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Building Meaningful Community Advocacy for Ethnic-based Health Equity:

The *RoAd4Health* Experience

Daniela E. Miranda, Manuel García-Ramírez & María Jesús Albar-Marín

CESPYD, Coalition for the Study of Health, Power and Diversity, Universidad de Sevilla

**Corresponding Author**

danimiranda@us.es

**Keywords**

Ethnic minorities, community advocacy, Roma, health inequities, transformative policies

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**Conflict of Interest**

There are no conflicts of interest to declare.

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Building Meaningful Community Advocacy for Ethnic-based Health Equity:  
The *RoAd4Health* Experience

## Abstract

The pervasive failure of policies aimed at overcoming health inequities suffered by European Roma (also known as Gypsies) reflects the oppressive and impoverished living conditions of many ethnic minorities in the Western world. The multiple social inequities that Roma experience and the cumulative effect on their health proves that the failure of health policies that impact Roma must be attributed to their ameliorative nature. These policies legitimize the mechanisms of oppression that sustain inequities, fueling fatalistic attitudes towards minorities, while these minorities internalize the stigma and attempt to survive on the margins of society.

This paper presents the *RoAd4Health* project, a community initiative in which academic researchers partnered with Roma communities to overcome health inequities. We present the multiple methods utilized for building meaningful advocacy, such as photovoice and asset mapping led by Roma agents of change. These methods provided the capacity to develop a local narrative of disparities, build alliances to gain capacity to respond to injustices, and take actions to promote social change. The results of effectively involving all significant stakeholders (i.e. community agents of change, residents, health and social care providers, Roma community grassroots organizations, and institutional actors) are discussed along with lessons learned.

*Keywords:* Ethnic-based minorities, community mattering, Roma, advocacy, health inequities

**Building Meaningful Community Advocacy for Ethnic-based Health Equity: The  
*RoAd4Health* Experience**

The absence of meaningful initiatives and policies aimed at overcoming European Roma health inequities highlights the pervasive discrimination embedded in social, economic, and political structures that impoverish many ethnic-based minority communities. This is the case for Roma—the largest ethnic-based minority in Europe—with a population estimated at between 12 and 15 million people. Roma “refers to Roma, Sinti, Kale and related groups in Europe, including Travelers and the Eastern groups (Dom and Lom), and covers the wide diversity of the groups concerned, including persons who identify themselves as Gypsies” (Council of Europe, 2012, p. 4).

Majority societies have historically defined ethnic minorities using their own perception of these new groups’ discrepancy from accepted structures and norms. These preconditioned structures have disempowered ethnic minorities, impeding their capacity to influence and shape health policies according to their values and traditional narratives. This has been done under the preconception that these narratives prevent them from being successfully accepted as part of the mainstream society (Garcia-Ramirez, de la Mata, Paloma, & Hernández-Plaza, 2011). Over centuries, Roma have survived oppressive living conditions while grounded in their sense of community and collective ethnic identity. Roma communities are often seen as an archetype of how ethnic minorities remain cohesive in the context of deeply embedded discriminatory structures that produce health inequities.

The central aim of this paper is to describe a meaningful community advocacy strategy to address health equity using a community psychology approach. The term “meaningful community advocacy” refers to the influential processes that develop psycho-political

empowerment at multiple levels (i.e. intrapersonal, organizational, community, institutional) to change existing policies and practice to promote social justice (Keys, McConnell, Motley, Liao, & McAuliff, 2017; Suarez-Balcazar, 2020; Toporek, Lewis, & Chethar, 2009). Psycho-political empowerment is understood as the liberation process by which oppressed people (a) build critical awareness and their own narratives about oppressive conditions; (b) gain the capacity to respond to them; and (c) take action for community change (Garcia-Ramirez et al., 2011; Miranda, Garcia-Ramirez, Balcazar, & Suarez-Balcazar, 2019). To achieve our purpose, we describe the challenges of Roma health policies, then, we describe our meaningful community advocacy strategies in three at-risk contexts in Spain. Finally, we discuss lessons learned and the implications for community psychology.

