



Ethnic Health Equity through Community Advocacy: Lessons learned from Roma in Spain

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Evaluating equity in health care: regional and international experiences
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Principal challenges with ethnic health equity & community participation

- Health policies are being developed **without participation** of ethnic communities
- Health agendas distribute resources that are not attractive to ethnic community creating **invisible accessibility barriers**
- Ethnic communities are **treated as users of services** and are excluded from governance process
- Mechanisms are being put in place that do not overcome real challenges, maintaining the status quo
- Community **participation is made instrumental** to institutions
- Current efforts do not incorporate a **rights-based approach**, equity is understood as overcoming barriers and not eliminating them

The example of Roma in Spain

- Research has attributed poor health outcomes attributed to **lack of participation**
- Roma health programs and practices developed **undermine Roma ability to represent themselves**, considered users
- Roma health mediation** is considered an exemplified practice
- Roma health mediators are not always recognized by community members, organizations and institutions
- Roma utilize and **frequent resources defined by them** (i.e. culto)

Objective: Develop community advocacy processes that allow meaningful participation for health equity

Essential Priorities in Roma Health



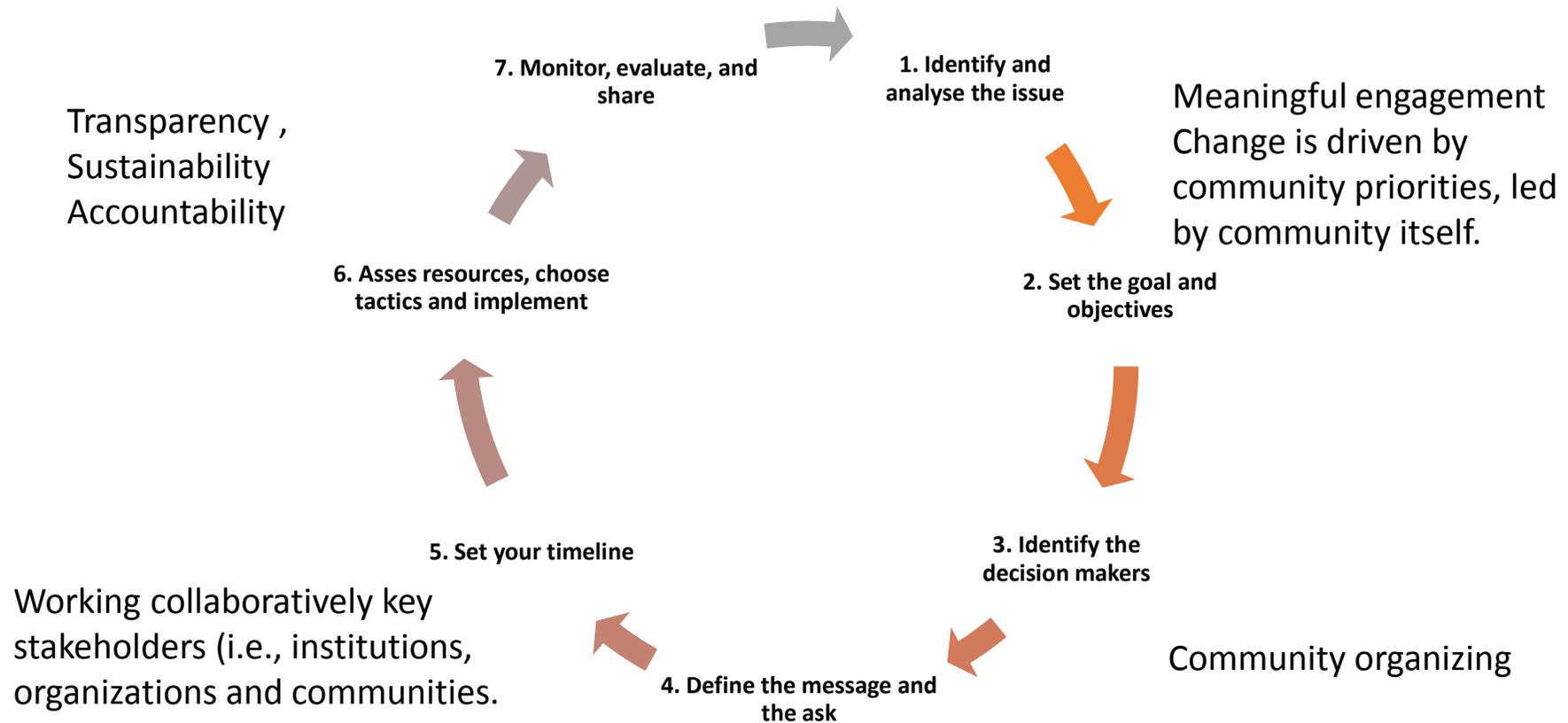
Developing policies aiming at closing the Roma health gap.

