

Primary Care for the Roma in Europe

Position Paper of the European Forum for Primary Care

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Abstract

This paper provides information on health needs of the Roma population in Europe. It gives an overview of local, national and international health policies and on examples of good practice with the purpose of strengthening service delivery by Primary Care for Roma.

For practitioners (GP's, nurses, social workers, others) tools are available to improve access to the consultation room and to develop an interaction with Roma patients that is effective in addressing the patient's complaints. Effectively dealing with low health literacy may increase trust and mutual understanding between patient and health care provider, a key element of quality care. For managers and policy makers, examples show how access to health services in the community can be enhanced, by the involvement of Roma Health Mediators and by other approaches to facilitate communication between Roma and health staff. Involving Roma organizations is key to this, including in research on health needs and health services.

Recommendations are made for policies at national and international level with a focus on training of primary care staff and development of local research.

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Introduction

The 12 million Roma population in Europe constitutes its largest ethnic minority. A history of migration and exclusion in ancient and recent times has led to their dispersion over many countries and a wide variety of identities and characteristics. Many Roma are part of mainstream society with few or no distinctive (health) features but, in contrast, low levels of education and illiteracy, low employment and a low income level are also frequent features of many Roma communities. This has resulted in a particularly low health status and high incidence and prevalence of a number of diseases among the Roma population^{1,2,3}. While this situation is chronic, a sense of urgency with regards to Roma exclusion and health issues finally has developed in Europe. In how far the current numerous initiatives to redress the situation are effective, is a matter of debate.

Primary Care is a comprehensive, multi-disciplinary, patient centred and community oriented approach to health and addresses the needs of all the population and patients for which it is responsible, irrespective of age, gender, creed and ethnic background.

This Position Paper is one in a series of the European Forum for Primary Care (EFPC)⁴. These Papers mostly address system or functional characteristics of Primary Care, in support to practitioners, researchers and policymakers. For example in 2012 the Paper »Improving inter- professional collaboration in Primary Care” was published⁵. However, some Papers address Primary Care for specific population groups, such as the elderly⁶.

There are many ethnic minorities in Europe and in principle Primary Care is shaped and functions in such a manner that it is able to adjust care to the needs of these groups and individuals. Therefore, in general EFPC does not intend to develop Position Papers for specific ethnic minorities. However, the situation and numbers of the Roma population, their health needs and the barriers to health care provision justify the development of this Paper.

The key objective of this Paper is to assist practitioners, policymakers and researchers in Primary Care by providing information on health needs of Roma and on research, policies and practices that intend to overcome the barriers to the delivery of effective Primary Care. It also formulates recommendations for further research, policies and practices.

This Paper first summarizes the characteristics of Primary Care. It then describes the specific needs of Roma in some more detail and the barriers for good Primary Care. It discusses the current context in which health care for the Roma population functions and shows various approaches in policy, practice and research intended to improve Primary Care for Roma communities. A number of suggestions is offered to strengthen the skills of practitioners.

Overall, this Position Paper intends to add to the efforts of Roma organisations, international organisations and government bodies alike to come to a meaningful Roma integration in Europe.

Primary Care, key notions.

The concept of Primary Care includes the notion that it adequately addresses the needs of all patients for which it is responsible, irrespective of age, gender, creed and ethnic background. In previous publications of the EFPC the characteristics of Primary Care have been described⁷, see Box 1 for a summary.

Box 1 – characteristics of Primary Care

Primary Care is the provision of universally accessible, person-centered, comprehensive health and community services, provided by a team of professionals accountable for addressing a large majority of personal health needs. These services are delivered in a sustained partnership with patients and informal care givers, in the context of family and community and play a central role in the overall coordination and continuity of people's care⁸.

Primary Care is not a fixed organisational structure or level of care that can be easily and unambiguously identified. Instead, it is considered as a combination of essential characteristics:

- Care that is easily accessible: as a first point of contact with health care, in the community, without financial, physical (distance) or other barriers.
- Person oriented care rather than disease or organ oriented care. This implies attention for functioning and autonomy of people and requires continuity of care; this implies that primary care ensures coordination.
- Comprehensive and quality care, implying evidence based generalist care for all common health problems. It includes collaboration with specialist services where generalist services are insufficient. It also includes a role in prevention and promotion. This leads to:
- Care that takes responsibility for the health of people in their community, which implies attention for determinants of ill-health and social aspects and a strong interaction with public health and social services
- Care that sees people as active partners in managing the health care process and in managing their own health.

While some consider that the simple single indicator of strong Primary Care is whether the country has a system of gate keeping GP's others argue that the elements of strong Primary Care as listed above can be realised without a system of obligatory gate keeping GP's⁹.

Primary Care and its providers are expected to adjust their care and the way it is given to the composition of the patient population. From the above follows that strong Primary Care adjusts the expertise, skills and organisation of its providers to the sub-groups in the population. For example, earlier papers of the European Forum for Primary Care discussed care for the elderly and care for COPD patients¹⁰. Therefore, we consider that Primary Care is universal and Primary Care for Roma is not different from other Primary Care, but it adapts to specific Roma population characteristics. Because of the variation in Roma communities as mentioned above, this adjustment, through medical education and research, needs to be done at local or regional level, there is no standard set of knowledge and skills. At national and international level, measures can be taken to facilitate this local or regional adjustment. In the chapters below, the specifics of Primary Care for Roma are reviewed.

