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

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CESPYD-Universidad de Sevilla

September 18-22, Alicante

# CESPYD – Coalition for the Study of Health, Power and Diversity

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 discipines, 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.

Research

Teaching

Activism

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CESPYD's Network and Sponsors
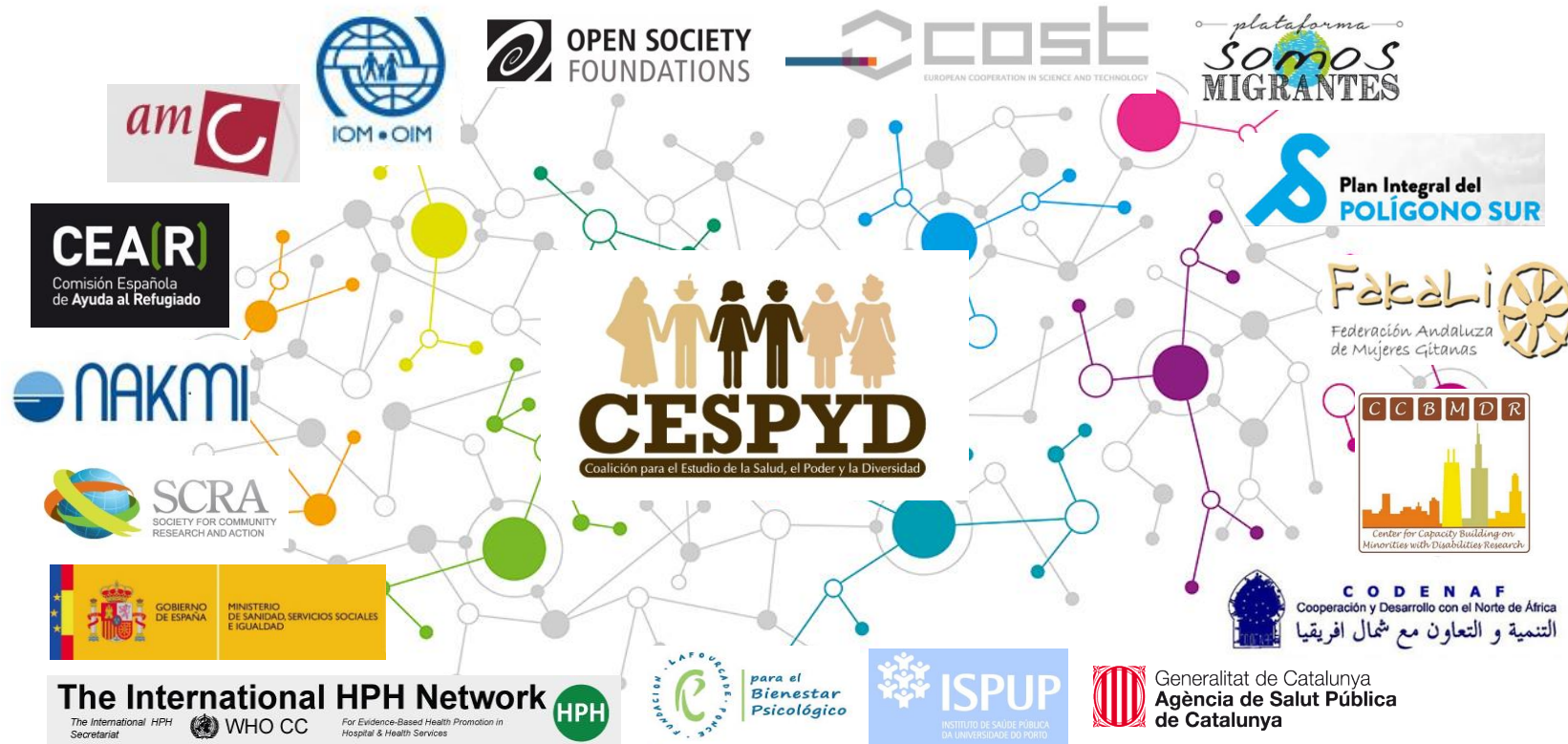
Developing a Multi-Level Advocacy Framework to Address Roma Health Inequities
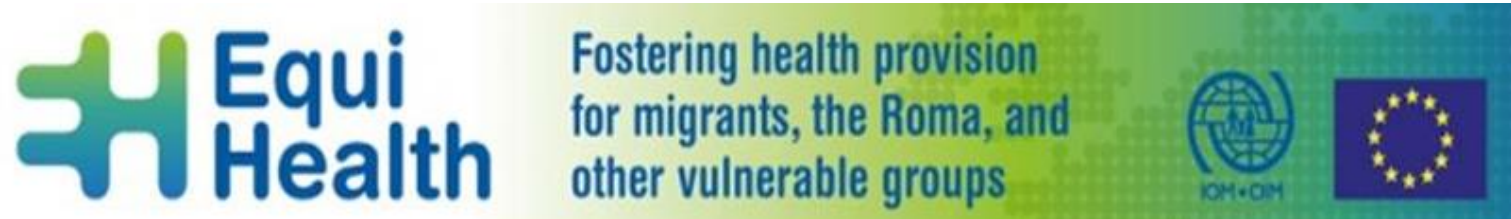
Content

- Background

- Roma health mediation models

- The evolution of Roma health mediation

- Mobilizing community for Roma health advocacy

- Lessons learned

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)

Indicador	Datos 2006 (PG) (edad ajustada)	Datos 2014 (PG) (edad ajustada)	Mejor Salud (2006 vs 2014)	Reducción de la desigualdad en salud (PG vs población general)
ADULTOS	%	%		
Autopercepción de salud	♂63.2	♂65.3	♂	♂
	♀48.9	♀55.5	♀	♀
Tabaco (consumidores)	♂51.6	♂54.1	♂	♂
Sobrepeso y Obesidad	♀61.6	♀62.6	♀	♀
Visitas ginecológicas	♀24.4	♀16.4	♀	♀
NIÑOS	%	%		
Sobrepeso y Obesidad	♂45.1	♂58.5	♂	♂
	♀40.1	♀42.2	♀	♀
Visitas al dentista (nunca)	♂17.4	♂14.8	♂	♂
	♀10.5	♀11.8	♀	♀

