Developing a Multi-Level Advocacy Framework to Address Roma Health Inequities

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CESPYD-Universidad de Sevilla

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CESPYD is the Center of Community Research and Action at University of Sevilla

- Ethnic minorities, immigrants, refugees, stranded migrants, at-risk groups.
- Participatory mixed methodology based on stakeholder collaboration, sinergies between disciplines, effective communication and utilization of available resources.
- Innovative programmatic capacity from practical and realistic community-driven needs.
- Transformative changes in health and wellbeing public policies.

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Developing a Multi-Level Advocacy Framework to Address Roma Health Inequities

Content

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• The evolution of Roma health mediation
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Background: The assessment of Spanish’s NRIS
Background

http://equi-health.eea.iom.int/

Coordinated by the International Organization for Migration (IOM) and co-funded by the European Commission's DG for Health and Consumers (DG SANTE)

**EQUI-HEALTH** pursues to improve the **access and appropriateness** of health care services and **health promotion and prevention** to meet the needs of the Roma in Europe by **promoting dialogue and capacity building among key stakeholders**.

- Assessment of the National Roma Integration Strategy (NRIS) in the field of Health in Spain from a Multi-Stakeholder Perspective.
## Background

### Decade of Roma Inclusion (2005-2015)

### European Framework for National Roma Integration Strategies (2012-2020)

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<td>♂65.3</td>
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<td>♂54.1</td>
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<td>♂62.6</td>
<td>♂</td>
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<td>♀42.2</td>
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<td>Visitas al dentista (nunca)</td>
<td>♂17.4</td>
<td>♂14.8</td>
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Background

- Assessment of the health strand of the National Roma Integration Strategy (NRIS-H) in Spain from a Multi-Stakeholder Perspective
Background

Assessment of the NRIS-H in Spain

Roma Health as a wicked policy planning problem

- Extremely difficult to address and solve
- Interdependent, persistent, systemic
- Multiple causes, definitions and solutions
- Multiple stakeholders with interests
- Constantly changing
- No linear solutions, no trial-error

Background

Assessment of the NRIS-H in Spain

Transformative policy changes to address Roma health inequities

Changes in policy that resort to the best available evidence, while incorporates stakeholders’ values and give them real power to influence the decisions that impact their lives

Processes:

1. Explicit and discussable problem framing
2. Citizen participation in policy formulation
3. Allocation of resources for policy formulation and implementation

Background

Assessment of the NRIS-H in Spain

Discursive approach to the assessment of the NRIS-H

• Creation of a coalition composed of 48 representatives from 25 institutions

• 4 focus groups (2 at the beginning, 2 at the end)

• 33 individual interviews with stakeholders (15 in Andalusia, 18 in Catalonia)
Background

Assessment of the NRIS-H in Spain

Evidence-based approach to the assessment of the NRIS-H

• Scoping review from 2005-2015
• Sources: MedLine, PubMed, PsycInfo, Google Scholar + 25 websites + 14 documents from stakeholders
• Keywords: health policy, strategy, plan, Roma, gypsy, Spain, Andalusia, Catalonia (EN, ES)
• 145 documents – 36 final documents according to the WHO’s analytical framework “Potential Criteria for the Review of the NRIS-H”
Background

Assessment of the NRIS-H in Spain

*Roma Health Integration Policy Index (RHIPEX)*

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Background

Assessment of the NRIS-H in Spain

Lessons learned for Roma health governance

• Effective intersectional vision and strong commitment for intersectoral approaches.
• Capacity building among multiple stakeholders.
• Redistribution of power and redefinition of roles among stakeholders.
• Transformative participation of Roma in policy formulation, implementation and assessment.
• Transparent monitoring and accountability: Evidence-base and equity-focused impact assessment.
• Prevention of institutional discrimination.
• Health mediation as a valuable strategy to address Roma health inequities

Roma Health Mediation Models
Roma health mediation models

Northern RHM

Southern RHM

Eastern RHM
Northern RHM – The example of Belgium

RHM based on communication

- RHM from public institutions and organizations
- Intercultural resources for the improvement of communication, translation and interpretation (e.g., Remote Intercultural Mediation)

www.mipex.eu
Eastern RHM – The Example of Romania/Bulgaria

RHM based on network of profesional health mediators

- Basic disease prevention and health promotion programs (e.g., personal hygiene)
- Access and navigation through the system
- Assistance in emergencies

www.mipex.eu
Southern RHM – The example of Spain

Roma Health Mediation from RCSO – The Equi-Sastipen-Rroma Network

Network composed of 19 Roma organizations and federations created and coordinated by UNGA who started in 2010 a joint effort to promote and reinforce actions in Roma health in Spain.

The goal is to share and train intercultural mediators in the health domain, spreading knowledge on the Roma community among healthcare professionals as well as using all their experience and knowledge at local interventions.


