





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

BULGARIA

A multi-stakeholder perspective report on 2005-2014 developments

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This 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 was undertaken by IOM within the framework of the project "Fostering Health Provision for Migrants, the Roma, and Other Vulnerable Groups" (Equi-Health). The EQUI-HEALTH project is co-financed under the 2012 work plan, within the second programme of Community action in the field of health (2008–2013), by direct grant awarded to IOM from the European Commission's Directorate General (DG) for Health and Consumers (SANTE), through the Consumers, Health, Agriculture and Food Executive Agency (CHAFEA).

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ACRONYMS

ADRA The Adventist Development and Relief Agency

BGN Bulgarian lev

EC European Commission

EU European Union

GGS Gender and Generation Survey

GP General Practitioner

HIV/AIDS Human Immunodeficiency Virus Infection and Acquired Immune Deficiency

Syndrome

IOM International Organization for Migration

IUD Intrauterine Device

LARGO Liberal Alternative for Roma Civil Unification

MLSP Ministry of Labour and Social Policy

NCCEII National Council for Cooperation on Ethnic and Integration Issues

NCHI The National Centre for Health Information

NGO Non-Profit Organization

NHIF National Health Insurance Fund
NRIS National Roma Integration Strategy

NSI National Statistical Institute

OSI Open Society Institute Foundation

PHARE Poland and Hungary: Assistance for Restructuring their Economies

RHI Regional Health Inspectorate

RHP The Open Society Institute-Roma Health Project

STD Sexually Transmitted Diseases
STI Sexually Transmitted Infections

TB Tuberculosis
UN United Nations

UNDP United Nations Development Programme

UNICEF United Nations Children's Fund

EXECUTIVE SUMMARY

The regulatory framework which organises and controls health-care system in Bulgaria, while also defines the rules of Bulgarian citizens' access to the system, is dispersed in numerous legislative and administrative acts. Laws often transfer the clarification of certain texts¹ to secondary legislation acts (regulations and ordinances) issued by various institutions (Council of Ministers, Ministry of Health, National Health Insurance Fund, Ministry of Labour and Social Policy).

Experts define this regulatory framework as inconsistent, sometimes contradictory, and in need of an overhaul.² Intense dynamics and lack of stability are typical for Bulgarian health legislation. Some acts (Health Act, Health Insurance Act, Medical Treatment Facilities Act, etc.) have been amended dozens of times over a decade. This hampers compliance and requires continuous changes in the behaviour of both citizens and health-care providers.

Several related strategic documents have been adopted at national and local level aiming to improve Roma situation in priority areas such as housing, health care, education, and employment: Framework Programme for Equal Integration of Roma in Bulgarian Society, Health Strategy for Disadvantaged Persons Belonging to Ethnic Minorities, National Action Plan for the Decade of Roma Inclusion 2005–2015, National Roma Integration Strategy of the Republic of Bulgaria (NRIS) 2012–2020, National Action Plan for the Implementation of NRIS, National Programme for Improvement of the Housing of Roma in the Republic of Bulgaria for the period 2005–2015 (for more details see the attached list of documents).

Over the last fifteen years, the Government of Bulgaria pursued a consistent policy of imposing purely market principles in the health-care system and commercial relations between patients and medical staff. As a result, access of socially vulnerable groups without health insurance³ (the poor and/or long-term unemployed not registered at regional Labour

¹ For example, there are special regulations concerning the scope of the basic package of health services guaranteed by the NHIF budget; additional payments of medical care on patient choice; emergency medical assistance; payment from the State budget for the treatment of certain diseases, etc. For more information, please, see the attached list of regulations.

² See Conception for Better Healthcare in Bulgaria 2010–2015; National Health Strategy (2014–2020). Annex 1. Health and Healthcare – Current Situation; Conception of Sustainable Development of Emergency Medical Care in the Republic of Bulgaria (Draft 2012).

³ According to Bulgarian legislation all Bulgarian citizens and their employers have to pay monthly health insurance tax in a proportion regulated by a special normative act. Health insurance of some social groups (children, students, pensioners, military, policemen, civil servants, etc.) is paid by the State budget. Long-term unemployed who receive monthly social allowances or energy assistance are also entitled to benefit from State funding of medical services. The problem is that there are hundreds of thousands of unemployed not registered at the regional Labour Offices, or people who lost the right to receive monthly social allowances or energy assistance, who are in turn not entitled to benefit from State funding for their medical treatment. According to NHIF data, over 800 000 Bulgarian citizens (or 11% of the entire Bulgarian population) were not health-insured at the beginning of 2015. If they do not pay health insurance themselves, or have missed more than three of the monthly payments in the last three years, they are considered uninsured and therefore have to pay all medical costs for treatment and drugs out-of-pocket.

Offices or not receiving monthly social allowances) to health services became very difficult. Roma are overrepresented in these vulnerable groups. There is a procedure to solve this problem which provides State funding of medical services in the hospital care delivered to the poorest and most vulnerable uninsured patients.⁴ However, hospitals usually avoid this procedure because they have no guarantee that Social Assistance Agency will approve their costs. (The Social Assistance Agency pays only for the treatment of socially vulnerable persons without any income or property that could be sold and cover the hospital's expenses.)

In outpatient care, however, the Health Insurance Law does not provide for medical services, rendered to the needy persons without health insurance, to be at the expense of the State budget. At the same time, few municipalities have their own funds and programmes to assist socially disadvantaged persons even when they need assistance for medical services and drugs, due to the permanent lack of sufficient budget in municipalities (and particularly in small ones). Having compulsory health insurance is the only option for people with average and below average income to use medical services at an affordable price. Thus, not having health insurance excludes the poorest and most vulnerable groups entirely from the outpatient care system. Poor people without health insurance were used to seek medical services in emergency departments. This practice overwhelmed emergency care with extrinsic functions and expenses. Recent regulations of emergency services led to further restrictions in the access to health services for people without health insurance.

The increasing number of uninsured people has been the main problem with Roma access to medical services for years, and it still continues to be a grave issue for the Bulgarian health-care system. The EU assessment of the progress in the implementation of the National Roma Integration Strategy in Bulgaria identified "ensuring health insurance for all" as a major challenge in the field of health care. The government intends to increase the period for which health insurance contributions have to be retroactively paid in order to restore one's health insurance rights from 36 months to 60 months and to raise threefold the amount which has to be paid for restoring health insurance rights. These changes will only reduce the possibility of socially disadvantaged people to become insured.

Concentration of low educational status, high unemployment rates, mass poverty, and poor living conditions in Roma community makes solving problems related to Roma health status and health-care service particularly difficult. It is not possible to achieve a significant improvement in Roma health status without coordination of the efforts of different institutions and without tackling the problems concerning Roma poverty, low educational level, poor living conditions, and high rates of unemployment simultaneously. Poor coordination is a continuous challenge and this is regularly stressed in all EU assessments of the progress in the implementation of the National Roma Integration Strategy in Bulgaria.

⁴ Decree 17/31.01.2007 lays out the conditions and procedures for spending of target resources on diagnostics and treatment in medical treatment facilities for hospital care for persons who do not have any income and/or personal property, which might secure their personal participation in the health insurance process. The whole mechanism is described in the main text.

At the same time, other large groups of Bulgarian citizens also live in poverty and face permanent difficulties in their access to health services, especially people in rural and mountainous areas, pensioners, unemployed and working poor. Solidarity between different social groups decreases with the increase of social inequality in the society.

Bulgarian politicians and media constantly present Roma as people not willing to pay their health-care insurance contributions but aggressively demanding to use National Health Insurance Fund (NHIF)-funded health services. These representations augment negative attitudes towards Roma and block social solidarity towards this vulnerable group. Mass negative attitudes towards Roma on their turn reduce political will (if any) to implement special measures to improve Roma access to State-funded health care and the situation with their poor health status and restricted access to medical services has generally remained unchanged. Not surprisingly, good practices for fully or partially addressing the health problems of Roma at national and local level can probably be counted on the fingers of one hand. In this situation, it seems more reasonable to formulate an amendment to the Health Insurance Law for a universal access to health care and health insurance for all vulnerable Bulgarian citizens, not to rely only on "special measures to improve Roma access to Statefunded health care" in NRIS.

The National Roma Integration Strategy addresses Roma health risk factors only partially. For example, a high number of measures and activities to improve Roma knowledge about family planning, mandatory vaccinations, healthy nutrition, and good child care are planned. The problem is that the majority of Roma have not money to pay for family planning or for healthy nutrition, thus reducing the potential impact of the information provided.

Another weakness of Bulgarian Roma Strategy is that it is setting low targets to achieve. For example: According to NRIS, in 2015 "more than 75 per cent of pregnant Roma women have to receive at least one specialized medical check during their pregnancy", but this has been the practice for more than 90 per cent of the pregnant Roma women before the adoption of NRIS, and there is a legal opportunity to ensure one medical check for all pregnant women in Bulgaria. The problem is that this one medical examination often is not provided, and at the same time it is not sufficient, according to specialists. Another example: According to NRIS, "in 2015 more than 75 per cent of the pregnant Roma women have to deliver their babies in hospital", while statistical data show that in practice more than 95 per cent of Roma women have delivered their babies in hospitals since decades. Special measures are needed to decrease the number of those few, who deliver their babies at home. Or again: "More than 75 per cent of Roma newborns have to be enrolled in general practitioners' lists of patients" which has been the practice for more than 90 per cent of the Roma babies before NRIS adoption. Setting low targets for the improvement of Roma access to health care is a sign of the Government of Bulgaria's underestimating of Roma health problems. This is a way to manipulate results: not to do much to improve Roma situation, but to be able to show "a progress".

Qualified experts from different areas (general practitioners, medical doctors, representatives of NGOs, including Roma NGOs, academicians) participated in the Strategy

preparation together with State employees from Ministry of Health and NCCEI. Some of these experts expressed dissatisfaction with the rejection of some of their proposals by the representatives of the State administration, which they regarded as crucial for improving Roma access to health services such as: any uninsured pregnant woman to be granted insured status for the period of the pregnancy, and introduction of a minimum package of guaranteed outpatient health services to all uninsured disadvantaged people. Roma health mediators and some NGO activists insist on another change in Bulgarian social legislation: to recognise the status of working people insured by the State budget for all unemployed women who take care of their babies in the first year after the delivery; this year to be considered length of service and mothers to have the status of health and socially insured people.

A significant drawback of the National Roma Inclusion Strategy (2012–2020) and the Action Plan of its implementation is the extremely low State funding of the planned activities, if any, and the lack of political will to continue the State financing of those policies, practices, and activities financed by EU funds or other external sources after the initial financing runs out.

Another weakness of the National Roma Inclusion Strategy (2012–2020) is that it does not include many previous activities tested and considered as good practices. As a rule, these are local activities implemented in NGO projects in sexual and reproductive health, family planning, maternal and children's health. After the end of external funding of these local projects, the State has never taken on their financing and the progress already made has been regrettably lost. Many gynaecologists, general practitioners, and health mediators working in Roma neighbourhoods demand State budget funding for sexual and reproductive health and for contraceptives for socially disadvantaged women and for all women at risk, for pregnant women's health-care, for prevention of sexually transmitted diseases (STDs). According to them, the Government of Bulgaria underestimate these problems.

Implementation of those few good practices included in NRIS and the Action Plan⁵ face also many difficulties and problems. The most common is the lack of sustainability due to uncertain and/or not sufficient State funding. Perhaps the only partial exception in this regard is the Health Mediator Network Development Programme, which is financially supported by the State, although this financing is also considered insufficient. A certain amount of money has been allocated for mobile medical units as well, but they operate for a very short period of the year because the available operative resources are limited and scarce. For the moment, the Government of Norway allocated needed amount of money for the programme supporting Bulgarian Roma medical students (through Norwegian Financial Mechanism), but in two years this money will run out. The HIV/AIDS Prevention Programme is already in a similar situation after the termination of its funding by the Global Fund to Fight AIDS, Tuberculosis (TB) and Malaria. Therefore, State involvement in programmes

⁵ These programmes are Prevention, control and treatment of TB, HIV/AIDS and sexually transmitted infections (STIs); Medical examinations with mobile medical units; National Network of Health Mediators; Programme for Support of Roma Medical Students.

which have already achieved positive results is probably the most important prerequisite for their success in the long run.

The Strategy has a separate section on monitoring of implementation. The Action Plan contains some relevant monitoring indicators, however, most of them are limited to "the number of conducted examinations" and "the number of given talks". In general, the indicators provided cannot give any meaningful information on the effectiveness of measures and on the progress with regard to the main purpose of health care: improving the access to health services, the quality of these services, and, ultimately, achieving better health status of the community.

RECOMMENDATIONS

Financing

- Ensuring the needed State funding for the activities aiming improvement of Roma access to medical services and the health status of Roma community in order to achieve sustainability of activities, provided in the National Roma Integration Strategy and the Action Plan for Implementation of the Strategy;
- ➤ Targeted seeking of external sources of financing and better utilization of funds from the European Commission (EC) for the activities aiming improvement of Roma access to medical services and the health status of Roma community;
- ➤ Continuing expiring programmes for prevention and/or improvement of Roma health that have shown good results, by providing the needed State funding; and, as a temporary measure, including them in funding proposals to sources of external financing.

Monitoring

- Regular (every second year) monitoring of the Action Plan for Implementation of NRIS activities and measures to improve the health of the Roma community and its access to health services. Creating an administrative unit for NRIS and its Action Plan monitoring with the participation of Roma health mediator, NGOs activists, and academia;
- Developing meaningful indicators for monitoring based on NSI data disaggregated by ethnicity (infant mortality, child mortality, mother mortality, early births, age-specific fertility rate, morbidity, hospitalisation, life expectancy, life expectancy in good health, disability rate etc.);
- Developing meaningful indicators to monitor the effect of NRIS and Action Plan for Implementation of the National Roma Integration Strategy measures, by taking into account both the achieved results from previous projects and the existing, but uncoordinated practices for community monitoring, community mapping, etc.;
- Regular monitoring (through specialized medical tests) of the health status of the Roma community by general practitioners, health mediators, and NGOs operating in the community.

Establishing a coordination mechanism

- Establishing an administrative unit for NRIS and its Action Plan coordination with the participation of Roma health mediators and NGOs activists;
- Developing a dynamic database of ongoing Roma health-care projects, providing a description of their content, sources and amounts of funding, result evaluation mechanisms, effectiveness monitoring and duration, with a view to coordination, evaluation, timely seeking of alternative financial sources, and sustainability of activities;
- Establishing a methodology for external evaluation of these projects' effectiveness plus a rating system with a view to giving priority to financing of the projects with the highest rates.

Health insurance of people belonging to socially vulnerable groups

- Preferential conditions for restoration of health insurance rights of socially disadvantaged people (living below the poverty line, long-term unemployed);
- ➤ Guaranteed health insurance from the State budget for socially disadvantaged pregnant women throughout the entire pregnancy and the opportunity to obtain the full scope of medical care under the Maternal Health-care Programme;
- Guaranteed health insurance from the State budget for socially disadvantaged/ unemployed mothers of infants.

Access to health services

- Introducing a minimum package of guaranteed outpatient health services, available free of charge to uninsured socially disadvantaged people;
- Changing the procedure of availing funds pursuant to Decree 17 of 31 January 2007 laying out the conditions and procedures for spending of target resources on diagnostics and treatment in medical treatment facilities for hospital care for persons who do not have any income and/or personal property, which might secure their personal participation in the health insurance process (Decree 17). Introducing the requirement for the patient to submit a document issued by the Social Assistance Agency certifying that the patient meets the conditions for using the State budget funding upon admission to a hospital;
- ➤ Better utilisation of funds under Decree 17 for hospital care services for socially disadvantaged people without health insurance. Experimental use of part of the unspent money under Decree 17 for funding outpatient care services for uninsured socially disadvantaged people.

Mobile health clinics

- Increasing State funding for mobile units' operational needs;
- Repeal of legal restrictions mobile health clinics to use financial sources other than the State budget;
- Coordinating the consultations at the mobile units with the NGOs operating in the community. Involving Roma NGOs in the process of better informing Roma people about the benefits using mobile health clinics;

- Establishing a monitoring mechanism for the further medical treatment of patients diagnosed with chronic and socially significant diseases after the examinations with mobile units;
- Exchanging information and coordination between mobile health units and general practitioners in the Roma community.

Health mediators

- Better pay for health mediators;
- Providing a better position description for health mediators. Release of health mediators from other administrative activities and social care services imposed on them by municipalities.

Programme for Support of Roma Medical Students

- Providing budget funds for entrance exam training of prospective Roma students and for their further tuition scholarships;
- Linking participation in the Programme for Support of Roma Medical Students with work contracts after graduation for two years serving as doctor/nurse/dentist, etc. in Roma communities, as well as with students' placement as general practitioners assistants or as health mediator assistants in Roma communities during their tuition;
- Focusing the programme on narrow medical specialties (medicine, dental medicine, pharmacy) in preference to specialties in the area of health management.

Local policies

Providing financial incentives to municipalities which implement local policies to improve Roma health status and Roma access to health services;

- ➤ Increasing financing through FLAG⁶ fund for municipal projects aiming improvement of Roma health care and Roma access to health services, Roma living conditions, and reduction of their poverty;
- Providing small municipalities with administrative support for preparing better projects when applying for funding from European funds and programmes;
- ➤ Establishing a mechanism for information and experience sharing among municipalities in the implementation of local Roma focused policies. Better involvement of Roma NGOs in the National Association of Municipalities' engagements in dissemination of good practices and information sharing;
- Organising seminars for mayors and local municipalities' staff to improve their knowledge and skills to work in multicultural milieu and with disadvantaged groups. For this purpose it is recommendable to draw on the experience of the Programme on Training of Prospective Roma Medical Students, which organizes such seminars for students in medicine.

⁶ Fund for Local Authorities and Governments. "Its aim is to provide financial assistance to municipalities for the absorption of funds from the Structural Funds and the Cohesion Fund of the EU".

1. INTRODUCTION

1.1. Background

The present report was developed under the Equi-Health project: Fostering health provision for migrants, the Roma, and other vulnerable groups, funded by the International Organization for Migration (IOM). The project 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 Health and Consumer Protection Directorate-General, EC within the Public Health Programme 2012.

The objective of the sub-action on Roma Health is the strengthening of national, regional, and EU level approaches to Roma. To this end, EU has to 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 vulnerable groups' health were planned to support EU Member States to better monitor, share, and strengthen their national approaches to Roma health.

1.2. Purposes

The study's purposes are to collect, summarise, and present information from various stakeholders (central and local administration, NGOs, health professionals, the Roma community) on the implementation of the NRIS (National Roma Integration Strategy) and other national commitments in respect to Roma health in Bulgaria. The main objective of the project is to deepen understanding of the factors which hamper Roma social inclusion, and more specifically that of Roma equal access to health services. This report will be considered as a baseline report to cover national developments from 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.

1.3. Methodology

The work required both desk and fieldwork research. The purpose of the desk research was to contextualize and provide the background for the fieldwork research. The fieldwork research consisted in interviews with stakeholders and case studies to form the final progress report. Research covered the following areas:

➤ Legal and policy developments in respect to national Roma health 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 including both binding and non-binding documents, issued by the EU bodies);

- ➤ Analysis of the Bulgarian Roma health status and access to health services;
- ➤ Mapping of promising practices, as well as lessons learnt from unsuccessful/poor practices on both national and local/community levels.

The Bulgarian team conducted 35 interviews with experts:

- ➤ Representatives of central institutions (Ministry of Health, National Council for Cooperation on Ethnic and Integration Issues (NCCEII) 3
- ➤ Local government representatives (Kavarna and Kyustendil) 14
- ➤ Health professionals (general practitioners and specialized doctors) 8
- ➤ NGOs leaders, some of them doctors (including Roma NGOs) 5
- ➤ Health Mediators (Kavarna and Kyustendil) 5

2. THE BULGARIAN HEALTH-CARE SYSTEM – LEGISLATIVE AND REGULATORY FRAMEWORK

The fundamental structure and principles of the Bulgarian health care are rooted in legislation developed after 1998, when the post-communist reforms in the health-care system began. At present, the acts regulating health care have the following characteristics:

1) The regulation is based on different acts, the main ones being:

The Constitution of the Republic of Bulgaria

The Health Act, regulating:

- the organisational structure of the national health-care system, the relationships and functions of its different units;
- the main parameters of health-care activities;
- the requirements for medical services;
- the rights and obligations of patients;
- the health protection of certain groups of the population (children, pregnant women);
- the medical education, profession, and science.

The Health Insurance Act, regulating:

- the types of health insurance;
- > the structure and functions of the NHIF;
- the rights and obligations of insured persons;
- the amount of health insurance contributions and the collection procedure;
- > the scope of medical care and the type of medical services delivered to the insured.

The Medical Treatment Facilities Act, regulating:

- the types of medical treatment facilities;
- the various requirements for those facilities;
- the activities carried out at said medical facilities;
- the principle behind their distribution on the territory of the country (in accordance with the National Health Map).

The Doctors and Doctors of Dental Medicine Professional Organisations Act, regulating:

- the structure, organisation, and activities of the professional organisations of doctors and dentists;
- the terms and conditions of medical and dental practices;
- the possible liabilities in cases of professional ethics violations.

The Medicinal Products in Human Medicine Act, regulating:

- ➤ the authorisation of the use, registration, manufacturing, and importation of medicinal products and active substances;
- the authorisation and conduct of clinical trials;

- the wholesale and retail trade in medicinal products and pricing;
- the safety monitoring of the medicinal products on the market;
- the procedure of prescribing and dispensing medicinal products;
- the preparation of the Positive Drug List.⁷

The Medical Products Act, regulating:

- the release of medical products on the market;
- the clinical trials of medical products;
- the supervision of the market.

The Social Assistance Act, regulating:

- the right of social assistance;
- the procedure of providing assistance to Bulgarian citizens;
- > the social integration of social assistance beneficiaries;
- the entrepreneurship in the social assistance sphere.
- 2) These Acts are accompanied by a large number of secondary legislation acts (regulations, ordinances, rules) which specify and clarify various texts.⁸
- 3) The operative legal framework in the field of health care is exceptionally dynamic and subject to frequent changes, with some of the Acts amended dozens of times. For instance, the Health Insurance Act has had 42 amendments between 1998 and 2014. There have been 19 amendments to the Medical Treatment Facilities Act since its adoption in 1999. The Health Act, adopted in 2004, has had 29 amendments so far.
- 4) In different national strategies, concepts, and plans for the development of health-care legislation, the current legislation is described as "fragmented and internally contradictory", "a lot of health-care acts are not logically inter-connected" and are in need of amendment, "the inadequate Medical Treatment Facilities and Health Insurance Acts" are discussed; 10 i.e. more changes are expected in the legal framework of the health-care system.

Current legislation is also connected with a range of strategic documents, which ascertain the societal problems in the field of health care and build up a system of national objectives, goals, and activities aimed at solving those problems. ¹¹ Some of these strategic documents are directed to the problems of the Roma community, including health-care problems. ¹²

Although these documents do not have the power of legislative acts, they contain, on the one hand, detailed information and analysis of the current situation of the Roma community

⁹ Concept for Better Healthcare in Bulgaria 2010–2015 of 12.2010.

⁷ List of drugs fully or partially paid by NHIF or Ministry of Health.

⁸ Cf. References – Acts, Secondary legislation acts.

¹⁰ National Health Strategy (2014–2020). Annex 1. Health and Healthcare – Current Situation.

¹¹ Cf. References – Strategic documents for healthcare in Bulgaria.

¹² Cf. References – Strategic documents directed at the problems of the Roma community.

in the priority fields of housing, education, employment, and health care and, on the other hand, they outline solutions of the current problems.

3. NATIONAL ROMA INCLUSION STRATEGY (2012–2020)

The National Roma Inclusion Strategy (2012–2020) was adopted by the Bulgarian National Assembly in March 2012. It was designed in accordance with the National Programme for Reforms of the Republic of Bulgaria (2011–2015), the National Action Plan for the initiative "Decade of Roma Inclusion 2005–2015", and is based on the Framework Programme for the Integration of Roma in Bulgarian Society (2012–2020). The Strategy "considers the situation of the Roma community in the country from a socioeconomic and demographic point of view. It adopts and unifies in one strategic document the aims and measures of strategic documents in the field of Roma integration such as: Strategy for Educational Integration of Children and Students from Ethnic Minorities; Health-care Strategy for People in Disadvantaged Position Belonging to Ethnic Minorities, 2005–2015 and the National Programme for Improving Housing for Roma in the Republic of Bulgaria for the period 2005–2015." Although the Strategy is generally aimed at Roma population, it is not ethnically limited and "does not exclude providing support to disadvantaged people from other ethnic groups." The Ministry of Health is the main institution responsible for implementing the objectives of the strategy's "health" priority.

The main aim of the Strategy is "to create conditions for the integration of Roma and other vulnerable Bulgarian minorities into the social and economic life of Bulgarian society through the provision of equal opportunities and equal access to rights, benefits, commodities and services, participation in all public spheres, and improvement of the quality of life by following the principles of equality and non-discrimination."

In terms of the health status of the Roma community, the Strategy outlines the growing impact of primary risk factors for the incidence and prevalence of diseases (growing poverty on a large scale, high rate of unemployment, adverse environmental and housing conditions, way of life, and genetic diseases), as well as of secondary risk factors (some chronic diseases which, in turn, create conditions for additional complications or other diseases).

The common aim of NRIS in the field of health care is "provision of equality in terms of access to quality health-care services and prevention programmes" and five specific objectives have been defined:

- 1. Improving preventive care for maternal and child health;
- 2. Ensuring equal access to health-care services for the disadvantaged;
- 3. Increasing the number of qualified Roma employed in the health-care system;
- 4. Developing of mediation and of different forms of work for and in the community;
- 5. Improving health awareness and access to health-related information;
- 6. Expanding the scope of health insured people.