1. Meaningful Roma participation in all stages of the policy process (designing, implementation and evaluation)
2. Sustainability and funding
3. Measures effectively targeting discrimination and antigypsyism

Advocacy is considered a powerful strategy to address these issues

Advocacy: Definition and process

Advocacy refers any intentional attempt that -using evidences-inform and influence public agents to define, implement and evaluate initiatives that protect the Roma rights



Challenges

- **Fatalistic attitude.** “It is what it is”
- **Lack of commitment from providers (i.e., professionals, mediators, users).** They feel that advocacy is a political action and it is not their responsibility
- **Tokenism.** Significant Roma are co-opted and instrumentalized
- **Rivalling interests between Roma organizations.** Competition for funding instead of collaboration
- **Evidence gap.** Roma health is an evidence-free field
- **Roma power structure jeopardise the engagement of some groups** (e.g., women)
- **New vulnerable groups** competing for media visibility
- **Systemized violation of human rights.** Public discourse against human rights is being normalized globally. Antigypsyism is increasing

New and innovative frameworks of advocacy based on a social justice approach and focused on empowering the mattering of communities and public services are needed

A Social justice approach

Social Justice. Each person ought to receive what is due him or her, and that burdens and benefits of society should be shared in an equitable manner.

Traditional participatory initiatives are based on Distributive Justice

- Deficits and needs are highlighted
- At-risk people are entitled of societal resources by experts based on scientific evidences
- The target is to ameliorate personal deficits.
- People are passive users

Advocacy approach requires to move forward a procedural justice

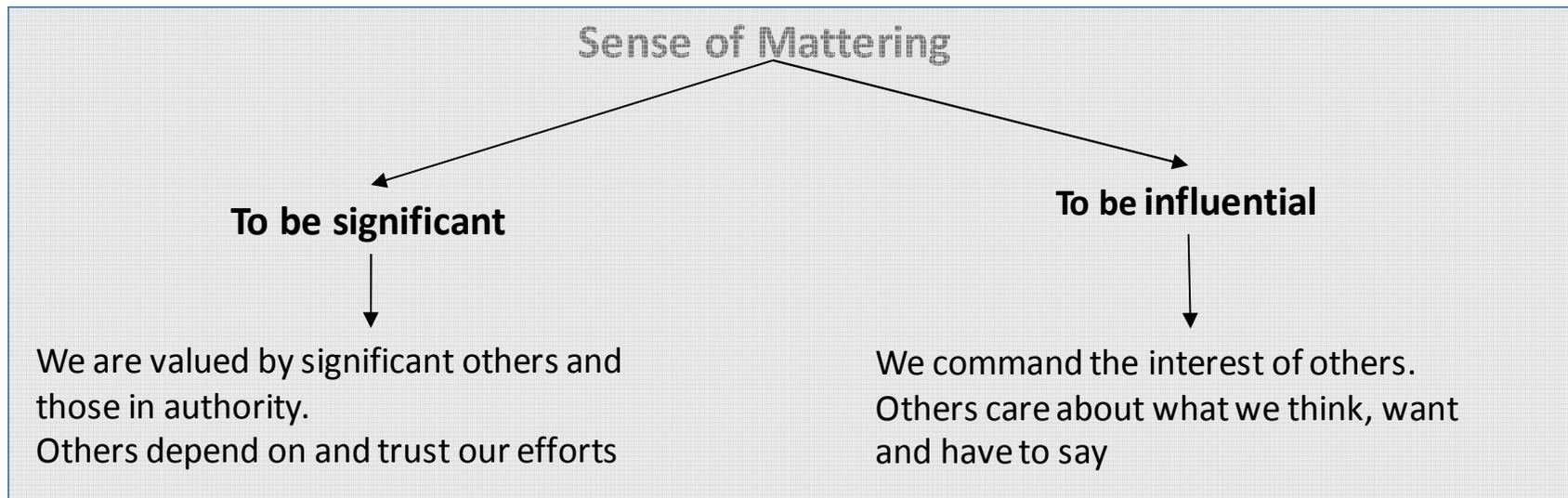
- Rights, values and strengths are highlighted
- At-risk populations have meaningful influence in the allocation of societal resources based on priorities defined by themselves.
- People should have psychosocial abilities to acquire control of their own lives.



