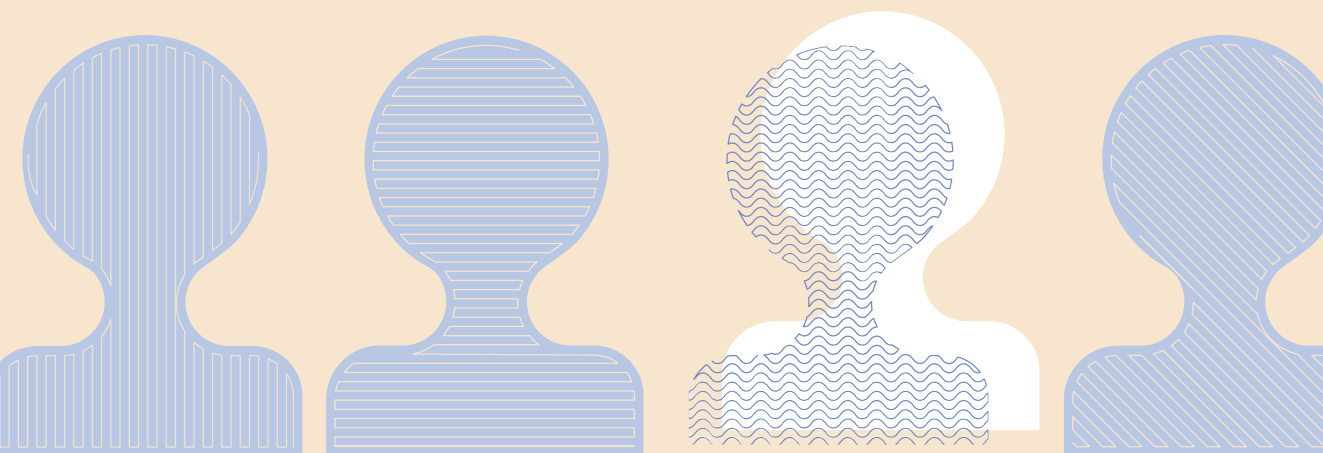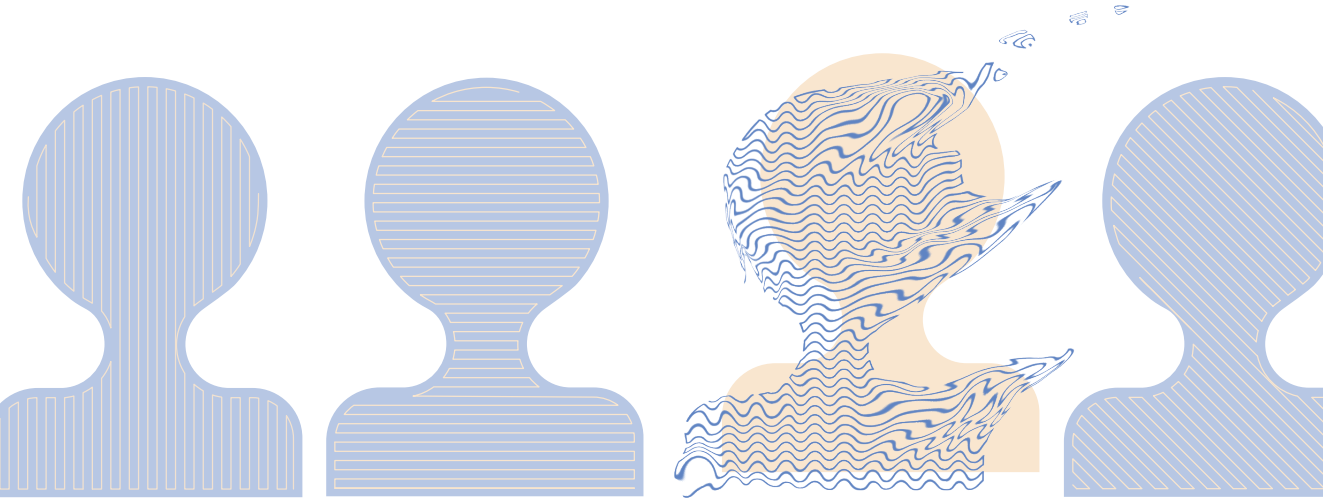# Guidelines for Activists on Access to Health Care & Vaccination for Roma and Sinti

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Designed by Hugo Balandra

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1 INTRODUCTION

The OSCE Office for Democratic Institutions and Human Rights (ODIHR) has a mandate to assist OSCE participating States in implementing commitments related to Roma and Sinti, stemming from the OSCE Action Plan on Improving the Situation of Roma and Sinti within the OSCE Area[1] (Action Plan), and three subsequent Ministerial Council Decisions.[2]

Chapter Four of the Action Plan focuses on "Addressing socio-economic issues" by recommending actions on health care. Through these recommendations participating States have committed themselves to "ensuring that Roma and Sinti people have access to healthcare services on a non-discriminatory basis" and to "encouraging access by Roma and Sinti populations to general public health services at an early stage" through information dissemination and strengthening confidence towards public health care providers.[3]

1 **OSCE Ministerial Council, Decision No. 3/03,** "Action Plan on Improving the Situation of Roma and Sinti within the OSCE Area", Maastricht, 1–2 December 2003.
2 **OSCE Ministerial Council, Decision No. 6/08,** "Enhancing OSCE Efforts to Implement the Action Plan on Improving the Situation of Roma and Sinti within the OSCE Area", Helsinki, 5 December 2008; **OSCE Ministerial Council, Decision No. 8/09,** "Enhancing OSCE Efforts to Ensure Roma and Sinti Sustainable Integration", Athens, 2 December 2009; and **OSCE Ministerial Council, Decision No. 4/13,** "Enhancing OSCE Efforts to Implement the Action Plan on Improving the Situation of Roma and Sinti within the OSCE Area, with a Particular Focus on Roma and Sinti Women, Youth and Children", Kyiv, 6 December 2013.
3 **OSCE Ministerial Council, Decision No. 3/03,** provisions 58 and 61.

