



Implementation of the National Roma Integration Strategy and Other National Commitments in the Field of Health

SPAIN

A multi-stakeholder perspective report on 2005–2014 developments

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ACRONYMS

ASPCAT	Public Health Agency of Catalonia (<i>Agència de Salut Pública de Catalunya</i>)
CatSalut	Catalan Health-care Service (<i>Servei Català de la Salut</i>)
AACC	Autonomous Communities (<i>Comunidades Autónomas</i>)
CESPYD	Coalition for the Study of Power, Health and Diversity
CSO	Civil Society Organizations
DG	Directorate General
DRI	Decade of Roma Inclusion
EC	European Commission
EU	European Union
IOM	International Organization for Migration
MIPEX	Migrant Integration Policy Index
NGO	Non-Governmental Organizations
NHS	National Health System (<i>Sistema Nacional de Salud</i>)
NRIS	National Roma Integration Strategy
PHC	Primary Health-care Centres
RDL	Royal Decree-Law (<i>Real Decreto Ley</i>)
RIPEX	Roma Integration Policy Index
SAS	Andalusian Health-care Service (<i>Servicio Andaluz de Salud</i>)
ToR	Terms of Reference of the Equi-Health project
TRHP	Transformative Roma Health Policies
WHO	World Health Organization

EXECUTIVE SUMMARY

Introduction: Building collaborative capacity among stakeholders in order to develop transformative Roma health policies

In February 2013, the Migration Health Division of the Regional Office for Europe and Central Asia of the International Organization for Migration (IOM) launched the project “Equi-Health: Fostering Health Provision for Migrants, the Roma and Other Vulnerable Groups.” Equi-Health’s sub-action “Roma Health” seeks to improve the accessibility, adequacy, adaptability, satisfaction with and the quality of health assistance, preventive care, and health promotion services for Spanish and foreign (EU and third country nationals) Roma. The first stage of this project focuses on elaborating progress reports from a multi-stakeholder perspective on the implementation of the NRIS and other national commitments with respect to Roma Health.

The Roma are one of the largest minorities in Europe and the main ethnic group in Spain. Roma health is a challenge that is extremely difficult for European society to tackle. The isolation, discrimination, and poverty in which many of them live are unacceptable sources of inequity that have been in place for hundreds of years.

In order to tackle this problem, in 2005, the European governments committed to a Decade of Roma Inclusion (DRI, 2005–2015) to “combat discrimination, poverty, and exclusion against the Roma population, and to reduce the unacceptable gaps between this population and the rest of society in education, housing, employment, and health.” A few years later, the World Health Organization’s (WHO) programme, Health 2020, provided a new framework for understanding public health in Europe as a response to the gaps in health caused by the economic crisis. However, in 2010 the European Commission (EC) elaborated a report on the Economic and Social Integration of the Roma in Europe (European Commission, 2010a), which evidenced the relative failures of these efforts, such as the existing gap between planning and implementation, the weak inclusion of strategies at different levels, the low participation of the Roma community, the inadequate use of funds, etc.

These assertions imply the acknowledgement that the Roma people’s health inequities are a “wicked problem”, that is, a problem that is extremely difficult to broach and solve (Rittel and Webber, 1979). Indeed, the chronic failure of existing policies intended to put an end to the Roma inequities may be explained by the fact that (a) Roma health has never been considered or defined as a social problem; (b) the political concern around Roma health has not translated into effective policies; and (c) the complexity of the problem does not derive from scientific but political and social difficulties which would require building collaborative capacity among all stakeholders to solve it.

We need to find innovative strategies to actively engage all the stakeholders in the design, implementation and assessment of Transformative Roma Health Policies (TRHP). Collaboration among the different stakeholders must be part of a permanent and proactive process of transformation to constantly shape the problem, as well as the strategies and actions implemented to solve it. Furthermore, stakeholder involvement needs to be implemented as a process of community mobilisation for building collaborative capacity among all stakeholders, leading to the development of shared understanding, and collective commitment and action for the future (De Freitas et al., 2014).

This report is the result of the work done by Spanish consultants to tackle the challenge of ensuring the equity of health policies for the Roma population, adopting the viewpoint of the different stakeholders involved while developing their capacity for collaboration and producing shared understanding of the problem (Petersen et al., 2012). This report is organized in the following chapters: (1) Framing the problem; (2) Building and releasing collaborative capacity to transform; (3) Promoting shared understanding from evidences and stakeholders and (4) Planning the future.

Framing the problem

According to official data, the population of Spain is currently 47,129,783 people. Out of the total population, between 700,000 and 970,000 people (1.5%–2.1%) are Roma, making Spanish Roma the biggest ethnic minority in the country (Fundación FOESSA, 2008). The Roma population is diverse and heterogeneous, and there are clear differences between national and foreign Roma. Nevertheless, there are also commonalities between them – for example, location, demography, and family structure.

The health of national Roma has improved in recent years thanks to housing improvement, the implementation of universal health care, the rehabilitation of marginal areas, and the expansion of compulsory schooling (Fundación Secretariado Gitano, 2012; Laparra et al., 2012). In spite of all this, work still needs to be done in order to reduce the social determinants and health inequities between the general population and the Roma minority, and between national and foreign Roma. The national Roma population has a more negative view of health, worse eye and ear health, and more traffic and domestic accidents than the rest of the non-Roma population. Some Roma children are not vaccinated, do not get regular paediatric check-ups, and have a deficient or unbalanced diet. Adults do not utilise preventive services and are more prone to suffer from cardiovascular, bone, joint, and chronic diseases. In particular, women tend to suffer from obesity, they make fewer periodical visits to the gynaecologist and suffer more mental health problems than that of the rest of the Spanish population (La Parra, 2009; Laparra, 2007, 2011; Ministerio de Sanidad y Consumo and Fundación Secretariado Gitano, 2007).

Although there is no reliable information about the health of foreign Roma living in Spain, several inferences can be made on the basis of data obtained in their countries of origin (Hajioff and McKee, 2000; McKee, Balabanova and Steriu, 2007; Parekh and Rose, 2011). Their life expectancy is 10 to 15 years lower than the rest of the population in their countries, with higher mortality rates among young adults and children. Many of them suffer from malnutrition and infectious diseases, as well as alcohol and drug abuse. The number of people with psychiatric or mental disorders is six times greater than in the rest of the population, and there are higher rates of teenage pregnancies, which increase child vulnerability. There has been an increase in the mobility of citizens from Eastern Europe since Bulgaria and Romania formalised their membership in the European Union (EU) in 2007, together with a waiver visa policy for Western Balkans' citizens (McKee, Balabanova and Steriu, 2007). This, together with the rise of xenophobic policies in EU Member States such as Italy or France,³ has made of Spain a preferred destination for many of the Roma population from Eastern European countries. Their arrival has become a challenge to human rights, and a possible risk for public health, since they get here in very precarious conditions and with no chances of finding a job:

³ El ministro del Interior francés arremete contra los gitanos, *El País*, September 2013. http://internacional.elpais.com/internacional/2013/09/24/actualidad/1380022331_876484.html
Miles de gitanos protestan en Roma contra la xenofobia, *El País*, June 2008. http://internacional.elpais.com/internacional/2008/06/08/actualidad/1212876007_850215.html

they do not have or look for housing and many of them live in temporary and unsanitary settlements where the same subhuman conditions of their countries of origin are replicated. Persecuted and stigmatised for their vulnerability, their precarious health condition contributes further to their marginalization, creating new risks and suffering.

To put an end to these inequalities, in April 2011 the European Commission adopted the EU Framework for NRIS up to 2020 (European Commission, 2011), by which EU countries committed to revising existing strategies and to developing new ones in order to improve Roma inclusion in European societies with respect to education, employment, housing and health. By 2012, each EU Member State had elaborated a National Strategy (European Commission, 2012) intended, on the one hand, to complement and reinforce the EU's equality legislation and to support policies and authorities at the national, regional, and local levels in monitoring, sharing, and strengthening effective and comprehensive approaches to Roma health; and, on the other, to build a coherent network to promote dialogue and participation among all key stakeholders and to delineate strategies and interventions to support capacity building and cooperation in order to address the specific needs of Roma.

In Spain, the NRIS was developed by the Ministry of Health, Social Services, and Equality (Ministerio de Sanidad, Política Social e Igualdad, 2012b) and implemented through the Operational Plan (*Plan Operacional*; 2014–2016) (Ministerio de Sanidad, Política Social e Igualdad, 2013a). Concerning adults' health, the targets are to improve the perception of the health status of the Roma population and to reduce traffic accidents and smoking. Special attention is also given to reducing obesity among women and to reducing the number of women who have never gone to the gynaecologist. In relation to child population, the NRIS aims to reduce the number of children suffering domestic accidents and increase oral health care. The key areas of NRIS implementation are: (a) promoting policies and actions aimed at reducing health inequalities; (b) reorienting health services towards equity; (c) fostering health promotion throughout the life course; (d) establishing mechanisms to ensure positive impact on Roma health; (e) promoting Roma participation; (f) promoting intersectoriality; and (g) supporting and promoting diversity training.

Building and releasing collaborative capacity to transform

Transformative policy change requires that new policies are both evidence and discursive, building policies based on the values and participation of all stakeholders (De Freitas et al, 2014; Nelson, 2013). Regarding the evidence-based approach, the expert team conducted desk research including literature review, legal review and policy research. The researchers further collected data and combined information from various sources in order to obtain the most comprehensive overview of the foreign and national Roma population of Spain, and more specifically in the Autonomous Communities (AACC) of Andalusia and Catalonia. To carry out the discursive approach, a coalition or stakeholders network was constituted in order to build collaborative capacity among them. The coalition comprised representatives of organizations with relevant role in the field of Roma health. Assuming a systemic view, policymakers, managers, health-care providers and users' representatives were invited to join the coalition.

A new tool, **the Roma Integration Policy Index (RIPEX)** was developed in order to analyse and integrate the results of the stakeholder interviews and the information obtained in the desk review. This index was promoted by the network set up in Equi-Health to assess and contrast how sensitive health policies are towards the Roma population. The indicators were selected from the WHO's

assessment recommendations for the health element of the NRIS, the Migrant Integration Policy Index (MIPEX) and those required by the IOM in the Equi-Health's Terms of Reference (ToR).

The resulting RIPEX categories and indicators used in this report are: (a) *Entitlement to Health care* (Requirements for obtaining entitlement, Co-payments, and Coverage); (b) *Access to Health-care Services* (Accessibility barriers, Consequences, Policies and strategies to suppress accessibility barriers, and Roma health mediation); (c) *Responsiveness of Health-care Services* (Health inequalities defined in the NRIS, Policies to make health-care services more sensitive, and Adaptation strategies of health-care services and providers); (d) *Achieving and Sustaining Change* (The political and economic context of the NRIS, Associationism, collaboration and participation of the national and foreign Roma community, Collaborative work among multiple, and Promoting intersectoral action).

Promoting shared understanding to transform Roma health policy

Regarding **entitlement to health care**, the NRIS in Spain and its Operational Plan are based on the universalisation of the National Health System (NHS). However, recent cutbacks and changes in the Spanish health-care legislation have led to the dismantling of the system and some of its core elements. All these have affected both the national and foreign population – Roma and non-Roma – as well as the implementation of the NRIS. This new health-care model has worsened the low socioeconomic conditions of most vulnerable people, especially the foreign Roma. Moreover, paperwork to obtain a Health Card involves bureaucratic procedures and additional documentation that are further barriers for the Roma population. As a response, some AACC such as Catalonia and Andalusia, have developed strategies to ensure health-care access for those excluded from the system by the law. Nevertheless, many challenges are still threatening the entitlement of the Roma to health care.

The NRIS establishes the **accessibility to the health-care system** as one of the strategic lines of action to improve Roma health. National and foreign Roma have developed non-normative patterns of access to and use of health-care services due to their historical marginalization and persecution; the bad public transport connection between their neighbourhoods and settlements with health-care services; and the blindness of the health-care system about the Roma culture, among others. To overcome these challenges, national and regional governments have developed policies to ensure health-care access. Health-care centres have also developed strategies to facilitate access (e.g. specific health programmes and committees, information points). However, the most effective actions have been conducted by health-care providers and social workers from civil society organizations (e.g. by taking part in community interventions and commissions with several other agents in the area, accompany programmes, developing alternative ways to access, etc.). In this undertaking, the health mediation processes play a central role in enhancing Roma's accessibility to medical services, while also improving the health of this community and bringing the NHS and communities closer.

The NRIS and its Operational Plan cover **responsiveness of health-care services** as a relevant subject through objectives aimed at reducing specific Roma health inequities and strategic lines of actions. However, attention has been drawn to some NRIS limitations - its focus on the national Roma population, its exclusively biomedical perspective, and the fact that its objectives are neither interconnect nor integrated with other policies and strategies of the NHS. Nevertheless, some efforts have been made to make the systems and its services more responsive towards the Roma community. At policy level, there are regional and national plans to culturally train providers. Also,

reports and guides about Roma health have been published and some health-care campaigns have been culturally adapted. This is complemented by the adaptation of general protocols by some health-care providers working in centres with high rates of Roma users. Other revisions are related to communication, balancing assistance with their religious beliefs, economic situation, etc. There are also other adaptations that demand great effort from providers, subsequently causing burnout. Such adaptations include adopting a more proactive attitude and having constantly monitored and locate Roma users.

To **achieve and sustain change**, the NRIS and the Operational Plan intend to enhance Roma health through administrative cooperation and stakeholders' participation. To achieve this, certain challenges should be taken into account. For example, the NRIS is being ineffectively implemented due to the current economic and political context in Spain. Moreover, the strategy is not sufficiently publicised and its implementation entails conflicts of interests among different institutions and bodies at different levels. The Roma are little engaged in policy planning and implementation, and there exists institutional discrimination among them. On the other hand, national Roma and their associations do not sympathise with, and even discriminate against, foreign Roma, who also lack forms of associationism. Besides, there is lack of international cooperation and networking among stakeholders. All this entails a progressive bureaucratization of Roma associations, which can hinder the construction of a solid system to encourage all Roma sectors to take active part in the process of improving their health status.

Planning the future

In order to achieve quality TRHP development and implementation, we must take into account that these are the outcomes of an innovation process that put into practice both evidence-based and discursive approaches. Hence, building TRHP from a multi-stakeholder perspective would be one thing, and implementing them would be another (Frank and Atkins, 1981; Meyers et al., 2012). When planning the future, some challenges may arise, such as the lack of common and shared interests and goals, unrealistic expectations, the lack of evaluation, communication and organizational barriers, segmentation of the network, unbalanced power relations, resistance to change and maintaining the status quo, lack of resources, etc. (Suarez-Balcazar et al., 2007). Bearing this in mind, TRHP from a multi-stakeholder perspective should follow principles to guide the development and implementation of Roma health priorities through specific community tools.

The principles of TRHP would be: (1) to seek **the effective involvement of multiple stakeholders in participatory mechanisms by building collaborative capacity**; (2) to be based on **health in all policies and intersectoral actions for health**; (3) to **better monitor and report progress, and to develop evaluation capacity among stakeholders**; (4) to **redefine the role of policy promoters**; (5) to **advocate for the elimination of institutional discrimination**; (6) to **assure cultural competence among stakeholders**; (7) to **institutionalize health mediation**; and (8) to **promote Roma health literacy**.

The TRHP priorities identified during stakeholder interviews and coalitions entail: (a) **strengthening entitlement to health care** (e.g. protecting national and European health rights, reviewing administrative procedures to obtain the Health Card, etc.); (b) **assuring accessibility to the health-care system** (e.g. denouncing human rights, distinguishing access and accreditation with care, reviewing formulas to access, increasing health mediation processes, etc.); (c) **promoting responsiveness in health-care services** (e.g. including foreign Roma in the NRIS, developing a culture

of care and a vision of community health, health in all policies, increasing diverse staff and health mediators, disseminating good practices, etc.); and (d) **achieving and sustaining change** (e.g. strengthening the Roma associative movement by promoting collaborative work, giving Roma a central role, employing community resources and methodologies, fostering criticism among Roma associationism, improving the viability of the NRIS – a higher budget would contribute to further the dissemination, commitment and sustainability of the strategy).

TRHP development and implementation follow an ecological approach, relying on continuous innovation by which stakeholders “learn by doing”, and making ample use of emerging technologies such as online platforms. The use of these platforms, such as the creation of a Roma Tool Box, would allow working in an exchange network that allows connecting multiple stakeholders at local and global levels who are engaged in transforming and building healthier Roma communities. Moreover, it would be an excellent support infrastructure that would provide opportunities for building capacity systems for change, ensuring the success of intervention and evaluating those within an open system environment.

1. INTRODUCTION: BUILDING COLLABORATIVE CAPACITY AMONG STAKEHOLDERS TO DEVELOP TRANSFORMATIVE ROMA HEALTH POLICIES

In February 2013, the Migration Health Division of the Regional Office for Europe and Central Asia of the International Organization for Migration (IOM) launched the project “Equi-Health: Fostering Health Provision for Migrants, the Roma, and Other Vulnerable Groups.” Equi-Health’s sub-action “Roma Health” seeks to improve the accessibility, adequacy, adaptability, satisfaction with and quality of health assistance, preventive care, and health promotion services for national and foreign Roma – EU and third country nationals. The first stage of this project focuses on elaborating progress reports from a multi-stakeholder perspective on the implementation of the NRIS and other national commitments with respect to Roma Health.

This report describes the activities of the Coalition for the Study of Health, Power, and Diversity (CESPYD),⁴ the Centre of Community Research and Action at the University of Sevilla, and the Public Health Agency of Catalonia (ASPCAT) as national consultants for the elaboration of the progress report on the NRIS in Spain. In this introductory chapter, we describe the background on the health challenges faced by the national and foreign Roma community in Spain. Then, the reasons for the failure of previous policies are analysed, followed by a rationale for the adoption of a perspective to build collaborative capacity among the different stakeholders to face these challenges.

1.1. Background

Roma health remains a difficult challenge for European society. The conditions of isolation, discrimination, and poverty in which many Roma people live represent an unacceptable source of inequity in Europe. This situation represents the secular oppression that Roma have suffered ever since arriving in Europe from the Punjab region in India in the Middle Ages, when they were mistakenly called *gypsies* as it was thought they come from Egypt. In Europe, which was then controlled by the Catholic Church, the Roma were soon persecuted for heresy, as they engaged in practices such as divination and chiromancy. As a matter of fact, it was the prestige that they soon gained as artists, musicians, storytellers, and magicians that made the Catholic Church fear losing its control over an ignorant and superstitious society (Strochlic, 2011). In 1554, being Roma was punished with death penalty in England if they had not left the country and, hundred years later, 15 European countries enforced laws intended to secure the deportation of Roma people and the annihilation of their communities. These laws forced them to adopt a travelling way of life (Strochlic, 2011).

In Spain, the history of Roma oscillates paradoxically between repudiation and fascination as well. Repudiation comes from them being seen as thieves and liars; fascination arises from the sensitivity and profoundness of their music, their dance, and their artistic talent – for example in bullfighting. This paradox is reflected in the norms and laws enforced in Spain since Roma entered the peninsula through the Pyrenees and coming from Africa through the Strait of Gibraltar. At first, the Roma were welcome and protected. Later, they were expelled and forbidden to speak their language and to maintain distinguishing traits. After Franco's death, racial discrimination became a criminal offense, and the regulations of the Guardia Civil regarding the surveillance of and control over Roma customs and ways of life were revoked (Fakali, 2013).

⁴ See at: www.cespyd.es

Between 12 and 15 million Roma currently live in Europe, of which around 10 million live in the EU. These figures indicate that in some countries the Roma population is an important part of the total. For example, the Roma represent 10 per cent of the total population of Bulgaria, 9 per cent of the population of Slovakia, and 8 per cent of the population of Romania. Furthermore, the Roma population is the poorest ethnic minority in Europe. They are ten times poorer than the rest of the population and their life expectancy is about 15 years lower than that of the average European citizen (Parekh and Rose, 2011). In Spain, it is estimated that 77 per cent of the Roma population live in relative poverty, with 37.5 per cent living in extreme poverty, compared to 37.2 per cent in Bulgaria (where 80.1 per cent live on less than USD 4.30 a day) and 43.1 per cent in Romania — (where 68.8 per cent live on less than USD 4.30 a day) (Fundación Secretariado Gitano, 2012).

In spite of the fact that Roma have lived in Europe for nearly a thousand years, they are still seen as foreigners and prejudice against them is deeply rooted in the whole continent. Segregation prevails in many countries and Roma people are constantly forced to move and to settle in the peripheries of urban centres or in segregated areas with no social services and where they suffer constant discrimination, poverty, and police brutality. Authorities tend to see delinquency and unemployment in Roma communities as irremediable ethnic problems and these are then used to perpetuate and justify the cycle of segregation and persecution (Strochlic, 2011).

1.2. Failure of European responses

The determination to expand the EU offered the opportunity for the EC – together with the Open Society Foundation and the World Bank – to organise the conference “Roma in an Expanding Europe: Challenges for the Future” in 2003 to raise awareness of the need to implement policies that enable the integration of Roma in European societies. Roma leaders, government representatives from Central and Eastern Europe as well as other international leaders were invited to this conference, where emphasis was placed on five fields of action: discrimination, education, employment, housing, and health. Moreover, fighting poverty and adopting a gender perspective became transversal concerns. In this way, participating countries committed to inaugurating a new decade, starting in 2005, to promote policies of inter-sectoral integration.

Consequently, the DRI⁵ (2005–2015) emerged as the first political commitment among some European governments⁶ to “combat discrimination, poverty and exclusion against the Roma and to reduce the unacceptable gaps between this population and the rest of society in education, housing, employment and health.” In order to achieve this, governments were urged to: (a) reallocate resources; (b) elaborate national and regional plans in collaboration with social organisations and the Roma community, involving them in the decision-making and experience-sharing process; and (c) adopt an accountability approach to measure the real impact of their actions. More specifically, Member States that endorsed the DRI reached the following conclusions during their 23rd International Steering Committee meeting in Zagreb in 2012: (1) the complexity of the problem requires that the final step in the project be effective transformation and implementation of fair and inclusive health-care policies; (2) policies must be more sensitive to the values, discourses and narratives of Roma communities and implicate all the agents involved (e.g., citizens, social networks, researchers, government representatives and other influential groups); (3) it is necessary to

⁵ Decade of Roma Inclusion 2005–2015. Available from www.romadecade.org/

⁶ Participating countries in the DRI: Albania, Bosnia and Herzegovina, Bulgaria, Croatia, the Czech Republic, Hungary, the former Yugoslav Republic of Macedonia, Montenegro, Romania, Serbia, Slovakia and Spain.

legitimise politically the Roma population, not only as service users, but also as political subjects that contribute to the health of society as a whole.

In this same vein, the World Health Organization's (WHO) programme Health 2020⁷ emerges as a new framework for understanding public health in Europe, and as a response to the gaps in health created by the economic crisis. It draws attention to the need to support and promote participation, leadership and collaborative action between governments and civil society in order to improve the health and wellbeing of citizens, reducing health inequities and strengthening the public health system to be people-centred, universal, equitable, sustainable, and with quality. In order to reach these objectives, Health 2020 is committed to develop strategic thinking for: (a) implementing whole-of-government and whole-of-society approaches that consider health and wellbeing as a shared responsibility; (b) tackling inequities and the social determinants of health; (c) innovative leadership and capacity for health and development; and (d) citizen empowerment.

However, in 2010, the EC elaborated a report on the Economic and Social Integration of Roma in Europe (European Commission, 2010a) which made clear the progressive deterioration of Roma living conditions, notwithstanding the aforementioned policies. The general failure of these initiatives has been due to a wide range of factors such as the gap between planning and implementing measures; the weak inclusion of strategies and bottlenecks at the national, regional and local levels; the lack of economic resources and inadequate use of EU funds; the low participation of Roma community in the development and implementation of policies; the deficient support, commitment and leadership of institutions and stakeholders involved; and the low impact of the programme on public opinion and the media (European Commission, 2010a; McKee, Balanova and Steriu, 2007; Parekhm and Rose, 2011).

1.3. Roma health inequities as a “wicked” problem

Due to its intersectional nature, Roma health inequities represent a “wicked problem” – that is, a problem that is extremely difficult to broach and solve (Rittel and Webber, 1979). Indeed, the fact that policies to that end are so few and so largely unsuccessful may be explained as follows (Commonwealth of Australia, 2007; WHO, 2012a):

- **Roma health has never been considered or defined as a social problem.** In fact, it is a problem that is difficult to define in a clear and durable way. Its nature and extension depends on who defines it – whether it is health-care service providers, the communities themselves or policymakers – and not on objective and stable causes. The disagreement that exists among the agents involved in its definition does not derive from whether the analysis is wrong or right, but rather from the dimensions that are emphasised, underlined and prioritised.
- **The political concern around Roma health has not successfully taken form into effective policies on the ground but only at a rhetorical level.** Moreover, many of the policies have had unforeseen and even paradoxical consequences. This is due to the fact that the circumstances of the problem are unstable and different in every country. Furthermore, its solutions are not verifiable in terms of right and wrong, but rather in comparative terms: solutions that are better or worse than others. As a consequence, it must be accepted that the problem will never be completely solved.

⁷ Health 2020. Available from: www.euro.who.int/en/health-topics/health-policy/health-2020-the-european-policy-for-health-and-well-being

- **The complexity of the problem does not derive from scientific but political and social difficulties.** As such, it does not require sophisticated resources, but agreements among social groups and commitment to solve the problem. In this sense, progress would imply changes in the lifestyles and conducts of agents and communities. Therefore, the motivation of agents to make sustainable changes in their conducts is of utmost importance.

1.4. Transforming Roma health policy through stakeholder collaboration

All these elements evidence the need to **find innovative strategies to actively engage all stakeholders** in the design, implementation, and assessment of TRHP. Traditionally, many of the stakeholders have played a secondary role in the elaboration of health policies and strategic plans, tasks that were reserved exclusively to policymakers. The other agents have been summoned to legitimate and facilitate the implementation and assessment of these – a role which has proven insufficient for Roma health policies. Collaboration among different stakeholders must be part of permanent and proactive process of transformation to constantly shape the problem, as well as the strategies and actions implemented to solve it.

Transformative policy change refers to changes in policy that incorporate the views of multiple actors and resort to the best available evidence, while aiming to accommodate people's values and to give them real power to influence the decisions that most impact their lives (Nelson, 2013). Transformative changes in policy can benefit from evidence-based and discursive approaches. The former asserts that policy should be informed by research-based evidence (Pawson, 2006). The discursive approach, on the other hand, understands policymaking as a political and value-laden process that deals with choice of directions and, as a result, can bring advantage to some groups and disadvantage to others. This approach also highlights the need to understand discourse not as reflective of objective social problems but as a reality itself, which needs to be explained and taken into consideration (Fisher, 2003). Thus, achieving transformative policy change depends on three fundamental processes: (1) explicit and discussable problem framing; (2) citizen participation in policy formulation; and (3) allocation of resources necessary for policy formulation and implementation (Nelson, 2013).

Transforming health-care policies to become more sensitive to diversity requires us to understand that engaging all stakeholders in policymaking is essential for the success of the process, but also that it is one of its greatest challenges. Contexts of diversity are complex settings characterised by uncertain and plural legitimate perspectives. Consequently, there is no single way of looking at particular problem and/or the expectation that one simple solution fits the needs and interests of all. Achieving transformative policy change requires that the various stakeholders participate in exchanging viewpoints and arguments within an empowering and organised participatory environment open to everyone and based on the values of effective partnership (e.g. reflexivity, respect for difference, mutual commitment and collaborative work) (Allen et al., 2013). The involvement of citizens in this process necessitates adequate allocation of resources as well as citizens' ability to take control of the resources they need to influence decision-making. Furthermore, stakeholder involvement in transformative health-care policymaking needs to be implemented as a process of community mobilisation in building collaborative capacity among all stakeholders, leading to the development of shared understanding and collective commitment and action (De Freitas et al., 2014).

Community mobilisation refers to bringing people and organisations together in particular geographic area (e.g., a neighbourhood, a city or county, a region or sometimes an entire State) to partner up in defining a problem, identifying possible solutions, and working together to implement them (Fawcett et al., 2000). **Building collaborative capacity** is associated with promoting a sense of community and a culture of learning, also referred to as communities of practice, among partners, in which individual members gain understanding, voice, and influence over decisions that affect their lives (Florin et al., 2010; García-Ramírez et al., 2009). **Communities of practice** are groups working together on enterprises with common values. The sense of community of practice in action allows members to produce a collective commitment to identify needs and lead initiatives by means of participation, dialogue, deliberation, and self-determination (García-Ramírez et al., 2009).

All stakeholders involved are part of the solution of the problems – or will be part of the failure of the policies that attempt to address these problems. This entails the development of structures to ensure that the needs of the different agents involved are covered in terms of mutual gains, reciprocal benefits, and a fair distribution of responsibilities (e.g. implementation, costs, responsibilities, time, and personal commitment). The relationships established among the stakeholders that define and implement policies and practices are central elements in social ecology. Any variation in the nature, intensity, range and authenticity of these relationships affects the processes in which they take part, as well as the overall results. As a consequence, health and health-care policymaking also requires a particular way of sharing and communicating the activities that are carried out. Disregarding the way in which actions are assessed and communicated may jeopardise the credibility of the efforts devoted to implementing those actions.

This report is the result of the work done by the Spanish consultants to tackle the challenge of ensuring the equity of health policies for the Roma population, adopting the viewpoint of the different stakeholders involved while developing their capacity for collaboration and building shared understanding of the problem. Following the model proposed in *Guidance for Uncertainty Assessment and Communication* (Petersen et al., 2012), this report consists of the following chapters:

- **Framing the problem.** This section describes how the problem is shaped from the different perspectives and information levels offered by the DRI, the Open Society Foundation and the World Bank among others. It presents a general overview of the national and foreign Roma communities in Spain, as well as the social determinants of health inequities that they suffer. Finally, it also describes the current policies that the EC and Member States have agreed as responses to Roma health inequities and challenges.
- **Building and releasing collaborative capacity to transform.** This section offers an inventory of the visions that have contributed to this report in shaping the problem. It includes all the documentation obtained from the desk review process as well as the viewpoints of different stakeholders that composed the coalition created for this report. The resulting information were analysed following the RIPEX, a tool composed of categories and indicators proposed by the different stakeholders, Equi-Health, the WHO, and the MIPEX.
- **Promoting shared understanding from evidences and stakeholders.** In this section, we provide a chain of evidences expressed in the RIPEX tool as a result of the shared understanding among stakeholders and the desk review findings. The results are presented following the RIPEX categories: (a) Entitlement to health care; (b) Access to the health-care system; (c) Responsiveness of health-care services; and (d) Achieving and sustaining change.
- **Planning the future.** This final section shows the principles that should guide the development and implementation of priorities in TRHP through different tools based on

methodologies for innovation and new technologies. Special attention is given to the development of a Roma Tool Box.