Decade of Roma Inclusion 2005-.2015 http://www.romadecade.org/
European Commission (2011). An EU Framework for National Roma Integration Strategies up to 2020. http://eur-lex.europa.eu/legal-content/EN/TXT/PDF/?uri=CELEX:52011DC0173&from=en
Ministerio de Sanidad, Servicios Sociales e Igualdad, DG Salud Pública. Segunda encuesta nacional de salud gitana, 2014. Madrid. 2016.
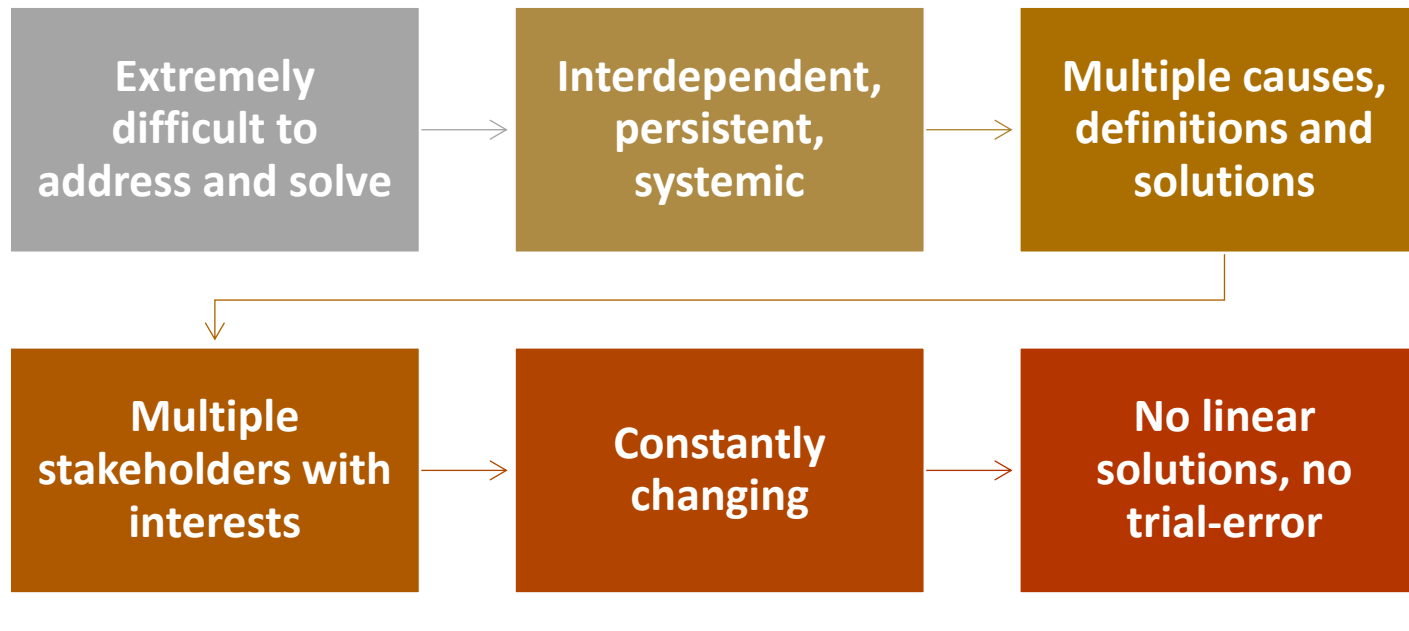
Background

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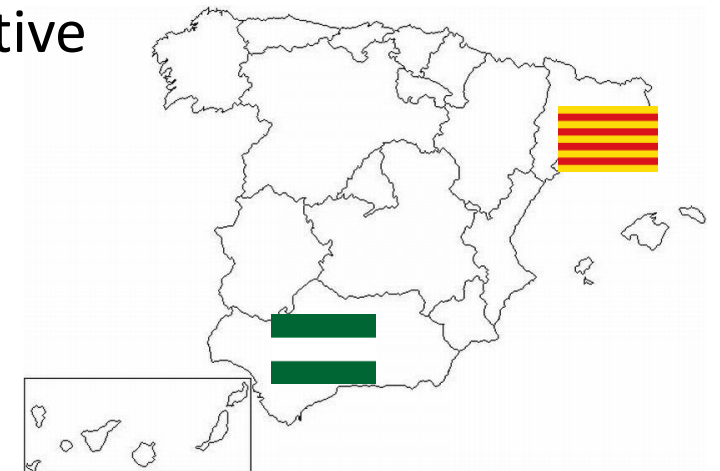
Background

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

GOOD LUCK

Rittel HWJ, Webber MW. Dilemmas in a general theory of planning. *Policy Sciences* 1973;4: 155–69.
Australian Public Service Commission. *Tackling wicked problems. A public policy perspective.* Commonwealth of Australia. 2007.
Weber EP, Khademian AM. Wicked problems, knowledge challenges, and collaborative capacity builders in network settings. *Publ. Admin. Review.* 2008: 334-349.

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

Nelson (2013). Community Psychology and Transformative Policy Change in the Neo-liberal Era. *American Journal of Community Psychology, 52,* 211-223.

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)
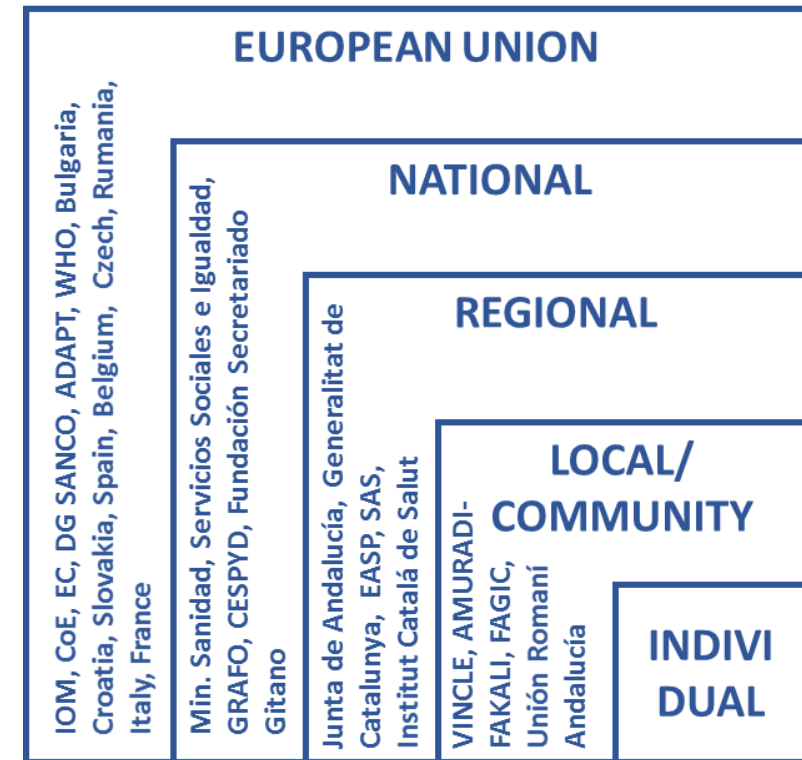
Background