The Roma population.

This Paper makes generalisations about the Roma population. They have to be understood as intended in this paper and in no way mean to stigmatise Roma and Roma communities. Further, some of the generalisations below do apply to other population groups, among them recent migrants from other continents.

The largest Roma populations are to be found in the central and eastern European states of Bulgaria, the Former Yugoslav Republic of Macedonia, Slovakia, Romania, Serbia and Hungary. In these countries, Roma make up between 7-12 per cent of the total population. In most other states Roma make up around one per cent, or much less, of the population.

There is no generally accepted definition of who is a Roma, in fact it is an umbrella term for different groups of people who share certain cultural characteristics and a history of discrimination: Roma, Gypsies, Travellers, Manouches, Ashkali, Sinti and Boyash. Features like genetic characteristics, social status, language and belonging to the group all have limited value and validity, depending on the purpose of the definition and the Roma subgroup being addressed by the definition. Attempts to determine the number of Roma population are not only less successful because of lack of clear criteria. Also, many Roma are reluctant to identify as such during a census, for fear of discrimination. Indeed, to avoid stigmatization or discrimination, legislation in many countries in Europe does not allow for ethnic registration by authorities or health services. This the case, amongst others, in France, Greece, Slovakia and the Czech Republic¹¹. This limits the registration of health data and the development of consistent health statistics on Roma and explains the unavailability of precise data in many instances on Roma health¹².

Health status

In line with the low socio-economic status of Roma and Roma communities, many health indicators are unfavourable for Roma. Life expectancy at birth in the EU is 76 for men and 82 for women. For Roma, it is estimated to be 10 years less¹³. A United Nations Development Programme report on five countries noted that Roma child mortality rates are 2 to 6 times higher than those for the general population. High levels of infant mortality among the Roma community are reported in other countries¹⁴

Specific patterns of morbidity and mortality in Roma communities obviously vary with composition and location of the community and with the precise socio-economic characteristics. A recent EU report, reviewing health status of Roma communities, highlights the higher incidence of major chronic diseases in the Roma community compared to the general population⁷. As could be expected, frequently TB prevalence is a major issue, as are sexual and reproductive health, including low age at first pregnancy, abortion rate and unmet contraceptive needs. Indeed, Roma women are generally in worse health and more disadvantaged than Roma men and non-Roma alike. Poor maternal health is a particular risk for Roma women. In many cases men decide about reproductive health of female.

As a consequence of generations long isolation, in some Roma communities in Eastern Europe hereditary diseases are highly prevalent, several of them are unique to Roma: hereditary motor sensory neuropathy type Lom, hereditary motor sensory neuropathy type Russe, congenital cataracts facial dysmorphism neuropathy syndrome, congenital myasthenic syndrome and hereditary inclusion body myopathy. Other disorders like G6PD deficiency are not specific for Roma but in certain sub-groups highly prevalent¹⁵. Due to migration in recent years, now families and individuals with these traits are living in other regions of the world as well.

While socio-economic status fully explains the worse health status of many Roma, it only partially determines their less healthy behavior. Therefore, efforts to improve the health of Roma should include a focus on socioeconomic status, but also cultural differences must be taken into account in developing public health interventions. This approach has been clearly documented and argued in Hungary^{16, 17}

In Slovakia, research shows that the prevalence of leisure-time physical activities such as walking or some other type of sport is significantly lower among Roma women than among non-Roma women. Men and women living in Roma settlements are more likely to smoke on a daily basis and they are heavier smokers in comparison with the majority population^{18,19}.

In absence of clear symptoms or ailments that interfere with the performance of daily activities, a large percentage of Roma claim good overall state of health. Surveys on

perceived health status therefore often show better results among Roma than non-Roma population, in spite of morbidity and mortality data being worse. However, when disaggregated by age, in the older age groups the results of self-assessment of health are inverse, with a higher percentage of Roma assessing their health as bad than the non-Roma population^{20,21}.

Access to health care

Various barriers limit Roma access to the health system. One can distinguish supply side and demand side barriers²², that often mirror each other. These barriers have been described abundantly in a number of reports and publications^{23,24}. The examples below illustrate the most common barriers.

On the supply side, the location of health services, including Primary Care, frequently is far from the Roma community. This influences demand, that is reduced when transport time and costs are prohibitive. Spatial segregation, meaning that Roma are living in areas predominantly populated by other Roma, is highest in Bulgaria (72%), Romania (66%), Slovakia (65%) and Greece (63%)^{12,25}. In many of these locations, no health center or any primary care facility is operating. Distance to the nearest facility often is large.

Affordability refers to the costs and prices of services. In view of the low economic status of many Roma, this is an obvious supply side barrier. Health insurance takes this barrier largely away. However, Roma are significantly less likely to have insurance coverage in most CEE countries and this gap remains when adjusting for socio-economic differences between Roma and non-Roma in many countries¹¹. Reasons are a lack of identity papers, they do not qualify for health insurance or do not know how to access health insurance. Thanks to dedicated efforts over the last decade, in several countries the proportion of Roma that has no identity papers or health insurance, has declined drastically. Still, as late as 2012, up to 26 % of Roma in Romania do not possess a health insurance and currently the numbers of not insured Roma in Bulgaria are increasing²⁶.