Prior to its final version, the Strategy included a sixth stated objective: "Reducing cultural barriers and discrimination against the Roma in the health-care system", which was then taken out (but which is present in the Action Plan for Strategy Implementation). This

deletion was done without any consultations with the Roma doctors and the NGOs activists who took part in compiling the Strategy and its implementation measures. ¹³ The rest of the stated objectives are the same as those formulated in the National Action Plan for the initiative Decade of Roma Inclusion 2005–2015, the Framework Programme for the Integration of Roma in Bulgarian Society (2012–2020), and the Health-care Strategy for People in Disadvantaged Position Belonging to Ethnic Minorities, 2005–2015.

The Strategy is accompanied by an Action Plan in the priority fields of education, health care, housing, employment, the rule of law and non-discrimination, culture and media, which contains the aims, objectives and activities for goal implementation, the institutions in charge, terms and conditions, allocation of the necessary resources and sources of finance, and indicators for progress monitoring.

The Action Plan for Roma health-care improvement has eight objectives:

- 1. Decrease in child mortality rate;
- 2. Improved health care for newborns and pre-school children;
- 3. Improvement of prophylactic activities;
- 4. Better access to health-care services;
- 5. Increased health awareness;
- 6. Better health-care services;
- 7. Increased number of health insured people;
- 8. Assessment and monitoring of the health status of the disadvantaged.

Regional strategies for Roma integration for the period 2012–2020, as well as municipal action plans for their implementation were designed on regional and municipal level. In accordance with the instructions of the NCCEII, the regional strategies and municipal action plans follow the structure of the National Strategy, provide information on local Roma communities, and specify the national aims depending on the situation in the region and the municipality.

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¹³ It is necessary to mention that almost the same group of experts – doctors in medicine – Roma and non-Roma, leaders of NGOs dealing with the problems of Roma access to health services, academicians, as well as experts from the Ministry of Health and NCCEII formed the working groups whose aim was to compile the parts for the Roma integration in the healthcare system in the National Strategy of the Republic of Bulgaria for Roma Inclusion as well as the respective parts in the previous documents: the National Action Plan for the initiative Decade of Roma Inclusion 2005–2015, the Framework Programme for the Integration of Roma in Bulgarian Society (2012–2020), Healthcare Strategy for People in Disadvantaged Position Belonging to Ethnic Minorities, 2005–2015. Among the experts with important input to the development of these documents we can mention Prof. Dr I. Turnev, a national expert on rare diseases, who discovered the genes of a great number of inherited diseases spread among different Roma sub-groups and who started preventive care to decrease their dissemination (Prof. Turnev was also the person who initiated the Programme for Roma Health Mediators in Bulgaria); Dr M. Dimitrova, Director of the Specialized Hospital for Active Treatment of Tuberculosis and Lung Diseases in the Region of Sliven (a Roma person); Dr S. Panayotov and Dr Z. Mladenov, GPs in Roma neighbourhoods, leaders of the Roma NGO The Health of the Romany People Foundation (Roma themselves); Dr Elena Kabackchieva, President of Health and Social Development Foundation who also took part in the formulation of the objectives and priorities of all Strategic documents dealing with Roma access to quality health services.

Health-care Chapter within NRIS is very concise. Its part describing Roma health status and difficulties they face in their access to health services is limited to 4–5 lines, listing the social causes of the complex health situation in the Roma community (high unemployment, poverty, poor housing, etc.), a list of major diseases, and a single sentence on the lack of health insurance as a serious problem. The section on the objectives consists of 20 lines (including the heading) and is the shortest one in the entire Strategy.

Unquestionably, brevity could be a merit. Moreover, the content of the chapter on health care is expanded in a broad and detailed list of measures and activities in the Action Plan. The existence of a Health Strategy for Disadvantaged Persons Belonging to Ethnic Minorities, which gives a broader picture of the health problems and the health status of the Roma community, might be one of the reasons for the concise format of the chapter. In any case, it is certain that both documents were drafted with the assistance of qualified experts, NGOs, and the abundance of information available — a number of studies on health care and the Roma community were conducted in Bulgaria in the last fifteen years.

We will focus on four topics in the evaluation of the Strategy and the Action Plan *Health-care* chapters:

- Preparation stage;
- Planned activities and actual measures taken to expand the health insurance coverage in the Roma community;
- Financing;
- Monitoring.

3.1. Preparation of the Strategy and Action Plan

As mentioned above, experts from different areas — researchers with knowledge of the Roma community and the health-care system, general practitioners, medical doctors and representatives of NGOs (including Roma) participated in the Strategy preparation together with State employees from Ministry of Health and NCCEI. All these experts had both the professional expertise and experience in the preparation of similar documents (as most of them had also been actively involved in the preparation of earlier strategies and plans for health care and health services aimed at the Roma community and at the disadvantaged in general). In this respect, the requirement set forth in the European documents and within the Strategy for the establishment and use of an advisory and coordination mechanism with the participation of civil organisations (including from the Roma community) in the discussion on, the preparation of, and the actual implementation of the proposed measures, was duly met.

However, some of the experts interviewed (who had participated in the drafting of the Strategy) expressed dissatisfaction with the rejection of some of their proposals by the representatives of the State administration, which they regarded as important for improving Roma access to health services. Namely, two of these rejected proposals were:

Any uninsured pregnant woman to be granted insured status for the period from pregnancy diagnosis to a specific time (varying between different experts) after childbirth. ➤ The introduction of a minimum package of guaranteed outpatient health services available free of charge to all socially uninsured disadvantaged people (there is no agreement on the content of such a health package among those who support this idea).

According to the experts interviewed, these proposals were turned down by the Ministry of Health and NCCEI employees mainly on financial grounds – the State is unable to fund such projects because of lack of money. Another objection was that such measures will lead to a further increase in the number of people who do not pay their health insurance.

Ultimately, there was disappointment expressed by the experts interviewed who took part in the preparation of the Strategy with the rejection of their proposals. They also assess the mechanism for involvement and participation of civil organisations as rather formal.

"It was not bad in terms of preparation because there were committees set up for the development of all these plans and strategies, involving people from the Ministry and people from the NGO sector. I myself was involved, other people from NGOs – too. We wasted out time, we gathered a number of times, we wrote... And then everything was adopted. It was voted for. It was adopted not by the government! It was adopted for the first time; it was ratified by the Bulgarian Parliament! With a budget! Then a new government came into office. New strategies started to be developed – this time on local needs by regions and municipalities. This was also done. However, the implementation of these tasks depended on the Norwegian Fund and on the Swiss Fund. But not on the State itself! To what extent it will be implemented is not very clear too. Financing is a constant and a major problem... I have put this question for more than 11 years to a thousand governments. And so far there is no political will for a decision, exactly because it comes to Roma. This is the question of health insurance of pregnant women. We want each pregnant woman to have health insurance throughout pregnancy: from the time of diagnosing pregnancy until the 30th day after birth. To use the preventive care maternal health-care programme. This is not happening. There is no will. ... There are many socially disadvantaged people who have been thrown out of the system. In my opinion, there should be a social package of health services for everyone, at least for laboratory tests."

(A physician representing an NGO)

"We said, 'Pregnant women – what a shame! A pregnant woman turns to have no health insurance.'... The government said, 'That is not true, we allowed one examination by a gynaecologist.' What does a single examination do!?... The proposal is that the State must do everything possible to provide health insurance within 10 days for every pregnant woman who is diagnosed in the 6–8 week of gestation and the pregnancy is desired... Another dream I have is to have social units or polyclinics, working with a minimum package, which will provide care to keep the person alive – an examination, manipulations, a complete blood count, an X-ray, prescription of medications. You will not be examined by a professor there; there won't be a scanner or a mammography unit. If you want more, you're welcome to pay your health insurance contributions. Here we provide care to people without health insurance... But this is the only way for people to receive care for free... I expressed my disagreement in the group, and at the very place, and I said that I quitted. Because we had

excellent communication, we created so many things and nothing was actually adopted. And it was done in the following manner, 'Tell me your opinion, but we'll do what I say.'... The participation of NGO representatives is treated as an alibi. In the sense that there are Roma taking part in the preparation, but after that they adopt what they have decided. Of course, all documents are open; however, this is not used sufficiently well. When you say, 'It is open, let's sit for 20 days and do something to fix it,' they start seeing red. Isn't it open! This was the way they crushed our opposition. They said it was an open document; it could be amended any time, but now it had to be adopted. So this is it – participation is mainly eyewash. And those of us involved, I can say, gave all of ourselves. But all too fast our voice was silenced."

(A physician representing a Roma NGO)

3.2. Activities on expanding the health insurance coverage in the Roma community

As already mentioned, the Strategy and the Action Plan outline the following specific objective: "Expanding the scope of health insured people among those in disadvantaged position by undertaking legislative initiatives." Since, as widely agreed, the large number of uninsured Roma is the main obstacle to their access to health services, this objective and the planned measures for its implementation deserve special attention. Moreover, as we shall see, it is difficult to find common ground between stated intentions and actual practice.

Aim 7 of the Action Plan tries to address the uninsured patients' problem. The two planned activities are "Drafting new normative act to resolve the problem with not paying the health insurance contributions on the side of poor and long-term unemployed people" and "Informing Roma people about their health insurance rights and obligations".

We could ignore the second measure: "Informing uninsured socially disadvantaged people about their health insurance rights and obligations and about their patients' rights and obligations" as not quite meaningful. Health insurance was introduced in Bulgaria fifteen years ago. People learned (through information campaigns and their own experience) that they have to be insured. Uninsured vulnerable persons and groups are without health insurance not because they are poorly informed about their rights and obligations, but mostly because they have no money to pay their health insurance contributions.

In terms of legislative measures, there is only one proposal mentioned above: providing free health insurance coverage for all uninsured socially disadvantaged pregnant women. That proposal, however, has been consistently rejected by the Government of Bulgaria.

Conversely, legislative measures are discussed and adopted which only reduce the possibility of socially disadvantaged people to become insured. An example is the gradual increase of the period for which health insurance contributions have to be retroactively paid in order to restore one's health insurance rights. That period was three months several years ago, it is 36 months now, and the Minister of Health proposes to extend this term up to 60 months. With the extension of this period, the amount which has to be paid for restoring health insurance rights also increased. It currently amounts to about BGN 600 for unemployed

people who have not paid health insurance contributions for three years (i.e. the total of the health insurance contributions for the same three years for this category of people). But at the end of 2014 a proposal was made by the Ministry of Health to increase this amount to BGN 2000 for all people without health insurance. The argument in favour of this proposal was that it would not be fair to provide full access to State-funded health-care services to people, who have not paid health insurance contributions for a long period of time after three monthly instalments are paid. The proposal to aggravate the conditions for restoring full access to State-funded health-care services to uninsured can only cause confusion since the majority of the uninsured are people who simply cannot afford to pay a monthly health insurance premium of BGN 17, let alone a lump sum of BGN 2,000. Labelling and marginalising long-term unemployed and poor as irresponsible is just a manifestation of the lack of capacity of the Government of Bulgaria to deal with those who have health insurance problems.

The restrictive approach of the Government of Bulgaria could be illustrated by Minister of Health's recent statements (we present them as they were reported by the media): First, that people without health insurance should be denied any health-care services. Second, that emergency care will cease to service Roma districts (on the grounds of protecting emergency care staff after numerous cases of physical aggression against health practitioners in such districts). The Minister made a correction a bit later – that emergency care ambulances will serve Roma districts only accompanied by police officers and/or when local communities can provide the safety for emergency care personnel.

It is no coincidence that all experts interviewed, regardless of constituencies spoke out against the State policy embodied in the legislative acts on continuous aggravation of the conditions for restoration of health insurance rights.

"What is needed in legislation is to make the rules more inclusive, criteria which will allow the inclusion of more people in the health insurance system, easier inclusion. They will of course be open to all and will have a significant effect in the Roma community."

(A representative of a Roma NGO)

"It is a barrier that a significant percentage of adult Roma do not have health insurance. In practice, they (the authorities) have extended the period for restoring health insurance rights and now several political parties advocate for its further extension...Now it probably costs about BGN 1,000 to have these rights restored."

(A physician representing an NGO)

"In my opinion, although it may seem justified, the policy of impeding the access to health services (in the sense to owe much more contributions when you want to re-enter the health system) has in fact cut out the access of Roma. Yes, it is clear that it is socially unjust not to pay and to enter the system with these three contributions when you need care. But it is better to pay these three contributions and re-enter the system rather than not to enter at all, because this person cannot afford them. He cannot afford to pay for a ticket from his village to the city to bring the child to see a doctor, let alone to pay these 20 contributions. And he remains outside the system. From which we are the ones to suffer and once again it is

the society which will eventually pay. First, because we create conditions for diseases, epidemics, etc. And, second, because having nothing else to do, they depend on emergency care. It is overwhelmed and burdened with extrinsic social duties."

(A representative of the Ministry of Health)

In conclusion: Based on government officials' attitudes and actions, it is highly unlikely that in the near future Bulgarians will see legislative initiatives and regulations contributing to the implementation of the strategic aim of "expanding the health insurance coverage of disadvantaged people."

3.3. Financing of activities

The other "systemic error" of NRIS and the Action Plan of its implementation is the extremely low State funding of the planned activities, if any, and the lack of political will to continue the State financing of those policies, practices, projects, and activities financed by EU funds or other external sources after the initial financing runs out. Let us just consider two examples:

According to NRIS Aim 3 health priority (Increase in the number of qualified Roma who work in the health-care system, as well as development of mediation and different forms of work for and in the community) and with Task 4.3.1. of the Action Plan (Preparatory courses for entry exams in medical universities and colleges for young Roma), BGN 200,000¹⁴ were planned from the national budget for 2012, and BGN 240,000 per year for 2013–2015. However, these funds were never provided, and the entrance exam training of prospective Roma medical students was left without any State financing until 2014 when Government of Norway allocated needed amount of money for the programme supporting Bulgarian Roma medical students for a period of two years (through Norwegian Financial Mechanism).

In compliance with Aim 1 (*Preventive care for maternal and child health*) and Aim 2 (*Equality in health-care access for the disadvantaged*), six different activities involving the use of the 23 mobile clinics bought by NCCEII with Poland and Hungary: Assistance for Restructuring their Economies (PHARE) funds were planned. For the implementation of two of these activities, no funds were allocated from the national budget at all. One of these activities is 3.3.1. (*Building capacity for work in the Roma community for the prevention and control of HIV/AIDS using mobile medical units*). The other one is 3.3.2. (*Activities aimed at improving the control of TB among the Roma community by screening for the risk and testing for TB*) despite the fact that two mobile fluorographs were bought by NCCEII. For the other activities planned, BGN 2.7 million were planned for the utilisation of the mobile units from 2011 to 2015. In fact, the mobile units were used for a very short period of time due to the insufficient financing (More information included later in this report).

A number of national health programmes financed by EU or UN funds are focused on Roma people. They correspond to some of the aims of the Strategy's "health" priority, and for this

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¹⁴ More than EUR 100,000.

reason they are included in the NRIS and its Action Plan. Usually, these are projects with a transparent and secure financing. We could mention here the National Programme for Prevention and Control of HIV and Sexually Transmitted Infections (STIs) 2008–2015 and the National Programme for Prevention and Control of TB, both funded by the Global Fund to Fight AIDS, TB, and Malaria. They are incorporated in the NRIS Plan of Action *health* priority as specific activities 3.3.1 and 3.3.2 to carry out task 3.3 – *Prevention of HIV/AIDS and STI and TB among vulnerable Roma communities*. For both activities only the external financing is mentioned in the Action Plan: EUR 757,238 for HIV/AIDS prevention in 2011 and no other financing for the 2012–2015 period; and EUR 881,644 for TB prevention in 2011 and 2012, and once again without any planned financing thereafter. It is not clear what will happen to these programmes when their external financing comes to an end. Most of the interviewed physicians working in Roma neighbourhoods are afraid that the end of the external funding could mean the end of the programmes themselves.

Other activities and measures in the NRIS and the Action Plan are parts of health programmes financed by the national budget, e.g. the National Plan for Rare Diseases. It is not specified in the NRIS Action Plan what amount of money will be allocated for genetic diagnostics in the Roma community (activities 1.2.2 and 1.2.3) from the budget of the National Plan for Rare Diseases.

Weakness of the National Roma Inclusion Strategy (2012–2020) is that it does not include activities tested and considered as good practices. As a rule, these are local activities implemented in NGO projects, with external funding and proved good results. Such good practices can be found in family planning, maternal health, and children's health. But after the end of external funding of these local projects, the State has never taken on their financing.

"The main problem is that the Strategy does not have financial backing. The Action Plan which was adopted in 2012 allocates some financing but it is minimal – at about 1 million annually. In fact, this million is not fully absorbed. These are minimal activities. I.e. the strategy itself is not bad, but there is not enough financial resources backing it...The problem is that some successful actions are tested within various programmes but then the State is silent on their institutionalization. Health mediators – yes, they were partially institutionalized. But overall, this is the only practice which has been institutionalized to a certain extent. There is a lack of commitment from the State budget to these practices; programmes rely mainly on donor funding. There is no comprehensive strategic approach towards what has to be done." (A representative of a Roma NGO)

"I can say that the last several governments have not stood in our way. In recent years we had better communication, which, of course, is very important. We rather see lack of funding and standing up for keeping the funding." (A physician representing an NGO)

"It is all about, first, political will, and, second, money. In my opinion, we lack both...If we have a formal look at the issue, the measures envisaged in the Strategy are implemented within the limits of the allocated resources which are definitely insufficient." (A representative of the Ministry of Health)

"When most national strategies related to Roma come to funding, something always comes in the way. This one was adopted by the National Assembly, great. They were thumping their chest – 'We are the only country that...' The fact is that a wonderful plan was developed in our town for the period 2012–2014. It is one of the plans associated with the Strategy. Everything is written in it. BGN 5 thousand were allocated but they were not provided. Most efforts must be done at the level of municipal plans and funds should be invested there. These funds must be real money, not virtual." (A physician representing an NGO)

It comes down to insufficient State funding as a general problem of the Strategy. Same phrases are constantly repeated in the interviews: "lack of State funding," "uncertain funding," and "insufficient funding" concerning all activities assessed by the interviewed experts as good practices (health mediators, support of Roma medical students, mobile clinics, HIV/AIDS and TB prevention).

3.4. Monitoring of activities

The Strategy has a separate section on monitoring of implementation. The Action Plan contains some relevant monitoring indicators, however, most of them are limited to "the number of conducted examinations" and "the number of given talks". In general, the indicators provided cannot give any meaningful information on the effectiveness of measures and on the progress with regard to the main purpose of health care: improving the access to health services, the quality of these services, and, ultimately, achieving better health status of the community.

We should take into account that the monitoring cannot rely on current statistical information (including health data) because the national statistics does not collect data disaggregated by ethnicity (except in national censuses). Data collected by the monitoring usually are: the number of examinations carried out by mobile clinics, the number of diseases diagnosed, the number of health talks given in the Roma community, the number of health mediators, the number of enrolled Roma medical students, the number of patients tested for HIV/AIDS, etc. But the monitoring contains no indicators for the effects of all these activities on children's and mother's mortality rate, number of abortions and early births, life expectancy of different ethnic communities, morbidity, disability, hospitalisation of Roma and other vulnerable minorities, even about the share of persons without health insurance in the Roma community. Information on the uninsured Roma comes from expert estimates (which are often contradictory) or on data from various sociological studies (which, however, focus on specific issues, work with various methods and indicators).

It is a fact that at one and the same time different organisations with different goals and methods collect mutually unrelated and uncoordinated information on health services and the health status of the Roma community (e.g. a Roma foundation carries out "community monitoring of health services" in the areas where it operates, health mediators conduct "mapping" of their Roma districts, the NCCEII tries to draw up a system of indicators, although, according to experts, such indicators have already been submitted twice to the Ministry of Health in previous years, etc.).

Experts view the lack of a unified monitoring system in particular as one of the main weakness in the implementation of the Strategy.

"There is not a single department, not a single directorate in the Ministry of Health which acknowledges these issues as their issues. Starting there, you can imagine what the attitude towards the Health Strategy is. It exists only on paper. And from time to time, a report is submitted on its implementation...The other thing which is important to be carried out, is to seek feedback from the community, from each and every community, on the services provided. What we do in terms of community monitoring of health services should be funded not by donors, it should be funded by the Health Insurance Fund. So that it can obtain feedback when it pays for certain services, what is actually provided to the community."

(A Roma NGO representative)

"The government has not introduced a monitoring system. Although there was a PHARE project and a monitoring system in the districts was developed and proposed, it was not implemented...There should be an operating implementation and monitoring system, which is absent. There is no real accountability. There might be something reported to the Ministries but in practice these Ministries do not report to the National Council (NCCEII)." (A physician representing an NGO)

The continuous failure to resolve the problems with health insurance, the insufficient financing and the neglect of proved good practices weakens the medical doctors' trust of all existing strategic documents aiming the improvement of the access of vulnerable groups (Roma including) to health care. Here are some comments by physicians with a large number of Roma patients, many of them without health insurance:

"The reform in the health-care system is totally wrong and the Health Strategies do nothing to correct this fact. How is it possible one third of the population over 18 not to have access to medical care because of lack of health insurance? It is wrong that pregnant women are not provided with health care on this ground! Well, some are able to pay, but the rest? Some time ago the Health Insurance Fund was covering the pregnant women checks and we never asked do they have health insurance or not. This is not the case anymore and the situation becomes serious. Doctors cannot afford to work without penny two thirds of their time: roughly two thirds of my patients who are pregnant, who give birth or would like to make an abortion are Roma women and most of them do not have health insurance. It is the same case with my colleagues who work in small towns or rural area."

(Interview with a gynecologist, 2014)

"Health Strategy, National Strategy for Roma Integration, their Action Plans – all these documents were written by bureaucrats for bureaucrats. They are not the things that inspire you to take care of and heal Roma without health insurance nor are they able to inspire you to work every day at least half of your time absolutely pro bono. It is not these documents who make you deliver a baby of a mother who suffered from AIDS at her own home...I am sure they recommend a number of good practices, but all these are implemented only until there is financing from abroad." (Interview with a general practitioner, 2014)

"Something radical has to be done, whereas politicians want only a painless solution. Some colleague physicians propose the introduction of a minimum health package for such people, but who are they to decide? Their ideas concern diagnostics only... this will cover the minimum diagnostics, but these patients need hospitalization and their medications will be so expensive, that they will not be able to afford them... If the treatment cycle does not come to its completion, the investment in diagnostics would be meaningless. I.e. what we need is a universal scheme for all: saving one's life should not depend on one's health insurance... We go exactly in the opposite direction: we have been restricting access to emergency care because, you see, it was overwhelmed by the treatment of patients without health insurance... I.e. we are going in the direction of more and more restrictions on the access to medical care, to banning treatment of the poor. What strategies are we then talking about?"

(Interview with a general practitioner, 2014)

4. STRUCTURE AND PRINCIPLES OF THE BULGARIAN HEALTH-CARE SYSTEM

At present, there is an established and functioning three-partite health-care system in Bulgaria – consisting of outpatient care, hospital care, and emergency services.

A two-component health insurance system – compulsory (represented by the NHIF) and voluntary (represented by private health insurance funds) – operates along with it.

Health insurance guarantees the patient's access to outpatient and hospital care. Uninsured people can receive outpatient and hospital care only provided that they pay its full cost. People with health insurance make monthly health insurance contributions, in return for which they receive the medical services guaranteed by the NHIF and the voluntary funds at the expense of the NHIF or the relevant private insurance fund. If they need medical care not included in the package of guaranteed services, patients have to bear its cost on their own.

Emergency services are free of charge and equally accessible for all people regardless of their health insurance status. In many cases, people without health insurance seek assistance from emergency care for standard, non-emergency conditions, taking advantage of this circumstance. Due to the impeded access to outpatient care and hospital medical care (as a result of distance, lack of 24-hour service or problems with health insurance status) in Bulgaria the number of ambulatory examinations done via emergency care equals to the number of emergency cases treatment. "Almost 50 per cent of the activity of European Mentoring and Coaching Councils is connected with providing medical care to patients who are supposed to be treated by medical treatment facilities for primary and specialized outpatient care and are not the subject of the emergency medical care system. The services provided by the emergency medical care system are used under specific conditions which do not allow for the health insurance status to be the grounds for a denial of medical care." ¹⁵

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¹⁵ Draft of Concept for Sustainable Development of Emergency Medical Care in the Republic of Bulgaria.

Not only citizens, but even administrative structures sometimes see emergency care as a mechanism of solving local problems related to the accessibility to health care. In the "Information of the Republic of Bulgaria about the implementation of the National Roma Integration Strategy 2012–2020," designed and presented in 2013, one of the regional administrations presented the following approach to the health-care services access problem: "Uninsured Roma patients are entitled to timely and qualified medical care by means of the Emergency Medical Care Centre and its branches, as well as the emergency ward of the general hospital."

For some, health insurance cost is entirely covered by the national budget, meaning that de facto they always have health insurance:

- pensioners;
- children below the age of 18, and if they continue to study after they have attained the age of 18 – until completion of their secondary education;
- > students full-time students at higher education institutions until they have attained the age of 26 as well as full-time doctoral candidates enrolled within the State quota;
- persons who are recipients of unemployment benefits;
- long-term unemployed who are eligible for monthly social assistance benefits.

According to the Health Insurance Act, anybody who owes three or more health instalments for preceding 36 months, loses their rights of an insured person and respectively loses access to the medical services from the basic package of the NHIF. Reinstatement of rights occurs on the date of payment of all outstanding instalments for the preceding 36 months. Due to the high unemployment and widespread poverty in the Roma community, its members often find themselves in such a situation – without health insurance and, therefore, without access to medical services under the preferential conditions of insured people. Restoration of one's rights only by paying a certain amount (which is often completely beyond the means of socially disadvantaged who make up a high percentage of the Roma community) significantly reduces the possibility of people from socially vulnerable groups to return into the insurance system.