Sense of community mattering

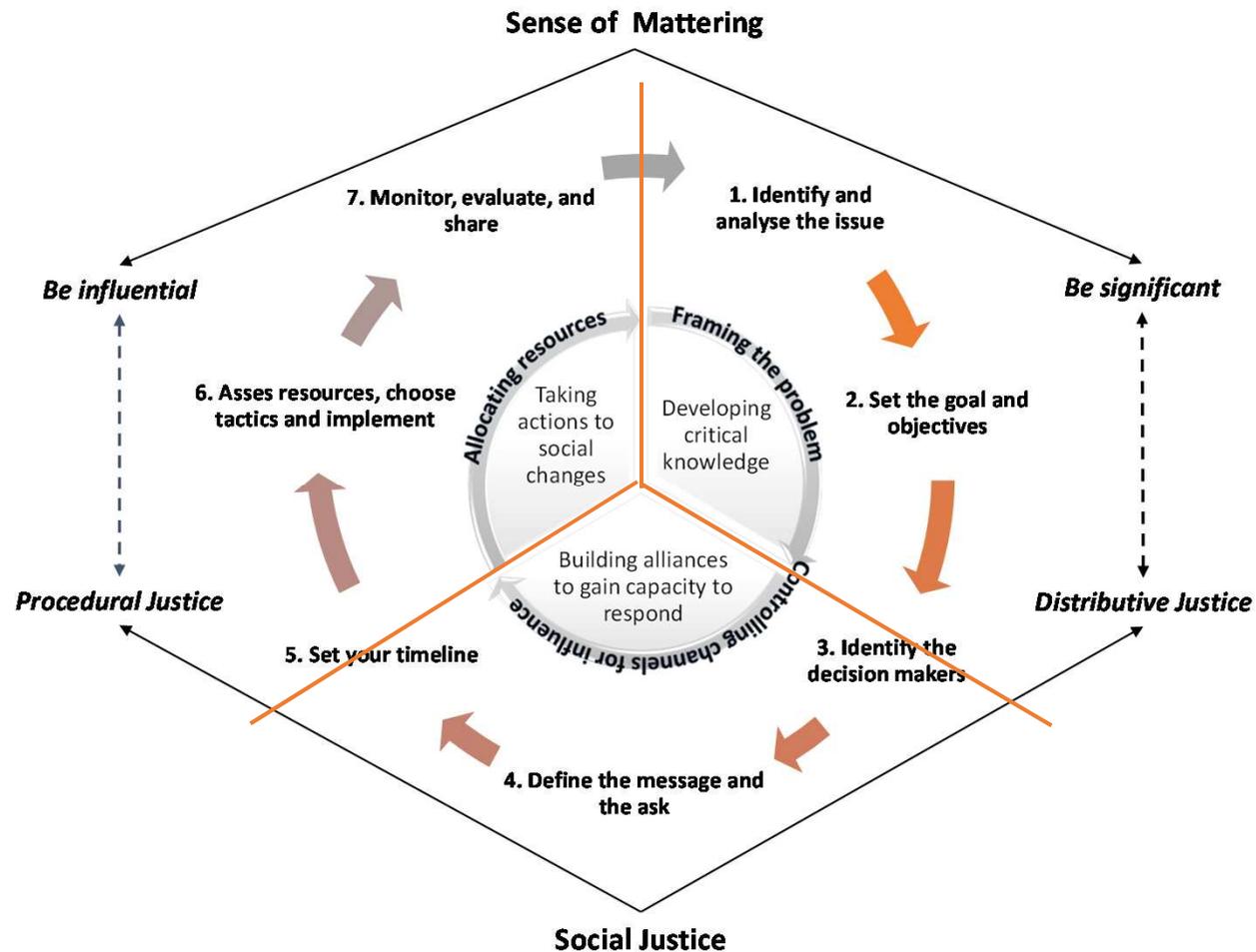
Sense of mattering is the perception and conviction that one cares for others and others depend on us

It 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 challenge is to empower sense of mattering linked to social justice among key community agents

Meaningful community advocacy



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

*The initiative of Road4Health: Roma Multi-Level
Advocacy for Health*

Contexts

Poligono Sur

Estimated 70,000 habitants, 80% Roma
Consequence of gentrification in the 1960s
Long history of activism
Local government authority and planning committee
No plans or programs specific to Roma
Roma living in the worst conditions

