could lead to improved health behaviours (Campbell and Jovchelovitch 2000).

In this thesis I have explored the different ways in which mediators can be said to be navigating between these knowledge worlds, how they engage in monological or dialogical relationships, as well as “which representations (associated with which groups) are privileged [or] suppressed” (Aveling 2011, 97). I have shown how actual contact between mediators and health professionals seemed to be extremely limited in most instances. This was already a major constraint on mediators' abilities to transmit information from communities to doctors. Generally, information travelled from health professionals to community members via the mediator, and only occasionally the other way round. This was visible, for example, in the way in which health professionals instrumentalised mediators to announce vaccination schedules in communities.



Very rarely, mediators attempted to act as a vessel for knowledge to travel “up” from communities to health professionals. Without this information, health professionals, local authorities, and health mediation programme implementers are unlikely to understand the social and material environment that impedes community members from engaging in healthy behaviours, nor the relevant knowledge about how these barriers to better health outcomes might be effectively tackled.

Lavinia told me that doctors should be taught about Roma customs to improve their relationship, aiming for a transformative encounter or a new, more plural form of knowledge that included both local and technical varieties (Aveling 2011), but this remained an unfulfilled demand. Another example of a thwarted attempt at promoting a more dialogical relationship between health professionals and community members was the way in which Marta was called in to mediate between local enactments of patienthood (the need for families to see their relatives in hospital because they understood suffering as a communal rather than as an individualised event) and technical enactments of patienthood (hospital regulations). She ended up trying to explain to the family why they should obey hospital rules, rather than explaining to the doctors why they should allow larger family visits. In this example, what began as dialogue ended in monologue when local knowledge about enactments of patienthood was subsumed into top-down definitions thereof. While health mediators only recounted a very small number of such incidents, and I personally witnessed even fewer, it is not difficult to imagine that mediators would struggle to negotiate a dialogue that engenders a change in perspective in health professionals. Mediators’ insecure employment situation gave them so little clout in the world of technical knowledge and patient enactments that it took very little for health professionals to block knowledge from travelling upwards from communities. In the given context, there is arguably little that mediators can do to address even overtly discriminatory behaviours on the part of health professionals.

As a participatory health intervention, the Roma health mediation programme is premised on the fact that mediators come from the communities for which they mediate, and that they spend time with these communities. In my interviews with them, many of

the mediators claimed that they spent a lot of time with communities. In my experience of observing mediators at work, most of them – with the notable exception of Inna in Movilă – had very little such interaction. The reasons for this were multiple, including an allocation of tasks that would otherwise fall to social workers, allocation of offices that were so physically distant from communities that they could not easily be reached on foot, and salaries too low to account for the cost of transport. Under these circumstances it was difficult or near impossible for mediators to establish a dialogue with community members. On the rare occasions that mediators did spend time in communities, such as the day I spent with Viorica in the “Roma neighbourhood” on the outskirts of Dacia, there was at least the possibility of dialogue, as witnessed in Viorica’s interaction with her former neighbour about issues that were close to her heart. But even then, there was also the possibility for mediators to fall back on monologue, as I witnessed in her encounter with the young woman and her new-born baby. On balance, in most of the interactions I witnessed, and in most of the interactions that mediators recounted to me in interviews and conversations, mediators tended to discipline community members into certain enactments of patienthood or citizenship. Considered in terms of the theoretical assumptions behind participatory health interventions, Roma health mediation can hardly be framed as a success story.

It is important to restate that different knowledge systems do not occupy a level playing field, so that mediators must not be seen as individual agents whose deliberate aim it was to discipline community members. Instead, they are actors within a context of severely unequal power dynamics that structure not only the monological way that health knowledge is translated and transmitted, but also the ways in which patienthood and citizenship are conceptualised in the first place. This is also why, as Campbell and Cornish (2013) argue, it is important to also talk about and address the wider context of participation.

As has been outlined by Timmer (2010) and Surdu (2016), it is not uncommon for NGOs and policy interventions to contribute to discourses of Roma as “needy subjects,” in part because such lines of argument chime with those who provide external funding for

interventions. In the case of the Roma health mediation programme, its very existence is dependent on an understanding of “need” among Roma communities that resonates not necessarily with those who are affected by the programme, but with the Ministry of Health who are funding it. With this in mind, it is perhaps not surprising that the benefit of the programme is constructed not so much in terms of what it can do for the community, but in the ways in which it may help to avert threats to mainstream society. Difficulties arise when this discourse is not merely produced as a strategy in order to secure funding, but when it co-produces the practice of health mediation from the training materials right down to the way in which mediators engage and speak with individuals.

When mediators communicated to community members how to enact certain normative forms of patienthood or citizenship, whose interests were being served? Even if community members had “internalised” the notion of Roma as inferior and defective patients or citizens, to a large extent they were unable to comply with normative enactments of patienthood and citizenship for structural, rather than cultural reasons. A politicised understanding of patienthood and citizenship recognises how Roma are constructed by health professionals and by mediators as defective and inferior. It also recognises that this construction justifies the need for “correcting” them. Instead of engendering dialogue, transformation and the empowerment of community members (Cornish 2006; Campbell and Jovchelovitch 2000; Marston et al. 2013), mediators engaged in what I came to see as a “civilising mission” (Trehan and Kóczé 2009) by communicating hegemonic interests to Roma communities. This meant that mediators did not engage with the structural environment of communities, they did not catalyse a process of co-conscientisation of why patients could not conform to normative notions of patienthood and citizenship. As a result of this, community members were confronted with being corrected, instead of using mediation as an opportunity to work with community members to collectively identify ways in which they could live lives that were healthy not only in the eyes of health professionals and state authorities, but which were also meaningful for communities themselves. Instead, mediators engaged in a top-down approach of teaching community members what was thought to be best for them by health professionals. This was apparent, for example, in the way in which Roberta spoke about her predecessor’s house visits, in

which she would apparently tell families how to bathe children, how to clean their houses and wash their dishes, and how to prevent flies from getting in, promoting the symbolic power of soap and cleanliness within the domestic sphere (Hall 1997). It was also evident from the way in which Marta spoke about taking contraception as a form of developmental progress, or in Amalia's ruse for getting girls in her community together for a health education meeting, disguised as a make-up session. She framed health education as something the community might be so opposed to that she had to get people into it surreptitiously. If the mediators' actions were met by mistrust from community members, then this may be because community members felt themselves treated as "ignorant" and "inferior" (Campbell and Jovchelovitch 2000). Mediators may have been met with greater acceptance by community members if they had instead treated them as participants whose knowledge and life experiences regarding health was recognised as valuable, and taken as the basis for developing interventions. Health mediation is likely to be more effective if community members feel like they are being engaged with, not as subjects to be corrected and civilised, but as respected individuals who have something to contribute to improving the health of the community. Following proponents of empowerment approaches to participatory health interventions, such a dialogical engagement is not only likely to produce better health outcomes, it also constitutes a more ethical way of relating to socially marginalised communities, fostering democratic participation and politically active citizenship (Guareschi and Jovchelovitch 2004; Renedo and Marston 2015b).