In emergency situations, people do have the right to access to health services without health insurance, but family planning and antenatal care in several countries are not included in the medical package for the uninsured. This results in low accessibility of antenatal care and a higher risk of complications during pregnancy and high rates of low birth weight.

Acceptability frequently is a supply side barrier when health staff attitude and interpersonal skills express lack of respect or empathy. These are an obvious requirement for the establishment of trust, but there is an overwhelming amount of personal accounts of Roma patients that experience an condescending or hostile attitude of their primary care provider(s). One research report concludes: Romani women in Serbia and Macedonia

experience high levels of antenatal care discrimination and every day discrimination; the frequency of these events is associated with access to adequate antenatal care and low birth weight²⁷. Fortunately, also the contrary has been documented: primary care providers committed to their Roma patients without hesitation. Prejudice and lack of trust easily becomes reciprocal and are often fed by Roma's' distrust in public services^{14,28,29,30}.

In terms of health messages, there is a growing body of evidence supporting lifestyle interventions for the prevention of chronic disease. However, it is unclear to what extent these evidence-derived recommendations are applicable to ethnic minority populations, including Roma³¹. Cultural adjustment of these messages has not been systematically undertaken.

On the demand side, several factors play into the actual use of health services. Language and literacy are among them. Nearly 40 % of Roma speak one of the Romani dialects. The proportion that does not speak a second language is unknown. Language barriers are responsible for misunderstandings with negative impact on health and health care, such as non-compliance with prescribed treatment or late admission. Even when language itself is no barrier, low literacy may be. Low literacy or little to no schooling, often coincides with low health literacy, and is frequent among Roma communities. This has negative consequences for health. Patients may not understand medicine prescriptions and instructions, leaflets and explanations can be misunderstood or wrongly applied. Adherence to treatment, once symptoms have disappeared, is often not understood, and self-management with chronic diseases such as diabetes can be a challenge. Many low literate people experience fear, uncertainty and shame about not being able to read or write. They often try to hide it by using excuses.

Many Roma regard health care institutions as distressing places. They are alien spaces in which everything is different and where the established norms are not only strange, but in many cases are at variance with their own³². Related to (health) literacy, is the frequent lack of Roma's' knowledge on the organization of the health care system. For instance the gatekeeper role of primary care often is not known. Opening hours of health centers or of a GP's surgery and the purpose of diagnostic and therapeutic procedures are not understood or accepted. The expectation in many Roma communities is that health services should be available when they are needed, not when the system is ready to offer them. The purpose and timing of childhood immunisation often is not known. In some Roma communities vaccine uptake is very low, while in others it is similar to that of the general population.

Health seeking behaviour is also influenced by concepts of health and disease. Following from the large diversity of Roma communities and subcultures, there is no single well defined set of concepts, beliefs and attitudes of Roma towards health, health behaviour and disease. However, some values like notions of purity and impurity are widespread among Roma and may explain avoidance of contact with particular material or individuals. Further,

individual communities do have strong beliefs and traditional knowledge concerning the causes of disease, healthy and unhealthy behaviour and the use of medicine and treatments. Knowledge and use of herbs for fever or minor ailments is part of this.

The place where we grew up shapes the way we think, feel, and act. Hofstede's *theory of cultural dimensions* describes the effects of a society's *culture* on the values of its members, and how these values relate to behaviour³³. Collectivism versus individualism is one of the dimensions Hofstede has identified and in which Roma differ from most of the surrounding populations: the group you belong to is more important than yourself. Individuals feel only complete within a group of peers. Family is playing a major role in decision making, the individual patient's responsibility is limited. This explains the strong wish of Roma patients to be accompanied by members of the group during consultation and hospitalisation. This easily leads to controversy with staff and other patients, when these feel overwhelmed and do not understand the importance of the group being together.

The following description on the website of the Ministry of Health of the Former Yugoslav Republic of Macedonia is an illustration of the common barriers to access to primary care: "For Roma women, timely access to antenatal services and consequently to the maternal monitoring card is compromised due to variety of reasons: low level of education and information; cultural factors that influence their health seeking behaviour: irregular and delayed visits to gynaecologist during pregnancy; economic barriers as a number of antenatal services is fee-based so women avoid going to gynaecologist; language barriers; low and socio-economic status rather than ethnicity, are additional barriers for the use of health services which are in the same time not sufficiently sensitive to diversity³⁴. A small number of Roma women does not have regulated ID and citizenship, which make them ineligible for free antenatal care and the Maternal card. According to official data, the estimated number is 500 women"³⁵.

The current policy context concerning Roma

Of relevance for the delivery of primary care to Roma are the current local, national and international policy initiatives that attempt to break the social barriers and widespread discrimination of Roma. These policies may provide opportunity and support to improve Primary Care for Roma. The main international initiatives are briefly reviewed below.

