



HEALTH INEQUALITIES: A PERSISTENT OBSTACLE FOR ROMA INCLUSION

REFLECTION PAPER ON UNION OF EQUALITY: EU ROMA STRATEGIC FRAMEWORK ON EQUALITY, INCLUSION AND PARTICIPATION

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EPHA is a change agent – Europe's leading NGO alliance advocating for better health. We are a dynamic member-led organisation, made up of public health civil society, patient groups, health professionals, and disease groups working together to improve health and strengthen the voice of public health in Europe.



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Health Inequalities: A Persistent Obstacle for Roma Inclusion

Reflection Paper on Union of Equality: EU Roma strategic framework on equality, inclusion and participation

Context

Persistent disparities between Roma and non-Roma are observed in EU Member States and Candidate countries regardless of the social and economic situation within the countries. Inequalities in employment, access to decent housing, quality education and healthcare, but also systemic discrimination and lower human rights protection have pushed Roma to the margins of European society.

Paradoxically in Europe -one of the richest regions of the world- Roma are affected by deep and generational poverty and social exclusion. The poverty rate, including severe material deprivation is four times higher among Roma than the average rate in the EU.¹ According to the II-EU MIDIS Survey published in 2014, 280% of Roma live below the poverty line, one out of three Roma does not have access to running water and every third child faces malnutrition and lives in a household where someone goes to bed hungry. The recent survey³ addressing the social and economic situation of Roma and Travellers in Western European countries has demonstrated that they still struggle to meet basic needs such as affording food, housing and clothing. A drastic contrast is observed in Sweden where 51% of the Roma and Travellers have difficulties in making ends meet, compared with 4% of the general population; this rate is lower in the Netherlands (31% for Travellers and 36% for Roma) but disparities between Roma and non-Roma remain high. Child poverty and exclusion have devastating consequences for child physical and psychological development, especially in the first 1000 days of life when growth is particularly intensive.⁴

1 Eurostat, People at risk of poverty or social exclusion, January 2019: https://ec.europa.eu/eurostat/statistics-explained/index.php/People_at_risk_of_poverty_or_social_exclusion#:~:text=In%202017%2C%20112.8%20million%20people,after%20social%20transfers%20in%202017

2 <https://fra.europa.eu/en/publication/2016/second-european-union-minorities-and-discrimination-survey-roma-selected-findings>

3 Roma and Travellers in six countries, Fundamental Rights Agency, 2020: https://fra.europa.eu/sites/default/files/fra_uploads/fra-2020-roma-travellers-six-countries_en.pdf

4 Healthy from the beginning: ensuring a good start in life for all Roma children, European Public Health Alliance, International Step-by-Step Association, Wide Open School, Institute for Development Policies, 2020

I. The EU Framework for National Roma Integration Strategies up to 2020- a first step towards coordinated actions to end Roma exclusion

To mitigate the disproportionate effects of poverty and social exclusion on Roma, in 2011 the European Commission took a new initiative proposing a common policy framework for Roma inclusion. The framework focused on strategic areas such as education, employment, housing and health whilst also tackling discrimination. Equality and non-discrimination principles were integrated into the framework, recognising them as key solutions for combatting the marginalisation of Roma people. Then, the Commission issued a communication calling for development, implementation and monitoring of National Roma Integration Strategies comprising measurable targets and comparable indicators to close the gap between Roma and non-Roma. These indicators were in line with the Europe 2020 Strategy seeking to ensure the sustainable and inclusive growth of European society and economy. The Council Recommendation⁵ adopted in 2013 outlined the measures required for achieving positive results through the EU Framework for Roma Inclusion, reiterating the Commission strategic objectives.

