



MEETING REPORT

Communicable disease prevention among Roma

Vienna, 27–29 November 2011

1. Background

The principal objectives of the Communicable Disease Prevention among Roma meeting, convened by ECDC in Vienna on 27–29 November 2011, were to:

- share best practices and lessons learned in improving the Roma population's access to public health programmes for the prevention of communicable diseases, by bringing together key stakeholders with experience in working with and for Roma;
- provide an opportunity to identify ways of improving health-seeking behaviour and empowering Roma people to take part in processes affecting their health whilst taking into consideration their social, historical, cultural and behavioural context; and
- provide a forum for discussion on how the identified approaches, knowledge and experiences could be used, in particular to stimulate the use of preventive services in the area of communicable diseases, including vaccination uptake.

The meeting included 72 participants from Bulgaria, Czech Republic, Greece, Hungary, Romania, Slovakia and Spain (the seven EU countries with the highest percentage or absolute number of Roma), EU agencies, WHO Regional Office for Europe and NGOs working on Roma health and inclusion. It was organised as an interactive workshop which, after some introductory presentations, allowed all participants to work in small inter-country and inter-agency groups to actively share their views and address questions posed to them.

Keynote presentations reviewed data on Roma discrimination and rights; the status of measles elimination in the EU; challenges related to engaging Roma in vaccination programmes and the successes and challenges of Roma health mediators. Special attention was given to a discussion paper specifically developed for the meeting which reviewed evidence on communicable disease incidence and prevalence among Roma, their social determinants and preventive interventions. In addition, representatives from WHO Regional Office for Europe and the organising committee for the Decade of Roma Inclusion shared ideas on cooperative activities.

This report summarises the main discussion points, conclusions and recommendations from the meeting.

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2. Meeting outputs

- A discussion paper was prepared which reviewed evidence pointing to a disproportionate burden of communicable diseases amongst Roma; described key obstacles to Roma inclusion and identified potential action areas for the empowering of Roma people. These included sensitising providers and systems and improving Roma access to preventive services in the area of communicable diseases, including vaccination uptake.
- Participants, working in mixed stakeholder and country-based working groups, shared best practices and lessons learned while implementing public health practices to prevent and control communicable diseases among Roma populations.
- Participants made suggestions as to what could be done at international, national and regional level by governments, EU agencies, media and the private sector.

3. Key discussion points, conclusions and suggested actions

Participants welcomed the meeting, organised by ECDC, which focused exclusively on Roma health. Of the four themes making up the Decade of Roma Inclusion (employment, housing, health and education), health had had the least focus and investment to date. Many of the stakeholders had not interacted with ECDC prior to the meeting and some had not worked closely with one other at national level before. In this way, the meeting was groundbreaking and demonstrated ECDC's facilitative leadership function in catalysing dialogue, research and action on key communicable disease challenges.

ECDC used a variety of approaches to collect as much information as possible on Roma health, particularly as regards communicable diseases. Data collected in a background/discussion paper, feedback from participants via questionnaires, presentations and group discussions during the meeting indicated that Roma are a heterogeneous population group. They are disproportionately affected by communicable diseases. Roma health and increased vulnerability to communicable diseases is strongly linked to their overall living conditions, health inequalities, health perceptions and behaviour and entrenched discrimination. Therefore, successful interventions will need to be multi-sectoral.

Despite other social determinants of health such as education, household or employment, and the fact that a comprehensive approach is needed to improving Roma health, specific interventions in the area of immunisation could make an immediate contribution.

All participating countries reported that current initiatives aimed at addressing Roma health needed to be strengthened. It was therefore felt to be appropriate that ECDC assist countries in seeking ways to address the disproportionate burden of some communicable diseases among the Roma who live in social exclusion, and others in the same situation. Moreover, the fact that the Roma are heterogeneous has to be taken into account when developing tailored approaches.

To tackle these inequalities, a comprehensive approach is required, taking into account social determinants of health to improve the health situation for the Roma people.

Obstacles to action

Many structural/environmental and perceptual/behavioural obstacles to Roma health in general were identified along with others specifically related to vaccination uptake.

Obstacles to Roma health prevention

Structural/environmental obstacles included poverty, high unemployment, low education, inadequate (knowledge and application of) rights protection, weak or complex registration systems (e.g. birth certificates, health insurance), poor living conditions including inadequate water and sanitation systems, housing, roads (with transportation challenges related to care), poor access to healthy food supplies, primary and secondary health services and lack of appropriate or inconsistent implementation of legislation related to mandatory vaccination, surveillance and reporting systems (e.g. absence of disaggregated social and economic data).