This attempted civilising mission of Roma communities, or communities constructed as Roma, extended beyond health and notions of "correct" patient behaviour to encompass "correct" behaviour as citizens more broadly. Teaching people how to be good citizens was mutually constitutive of correct enactments of patienthood. For example, in order to be a good patient, it was necessary to have the right paperwork (insurance and GP registration), which was conditional on having fulfilled certain obligations as a citizen (either working, registered as unemployed, or paying insurance contributions). Similarly, being looked upon as a good citizen, for example as a responsible parent, necessitated the appropriate enactment of hygiene, or else state authorities (sometimes with health

mediators as their messenger) threatened to curtail parenthood by removing the children and placing them into state care. Health professionals and mediators questioned not the system or the structures that permitted or prevented people from enacting certain forms of patienthood and citizenship, but the individuals themselves. This was evident, for example in the way in which Viorica questioned and lectured the family who came to her for support in having their deceased grandchild released from hospital.

Depending on whether it engenders monologising or dialogical relationships, knowledge brokering can promote the reproduction or the transformation of power relations (Aveling 2011). Ideally, a participatory approach to intervention allows different groups to interact with each other, and take each other's social knowledges and the conditions in which these develop seriously (Campbell and Jovchelovitch 2000). In practice, however, health mediators' perpetuated unequal power dynamics between community members and state institutions through monological encounters that did not allow community members to articulate their own problems or develop their own solutions. This only disempowered them further. At the same time, these monologising interactions were part of an attempt at the biopolitical regulation of Roma communities by "teaching" them how to behave as patients, how to be clean, how and when to vaccinate their children, and how and when to reproduce. Through the Roma health mediation programme, the way that community members engaged with hygiene, vaccination, and contraception was turned into a moral issue and subjected to medical intervention. These areas are archetypal of the state's attempts to bring its population under biopolitical control, precisely because there are intractable problems that are difficult to govern (Foucault 2008). This is biopolitics as a form of governmentality, in which control over these health related domains simultaneously aims to consolidate the power of state authorities over the population. By engaging in top-down "teaching" of community members on hygiene, vaccination, and health, mediators arguably form a part of state governmentality, reaching into parts of the population that it might otherwise be hard for state institutions to access.

Bhopal recommends that "participation by ethnic minorities in research, policy making, and the development of services might be one safeguard" against dangerous and racialised

practices in health. My examination of the Roma health mediation programme shows that it is not enough to ensure participation: the way in which participation is organised and enacted is crucial to its capacity to transform practices and power relations. As Uma Kothari remarks, “programmes designed to bring the excluded in often result in forms of control that are more difficult to challenge, as they reduce spaces of conflict and are relatively benign and liberal” (2001, 143).

## **Relationships between participants**

### **How did participants negotiate relationships between each other?**

In discussing knowledge encounters, the previous section has already addressed important aspects of inter-participant relationships. In this section I address in more detail the figure and the position of the mediators, and how their positionality impacted on their relationships with community members and health professionals. I discuss the position of the mediator specifically in relation to intersectional considerations that have run throughout this thesis, and examine what effect their position had on relationships of trust.

The programme clearly states that mediators must come from the communities for which they mediate (Nanu et al. 2008; Wamsiedel 2013). One of the underlying assumptions of the programme seems to be that this “belonging” would automatically engender a sense of trust between community members and health mediators, therefore by extension enabling them to fulfil their role of promoting trust between communities, health professionals, and local authorities (Nanu et al. 2008; Wamsiedel 2013). At the same time, the programme does not clearly outline or define what it means by “community”. This lack of definition can complicate relationships between mediators and community members, if community members do not recognise mediators as part of their community or if mediators do not recognise certain community members as part of theirs. Such fractured relationships were clearly visible in almost all of the communities I visited. Another condition of becoming a mediator was having a high standing within the Roma

community. This usually meant that mediators had a higher level of education, and often that they had grown up in families with greater socio-economic standing than others in the same community. Because Roma health mediator is a listed and recognised position within the structure of local government, the job itself provided mediators with a title and an (albeit very small) salary that was a rarity among communities in which unemployment rates were high and most people worked in the informal economy. Their status as employees, in addition to their status within communities (where some had family contacts with informal leaders, such as in Stăvilă) put mediators in a position of relative privilege. Because of the heterogeneity of Roma communities, mediators were perceived by many community members as not “properly” belonging. As a result, the fact that mediators were also *Roma* did not necessarily bring them any closer to communities. On this intersectional dilemma, Miklavcic and LeBlanc (2014) note that “the apparent cultural proximity between the patient and the culture broker did not necessarily bring about a mediated understanding of the patient’s predicament.” Instead, they write, “gender, education, social class, and other key markers of identity may emerge as crucial elements in the relationship between the culture broker and the patient” (134).

This was clearly the case with the Roma health mediation programme: sharing a sense of belonging to the same community was more complex than simply sharing what was called Roma ethnicity. Roberta self-defined as Roma, though she was not recognised as such by the inhabitants of Colină. This, I gathered, was because she came from a different part of Romania, was educated and spoke in a different regional accent. Despite coming from a “traditional Roma” community, Amalia was not recognised as such by another such community living on the edge of the village in Padureă – possibly because of her educated elocution and because she dressed in a “modern” way. In contrast, Inna had grown up in the same micro-neighbourhood for which she was now the mediator, spoke the same language, practiced the same religion, and occupied a similar socio-economic position as her neighbours, and was – as far as I observed – fully accepted as a member of this community. Sometimes, a sense of belonging was engendered even though people did not share characteristics. Viorica, for example, an educated woman who self-defined as Rudari Roma, and who had grown up in a mixed neighbourhood in the centre of Dacia

City, was a trusted and much frequented point of contact for a family of Căldărari Roma, even though she did not speak their language, share their religion, or dress in a similar way. At the same time, she was outright rejected by the evicted community from Uscat, who spoke yet another language and practiced yet another religion. Sense of place and mutual trust was defined not only by ethnicity, but also by other intersecting identities such as language, religion, local custom, regional and local identity, education, social standing, and economic class.