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"
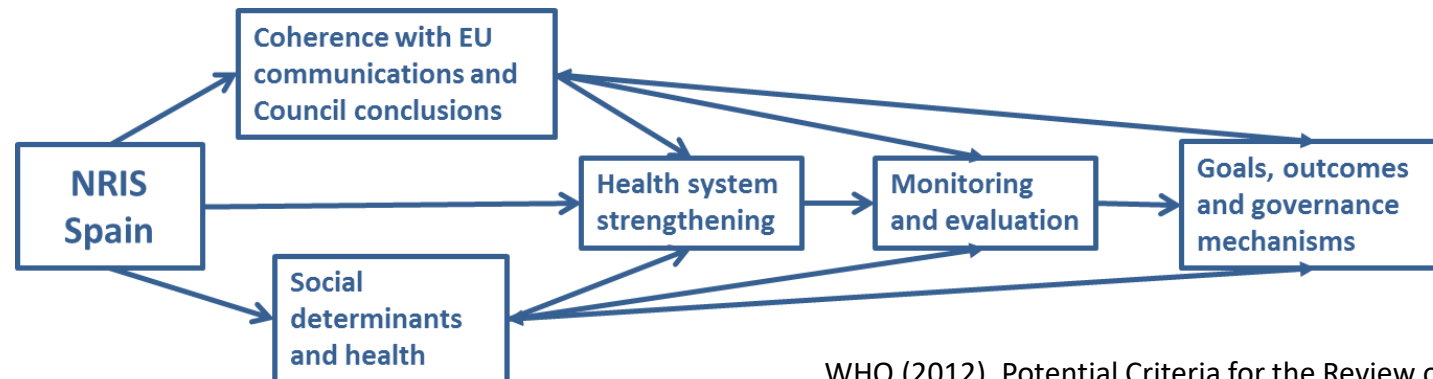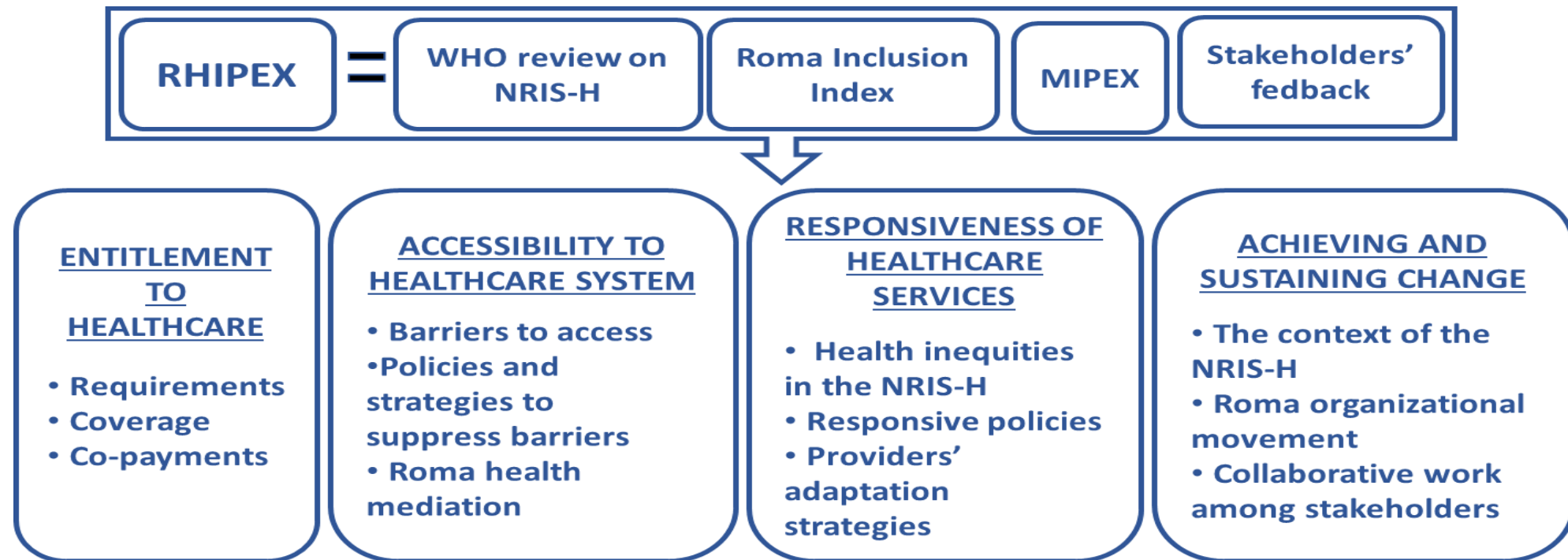

WHO (2012). Potential Criteria for the Review of the HEALTH COMPONENT of the National Roma Integration Strategies.

Background

Assessment of the NRIS-H in Spain

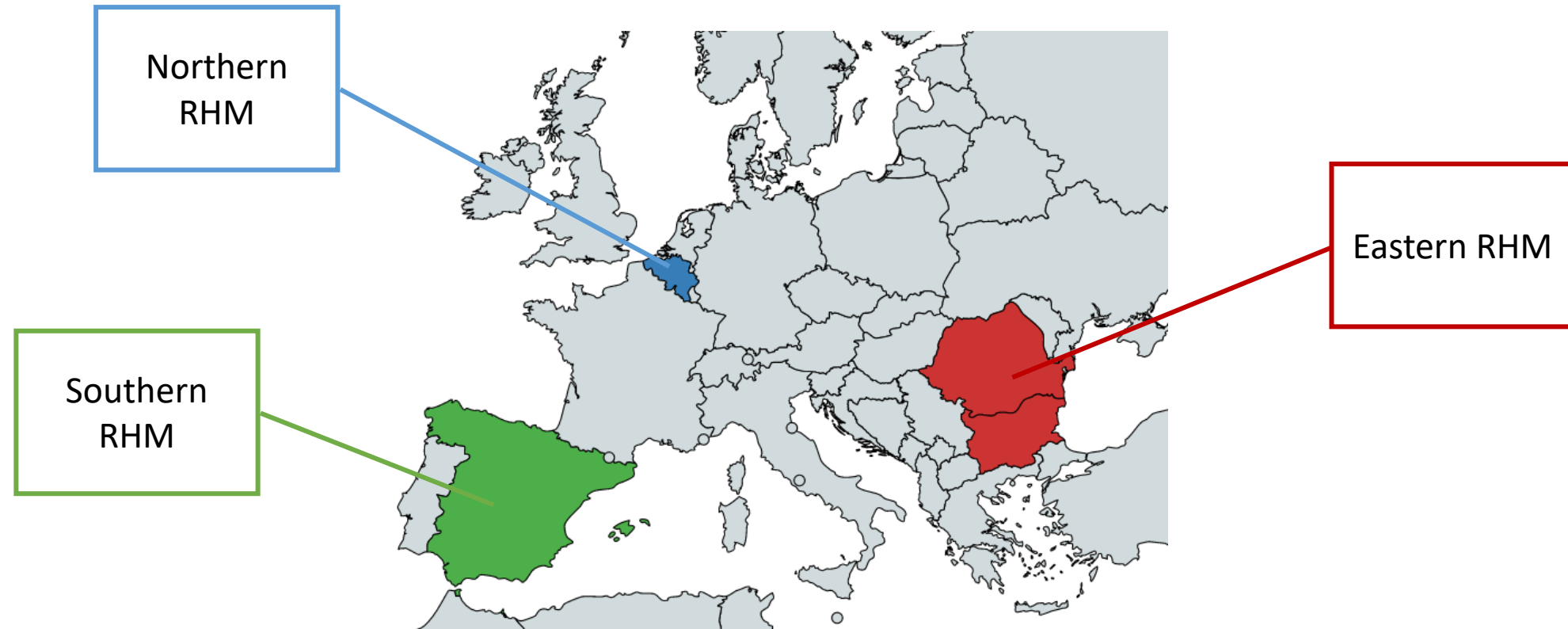### Roma Health Integration Policy Index (RHIPEX)

García-Ramírez, M., Escobar-Ballesta, M., Lizana, T. (2015) *Implementation of the NRIS and other national commitments in the field of health - Spain*. International Organization for Migrations. http://equi-health.eea.iom.int/images/NRIS_Spain_final.pdf

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**

García-Ramírez, M., Escobar-Ballesta, M., Lizana, T. (2015) *Implementation of the NRIS and other national commitments in the field of health - Spain*. International Organization for Migrations. http://equi-health.eea.iom.int/images/NRIS_Spain_final.pdf

