

# Roma Health and Policy: Equality and Participation



**Executive workshop**

18–23 March 2018 | Budapest, Hungary

# Background



Substantial evidence suggests that the health status of Roma is significantly less favorable than that of the general population independent of the country in which they live. Despite various policy initiatives and targeted interventions in many European countries, progress has been limited in reducing health inequalities endured by Roma. This five-day executive workshop in Budapest, co-organized by Open Society Foundations' Public Health Program and CEU's Global Policy Academy, will gather public health professionals, experts and civil society representatives from the region to share expertise and resources relevant to improving Roma health and to define future collaborative interventions that support Roma inclusion in national health policies.

Overall, the executive workshop at CEU will be an opportunity to take stock of our collective knowledge and build upon it. In particular, the workshop will help participants to understand the mechanisms of exclusion of Roma from health services and to analyze the two approaches in policy making towards Roma in healthcare – needs-based and rights-based approaches – from the perspective of Roma equity and inclusion. By the end of the workshop, participants will be able to discuss access to healthcare through the lens of intersectionality using multiple angles such as social determinants of health status, health indicators, and healthcare inequalities and exclusion. The workshop will, crucially, build skills to initiate and draft policy recommendations on the social inclusion of Roma using a rights-based approach, and promote diversity, human rights, equality and inclusion as values that should govern policy-making towards Roma.

Practitioners and academics will lead course participants in an in-depth exploration of key themes including antigypsyism and discrimination; data collection; health indicators; disparities in access to health; patients' and practitioners' rights; ethics and privacy; narratives on Roma and health; reproductive health; drugs, sex work and HIV; social accountability; and community mobilizing. The participatory course design will also emphasize peer-to-peer learning through small group work.

# Participant Profile



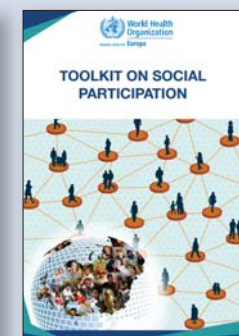
The course is intended for professionals whose work and interests are directly related to Roma health in the region of Central and Eastern Europe.

This includes:

- leaders of civil society organizations who are running Roma advocacy and health equity programs and are involved in the design, implementation or monitoring of policies and practices that most impact on the health of Roma;
- government officials (ministries of health, justice or development, centralized planning units, NHRIs) with the power to support or regulate equitable access to health institutions;
- international organization representatives working on public health at an international or country level;
- health care professionals working in particular with marginalized communities; and
- academics and researchers interested in Roma health.

Participants should be comfortable participating in the seminar in English (both understanding presentations, and speaking during participatory exercises). Roma applicants who meet these criteria are particularly encouraged to apply.

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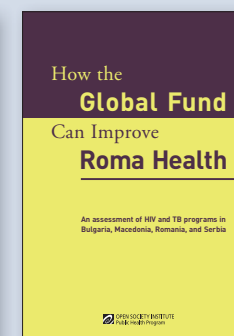
# The Course



## COURSE STRUCTURE

Monday 19 March	Tuesday 20 March	Wednesday 21 March	Thursday 22 March	Friday 23 March
Introduction / course overview & Policy-making towards Roma  <b>Iulius Rostas</b>	Understanding research and data collection  <b>Kristin Makszin</b>	Patients' rights  <b>Mary Black</b>	Narratives on Roma and health  <b>Katarzyna Pabijanek</b>	Social accountability  <b>Adriatik Hasantari</b>
Antigypsyism  <b>Iulius Rostas</b>	Understanding research and data collection ( <i>continued</i> )  <b>Kristin Makszin</b>	Practitioners' rights  <b>Mary Black</b>	Reproductive health  <b>Judit Sándor</b>	Mobilizing community for social change  <b>Adriatik Hasantari</b>
Discrimination  <b>Dezideriu Gergely</b>	Health indicators  <b>Daniel La Parra</b>	Obstacles to accessing health care and insurance  <b>Mary Black</b>	Drugs, sex work and HIV —combating marginalisation  <b>Julia Buxton</b>	Closing and evaluation
Discrimination ( <i>continued</i> )  <b>Dezideriu Gergely</b>	Disparities in access to health  <b>Daniel La Parra</b>	Ethics and privacy  <b>Judit Sándor</b>	Drugs, sex work and HIV ( <i>continued</i> )  <b>Julia Buxton</b>	
				<b>Iulius Rostas</b>

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## PRELIMINARY COURSE PROGRAM

The workshop will combine keynote lectures and participatory exercises. Participants will identify a concrete challenge or growth opportunity or research question before the course, and then develop an action plan during the course with the help of co-participants and faculty. The course will be organized as follows:

### 1. PREPARATORY WORK

Participants will review selected readings in advance of the course. They will also prepare and submit one of the following:

- a) a problem statement, describing a challenge area or inquiry facing them in their work, or
- b) a proposal for research or action that they wish to workshop throughout the course.