The mediators I encountered during fieldwork generally held a higher position within local power dynamics than the communities in which they were working. In contrast, on account of the higher status of technical knowledge with regards to social knowledge, the health professionals and local authorities with whom the mediators worked saw them as inferior. Aveling (2011) writes that dialogical relationships may be able to build trust between different groups. Given mediators' positions within these intersecting identities, as well as their frequently monological approach to communicative actions and relationships, it was difficult for them to act as role-models, to counter-act biomedical approaches to health (Campbell and Jovchelovitch 2000), or to promote trust between community members and health professionals or local authorities.

To further complicate matters, it should be recognised that individuals have the capacity to simultaneously inhabit several different representational fields (that is, systems of social knowledge) and several different social identities (Renedo 2010). The mediator can be conceptualised as a marginal figure, with “membership in more than one community of practice”, who “has a double vision by virtue of having more than one identity to negotiate” (Bowker and Star 1999, 320). Mediators experience both the reality of Roma communities and that of the health system, thereby occupying a kind of “borderland” (Anzaldúa 1987). Their ability to mediate between these worlds is premised precisely on their ability to simultaneously inhabit both these worlds.

In the cases that I observed, however, mediators tended to not give equal weight to both of these worlds. Given the unequal relationship between different forms of knowledge, as



well as the forms of dominance, or even violence (both discursive and practiced) that health professionals and local state authorities exercised over local Roma communities, mediators tended to align themselves both discursively and in their enacted practice with more powerful actors and knowledge systems. This, however, had repercussions on their credibility and trustworthiness within communities. If the aim of promoting trust between community members and health professionals or local authorities was to smooth communication between them (Thiede 2005), it is also worth asking who was likely to benefit from increased levels of trust. In the context of the asymmetrical power dynamics that I have highlighted throughout this thesis, and in the context of state institutions' attempts at disciplining communities, it is not surprising that many of the community members I met (such as Aurelia and Adela) showed themselves to be both suspicious of and resistant to mediator's attempts to engage with them.

### **How does health mediation as a participatory intervention translate into practice?**

National and international political bodies have called for Roma to participate in decisions about and provisions for health care. It is important to engage critically with the question of who is being interpellated to participate in what, and on what basis, when it comes to such calls. Simply having Roma participation in health does not guarantee an emancipatory project.

I have argued in this thesis that the Roma health mediation programme is expected to address culturally determined barriers to accessing health services, as well as difficulties with communication, but that these barriers and difficulties do not constitute community members' main obstacles to accessing health care, nor are they the likely main cause of ill health. Having said this, the health mediators I encountered appeared to be spending surprisingly little of their time engaging with anything that fell under the aegis of "cultural" issues or communication. When they did, their ability to advocate for community members was severely hampered by their employment status, as well as by a system of values that brushed aside social knowledge in favour of technical knowledge.

Based on the interviews, conversations, and participant observation that I conducted in Romania in 2014/15, the health mediation programme was ostensibly designed to strengthen patienthood and citizenship, while simultaneously working towards tighter social control over patients and citizens (Isin 2012). The programme was largely governed by a utilitarian approach to participation which tended to mediate between communities and authorities in order to engage with Roma communities on behalf of state interests. It was both unable to, and fundamentally uninterested in addressing the socio-economic circumstances that determined people's health, let alone how community members engaged with health care and state authorities more broadly. Mediators were inclined to perpetuate a biomedical outlook at the cost of ignoring the underlying community context. Their practice tended towards the assimilation of communities within a normative concept of both patienthood and citizenship. In this, the programme seemed to support broader critiques of mediation as tending towards assimilation (Agusti-Panareda 2006). Specific intimations to that end have been made by one previous study on the programme (Schneeweis 2013).

In its tendency to regard the law as fixed (Agusti-Panareda 2006) and in some instances just, mediators contributed to the biopolitical creation and regulation of locatable and disciplined citizens, thereby playing a part in an individualising nation-building project (Geertz 1960) that organises people into distinctive categories along lines of class, occupation, ethnicity, and locality (Alonso 1994). In adhering to a largely binary and spatially contained conceptualisation of Roma ethnicity, the programme may even contribute to what Crenshaw (2000) calls the "the symbolic other" (550). The failure of the Roma health mediation programme to challenge the notion of this symbolic other, therefore, can be said to contribute towards the building of "a burgeoning common identity of all nonstigmatized parties – whose identity and interests are defined in opposition to the other" (550). The Roma health mediation programme is marked by pitfalls for which "Roma civil society" has been criticised; namely that it fails to transmit Roma demands "up" to those in power (Kovats 2003), and that it fails to empower community members themselves to make their voice heard themselves.

From a postcolonial perspective, health mediators' attempts at correcting and assimilating community members are painfully reminiscent of imperial treatments of colonial subjects (Vaughan 1991), and contemporary development projects across the globe (Cooke and Kothari 2001). In particular, mediators' alleged and observed involvement in the field of child protection, which often sees children forcibly removed from their parents in an attempt to force their eventual assimilation, is familiar from British and Habsburg treatments of their colonial subjects (Trehan and Kóczé 2009).

As I have already highlighted, mediators have been put in a difficult situation, to put it mildly. They often act as the messengers of an austerity-focused state apparatus, in the context of a fiscal crisis that has led to increased conflict over redistributive politics and the allocation of infrastructure projects, public contracts, social benefits, and so on, alongside ever stricter and more neoliberal conceptualisations of citizenship (Mbembe 2001). Austerity was thus the broader context against which health mediation must be understood, not least since decentralisation has been part of the response to it (Zentai 2014). The mediators I spoke to, as well as others involved in the project believed decentralisation to have had a disastrous effect on the programme, since local Public Health Authorities had to a large extent lost their supervisory role and mediators were now beholden and accountable to the mayor. This substantially decreased their ability to focus on community work, as well as shouldering them with tasks that should have firmly been outside of their remit.

On a larger scale, it is not only the programme's decentralisation which could be analysed in terms of the neo-colonial grip of Western neoliberalism over Eastern Europe – the dynamic that forms the backdrop for Trehan and Kóczé's (2009) neo-colonial analysis of Romani activism. The ways in which citizenship was constructed and enacted to emphasise the mobilisation of human and social capital, the transformation of “welfare dependent subjects” into “responsible individuals”, rather than the performance of collective rights, strongly resonates with van Baar's (2011) examination of EU- and World Bank-supported employment or “activation” schemes for Roma in East Central Europe.