Southern RHM – The example of Spain

RHM based on RCSO

Tasks of the Roma Health Mediator from RCSO

1. To facilitate critical awareness about the health needs of the Roma.
2. To work with the Roma to improve their health at different levels (e.g., family, work, community).
3. To navigate the healthcare system and acquire status among healthcare staff.
4. To work with the healthcare system to improve Roma’s health (e.g., adaptation of practices).
5. To culturally train providers and to increase Roma’s literacy about the healthcare system (e.g., navigation).
6. To assess the impact of health mediation in terms of quality of assistance and impact on Roma’s health.
7. To receive training and train other Roma health mediators.

IOM (2015). NRIS’ Spain [link to PDF]

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<table>
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<tr>
<th>1. To facilitate critical awareness about Roma’s needs</th>
<th>2. To work with the Roma to improve their health</th>
<th>3. To navigate the healthcare system and acquire status</th>
<th>4. To work with the healthcare system to improve Roma’s health</th>
<th>5. To train providers and increase Roma’s literacy on the system</th>
<th>6. To assess the impact of health mediation</th>
<th>7. To receive training and train other health mediators</th>
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<tbody>
<tr>
<td>Field observation and workshops with users</td>
<td>Health education programs</td>
<td>Meetings with providers, academia, platforms, forums</td>
<td>Training, guide against anti-Roma, working groups, media</td>
<td>Satisfaction surveys</td>
<td>Own training programs and projects, assistance to</td>
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<tr>
<td>Workshops on parenting, adherence, conflicto manag.</td>
<td>Promote mobilization and autonomy: users as mediators</td>
<td>Dissemination in centers, meetings with political entities</td>
<td>Permanent mediators within the healthcare system</td>
<td>Intercultural training to providers, social networks</td>
<td>Receive training</td>
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<tr>
<td>Visits schools to contact Roma</td>
<td>Workshops on healthy habits, VAW, HIV, reproductive h.</td>
<td>Coordination with the system and other entities</td>
<td>Urges and assist the system to monitor health in settlements</td>
<td>Train providers in centers</td>
<td>Training Roma neighbours as health mediators</td>
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<tr>
<td>Needs assessment with other CSO and users</td>
<td>Workshops to reduce self-medication</td>
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<td>Receive training</td>
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The Evolution of Roma Health Mediation

What are the implications?
From a traditional concept of RHM...

STRENGTHS
- Mitigation of damages at individual level
- Roma already in need
- Assistance of providers and healthcare centers
- Building bridges: Improvement of accessibility

WEAKNESSES
- Dependency of mediators
- Not systemic changes
- Not impact on structural inequities
- Maintain institutional discrimination: consolidation and increase of the gap

...towards Roma Health Advocacy

1. Short-term objective: **Building bridges** between the Roma population and the healthcare system and services.

2. Long-term objective: **Filling in the gap by bringing together** the Roma population and the healthcare system and services.
The Roma Health Advocator

A Roma Health advocate is a figure who plans actions directed at changing the policies and programs of institutions, and/or the beliefs, attitudes and behaviour of Roma citizens in the pursuit of equitable healthcare.

- **ROMA POPULATION**: brings the Roma population and the local services and institutions closer to each other.
- **HEALTHCARE SYSTEM**: works in the community with the available resources taking into account Roma practices.
- **ROMA HEALTH ADVOCATORS**: identifies Roma needs and works to organize processes that have the potential to influence changes in policy and services.
- **ROMA HEALTH ADVOCATORS**: initiates collaboration between neighbours and institutions.
Becoming a Roma health advocator through developing transformative mattering

• **Mattering** is the "perception and conviction that one cares for others and others depend on us" (Rosenberg & McCullough, 1981, p. 165).

• Mattering involves **recognition**—signs that we are accepted in our environment—and **influence**—certainty that others need us (Scholossberg, 1989).

• Mattering is essential in **the development of the self and meaning-making** in order to be a **significant member** of one’s own social sphere.
The empowering and mattering processes of becoming a Roma Health Advocator

From
- Stigmatization
- Discrimination
- Powerless
- Impunity
- Distrust
- Isolation
- Conflict
- Dispair
- Fear, shame
- Suffering

To
- Sense of belonging
- Equitative services
- Political empowerment
- Accountability
- Secure attachment
- Social support
- Commitment
- Control
- Psychological wellbeing
- Self-determination

Changes implied from RHM to RHA

From Roma Health Mediation  towards  Roma Health Advocacy

- Perpetuate the status quo  →  Eliminate institutional discrimination
- Passivity of the Roma population  →  Mobilization of the Roma population
- Bridge the gap  →  Fill in the gap
- Government  →  Governance

Roma Health Governance involves “the distribution of economic, intellectual, normative, and political resources” and the effects this resource distribution has on health (Ottersen et al., 2014, p. 630)
Multi-Level Advocacy Model