Perceptual/behavioural obstacles noted included: negative attitudes and mistrust (bi-directional) between the Roma communities and public institutions; low health literacy; poor access to health information, poor understanding of the various risks of infectious diseases, difficulty in navigating health and social care systems; stigma and discrimination; negative perceptions of and attitudes towards Roma by healthcare staff; poor communication skills of healthcare providers and lack of specific information materials at health facilities.

A wide variety of possible interventions related to governance, engagement, management/delivery and communications strategies were discussed.

Interventions to enhance health prevention among Roma

Governance – participants described a variety of effective cross-government (intersectoral) coordinating approaches to Roma health policy development and implementation such as a government council for Roma minority affairs, a state council for Roma health, or locally based integrated medical and social care centres providing information and performing monitoring tasks.

Engagement – initiatives described included the pro-active involvement of Roma populations in participatory research, priority setting, policy development and implementation (Roma to Roma activities with the enhanced use of Roma social workers, teachers, assistants and mediators); incentive programmes (e.g. offering cash incentives or in-kind rewards for positive health behaviour such as vaccination) and educational behaviour (e.g. attending classes).

Management/delivery – initiatives described included enhanced service outreach with home visits by doctors; use of mobile teams, community nurses and school settings as platforms for health promotion and increased involvement of local NGOs, including religious workers and other actors (related to alert systems, information services, health education and promotion) in the vaccination process. Roma health mediators were noted to be a critically important resource. Recent studies have shown that they have helped increase vaccination rates, procure identification and insurance documents, provide health education to Roma children and adults and improve health care provider knowledge and attitudes towards Roma.

Communication initiatives noted included training for providers, health literacy improvement strategies for health systems; information campaigns (community-based and/or mass media, use of Roma celebrities); reminder programmes for vaccination and health checks (e.g. use of SMS and social media); customised communications for different target audiences and different Roma populations.

Suggested actions

General

- Apply a human rights approach to Roma inclusion policy at all levels. Cultural sensitivity will need to be a core element in any proposed actions or initiatives on Roma and communicable disease. Address discrimination through awareness-raising campaigns, monitoring and documentation of action in relation to violations of human rights and discrimination.
- Initiatives should look at communicable disease (and immunisation needs) in a wider context and move away from isolated projects to focus on systems addressing health inequalities and supporting sustained inclusion solutions: e.g. resource building (formalising the role of health mediators), improving service delivery (adjusting opening hours, using mobile units) and financing (reducing the burden of out-of-pocket payments).
- Programmes and campaigns should work towards mainstreaming initiatives. Although supplementary immunisation or extra vaccine campaigns are sometimes needed, it is important to integrate people into the mainstream programmes.

ECDC and other organisations¹

- ECDC and WHO Regional Office for Europe can provide valuable expert support for organising scientific studies, developing tools and seeking political support and resources for research and action. For example, ECDC could use its access to the Directorate-General for Health and Consumers, the Directorate-General for Employment, Social Affairs and Inclusion (for ESF funds) and the Directorate-General for Research and Innovation to mobilise support from the European Commission for actions on Roma health. Specific studies might focus on:
 - organising sero-surveys in multiple countries to provide information on the level of protection against vaccine-preventable diseases;
 - supporting implementation of integrated community-based services, e.g. childcare for the Roma population;
 - improving data collection – developing and disseminating software to check data on vaccination.

¹ These suggestions for action were generated by participants. In some instances they may not reflect an understanding of the mandate and scope of ECDC or other organisations.

- ECDC could create an information exchange platform with a database of good communicable disease prevention practices in relation to Roma health. This platform would be accessible to all EU countries and relevant stakeholders at national, regional and local level and would support a long-term, comprehensive, sustainable approach to Roma health in which immunisation programmes are just one component.
- ECDC could provide technical support and training for tenders; training for multidisciplinary teams on different topics, including communicable diseases, communication and team building activities; sending experts (including EPIET fellows) for a couple of months to support programme planning, implementation, monitoring and evaluation processes. ECDC could work with WHO and other organisations to support Member States in creating national Roma integration strategies with a comprehensive view of health, including a Health-in-All-Policies approach (HiAP).
- ECDC could be a useful coordinator and mediator between countries to find appropriate partners for project/programme preparation, implementation, monitoring and evaluation.
- ECDC could help define the functions of health mediators and assist countries in reaching a consensus on the roles of health peer educators and mediators.
- ECDC could advocate for the development of a Council resolution on:
 - vaccination and communicable diseases surveillance, including monitoring, a request that Member States prioritise these activities and ensure appropriate human and financial resources and the establishment of a 'Measles Day';
 - identification document (ID) solutions for all citizens.