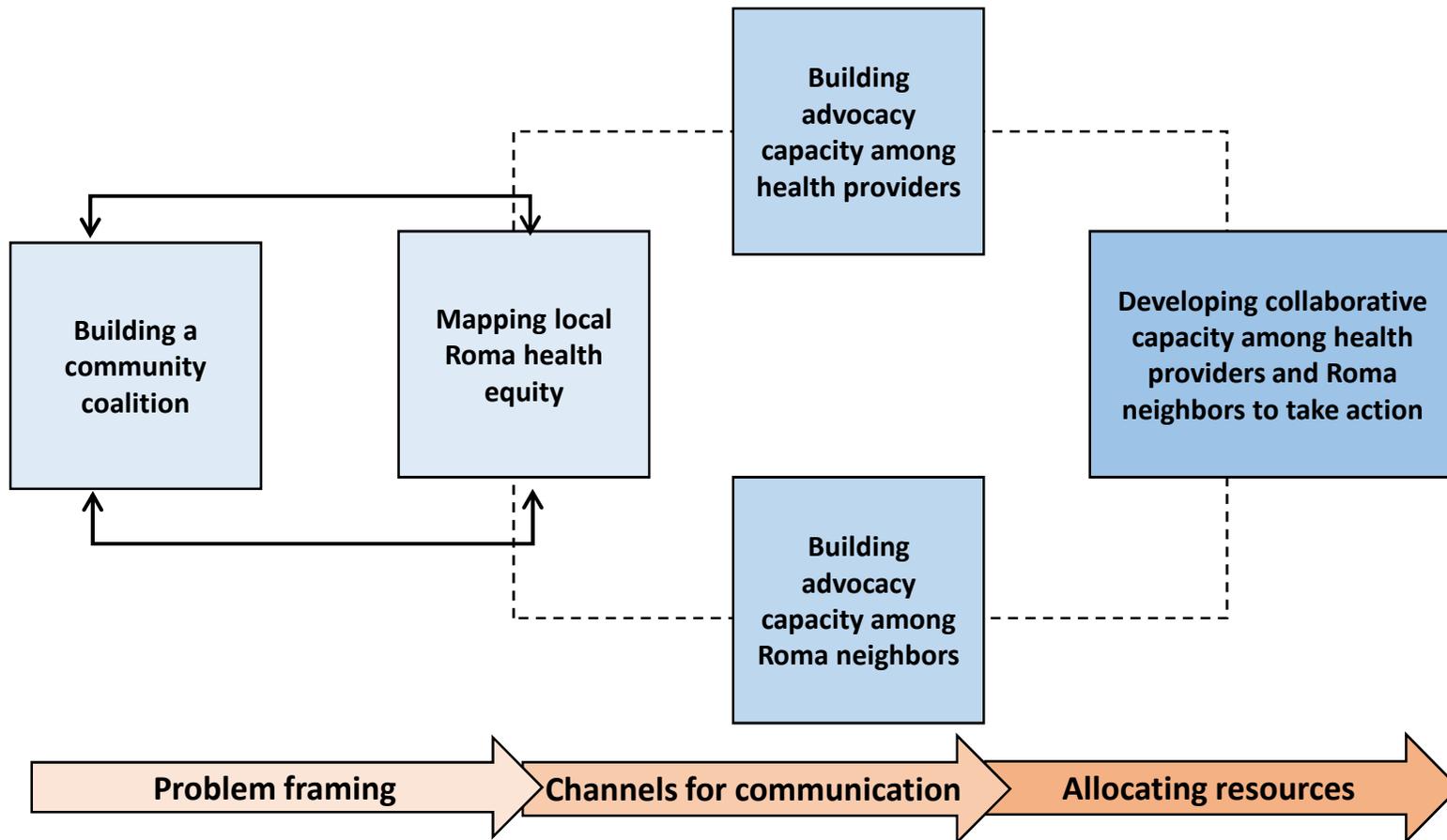


Torreblanca

No clear pertinence geopolitically– Sevilla vs. Alcala
Roma population live in prefabricated homes and settlement
Lack of formal community services
Strong sense of community



Mobilizing Roma communities to advocate for their health rights



- Developing multi-stakeholder influence and recognition – *community mattering*
- Identifying and evaluating existing Roma health assets
- Utilizing advocacy processes for psycho & sociopolitical empowerment
- Creating new local decision-making platforms for social justice (distributive + procedural justice)

Building a Community Coalition

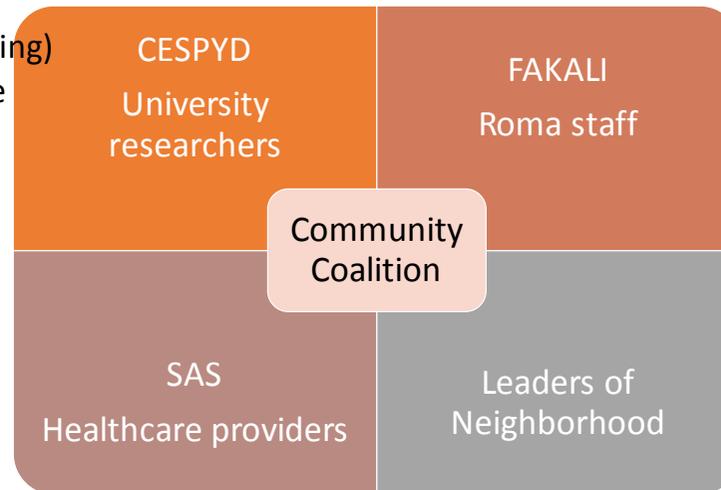
Create alliances between multiple stakeholders: Build trust, exchange resources, establish communication, define common goal, mutual learning relationships, community-based needs, intersectoral approach, action-research agenda

University

- Access to resources (i.e. grant funding)
- Provide evidence-based knowledge
- Identify good practices
- Systemize existing good practices