However, despite these laudable aims the EU Framework for Roma Inclusion promoting National Roma Integration Strategies up to 2020 has not achieved any significant progress and Roma remain the most disadvantaged and socially excluded ethnic minority across the Union. The midterm evaluation of National Roma Integration Strategies (2018) has shown slight improvements in health-care, however 58% of those surveyed have not perceived any change in Roma health and 8% considered that Roma health was worsening.⁶ The European Commission emphasised that the progress in Roma health refers mainly to prevention, awareness-raising and some measures such as health mediation. The actions adopted by national governments have not been strong enough to ensure equal access to healthcare; health coverage and vaccination continues to be limited among Roma.

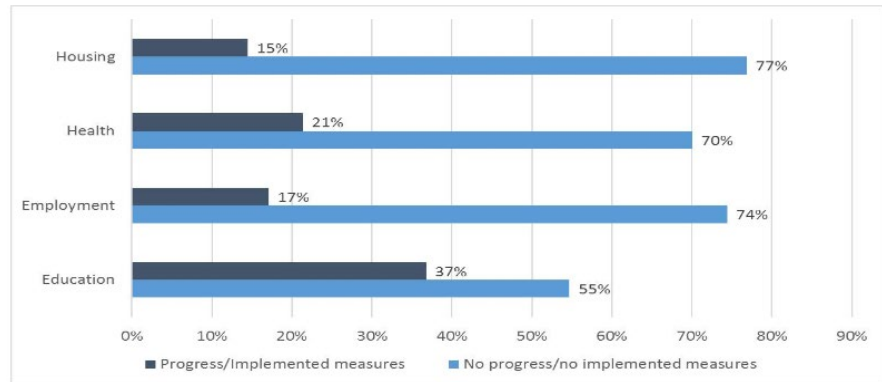
Promoting progress monitoring in health to effectively tackle health inequalities

In some countries the rate of Roma who do not have health coverage can reach 50%⁷, which is in relation with inequalities in employment and social protection. High unemployment rates, employment precariousness and the lack of regular work prevent Roma from accessing the health coverage which is indispensable for accessing healthcare and prevention. It prevents people from meeting their needs, including medical treatment and follow-up, hospitalisation, prevention of chronic and non-communicable diseases, child and women's obesity. Thus, Roma families, who are exposed to poverty, material deprivation and social exclusion may be driven to make a choice between health and prevention and covering basic needs such as accommodation and food. Unmet medical needs, including lower availability and accessibility of relevant health and prevention services, is particularly worrying for pregnant women, people with disabilities, as well as those suffering from chronic diseases requiring long-term treatment, including regular medical checks and medicines.

⁵ Council Recommendations on effective Roma integration measures in Member States, 2013: [https://eur-lex.europa.eu/legal-content/EN/TXT/PDF/?uri=CELEX:32013H1224\(01\)&from=en](https://eur-lex.europa.eu/legal-content/EN/TXT/PDF/?uri=CELEX:32013H1224(01)&from=en)

⁶ <https://eur-lex.europa.eu/legal-content/EN/TXT/?qid=1544112037077&uri=CELEX:52018DC0785>

⁷ Second European Union Minorities and Discrimination Survey Roma – Selected findings, FRA 2016



Perception of progress/implemented measures to fight discrimination in the four main policy areas 2011-2016 (source: EC8)

The midterm evaluation did also not observe any notable progress in fighting against discrimination in healthcare. Unequal treatment further deprives Roma of the right to health and prevention of good quality. Ethnic discrimination remains, therefore, a significant obstacle for closing the gap in health and limits the access to timely and effective health protection. Discrimination in the healthcare sector, including ethnic segregation has long-term consequences on Roma equality and inclusion impacting many social outcomes such as physical and mental health, early childhood development, educational attainment of Roma pupils and students and adults' capacity to access and maintain employment.