Since the '90's, the Open Society Institute / Foundations have supported the emancipation of Roma and they have worked with Roma communities to secure Roma's rightful position in society, including access to health care, with the motto: "Justice sometimes is the best medicine"³⁶.

In spite of limited data availability as mentioned above, in 2003, the UNDP report *Avoiding the dependency trap* provided for the first time robust statistical evidence showing that a

significant number of Roma in the EU face severe challenges in terms of illiteracy, infant mortality and malnutrition.

This report was followed by, among others, the initiative to develop the “Decade of Roma inclusion 2005-2015”. Currently, 13 countries in Central and Eastern Europe participate as member or observer, plus Spain, Norway and the United States. The Decade acts as an umbrella for international collaboration on national actions. Four priority areas have been defined: housing, education, employment and health³⁷. While some successes can be claimed, in early 2014 the members of the Roma decade did conclude that the ultimate aims by far have not been achieved and the Decade needs to be followed up by similar actions.

The EU Fundamental Rights Agency (FRA) was established in 2007 as an EU Agency with the specific task of providing independent, evidence-based advice on fundamental rights¹. It is the EU’s channel for many of its Roma policies. The EU Commission concluded in 2011 that “..in spite of some progress achieved both in the Member States and at EU level over the past years, little has changed in the day-to-day situation of most of the Roma.Strong and proportionate measures are still not yet in place to tackle the social and economic problems of a large part of the EU's Roma Population”. Following earlier EU initiatives, an “EU Framework for National Roma Integration Strategies up to 2020” has been established in 2011, which focuses on the same four priorities as the Roma Decade. Member states have to develop a National Roma Integration Strategy and the European Commission provides an annual report to the European Parliament on progress made regarding Roma integration. The health chapter of the 2014 report concludes: “Following the analysis of health measures, it can be concluded that healthcare and basic social security coverage is not yet extended to all. Investing in adequate healthcare and preventive measures for all Roma, in particular children, is essential as it will prevent further health problems in the long term. Promising initiatives should be extended and multiplied to make a real impact on the ground”³⁸. In line with these conclusions, the European Centre of Disease Prevention and Control (ECDC) runs a program addressing vaccination uptake by Roma. This will be discussed in the next chapter.

The Council of Europe, representing a much larger country membership than the EU, 47 versus 28, adds its voice and moral and practical guidance, through another four distinct approaches: (1) Effective monitoring and evaluation of the implementation of national strategies for Roma; (2) From targeting to mainstreaming policies for Roma, because comprehensive targeted strategies adopted and implemented in various member states for the last ten years cannot be a permanent policy solution; (3) Ensure Roma and Travellers participation in the political process; (4) Strengthen co-operation between all stakeholders³⁹.

¹ <http://fra.europa.eu>

The Regional Office for Europe of the World Health Organisation supported the development of a WHO Collaborating Centre on Social Inclusion and Health in Alicante, Spain. The Centre runs a programme dedicated to the health of Roma⁴⁰. It publishes a quarterly electronic “Roma health newsletter”⁴¹ and supports initiatives like a symposium in Hungary on healthy ageing of Roma in late 2014.

The European Public Health Alliance has issued a “Position” on Roma Health in Europe in 2014. This includes recommendations to address Roma inequalities in health⁴².

All the above initiatives emphasise the importance of the collection and use of specific data on Roma health and on participation of Roma in defining, implementing and monitoring the policies that aim to help Roma to integrate and eliminate exclusion. Many initiatives aim at collecting data on and improving the (health) situation of Roma at local level, although few of them aim at systematically supporting or improving Primary Care for Roma.

The EU observation in 2011 that *little has changed in the day-to-day situation of most of the Roma* suggests that the many (health) policy initiatives did not yet lead to many changes in practice.

Primary Care delivery: establishing an effective relationship with Roma communities and patients

The previous chapters have outlined a number of obstacles and challenges to adequate provision of Primary Care to the Roma population. We have listed supply and demand barriers. The previous chapter concludes with the observation that many policy initiatives did not yet lead to many changes in practice. This chapter reviews developments in practice and identifies tools to improve Primary Care for Roma, with the purpose of stimulating application by Primary Care providers.

Since trust and good inter-personal relations and communication are key to overcome barriers to access to Primary Care, we focus on the interaction between the providers in Primary Care, mostly GP's, nurses and social workers, and Roma.

Building mutual trust requires mutual effort. As many of the contributors to this paper have experienced and witnessed, proximity and joint activity, like establishing contact with the local Roma community to plan research on health needs and attitudes, help to erode prejudice and build a relationship of trust. Other approaches to building trust and an effective relationship is the strengthening of competences of primary care providers in

interacting with Roma patients. This will be discussed in the following pages. Further, strengthening communication by involving intermediaries is an option when Primary Care is in charge of care for larger Roma communities.

Generic competences

Effective communication between health care provider and patients and persons under their care is a one of the key competences of primary care providers⁴³. It needs genuine motivation and it needs training. Communication skills increasingly are part of the training curriculum of doctors and nurses in various countries. The training of GP's includes practical exercises in communication skills. Textbooks with case studies on effective communication are being used in several countries. In the UK, in 2014 "Working with vulnerable groups: A clinical handbook for GPs" was published which specifically is meant to support care for Gypsies and travelers⁴⁴.