ODIHR is mandated to "[…] draw upon existing research data to identify socio-economic, political and cultural factors that have an impact on the health status of particular Roma and Sinti populations, and […] advise participating States regarding public health programmes which would respond to needs identified."[4] ODIHR is also mandated to "assist participating States in launching educational initiatives to help Roma and Sinti people make full use of regular health services" including through "collecting, producing and disseminating relevant information on good practices."[5]

On average, Roma and Sinti life expectancy is between five to twenty years shorter than that of the mainstream population. This is mainly due to preventable risks such as malnutrition, inadequate housing conditions and the inability to afford healthcare services, as well as the impact of racist and discriminatory practices from healthcare institutions and professionals.[6] Roma and Sinti people often live in locations that have severe consequences for their health,[7] and many of them face barriers in accessing quality health care resulting in low well-being, which in turn affects their children's educational outcomes.[8] Moreover, Roma and Sinti patients have regularly reported ill-treatment and violation of their human rights within healthcare institutions. This ranges from the denial of healthcare services, delivery of inferior medical care, abusive behaviour and treatment, segregation, extortion, and violation of privacy and confidentiality, to name just a few examples.[9]

4 *Ibid*., provision 64.
5 *Ibid*., provisions 65.
6 Post-2020 EU Framework for National Roma Integration Strategies — Five Recommendations for Better Health European Public Health Alliance, October 2017.
7 Roma health in the European Region, World Health Organization.
8 Post-2020 EU Framework for National Roma Integration Strategies — Five Recommendations for Better Health European Public Health Alliance, October 2017, <https://epha.org/wp-content/uploads/2018/05/Roma-position-paper-2017-18.pdf>.
9 Roma Health Rights in Macedonia, Romania, and Serbia — A Baseline for Legal Advocacy, The Open Society Foundations, Public Health Program, June 2013.

In several participating States, access to quality health care has been significantly affected by the COVID-19 pandemic, in particular for the treatment of non-communicable diseases.[10] Coming on top of the challenges already faced by Roma and Sinti and compounded by a long history of neglect and marginalization, the pandemic has exacerbated problems with their access to quality healthcare services. Many Roma and Sinti do not have proper access to running water, sanitation and sewerage,[11] and consequently, they are more exposed to the risks of infection.[12]

Civil society, human rights defenders and activists, public institutions and other health-related stakeholders are vital in promoting health rights. They give voice to the issues faced by rights holders, monitor the activities of public institutions, advise policymakers and hold the authorities to account. All of these actors must collaborate and cooperate in order to understand the healthcare issues faced by disadvantaged Roma and Sinti communities and to create a platform for dialogue to support the implementation of social inclusion policies.

This guide aims to support civil society, human rights defenders and activists, public institutions and other stakeholders in implementing health-related activities to increase Roma and Sinti access to health care and vaccination services as a core human right.

10 **COVID-19 significantly impacts health services for non-communicable diseases,** World Health Organization website, 1 June 2020.
11 "According to the findings of the EU-Midis II, one in every three Roma lives in housing without safe drinking water, while connection to a water supply system remains particularly low. Drastic disparities in access to water and sanitation are observed in many EU Member States increasing the health risks for Roma." See more at: Radost Zaharieva, **Access to water – a major driver of health inequalities for Roma,** European Public Health Alliance, 26 March 2021. In addition, the EU Fundamental Rights Agency reports that washing is a challenge for 30% of Roma because they live in households with no tap water. In comparison, 80% of Roma in some countries also live in cramped Roma neighbourhoods with overcrowded housing. This makes physical distancing, a key element of public health measures, close to impossible. See more at: **Second European Union Minorities and Discrimination Survey Roma** – Selected findings, FRA, 29 November 2016.
12 **OSCE Human Dimension Commitments and State Responses to the Covid-19 Pandemic,** OSCE/ODIHR, 17 July 2020.

1.1 The right to health care and vaccination

According to the World Health Organization (WHO), health care is a fundamental human right through which people can access medical information and quality medical services to maintain their well-being. The right to health care is closely related to physical and mental, individual and social existence, and is defined as such in several international documents, such as the Constitution of the World Health Organization, the Universal Declaration of Human Rights, the International Covenant on Economic, Social and Cultural Rights, and the Charter of Fundamental Rights of the European Union.[13]

According to article 25 of the Universal Declaration of Human Rights, every person has the right to a standard of living that gives them health and well-being, both for themselves and their family. The standard of living implies food, clothing, housing, medical care, and other necessary services.[14] This is also re-affirmed under article 12 of the International Covenant on Economic, Social and Cultural Rights, which recognizes the right to enjoy the highest standard of physical and mental health.[15]

The right to health, as with other rights, includes both freedoms and rights. Freedoms include the right to control one's own health and body (e.g., the right to vaccination or reproductive health) and to be free from interference; for example, no torture, or non-consensual medical treatment (such as medical experiments and research, or forced sterilization). Rights include the right to a health protection system that gives everyone an equal chance to enjoy the highest possible level of health.[16] One essential aspect of the right to health is the protection of the mother and child, who enjoy equal rights, especially in accessing health services and epidemic disease prevention programmes managed through vaccination.

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13 Constitution of Health World Organization, World Health Organization, 9 October 2006.
14 Universal declaration of human rights United Nations, 1948, article 25.
15 International Covenant on Economic, Social and Cultural Rights, United Nations, 16 December 1966.
16 The Right to Health, OHCHR Fact Sheet No. 31, Office of the United Nations High Commissioner for Human Rights, World Health Organization, 2008.

Another relevant document that regulates the right to health protection is the European Social Charter adopted within the framework of the Council of Europe. According to Article 11, to effectively exercise the right to health care, the States' signatories to the Charter undertake, either directly or in collaboration with public and private organizations, to adopt appropriate measures aimed at eliminating the causes of poor health, providing consultation and education services on improving health, developing the individual's sense of responsibility for their health, and preventing epidemics and other diseases as well as accidents.