Roma Health Mediation Models

Roma health mediation models

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

IOM (2015) NRIS' Belgium. https://publications.iom.int/system/files/pdf/nris_belgium_0.pdf

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 hygene)
- Access and navigation through the system
- Assistance in emergencies

www.mipex.eu

IOM (2015) NRIS' Bulgaria https://publications.iom.int/system/files/pdf/nris_bulgaria.pdf

IOM (2015) NRIS' Romania https://publications.iom.int/system/files/pdf/nris_romania.pdf

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

Arza, J. (2015). Equi Sastipen-Rroma. Manual para la promoción de la salud en la comunidad gitana
https://www.msssi.gob.es/profesionales/saludPublica/prevPromocion/promocion/desigualdadSalud/docs/Equi_sastipen_rroma.pdf

www.mipex.eu
IOM (2015). NRIS' Spain https://publications.iom.int/system/files/pdf/nris_spain.pdf

Southern RHM – The example of Spain

RHM based on RCSO
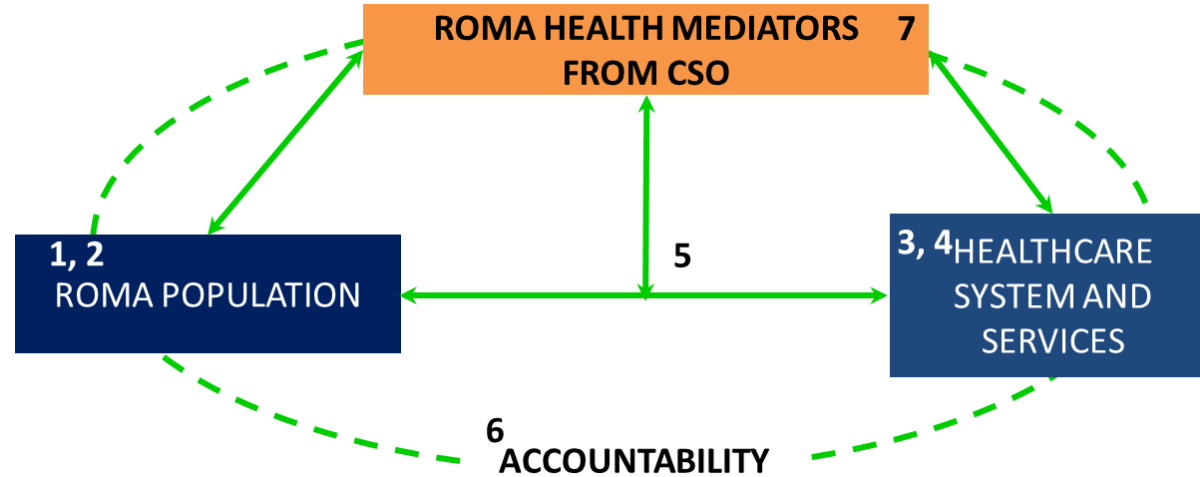
Tasks of the Roma Health Mediator from RCSO

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 https://publications.iom.int/system/files/pdf/nris_spain.pdf

	1. To facilitate critical awareness about Roma's needs	2. To work with the Roma to improve their health	3. To navigate the healthcare system and acquire status	4. To work with the healthcare system to improve Roma's health	5. To train providers and increase Roma's literacy on the system	6. To assess the impact of health mediation	7. To receive training and train other health mediators
FAGA COMUNIDAD VALENCIANA	Field observation and workshops with users	Health education programs	Meetings with providers, academia, platforms, forums		Training, guide against anti-Roma, working groups, media	Satisfaction surveys	Own training programs and projects, assistance to
PLATAFORMA ROMANES		Workshops on parenting, adherence, conflicto manag.		Permanent mediators within the healthcare system	Intercultural training to providers, social networks		Receive training
FakaLi Federación Andaluza de Mujeres Gitanas	Visits schools to contact Roma	Promote mobilization and autonomy: users as mediators	Dissemination in centers, meetings with political entities	Development of protocols adjusted to the Roma	Workshops in centers, training of students, com. coalitions	Assessment indicators of HM programs	Training Roma neighbours as health mediators
FAGiC Federació d'Associacions Gitanes de Catalunya		Workshops on healthy habits, VAW, HIV, reproductive h.	Coordination with the system and other entities	Urges and assist the system to monitor health in settlements	Train providers in centers		Receive training
KAMIRA	Needs assessment with other CSO and users	Workshops to reduce self-medication			Train providers in centers	Assessment indicators of HM programs	Receive training

The Evolution of Roma Health Mediation

What are the implications?

From a traditional concept of RHM...

| ROMA POPULATION | ROMA HEALTH MEDIATOR — GAP! | HEALTHCARE SYSTEM AND SERVICES |

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

Open Society Foundations (2005). Mediating Romani Health: Policy and Program Opportunities.
Open Society Foundations (2011). Roma health mediators: Successes and challenges

...towards Roma Health Advocacy

| ROMA POPULATION | ROMA HEALTH ADVOCATOR | HEALTHCARE SYSTEM AND SERVICES |

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 advocator 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 — **HEALTHCARE SYSTEM**

ROMA HEALTH ADVOCATORS

brings the Roma population and the local services and institutions closer to each other

initiates collaboration between neighbours and institutions.

identifies Roma needs and works to organize processes that have the potential to influence changes in policy and services

works in the community with the available resources taking into account Roma practices

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

To

Stigmatization
Discrimination
Powerless
Impunity

Take action to promote social changes

Sense of belonging
Equitative services
Political empowerment
Accountability

Distrust
Isolation
Conflict

Make contact to gain capacity to respond

Secure attachment
Social support
Commitment

Dispair
Fear, shame
Suffering

Develop critical thinking and strengths

Control
Psychological wellbeing
Self-determination

Garcia-Ramirez, M., De la Mata, M., Paloma, v., & Hernandez Plaza, S. (2011). A liberation psychology approach to acculturative integration of migrant populations. *American Journal of Community Psychology, 47,* 86-97