As mentioned in the previous chapters, collectivity is a very important dimension of Roma culture. Roma often come in groups to emergency services or primary care consultations, which is an expression of the group solidarity. Acceptance of this culture and behavior reflects competence of health care providers. Making practical arrangements, like creating the necessary space in waiting rooms or consultations rooms when that is possible, is part of the acceptance. For example,

A main competence of practitioners is their ability to adequately assess their patient's individual (health) literacy. It takes training and experience to pick up, for example, the signs that may indicate a low literacy level and to ask questions to explore this in a non-confrontational manner⁴⁵, see Box 1.

Box 1

Indicators of patients' low level of literacy and questions to explore the literacy level.

Beware of low literacy in the following situations.

Patients:

- * Don't show up on time or not at all
- * Don't take medication correctly, unable to name medication or why they are prescribed, unable to recall times of medicine taking
- * Don't fill out medical forms (excuses like forgetting of glasses)
- * Difficulties in chronologically presenting their symptoms.
- * Never ask questions

For health care professionals it can be a challenge to ask about literacy without embarrassing the patient. The following questions are helpful:

- * How often do you have someone (like a family member, friend, or health worker) help you read hospital materials?
- * How often do you have problems learning about your medical

condition because of difficulty understanding written information?
 * How confident are you filling out medical forms by yourself?

In case of language or literacy restrictions, there is a range of approaches that help to establish effective communication²⁹, see Box 2:

Box 2

Approaches to establish effective communication

- Warm greeting: Greet patients with a smile and a welcoming attitude.
- Eye contact: Make appropriate eye contact throughout the interaction
- Plain, non-medical language: Use common words when speaking to patients. Take note of the words they use to describe their illness and use the same words in your conversation
- Slow down: Speak clearly and at a moderate pace.
- Specific and concrete: Be specific and concrete in your conversation
- Limit content: Prioritize what needs to be discussed and limit information to three key points. Do not explain everything in detail.
- Repeat key points
- Graphics: Draw pictures, use illustrations, or demonstrate with 3-D models.
- Patient participation: Encourage patients to ask questions, to be involved in the conversation and to be proactive in their own health care.
- Be positive and affirmative
- ‘Teach-back method’: Check patient’s understanding by asking him or her to repeat your words. Make sure to ask this in a respectful way, for example ‘I want to be sure that I have explained you everything well’ instead of ‘I want to make sure that you understood me well’.
- Don’t use idioms or sayings

When there is no shared language and cultural background, establishing a feeling of trust and understanding can be difficult. The most important cultural competences of caregivers when dealing with patients from different cultural background are openness and respectfulness and asking questions out of genuine interest. See the suggestions in Box 3.

Box 3

Suggestions for effective communication

- Communicate expectations and aims of the consultation, and reach consensus with your patient.
- Always explain what you do and why.
- Make sure patient and family members participate in decision-making.

- Make in between summaries of your observations and conclusions and check understanding, such as: Observation: 'I see that....., is that correct? Interpretation: 'I have the impression that..... , correct? Conclusion: I think that..... , correct?'
- Take time to find out patient's thoughts, feelings and explanations of the symptoms, as well as those of the family members. Try to understand the world of your patient.
- Show empathy
- Be sensitive to cues of the patient, they might be non-verbal
- Show interests in patient's family where appropriate. It often is highly appreciated.
- Do not be straightforward about sensitive issues.
- Asking indirect questions can be useful in helping a patient to avoid speaking out, for example: 'How in in your culture a person with your symptoms (disease) would be helped? How is your family explaining your symptoms?'
- Show interest and respect for patient's own solutions or remedies
- Ask about cultural or religious customs or treatments in the home country
- Ask about consulting of traditional healers

The communication skills and approaches described above are generic: they are needed not only for Roma patients but for any patient in primary care.

Specific competences

As mentioned, language often is one of the obstacles that need to be overcome. The practice of involving family members to translate between patient and care provider has several negative effects and guidelines have been developed to support the practice of translation. The current European RESTORE project aims to investigate the implementation of guidelines and training initiatives that support communication in cross-cultural general practice consultations⁴⁶. In several countries, including Belgium and Spain, a telephone Romani translation service is available.

Understanding the views, needs and expectations of Roma patients requires knowledge of culture, living conditions and of the further context. The effectiveness of life style messages increases when they are culturally adapted. Generating evidence of the effectiveness in general is beyond the scale, capacity and resources of Primary Care practitioners but these are well positioned to support and facilitate the research.

Liaising and partnering with the community is the first step. Local or regional Roma organisations can be an effective partner to establish a relationship. In Romania, a guide for General Practitioners on Roma culture was developed through an intensive consultative process between health providers and the Roma community⁴⁷. In Spain, a handbook for use of health providers was developed as well⁴⁸. Local studies on Roma health status, life style and health (seeking) behaviour may have the double benefit of establishing relationships through the studies and of providing knowledge to primary care practitioners. Below, several examples are given of local, regional and national initiatives.

Romania.