### **The challenges of Roma health policies**

For over a thousand years, consistent persecution of Roma caused displacements of their communities across the European continent and internal displacements within countries. Roma arrived in Spain during the 15<sup>th</sup> century and were ostracized by a series of laws that mandated the disappearance of their people and culture. This situation stimulated a process of dehumanization by majority society that legitimized them as an inferior ethnic group (Ringold, Orenstein, & Wilkens, 2005). At the socio-political level, dominant narratives have produced structures that assume Roma exclusion as a societal norm, while blaming Roma for their marginalization and justifying their social illegitimacy. Over time these dominant narratives have had negative impacts on Roma's daily living conditions, and consequently their health (Oosterlynck, Loopmans, Schuermans, Vandenabeele, & Zemni, 2016). Roma settlements are characterized by disenfranchised housing, abandonment and discrimination from the local city government, lack of waste management, absence of running water, and limited access to community resources

(Miranda et al., 2019). The negative impacts on their health are manifested in a shorter lifespan and a lower self-perceived health status compared to non-Roma populations (La Parra, Gil González, & de la Torre, 2016). The 10-15-year shorter lifespan has forced earlier patterns of adulthood. Many government policies and practices have cast Roma as helpless and inferior beings who are unable to integrate successfully into the social fabric (Chang, 2018; Matache, 2017), resulting in the exclusion of Roma from the labor market and other aspects of society. As a response to these injustices, Roma people have created alternative economies and have built a cohesive group identity (Sardelić, 2017).

The World Health Organization has urged scholars to move toward a social determinant of health (SDH) perspective. This perspective recognizes the avoidable health inequalities caused by contextual factors such as unfair housing, unemployment, low educational levels, and decreased access to health care (Marmot, 2005). In 2005, the SDH perspective inspired the Decade of Roma Inclusion (ISC, 2005). This was the first political commitment among European governments to address discrimination and the gap between Roma and non-Roma in terms of education, housing, employment, and health. Nevertheless, in 2010 the European Commission (EC) admitted to the failure of this initiative. The main conclusions were that the funds were not being used properly. Roma civil society was not involved in the development and implementation of policies and there was poor commitment from local institutions and stakeholders (Brüggemann & Friedman, 2017). Today, a decade later, 80% of Roma continue to live in extreme poverty (European Union Agency for Fundamental Rights, 2018). Persistent evidence reflects the failure of top-down approaches to Roma health policy design and evaluation, a lack of political accountability, and the tokenized participation of Roma communities (Escobar-Ballesta, Garcia-Ramirez & de Frietas, 2018).

Institutions and scholars stress the need to mobilize towards an approach that guarantees Roma leadership as political agents, challenges dominant discourses of health policy design, and develops social and political responsibility (European Commission, 2018). This optimum approach would be one “where communities articulate their interests, exercise their legal rights, meet their obligation and mediate their differences” (UNDP, 1997, p. 12). The next section will describe a meaningful community advocacy strategy that responds to the challenges of Roma health policies, illustrated in three contexts/neighborhoods in Seville, Spain.

### **Building Meaningful Community Advocacy**

Community psychology offers a fundamental perspective for approaching the challenges facing Roma health policies through its principles of social justice and psychological and political empowerment. Social justice postulates that all citizens should be treated fairly by all social systems and should have full access to quality community resources (Prilleltensky, 2019). As will be described in the proceeding section, the conditions in which the Roma population live in Spain are quite far from those ideals.

Community psychology underscores the meaningful participation of communities in health policies, designing interventions to address inequities, and building collaborative capacity among multiple agents of change (Escobar-Ballesta et al., 2018; Nelson, 2013; Suarez-Balcazar, 2020). Garcia-Ramirez et al. (2011) described how a group of Moroccan migrant women increased their level of well-being by taking effective actions to overcome oppressive conditions in the communities of Southern Spain. Albar-Marín and Miranda (2019) illustrated how healthcare providers developed the capacity to advocate at the policy level for Roma rights and prevent discriminatory practices. In summary, these lessons learned call for meaningful community advocacy strategies that allow the reconstruction of minority narratives built on their



own priorities, through psychological and political empowerment (Toporeck, Lewis, & Crethar, 2009).

Meaningful community advocacy gives ethnic communities the conviction that they are politically active members who can contribute to effectively reversing health inequities (Suarez-Balcazar, 2020). Through meaningful community advocacy, communities develop conviction that they can advocate for themselves, by learning and developing skills to do so (Glidewell, 1984). These processes include building stable relationships between community members, providers, and scholars, while building the community's capacity to create social changes (Jason, Beasley, & Hunter, 2015). In Figure 1 we present the main components of our process: (a) building local narratives of how the community's poorer health is tied to their disenfranchised living conditions; (b) expanding their local allies and networks and (c) implementing multi-level advocacy actions for building fair, cohesive, and healthy communities.