In consonance with neoliberal notions of patienthood and citizenship, the programme did not challenge, and even promoted the conceptualisation of access to health care – and ultimately also of poverty – as an individual concern. Similar to the activation programmes analysed by van Baar (2011), the health mediation programme can be understood as a form of “ethnicity-based neoliberal governmentality” (202).

By paying attention to the context and enacted practice of health mediation instead of relying on mediators’ own accounts of their work, this thesis has revealed how health mediation figures in a range of strategies, technologies, and rationalities for the governing of Roma communities. For example, it contributes to reproducing a “master morality” in which Roma are constructed not only as inferior, but also as “bad” patients and citizens. I have shown how at least one mediator was complicit in rounding up people for workfare, and thought it was her role to find employment for people so they could become homeowners; others promoted the idea of morality as participation in capitalist markets and paying taxes. This thesis has also brought to light how mediators create “inventories” of Roma communities which serve the biopolitical containment of disease, and paper containment of undocumented citizens. This thesis has argued – against my expectations – that the health mediation programme played a role in policing Roma and their enactments of patienthood and citizenship while paying lip service to the emancipation, empowerment and inclusion of Roma communities “on their own terms” (189). In this way, mediators have been co-opted from within participatory spaces to contribute towards the neoliberal status quo that perpetuates the precarisation and racialisation of poor Roma communities inasmuch they can be exploited as cheap labour (Vincze 2015).

While part of health mediators’ involvement in these disciplining and regulating processes can surely be explained by their position within the state apparatus, their enacted practice may also be linked to internalised inferiority. Such a sense of inferiority, according to Fanon, results from the imposition of values that are supposedly universal, but are in fact norms which groups that are not born into white European privilege are bound to fall short of. This can lead to people from minority groups abandoning themselves “individually and collectively in quest of white acceptance” (Hook 2004). As Amelia’s

affecting account of growing up as a young Roma woman so eloquently indicates, the experience of having grown up as Roma may plausibly lead to an internalised sense of inferiority even when mediators inhabit more privileged backgrounds than the communities they mediate for. This, in turn, may express itself in attempts to correct others. Perhaps the disparaging way in which many mediators spoke about members of communities for which they mediated points in this direction. This, in combination with their precarious employment position, and the neoliberal environment in which individuals were played off against each other in their intersecting experiences of oppression, may well explain why a new opportunity structure such as the Roma health mediation programme was able to “turn old stereotypes into new exclusion mechanisms” (van Baar 2012, 290).

Having considered the Roma health mediation programme as a utilitarian health intervention aligned with state rather than community interests, I propose that the health mediator may be seen in the role of the *comprador*. In Portuguese, *comprador* originally referred to merchants who acted as middlemen between local markets and foreign producers. In post-colonial studies the term is now used more broadly to refer to the intelligentsia among the colonised group who both materially rely upon and culturally and ideologically identify with the colonising powers (Ashcroft, Griffiths, and Tiffin 2013). While the mediators I met would scarcely qualify as “intelligentsia”, they were nonetheless relatively privileged, in that they had paid government jobs and belonged to Roma civil society. This is a useful notion particularly for explaining how it was possible for health mediators to adopt a version of the role of “spokespersons” (Spivak 1988; M. Surdu and Kovats 2015a) for oppressed communities that arguably ran counter to struggles for these communities own emancipation and empowerment. Fanon writes of the contempt of oppressed groups for members of their own who try to enter the society of the oppressor by attempting to “make themselves less black” (Burawoy and Holdt 2012, 90). Mediators often distanced themselves from Roma communities, referring to them as “them” rather than “us”, and pointing to ways in which “they” behaved in uncivilised ways. This recognition opens new avenues for understanding why community members generally did

not seem to trust health mediators, and why – as a result of this – mediators’ attempts at governing and disciplining Roma were largely futile.

## **Leaking containers**

Despite an array of power interests aiming for the containment of community members, many of the discursive and enacted practices to this end were relatively fruitless. “Leakiness” is a useful analogy for examining reactions to attempted containment. I use the image of the “leaking container” to refer to the negotiations and small acts of resistance that accompanied the endeavour to regulate and discipline Roma communities, to show that power and agency, whilst exerted most powerfully and bluntly from “above”, was also to be found “below”.

In Gramsci’s view, hegemony is not a monolithic and complete ideological formation. Instead, it is contested and struggles for domination. “Hegemony is fragile” and must therefore be constantly “renewed, recreated, defended, and modified” (Alonso 1994, 381). This may be one of the reasons that mediators are tolerated, even funded by state agencies. They contribute to the renewal of hegemony at a level that state authorities believe to be out of their reach. If hegemony is fragile, then there should be hope for resistance. Resistance can be conceptualised in different ways. Analogous to my earlier conceptualisation of power as exerted either directly from above, or more diffusely from below, I propose such resistance to be both overtly rebellious, and more intangible and diffuse.

Traditional approaches to decolonisation have called for anti-colonial revolutions and national liberation movements to end colonial oppression (Fanon 1963; Biko 2015; Carter 2006; Bowker and Star 1999). Such approaches have only limited application in the context of a Roma minority which is heterogeneous and difficult to delineate; unlike the colonised majorities in Algeria, the Caribbean, or South Africa, who suffered oppression at the hands of a small but violent minority, the Roma – however defined – constitute a minority population. What is more, in the contexts that informed the likes of Fanon and

Biko, land dispossession played a crucial part in the “inaugural violence” of colonial domination (Bowker and Star 1999, 96), and therefore a radical distribution of means could be achieved, for example, through land reform. In Romania, the concept of “inaugural violence” (that is the violence experienced by groups when they were first colonised) against Roma might potentially be applied to the period of slavery, serfdom, and deportation, and therefore deserves greater recognition as an explanatory category for the contemporary status of Roma population groups. However, since these Roma-relevant cases involved economic domination, ascertaining even a theoretical act of retribution is an arguably much more complicated affair than it might have been in Western European colonies.