Strengthening human rights protection to improve Roma health

Although existing legal frameworks aim to guarantee the right to health, Roma struggle to access essential health services due to multiple discrimination, impacting many social determinants of health. The Racial Equality Directive prohibits any racial or ethnic discrimination and promotes equal treatment in healthcare, however ethnic segregation persists in Member States and Candidate countries and can be observed in housing; education; hospitals, clinics and maternity wards. Article 35 of the EU Charter of Fundamental Rights enshrines the right of everyone to preventive healthcare and medical treatment. The European Social Pillar promotes further "timely access to healthcare of good quality" and constitutes a policy framework for promoting the health, social and economic protection of the most vulnerable. Nevertheless, the situation is more complex when it comes to disadvantaged groups such as Roma.

In most of the Member States health protection remains strongly linked to employment and social protection benefits, leaving behind many social and economic groups such as the unemployed, seasonal workers, the self-employed, or those in precarious work. . In countries where Universal Health Coverage exists, Roma may not have access due to administrative barriers (the lack of ID cards, postal addresses, employment benefits etc.), or forced evictions and

8 Report on the evaluation of the EU Framework for National Roma Integration Strategies up to 2020, EC 2018: <https://eur-lex.europa.eu/legal-content/EN/TX/T/?qid=1544109661990&uri=CELEX%3A52018SC0480>

homelessness. In such conditions, the accessibility of health services depends on individuals and communities' capacities to afford out-of-pocket payments. Lower health coverage, as well as financial hardship caused by frequent out-of-pocket payments deprive people from enjoying the right to health guaranteed by the EU Directive, the Fundamental Rights Charter and promoted by the Social Pillar.

Advancing an evidence-based approach towards health for effectively meet the needs of Roma

The progress in health noted in the midterm evaluation conducted by the European Commission is based on self-perception of health status, underlining that the health status of Roma not self-reporting remains unknown. The state of health of different socio-economic groups among Roma, their medical needs and capacity of national health systems to meet these needs also remains unknown. The midterm evaluation of the implementation of National Roma Integration Strategies has not assessed the rate of unmet needs of people suffering from chronic and non-communicable diseases; people with disabilities and elderly Roma who are more vulnerable to illness. The health impact of substandard housing conditions were only addressed through indirect evidence – existing studies demonstrating the link between poor housing and health. The midterm evaluation has not assessed mental health protection, prevention of non-communicable diseases or child obesity; the assessment's outcomes remain very limited in terms of health progress among Roma. This lack of data remains a persistent challenge for addressing Roma health in the post-2020 Roma Equality and Inclusion Framework and promoting an efficient policy response to tackle health inequalities that Roma face across Europe.

II. Health in the post-2020 Roma Equality and Inclusion Framework

The poor social and economic conditions of Roma people reveal severe inequalities between Roma and the general population, raising issues of social fairness and health equity. Mortality and premature deaths are higher among Roma, who live 15 years less compared with the general population, which is in correlation with the lower access to healthcare and prevention, poor housing conditions, ethnic segregation, higher exposure to environmental burdens in segregated settlements. Systemic discrimination in access to social and economic rights is also responsible for the poor health of Roma and their shorter life expectancy.

Life expectancy is a main indicator of health and well-being and has been identified as a main health target in the post-2020 Roma Equality and Inclusion Framework. The Framework sets up the ambitious goal to lessen the life expectancy gap and ensure that by 2030 Roma women and men live 5 years longer.

Selecting lifespan as a main target is a crucial step towards improving Roma health. To achieve positive results in health the Framework focuses on equal access to quality healthcare and social services, which is indispensable for improving health protection, people's well-being and life expectancy. The Commission proposes a series of common actions and sets up minimum policy commitments for National Strategies for Roma Equality and Inclusion, but has missed the opportunity to promote measurable targets in health coverage, prevention of non-communicable disease, vaccination, and mental health protection. Such targets work towards reducing inequalities, which in turn, will contribute to increase the quality of life of different socio-economic groups among Roma. The

lack of specific targets in health protection makes it difficult to monitor the progress in individuals' and communities' health status as well as the effectiveness of the adopted policy measures in this field.