[Insert Figure 1]

### **Building local narratives of health inequities**

The role of community psychologists is to create a space for community members to use their own voice to identify and analyze issues that matter to them (Suarez-Balcazar, 2020). In order to develop critical awareness, communities must give meaning to their daily experiences and link those experiences to the underlying discriminatory structures that sustain their unfair living conditions (Suffla, Seedat, & Bawa, 2015). Communities can further analyze the cause and effects of discrimination by gathering evidences in order to build local narratives of health inequities and health equity based on their own experiences. This local narratives serves as a guide to set their advocacy goals and objectives, and a baseline for evaluation and monitoring (O'Connell, 2007).

### **Expanding their local allies and networks**

Based on the community's objectives, we must identify decision-makers and community influencers who shape local policy agendas. In order to gain the capacity to influence decision-makers, communities should increase their social support by identifying allies with similar values (Sarason, 1972; Wickes, Hipp, Sargeant, & Homel, 2013). Allies can range from informal ties that have a direct contact with the wider community—such as local religious leaders or grassroots organizations—to those allies working in larger non-governmental organizations, coalitions, community-based organizations, and other service providers from public institutions. Together, communities and their allies can gain a voice by exchanging skills, sharing resources, and defining a common goal. Communities and their allies should create a strategic timeline for their actions based on a contextual and political landscape to ensure their relevance and the opportunity to be heard.

### **Implementing multi-level advocacy actions**

Systemic changes require a multi-level approach that can influence policy, practice, and attitudes that are rooted in health inequities. Community psychology proposes a set of tactics for meaningful community advocacy. These include citizen involvement, collective action, citizen mobilization, and culture change (Paloma, García-Ramírez, & de la Mata, 2010). Building a common agenda, with a combination of short-term and long-term actions, will help maintain the momentum for real change, strengthen the relationship between allies, preserve the pressure on decision-makers to respond, and ensure the sustainability of efforts.

### **Methods**

We present the initiative titled “Roma Advocacy for Health in At-Risk Local Context in Sevilla” (*RoAd4Health*) financed by the Open Society Foundations. The main objective of

*RoAd4Health* was to promote advocacy processes grounded in a Community-based Participatory Research approach, led by Roma agents of change in three contexts. These three contexts exemplify the historical discrimination suffered by Roma and reflect different strategies of marginalization. The university-community partnership (henceforth, “the partners”) was comprised of researchers from the Center for the Study of Health, Power and Diversity at the University of Seville (the research partners); representatives from an influential Roma organization; a local Roma community leader from a grassroots organization, Studio 41013; and the local primary healthcare centers directors. The partners had a trajectory of collaboration in other projects aimed at Roma policy evaluation.

### **Contexts**

The study took place in three contexts located on the outskirts of Seville, Spain: Polígono Sur (PS), Torreblanca (TB), and El Vacie (EV). PS and TB are neighborhoods of Seville with high Roma populations and are among the poorest neighborhoods in the country (Instituto Nacional de Estadística, 2019). Meanwhile, EV is the oldest Roma settlement in Europe and is hidden within the city of Seville. Over the years, the inhumane living conditions of the settlement have become part of the city’s norm.

### **Participants**

The partners nominated potential residents to participate through contacts with grassroots organizations and institutions. The following criteria were established for eligibility to participate: (a) self-identified as Roma, (b) the resident had a positive relationship with a local organization or institution at the time the study was conducted, and (c) demonstrated leadership capacity (history of engaging in leadership efforts). Eight nominated candidates from each neighborhood described above were interviewed by the partners to gain a deeper understanding

of their motivation and capacity to influence change. A total of 24 residents were interviewed and 14 were recruited. We refer to these participants as *agents* (agents of change) in the remainder of this paper. These agents reflected the diverse sociodemographic realities of the neighborhoods. The group was comprised of 11 women and 3 men, ranging in age from 16 to 51. Thirteen of the agents had lived in their respective neighborhoods their whole lives.

## **Procedure**

We present the methodologies utilized in each of these phases of the model. These three phases included building local narratives of health inequalities, expanding social networks and building alliances, and implementing multi-level advocacy actions.