For more than 20 years, Doctor C. has been a family doctor in seven villages working to overcome barriers to healthcare in Roma tradition. Because community members are not well-educated, the doctor takes care to provide health care information in an appropriate and understandable manner. He patiently explains the importance of family planning and the importance of having a child only when the couple is ready. In the very poor communities where he works, the “roll and milk” initiative has significantly increased school attendance. In order to get his messages out, Dr. C. relies on a group of helpers—the children who attend school—to assist him in the administration of medication to those who cannot read.

In 2013, a cervix cancer screening program among Roma women in Oradea, Romania, gradually gained more acceptance, after early hesitations. GP’s took responsibility for the program and careful explanations to both the male and female population, with the help of a Roma Health Mediator (ed: see below), ensured acceptance. Practical obstacles like distance and travel expenses however, were difficult to overcome. A major blow to the program was when the funding from the health district dried up within one year and the service was discontinued. This affected trust, since earlier promises to the Roma target group could not be kept. The lesson learned here is on the need for continuity in (funding) policies and services.

Macedonia, Skopje.

One GP with many years of working experience in the Roma community of Suto Orizar acquired experience of effective communication with the Roma population:

- working in small groups 3-4 persons maximum (persons with similar problems where they can share experiences, or
- one to one education (doctor-patient) and
- educational interactive sessions in schools

Another initiative in Suto Orizar is the use of the Community Assessment Card (CAC) by the Health Center to register the results of a community survey. A total of 70 interviews have been carried out with Roma women who are pregnant and are in the seventh to ninth month of pregnancy, as well as women that have given birth in the last six months. The

interviews were conducted by trained staff from the community or from local CSO's during visits to the homes of the Roma women living in this municipality. The CAC uses the three traffic light colors for rating, where red indicates positive answers up to 50%, yellow marks the 50 to 75% range, while green shows positive response over 75%, see Figure 1. The assessment is carried out periodically for the purpose of continuous measurement of the progress achieved over a period of time.

Figure 1

Family doctor coverage	85,70 % green
Level of information of Roma women about the costs and health services during pregnancy	48,35 % red
Practices of Roma women related to health care during pregnancy	76,32 % green
Cooperation of the community service with the maternity hospitals and family doctors	44,44 % red
Costs for services during pregnancy	45,58 % red
Scope of services during pregnancy provided by the family gynecologists	66,24 % yellow
Communication of health care staff with Roma women in the family gynecologist practice	66,10 % yellow
Visits by a community nurse	44,49 % red
Scope and quality of services provided by a community nurse	65,42 % yellow

The CAC is one of the tools for community oversight, which includes processes such as community building and mobilization, conducting research and advocacy aimed at improving the situation in accordance with key research findings⁴⁹.

Research and dissemination

In a number of countries, GP's and local health services develop research, as is shown by the example above from Macedonia. Below several cases are described of research at local level that is undertaken or supported by academic institutes. A major point to emphasize is the close collaboration between academia, local primary care providers and Roma organisations, that helps to implement the research and that in itself may contribute to trust-building. Also, researchers may reach out to their professional peers and demonstrate and advocate for Roma oriented research.

Slovenia

The Universities of Ljubljana and Maribor have undertaken a research program, of which three outcomes are highlighted below.

A study on smoking and smoking behavior among Roma showed a strong cultural dimension of smoking. Traditional strategies for smoking cessation are largely ineffective among the Roma. Therefore, innovative and culturally acceptable methods need to be developed⁵⁰.

The “Health beliefs and practices among Slovenian Roma in response to febrile illnesses⁵¹” study concludes that Roma generally do not use a thermometer, but instead define health or illness according to their general wellbeing. However, more than half were aware of the benefits of antipyretics. The Roma frequently use traditional folk medicine (teas, compresses) to treat fever. They only see the doctor if their health problems last more than 3 days. This knowledge helps GP’s in advising their Roma patients.

A study on quality of life highlighted the occurrence and specific features of chronic conditions of the muskulo-skeletal and cardio-vascular systems and demonstrated the need to pay more attention to individuals with chronic mental health problems⁵².

Research results have been used to establish education programs. For example, in Goričko region, the University of Maribor supports local primary care by helping to organise education workshops for groups of Roma patients. The figure shows cards for the Roma participants. The four circles are used to write topics of the workshops and are coloured when the card owner has attended the workshop. The cards help the owner to remember the whole workshop program. Topics are asthma, blood pressure, diabetes mellitus and emergency.

The Association of Family Doctors of Slovenia organized a special scientific meeting regarding health of Roma in 2008 as a part of CME education. Subjects were communication when working with Roma patients, characteristics of Roma families and views of Roma regarding health care. The latter was presented by representatives of Roma. Problems about literacy and education were discussed. Plenary presentations were continued in small groups discussions where GPs had an opportunity to present their approaches and exchanged ideas with district nurses and Roma representatives.

In 2012, a new edition of the textbook on Family Medicine included a chapter on anthropology and in 2014 a module in the 3 year training of GP’s provides information on the specificity of the Roma population, their usual way of visiting primary care doctor and recommendations on how the family doctor communicates with Roma patients. Trainees are encouraged to research how Roma use their lay methods of healing, i.e. herbs, bandages, etc. Several publications, including “How often Roma use self-healing methods before they go to the doctor” and “ Self-treatment of Roma in Prekmurje” resulted from this⁵³.