1. Mapping Roma Health Assets
2. Building advocacy capacity among health professionals
3. Building advocacy capacity among Roma neighbors
4. Achieving and sustaining changes
5. Impact evaluation
6. Dissemination
Putting Framework in Practice: The Case of Poligono Sur
The district of Polígono Sur, Seville

Characteristics:
• Unemployment ~40%
• School dropout ~45%
• Areas of prefabricated homes and poor housing conditions
• Highest rate of drug use and dual pathologies in Sevilla

70,000 inhabitants
20-25% Roma
A multilevel advocacy partnership
Mapping Responsiveness of Roma Health Assets: Overview

Identify all available resources
Evaluate local policies, programs and plans
Evaluate organizations and professionals
Coding to GIS

Map local roma health assets to assure implementation of NRIS-H

Mapping Roma responsiveness in local policies

- Are local policies, plans and programs Roma-sensitive?

Search of all health PPP in Polígono Sur and content analysis.

Instrument to assess Roma responsiveness.

Feedback from neighbors and policymakers in a meeting *ad hoc*

<table>
<thead>
<tr>
<th>Category</th>
<th>Indicator</th>
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<tbody>
<tr>
<td>Entitlement</td>
<td>Components of health service Entitlement requirements</td>
</tr>
<tr>
<td>Accessibility</td>
<td>Utilization of at-risk Roma groups (type, context, provider, objectives, time) Accessibility barriers Identify Roma non-users of services RP health mediator</td>
</tr>
<tr>
<td>Responsiveness</td>
<td>Health inequities identified by the NRIS-H’s OP Health service satisfaction of at-risk RP Mechanisms to confront barriers and more sensitivity to Roma at-risk groups Mechanisms for professionals to adapt services for at-risk RP Mechanisms to adjust health services to respond to particular needs of Roma users</td>
</tr>
<tr>
<td>Achieving and Sustaining Change</td>
<td>Participation of at-risk RP in the implementation of programs Collaboration between stakeholders</td>
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Mapping local Roma responsiveness

Building Advocacy Capacity among Multiple Stakeholders

Professionals from different institutions and organizations

- Raise awareness
- Identify needs and assets

Roma neighbors

- Weekly meetings
- Safe space for sensitive discourse
- Prepare for joint meeting

Building Advocacy Capacity: Professionals

- Group composed of different representatives at the local level
- Raising awareness regarding Roma health and National Roma Integration Strategies
- Weekly meetings to assess and evaluate Roma Health Community Agents procedure
  - Intro to Roma Health
  - Daily experiences with Roma neighbors
  - Reflection of discrimination towards Roma
- Democratic nomination of possible Roma Health Community Agents

Professionals from different institutions and organizations

Roma Neighbors


Building Advocacy Capacity: Roma Neighbors

Selection Criteria:
• Roma from the district
• Reside in most excluded areas of the district identified by mapping process and community health roundtable
• Demonstrate leadership skills and capacity to influence

Identify needs and assets

Assess and increase capacity to act

Be aware

Take actions

Professionals

Building Advocacy Capacity: Identifying needs through PhotoVoice

Roma Health Advocators: Achieving and Sustaining Change

- **Joint workshop**: A position of equality between Roma and local services in order to negotiate practices, local policies and future actions that influence Roma in the district.
- Utilized PhotoVoice results
- Defined actions for improvements
- Exchanged contact information to integrate Roma neighbours in collaboration with existing platforms, plans and programs

Lessons Learned & Future Implications

• Advocacy understood as a multilevel **empowerment process** – giving tools to RP in order to respond to health inequities – improving Roma health governance

• This multilevel process implies **individual, relational, organization, community, and policy/legal levels**

• Organizations and institutions should create spaces for negotiation for the **redistribution of power**

• **Building trust** between RP and other stakeholders for sustainable changes

• Collective action -- Engaging local RP and organizations to generate **social accountability** to increase Roma community health assets responsiveness

Roma Health Advocacy: Implications at Multiple levels

- Roma Health advocacy as an opportunity to make transformative changes
- Positive impact from the individual to collective and political levels
- Interaction between recognition and influence

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<tr>
<th>Individual Mattering</th>
<th>Knowledge of choices – navigating systems (Procedural)</th>
<th>Participation and involvement in social life</th>
<th>Meaning making</th>
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<tbody>
<tr>
<td>Collective Governance</td>
<td>Making choices available (Distributive)</td>
<td>Social Accountability</td>
<td>Sustainable changes, shifting power structures</td>
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Opportunities for Health Mediation

Join HM networks

 eurohealthmediator s.eu

Advocacy with different groups

- minors (e.g. early motherhood)
- migrants with high mobility

Collaboration with other high RP countries

- eastern European countries
- northern European countries
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