### **Building local narratives of health inequities**

This is a collaborative process of knowledge creation that promotes individual and collective sociopolitical empowerment through developing narratives of local Roma health inequities and possible solutions. Following a photovoice methodology, agents gathered evidence through photographs, and shared their narratives and articulated their health concerns through the photos taken. The partners facilitated dialogue utilizing the SHOWED methodology (see: Wang & Burris, 1997) to collect residents' narratives. The sharing, which took place during two meetings, was followed by agents grouping photographs into categories based on similarities between them.

The agents proceeded to analyze the causal and contextual factors by clustering categories into subthemes and then overarching themes (Foster-Fishman, Law, Lichty, & Aoun, 2010). Utilizing their narratives, the agents converted the messages into objectives of their advocacy efforts in the initiative. The research partners and residents developed a PowerPoint presentation and a report of their findings that served as a basis for advocacy actions.

### **Expanding social networks and building alliances**

Along with the photovoice method, we implemented community organizing strategies to bring people together to build community power to solve local problems on their own terms. These community organizing strategies as proposed by Christens and Speer, (2015) included: (a) relationship development, (b) participatory research, (c) action or mobilization, and (d) evaluation and reflection. Aligned with these strategies, we chose community asset mapping as a participatory method that would allow the agents to assess local relationships and resources, identify allies for advocacy, and engage in meaningful spaces to gain local support from others (Kretzmann & McKnight, 2005). In collaboration with the partners, the agents decided to develop a brief community survey to identify local community health assets. The survey included a short list of local institutions (primary healthcare centers, social services, schools, employment offices), community-based organizations (including Roma, non-Roma, faith-based, and other types of organizations), outdoor spaces (squares, parks), and nearby restaurants and shops. The research partners assisted the agents with data collection and data analysis. Following a convenience sample strategy, a total of 200 surveys were collected in each of the three-participating neighborhoods. Surveys were collected at supermarkets, faith-based organizations, and local community agencies. Roma residents were asked to identify assets, rate assets, and rate the quality of the asset using a Likert-type agreement scale. Once assets were identified they were mapped by the agents of change.

Through the mapping process, the agents identified meaningful Roma spaces that could serve as spaces to build meaningful community advocacy as well as leaders who could act as potential allies. The university and the community partners supported agents in building alliances with these identified assets through meetings and organized events in community spaces. The

community partner, Studio 41013, organized one-on-one meetings with leaders representing the settings, spaces, and organizations identified as strengths and most frequented by Roma residents. This allowed the research partners to engage in these meaningful spaces with community leaders, agents of change, and organizational partners. Finally, the directors of local healthcare centers supported the research partners in organizing workshops to raise support for an awareness about advocacy efforts among health care providers.

### **Implementing multi-level advocacy actions**

In order to address the structural nature of health inequities, this phase consisted of implementing advocacy plans across interpersonal, organizational, community, and institutional levels. At the interpersonal level the partners supported the agents in building a sense of identity and cohesion in order to strengthen group efficacy for representation in multiple settings. At the organizational level, research partners facilitated meetings between the participants, social services, and healthcare centers in order to expand their local networks, share evidences, and consolidate an action plan. The research partners and agents organized themselves to identify funding opportunities to create a formal organizational structure to advocate for Roma health. At the community level, partners facilitated community mobilizing strategies to raise awareness (i.e. campaigns and cultural events). At the institutional level, the agents and partners developed an action plan aimed at the City Council and redefined a common agenda with multiple stakeholders to contact local representatives. Finally, the researchers translated the agents' local agenda through participation in policy planning meetings within local, national, and European institutions.

## **Results**

### **A Local Narrative of Roma Health Inequities through Photovoice**

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4 During the photovoice sessions, the 14 agents of change grouped their photographs into  
5 themes/categories. Agents proceeded to cluster the categories into twelve subthemes which were  
6 then clustered into overarching themes that included the following: (a) neglect by public  
7 services, (b) discrimination, (c) normalized undignified living conditions, (d) lack of Roma  
8 presence in decision-making spaces, and (e) psychological problems. In Table 1, we present the  
9 photovoice data analysis that reflects the themes with their corresponding subthemes, quotes, and  
10 brief photograph descriptions. Next, we will describe each of the themes with a numbered  
11 reference corresponding to the quotes in Table 1.  
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23 [Insert Table 1]  
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#### 26 **a. Neglect by public services**