2. FRAMING THE PROBLEM

When we are dealing with a “wicked” problem, one of the first challenges that we must tackle is defining and framing the problem (Nelson, 2013; Petersen et al., 2012). In order to do so, we must pay attention to: (a) the existing definitions or frames of the problem – including likely definitions and points of view of the researchers, the end-users, and all stakeholders; (b) interconnections with other problems; (c) other relevant aspects that have not been addressed before; (d) the role of the study in the policy process; and (e) the way in which the study connects to previous studies on the subject.

The Roma health problem is shaped from diverse perspectives and levels of information provided by different organizations such as the DRI, WHO, EC, the Open Society Foundation, the World Bank and the Ministry of Health of Spain. In this task, it is important to highlight the special role of the Roma associative movement and its increasing international and European presence since the First World Romani Congress in 1971 and the involvement of EU Member States in redefining the problem and demanding new acting mechanisms. This section offers a general overview of the health problems of the national and foreign Roma population in Spain, providing information about the background and some of the characteristics of this population. This is followed by a description of the health inequities, as well as the social factors that determine these. Finally, this section outlines the current challenges in Roma health and discusses the European response to this problem.

2.1. National and foreign Roma in Spain

According to official data, the population of Spain currently stands at 47,129,783. Out of the total population, between 700,000 and 970,000 (i.e. 1.5–2.1%) are Roma, which means that it is the main ethnic group in the country (Fundación FOESSA, 2008). Most of the national Roma people in Spain live in Andalusia, Catalonia and Valencia. It is estimated that between 170,000 and 350,000 national Roma live in Andalusia, whereas between 40,000 and 60,000 live in Catalonia (Laparra, 2011). The total number of both national and foreign Roma remains unknown. There are no censuses or official statistics regarding ethnic origin or religion despite the fact that the Organic Law 15/1999 of Protection of Personal Data⁸ and the European Directive 2000/43/EC on implementing the principle of equal treatment between persons irrespective of racial or ethnic origin,⁹ encourage collecting ethnic data in order to improve the quality of health-care assistance and the wellbeing of those affected.

The Roma population is diverse and heterogeneous, with clear differences between national and foreign groups. Nevertheless, there are also commonalities between them. The foreign Roma population shows the highest levels of mobility, although this must not be understood as *nomadism*, since in many cases they are forced to move against their will. As a matter of fact, they are often expelled from settlements, or they find it difficult to rent properties, either because they go back to their countries for short periods of time, or because they do temporary jobs in different locations (Laparra, 2007). Also, both groups have the largest population of children under 16 – nearly a third

⁸ Organic Law 15/1999 of Protection of Personal Data. Available from www.boe.es/buscar/act.php?id=BOE-A-1999-23750

⁹ COUNCIL DIRECTIVE 2000/43/EC of 29 June 2000 implementing the principle of equal treatment between persons irrespective of racial or ethnic origin. Available from <http://eur-lex.europa.eu/legal-content/ES/ALL/?uri=CELEX:32000L0043>

of the total population – and the lowest percentage of people over 65. This reveals Roma population's capacity for rapid growth: it enjoys high birth rates (although progressively declining in recent years), decreasing death rates, and a higher life expectancy (although lower for males) (Laparra, 2011; Ministry of Health, Social Services and Equality, 2012a). Women outnumber men in both age groups, higher and their role, at least within the national population, is central for the family and the community, becoming a driving force, acquiring social relevance, leading change and modernisation within the Roma community (Esparcia, 2009). Some cultural values and customs are similar in both populations, such as the family and social structures: their social organisation is based on communities where the extended family plays an important role (Laparra, 2007; Mendez, 2007). In contrast, the majority language of foreign Roma is Romani, whereas national Roma speak the *Caló* variant of Romani and Spanish (Ministry of Health, Social Services and Equality, 2010). These similarities and differences are also present in more specific contexts, such as health inequities and the social factors that determine these.

2.2. Roma health inequities and social determinants

National Roma health has improved in recent years thanks to the implementation of universal health care, the rehabilitation of marginal areas, housing improvement, and the expansion of compulsory schooling (Fundación Secretariado Gitano, 2012; Laparra et al., 2012). In spite of all this, work still needs to be done in order to reduce the social determinants and health inequities between the mainstream population and the Roma, and between the national and foreign Roma.

The most important factor that determines directly or indirectly Roma health is socioeconomic status. Around 77 per cent of the Roma population in Spain live in relative poverty, and 37.5 per cent live in extreme poverty. These percentages increase when dealing with the European Roma community: if we extrapolate their countries' statistics, 37.2 per cent of Roma Bulgarians live in relative poverty and 80.1 per cent live in extreme poverty; whereas in Romania, it is 43.1 per cent and 68.8 per cent respectively (Fundación Secretariado Gitano, 2012). These socioeconomic differences give rise to serious inequalities regarding education, housing, health and employment, inequalities that are even greater for foreign Roma coming from Eastern Europe, due to the chronic poverty and social exclusion that they suffer in their own countries (Laparra, 2012; Rodríguez-García and San Román Espinosa, 2007).

Nevertheless, socioeconomic status is not the only factor that influences social inequalities. It is well-documented that Roma health is worse than that of the rest of the population in all age segments (Ministerio de Sanidad, Política Social e Igualdad, 2010). This may be due to additional determinants, such as labour market segmentation, gender roles, the concept of health and other cultural values of the general population rooted in social persecution and stigmatisation. These sociocultural determinants prevent equal access to and adequate use of the NHS, increasing the health vulnerability of the Roma groups. For example, they often live in cramped and insanitary dwellings in segregated areas with structural deficiencies and poor urban planning, far from public services. There are also other determinants related to the health system itself and its services, such as accessibility barriers or the lack of intercultural competence of its centres and providers. Furthermore, health inequities are intrinsically related to inequities in other fundamental aspects for human development. For instance, the high rates of school absenteeism and school failure among Roma children lead to high illiteracy rates among adults, which at the same time determines their

level of employability, their opportunities to access decent housing, as well as the information and skills necessary to successfully manage their health (Laparra, 2007, 2011; Parekh and Rose, 2011). As a consequence of all these inequities, the national Roma population has a lower life expectancy, more negative view of health, worse eye and ear health, and more traffic and domestic accidents. Some sectors of the infant population have not received their vaccinations, do not get regular paediatric check-ups and have a deficient or unbalanced diet, which may lead to obesity, worse dental health, diabetes, and the like (La Parra, 2009; Laparra, 2007, 2011). Regarding adults, they make deficient use of preventive services and are more prone to suffer from silent diseases such as cardiovascular, bone, joint and chronic diseases. In particular, women tend to suffer from obesity; they do not do gynaecological prevention, which causes related problems, such as early pregnancy; and they suffer more mental health problems (e.g., stress, depression, anxiety and so forth) than that of the rest of the Spanish population (La Parra, 2009; Laparra, 2007, 2011; Ministerio de Sanidad y Consumo and Fundación Secretariado Gitano, 2007).

Although there is no reliable information about the health of foreign Roma living in Spain, several inferences may be derived from the data obtained in their countries of origin (Hajioff and McKee, 2000; McKee, Balabanova and Steriu, 2007; Parekh and Rose, 2011). Their life expectancy is 10 to 15 years lower than the rest of the population in their countries, with higher mortality rates among young adults and children. Many of these suffer from malnutrition and infectious diseases such as tuberculosis, hepatitis, polio and measles, as well as alcohol and drug abuse. More than 84 per cent of the population live under the poverty threshold and almost 80 per cent are unemployed. Only 50 per cent have access to running water and 15 per cent have hot water. Also, the number of people with psychiatric or mental disorders is six times higher than in the rest of the population. Moreover, traditions such as big families and early marriages lead to teenage pregnancies and increase child vulnerability. Finally, the lack of health-care centres in segregated areas and the absence of public transport make it more difficult for Roma people, including children, to get the necessary documents to register with and access health-care system.

In recent years there has been an increase in the mobility of citizens from Eastern Europe (McKee, Balabanova and Steriu, 2007). This, together with the decline of European economy, has become one of the main challenges that need to be dealt with in order to abolish the gap between foreign Roma health and that of the rest of society. In 2007, Bulgaria and Romania formalised their EU membership, gaining freedom of movement across the countries of the EU and the right to work in the European labour market. These events, together with a waiver visa policy for Western Balkans' citizens, have been the cause of an increase of foreign Roma population in Spain, and it is expected that it will continue to grow in the short and medium term. It is also likely that most of these immigrants will be of Roma origin, since many of them are forced to leave their countries due to marginalization and poverty. At the same time, the rise of xenophobic policies in certain EU Member States,^{10,11,12} have made of Spain preferred destination for many of them since it has one of the largest Roma populations in Europe and, in recent years, it is also one of the countries in the EU with more inclusive policies towards Roma.

¹⁰ El ministro del Interior francés arremete contra los gitanos, *El País*, September 2013. http://internacional.elpais.com/internacional/2013/09/24/actualidad/1380022331_876484.html

¹¹ Miles de gitanos protestan en Roma contra la xenofobia, *El País*, June 2008. http://internacional.elpais.com/internacional/2008/06/08/actualidad/1212876007_850215.html

¹² París detiene y deporta a una alumna gitana durante una actividad escolar. http://internacional.elpais.com/internacional/2013/10/14/actualidad/1381773587_389978.html

At the same time, foreign Roma arrivals have become a challenge to human rights, and a possible risk for public health, since when these Roma get to Spain in very precarious conditions and with no chances of finding a job, many of them are forced to live in shanties, in temporary and unsanitary settlements where the same subhuman conditions of their own countries are replicated. Consequently Roma people are subject to extreme forms of discrimination and segregation, and are often confined to ghettos with no access to social or health-care services. The precariousness of their settlements, together with their extreme poverty, makes them vulnerable to many health risks. Furthermore, the situation is getting worse now, since constant evacuations lead families to stop devoting their time and efforts to build safer shanties and settlements, as they know these will be soon destroyed. They sleep in tents that are packed up in the morning, when they leave the place in order to go begging or collecting scrap metal for the day. Persecuted and stigmatised for their vulnerability, their precarious health condition contributes further to their marginalization, creating new risks and suffering.

2.3. The EU response to Roma health inequities

The progressive deterioration of health conditions and access to health services of Roma population, together with the failure of policies aimed at reducing these inequities, drove the attention to the need of fostering further collaboration among EU Member States. Thus, in April 2011, the EC adopted the *EU Framework for National Roma Integration Strategies (NRIS) up to 2020* (European Commission, 2011), by which EU countries committed to (a) complementing and reinforcing the EU's equality legislation and as well as supporting policies and authorities at national, regional and local level in monitoring, sharing and strengthening approaches to Roma health, education, employment, and housing; and (b) building a coherent network to promote dialogue and participation among key stakeholders and to delineate strategies and interventions to support capacity building and cooperation in order to address the specific needs of the Roma.

By 2012, each EU Member State had to elaborate a National Strategy included in the document entitled *A First Step in the Implementation of the EU Framework* (European Commission, 2012). Later in 2013, the EC drafted the document *Steps Forward in Implementing NRIS* (European Commission, 2013), which established the necessary requirements for each EU country to achieve Roma inclusion in the different areas mentioned above. Regarding health, the NRIS's aim is to make possible for Roma people to access quality health care, preventive assistance and social services in the same conditions as the rest of the population, placing the focus on women's and children's health. Also, it sought the participation of qualified Roma in their communities' health programmes. More specifically, EU members were advised to: (a) extend health and basic social security coverage and services; (b) improve the access of Roma, alongside other vulnerable groups, to basic, emergency and specialized services; (c) launch awareness raising campaigns on regular medical checks, pre- and postnatal care, family planning and immunization; (d) ensure that preventive health measures reach out to Roma, in particular women and children; and to improve living conditions with focus on segregated settlements (European Commission, 2012).

The Spanish NRIS was developed by the Ministry of Health, Social Services, and Equality (Ministerio de Sanidad, Política Social e Igualdad, 2012b). This document adopted the objectives and suggestions made by the EC, aiming to improve Roma health status and to reduce the social inequalities in health with differentiated targets for adults and children. Concerning adults' health, the targets are to improve the perception of health status of the Roma population and reduce traffic accidents and

smoking. Special attention is also given to reducing obesity among women and to reducing the number of women who have never gone to the gynaecologist. In relation to the child population, the NRIS aims to reduce the number of children suffering domestic accidents and increase oral health care. In 2014, an Operational Plan (*Plan Operacional, 2014–2016*) was approved in order to implement lines of action to achieve the objectives proposed by the Spanish NRIS. These are: (a) promoting policies and actions aimed at reducing health inequalities; (b) reorientation of health services towards equity; (c) fostering health promotion throughout the life course; (d) establishing mechanisms to ensure the impact on Roma health; (e) promoting Roma participation; (e) promotion of intersectoral work; (f) support and promotion of diversity training; and (g) cultural adaptation of resources (Ministerio de Sanidad, Política Social e Igualdad, 2013a).

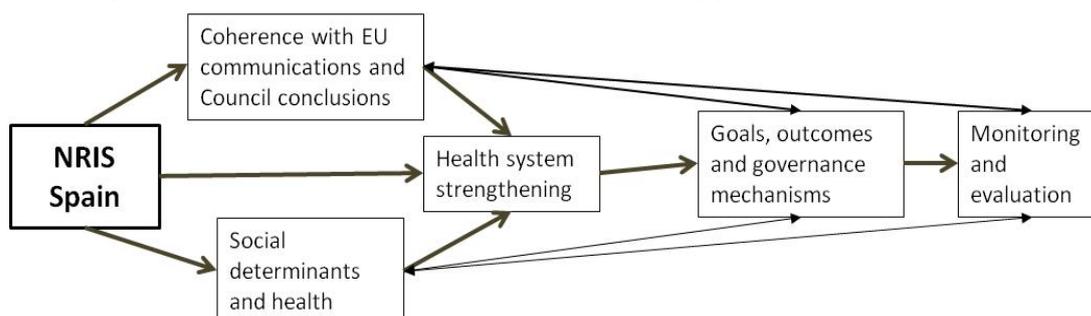
3. BUILDING COLLABORATIVE CAPACITY TO TRANSFORM

As discussed above, transformative policy change refers to policy changes that are rooted in the available scientific evidence together with the vision of multiple stakeholders and their values, thus providing real capacity to influence in the decision making process. According to the principles stated in the introduction, this requires the new policies to be based both on an evidence-based approximation – that is to say, the policies must be informed by evidence-based scientific research; and on a discursive approach – which means building policy as a process based on the values and participation of all stakeholders (De Freitas et al, 2014; Nelson, 2013). In this section, we first provide the methodology employed in this report: a systematic review of the literature and the creation of a coalition. After that, we present the tool used to analyse and discuss the collected information.

3.1. Evidence based approach: systematic review

The desk research has been an ongoing process throughout the preparation of this report. It was organized following the Community Guide on Systematic Review Methods.¹³ This consisted of literature review, legal review and policy research collecting data and combining information from various sources in order to obtain the most comprehensive overview of the foreign and national Roma population in Spain, and more specifically in the AACC of Andalusia and Catalonia. We focused our search on information on the period between 2005 and 2013. To carry out the desk research we first searched the international databases MEDLINE, PubMed and Google Scholar using keywords such as “health”, “Roma”, “gypsy”, “Spain”, “policies”, “strategies” both in English and Spanish. Next, we did a comprehensive search using websites pertaining to departments of health – national and regional, different Roma Civil Society Organizations (CSOs)’ websites, sources of information provided by Equi-Health, and so on. Out of the total of publications found, we selected the most relevant documents (Annex 1) that fit within the analytical framework (Figure 1) proposed by the WHO’s Potential Criteria for the Review of the Health Component of the NRIS (WHO, 2012a).

Figure 1: Analytical framework to assess evidence based approach



3.2. Discursive approach: key stakeholder involvement

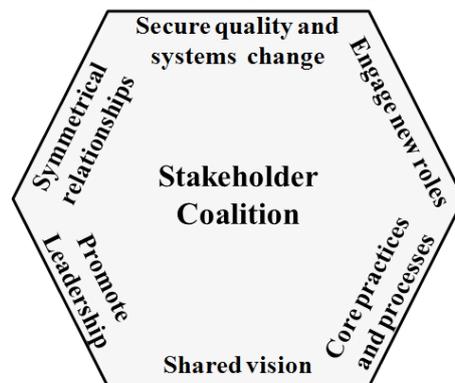
To carry out the discursive approach a coalition or stakeholder network was constituted in order to generate collaborative capacity building among them. Collaborative capacity allows us to study stakeholder networks as multicultural empowering settings (Box 1).

¹³ Community Guide on Systematic Review Methods. See at: www.thecommunityguide.org/about/methods.html

Box 1: Stakeholder network as multicultural empowering settings

An empowering community setting is understood as a community-based structure which facilitates development of the members, community betterment and positive social change (Paloma, García-Ramírez, de la Mata and AMAL, 2010). These settings are characterized by the following features:

Figure 2: Stakeholder network as multicultural empowering settings

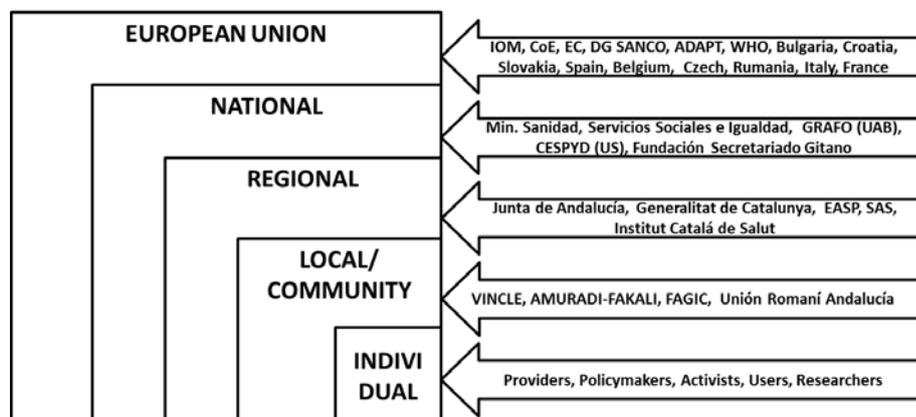


1. **Capacity to adopt a shared mission**, embracing equality and diversity as values; recognizing diversity of origin, cultural and linguistic experiences; assuming models of services and care based on the individual; acknowledging the specific needs generated by being of minority status in European society; including reciprocity, compromise, and collaboration as strategic principles.
2. **Adaptation of services and organizational processes** (policies, standards and procedures) to the needs of the multicultural collective group; probing and sharing evidence and best practices that integrate knowledge, the view of multicultural populations users of services; and developing evidence-based practices.
3. **Promote horizontal and reciprocal relationships**, by including users of services and representatives from other community agencies in the decision making process in the organizations; establishing strong partnerships with universities; and fostering the exchange of ideas and multicultural events among multicultural communities, community settings and providers.
4. **Create capacity to engage different roles**, encouraging diversity among members; identifying cultural mediators, community gatekeepers, volunteers, and including spiritual and cultural healers.
5. **Promote leadership** among members who are pluralistic, multicultural individuals, capable of equally representing the needs and views of all constituents and relate with ease with multicultural communities.
6. **Secure quality and systems change**, instead of pursuing a quick fix approach to addressing changes in services, focus on pursuing long-term social change, seeking to maintain the quality of services and protecting changes to policies and practices that support multicultural populations.

To assure the stakeholder participation in the elaboration of the report, the Spanish Equi-Health coalition included representatives of organizations with relevant role in the field of Roma health (Figure 3; Annex 2). Assuming a systemic view, policymakers, managers, health-care providers and end-user representatives were chosen. Other participants include members of research groups and representatives of institutions, organizations and associations working in health care for Roma people in Andalusia and Catalonia. Moreover, and due to its European context, several European stakeholders have contributed to this report, including representatives of the IOM, the EC, the ADAPT

project, which belongs to the European Cooperation in Science and Technology research network (COST); and the WHO. Stakeholders from other countries involved in the Equi-Health action (i.e. Bulgaria, Croatia, Slovakia, Belgium, Czech Republic, Romania, Italy, and France) also took part.

Figure 3: Spanish Equi-Health Coalition



The discursive approach was organized in the following way: First, two initial coalition meetings were organized in Sevilla and Barcelona in February and March 2014 – respectively – in which the Equi-Health project was presented, key stakeholders were invited to participate both in the coalition and the report, and first discursive data was collected. After that, stakeholders were individually interviewed during March and April 2014. National consultants drew the interview guideline (Annex 3) from the indicators set out in the ToRs of Equi-Health (Annex 4). In total, 33 interviews – 15 in Andalusia and 18 in Catalonia – were conducted by five researchers. These were recorded under the informed consent of the interviewees, transcribed, and qualitative analysed by two researchers using the software ATLAS.ti 5.0 and following the assessment categories and indicators developed by this report (i.e. the RIPEX; see next section). Later in October and November, two new coalition meetings were organized – again in Sevilla and Barcelona – to present the preliminary findings of the report. Stakeholders were also asked to provide feedback on the work done as well as to propose and discuss recommendations and priorities for planning the future in Roma health. This new information has also been incorporated in our report (see chapter 5).

3.3. RIPEX: an NRIS assessment tool

A new tool, **the Roma Integration Policy Index (RIPEX)**, was developed in order to analyse and integrate the findings of the stakeholder interviews and coalitions, as well as those obtained in the desk review. This index was promoted by the network set up in Equi-Health to assess and contrast how sensitive health policies are towards the Roma population. It is composed of a series of categories and indicators selected from: (a) the WHO’s assessment recommendations for the health branch of the NRIS; (b) the MIPEX; (c) those required by the IOM in the Equi-Health project; and (d) the suggestions made by the stakeholders.

The WHO has elaborated a list of indicators to assess the health content of the NRIS (WHO, 2012a). The criteria used can be grouped in five different areas: (1) coherence with the EU’s and the Council of Europe’s communications; (2) strengthening the health system; (3) social determinants of health; (4) objectives, results and governing mechanisms; and (5) monitoring and assessment. According to the document elaborated by the WHO’s international committee, these criteria are based on the EU

Communications and Council Conclusions on Roma Inclusion, the Communication “Solidarity in Health: Reducing Health Inequalities in the EU” and recommendations made by the Council of Europe and the Open Society Foundation’s Roma Health Project. They reflect the policy guidance and evidence base represented by sources such as Article 12 on the right to health of the International Covenant on Economic, Social and Cultural Rights; the work of the Commission on Social Determinants of Health; the emerging findings of the Task Group on Disadvantage, Social Exclusion and Vulnerability of the WHO-commissioned European Review on Social Determinants and the Health Divide; and the Health 2020, among others (WHO, 2012b:1).

The MIPEX¹⁴ is a fully interactive tool and reference guide to assess, compare, and improve integration policy. MIPEX measures integration policies in all EU Member States plus Norway, Switzerland, Canada and the USA up to 31 May 2010. Using 148 policy indicators, MIPEX creates a rich, multidimensional picture of migrants’ opportunities to participate in society by assessing governments’ commitment to integration. By measuring policies and their implementation, it reveals whether all residents are guaranteed equal rights, responsibilities and opportunities. MIPEX draft health policy indicators are being elaborated in collaboration with the network ADAPT, whose aim is to develop a series of changes to adapt European health systems to the demands of a multicultural society, placing emphasis on vulnerable groups. It focuses on four sources of variation: (1) entitlement to health-care services; (2) policies to facilitate access; (3) responsive health services; and (4) measures to achieve change. Regarding entitlement, it involves coverage for different groups, including the most vulnerable ones, affordability and co-payment. With regard to policies to facilitate access, it includes availability of information for providers about the rights of minorities, mechanisms to facilitate communication, measures to reduce the obstacles in access to health care and the use of cultural mediators. With respect to responsive health-care services, it focuses on methods used for interpretation, the creation of culturally competent services, and the involvement and participation of users in the provision of services. Finally, the measures to achieve change include support for research and the adoption of the “health in all policies” approach.

Through the Equi-Health ToR (Annex 3), the IOM includes a series of indicators to assess the NRIS. In the case of Spain, these were: (a) barriers in the access to basic, emergency and specialized health-care services for Roma; (b) social security coverage and existing local solutions to low coverage for Roma communities; (c) process of development and revision, the implementation of national commitments, evaluation/monitoring mechanisms, funding and sustainability, involvement of local authorities and civil society organizations; (d) how national strategies and actions relate to and contribute to EC policies on health inequalities, with particular attention to Europe 2020; and (e) Roma health mediators programme (e.g. implementation, challenges, monitoring, evaluation, sustainability and institutionalisation).

Consequently, the final **RIPEX** tool consisted of the following categories and indicators – discussed by the stakeholders in the development of this progress report:

Entitlement to health care

- *Requirements for obtaining entitlement:* this indicator focuses on the formal and informal requirements for national and foreign Roma to access the health-care system and its services.

¹⁴ Migrant Integration Policy Index (MIPEX). See at: www.mipex.eu

It includes aspects related to the Health Card application process and other requirements related to forms of identification, registration, and so forth.

- *Co-payments*: this indicator deals with the payment system that the Roma population has to use to have access to medical attention. It examines the prevalence of out-of-pocket payments and the cases of exemption from payment (such as low income or chronic diseases).
- *Coverage*: it is referred to the list of services to which the Roma population has access. It distinguishes between health-care coverage for national Roma and that for foreign Roma.

Access to health-care system

- *Accessibility barriers*: this indicator determines the different barriers that hinder national and foreign Roma's access to the NHS and its services. These barriers may be related to the culture of the Roma community or derived from the system itself and its providers, among others.
- *Policies to suppress accessibility barriers*: policies developed and implemented by local, regional or national plans intended to tackle accessibility barriers.
- *Adaptation strategies to suppress accessibility barriers*: strategies are specific actions developed by providers of health-care centres or CSOs to eliminate the barriers that hinder the Roma population's access to health care.
- *Roma health mediation*: this indicator includes aspects related to the tasks of health mediators working with Roma people. It deals with the training of providers, the collaboration of Roma patients with health-care services, and so on.

Responsiveness of health-care services

- *Health inequalities identified in the NRIS*: including inequities described in the Operational Plan 2014–2016 and their critical review.
- *Policies to make health-care services more responsive*: it includes aspects related to the training in cultural competence of service providers.
- *Adaptation strategies of health-care services and providers*: these are the measures adopted by health-care providers and some health centres to adapt to the characteristics and needs of the Spanish and foreign Roma population.

Achieving and sustaining change

- *The political and economic context of the NRIS*: this indicator assesses the health-care system's capacity to achieve the objectives of the Operational Plan of the NRIS. The focus is placed on how these objectives are shaped by the current restrictions imposed on the NHS.
- *Associationism, participation and collaboration of the national and foreign Roma community*: it describes the relationships between national and foreign Roma, Roma associationism and participation, as well as the collaborative relationships among different organisations and how these contribute to improving Roma health.
- *Collaborative work among multiple stakeholders*: this indicator outlines the synergies among different organisations and how these contribute to improving the health and wellbeing of the Roma community. These organisations include local, regional and national institutional bodies, health care and academic institutions, Roma associations, social organisations and non-governmental organizations (NGOs).
- *Promoting intersectoral action*: this indicator examines the synergies between the different programmes intended to promote and improve the use of health-care services within the framework of the NRIS.

4. PROMOTING SHARED UNDERSTANDING TO TRANSFORM ROMA HEALTH POLICIES

In order to take stock of all the challenges and recommendations obtained through the stakeholder interviews and desk research, the chain of evidences will be presented following the RIPEX structure:

4.1. Entitlement to health care

The NRIS is based on the idea that health-care assistance in Spain is free and universal for all those who live in the country, regardless of their ethnic origin, their legal or social status. This is the starting point for the Operational Plan of the NRIS for forthcoming years: “for the universalization of the whole system, the priorities are (a) counselling on lifestyles in primary care [...] during pregnancy and lactation [...] and the promotion of the emotional wellbeing of the infant population” (Ministerio de Sanidad, Política Social e Igualdad, 2013a:28). National Roma are entitled to health care by virtue of the same legislation that entitles the rest of the Spanish population. In the case of foreign Roma from EU and non-EU countries, the laws that apply are those addressed to the foreign population. However, it is important to outline the health-care legislative changes that have taken place in Spain since 2012 at the hands of the Government of the Popular Party (*Partido Popular*) and which represent the main milestones for the implementation of the NRIS in Spain (Box 2).

Box 2: Latest changes in the Spanish legislation

(1) Article 43 of the Spanish Constitution of 1978 establishes the right to health protection and health-care assistance of all citizens. Similarly, Articles 1 and 3.2 of the Law 14/1986 on General Health entitles all Spanish and foreign citizens who reside in Spain, applicable to all the Spanish population, to health protection and health-care assistance. Since then, health insurance for Roma people expanded until they were entitled to health care in the same conditions as any other Spanish citizen (Fundación Secretariado Gitano, 2012; Laparra, 2007).

(2) This process of universalisation was shaped further with the Law 16/2003 of Cohesion and Quality of the NHS, whose aim was to put forward a new definition of health-care entitlement, where users are no longer insured by the Social Security System but beneficiaries of the NHS. Article 3 of this law established entitlement to health protection and primary care for: (a) all Spanish and foreign people in Spanish territory; (b) nationals from EU Member States that hold agreements with Spain to entitle them to health-care assistance; and (c) non-EU nationals who are entitled by virtue of laws, treaties and agreements subscribed by both parties.