However, more recent post-colonial scholarship has moved on from the proposition of mass mobilisation and revolution as a response to oppression, focusing instead on more diffuse forms of resistance (Carter 2006). The relationship between oppressor and oppressed is not one of “resistance or collaboration”, but is instead characterised by its conviviality; that is, the fact that subjugator and subjugated “share the same living space” (Mbembe 2001, 103). Conviviality also explains why it is difficult to classify responses to oppression in terms of either accommodation or resistance. Subjection seems stronger, Mbembe writes, because “subjects of the *commandement* [colonial rule] have internalised authoritarian epistemology to the point where they reproduce it themselves in all the minor circumstances of daily life” (128). It is because of the location of oppression at the internal level and in everyday life that resistance must also be sought at the level of the quotidian, as I go on to show below. This is why small acts of resistance nonetheless constitute an important intervention in the project of redistributive justice and the struggle against hegemonic power (Carter 2006).

Van Baar (2011) follows Foucault in calling these productive (as opposed to oppressive) forms of power “counter-conduct” (13), which is to say that they are neither revolutionary nor even necessarily conceptualised as constituting resistance by the actor. He proposes that “dynamic interactions between citizenship as rights-related status and citizenship practices” can lead to “new sites, subjects, scales and forms of citizenship” (van Baar 2012,

291).

Community members performed their claims to their rights and their own versions of citizenship in mundane ways. Cumulatively, however, these claims were part of a larger political act of counter-conduct. Community members displayed agency in the ways they negotiated ethnicity, patienthood, and citizenship. For example: in the *Preface* I mention that some of the people who were evicted from their houses moved back to the plot from which they had been forcibly moved and set up an illegal camp there, thereby resisting their eviction as best as they could while simultaneously rendering visible the absurdity of the empty plot, which had allegedly been destined to become a car-park but was still an empty field in the middle of nowhere. A different kind of agency might be found in the way that many of the people I met would not allow themselves to be categorised in binary ethnic terms, thereby refusing the containment of classification. Though some may not have resisted ethnic classification publicly (Anita, for instance, told me she did not like being called *tigan*, but that there was nothing she could do about it), others (like Adela) instrumentalised different ethnic affiliations to their own benefit as and when it suited them.

Even though I did not get to know many of the people with whom I saw the mediators interact, those whom I did get to know did not conform to the kinds of patienthood and citizenship that mediators were advocating: they often continued to lack documents, to be unemployed or work in the informal economy, not to send their children to school. Of course, their life circumstances should not be understood as forms of resistance (which would in any case perpetuate the notion that they were doing so by choice). Some community members, however (like Aurelia) showed themselves to be distrustful and suspicious of mediators' meddling in their lives, and told me they kept their distance from them. On a small scale, this constituted an important display of agency. Because my methodology mainly followed mediators and people with whom mediators had contact, I cannot say how common this was. Speculatively, if distrust was common then this may further explain why mediators spent little time in communities, namely for fear of embarrassment, of being rejected, of not being able to engage, of wielding little influence.



When community members did approach mediators of their own volition, it was often in an attempt to claim a right which they believed they were entitled to. This was the case, for example, with the woman who came to ask Viorica where she could get a free abortion, with the family who wanted the body of the dead child released, or with the women in the Dacia neighbourhood who approached Viorica for advice about accommodation, benefit allowances, and education.

If mediators put up their own resistance, then my position as an outsider, perceived to be connected with those who managed and supervised the programme, perhaps did not allow me to observe it. Only Inna's remarks about the sporadic necessity to act in defiance of the law for the benefit of the community, and her explanation of how she signed up a dead man to social benefits hinted at the fact that there may be more of these kinds of counter-conducts. It should also not be forgotten that on occasion mediators were also involved in advocating for community members and tried to claim rights on their behalf. In the cases that I witnessed or was told about (Viorica trying to reinstate the family who was removed from their GP's list, or her attempts at trying to find out who was responsible for sterilising the young woman in hospital), these attempts remained unsuccessful. The procurement of official documents could also be considered an act of "claiming" citizenship, especially since it often very literally instated people as such. However, as I have discussed in detail, this cannot be seen in isolation from the way in which any attainment of citizenship was simultaneously policed.

These exceptions notwithstanding, given the way in which the programme is currently set up within dominant material and power inequalities, health mediation does not promote resistance from below. Similar to other programmes that are designed with nominal claims to community participation (Isin 2012; Komporozos-Athanasiou, Fudge, and McKeivitt 2016), the Roma health mediation programme is, in a way, designed to suppress more radical demands from communities, and to paper over cracks that could lead to more fundamental changes (Cooke and Kothari 2001). One of the consequences of mediating conflict is that conflict about legitimate demands for change is not brought to the fore:

after all, the “production of calm could be dangerous when what [is] called for [is] the emergence of a collective consciousness about injustices in society” (Mulcahy 2000, 134).

## **Limitations, theoretical reflections, methodological considerations**

### **Framing the problem**

How research is framed depends on who is performing it and their previous experience or knowledge about the subject. The framing therefore has its roots in the social realities of the researcher. At the same time, the identification and perception of the problem influences the development of public policy responses, influenced by the representations brought forward by the research (Fosztó and Anastasoiaie 2001, 352). As I have outlined in the *Introduction* and the *Methods* chapters, I began this research project with the notion of two different population groups, the Roma and the non-Roma. In my research, I aimed to address the relationships between these two groups, as negotiated by the Roma health mediator, whom I imagined as sitting squarely between the two worlds. While I still maintain that the mediator sits between these two worlds, or rather, inhabits both, this was a simplistic and fundamentally essentialist view of a world I had not yet engaged in with any depth, informed largely by an uncritical reading of ethnicity as presented in the consensus narrative literature. In my topic guide, I generally framed questions through generic descriptors, talking about “this community,” or “the people with whom you work.” Every now and again, however, I framed some of my questions around ethnicity, for example when I asked mediators: “What kind of relationship do you think Roma have with health professionals?” or “What do you think doctors think of Roma?” At some point I realised that respondents answered in kind, giving very broad, essentialising answers about the relationships between “the Roma” and “health professionals.”