In addition, Article 13 of the Charter obliges signatory States to ensure that any person who does not have sufficient material resources is granted the right to health, to benefit from resources allocated from a social security system, and to make every effort to ensure people in difficulty do not suffer a diminution of their rights to medical care.[17]

Signatory States are considered to have fulfilled their obligations in this regard when the medical system has the following characteristics:

- Public health policy is coherent and made available to the population, and medical practitioners and the necessary pieces of equipment for the main health problems are provided to ensure adequate medical assistance, prevention and diagnosis of diseases;

- Measures for the protection of the health of the mother and child, and the elderly;

- Measures for vaccination, disinfection, control of epidemic diseases and for combating epidemic and endemic diseases; and

- A health insurance system organized by collective bodies supporting all or part of the costs of medical services.[18]

17 **European Social Charter (revised), Council of Europe,** Strasbourg, 3 May 1996.
18 Lenia Samuel, Fundamental social rights. Case law of the European Social Charter, 2nd edition, Strasbourg, 2002, p. 263.

Within the European Union, the legislative framework and public policies for health care developed by each Member State are based on a set of clear principles for the implementation of patients' rights and the provision of health services to the population. They aim at non-discrimination, equal access and equal treatment for all patients, regardless of race, nationality, ethnicity, language, religion, social status, beliefs, or other characteristics. From the human rights perspective, the Member States of the European Union regulate the equal access to health services for the general population, including vaccination activities for control of severe and potentially deadly infectious diseases. The regulation stems from a constitutional legislative framework elaborated following the Universal Declaration of Human Rights, the Charter of Fundamental Rights of the European Union and other essential documents. Examples of the legislative framework include state constitutions, health system legislation, National Health Strategies and other relevant documents specific to each state.

2

What are the main barriers for Roma and Sinti in accessing healthcare services and vaccination?

2.1 An overview of the situation of Roma and Sinti regarding access to health care and vaccination

Due to complex social disparities and the lack of social justice for vulnerable groups, access to public health services is still a significant problem in several participating States. In some, Roma and Sinti live on the edge of society, in segregated and underdeveloped areas where access to clean water, sanitation, waste disposal and infrastructure is still a challenge.[19]

The European Commission has highlighted that life expectancy among Roma is between five to twenty years shorter than that of the mainstream population. The disease and mortality rate of Roma is much higher than for the majority population due to low levels of access to public health services and lack of information about the risk factors of illnesses.[20]

In their evaluation reports on the implementation of the EU Framework for National Roma Integration Strategies up to 2020,[21] the European Agency for Human Rights (FRA)[22] and the European Commission[23] have noted that in the field of health there has been little progress on achieving key indicators and on implementing concrete measures to improve Roma access to health services.

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19 Leaping forward. Adapting the post-2020 EU Roma Framework to the real needs of beneficiaries, European Public Health Alliance, October 2019.

20 Roma Health Report — Health status of the Roma population. Data collection in the Member States of the European Union, European Commission, written by Matrix, 2014, p. 40.

21 For more information about the EU Roma national strategic frameworks see: <https://ec.europa.eu/info/policies/justice-and-fundamental-rights/combatting-discrimination/roma-eu/roma-equality-inclusion-and-participation-eu/eu-roma-national-strategic-frameworks-commission-evaluations-and-annual-reports_en>.

22 EU-MIDIS II, European Union Agency for Fundamental Rights, 29 November 2016.

23 Evaluation of the EU Framework for National Roma Integration Strategies up to 2020, European Commission, 7 October 2020.

This lack of improvement in critical areas such as health and housing has resulted in poor health, high child mortality rates and lower life expectancy for Roma and Sinti. This confirms the need for further political commitment, civil society engagement and increased investment to challenge the social injustice faced by Roma and Sinti in various participating States.[24]

2.1.1 Vaccination in Roma communities

According to a study conducted by the European Public Health Alliance in 2018, the level of immunization of Roma and Sinti is not consistent across European Union Member States.[25]

A little over half of the Roma population in Slovakia has received some sort of vaccination, compared to up to 99 per cent in the wider population. The fact that Roma are far behind in vaccination is likely to be a result of more difficult access to general health services, and thus irregular contact with general and other health practitioners.[26]

In Romania, only 20 per cent of the respondents declared they had been informed by a doctor about the importance of immunization, with others receiving this information from a healthcare worker or health mediator. Seventeen per cent of the respondents had not received any explanation or information about the importance of immunization. In contrast, more than half of the respondents replied that their children were vaccinated, with 1176 out of 1998 having been immunized.[27]

24 **Health inequalities: a persistent obstacle for Roma inclusion,** European Public Health Alliance, October 2020.
25 **Closing the life expectancy gap of Roma in Europe,** European Public Health Alliance, 10 December 2018.
26 *Ibid.*
27 *Ibid.*

2.1.2 The main barriers faced by Roma and Sinti in accessing health services

Roma and Sinti face several systemic barriers in accessing public health services. Adequate and accessible medical services are critical in shaping overall health and are essential in increasing social inclusion and ensuring equal opportunities for all. The main barriers restricting Roma and Sinti access to health services and contributing to the exacerbation of social exclusion, including increasing the life expectancy gap, are:

Lack of health data collection for Roma and Sinti: in the vast majority of studies conducted over the years, the method of assessing the health situation of Roma and Sinti has been based on estimated data rather than verified sources mandated to produce such information. These estimates were often collected from local Roma and Sinti activists and civil society organizations.[28]

Lack of personal identity documents and health insurance: Roma and Sinti are often unable to access national health programmes and interventions, as they do not meet the general conditions. The most cited conditions include lack of personal identity documents or inadequate health insurance coverage.[29] The lack of identity documents prevents access to many essential services, including medical care. This increases the incidence of births without medical supervision, which in turn is another obstacle to identity registration.[30]

28 Roma Health Report.
29 Inclusion of all Roma in the health insurance system, United Nations International Children's Emergency Fund, 2016.
30 Ibid.