Equal access to health and social services of good quality is the basis of successful social inclusion of Roma, however it raises many issues in terms of effective protection against discrimination and access to justice for vulnerable Roma groups. Roma are disproportionately affected by health inequalities reflecting lower access to health coverage, prevention, sexual and reproductive services and family planning, access to early childhood development services, revealing systemic discrimination in many areas of life. Therefore, increasing life expectancy in a decade requires strong policy measures to guarantee the right to health and prevention; adequate social investment and political commitment for ensuring the health protection of vulnerable socio-economic groups, such as elderly, people with disabilities, women, LGBTQI+ persons.

The costs of lower commitment

The recent pandemic caused critical disruptions in healthcare and prevention services, exacerbating further health inequalities but also demonstrated how public health systems are delivered when it refers to vulnerable groups. Roma women and children were particularly hit by the social effects of the public health crisis which limited the access to reproductive rights, pre and post-natal care, early childhood development services and child protection. Reduced capacities of social protection services in COVID-19 led to increased poverty rates which further influenced people's ability to maintain good health status. Lockdowns and isolation of entire Roma settlements; increased stigma, discrimination and hate motivated incidents greatly deprived Roma of accessing healthcare and prevention causing severe challenges for Roma inclusion within the post-2020 Framework.

To prevent the further rise of health inequalities, National Roma Equality and Inclusion Strategies must incorporate the lessons learned from the pandemic and strengthen the health, social, economic and human rights protection of vulnerable Roma groups. In this regard, the post-2020 EU Framework sets up a basis for integrated measures based both on social inclusion and equality aiming to strengthen the protection of the most vulnerable against further social and economic crisis.

The Commission advances policy measures addressing in parallel the four key policy areas (education, employment, healthcare and housing), to maximise the impact of National Strategies on Roma Equality and Inclusion. Comprehensive policy measures need to include a strong equality and non-discrimination dimension to remove the barriers in accessing social and economic rights influencing Roma health. Combatting discrimination and racism against Roma is recommended as a cross-cutting priority in each policy area of National Strategies, which should complement social inclusion actions. Integrating antigypsyism into the EU Framework is a major achievement for advancing social justice and equality for Roma, nevertheless, the results in health equity depends mainly on the policy commitment of national governments. They have the responsibility to ensure equal access to healthcare and prevention and it depends on national policy and legislative frameworks in the field. Health is a competence of Member States but there is a need for coordinated actions in which the role of the Union is redefined. This became particularly relevant in COVID-19, especially for tackling cross-border challenges, building resilience and boosting Europe's social and economic recovery.

III. Making National Strategies for Roma Equality, Inclusion and Participation efficient and purposeful

In order to propose effective measures for reducing the life expectancy gap, National Strategies must comprise assessment that makes it possible to better analyse the state of health of vulnerable Roma groups whilst establishing inter-sectional links. The most recent report on Roma health, released in 2014 by the European Commission,⁹ focused on some specific topics such as life expectancy, child mortality, non-communicable diseases based on a national data and policy review. Some of the report data was collected in the beginning of the 2000's and requires to be updated taking into consideration the effects of the economic crisis, the evolution of national health and social protection systems, national reforms influencing Roma health, as well as the COVID-19 pandemic. Assessing the physical and mental health status of Roma women, children, elderly, LGBTQI+, prisoners, people with disabilities will make it possible to adopt an adequate policy response to health inequalities. Investing in data collection will contribute to identify the communities' health needs and implement targeted measures proportionate to the challenges that each community/socio-economic group experiences. Positive results can be reached when political commitment becomes stronger and the adequacy of public investment in health, social, economic and environmental protection of vulnerable Roma groups is ensured.

The negative trend in life expectancy cannot be reversed without addressing the factors provoking health inequalities. The gap in health and lifespan are exacerbated by poor housing conditions, environmental pollution, poor infrastructure and social inequalities as a whole. Roma have been subjected to ethnic segregation in housing for decades and this has long-term consequences on access to quality health and social protection services.