Research is relational. Just as knowledge is co-constructed between interviewer and participants, so too are identities (Gergen 2009). The framing of questions in generic terms produced answers that were too unspecific to be analytically useful, and also left no room

for more complex, hybrid, and multi-representational identities (such as being both Roma and Romanian, both patient and non-patient, *et cetera*). I soon began to feel uncomfortable about the binary distinction, but nonetheless continued using it as shorthand while remaining aware of the underlying complexities. During analysis and the writing process I truly started to question the relative merit and harm of the category. The whole research process was therefore framed around the idea of “Roma” and “non-Roma”. Had I taken a more anti-essentialist perspective from the beginning, I might have broadened the range of participants to include those self-defining as Romanian but finding themselves in precarious situations, or participants belonging to one of Romania’s other 19 official ethnic minorities. An anti-essentialist approach would have also given me a better perspective of how community members negotiate ethnic classification, a perspective that I have now only been able to analyse tangentially. My research focus on the Roma health mediation programme was necessarily ethnocentric. Nevertheless, I hope that my subsequent critical approach to ethnic classification contributes to the destabilisation of racialised accounts, shifting the focus to a more politically productive framing of Roma health.

### **Theoretical considerations**

As I have shown, others have already made the case for understanding the situation of the Roma as postcolonial, and the Roma as subaltern. It is important to see postcolonial theory as a critique of binary constructions of group relations, questioning hegemonic forms of knowledge, while taking into account historical, material, and political contexts, as well as calling attention to the agency of those who are commonly victimised. For its critical force to be transplanted, it does not require absolute commensurability in context. Perhaps surprisingly this approach in itself does not guarantee an anti-essentialist approach. When it is applied unselectively or uncritically, it can solidify monolithic notions of Roma as an oriental, nomadic, and victimised population group (Ashton-Smith 2010). I have tried to avoid these pitfalls. An important limitation to postcolonial theory and its application to the everyday struggles of ordinary people (as opposed to its original purpose as an instrument of literary and art criticism (i.e. Said 1978)), is that its theoretical concepts

might not be straightforwardly graspable by those identified in postcolonial studies as being “subaltern”. My own research is positioned within the academy, and aims to contribute to theoretical debates within critical public health, medical anthropology, and Romani studies. For the purpose of influencing the future of the programme, I will write a separate policy briefing that will summarise my critical approach but mainly concentrate on practical recommendations (included in the next chapter, *Conclusions*).

An issue that may be controversial for the designers and implementers of the Roma health mediation programme is my framing of the Roma health mediation programme as a participatory community intervention. The Roma health mediation programme does not clearly specify what it wants to deliver, nor does it comprehensively outline the mechanisms by which it wants to achieve its vague aims. However, I believe that this theoretical framing is a contribution to a more critical and in-depth understanding of the programme, because it has allowed me to interrogate the production and relationships of knowledge between participants, as well as the potential contribution that the programme could make if it took a more dialogical approach to local knowledge. Because it was conceived in a policy environment that stresses participation (Ringold 2000; Ringold et al. 2006), because it employs community members to improve access to health care and improve outcomes, and because it aims for the empowerment of Roma women, I believe it is productive to examine it with a theoretical understanding of what participatory programmes can be, and how they can achieve empowering, rather than instrumental forms of community participation. The resulting recommendations should offer new perspectives on the programme which will be of interest to programme managers and funders, while the analysis itself provides a theoretical contribution to the field of mediation and Roma policy, neither of which – to the best of my knowledge – have previously been considered from this perspective.

Finally, my use of intersectionality as a theoretical frame has been productive in understanding the ways in which ethnicity and class interact and produce new forms of oppression. The strength of intersectional theory, however, is that it opens up perspectives about a number of different forms of oppression. I could have expanded my analysis to

include considerations of gender, skin colour, or religious identity, all of which I saw to be at stake during fieldwork. Many of these topics, while interesting, would have taken me beyond the scope of this thesis. I ended up not including a gendered analysis, precisely because my field of interaction was predominantly female: the overwhelming majority of mediators is female, and I am myself a woman. A man doing the same research with the same methodology would no doubt have gained a different perspective on health mediation as a process. Within communities I fell into conversations with other women much more easily than with men, in both my main field sites I also happened to live with other women, and the majority of doctors I interviewed were women. In contrast, I was exposed to people from a vast variety of different socio-economic backgrounds, which permitted me to include in my analysis observations on how class affected participants' discursive practices and enacted interactions with one another.

### **Methodological considerations**

Finally, my position as a clear outsider limited what people told me and what I could observe. I was an outsider not only in the sense that I was foreign, but also in the sense that it was difficult for participants (especially mediators) to place me with regards to their own position in the programme. Despite my best efforts to reassure people that I would not pass on any information about them as individuals, and that everything they spoke about was only ever going to be reported on anonymously, I felt that I never quite overcame the suspicions that mediators harboured towards me as somehow connected to, or even a potential informant for the Roma civil society elite in Bucharest. These suspicions were, I should add, not entirely unreasonable, given that this thesis exposes their practice in great detail, and without the protection of anonymity would potentially make them very vulnerable indeed. However, this study is not intended as an evaluation, whether of individual mediators or the programme as a whole, and I must stress the context in which I have placed the mediators' actions. I hope that I have made clear throughout that where mediators appeared to be flailing or failing, this should not be seen as their fault. More often than not, their actions were understandable and reasonable given the precarious employment position and programmatic hierarchies in which they

were placed. If mediators' tendency to not quite trust me had any advantage for this study, it was that they gave me their own "official" versions of what they believed their job should entail. Even when it was difficult at the time to resist the urge to dig for "the truth", as soon as I started writing I became less attached to the idea and have since acknowledged that the relational nature of research and the co-construction of knowledge means that researchers can only work with the narratives with which they are presented. Mediators' "official" narratives have added an important dimension to the research, and have proven a useful point of contrast with enacted practice that I observed.

## Chapter 7: Conclusions

“The capacity to live with difference is, in my view, the coming question of the twenty-first century”  
Stuart Hall (1993, 361)

This thesis has focused on one programme that has attempted to address Stuart Hall’s question (“how to live with difference”) in the context of the Romanian health system. I have argued that the Roma health mediation programme provides unsatisfactory answers inasmuch as it does not take adequate account of the fluidity of identity, nor of the social representations and knowledges that texture the lived experience of diversity in Romania. In this closing chapter, I summarise some of the implications of my research for health policy, participatory intervention, and future research, and outline some suggestions for how the health mediation programme could be productively restructured. I close by briefly reviewing the practical and theoretical contributions that this thesis has made.

### **Implications for health**

In some ways, Roma health mediation makes a very direct contribution to improved access to health care for the community members it works with. It does so mainly by supporting people trying to gain access to documents, the absence of which I observed as one of the most salient obstacles to receiving care. Some mediators also help directly at the point of entry to the health system, by scheduling appointments or accompanying community members to medical consultations. However, this contribution comes at a price: the process of enabling patienthood and citizenship is accompanied by its discursive and enacted containment. At the same time, direct and indirect forms of discrimination on behalf of health professionals went largely unchallenged, thereby leaving one of the main purposes of the Roma health mediation programme unaddressed.