Obtaining health services is also associated with additional costs — a user fee paid at each visit to outpatient care, a hospitalisation fee paid in case of inpatient care, drugs' cost, consumables' cost, partially — medical tests' cost, and medical procedures' cost. These amounts present yet another barrier between health services and socially vulnerable groups.

5. ACCESS TO MEDICAL CARE

5.1. Opportunities for access to hospital care for socially disadvantaged people without health insurance

In order to ease the access to hospital medical services for people without health insurance and without financial means to pay for such services, the State has introduced a separate funding mechanism (set forth in Decree 17 of 31 December 2007) laying down the conditions and procedures for spending of target resources on diagnostics and treatment in

medical treatment facilities for hospital care for persons who do not have any income or personal property. The mechanism was introduced in 2008 and its objective is to cover the costs of hospital care provided to socially vulnerable Bulgarian citizens without health insurance through the Ministry of Labour and Social Policy's budget and to ultimately improve vulnerable social groups' access to hospital services. To benefit from this programme, one must:

- have no health insurance;
- have no income;
- have no receivables, deposits, shares, or securities with a total value over BGN 500;
- not own any moveable and immoveable property which can be used as a source of income, with the exception of any possessions needed for routine use;
- not have a signed contract for conceding any property against the obligation for payment of an allowance or provision of care;
- > not have sold or transferred any property or shares of any property under a donation agreement in the preceding year.

Decree 17 sets the following administrative procedure for the hospital service payment:

- 1. Upon admission to the hospital, the patient submits an application requesting Social Assistance Agency to pay for the needed medical services.
- 2. The hospital forwards the application to the Social Assistance Directorate in whose territory the patient resides.
- 3. Within seven days the Social Assistance Directorate conducts an inquiry to determine whether the person meets the eligibility conditions and then notifies the hospital of its outcome.
- 4. If the patient meets the eligibility conditions, the hospital sends an application to the Health Insurance Fund requesting payment for the provided medical services.
- 5. The NHIF conducts a review of the documents and sends a request for payment of the respective amount to the Social Assistance Agency.
- 6. The Social Assistance Agency transfers the amount to the NHIF within 10 days.
- 7. The NHIF pays to the hospital for the provided medical services.

All experts interviewed in connection with this study share the opinion that this mechanism is used very rarely and is practically inoperative, for the following reasons: 1) this payment option is virtually unknown to the public; 2) few hospitals are familiar with this option; and 3) the hospitals themselves are not willing to use this mechanism and try to avoid it.

It is unclear what the levels of citizen awareness and of competence of hospital legal departments are, but it is easy to see why hospitals avoid this type of funding mechanism: upon his/her admission, the patient who wants to avail of this payment procedure has a completely unclear status. Whether he/she meets the eligibility conditions becomes clear only after the inquiry and the response of the Social Assistance Directorate. Pending the inquiry outcome, the hospital provides diagnostic and treatment services to the patient and, respectively, incurs all related financial costs. If it turns out that the patient is not eligible for assistance, these costs have to be borne by the hospital and/or the patient, if the hospital is actually able to collect. In other words, payment for services rendered becomes problematic and it is highly likely that the hospital ends up writing off these expenses as losses. Let us

recall that hospitals in Bulgaria, including State and municipal hospitals, work (and should work)¹⁶ as commercial rather than social enterprises (one interviewed expert said that he was impressed by the fact that hospitals in a Western European EU Member State provided the medical services first and only after that were interested in getting paid, whereas in Bulgaria it was the other way round – hospitals first sought a payment guarantee and only after that focused on medical care).

"In practice, the fund for treatment of socially disadvantaged people does not work...If you go to Belgium, for example, you will be treated first and then the hospital will look for who is to pay. It is just the opposite here! If a Bulgarian Roma goes to Belgium, he will get better treatment than here! I constantly see patients who had been hospitalized 10 times already but are without a diagnosis and without adequate treatment. This is it — quality has rapidly declined. Because doctors no longer think about the diagnosis. They think about the clinical pathway and the financial result. Diagnosis is somewhere at the background. This is the reason why some hospitals have simply banned some types of tests. Not for a particular patient, but in general." (A physician representing an NGO)

"Under Decree 17 BGN 5 million are allocated for citizens who cannot afford to contribute to the health-care system...The hospitals here want the uninsured person to pay first and to be hospitalized after that because there is no guarantee that sooner or later the Social Ministry will pay. Whereas regarding this fund, if it turns out that the patient has lost his/her rights to receive social assistance, the physician will be screwed up; the money will not be reimbursed at all. The hospital cannot check such patients, there is no such system. So, this is the situation with this money. Some hospitals even say, "There is no such thing," and they do not have such cases at all. They do this because it is more difficult to have the money reimbursed." (A physician representing a Roma NGO)

5.2. Physical access to medical care

The problem with physical access to medical services and the remoteness of health units is topical "particularly in municipalities where market mechanisms have led to the almost complete collapse of municipal health care and deprived the residents of small towns and villages of access to basic health services." 17 "The closure of municipal hospitals, which provide medical care to the residents of small and remote villages, with a low social and health insurance status and poor demographics will lead to reduced access to medical care." 18

Small municipal hospitals rarely have modern medical equipment and/or sufficiently qualified personnel,¹⁹ due to which they take only less severe medical cases, whereas

18 N. .: 141 N. C. . . (2014–2020)

¹⁶ This has been the predominant view among politicians and in the media over the last 15 years.

¹⁷ National Health Strategy 2014–2020.

¹⁸ National Health Strategy (2014–2020). Annex 1. Health and Healthcare – Current Situation.

¹⁹ The continuous emigration of doctors and the long-time deficit in certain specialties have played a particular role with regard to the availability of personnel in the field.

patients with more serious diseases are referred to bigger hospitals.²⁰ When in need of hospital treatment, more affluent patients often seek the services of bigger hospitals (precisely due to the better diagnostic equipment and more qualified doctors) and prefer to travel to them, even if they can be treated at the local hospital. However, for the most vulnerable social groups (including those in the Roma community), transport costs are a barrier to their access to better hospitals when the patient is seriously ill and has to be treated there. The transport costs are always at the expense of the patient and his/her relatives (unless using specialized medical transport.²¹

Although not entirely consistent,²² in recent years national health-care strategies, and particularly Roma focused ones, have consistently developed the idea of bringing medical services closer to the community by opening health centres for primary outpatient care in the close vicinity of larger Roma neighbourhoods. Various national plans²³ provide support with mobile clinics for these health centres. In some Roma districts, these centres perform multiple functions as community centres for development and social support.

"There are already places where patients have to travel 80–100 km for an X-ray or a clinical laboratory. So, as a whole making specialized tests becomes very difficult because they are associated with additional travel costs, and in some cases with paying for the test itself. These people always come very late. They come at a very advanced stage because it takes them a lot of time until they are diagnosed. In practice, they are excluded from the health system, from any preventive care programmes... Recently I had to travel throughout the country to pay visits to about 100 patients suffering from myasthenia. It turned out that at least 10 per cent of my patients had died. I have never heard of any other EU country with such a mortality rate...This means that parents do not bring their children to the doctor for curable diseases, they cannot afford to do it. They do not treat them. We permanently see children, not to mention adults, but even children, who are left to natural selection. In cases of curable diseases!... A very intelligent girl had to come for a check-up in the hospital, she suffers from the same disease, and her parents are also very intelligent. The school year came to an end. I called them to ask why they were not coming. They said, 'We don't have money to travel.'" (A physician representing an NGO)

"In the villages – problems are associated with the lack of general practitioners and specialized medical care. Because here in the city they can whine and complain, but they can take the cart and go to see a neurologist. There are many neurologists here. But in the villages there are none. There is no doctor. The problem is in these mountainous and

²⁰ This is the objective of the national hospital network – less severe cases are treated locally and more severe cases are treated by larger medical treatment facilities.

²¹ In interviews with experts they gave an example of two rural children, diagnosed with a curable disease, who died within a year because their parents could not find the resources to travel to Sofia, where a hospital was ready to admit and treat the children.

²² There is also a view that the establishment of medical services in Roma districts results in the use of limited and low quality medical services by their residents.

²³ National Action Plan for the Decade of Roma Inclusion 2005–2015, Action Plan for Implementation of the National Roma Integration Strategy of the Republic of Bulgaria 2012–2020.

unattractive areas. Roma ghettos are also considered unattractive areas. We have 20 thousand residents here in the Roma neighbourhood, we would have had otherwise 8 general practitioners. But they do not come because it is difficult here."

(A physician representing a Roma NGO)

5.3. Health insurance and access to medical services in the Roma community

All studies and analyses on the topic of health care in Bulgaria rank lack of health insurance as the most significant obstacle to health-care access. For people with medium and low income, the health insurance is the only key to the entire health system²⁴ (if we leave aside emergency medical care). As already mentioned, the lack of compulsory health insurance leaves the patient to the mercy of free market. We need to note, however, that lack of health insurance affects only the people aged from 18 to 63 years and without a permanent job.²⁵ The State provides health insurance for anyone below 18 and for every pensioner.²⁶ All people with a permanent job and a valid employment contract have insurance as well, because even in the case of unpaid health insurance contributions, health insurance rights are not interrupted and only the employer is liable for these omissions. Nonetheless, according to NHIF data about 1.4 million people did not have compulsory health insurance at the beginning of 2013.²⁷

Roma are at a greater risk of being uninsured – due to the high share of Roma working in the grey economy without social and health insurance and to the mass long-term unemployment in the community.²⁸ Many Roma are self-employed or work for informal (shadow) economy enterprises. Their income is usually irregular and low and they often are not able to pay the health insurance tax due to poverty. Poverty is extremely rampant in the Roma community. The relative poverty rate among Roma in 2011 was 81 per cent – almost four times higher than the national average of 22 per cent (Ivanov, 2013).

Several sociological studies since 2000 provide highly diverging information about the share of uninsured Roma. According to data from Fact Marketing representative study on the health status and access of large ethnic groups to health services in 2003, 31.7 per cent of the Roma adults in Bulgaria did not have health insurance (PHARE, 2003). Same are the 2007 numbers provided by the Open Society Institute (OSI) on the health status of the Roma aged over 18 years – 31 per cent of the Roma claimed they were not insured or were insured only

²⁴ Because only well-to-do patients are able to pay the full cost of health services.

²⁵ For people pursuing liberal professions and for self-employed people who have to take care of their health insurance on their own, it is assumed that they have income to address this problem.

²⁶ The pension age in Bulgaria is 60 for women and 63 for men.

²⁷ National Health Strategy (2014–2020). Annex 1. Health and Healthcare – Current Situation.

²⁸ The Government of Bulgaria pays health insurance contributions for groups such as all children under 5, youths aged 6–18 if they are enrolled in school, all pensioners, and those unemployed who receive monthly social benefits. The problem is that a large number of unemployed are excluded from the list of the people entitled to monthly social benefits for different reasons: lack of a complete registration in the Labour Bureau or lack of documentation; higher household income or if the person or his/her spouse has travelled abroad, etc.

for a part of the year, which prevented them from using public health services. A much lower estimate (18.4%) gave Dr Turnev and M. Grekova in their 2007 study on the health status of the Roma in 17 settlements, but their data covered the uninsured persons in the entire Roma community, and not just the adults.

The Health and the Roma Community: Analysis of the situation in Europe study provided representative information on the health insurance status of the Bulgarian Roma at the end of 2008. The data were collected and evaluated for two different aggregations — for the entire Roma population, and separately — for adults (defined as those over 16). In the first case, the Roma people without health insurance or with unpaid instalments were 18 per cent, and in the other — 26 per cent. More than half of the Roma (52.6%) were insured by the State budget — as children, as registered unemployed with the right to health insurance, as retired or disabled. A quarter (24.4%) were insured by their employer, and 5.3 per cent were self-insured (Tomova and Nikolova, 2011).

According to data provided by a 2010–2011 EC, UNDP, and World Bank financed comparative study on the Roma in Central and Eastern Europe, ²⁹ 85 per cent of Bulgarian Roma, compared to 97 per cent of the rest of the population, had access to public health care (meaning that they could use, at a minimum, emergency medical services and those of a general practitioner) (Mihailov, 2012). More precise data on the share of those without health insurance according to the same data set are published in a Kuhlbrandt, Footman, Rechel, and McKee's paper (2014). According to them, 42.6 per cent of Bulgarian Roma in 2011 did not have complete health insurance. As well as constituting a substantial health risk to those without health insurance, this situation is likely to put additional strain on the health system as a whole. Those Roma who are excluded from health insurance coverage often rely on emergency services, the benevolence of individual health professionals, or try to find health advice from pharmacist.

There is a compensating mechanism available, which is intended to somewhat resolve the issue with the compulsory health insurance for this most vulnerable group – people receiving unemployment and social benefits are insured by the State. This mechanism, however, is only temporary and unreliable – unemployment benefits are paid only for a certain period of time (up to 12 months) and the allocation of social benefits requires meeting various conditions. Suspension of either benefit immediately creates a gap in the health insurance record. If this gap extends to a period of three months, health insurance rights are automatically lost, which in turn terminates access to the guaranteed package of health services. Out-of-pocket payments have to be made for the reinstatement of health insurance rights. With a policy making the return to the health insurance system more difficult, in practice access to health services for the poorest and most socially vulnerable groups is impeded.

²⁹ The survey was conducted in 2011 in Albania, Bosnia and Herzegovina, Bulgaria, Croatia, the Czech Republic, Hungary, the former Yugoslav Republic of Macedonia, Montenegro, Republic of Moldova, Romania, Serbia and Slovakia.

³⁰ Regulations for the implementation of the Social Assistance Act.

"The access of this population is made extremely difficult for several reasons. There are 2–3 main reasons. First, the soaring unemployment rate, the lack of economic status, directly related to the lack of health insurance. In fact, a huge percentage, perhaps more than 90 per cent of this population group, is not covered by the health system. Even those who are formally covered, i.e. the children up to 18 years because the State pays for them, even they do not fully benefit from this care. Because even if there is a formal payment by the State, there are some actions which the parent is required to do. Such as choosing a family doctor and taking the child to the doctor for regular check-ups and immunizations, which does not happen." (A representative of the Ministry of Health)

"The fact that a large percentage of Roma do not have health insurance is a component of accessibility. And this is where the harrowing hardships begin. You go to the emergency care, they send you away. Then you come to the general practitioner...The patient comes and says, 'Please, examine me, I have no money'. I say, 'OK. But you have to pay. Here is what doctors say — I have to charge you 20 leva.' Then we start bargaining like that: 'Give me 3 leva, 5 leva.' 'I don't have any.' 'OK, then. I'll examine you and you will pay when you have money'. You actually lose. Time as well because 8 people with health insurance are in the waiting room. And if they find out that this patient does not have health insurance, they are ready to jump." (A physician representing a Roma NGO)

5.4. Individual financial resources and access to health services

Although a health insurance model functions in the country based on the principle of solidarity in financing, individual financial resources play a major role in the access to medical care. As a rule, the basic package of medical services guaranteed by the NHIF is associated with additional costs: user fees, hospitalisation fees, co-pays for required services or medical devices beyond the NHIF package, and the cost of medications. Sometimes these costs are minimal (but the most vulnerable and poor groups have difficulties in covering even such costs from their individual and family budgets), whereas sometimes they are considerable and are beyond the financial resources of the patient and his/her relatives who are forced to seek other sources of funding or decline the medical care altogether. 31 Official documents provide a sufficiently accurate and detailed picture of the current state of affairs in health care: "Due to the limited amount of public funding, the burden of payment of these costs is shifted onto the personal payments by the population for certain health services and medications. If public health expenditure in health care in the period 1999-2009 increased by 278 per cent, or nearly three times, consumer expenses of households for health care rose by 581 per cent, or nearly six times, in the same period. These costs include: medications for home treatment, user fees, access to specialized outpatient medical care, payment for medical supplies and devices, which are not included in the clinical pathways for hospital treatment, clinical laboratory tests and for avoiding the waiting lists at the

³¹ An example from another study on a similar topic: a permanently unemployed Roma concluded a contract with a company offering fast loans in order to buy a medical device for his retired mother, who was insured by the State but the device in question was not paid by the NHIF.

medical treatment facilities. About 74 per cent of these costs are for medications and medical supplies, 16 per cent – for outpatient services, and about 10 per cent – for hospital services. We should pay particular attention to the citizens' payment for "choosing a team" in hospital care. From a patient's right to choose, it becomes his/her duty without any guarantees for receiving better quality, and, if the patient fails to do so, it often leads to refusal of treatment. ... Whereas European governments fund an average of about three quarters of their total expenditure for health care with public funds (France and Germany – in the range of 77–79%, Poland and Hungary – in the range of 70–72%), this figure in Bulgaria varies in the range of 55–60 per cent. If we also take into account the informal, unregulated out-of-pocket payments or "under-the-table" payments, which are not recorded in official statistics, the share of public expenditure in the total expenditure for health care in the country will fall below 50 per cent." 32

In some cases, the legislation provides for easing the financial burden for medical services: payment of the health insurance contribution by the budget, a reduced or fully waived user fee for pensioners and/or disabled persons, prevention, check-ups and obstetric care for pregnant women without health insurance,³³ payment for medications for certain diseases, and an option for full payment of hospital treatment for socially disadvantaged patients.

Despite the fact that equality is accepted as a universal health-care principle, and that the "policy of the Ministry of Health aims at creating better conditions and ensuring equal access for all citizens of Bulgaria to health services regardless of their gender, age, ethnical and social background, [and that] particular attention is paid to the improvement of the health services provided to disadvantaged groups", ³⁴ the actual use of health services depends on patients' financial status. The existing support mechanisms are inconsistent or insufficient. It is indicative that in evaluating the overall progress of resolving Roma health problems over the past ten years, all experts interviewed spoke either of deterioration of the situation, or (most often) lack of substantial improvement. ³⁵ At best, some individual cases are resolved, but for the time being no positive progress has been achieved for the Roma community as a whole.

"From what is being done, I would identify two—three good practices. Some of them have received international recognition, which at least shows that they have some value. But this hardly influences the overall situation. In other words, they are good as practices, but they

³² National Health Strategy (2014–2020). Annex 1. Health and Healthcare – Current Situation.

³³ The right to free, State-funded routine check-ups, tests and obstetric care for all women without health insurance is limited. An ordinance sets the number of free routine check-ups for the entire pregnancy to one (including tests). "The subsequent actions on ante-natal care are not included in the performed examination and respectively do not fall within the scope of activities the patient is entitled to under this Ordinance as a person without health insurance" (Ordinance 26 of 14.06.2007 r. on delivering midwifery care to women without health insurance).

³⁴ Information of the Republic of Bulgaria on the Progress of Implementation of the National Roma Integration Strategy of the Republic of Bulgaria 2012–2020, Health Priority.

³⁵ In fact, this is also their evaluation of the trend in the whole health system, part of which accounts for the problems of socially vulnerable groups. These trends, however, also apply to all other citizens.

rather have either local influence or are very limited in time and cannot change the course of things for the better. I mean, the Roma issue is so huge, including in its health part, that everything which has been done so far has been insufficient, I would say extremely insufficient. This is the reason why none of the indicators has improved. Neither their life expectancy, nor morbidity, nor access to health-care, nor their attitude, nor their level of health culture, nor raising children... I cannot see any positive, optimistic trends in any of these areas... Well, let us not be over-pessimistic to say that things are getting worse, but at least I do not see any improvement."

(A representative of the Ministry of Health)

"In general, I am an optimist, but there is no way to say there is improvement. Because it was long ago when we realized that you cannot improve health care, if you work only on health care. This has brought the so-called integrated impact, integrated projects, especially in districts as ours. There should be 4–5 general practitioners having their practices here, 10 health mediators...In this way, the community will be covered. However, there will not be a huge impact. Because it is not possible to make health care in the same neighbourhood where rats and mice eat the ears of children and where fecal water flows. Your people have to be educated, or at least informed. This means education. And when I prescribe medications, someone has to buy them. This means they have to be employed... So, there is hardly any improvement – because most of the work is partial and fragmented, just piecework.

(A physician representing a Roma NGO)

6. ROMA COMMUNITY AND HEALTH CARE IN BULGARIA

6.1. Demographic characteristics of the Roma community

According to National Statistical Institute (NSI) data from the 2011 census, Roma remain the third largest ethnic group in Bulgaria (after the Bulgarians and the Turks). 325,343 people identify themselves as Roma, or 4.9 per cent of Bulgarian citizens (0.2% more than in 2001, but with 45,565 people less than in the 2001 census, when 370,908 people identified themselves as Roma). However, projections for the number of Roma had been significantly higher, based on 1992–2004 population growth patterns. It was expected that their number in 2011 would exceed 450,000, albeit with the assumption that natural population growth rates remain constant and without taking into account any possible emigration effect.

6.1.1. Self-identification

Self-identification is a fundamental principle for determining the number of ethnic communities. However, researchers of marginalised and stigmatised groups usually note that some of the members of such groups prefer to publicly declare another ethnic identity, hoping to avoid contempt, discrimination, or violence. This process is observed among the Roma in most European countries. Therefore, experts rarely limit their evaluations to quoting official data of the statistical institutes, and make their own estimates of the number of Roma, though in most cases these estimates are quite controversial. Experts believe that

the number of those identified by the other Bulgarian citizens as "Roma/Gypsies" exceeds 800,000 people³⁶ (over 11% of the Bulgarian population).

6.1.2. Urban and rural population

The degree of urbanization of different ethnic groups in Bulgaria varies. In the urban areas live three quarters of the people who identify themselves as Bulgarians (77.5%), more than half (55.4%) of those who identify themselves as Roma, and almost two fifths of the Turks (37.6%).

Place of residence determines to a large extent the population's access to quality health care and good education, the possibility of finding work and generating decent income, the quality of infrastructure, housing environment, the spread of poverty. Hence the difference in infant and maternal mortality, average life expectancy, power relations within the families and related birth rate. On all these indicators rural population seriously differs from the urban population. Disturbing fact is that the differences between town and country deepened during the years of post-communism.

Table 1: Place of residence of the major ethnic groups (in %)

	E	Bulgarians			Turks			Roma		
	1992	2001	2011	1992	2001	2011	1992	2001	2011	
Town	71.6	73.5	77.5	31.6	37.0	37.6	52.3	53.8	55.4	
Village	28.4	26.5	22.5	68.4	63.0	62.4	47.7	46.2	44.6	

Source: NSI, 1994, 2004 and 2011.

6.1.3. Age structure

The Roma community is the youngest in the country. Three-fifths of the Roma are children and young people, over two times more than ethnic Bulgarians³⁷ of the same age. Younger age structure determines the higher birth rate this community boasts, in the medium and long term.

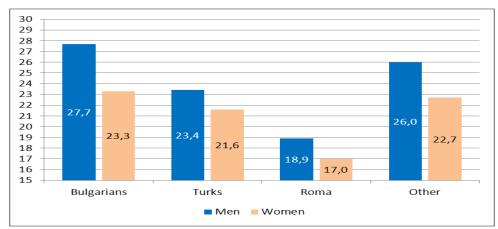
³⁶ Bulgarian ethnologists E. Marushiyakova and V. Popov made an "expert estimate" of the number of Roma in the country as of 800,000 people in 1992, without reporting any methodology or serious arguments for their opinion. Later this figure was repeated by Jean-Pierre Liegeois, whom they consulted. Bulgarian sociologists were quite sceptical and even some years later they continued to believe that this number was greatly overstated. This assessment was based on another controversial expert evaluation – of the Ministry of Interior of 1989, when, using "objective criteria" 576,927 people were identified as Roma.

³⁷ According to the last census (2011), in which no account was taken of the ethnic identity of a large number of children (most likely from minority ethnic groups), 57.3 per cent of the Roma were aged from 0 to 29 years. With ethnic Bulgarians this share was 28.1 per cent (NSI).

6.1.4. Early marriages

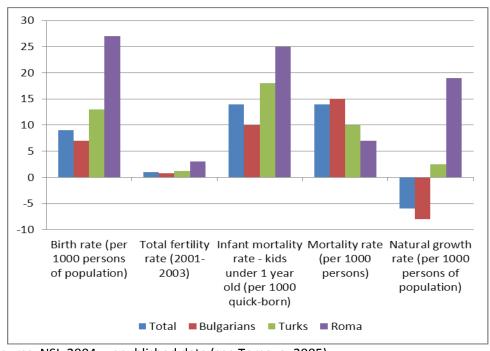
Roma are the ethnic group with the earliest marriages/marital cohabitations (partnerships) in the country. According to 1994 data, about 80 per cent of them start families before 18 (Tomova, 1995:42). More recent sociological studies found a continuation of this trend, especially among the poorest and least educated youth (Turnev and Grekova, 2007). Early marriages are a prerequisite for early deliveries and more children, but increase the risk of various pregnancy complications and health problems in newborns.

Chart 1: Average age at the start of family life (marriage or marital cohabitation) of the major ethnic groups in Bulgaria according to gender in 2004



Source: NSI, 2004 (see Tomova 2005).

Chart 2: Birth rate, infant mortality rate, death rate and natural growth rate of major ethnic groups in Bulgaria as of 1 March 2001



Source: NSI, 2004, unpublished data (see Tomova, 2005).

6.1.5. Birth rates

Bulgaria has one of the highest early birth rates in Europe. Early births occur 10–12 times more often in Roma groups than among ethnic Bulgarian women. Early and extremely early Roma births are currently on the decrease, though this could hardly be due to State policies for improving the health and reproductive culture of Roma. In the post-communist period, early marriages' frequency in the Roma community dropped rapidly and this was the main reason for the drop in the early birth rate (the frequency of juvenile mothers giving second and third births decreased). Both poverty and restrictions in the access to social allowances and services oriented toward families and children were also significant factors for postponing the second and following births among all ethnic communities.

Table 2: Early birth rate per 1,000 girls under the age of 18

ETHNIC GROUP	1992	2001
Bulgarians	66.2	41.3
Turks	283.1	179.6
Roma	690.3	508.8

Source: NSI, 2004 (unpublished data).