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**
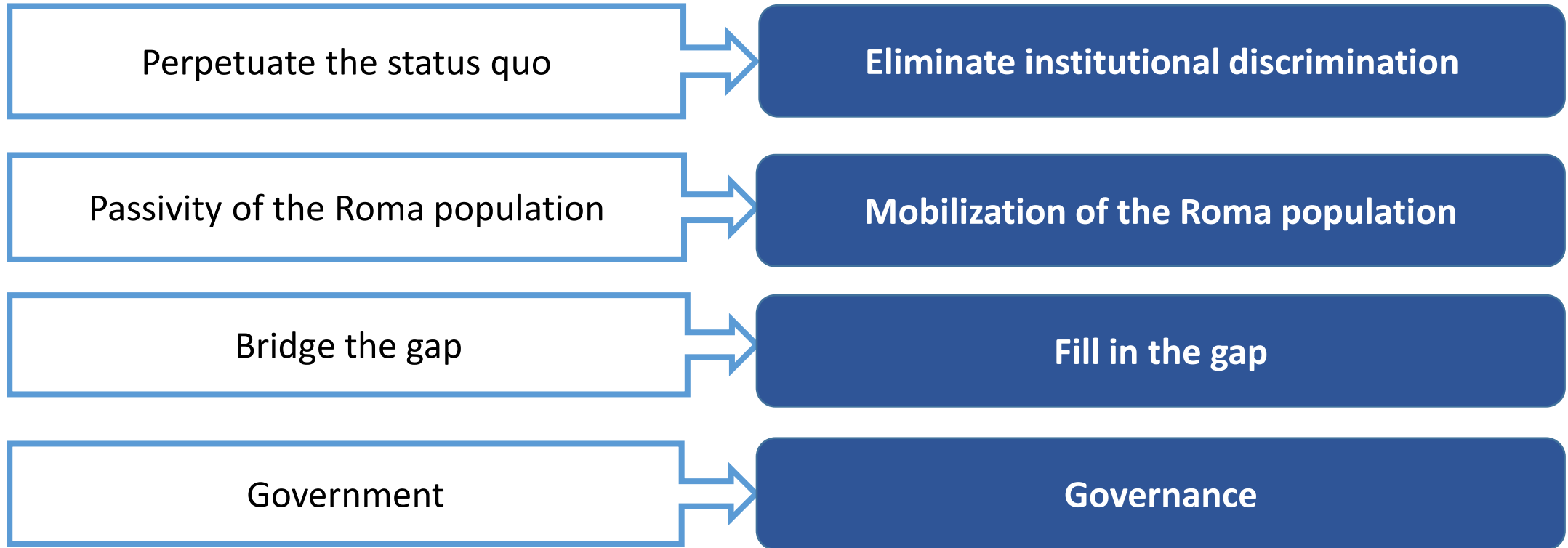
Roma Health Governance involves "the distribution of economic, intellectual, normative, and political resources" and the effects this resource distribution has on health (Ottersen et al., 2014, p. 630)

Multi-Level Advocacy Model
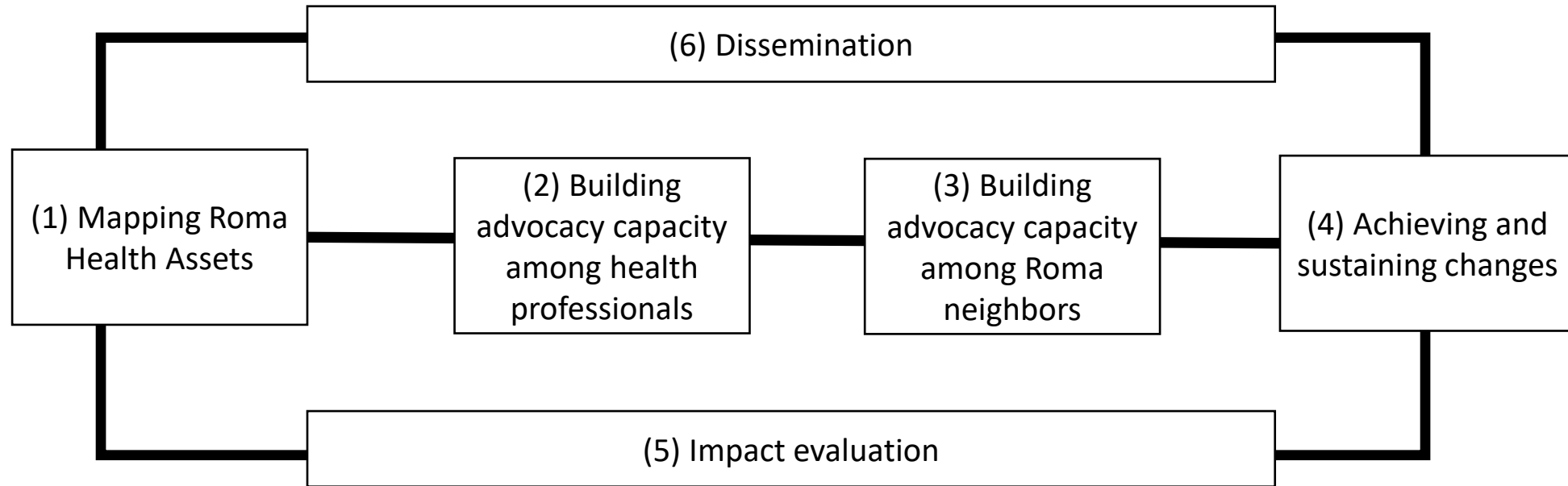
Putting Framework in Practice: The Case of Poligono Sur

The district of Polígono Sur, Seville

70,000 inhabitants
20-25% Roma
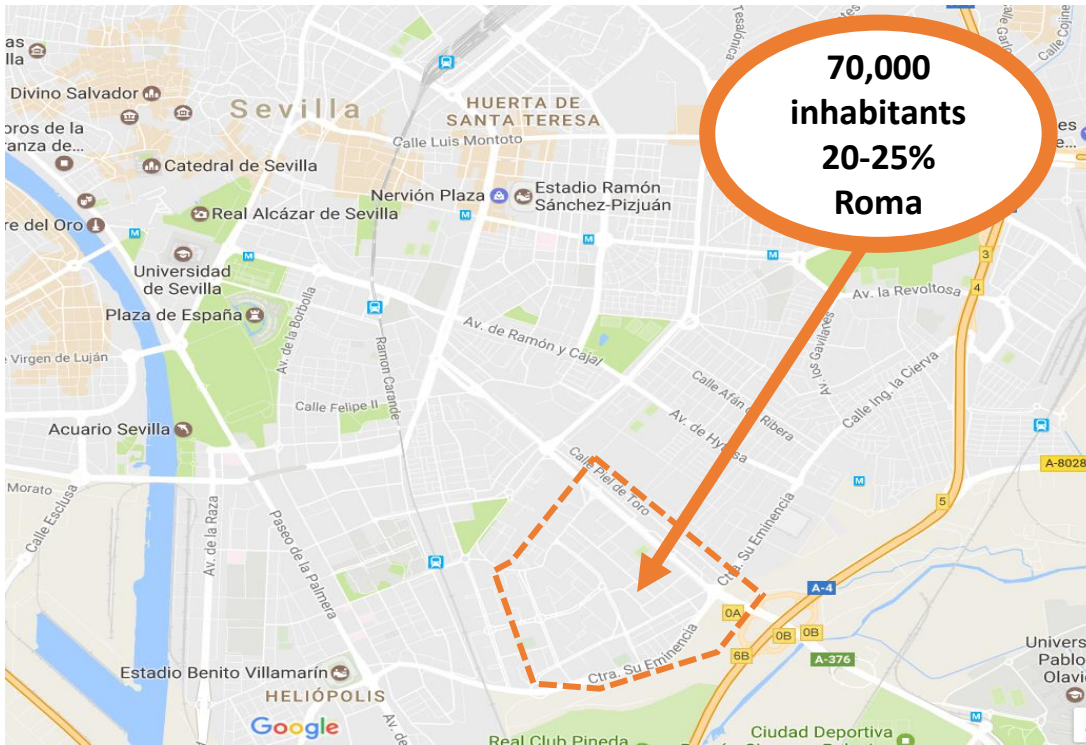
Characteristics:
- Unemployment ~40%
- School dropout ~45%
- Areas of prefabricated homes and poor housing conditions
- Highest rate of drug use and dual pathologies in Sevilla
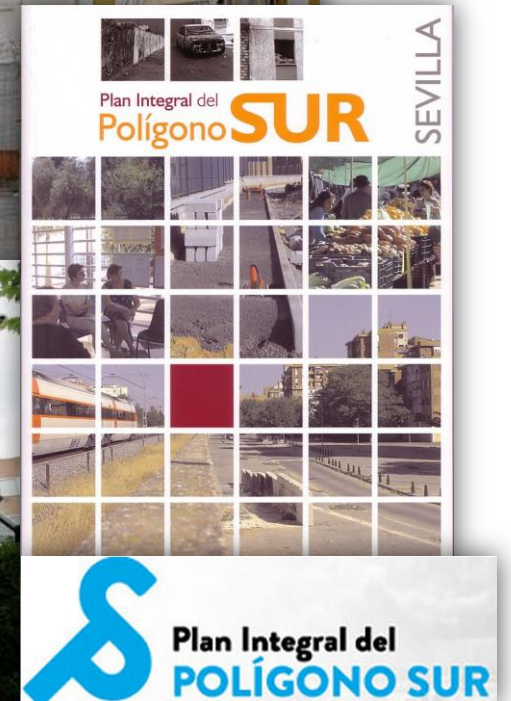
A multilevel advocacy partnership