Health is relational, and shaped by historical, spatial, political and cultural aspects (Cornish 2004), as I have shown. It was striking how little attention the programme paid

to the relational, material, and structural determinants of health. I have suggested that the programme's cultural approach to health masks deeper, underlying economic asymmetries. Following Fanon, I argue that "acknowledging the key role of the social order" is mandatory in order for a programme of this kind not to end up blaming its own target population for its circumstances, while also failing to recognise the "ability of humans to transform the social order" (Hook et al. 2004, 94). In its failure to acknowledge and to engage with the community members' social and political context, the programme shifts not only the blame but also the responsibility of addressing their circumstances to individuals themselves, without recognising that these very same circumstances prevent them from doing so. Because of the circularity of this logic, the programme falls short of its aim to substantially improve access to health, or, for that matter, health outcomes for community members.

Given that the Roma health mediation programme is one of the only targeted measures for tackling health inequalities in Romania, this should give policy makers pause for thought. I propose several ways to address the given situation: the first is to address the "upstream" causes of health inequalities through different, targeted interventions. A second, more radical option is to refocus attention on "mainstreaming"; that is, focusing not on behaviour change among targeted population groups, but on systemic transformation (Kostka 2015a). In a dedicated section below, I also consider a third option, which is to reframe the mediation programme so as to focus less on top-down practices and more on dialogue and empowerment.

Given the immensity of the problem, as well as the "upstream" nature of the causes for lacking documentation and health insurance, it makes little sense to provide this service through individuals. Instead, upstream solutions, such as changes in legislation, are much more likely to be effective. One precedent for such an approach is the case of Serbia, where legislative and administrative hurdles for obtaining health insurance were simplified as a result of NGO advocacy and epidemiological health research, which showed undocumented Roma to have limited access to health services (Kaluski et al. 2015; Abdikeeva, Covaci, and Ezer 2013). The literature on Serbian health insurance also



reports a comprehensive exemption from health insurance payment for all Roma (Arsenijevic, Pavlova, and Groot 2014), though this begs the questions of how ethnicity can be ascertained in this context. While such measures do seem to equalise insurance coverage, they do not necessarily prevent out-of-pocket payments, which may disproportionately affect poorer parts of the population. Another approach that has been implemented in Romania is to promote education about Roma culture for medical students. While a shift in attention from “object” of discrimination to “subject” (Morrison 1992) should theoretically be applauded, such measures may also have unintended consequences of further essentialising and solidifying ethnic boundaries.

Across EU institutions, mainstreaming is the accepted approach to gender inequalities, since targeted interventions are recognised as often “undermining or even stigmatising differences”, normalising “structural discrimination” and erecting “barriers to meaningful participation” (Kostka 2015a, 72). The main criticism of mainstreaming policies has been that they are difficult to monitor and evaluate, that they do not engender the same political motivation, and that they risk diluting existing policies. However, these may not be such strong arguments in the Romanian context, since targeted policies such as the Roma health mediation programme have not yet been adequately monitored or evaluated – in Romania the political motivation to address Roma health inequalities seems to already be low, and there are only a small number of policies for affirmative action that have been continuously supported by the state (Moisă et al. 2016). Joanna Kostka (2015b) has compared the comparative merits of targeted versus mainstreaming policies that address Roma inequalities in Slovakia and Spain, and has found that an “ethnically neutral approach fostered stronger political attention to patterns of social exclusion” (87), and that the “mainstreaming approach is more conducive to successful policy outputs than affirmative action and targeting” (2015a, 68). In Romania such policies could include the facilitation of obtaining identity documents for *everyone*, as well as the promotion of dialogical relationships between health professionals and patients over paternalistic or instrumental approaches. These policies could be framed in an intersectional way, that is, paying special attention to all manner of vulnerabilities. They would therefore benefit not just Roma, but all patients.

### **Implications for health mediation as a participatory health intervention**

Given the current political and economic climate in Romania (which continues to see cuts to public budgets and further promotes neoliberal notions of individual responsibility), it is unlikely that measures founded on a broad understanding of social solidarity will be implemented in the near future. Within the given political constraints, it is understandable that Roma civil society groups have promoted targeted interventions which – unlike mainstream policies – can be launched with a smaller budget and sustained by the support and enthusiasm of a smaller group of engaged activists. Bearing these very real constraints in mind, how can the existing mediation programme be refocused so that it becomes more effective on the one hand, and more politically and ethically grounded on the other?

In their current form, I have argued, mediators are one-way conduits of change. The programme has been instrumentalised in such a way that it serves to govern the Roma population rather than contributing to the emancipation of poor and marginalised communities. While this is not explicitly its ambition, if it is to benefit community members rather than to promote the interests of state authorities the programme should shift its aims to more directly target dialogical engagement. This, I have argued, could empower communities to recognise the constraints of their conditions, and to co-design interventions that promote healthy behaviour by focusing not only on technical and biomedical knowledge about health, but also on the wider social, material, and cultural determinants of health.

Communities should have room to define their own health priorities. The programme should engage with material context, since this is clearly one of the major influences on health, independent of ethnicity. Furthermore, if health mediation is to effectively engage with cultural difference, it has to engage with the “social knowledge” of the people whom it is targeting. It should challenge not only how different kinds of knowledge are placed in a hierarchy where the knowledge of “experts” (i.e. clinicians and researchers) is deemed more relevant to the context than the “local knowledge” of the people at whom the

programme is targeted (Jovchelovitch 2007): what is entirely missing in this way of “mediating” is a challenge to hegemonic discourses about Roma as inferior and needing intervention.

This could be achieved by adopting a Freirian approach to participation (Campbell and Jovchelovitch 2000). As Cornish and Campbell (2009; 2013) have shown, participatory community interventions are more successful at positively changing outcomes when they work with communities to recognise the sources of their oppression, to reflect on the barriers that prevent them from leading healthy lives, and to devise strategies to change these conditions of living (Marston et al. 2013).