Table 3: Extremely early birth rate per 1,000 girls under the age of 15

ETHNIC GROUP	1992	2001
Bulgarians	3.1	2.4
Turks	20.3	21.5
Roma	70.1	35.6

Source: NSI, 2004 (unpublished data).

Table 4: Bulgaria: Age specific fertility rates (births per 1,000 women)

PERIOD	15-19	20-24	25-29	30-34	35-39	40–44	45–49
1955-1960	63.9	179.8	122.3	57.5	25.9	8.4	1.5
1960-1965	70.2	183.0	114.5	50.4	18.7	6.0	0.8
1965-1970	69.7	183.7	108.8	43.9	15.5	3.9	0.6
1970-1975	71.3	191.1	110.1	42.1	13.4	3.1	0.3
1975-1980	77.4	201.4	106.4	38.7	11.9	2.5	0.2
1980-1985	79.8	186.9	92.0	32.3	9.7	2.0	0.1
1985-1990	75.8	178.8	90.2	32.6	9.9	2.0	0.1
1990-1995	66.7	138.5	69.4	25.6	8.5	1.8	0.1
1995-2000	48.2	94.0	63.6	24.8	7.8	1.6	0.1
2000-2005	41.7	84.2	74.3	35.8	10.7	1.8	0.1
2005-2010	42.1	79.3	85.8	56.2	18.9	2.8	0.1

Source: NSI, EUROSTAT, 2012.

In 2011, 11 per cent of all births were by mothers aged 12–19 and 10.3 per cent of all abortions came from the same age group. The fertility rate of 15–19 year olds in Bulgaria

was 44.8 per 1,000 in 2010; 44.9 per 1,000 in 2011; 45.5 per 1,000 in 2012; and 45.1 per 1,000 in 2013 (NSI; EUROSTAT 2014).

The Roma community is very heterogeneous, and any generalizations rather obscure than clarify the studied social processes within it. It is important to know that demographic attitudes and behaviour among Roma with secondary and higher education are identical to those of the ethnic Bulgarians (Tomova, 1995; Tomova and Nikolova, 2011). The problem is that the group of Roma with higher education is very small (only 0.5% of Roma aged over 20 years has University degree).

6.2. Employment

The correlation between employment and ethnic group has been very high throughout the post-communist period. According to a 1980 survey of 4,943 Roma done by the Central Committee of the Bulgarian Communist Party, the employment rate in their group was very high. Permanently employed were 88 per cent of the men and nearly 80 per cent of the women of working age, for a total of 84 per cent for the whole community (Dimitrov, Chakalov, Georgieva and others, 1980). This level of employment was maintained until the end of the 1980s. In 1992, according to data from the census, employed were 47 per cent of working age Roma. In 2001 the percentage of employed Roma fell to 17.9 per cent (Table 5).

Table 5: Economic activity of major ethnic groups in Bulgaria (in %)

	Employed		Unemployed		Economically inactive	
Ethnic group (aged 15-59 years)	1992	2001	1992	2001	1992	2001
Bulgarians	65.4	56.4	11.0	21.9	23.6	21.7
Turks	59.3	39.7	19.8	39.0	20.9	21.3
Roma	47.0	17.9	30.2	59.9	22.8	22.2

Source: NSI, Census 1992 and 2001 (see Tomova, 2005).

Since 2002, the number of employed Roma has gradually increased; in the period 2007–2008 it increased to around one third of the working age members of the community. This increase, however, was temporary and was quickly replaced by a new decline due to the global financial and economic crises. According to NSI data from the 2011 census, only 20.6 per cent of the Roma of working age (16–64) were employed (Table 6). None of the other ethnic communities in the country was hit so hard by massive unemployment.

Table 6: Economic activity of the population aged 15 years and over from the major ethnic communities in Bulgaria, 2011 (in %)

Economic indicators	Bulgarians	Turks	Roma
Economically active	68.7	53.3	41.1
- Employed	60.1	39.6	20.6
- Unemployed	8.6	13.7	20.5
Economically inactive	31.3	46.7	58.9

Source: NSI, Census 2011, independent calculations.

6.3. Education

Education is a basic status indicator in modern and post-modern society. Lack of education and lower level of completed education certainly situate the individual and the social (including ethnic) group at the bottom of the social ladder. Lack of education sharply limits the possibility for positive social mobility and determines the risk of social exclusion. It is one of the most important factors in determining the risk of unemployment and poverty, and for the transmission of poverty and social exclusion to subsequent generations.

The Roma community has the lowest level of completed education in Bulgaria (Table 7). Another characteristic is that functional illiteracy is three times more common among Roma women than among men. As women take care of children in the Roma community, their illiteracy or low level of education have a negative effect on educational aspirations and school success of Roma children (Table 7).

Table 7: Educational structure of the major ethnic communities in Bulgaria in 2001 and 2011 (persons over 20 years old)

	Bulgarians		Turks		Roma	
	2001	2011	2001	2011	2001	2011
University	19.2	25.6	2.4	4.9	0.2	0.5
Secondary	47.6	52.3	21.9	29.7	6.5	9.0
Elementary	24.9	18.0	46.9	44.5	41.8	40.8
Primary	6.9	3.4	18.6	13.4	28.3	27.9
Unfinished primary and illiterate	1.4	0.9	10.2	7.5	23.2	21.8

Source: NSI, 2004, 2011 (restated data for the persons aged over 20 years).

Between the last two censuses, there has been an overall increase in the educational attainment across all socioethnic groups, yet among the Roma this upturn has clearly lagged behind that of the other two groups (Bulgarians and Turks).

6.4. Health status

6.4.1. Self-evaluation

Studies on health status of the population show that Roma tend to assess their own health as good.³⁸ In Bulgarian Roma community where two thirds of the population is under 30

³⁸ Vassileva, L., A. Aleksandrov, Karamanova B. Alexandrova, E. Bogdanova, E. Dimitrova, T. Kotzeva I. Todorova, 2008. *Behavior and health in children of school age*; Fact Marketing, 2003. *Ensuring minority groups with access to healthcare*. Results of the qualitative and quantitative study; *Health and the Roma Community, Analysis of the Situation in Europe. Bulgaria, Czech Republic. Greece, Portugal, Romania, Slovakia, Spain.* 2009 FSG; Mihailov, D., 2012. *The health situation of Roma communities: Analysis of the data from the UNDP/World Bank/EC Regional Roma Survey 2011;* NSI, 2002-b. Census of Population, housing and farms in 2001, Volume 6, Book 4. Sample surveys. Health of the population; NSI, 2010a. European health interview (Main Results); NSI, 2010-b. European Health Interview – 2008. Main results by statistical regions and

years and only about 5 per cent over 65, this seems perfectly logical. But often these seemingly positive responses belie Roma community's poor health status and serious health problems. The health self-assessment of Bulgarian Roma aged 35–44 corresponds to that of the general population in the 45-54 age group. Then it rapidly deteriorates, so Roma over 55 assess their health like the 75 and over age group does in the general population (*Health and the Roma Community: Analysis of the Situation in Europe...* 2009:32).

In 2001, the share of the Roma who had declared poor health was 31 per cent, compared with 41.8 per cent of the Bulgarians (Chart 3).

45 40 35 30 25 20 41,8 33,9 35,6 15 10 22,8 31,1 18,9

Chart 3: Proportion of people with poor health and those with long-term disease from the major ethnic groups in Bulgaria, 2001 (in %)

Source: NSI, 2001.

Bulgarians

People with poor health

5 0

Data from different representative studies on the major ethnic communities in Bulgaria conducted after 2001 show that, despite the relative improvement of the living conditions in the country, people assess their health as relatively unchanged and quite poor in general. According to Gender and Generation Survey (GGS) study, during 2004–2007, the share of Bulgarians who rated their health as poor or very poor had decreased to 9.8 per cent, compared with 25.3 per cent of the Roma people (Table 8).

Turks

Roma

People with long-term disease

Table 8: Distribution of persons by major ethnic groups in Bulgaria, according to their self-assessment of health status in 2003, 2004, and 2007 (in %)

	Bul	garians		Turks		Roma	
Self-assessment of health	2004,	2007,	2004,	2007,	2003,	2004GGS	2007,
status	GGS	GGS	GGS	GGS	Fact		GGS
Very good	21.3	23.3	23.1	27.1	19.4	21.6	13.7
Good	44.5	45.9	42.0	40.2	49.6	48.0	32.8
Fair	23.7	20.9	23.0	18.9	-	17.6	28.2
Poor	8.4	7.5	10.4	11.3	26.9	10.6	17.6
Very poor	2.0	2.3	1.5	2.4	4.2	2.2	7.7
Total	100.0	100.0	100.0	100.0	100.0	100.0	100.0

Sources: GGS, 2004; GGS, 2007; Fact Marketing, 2003; OSI, 2007.

The Health and the Roma Community: Analysis of the Situation in Europe (2008) study uses various indicators for monitoring self-assessment of the Roma's health status. One of them is related to the assessment of their health and that of the members of their households during the 12 months prior to the interview. Most of the respondents (Bulgarian Roma) rated their health and that of their relatives rather positive, but there was a strong correlation between health self-assessment and age. Less than a quarter of the Roma who were over 45 years old rated their health positively. The correlation between self-assessment of health status and gender was low.

6.4.2. Diseases and health problems

Numerous sociological studies showed an increase in serious health problems for the Roma practically throughout the whole post-communist period (Tomova, 1995; 2000; Tomova, Vandova and Tomov, 2000; Turnev, 2002; PHARE, 2003; Turnev and Grekova, 2007; Tomova and Nikolova, 2011; Kling, 2013).

Mass poverty, restricted access to health services, malnutrition, everyday stress, poor living conditions, early and frequent births, heavy physical work, and unhealthy lifestyles were the reasons that led to serious deterioration of the Roma health. These adverse developments were deepening at a time when the State abruptly cut health funding, the package of subsidised medical services decreased significantly, and the low incomes of Roma households put paid medical services and medications inaccessible to most of them.

According to the 2010–2011 international comparative survey of EC/UNDP/World Bank on the Roma of Central and Eastern Europe, 33 per cent of Bulgarian Roma live in absolute poverty i.e. have less than PPP USD 1³⁹ daily, and 42 per cent of the Roma in Bulgaria suffered from acute malnutrition (compared to 6% of Non-Roma). Only 30 per cent of Roma said they were able to purchase prescribed medication (compared to 79% of Bulgarian non-Roma population) (Kling 2013).

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³⁹ PPP - Parity Purchase Power.

Doctors' evaluations demonstrate that despite Roma being the youngest community in the country, they in fact suffer from particularly acute health problems. According to data from the largest representative study on the health status of Bulgarian Roma, conducted by the Ministry of Health in 2003, during which doctors examined nearly 10,000 people, in about 80 per cent of the Roma households there was at least one sick person, in half of the households there was a chronically ill person, and in one fifth of the households there were two or more chronically ill persons. Over two fifths of the Roma community had serious health problems (Fact Marketing, 2003). According to data from another major study conducted by doctors and sociologists in 2006 in 16 villages in the country, there was at least one chronically sick or disabled person in 14.4 per cent of the households (Turnev and Grekova, 2007). According to the data from OSI survey conducted at the end of 2007, 30.9 per cent of the Roma households had someone suffering from severe illness, chronic illness, or disability; while in one out of every four households there were two or more chronically ill or disabled household members.

The most widespread diseases in the Roma community (according both to the Roma themselves and to their general practitioner (GPs)) are hypertension and other cardiovascular diseases, acute catarrh of the upper respiratory tract, lung diseases (bronchitis, bronchopneumonia, chronic obstructive pulmonary disease), asthma (about half of the patients are children), diabetes, and various gynaecological diseases. Musculoskeletal disorders are also common. Due to heavy physical work Roma develop early degenerative joint or disc changes that lead to disability. Relatively common are ulcer, various kidney diseases, endemic goitre, and thyrotoxicosis (Tomova, 1995; Tomova, Vandova and Tomov, 2000; Turnev, 2002, PHARE, 2003; Turnev and Grekova, 2007).

According to a 2007 OSI survey, Roma suffered from the following diseases diagnosed by a general practitioner or a specialist (Table 9).

Table 9: Proportion of the respondents who have suffered from acute or chronic illness in the month before the survey, 2007 (in %)

Disease	%
Disease of the cardiovascular system	22.9
Headache, migraine, or other neurological disorders	21.1
Malaise, fever, contagious disease	20.5
Disease of the bones or joints	14.2
Disease of the digestive system	13.9
Disease of the ear, nose and throat (Otorhinolaryngological diseases)	11.3
Neurosis, prolonged insomnia or other mental illness	11.2
Respiratory diseases	10.3
Ophthalmological diseases (diseases of the eyes)	9.7
Kidney stones or infection of the urinary tract	8.8
Gynaecological problems	4.9
Diabetes	4.6
Inflammation of the lymph nodes or blood disease	3.0
Complaints of prostate	2.7

Eczema and other skin diseases	2.6
Thyroid disease	2.3
Problems related to pregnancy	1.7
Hydatid cyst surgery (Echinococcus granulosus)	0.5
Other	4.3
Source: OSI, 2007.	

The OSI survey provides important information on what portion of Roma patients suffering from a chronic disease have medical insurance. It turned out that around half of those who had had a myocardial infarction or hepatitis A, B or C, hypertension, heart failure, asthma, TB, osteoarthritis or rheumatoid arthritis, depression, migraine, gastritis, ulcer, kidney disease, allergies or echinococcosis, were not insured.

The 2008 Health and the Roma Community: Analysis of the Situation in Europe study provides data on diseases the Roma suffer from and which were diagnosed by a doctor. They relate not only to the adult Roma population, but also to children (Table 10).

Table 10: Share of Bulgarian Roma suffering from chronic diseases, diagnosed by a doctor, by gender, adults and children in 2008 (in %)

	Men	Women	Children	Adults	Total		
Children and adults							
Hypertension	22.3	22.9	2.3	32.5	22.6		
High cholesterol	6.8	8.0	0.4	10.8	7.4		
Diabetes	6.4	6.4	0.4	9.3	6.4		
Asthma, chronic bronchitis	13.0	15.2	14.3	13.9	14.0		
Heart disease	8.2	10.1	1.5	12.8	9.1		
Stomach ulcer	5.5	8.0	1.1	9.3	6.6		
Allergy	8.2	10.9	9.4	9.5	9.5		
Depression	1.8	5.1	0.8	4.6	3.3		
Other mental illnesses	1.4	2.9	2.6	1.8	2.1		
Migraine or headache	9.8	20.0	4.1	19.5	14.5		
Hernia	3.6	3.5	2.3	4.2	3.6		
Ad	ults only	/					
Blood circulation problems	3.5	4.9	-	4.2	4.2		
Arthritis and rheumatism	11.7	18.8	=	15.1	15.1		
Osteoporosis	1.1	4.6	-	2.8	2.8		
Prostate problems	8.9	_	-	8.9	8.9		
Problems associated with the menopause	-	11.7	-	11.7	11.7		
Basis (number)	(439)	(375)	(266)	(548)	(814)		
Source: EDIS S.A. European Survey on Health and the Roma Community.							

Infectious diseases are a serious problem in Roma neighbourhoods, where overpopulation makes the isolation of virus carriers challenging and diseases often grow into epidemics. Some cultural characteristics (empathy with the patient requires visits, care, and emotional support from all the relatives, neighbours, and friends during the illness) also contribute to

the spread of infections. Unhealthy diet, exposure to long-term daily stress caused by poverty, unemployment, and uncertainty about the future weaken the body's resistance and sometimes contribute to medical complications.

Viral hepatitis is a serious problem for most of the Roma neighbourhoods in Bulgaria. In 2006 a severe hepatitis epidemic broke out in the Plovdiv neighbourhood of "Stolipinovo" and soon after spread to other Roma neighbourhoods. In 2011 and 2012 the incidence of viral hepatitis was the highest in Bulgaria since 2007 (NSI, 2014). Poor living conditions are the reason for outbreaks of intestinal infections during the summer months. In almost every Roma neighbourhood, there are cases of echinococcosis and other parasitic diseases. Extremely frequent are skin infections, especially mycoses (Tomova, Vandova and Tomov, 2000; Turnev, 2002; UNICEF, 2003; UNDP, 2003; Turnev and Grekova, 2007; 2008).

TB is also widespread in Roma neighbourhoods. Prevalence of active TB in 2012 was 75.8 per hundred thousand of the total population. The incidence of new cases of TB decreased – in 2012 they were 26.6 per hundred thousand of the total population (NSI, 2014). NSI does not publish disaggregated data on ethnic basis on the health issues.

According to Gender and Generation Survey (GGS), there is a correlation between ethnic group and chronic diseases in older age (over 45). For example, in the age group (45–60), three fifths of the Roma compared to two-fifths of Bulgarians suffer from various chronic diseases, and a third of the Roma (compared to one tenth of all Bulgarians) have varying degrees of disability.

According to the *Health and the Roma Community: Analysis of the Situation in Europe* survey, 12.6 per cent of the entire Roma population in Bulgaria is either disabled or has serious chronic diseases. There is correlation between major chronic diseases and disability by the age and gender of the respondents. A distinctive feature of Bulgarian Roma is the very early onset of disability and mass chronic diseases even in middle age. One-third of men and two-fifths of women aged 45–60 years have already lost part or all of their ability to work due to poor health. The proportion of elderly Roma (those over 65) diagnosed with a chronic disease or disability hovers around 70 per cent – three-fifths of men and three quarters of women. The data in Table 11 refers to all members of the households included in the study (a total of 3,947 people).

Table 11: Distribution of the Roma people with disability or a chronic disease by gender and age group, 2008 (in %)

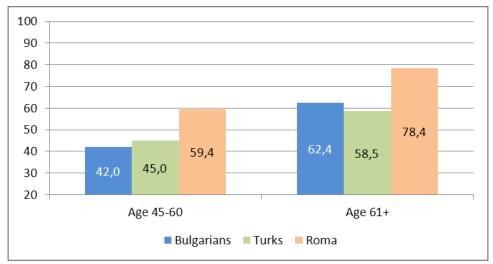
	Men	Women	Both genders
0–4	3.8	7.9	5.5
<u>0–4</u> 5–9	4.7	6.2	5.4
10–15	3.9	1.8	2.9
16–29	5.4	5.0	5.2
30–44	8.9	11.8	10.4
45–64	33.9	39.4	36.4
65+	61.7	75.0	69.2

Average	11.6	13.6	12.6
Basis (number)	(1,998)	(1,949)	(3,947)

Source: EDIS S.A. European Survey on Health and the Roma Community.

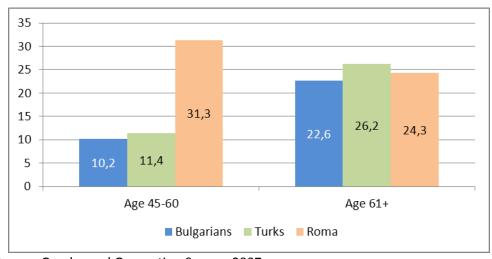
Charts 4 and 5 show the proportion of individuals from the major ethnic communities with long-term or chronic diseases, and those with limitations in performing normal activities in their personal lives due to health problems or disability. It should be borne in mind that according to data from the *Gender and Generation Survey 2007*, the Roma are the group with the longest duration of chronic maladies.

Chart 4: Proportion of individuals from the major ethnic groups who have a long-term or chronic illness, 2007 (%)



Source: Gender and Generation Survey, 2007.

Chart 5: Proportion of individuals of the major ethnic groups, who have limitations in performing normal activities because of health problems or disability, 2007 (%)



Source: Gender and Generation Survey, 2007.

A particular problem for some endogamous Bulgarian Roma subgroups is the hereditary diseases. According to Dr Turnev, 60 per cent of the marriages among the Thracian Tinkers, 45 per cent in the Kalderash subgroup and 28 per cent in the Kopanari group are consanguineous. Endogamy and inbreeding, characteristic especially for the subgroups belonging to the Vlax Roma groups, have led to different manifestations of hereditary diseases (inbreeding depression). Thus, among the Kalderash and the Kopanari families there is an accumulation of neuropathies, hereditary (congenital) angioedema, galactokinase deficiency, and among the Thracian tinkers – epilepsy (Turnev, 2001; 2002). During the study of Roma in 16 settlements in 2006, Turnev determined that 1.9 per cent of households has hereditary diseases (Turnev and Grekova, 2007). At the same time, many of the other medical specialists we interviewed talk of "constitutional predisposition" or "hereditary predisposition" for a variety of diseases in their patients.

6.4.3. Accidents

Doctors who work in Roma neighbourhoods state that Roma are victims of accidents more often than the general population, for the following reasons:

- ➤ Because of the high percentage of children and young people in the Roma community, risky behaviour often leads to injuries characteristic of adolescence and young age;
- Many young children are left in the care of their older sisters, which increases the risk of minor injuries, burns and absorption of harmful substances or drugs;
- Roma men and youngsters are often involved in heavy physical labour, where accidents occur frequently;
- Roma are more often than non-Roma victims of harassment and physical violence as a result of racial hatred;
- ➤ The aggressive behaviour of boys and men is tolerated by the Roma community, and the results are frequent incidents in everyday life, on the street, at school, and in the workplace.

Table 12: Proportion of men, women, children and adult Roma, who have had an accident in the year before the study, according to the place of incident, 2008 (in %)

	At home	Road accident	Outside, not on road accident	At work/at school	Other place	Total:	Basis (number)
Men	32.0	18.8	24.3	16.3	8.6	100.0	(472)
Women	56.1	13.5	15.5	9.7	5.2	100.0	(414)
Children	42.2	9.0	25.2	15.9	7.6	100.0	(353)
Adults	43.1	20.9	17.5	11.7	6.8	100.0	(533)
Total	42.8	16.5	20.3	13.3	7.1	100.0	(886)

Source: EDIS S.A. European Survey on Health and the Roma Community.

Data from the *Health and the Roma Community: Analysis of the situation in Europe* survey indirectly supports the findings of experts and doctors. Children are more often victims of

accidents, and they make up a third of the Roma population. Among adults, those over 60 are the most vulnerable group. The number of accidents among those over 45 is due to poor working conditions, ill health, and unhealthy lifestyle.

Most Roma have had accidents in their own homes. Roma female respondents declared that three fifths of the accidents they had experienced over the past year took place at their homes. Two fifths of the accidents Roma children had experienced also took place at their homes. Probably in some cases they were victims of domestic violence. Numerous studies have shown that physical violence is an essential tool used by men in Roma households to impose their power over women and children. Beatings and physical punishment are perceived as a routine disciplinary measure for children in most conservative patriarchal communities, including Roma ones. Only in recent years has Bulgarian society began to form a negative public opinion and increased its intolerance towards domestic violence, but in closed, paternalistic, and marginalised communities such abusive attitudes persist.

6.4.4. Hospitalization of the Roma

According to data from a 2003 Fact Marketing survey, Roma had used hospital services more often than other ethnic groups, but their assessment of the quality of the services they had received was in fact the lowest. For a period of one year, about 30 per cent of the Roma respondents had used hospital medical treatment. About 75 per cent of them were satisfied with these services (PHARE, 2003). According to the *Health and the Roma Community: Analysis of the Situation in Europe* study, in 2008 the percentage of hospitalised Roma in Bulgaria was significantly smaller – one fifth of the respondents had used hospital medical treatment in the year preceding the interview (Table 13).

Table 13: Distribution of the Roma who were hospitalised for at least one day in the past 12 months, by gender and age, 2008 (in %)

	Hospitalised	Not hospitalised	All	Basis (number)
Total	19,7	80,3	100	(814)
	Children	and adults		
Children	20.7	79.3	100.0	(266)
Adults	16.6	83.4	100.0	(548)
	Gen	der		
Men	16.4	83.6	100.0	(439)
Women	19.7	80.3	100.0	(375)
	Age gr	oups		
0–9	29.2	70.8	100.0	(144)
10–15	10.7	89.3	100.0	(122)
16–29	14.6	85.4	100.0	(198)
30–44	12.2	87.8	100.0	(181)
Over 45 years of age	23.7	76.3	100.0	(169)

Source: EDIS S.A. European Survey on Health and the Roma Community.

Highest was the share of hospitalisations among young children (0–9) – almost a third of them were hospitalised, and among the elderly – those over 45, of which a quarter were hospitalised. Due to women's higher life expectancy, usually in poor health, their share among the hospitalised persons was higher than that of men. As expected, hospital access was most challenging for the poorest Roma. Only 13.5 per cent of those living in the most miserable conditions – in squalid homes they have built themselves out of available materials – were hospitalised.

We can find an indirect confirmation of the high degree of child hospitalisation in national health statistics for the general population. During 2000–2006, the number of patients with neonatal problems increased twofold. The number of hospitalised premature babies, hypotrophic and injured infants and children of nursing age increased two and a half times. Due to early pregnancies and poor living conditions of many Roma women, the proportion of babies with similar problems in the Roma community is much higher than the national average. Looking at the chart of the 10 most common diseases leading to hospitalisation of children, we find that these are the same diseases that doctors say are far more common among the Roma children – pneumonia and bronchitis, infectious diseases and parasites, medical conditions in the perinatal period, dysentery, early and extremely early pregnancy and birth, etc.

The National Centre for Health Information (NCHI) provides data on the main classes of diseases for which children were hospitalised. The first three of them, for which 88.4 per cent of the children of age 0–7 were hospitalised, are more common among Roma children than among Bulgarian ones — respiratory diseases, conditions originating in the perinatal period, infectious and parasitic diseases (Table 14).