Mapping Responsiveness of Roma Health Assets: Overview

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

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

Chan, D. V., Helfrich, C. A., Hursh, N. C., Rogers, E. S., & Gopal, S. (2014). Measuring community integration using Geographic Information Systems (GIS) and participatory mapping for people who were once homeless. *Health & place*, *27*, 92-101.

Mapping Roma responsiveness in local policies
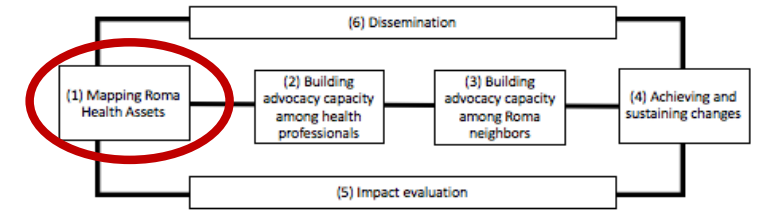
> **Are local policies, plans and programs Roma-sensitive?**

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

Instrument to assess Roma responsiveness.
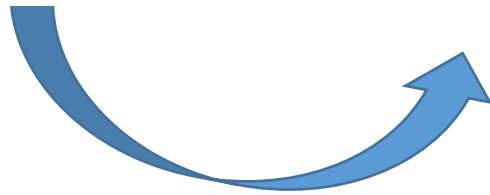
Feedback from neighbors and policymakers in a meeting *ad hoc*

Category	Indicator
Entitlement	Components of health service Entitlement requirements
Accessibility	Utilization of at-risk Roma groups (type, context, provider, objectives, time) Accessibility barriers Identify Roma non-users of services RP health mediator
Responsiveness	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
Achieving and Sustaining Change	Participation of at-risk RP in the implementation of programs Collaboration between stakeholders

Mapping local Roma responsiveness

Miranda, D., Oreja-Duran, I. & Escobar-Ballesta, M. (2016). Evaluación del Componente de Salud de la Estrategia Nacional de Integración de la Población Gitana en el Poligono Sur. IOM.
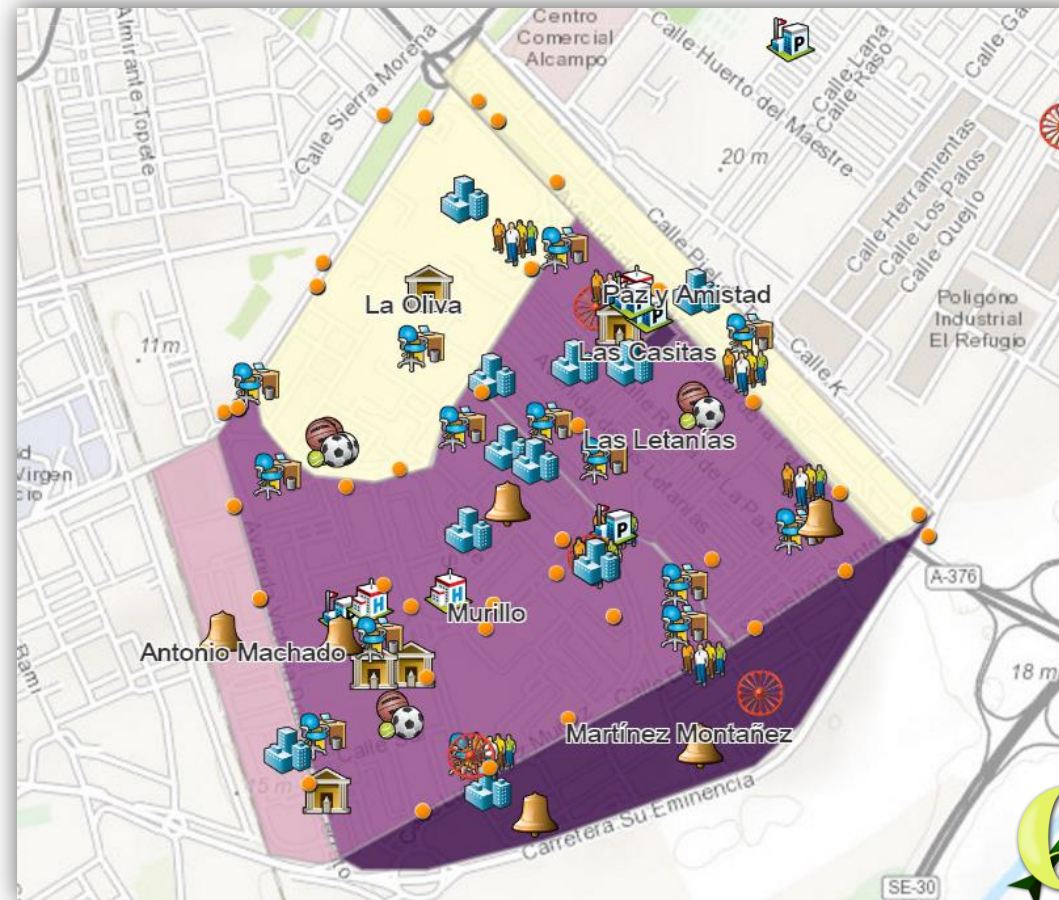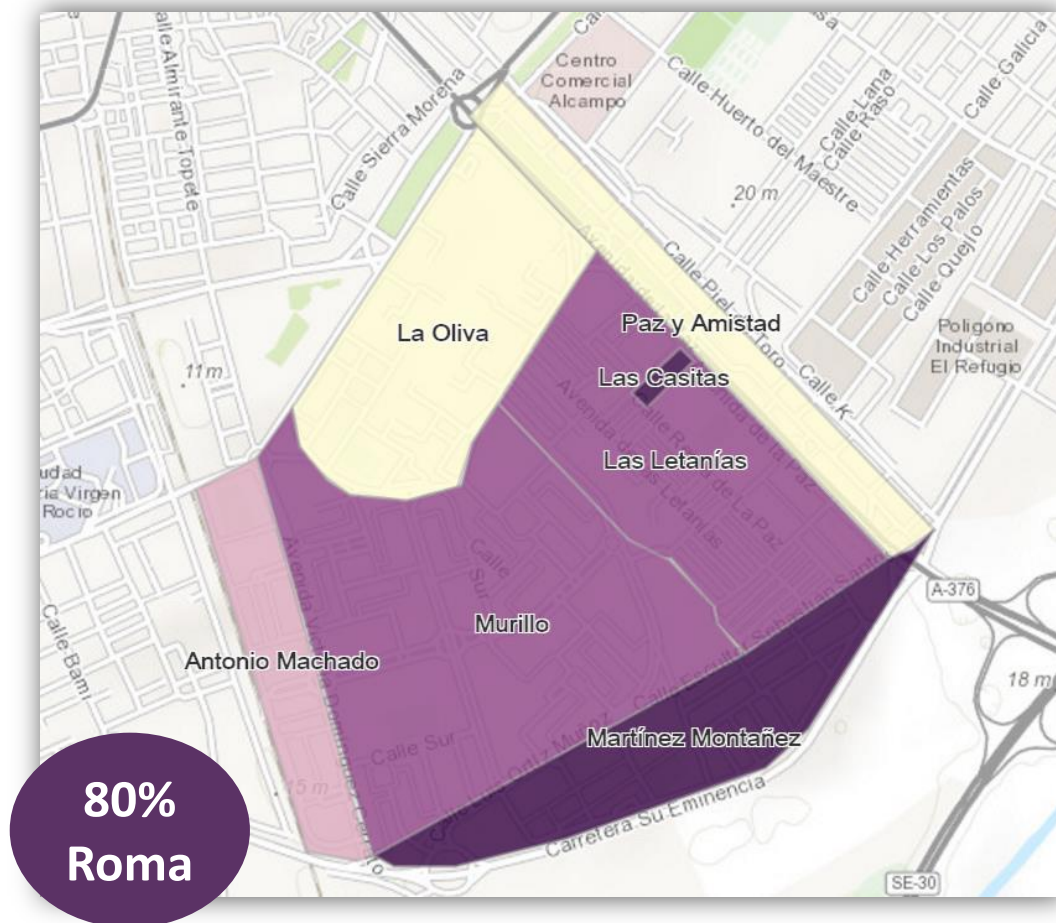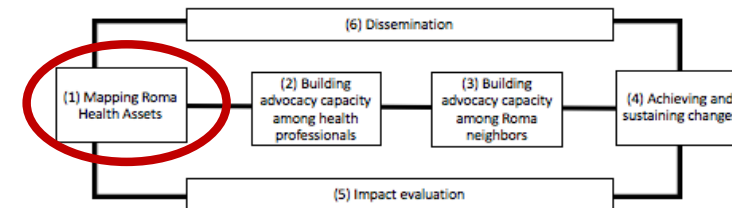
Building Advocacy Capacity among Multiple Stakeholders