Low public investment in these settlements leads to deterioration of the conditions in which many Roma are born, live and work. Under-developed areas where Roma face substandard housing conditions, poor infrastructure, poor access to safe drinking water and sanitation increase notably the risk of communicable diseases.

Pushed to the outskirts of cities and villages, Roma face higher exposure to environmental burdens further worsening communities' health. The lack of decent living conditions increases the vulnerability to poor physical and mental health, contributing to higher child mortality rates and shorter lifespans among Roma. Moreover, substandard housing has devastating effects on a child's health: children living in overcrowded homes have less chances for healthy growth and to develop their full social and economic potential in adulthood.

Forced evictions and house demolitions, exacerbating child poverty and homelessness raise another barrier to accessing health and preventative care, and ensuring regular medical checks and follow-up for children and adults, causing severe issues for those who suffer from chronic diseases or disabilities. While cutting the life expectancy gap between Roma and the general population is an economic and demographic imperative for the Union as a whole, it remains a major challenge in terms of advancing health equity and social justice.

⁹ Health status of the Roma population. Data collection in the Member States of the European Union, EC 2014: https://ec.europa.eu/health/sites/health/files/social_determinants/docs/2014_roma_health_report_en.pdf

Guaranteeing the implementation of equality and non-discrimination principles in National Strategies

Increasing the Roma lifespan through the post-2020 Roma Equality and Inclusion Framework requires strong measures for guaranteeing access to social and economic rights at national and local levels whilst reinforcing equality and non-discrimination principles, not only through National Roma Equality Inclusion Strategies, but also in national mainstream policies and mechanisms. The policy efforts in equality and non-discrimination must focus on improving the availability and accessibility of national mechanisms for protection against discrimination in health and comprise annual assessment, monitoring and accessible reporting mechanisms.

Building synergies between relevant policies

Achieving positive and sustainable results on Roma health necessitates comprehensive National Strategies that address holistically the social determinants of health. They should be complemented with mainstream social and economic policies whilst ensuring that mainstream measures meet the needs of vulnerable socio-economic groups among Roma. Making mainstream policies more integrated and inclusive contributes to tackling inequalities in education, employment, housing and healthcare, which in turn will improve Roma health and well-being, quality of life, and in the long-term, will impact life expectancy. Building synergies between the EU Framework for Roma Equality, Inclusion and Participation and major EU policies such as the Green Deal, the EU Child Guarantee, Europe's Beating Cancer plan offer further opportunities to increase health protection and prevention for Roma.

These conditions are crucial for building solid systems that will successfully meet the needs of the most vulnerable and increase their protection in case of further social and economic crisis. Inequalities in health coverage, affordability of health services and medicines affect not only Roma, but also other vulnerable communities and such gaps prevents sustainability of health protection and the economic stability within the Union. Roma experience poor health, making them more vulnerable to long-term unemployment, generational poverty and social exclusion leading to notable social and health disparities between Roma and the general population. Therefore, policy measures tackling holistically health inequalities are an indispensable factor for achieving positive and sustainable results on economic recovery and stability whilst advancing health equity and social justice across Europe.

IV. The role of Roma in the implementation of policy frameworks

Inequalities in health, education, housing, employment, but also social exclusion and systemic discrimination also greatly affect political and social participation of Roma. They have been left behind for years reducing their participation in policy design, implementation and monitoring at all levels. The Fundamental Rights Agency (FRA) recommends targeting national and local authorities to improve Roma participation.¹⁰ It highlights the role of public authorities in creating adequate conditions for ensuring Roma participation in the design and implementation of social inclusion measures and removing the obstacles preventing Roma from taking part in policy making. This process requires efforts in empowerment

¹⁰ Working with Roma: Participation and empowerment of local communities, FRA 2019: https://fra.europa.eu/sites/default/files/fra_uploads/fra-2019-working-with-roma-summary_en.pdf

of vulnerable groups with a focus on social and political participation, including training and inclusive consultation processes with relevant socio-economic groups among Roma. Moreover, FRA emphasises the need for ensuring that participation “does not become a superficial, tokenistic exercise” which reduces the efficiency and transparency of the process.