Table 14: Distribution of hospitalised children aged 0–17 in hospitals for 2007, 2010, 2011 and 2012 in Bulgaria (in %)

Disease	2007	2010	2011	2012
Diseases of the respiratory system	41.2	35.0	35.0	34.1
Certain infectious and parasitic diseases	13.3	12.5	8.2	8.2
Injury, poisoning and other consequences of external causes	8.0	6.3	6.2	6.3
Certain conditions originating in the perinatal period	7.0	6.0	6.8	7.3
Diseases of the digestive system	6.9	4.2	5.5	6.2
Diseases of the urogenital system	4.4	2.9	3.7	4.0
Pregnancy, childbirth and the postnatal period	4.1	2.5	2.7	2.5
Congenital malformations, deformations and chromosomal aberrations	1.8	1.4	1.4	1.6

Source: NSI and NCHI, 2008, 2012, 2013.

Paediatricians often claim that hospitalise Roma children more often than Bulgarian (especially children aged 0–1). The reasons are:

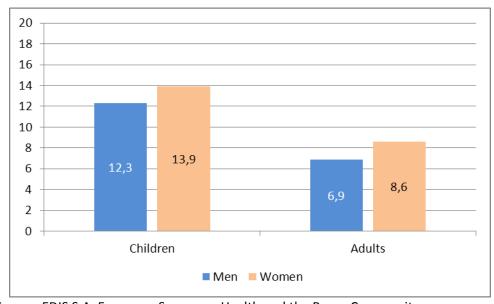
Roma infants are exposed to respiratory and infectious deceases more often than Bulgarian due to their permanent contacts with many siblings and other relatives in Roma households;

- Roma children live in worse conditions than Bulgarian ones: only one fourth of Roma households live in neighbourhoods with indoor plumbing compared with three fourths of Bulgarian households, and Roma houses are of worse quality than Bulgarian;
- ➤ Half of the Roma children (compared to less than one fifth of Bulgarian children) live in rural area with bad access to health-care services: quite often a general practitioner serves several villages and visits each of them once per week, but there are several hundred villages without general practitioner at all. When parents bring their sick children to see a doctor, it often turns out that the sick child's health condition is so bad that he/she needs hospitalisation;
- ➤ Poverty: two thirds of Roma families don't have enough money to pay for medicines prescribed by general practitioner and doctors are forced to hospitalise sick Roma children to prevent further deterioration of their health.

6.4.5. Length of hospital stay

According to the National Centre for Health Information, the average length of hospitalisation decreased from 11.5 days in 2000 to 6.1 days in 2010. This was one of the reform targets of the Government of Bulgaria in the hospital sector (NSI, 2013). When we compare NCHI data for the average hospital stay in Bulgaria with data from the *Health and the Roma Community: Analysis of the situation in Europe* study, we find that Roma remain in hospital longer than the general population. In 2008, the average stay of Roma in hospital was 9.8 days – 3.3 days longer than the average for the whole Bulgarian population. The average hospital stay was 5 days longer among Roma children compared to adults. Roma women remain hospitalised longer than men (Chart 6).

Chart 6: Average number of days of hospitalisation of the Roma population during the last hospitalisation by gender, 2008 (in %)



Source: EDIS S.A. European Survey on Health and the Roma Community.

Based on Roma health surveys' data and medical doctors' interviews, we can make several conclusions:

- Roma stay in hospital longer than the general population;
- Roma children are often hospitalised with multiple disease symptoms in severe form, which calls for a lot of medical checks for accurate diagnosis;
- Roma children often need long-term treatment of comorbidities (accompanying diseases);
- Adult Roma often have to stay longer in hospital than Bulgarians due to the severity of the disease for which they have been hospitalised and/or because of their poor general health (comorbidities).

6.5. Conclusions

Bulgarian Roma are a socially vulnerable group with a restricted access to the State-funded health care due to the large number of uninsured and the mass poverty in their community. Roma live in good health much shorter than the rest of Bulgarian citizens and are at a higher risk for infectious and parasitic diseases due to restricted access to State-funded health care, poverty and poor living conditions.

At the same time, Bulgarian politicians and media constantly portray the Roma as people not willing to pay their health-care insurance contributions but aggressively demanding to use NHIF funded health services. These representations augment negative attitudes towards Roma and block social solidarity towards this vulnerable group. Mass negative attitudes towards Roma in turn reduce political will (if any) to implement special measures to improve Roma access to State-funded health care. In this situation it seems more reasonable to formulate an amendment to the Health Insurance Law for a universal access to health care and health insurance for all vulnerable Bulgarian citizens, not to rely only on "special measures to improve Roma access to State-funded health care" in NRIS.

Bulgarian National Roma Integration Strategy and the Action Plan for its implementation put the accent on measures to improve Roma mothers and children health care. Bulgarian Roma mothers and their children are at higher risk of poor health due to the same factors as the whole Roma community:

- uninsured pregnant women and mothers' restricted access to State-funded healthcare services even during the pregnancy;
- mass poverty in the Roma community that makes private funded health services and buying medicines not available for the majority of Roma households;
- poor living conditions;
- early births and/or short intervals between following deliveries;
- ➤ lack of confidence in the health-care system and health-care personnel, etc.

The National Roma Integration Strategy addresses Roma health risk factors only partially. For example, a high number of measures and activities to improve Roma knowledge about family planning, mandatory vaccinations, healthy nutrition, and good child care are planned. The problem is that the majority of Roma don't have the funds to pay for family planning

devices or for healthy nutrition, thus reducing the potential impact of the information provided. Planned financing to improve the access to specialized health care for uninsured pregnant women is not sufficient. Allocated funding to improve Roma living conditions is also not sufficient.

Another weakness of Bulgarian Roma Strategy is that it is setting low targets to achieve. According to NRIS, in 2015 "more than 75 per cent of pregnant Roma women have to receive at least one specialized medical check during their pregnancy", but this has been the practice for more than 90 per cent of the pregnant Roma women before the adoption of NRIS, and there is a legal opportunity to ensure one medical check for all Roma women. The problem is that this one medical examination often is not provided, and it is not sufficient, according to specialists. Another example: According to NRIS, "in 2015 more than 75 per cent of the pregnant Roma women have to deliver their babies in hospital", while statistical data show that in practice more than 95 per cent of Roma women have delivered their babies in hospitals since decades and special measures are needed to decrease the number of those few, who deliver their babies at home. Or again: "More than 75 per cent of Roma newborns have to be enrolled in general practitioners' lists of patients" which has been the practice for more than 90 per cent of the Roma babies before NRIS adoption. Setting low targets for the improvement of Roma access to health care is a sign of the Government of Bulgaria's underestimating of Roma health problems. This is an easy way not to do much to improve Roma situation, but to be able to show "a progress".

7. GOOD PRACTICES AT THE NATIONAL LEVEL

Successful practices oriented towards the health of Roma communities at a national level are:

- The programme for preventive care;
- The national network of health mediators;
- ➤ The programme for encouragement and support of students of Roma origin in medical specialities.

These three programmes were specified in the Information of the Republic of Bulgaria on the progress of the implementation of the National Roma Integration Strategy 2012-2020 submitted to the European Committee. All experts we interviewed qualified them as "good practices at the national level".

7.1. Prevention, control, and treatment of tuberculosis, HIV/AIDS, and sexually transmitted infections

In 2012, the National Programme for Prevention and Control of Tuberculosis in the Republic of Bulgaria for the period 2012–2015 was adopted, which continued the current National Programme for Prevention and Control of Tuberculosis in the Republic of Bulgaria for the period 2007–2011.

Its main aim is to reduce the spread of TB and especially of its medicine-resistant forms. To achieve its aim, the Programme envisages a series of measures:

- Consolidation of the network of specialized medical facilities;
- Timely diagnostics, including children and medicine-resistant forms;
- Active tracking down of cases among the vulnerable groups;
- Improvement of the treatment quality.

The Health Act and Ordinance 34 of the Ministry of Health envision free treatment in case of TB and HIV/AIDS for all patients irrespective of their health insurance status. The Ministry of Health provides resources from its budget to secure:

- Consumables for TB testing;
- Medical products against TB;
- Subsidies for the hospitals treating TB;
- Vaccines against TB within the frameworks of the National Immunisation Calendar. 40

From 1990 to 2000, the number of Bulgarians with TB almost doubled (from 106 to 173 per 100,000), but after the year 2,000 their number constantly decreased to reach 69 per

⁴⁰ National Programme for Prevention and Control of Tuberculosis in the Republic of Bulgaria for the period 2012–2015.

100,000 in 2013. In 2012, there were 27 new cases of TB per 100,000, and 24 per 100,000 in 2013.41

Poverty, social insecurity, malnutrition, as well as over-crowded housing, detention centres, and social care facilities are the main reasons for the re-emergence of TB. That is why higher risk groups include people living in detention centres and social care facilities, poor and socially vulnerable people, people with alcohol and drug addiction, people with HIV/AIDS, medical staff working with TB patients, as well as people from the Roma community.

The Roma community has very poor socioeconomic indicators, much lower than the average in the country in terms of housing, access to utilities (including water supply and sewerage), poverty and unemployment rate, health insurance and hence — access to health care services. All these factors increase the risk of TB. "Due to malnutrition and poverty, the state of many TB patients is getting worse despite the applied treatment. Amongst the Roma community, TB goes hand in hand with other chronic diseases, which further complicates their state." 42

Analysis undertaken during the National Programme for the Prevention and Control of Tuberculosis in the Republic of Bulgaria for the period 2012–2015 showed that in 17 big cities in Bulgaria, Roma patients represented 50 per cent of all TB cases. This is why some Roma NGOs and many Roma health mediators were engaged in 28 regional teams to work among the Roma population in order to achieve timely diagnosis and improved cure rates of TB in Roma communities.

The National Programme proposes the following steps in its efforts of controlling the spread of TB in the Roma community and treating Roma TB patients:

- Screening for risk of TB;
- Conduct of timely medical and clinical testing;
- Treatment of registered cases;
- TB patient tracking;
- Raising awareness of TB;
- Creation of networks for liaison and cooperation between medical treatment facilities and the Roma community with the support of NGOs and representatives of the community.

In the period from the beginning of 2011 until the end of 2013, the following activities were carried out in the Roma community in connection with the implementation of the National Programme for Prevention and Control of Tuberculosis:⁴³

⁴¹ National Centre of Public Health and Analyses, Registered cases of active TB.

⁴² National Programme for the Prevention and Control of Tuberculosis in the Republic of Bulgaria for the period 2012–2015.

⁴³ Information of the Republic of Bulgaria about the progress made in connection with the implementation of the National Strategy of the Republic of Bulgaria for Roma Integration 2012–2020, November 2013.

Table 15: Prevention and Control of TB - activities in the Roma community

	2011	2012	2013 ⁴⁴	Total
Screening the risk of TB	20,272	16,594	3,591	40,457
Cases of active TB found	137	114	29	280
Cases of latent TB found	546	515	56	1,117
High risk people directed to medical treatment facilities	4,529	3,363	355	8,247
Disseminated health educational materials	32,432	27,545	6,942	66,919

An important characteristic of the spread of TB is its link with HIV/AIDS infection. The HIV/AIDS virus badly weakens the immune system and thus increases the possibility for infection and development of TB. Until 2007, approximately 40 per cent of the total number of AIDS cases in Bulgaria had TB too. In the period 2007–2010, from the total 115 newly diagnosed AIDS cases, TB was also diagnosed in nearly 30 per cent of them.⁴⁵

The proliferation of drugs, prostitution, and people trafficking create an environment ripe for the spread of HIV/AIDS. Until the first half of the 1990s, they were something exceptionally rare in Bulgaria. After the mid-1990s, these problems drastically increased, and neither the government nor civil society was prepared for them. In 1994, the Government of Bulgaria established the National Addiction Centre on the basis of the State University Hospital "Prostor" Addiction Clinic. In the 1990s, various foundations and NGOs tried to attract the attention of Bulgarian health institutions and the civil society to the problems drug addicts in Bulgaria face and to find solutions for those problems. According to National Addiction Centre data, at that time more than 70 per cent of heroin addicts took the drug by injecting and about 8 per cent of the injecting drug users were Roma.

These facts made it necessary to develop activities for reducing the social and medical harm of drug use, and for limiting the spread of HIV/AIDS. The "Initiative for Health" Foundation launched its first programme ("Steps in a Positive Direction" — HIV/AIDS Prevention), financed by "Open Society" Foundation. The programme began in Sofia, and since 2000, similar programmes have been designed in Plovdiv, Pleven, and Burgas. From its very beginning, the programme reached more than 4,000 addicts, 53 per cent of whom were Roma. The programme goals are to reduce the risk of HIV and hepatitis infections, to improve addicts' health, as well as to limit the risky lifestyle behaviour.

In 2001, Dr Turnev and his team found that in the Roma neighbourhood in the city of Kyustendil, more than 160 young people were injecting drugs. With his support, the programme was launched there too.

From 2004 to 2013, Bulgaria had a National Programme for the Prevention and Control of HIV/AIDS, financed by the Global Fund to Fight AIDS, Tuberculosis and Malaria. The main

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⁴⁴ For the period January – June included.

⁴⁵ National Programme for the Prevention and Control of Tuberculosis in the Republic of Bulgaria for the period 2012–2015.

socially vulnerable groups the program assisted were intravenous drug users; prisoners; Roma communities; homosexual males; prostituting females and males; young people (aged 15–24); and HIV/AIDS positive people.

The programme comprised nine components, which were implemented at a national and local level in all the 28 regions of the country. Component 5 was specially aimed at reducing the vulnerability to HIV/AIDS among the Roma community by means of expanding the scope of the prevention and direction services group. Roma health mediators were included in the Programme's activities. Roma clients accounted for 40 per cent of the total number of clients in some cities. 46

From the beginning of 2011 until the end of 2013, the following activities were completed in connection with the measures taken to reduce the vulnerability to HIV among people from the Roma community who face the highest risk (aged 15–25):⁴⁷

Table 16: Prevention and Control of HIV – activities in the Roma community

	2011	2012	2013 ⁴⁸	Total
Total number of clients, reached through field services	28,929	33,739	13,129	75,797
People tested for HIV	10,048	7,825	2,562	20,435
Examinations for diagnostics of STD	5,548	3,135	1,087	9,770
Participants in health education on HIV and STD prevention	1,852	1,176	120	3,148
Condoms given	256,394	340,871	153,473	750,738
Health educational materials disseminated	50,567	36,750	19,787	107,104

Bulgaria and Romania are no longer eligible for new Global Fund grants due to increases in Gross National Income (GNI). As of 2014, the Programme HIV/AIDS Prevention is not being financed any more by the Global Fund, and most of the people still working on it receive no payment. Many NGOs and doctor organisations are worried that there is no information whatsoever whether (and to what extent) the State will comply with its commitment to fund the Programme's activities after its financing by the Global Fund has ended.

"The Programme for the Prevention of HIV, AIDS and STD should continue. We knew that its funding was to stop in 2014 but we thought that there would be found State funding for it too... This Programme is crucial for us here! You know that since the 1990s we have had almost 160–200 young people who are injecting heroin users... You most probably know about the new practice in the Roma neighbourhood too – "the Cyprus marriages". Affluent men from Africa, from the Middle and Far East go to Cyprus with the purpose of entering into a sham marriage with a citizen from an EU country so that they can then move to Western

⁴⁶ OSI (2007), Interviews with programme staff in Bulgarian cities of Sofia, Plovdiv, Varna and Kyustendil, January 2007.

⁴⁷ Information of the Republic of Bulgaria about the progress made in connection with the implementation of the National Strategy of the Republic of Bulgaria for Roma Integration 2012–2020, November 2013.

⁴⁸ For the period January – June included.

Europe... These men offer 1,000 Euro to a poor woman to enter into a sham marriage... Many women agreed. However, it turned out that even if the marriage is a sham one, many of those women got pregnant. They came back here, gave birth, we now have all kinds of babies... But you know what it is like in Africa, in all those countries "the grooms" come from! Tomorrow there might be an outbreak of an AIDS epidemic! ... This Programme had additional positive effects too. All the uninsured pregnant women used it to test themselves for AIDS, Wassermann, and STD free of charge. Now they cannot do that anymore. It is just Wassermann that is compulsory; it is cheap, but the rest... Syphilis is easy to detect – the symptoms just appear, you cannot make a mistake, but HIV..." (An interview with a GP, Kyustendil, 2014)

"The Roma organization that is actively involved in the Programme for the Prevention of HIV and TB... not only informs Roma about the risk and motivates them to test themselves, but also actively tracks them down... I can say the results achieved are pretty good... We found a case of HIV, several cases of hepatitis B, hepatitis C and many cases of syphilis in the Roma community... We can especially see the progress we have made in relation to TB... The uninsured pregnant women were able to have a free HIV/AIDS test with us as well as a test for hepatitis B or C and Wassermann. For the tests we did we used reagents from the Programme for the Prevention of HIV and AIDS and they were given to us free of charge by the Ministry of Health. In case nobody supplies the reagents, we, the Regional Health Inspection, will not be able to afford the reagents for such large-scale tests."

"Under the HIV/AIDS Prevention Programme the Ministry of Health established health and social centres in the Roma community through Roma organisations. Unfortunately, the funding for these centres will now be cut with the end of the programme. And something good, which was done, will just discontinue... What is important for me is to have these programmes, programmes on HIV/AIDS and TB in the Roma community continued.

Something good has commenced, it should not be cut short."

(An interview, Regional Health Inspection, Kyustendil, 2014)

(A Roma NGO representative)

7.2. Medical examinations at mobile medical units

In 2005, the NCCEII⁴⁹ and the Council of Ministers drafted a project for the purchase of mobile units for TB, cervical cancer, and breast cancer screening, and for active diagnostics of various diseases in vulnerable minority communities. These mobile units were bought in 2007-2008 and a programme for active disease diagnostics in the Roma neighbourhoods started at the end of 2008. The Ministry of Health disposes with a total of 23 mobile units for this purpose: five mobile units for general preventive care check-ups, two mobile fluorography units, two mobile mammography units, three mobile ultrasound units, four paediatric units, four gynaecological units, and four mobile laboratories.

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⁴⁹ At that time it was called the National Council on Ethnic and Demographic Issues (NCEDI).

According to NCCEI information for the initial period of this programme implementation (2008–2011),⁵⁰ Roma aged 30–45 were most interested in the screenings. Young Roma paid virtually no attention to the opportunity to have a preventive care check-up. There were some organisational problems: in 2008–2009 the mobile units for screening of breast and cervical cancer did not operate in the Roma neighbourhoods but in university hospitals (according to the information from interviews with Dr Turnev and Dr Panayotov, June 2009).

The mobile units programme is included in all strategies and plans on the provision of health services to the Bulgarian Roma community. Mobile clinics are considered by the government as an important resource to improve the access to medical services both of uninsured Roma and of all residents in remote areas without access to medical treatment facilities and local GP practices. From early 2011 to the end of 2013, the mobile units carried out the following operations⁵¹ in providing services to uninsured Roma and people with impeded access to medical treatment facilities:⁵²

Table 17: Mobile units – activities

	2011 and 2012	2013	Diseases detected in 2013
Immunization of children with incomplete immunization status	2,120	905	
Preventive care examinations of children	4,630	2,706	420
Mammography screenings	2,124	1,041	281
Gynaecological examinations	5,221	2,711	818
Fluorography screenings	2,494	1,010	293
Ultrasound screenings	3,289	1,510	611
Laboratory tests	3,312	1,507	296
Examinations with mobile units for general check-ups	No data	968	21
Total	23,190	12,358	2,740

Ultrasound units (with a disease detected every 2–3 examinations) and gynaecological medical units (with a disease detected approximately every three examinations) were the most frequently detected diseases.

An issue concerning the ultimate effectiveness of the mobile units is the fact that people diagnosed with specific diseases generally have difficulties accessing both medical treatment facilities to undergo treatment (due to the lack of health insurance) and medications (due to lack of financial resources). In other words, mobile units diagnose diseases which will in

⁵⁰ There is no data available for the following years.

⁵¹ According to data from Information of the Republic of Bulgaria about the Implementation of the National Roma Integration Strategy 2012–2020, November 2013 (for 2011 and 2012) and the Ministry of Health (for 2013).

⁵² I.e. residents of remote areas without a GP practice.

many cases go untreated (unless treatment is provided for free, funded by the State or local budget).

Concomitant health lectures and discussions to local Roma communities are an important part of the work of mobile units. "The topics discussed are in the field of birth control, STIs, breast cancer, cervical cancer, health nutrition, immunization, patient's rights, socially significant diseases, the environment and health, osteoporosis and smoking. Increasing health awareness is largely conducted with the help of information materials – brochures and leaflets – which explain the relevant health problem in a comprehensible form." ⁵³

The operation of mobile units is financed from the budget of the Ministry of Health. About 2.7 million leva have been allocated in total for the period 2011–2015, and the amount of the annual funding has been fixed:

Table 18: Mobile units – financial resources

	2011	2012	2013	2014	2015	Total
For gynaecological examinations	126,00	200,000	200,000	200,000	200,000	926,000
For immunizations	60,000	60,000	60,000	60,000	60,000	300,000
For paediatric examinations	56,000	75,000	75,000	75,000	75,000	356,000
For mammography screenings	44,000	55,000	55,000	55,000	55,000	264,000
For fluorography and ultrasound Screenings and laboratory tests	119,000	180,000	180,000	180,000	180,000	839,000
Total	405,000	570,000	570,000	570,000	570,000	2,685,000

Efficient use of mobile units depends on the funds provided. Once the funds for examinations are spent, these units cease to operate until the next year. Thus, (according to the information provided by the experts interviewed) they operate only 1–2 months per year. During this period, they carry out the examinations and screenings according to the available financing, and during the remaining 10–11 months these units remain practically useless. According to the rules for their use, their operation can be funded only from the budget of the Ministry of Health, so even if there is funding provided by another source, these units remain idle and unusable for other preventive or screening projects.

Ultimately the potential of mobile units, which is seen and recognised not only by experts (mobile units are mentioned 6–7 times in the Action Plan as part of different measures in the field of health care for the Roma community), remains largely unfulfilled due to the lack of sufficient State budget funding. Since there is minimal likelihood that these funds will be increased from the national budget, external sources of funding have to be sought, and, if necessary, the status of these units has to be changed as well.

⁵³ Information of the Republic of Bulgaria about the Implementation of the National Roma Integration Strategy 2012–2020, November 2013.

"Right now it is the sole responsibility of the State to fund it from its budget – it covers the use of some 23 mobile units, which target entirely the needs of the Roma community... These 23 units are very good, but there is no way with them to turn the tide. Moreover, the administrative organization is very burdensome, it requires extensive planning, allocation by Regional Health Inspectorates (RHIs), they on their turn are obliged to announce procurement procedures under the Public Procurement Act, then interested medical treatment facilities take part, then a contract is concluded, then a specific number of examinations is paid for, which is quite large – between 300 and 500 per unit. The interest is huge, people seek such care. Then in practice these units work for no more than a month per year, the limit is reached and they stop operating once again until the next spin of the wheel. The financial limit is reached. Moreover, when something is not included in the overall picture, it is rather ineffective. What do I mean? The unit goes there, a health professional is hired, clinical tests and examinations are performed, something is diagnosed and that's it! This person has no access to the health system! So what if I diagnose the patient with diabetes? If I cannot send him to the hospital, if he cannot enter the system to obtain medications... everything just crashes down! Their value as emergency care is very high because they clarify the patient's status. People, who have never had access to a physician, get a diagnosis. But they are just a small link in the chain. And they cannot solve the problem". (A representative of the Ministry of Health)

"There are mobile medical units. There is some institutional nonsense: They are not used because, for example, no public procurement tenders were announced or there are delays. While these units are wonderful, they are great inside. Very good quality...and they actually hibernate. They are on the move only when there is allocation of funds, because funds come from the Health Strategy for Disadvantaged Persons. When money comes, they suddenly wake up just like sleeper cells of al-Qaeda and begin to operate. And they say, 'Now let's carry out 23 thousand examinations of people without health insurance'. Race, race, and they do it... These units find something, carry out pap test checks. What happens with this person next? Would he/she be called somewhere? You've been diagnosed and congratulations! Just like fireworks — you shoot in the air, you gather the cartridge cases and leave. That is a problem. Otherwise, in principle it is good."

(A physician representing a Roma NGO)

7.3. National Network of Health Mediators

The National Health Mediator Programme is another mechanism which is invariably mentioned in all strategies and plans for providing health care to the Roma community.

The Health Mediator position is included in the National Classification of Professions and Occupations in the Republic of Bulgaria. The programme has several objectives:

- ➤ To provide a liaison between the Roma community and the medical treatment facilities;
- To optimize the preventive care programmes among the Roma community;
- To provide health education of Roma and active social work in the community and especially with the vulnerable groups in this community;

- To overcome the cultural barriers in communication between the Roma communities and the medical personnel;
- > To overcome the existing discriminatory attitudes in the health services for Roma.

105 health mediators were employed in 57 municipalities in 2011, 109 mediators were employed in 59 municipalities in 2012, and in 2013 their number was 130 (in 71 municipalities). The number of health mediators is supposed to increase to 150 in 2014.⁵⁴ Health mediators are appointed by the municipal administrations, they receive the minimum wage (BGN 310 in 2013 and BGN 340 in 2014), and their salaries are paid to the municipalities from the national budget.

The programme was launched in 2001, when Ethnic Minorities Health Problems Foundation developed the concept of the health mediator and successfully introduced this new position in Iztok District in the town of Kyustendil. The mediator works as a coordinator between the Roma community and the health services. She/he helps to overcome cultural barriers in communication and maintains a dialogue with institutions, is involved in the optimization of preventive care programmes and health information campaigns among Roma communities, accompanies illiterate Roma to health and social institutions, protects the patients' rights, etc.

The health mediator as a professional occupation model has been successfully introduced in Spain, France, Finland, and other countries.⁵⁵

The training programme for health mediators consists of 240 academic hours (220 hours of lectures and 20 hours of field work). The medical universities in Sofia, Plovdiv, and Varna have been licensed to provide health mediator training, and the training course provides basic knowledge and skills on topics such as socially significant diseases, reproductive health, communication and conflict resolution, health policy and public health programmes, legislation in health care, and patients' rights.