(3) In 2012, the Government of the Popular Party modified the law by approving the Royal Decree-Law (RDL) 16/2012 on urgent measures to guarantee the sustainability of the NHS. This decree represents a backward movement in the universalisation of the NHS, thus restricting the entitlement of national and foreign Roma as it has modified Article 3 of the Law of Cohesion and Quality of the NHS, eliminating the concept of universal health care in favour of health-care insurance. These changes may affect the implementation of the NRIS and its Operational Plan in Spain. According to this decree, only the following groups are eligible for health-care insurance: (a) workers affiliated to the Social Security System; (b) pensioners of the Social Security System; and (c) recipients of jobseeker’s allowance and unemployment benefits. Spanish nationals and nationals from EU Member States who do not belong to any of these groups may be eligible for health-care insurance if they can prove that their income does not surpass certain established

limits. This decree also extends pharmaceutical co-payment to prosthetic treatments, dietary products and ambulance services. In the case of foreign Roma, the RDL 16/2012 hinders their access to health services because it limits the entitlement to health care of people who are not resident in Spain. Therefore, and in spite of their being EU citizens, these people's entitlement to health has been considerably restricted, and they are doubly marginalized for being both Roma and immigrants before the law. This decree has also generated obstacles for the national population, as it has eliminated the entitlement to health of those above 26 that have not contributed to Social Security, it has toughened the requirements for disability allowance, it has imposed stricter forms of control of access to medical assistance by means of the Health Card, and it has implemented a pharmaceutical co-payment system.

(4) For those who are excluded by this decree, including irregular and unemployed immigrants, the Government passed the RDL 576/2013, turns the NHS into a sort of health insurance company that charges EUR 60 a month for users under 65, and EUR 157 for those over 65. These fees may be raised by the autonomous communities or in accordance with the cost of services.

In the same line, Andalusia approved an instruction of the DG de Asistencia Sanitaria y Resultados en Salud of Andalusian Health-care Service (SAS) intended to recognise and secure entitlement to health-care assistance for irregular immigrants and people with no resources. This instruction establishes that medical coverage for these people will be the same as for those who are covered by the system, that is, they will have access to all the services offered by the SAS. This entitlement will be valid for extendable one-year periods. Furthermore, pharmaceutical co-payment will be 40 per cent for people under 65, and 10 per cent for those over 65. To benefit from these measures, applicants must meet the following requirements: (a) they must be irregular immigrants; (b) they must not come from any of the EU Member States, the European Economic Area or Switzerland, or from non-EU countries that have signed agreements with Spain regarding health-care assistance; (c) they must not be insured by or beneficiaries of the NHS or any other health system; (d) they must be over 18; and (e) they must not have economic resources – although the instruction does not specify thresholds. Also, the documentation required is: (a) an application form; (b) although no form of identification is required, the information provided must be truthful and is liable to be checked; (c) if the applicant has an old Health Card, it should be produced to facilitate the application process; (d) in the case of EU citizens, it is necessary to produce a document issued by their countries of origin confirming that transferral of entitlement does not apply in this case.

However, although the Instructions in Catalonia and Andalusia have entitled many excluded people to health-care assistance, these measures have not prevented the deterioration of the NHS in Spain.

There are several evidences collected in international and national reports which emphasize the negative consequences of these changes affecting both national and foreign Roma populations, and creating barriers to the effective implementation of the NRIS (Casino, 2012). Due to their high levels of unemployment, informal economy, and poverty, national and foreign Roma populations have been particularly hard hit by the financial crisis. Indeed, it is the poorest people and those who rely more heavily on public services that are more seriously affected by government cuts. In this regard, there is evidence of direct relationship between the loss of purchasing power of these families and an increase in health problems derived from malnutrition (e.g. gastroenteritis and growth problems and so on), poor sanitation, overcrowding and the impossibility of healthy shopping, paying for hot

water or paying the rent (Fundación Secretariado Gitano, 2013). Economic problems also bring about worse mental health (e.g. stress, depression, anxiety and so forth), especially for women with work overload and family obligations.

At the same time, the lack of material, human, and economic resources derived from cuts and the privatisation of services also gives rise to a series of consequences, such as: (a) the closure of primary health-care centres (PHC) and specialised services near marginalized communities, making it more difficult for these to receive assistance and monitoring; (b) the reduction of and subsequent strain put on shifting workforce; (c) staff shortage and their lack of cultural sensitivity due to professional burnout and work overload; and (d) new pharmaceutical co-payments. All this has increased the number of people that demand medical assistance while it has also limited their rights and opportunities to access health-care services, to the point that sometimes it is not possible to assist them (Fundación Secretariado Gitano, 2013).

As has been shown, the RDL 16/2012 strictly regulates access to health-care service through the Health Card. Free access is only granted to emergency cases, pregnant women and minors. Without a Health Card, it is not possible to arrange appointments, to be transferred to specialised services or to follow certain protocols. Some stakeholders agree that this procedure is simply a thinly veiled excuse to deny medical assistance, since primary care can be easily offered without a card, and it is specialised treatment and prescriptions that are more problematic in this sense:

“I can order blood tests and other things, but I can’t prescribe them medicines because they are not in the system.”

(Health-care provider1)

However, applying for a Health Card involves, together with all the legal requirements mentioned above, several bureaucratic procedures and additional documentation that are further barriers for the Roma population, especially foreign Roma, who do not have the necessary resources to navigate the system or to certify that they are unemployed or poor. For example, to register in the census of the community, many city councils ask for information regarding family income, rental agreement, etc. – impossible to provide for people who sublet or occupy flats or those who live in shanties or in caravans. Also, they need to produce some form of identification such as an ID card or a passport, which foreign Roma do not generally have, have lost, or have let it expire:

“They are not undocumented immigrants in the sense that they don’t have a visa, but in the sense that they don’t have any documents at all. That is, we know their names because they tell us. We don’t have any information about the family structure that they say they have.”

(Policymaker1)

In the case of foreign Roma, they must go to their respective consulates to get some form of identification or official documents to prove that they are not insured in their own countries. However, they are often ignored or unduly charged:

“We have this problem with Roma population, mainly Romanian, which are ignored by their consulate (...). Sometimes the consulate “charges them” for the authentication of these documents; a thing that shouldn’t be doing since other consulates of richer countries don’t do it.”

(Policymaker3)

The cynicism of all these requirements is made evident when dealing with a population whose social determinants are precisely the fact that they do not have stable housing, that they live in conditions of extreme poverty in precarious settlements, that they have low education level and that, in the case of foreign Roma, they come from highly dysfunctional, broken homes. All the bureaucratic procedures that they have to go through to prove that they are poor, that they have neither a place to live or nor a steady job require a degree of specialisation and skills difficult to find in person with this profile. All this creates additional barriers that hinder further the national and foreign Roma population's access to the NHS and its services.

Box 3: Highlights of entitlement to health care

The NRIS in Spain and its Operational Plan are based on the universalisation of the NHS, enabling every Roma and any other citizen to access and enjoy their right to health. However, the latest changes (e.g. RDL 16/2012) in the legislation and the consequent cuts in the funding of the NHS have dismantled its core elements that characterized it for being universal, public and free. The main threats for the entitlement to health care are listed below:

- The new insurance-based health-care model affects both national and foreign Roma. However, it has worsened the low socioeconomic conditions of most vulnerable people, especially the foreign Roma. Co-payment is not an option for Roma people living below the poverty line even when they are entitled to health-care services.
- There is direct relationship between the loss of purchasing power of these families and an increase in health problems derived from malnutrition and mental health problems.
- The cuts on the NHS' material, human and economic resources and the privatisation of services have given rise to consequences (e.g., closure of PHC and specialised services, staff shortage with lack of cultural sensitivity and/or burnout and work overload, co-payments)
- Applying for a Health Card involves bureaucratic procedures and additional documentation that are further barriers for the Roma population to obtain entitlement, especially for foreign and the most vulnerable national Roma.

4.2. Access to the health-care system

According to NRIS, access to and use of the NHS and its services is key for improving the health conditions and the standards of living of the Roma population. The Operational Plan 2014–2016 of the NRIS "aims at an equitable, accessible and quality health-care system, reorienting services to equity and removing barriers to access" (Ministry of Health, Social Services and Equality, 2013a). It is also proposed to remove the barriers for Roma to participate in prevention and health promotion programmes. It also places special emphasis on removing barriers arising from cultural differences and the marginalized living conditions of some groups.

This section focuses on the following aspects regarding accessibility: (a) accessibility barriers for national and immigrant Roma; (b) consequences of these barriers for the Roma population, the health system and its providers; (c) policies and strategies implemented to eliminate these barriers; and (d) Roma health mediation.

4.2.1. Accessibility barriers

Several barriers that hinder the access of the Roma community to health-care services arise in the contact between the Roma population and the NHS and its providers. These barriers have been

intensified by the current socioeconomic situation (Fundación Secretariado Gitano, 2013; Laparra, 2007; López Catalán, 2012; Ministerio de Sanidad y Consumo and Fundación Secretariado Gitano, 2007). Many of the barriers presented here are due, first, to the lack of a health-care system designed to reduce social inequalities (e.g. community work approach, integrating social and health services, no discrimination towards culturally diverse population), and secondly, to the Roma's living conditions (i.e. "living day by day", "survival", victims of racism, low educational level, etc.).

4.2.1.1. Barriers related to the scientific culture of the NHS

The NHS has been configured following a health science model characterized for looking the quickest solution to health-care problems and for seeing patients as individuals unconnected to their culture (Trickett, 2011). Consequently, the current NHS implements a hospital-centered and ethnocentric model of assistance. As one of the providers interviewed for this report asserts:

“It is a system that does not cater for individual contexts (...). A patient may come here with a backache and painkillers are prescribed, but the fact that this person sleeps on the floor goes unnoticed. The context is the key; how patients live and where they live is also part of our concept of health (...). The system is made for the mainstream population and not for people in marginalized contexts.”

(Mediator1)

This may lead providers to confuse equity and equality, mistakenly identifying people's right to health care with the accessibility of health-care services:

“We don't treat anyone differently (...). They are all equal, so we don't have to implement positive discrimination with Roma families (...). What is it that they don't have access to? (...) They can come and visit patients, just like everyone else, but they can't come 20 at a time, but in twos and during visiting hours. It is a question of organization. (...) They can come to the emergency service as many times as they like but, again, not 20 at a time. (...) They have a right to vaccinations, but they need to bring their children here to be vaccinated, just like everyone else. (...) They are given all the information they need (...) and they are given the informed consent forms for them to read, or for someone else to read it for them, or they are informed orally. (...). So, they enjoy the same accessibility as we or other ethnic groups do.”

(Manager2)

However, access to health-care services does not depend so much on the rights of an individual or a social group (equality), as it does on the adaptation of these services to the characteristics of this population, ensuring complete access to and use of these services (equity). At the same time, the system's ethnocentric outlook focuses on the dominant culture, and is not sensitive towards cultural differences and minority groups. In some cases, these differences may be even seen as cultural flaws, and the Roma community itself is made responsible for its health problems. All this results in a lack of specific protocols adapted to the characteristics and customs of the Roma population. One of the most recurrent examples is when hospitalised Roma patients are visited by relatives:

“If the patriarch, (...), the venerable elder, is ill, it is normal for different Roma communities to want to go and visit him; but there is a system, certain visiting hours and so forth, and that's when both cultures clash.”

(Policymaker2)

Another unfortunate consequence of this NHS model is the cultural differences when defining the concept of health. The NHS acknowledges WHO definition of health as “a state of complete physical, mental and social well-being and not merely the absence of disease or infirmity” (WHO, 1998). This concept implies the need to promote health, to gain control over it and to be able to improve it. At the same time, it also draws attention to the importance of reducing risk factors, preventing diseases, halting their advance and minimising their consequences. These ideas clash with those of the national and foreign Roma community – as well as other groups with low health culture – for whom health is simply the absence of disease. They understand disease in terms of symptoms, and their treatment in terms of eliminating these symptoms. This implies that they generally abandon treatment as soon as symptoms disappear:

“They only request health-care assistance when they see symptoms.”
(Health-care provider2)

This means that Roma people only request health-care services - mostly emergency services - when they are seriously ill or in acute disease processes that prevent them from going on with their lives (Mendez, 2007; Ministerio de Sanidad y Consumo and Fundación Secretariado Gitano, 2007):

“A woman suffering from toothache went to the emergency service three times (...). She was given antibiotics and an appointment was arranged to remove the tooth. Because the antibiotics got rid of the infection and therefore of the pain, she thought it unnecessary to go to the doctor’s again and get the tooth removed.”
(Social worker2)

This kind of ideas prevent Roma patients from anticipating health problems, planning actions and making medium – and long-term health-related decisions, something that makes prevention and health promotion rather difficult (Laparra, 2007):

“This is a community that (...) is not ready for prevention. They don’t control pregnancies, and they don’t do it because it is part of their way of thinking (...) in spite of the fact that they do have access to this kind of control.”
(Manager3)

“If a woman goes into labour, they can even close down a whole market and get 200 people to accompany her, but they don’t get a leukemia test because it’s not important for them.”
(Health-care provider2)

Situations like the described above may give rise to conflicts between the values of the Roma community (e.g. support and emotions in the face of illness and death) and the health-care rules and regulations (e.g. visiting hours, number of visitors allowed, and so on). In this debate, some stakeholders wonder whether these conflicts arise from a lack of accessibility of health-care services or from a lack of compliance with the rules by the Roma:

“Some of the difficulties that we encounter with the Spanish Roma population is precisely their lack of compliance with basic codes of conduct (...). There are complaints sometimes when there is a Roma patient in the Intensive Care Unit and about 50 relatives in the waiting room, with a little

stove and cooking a stew (...). I understand these are their customs, but they are irreconcilable with those of the mainstream population, aren't they? So, conflicts arise, but these are not related to assistance or equity."

(Manager3)

Very often, this cultural gap is rooted in the system's blindness of the Roma culture, something that is accentuated by the fact that very few health providers – and prospective providers – have received adequate training in managing diversity:

"Our NHS is not ready professionally to deal with exclusion, and it does not know how to manage diversity because neither at university nor anywhere else are providers trained to work in conflict areas."

(Mediator1)

This unawareness encourages prejudiced and stereotyped visions among providers, who sometimes see the Roma community as a self-marginalized people, and consequently leads them to use strategies that result in communication problems.

The above shows that the Roma community has cultural codes that are reflected in their customs, values and practices. An example of this is when Roma people – even those in relatively better socioeconomic situations – consider disease and other health problems as taboos, sometimes even denying they exist. This may be one of the reasons why many Roma women do not go to the gynaecologist:

"Whether in marginalized contexts or not, the truth is that Roma women don't go to the gynaecologist; it is a taboo subject for them."

(Mediator1)

It may also be one of the reasons why they do not report gender violence:

"In order to set up a protection protocol for gender violence, the woman or the family need to report to another Roma and to a non-Roma institution. This may lead to a conflict between Roma families and this is the reason why, except in extreme cases, they don't generally report it."

(Policymaker1)

4.2.1.2. Barriers derived from miscommunication and misinformation

The NHS has rigorous protocols of access that make use of *"a whole new language and an internal organization that you need to learn to understand the system."* **(Social worker4)**. For example, administrative and bureaucratic procedures are the first barriers that Roma people encounter when attempting to access the system or when following stipulated procedures. Basic knowledge and communicative skills that are beyond the users' own resources are required to navigate the system. In the case of foreign Roma, they do not even know the language. It is for this reason that some users feel immediately excluded from it:

"Is the system in favour of people or in favour of bureaucracy? (...) There are several barriers if one wants to understand how the system works."

(Social worker4)

“Regarding Eastern European Roma, the first obstacle is always the language (...). We have serious difficulties in communicating with them.”

(Manager3)

Regrettably, the NHS offers scarce resources to reduce these barriers. For example, the information available is mainly produced in written form (e.g., brochures, posters and websites, among others), and it does not reach the national and foreign Roma population because it is not adapted to their culture, language, or education level. Translation services – either face-to-face or online – are not generally available in Romani. Also, there are very few intercultural mediators immediately available for health-care providers and users:

“There is not a mediator in the clinic that can become a reference person for Roma patients (...). As it happens, they generally get the information from someone who has nothing to do with health care and has no responsibility in the centre (...). It is not compulsory for health centres to offer this kind of service, a person who can explain everything to these people”

(Policymaker2)

On the other hand, access to the system and, consequently, to health-care services and resources, depends on the information that both users and providers have about users’ rights:

“People who don’t have information about their rights cannot claim them.”

(Social worker1)

As a general rule, Roma patients are not aware of their health-care rights or the way in which the NHS works. However, approximately 91 per cent of national Roma used public health services in 2011, compared with 69 per cent of foreign Roma, 75 per cent of Moroccans and only 50 per cent of Indian–Pakistani immigrants. This data seems to suggest that national Roma are highly aware of their rights (Laparra et al., 2012). In contrast, foreign Roma’s knowledge of the NHS and their rights is scant, either because they reproduce the patterns of access and use in their countries of origin, or because the information they have is inadequate, since they get it from relatives or friends (Slavkova, 2010):

“Foreign Roma (...) are not integrated in our health culture, they are not aware of the services and resources to which they have right, because in most of the countries where they are from, mainly Central Europe, there are difficulties regarding access, so they think it’s the same here.”

(Manager5)

Together with this lack of awareness on the part of users, providers are also generally unaware of users’ rights. The providers who have been interviewed for this report maintain that they have encountered this barrier when this should be part of the basic knowledge and training of all providers, especially of those in the administration who manage access. This lack of awareness, together with the high level of staff turnover, means that some social workers from the health-care centre or CSO have to accompany users to health-care centres in order to “re-educate” these providers and guarantee access for Roma users:

“In many centres, they say ‘no’ straightaway to Roma users (...): minors, pregnant women, emergency cases... But then you accompany them and you tell the professional what the law says, that they have to issue a Health Card and that they have to assist them, and that’s when they do it.”

(Social worker2)

“The access depends on the person who is at the entrance of the health-care centre (...) once we accompanied a pregnant woman and the administrative asked us “how do we know if she is pregnant?” first, she has to pay the bill and then we will know whether she is pregnant or not”.

Well, that is not a misunderstanding of the Law...”

(Social worker3)

“Theoretically, they have to assist them even without a Health Card, but (...) sometimes (...) they make them pay first, telling them that they can claim their money back when they have their Health Card. If we go with them, they are assisted straightaway because we ask them to (...). It all depends on the centre and the person at the reception desk.”

(Social worker2)

This misinformation results in a deficient application of the rights that ensure access to the NHS for some national and foreign Roma. The providers interviewed maintain that they do not deny medical assistance to anyone even if they are not entitled. In the same line, the Roma Decade Civil Society Monitoring Report 2012 (Laparra et al., 2012) states “the percentage of Roma people that requested medical assistance and did not receive it is similar to that of the general population” which is among the lowest percentages in Europe. The current legislation (see section Entitlement) guarantees access to the NHS and its services for pregnant women, children under 18, and emergency cases. Nevertheless, there are situations in which the lack of information on the law prevents its right application. For example, in some AACC there are inconsistencies and unresolved questions about how to apply the law when dealing with population that is not registered in the census (Fundación Secretariado Gitano, 2012):

“Adults not registered in the census may not access the system (...) unless it is an emergency; but it is the person at the front desk who decides what an emergency is and what is not.”

(Social worker1)

Pregnant women are sometimes only assisted when they have pregnancy-related problems but not in other health situations:

“Theoretically, the law says that they have to be offered assistance (...). In the past, there used to be monitoring during pregnancy and the forty-day period after childbirth, but the situation is worse now. (...) For example, a pregnant woman is not offered assistance if she suffers from gastroenteritis or dental problems, all of which may be caused by pregnancy, because the law is interpreted as concerning strictly gynaecological problems.”

(Social worker4)

In the case of children, the law guarantees that they receive medical assistance under the same conditions as any other Spanish citizen. However, in these cases (i.e. pregnant women and children), the NHS does not cover specialized assistance (e.g. rehabilitation, ophthalmology, otolaryngology, etc.) which is only provided via emergency services:

“This means that if a child suffers from otitis, she is given everything she needs, antibiotics and so on. However, if she has a perforated eardrum and she has to be seen by a specialist, she can’t.”

(Social worker3)

4.2.1.3. Barriers derived from exclusion and marginalisation

Historically, the Roma community has suffered discrimination and social exclusion experiences that have been assumed and perpetuated generation after generation. This has given rise to situations of marginalization and segregation that affect the relations between this community and health-care services. In the first place, the Roma community does not identify with, no feel represented by, the NHS. Moreover, many Roma distrust and are afraid of health-care services (Slavkova, 2010):

“They are really afraid (...) afraid that their children might be taken away if Social Services believes there is parental negligence (...). So, they think of it as a form of surveillance, rather than as a form of help.”

(Mediator2)

Similarly, some health-care providers are often reluctant to work with the Roma community due to prejudices and stereotypes, thus resulting in racist and discriminatory health practices towards the Roma. Secondly, the system disregards the geographical exclusion of its potential users, something that perpetuates the segregation of the most vulnerable sectors of the Roma community. In this way, the geographical location of marginal areas and settlements, together with bad transport connections between these areas with health-care centres, or the fact that there are no health centres in these areas, create further barriers, preventing these people from accessing the NHS and its services. In fact, **these areas and settlements are very rarely the sites of health visits, health prevention programmes or programmes to engage users who have never accessed the system.** Some studies (Laparra, 2007; 2011) have found a direct relation between housing difficulties and lack of access to health-care services, and also between the need to access specialised assistance and difficulty in reaching these services. Moreover, the mobility of the Roma population further accentuates these and other barriers: for example, traveller patients are difficult to monitor because every time they move they need to be assigned with new doctors and new medical records are open.

4.2.2. Consequences of accessibility barriers

The main consequence derived from these barriers and the Roma community’s health condition is the fact that national and foreign Roma have developed **non-normative patterns of access to and use of health-care services** (Fundación Secretariado Gitano, 2012; La Parra, 2009; Laparra, 2011; Mendez, 2007):

“Primarily, what you see is that they don’t keep their appointments, that they use the emergency service a lot and that they don’t generally continue treatments”

(Mediator1)

As a general rule, Roma people make deficient use of health-care services because they do not stick to established times, because they find it difficult to continue treatments or to keep their appointments, because they do not go for check-ups, or because they do not follow prevention

programmes. Also, this population's access to services that are not covered by the NHS - preventive services such as dental care or eye care – is much lower than that of the general population (Laparra, 2007; Ministerio de Sanidad y Consumo and Fundación Secretariado Gitano, 2007). However, this assertion should be qualified: Roma children use health-care services more often than adults, although less than the general population; and also Roma children make use of hospitalisation and emergency services more often than of primary care and healthy child programmes (Ferrer, 2003; Sánchez-Serrano et al., 2002).

All this leads to increase reliance on emergency services. This overuse has been discussed by some stakeholders, who contend that integrated Roma make rational use of the NHS, the difference with the mainstream population being minimal:

“There was time when adults were issued Health Cards if they applied for them. Even back then, they did not use the service more often than they do now, because, in any case, they don't come here unless they are really, really ill.”

(Social worker4)

Furthermore, it is stated that the increase in health-care costs is not exclusively due to service overuse on the part of Roma patients, but rather to the fact that their access has been limited to emergency services:

“They don't incur expenses of public money such as health centres or nursing homes. The elderly are taken care of at home, there is a big family network to tend ill people at home, where care is normally done. If we really did the numbers, we would realize that Roma people spend much less money than other communities.”

(Manager4)

“Current policies promote a very bad use of emergency services, which are also more expensive than primary care.”

(Social worker1)

Although Roma people generally do use the NHS, a small “upper-class” of Roma resorts to private health care, which provides them with the immediacy, familiarity, and empathy they expect from health-care service (Cabedo García et al., 2000; Laparra, 2007):

“They want to spend their money on that kind of service, but they don't receive preventive information there.”

(Health-care provider2)

4.2.3. Policies to suppress accessibility barriers

In order to ensure that everybody can access the NHS and its services, regional governments, CSOs, health-care organisations, and providers implement a series of actions and strategies to prevent the exclusion of Roma people from the system. Together with the guidelines elaborated by the Governments of Catalonia and Andalusia (see Entitlement), which secure access for those excluded by the RDL 16/2012, there are other national and regional policies intended to eliminate these

accessibility barriers. For example, at a national level, the Action Plan for the Development of the Romani population (2010–2012) attempted to improve the use of health-care services, reducing accessibility barriers and improving access to certain specialised services and tests, such as ophthalmology and otolaryngology. At a regional level, the Integrated Plan for the Roma Community of Andalusia (1996) intended to expand medical coverage and to guarantee full accessibility by improving the mechanisms of guidance and access, and by promoting Roma patient’s knowledge and use of the system.

4.2.4. Strategies implemented to overcome accessibility barriers

From an organisational viewpoint, the NHS and its regional services have **a series of mechanisms and strategies in order to facilitate access for the Roma community**. For example, there are some specific health programmes that offer assistance to people suffering from tuberculosis or drug abuse, even if they are not registered in the census, as well as committees set up to discuss important health issues and cases of people who are not covered by the system:

“In this committee we have dealt with 70 to 80 cases, 90 per cent of which have been approved.”
(Policymaker3)

Also, both the Catalan Health-care Service (CatSalut) and SAS have electronic information points (i.e., *Sanitat Respon* and *Salud Responde*) and websites with information concerning health-care access.

However, most of the efforts made to remove accessibility barriers are within the scope of individual responsibility of providers, thus implying a high component of improvisation, voluntarism, ad hoc approaches, etc. which may involve work exhaustion and burn-out. For instance, health-care providers may accompany Roma patients to the front desk and demand the administration staff to include them in the system even if they are not entitled to health and hence not registered in it:

“In order to treat these people, they have to be in the system. Administrative officers may create a conditional medical record (...). There is always a way to do it.”
(Health-care provider2)

Social workers also play an important role in Primary Health-care Centres (PHC) – for example, by taking part in community interventions and commissions with several other agents in the area (Box 4):

“We run a community project in order to include families in the system (...). Mediators who know them call me and we meet (...). I accompany them to the reception desk, we do all the paperwork, I clarify things for them.”
(Social worker4)

Box 4: Community intervention within a Basic Health-care Area

The Santa Rosa Basic Health-care Area (Santa Coloma de Gramenet, Barcelona) is the responsible for promoting and guaranteeing health-care attention to the whole population located in the territory (i.e. Sta. Rosa, Raval and Safareigs de Sta. Coloma de Gramenet). In order to do so, the Basic Health-care Area focus on the community dimension of intervention, detection and health prevention. In this area, there are Romanian Roma disconnected from the PHC Sta. Rosa, in

negligence and health risk that only makes use of emergency services through the hospital. Within this group, the Basic Health-care Area detected in 2006 minors without register in the city council or school, without health-care card, without vaccinations, and pregnant minors without gynaecological monitoring. Facing these challenges, the social workers of this health-care area, contact the different competent authorities (e.g. NGOs, social services, area of education of the municipality, etc.) to raise awareness about this situation, this creating a commission for the community work in the area.

Regarding CSOs, the work of mediators and social workers is key in guaranteeing health-care access for the national and foreign Roma population. Along this line, alternative forms of access have been created: for example, by elaborating non-official censuses, which allow providers to engage, identify and monitor users in situation of exclusion. Also social workers may certify that a given family or individual is in a situation of exclusion so they can be granted access; or if a family do not have a fixed address, they may be registered in the census under the address of a CSO (López Catalán, 2012):

“They manage (...), the social worker in the centre may make a report so that the child that is not registered in the census may have a Health Card in the same conditions as any other child.”

(Social worker2)

“It is difficult if the person is not registered in the census (...). However, I know of an association in Barcelona whose address can be used if the patient doesn't have a fixed address.”

(Manager3)

Health mediation programmes are also a very important strategy, as they seek to raise awareness, to empower users and to enhance their autonomy by promoting knowledge about their rights, about how to do paperwork, how to make appointments, and so on:

“The idea is (...) that people must know their rights, they must know that they can go to the doctor's if they are sick, but also that they have to go (...) that this is something that affects all of us (...). I remember the case of a foreign Roma with tuberculosis. We had to convince him to go to the doctor's in order to prevent all of us from getting it.”

(Social worker1)

“It is already difficult to get them [Roma population] to go and do prevention and monitoring programmes, things that they don't do in their own countries. Imagine if we send them to the PHC here and they are denied access (...). What we want is the guarantee that they can go there on their own and that the law is complied with.”

(Social worker3)

Nevertheless, these alternative forms must be constantly updated or fine-tuned in order to continue to guarantee access to both primary care and specialised services. Moreover, these strategies and programmes cannot completely eliminate accessibility barriers, leading social workers and users alike to exhaustion or burnout, generating dependence on social services and the collapse of the most sensitive centres.

Yet another way to access the NHS is via other systems, such as schools and workplaces. As shown in the case study presented in the section on achieving and sustaining change, participation in job

placement programmes and discussion groups did not only allow Roma women participants to be trained in occupational health, but it also favoured the creation of alternative forms of access to health-care services, especially regarding healthy habits, prevention, and promotion programmes.

4.2.5. Roma health mediation

An urgent task to improve Roma health equity is to bridge the gap between minority cultural groups suffering vulnerability and the NHS. Health mediation is addressing these challenges in Spain through public institutions participating in policymaking, health centres, and programmes and activities implemented and funded by social institutions (e.g. La Caixa). However, the most successful health mediation actions, programmes, and activities are those implemented by CSOs). These programmes often have a localized character, they are organized through a small number of workers or mediators in these associations, and the degree of institutionalization and integration in the NHS is rather limited.

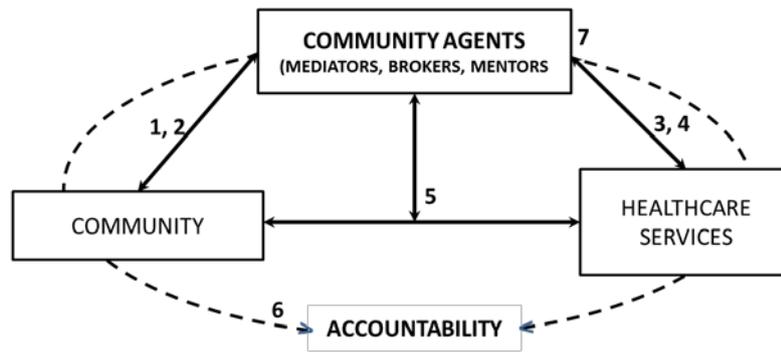
Health mediators are both community liaison officers and cultural brokers. They must be acknowledged by the community, share its values, beliefs and practices, and become community mobilisers. They also have to be proficient in medical communication, act as interpreters for the community and promote channels of communication among all social levels. Finally, they must have in-depth knowledge of the community's needs and strengths and be expert navigators in health-care organisations and systems (Family Voices, 2009):

“They are not translators, they are not doctors, they are not nurses, but they have to be all these things at once.”
(Mediator2)

Furthermore, health mediators work at different levels: (a) community (e.g. families, individuals, and so on); (b) public services (e.g., schools, hospitals, health centres and so forth); and (c) policymaking institutions (e.g., regional and local governments).