Local health providers

- Knowledge of healthcare system
- Access to other influential stakeholders



Roma Civil Society Organization

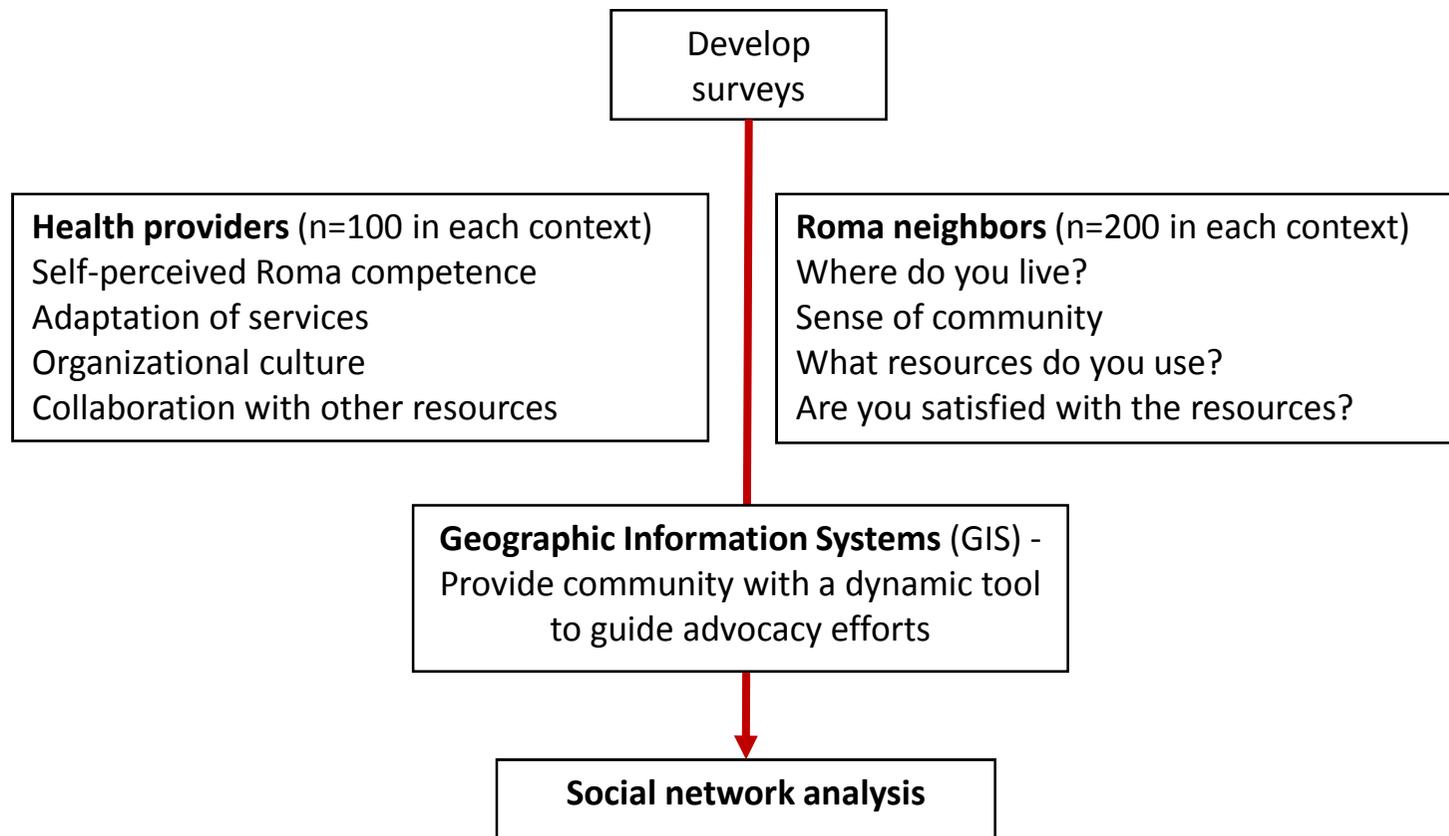
- Entry into community setting
- Access to key informants and networks
- Experiential knowledge of issues
- Cultural and contextual characteristics
- Have to gain influence among silent ranks