One of the reasons for the failure of Roma inclusion is the lower participation of Roma and pro-Roma civil society and Roma communities in the design, implementation and monitoring of National Roma Integration Strategies. The new EU Framework offers another opportunity to combat social exclusion of Roma and effectively promote Roma participation in the next programming period. The constantly increasing challenges for Roma health in EU Member States and Candidate countries give another dimension of Roma participation, making it a major condition for ensuring the efficiency and adequacy of implemented social inclusion and equality measures. Promoting Roma participation in policy and decision making necessitates improved cooperation with Roma and pro-Roma civil society actors and Roma communities through a space for dialogue and mutual learning and this is particularly relevant within the context of the cross-country challenges that Roma face in social inclusion.

Driven by the will to make Roma voices heard at all levels, Roma and pro-Roma civil society organisations, experts, academics and activists have decided to unite their forces and create the Roma Health Network.¹¹ This public health community which became operational in the beginning of the pandemic was officially launched¹² in October 2020 advancing the participation of Roma and pro-Roma civil society, activists and health professionals in policy making with a focus on health inequalities that Roma face across Europe. Meaningful participation is an essential determinant of effective public policies that impact Roma inclusion and equality, especially in health, where knowledge about the state of Roma health is very limited. Public health strategies, actions and interventions developed and implemented by Roma, together with key stakeholders, is a working model advanced by the network which aims to ensure that policy measures meet the needs of different socio-economic groups among Roma. It can be successfully applied to other vulnerable groups to promote inclusive and comprehensive policies at national and local levels.

The Roma Health Network seeks also to improve Roma health by highlighting effective measures for reducing health inequalities from the first years of life. Looking beyond the health sector, the Roma Health Network encourages cooperation between a wide range of actors for closing the health gap and actively engaging with Roma communities. The network provides space for policy dialogue, but also enhances research, monitoring and reporting that may contribute to better assessing, analysing and addressing the health challenges faced by Roma women, children, elderly, persons with disabilities, LGBTQI+ persons having Roma background.

¹¹ <https://epha.org/roma-health-network/>

¹² <https://epha.org/online-discussion-health-inequalities-a-challenge-for-roma-inclusion-in-europe/>

Conclusion

Individual health status depends on many constituents such as pre-existing conditions, access to health and prevention, healthy behaviour, the quality of essential health services, but also the individual's and communities' living and working conditions. As a result, inequalities in housing, education, employment and healthcare worsens physical and mental health and lessens quality of life of entire population groups. Specific factors such as ethnicity, disability, sexual orientation, gender, age, religion reveal the systemic character of health inequalities affecting entire communities. It raises many questions about equality and non-discrimination in access to rights and services impacting individual' and communities' health.

Roma, who are the largest ethnic minority in Europe, remain greatly vulnerable to disparities in health, but also to lower human rights protection. Many generations of Roma are born, live and work in disadvantaged conditions responsible for their higher exposure to ill-health. They have been facing systemic discrimination and anti-gypsyism depriving them of optimal conditions to maintain good health status. Poor health makes them more vulnerable to long-term unemployment, child poverty and social exclusion leading to severe social and health disparities between Roma and non-Roma. Such inequalities have deep roots and different dimensions and deserve special attention from policy and decision makers.

Roma should have equal opportunities to participate in social and economic life and repair the damage caused by social exclusion, break the vicious cycle of poverty and inequalities and play a better role in the decision making process in the post-2020 EU Framework for Roma Inclusion. However, this will not be possible without the strong commitment of European and national decision makers, to adopt and implement holistic and integrated policy measures for combating inequalities whilst engaging with Roma communities and civil society actors.



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