The health mediation process seeks to achieve two main goals: in the short term, it seeks to build bridges between the community and health-care services; in the long term, it aims to bring the community closer to health-care services. This process consists of seven stages (see Figure 4):

Figure 4: Health mediation process



1. Being aware of community needs through their participation in the community
2. Working with the community to improve their health at different levels (e.g. family, children, workplaces)
3. Navigating and acquiring a status among healthcare staff
4. Working with healthcare systems to improve community's health
5. Making culturally sensitive healthcare services and increasing community health literacy
6. Assessing the impact of health mediation processes in terms of quality of healthcare and health status
7. Training health mediators

In the first place, in order to *be aware of community needs through the participation of mediators in the community* (1), most CSOs develop participant observation, asking different members of the community, listening to their requests, doing photo voice activities and answering the demands of services to develop specific protocols (e.g. the voluntary interruption of pregnancy programme by Unión Romaní). Other examples are the visits paid by Unión Romaní to shantytowns in order to locate unvaccinated children, carry out first aid workshops, and elaborate a contextual census of excluded people. In the same line, members of FAKALI visit schools to contact parents and know about their children's needs, while VINCLE has created a network to study the condition of foreign Roma.¹⁵

Secondly, in order to *work with the community to improve their health at different levels* (2), organisations like FAKALI and Unión Romaní promote community revitalisation and autonomy. For example, because they do not intend to be permanent mediators, they encourage Roma users to become mediators – and role models – for their families. Also, Unión Romaní develops programmes and protocols to teach how to navigate in the NHS, how to get children vaccinated, to do paperwork, to buy medicines and shop healthy, and to raise awareness of patients' rights and responsibilities in health care. FAGIC, FAKALI, and Fundación Secretariado Gitano also develop training programmes on healthy habits, reproductive health, nutrition, violence against women, HIV prevention, addictions, and so on. Most organisations accompany families to health centres to ensure access and to facilitate communication with providers. VINCLE and Unión Romaní also provide information and do paperwork for Roma users.

In the third place, to *navigate and gain acknowledgement among health-care staff* (3), FAKALI and FAGIC organise conferences and meetings in hospitals and PHC where mediators disseminate the results of their work and build critical awareness among staff. Unión Romaní establishes agreements with health centres to help health-care providers and to get them involved in the association. At the same time, FAKALI attends meetings with regional and national political organisations to secure the role of health mediators as new health-care providers. Also, they collaborate with social workers in health centres for planning interventions. Finally, most organisations use communication platforms to publicise their work (e.g. websites, reports and papers, among others).

¹⁵ See at: www.romest.cat

In addition, *working with health-care systems to improve the community's health* (4) is done by Unión Romani – for example, by offering mediation and translation services to health-care centres in specific situations. FAKALI and FAGIC train health providers in law, cultural competence and knowledge of the Roma population in hospitals and health centres. FAKALI also organises training courses for health-care students. Finally, some organisations have developed guidelines such as the Handbook for Action in the Area of Health Services with the Roma Community (Fundación Secretariado Gitano, 2006).

Furthermore, *to make culturally sensitive health-care services and to increase community health literacy* (5), FAKALI and FAGIC create spaces for dialogue, facilitating channels of communication, redefining problems and redistributing power and resources. For example, they have created health coalitions where health-care providers and the Roma community get together, creating local/regional/national networks among multiple stakeholders (e.g. Roma organisations, user representatives and policymakers):

“We are going to change the way we work, at least we are going to try, we are going to create a health committee, we are going to invite all Roma women to come and participate.”

(Mediator1)

Regarding the *assessment of the impact of health mediation processes in terms of quality of health care and health status* (6), formal methods using quantitative and qualitative indicators are not frequently used in health mediation in Spanish organisations. Rather, assessment is generally carried out in a more contextual, participatory, and observational way. For example, through familiarisation with and commitment to the community, its characteristics and needs; also, by being acknowledged by the community and being part of it; finally, by ensuring quality in the mediation process, by facing and adapting to changes, and by being sustainable.

Therefore, health mediator training should cover: knowledge about the NHS (e.g. navigation); medical knowledge (e.g. nutrition, STD, smoking, maternal and child health); legal knowledge on health issues; social skills – especially empathy and leadership; cultural competence; and knowledge of the Roma community and their health. Some examples of these courses are Catalonia's Migration and Intercultural Mediation Health Plan 2008–2012¹⁶ or the Training Course for Roma Mediators “ROMED”¹⁷ (MSPSI, CoE and FSG).

Box 5: Highlights of Access to health-care system

The NRIS establishes the accessibility of health-care services as one of the strategic lines of action to improve Roma health. National and foreign Roma have developed non-normative patterns of access to and use of health-care services due to the following challenges and barriers:

- The Roma fear and distrust the systems and its providers due to their historical marginalization and persecution.
- The NHS disregards the geographical location of marginal areas and settlements where many Roma live. Plus the bad transport connections and the mobility of the Roma population create further barriers to access the NHS.

¹⁶ See at:

https://obrasocial.lacaixa.es/deployedfiles/obrasocial/Estaticos/pdf/Inmigracion/Mediacion_intercultural_es.pdf

¹⁷ ROMED. See at: www.gitanos.org/actualidad/archivo/60869.html

- The NHS ignores the Roma culture (e.g. few providers are trained in managing diversity, lack of adaptation of health-care services and protocols to the Roma population, and deficient channels of communication).
- The lack of ethnic-related information prevents knowing the exact number of Roma people, which further their invisibility in plans and strategies not developed in accordance with their needs.

However, there are some strategies that have been developed in order to ease these accessibility challenges:

- National and regional policies have been created to ensure access (e.g. the Instructions of Andalusia and Catalonia, the Action Plan for the Development of the Romani population 2010–2012, or the Plan for the Roma Community of Andalusia 1996)
- Health-care centres have developed mechanisms and strategies in order to facilitate access for the Roma community (e.g. specific health programmes, committees, information points).
- Providers from health-care centres and CSOs make a great effort to reduce accessibility barriers (e.g. by taking part in community interventions and commissions with several other agents in the area, accompany programmes, developing alternative ways to access, etc.)
- Health mediation processes carried out by CSOs are the most effective way to enhance the accessibility of Roma population while improving the health of this community. The objectives are to build bridges between the community and health-care services, as well as to bring the community closer to health-care services.

4.3. Responsiveness of health-care services

The Operational Plan of the NRIS (2014–2016) (Ministry of Health, Social Services and Equality, 2013a) aims to reorient health services towards equity, both in the areas of health promotion and disease prevention and health care, with special emphasis on groups that accumulate more risk such as children and women. The activities proposed are: provide training to improve equity in health-care services, improve cultural sensitivity of resources, support and promote training actions for diversity and cultural competence among health providers; and train CSOs for effective mediation between communities and services.

In this section these aspects are evaluated following these subsections: (1) prioritized health inequities in the NRIS (Plan Operativo, 2014–2016); (2) policies for more responsive NHS for the Roma population; (3) adaptation strategies and service providers; and (4) good practices addressing Roma specific health needs.

4.3.1. Health inequities identified in the NRIS

The NRIS health objectives are based on the results obtained in the only reference comparative study done in Spain. This comparative study primarily draws on the national surveys carried out with Roma and non-Roma population in 2006 (La Parra, 2009) and, to a lesser extent, on the Health and the Roma Community survey (Ministerio de Sanidad y Consumo and Fundación Secretariado Gitano, 2007). The study compares the differences between national Roma and non-Roma population regarding certain types of diseases and lifestyles. As a result, the NRIS focuses on the health inequities

of national Roma, disregarding the increasing number of Roma coming from Romania and Bulgaria. This may be explained by the lack of information about foreign Roma and their health inequalities and social determinants in Spain:

“We have to know exactly what to tackle. So far, we don’t have that information, so we are acting blindly.”

(Manager1)

Although the people interviewed for this report acknowledge the importance of the objectives set by the NRIS, they also draw attention to the limitations of its exclusively biomedical perspective, disregarding the social determinants that surrounded these communities, especially the foreign Roma:

“Regarding health in the NRIS, I’ve been hearing the same things for years. Look, in three years, we’ve gone this far and, in four years, we’ve achieved this. This is all consolidated now, so why should we repeat the same objectives over and over again?” **(Manager5)**

“An unfavourable setting such as a settlement (...) raises a child’s chances of getting sick or of having an accident. If the father does not work (...), if he has a low education level and other more serious problems, (...) he is not going to be concerned with healthy eating.”

(Social worker1)

“Why are there 20 people living in a flat? Because people don’t generally rent out flats to them. It’s not that they want to live in these conditions. (...) Here we meet smelly children, we ask them and it turns out they don’t have running water (...). Housing is also health. If they suffer from scabies, how do we treat them at home? (...) Treatments are very specific in this case: to throw everything out, to wash everything at 60 degrees, lotions, no contact (...). If there are 20 people in a flat, what can you do?”

(Social Worker4)

The interviewees also explain that the **objectives are not interconnected and integrated within other existing strategic elements of the NHS** (e.g. regional health plans, national legislation, national strategies for cancer, cardiovascular diseases, etc.), in spite of the fact that the NRIS proposes certain cross-sectoral lines of action (e.g. administrative participation and collaboration, accessibility, and use and efficiency of health-care services).

4.3.2. Policies to make health-care services more responsive

In the elaboration of some of the plans and policies implemented in Spain, the need to create services, procedures, and resources that are responsive to the Roma population has been considered by different sectors. At national level, the focus has been placed on the **training of providers, the implementation of integrated and sensitive practices, the elaboration of reports and reference guides about the health of the Roma community, and the adaptation of informative, preventive and promotional campaigns** (National Action Plan on Social Inclusion in Spain, 2008–2010; Action Plan for the Development of the Romani population, 2010–2012; National Strategy for Health Equity for the Roma Population, 2003). At regional level, Catalonia and Andalusia follow the same guidelines, stressing the training of providers and the adaptation of resources, services and

programmes to this population. As an innovative measure, they seek to appoint providers in health centres and regional health agents of Roma origin, and to expand awareness of the Roma population within the NHS (e.g. providing meeting spaces in hospitals) (Immigration Master Plan for Health in Catalonia, 2006; Integrated Plan for the Roma Community of Andalusia, 1996; I and II Integrated Plan for the Roma People in Catalonia, 2005–2008/2009–2013).

Despite all previous attempts to make a more culturally sensitive NHS, there is no integration of all the above contents in the academic curriculum of health studies at Spanish universities (e.g. medical and nursing degrees) or in permanent training programmes of the different regional Ministries of Health. The few existing exceptions are elective courses or courses outside the official curriculum (e.g. special courses, degrees of expertise), which are more focused on immigrant population rather than the Roma community.

4.3.3. Adaptation strategies of health-care services and providers

For the most part, health-care services do not have protocols specifically adapted to the Roma community (Cabedo et al., 2000):

“Lack of access to preventive programmes is mainly due to policies not being adapted to the circumstances of this community. Health-care providers can’t materially promote these programmes and informative brochures are written in a language that patients don’t understand.”
(Manager5)

Nevertheless, in areas with a high Roma population density, health-care centres and providers have adapted these general protocols and practices to the circumstances and needs of the Roma users. Most of these adjustments are not official although all providers implement them. This involves, at the very least, a great degree of coordination and collaboration among staff:

“One of the principles that we apply is that we immediately vaccinate children that have not been vaccinated. (...) The priority is for the child to be protected.”
(Social worker4)

Staff needs to be proactive and constantly vigilant, especially regarding the locating and monitoring of patients (e.g. system alerts, telephone calls, contact with regional services and agents, home visits outside working hours). All this may lead to occupational *burnout* or emotional exhaustion, in spite of the fact that these actions are also seen by providers as *“investments to improve the health of the Roma”* **(Social worker4)**.

Some of these adjustments have to do with adapting health practices to the Roma religious beliefs which foster spiritual health and strengthen support networks. However, these must also be compatible with medical treatments and not interfere with the decisions and guidelines of practitioners:

“In the case of a child, we had to intervene because the parents refused medical treatment arguing that God would heal her.”
(Manager4)

In case of death, in order to make medical procedures and religious beliefs more compatible, some hospitals in Catalonia have implemented the use of a “mourning assistant”:

“Roma people deal with death in a way that we don’t understand; and the way we manipulate and transport bodies is unacceptable for them.”

(Policymaker2)

Another adjustment is the possibility of choosing a male or female doctor, especially when dealing with women’s health problems. This sometimes generates contradictions:

“If the only two gynaecologists in one centre are male, we tend not to refer the patient to a different centre. Adaptation is a mutual process.”

(Policymaker3)

Also, and due to the current economic crisis, many providers have adapted their practices to their patients’ economic situation, for example, by prescribing cheaper medicines or by resorting to charity resources and drug banks outside the system. These adaptations are easier to implement in PHC than in specialised centres and hospitals:

“Here [at the PHC centre], we are quite aware of all this, but specialists’ prescriptions can be really expensive for a Roma patient”

(Health-care provider1)

Notwithstanding, Roma patients consider that the assistance they receive from the NHS is deficient. What they expect from a quality health-care service is to offer longer consultations in a more empathic and intimate atmosphere. These expectations clash with the reality they face when they seek assistance and this is the reason why they stop going to the doctor’s appointment:

“The language used by practitioners is rather technical (...). This makes Roma patients feel uneasy (...). It is also important for them to be with the doctor for a little bit longer, to have the chance to speak at ease. Nowadays five minutes is just not enough for them.”

(Mediator2)

“Medical jargon is difficult to understand for a person with no academic qualifications (...). They feel that they can’t communicate with doctors, that doctors can’t teach them anything (...) and so they either confront the situation the best way they can or they stop using the service and only resort to it when they are already very ill.”

(Mediator1)

That is why changes in the communication between patient and doctor are also done in order to offer high quality care (e.g. informative and visual collages). The most responsive staff is aware of the communicative and interpersonal characteristics of the Roma population when organising workshops and talks in health centres and schools:

“They don’t really like doing things in groups, especially things related to maternal education; they are afraid or ashamed, I’m not sure.” **(Health-care provider2)**

At the same time, health-care providers have to follow bureaucratic protocols that contemplate a series of objectives that are neither adapted to the characteristics of Roma population nor to the circumstances in which the service is provided:

“There is pressure because the objectives set for doctors in all the centres, including this one, are linked to economic incentives, and these are not adapted. We are given economic incentives according to certain recommendations, to prescription prices, the number of prescriptions by active ingredient, or the number of referrals (...). Here, for example, when you refer patients and the appointment is in six months, they end up missing it. Then they come to see you again and you refer them again, four or five times if necessary, and they keep missing the appointment. Also, because we know these people don’t have a chance to go the dentist, we tend to prescribe antibiotics a lot. We are penalized for all this.”

(Health-care provider1)

“Doctors here are supposed to have a smaller number of patients than in other areas in Seville (...). The difference is that this is the only health centre in the area. In Los Remedios, in Huerta del Rey, out of 2000 patients per doctor, only 500 actually demand public health services. The rest of them either have private health care or don’t go to the doctor’s for every single thing.”

(Health-care provider1)

Box 6: Good practices addressing specific Roma health needs

One of the measures enlisted in the NRIS to improve the responsiveness of the NHS is to create **new services and programmes that address the specific needs of the Roma population**. In this way, the NRIS promotes the effective integration of equity through the translation and implementation of the *Methodological Guide to Integrate Equity within Strategies: Health Programmes and Activities (Guía Metodológica para integrar la Equidad en las Estrategias: Programas y Actividades de Salud*; Ministry of Health, Social Services and Equality, 2012c).

- **“El deporte traspasa fronteras”¹** Initiative promoted by the CSO Fakali and sponsored by Decathlon and Lot of Colors which aim to promote health through sport in Roma women, female teenagers and girls at risk of exclusion. Other transversal objectives are to promote the values of sport (e.g., effort, perseverance, teamwork...), improve self-esteem, nutrition and hygiene, as well as improve coexistence and rehabilitation of the neighbourhood. This programme took place in Sevilla, in the marginal neighbourhood “Las 3000 viviendas” located in Polígono Sur during 2014, in which different sports and physical activities were organized weekly (e.g. cycling, football, zumba, aerobic, skating, field excursions, etc.).
- **“Sol i Escola”** is a community intervention project for Roma minors as a result of the commission created by the Santa Rosa Basic Health-care Area (Box 4) and which took place from July to September, 2007. Among the general objectives there are to detect and prevent risky situations for Roma minors, to work hygienic habits with them, to know Roma families living in the area and work with them schooling for their children. More specifically, in health, the objectives are to tackle every dimension of health within the families’ difficult situations, to prevent risks for public health, to incorporate minors to the NHS as well as to the healthy children programme, to reduce the use of emergency services, and to guarantee the continuity of medical treatments. Among the services and activities, the programme offered shower and launderette facilities, as well as clothes and equipment for school.

- The project implemented by **La Mina PHC centre** (Barcelona), aimed to improve the mental health of Roma mothers. These mothers attended the community centre with their babies and, through collaboration and daily activities, they were trained in positive parenting. Besides, their babies were taken care of so they could have time for themselves. This project also included talks about topics chosen by the mothers, and experts from the area were invited to take part. This was a way to empower communities by stressing the work of their providers and by increasing their involvement in the community.

4.3.4. Case study: The sexual and reproductive health programme for national Roma women in the Polígono Sur neighbourhood of Sevilla

4.3.4.1. Background

Polígono Sur in Seville, the capital city of Southern Spain, is an area of about 145 hectares made up of six districts in need of economic and social development. Population is estimated at 50,000 inhabitants. Over two thirds of the inhabitants are illiterate and only 7.3 per cent of the population hold professional or academic qualifications. The current working plan in the area is the “Plan Integral del Polígono Sur de Sevilla” (2006–2014), a programme focused on four types of actions: (1) Urbanism and coexistence; (2) Social and professional integration and economic activity promotion; (3) Community welfare; and (4) Socio-educational and family mediation.

In the area, there are districts with poor health and sanitation levels. Specifically, there are faecally contaminated waters on the streets, damp houses, rats, cockroaches, insects, buildings with no water supply, and the like. Polígono Sur doubles the number of cases of health issues of the rest of the city. The male population mostly suffers from AIDS, chronic obstructive pulmonary disease, stomach and lung cancer, and respiratory and infectious diseases. In the case of women, they mainly suffer from infectious diseases, breast cancer and respiratory and digestive diseases. Regarding sexual health, teenage pregnancy represents 17 per cent of the total population and 35.7 per cent of the cases are unintended. With regard to voluntary interruption of pregnancy, 64 per cent of the women had never visited a family planning centre. In most cases, the reasons are economic (55.35%) or not wanting to do it (35.71%) (Comisionado para el Polígono Sur, 2006).

There are two PHC in the area – “Polígono Sur” and “Las Letanías.” There is also a drug abuse treatment centre. For specialised services or mental health problems, patients must go to a hospital outside the area, Hospital Virgen del Rocío.

In the above referenced context of social vulnerability, this study aims to assess the achievements and good practice of health-care providers in the family planning programme addressed to the Roma community in the Polígono Sur PHC centre. In particular, this analysis focuses on the elements and procedures that explain the success of this programme among the Roma population, offering an example of good practice that can be transferred to other centres in similar conditions. The centre has been running since 1989. It is open from 8am to 8pm Monday to Friday, providing primary care and emergency services.

4.3.4.2. Research questions

- a) Which indicators define the success of the family planning programme in the Polígono Sur PHC centre?
- b) What are the challenges regarding the Roma population in terms of family planning?
- c) What skills and strategies have health practitioners developed in order to efficiently tackle these challenges?
- d) What elements are considered challenges that still need to be faced?

4.3.4.3. Research process

Information and data collection was done by three researchers and two collaborators (members of the Coalition for the Study of Health, Power and Diversity, CESPYPD) from the Faculty of Psychology at Universidad de Sevilla. In order to obtain evidence necessary to answer the research questions, the following qualitative methods of data collection were used:

- *Data collection*: Analysis of written documents or registers produced by the people involved in the family planning project.
- *Participant observation*: Description of what researchers have observed during their time at the PHC, in interviews and in the focus group.
- *Interviews*: As a result of the communicative interaction between researchers and participants, individual narratives of the people involved in the family planning programme were obtained. Specifically, there were in-depth interviews with (a) the midwife, (b) one of the family doctors, and (c) five users of the family planning service of Roma origin.
- *Focus group*: Group interview addressed to the practitioners in charge of the family planning programme in the PHC centre (i.e. two family doctors, two nurses, and two nursing assistants). The information obtained came from interactive dialogue and shared knowledge.

During the process of data collection, extreme care was taken to ensure that the information collected was representative of the community by guaranteeing the participation of different user profiles. This required researchers to absorb the culture of the people involved in the study (i.e. to understand their point of view, their values, jargon, ways of thinking, and the like). Also, informed consent was obtained from all interviewees to record and use the collected data, ensuring both their anonymity and the use of the information for research purposes only.

All the providers in charge of the family planning programme who were interviewed were women with two to twenty years of experience in the PHC. Their real names have been changed in order to maintain their anonymity.

Some of the open questions used in the interviews with the users of the family planning programme were: When did you start attending the programme? How often do you attend? How will you rate the way you were treated in the programme? How do you consider communication with the practitioners? Have you faced any problems in this programme? Will you recommend the programme? Some of the questions addressed to the providers in the centre were: When, how, and why was the programme created? Which are the indicators of success of the programme? Why do you think the programme is successful? What are your motivations for working in such adverse circumstances? Which competences contributed to the programme's success?

All the interviews and the information provided were transcribed and analysed. The discourse extracts that allowed us to answer the research questions were selected, and the results obtained from the independent analyses of three researchers were contrasted.

4.3.4.4. Chain of evidences

a) Which indicators define the success of the family planning programme in the PHC Polígono Sur?

All PHCs in Spain are responsible for a family planning programme addressing the needs of the particular community they serve. However, this programme is developed differently in each centre. As one practitioner states:

“Usually, each centre has its own family planning programme, but in some centres there is only one professional, or the programme has been suspended and in this case the family doctor provides care for a specific community... We consider that in this area the programme must be especially reinforced, so we really take care of it.”

(Doctor 1)

All the providers in the centre consider that the programme is indispensable due to the vulnerability of the social group to which it is addressed. It has been running for almost twenty years in the centre, and it has developed different operational methods throughout this time. One of the practitioners recalls the beginnings of the programme as a failure:

“At first there were times when all I wanted was for June to arrive so I could leave on vacation. I could not stand the fact that the same patients underwent several abortions (...), and that was something that really killed me, because I felt that the programme was such a failure.”

(Nursing Assistant 1)

In contrast, nowadays, providers are more optimistic regarding the success of the programme:

“I can see it because there are fewer pregnancies now, which means that, leaving the economic situation aside, this decrease is also due to family planning. As a midwife, I monitor users, and so I can see that the programme is working.”

(Midwife)

The efficiency of the programme can also be seen in the cases in which mothers teach their daughters the necessity for family planning, just as they once learned:

“You see that mothers bring their daughters before they get married, and mothers-in-law that bring girls before they have intercourse (...). Because they get married at a very young age, don't they? When they are just 14. So, this is motivating”

(Nurse1)

The users that were interviewed openly declare their satisfaction with the family planning programme. Especially, they praise how practitioners treat them:

“We come here because they really care... That's why. In the other hospital you are not treated the same way, they are crabby, the doctors there.” **(User 2)**

“Here they help you, and the midwife, when I was pregnant, told me: ‘When you have your baby, just come along and we will give you contraceptives.’ They help with family planning, they give us injections, or they prescribe what they consider good for you, or they tell other doctors to provide you with an IUD.”

(User 1)

Also, these women patients value the fact that providers make great efforts to be flexible:

“Here, they really understand us, they know us, our circumstances (...). Even without an appointment, we come here and they try hard to see us.”

(User 2)

In general terms, they value their participation in the programme:

“I have come all these years, perfect. I can say I never had a problem here.”

(User 3)

“Everything is fine with me since I come here.”

(User 4)

The level of patient satisfaction and their responses to the programme are reflected in the motivation and satisfaction of the providers, particularly in the case of the midwife of the programme:

“I am happy, because I think I have achieved many things, mostly with monitoring during pregnancy and postnatal care (...). I offer support for these women’s family planning (...). I have my patients’ respect (...) I am getting them to do the follow-ups (...). I am very satisfied because they come looking for the midwife all the time, morning or evening, they look for me. I feel that they need me, that I am useful to them.”

(Midwife)

b) What are the challenges regarding the Roma population in terms of family planning?

The first challenge that providers are faced with is that patients generally lack the necessary documentation to apply for a Health Card in order to be assisted as full citizens within the NHS. Although all the providers declare that they never refuse medical assistance to people without a Health Card, they acknowledge that this makes the process very difficult (e.g. they cannot have access to medical records, or prescribe proper treatments). These administrative barriers regarding the access to the health system are highlighted by one practitioner:

“For me, the main difficulties are administrative, because these people don’t usually do their paperwork (...). Many young people don’t even have an ID card. Many pregnant teenagers don’t have an ID card. There was the case that one of them was missing from all the records, as sometimes they don’t even have a birth certificate.”

(Midwife)

Another characteristic of this social environment is that many of the Roma assisted by the PHC are travellers. This is a great challenge for practitioners, as it is difficult to establish a close and long-lasting relationship with patients. In their own words:

“Something that characterizes this centre is that people who have normalized their lives suddenly move to a different place, and then comes another person with a dysfunctional family background. Then everything has to start afresh.”

(Nursing Assistant 1)

“The travelling population represents a high percentage of the users, they come and go, and this affects your work. If there is an incident or something, we suddenly notice a gain or a loss of patients.”

(Doctor 1)

One of the major challenges that providers highlight is the lack of family planning as an intrinsic characteristic of the Roma population they assist:

“The field of contraceptives or family planning is unfamiliar to them; they don’t have this planning culture, not even for nutrition (...). Whatever requires planning is a big effort for them.”

(Nursing Assistant 2)

Thus, providers observe that women patients only realise they need contraceptives when it is too late – that is, when they are already pregnant. The same happens when they deal with treatments that have no immediate effect on the pain that patients are suffering from at the time:

“Medication must be something that shows some effect. If they don’t see this effect, it is very difficult to convince them to take it. In fact, chronic diseases are much more common in this population than in others.”

(Doctor 1)

This lack of future planning generates inconveniences for the Roma users as well as for the centre’s appointment system:

“You give them an appointment in a month’s time, you give it to a person who has no watch, no calendar. And, in a month’s time, this person could be selling in a market somewhere or doing whatever.”

(Doctor 1)

This results in a high number of missed appointments, while at the same time many users go to the PHC at any time, expecting to be seen without an appointment.

Along with this, practitioners also highlight certain peculiarities in the Roma population’s access to health-care services. For example, they have observed that this population often go to the centre for minor issues:

“Here, they come to the doctor’s for everything. If they have a common wound, they don’t buy a sticking plaster or Betadine, they come to the centre to get it cleaned.” **(Doctor 1)**

However, specific symptoms of certain diseases that these women suffer are disregarded, and therefore they do arrange check-ups to treat them:

“Roma women assimilate aging quite soon, they accept early aging, so there are symptoms they are not going to tell their doctor about because they think it’s normal (...), for example, urinary incontinence. They will never tell you about it.”

(Doctor 1)

Finally, a challenge that is always present when working with Roma population is poverty, which prevents patients from being able to pay for treatments or prescription contraceptives (the NHS partly subsidises prescription drugs, but patients must pay a small part of the total price). The price of drugs is, then, one important aspect that practitioners bear in mind when issuing prescriptions:

“We prescribe Adepo in most cases, an injectable contraceptive that lasts for 3 months, and each dose is roughly a euro. Most people in this area don’t carry any money with them, they don’t use any money at all.”

(Doctor 1)

In response to this critical situation, some social and religious associations offer some medications for free. Many women go to these “charity drug banks” to get contraceptives:

“In this area, drug banks are widely used (...), not only by undocumented people, who are not as many as those who don’t have any money. Now I am starting to prescribe considering the price of some treatments, because patients ask me: But how much is that? (...) And then they go to Cáritas to get them.”

(Doctor 1)

c) What skills and strategies have health practitioners developed in order to efficiently tackle these challenges?

Health practitioners in charge of the family planning programme in the PHC Polígono Sur have become very aware of their needs as providers and as a public institution to adapt to the particular features of the community they assist. As one practitioner states:

“I am going to provide health assistance to a population with particular characteristics. I think that health care should adapt to the people for whom it is provided. If this community demands immediate assistance, then what’s with giving appointments in a month’s time? The service must be adapted to suit the characteristics of the population.”

(Doctor 1)

As a consequence, they have developed a series of practices throughout the years: **Practitioners adapt certain clinical protocols to the population they assist.** For example, regarding the prescription of contraceptives after childbirth:

“We also adapt some contraceptive protocols. For instance, in the forty-day period after childbirth contraceptives are not generally prescribed. The Roma community is one of the few where we do it,

we prescribe contraceptives, because it is one of their customs (...) to have full sexual relations very soon, and some women get pregnant within one month of childbirth.”

(Doctor 1)

They also adapt the way routine gynaecological examinations are carried out:

“Many times they stop coming because they think that in order to get the pill or something else they have to undergo a smear or a pelvic exam, and they don’t (...). And so, at first, we don’t do any examination.”

(Doctor 2)

In order to adapt to the lack of formal education of the majority of the population they assist, practitioners make **great efforts to communicate relevant information orally to users:**

“This population can’t read, written information is the worst, so we don’t use it.”

(Doctor 1)

Practitioners are aware that their role is not only to provide certain services, but also to provide education in reproductive health:

“I organize workshops on maternal education, where we deal with health topics, with family planning. Then there’s also my postnatal workshop, where I also get them engaged. I know this work because I try hard so they don’t drop out: I give them appointments, I see them and I keep preparing them, educating them.”

(Midwife)

Furthermore, the midwife also visits the local school regularly to teach teenagers about contraceptive methods and sexually transmitted diseases. In spite of all this, practitioners also acknowledge that this is a complex, long, and slow process:

“It takes a long time and a lot of energy to explain everything to them until you think they have understood. But then you see them in the blood collection service, and you know they haven’t understood a thing. (...) But we have to educate them, don’t we? (...) and there and then I try to engage the patient and educate her so she keeps taking steps in this direction.”

(Nursing Assistant 1)

Practitioners have developed what they call “opportunistic engaging” – that is, they try to engage a user of a different programme in the centre and transfer her to the family planning programme:

“What I do is mainly active engaging. Not only when I am in family planning, but also when I am in any other service or in the accident and emergency department, because this is a group that does not regularly follow preventive programmes of any kind, because they don’t think it’s necessary (...). Opportunistic engaging is essential.”