### 2. PARTICIPATORY CURRICULUM

Each day should include three types of sessions: cross-cutting sessions, case studies and small working group discussions.

#### ► Sessions

Cross-cutting sessions will address special challenges faced by the health equity movement.

- **Policy Making towards Roma (Iulius ROSTAS)**

The current state of policy-making on Roma in healthcare suffers from multiple risks of policy failures: problem definition, lack of data, limited Roma participation, poor policy design and public and expert consultations, limited policy tools, inadequate resource allocations, lack of monitoring and evaluation mechanism, etc. The session will introduce participants to the main challenges in policy making towards Roma by analyzing policy making processes at a national level in the past three decades.

- **Antigypsyism—racism and discrimination against Roma and its role in policy making (Iulius ROSTAS)**

The sessions will explore the meanings of antigypsyism as a specific form of racism targeting Roma and discuss its dimensions and manifestations in the public sphere. The session will clarify the connection between antigypsyism, discrimination and segregation of Roma. The participants will be invited to reflect on and answer questions related to how antigypsyism could be tackled in times of crisis.

- **Discrimination (Dezideriu GERGELY)**

Discrimination is often a misused and abused concept when discussing the situation of Roma. The session will explore its meanings and manifestations, making a clear distinction between its everyday use by people and its legal meaning. Specific cases of discrimination against Roma in accessing health care services will be presented and analyzed.

- **Understanding research and data collection on Roma (Kristin MAKSZIN)**

The session will develop skills necessary to analyze and understand the results, strengths and weaknesses of research reports specifically focusing on Roma health. Participants will work with practical exercises and analyze real cases and their consequences for policies.

- **Health Indicators (Daniel LA PARRA)**

The session will familiarize participants with the social determinants of health and will define a set of indicators to measure health status and monitor health policies. One additional session will discuss the disparities in access to healthcare and health status inequities. Participants will also learn how to measure and how to effectively address health equity gaps.

- **Patients' and practitioners' rights (Mary BLACK)**

This session will bring a rights-based approach to public health policies targeting Roma in particular as a way to balance the needs-based approach promoted primarily by managers as well as policy makers.

By incorporating the perspectives of patients and practitioners on their rights, policies need to set standards that should be respected in the implementation phase. A second and third session will discuss obstacles to accessing health care services and issues around ethics and privacy.

- **Changing narratives on Roma in healthcare settings**  
(Katarzyna PABIJANEK)

People and communities use narratives to understand the world and our place in it. These narratives are always embedded with power—the power to explain and justify the status quo as well as the power to make change imaginable and urgent. A narrative analysis of power encourages us to ask: Which stories define cultural norms? Whose stories were ignored or erased to create these norms? And, most urgently, what new stories can we tell to help create the world we desire? The session will showcase OSF grantees' projects aimed at changing stories in the dominant culture to create more political possibility for social justice for Roma in healthcare settings.

- **Reproductive health** (Judit SÁNDOR)

Historically, the number of Roma was a matter of concern—and sometimes obsession—for politicians and policy-makers. Regulating Roma's reproductive behavior was a tool for social control. This session will explore the most important issues related to reproductive health and the impact recent policies and practices have had on Roma, especially on Roma women.

- **Drugs, sex work and HIV policies—combating marginalization**  
(Julia BUXTON)

The session will focus on public health harms caused by the criminalization of drugs and also other morally framed concerns such as sex work and homosexuality. Harm reduction approaches that seek to minimize the risk of unsafe practices to individuals, families and communities will be discussed and strategies for advancing evidenced based policies and legal reforms assessed.

- **Social accountability** (Adriatik HASANTARI)

The session will explore the meaning of social accountability and the need to engage in such matters. Lessons from social accountability will be presented and discussed and real life examples will be provided. A second session will analyze different strategies to mobilizing the community and ways their social growth can be supported. What are the aims and the results of community mobilization: is it fostering community cohesion, building relationships, trust, credibility, and a sense of ownership? The session will focus on concrete steps with regard to planning and acting toward social change.