Lack of health education in Roma and Sinti communities: a study from the Institute for Public Policy in Romania showed that about 46 per cent of Roma children did not benefit from the national vaccination programme due to lack of information/education among Roma community members. In comparison, the vaccination rate among the general population exceeds 95 per cent.[31]

Geographical isolation from healthcare facilities: in marginalized communities, the absence of public transport or material resources to allow patients to travel to a dispensary is an important barrier to accessing health services. It is primarily Roma and Sinti communities in rural areas that suffer from limited access to quality medical services.[32] One example of a geographically isolated community is the Ocolna village, in Dolj County, Romania, inhabited only by Roma. This community is 10 kilometres from the communal dispensary, Dabuleni City Hospital, and 70 kilometres from Craiova Emergency Hospital. The Local Authority has not identified a viable solution to ensure daily public transport for this community.[33]

31 Accesul echitabil al copiilor romi la servicii de sănătate, (Fair access for children to health services) Institute for Public Policy, 2015, Romanian version.
32 H. Frazer and E. Marlier, Promoting the social inclusion of Roma, UE Network of Independent Experts on Social Inclusion, Synthesis Report, December 2011.
33 Roma Center for Health Policies "Sastipen", Internal Report (2014).

Lack of medical infrastructure in Roma and Sinti communities: Roma and Sinti communities often lack medical infrastructure nearby, including specialist doctors or family doctors to provide quality medical services. According to a special report from the Romanian Ombudsman Institution, several communities have been identified which have no family doctors for various reasons (retirement, closure of medical services, etc.). The report also highlighted the problems of family doctors, such as the lack of equipment and materials needed to perform medical acts safely, both for them and for their patients.[34]

Lack of trust in health care service providers: acceptance is a supply-side barrier when the attitudes of health workers express lack of respect or empathy. Overwhelming numbers of personal accounts from Roma and Sinti patients highlight the condescending or hostile attitude of their primary care providers. Prejudice and lack of trust quickly become reciprocal and are often fed by Roma and Sinti distrust in public health services.[35] Cultural and linguistic barriers, as well as racist and discriminatory practices, such as segregation in hospital units, also play a significant role in hindering Roma and Sinti access to public health services.[36]

34 Special Report on lack of family doctors from rural areas, disadvantaged area or hard to reach area, Romanian Ombudsman Institution, 2021, Romanian version.
35 Pim de Graaf, Primary care for the Roma in Europe: Position paper of the European forum for primary care, National Library of Medicine, 1 September 2016.
36 G. Roman, R. Grama, The health mediators and the need for an intercultural approach to health within Roma communities, University of Medicine and Pharmacy Iaşi, Romania, 2012.

2.1.3 General observations on the impact of the COVID 19 pandemic on Roma communities

The COVID-19 pandemic has also hampered access to health services, mainly for marginalized communities including Roma and Sinti. More often than not, Roma and Sinti communities across the OSCE region were at high risk of infection, as they live in rural and close-knit communities where physical distancing measures are hard to implement. Some of these communities also lack access to water that enables them to care for their personal hygiene. High poverty rates make them 'hard-to-reach' in public health terms. Consequently, these locations and their inhabitants are more prone to the risk of infection. The long history of neglect and marginalization of Roma and Sinti compounds the challenges posed by the pandemic, with many people already suffering from poor health.[37]

In an attempt to tackle vulnerability during the pandemic, many governments applied one-size-fits-all policy measures. However, a study by the European Public Health Alliance looking at health inequalities notes that such approaches have had a negative impact on Roma and Sinti. The study argues that the inequality of rights and access to resources makes Roma and Sinti much more vulnerable to a health crisis and that a targeted approach would therefore be needed.[38]

In general, vaccination saves millions of lives every year. There are currently about 25 vaccines in use to prevent and control infectious diseases, helping people of all ages live longer and healthier lives. For COVID-19, vaccination remains a viable step towards building immunity to the virus. According to the Strategy to Achieve Global COVID-19 Vaccination by mid-2022 issued by World Health Organization, every state must act with urgency to optimize their national strategic framework on vaccination.

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37 OSCE Human Dimension Commitments and State Responses to the COVID-19 Pandemic.
38 Meaningful Advocacy for Roma Health During the Covid-19 Crisis: The Yilo Experience, European Public Health Alliance, December 2021.

Policies and prioritization are needed to harness emerging evidence to maximize access to the new vaccines.[39] All national strategic frameworks on vaccination should ensure the following principles:

Equal, safe access to vaccination against COVID-19	Efficacy and fairness to prevent COVID–19	Limitation of COVID–19 epidemics

Unfortunately, many participating States lack official data on the rates of COVID-19 vaccination in Roma and Sinti communities. However, one civil society organization from Romania conducted a study with a sample size of 801 Roma. They found that 34 per cent of Roma were fully vaccinated with two doses of the COVID-19 vaccine. This is 9 per cent below the non-Roma population of Romania. The main reasons for reluctance to vaccinate against COVID-19 are:

Low confidence in the vaccine (22% Roma are confident, compared to 28% non-Roma)	Fear of side effects (20% Roma, compared to 12 % non-Roma)
Contraindications (14% Roma, compared to 11% non-Roma).	The belief that they do not need a vaccine (9% Roma, compared to 14% non-Roma).

The study also showed that only 45 per cent of the Roma respondents had great confidence in the information given by doctors about the COVID-19 pandemic, about 5 per cent less than the non-Roma population. Encouragingly, the same study also found no evidence of discriminatory barriers; vaccination centres provided equal treatment to all who wished to be vaccinated. This was the most important factor in reducing COVID-19 infections among Roma communities.[40]

39 Strategy to Achieve Global Covid-19 Vaccination by mid-2022.
40 Assessing Roma perceptions, attitudes and knowledge about vaccination against COVID 19, IRES, Agentia Impreuna, Romanian version, November 2021.