National authorities²

- Underpin targeted/adapted measures for Roma health with reinforced universal measures for health equality in general.
- Apply the Common Basic Principles on Roma Inclusion³ (see Box 1) when developing Roma health interventions.

Box 1. Ten Common Basic Principles on Roma Inclusion

1. Constructive, pragmatic and non-discriminatory policies
2. Explicit but not exclusive targeting
3. Inter-cultural approach
4. Aiming for the mainstream
5. Awareness of the gender dimension
6. Transfer of evidence-based policies
7. Use of European Union instruments
8. Involvement of regional and local authorities
9. Involvement of civil society
10. Active participation of Roma.

- Secure budget for health and, in particular, prevention and control of communicable diseases.
- Provide multidisciplinary training (with ECDC support) to include Roma health mediators, health visitors and general practitioners.
- Develop and disseminate software (e.g. e-register vaccination system) with ECDC to collect data on vaccination among disadvantaged population groups.
- Improve collaboration with EU stakeholders on exchange of experience and best practices.
- Consider the requirement of a vaccination certificate for school entry.
- Recognise and stabilise the role of Roma health mediators and provide secure funding and formal training.
- Strengthen health system links with Roma communities; involve cities/village halls/local authorities.
- Develop evidence-based, up-to-date national action plans with high-level political commitment and sustainable funding that apply an integrated and comprehensive approach to health and mechanisms for the involvement of all stakeholders: Health Ministry, Ministry of Internal Affairs, Ministry of Finance, United Nations Human Rights Council, civil society, universities, etc.
- Build up a network with a central office in order to communicate and coordinate activities at regional, local and national level.

² This section summarises suggestions made by individual participants for action by national authorities. These suggestions do not necessarily reflect the opinion of ECDC or other organisations/participants attending the meeting.

³ http://ec.europa.eu/justice/fdad/cms/stopdiscrimination/downloads/Vademecum_Roma/FDAD_Roma-vademecum-EN.pdf

Local level⁴

- Survey and study needs.
- Establish community centres in segregated villages; improve communication between stakeholders.
- Establish support (national and local) for the centres, with sustainable funding for sufficient, trained personnel, vaccines, training, research on the profile of those requiring care, successful strategies and interventions. Enable Roma participation.
- Integrate community services; run supplementary vaccination campaigns where needed: reinforce general practitioner/Roma health mediator roles; pilot evaluation of vaccination activities.
- Ensure participation of Roma in cross-sectoral work and multidisciplinary teams, local research, training, intercultural mediation and peer education, adaptation of teaching materials, information and awareness campaigns.
- Support communication initiatives to influence prevailing health concepts among Roma.
- Promote family instead of individual intervention.

⁴ This section summarises suggestions made by individual participants for action by local authorities. These suggestions do not necessarily reflect the opinion of ECDC or other organisations/participants attending the meeting.

Annex 1. Meeting agenda

Communicable disease prevention among Roma
27–29 November 2011, Rainers Hotel, Vienna

Sunday, 27 November 2011

18:30 Registration. Welcome address.
19:00 Dinner

Monday, 28 November 2011

8:30–9:00 Participant registration
9:00–9:20 Session 1: Introduction to the meeting
Challenges and opportunities to prevent and control communicable diseases in the EU – Ülla-Karin Nurm, ECDC
How are we going to work together to meet expectations? – Tamsin Rose, WHCA
9:20–10:45 Session 2: Keynote speeches
The work of the EU's Fundamental Rights Agency on Roma – Eva Sobotka, FRA
Why is measles still a threat to Europe? – Pier Luigi Lopalco, ECDC
What we know about MMR vaccination among sub-groups in Europe – Focus on Roma/travellers
VENICE survey 2010 – Suzanne Cotter, VENICE Project
Roma health mediators – Successes and challenges – Alina Covaci, Open Society Foundations
Presentation of the discussion paper – Irina Dinca, ECDC
10:45–11:15 Coffee break
11:15–12:30 Session 3: From policy to practice (I) – Accessing preventive and healthcare services
(Plenary session followed by group work)
Speakers: Angel Kunchev, Ministry of Health, Bulgaria, Ricardo Hernandez Jimenez, Health Working Group of the State Council for Roma Population, Spain, Eva Csernus, District Public Health Authority Budapest, Hungary
12:30–13:30 Lunch
13:30–14:15 From policy to practice (II) – Feedback from group work
14:15–15:30 Session 4: Successful experiences in providing childhood immunisation to Roma (I)
(Plenary session followed by group work)
Speakers: Anastasia Pantazopoulou, Ministry of Health and Social Solidarity, Greece, Elena Marusakova, The Association for Culture, Education and Communication, Slovak Republic, Carmen Dinescu, District Public Health Authority Bihor, Romania, Hana Orlikova, National Institute of Public Health, Czech Republic
15:30–16:00 Coffee break
16:00–17:15 Successful experiences in providing childhood immunisation to Roma (II) – Feedback from group work
17:15–17:30 Summary of Day 1
17:30–18:30 Session 5: Exhibition
19:00 Dinner