- ▶ **Case studies**

The course will feature a comparative exploration of common themes across case studies. Themes include: discrimination; patients' rights; reproductive health; privacy and community mobilization.

- ▶ **Working group discussions**

Each afternoon, participants will come together in small groups to apply the day's lessons to their individual challenge or research question. Experts and instructors will be available during this time for consultation and support in developing their action plan.

### 3. POST-COURSE

After the course, participants will either submit their final reflections on their problem statement, or a revised version of their research proposal. In either case, candidates should detail a course of action for acting on, or exploring further, what has been learned over the five days of the course. A course alumni site will be set up on facebook where participants can pose questions and seek to support others with their action plans so our cohort of learners stay engaged in the future.



## ARRIVAL AND DINNER RECEPTION: **Sunday, 18 March 2018**

The course will be held at the **School of Public Policy**, on the campus of the **Central European University** in Budapest, Hungary.

There will be no course tuition. Most participants will, however, need to pay for their own travel to Budapest and their accommodation. A limited number of scholarships covering travel and accommodation will be available on a competitive basis for participants from Hungary, Serbia, Macedonia, Bulgaria and Romania.

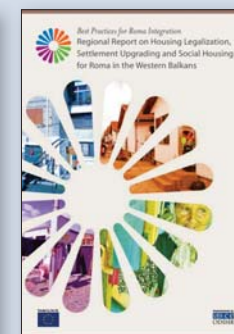
Interested individuals should complete the application form at <https://spp.ceu.edu/romahealth> by **11 February 2018**. Selected candidates will be notified in the week of **19 February 2018**.

There, you will be asked to submit

- a short problem statement, describing a challenge area or inquiry facing you in your work, **or**
- a short proposal for research or action that you wish to workshop throughout the course; **and**
- your CV.

The course will finish on **23 March** (late afternoon).

### Gallery of reports



# Faculty



## COURSE DIRECTOR

### **Iulius ROSTAS** | Central European University

Iulius is the chair of Romani studies and an assistant professor at CEU. He was an affiliated fellow with CEU's Institute for Advanced Studies, senior fellow with the Open Society Foundations Roma Initiatives Office and visiting lecturer at Corvinus University of Budapest. He has worked for OSF, the European Roma Rights Center and the government of Romania and consulted for the OSCE, the World Bank, the European Commission and the Roma Education Fund. Iulius is the editor of "Ten Years After: A History of Roma School Desegregation in Central and Eastern Europe" (CEU Press, 2012) and in 2011 he published *Social Inclusion or Exclusion: the Rights of Persons Living with HIV in Moldova* (Cartier Publishing, 2011). His upcoming book, titled "Ethnicity, Power and Inclusion: Why Policies Towards Roma in Europe Are Failing" will be published by CEU Press in 2018.

## FACULTY

### **Mary E. BLACK** | Public Health England

Mary is a medical doctor, public health specialist, health service manager, and technology entrepreneur from Northern Ireland. She is Head of Strategy in the Digital team in Public Health England. Mary is widely published in scientific journals and has extensive experience in change management. Her roles have included establishing a new medical school in Australia, working with the UN, and consulting on data and health management worldwide.

### **Julia BUXTON** | Central European University

Julia is a professor of comparative politics at CEU's School of Public Policy and a specialist on South America, receiving her PhD from the LSE, where she also studied for her MA (Distinction) in comparative politics. Her current research focuses on the drugs and development nexus and the development impacts of counter narcotics programs. A published expert on the drug trade, Julia has a particular interest in the impact of narcotic drugs and counter narcotics policies on development, peace building, public health, poverty and human rights.



### **Dezideriu GERGELY | Association for Development and Social Inclusion**

Dezideriu is a lawyer and trainer on non-discrimination and Roma issues and cooperates with the Council of Europe, among others. Most recently, he was involved in the CoE's draft working group of CAHROM elaborating the recommendation on improving the access to justice for Roma and Travellers in Europe adopted by the Committee of Ministers in 2017. Previously he was Executive Director of the European Roma Rights Centre in Budapest (2011–2014). He was a member of the National Council for Combating Discrimination, the Romanian equality state body where he served for six years as a member of the Steering Board and Secretary of State. Dezideriu is a human rights lawyer and a member of the Bucharest Bar.

### **Adriatik HASANTARI | Roma Active Albania**

Adriatik is the Director of Roma Active Albania and the vice chair of the European Roma Grassroots Organisations Network board, and a “ternYpe” International Roma Youth Network activist. He holds a university degree in medicine and was involved in research and development policies. Adriatik served as a coach and trainer on NGO management and project development and has more than 15 years of experience in community development projects in particular on Roma empowerment.