Roma Community

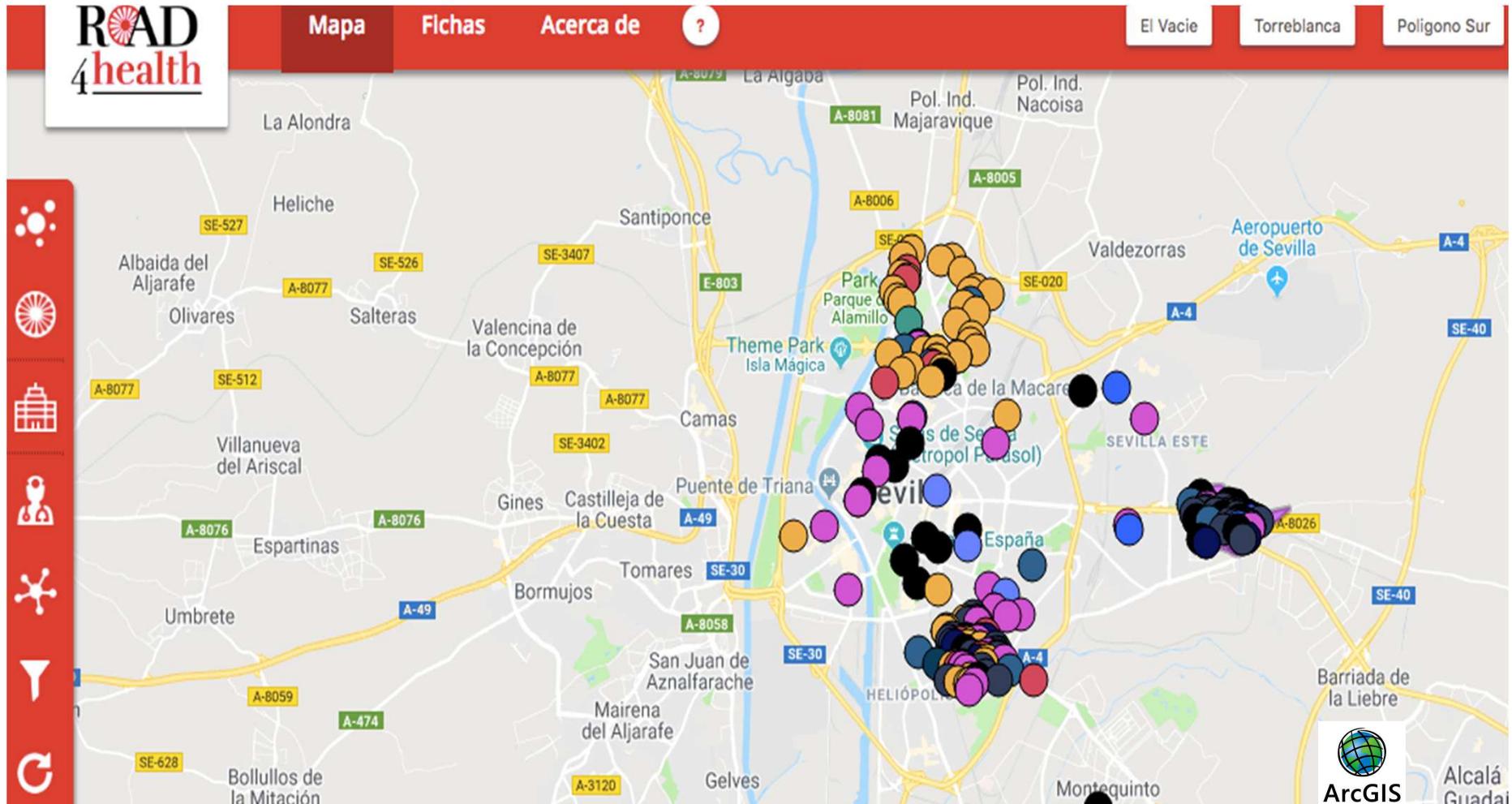
- Experts of their realities
- Real actors of the process
- People radiating influence among their families and neighbors.
- Mentors and models

Mapping Local Roma Health Equity

Identify and evaluate formal (i.e primary healthcare centers, social services, organizations) and informal (i.e. parks, bars, squares) **Roma assets** in each community