Tuesday, 29 November 2011

9:15–10:30 Session 6: Discussion paper (I)
(Plenary session followed by group work)
Presentation of points from the discussion paper – Niklas Danielsson, ECDC
10:30–11:00 Coffee break
11:00–12:00 Discussion paper (II) – Feedback from group work
12:00–12:25 Session 7: Joining efforts for sustainable change
Roma-related activities at WHO Regional Office for Europe – Robb Butler
WHO Regional Office for Europe's Roma Decade – Perspective from the Macedonian Presidency – Mila Carovska, HERA
12:25–12:30 Closure: Tamsin Rose, Ülla-Karin Nurm
12:30–13:30 Lunch
13:30 Departure

Annex 2. List of participants

Country representatives

Name	Organisation, country
Rositsa Ivanova	Senior Programme Officer, Secretariat of the National Council for Cooperation on Ethnic and Demographic Issues, Council of Ministers, Bulgaria
Elena Kabakchieva	Chair, Health and Social Development Foundation, Bulgaria
Krasimir Kirilov	Roma Health Mediator, Doctors of World and National Network of Roma Health Mediators, Bulgaria
Angel Kunchev	Chief State Health Inspector, Ministry of Health, Bulgaria
Lili Marinova	Department of Epidemiology and CD Surveillance, National Centre of Infectious and Parasitic Diseases (NCIPD), Bulgaria
Stefan Panayotov	Chair, Health of Roma Foundation, Roma doctor, Sliven, Bulgaria
Ivaylo Tournev	Chair, Ethnic Minorities Health Problems Foundation and National Network of Health Mediators and Head of the Department of Neurology, Sofia Medical University, Bulgaria
Galya Stefanova Traykova	Expert – Consultant on Roma health problems, Public Health Directorate, Ministry of Health, Bulgaria
Petar Tsvetanov	Roma Health Mediator, Chair, National Network of Roma Health Mediators, Bulgaria
Hana Janatova	National Institute of Public Health, Czech Republic
Martin Martinek	Public Officer, Office of the Government Council for Roma Minority Affairs, Czech Republic
Irena Martinkova	Regional Public Health Authority, Ostrava, Czech Republic
Pavel Nepustil	Head, Centre 'Pasaz' Association 'Helping Hands' [Podane Ruce], Czech Republic
Hana Orlikova	Epidemiologist. National Institute of Public Health, Czech Republic
Iva Piskova	Officer, Epidemiology Unit, Ministry of Health, Czech Republic
Lenka Simunkova	Regional Public Health Authority, Usti n. Labem Region, Czech Republic
Dzamilia Stehlikova	National AIDS Programme Manager, National Institute of Public Health, Czech Republic
Josef Trmal	Director, Regional Public Health Authority, Usti n. Labem Region, Czech Republic
Sri Kumar Vishwanathan	Director and community worker, Association 'Life Together' [Vzajemne Souziti], Czech Republic
Giorgos Ferentinos	Medical Doctor, Hellenic Centre for Disease Control and Prevention (KEELPNO), Greece
Agapi Kiritsi	Health visitor, Support Centre for Children and Family, Greece
Katerina Kourea	Psychologist, Hellenic Centre for Disease Control and Prevention, Greece
Foteini Koutsiri	Supervisor of Public Health, Ministry of Health and Social Solidarity, Greece
Anastasia Pantazopoulou	Director General, Public Health and Quality of Life Directorate, Ministry of Health and Social Solidarity, Greece
Olga Theodorikakou	Board of Directors Executive Assistant – Head of Projects, Programming and Monitoring Implementation Unit, NGO KLIMAKA, Greece
Vagia Tsakatara	Head of Directorate, Ministry of Health and Social Solidarity, Greece
Foteini Tsalikoglou	Public Health Physician, Ministry of Health and Social Solidarity, Greece
Angeliki Tseva	Psychologist, Efxini Poli – Local Authorities Network, Greece
Istvan Aba-Horvath	Head of the Roma Minority Administration for Debrecen City and Hajdu County, Hungary
Eva Csernus	Chief Medical Officer, District Public Health Institute, Hungary
Agnes Galgoczi	Head Medical Officer, Public Health Office of Balmazujvarosi, District of Hajdu-Bihar County Administration, Hungary
Zsuzsanna Kohut	Chief Medical Officer, Public Health Office of Hajdu-Bihar County Administration, Hungary