(Nurse 1)

“We try to engage them even on the corridors (...). We even do it outside service hours.”

(Nurse 2)

One of the key moments for engaging new users is at pregnancy tests:

“We established that, if an urgent pregnancy test is requested, the result is not given to the woman immediately. Rather, she has to see the doctor first, who transfers her to the midwife so she can engage her in the programme or address her regarding contraceptive methods.”

(Nurse 2)

As far as “opportunistic engaging,” practitioners’ **monitoring of users is very personalised**, and they stress that they use the telephone to contact them:

“I use the telephone a lot, I call them a lot. I call them when they miss an appointment. Sometimes I also go to their places to look for them, so they can have a proper follow-up.”

(Midwife)

All the practitioners agree that this community requires very active and consistent monitoring, in order to ensure the continuation of treatments:

“How do we do it? How do we adapt? For example, we know that it is not simply a question of giving an appointment and then you can just sit and relax (...). We are always watchful, always (...), and we call them and we ask them about their activities: Are you going to set up a market? When are you leaving?”

(Doctor 1)

Practitioners have developed **great flexibility to facilitate Roma population’s access to medical care:**

“I think that making it easy for people to access the programme is very important.”

(Nursing Assistant 2)

In fact, it is not compulsory to arrange an appointment to be seen; they try to assist them as they go along:

“If there is a problem related to planning, they don’t have to wait so much, we assist them on the go (...), we even assist them on the corridors, like ‘come over here to this room and see such and such doctor.’ And they go there and a method is prescribed.”

(Nurse 1)

Moreover, practitioners take their patients to their fellow practitioners’ rooms in order to facilitate referral and so that they can be assisted promptly:

“If, in a postnatal appointment, the midwife learns that intercourse has already been resumed and that the woman might get pregnant again, even if it’s only within twenty days from childbirth, she calls one of the doctors so that something may be prescribed straightaway. That woman can be seen straightaway, she doesn’t need to arrange an appointment.”

(Doctor 1)

As can be seen, there is a **great degree of collaboration among practitioners**, who find that teamwork is the best way to tackle the complex social reality that they face:

“We have been trained together; we have become aware of the need to be coordinated, beyond what the planning programme requires from us.”

(Midwife)

Although each health-care professional has a specific role, all of them take care of users to the same level, especially when it comes to opportunist engaging:

“All the staff is very much involved in everything. Because, if her patient is a woman with three children, she will immediately tell her: listen, have they been vaccinated? The same with me, I mean, we do everything, we try to engage them from any of the programmes.”

(Doctor 1)

At the same time, two providers who are not involved in the family planning programme liaise between practitioners and other CSOs and public institutions in the area:

“The social worker and the laser nurse are generally involved with the city council. This neighbourhood has to work as a team; it has to be interconnected (...). Those people act as a link.”

(Doctor 1)

That way, they manage to have a broader view of the social problems that they face, and of the actions that are carried out from different areas.

Practitioners have been able **to develop a series of skills that help them tackle efficiently the problems that they face at work and ensure the success of the family planning programme**. Among these skills, practitioners highlight:

(1) familiarity with users:

“I think familiarity, we are very approachable (...). I think that it is very valued here, for example, if you know their family: ‘Well, you know, I am going to treat your grandfather.’ And many times it is through the family that we get to engage the person, either for planning or vaccinations.”

(Nurse 2)

(2) empathy towards the users’ personal circumstances:

“A little bit of empathy is good, to put yourself in their shoes, to know what they’ve had to live through, the society where they have to live, they haven’t chosen it, and well, sometimes it is exasperating, but some other times, this is precisely what makes you aware of things, isn’t it?”

(Nursing Assistant 2)

(3) resoluteness in the face of everyday problems:

“To have a calling for solving problems, right? To solve problems (...). What’s the problem? (...) Let’s do it, right?”

(Nursing Assistant 1)

and (4) a **positive attitude towards other cultures:**

“It’s like an attitude or a capacity to be constructively amazed. For me, the Roma community is very different from me, I consider them different, but they amaze me constructively, I don’t know, I like seeing those differences (...). That is very gratifying for me, it is something that I find gratifying. I think that if you have that curiosity, well, then your job becomes more logical and interesting, because sometimes it’s a bummer, of course, because there are many little failures.”

(Nursing Assistant 2)

As a health-care organisation, **the PHC itself has made several adjustments in order to adapt to the characteristics of the population that it assists.** Thus, the practitioner–patient ratio is lower in this centre than in other areas of the city, because they understand that work here is more demanding. Furthermore, the family planning programme is open three mornings and one afternoon every week, because of the little availability of the Roma population to adjust to the schedules provided by most PHCs:

“In the morning, the women generally go to the street markets, and so they would never attend the programme.”

(Doctor 1)

Lastly, the centre is open for training programmes meant for its health-care providers to improve their competencies, especially with respect to how to deal with the Roma population:

“Members of Fakali have come here to deliver talks (...). They’ve come here to tell us about their life, their way of being, their feelings (...), what they feel is their people. They’ve talked about the history of the Roma people.”

(Midwife)

d) What elements are considered challenges that still need to be faced?

Even though the family planning programme is considered successful by providers and satisfactory by users, practitioners are aware that many challenges remain.

In the first place, they believe that there should be a medical record specifically designed for the Roma people. With a record of this kind, they could carry out quantitative assessment of how effective their family planning programme is. Without a record, the assessment of the programme is limited to the practitioners’ perceptions, which generates some uncertainty as to the actual efficacy of the programme:

“We do our best, we do what we can, that’s true. Then the results will be what will be, but very often we don’t know them.”

(Nurse 2)

Secondly, practitioners still see Roma teenager pregnancy prevention as a daunting challenge, due in part to cultural values, much ingrained in this population, which have proven difficult to modify:

“It is very difficult to prevent 14–15 year-old girls from getting pregnant (...). It’s easier when they are older, but it is very difficult to prevent the first pregnancy (...). For Roma girls, well, for many of

them (...) it is very important to get married and have children and the sooner the better. They even ask for fertility tests at 17. If they don't get pregnant soon, they start thinking that they are sterile and that they need a test (...). In these cases, we don't know how to proceed, because it's a cultural thing, and very difficult, isn't it?"

(Doctor 2)

Finally, practitioners think that work with Roma men would be a necessary complement to their work with women. Nevertheless, so far they have not managed to get them involved in the process:

"Roma men are very difficult, they don't get involved in anything, many women even come here to get contraceptive methods behind their partner's back (...). Men are in worse health conditions, much worse than women, they let themselves go (...). We always treat women, but it is culturally very difficult to approach men."

(Doctor 2)

4.3.4.5. Lessons learned

There are several reasons for considering the family planning programme implemented in the PHC Polígono Sur as an example of good practice in work with the Roma population: (a) practitioners are capable of developing the necessary **competences** to assist their users adequately, adapting to their peculiarities as a people, and to satisfactorily manage the stress conditions and the adverse social situation in which they work; (b) **professional practices** have been adapted to the characteristics of the population, especially regarding clinical protocols, active engaging and personalised monitoring; (c) there is **close collaboration** among the health-care providers involved in the family planning programme, as well as between these and other social agents in the area, something that gives them a wider view of the social problems that they face; and (d) the **health-care organisation is sensitive** to the peculiarities of the population it assists, concerned with the training of its providers, and capable of adapting to the demands for improvement of its members.

The information drawn from this case study is helpful for adapting the design and implementation of health-care practices to the characteristics of the Roma population in other similar contexts. Specifically, the most important lessons learned from this case study are the following:

- It is important to be aware of the fact that **being of Roma origin generally goes hand in hand with poverty and a low level of education**. This fact evidences the need to consolidate a coordinated network of intervention stakeholders (e.g. providers within the public administration, members of social organisations, practitioners and technicians) to work simultaneously on different levels (e.g. educational, social, cultural, professional and public health).
- Bearing in mind **the central role that women have in care processes**, it is important for CSOs to create workshops to train Roma women in symptom recognition, personal and family care, and such similar health issues.
- It is essential **to privilege the concept of prevention over the concept of treatment**, especially in the information given to Roma children and youths in schools.
- It is an innovative and interesting measure **to locate Roma men who can become referents of healthy habits for their community**, in order to promote these also among the male population.

- The recruitment and **training of human resources** to work directly with Roma people must include the following skills: **familiarity, empathy, resolution skills in adverse situations and openness to other cultures and worldviews.**
- It is necessary for health-care providers **to play an active role in the situations of vulnerability** with which they deal, constantly engaging new patients and personalising monitoring through home visits or telephone calls.
- There is a **direct relationship between users' satisfaction and providers' motivation.** Therefore, it is beneficial to provide practitioners with feedback that shows the users' satisfaction with their performance.
- In work with the Roma population, it is important for **professional health-care practices to remain flexible and to adapt to the particular characteristics of Roma population** (e.g., adaptation of clinical protocols, oral transmission of information, morning and afternoon shifts for user assistance services, and so on).
- It is necessary **to simplify the administrative procedures that ensure medical assistance for the Roma population.** In order to do so, a person of reference in the centre should be in charge of dealing with the required documentation.
- **The implementation of an efficient appointment system** is needed, with limited waiting periods adapted to the Roma patients who are travellers.
- In order to acknowledge the work of its professional, **the health-care institution must lower practitioner–patient ratios and provide constant support through specific training programmes.**
- **Health-care organisations must encourage teamwork and implement reward systems that promote cooperative work** over competitive work. This is the best way to deal with professional stress and to offer a quality service.
- It is important **to implement an assessment system** that, without obstructing their work, may allow practitioners to assess the real impact and efficiency of health-care programmes.

Box 7: Highlights of responsiveness of health-care services

The NRIS and its Operational plan cover the responsiveness of the NHS through the objectives aimed at reducing specific Roma health inequities and the strategic lines of actions to do so (such as use and efficiency of health-care services). However, attention has been drawn to the limitations of the NRIS in this way:

- It is mainly focused on the national Roma population, disregarding the foreign Roma community.
- Its perspective is exclusively biomedical
- Its objectives are neither interconnect nor integrated with other existing policies and strategies of the NHS.

Some efforts have been done to make the NHS more responsive towards the Roma community:

- At a policy level regional and national governments have developed plans to culturally train providers, published reports and guides about Roma health, culturally adapted campaigns, deployed health agents (e.g. Action Plan for the Development of the Roma Population 2010–2012, or the I and II Integrated Plan for the Roma People in Catalonia). However, nothing of the above is integrated in the academic curriculum of health degrees.
- Generally, health-care centres do not have specific protocols for the Roma. Although some of them adapt the general protocols to their Roma population and needs.

- Some of these adaptations are related to the ways to communicate with Roma users, balance health-care assistance with their religious beliefs, economic situation, etc.
- There are also other adaptations that imply a great effort on the part of providers, such as being more proactive, constantly vigilant on monitoring and locating Roma users; which can cause burnout among providers.

4.4. Achieving and sustaining change

The NRIS Operational Plan focuses on the need to improve the coordination and collaboration among different stakeholders (Ministry of Health, Social Services and Equality, 2013). Their coordination will be central for the planning and guiding of State general administrations and the AACC. To ensure its success, this plan proposes a series of changes to overcome the difficulties encountered in previous projects, including the promotion of policies and actions intended to reduce the inequalities in health of the Roma population and to have more equitable health-care services. In this sense, special attention must be paid to the foreign Roma population. Therefore, this plan requires the active participation of the Health Working Group of the Roma State Council in all its actions. At the same time, the plan also guarantees collaborative work among the different agents involved, reinforcing intersectoral, multiterritorial and institutional collaboration.

In this regard, this report considers the following indicators: (1) the political and economic context of the NRIS; (2) the challenges regarding Roma collaboration and participation, including the relationships between national and foreign Roma, Roma associationism and the collaborative relations among organisations; (3) collaborative work among the different agents involved, placing the focus on the impact of the power relations between them; (4) the promotion of intersectoral collaboration and the synergistic role that health promotion plays in this sense.

4.4.1. The political and economic context of the NRIS

One of the challenges that could hinder the implementation of the NRIS in Spain is the current unstable economic and political climate characterized by cutbacks in public protection services such as health or education. This difficult situation not only limits the distribution, planning, and recruitment of human, economic and material resources, but also reduces the impact of previous achievements in Roma health. As a matter of fact, it is important to highlight that the NRIS in Spain could not be implemented in 2012 and 2013, since the Operational Plan was not developed until the mid of 2014 – when this report was already being written.

At the same time, the fact that the strategy is not sufficiently publicised among stakeholders and civil society alike also hampers its correct implementation. More specifically, the NRIS is known within national and regional institutions because it is compulsory for proposals for funding to be correspondent with existing national and European projects – it is for this reason that the future comprehensive plans for the Roma population in Catalonia and Andalusia incorporate the objectives of the NRIS. However, **at local level, the strategy is hardly known**. Some stakeholders are aware of its contents, but because the information has come from other sources (e.g. websites and CSOs' reports).

The interviewees, who work more closely with the Roma community, blame their ignorance of the NRIS as well as its deficient implementation on the **little commitment and interest among those in charge of the strategy**. They also highlight the **lack of shared responsibility among multiple stakeholders** in making the strategy fully functional:

“We [providers and policymakers] are also responsible; they [the Roma] do what they can.”
(Social Worker4)

The lack of information, coordination, and communication among stakeholders may be due to the **decentralisation of the competencies of the NRIS to national, regional and local institutions, which makes the accountability of its implementation and monitoring unclear**. As a matter of fact, the NRIS is an initiative of the Spanish Ministry of Health, Social Services, and Equality (*Ministerio de Sanidad, Política Social e Igualdad*) which works in coordination with other ministries and delegates responsibilities to the AACC, in charge of implementing the strategy through regional plans. In order to assess this decentralisation of competencies, there is a group of technical cooperation made up of representatives of the NRIS in the Ministry and policymakers in the AACC. From that point, the process of implementing the strategy encounters a series of difficulties. Firstly, because regional bodies also delegate powers to local institutions and this may generate a conflict of interests (e.g. if the political party that governs a city council is different from that of the regional government). Secondly, because **the NRIS does not have its own budget, but rather gets funding from existing budgets** (e.g. the budget of the Roma Development Programme, Personal Income Tax, national benefit schemes and European funds):

“Writing plans down is not expensive and it makes them look good, but developing everything that has been written down is expensive and that’s when plans begin to founder.”
(Policymaker1)

As a result of all this, the government cannot, either from a political or administrative position, force regional and local governments to implement a plan that does not have its own budget:

“The Government of Spain has created a project that does not contemplate funding. In order to implement such a specific strategy, funding is needed.”
(Policymaker1)

This means that national plans and strategies are only carried out when regional or local governments deem it appropriate. In other words, if any AACC wants local government or organisation to implement the NRIS, they have to make these objectives eligible for public funding. In conclusion, economic limitations and those related to coordination may have a negative impact on the implementation and sustainability of the NRIS.

4.4.2. Associationism, participation and collaboration of the national and foreign Roma communities

The participation of the national Roma community in the political and social spheres has evolved positively in recent years and the associative movement has gained momentum. Nevertheless, there are still some challenges in this respect. The first challenge is that there is still institutional discrimination against Roma people, especially against foreign Roma. This is reflected in their

complaints about the lack of people of Roma origin in associations' and institutions' executive teams, and lack of representation that is worse when considering the case of women and public institutions. In these, Roma involvement is often restricted to collaboration in working groups or counselling activities:

“In public institutions, positive discrimination is not possible. A different thing is if they apply for these positions or if the programmes applying for funding contemplate this kind of measure.”

(Policymaker1)

Consequently, stakeholders are concerned that it is non-Roma people who are mostly in charge of designing and implementing actions addressed to the Roma community, a fact that, in spite of their good will, has poor results. Considering this, the Roma community demands collaborative work where Roma people can play a central role:

“It is very important for the Roma community to become involved and participate in all the actions, and we welcome all those who want to help.”

(Policymaker2)

At the same time, the breach of the personal data protection act (Organic Law 15/1999) as well as the European Directive on this issue, prevents knowing the exact number of Roma people in the country and knowing whether existing estimations include both national and foreign Roma (Laparra, 2007). This entails the **invisibility of the Roma people in plans and strategies**, which means that actions are not developed in accordance with their needs (La Parra, Gil-González and Jiménez 2013). All this affects foreign Roma more acutely, since neither their community nor their settlements are acknowledged by the system. For example, some local governments refuse to register this population in the census as this would imply the recognition of a problem and the assumption of the responsibility to address it:

“If a child is born in El Vacie [foreign Roma settlement in Seville], she cannot be registered as a Spanish citizen because this is a zero-growth area. If they start registering them, the census goes from 3,000 to 6,000 people, which means that more money, a larger space and institutional help are needed (...). And what they are doing now is precisely cutting down expenses.”

(Mediator1)

This sort of discrimination has worsened since Bulgaria and Romania joined the EU, which left foreign Roma people in institutional limbo, as they cannot longer benefit from the resources and services addressed to the foreign population. At the same time, the resources and services addressed to the national Roma population have not been reassigned to ensure that competent bodies (i.e. social services) continue to assist this minority. The system considers them as immigrants:

“So, what are they? They are immigrants, but from Member States, with full rights (...). So, they should be assisted by the administrations that deal with people from ethnic minorities”

(Policymaker1)

According to some stakeholders, the second challenge that Roma associationism faces is the fact that many national Roma population and associations do not sympathise with and even discriminate

foreign Roma. This means that they do not see themselves as belonging to the same community, something that creates further breaches between both groups:

“There are Roma people who believe that they are all Roma and that they are all equal, regardless of where they come from. However, there are others who feel more Spanish. Foreign Roma suffer double discrimination in this sense.”

(Mediator2)

“When there is an international forum, Bulgarian, Romanian and Polish Roma speak their native language, Romani; Spanish Roma don’t.”

(Social worker1)

As a consequence of this, there are complaints about the national Roma organisations’ disregard for foreign Roma, and about their lack of awareness of and concern with this population:

“Well, regarding Eastern European Roma, all we know is that we know nothing about them. (...) There is willingness to know, but not beyond what we already know: that they come in families, that they settle somewhere [and] that they travel from one place to the next.”

(Manager5)

This lack of information may hinder even further the inclusion of foreign Roma health within the objectives of national Roma organisations:

“If it’s difficult to find people dealing with the health of Roma people, imagine how difficult it is to find somebody working on the health of foreign Roma community.”

(Mediator2)

This discrimination of national Roma against foreign Roma is reinforced by public bodies that promote plans and grants exclusively addressed to well-organised and well-established associations – which are mainly national Roma associations:

“Institutions award grants to provide resources, but we know we can’t give [grants to national associations] if we want to help the foreign community (...) because they are not going straight [to them].”

(Policymaker4)

At the same time, collaboration and organizational association between foreign and national Roma is practically non-existent, due to the fact that inclusive social networks are not promoted and that the disastrous living conditions of the foreign population does not make it easy for them to unite:

“It is very difficult for people in such a precarious situation to get together, isn’t it? Sometimes you need to cover some basic needs to have the energy to do it.”

(Manager1)

As a result, foreign Roma lacks of formal associationism and the collaboration among them is often casual:

“There are support networks (...). I’ve seen families of scrap metal collectors who have managed to get the money to repatriate the body of a relative thanks to the help of the community. This is for me a form of association, a form of collaboration. The thing is that these are not formalized.”

(Social worker1)

Finally, there is a progressive and dangerous process of bureaucratisation of Roma associations:

“Is the associative movement representative of the population? Or is it representative of its affiliates and members?”

(Manager1)

According to interviewees, the national Roma community must not be the only interlocutor when working with the foreign Roma population:

“National Roma associations should represent all the Roma, but they don’t.”

(Manager5)

Interviewees also believe that organisations need more people who are more: *“capable of siding [with the Roma community] while maintaining professionalism”* **(Policymaker4)**. In order to do so, it is important to have interlocutors within the community, such as service providers that work directly with Roma people. Furthermore, recent cuts in material and economic resources has resulted in a competition for such resources – especially in situations of exclusion where goods are scarce – that further hampers collaboration between national and foreign Roma:

“In Badalona, there is now a very xenophobic campaign that is, I have to say, brainwashing national Roma against foreign Roma.”

(Mediator2)

This kind of rivalry is also present among national Roma associations that compete for resources and, consequently, only work for the benefit of their own communities and the continuity of their programmes. This implies that many of them cease to represent some sectors of the national Roma population itself:

“Now that, to be honest, there are cuts in resources for everyone, the general tendency is towards overprotection and ensuring the continuity of what you do.”

(Manager5)

“Association also has its limits, right? It’s not all the Roma, but those who, for one reason or another, have joined forces to get a grant, or to get a job, because they really want to improve their conditions. But association within the Roma population is generally quite limited.”

(Manager1)

Also, this has resulted in clientelism between associations and administration, and between users and associations, which promotes a subsidy culture and a culture of poverty that stigmatises this community when it should be empowered:

“We have created a series of patronizing aids, a sort of charity. We’ve reached the point when we confuse Roma culture with living on benefits. This is not Roma culture! It has been easier to give them money than to empower them, than to work with them (...) because this is a slower process and the results take a while to be seen.”

(Mediator1).

All these issues are undermining Roma associationism, hindering the creation of a solid system to encourage all the sectors of the national and foreign Roma community to take active part in the process of improving their health status.

4.4.3. Collaborative work among multiple stakeholders

Collaboration among different stakeholders generally takes place on two different levels: a horizontal level, where collaborative work is carried out by people or organisations at the same level (e.g. service providers); and a vertical level, where collaboration takes place among stakeholders from different levels (e.g. providers and policymakers).

Horizontal relationships between organizations and providers that work closely with the community (e.g., schools, primary care centres and social organisations) are generally highly regarded. An example of this is the creation of strong social fabric through community roundtables, working groups or networks that develop activities to improve the health of the Roma population (e.g. locating people, health education workshops, visits to settlements, promotion, and training). The main problems at this level emerge from the **lack of coordination among different stakeholders**. This gives rise to situations in which, for example, several organisations work independently on similar programmes in the same areas, something that wastes resources and produces uncertain results:

“Yes, it’s true, sometimes we are not coordinated. They ask me to give talks here and there, but they don’t get together so we can address a whole lot of women. Each association requires you to do something.”

(Health-care provider1)

Also, horizontal relationships on higher organisational levels (i.e. between regional institutions in charge of implementing plans and strategies) often happen through official participation bodies such as committees or governments’ interdepartmental groups. The difficulties in these cases are mainly due to budget issues, but also to the fact that these **meetings are not frequent and to institutions’ lack of involvement and interest in Roma issues**.

Vertical relationships between community organisations and highly hierarchized/politicised institutions are often difficult. Stakeholders who work directly with the community complain about the lack of awareness of the Roma population, and the deficient communication, collaboration and commitment of institutions. They also complain about **institutions’ passivity and lack of a proactive involvement regarding stakeholders’ needs**:

“I think that among us [providers], who work directly with them, there are no problems. As a matter of fact, we know each other and we have good relationships (...). We are often in touch and we speak the same language (...). It is in the more institutional, more political, dimension that problems arise and collaboration is scant.” **(Mediator2)**

4.4.4. Promoting intersectoral action

In order to facilitate this collaboration, Roma associations and CSOs participate in periodic roundtables and meetings with government institutions, as well as in national and international conferences that favour dialogue between different stakeholders and facilitate the implementation and assessment of different programmes and strategies. Also, at national and regional level, plans to promote collaboration have been developed. In this way, the Roma Development Programme in 1989 and the creation of the National Roma Council in 2005, promoted the participation of the Roma community, their association and networking with different agents. Indeed, the Council participated in the elaboration of the National Action Plan for Social Inclusion (2008–2010), defending the need to mobilise institutional bodies and agents at different levels (e.g. AACC, CSOs, etc.) to achieve Roma integration. Also, the Action Plan for Development of Roma Population (2010–2012) involved the Roma community in the design, development and assessment of actions intended to reduce health inequities, drawing attention to good practices and promoting the creation of intersectoral spaces to foster dialogue and disseminate findings. This plan emerged from the process of bringing together the plans of different ministries. Currently, in Andalusia, the Ministry for the Roma Population (*Secretaría para la Comunidad Gitana*) is a body that advises and coordinates the actions directed to promote the Roma community. The Integrated Plan for the Roma Community of Andalusia (1996) encourages the active participation of the Roma community, both individually and collectively, through sensitive plans and policies, health education programmes and the training of providers. In Catalonia, the first and second Integrated Plan for the Roma People includes the incorporation of Roma providers into the CatSalut system and the ASPCAT.

4.4.5. Case study: Intersectoral working model for improving the participation of Roma women in prevention and health promotion programmes

4.4.5.1. Background

La Mina neighbourhood is part of the Sant Adrià de Besòs district of the Barcelona metropolitan area. It is located in the south–west corner of the municipality, separated from the city centre by the River Besòs, the Ronda Litoral coastal ring road, a railway line and La Catalana neighbourhood. In recent years, the areas bordering La Mina neighbourhood, especially the Fòrum area and the last section of Avinguda Diagonal have seen redevelopment with a new hotel, leisure, sports and commercial activities, which has put La Mina back on the map of the Metropolitan Area of Barcelona. For decades though, it had been physically isolated, cut off by industrial areas and others with no fixed use that were quickly turned into dumping grounds and prevented the exchange and connection of the residential area of the neighbourhood with its surrounding environment and the waterfront.

In 1969, the Barcelona Municipal Housing Board bought the land on which La Mina neighbourhood was built from the Town Council of Sant Adrià de Besòs. The transaction was intended to eradicate various shanty towns that had sprung up in different parts of the municipal area of Barcelona City (i.e. Camp de la Bota, Somorrostro, Pekín, La Perona, Can Tunis and Montjuïc) as a result of the high numbers of migrants entering Catalonia. The bulk of occupation took place between 1973 and 1974: by 1975, 15,000 people were living in La Mina.

Due to the way in which it was designed and the unique social and urban circumstances of the time, the neighbourhood was marked by:

- Cultural conflicts due to the highly diverse origins of the new residents in a hostile environment for relationships and contact between social groups.
- Deterioration of the surrounding environment due to the proximity of facilities with a strong environmental impact (e.g. power plant, sewage treatment plant and incinerator).
- Lack of resources to improve living conditions and solve the social, labour and economic problems of residents.
- Poor professional skills and part of the population without work, who sometimes suffered from other problems (social exclusion, drug addiction, crime).
- Low involvement of residents in their immediate community environment.

Despite the public investments made in the 1980s and 1990s to address these issues, the lack of coordination between the actions and the difficulty of committing to long-term investment prevented any effective change in the social situation of La Mina. Towards the end of the 1990s, the Town Council of Sant Adrià and the Government of Catalonia, in conjunction with the Provincial Council of Barcelona and Barcelona City Council, launched the Transformation Plan of the La Mina neighbourhood for 2000–2010, which was subsequently extended for another five years (2011–2015), and set up La Mina Neighbourhood Consortium to implement the plan.

The basic aim of the Consortium – as set out in its articles – is to direct, coordinate, and implement the Transformation Plan of La Mina neighbourhood by focusing on education, culture, occupational and social integration, housing, safety, and health prevention programmes. These actions are conducted considering that many will have an impact on the health of the population in the neighbourhood as well.

The Consortium is required to coordinate intersectoral work in the implementation of social, labour, cultural, educational, health, housing and urban development actions in the neighbourhood.

The social, health, and education resources allocated to La Mina do not fall short in comparison to those allocated to other neighbourhoods. However, more significantly the neighbourhood perhaps lacked a more global project to ensure that the actions different authorities were well coordinated and complementary, and to overcome the dynamic of one-off interventions and short-term aims, as had been attempted several times since 1982.

Thus, La Mina can be described as a neighbourhood of “instantaneous creation”, a result of the relocation of different population groups originally from other parts of Spain and whose initial services and facilities were soon outgrown by the needs of newcomers, mainly young families with children. In many cases, this population had social, occupational, cultural and/or economic deficits. The number of neighbourhood residents fell from 10,664 in the early 1990s to 8,847 in 2008. At this point, the trend reversed and the population is growing since then. On 1 January 2014, the municipal register recorded a resident population of 9,777 people aged between 25 and 44 years old and 27 per cent under 20 years. Fifty-one per cent are men and 48 per cent are women. In this neighbourhood, Roma families live alongside migrant families, Catalan families and those from other parts of Spain.

Sant Adrià is one of the leading municipalities of Catalonia in terms of Roma population, besides Barcelona and Badalona, and La Mina is the neighbourhood with the largest number of Roma residents (Abajo and Carrasco, 2004). Some estimates indicate that Roma make up 30 per cent of all neighbourhood residents (Méndez, 2005:243). A total of 10 per cent are third-country nationals, particularly from Pakistan, Morocco, and China.

The economic activity of the neighbourhood is based on small local shops with little diversification. Almost half of its businesses (40%) are bars and restaurants. The labour market situation is marked by instability and high unemployment, with significant inequality in access to employment for men and women, to the detriment of women. These issues have formed the cornerstones of the Transformation Plan, addressed by the Consortium of La Mina through its Network of Social and Occupational Integration Services to promote employment and training. Along these lines, the Consortium funds occupational and social integration pathway for women of La Mina neighbourhood project, designed to promote the inclusion of women into the labour market by increasing their motivation to work and accompanying them in developing their professional skills in particular job through technical training at work placements.

There are currently around 30 civil society associations in La Mina, many of which contribute in varying degrees to the improvement and transformation of the neighbourhood. Besides their own activities, they participate in community life by organising various community celebrations over the year to reinforce the sense of belonging. These include Women's Day, Games Day, the Week of Culture, Children's Rights Day, and Gender Violence Awareness Day and so on.

In January 2013, the Catalan Government approved the contract to construct the new PHC of La Mina, one of the key facilities of the Neighbourhood Transformation Plan. The works are scheduled for completion in 2014.

4.4.5.2. Research questions

- a) What success indicators define the occupational and social integration pathway for women of La Mina neighbourhood project?
- b) What are the health problems of Roma women from La Mina and what challenges do they face for the implementation of prevention and health promotion strategies?
- c) What skills and strategies have been developed to manage these challenges properly?
- d) What elements are considered challenges that still need to be faced?

4.4.5.3. Research process

The information was compiled by three technicians from the Catalan Agency of Public Health (Ministry of Health of the Government of Catalonia). To collect relevant evidence, the following qualitative methods of data collection were used:

- *Documentary compilation*: Analysis of written documents or records cited by those involved in the study project.
- *Participant observation*: Description of what the researchers observed during interviews.
- *Interviews*: Through communicative interaction between researchers and participants, to obtain individual narratives from two of the people involved in the project. Specifically, we conducted in-depth interviews with the project's Roma mediator and social educator.