### **Daniel LA PARRA | University of Alicante**

Daniel has been a senior lecturer in sociology at the University of Alicante since 2007. He is also director of the Interuniversity Institute for Social Development and Peace (IUDESP), a World Health Organization Collaborating Centre on Social Inclusion and Health. He is a member of the State Council of the Roma People in Spain and the editor of the Roma inclusion newsletter published by WHO/Europe in cooperation with the European Commission – Directorate-General for Health and Food Safety and IUDESP. Daniel holds a PhD in sociology from the University of Alicante and an MSc in epidemiology from the London School of Hygiene & Tropical Medicine, University of London.

### **Kristin MAKSZIN | Hungarian Academy of Sciences**

Kristin is a research fellow at the Hungarian Academy of Sciences' Centre for Social Sciences and teaches public policy and comparative politics at McDaniel College Budapest. Her current research projects relate to the politics of austerity and the role of experts in policy change. She has taught research design and methods in international relations at CEU and has worked as a research fellow at the Center for the Study of Imperfections in Democracies (DISC) at CEU. Her publications have appeared in the Socio-Economic Review, Journal for Labour and Social Affairs in Eastern Europe, and the Czech Sociological Review. She completed her PhD in political science at CEU in 2013.

### **Katarzyna PABIJANEK | OSF Public Health Program**

Katarzyna is a program officer with OSF's Public Health Program, where she coordinates narrative change activities on sex work and Roma health and supports grantees in Europe working to change social narratives that negatively impact access to health services. Before joining OSF, Katarzyna worked for the European Gender Equality Institute and ASTRA Central and Eastern European Network for Sexual and Reproductive Rights and Health, where she coordinated advocacy efforts at the UN and with UN agencies. She holds MA degrees in linguistics from Eötvös Loránd University and in gender studies from CEU, and a PhD in cultural studies and neophilology from the University of Social Sciences and Humanities in Warsaw.

### **Judit SÁNDOR | Central European University**

Judit is a full professor at the faculty of political science, legal studies and gender studies at CEU. She conducted legal practice at Simmons & Simmons in London, had fellowships at McGill (Montreal), at Stanford (Palo Alto), and at Maison de sciences de l'homme (Paris), at NYU (New York, as a Global Research Fellow). In 1996 she received Ph.D. in law and political science. Judit was a member of the Hungarian Science and Research Ethics Council, and is currently a member at the Hungarian Human Reproduction Commission. She participated in different national and international legislative, standard setting and policy making activities in the field of biomedical law and bioethics. Since September 2005 she is a founding director of the Center for Ethics and Law in Biomedicine (CELAB) at CEU.

# Organizers



## Open Society Foundations Public Health Program

The Public Health Program works to build open societies where all people enjoy health and human rights. We work to fight discrimination and abuse in health care and support communities that receive minimal or substandard care because of who they are—including Roma and other minorities, transgender and intersex people, people with intellectual and psychosocial disabilities, sex workers, people who use drugs, and migrants and refugees. We also seek to advance this inclusive vision by reclaiming health as a public good—so that health care is available to all, laws and policies governing health are transparent and democratically accountable, and medical innovation delivers solutions that are accessible to everyone, from affordable medicines to palliative care.

## CEU School of Public Policy, Global Policy Academy

SPP's Global Policy Academy (GPA) organizes academically rigorous and policy-relevant courses that are designed not as traditional training seminars but as hubs for sectoral dialogue and experience exchange. The Academy leverages the broad and deep expertise of SPP faculty to address the needs of policy professionals who wish to broaden their knowledge as they serve the public good. Participants from the public, private, and non-profit sectors enroll in GPA courses to gain relevant practice-oriented skills grounded in research-based knowledge. They also take advantage of the School's global reach to grow and enrich their professional networks in an exceptional learning environment.

## CEU Romani Studies Program

Supporting Roma and the development of Romani Studies is part of CEU's mission. Building on its longstanding reputation in enhancing higher education, research, and professional opportunities for Roma, CEU's Roma Access Programs (RAP) has been transformed into the Romani Studies Program (RSP). RSP encompasses the Roma Graduate Preparation Program and the Roma in European Societies initiative.

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Design, layout: Judit Kovács | Createch Ltd.

Cover photo and photos on pages 2, 4, 6, 12, 14, 18:  
Boryana Katsarova for the Open Society Foundations