Mapping Local Roma Health Equity



<http://sessimonium.com/mapa/>

Mapping Local Roma Health Equity

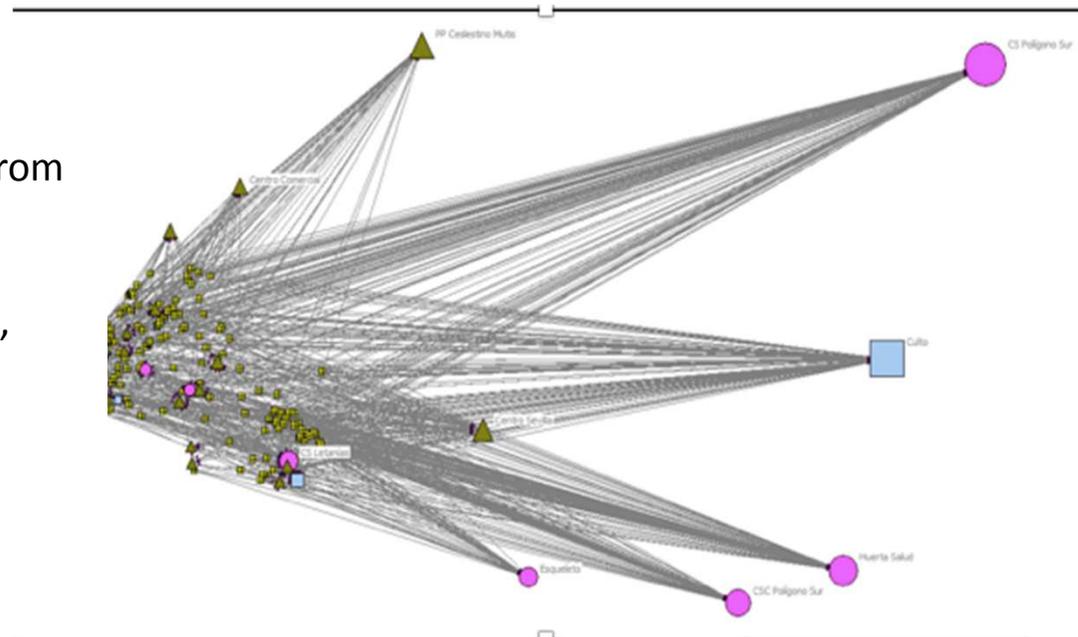
Poligono Sur Social Network Analysis

Level 1. Identify existing relationships between assets that are most frequented by Poligono Sur Roma community

Level 2. Identify type of relationship services had (meetings or referrals)

21 assets have been selected utilizing the data and feedback from Roma neighbors

Community-based organizations, local commissioner's office, healthcare centers, catholic churches, *cultos*, and schools



Most frequented asset are the faith-based organizations in which no collaboration with other assets occurs – lack of recognition and limited influence - invisible

Building advocacy capacity among health and social care professionals

Session Part 1 – Raise awareness through poster

- Antigypsyism
- Identifying dominant and liberating narratives
- Roma health policies
- Provider responsibility in protecting health rights
- Advocacy process
- Sharing local good practices



Session Part 2 – Reflection and dialogue in working groups

- Reflection
- Brainstorm local Roma health problems
- Dialogue
- Analyze cause and effects
- Prioritize
- Identify potential allies and barriers
- Actions



Example. Environmental health.

Brainstorm – 17 items

Priorities – (1) Rats & other animals; (2) violence & insecurity; (3) domestic accidents

Causes – Lack of political commitment, indifference from waste management

Effects – physical and psychological effects

Allies – Organizations, Roma neighbors, schools, social services

Barriers – Lack of interest at institutional level

Actions - Present epidemiological evidences to healthcare district

Building Advocacy Capacity among Informal Roma Assets

Open new collaboration with influential Roma assets to ally for Roma health advocacy

Example. Researchers Collaboration with the Roma *Culto*

Important Roma niche– identified by mapping
Spaces for participation – attending **4-5 times a week**

Entry point to most at-risk population

No collaboration with other resources

Roma community agent navigated *culto* structure for Interviews with pastors

Researchers Invited to attend services

Contact and collaboration with pastors and pastors wives



Building Advocacy Capacity among Roma Neighbors through Photovoice



Photovoice is a method by which people can identify, represent and enhance their community through a specific photographic technique

- 5 Roma neighbors per contexts as co-researchers and experts of their realities
- CESPYP and FAKALI act as facilitators
- Generate evidences by taking photographs
- Develop critical knowledge through brainstorming reflection in small groups and dialogue in large groups
- Identify new allies
- Take action to advocate



Foster-Fishman, P. G., Law, K. M., Lichty, L. F., & Aoun, C. (2010). Youth ReACT for social change: A method for youth participatory action research. *American journal of community psychology*, 46(1-2), 67-83.

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.