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28 The agents of change expressed through photos and reflections that the areas where they  
29 lived were neglected by public services. All three groups of agents expressed concern about the  
30 trash that had accumulated near their homes [1.1]. Photographs of overflowing trash bins were  
31 the most common health hazard in all three neighborhoods. The city's waste management had  
32 provided only one large waste container per neighborhood. Some of the photographs reflected  
33 that Roma residents had created trash points in their neighborhoods as an alternative, typically at  
34 street corners. Yet, this had attracted more rodents and insects to the area than usual [1.2]. The  
35 participants were told by the municipality that the waste management vehicles were too large to  
36 enter the settlement, and, therefore, the problem was left unresolved.  
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#### 50 **b. Discrimination**

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52 Agents of change interpreted the lack of institutional responsiveness to their concerns as  
53 discrimination. For instance, photographs of overgrown plants and shrubs near the homes of  
54 Roma participants were interpreted as the lack of institutional responsiveness towards the local  
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Roma community [2.1]. For example, PS had photographs of fecal waters in outdoor communal spaces through which many of the neighbor's children passed on a daily basis. Roma residents were consistently ignored when expressing their concerns about waste management to the local city housing office.

Agents of change shared other instances of discrimination. For instance, one TB agent described an experience with the principal of the elementary school her children attended. The principal had publicly humiliated her and other Roma mothers because of how they were dressed and consequently, they were not allowed to enter the school building [2.2]. These types of experiences of mistreatment by those in position of power were recurrent in the dialogue among agents when discussing their photos.

### **c. Normalized undignified living conditions**

Participants acknowledged that they had normalized the poor living conditions [3.1]. Not until they photographed and discussed their concerns with the other residents, did they realize the unfairness of their living situation. For example, TB participants decided to take photographs to compare the Roma and non-Roma areas. The photographic evidence was drastically different. Non-Roma areas had trash and recycling bins on every block. Some blocks had water fountains while Roma neighborhoods did not. In some cases, Roma residents had assumed the blame for their living conditions. The situation was not only normalized but internalized as their fault [3.2]. EV residents had learned to survive in the extreme poor conditions in the settlement.

### **d. Lack of Roma presence in decision-making spaces**

Agents of change from the El Vacie neighborhood expressed no sense of belonging and wanted to leave their neighborhood as soon as possible due to the extreme poor living conditions. They shared stories of negative treatment by social services and the lack of knowledge regarding



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4 the housing reallocation process that had been implemented by the City Council. According to  
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6 the agents, they could not engage in any activity that would jeopardize leaving EV, and this  
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8 included basic requests such as trimming the overgrown shrubs that were causing infestations of  
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10 insects or fumigating the insects [4.1]. EV agents were hostages in this situation, and the need for  
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12 allies to represent them at the institutional level was discussed at the residents' meetings.  
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16 Although the City Council was developing a new urban plan to improve neighborhood  
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18 conditions, there was no knowledge of Roma presence—residents or Roma organizations—  
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20 representing the voice of the community.  
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### 23 **e. Psychological concerns**

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26 In all three neighborhoods/contexts, the agents referred to mental health concerns that  
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28 developed as a result from their living conditions. For example, EV Roma residents were in  
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30 constant tension; they were afraid to speak to each other because they never knew whether the  
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32 other person might react violently even to simple comments or questions about the neighborhood  
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34 [5.1]. Agents referred to the safety and wellbeing of children and older adults, and how both  
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36 groups were the most effected by the living conditions. Older Roma adults rarely left their homes  
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38 and children were sent to schools outside their neighborhood, if possible, to seek healthier and  
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40 safer spaces [5.2]. All the EV agents shared similar stories of the unsanitary conditions and how  
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42 this had led to a sense of hopelessness, anxiety, and fear [5.3].  
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49 Based on the data collected and issues identified—through photovoice, reflections that  
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51 followed, and survey data from the asset mapping—each neighborhood developed a set of  
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53 objectives for advocacy plans. Specifically, in the PS neighborhood the objective was to dignify  
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55 Roma people's living conditions by gaining local institutional support to improve environmental  
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57 conditions; and in the TB neighborhood, the objective was to develop a sense of belonging in  
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4 their neighborhood through Roma representation in local plans. In the EV neighborhood the  
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6 objective was threefold: to find allies to represent residents, to report the unjust living conditions  
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8 as a violation of human rights, and to advocate for transparency to the city government in the  
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10 process of reallocating families to another neighborhood.  
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### 13 14 **Expanding Local Allies and Networks through Community Mapping**