2.2 Discrimination against Roma and Sinti in accessing health care

The refusal to provide health care services to Roma and Sinti can often constitute direct discrimination. It can take many forms, including refusing entry to medical facilities, limits on when Roma and Sinti patients can be treated and refusing to help family members or visitors.[41]

In some cases, Roma and Sinti have been physically barred from entering health care centres based on their ethnicity. Also common are limits on the days and times when healthcare workers see Roma and Sinti patients.[42] Segregating Roma and Sinti patients in healthcare centres in Roma-only rooms, showers, dining rooms/kitchens and other facilities is an alarming example of direct discrimination by healthcare institutions. This practice seems particularly common in maternity wards. Roma and Sinti women perceive racial stereotyping as the motivation for separation into "Roma" and "white" rooms; Roma and Sinti women are seen as "anti-social", "undisciplined", "dirty", or "thieves". Healthcare workers often attempt to hide these prejudices by claiming that Roma and Sinti women would be more comfortable sharing rooms with each other.[43]

41 Breaking the Barriers — Romani Women and Access to Public Health Care, Council of Europe, Luxembourg, 2003.
42 Human Rights Report on Situation of Roma in Eastern Slovakia, 2000-2001, Roma Rights Centre, Košice, Slovakia, p.10.
43 Romani Mothers Win Hospital Discrimination Case in Hungarian Supreme Court, European Roma Rights Centre, 31 August 2020. Watson, Helen L, and Soo Downe. Discrimination against childbearing Romani women in maternity care in Europe: a mixed-methods systematic review Reproductive Health, vol. 14,1 1, 5 January 2017. Mariya Cheresheva, 'Roma Segregated' in Bulgarian Maternity Wards, Balkan Insight, 18 December 2017. Breaking the Barriers — Romani Women and Access to Public Health Care, Council of Europe, Luxembourg, 2003.

The perception that Roma and Sinti are discriminated against should not be underestimated, particularly in cases of hospital segregation and access to health services. It is therefore necessary to ensure that civil society organizations, human rights defenders and activists have an adequate mechanism for monitoring and documenting cases. These cases should be flagged to human rights institutions. At the same time, Roma and Sinti patients and those caring for them should be encouraged to make complaints through confidential reporting mechanisms, with assurances that access to health services will not be threatened or revoked by speaking up. Moreover, healthcare institutions should take measures to prevent, monitor and sanction such behaviour.[44]

44 *Ibid*.

3

How can access to health care and vaccination be improved for Roma and Sinti communities?

3.1 Brief interventions that may be conducted by activists and civil society to increase access to health care and vaccination for Roma and Sinti

- Map problems with Roma and Sinti access to health care in order to develop public health policies adapted to the actual needs of the communities;

- Empower local civil society organizations and community leaders to become partners in dialogue with local authorities to improve access of Roma and Sinti to public health services, using community monitoring tools;

- Develop and strengthen partnerships with public authorities and Roma and Sinti community representatives to implement education and awareness-raising campaigns on disease prevention and the importance of immunization, including vaccination against COVID 19;

- Implement advocacy campaigns among local, national and international institutions about Roma and Sinti health to reduce health inequalities at the community level;

- Initiate and develop pilot programmes to establish Community Medical and Social Assistance Centres at community level, providing primary medical services to all Roma and Sinti community members;

- Promote models of positive practices to increase trust between Roma and Sinti and medical staff through training to sensitize general practitioners and students from universities of medicine and pharmacy about ethics and non-discrimination towards vulnerable groups in the healthcare system;

- Actively participate in developing, monitoring, and evaluating local/regional/national public policies about Roma and Sinti health;

- Develop comprehensive training programmes for public health service providers to prevent all forms of discrimination. These should cover national and international human rights law, the specifics of local Roma and Sinti communities, and vulnerable groups; and

- Monitor and document cases of discrimination in access to health services for the Roma and Sinti population and combat this with health institutions.

3.2 Mapping community structures and why it is very important

Community Mapping is generally understood as a visual, geographic representation of community characteristics. However, the term can also be used conceptually; as a database of information with or without visual representation.

The primary objective of Community Mapping is to collect data to create a map of community resources within a defined area. A community map highlights the people, physical structures, organizations and institutions that can be utilized to create a meaningful service project.

There are many benefits to mapping community resources but, in particular, the process itself can help a community to:

- Gain in-depth information about a public authority's policies, procedures, funding streams and collaborative practices;

- Identify opportunities and challenges for meeting Roma and Sinti health needs;

- Provide a comprehensive set of policy recommendations for public authorities and opportunities for collaboration on Roma and Sinti health issues;

- Identify new resources to develop, enhance, and sustain Roma health policies;

- Determine whether existing resources are being used effectively to achieve the expected reduction in health inequalities;

- Improve alignment and coordination of human resources on Roma and Sinti health;

- Enhance coordination and collaboration among Roma and Sinti communities, civil society organizations, human rights defenders and activists, and other relevant stakeholders; and

- Develop new policies and legislation to improve Roma and Sinti health.[45]

When mapping a community,[46] you should take the following steps:

STEP 1: Reach consensus on the parameters of the map; select a mapping factor. Here it is essential to determine what kind of resources you need in order to collect information. You should factor in human resources, equipment, financial resources and identification of knowledge base holders, as well as community members who can assist the process. The aim is to identify the right resources, which will help you attain necessary information for making informed decisions about the change you want to make.

STEP 2: Select the data to be collected based on these parameters. Decide what data you would like to collect (number of households, total number of Roma, gender, number of Roma children, number of Roma who have and do not have health insurance etc.). The type of information you collect will depend on what factor you are aiming to map.

45 **Community Mapping,** Salem State University, Enterprise Centre, 30 August 2016.
46 **Essential Tools in Community Resource Mapping"** University of Minnesota, The College of Education and Human Development, May 2005.