Sharing results within the community and collect more evidences

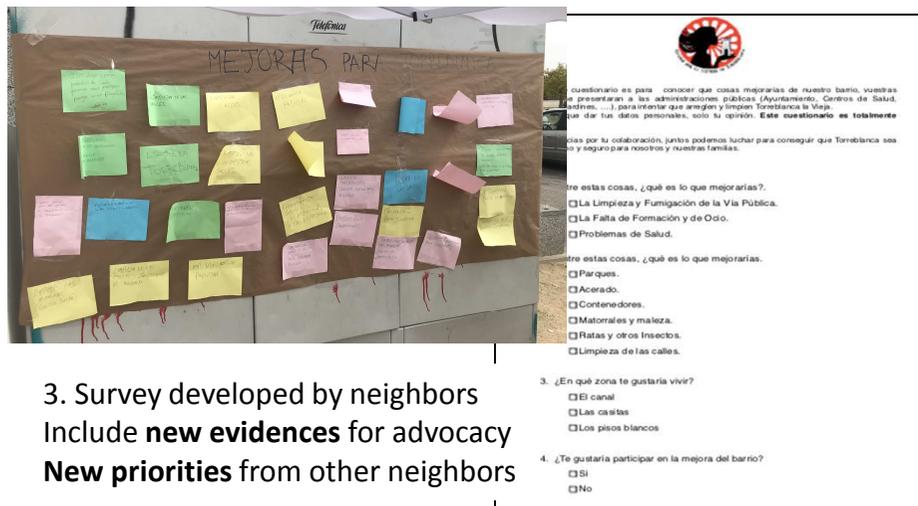


1. Build sense of group identity



2. Utilize Photovoice evidence to **raise collective awareness** among community

Gain support from other neighbors



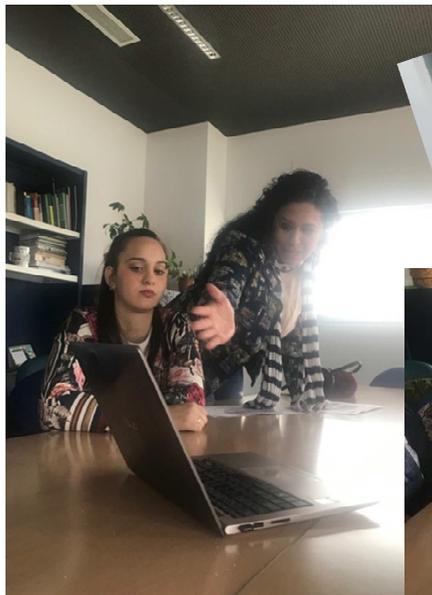
3. Survey developed by neighbors
Include **new evidences** for advocacy
New priorities from other neighbors

Challenges

- ✓ Resistance in shifting FAKALI's relationship with the community from service-user to equal collaborators
- ✓ Conflict of interest between FAKALI with. Neighbor's priorities and municipal priorities (evictions)
- ✓ FAKALI is obligated to follow governments priorities to maintain future funding
- ✓ Obtain and compete for funding (conflict with other Roma community-based organizations)

Bringing together Roma neighbours and health and social care professionals

Meetings with ombudsman, social services, local policymakers and healthcare centers
Presentation of Photovoice results
Reflection and dialogue
Define actions and commitments
FAKALI does not agree to participate in these meetings due to this is their role: to represent neighbors.



Example. Torreblanca Primary Healthcare Center.
Primary healthcare center director and two neighbors
Actions & commitments (1) gather more evidences; (2) ally with healthcare district to pressure city council and waste management to improve services; (3) media; ((4) Follow-up meeting with other health providers

Building a common agenda

- ✓ **Triangulate** neighbors evidences with epidemiological evidence from health providers
- ✓ Prioritizing **social determinants of health** – poor housing and environmental factors (ignored by waste management and lack of commitment from city council)
 - ✓ Effects on **mental health**
- ✓ Advocate for **institutional support** within the healthcare system for both neighbors and providers
 - ✓ Providers gain influence within their institutions to advocate for Roma sensitivity protocols
 - ✓ Providers gain influence to be recognized for their efforts (i.e. economic incentives and guarantee employment stability)
- ✓ **Network** and create new alliances with religious leaders, schools and local government officials
- ✓ **Strategize a timeline** to raise awareness during pre-electoral period (i.e. utilizing the media as a form of political pressure and shift public opinion)
- ✓ Set **monitoring mechanisms** – identify public spaces most effected, monitor waste management, follow-up meetings

Reflections & Discussion

Dominant ameliorative perspective

- User participation initiatives have been a useful and well-intentioned to pursue in improving Roma inequalities, but it is not enough.
- One of the most relevant weaknesses is that it is mainly focused on individuals instead of communities, biomedical deficits instead of social determinants, distributive instead of procedural justice.
- This is not random. This focus is an expression of the systemic antigypsyism of our society. This specific racism against Roma has validated the idea that Roma are unable to have a successful life as a well recognized part of our society. This is a way to victim blame and a way to justify the discrimination.

Incorporating an Intersectional approach

- New transformative actions have to assure that key decision makers are involved.
- Real impact in Roma health outcomes is not only an issue related with procedures or perspective. It is also about actors. Women, children and other Roma minorities as refugees, LGTBI+, traditionally stigmatized groups have to be influential and recognized. New initiatives has to be sensitives to a intersectional perspective.
- This intersectional approach will imply to pay more attention to an intersectoral approach from a collaborative vision

Fight against the scarce influence of populations

- The scarce influence ethnic “users” and other sensible healthcare professional have in the healthcare system is not random either.
- The authorities are not interested in them gaining influence because this poor value is another perverse strategy of systemic discrimination to preserve the status quo.
- A very significant evidence of this is how often authorities have co-opted and tokenized some of the Roma community based organizations. This has devalued their influence within communities, converting them into bureaucratic structures trying to maintain themselves.

From paternalism to emancipation

- New approaches have to be focused on giving influential voices to the most marginalized groups.
- They don't need others to represent them. They have powerful capacities to talk by themselves about themselves if they have opportunities to do so.
- Mediators and organizations have to facilitate these opportunities. Healthcare providers and policymakers have to trust in them and offer a seat at the table to make decisions on issues that affect them.



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