Professionals from different institutions and organizations

Roma neighbors

Raise awareness

Identify needs and assets

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

Balcazar, F. E., Suarez-Balcazar, Y., Adames, S. B., Keys, C. B., García-Ramírez, M., & Paloma, V. (2012). A case study of liberation among Latino immigrant families who have children with disabilities. *American Journal of Community Psychology*, *49*(1-2), 283-293.

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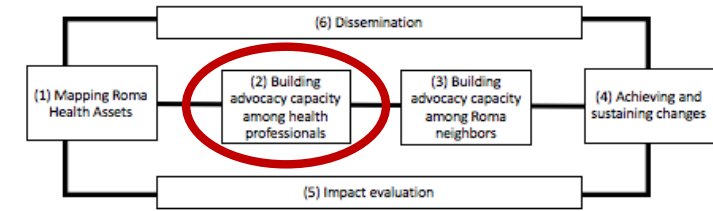
- Group composed of different representatives at the local level
- Raising awareness regarding Roma health and National Roma Integration Strategies
- Weekly meetings to assess and evaluate Roma Health Community Agents procedure
  - ✓ Intro to Roma Health
  - ✓ Daily experiences with Roma neighbors
 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

Professionals from different institutions and organizations

Raise awareness

Roma Neighbors

Loue, S. (2006). Community health advocacy. *Journal of epidemiology and community health, 60*(6), 458-463.

Mendes, R., Plaza, V., & Wallerstein, N. (2016). Sustainability and power in health promotion: community-based participatory research in a reproductive health policy case study in New Mexico. *Global health promotion, 23*(1), 61-74.

Building Advocacy Capacity: Roma Neighbors

Roma neighbors

Professionals

Be aware

Assess and increase capacity to act

Take actions

Identify needs and assets
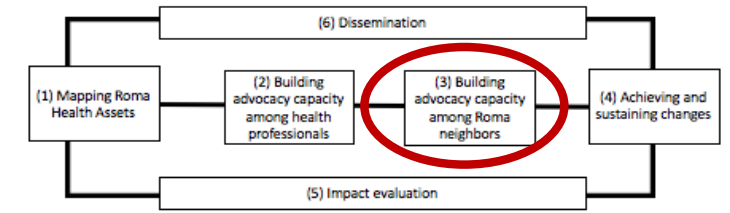
Selection Criteria:
- Roma from the district
- Reside in most excluded areas of the district identified by mapping process and community health roundtable
- Demonstrate leadership skills and capacity to influence
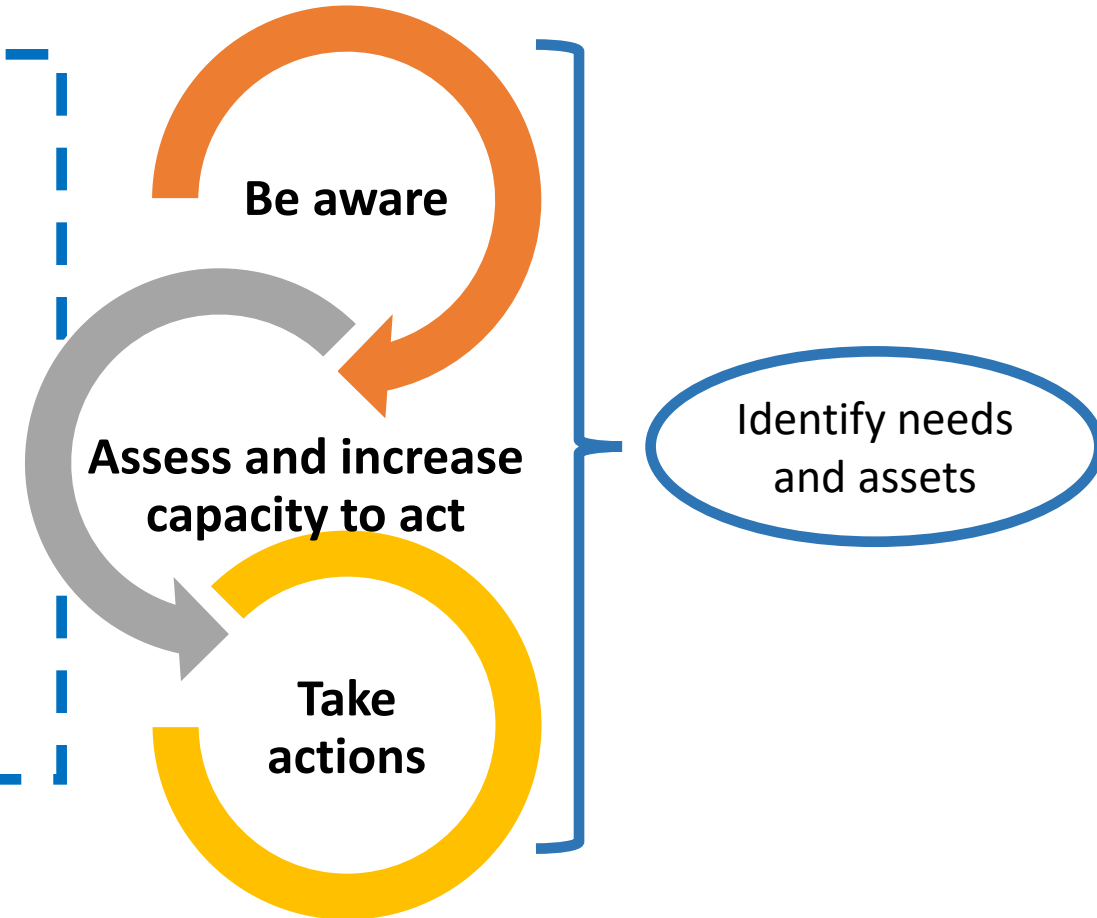
Weeks, M. R., Convey, M., Dickson-Gomez, J., Li, J., Radda, K., Martinez, M., & Robles, E. (2009). Changing Drug Users' Risk Environments: Peer Health Advocates as Multi-Level Community Change Agents. *American Journal of Community Psychology*, *43*(3-4), 330-344.