Belgium

Figure 2



In Ghent, with a population of 5000 Roma, a group of primary health care centers since many years is strongly oriented towards community care.

In 2014, the city of Ghent in collaboration with Ghent University, conducted research that focused on the experiences of the Roma population in Ghent with regard to (access) to healthcare. The main objectives were (1) to gain insight in the barriers that are experienced by the Roma-population; (2) explore how Roma experience their health; (3) To identify factors which contribute to a mutual relation of trust and respect between patient and healthcare provider.

Results indicate that the Roma population in Ghent encounter similar barriers as the Roma in other European countries. The most prominent is the financial barrier. Just as in other countries Roma often have trouble to pay for health services. Taking into account that a lot of Roma are unable to gain a legal status as migrant (because of the free movement of persons within Europe) and as a consequence are not entitled to social security, the cost of health care is significant. Also language and transport seem to be important barriers. Beside these more practical aspects, it was also found that social expectations can hinder the access to care. In this matter, trust is a central characteristic. Possibly due to lifelong discrimination, Roma tend to foster distrust towards mainstream society. This not only complicates the relationship between patient and provider but also prevents people to seek care in the first place. In order to establish a relationship of trust, some specific measures can be taken. In the first place, both parties should be able to understand each other. E.g. translating services should be available. Longer consultation-times are also mentioned as being important, giving patients and providers more time to come to an understanding of the problem. Lastly, collaboration between health care providers and between health care and welfare professionals, and a centralisation of care means that patients can rely on one or two providers that know their background and situation, instead of many different professionals who have not an established personal relationship⁵⁴.

The findings of the study have been shared with staff from local primary care and hospitals in Ghent, in December 2014 during a workshop entitled "Roma and health care". The audience of around 80 persons felt particularly supported and encouraged by the exchanges of experience, including a dialogue with a Bulgarian GP of Roma descent. Such a workshop can be considered as good practice.

Box 4

Nonverbal communication

Dr Panayotov from Bulgaria, Roma himself, in a dialogue with his Flemish hosts, emphasises the importance of trust-building during consultations. In terms of nonverbal communication, sitting alongside the patient instead of in front of him, keeping a short physical distance and a friendly light touch of the patient, on the arm for example, help to establish good communication.

Bulgaria.

During the 90's, alerted by the diseases of a number of their Roma patients, neurologists from the Sofia University Hospital explored the prevalence and clinical manifestations of a range of neuro-muscular conditions among Roma in virtually all the Roma communities in the country. Through many visits over the years they identified a number of rare hereditary neuro-muscular diseases, some of which had not been described before in other population groups. By quietly and respectfully explaining the symptoms and heredity, they succeeded in gaining the trust of the Roma communities, in spite of the sensitivity of the subject.

Gradually, the visits developed in counselling sessions whereby couples could discuss family planning and risk of hereditary diseases among their offspring. The good practice here is to gradually develop a relationship of trust. This practice does not originate in primary care but serves to inspire primary care practitioners.

Multi-country study

ECDC studied how the uptake of vaccinations can be improved. It concluded that one of the top interventions is to invest in education for physicians and nurses to communicate more efficiently and emphatically. It has published short guides for health staff in various languages: let's talk about protection⁵⁵. Figure 3a shows how to frame the communication and figure 3b shows the guides in various languages and in various adaptations..

Figure 3a

Develop the communication guide 

REFRAMING

- Reframe the focus of discussions on the benefits of getting protected and protecting – prevent diseases/ **POSITIVE** rather than on side effects of vaccination/ **NEGATIVE**
- Make vaccine communication more of a two-way information exchange; strengthen HCP capacity to become more "client-centered"
- "Give voice" to the beneficiaries – messages are based on research done with the beneficiary groups



5

Figure 3b

Cultural adaptation in pilot MS 

- in: Bulgaria, Czech Republic, Hungary, Romania
- content and format adaptation of the guide and flip book
- + methodology of adaptation



6

Mediation between primary care and Roma communities and patients.

In several countries (Romania, Bulgaria, Spain, Belgium, Serbia, Macedonia, Ukraine) there have been positive experiences with the Roma Health Mediator (RHM): a person from the Roma community, mostly female, who is trained to liaise and create understanding between the Roma and the (primary) health care services. In Bulgaria it is formulated as follows: "The job position of the Health Mediator is the bridge between the Roma communities and the health and social services for the improved access of Roma to health and social services and

for overcoming of discriminative attitudes towards them⁵⁶. The recent report "Roma Health Mediators, SUCCESSES AND CHALLENGES" reviews the experiences⁵⁷.