The informed consent of the interviewees for the recording and use of the data they provided was requested, guaranteeing both full anonymity and that the information would be used strictly for research purposes.

The open questions asked during the interview to the persons in charge of the project included: What does the programme involve? How many women are you in charge of? What health problems have you identified in this group? What do you think the cause of these problems is? Do women participate in prevention and health promotion programmes? What opportunities have you identified and how do you think they could be leveraged? What actions have been undertaken to improve the health of this group through the programme?

The interviews were transcribed and studied in conjunction with the cited documentary material. The fragments of the conversation that could be used to answer the research questions formulated previously were selected and contrasted with the results obtained by analysing the content.

4.4.5.4. Chain of evidences

a) What success indicators define the occupational and social pathway for women of La Mina neighbourhood project?

The project offers a guidance and training pathway. In addition to its guidance actions, group and individual tutoring, work placements and tailored training, the pathway also includes intercultural mediation actions. It is funded by the Consortium of La Mina neighbourhood and seeks to promote the inclusion of women into the labour market by increasing their motivation to work and accompanying them in developing their professional skills in particular to find a job through technical training at work placements. The project also works with Roma women on eliminating labour prejudices and their idea of what non-Roma population thinks about them as a group and as workers.

One of the factors for programme success has been to work with the community to stamp out prejudices and solve problems linked to this. The project seeks to equip participants with the tools to defend themselves and gradually adapt and integrate in their new working environment so that they do not walk out of their jobs. At the starting point, women could not see themselves being able to work because they did not value themselves, and they said that shops would not hire them because they were very dark skinned and would not want them because they would see them as thieves. All based on the prejudices that they thought mainstream society had against them, as if they were coming to steal something, which caused them distress and contradictory emotions that then stopped them from going back to work.

All projects aimed at bringing change at a community level should be carried out with community leaders, in this case with Roma women recognized by their community. This statement is based on the understanding that community recognition is associated with integration and acceptance of culture, codes, and customs.

“To be considered a leader, a professional needs to be in and recognized by their community and to know its codes; otherwise, they are better off working in some other area. (...) Some Roma people work for the community but they are not leaders and they are not recognized by the community; it

is important for them to be inside the community so that they understand how it works, because Roma are community based. Community is more important than individuality.”

(Mediator)

Another factor to note in this project is its intersectoral work. The project has used professional reintegration – an activity that Roma women do out of need or obligation – to identify other problems and needs that they do not see as priorities, such as health problems:

“The group of women we are working with on employment issues don't come because they have decided to, they come for practices in the hospitality industry, which is what they are going to do. This is their real aim and through that, we work on other things.”

(Social Educator)

In these groups, women are given the opportunity to participate and communicate with the leaders, allowing them to express their views on employment and family, and understandings of health problems. Ultimately, the aim is to address other problems affecting this group, besides employment:

“Because we really believe that to work on health issues we have to work with their needs”

(Mediator)

Another interesting approach to their problems is through the sense of interdependence generated by creating an informal relationship with groups of non-Roma women, which promotes critical thinking by both groups and encourages empathy. Working with the two communities generates space for reflection and integration in which one of the communities focuses on the skills profile of the other – rather than its origin – to increase awareness and generate critical competence. The idea is to create social environment conducive to the processes of communication and collaboration between people from different backgrounds. This interaction facilitates that Roma women can see their taboos in a different way and relativize them. They can decide to change their attitudes and cultural habits:

“There were a lot of prejudices against them and they got down to work with both groups together, Roma women with non-Roma women, which didn't cause any problems between the Roma and non-Roma women of the neighbourhood.”

(Mediator)

“Why do you think that eighty-year-old non-Roma women can get on the underground alone and yet it's unthinkable for our eighty-year-old mothers to travel by themselves on the underground? Because they're at home; they need to be cared for, they're like centenarians.”

(Mediator)

b) What are the health problems identified in Roma women from La Mina and what challenges do they pose to the implementation of prevention and health promotion strategies?

One of the main problems identified by the project is unhealthy lifestyle of Roma women. Roma women have unhealthy eating habits and do not get enough physical exercise. Cultural stereotypes are one of the main factors preventing Roma women from taking care of their health; for example, the community does not see exercise as positive. Since doing sports requires women to wear certain

type of clothing (i.e. tracksuits) or doing activities in potentially embarrassing postures, it is difficult for them to practise sport:

“Looking after your health is frowned upon among women. Now men are really starting to get out and play sport and go to the gym but women aren't; it's frowned upon.”

(Mediator)

Roma women tend to associate health with physical appearance and the absence of illness. Being slim and tanned and having nice skin or hair are the factors determining good health for them:

“What is on the outside is what is valued because Roma people put a lot of emphasis on body image. (...) Being slim is a sign of good health... having nice hair is a sign of good health, having good skin is a sign of good health, being tanned or having a good skin colour is a sign of good health. Being well dressed is a sign that you feel good or are in a good mood... these are the factors that are really valued within the community.”

(Social Educator)

Nonetheless, they do not take into account the risks associated with lifestyle habits they adopt to achieve this look:

“What I do is eat the stew my mother-in-law makes at lunch time, that's what we all eat, and then at night I'll have one piece of fruit, otherwise I'll stuff myself on fruit. (...) ‘What do I do?’ I eat at lunchtime and then I don't have anything else after that. And what do you do not to feel hungry? I go to bed early so I don't get hungry because I don't want to be overweight for the summer.”

(Social Educator)

They have health problems linked to the strenuous nature of their work and illnesses caused by their unhealthy habits – poor diet and lack of enough exercise, resulting in diabetes and high blood pressure:

“These women have very heavy burdens; they are working in physically demanding occupations, such as cleaning ladies, and they need physical strength.”

(Mediator)

It is very difficult for them to reconcile work and family life, which can lead to depression, anxiety and low self-esteem because they have to meet multiple demands in their day-to-day lives (e.g. employment/unemployment, domestic chores and the family economy, caring for their families and caring for others). Early marriages – with all the family responsibilities this entails – lead to premature ageing among Roma women and health problems associated with their workload and the fact that they are more concerned about others than caring for their own health:

“This is a really hard job, too hard... in women with a triple burden. Here we have women in their forties who are cleaning lots of flats and also have to care for their children, their daughters-in-law, their husbands, their mothers... do you see what I mean? their grandchildren... and there's mental health too; we see that on a daily basis in terms of failure at work and how it affects them; the power of the group is also very strong.”

(Mediator)

There is no concept of prevention. Care for them is to go to a professional when the symptoms are already apparent. The providers consider that Roma women have strong tendency to self-medicate:

“Well, naturally, because I'm very tired, my head hurts, because I've got a problem; they take an anti-inflammatory. (...) We are saying that we have a different concept, and our concept is to take care of ourselves when something hurts...” (Mediator)

They lack of awareness among providers to tailor prevention and health promotion programmes to the cultural needs of these groups, can be seen in the recommendation of certain activities that are completely off-limits due to cultural barriers:

*“Almost every granny has a back pain; they can't move. And what did the doctor prescribe? He prescribed swimming... He told her to go swimming or something... something they can't do. And when I say: ‘Why don't you go to the swimming baths?’ For them it's impossible. First, they'd have to go alone and grannies are never left alone without someone from their community. They have to wear a cap that we'd be all right with, considering appearance. You have to wear a bathing suit with all the taboos associated with that, when they can go... they don't go swimming. Grannies swim in a housecoat, generally, most of them do.”
(Mediator)*

c) What skills and strategies have been developed to manage these challenges properly?

One strategy identified as effective by the providers in this project was the need for intersectoral work, considering health in a holistic manner dependent on the social environment (e.g. employment, housing, education and the like).

*“The service has worked with 173 women in 2013, almost all for employment needs (...) the problem is that behind these needs there are many others, which, on a holistic level, can be social demands and health problems, and they are clearly not going to ask about those here because they know we aren't health professionals. But you can see that not taking care of their health is not doing them any favours.”
(Mediator)*

This interdisciplinary work has allowed them to identify the health problems and needs of the women attending their professional reintegration programme and to jointly develop intervention strategies tailored to their needs and cultural context. They have managed to optimise public resources for the professional reintegration of this group in order to attract their interest in possible behavioural changes that would allow them to acquire healthy lifestyle habits, which does not appear to be a need for them.

*“There is a reintegration part associated with working on the status of individuals, that is, a life project as opposed to a professional project. A life project to empower women in every facet of their lives.(...) So it's a protected environment, which is justified because basically you are looking for work... and if I get home at half past one nobody's going to say anything because I am justifiably working to improve the community, which is looking for work, and my husband is not going to say anything.”
(Mediator)*

They have created working environment in which Roma women feel comfortable and protected, working with people considered by these women to be leaders in their community.

The project and its providers work to promote physical activity and a healthy diet by adapting the interventions to the cultural context of the Roma community and their understanding of health. For that, the women who started the project used the areas of interest or concept of health among Roma women to design successful strategies in prevention and health promotion (e.g. running out of the neighbourhood in order not to be seen for the rest of the community). If they feel that a particular physical aspect is what determines good health, then it must be used to schedule actions to meet these demands. Physical appearance can be used to work on many other health needs, such as walking, chatting about healthy eating and so on. The important thing, however, is to attract their interest and ensure that they go to these meetings. The project addresses the need to break the taboos of Roma culture with regard to physical activity and raise awareness of the options for practising sport, such as the use of public facilities. There is no need to join a gym if it is not generally culturally accepted.

“So what have we done here?’ Actually, a woman from the neighbourhood started to come who was not Roma, and she would do sport every day outdoors, basically running and using the outdoor machines... climbing stairs... and she'd say to us, ‘come on, come and join me’. And so we said, quite strategically really: ‘All right, we'll join you!’ and there was this course full of women but then some were saying ‘I'm not running because it's frowned upon’, ‘I'm not going out because they're going to call me crazy’. So we came up with a plan: we'll go running outside the neighbourhood. We went out in tracksuit and trainers and walked to the Fòrum; nobody walks there – you're alone there – and we run around the Fòrum, where nobody can see us, and we do a bit of sport there. And more women have been joining us, they joined because nobody will see them. (...) Because they can't use those public spaces they have never been in ... And they don't know what a gym is like inside because they have never been in one... they don't know what the machines are for or what aerobics classes are like.”

(Mediator)

The project has set up working groups with Roma and non-Roma women, in which both groups can identify different models from which to learn and set up collaborative – as opposed to competitive – relationships.

“We think it's good to have Roma and non-Roma women, but there needs to be majority of Roma, otherwise they won't identify. And we also believe that there needs to be non-Roma women who already have habits because they are the ones who are going to move the group. Am I making sense? I mean that they will encourage the others... a women who has lost weight and been on a diet will explain to them ‘What have you done to get like that?’ Some people have certain awareness and encourage the rest. This is the best thing that can happen in a group.”

(Mediator)

d) What challenges remain?

- Improve the health of the population through intersectoral work, considering the impact on health of any public policy and taking advantage of intervention in one area to identify needs in others.

- The importance of working with and from within the community both on employment issues and on health care with referents from Roma people.
- Breaking stereotypes that may adversely affect the health of Roma women, while creating open spaces for discussion but always taking into account the Dialogue between Roma and non-Roma women.
- Preventive and health promotion intervention for Roma women should be tailored to the real needs of these women and their context and lives, so that they can balance self-care with family life.
- We should study and develop strategies for prevention and health promotion tailored to the needs of elderly Roma groups.

The project highlights the need and opportunity to improve Roma health through intersectoral work, considering the impact on health of any public policy and taking advantage of intervention in one area to identify needs in others. The project developed in this Roma community is a model for intervention in improving women's health through publicly funded interventions in other areas. The objective is to use an area of interest for the group to be able to use this space to catalyse Health promotion policies that otherwise have not been a priority for Roma women so far, such as to improve their diet and improve their life styles in general. It also highlights the importance of working with and from within the community both on employment issues and on health care, which can bring about changes in habits and behaviours in self-care and health promotion. We must work with Roma women leaders from the community if we want to influence change in its lifestyle habits. These referents must know the community codes and rules and must be recognized as members of this community in order to achieve some success. When we deal with sensitive subjects that can break the community cultural rules imposed on women, it is better to begin with women leaders, as Roma women will feel closer and more relaxed when talking about these issues. The use of leaders (e.g., religious leaders) can be of help when the own community women have already accepted the change.

We are confronting some repetitive processes of habits and stereotypes that can affect negatively the health of Roma women, diminishing their chances for labour market integration and general health improvement. Change must be engendered from inside of the community, and must generate open spaces for debate, while taking into account dialogue between Roma and non-Roma women. Using community referents and creating non-formal spaces for diversity allow the exchange of different points of view and give the possibility for personal growing.

This interrelationship between the two groups may allow them to expand their cultural boundaries and visualize similarities between the two contexts in terms of responses to these problems or making more permeable a possible change in behaviour. An important feature of this type of situation is to enable participants to integrate the experiences of group differences at the same time that they develop different personal identities.

It is also important to work with non-Roma women to create informal spaces for diversity. The interrelationship between the two groups can encourage them to expand their cultural boundaries and see similarities between the two contexts in terms of responses to these problems or making a possible change in behaviour more permeable. One important function of this type of situation is to enable participants to integrate the experiences of group differences while analysing different personal identities.

Preventive and health promotion intervention for Roma women should be tailored to their real needs and their socioeconomic realities, so that they can balance self-care with family life. Their behaviours are also dependent on the family environment: whether the woman is a mother, whether she has found employment, whether her husband is supportive and so forth. We must consider the home environment of the individual woman in order to tailor intervention strategies to each situation and incorporate healthy habits and exercise into the lives of Roma women. Community leaders can be made aware of the situation of each woman in order to then work on different strategies. The better and more closely the problem is known, the better and more effective solutions may be applied.

Finally, once the role of female Roma has been analysed, we should study and develop strategies for prevention and health promotion tailored to the needs of elderly Roma groups as a future challenge, since there are few interventions for them within this sector.

4.4.5.5. Lessons learned

The defining characteristic of Roma employment status in Spain is precarious underemployment, although in recent years Roma women have increased their labour participation, albeit below the employment rate of non-Roma women. As a result, many women have been confronted with cultural stereotypes that have led to many difficulties and required efforts for their integration in the labour market.

This situation has led to initiatives such as the occupational and social integration pathway for women of the La Mina neighbourhood project, designed to promote the inclusion of women into the labour market by increasing their motivation to work and accompanying them in developing their professional skills for particular job through technical training and work placements.

The main reason of Roma women to incorporate themselves to the formal labour market is economic – to help their families – but there is also an interest in gaining economic independence and increase social and personal recognition.

The social determinants of the Roma community bring with them significant health inequalities. Problems with housing, employment and financial resources in general, combined with certain cultural factors, determine their perception of health and their health status. Social and cultural factors influence women's health even more because of the added problems of family burdens and being overworked.

The case described in this report reflects all the evidence published on the situation of Roma but provides us with new strategies for intersectoral collaboration to identify the problems of this group and define strategies with a greater impact.

Work, housing and education appear to be much bigger priorities for the Roma population than health promotion, so it is logical that more resources are allocated to these factors. However, we can leverage interventions in these other areas of interest to introduce an interest in or concern for the promotion of their health. We must optimise the resources allocated to Roma to ensure that the Roma community itself changes the way it sees its health and what they can do to prevent health problems.

Within the NHS, there appears to be lack of information tailored to the needs of Roma patients. Prevention and health promotion programmes must take into account the cultural differences of each group and its lifestyle in accordance with the norms of the community.

One intervention strategy with potential for success is to implement communication and information strategies using common spaces where Roma women feel free to talk, in communal areas where they can interact with other Roma women in the same situation or perhaps non-Roma women with whom they forge ties for comparison of interpersonal skills in order to foster critical awareness. This could be done through mediators recognised by the community and focusing on areas of concern for these women, such as their perception of healthiness, their interest in an occupational integration programme or curiosity for a television programme about physical activity.

Roma women should be part of the creation process of prevention and health promotion programmes and even in the development of public policies that affect them, both in their design, planning and implementation, in order to detect possible deviations and provide most accurate picture of the community in which they live. It is only through Roma leadership that change can take place.

The information drawn from this case study is helpful for adapting the design and implementation of health-care practices to the characteristics of the Roma population in other similar contexts. Specifically, the most important lessons learned from this case study are the following:

- **Intersectoral policies need to be developed to improve women's health and strengthen their self-esteem.** An inter-institutional approach should be adopted to improve equity in health through health policies that act on social determinants in health.
- **Improve living and working conditions** and generally create favourable environments for health.
- **Focus action on the socioeconomic determinants of health in the Roma population, incorporating gender mainstreaming.** Access to education, work, health and improved housing quality are strategic areas, as indicated in the Decade of Roma Inclusion 2005–2015.
- **Increase the participation of Roma women in prevention and promotion programmes** in order to improve their healthy life styles and consequently to have better care of their own health. Thus, they can also have an impact on the health of their families and the Roma society in general due to their caring and referent role for the group.
- **Work with community leaders recognised as members** of the latter who can help negotiate without being seen as an element of pressure and who mediate between the Roma community and the health system.
- **Use meeting spaces accepted by women and the Roma community** in general (e.g., places of worship).
- **Adapt intervention strategies in prevention and health promotion to the needs of Roma women** (e.g. personal, employment, family and cultural context, taking into account their age).
- Focus actions on **reducing the rapid ageing of men and women.**

Box 8: Highlights of achieving and sustaining change

The last fundamental pillar of the NRIS and the Operational Plan is to enhance Roma health through administrative and institutional cooperation and stakeholders' participation. Nevertheless, some challenges should be highlighted:

- The poor implementation of the NRIS is due to the current economic and political context in Spain.
- The fact that the NRIS does not have its own budget not only limits its implementation and recruitment of resources, but reduces the impact of previous achievements in Roma health.
- The NRIS is not sufficiently publicised among stakeholders and the civil society.
- To carry out its implementation, regional bodies delegate powers to local institutions, thus generating conflicts of interests among the different governments.
- There is a lack of Roma engagement and collaboration in Roma health policy planning.
- There exists institutional discrimination against Roma people, especially against foreign Roma.
- Roma community is concerned that it is non-Roma people who are mostly in charge of designing and implementing actions.
- There is lack of cooperation, coordination and networking among stakeholders, especially in countries of origin (e.g. Bulgaria, Romania).
- The national Roma and their associations do not sympathise with and even discriminate foreign Roma.
- Foreign Roma lack of associations to represent them.
- There is a progressive bureaucratization of Roma associations.

5. PLANNING THE FUTURE

In order to achieve a quality development and implementation of Transformative Roma Health Policies (TRHP), we must take into account that these policies are the outcome of an innovation process that put into practice both evidence-based and discursive approaches. Hence, building TRHP from a multi-stakeholder perspective would be one thing, and implementing them would be another (Frank and Atkins, 1981; Meyers et al., 2012). When planning the future, some challenges may arise, such as the lack of common and shared interests and goals, unrealistic expectations, the lack of evaluation, communication and organizational barriers, segmentation of the network, unbalanced power relations, resistance to change and maintaining the status quo, lack of resources, etc. (Suarez-Balcazar et al., 2007). Bearing this in mind, TRHP from a multi-stakeholder perspective should follow principles to guide the development and implementation of Roma health priorities through specific community tools.

5.1. Principles

Box 9: Principles of Transformative Roma Health Policies

- To effectively involve multiple stakeholders by building collaborative capacity.
- To be based on health in all policies and intersectoral action for health perspectives.
- To better monitoring and reporting progress and develop evaluation capacity among stakeholders.
- To redefine the role of the promoters of policies.
- To prevent institutional discrimination.
- To assure cultural competence among stakeholders.
- To institutionalize health mediation.
- To promote health literacy among Roma users.

(1) TRHP should assure **the effective involvement of multiple stakeholders by building collaborative capacity**. Sustaining and strengthening stakeholders' engagement should be an action-oriented process that gives voice to marginalized voices and focus on strengths and capacity building for systems change. The pursuit of systems change often requires engaging multiple stakeholders across multiple sectors in joint action to produce desire and quality changes in the community (Allen et al., 2013). TRHP should adopt a perspective based on the principle of **social justice** by which people may have the resources and skills that are inherent to their rights and allow them to participate in the decision-making process. Significant benefits may arise from this principle. Among the tangible benefits, the NRIS states that **involving and engaging stakeholders – prioritizing the Roma community** – in policymaking is an important health component itself. Besides, it is an ethical and moral imperative: "giving people a voice in matters that affect their lives is an act of fairness" (Prilleltensky, 2014:152). In addition, it turns Roma stakeholders into legitimate political agents and leaders, thus implying greater effectiveness and recognition for this community within a paternalistic sector that has traditionally assumed the inability of the Roma to successfully lead their own policies (Case et al., 2014). Among the intangible benefits, bringing together all stakeholders will not only entail major changes in the structures and practices of participating organizations, but also in the stakeholders' attitudes, beliefs and perspectives over time. This will allow organizations to be ready for change, ensuring the successful implementation of innovative measures increasing the resilience of the community. Building collaborative capacity also promotes interdisciplinary work, allowing for advance in scientific knowledge through creative solutions based on stakeholders'

different sensitivities and worldviews. Moreover, the Roma will be progressively included in the lobbies responsible for planning and implementing policies, thus guaranteeing the consistency of policies with their needs as well as the diversification and flexibility their roles. At the same time, the Roma community will increase their health literacy and will become active agents of their health, developing skills and motivation to address health challenges and to defend their rights to promote and maintain good health (Balcazar et al., 2012; Case et al., 2014; Reich and Reich, 2006; WHO, 2009).

(2) Roma health is considered a “wicked problem” due in part to its intersectional nature: the Roma community is not vulnerable due to its ethnic, but also social determinants (e.g., low educational, socioeconomic and employment level) that interact and position this group in a disadvantage situation in comparison with the rest of the society (Bastia, Piper and Prieto, 2011). Therefore, it is required agreed transversal solutions among different sectors in order to tackle effectively the Roma health issue. Consequently, TRHP needs to be guided **in all health related policies and inter-sectoral actions** by different public policies from different sectors (i.e. education, employment, housing, mobility, justice, culture, environment, etc.) collaboratively assume social responsiveness by incorporating the goal of influencing health determinants so as to improve, maintain and protect health (Mannheimer et al., 2007). This vision implies a higher degree of shared responsibility and proactivity which cannot fall exclusively on the Roma, but rather among all stakeholders involved in the health of this community (i.e., policymakers, service providers, the NHS itself, the social context and socioeconomic and cultural conditions have a direct impact on Roma health).

(3) In the same vein, the Jakarta Declaration on Health Promotion highlighted social responsibility for health and the need of a comprehensive, equity-focused health impact assessment at community level, as essential for constructing socially responsible health policies and practices (Mittelmark, 2001). Consequently, TRHP should encourage and assure **better monitoring and reporting progress, and developing evaluation capacity among stakeholders**. Monitoring is key to assess processes and outcomes, as well as to carrying out quality improvement plans and sustainability strategies to ensure the fulfilment of goals (Taylor-Ritzler et al., 2013). Monitoring progress should incorporate traditional evaluation, empowerment evaluation, results-based accountability, and continuous quality improvement that enhance stakeholders’ skills while empowering them to plan, implement, and evaluate the programme. All this may lead to involving stakeholders in order to understanding and strengthening the implementation of initiatives (e.g. conducting focus groups to assess the satisfaction with policy, monitoring participation of stakeholders), improving the quality of results (e.g. assess if the policy still fits with the needs and goals of stakeholders, assess availability of resources), and meeting accountability and sustainability within the Roma civil society (e.g. creation of a committee, get funding, ensure cross-directional character of the policy) (Chinman, Imm and Wandersman, 2004). In order to predict and ensure effective monitoring and reporting, it is necessary for stakeholders to be aware of the importance of participatory and inclusive evaluation, to be motivated to conduct the evaluation, and to develop competences to become involved in the evaluation process. At the same time, it is important for the stakeholder coalition to promote leadership for evaluation, to create an environment that fosters evaluative thinking, and to provide resources to support evaluation. Evaluation should be an ongoing routine embedded in the stakeholders’ activities and practices aimed at improving Roma health, and evaluation findings should be seen as resources by all stakeholders (García-Ramírez et al., 2009).

(4) The following principle is **to redefine the role of promoters of policies** in order to be **instigators of change, mediators and advocators** of Roma health (Balcazar, Garate-Serafini and Keys, 2004).

First, they have **to develop skills** to consider the actions that may most likely achieve the desired outcomes while attempting to address the needs of the Roma population. Secondly, they have **to build trust with all stakeholders** as well as provide mentoring support among the Roma, liaising between the community and health-care services in order to better access resources and supports. And, finally, **they have to assume the responsibility to guide research and action** towards social justice by developing equity policies to promote Roma health. These roles should be considered in terms of power redistribution so that leadership as well as other values and roles are shared and assumed by all stakeholders, thus enhancing members' critical awareness, information, social relationships, willingness to become involved, interpersonal competences, persistence, experience and advocacy skills (Balcazar, Garate-Serafini and Keys, 2004).

(5) TRHP should also advocate for the **prevention of institutional discrimination embedded in the configuration of the NHS, as well as the policies and laws that underlie the entitlement and enjoyment of health-care services**. The NHS and the power relations that characterize it involve a subtle discrimination against the population that does not comply with it. Also, laws are defined in a way that the consequences are discriminatory and classist for a sector of the population that is not included within the mainstream society. In both cases, the Roma population is severely affected. Dismantling discrimination is a systems change intervention designed to change the underlying infrastructure within an institution to be more fair, just, and equitable. It seeks to demonstrate that all who seek health care receive equal, high quality services. The main objectives of this process should be: (a) **increasing the accountability of individuals and systems** to create a system for monitoring the elimination of health-care disparities; (b) **reorganizing power by strengthening relationships** between organizations and community; (c) **developing a common analytic framework** for understanding why discrimination is happening in both domains; and (d) **creating opportunities for the growth and development** of all stakeholders involved in the elimination of institutional discrimination (Griffith et al., 2007).

(6) **Assuring cultural competence among stakeholders** should also guide these TRHP. According to Napier et al. (2014) "health-care providers should acknowledge their own cultural values, and organizations should invest in understanding how their practices and values are cultural and in which extent these are adequate to the users." Being culturally competent requires learning to be effective in diverse communities-contexts that challenge the own cultural belonging (Trickett, 2009). It entails changes at cognitive level - **critical thinking**, relational level – **capacity to act**, and behavioural levels - **community embedding**: Cultural competent providers empower themselves to promote equal enjoyment of community resources, acquiring new skills, promoting changes in their organizations while instigating and advocating for the overcoming of disparities and asymmetries (García-Ramírez et al., 2011). In this sense there is a need of cultural competent providers in health-care organizations. Furthermore, it is essential for future providers to receive training in cultural competence before leaving college and university (Suurmond et al., 2013). The key is to link individual cultural competence training with organizational support, culturally sensitive practices, policy planning, and community engagement. In the same vein, a way to make health-care services and providers more culturally sensitive would be the **institutionalization of health mediation**. TRHP should promote the creation of models of care that take seriously the importance of community health mediators (Napier et al., 2014). In addition, these mediation processes would connect the NHS with the communities, thus **promoting health literacy among users**. As emphasized by Napier et al. (2014), "When patients lack ability, they become disproportionately incapable of participating in their own improvement, meaning that the cost of caring does not rise proportionately for those with resources, but it does

rise substantially for society.” Consequently, the Roma community should be given the educational resources, information, and abilities to understand and to be empowered in order to adjust their behaviours to improve their own health and wellbeing (Napier et al., 2014).

5.2. Priorities

The principles presented above should guide the development and implementation of priorities in TRHP. The following priorities on how to tackle Roma health inequities were identified during the stakeholder interviews and meetings of the coalition to: **Strengthening entitlement to health care; Assuring accessibility to the health-care system; Promoting responsiveness in health-care services; and Achieving and sustaining change.**

In order to **Strengthen the entitlement to health care** of national and foreign Roma, it is necessary (a) **to work for the defence of the right to health and to establish mechanisms and institutions to guarantee this right**, forcing laws at local, regional and national levels to comply with European directives and fundamental rights (e.g. the abolition of the RDL 16/2012); and (b) **to review the unjust administrative procedures for obtaining the Health Card** required by the Social Security System - more specifically the requirements needed for EU citizens (e.g., document provided by consulates to proof they have no health insurance in their countries of origin). These bureaucratic procedures are a **great barrier** for the most vulnerable population, especially the foreign Roma for whom obtaining the entitlement becomes almost impossible.

To **Assure accessibility to the health-care system** through TRHP, it is necessary to go beyond good practices – that work as temporary patches - and to establish measures capable of transforming the current NHS, such as: (a) **To denounce the violation of human rights**, advocating for the defence of international laws and ensuring the implementation of superior rights; (b) **To strive against the belief that "access is equal for everyone"** or that "care is provided in equal terms", distinguishing between "equity" and "equality" and also differentiating between "access and accreditation" with "care"; (c) **To establish corrective measures or exceptional mechanisms for access** the NHS in order to reconcile situations of vulnerability and human mobility with bureaucratic requirements; and (d) Other options are **to increase the health mediation processes by promoting networking with the community**, building trust and proximity with the most silent ranks, providing them with autonomy through knowledge about the NHS and their own health, as well as facilitating access to the NHS through other domains (e.g. education, employment, etc.).

TRHP should work on the following priorities to **promote responsiveness in health-care services**: (a) **to include both foreign and national Roma in plans and strategies**, and even those who due to the crisis have returned to vulnerable conditions and are unhooked of the system. In order to do so, it is crucial to have **reliable information** about the number of Roma, their location, social determinants and health inequities to effectively design policies; (b) it is also necessary **to redefine the current NHS**, which is more focused on curing and finding quick solutions to health problems than **caring for the users** and the community's wellbeing. In this sense, the NHS needs to recover a **community health approach** that takes into account the practices and traditions of the Roma and its influence in every life domain and context (e.g. schools, neighbourhoods, workplace, etc.); (c) From this point of view, **broader and more comprehensive health objectives from an intersectoral perspective** should be set, such as: improving child health; expanding knowledge about first aid in Roma settlements; continuing to tackle obesity and unhealthy eating in children; increasing the number of home

assistance services, locating potentially excluded users and identifying specific needs; improving workplace health; promoting active aging; improving emotional health, especially in women; eliminating gender violence; (d) These goals can only be attained through the elaboration of **preventive programmes rooted in the community** – especially for chronic diseases such as diabetes and hypertension, and activities **to promote health and health literacy that are adapted to the realities**, needs and characteristics of the Roma community. These programmes must contribute in empowering the Roma population and strengthening health protective factors; and (e) Moreover, the NHS should adopt other priorities to become more responsive, for example: to improve the knowledge about available resources to work with the Roma community and disseminate them among providers and users in centres with high density of Roma population; to increase the number of Roma staff in health-care centres; to strengthen the role of Roma health mediators and Roma women as health agents in Roma communities; to develop care programmes aimed at preventing burnout among providers who work with the Roma community; to promote cultural and Roma sensitive training for future and current providers; to value and disseminate examples of existing good practices and specific health programmes aimed specifically at the Roma community.