The first health mediators were appointed by municipalities in 2007. Many municipal administrations gradually extended the scope of the initial duties of the health mediator (which were at first planned exclusively in the field of health care and health services) by adding the functions of social and labour mediator on them without any increase of mediators' salaries.

Also in 2007, the National Network of Health Mediators was established by health mediators, doctors, nurses, and experts in the field of health care.

Health mediators are required to have completed secondary education and a specialized training course for health mediators (or to possess a diploma from a medical college), to speak Romani and/or Turkish (a preference but practically a requirement for the position

⁵⁴ Information of the Republic of Bulgaria about the Implementation of the National Roma Integration Strategy 2012–2020, November 2013.

⁵⁵ Health Strategy for Disadvantaged Persons Belonging to Ethnic Minorities.

due to the very nature of the job), and to have a working knowledge of relevant legislation. Most health mediators are representatives of their respective local Roma communities.

The main issues faced by the health mediator programme are the low pay, which makes the position unattractive and difficult to keep staffed, and the selection of suitable candidates – on the one hand, the overall level of education of the Roma community is significantly lower than the national average, and, on the other hand, those representatives of the Roma community who actually have better training prefer to work at a higher paying job.

However, this programme has been recognised by all interviewed Bulgarian experts as one of the most successful Roma programmes in the country. This is one of the two initiatives (the other one being mobile units) where the State provides continuous financial support by allocating funds from the national budget. One possibility for the further development of the programme is to integrate the activities of health mediators with similar activities in the field of education, employment, and community development centres in order to achieve an integrated approach to the problems of the Roma community. Integrating the health mediators within the Ministry of Health is also an option. This would help strengthen the State's commitment to the programme, increase its sustainability, raise the pay of health mediators, and keep their activities in the field of health care only.

"A practice which I personally consider successful is the health mediator one. Of course, we have to make a few clarifications here. It varies significantly from one municipality to another... These people get the minimum wage. In some areas mayors and municipal authorities burden them with purely technical or social work... I consider this practice successful, but it is in no way a solution to the situation. We witness a kind of exaggeration both on the part of the government and the European Commission because mediation is a very simple solution. You take someone, make him/her a mediator, they can be health, employment or education mediators, and you say, 'I work for Roma integration'. I find this a very serious strategic problem." (A representative of a Roma NGO)

"The Health Mediator Programme is one of the sustainable programmes. Because we know that a large part of the integration policies in Bulgaria did not happen. There was either insufficient consensus or the State discontinued them. We can say that this programme has maintained its sustainability and has experienced a positive development for about ten years already despite the changing governments. Yet, it still has its serious problems. The fact that each year its allocated budget has to be ratified by the government — which means it is not a practice established as a permanent measure. There is no standard for the profession yet; we are currently working on its development. Salaries are very low; they are fixed at the minimum wage level. Another thing — at a certain point some of the best mediators who do their work very well become inconvenient for some mayors. They ask too much, they assert too many rights, they create problems for the mayors in one way or another. So these people are dismissed. There is a high staff turnover. Usually those who get a university degree find another job... The training of mediators has significantly improved, and it has made its way to the Faculty of Public Health. They assigned to us, the NGO sector, to organize one third of the education — which is good because in practice they cannot teach them what we can."

"Health mediators built a network. It turned out that it is sustainable enough since it has been operating for 5–6 years. We saved the day with it (the programme) when we institutionalized it at the last moment and the State made the commitment to at least pay the salaries. The problem is that salaries are extremely low, they are not motivating and indeed we lost some of these people. Some of them even leave the country in order to work as social workers abroad... We involve them in all emergencies. They are efficient, they help, but we witness the same thing here – you cannot say that 150 Roma mediators (which means that there are whole regions, whole towns without mediators) can change things too much." (A representative of the Ministry of Health)

7.4. Roma Medical Students Support Programme

This is the third programme whose development is set as an objective in the strategies and plans for providing health care to the Roma community. Organisation and funding of courses for the entrance examinations preparation for Roma applying to medical schools and colleges, and provision of scholarships for Roma medical students is set as one of the priorities of the Ministry of Health for the period by 2020. Faccording to the financial statement of the Action Plan for the Health Strategy for Disadvantaged Persons Belonging to Ethnic Minorities, the State budget has to allocate about 1.1 million leva for training of prospective Roma students and for scholarships for Roma medical students in medical universities in the four-year period between 2012 and 2015.

This programme was launched in Bulgaria in 2009 on the initiative of The Open Society Institute – Budapest. The Open Society Institute-Roma Health Project (RHP), in collaboration with the Roma Education Fund-Scholarship Programme (REF-SP) provided the initial financial support for health education, mentorship, and advocacy training for Roma students. The programme was jointly administered by RHP and REF-SP. A similar programme was launched in Romania a year earlier.

"The programme is the first academic assistance programme tailored for Roma medical doctors and nurses and will contribute to combating discrimination in the health system and to offer much needed role models for Roma youth choosing a medical career. The purpose of the programme is to provide support for health education, mentorship and advocacy training for Roma students in graduate medical education (nurses and midwives colleges, medical schools), as well as for Roma resident doctors so that they can become medical professionals able to advocate for their communities... Roma communities will feel more comfortable interacting with health care systems knowing that there are Roma individuals acting in the system as equitable peers with non-Roma counterparts." 57

The Roma Health Scholarship Programme has four components:

Scholarships for resident doctors and for students in medical schools and colleges;

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⁵⁶ Information of the Republic of Bulgaria about the Implementation of the National Roma Integration Strategy 2012–2020, November 2013.

⁵⁷ Roma Health Scholarship Programme, Bulgaria 2009, Open Society Institute.

- Mentorship for the grantees;
- Advocacy training for both the grantees and the mentors;
- Promotion of the programme and publicity of its objectives.

The admission of beneficiaries is based on academic merit, extracurricular activities, leadership potential, and motivation in working with Roma communities. Selection Committee representing the Ministry of Health, the Ministry of Education, and representatives of Roma NGOs reviews and evaluates all completed applications. Selected students and doctors are invited to an Advocacy training which includes elements of personal development skills (communication, intercultural dialogue, self-development, leadership skills, and IT information), advocacy skills, and the right to health.

The beneficiaries of the programme participate in a mentorship programme and each grantee is assigned to a mentor who provides support on academic and professional issues. The mentors are selected by a selection committee including representatives of OSI, the Ministry of Health, and the Ministry of Education.

A representative of the Ministry of Health participates in the selection of the mentors beneficiaries. A representative of the Ministry of Health also participates as a guest at the Advocacy training organised for all grantees and mentors. The Ministry of Health provides support in disseminating information on the scholarship programme and in assessing and developing the project.

Two Bulgarian partner organisations participate in the implementation of the programme: OSI – Sofia is engaged with the mentorship component of the programme and Amalipe Center for Interethnic Dialogue and Tolerance is responsible for the advocacy training.

After 2009, the number of students participating in the programme significantly increased. At its launch as a pilot project in the academic year 2009–2010, the programme supported 23 students in medical schools and colleges; in the next academic year – 57 students; in 2011-2012 the number of grantees was already 80; in 2012–2013 – 77, and in 2013–2014 – 64 people were supported.

At present, the following **problems associated with the programme** can be outlined:

First, the funding is uncertain. At the very start of the programme the founding organisations expressed their readiness to finance it temporarily for a period of 3–4 years, after which its funding should be borne by the State (through the aforementioned funds provided in the Financial Plan of the Health Strategy for Disadvantaged Persons Belonging to Ethnic Minorities – about 1.1 million leva for four years). According to an evaluation of the programme conducted at the beginning of 2011, the programme beneficiaries hoped that the programme would not only continue in the years to come, but would also be upgraded to the status of a State policy. According to the information received from the experts interviewed, however, the planned State funding was not provided. The initial external funding was suspended and replaced by another external funding (by the Norwegian Financial Mechanism) which is again temporary (for a 2–3 year period). In the absence of

State financial support, the programme does not have a sustainable financial basis which makes its future more or less uncertain.

Second, according to experts involved in the mentoring component of the programme, no funds are provided for training of young prospective Roma students to be able to pass the medical school entrance exams. In their opinion, without such training, young Roma are much less likely to pass these examinations (in chemistry and biology), because they usually cannot afford to pay for private tutoring and other preparatory classes, whereas the standard education at secondary schools does not provide them with the necessary knowledge.

Third, there is no mechanism guaranteeing the employment of programme graduates as medical professionals serving the Roma community. After completing their education, they are completely free to choose a career environment other than the Roma community and to even pursue a profession not in the medical field. Experts – mentors of the programme have the impression that grantees prefer career development which is not directly related to serving the Roma districts.

And fourth, the programme also supports students in majors which are not specifically medical in nature but related to the organisation and management of the health system (e.g. health management). In the opinion of the experts interviewed, this once again reduces the potential of the programme because in such cases it does not result in medical graduates working directly within the community.

The already mentioned 2011 evaluation outlined the following strengths and weaknesses of the programme:

Strengths

- The programme generates interest in the target group;
- It has the potential to attract new entrants;
- > The programme engages participants with its objectives and makes them empathetic;
- All its three main components (financial assistance, mentoring, and advocacy) are highly valued by participants;
- The financial assistance covers most of the studying costs;
- Through mentoring it supports the professional development of the participants, and through advocacy – their personal development;
- The mentors are recognised professionals;
- > The content of the advocacy training is really interesting, according to Roma students.

Weaknesses

- Information about the programme is spread mainly through Roma activists and reach a very small number of Roma students;
- Applicants are not familiar with the criteria for the selection procedure;
- Applicants are not informed on time if they are approved to participate in the programme;

- Mentorship is often not efficient: mentors are usually heads of departments or heads of clinics with a lot of responsibilities and lack of time for mentorship;
- Uneven distribution of the programme engagements among the grantees: only some of them are obliged to promote the programme through the media;
- Media often present the programme as a privilege on ethnic basis.

"I find the Programme for Support of Roma Medical Students as the best practice. This year the programme will continue under the funding of the Ministry of Health through the Norwegian Financial Mechanism... Of course, from now on the big question remains how this programme will continue in two years. An option is once again to seek financing either through the Bulgarian–Norwegian Financial Mechanism or through the Bulgarian-Swiss Partnership Agreement. Somehow I think that the most logical way – to use State budget – will just not happen." (A representative of a Roma NGO)

"There has been suspension of students after the withdrawal of the Roma Education Fund. The whole programme was very successful and right now we have many students. But this is the first year when we do not have any prospective students. I.e. the State did not continue the programme... We applied with a consortium to the Norwegian Fund. Training courses were removed from the activities related to the Norwegian Fund. This means giving scholarships only to those, who have already been enrolled, and not to have any more students. Yet, it is obvious that Roma students cannot be admitted to study medicine without additional training... People from the Ministry of Health say: "We have to talk with medical university rectors to put them in the training courses for free". But how do these people imagine such things!? These are people who have absolutely no idea! We look for all these children, then we persuade them, then we work with their families, who generally pull them back, there are mothers who do not believe in their children. Then we take care of them here, we welcome them, we accommodate them, we feed them. And after that, at one time or another, they lose motivation, they fall in love. Or they change their mind, get disappointed, or I don't know what... So we start working with them individually, we spend extra hours, etc. It is a very hard work to have this product! We developed a comprehensive work methodology, 5-6 people worked on this project. And this is probably the most successful and most meaningful project I have ever participated in... Yes, there are also many Roma in health management, but I make a distinction between students of medicine, dental medicine and pharmacy, and students in college or at the Faculty of Public Health, where all willing perspective students are admitted... Those who study health management – this is a major for managers, hospital directors, clinic directors. I.e. these people will not find a job. So here we have some manipulation with the topic that we have many students. It is not important to have 150 students, it is important to have 50, but they to become medical professionals. ... There are others who even give up their scholarships in the course of studies because they stop identifying themselves as Roma. And they give up their scholarships. Not to mention their employment in the Roma community. I hope that 30–40 per cent will probably work in a Roma community. But so far there is no sufficient information because we do not have enough graduates." (A physician representing an NGO)

"I found it interesting to understand that problems were that complex, that if you do not select the right children, if you do not talk beforehand with their parents, who generally stop

them from school during the first year after facing the first economic problems, they take them back and they lose a lot of training and a lot of money. So, selection first, second — motivation, third — finding mentors, who will help them in college or university, each of these links in the chain is extremely important... Because they are so interrelated, that if one fails, the whole chain will break. This, if we look at it as a perspective, I mean a perspective of 15—20 years, is the most effective step. Yet, it is very slow and very small. If we can educate 2—3 such children in each large community, in the big towns and cities, in the big districts, and then bring them back willing to stay and work, which is the other problem which will have a direct impact, but in the long run. This programme has almost been ruined — and not by someone else, but by our Ministry. Financing the programme from the State budget was not adopted. Yet, it coincided with the Norwegian fund... and it was preserved to a certain extent." (A representative of the Ministry of Health)

8. GOOD PRACTICES AT THE REGIONAL LEVEL

8.1. Kavarna municipality: an integrated approach to health problems

Roma integration in the town of Kavarna is the Bulgarian best practice for equal treatment of Roma, respect for their fundamental rights, including equal access to health care, housing, education, and employment according to most Roma NGOs in Bulgaria. Roma integration in Kavarna is acknowledged as European good practice by EC. Kavarna has been awarded twice with the honorary flag of the Parliamentary Assembly of the Council of Europe – in 2007 and 2009.

Kavarna is one of the very few examples of a Bulgarian municipality which has implemented systematic and multidirectional actions to address the challenges facing the local Roma community, including its health-care problems. This is why we present the entire record of these activities, which even when not explicitly targeting specific health components, eventually contribute to improving Roma's individual and group health status.

Kavarna is a small town of about 12,000 on the Black Sea coast. During the 2011 census, 2,095 of its residents self-identified as Roma, and another 2,000 – as Turks, Millet, or Bulgarian. The rest residents of Kavarna consider all these 4,000 people "Turkish Roma" on the basis of their kinship relations, endogamy, common culture and lifestyle.

By 2003, the lives of Roma in Kavarna did not differ significantly from those of many other Roma groups in Bulgaria – they lived in a separate overpopulated district on the outskirts of the town, surrounded by towering heaps of garbage in the unauthorised dumpsites. There was no sewerage. The streets were not paved. There was no street lighting. Unemployment was widespread, and on that account young people looked for work in the informal

⁵⁸ Their mother tongues are Romani and Turkish, but most of them also speak some Bulgarian. Their "traditional" religion is Islam, but after 1990 part of them became Pentecostals, Adventists or members of Bulgarian God's Church.

economy and abroad. All children were enrolled at the elementary school in the neighbourhood, but many of them progressed from one grade to the next one without going to school and without mastering even reading and writing in Bulgarian. There was a language communication barrier between Bulgarians and Roma.

In 2004 Mr Tsonko Tsonev, a lawyer and an activist from The Bulgarian Helsinki Committee was elected as Kavarna municipality mayor. He initiated a programme for town's and municipality's development supported by the Municipality Council that led to transformation of the Roma neighbourhood and the interethnic relations in the town.

8.1.1. Socioeconomic background

The transition from an authoritarian to a democratic political system and from a command to market economy in Bulgaria was considerably impeded by the extremely deep and prolonged economic crisis in 1990–1997, which triggered the process of deindustrialization in the country.

Kavarna Municipality was hit hard by deindustrialisation and by the economic crisis. Almost all industrial plants in the town and workshops in the surrounding villages were closed in the very early years of the transition period. More than 3,000 people lost their jobs because of the closure of the local agrarian-industrial complex (AIC).⁵⁹ All construction works which provided employment for more than 1,000 people in the past were suspended for an extended period.

According to 2001 census data, the registered unemployment in the municipality affected 49.7 per cent of the economically active population, a total of 4,148 people. ⁶⁰ The number of discouraged unemployed who did not register at the labour offices, and of those who made their living working occasional/seasonal jobs was double – 8,272 people (NSI, 2005). Widespread long-term unemployment affected particularly hard those with low skills and education, i.e. the majority of villagers and Roma. ⁶¹ For thousands of people labour

⁵⁹ According to an estimation of a chief expert at the Regional Employment Service Directorate, by 1990 more than 3,000 people were employed in AIC-Kavarna, mostly from the villages and the Roma neighbourhood in the town. They produced and processed agricultural products, the vast majority of which was exported. In addition to their wages, they received in-kind compensation in the form of locally produced food. The land on their personal farms (an average of 5 decares per family) was cultivated free of charge, which allowed the majority of them to produce food for the "free market". The AIC provided fodder at very low prices for breeding livestock on the workers' private farms and bought in part of the farmed animals. In rural schools and the school in Hadzhi Dimitar District, populated mainly by Roma, children received free lunch meals and in the other town schools meals were subsidized. In 1992 all workers in the AIC were laid off and lost all these benefits.

⁶⁰ The National Statistical Institute did not publish disaggregated data on the educational status, employment, unemployment and living conditions of Bulgarian citizens by municipalities for the 1992 population and housing census; therefore, no data can be provided for Kavarna for an earlier period.

⁶¹ Unlike Roma, most villagers own land. Some of them grow vegetables, melons and watermelons on it, whereas others lease the land to big grain producers for BGN 50–60 per decare, receiving grain or sunflower

immigration was the only way out of unemployment. This (along with the low birth rate) was the major reason for the population decline in the municipality by over 15 per cent in the period 1992–2011 (NSI, 2012).

Table 19: Employed, unemployed and economically inactive people from the major ethnic groups in Kavarna Municipality, 2011 (%)

Economic activity	Bulgarians	Turks	Roma
Employed	55.6	37.5	12.4
Unemployed	8.4	10.9	10.7
Economically inactive	36.0	51.6	77.6

Source: NSI, 2012, own calculations.

8.1.2. Active absorption of EU funds, attracting foreign investors, raising own-source revenues

In the first six years of Mr Tsonev's term, the own-source revenues of the municipality increased more than sixfold and made up three fourths of the municipal budget. He is one of the most active Bulgarian mayors in the absorption of EU funds. The largest implemented projects in Kavarna aimed at improving the infrastructure, educational conditions, health care, tourism, sport, culture, and environmental protection. The implementation of these projects and the construction boom at Bulgarian Black sea coast led to a significant decrease in unemployment, including in the low education groups.

"There is no crisis here. 300 people from the neighbourhood were on social benefits before, now they are only 30 – most of them chronically ill or with another serious problem... Even those who do not work in Poland, most of them are also making a good living – they grow melons and watermelons, they work in construction... If the mayor wins another term, the differences between Roma and Bulgarians will disappear, we all will be one..." says a man from the Roma neighbourhood whose son is a student at the Varna Free University.

The municipality pursues an active policy to attract foreign investment. In 2009, the US company A&S Geo Power commissioned a 156 megawatt capacity wind farm. The investment is worth EUR 270 million. EVN built 25 wind turbines – an investment of EUR 95 million. In 2009, the municipality saw about EUR 500 million invested in tourism, wind farms,

oil in kind. After the closure of most industrial plants, Roma could rely only on seasonal employment and social benefits.

⁶² All kindergartens and schools in the town and in the municipality villages were fully renovated with funds from the EU pre-accession programmes, own resources, and project funds. All schools were equipped with computer labs. All schools now have newly built sports facilities. Two internet centres were built in the Roma neighbourhood.

⁶³ In the year preceding the global economic crisis (2008) the unemployment rate in Kavarna Municipality was only 6.4 per cent. According to NSI data from the 2011 census, the unemployment rate in the municipality climbed back significantly as a result of the crisis and reached 16 per cent (14.4% in the town and 23.1% in the rural areas), levels higher than the national average, but significantly lower than those measured in 2001. It should be noted, however, that the census was carried out during the winter, whereas the municipality is characterized by seasonal employment.

agriculture and real estate, which had a positive effect on employment as well. In 2012 an Austrian work-wear and uniform manufacturer created 200 new jobs when it opened a local factory. The regular analyses of the economic position of Kavarna Municipality show that the development trends of the municipality are very good. There is rapid and sustainable cumulative growth of own-source revenues and invested capital funds by the municipality.

8.1.3. Bilateral agreements with towns in Poland, taking Roma from Kavarna

According to NSI data only 125 Roma in the municipality held a job in 2001,⁶⁴ mainly in social programmes for employment assistance. The unemployed in the Roma community reached 88.1 per cent (NSI, 2005). Since the beginning of the transition period, Roma had practically been unemployed and many of them had started looking for work abroad. A few Kavarna Roma families opened retail shops for cheap clothes on the German–Polish border. Gradually, more than two thirds of all Roma households in Kavarna sent at least two of their younger members to work in Poland. By 2007, they worked entirely in the informal sector – without work permits, and constantly forced to hide from the authorities.

In 2007 Bulgaria joined the European Union but Bulgarian citizens were still not authorized to work in the other EU countries. That is why the mayor Mr Tsonev signed bilateral agreements with his counterparts in four Polish towns where the majority of the Roma from Kavarna worked: Poznan, Opole, Kielce, and Radom. Since then Roma have worked legally in these towns, they have registered companies and paid their fees and taxes. Some of them report that they make more than EUR 3,000 a month. According to the mayor, the perception of Roma as economically prosperous group is a prerequisite for changing the interethnic attitudes and relations in a positive direction: "Bulgarians see them as drivers of local business. 16 weddings are scheduled for this winter in the most prestigious four-star hotel in the town centre, each costing EUR 10–15 thousand on the average. They make up a huge part of the business of the hotel in the winter. Then come architects, builders, furniture stores, designers – everyone is happy to have them as customers." (Interview with the mayor of the municipality)

8.1.4. Active use of the social programmes of the Ministry of Labour and Social Policy (MLSP) for reducing unemployment

The Labour Office in Kavarna implements MLSP's active policies to reduce unemployment. An increasing number of Roma attend training courses in cooking and hairdressing which increase their chances to find work, especially during the tourist season. Many Roma take part in the Development Programme which offers literacy. After the successful completion of these courses, around half of trainees are employed by various local businesses for at least a year. The problem is that the funds for an active policy to reduce unemployment are insufficient and are constrained by continuous cuts. ⁶⁵

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⁶⁴ This makes only 6.1 per cent of all people who identify themselves as Roma.

⁶⁵ For example, several years ago 200–300 people, mostly Roma and low educated people from the villages, were employed annually under "From Social Assistance to Employment" Programme. In recent years, the

8.1.5. Activities in the field of education⁶⁶

The educational structure of the population of Kavarna Municipality is worse than the average for the country. This is due to the permanent emigration of people with the highest level of education as well as to the considerable proportion of rural and minority population. Since 1985, a slow increase in the educational status of the residents of the municipality is observed.⁶⁷

Table 20: Population of Kavarna Municipality of 7 years and above by level of completed education in the 1985, 1992, 2001, and 2011 censuses

Census	University and college	Secondary	Primary	Elementary	Incomplete elementary/ illiterate
1985	4.7	19.7	34.2	26.9	14.6
1992	6.3	26.9	30.2	23.7	12.9
2001	8.6	30.4	29.8	20.2	11.0
2011	11.9	37.1	26.3	15.4	9.3

Source: NSI, 2012, own calculations.

The large ethnic communities in Kavarna Municipality (and across the country) vary significantly by their level of education (Table 21).

Table 21: Population of Kavarna Municipality of 7 years and above by level of completed education and ethnic groups in the 2011 census

Education	Bulgarians	Turks	Roma
University and college	15.2	5.6	0.0
Secondary	45.6	23.9	3.2
Primary	25.2	37.2	30.0
Elementary	9.2	20.0	38.7
Incomplete elementary and illiterate	4.8	13.3	28.1

Source: NSI, 2012, own calculations.

All interviewed experts in Kavarna (school headmasters, teachers, experts in the Regional Inspection of Ministry of Education, etc.) confirmed that since 2001 the educational status of Roma had steadily improved. All Roma children aged 7–10 are enrolled in school, most of them – in the Roma neighbourhood. But after completing their fourth grade, virtually all Roma children in the town attend integrated schools. An increasing number of Roma children complete their secondary education. In 2010, a Roma from Kavarna was for the first

quota for Kavarna and Shabla has been reduced to 20–30 jobs per year (interview with a chief expert from the Labour Office).

⁶⁶ We detail all activities and measures in the field of education because they have an important, albeit an indirect relation to the health status of the Roma community.

⁶⁷ This does not necessarily mean higher literacy and general knowledge, especially for lower levels of education due to the low criteria and the decline in the quality of education nationwide.

time admitted to a university. In 2014, already a dozen of young Roma men from this small town studied at universities.

Poor knowledge of Bulgarian is one of the most essential factors for early school dropout rates of Roma children. To counteract it, a number of measures have been launched in Kavarna: inclusion of all children in preschool education, free extracurricular activities, all-day schooling, summer schools and green schools attended by Roma and Bulgarian children, involvement of children in various forms of development of their abilities, bilingual education.

"Almost 100 per cent of Roma children now attend kindergarten. We have the largest kindergarten in the Roma Hadzhi Dimitar district. 200 children are raised and educated there. 45 children, 40 of whom are Roma, attend the kindergarten in the village of Septemvriytsi. 100 per cent of the children in the kindergarten in the village of Rakovski are Roma. In the village of Vranovo we have a group of Roma children... A culture of attending kindergarten has been created. Parents pay the fees. Principals and educators continuously work with parents and convince them to be supportive of the children's success in learning Bulgarian and developing their abilities. They regularly organize events and performances, where children demonstrate what they have learnt and what they can do. Roma children have an excellent ear for music and rhythm; they are outstanding dancers; they learn to draw, to model, to make paper collages. Parents are very proud when they see them on the stage, when they see their child's name at the exhibitions of children's works. Thus the transition from kindergarten to school becomes much easier."

(Interview, Head of Education, Youth Activities and Sports Department, Kavarna Municipality)

Roma women employed in kindergartens and elementary schools provide indispensable assistance to teachers in teaching Bulgarian to Roma children and students, and in their efforts to help children overcome the stress of the transition from family to school environment. With their help, most kindergarten educators and primary school teachers learn Turkish and Romani. On the other hand, parents have peace of mind that their children are taken care of by their relatives, neighbours, or acquaintances.