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16 The mapping process revealed that Roma grassroots organizations that were  
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18 geographically close to the agents' homes were identified as allies, as well as schools that were  
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20 collaborating with Roma organizations. Local bars and neighborhood plazas were identified as  
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22 assets and spaces that were frequented by Roma residents, in which neighbors spend most of  
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24 their time engaging with one another and sharing their day-to-day experiences. In the PS  
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26 neighborhood, government services such as the employment office, housing office, social  
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28 services, and the local administration office were rated by residents as weaknesses, not assets,  
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30 and the lowest in quality compared to other settings. TB agents identified the Red Cross as the  
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32 only asset in the neighborhood; they had no local allies in community-based organizations.  
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34 Despite the presence of a community center in the TB neighborhood, there were no programs  
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36 being implemented that were of interest to the Roma community. In this community the  
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38 neighborhood plaza was often used by residents to socialize.  
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46 In the EV neighborhood, one organization was identified that provided childcare, basic  
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48 resources for mothers, and after-school programs for children. The local grocery store and social  
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50 services were the most frequented assets according to the mapping data. The grocery store served  
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52 as a meeting point for informal economy while the social services within the neighborhood  
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54 supported families' actions within the housing reallocation process.  
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4 In all the neighborhoods, the residents identified the Evangelical churches as the most  
5 frequented and valued setting; therefore, they sought to develop alliances with religious leaders  
6 in these settings. The community partner from Studio 41013 coordinated meetings with  
7 Evangelical church leaders and representatives from community-based organizations in order to  
8 discuss the project and open new possibilities for collaboration. A total of seven meetings were  
9 held with pastors from Evangelical churches and other influential community leaders at local  
10 cafes near PS and TB. Research partners were invited to attend the religious services in all three  
11 contexts and share the project objectives with church leaders. These encounters cultivated trust  
12 between researchers and the community, helped to redefine alliance, and gained the support of  
13 influential community leaders.  
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28 During the photovoice and community mapping process, the partnering organization  
29 revealed they did not want to partake in local advocacy because of conflicts of interest with the  
30 City Council. Agents stated that they needed to seek alliances with other Roma or non-Roma  
31 organizations that would be willing to challenge these institutionalized structures. This led to a  
32 stronger connection among agents from all three different contexts, supporting each other's  
33 advocacy efforts.  
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43 Partnering healthcare center directors in the three contexts identified potential allies  
44 within their centers. Five providers in each center were identified as sensitive to Roma needs. A  
45 total of 15 providers engaged in a workshop. In this workshop, the providers discussed the health  
46 issues that were common in their healthcare centers and identified environmental issues as a  
47 health priority. Participants were committed to continue collaborating in future advocacy efforts  
48 with partners and agents of change (see Albar-Marín & Miranda, 2019).  
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### 57 **Implementing Multi-Level Advocacy Actions through Collaboration**

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In the following section, we present the results by interpersonal, organizational, community, and institutional levels. These results were not necessarily linear but concurrent with one another.

### **Interpersonal level**

The agents expressed their need to meet with each other to reflect on the similarities and differences from the three contexts and consolidate an advocacy plan. Therefore, the researchers facilitated two meetings at the University. The 14 agents, 6 researchers, and 5 Roma organizational representatives attended these meetings. In these meetings, the group shared narratives about the following: (a) Roma people were blamed by the city and society in general for their living conditions; (b) waste management pickup schedule was not taking place as planned by the city and communicated to residents; (c) each neighborhood had a small group of residents that generated a sense of insecurity due to inappropriate behaviors; (d) living conditions were affecting children and communities' mental health; and (e) the extreme unfair living conditions of EV required comprehensive advocacy and system level changes. These meetings consolidated a common goal and helped neighbors build a common narrative around their shared experiences. PS and TB agents shared their solidarity with EV agents and committed to supporting and representing them in joint advocacy efforts. The agents shared their contact information and committed to a follow-up meeting. Both the PS and TB agents developed their own logo and group name to consolidate their local identities. Through this new network, the agents requested technical support from the research partners in order to seek continued funding for sustainable advocacy efforts. The residents took steps towards officially organizing themselves in a community-based organization, legitimizing their presence in local policymaking spaces, and allying with members of the Roma State Council. Researchers and agents continued

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4 their collaboration designing actions aimed at addressing the local agendas once the project  
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6 concluded.