Lastly, **strengthening Roma associative movement is a priority for achieving and sustaining change** through TRHP. To accomplish this is important to: (a) promote and better the communication and collaborative work among stakeholders and institutions at different levels – including sending countries; (b) promote the leadership of the Roma, (c) increase the presence of the Roma – especially foreign Roma – in associations and organizations as active citizens in the community; (d) use participatory community methodologies, resources, and networking, (e) identify valid interlocutors to work with Roma communities; (f) promote cultural exchanges among multiple stakeholders; (f) revitalize Roma organization movement by promoting new structures; and (g) foster self-criticism to reduce the fragmentation among Roma associations and prevent overprotection, tokenism and co-option. To put in practice all of the above, it is imperative to improve the viability and sustainability of the NRIS, for example, by allocating budget for the strategy, especially for its dissemination. Other measures could be to elevate the range of the commitments made by institutions towards the strategy. As a matter of fact, the Spanish NRIS is currently a Cabinet agreement that is not even published in the Official Bulletin of the State (*Boletín Oficial del Estado*). In this sense, the NRIS could be transferred to the Parliament to acquire legal status (e.g. Organic Law, RDL), so that it could be transposed to the AACC and included in the general State and regional budgets.

5.3. Tools

The development and implementation of TRHP follows an **ecological approach**. At a community level, the tools to work for the involvement of multiple stakeholders and the development and implementation of TRHP within a specific context are the ones provided by methodologies for innovation and new technologies – more specifically, online platforms.

5.3.1. Methodologies for innovation

When involving multiple stakeholders by building collaborative capacity, special attention should be paid to the barriers that prevent the most vulnerable groups – especially foreign and hard-to-reach Roma – from taking part in institutional decisions (e.g. lack of information about participation opportunities, economic and time constraints, language barriers, limited self-confidence,

asymmetries in power, unattractive goals, failure to accommodate cultural diversity, invalidation of users' voice, disempowering experiences).

Methodologies for innovation offer opportunities to overcome these challenges and to connect people, ideas, and resources at the same time, thus enhancing collaborative capacity. Some examples are: (a) platforms and processes for involving Roma children in generating innovations, decision making, planning, and influencing health public policy; (b) Citizen petitions online platforms for capturing Roma's ideas on health-related issues; (c) Events and conferences for networking and learning; (d) Participatory workshops where Roma community, civil society and other stakeholders analyze, share and enhance their knowledge to plan, manage and evaluate health actions and programmes; (e) Virtual meetings, webinars, and dialogue café to link up stakeholders around the world; (f) Innovation hubs are shared work spaces designed to promote collaboration and innovation among different stakeholders working to tackle wicked problems such as Roma health; and (g) Think tanks and do tanks to generate ideas and engage them into practice in the Roma health fieldwork (Murray, Caulier-Grice and Mulgan, 2010).

These methodologies follow the **learn by doing premise**, with the following benefits: (a) developing stakeholders' skills and knowledge to work in collaboration; (b) creating positive environment and relationships among stakeholders; (c) encouraging effective leadership and communication; (d) setting realistic community-driven goals; and (e) promoting engagement and accountability in the planning, implementation, evaluation and sustainability of policies and practices (Florin et al., 2010; Foster-Fishman et al., 2001; García-Ramírez et al., 2009; Goodman, Speers and McLeroy, 1998; Fetterman, Kaftarian and Wandersman, 2004).

5.3.2. New technologies

A good way to implement TRHP is by taking advantage of **new technologies** in the field of public health. According to the EUPHA and *The Lancet*, these tools may serve not only for communities' empowerment and self-management of their own health, but also for enhancing and sustaining networking, sharing resources, knowledge, and training skills for those providers and stakeholders involved in community health with the Roma (Boyce, 2012; Zeegers et al., 2013). Box 10 provides some examples on these tools.

Box 10: New technologies in Transformative Roma Health Policies

- **Smartphones, videogames, social media, internet and mobile apps.** The *Journal of Medical Internet Research*¹⁸ is an excellent source to find a wide range of research and actions related to web-based and mobile health interventions, e-learning, eHealth literacy, tele-health and tele-monitoring, among others. But also, to find guides for public health researchers and practitioners on how to develop these interventions (Horvath et al., 2015). Some examples about the application of these technologies in health are serious videogames aimed at preventing child and adolescent obesity (Thompson, 2014), also apps for making healthier food choices (Dunford et al., 2014), for assessing youth sexual health programmes using text messaging technology (Sheoran et al., 2014), or mobile health interventions for self-management and lifestyle change for type 2 diabetes (Holmen et al., 2014) among others.

¹⁸ *Journal of Medical Internet Research*. Available from www.jmir.org/

- **Participatory mapping and Geographic Information Systems (GIS).** In fields like geography and territorial policy, participatory mapping is a well-established tool since it allows improved information exchange between community members and different stakeholders in the design and implementation of actions and policies within the community (Di Gessea, 2008). Probably, the use of maps in health care has been mostly restricted to physiological and epidemiological studies. However, its applications can go beyond this, for example, such as a tool for empowerment. Maps can help monitor and secure access to health-care services and resources, to facilitate their management, and to support community advocacy on health-related issues. Some examples of this are The WHO's Substance Abuse Instrument for mapping services (Babor and Pozniak, 2010), the experience on mapping mental health advocacy services in London (Foley and Platzner, 2007), or health promotion programmes using intervention mapping (Kok and Mesters, 2011). In the same vein, Geographic Information Systems are creating valuable contributions for enhancing health care and health information systems in the last years (Nhavoto and Gronlund, 2014).

In particular, we would like to focus on internet-based support systems such as the online platform "Community Tool Box,"¹⁹ developed by the University of Kansas in the United States (Box 11). **Online platforms** facilitates multiple stakeholders to be better prepared to work together to change health conditions that affect their lives, thus reducing the inequities that hinder the pursuit of social change and justice (Holt et al., 2013). This way, a **Roma Tool Box** could work as an **exchange network** that allows connecting multiple stakeholders at local and global levels who are engaged in transforming and building healthier Roma communities. A tool like this is **a means to give voice** to local concerns and silent ranks, thus working for the empowerment of Roma users and the Roma community itself (e.g., enhancing their involvement in health service delivery design and development) (Francisco et al., 2001). It is also a great opportunity for **building capacity for systems change**, for creating and adjusting contexts **to ensure the success** of interventions, and also for **evaluating** interventions within an open system environment (Francisco et al., 2001; Holt et al., 2013). Moreover, a Roma Tool Box could be an excellent **support infrastructure** with a wide range of resources for learning courses, training materials, workshops, assistance, access to community building skills, networking, connecting ideas, etc.

Following the recommendations of Francisco et al. (2001), the Roma Tool Box should have the following features: (a) to have a comprehensive content; (b) the information needs to be easily available on demand (e.g., readable, printable, and downloadable); (c) the information must be useful, providing step-by-step guidance to be directly applied in practice; (d) the material should be friendly and supportive for users who may lack sufficient knowledge or skills on the subject; (e) there should be exchange mechanisms to connect experts with people in need of help; (f) it should be universally available and free; and (g) it should pursue lifelong learning, being useful and helpful across generations.

Box 11: The Community Tool Box

- The Community Tool Box was created in 1994 by the Work Group for Community Health and Development at University of Kansas, and collaborators (Francisco et al., 2001; Holt et al., 2013). It is a free online resource, available in different languages (i.e. English, Spanish and

¹⁹ Community Tool Box. Available from <http://ctb.ku.edu/>

Arabic), widely accessed – more than a million users around the world – by multiple people, settings and organizations that seek to enhance their skills in competencies for community work. The Community Tool Box content is organized in the following way:

- *Learn a skill.* This section offers practical and step-by-step guidance in community building skills related to (a) Understanding community context (e.g. assessing community assets and needs), (b) Collaborative planning (e.g. developing a vision, mission, objectives, strategies, and action plans), (c) Developing leadership and enhancing participation (e.g. building relationships, recruiting participants), (d) Community action and intervention (e.g. designing interventions, advocacy), (e) Evaluating community initiatives (e.g. programme evaluation, documentation of community and systems change), and (f) Promoting and sustaining the initiative (e.g., social marketing, obtaining grants).
- *Do the Work.* It contains toolkits with detailed how-to outlines and checklists, real world examples, training materials, etc. for different competencies (e.g. creating and maintaining coalitions, assessing community needs and resources, developing a strategic plan, developing an intervention, enhancing cultural competence, evaluating the initiative, implementing social marketing, and planning for sustainability).
- *Solve a Problem.* It offers additional support through troubleshooting guides and training courses for common dilemmas faced when starting and developing community work (e.g. planning, assessment, participation, publicity, programme development, leadership, or advocacy). There is also an Ask an Advisor service by which experienced community members and experts provides brief and personalized answers to these questions.
- *Use Promising Approaches.* It provides links to comprehensive databases of evidence based practices and online resources for addressing specific community problems or goals. Community WorkStations facilitate users to easily share materials, make announcements, access tools, learn from successful community stories, and access guidance from peer discussions.
- *Connect with Others.* Besides the Ask and Advisor service, other ways to facilitate networking is through links to online resources, e-newsletters and social media.

FINAL THOUGHTS

Roma health has become an issue of global importance and awareness in Europe. However, we find ourselves in a society ruled by States that are reducing social and economic public interventions due to changes in the distribution of power and resources, which benefit some groups in detriment of others. This is reflected in new public health policies that promote (a) the transformation of NHS in privatize and insurance-based health-care systems, (b) the reduction of public responsibility in the health of the population, (c) making individuals themselves solely responsible for their health, and (d) understanding health promotion as behavioural change (Navarro, 2013). Nevertheless, these principles are being impossible to sustain due to the current and difficult economic, social and political context, but also due to the fact that traditional responses of health-care systems are insufficient to tackle these challenges in health. First, these systems are based in a health-care model that aims to cure instead of caring – even when the main causes of mortality are due to diseases which cannot be cured with medical interventions (e.g. cancer, cardiovascular diseases). And second, because these systems support health prevention and promotion programmes focused on individual and behavioural changes rather than structural changes, hence resulting ineffective to eliminate health inequities. Therefore, it is necessary that TRHP include political, economic, social, and cultural interventions in order to change the structural and social determinants of health. In this vein, these new public health policies should (a) encourage participation and influence in society, (b) focus on social and economic determinants, (c) carry out contextual interventions that protect users, (d) secure favourable conditions for the children, the adolescent and the elderly; and (e) create health-care interventions that promote health. Furthermore, all these interventions should begin, in the first place, with the empowerment of Roma people as well as the rest of the civil society (Navarro, 2013).

In this endeavour, all stakeholders are called upon to play a central role in overcoming the unacceptable persecution, discrimination, and inhumane life that Roma people suffer in opulent Europe. The difficult circumstances in which many Roma live drives us to develop creative TRHP and initiatives while trying to reduce their suffering, which is an urgent matter. How can we walk this fine line without our work being allied with the dominant structures that uphold existing inequities and perpetuate discrimination and prejudice? First, our task is to erase the “social inequalities kill” misconception by bringing up the issue of power, thus pointing out that those who kill are responsible for and the ones who benefit from the inequalities that kill (Navarro, 2013). And second, we are obliged to help Roma communities to live day by day, to strengthen their critical thinking, and to build expectations of prosperity among people whose situation prevents them from recognizing their own potential for liberation and happiness. These can be overwhelming tasks. However, both endeavours are an example of how stakeholders are committed in the pursuit of meaning for Roma people and their communities (Prilleltensky, 2014). With this overall objective in mind, this paper hopes to provide a valuable and critical example of the complexity of overcoming inequities in well-being and health, by balancing transformative and ameliorative purposes in policies from a stakeholder perspective when conditions of inequality seriously jeopardize the health and well-being of voiceless groups.

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ANNEX I. DESK REVIEW

- **Cabedo García, V.R. et al. (2000). *Cómo son y de qué padecen los gitanos. Atención Primaria, 26(1)*.** This study is of interest as it compares national Roma and non-Roma according to their socio-demographic characteristics and health status. The results showed more social and health risks and higher incidence of some diseases in Roma. They also showed an early average age of death, labour situation and education level more unfavourable than non-Roma. The fact that Roma use more the private health care was also found.
Correspondence with analytical framework: Social determinants and health.
- **Consejería de Salud y Bienestar Social, Junta de Andalucía (2012). *Instrucciones de la DG de Asistencia Sanitaria y Resultados en Salud del Servicio Andaluz de Salud sobre el reconocimiento del derecho a la asistencia sanitaria en centros del Sistema Sanitario Público de Andalucía a personas extranjeras en situación irregular y sin recursos*.** This document is response to the Royal Decree-Law 16/2012. This instruction recognizes the right to health care for undocumented foreigners without resources in centres of the Public Health Service of Andalusia.
Correspondence with analytical framework: Coherence with EU Communications and Council Conclusions; Health system strengthening; Goals, outcomes and governances mechanisms.
- **Consejería de Trabajo y Asuntos Sociales, Junta de Andalucía (1996). *Plan Integral Comunidad Gitana de Andalucía*.** This plan seeks the promotion of Roma with special social problems in different areas (housing, education, training and employment, health, culture, social action and woman) such as: (1) to carry out action strategies aimed to Roma's promotion, prevention, treatment and elimination of marginalization; (2) to coordinate and make profitable the existent resources and set up new ones in order to improve the quality of the attention of the Roma community; (3) to promote the participation and action of this community in issues that affect their development; (4) to provide sensitivity to public opinion; and (5) to promote the knowledge of Roma on public systems of social protection and normalize its use.
Correspondence with analytical framework: Coherence with EU Communications and Council Conclusions; Health system strengthening; Goals, outcomes and governances mechanisms; Monitoring and evaluation.
- **Cortes Generales de España (1978). *Constitución Española*.** The Spanish Constitution is the supreme law of the Kingdom of Spain and it includes the most basic rights – including health – that must be applied to every citizen.
Correspondence with analytical framework: Coherence with EU Communications and Council Conclusions; Health system strengthening; Goals, outcomes and governances mechanisms.
- **Departament de Benestar Social i Família, Generalitat de Catalunya (2006, 2009). *I and II Pla Integral del Poble Gitano a Catalunya 2005–2008*. Departament de Benestar i Família.** Both plans aim to combat, from a global perspective, the inequality suffered by the Roma population in Catalonia as well as promote and recognize the cultural features that are unique to this group. For that, they have action plans for different areas: culture and identity, family, housing and urban development, education, employment, health and sanitation, social participation, language, media and social image, justice and public safety.

Correspondence with analytical framework: Coherence with EU Communications and Council Conclusions; Health system strengthening; Goals, outcomes and governance mechanisms; Monitoring and evaluation.

- **Departament de Salut, Generalitat de Catalunya (2006). Pla Director d'Immigració en l'Àmbit de la Salut. Departament de Salut.** This plan targets improving the health of the immigrant population by defining a model of attention and service reorganization of the Catalan health system. Its objectives focus on maternal and child health, HIV, sexually transmitted diseases, tuberculosis and cancer.
Correspondence with analytical framework: Coherence with EU communications and Council conclusions; Health system strengthening; Goals, outcomes and governance mechanisms; Monitoring and evaluation.
- **Departament de Salut, Generalitat de Catalunya (2012). Instrucció 10/2012. Accés a l'assistència sanitària de cobertura pública del CatSalut als ciutadans estrangers empadronats a Catalunya que no tenen la condició d'assegurats o beneficiaris del Sistema Nacional de Salut.** This instruction discusses access to the public health-care system of Catalonia for registered foreigners without legal residence and not recognized by the NHS. This document is the regional response to the Royal Decree-Law 16/2012.
Correspondence with analytical framework: Coherence with EU communications and Council conclusions; Health system strengthening; Goals, outcomes and governance mechanisms.
- **Family Voices (2009). Growing Your Capacity to Engage Diverse Communities by working with Community Liaisons Cultural Brokers.** This report offers an overview of the work developed by cultural brokers and community liaisons, as well as it provides tools to make informed decisions, advocate for improved public and private policies, build partnerships among families and providers and serve as a trusted resource on health care.
Correspondence with analytical framework: Health system strengthening.
- **Ferrer, F. (2003). El estado de salud del pueblo gitano en España. Una revisión de la bibliografía. Gaceta Sanitaria, 17 (Supl. 3):2–8.** This article discusses which Roma health-related issues had received attention in the literature, and whether their ethnic differences and social inequalities had been studied. The results show that most frequent topics were genetics or congenital anomalies, transmissible diseases, child health, and health sociology. They also show that 57 per cent of the studies reported some social inequalities in health.
Correspondence with analytical framework: Social determinants and health.
- **Fundación Secretariado Gitano (2006). Handbook for Action in the Area of Health Services with the Roma Community.** This Handbook is of interest because it was compiled as a contribution to the reduction of health inequalities in the NHS. Its goal is to achieve equally and culturally adapted treatment for users and their needs. To that end, the Handbook lays down a series of action proposals designed to correct inequalities regarding the access of Roma to the public health system.
Correspondence with analytical framework: Coherence with EU Communications and Council Conclusions; Social determinants and health; Health system strengthening; Goals, outcomes and governance mechanisms; Monitoring and evaluation.

- **Fundación Secretariado Gitano (2012). Políticas De Inclusión Social Y Población Gitana En España. Editorial Dobrogea, FSG.** This report consists of review and assessment of the past and current policies and factors that have contributed – and hindered – the social inclusion of Roma population in Spain.
Correspondence with analytical framework: Coherence with EU communications and Council conclusions; Health system strengthening; Goals, outcomes and governances mechanisms; Monitoring and evaluation.

- **Fundación Secretariado Gitano (2013). El impacto de la crisis en la comunidad gitana. Madrid: Autor.** In this document is described the impact that the economic crisis and austerity measures have on the Roma community in Spain, including the area of health. It is found that the crisis affects more the groups who were already vulnerable, causing decline or stagnation in the progress made by the Roma community in recent decades.
Correspondence with analytical framework: Coherence with EU communications and Council conclusions; Social determinants and health; Monitoring and evaluation.

- **Ley 14/1986, de 25 de abril, General de Sanidad.** This Law establishes the general regulations of the health-care services in Spain. Also, it contemplates all its actions that afford to implement the right to health protection, being holders of this right all Spanish and foreign citizens who have established their residence in the country.
Correspondence with analytical framework: Coherence with EU communications and Council conclusions; Health system strengthening; Goals, outcomes and governances mechanisms.

- **Ley Orgánica 15/1999, de 13 de diciembre, de Protección de Datos de Carácter Personal.** This Organic Law aims to guarantee and protect the processing of personal data, civil liberties and fundamental rights of physical persons, and especially their honour and personal and family privacy. It is relevant to our study as it contemplates the protection of ethnic data, this having consequences for Roma policies and strategies.
Correspondence with analytical framework: Coherence with EU communications and Council conclusions; Goals, outcomes and governances mechanisms.

- **Ley 16/2003, de 28 de mayo, de cohesión y calidad del Sistema Nacional de Salud.** The object of this Law is to establish the legal framework for coordination and cooperation actions of the public health authorities in the exercise of their respective powers, so that equity, quality and social participation in the NHS is guaranteed, as well as the active participation of the latter in reducing health inequalities.
Correspondence with analytical framework: Coherence with EU communications and Council conclusions; Health system strengthening; Goals, outcomes and governances mechanisms.

- **Real Decreto-Ley 16/2012, de 20 de abril, de medidas urgentes para garantizar la sostenibilidad del Sistema Nacional de Salud y mejorar la calidad y seguridad de sus prestaciones.** This document represents an important milestone in shaping the Spanish health-care system. Until 2012, the NHS was aimed at universality. Since the entry into force of this Royal Decree-Law (RDL), the beneficiary status of the NHS changed into insured of the Social Security system, thus limiting the right and access to health care for those who are not considered as such.

Correspondence with analytical framework: Coherence with EU communications and Council conclusions; Health system strengthening; Goals, outcomes and governance mechanisms.

- **La Parra, D. (2009). Hacia la equidad en salud: Estudio comparativo de las encuestas nacionales de salud a población gitana y población general de España, 2006. Ministerio de Sanidad y Fundación Secretariado Gitano.** This is a comparative study of the National Health Surveys of 2006 to Roma and non-Roma population of Spain. We consider it interesting, as it is the first study done in Spain describing the impact of social determinants on Roma health in order to detect possible health inequalities affecting this community in comparison with the general population. Lifestyle and access to health-care services are issues that affect in a negative way the Roma community's health.

Correspondence with analytical framework: Coherence with EU communications and Council conclusions; Social determinants and health; System strengthening; Monitoring and evaluation.

- **La Parra, D., D. Gil-González and A. Jiménez (2013). Los procesos de exclusión social y la salud del pueblo gitano en España. Gaceta Sanitaria, 27(5):385–386.** This article presents a review of the Roma health and social situation in Spain. It provides information on both topics and analyses the main EU programmes implemented in recent years for this population and the plans carried out in Spain in line with the EU. It also offers recommendations for actions to advance social equity and better health of Roma in Spain.

Correspondence with analytical framework: Coherence with EU communications and Council conclusions; Social determinants and health; Monitoring and evaluation.

- **Laparra, M. (ed.) (2011). Diagnóstico social de la comunidad gitana en España. Un análisis contrastado de la Encuesta del CIS a Hogares de Población Gitana 2007. Madrid: Autor.** This report is interesting due to the data and information provided on the Roma community, its structure, population size, and data about their health status and social factors that influence it.

Correspondence with analytical framework: Coherence with EU communications and Council conclusions; Social determinants and health; Monitoring and evaluation.

- **Laparra, M. (ed.) (2007). Situación social y tendencias de cambio en la Comunidad Gitana. Ministerio de Sanidad.** This report reviews the research and studies on Roma community that had been carried out in Spain during the last decades. It is of interest because it provides information about Roma population and demographic structure, as well as issues regarding their health, analysing the relationship of this community with the health-care system and its health-care models.

Correspondence with analytical framework: Coherence with EU communications and Council conclusions; Social determinants and health; Monitoring and evaluation.

- **Laparra, M. et al. (2012). Civil Society Monitoring Report on the Implementation of the National Roma Integration Strategy and Decade Action Plan in 2012 in Spain. Budapest: Decade of Roma Inclusion Secretariat Foundation.** This is a monitoring report on the NRIS actions developed in Spain until 2012. It presents alternative information to the assessment made by the government, describing the results obtained in several areas. Regarding health,

it provides data on the Roma health status and its factors, stressing the consequences of the economic crisis such as the deterioration of the public health services.

Correspondence with analytical framework: Coherence with EU communications and Council conclusions; Social determinants and health; System strengthening; Monitoring and evaluation.

- **López Catalán, O. (2012). Visión General de la Población Rom/Gitana Rumana.** The aim of this document is to provide an overview of foreign Roma in Spain, thus being of interest to this report. It offers a coherent and basic framework to understand some of the specificities regarding this population. Among others, information about their relationship with health-care services and their difficulties encountered to access and enjoy them.
Correspondence with analytical framework: Social determinants and health.
- **Mendez, C. (2007). Desigualtats socioeconòmiques i diferència cultural a l'àmbit de la salut en barris d'actuació prioritària de Catalunya.** This document talks about inequalities in health and access to health-care services through the prism of cultural differences and diversity within the Roma community. It also provides some suggestions for action to improve the health status of this group.
Correspondence with analytical framework: Social determinants and health; Health system strengthening.
- **Ministerio de Educación, Política Social y Deporte (2008). National Action Plan on Social Inclusion of the Kingdom of Spain 2008–2010.** This document represents the development of national plan aimed for people who are at risk of social exclusion. The priority objectives are fostering access to employment, guaranteeing minimum economic resources, achieving an equitable and quality education system, supporting the social integration of immigrants and guaranteeing equality in assistance to persons in a situation of dependence. It includes also actions aimed at the Roma community.
Correspondence with analytical framework: Coherence with EU communications and Council conclusions; Health system strengthening; Goals, outcomes and governances mechanisms; Monitoring and evaluation
- **Ministerio de Sanidad y Consumo & Fundación Secretariado Gitano (2007). Health and the Roma Community. Analysis of action proposals. Madrid: Ministerio de Sanidad y Consumo.** This document provides an initial diagnosis of the health status of national Roma in Spain in order to identify their principal needs and thus contribute to the elimination of the existing health inequalities faced by this group. It describes the main weaknesses, threats, strengths and opportunities of the Roma community related to health and it also provides recommendation for actions.
Correspondence with analytical framework: Coherence with EU communications and Council conclusions; Social determinants and health; Monitoring and evaluation
- **Ministerio de Sanidad, Política Social e Igualdad (2010, 2012). Progress report 2010 and 2012 on the NRIS in Spain.** These reports provide information on the implementation of the NRIS in Spain in 2010 and 2012 as well as data on the Roma and the programmes and actions carried out in Spain within the action plan of the Decade of Roma Inclusion during those years.

Correspondence with analytical framework: Coherence with EU communications and Council conclusions; Social determinants and health; System strengthening; Monitoring and evaluation.

- **Ministerio de Sanidad, Política Social e Igualdad (2011). Action Plan for the Development of the Romani population 2010–2012.** This plan is relevant, as it was developed to promote new actions to correct the existing imbalances between the Roma and the rest of the Spanish population. In order to achieve this, it highlighted the need of encouraging different forms of participation and social development that ensure Roma full exercise of social rights and access to goods and services; improving their image and promoting equal treatment; and contributing to the promotion of the European policy in favour of the Roma and its participation in the development.

Correspondence with analytical framework: Coherence with EU communications and Council conclusions; Social determinants and health; Health system strengthening; Goals, outcomes and governance mechanisms; Monitoring and evaluation.

- **Ministerio de Sanidad, Política Social e Igualdad (2012b). National Roma Integration Strategy in Spain 2012–2020.** This is the core document on which the national consultants have relied on to develop this progress report on the implementation of the NRIS in Spain. This strategy was conceived as European opportunity to strengthen and heighten the channels and measures aimed at integrating the Roma in different areas of our societies (these are education, housing, employment and health).

Correspondence with analytical framework: Coherence with EU communications and Council conclusions; Social determinants and health; System strengthening; Goals, outcomes and governance mechanisms; Monitoring and evaluation.

- **Ministerio de Sanidad, Política Social e Igualdad (2012c). Guía metodológica para integrar la Equidad en las Estrategias, Programas y Actividades de Salud.** This methodological guide aims to raise awareness among health providers, policymakers and other sectors whose policies have an impact on health and social determinants. It provides a practical tool to facilitate the effective integration of equity in health strategies, programmes and activities.

Correspondence with analytical framework: Coherence with EU communications and Council conclusions; Social determinants and health; System strengthening; Goals, outcomes and governance mechanisms; Monitoring and evaluation.

- **Ministerio de Sanidad, Política Social e Igualdad (2013). Plan Operativo 2014–2016 de la NRIS.** This is the first Operational Plan that supports the implementation of the NRIS in Spain. Following the guidelines of the EU, it establishes measurable objectives and facilitates strategies in the areas of education, employment, housing and health to achieve in the timeframe of 2020. In this document some activities are already proposed for 2014. These activities can be specific for the Roma or for the general population.

Correspondence with analytical framework: Coherence with EU communications and Council conclusions; Social determinants and health; System strengthening; Goals, outcomes and governance mechanisms; Monitoring and evaluation.

- **Ministerio de Sanidad, Política Social e Igualdad (2013b). Real Decreto 576/2013, de 26 de julio, por el que se establecen los requisitos básicos del convenio especial de prestación de**

asistencia sanitaria a personas que no tengan la condición de aseguradas ni de beneficiarias del Sistema Nacional de Salud y se modifica el Real Decreto 1192/2012, de 3 de agosto, por el que se regula la condición de asegurado y de beneficiario a efectos de la asistencia sanitaria en España, con cargo a fondos públicos, a través del Sistema Nacional de Salud.

This document states another milestone in the configuration of the NHS in Spain. After the RDL 16/2012, this decree represents the transformation of the NHS – previously universal and funded by the State – in a sort of private health insurance company through which those excluded from the health-care system can access by paying a monthly fee.

Correspondence with analytical framework: Coherence with EU communications and Council conclusions; Health system strengthening; Goals, outcomes and governance mechanisms.

- **Sánchez Serrano, F.J., et al. (2002). Diferencia étnica en la actividad asistencial de urgencias. Aproximación a la realidad gitana. *An Esp Pediatr*, 56:17–22.** The study shed light on the situation of Roma children. This article aims to determine the health, social and welfare characteristics of Roma children in comparison to the rest of the population.

Correspondence with analytical framework: Social determinants and health; Health system strengthening.

- **Slavkova, M. (2010). Estrategias migratorias de la población gitana búlgara en España. *Revista de Recerca i Formació en Antropologia*, 12.** This paper is relevant to know about foreign Roma in Spain coming from Bulgaria. It presents the reasons and characteristics of migration flows of Bulgarian Roma, as well as it provides information about their access to health-care services and the strategies and difficulties in this area.

Correspondence with analytical framework: Social determinants and health.

- **World Health Organization and Ministerio de Sanidad y Consumo (2008). *Promoción de la salud. Glosario*. World Health Organization, Ginebra.** The basic purpose of the glossary is to facilitate health communication between countries and within them, as well as between the different organizations and individuals working in this field. It provides an agreed definition on health within European framework.

Correspondence with analytical framework: Coherence with EU communications and Council conclusions; Social determinants and health; Health system strengthening.