Official RHM job descriptions vary little by country, although the actual work may vary. In general RHM's are required to:

- Translate between the Roma patient/family and the care provider.
- Assist individual clients in obtaining personal documentation and health insurance. This is a need in all countries except for Slovakia, where almost all Roma have documentation and health insurance coverage.
- Assist (and encourage) individual clients to go to the doctor.
- This may entail explaining to clients the importance of preventive care, educating clients about the costs for particular services and ensuring that they are not asked to pay more, and providing linguistic translation during consultations. RHM's might ensure that clients are taking prescribed medicines, that they return to the doctor if they still feel ill.
- Assisting local health authorities with particular health campaigns, particularly related to vaccination.
- Refer clients to relevant health, social, and educational services. RHM's may actually accompany clients to health or social service offices, or they may simply refer them to the appropriate place.
- Conducting health education sessions in the community. Such sessions may include inviting women to attend lectures on topics related to maternal, reproductive, and child health, informing individual families about the importance of preventive care, and lecturing school children on healthy lifestyles.
- Providing targeted health assistance. RHM's in a few countries have been taught to monitor blood pressure. Others provide observation and support to Roma patients on TB treatment. No RHM program includes first aid or direct medical care.
- Providing legal referrals for individual clients who have experienced discrimination or other human rights violations in health care settings.

RHM's in almost all countries have had some training related to patients' rights. Incomprehension between Roma and health staff is greatly reduced when communication channels function and both parties have opportunity to explain their views and wishes. Also in the education sector Roma mediators have proven to be effective to improve mutual understanding and relationships, as reports from the UK, Belgium and Spain testify.^{58, 59}.

Similar experiences with mediators between health practitioners and Turkish / Moroccan and other minority populations in Western European countries have shown that this is a valid model to improve access to health care for minority populations.

For the RHM, training curriculum, certification and conditions of work gradually have been optimized, supported by international studies and exchanges. A challenge remains the funding for this group of workers, since they are between the health system and community, and the final responsibility for their functioning and employment varies between and within countries. In Romania, the RHM initially was employed by NGO's and the Ministry of Health,

but currently the municipalities take over responsibility for their employment, emphasising that the RHM is not a health professional but a member of the community. After more than 10 years of experience with the RHM, a number of lessons learned is worthwhile to quote:

- Mediators can be ineffectual if health professionals have an unclear understanding of the mediator's functions, and resulting in:
 - Delegating all the weight of the intervention to the mediator.
 - Delegating all activities that healthcare professionals dislike, i.e. community interventions, to the mediator.
 - Using the mediator's service exclusively in situations of conflict. Therefore, a number of requisites should inform the actions of mediators:
 - Clear definition of their role and functions;
 - Adequate training;
 - Recognition and support by administrations and healthcare professionals;
 - Coordination of their work with healthcare professionals;
 - Conditions allowing for stable and durable interventions, considering that high staff turnover discomforts patients and undermines the credibility of the mediator.

In no country the numbers of RHM's are sufficient yet to cover at least all the larger Roma communities.

Perspectives

The previous chapter highlighted some experiences and initiatives in the field of primary care practice, training and research with regards to the Roma population. This final chapter looks forward and suggests approaches to further strengthen primary care.

Key issues for further research.

The unavailability of data on health of the Roma population in most countries has led to suggestions in the last years to start collection of health data based on ethnicity, as is already done in the UK. With safeguards on the use of data and in a climate of trust, as the Bulgarian example shows, fear for stigmatisation may diminish. National legislations and regulations, including the creation of ethical committees to assess research plans, are required to establish research activities that are unchallenged and productive.

Amongst others, research should collect information on cultural and other characteristics of local Roma communities and include a process of establishing a stable relationship between the researchers and the population to be studied. Since the research necessarily takes place at local level and at limited scale, primary care practitioners need to be actively involved, if not leading. Universities and other groups need to support local research by providing time and skills.

Generic communication skills among primary care staff need to be further developed and taught, as part of undergraduate training, the GP specialisation and as Continuous Medical Education. Research needs to identify how to motivate primary care staff to participate and what learning processes are most effective and (time) efficient.

Recommendations for policy measures on national and European level

As has been described in the introduction, currently, several international initiatives are ongoing to support the development of policy and practice in terms of health care for Roma patients.

One main recommendation resulting from many reviews and analyses is to sustain and expand the funding for the RHM.

Communication skills in general and knowledge on Roma health and culture should be built in in the training curriculum and CME of Primary Care providers in settings with a high proportion of Roma population. In general, Primary Care providers should develop their cultural competency

Programs and projects oriented towards improving Primary Care for Roma, like for example training programs for primary care providers and screening programs, need time to be prepared, implemented and to be institutionalised, also in the financial sense. Therefore, funding should be long-term and not be limited to a short action. Even the 10 years of the Roma Decade are not too long.

Outlook.

Motivated by the specific historic and current conditions of Roma in Europe and the intention to reduce health inequalities, this paper summarizes evidence of the need to strengthen primary care for the Roma population. It also provides a number of suggestions for policy, practice and research. One major point this paper makes is that general cultural competence is a generic characteristic of strong primary care: not only for Roma but for any population group: the young, the elderly, migrants, disabled. These competences are individual and also at the organisational level.

Wider initiatives to measure and strengthen these competences are supportive to health of the Roma population as well. One example is the project to establish standards for equity in healthcare⁶⁰. This originates from the hospital sector and is an opportunity for primary care and its patients as well: strong primary care offers seamless care for its patients and therefore closely works together with secondary care.

Equity in health is an ambition of strong primary care and comprises all population groups, including the Roma population.

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