### 9 **Organizational level**

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11 The agents from PS and TB met with the local healthcare center providers to share their  
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13 narratives, photos, and mapping of assets, and to triangulate such evidence with providers'  
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15 epidemiological data. The residents' analysis was confirmed by the provider's analysis from  
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17 their respective healthcare centers—alarming rates of anxiolytic prescription medication, mental  
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19 health problems, domestic accidents, and frequent incidences of rat and insect bites were  
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21 reported. Together the agents and providers developed a report for each neighborhood with  
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23 complementary information. Reports were utilized by the providers to advocate for institutional  
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25 support for Roma-sensitive protocols and to be recognized for their efforts as sensitive providers.  
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27 The Roma-sensitive protocols were included in an in-service training program for health  
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29 professionals.

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36 PS agents contacted local school professionals in order to triangulate information with  
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38 incidences caused by environmental factors (i.e., rashes, bites, etc.). Both PS and TB planned a  
39  
40 watchdog effort to monitor waste management. This effort included meeting with their  
41  
42 respective local waste management offices to receive a copy of the cleaning and trash pick-up  
43  
44 schedule for their neighborhoods and begin observing and monitoring weekly pick-up routes.  
45  
46 Partners, agents, and health providers defined a common agenda that was linked to  
47  
48 environmental factors as the main priority. The actions included developing a written report and  
49  
50 including the photovoice and mapping evidence to gain wider support from the healthcare  
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52 district, waste management, and City Council.

### 53 **Community level**

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4 The agents of change organized two local campaigns in PS and TB to collect additional  
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6 evidence from other residents and raise awareness regarding their local narratives of inequities,  
7  
8 utilizing the photovoice results. These campaigns were located in spaces with a large volume of  
9  
10 Roma movement at specific times of the day identified in the community mapping. Participating  
11  
12 agents explained their group's purpose to other Roma residents, developed short surveys to  
13  
14 identify new priorities and other interested community members. This was an opportunity for the  
15  
16 agents of change to increase their capacity to articulate their concerns, consolidate their group  
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18 identity, and expand their local networks. The majority of Roma residents agreed that there was  
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20 an urgent need to prioritize environmental issues.  
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26 The community partner from Studio 41013 organized a cultural event that mobilized PS  
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28 Roma residents to engage in community Flamenco events. These events, called *3000*  
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30 *Descencias*, engaged a high volume of Roma residents in a voting process to elect their favorite  
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32 local artists to partake in a citywide show. This shifted the use of communal spaces towards  
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34 healthy activities, which resulted in catalyzing mass participation of Roma residents, local  
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36 policymakers, and providers. Currently, Studio 41013 is seeking continued funding to utilize  
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38 cultural events as a means to increase participation.  
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### 43 **Institutional level**

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45 The research partners accompanied EV agents in confronting the City Council structures  
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47 that controlled the housing reallocation plan. A meeting with social service representatives was  
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49 held to present the report that contained the agents' evidence. The City Council was investing  
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51 resources towards reallocation and allowed the neighbors to continue living in these extreme  
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53 conditions as they waited for months—in some cases, years—for a new home. This violation of  
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55 rights drove the partners to write a letter to the ombudsman denouncing the situation. The  
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ombudsman proceeded to invite agents of change and residents to present their evidences to the City Council and invited the partners to take part in the housing reallocation committee. The research partners were invited to form part of the Sevilla City Council of urban planning for 2030. This plan is aimed at improving the living conditions of areas all three neighborhoods.

At the national level, the partners identified other allies and sought funding in five different Spanish regions. This project is aimed at building the capacity of Roma organizations to incorporate strategies for participatory action research for advocacy within their programs. Recently, the Roma State Council committed to incorporating actions that were identified by the community partnerships: highlighting Roma health assets, ensuring the real participation of individuals and communities, including a health equity perspective, and building Roma capacity to influence change. Finally, the research partners were invited to attend Roma health meetings in two European institutions to include project results in upcoming policy agendas.