ANNEX II. EQUI-HEALTH STAKEHOLDERS IN SPANISH COALITION

Policymakers and health-care organizations

- **Direcció General (DG) per a l'Immigració (DGI – Dept. Benestar Social i Família, Generalitat de Catalunya):** They propose policies for the integration of immigrants, which are then considered by the Government of Catalonia. They also coordinate the actions of the different departments and local organizations working in this field. They have developed social cohesion programmes in areas with a high Roma population density from Eastern Europe. Finally, they have constituted a technical team to coordinate the assistance of immigrant Roma population in all policy areas. For more information: www.gencat.cat/benestarsocialifamilia/immigracio
- **DG d'Atenció a la Infància y l'Adolescència (DGAIA - Dept. Benestar Social i Família, Generalitat de Catalunya):** This institutional body has collaborated with the Catalanian Fundación Secretariado Gitano in the social inclusion programme for Roma coming from Eastern Europe. Some of its main activities within this programme included social and medical care support and accompaniment, promotion of family health, schooling support and school reinforcement. For more information: www20.gencat.cat/portal/site/bsf/menuitem.7fca6ecb84d307b43f6c8910b0c0e1a0/?vgnextoid=4e0622a30e5a4210VgnVCM1000008d0c1e0aRCRD&&
- **DG d'Acció Cívica i Comunitària (Dept. Benestar Social i Família, Generalitat de Catalunya):** This institution has chaired the Inter-departmental Commission of the Comprehensive Plan of the Roma population, whose committee is composed of representatives from the different departments in the Government of Catalonia. They put forward measures to coordinate and monitor interdepartmental actions within the Plan Integral. For more information: www20.gencat.cat/portal/site/bsf/menuitem.cb7c44c1c72cf6b43f6c8910b0c0e1a0/?vgnextoid=81c2e5f0edf6d210VgnVCM2000009b0c1e0aRCRD&vgnnextchannel=81c2e5f0edf6d210VgnVCM2000009b0c1e0aRCRD&vgnnextfmt=default
- **Direcció d'Atenció al Ciutadà. Regió Sanitària Barcelona (Generalitat de Catalunya):** They provide Health Cards for citizens and process and monitor users' access to the NHS, being in charge of monitoring waiting lists and accessibility. They also assess user assistance, manage complaints and claims, and process cost recovery, benefits applications and support services. For more information: www14.gencat.cat/sacgencat/AppJava/organisme_fitxa.jsp?codi=7001
- **Agència de Salut Pública de Catalunya (ASPCAT – Secretarí General de Salut Pública del Departamento de Salud - Generalitat de Cataluña):** The main aim of this agency is to protect citizens' health and safety through prevention, promotion and protection health programmes. They also offer troubleshooting services in public health. Their work is based on cross-sectoral collaboration and shared responsibility among different agents. Regarding their specific role with Roma population, ASPCAT has promoted the development of health policies adapted to the needs of the Roma community, for example, by implementing programmes that improve the accessibility and quality of health services, training programmes for health-care providers, and mediation programmes. For more

information: www20.gencat.cat/portal/site/salut/menuitem.81a4919118f3026913a90f10b0c0e1a0/?vgnnextoid=afc125837e73f310VgnVCM2000009b0c1e0aRCRD&vgnnextchannel=afc125837e73f310VgnVCM2000009b0c1e0aRCRD&vgnnextfmt=default

- **Centro de Atención Primaria Santa Rosa (Institut Català de la Salut, Generalitat de Catalunya):** This PHC centre is in Santa Coloma de Gramanet, a city in the province of Barcelona with nearly 40 per cent of immigrant population, mostly from Eastern Europe. This centre carries out important community health actions addressed to foreign Roma, including assistance to excluded users, health promotion and childhood health projects, among others. For more information: www14.gencat.cat/sacgencat/AppJava/organisme_fitxa.jsp?codi=7978
- **Hospital del Mar (Institut Català de la Salut, Generalitat de Catalunya):** This is the main health-care service in Parc de Salut Mar, on the coast of Barcelona. It is a community hospital very much involved in primary care that has become a model for nearby districts such as Ciutat Vella and Sant Martí. This hospital assists large numbers of national and foreign Roma patients and it has implemented mediation programmes for this population. For more information: www.parcdesalutmar.cat/hospitals/hospital-del-mar/
- **Hospital Universitari Germans Trias i Pujol (Institut Català de la Salut, Generalitat de Catalunya):** This is the most important health centre in the Northern Metropolitan area of Barcelona and it is on the Can Ruti campus in Badalona. It assists a large national and foreign Roma population. Some of the Roma immigrants it assists are undocumented, which means that the hospital has to work closely with NGOs so that this population can access social and health services. For more information: www.gencat.cat/ics/germanstrias/
- **DG de Coordinación de Políticas Migratorias (Junta de Andalucía):** This body is in charge of promoting, coordinating and assessing the public health policies of the different offices in the Andalusian regional government. It also liaises with other public administrations and citizens in order to adequately implement these policies. Finally, it encourages intercultural tolerance and respect for diversity in Andalusia. Furthermore, it has subsidised programmes specifically addressed to the Eastern European Roma population in Andalusia up until 2009, when this population became part of the EU. For more information: www.juntadeandalucia.es/organismos/justiciaeinterior/consejeria/dgcpm.html
- **Secretaría para la Comunidad Gitana (DG de Servicios Sociales e Inclusión, Junta de Andalucía):** It is in charge of advising and coordinating actions to provide comprehensive assistance to Roma people. It also elaborates, implements and assesses the Plan Integral para la Comunidad Gitana in Andalusia, as well as the actions of the Plan Nacional de Desarrollo Gitano that apply to the region. Among other activities, it has created and runs the Centro Sociocultural Gitano Andaluz. For more information: www.juntadeandalucia.es/organismos/igualdadsaludypolicassociales/areas/inclusion/comunidad-gitana/paginas/secretaria-comunidad-gitana.html
- **Centro de Atención Primaria Polígono Sur (Servicio Andaluz de Salud, Junta de Andalucía):** This PHC centre is located in Polígono Sur, one of the most depressed and marginalized areas

in Seville with a large national Roma population and other vulnerable groups. This centre is important for its work in the promotion of reproductive and sexual health among Roma women through a successful family planning programme, which is the case study used in this report.

Academia

- **Grupo de Recerca en Antropologia Fonamental i Orientada (GRAFO, Universitat Autònoma de Barcelona):** This group develops research and actions for sociocultural transformation. It focuses on the study of the Roma community, its cultural representations and customs, its presence in institutional contexts, as well as processes of social integration, social relations and associationism. For more information: www.grafo.cat
- **Coalition for the Study of Health, Power and Diversity (CESPYD – Universidad de Sevilla):** This interdisciplinary research group develops research on and actions with intercultural and vulnerable groups, especially in relation to health care and social action. Its main aim is to empower communities and social agents to get involved in processes of social change. This is done through interventions that take into consideration these groups' needs and strengths. For more information: www.cespyd.es

Community

- **Federació d'Associacions Gitanes de Catalunya (FAGIC):** This is a non-profit organisation that brings together all the Roma associations in Catalonia. Its main aim is to defend and promote Roma rights and culture. It also mediates with the public administration in order to optimise resources and adapt its actions to the needs of the Roma population. Among other activities, it offers advice, support, troubleshooting and mediation services in health care. It also organises training courses for health-care providers in order to ensure the quality of health-care services. For more information: www.fagic.org
- **VINCLE. Serveis a la persona i a la Comunitat. Associació per la recerca i l'acció social:** This is an institutional body devoted to promoting positive changes in society. It intends to raise social awareness, to increase social involvement and to empower vulnerable groups in order to ensure their social integration. Collaborative work between public institutions and citizens allows them to develop community actions that encourage social participation and the integration and support of socially excluded groups such as the foreign Roma. For more information: www.vincle.org
- **Fundación Secretariado Gitano (Cataluña y Andalucía):** This is an intercultural, non-profit social organisation that promotes the development of the Roma community. To do so, it works towards achieving full citizenship for the Roma population, promoting their access to rights, services, goods and social resources, improving their social conditions, fostering equality, and valorising Roma culture and identity. In the field of health care, it elaborates national and international reports on the health of the Roma people. It also collaborates regionally and locally by providing technical assistance to public and private health centres and by organising cultural training courses for health-care providers. For more information: www.gitanos.org/

- **Federación de Mujeres Gitanas (FAKALI) y Asociación de Mujeres Universitarias Romí Andaluzas (AMURADI):** FAKALI is an organisation that comprises several associations of Roma women in Andalusia, including AMURADI. Both seek to promote associative actions among young Roma women as agents of social change; to provide the public administration with the necessary tools to facilitate the implementation of policies that are sensitive to Roma women; to promote gender and ethnic equality; and to make the Roma culture and heritage known to society. For more information: www.amuradi.org/

- **Unión Romaní Andalucía:** This is an NGO created and directed by Roma people. It works towards the recognition of their culture as a positive contribution to society, both nationally and internationally. Some of its activities in health care include intercultural mediation and the training of mediators and health-care providers and support to health centres in assisting the Roma community. They also offer support for health centres assisting Roma patients; transportation and accompaniment to health centres for families; and health education for communities excluded in settlements. For more information: www.unionromani.org

ANNEX III. SPANISH GUIDELINE FOR STAKEHOLDERS INTERVIEW

- ¿Cuáles son las principales barreras en el acceso a los servicios de salud primarios, de emergencia y especializados para los gitanos nacionales, Romaníes europeos y de terceros países?
- ¿Cuál es la cobertura actual de salud de estos grupos? ¿Qué soluciones existen a nivel local para aquellos con baja cobertura?
- ¿Conoce la National Roma Integration Strategy?
 - ¿Sabe cómo se está implementando? ¿Y financiando?
 - ¿Sabe cuáles son los mecanismos de evaluación y monitorización?
 - ¿Cómo participan las autoridades regionales, locales y nacionales en esta estrategia?
- La NRIS pretende mejorar:
 - En población adulta, la percepción de salud, reducir los accidentes de tráfico, el consumo de tabaco en hombres, la obesidad en mujeres así como el número de éstas que nunca han acudido al ginecólogo. ¿Conoce intervenciones encaminadas a conseguir estos objetivos?
 - En menores, los objetivos son reducir el número de accidentes domésticos, la obesidad infantil y mejorar la salud dental. ¿Conoce intervenciones encaminadas a conseguir estos objetivos?
- ¿Se incluyen objetivos específicos para reducir la desigualdad y la atención a la diversidad en los servicios del Sistema Nacional de Salud?
- ¿Se adaptan culturalmente los recursos y servicios del SNS cuando es necesario?
- ¿Conoce políticas y acciones dirigidas a reducir las desigualdades de salud en niños, adolescentes y mujeres?
- ¿Se reorientan los servicios de salud hacia la igualdad en áreas de promoción, prevención y la asistencia sanitaria?
- ¿Se llevan a cabo medidas activas de promoción de la salud en niños y adolescentes Romaníes? ¿Sabe si los servicios de pediatría proveen información y promueven formación para la población Romaní?
- ¿Existen mecanismos que aseguren un impacto en la salud de la población Romaní en las estrategias y planes propuestos por el Ministerio de Sanidad y por las Comunidades Autónomas?
- ¿Se fomenta el trabajo transversal y la coordinación con otras entidades, instituciones y planes?
- ¿Se fomenta la colaboración y la participación de la comunidad Romaní?
- ¿Se apoyan e impulsan actividades de formación para proveedores sanitarios en diversidad, capacidades interculturales e igualdad?
- ¿Conoce algún programa sobre mediadores en salud con población Romaní?
- ¿Podría decirnos alguna buena práctica con un enfoque integral de la asistencia sanitaria a población Romaní a nivel nacional/regional/local? ¿Y lecciones aprendidas?
- ¿Sabe cómo las estrategias y acciones nacionales/regionales contribuyen o se relacionan con las estrategias sobre desigualdades en salud de la Comisión Europea (e.g. Europa 2020, Health 2020, EC: Solidarity in health, etc.)?
- ¿Conoce otros programas de salud a nivel nacional o regional relevantes para la población Romaní financiados por la Comisión Europea (e.g. en educación, empleo)?
- Recomendaciones/sugerencias para planificar futuras políticas y planes en salud para los Roma.

ANNEX IV. TERMS OF REFERENCE OF THE EQUI-HEALTH PROJECT



Terms of Reference National Consultant [country]

Title of contract

Progress report from a multi-stakeholder perspective on the implementation of the NRIS (National Roma Integration Strategy) and other national commitments in respect to Roma Health in [country]

Project background and purpose of contract

In February 2013, the International Organization for Migration launched the Equi-Health project: *Fostering health provision for migrants, the Roma, and other vulnerable groups* aimed at improving the access and quality of health care services, health promotion and prevention to address health inequities in the EU. The Equi-Health is a direct grant awarded to IOM by the EC DG Health and Consumers, within the Public Health Programme 2012.

The sub-action on Roma Health has for an objective strengthening of national, regional, and EU level approaches to Roma. To this end, it will develop a coherent network and promote dialogue among key stakeholders on Roma health related issues and delineate strategies and interventions to support capacity building and cooperation within and between participating states. As part of the activities, progress country reports on national integration strategies for Roma health, as well as case studies on good practices and recommendations for better use of structural/cohesion funds for health and vulnerable groups are planned to support EU Member States to better monitor, share and strengthen their national approaches to Roma health.

Planned participating countries include EU countries with high percentage of Roma nationals and committed/interested EU countries with high percentage of Roma migrants.

These Terms of Reference (ToR) outline the details of the assignment to be carried out by the Consultant on assessing the actions taken to date in respect to health, including the implementation of national programmes and promising practices as well as lessons learnt from unsuccessful/poor practices in selected countries. The analysis will focus on the implementation of the Roma Integration strategies, as well as national action plans and commitments as to improving Roma health.

Scope of work to be performed by the Consultant

The Consultant's task shall include drafting of a **progress report from a multi-stakeholder perspective** on the implementation of the NRIS (National Roma Integration Strategy) and other national commitments in respect to Roma Health in [country]. This report will be considered as a baseline report to cover national developments since 2005 to 2013 in the field



of Roma health policy interventions. It will be followed by a second report to assess the progress made in comparison to the baseline situation in 2015.

The work will require both desk and fieldwork research. The purpose of the desk research will be to contextualize and provide the background for the fieldwork research consisting of interviews with stakeholders and a case study to form the final progress report.

The research should cover the following areas:

- Legal and policy developments in respect to Roma health national programmes and action plans with special focus on the NRIS (process of development, objectives, planning and implementation on both national and local levels and in respect to relevant recommendations incl. both binding and non-binding documents, issued by the EU bodies)
- Mapping of promising practices as well as lessons learnt from unsuccessful/poor practices (a possibility for such is suggested in the form of a case study/ies) on both national and local/community levels

Target group(s)

Health, social inclusion and other national authorities of EU Member States (MS) directly and/or indirectly involved in the provision of and access to healthcare services to Roma communities.

The final beneficiaries of the project are European Roma communities being national citizens and/or migrants within the EU.

Glossary of terms

The Equi-Health glossary of Roma and Travellers is following the terminology used by the Council of Europe (CoE).¹

In addition, the following terms will be used:

- Roma nationals, referring to citizens of EU MS from Roma ethnic origin;
- Roma migrants referring to migrants, EU citizens from Roma ethnic origin (in the sense of EU internal migration/ mobility), and;
- Roma TCN (third country nationals), referring to migrants from third countries to the EU from Roma ethnic origin (for example migrants to the EU from the Western Balkans).

¹ See CoE's (2006) *Glossary on Roma and Travellers*: http://www.coe.int/t/dg3/romatravellers/default_en.asp



Specific activities

Activity 1: Desk research

1. The desk research will provide an overview of existing studies and data from 2005 onwards (with an indicative start of the Roma Decade) on the Roma health situation in the country, as well as a review of any national programmes and developments relevant to the topic of Roma health.
2. The desk review should consist of:
 - a) *Literature review* to revise available data and information on Roma population (national and/or migrants) in terms of numbers, health status and access, quality of health with special focus on basic, emergency and specialized health care services, as well as women and children health (*Please see content of progress report*).
 - **Sources:** Published peer-reviewed literature (journals, online health databases); reports from governmental and non-governmental agencies as well as intergovernmental and UN agencies; bibliographies of recent EC/FRA publications and other major references; databases on ethnicity and health; relevant internet sites/databases of good practices such as that of OSI, Roma Decade, CoE, etc.
 - b) *Legal review* to outline the legal provisions in terms of access to health care services for Roma population (national and/or migrants) in the country, discrimination, right to health and existence of complaint mechanisms in case of discrimination in access to health with special focus on basic, emergency and specialized health care services, as well as women and children health.
 - **Sources:** Identification/collection and analysis of legislation incl. local resources, and documents at national, regional/provincial, and community levels.
 - c) *Policy research* to review barriers in access to health services (e.g. geographic, economic, etc.) experienced by Roma population (national and/or migrants) and how these barriers are tackled by the national policies and strategies incl. the NRIS, analysis of “good”/ promising practices as well as lessons learnt from unsuccessful/poor practices with special focus on basic, emergency and specialized health care services, as well as women and children health.
 - **Sources:** EU and national statistics on health, academic research, NGO reports and other sources, health authorities’ documents and websites in English, as well as national languages.
3. Taking into account the challenges in data collection, the Consultant should aim to identify and combine information from various sources in order to obtain the most comprehensive country overview. If any specific data is not available, the Consultant should indicate the respective data gaps in the report.
4. IOM will provide a list of sources available in English to be thoroughly considered during the desk research phase as a starting point of the analysis (*see annex I*).



5. The Consultant is responsible for the analysis of additional information from sources available in the national language and the collection of additional data locally.

Activity 2: Development of questionnaires for stakeholder interviews

1. On the basis of the findings from the desk research (*on topics of major concern, identified gaps, where insufficient information for valid research conclusions, and/or evidence on promising/poor practices*) the Consultant shall draft (a) questionnaire(s), in close coordination with IOM, for semi-structured interviews to be used during the fieldwork with varied groups of stakeholders, relevant to the topic of research.
2. The Consultant shall provide a list of topics he/she would suggest to further investigate in respect to NRIS national commitment' implementation and other programs of relevance. The following issues should be considered in the questionnaire(s) as minimum:
 - Barriers in access to basic, emergency and specialized health care services for Roma
 - Social security coverage and existing local solutions to low security coverage amongst Roma communities (*if such exist*)
 - National context:
 - o NRIS (health strand): process of development (and revision), national commitments' implementation, evaluation/ monitoring mechanisms, funding & sustainability, involvement of local authorities and CSO.
 - o Other national (health) programmes relevant to the issue of Roma health (i.e. EC funded programmes in the field of regional development, education, employment, etc.)
 - EU context: how national strategies (and actions) relate to and contribute to the EC policies on health inequalities, with particular attention to the Europe 2020 Strategy for smart, sustainable and inclusive growth, COM(2009) Solidarity in Health: Reducing health inequalities in the EU, the EU cohesion policy and other EU strategic documents (*as per references provided in annex*)
 - Roma Health Mediators Programme(s) (implementation, challenges, monitoring mechanisms, evaluation, sustainability and institutionalization).
 - Collection of disaggregated data to support evidence based policies at national/ local level.
 - Examples (promising initiatives and/or lessons learnt from unsuccessful ones), practices of integrated approach to healthcare at national/ local level.

Activity 3: Key stakeholder interviews

1. The Consultant should suggest and then conduct an agreed number of semi-structured interviews with the objective to generate a multi-stakeholder perspective on the situation in the country.
2. The respondents will include representatives of national/regional and local authorities in selected municipalities, CSOs and experts working in the field of Roma health, as well as Roma in order to account from a multi-stakeholder perspective on the challenges faced by the Roma population in access to health and identify existing policy solutions and their



implementation in response to these challenges in the context of NRIS and other national programs.

Activity 4: Case study

1. On the basis of the desk research and key stakeholder interviews, the Consultant should propose a topic for a case study to focus more in details on specific problem of interest for the analysis.
2. The topic can be any of the previously mentioned issues of concern and/or a new problem or initiative, as far as its relevance to the national context is well argued and coordinated with IOM.

Activity 5: Analysis and presentation of results

1. Presentation of preliminary results at NCC (National Consultative Committee) Meeting in the country (organized by IOM country office)
 - The Consultant will contribute to the presentation of the results from the study at a National Consultative Meeting in the country within the framework of Equi-Health project.
 - The Consultant will consider the recommendations and conclusions from discussions at the NCC and reflect them in the final version of the national progress report.

Activity 6: Finalization of deliverables

1. The final output of the work will be the **report from a multi-stakeholder perspective on the implementation of the NRIS and other national commitments in respect to Roma Health** in [country], complemented by:
 - A power point presentation, and
 - A fact sheet document, in English and the country national language, summarizing the research findings and outlining recommendations for follow-up actions
 - Individual stories/ quotes/ perspectives (in the form of boxed stories, etc.) and photos (taken with all due acquiescing of involved persons) for further dissemination of project activities.

Structure and content of the progress report *sample*

The progress report will incorporate the results from the desk research, stakeholder interviews and the case study.

The progress report should be organized according to the following structure:



A. Executive Summary

B. Introduction

C. Background/ overview of the situation (method: desk research)

- **Number of Roma population** (official statistics & unofficial estimations of Roma national/ Roma migrants/ Roma third-country nationals)
- **Data/information from desk research** (literature, legal and policy review) on Roma population health status, health needs and barriers in access to basic, emergency and specialized health care services

D. Overview of policy developments at national level from a multi-stakeholder perspective (method key stakeholder interviews)

- NRIS:
 - overview of the process of development, main national stakeholders involved, process of decision of health priorities, development of action plan and linkages to other national programmes (health program, etc.), implementation and/or process of revision of strategy, funding mechanism, monitoring mechanisms, planned evaluations of the NRIS);
 - EC evaluation of the NRIS and country specific recommendations: main challenges identified in terms of health and respective MS actions;
- Other health programmes/ relevant national programmes in respect to Roma health (i.e. EC funded programmes in the field regional development, education, employment, etc.);
- EU context: it is also important to outline in the report how the national strategies (and actions) relate and contribute to the EC policies on health inequalities, with particular attention to the Europe 2020 Strategy for smart, sustainable and inclusive growth, COM(2009) Solidarity in Health: Reducing health inequalities in the EU, the EU cohesion policy and other EU strategic documents listed in Annex I.

Special focus need to be devoted to the following priorities, listed in the EC Communication "National Roma Integration Strategies: A first step in the implementation of the EU framework" (May 2012) as part of an integrated approach to healthcare:

- Extend health and **basic social security coverage** and services (also via addressing registration with local authorities);
- Improve the **access of Roma**, alongside other vulnerable groups, to **basic, emergency and specialized services**;
- Launch **awareness raising campaigns** on regular medical checks, pre- and postnatal care, family planning and immunization;
- Ensure that **preventive health measures** reach out to Roma, in particular **women and children**;
- Improve **living conditions** with focus on segregated settlements



E. Overview of policy developments at local/municipal level from a multi-stakeholder perspective (method key stakeholder interviews)

- Roma Integration strategy at local level (process of adoption, implementation and challenges as to NRIS, main actors involved, link to other local programmes/initiatives, funding)
- Other health programmes implemented on local/municipal level (i.e. EC funded programmes in the field regional development, education, employment, etc.);

F. Case study [country specific]

- Results from the case study

Annex

A summary and key findings concerning all interviews, structured according to relevant categories that will have been emerged as the result of the qualitative research are expected to be annexed to the progress report, complemented by photographs (taken with appropriate approval is persons are recognisably shown).

Format

The progress report will comprise of desk research, field research and case study/ies, for a total of approximately 24,000 words (around 60 pages), excluding tables and annexes. **The final length of the report may change depending on the country context.**

The report should be prepared in English, at a proof-reading quality and submitted in MS Word, single spaced, Times New Roman, font size 12 format and sent by e-mail to ROBrusselsMHUnit@iom.int.

Any data used for graphs or tables should also be provided in Excel format for editing purposes. A bibliography with all the sources analysed – both in English and in the national language - should be inserted following the IOM style guide.

Application process

In order to be selected for a national Consultant, the applicant shall submit a proposal (up to 10 pages) and a CV, outlining relevant research experience in the field of migration and ethnic minorities' health to the Migration Health Division, RO Brussels. The proposal should provide a brief overview of the situation in country in respect to Roma health, methodology for research, suggested list of respondents for key stakeholder interviews and an initial proposal for a case study research.

Deliverables/Outputs

The work should begin immediately after the signature of the contract.



1. No later than two weeks after the signature of the contract, the national Consultant shall submit **the final list of potential stakeholders for key informant interviews from a multi-stakeholder perspective, methodology, draft questionnaire(s) as well as a detailed work plan** to the Migration Health Division, RO Brussels.
2. No later than one month after the signature of the contract, the Consultant should submit **the draft desk review, update as to the on-going interviewing process with key stakeholders and provide a proposal for case study.**
IOM might suggest a few additional interviews with stakeholders based on the results from the desk research.
3. No later than 31 January 2014, the Consultant shall submit **a draft progress report including new and generated qualitative data.**
4. No later than 31 February 2014, the Consultant shall submit **the second draft of the progress report which should incorporate all the findings from the research (if not previously) from the case study /interviews.** The report shall be in English, in accordance with the provided guidelines, and include an overview on statistics, summary and key findings of interviews, and any report(s) on additional data/ material/ information/ documents.
5. No later than 20th March, the Consultant shall submit **the final progress report, a ppt presentation, a fact sheet presenting the research results and individual stories/quotes/photos for further dissemination of project activities.** Some final clarifications and revisions might be requested until the end of March when the progress report should be finalized.

Reporting:

The national Consultant will coordinate closely with MHD RO Brussels the preparation and conducting of the research, as well as the drafting of the final progress report.

The national Consultant will report to the Migration Health Division, RO Brussels and keep them apprised of any developments which could affect the implementation and timelines during the course of the study.

By the 10th day of each month for the duration of the contract the Consultant must submit a brief written progress report to the IOM Migration Health Project Officer based in Sofia, Bulgaria. These should respectively detail activities, undertaken in the above mentioned research project and time spent on these activities.

Timeline for the Consultancy: November 2013 – April 2014

Remuneration: Negotiable, subject to previous experience, skills

Required competencies of the lead researcher:

- a) PhD or equivalent experience in the fields of social research, public health, migration and ethnic minorities' health or related fields;



- b) Experience in conducting quantitative and qualitative social research;
- c) Excellent English writing skills;
- d) Excellent communication and negotiation skills;
- e) Experience in liaising with governmental authorities, national/regional and international institutions, including research institutes and universities;
- f) Ability to work harmoniously and effectively in a multinational, multidisciplinary team;
- g) Previous research experience or work on Roma health would be a definite advantage.

The national Consultant should ideally be based in the country where the work is to be done.



Annex I: Sources of information

EU strategic documents

DG REGIONAL POLICY (http://ec.europa.eu/regional_policy/index_en.cfm) (with focus on EU Structural funds and Roma inclusion policy in EU MS incl. specific recommendations for MS with Roma population)

DG JUSTICE (http://ec.europa.eu/justice/discrimination/roma/index_en.htm)

DG EMPLOYMENT AND SOCIAL AFFAIRS
(<http://ec.europa.eu/social/main.jsp?langId=en&catId=750>)

<http://ec.europa.eu/europe2020/making-it-happen/country-specific-recommendations/>
(with focus on country specific recommendations in relation to social inclusion of Roma population)

Communication from the Commission Europe 2020 **A strategy for smart, sustainable and inclusive growth** (with focus on country specific recommendations in relation to inequalities in health and Roma)
(<http://eur-lex.europa.eu/LexUriServ/LexUriServ.do?uri=COM:2010:2020:FIN:EN:PDF>)

EU Communication “Solidarity in health: reducing health inequalities in the EU” (2009)

Council conclusions on the Inclusion of Roma and the Common Basic Principles on Roma inclusion (2009)

EC Communication on EU framework for National Roma integration strategies up to 2020 (2011)

Council conclusions on an EU framework for National Roma integration strategies up to 2020 (2011)

European Parliament Resolution on the EU strategy on Roma inclusion (2011)

EU Communication “The social and economic integration of the Roma in Europe” (2010)

EC Communication “National Roma Integration Strategies: A First Step in the Implementation of the EU Framework” (May 2012)

EC, Steps forward in implementing national Roma integration strategies (2013)

EC, Proposal for a Council recommendation on effective Roma integration measures in Member States (2013)

EP motion for a resolution on strengthening the fight against racism, xenophobia and hate crime (2013)



<http://www.europarl.europa.eu/sides/getDoc.do?type=MOTION&reference=B7-2013-0123&language=EN>)

FRA The progress of Roma in 11 EU Member States, Survey results at a glance (2012)

Roma platform website

http://ec.europa.eu/justice/discrimination/roma/roma-platform/index_en.htm)

CoE

Protecting the rights of Roma (2011)

Human rights of Roma and travelers in Europe (2012)

ROMED programme (I and II phases)

Romact programme

Good practices database (with special focus on health practices in the database)

IOs

Interagency Coordination Initiative *Scaling up action towards Millennium Development Goals (MDGs) 4 and 5 in the context of the Decade of Roma Inclusion and the National Strategies for Roma Integration*

UNDP Thematic reports: Roma Inclusion Papers series, country reports, online database of the UNDP Regional Centre for Europe and the Community of Independent States;

Reports of CSOs

European Roma Policy Coalition, Analysis of the national Roma integration strategies / European Roma Policy Coalition, 2012

European Roma Information Office, The European Commission's main achievements in Roma inclusion/ 2012

EUroma (European Network on Social Inclusion and Roma under the Structural Funds) Facts by country

OSI

Roma Health Mediators Successes and Challenges (2011)

Beyond Rhetoric: Roma Integration Roadmap for 2020 Priorities for an EU Framework for National Roma Integration Strategies compiled by Bernard Rorke, International Research and Advocacy Director for the Open Society Roma Initiatives (2011)



Critical Review of EU Framework National Roma Integration Strategies (NRIS), Open Society Foundations Review of NRIS submitted by Bulgaria, the Czech Republic, Hungary, Romania and Slovakia (2012)

Decade of Roma inclusions (<http://www.romadecade.org/>)

- Decade Progress reports (2010, 2011, and 2012)
- Civil Society Monitoring reports (2012)
- Other relevant publication to HEALTH

DG SANCO funded projects

- Mighealthnet

[http://mighealth.net/eu/index.php/Roma %26 Traveller communities](http://mighealth.net/eu/index.php/Roma_%26_Traveller_communities)

[http://mighealth.net/eu/index.php/3. Projects on Roma health](http://mighealth.net/eu/index.php/3_Projects_on_Roma_health)

- Roma Health Project

Health and the Roma Community, Analysis of the Progress in Europe. Bulgaria, Czech Republic, Greece, Portugal, Romania, Slovakia, Spain
(http://ec.europa.eu/justice/discrimination/files/roma_health_en.pdf)