The low educational status of parents and legal guardians of Roma children exerts a strong negative influence on the children's motivation to study. It is a major obstacle for parents to exercise control over their children's grades at school and to help them with homework. Countering these negative factors required the allocation of additional funds from the municipal budget for extracurricular activities for children throughout elementary school. This practice gave good results and only in several months it developed into all-day schooling, which began in Kavarna in 2004 for the first time anywhere in the country.

The positive results are particularly visible among Roma girls. The share of girls with completed primary education has sharply increased. The number of extremely early marriages and births has been on the decrease. The number of girls enrolled in secondary education has also gradually increased.

8.1.6. Improving housing

A huge unauthorised dumpsite and the repulsive appearance of the Roma neighbourhood, both located on the main road from Varna, proved to be an obstacle to the development of the town as a tourist destination. In 2004 the Municipal Council voted to allocate funds for improving the infrastructure in the Roma neighbourhood and restoring the land previously used as an unauthorised dumpsite adjacent to the neighbourhood. The entire infrastructure in the Roma neighbourhood was rebuilt: water mains were replaced, a sewerage system was built, telephone and Internet cable networks were laid, a gas pipeline was installed, and the streets were asphalted. The first lampposts, garbage bins, and separate collection containers appeared in the neighbourhood. Many Roma families obtained building permits and 117 new large houses were built in the Roma neighbourhood.

According to the annual municipal financial reports, large amounts of funds⁶⁸ were allocated for the urban development of the Roma neighbourhood as well as for enhancement of the skills and employment of Roma. Here are some of the planned and spent funds:

- For the construction of a water supply network in Hadzhi Dimitar District BGN 751,350 from the municipal budget;
- For sewerage BGN 1,746,000 from the municipal budget;
- ➤ For asphalt pavement and reconstruction of streets BGN 1,871,800 from the municipal budget;
- For reconstruction of sidewalks BGN 261,130 from the municipal budget;
- For playgrounds BGN 49,880 from the municipal budget;
- For infrastructure, sewerage, water supply network BGN 11,000,339 under Operational Programme Environment and from the municipal budget;
- For training and employment in agriculture EUR 176,086 under PHARE 2004;
- For youth employment and training of young Roma EUR 50,665;
- ➤ Under the Human Resources Development Operational Programme for various projects in education over BGN 400,000.

8.1.7. Improving access of Roma to quality health care

The following units work in the provision of health-care services to the population of Kavarna Municipality:

- A hospital in Kavarna with eight wards, 90 beds, and 115 personnel. The hospital serves residents of two municipalities: Kavarna and Shabla. It offers services for diagnostics and treatment in the following medical specialties: paediatrics, internal medicine, obstetrics and gynaecology, surgery, neurological diseases, anaesthesiology and intensive care, orthopaedics and traumatology, physical medicine, and rehabilitation.
- Kavarna Medical Centre provides specialized outpatient medical care in the following medical specialties: neurology, obstetrics and gynaecology, cardiology, surgery, ENT,

⁶⁸ The annual budget of Kavarna municipality was only BGN 4.5 million in 2004, and it increased approximately by half a million in the following years.

- ophthalmology, paediatrics, orthopaedics, dermatology, psychiatry, pulmonology, nephrology, endocrinology. Eight general practitioners and two dentists also have their practices located in the centre.
- Emergency care branch Kavarna, located in the building of the municipal hospital. It provides emergency medical care in life-threatening situations to local residents. Five doctors, seven paramedics and nurses, six drivers and three hospital attendants are employed there.

In 2008, the first Roma woman with secondary education in the town attended a specialized course for health mediators and became the health mediator in Kavarna municipality. She was appointed on a permanent contract in the municipal administration, and is involved in the development of local health strategies and programmes. She also participates in the Committee for Administration of Social Benefits and in the distribution of food from the EU stocks for the socially disadvantaged people through the Bulgarian Red Cross. The health mediator works with four general practitioners. She participates in all activities for health prevention in the municipality. A number of informative, promotional, and preventive activities have been conducted in the Roma community in connection with the full immunization coverage of Roma children, prevention and promotion of maternal and child health care, prevention of TB, AIDS, and viral hepatitis, preventive check-ups at mobile gynaecological and paediatric clinics, prevention of cardiovascular diseases, etc.

According to interviewed doctors and officials in Kavarna, the health status of the Roma in their municipality seems to be better than the average for Bulgarian Roma. According to the local health statistics, there is a steady decrease in infant and childhood mortality in Kavarna compared to 2003 data.

"Every child in the municipality is registered at a paediatrician. All pregnant women have health insurance; they make regular visits to gynaecologist and have all necessary medical tests. Early births are rare and usually occur at the age of 17–18, although there are still cases of girls starting their family life at the age of 14. All Roma children receive the required immunizations." (Interview with the Health Mediator in Kavarna)

"There is a low incidence of infectious diseases in the Roma community in Kavarna. During the 2009-2010 measles outbreak in Bulgaria, only 16 children were infected in Kavarna: 13 Roma and 3 Bulgarian, who had recently returned from abroad and had not been vaccinated due to their absence from the country. In general, there is very good immunization coverage of the children throughout the municipality. There are no cases of TB and AIDS in the district. Cardiovascular diseases once again prove to be the most serious problem here, often leading to heart attacks and strokes among the Roma aged 50–55." (Interview with the Deputy Mayor on Health and Social Issues)

The 2007–2013 Plan for Local Development of the Municipality of Kavarna identifies that: "The timely provision of health assistance in remote villages and the presence of 3,265 people who do not have health insurance and who face difficulties in their access to health services remain a serious problem." The municipality has implemented a number of measures to tackle this problem. The Municipal Council allocated 2007–2013 revenues from

the wind turbines for improving the quality of education and health care. The municipal hospital has been renovated. It has been equipped with high-tech equipment for diagnostics and treatment of patients. A significant part of the above mentioned revenues was allocated for the provision of the necessary resources for outpatient and hospital care for all residents of the municipality who did not have health insurance. In 2011 alone, the hospital was granted BGN 480,000 for this purpose.

"There used to be a good practice in Kavarna. The Municipal Council allocated additional budget for the hospital mainly to provide services to people without health insurance. So, when such a person went to the hospital, he/she was guaranteed at least the minimum of tests. But this was at the time when the mayor had the strong support of the Municipal Council. After that I think this support gradually dwindled and I am afraid this practice was discontinued.

(A physician/NGO representative)

For 2012–2014, the municipality has allocated about BGN 60,000 annually from its own resources to ensure access to health care for the poor and the uninsured.

Two programmes for people with disabilities are currently implemented in the municipality: the National Programme for Assistants for Disabled People, through which personal assistants are employed for six people with disabilities, four of whom are Roma, and Support for a Decent Life Municipal Programme, with the financial support of Operational Programme Human Resource Development, through which social services are provided for twenty-five disabled people, eight of whom are Roma. Altogether 31 people with disabilities in the municipality are provided with the services of personal assistants through these two programmes.

The results achieved in Roma integration will have a long-term effect if and when anti-Roma attitudes in the media on both national and regional levels significantly reduce their influence on the policies implemented by the local government. Over the past decade the mayor has managed to unite citizens to jointly pursue common goals whose achievement would benefit the municipality. He has actively involved the widest possible range of people, including Roma, in outlining priorities and implementing common tasks. In this way, they have gradually turned into a community – "Kavarnans" and not just Roma and Bulgarians. The result is a thriving small town with a very good quality of life, low crime rates, rich cultural life, and vibrant family atmosphere.

"I have also heard about the programmes of Kavarna Municipality... However, their focus is more on housing conditions, the district is indeed radically different from what we are used to seeing in Roma neighbourhoods... But there is a kind of a concurrence of circumstances in Kavarna. They have a huge community which has left for Poland and is concentrated in one or two towns there. Three-quarters of the residents of the district work in Poland bringing back a lot of money. This symbiosis between good municipal policy and good income has managed to raise the level." (A representative of the Ministry of Health)

8.2. Municipality of Kyustendil: equal access to medical services

We chose Kyustendil as a case study for the following reasons:

- ➤ Since 2004, a number of pilot programmes and projects to improve Roma health care have been implemented in the municipality of Kustendil. We intended to see what has happened as a result of their implementation;
- ➤ There is a lot of information available from previous studies of Roma health care in the municipality, which makes possible to track the progress (or failure) of Roma integration over the last 20 years. This information is further expanded by data from 28 interviews with various local experts (physicians, health mediators, officers of state and municipal institutions) which were conducted in the spring of 2014 for the purposes of this study.

The review of the situation in the Roma neighbourhood in the town of Kyustendil was also intended as an attempt to publicly discuss an important question: How is it possible to organise equal access to quality medical services for the residents of a large and spatially segregated Roma neighbourhood, where the majority of people are poor, have multiple health problems, and in the same time are uninsured and have a restricted access to Statefunded health services?

In the very early 1990s, a significant number of Roma leaders and some human rights organisations in the country stood firmly on the position that the existence of different institutions in the segregated Roma neighbourhoods – kindergartens, schools, polyclinics, labour and social assistance offices, police stations, etc. – increased the spatial isolation of the residents. In many places at the beginning of the transition period, local authorities closed down medical centres, kindergartens, social bureaus, cultural centres, and other institutions providing various services in the Roma neighbourhoods. They claimed that doing this they have fulfilled also the Roma leaders' recommendations, despite the fact that their actual goal was to drastically cut public spending.

The proponents of these closures in Roma neighbourhoods argued that the quality of medical services there was lower, that it was better to have the centres closed and that Roma should use the services provided by the town or district polyclinics, hospitals, or diagnostic consultative centres. This might be a reasonable argument when and if the Roma neighbourhood is relatively small and there is another medical centre in its vicinity. However, when the Roma neighbourhood is located far from the city centre (where the hospital and other health institutions are usually located), its residents, particularly the poor ones (who are the majority), prefer to have a health centre in the neighbourhood in its immediate vicinity. Numerous studies conducted since 1992 have consistently confirmed these observations. There are two main arguments in favour of health centres in or near Roma districts: cost reduction and saving time when visiting a physician, which is particularly important for suffering sick people and for parents with young children. Another argument, though rarely used, can also be added: the closure of the medical centres in and near Roma districts which in most places coincided with massive layoffs of Roma was viewed by many Roma as another manifestation of institutional discrimination.

In the late 1990s, local Roma organisations created opportunities for the residents of Roma neighbourhood in Kyustendil to formulate their problems, to identify those of them which they considered as priority, and to seek ways to address them. Roma asked for jobs, health-care centre in the neighbourhood, and improving the living conditions. The information obtained in 2007 and 2014⁶⁹ showed that local residents regarded the medical centre built with the support of the Adventist Development and Relief Agency (ADRA)⁷⁰ as one of their greatest social achievements.

8.2.1. Health-care services for Roma in Iztok District

According to local experts' estimates, about 10–12 thousands of people live in Kyustendil segregated Roma neighbourhood called Iztok District. Until 2003, there was a small health facility in the Roma district where the general practitioners serving local residents had their practices. According to the Dr Turnev's study, in 2001 85 per cent of the Roma in Kyustendil gave a negative assessment of the recently launched health-care reform. In their opinion, it limited their access to health services. The majority complained that they had serious difficulties in paying their user fees for examinations, tests and medications, and that their access to specialized care was seriously impeded compared to the period before the reforms. As a result of this, they visited doctors less frequently and increasingly hoped that their conditions would clear up on their own. This was the main reason for the large number of cases of neglected health, complications, and chronic diseases encountered by Dr Turnev. Many of the Roma he examined complained of disinterested and rude attitude by some general practitioners. Another common complaint concerned the segregation of pregnant Roma women in separate rooms in the gynaecological ward of the hospital (Turnev et al., 2002).

In 2003, after consultations with the local residents and with the financial support of ADRA Foundation, a medical centre was built at the site of the health facility. It has fully equipped surgeries for general practitioners, a gynaecologist, and a paediatrician. There is a six day a week pharmacy in the district as well.

After graduating from the University of Medicine in Sofia, a young Adventist physician from Kyustendil agreed to start his practice at the Roma neighbourhood's medical centre. He became a general practitioner there. He earned a high level of respect and trust of Roma because of his dedicated work and attentive attitude towards his patients. The paediatrician at the centre was a physician with extensive experience: for many years she had worked as

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⁶⁹ From interviews with the regional expert on ethnic issues, the former deputy mayor of the Roma district, health mediators, local Roma and representatives of the local government in Kyustendil carried out in 2007 and 2014.

[&]quot;ADRA Bulgaria has been started as result of the consorted efforts of a local group volunteers from the national Seventh-day Adventist Church to contribute to the global initiative of ADRA International to serve and care for those in need, to invest in the potential of individuals through advocacy, training and supported education, supporting families, promoting health, establishing livelihoods and responding to emergencies. ADRA Bulgaria Foundation is established in 1992 in Sofia as an independent humanitarian and not-for-profit organization". Source: ADRA Bulgaria homepage.

the head of the children's ward in the polyclinic in Kyustendil and as an orphanage director. In the 1970s, she began her career as a paediatrician in the same Roma neighbourhood. She knew many of the parents and even grandparents of her patients. She was one of the professionals who contributed to the dramatic reduction in infant and maternal mortality in the neighbourhood, and to the improvement in the Roma health culture and their trust in health professionals. A local Roma organisation managed to attract one of the best gynaecologists in Kyustendil to work at the centre. She made an indisputable contribution to the good reproductive health of a considerable part of young Roma women and to the adoption of modern family planning methods by nearly 40 per cent of Roma households. The health centre also employed qualified nurses and a health mediator.

According to 2007 study of OSI on the socioeconomic status of the Roma in Kyustendil, nine out of ten Roma respondents who took part in the representative survey expressed a positive attitude towards their family doctor and towards the other physicians at the health centre. There were no other officers or institutions in the district or the town enjoying such overwhelming approval by the residents of Iztok District.

As a result of the efforts of the entire team of health professionals working at ADRA Centre, there was not a single case of maternal mortality in Iztok District in 2001–2007, and the rate of infant mortality was very close to that of the rest residents of Kyustendil. There was only one case of infant mortality in the district in the period 2003–2007. The proportion of fully immunized with the obligatory vaccines children increased from 40 per cent to almost 70 per cent.

In 2007, most Iztok residents used the services of ADRA Health Centre. According to them, being able to receive treatment at a local health centre had a number of benefits:

- Transportation costs savings;
- > Time savings in carrying out medical examinations in acute and chronic diseases, which was essential for early diagnosis and treatment;
- ➤ It enabled doctors and nurses to quickly visit patients in their homes when necessary a problem of Bulgarian health care in all towns and cities;
- Thanks to the trust Roma have in the general practitioners and specialists at the medical centre, patients strictly observed the prescriptions and recommendations and mobilised psychologically to cope with the diseases;
- ➤ Poor patients could rely on receiving free medications and sanitary products essential for the actual access to medical services after prices of medications soared in Bulgaria in 1990;⁷¹
- Some doctors knew personally two and even three generations of local residents, who had been their patients for years. This facilitated the work for early diagnosis of socially significant and hereditary diseases and for their successful treatment or prevention of their transmission to younger families;

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⁷¹ From 2003 to 2006 the Swiss medical organisation Doctors Without Borders and a Dutch NGO donated free medications and sanitary products to ARDA Health Centre. The last quantities of these supplies were used in 2007.

It created good conditions for systematic improvement of the culture of health and hygiene habits of the residents of the Roma district.

The health centre still operates in 2014 but with reduced medical personnel. The Adventist physician still works there with the largest practice in the neighbourhood: 2,700 patients. Besides him, two other general practitioners, a paediatrician, and a nurse work at the health centre, but there is no longer a gynaecologist. The number of health mediators has increased to five. The opening of another position for a health mediator is expected in the children's ward of the municipal hospital where there are a number of conflicts between nurses and young Roma mothers.

8.2.2. Health insurance

As reported by physicians, RHI officers and the local administration, the share of uninsured has increased in recent years. According to surveys carried out in Iztok District in 2006–2007, uninsured Roma made up 18–23 per cent of people aged 16–64 (Tomova, 2009). In 2014, two fifths of all Roma in the town were without health insurance.

There are several risk groups which most often do not have health insurance. The first one is the 16–19 age group. This is the age at which they are supposed to go to school and to be insured by the government budget. However, due to social and cultural reasons, many local young Roma of this age do not attend school and, therefore, have no health insurance paid by the State budget. Many pregnant young women in this age group are also taken by surprise when they find out they do not have health insurance.

The second group of frequently uninsured is that of the long-term unemployed, who for various reasons have lost their right to receive monthly social assistance. Along with it, they also lose the right to health insurance from the government budget.

The third group comprises individuals who hold temporary positions in other cities or abroad, as well as their family members. A public servant from the regional Agency for social assistance explained that monthly social assistance (and respectively health insurance coverage) is provided to members of families with at least two unemployed adults or to unemployed single mothers. That is why unemployed adults in families with one working person are uninsured.

Here are some comments by physicians:

"Health insurance coverage is a very serious problem for all physicians who have predominately or exclusively Roma patients. I have worked as a general practitioner in Iztok District since 2003. My practice presently consists of 2,700 patients, all from the neighbourhood, and at least 1,200 do not have health insurance. I used to have even more patients in the past. Since 2005 the Health Insurance Fund has not paid a single lev for people without health insurance. It became very difficult but I decided that I shall cope with it and shall treat all regardless of the fact whether they have health insurance or not. It turned out to be impossible: all patients without health insurance who were registered with other

physicians came to me. My practice was overwhelmed, there were long queues of patients waiting and those with health insurance began suffering and leaving me: they went to other physicians where they did not wait that much, and the doctor had more time to spare on them... So, I was forced to announce that I could not accept all people without health insurance and to put a note that those insured would enter with priority... i.e. you unwillingly start to discriminate them... The altruistic motive with which I started my practice proved inefficient in the long term... We do not have a solution for people without health insurance; it is not incorporated in any strategy you ask me about."

(Interview with a general practitioner, 2014)

"Young Roma women are without health insurance as a norm. Most of them are already pregnant when they are 17–19 years old, but they are not anymore children, do not go to school and the State no longer pays their health insurance. And they come to check if they are pregnant or to give a birth... I check them for free even when they do not have health insurance and explain them what they have to do to obtain the status of a person with a health insurance... But when they come for the next consultation, once again it comes out that they do not have an insurance and are not entitled to free tests... Some of them are able to pay for the gynaecological check, the tests, and even the delivery, but the majority are not."

(Interview with a gynaecologist)

8.2.3. Diseases

Infectious diseases are a serious problem in Iztok District (as they are in Roma neighbourhoods across the country). The overcrowded living conditions hinder the isolation of virus carriers and diseases often cause epidemic outbreaks. Some cultural characteristics (the norm for empathy with patients obliging all relatives, neighbours, and friends to visit and provide emotional support during the course of the disease) also contribute to spreading the diseases. Poor nutrition, daily stress of poverty, unemployment, and uncertainty for the future weaken the body resistance and contribute to a more severe course of the disease.

Kyustendil participates in the National Programme on Prevention of Tuberculosis, HIV and AIDS. Health mediators and activists of the Roma LARGO NGO take part in the implementation of activities among Roma and drug addicts. There are cases of sexually transmitted diseases, of parasitic diseases, and of echinococcosis in the neighbourhood, though not in such large proportions as found in other large urban ghettos in the country. Cases of hepatitis A are rare, but due to the presence of a large group of Roma injecting heroin users, there are many hepatitis B and C carriers.

All health practitioners put a lot of efforts to improve children and maternal health. The rate of immunised children increased: all Roma children 0–12 are vaccinated; the rate of the vaccinated Roma children aged 0–18 is above 75 per cent. Most physicians and health mediators emphasize that the incidence of infectious diseases in the Roma neighbourhood in Kyustendil is lower than the average for Roma in the country.

"A programme which definitely must continue is that on prevention of TB. It is true that we dramatically increased the immunization coverage: this considerably burdened general practitioners but it is only for good... Yet, this programme should not be abandoned. The coverage now is at over 75 per cent, whereas in the past it was even below 50 per cent. Young people above 17 are a serious problem, they are just like hell. They are not interested in immunizations; they think they'll live forever. It is very difficult to work with them; you cannot find many of them: they continuously travel abroad or to Sofia. Others refuse to come to the doctor even if you send out a health mediator to bring them to the practice. But, generally, we manage to cover the Roma with vaccines; we vaccinate all infants and children by the age of 12 with all required immunizations. In the past, more than half of them were not immunized, you should not listen to what they say and what the official medical statistics show for the period 1990–2005..." (Interview with a general practitioner, 2014)

8.2.4. Roma women's reproductive health

Roma women's reproductive health has been the subject of special attention by the physicians and health mediators in Iztok District. As early as in the late 1990s gynaecologists and general practitioners in the town worked under the project "Reproductive Health, Health, and Sexual Education of the Roma Population in Bulgaria" financed by PHARE and under programmes financed by Partners for Bulgaria Foundation. Health professionals were involved in intensive training and family planning programmes as trainers to Roma women and young men. Partners for Bulgaria Foundation donated Centre with free intrauterine devices (IUDs). Many Roma women with three or more children and multiple abortions started to use IUDs. According to 2007 survey on Roma health in municipality of Kyustendil, a very important change had occurred in the young Roma women and men attitudes towards modern family planning methods: significant numbers of young Roma women in Kyustendil had approved these methods and even the young men's and older women's attitudes towards IUDs had become more tolerant. This was the Roma district with the most modern and healthy reproductive behaviour in the country: 40 per cent of the women (aged 20–40) have used IUDs (Tomova, 2009b).

In 2014, however, the situation took a turn for the worse. For years, the health centre has not received grants to enable the purchase of large quantities of IUDs. LARGO and ADRA foundations periodically provide small quantities for individual cases of very poor women with many children. Abortion has once again become the most common family planning method. Moreover, physicians and health mediators express concern that in the last few years early marriages and births have become more frequent in the neighbourhood. They all agree that the reproductive health programmes for Roma women were among best practices in the country, that they must be financed again, and that this should be set as a priority in the Roma integration strategies and in their implementation plans.

"I personally still consider the programme on reproductive health and family planning as good practice but it ran out of funding and it is now over. We started with 40 donated IUDs. At the beginning there was a lot of tension in the neighbourhood, some "leaders" jumped into accusing us of racism and genocide – claiming we wanted to reduce their birth rates and wipe out their minority... Nonsense, but people here can easily be manipulated and they

finally decided to have such IUDs placed only on mothers of many children who did not want to have more children at that moment. Quite expectedly the effect was very good: there was a sharp decrease in abortions and all complications associated with multiple births in a short period of time both for the mother and the child. The project went on; an increasing number of women had IUDs placed. Finally, when all devices were used it turned out there were many poor young women who wanted to have IUDs placed as well. LARGO found another 15 or so from somewhere and that was the end... The neighbourhood now still rests on these old IUDs – about 30 per cent of women with 3 and more children still use their old IUDs. The problem is with the young ones – we are losing hold of them and we gradually lose what we have achieved." (Interview with a general practitioner, 2014)

As reported by physicians, a significant part of pregnant Roma women without health insurance are admitted for delivery in hospitals without being monitored by a doctor during their pregnancy and often — without being performed any obligatory tests, even Wassermann. According to the law, the uninsured pregnant women have a right for one free medical check to a gynaecologist but usually NHIF refuses to pay for it and even imposes fines on doctors who claim for payment for this service. In order to reduce the risk of a significant number of Roma women to be admitted for delivery without being monitored during pregnancy, the local authorities in Kyustendil decided to allow pregnant women without health insurance to exercise their right of one free examination by a gynaecologist in the municipal hospital. Not all pregnant Roma women, however, are informed about this option.

Over the past two years, another alarming practice has appeared in the Kyustendil Roma neighbourhood: the so-called "marriage tourism." Poor women abandoned by their husbands or deep in debt to local money lenders travel to Cyprus for "marriage of convenience" with immigrants from Africa, the Middle and Far East, who use this opportunity to acquire EU citizenship and to then travel onto Western Europe. Many of these women consume this "marriage of convenience" and come back pregnant. Accordingly, the risk of spread of HIV/AIDS in the neighbourhood increases.

"The Programme on Prevention of HIV, AIDS and sexually transmitted diseases must continue... An outbreak of AIDS can burst out tomorrow! ... Poverty has increased, marginalization has increased, overexploitation by money lenders has increased, drug use has increased... Some areas in the neighbourhood have turned into typical ghettos, this further increases the risks...Now the risk has increased as a result of marriage tourism as well... You have to be irresponsible to stop the programme when the risk has been increasing." (Interview with a general practitioner, 2014)

8.2.5. Conclusion

The study of the access of Roma from Iztok District in Kyustendil to medical services demonstrates that really good results could be achieved when health services employ good physicians with a positive attitude towards Roma, when there is cooperation between local authorities and Roma NGOs, and when physicians and health mediators are actively involved

in health promotion programmes. But it also demonstrates that without State's funding the good effects of pilot programmes expire in a very short time.

Kyustendil is a concrete example that many of the projects and programmes financed by foreign donors do not continue after the initial funding has run out, although they have been proven as good practices. It is unacceptable that the State does not continue their funding even after it has committed to do so. Physicians, health mediators, and local administrators report a deterioration of the situation in the Roma neighbourhood with regard to women's reproductive health, which is largely due to the lack of funding. In connection with the increased risk in the neighbourhood, another concern is the lack of clarity whether the funding of the programme on prevention of HIV and AIDS will continue.