Zsuzsanna Molnar	Epidemiologist, National Centre for Epidemiology, Hungary
Tibor Pavay	Hungary
Edina Stunya	Senior paediatrician in Miskolc City, Borsod- Abaúj- Zemplén County, Paediatric Primary Health Care Association, Hungary
Eugenia-Claudia Bratu	Project Assistant. Roma Centre for Health Policies SASTIPEN, Romania
Carmen Valeria Dinescu	Biologist, Department of Public Health, BIHOR, Romania
Istvan Haller	Member of the Steering Committee, National Council to Combat Discrimination, Romania
Daniela Pitigoi	Senior Epidemiologist, Carol Davila University of Medicine and Pharmacy, Romania
Daniel Radulescu	Manager, Roma Centre for Health Policies SASTIPEN, Romania
Gheorghe Sarau	Professor, Bucharest University
Aurora Stanescu	Senior Epidemiologist, National Centre for Surveillance and Control of Communicable Diseases, National Institute of Public Health. Romania
Maria Voicu	National Institute of Public Health, Romania
Marius Wamsiedel	Sociologist, Romani CRISS, Romania
Helena Hudecova	Public Health Authority of the Slovak Republic
Jana Kollarova	Head, Department of Health Promotion, Regional Public Health Authority, Kosice, Slovak Republic
Michal Kubo	Project Manager. ACEC (The Association for Culture, Education and Communication), Slovak Republic
Elena Marusakova	ACEC (The Association for Culture, Education and Communication), Slovak Republic
Timea Ostrihonova	Health Promotion, Regional Public Health Authority, Rimavska Sobota, Slovak Republic
Maria Pompova	Regional Public Health Authority, Poprad, Slovak Republic
Hana Vrbanova	Regional Public Health Authority, Banska Bystrica, Slovak Republic
Pilar Campos Esteban	Technical Officer of Health Promotion Area, Ministry of Health, Social Policy and Equality, Spain
Ricardo Hernandez Jimenez	Member of the Working Group on Health, State Council for Roma Population, Federación de Asociaciones Gitanas de Navarra Gaz Kalo, Spain
Barbara Navaza	Interpreter and Intercultural Mediator, Hospital Ramón y Cajal, Spain
Mila Carovska (Observer)	Programme Coordinator, Health, Education and Research Association, Former Yugoslav Republic of Macedonia

Intergovernmental bodies and international organisations

Eva Sobotka	Programme Manager, EU Fundamental Rights Agency
Alina Covaci	Programme Officer, Open Society Foundation, Former Yugoslav Republic of Macedonia
Suzana Velkovska	Public Health Programme Coordinator, Former Yugoslav Republic of Macedonia
Robb Butler	World Health Organization, WHO Regional Office for Europe, Denmark
Theadora Koller	Technical Officer, WHO European Office for Investment for Health and Development, Italy

Consultants

Franklin Apfel	Managing Director, World Health Communication Associates
Sabrina Cecconi	World Health Communication Associates
Suzanne Cotter	VENICE Project
Mark Muscat	VENICE Project
Tamsin Rose	World Health Communication Associates

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Ida Czumbel	Expert Vaccine-Preventable Diseases, Surveillance Section
Niklas Danielsson	Senior Expert in Communicable Diseases, Public Health Capacity and Communication Unit
Irina Dinca	Senior Expert Communicable Diseases, Public Health Capacity and Communication Unit
Pier Luigi Lopalco	Head of Disease Programme, Vaccine-Preventable Diseases, Office of the Chief Scientist
Barbora Neubauerova	Country Information Data Manager, Public Health Capacity and Communication Unit
Ülla-Karin Nurm	Head, Public Health Development Section, Public Health Capacity and Communication Unit
Svetla Tsolova	Senior Expert Monitoring and Evaluation, Public Health Capacity and Communication Unit
Andrea Würz	Information Officer, Public Health Capacity and Communication Unit