STEP 3: Develop tools for collecting your data. Depending upon the focus of your map, you need to obtain or develop appropriate data collection tools. The main tools for collecting quantitative and qualitative data are questionnaires, interviews and focus groups. Using the same tools to collect data from different sources will enable you to draw comparable conclusions.

STEP 4: Collect data with the help of stakeholders. Involving and consulting stakeholders - such as local authorities, civil society organizations and community members - in collecting data is paramount to the success of your community mapping efforts, as well as in attaining verifiable and reliable data. Information collected through the involvement of various stakeholders can encourage the development of new partnerships within the community. For the most part, the degree and type of stakeholders you decide to engage will also depend on their own skills, knowledge and influence of the subject matter.

STEP 5: How best to organize a community (or environmental) scan. Organize yourself into teams and divide a geographical map of the community into as many areas as needed. Each team will visit one area. During the visit, a team should identify and investigate the existing "resources", such as health related institutions, local authorities relevant for addressing health care issues and civil society organizations. Try to identify the current problems and needs by looking into areas where certain health services are not provided or are precarious. Talk to the citizens who live there; they are the best people to explain the problems they face with access to health care.

3

STEP 6: Synthesize, analyze and interpret your data.
Summarize the information obtained by creating a list of all the "resources" identified at the community level and then systematically detailing the identified needs and problems of Roma and Sinti in accessing health care. When processing your data, you should conceptualize and establish what you are measuring it against, such as unfulfilled or violated rights or relevant health care policies/frameworks, to name a few. Through this process, you should begin planning relevant measures for addressing the identified needs and problems.

STEP 7: Communicate your findings. It is important to share the results of your mapping with stakeholders (local health care institutions, local authorities which can address healthcare policies, national authorities, local, national and international organizations, etc.). The information can help stakeholders make decisions about improving, developing and/or continuing new and existing healthcare practices or programmes. It can also be used in public relations campaigns to raise awareness about the identified needs and problems and to motivate relevant individuals and healthcare entities to improve their performance. As you analyze the map, keep in mind your original goal(s) and think about the best way to present your findings in order to meet the needs of different audiences and, ultimately, improve performance. Justifying your deduced data and its interpretation through effective communication also involves tailoring your message to different stakeholders, as each one is prone to understand it differently.

STEP 8: Set priorities and develop related actions. Developing a written plan detailing the action you intend to take to build your intervention system is the critical final step of community mapping. The intervention actions should be based on the actual needs of the community as highlighted by your community mapping exercise. Your goal is to build consensus around the identified needs and problems, and from it advocate tangible solutions.

3.3 Community engagement and why it is important

The World Health Organization has defined community engagement as "a process of developing relationships that enable stakeholders to work together to address health-related problems and promote well-being in order to achieve positive health outcomes."[47] Civil society organizations are among the key actors in community engagement. They are close to the communities, can access hard-to-reach groups and often act as first responders to crises or unexpected new needs because of their continual presence and grassroots nature.

They play an active role in enabling communities to participate in decision-making and two-way communication with the authorities. Working with civil society organizations is important in identifying core problems and barriers to community engagement. The aim is to empower communities to be more involved in the development process of their community and, in particular, to improve access to healthcare services, including vaccination.

Some key community engagement and mobilization strategies[48] include:

- **Reaching out to community leaders.** Meet with community leaders to learn about issues and how to access other community members. Community leaders can also help spread the word by disseminating important information;

- **Hold public meetings.** This can include organizing local meetings to hear opinions and share information with attendees;

- **Go door to door.** This can break down barriers and suspicions, gather unfiltered information, and will add to the credibility of your efforts;

47 Community engagement: a health promotion guide for universal health coverage in the hands of the people, World Health Organization, 5 October 2020.
48 Key Practices of Community Engagement, Community Benefit Connect, Advancing Community Benefit to Improve Community Health website.

- **Raise community awareness by establishing a Local Initiative Group (LIG).** This is an essential strategy and commonly used in mobilizing a community;

- **Attend community meetings (LIG),** if established. This shows you are genuinely interested in what the community finds important; and

- **The community should be directly involved in the evaluation of actions taken by the authorities.** This helps to build trust and authenticity in community involvement. Community members and other stakeholders can help assess the community's resources and determine the health needs.

3.4 Community-centred solutions

Community-centred solutions are a way to design programmes that enable social service providers, organizers, designers and evaluators to serve specific communities in their environment. The programme design relies on a participatory approach to community development, based on social work and community needs. For this approach, civil society should assess the resources and needs in a community and involve community stakeholders, including community members, in the process. Such approaches have highlighted immense value and success in addressing health care issues, such as addressing structural barriers and violations of rights. Using the following strategies, it should be possible to create a sustainable and equitable solution to address the needs of the community:[49]

- **Identify and empower community leaders.** When introducing a transformational change to a community, it is imperative to identify collaborative and innovative leaders;

49 3 Strategies for Taking a Community-Centered Approach to Care Coordination, Healthify, 13 December 2017.

- **Build trustworthy relationships.** It is vital to ensure that each individual and community organization feels like part of the team. In this respect, organizing a series of collaborative workshops, focus groups and networking sessions creates opportunities for more robust partnerships between community organizations to work together to discuss the challenges, ideas and best practices; and

- **Listen to the problems of community health workers,** both Roma and non-Roma. Community health workers matter the most in this process. These include health mediators, community medical nurses, family doctors, social workers, local Roma experts and other local health experts. It is very important to empathize, adapt and improve measures to ensure increased access for Roma to health and social services.

3.4.1 Model intervention on health in Roma communities in Romania – case study

From 2014 to 2016, the Roma Centre for Health Policies, SASTIPEN, developed a model of intervention on health in the Roma community, based on community needs. They created a drop-in Community Centre for Socio–Medical Assistance, an innovative and viable tool that ensured access to primary healthcare services at the community level. The health care was delivered by a community team composed of a general practitioner, a community medical nurse and a health mediator and was coordinated by a social worker. The design was based on an integrated approach, bringing together local services (health, education, housing and community development) that were adapted to the community's real needs, using case management.