Mediator training should provide a greater emphasis on community engagement and dialogue. As participatory health interventions in other challenging settings (such as the red light district in Kolkata (Campbell and Cornish 2013) have shown, this is possible if the programme treats community members as participants whose knowledge is valid and valuable, rather than as instruments to generate top-down notions of change. Rather than continuing the monologist practice which I have shown to be the dominant mode of interaction, a greater involvement from the community could also lead to more meaningful interactions between communities and health professionals. It is possible to envisage a scenario in which mediators worked towards building a dialogue in which participants are encouraged to respect and listen to each other, where different forms of knowledge are respected rather than subsumed in the maelstrom of existing power dynamics. This is important not only from an ethical perspective in which community members are respected as autonomous individuals rather than objectivised or infantilised. A dialogue would also mark a shift towards an intercultural approach to mediation, in which “there is space for creation and mutual accommodation” (Agusti-Panareda 2006, 427): it is through “contact with conflicting social representations that human beings begin to reflect on their own views and realise what is distinctive about the representations they hold” (Voelklein and Howarth 2005, 13). Recognising what is locally distinctive would allow for contextually relevant responses to enable healthier behaviour. This kind of local response should be possible in the case of Roma health mediation, given that mediators

work locally and even come from the local area in which they work. Lastly – and, from a public health perspective, perhaps most importantly – engagement on people’s own terms, an appreciation for community members’ own priorities, taking into consideration their circumstances and social knowledge is much more likely to lead to lasting change.

To this end, part of mediators’ training should be to raise their awareness of essentialising discourses, as well as the more direct forms of discrimination on which training currently focuses. The programme should be re-designed in order to avoid making essentialising claims itself, and aim to challenge this discourse by setting a different tone and approach to mediation, approaching people and communities on a case-by case basis. An intersectional approach that takes seriously both discourse, space, and materiality would be one way of introducing a more politically acute form of mediation, one which articulates the intersections between multiple oppressions such as race, class, and gender. Such an approach would allow mediators to recognise their own position within these hierarchies, and to address their own role as part of a system of perpetuating difference and contributing to neoliberal state governmentality.

Realistically, such a refocusing of the programme would have to be premised on the financial and organisational uncoupling of health mediation from local authorities, a fairly large, but eminently possible organisational shift. Only if health mediators can be assured of their ongoing and stable employment may they act independently from local authorities, and be protected from having to fulfil tasks that lie outside their remit. From conversations with key informants, I gathered that there have already been informal calls for the programme to be re-centralised. Since this would require a mere organisational shift without increasing the overall budget for mediation, it seems like this would be possible if enough support was garnered within the Ministry of Health. At the same time, arguments in favour of uncoupling mediators from local authorities may threaten both national and local authorities, and contribute to mediators being seen as anti-discrimination inspectors, unlikely to be readily welcomed by either national or local institutions. Since it is likely that mediators will continue to be dependent on the good-will and cooperation of local authorities in order to be employed, the argument for their

financial uncoupling would have to be made strategically and delicately, in a way that does not overtly threaten government institutions.

### **Implications for research and future directions**

This research project did not set out with a clear anti-essentialist perspective. However, in the course of carrying out the research that has gone into this thesis, I have recognised the urgent need for an explicitly anti-essentialist research agenda. This should include not only investigation into all the different ways in which boundaries between peoples are constructed and maintained, and how they serve to maintain the status quo. It should also include research that rejects binary assumptions. While some may understandably argue that data which is segregated according to ethnicity is needed in order to measure change and monitor progress, the critical literature on Roma integration raises two questions. Are the methods currently employed to measure inequalities in social outcomes in fact measuring what they are attempting to measure? And has this measuring and monitoring brought about policies that have helped in “closing the gap” between Roma and non-Roma? The Decade of Roma Inclusion, has had an underwhelming impact for the communities that it has targeted (Brüggemann and Friedman 2017). Perhaps it is time to fundamentally change the dominant approach, and emphasise not only intersectional interventions, but also intersectionally sensitive research.

A number of topics have emerged from my own research that merit in-depth investigation. Although I mentioned at the outset that I aimed to follow the “subject” as well as the “object” of discrimination, much more needs to be done to uncover and investigate practices of discrimination that are pervasive throughout the different sectors of the medical system. This research should be done with a view to identifying strategies for addressing institutional racism, and, following Back and Solomos (2000), such research must “focus on de-colonising the definition of ‘normal’, and [...] avoid the reification of whiteness as a social identity” (22). Second, a large and fundamentally under-researched area is the historical production of poverty and marginality. This could be researched both in the archives, and in contemporary narratives of historical developments. From an archival

perspective, it would be interesting to take an intersectional approach; that is, to not assume the existence or project present-day understandings of ethnic categorisations, and instead to examine how they have been historically produced. I am thinking in particular about the role of spatial practices in the creation of categories, and the imagination of national identities.

Instead of producing more knowledge “about Roma,” which through its insularity often inevitably finds the cause of problems within Roma communities themselves, inadvertently perpetuating discourses of victim-blaming, I propose that research employ methodologies and terminologies that have grown out of intersectional, post-colonial, and de-colonial approaches to knowledge production. For example, “knowledge” should be understood to encompass social and local knowledge, rather than purely “technical knowledge” (Jovchelovitch 2007). Instead of thinking in terms of binary or exclusive senses of “ethnic identity”, researchers could employ the notion of “filiations” (Hall and Du Gay 1996; Bowker and Star 1999), thereby acknowledging the sometimes loose ties that people have to groups, as well as the inherently fluid and multiple character of social belonging. Rather than thinking in terms of segregation, which produces the notion of unitary and monolithic forms of identity, research would benefit from paying more attention to conviviality (Mbembe 2001) and the complexities this brings to strategies of resistance and empowerment. Instead of framing research as being about either identity *or* class *or* gender, it could take an intersectional perspective, recognising the way in which different filiations interact and multiply to create unique and different experiences of social oppression, requiring radical and locally specific approaches to community emancipation.

### **Contributions and concluding statements**

This thesis has provided an in-depth examination of how classifications of Roma and knowledge constructions and enactments around Roma health occur at the local level. It thereby contributes to an understanding of how essentialising and neoliberal narratives about Roma as undeserving and Other are perpetuated, not only by local state institutions, but also by those who are formally employed to improve the condition of

Roma communities. Second, it has contributed the first critical examination of the processes involved in Roma health mediation by conducting participant observation, thereby yielding findings that substantially differ from the overwhelmingly positive coverage that the programme has received so far. This thesis has aimed to destabilise the wider consensus narrative on Roma health by introducing theoretical concepts and lines of argument from intersectional, post-colonial, and dialogical theory. Finally, I have outlined suggestions for a mediation programme based on dialogical relationships instead of containment.

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