The planned improvement of the access of the Roma in Kyustendil to health services is not implemented uniformly. The share of people without health insurance has increased, which is an extremely serious barrier to access to NHIF funded health services. The problems of mass unemployment and poverty are not being resolved, and in fact financial resources (both personal and family) are the main factor in Roma's actual access to medical services. Some problems of institutionalized discrimination against the Roma by individual physicians or health-care facilities have been resolved, but new problems have emerged in their place. However, several positive changes can still be outlined:

- there is better access of Roma to medical services in their local neighbourhood;
- higher satisfaction of local residents with medical services has been achieved, which is an important indication of the better quality of life in the neighbourhood;
- there are serious indications of the overall improvement in the health status of the residents of Iztok District;
- the share of people with poor health, chronic and long-term diseases is lower than the average for Roma in the country;
- ➤ the share of people suffering from socially significant diseases like TB, hepatitis, HIV/AIDS, etc. is lower;
- the number of parasitic diseases is lower than the average for Roma;
- the share of people surviving serious diseases, such as heart attacks, strokes and different oncological diseases has increased;
- maternal and infant mortality has decreased;
- child health parameters (a decreased number in premature births, rickets and congenital heart defects) have improved;
- Roma health culture, including reproductive culture, has improved.

Some of the successes achieved have proven sustainable. It is imperative to make further efforts to improve the education of children and young people, which is also related to health culture and awareness, as well as to the gradual change of power relations between the sexes.

Despite all the progress, Roma's health status in the district is still lower than that of ethnic Bulgarians in Kyustendil. To improve the situation, it is necessary above all to raise the living standard, to increase employment and income, and to improve the living conditions and

hygiene in the district. An important step in the right direction would be improving the quality of education and raising the educational level of Roma children and youth.

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- 2012e Census of Population and Housing in 2011, Volume 1, Book 8. Population. Birth rates.
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ANNEX 1 – LIST OF LEGAL ACTS AND STRATEGIC DOCUMENTS

Acts

- 1. Constitution of the Republic of Bulgaria
- 2. Health Act
- 3. Health Insurance Act
- 4. Medical Treatment Facilities Act
- 5. Doctors and Doctors of Dental Medicine Professional Organisations Act
- 6. Medicinal Products in Human Medicine Act
- 7. Medical Products Act
- 8. Social Assistance Act

Secondary legislation acts (ordinances, regulations and rules)

- 9. Ordinance on ensuring the right of access to medical care
- 10. Ordinance 8 of 29.12.2005 on the contents, time periods, manner and procedure of filing and storage of data by employers
- 11. Ordinance 10 of 24.03.2009 on the conditions and procedure of payment for medicinal products under article 262, paragraph 4, item 1 of the Medicinal Products in Human Medicine Act
- 12. Ordinance 15 of 12.05.2005 on Immunizations in the Republic of Bulgaria
- 13. Ordinance 22 of 9.12.1997 on the conditions and procedure of payment of medical care of the patient's own choice
- 14. Ordinance 25 of 4.11.1999 on delivering emergency medical care
- 15. Ordinance 26 of 14.06.2007 on delivering midwifery care to women without health insurance and on delivering clinical tests outside the scope of the compulsory health insurance for children and pregnant women
- 16. Ordinance 29 of 23.11.1999 on the main requirements for the structure, operation and internal order of the medical treatment facilities for hospital care, of dispensaries and of nursing homes for medical and social care
- 17. Ordinance 34 of 25.11.2005 on the method of payment from the national budget for the treatment of Bulgarian citizens in case of diseases beyond the scope of the compulsory health insurance
- 18. Ordinance 38 on the list of diseases, whose treatment takes place at home, for which the NHIF wholly or partially provides financing for the medicines, medical devices and dietetic foods for special medical purposes
- 19. Ordinance 39 of 16.11.2004 on routine check-ups and dispensarisation
- 20. Ordinance 40 of 24.11.2004 on defining the basic package of health activities guaranteed by the budget of the NHIF
- 21. Decree 17 of 31.01.2007 laying out the conditions and procedures for spending of target resources on diagnostics and treatment in medical treatment facilities for hospital care for persons who do not have any income and/or personal property, which might secure their personal participation in the health insurance process
- 22. Decree 193 of 28.08.2012 on defining the amount of money due for a visit to a doctor, a dentist or for hospital treatment for insured persons

- 23. Decree 312 of the Council of Ministers of 27.12.2013 on amending and annexing Decree 193 of the Council of Ministers of 2012 on defining the amount of money due for a visit to a doctor, a dentist or for hospital treatment for insured persons
- 24. Decree 353 of the Council of Ministers of 27.12.2012 on the adoption of methods for the cost and payment for medical care under article 55, paragraph 2, (2) from the Health Insurance Act
- 25. National Health Map of the Republic of Bulgaria
- 26. National Framework Contract
- 27. Immunization calendar of the Republic of Bulgaria
- 28. List of medical treatment facilities in inaccessible and remote areas
- 29. Regulations for the structure and activity of the National Health Insurance Fund
- 30. Regulations for the structure and activity of the Emergency Medical Care Centre
- 31. Regulations for the implementation of the Social Assistance Act
- 32. Social Security Code

Strategic documents for health care in Bulgaria

- 33. National Health Strategy (2014–2020)
- 34. National Health Strategy (2014–2020). Annex 1. Health and Health care Current Situation
- 35. National Health Strategy (2014–2020). Annex 2. Financial Plan
- 36. National Health Strategy (2014-2020). Annex 3. Action Plan 2014-2020
- 37. Concept for Restructuring the Hospital Care in the Republic of Bulgaria, November 2009
- 38. Addendum to Concept for Restructuring Hospital Care, 2010
- 39. Amendment of Concept for Restructuring Hospital Care, 2010
- 40. Amendment of and Addendum to the Concept for Restructuring the Hospital Care System, 2011
- 41. Amendment of and Addendum to the Concept for Restructuring the Hospital Care System, 2012
- 42. National Strategy "Vision for De-institutionalisation of Children in the Republic of Bulgaria"
- 43. Guidelines for the de-institutionalisation of children from homes for medical and social care
- 44. Concept for Better Health care in Bulgaria 2010–2015 of 09.2010
- 45. Concept for Better Health care in Bulgaria 2010–2015 of 12.2010
- 46. Project of the Concept for Sustainable Development of Emergency Medical Care in the Republic of Bulgaria
- 47. Project of the Strategic Framework of Health-care Policy for Improving the Nation's Health in the period 2014–2020
- 48. Report on the extent of completion of the established policies and programmes of the Ministry of Health to 31.12.2011.
- 49. Project of Methods of Subsidising Medical Treatment Facilities in 2014
- 50. National Programme for Prevention and Control of Tuberculosis in the Republic of Bulgaria for the period 2012–2015

Strategic documents directed at the problems of the Roma community

- 51. National Roma Integration Strategy of the Republic of Bulgaria (2012–2020)
- 52. Action Plan for Implementation of the National Roma Integration Strategy of the Republic of Bulgaria (2012–2020) and Decade of Roma Inclusion 2005–2015
- 53. National Action Plan for the Decade of Roma Inclusion 2005–2015
- 54. Framework Programme for Equal Integration of Roma in Bulgarian Society
- 55. Health Strategy for Disadvantaged Persons Belonging to Ethnic Minorities
- 56. Action Plan for the period 2011–2015 from the Health Strategy for Disadvantaged Persons Belonging to Ethnic Minorities, 2005–2015
- 57. Financial Plan for the Action Plan 2011–2015 from the Health Strategy for Disadvantaged Persons Belonging to Ethnic Minorities 2005–2015
- 58. National Programme for Improvement of the Housing of Roma in the Republic of Bulgaria for the period 2005–2015
- 59. Action Plan 2006–2007 for implementing the National Programme for Improvement of the Housing of Roma in the Republic of Bulgaria
- 60. Monitoring Report of 2011 on the implementation of the National Action Plan of the initiative "Decade of Roma Inclusion 2005–2015"

EU Documents

- 61. European Charter of Patients' Rights
- 62. Joint Memorandum on Social Inclusion, Republic of Bulgaria, 2005
- 63. EU Framework for National Roma Integration Strategies up to 2020
- 64. EU Framework for National Roma Integration Strategies for the period up to 2020, Council conclusions
- 65. Information of the Republic of Bulgaria on the progress of the implementation of the National Roma Integration Strategy 2012–2020, November 2013
- 66. Assessment of the progress in the implementation of the National Roma Integration Strategy in Bulgaria

Other documents

- 67. Roma Health Scholarship Programme, Bulgaria 2009, Open Society Institute
- 68. Clinical pathway 141. Delivery
- 69. Regional Roma Integration Strategy in Sofia Region 2012–2020
- 70. Action Plan of Dolna Banya Municipality to Support Integration Policies 2012–2014
- 71. Action Plan of Intiman Municipality to Support Integration Policies 2012–2014
- 72. Municipal Action Plan for Integration of Roma People and People Living in Similar Conditions in Slivnitsa Municipality
- 73. National Council for Cooperation on Ethnic and Integration Issues Guidelines for regional planning
- 74. Centre for Interethnic Dialogue and Tolerance "Amalipe" Participation of the community in the Municipal Roma Integration Plans 2014–2020
- 75. National Association of General Practitioners Good Medical Practice for General Practitioners

ANNEX 2 – RIPEX HEALTH STRAND

POSSIBLE ITEMS FOR A "RIPEX" HEALTH STRAND Target group: members of resident Roma communities (nationals)

	Target group: members of resident Roma communities (nationals)							
	A) ENTITLEMENT TO HEALTH SERVICES	Option 1	Option 2	Option 3	Comments			
1a	Entitlement to services: Do Roma enjoy the same entitlement?	Entitled to the same services	Entitled only to part of services	Not entitled to any services	Roma fall more frequently in the group of unemployed people, people without health insurance and the poor, which limits their access to health services to the extent that such services involve some form of payment — health insurance or the full price of the particular service. Wealthier Roma have access to all health care service.			
4	Special entitlements for vulnerable groups. Do these exist for: a. Pregnant women (ante-natal care) b. Mothers and babies (childbirth and post-natal care) c. Children d. People at increased risk of exposure to, or suffering from, infectious diseases e. Victims of violence or psychological trauma. f. Victims of human trafficking. g. Others (please specify)	Special entitlements for four or more of these groups (please specify)	Special entitlements for two or more of these groups (please specify)	No special entitlements for vulnerable groups (or only one) (please specify)	A. Pregnant women - if they have compulsory health insurance: guaranteed ante- natal care and childbirth - if they do not have compulsory health insurance: one guaranteed ante- natal check-up and childbirth - exempt from paying the user fee B. Exempt from paying the user fee C. Health insurance coverage from the national budget for everyone below the age of 18 and exemption from paying the user fee D. Free treatment of patients with TB, AIDS G. Pensioners, patients with socially significant diseases (incl.			

					oncological), socially disadvantaged people
	A) ENTITLEMENT TO HEALTH SERVICES	Option 1	Option 2	Option 3	Comments
5	Difficult requirements for obtaining entitlement note: Refer to the paper on insurance, item on discrimination? Requirements for obtaining entitlement to health services which may be especially problematic for Roma, for example: a. Documentation of citizenship b. Declaration of legal address required c. Entitlement dependent on having an employer who will pay premiums d. Complicated procedures demanding high levels of language proficiency and know-how e. Obstruction due to individual discrimination. f. Others (please specify)	None of these requirements	One of these (please specify)	Two or more of these (please specify)	1. Requirement for health insurance 2. Closing down health care units in smaller populated areas, which imposes travel and transport expenses 3. Individual complaints of discriminatory treatment by health professionals 4. Cases of language-related problems 5. Requirement for address registration and an identity document 6. Difficulties in overcoming highly complicated administrative procedures
6a	Prevalence of out-of-pocket payments: formal payments (for all users, whether Roma or non-Roma). (Question 6 will be filled in later using WHO data. Other available information can be inserted here.)	No out-of- pocket payments demanded	Limited out- of-pocket payments demanded (please specify)	Systematic use of out-of- pocket payments (please specify)	Payment of the user fee when visiting a doctor; a hospitalisation fee when receiving hospital treatment; payment for health and dental services, medications for home treatment and medical devices, which are not included in the compulsory health insurance. According to official documents of the Ministry of Health, the share of patients' out-of-pocket payments is up to 40–50 per cent.

	A) ENTITLEMENT TO HEALTH SERVICES	Option 1	Option 2	Option 3	Comments
6b	Exemptions from out-of-pocket: formal payments (for all users, Roma or non-Roma): a. Complete or partial exemption (please specify) for low-income or unemployed patients b. Exemptions for people with illnesses that generate high out-of-pocket payments	Both a and b (please specify) OR: Exemptions are not necessary because there are no out-of-pocket payments.	Either a or b (please specify)	Neither a nor b	A. Welfare recipients and the unemployed are exempt from paying the user fee; there is an option for socially disadvantaged people to receive hospital services at the expense of the State. B. The NHIF pays partially or in full the drugs included in the Positive Drug List, which is regularly updated. These include drugs for rare and oncological diseases. Health insurance is a requirement for the use of this right.
6c	Prevalence of out-of-pocket payments: informal payments Include "informal payments" where these are a normal practice in the health care system. Note: Is this a barrier or not (chocolate or money)				Informal payments are usually made in hospital care, where besides purely corrupt practices, "the right to choose a team" is also used, which is additionally paid for and the patient is solicited to use it in order to receive better service. This type of payments is most common in maternal care. Usually, however, this approach is applied to more affluent patients. For socially vulnerable groups, the regulated payments they have to make (for fees, medications, services and medical devices not included in the compulsory health insurance) is the main barrier to health care.

	A) ENTITLEMENT TO HEALTH SERVICES	Option 1	Option 2	Option 3	Comments
6d	How equitable is the national system of health care coverage?	Coverage system is classified as equitable	Coverage system is classified as moderately inequitable	Coverage system is classified as highly inequitable	The health care system implies dependence of the volume and quality of the used health care services on the income and the financial position of the person.
	B) POLICIES TO FACILITATE ACCESS	Option 1	Option 2	Option 3	Comments
7a	Targeted information for Roma concerning entitlements and use of health services In order to reach and influence Roma effectively, three aspects need to be adapted: method of dissemination, content and (where necessary) language. Which aspects are commonly adapted?	All aspects adapted	One aspect adapted (please specify)	No targeting. Only information for the general population is available.	In the information specifically targeting the Roma community, besides the usual methods of dissemination (the media), the capabilities of the health mediator network are used to bring the information to the community and adapt it to the needs and dominant cognitive models. They use Romani, if necessary. The content of this information is adapted to the lower educational level and possible literacy and linguistic problems by using more illustrations. Modification of information is also conducted by NGOs within different projects and as part of different campaigns.
7b	Groups covered by the above targeted information				Such information targets the entire Roma community without any modifications to any specific groups within the community.

	B) POLICIES TO FACILITATE ACCESS	Option 1	Option 2	Option 3	Comments
8	Information for service providers about entitlements Are service providers (individuals and the organisations they work in) explicitly trained or informed about entitlements?	No evidence of ignorance or confusion about the rules among service providers	Evidence of occasional ignorance or confusion about the rules among service providers (please specify)	Evidence of widespread ignorance or confusion about the rules among service providers (please specify)	There is widespread non-compliance with the requirement to have a receipt issued after the user fee has been paid. In some cases the right of pregnant women without health insurance to one ante-natal check-up is violated. The practice (including of institutions) contravenes the law which stipulates the right of children below the age of 16 to use services beyond the scope of the compulsory health insurance at the expense of the national budget. During their academic studies health providers study the legislation in the field of health care and the general rights of patients. There are no other forms of education or provision of information on health legislation, patients' or social groups' rights organized as a State policy. Such information is provided by the professional organizations of doctors and by NGOs.

	B) POLICIES TO FACILITATE ACCESS	Option 1	Option 2	Option 3	Comments
9a	Targeting of health education and health promotion for Roma (other than the issues covered in question 7) Examples: campaigns to reduce health risks (smoking, unhealthy eating, substance abuse, etc.) and assistance in managing health problems. To what extent is the method of dissemination and the content adapted in order to reach and influence Roma more effectively? (Language barriers are dealt with in 9c)	Both methods of dissemination and content adapted in order to better reach and influence Roma	Either method of dissemination or content adapted in order to better reach and influence Roma	No targeting. Only measures directed at the general population are implemented	In projects of NGOs or health campaigns specifically targeting the Roma community.
9b	Methods used in activities mentioned in 9a a. Printed materials (e.g. patient folders, brochures, handbooks) b. Materials on websites c. Courses or meetings for target group d. Community-based interventions (e.g. hotlines, mobile vans or units, media campaigns, use of social media) e. Other (please specify)	At least three methods are used (please specify)	At least two methods are used (please specify)	Only one method is used (please specify), or none at all	Methods A, C and D are used in projects of NGOs or health campaigns.
9c	Language of targeted measures referred to in questions 9a and 9b. In how many and which languages is information commonly available?	Available in more than two languages of origin (please specify)	Available in one or two languages of origin (please specify)	Only available in the official language(s), or no targeting at all.	Translation of information is offered by the network of health mediators or by informal channels when required.
10a	Measures to reduce practical obstacles to access a. Roma do not have to go through additional procedures to receive care (e.g. bring residence permit to consultations) b. Geographical location of services is convenient for Roma (or mobile services are available) c. Opening hours take needs of Roma into account d. Cost of transportation. e. Other measures	No such measures have been reported	Only one such measure has been reported (please specify)	At least three such measures have been reported (please specify)	B. Health community centers are established in Roma neighbourhoods, mobile units operate in remote areas. E. Socially disadvantaged and unemployed people are exempt from paying the user fees, pregnant women without health insurance are entitled to one free check-up and to free childbirth, there is an option to receive hospital care paid by the welfare services.

	B) POLICIES TO FACILITATE ACCESS	Option 1	Option 2	Option 3	Comments
11	Provision of "cultural mediators" or "patient navigators" to facilitate access Are there policies? To what extent are they implemented?	Provided on an adequate scale	Provided on a small scale, but not enough to meet needs	Not provided	
	C) RESPONSIVE HEALTH SERVICES	Option 1	Option 2	Option 3	Comments
13a	Requirement to provide qualified interpreters for patients with inadequate proficiency in the official language(s)	Interpreters are available free of charge to patients	Interpreters are available but patients must pay all (or a substantial part) of the costs	No provision of interpretation services	In places where health mediators are employed, their assistance services can be used.
14	Requirement for "culturally competent" or "diversity-sensitive" services Standards or guidelines require that health services take account of individual and family characteristics, experiences and situation, respect for different beliefs, religion, culture, competence in intercultural communication. a. Standards or guidelines exist on "culturally competent" or "diversity-sensitive" services b. Compliance with these standards or guidelines is monitored by a relevant authority.	a and b	Only a	Neither of these	Pursuant to the Health Act (article 86), every patient is entitled to respect for his/her civil, political, economic, social, cultural and religious rights, to be acquainted with his/her rights and obligations in a language comprehensible to him/her, to clear and accessible information on his/her health condition and the methods of treatment. However, there are no compulsory standards or guidelines (understood as a description of specific procedures), thereby guaranteeing the respect of these rights, including in the Code of Professional Medical Ethics.

	C) RESPONSIVE HEALTH SERVICES	Option 1	Option 2	Option 3	Comments
15	Training and education of health service staff Policies exist to support training of staff in providing services responsive to the needs of Roma. a. Training is an obligatory part of basic professional education b. Training is an obligatory part of in-service professional development c. Training is provided not only for carers but also for staff in other functions.	All of these	Only b and c	No such training is available	Such training is provided outside academic courses as part of NGO projects on the health status and needs of the Roma community (e.g. in the Advocacy component in the program supporting Roma medical students).
16	Involvement of Roma in information provision, service design and delivery a. Roma are involved in service delivery (e.g. through the employment of "cultural mediators") b. Roma are involved in the development and dissemination of information c. Roma are involved in research (not only as respondents) d. Roma patients or ex-patients are involved in the evaluation, planning and running of services. e. Roma in the community are involved in the design of services. Mention only forms of Roma involvement that are explicitly encouraged by policy measures (at any level)	Four or five of these (please specify)	One to three of these (please specify)	None of these	A. B. C. D. E.
17	Encouraging diversity in the health service workforce Recruitment measures (e.g. campaigns, incentives, support) to encourage participation of people with a Roma background in the health service workforce: a. Aimed at diversifying entry to professional training b. Aimed at diversifying the workforce of individual service providers	Both a and b	Either a or b (please specify)	Neither a nor b	

	C) RESPONSIVE HEALTH SERVICES	Option 1	Option 2	Option 3	Comments
18a	Development of capacity and methods Diagnostic procedures and treatment methods are adapted to take more account of variations in the sociocultural background of patients	Policies exist to encourage the adaptation of diagnostic procedures and treatment methods to sociocultural diversity	Adaptation of diagnostic procedures and treatment methods is to a limited extent tolerated, but not encouraged	Policies are exclusively focused on standardising diagnostic procedures and treatment methods	- There are no bans on the practice of diagnostic procedures and treatment methods other than those of conventional medicine (homeopathy, oriental medicine and traditional medicine) In medical treatment facilities applying conventional

		and recom	observed) mendatory od medical nave been
		established	1.

	C) RESPONSIVE HEALTH SERVICES	Option 1	Option 2	Option 3	Comments
18b	Specific forms of the above (gender aspect) Policies exist to encourage: a. Development of treatments for health problems specific to certain Roma communities b. Adaptation of standard treatments for routine health problems in order to better serve Roma communities c. Use of complementary and alternative 'non-Western' treatments for physical and mental health problems	All three of these (please specify)	One or two of these (please specify)	None of these	Several extremely rare diseases and conditions caused by consanguinity are found only in Roma. Naturally, new, unknown diseases presuppose an entirely new or adapted treatment on medical grounds. In all other cases, there are standard diseases which only occur more frequently in Roma (due to poor hygiene, housing conditions, nutrition and lifestyle), for which, however, there is a standard treatment. Therefore, in all these cases the treatment adaptation (if applicable) is due to social, rather than medical reasons. For example, cheaper and more affordable drugs are prescribed. Or, in order to ensure adequate therapeutic environment, hospital care is prescribed for cases, which are generally treated at home. If the doctor has the necessary knowledge and is confident that the same therapeutic effect can be achieved by using herbs (a cheaper option, traditional medicine) instead of antibiotics (a more expensive option,

				1	conventional medicine), herbal medicine can be recommended.
	D) MEASURES TO ACHIEVE CHANGE	Option 1	Option 2	Option 3	Comments
19	Collection of data on Roma health Data on Roma status, medical records containing information on health and utilisation of health services. Alternatively, it must be possible to link databases containing information on health with databases containing the above personal information.	Information about ethnicity is routinely included in (or linkable to) data regarding health. (Please give details)	Information about ethnicity is occasionally included in (or linkable to) data regarding health. (Please give details)	Information about ethnicity is (almost) never included in (or linkable to) data regarding health.	Neither the standard statistical information nor the individual medical records contain data on the ethnicity of the person. This definitely hampers the study of the social and health problems of the community. Such information is collected and presented (in aggregated form) only in censuses and sociological studies.
20	Support for research on Roma health Funding bodies have in the past five years supported a significant amount of research. Please list the topics covered: a. occurrence of health problems among Roma b. social determinants of Roma health c. issues concerning service provision for Roma d. evaluation of methods for reducing inequalities in health or health care affecting Roma	Three or four topics	One or two topics	None of these topics	
21	"Health in all policies" approach Attention to the health impact of all policies To what extent is attention paid to the impact on Roma of policies in other sectors than health? Is such attention structural or incidental?	Mandatory consideration of the impact on ethnic minority health of policies in all sectors	Incidental consideration of the impact on ethnic minority health of policies in all sectors	No account taken of the impact on ethnic minority health of policies in any sectors apart from health care.	

	D) MEASURES TO ACHIEVE CHANGE	Option 1	Option 2	Option 3	Comments
22	Whole organisation approach Roma or ethnic minority health is a priority throughout service provider organisations and health agencies ("integrated" versus "categorical" approach). This does not exclude a certain amount of specialization.	Commitment to providing equitable health care for ethnic minorities is present in all departments of service provider organisations and health agencies	Concern for ethnic minority health is regarded as a priority only for specialized departments or organisations	No systematic attention is paid to ethnic minority health in any part of the health system. Measures are left to individual initiative.	
23	Leadership by government Note: in countries where a large amount of responsibility for health services is devolved to regional or local government, the term "government" may refer to these levels.	Government publishes an explicit plan for action on Roma health and implements policies to support it	Government takes ad hoc measures to support Roma health but has no explicit, implemented plan of action or systematic policies	Government does not promote Roma health but leaves the issue to "the field" (service providers, professional bodies etc.).	
24a	Roma' contribution to health policymaking at national level How do Roma stakeholders (e.g. NGO's and CSO's) participate in national policymaking affecting health? NB: participation at service provider level is covered by q. 16)	Directly involved in policymaking (please give details)	Advisory role without power to make decisions (please give details)	No participation	It is accepted as a good practice to discuss policies relating directly to the Roma community with the participation of Roma NGOs. Roma NGOs are invited to participate in the work of the National Council for Cooperation on Ethnic and Integration Issues, incl. in the formulation of the relevant national policies.

	D) MEASURES TO ACHIEVE CHANGE	Option 1	Option 2	Option 3	Comments
24b	Creation of synergies between stakeholders Stakeholders may include: international, national, regional and local administrations and health authorities; service providers; health insurers; Roma organisations; professional bodies; universities; accreditation agencies; NGO's; and commercial organisations. To what extent is the creation of such synergies anchored in policy?	Systematic efforts are made to create synergies between most of the stakeholders listed AND: one or more national centres of expertise exist to support these efforts.	Systematic efforts are made to create synergies between at least half of the stakeholders listed (please give details)	No attempts are made to create synergies between these stakeholders	Roma NGOs are invited to participate in the work of the National Council for Cooperation on Ethnic and Integration Issues. Representatives of ministries and central institutions, local governments, academic institutions, health mediators and NGOs (incl. Roma) participate in the Commission for the Implementation of the National Roma Integration Strategy of the Republic of Bulgaria (2012–2020).