Services provided at the Community Centre:

- **Primary medical services** such as first aid, preliminary consultations, screening campaigns for risk factors or common diseases (e.g., blood pressure and blood glucose measurement), referrals to doctors, etc.;

- **Health campaigns** tailored to the community's needs on, among others, adopting a healthy lifestyle, preventing high blood pressure, and promoting vaccination among children;

- **Medical and social counselling** such as guidance and prescription, referral to a specialist or therapist, help with obtaining identity documents and other social benefits;

- **Help to register new-borns** with general practitioners;

- **Health programmes and services** for both healthy and sick people, focused on their individual needs.

- **Support with access to specialist medical services** or social services; and

- **Identification and reporting of possible cases of discrimination** against people using public health services as well as possible child abuse or neglect.

In terms of case management, any intervention followed the following steps:

- **Welcoming new clients to the Community Centre** after an information campaign on the services available at the community level. Clients were either approached within the community or came directly to the Community Centre to request support.

- **Initial assessment** conducted by a Community Centre expert in an interview with the client to diagnose and identify a specific medical or social problem.

- **Development of a tailored medical-social support plan.** The Community Centre expert took the information from the initial assessment to create an intervention plan agreed with the client.

- **The individualized plan** usually included initial medical consultations, referrals to specialized medical services, medical counselling and social counselling.

- **The community nurse** and the health mediator carried out monitoring of each case. They conducted home visits, talked to the family doctors and followed the progress of each case.

- **Case completion and evaluation of client feedback.** A case was closed once the identified problem had been solved and the objectives of the tailored intervention plan were achieved. Evaluating the client's opinion on the Centre's services and their evaluation of the family doctor-patient relationship were important elements in the success of the intervention.

After two years implementing the concept and demonstrating its effectiveness, three Community Centres were taken over by local authorities: Slatina (Olt County), Amarastii de Jos (Dolj County) and Baia de Fier (Gorj County).

3.4.2 How to develop health promotion campaigns in Roma and Sinti communities

For a health promotion campaign to be successful it must be based on understanding the needs and perceptions of the local Roma and Sinti communities and these may change as the campaign progresses. For a better understanding of the process, it is divided into four major stages:

1. Strategy planning and development;

2. Development and pre-testing of concepts, messages and materials;

3. Programme implementation; and

4. Impact assessment and programme adjustment.

These stages are part of an iterative, cyclical process in which the last stage feeds back into the first stage in a continuous process of quality planning, implementation and adjustment.

STAGE 1: Planning and developing the strategy. Planning is crucial to the success of any health promotion communication campaign. Careful planning can avoid crises and bottlenecks in implementation and any additional costs these may incur.

- Assessing health problems; identifying the knowledge, attitudes and practices (KAP) of community members in relation to the identified problems and Identifying Possible Solutions (IPS);

- Defining communications objectives;

- Defining and understanding your target audience and exploring the most appropriate context, channels and activities with which to reach your target audience;

- Identifying potential partners and developing partnership plans;

- Developing a communications strategy for each target audience and outlining the communications plan; and

- Developing an impact assessment plan.

STAGE 2: Development and pre-testing of concepts, messages and materials. This stage includes developing relevant messages, planning the activities, designing materials and pre-testing messages and materials with members of the target audience.

- Review existing materials;

- Develop and test the messages;

- Establish what kind of materials are needed; and

- Draft/prepare tested messages and materials.

STAGE 3: Implementing the programme. The campaign goes live with the messages distributed and promoted through all relevant channels along with any other planned activities (e.g., awareness-raising activities, press conferences, open letters, public statements, capacity-building events, etc.). The implementation steps can be grouped as follows:

- Preparing for implementation;

- Launching the programme at the community level;

- Promoting the campaign on various communications channels;

- Holding campaign events or other activities; and

- Administering, monitoring and problem solving.

STAGE 4: Evaluate efficiency and make adjustments. Monitoring the reach of the programme among the target audience and their response to it is also an integral part of the programme. All elements should be reviewed and adjusted as necessary. Here the preparatory steps developed in Stage 1 will be used to identify whether and how much the programme has caused changes in the knowledge, attitudes and practices (KAP) of the target audience. Evaluating the progress and the impact of the programme will show whether it works or not, and why. However, planning how to evaluate the programme should be an integral part of the planning process from the outset. The steps for evaluating a health promotion campaign can be grouped as follows:

- Quantitative and qualitative impact assessment;

- Refining the health communication campaign; and

- Producing a final evaluation report.