Building Advocacy Capacity: Identifying needs through PhotoVoice
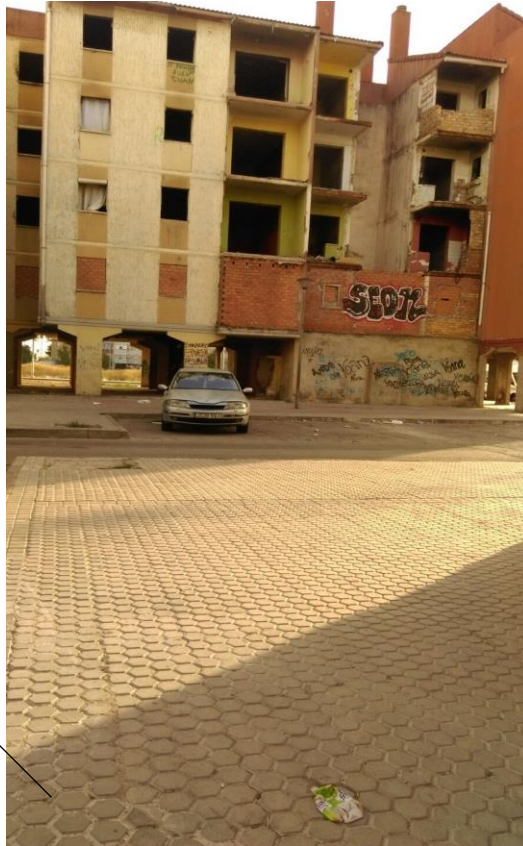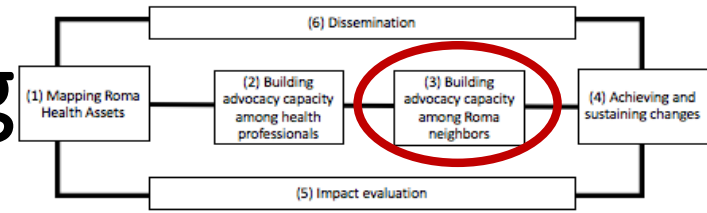
Wang, C., & Burris, M. A. (1997). Photovoice: Concept, methodology, and use for participatory needs assessment. *Health education & behavior*, 24(3), 369-387.

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
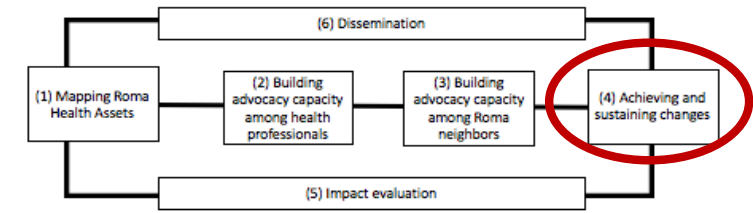
Griffith, D. M., Mason, M., Yonas, M., Eng, E., Jeffries, V., Plihcik, S., & Parks, B. (2007). Dismantling institutional racism: theory and action. *American Journal of Community Psychology*, *39*(3-4), 381-392..

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

Open Society Justice Initiative:
https://www.opensocietyfoundations.org/sites/default/files/lep-working-paper-20120701.pdf

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

Individual Mattering	Knowledge of choices – navigating systems (Procedural	Participation and involvement in social life	Meaning making
Collective Governance	Making choices available (Distributive)	Social Accountability	Sustainable changes, shifting power structures

Recognition

Influence
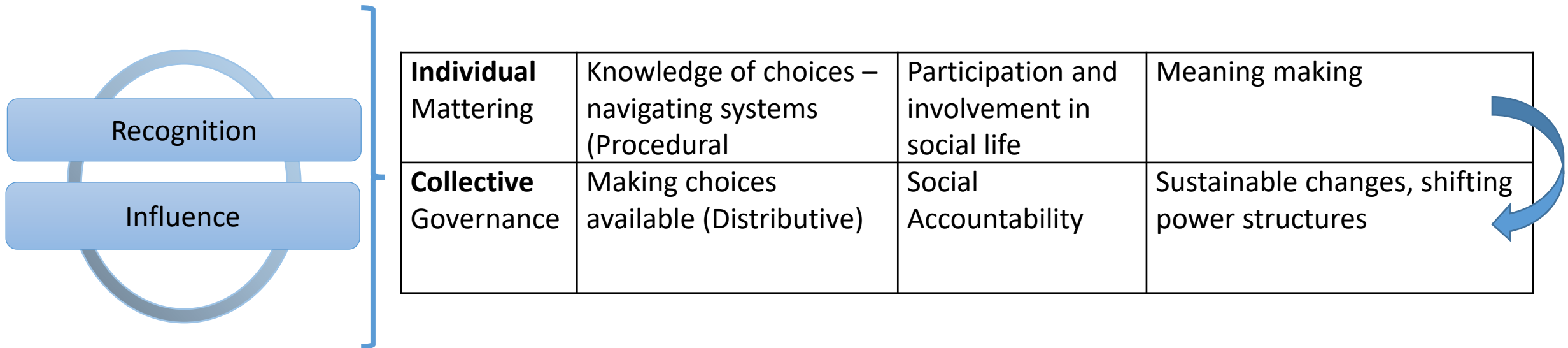
(1) Prilleltensky, I. (2012). Wellness as fairness. *American journal of community psychology*, *49*(1-2), 1-21.
(2) Global Partnership for Social Accountability: Fox, J. A. (2015). Social accountability: what does the evidence really say?. *World Development*, *72*, 346-361.
(3) Toolkit on Social Participation: http://www.euro.who.int/__data/assets/pdf_file/0003/307452/Toolkit-social-partecipation.pdf

Opportunities for Health Mediation

Join HM networks $\rightarrow$ eurohealthmediators.eu

Advocacy with different groups $\rightarrow$ -minors (e.g **early motherhood**) -migrants with high mobility

Collaboration with other high RP countries $\rightarrow$ -eastern European countries -northern European countries

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CESPYD-Universidad de Sevilla

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