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Summary recommendations
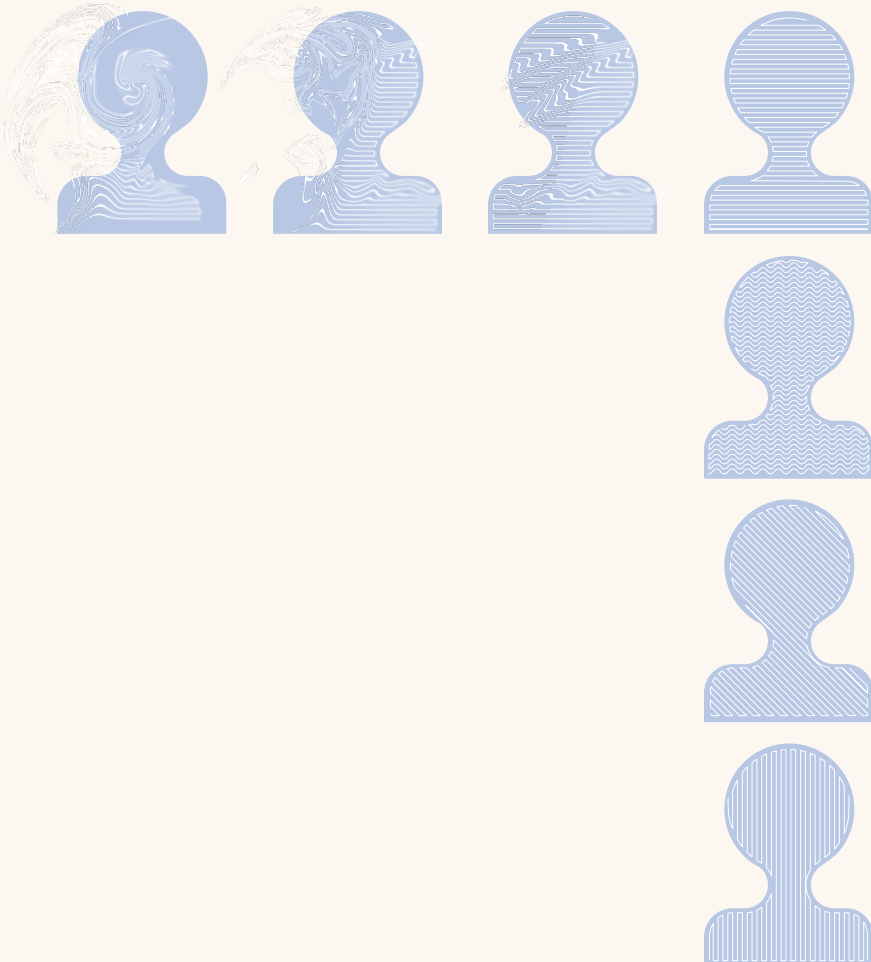
For national and local authorities:

- In partnership with Roma and Sinti civil society, national and local authorities should train healthcare professionals at national/regional and local level on how to communicate and work with minority and marginalized populations. They should also establish community health centres within Roma and Sinti communities.

- Roma and Sinti health policies should ensure the active participation and engagement of Roma and Sinti and civil society organizations. Cooperation with local civil society, regional and local authorities can contribute to reviewing and monitoring their local and national strategies.

- Collaboration and cooperation between national/local authorities and civil society organizations is vital to understanding the issues of disadvantaged Roma and Sinti communities. It is also necessary for creating a platform for dialogue to support the implementation of Roma and Sinti health policies and health promotion campaigns about healthy lifestyles and vaccination, including vaccination against COVID-19.

- Local authorities should develop health action plans based on the specific needs of Roma and Sinti, which can be used to secure the required funding. Given the lessons learned from COVID-19 prevention activities, local authorities can play a significant role in improving the health situation of Roma and Sinti.
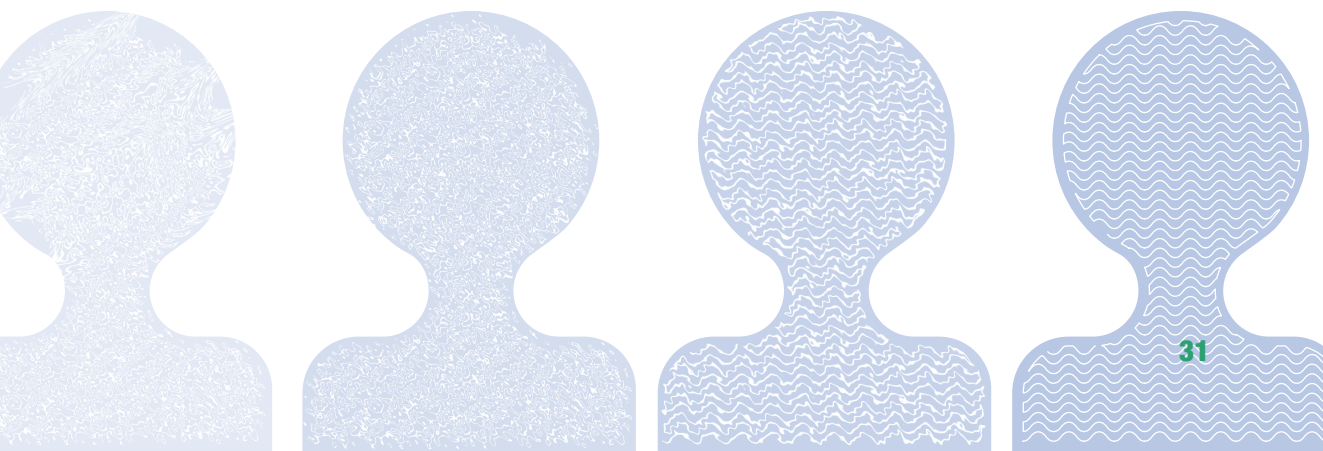
For civil society organizations, human rights defenders and activists:

- Continue to lobby local, national and international institutions about Roma and Sinti health, pushing to reduce health inequalities at the community level, to develop medical infrastructure and to improve Roma and Sinti access to healthcare services, especially in isolated Roma and Sinti communities.

- Monitor and evaluate local/regional/national public health policies for Roma and Sinti and propose measures for improving Roma and Sinti health.

- Propose measures to national, regional or local authorities aimed at improving Roma and Sinti access to health services based on the actual needs of communities.

- Initiate and develop pilot programmes to establish community health centres that will provide primary medical services to all members of Roma and Sinti communities.

- Support national vaccination campaigns, including against COVID-19, by raising awareness and educating members of Roma and Sinti communities about the risks associated with infection and the benefits of vaccination.

- Develop actions aimed at empowering Roma and Sinti to participate in decision-making processes. This should be done at the individual level (in terms of health, education, etc.) and at the collective level (the ability to organize and mobilize to collaborate towards solving their problems).

- Roma and Sinti civil society should become more familiar with national and international instruments designed to protect and promote human rights, including the right to equal access to health. They should also promote positive practices by developing training materials for sensitizing general practitioners and medical students about ethics and non–discrimination towards vulnerable groups in the health system.

- Civil society and human rights defenders and activists should continue to monitor and report possible cases of discrimination against Roma and Sinti, such as restricted access to health services, hospital segregation, residential segregation, etc. This approach would support potential victims in seeking redress while raising awareness about the issues among relevant stakeholders.

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