### **Discussion**

We have presented a meaningful community advocacy strategy that facilitated the psycho-political empowerment of Roma communities to advocate for health equity in their neighborhoods. Our study took into account the political nature of the social determinants of health and promoted collaboration among multiple stakeholders by empowering the voice of Roma communities for health governance. First, our results revealed that the dominant social structure maintained a discriminatory and oppressive role, causing health inequities and silencing the voices of the Roma community. Accordingly, traditional approaches to health governance use processes that control and co-opt Roma voices, or what the agents identified as being “silenced” and “not represented” (Baez-Camargo, 2020; Vermeersch & Van Baar, 2017).

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4 Meaningful community advocacy promotes multiple voices and legitimatizes the narratives of  
5  
6 Roma people highlighting what works, for whom, and in what circumstances.  
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9 Through photovoice and critical dialogue, agents of change were able to develop a  
10 narrative of their health inequities. Their narrative was consistent with those obtained from  
11 different methodologies (La Parra et al., 2016) and described by others in other contexts  
12  
13 (Escobar-Ballesta et al., 2018). Beyond the findings—and as an added value—participants raised  
14  
15 a strong critical awareness of how the abandonment of protection systems is not coincidental and  
16  
17 how they had internalized oppressive narratives. When the agents compared their living  
18  
19 conditions to those of non-Roma residents, their self-blame transformed into anger and  
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21 frustration, and later that anger and frustration transformed into a sense of entitlement.  
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25 We applied community mapping to identify health assets that were hidden from formal  
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27 structures. This highlighted the respect felt by the community for some public services, but  
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29 mostly grassroots and faith-based organizations. The assets were gatekeepers to other types of  
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31 services, and had the potential to disseminate information and coordinate collective actions.  
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33 Through community advocacy actions, local communities must be considered essential  
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35 stakeholders instead of beneficiaries of health services (O’Connell, 2007).  
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39 Our study revealed limitations to meaningful advocacy that should be addressed in future  
40  
41 initiatives. First, in order to ensure that local communities are the central stakeholder we must  
42  
43 take a step further in legitimizing their knowledge as evidence. For example, neighbor’s mapping  
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45 assets should be transferred into quantifiable data for a social network analysis to guide policy,  
46  
47 research, and community development (Maya-Jariego, 2018). Social network analysis based on  
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49 citizen knowledge can provide a monitoring system that engages local communities to ensure  
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51 transparency between formal and informal networks.  
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4 As the participation of agents of change increased, or the “participation of citizens in  
5 local public life” (Council of Europe, 2018, p.1), we revealed other limitations such as the  
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7 conflicts that arise from opposing research agendas, lack of organizational funding, existing  
8  
9 power structures, and dominant ideologies. To address these complex issues, we included  
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11 grassroots organizations in the initiative. However, these organizations were fragile structures  
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13 due to their lack of sustainable funding, slowing down the momentum of continued efforts.  
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15 Future initiatives should explore new ways of redefining the role of organizations and their  
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17 relationships to the citizens they represent. Lastly, the low number of agents of change that were  
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19 involved limited the diversity of entry points into the community. The diversity within ethnic-  
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21 based communities requires tapping into different actors in order to ensure that we do not  
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23 replicate homogenizing their priorities and further silencing hard-to-reach layers.  
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31 In summary, our experience offers insights for conducting community psychology in the  
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33 field of public health policies. First, it highlights the unquestionable relevance of having  
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35 community residents as co-researchers and meaningful partners rather than passive users  
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37 (Suarez-Balcazar, 2020). This reinforces their conviction that they make decisions; they are  
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39 influential; they matter (Prilleltensky, 2019). Second, community psychologists should deeply  
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41 reflect on what we understand as evidence in policy design (Canavan, 2019). Our experience  
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43 highlighted that evidence for effective policy should be observed at the intersection—and not in  
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45 the juxtaposition—of three conceptual domains (i.e. policy and practice, science, and rights and  
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47 values). In this process, communities must have undisputed leadership, because it rightfully  
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49 belongs to them. Lastly, overcoming ethnic minority health inequities requires understanding  
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51 health governance based on the rules of formal and informal networks that distribute roles,  
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53 define practices, and shape collective behaviors to achieve effective health outcomes (Baez-  
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4 Camargo, 2020). This requires scientific evidence-based policies that are respectful of  
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6 democratic rights and freedoms. Ethnic health inequities are multiple, intertwined, and complex;  
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8 therefore, all key actors must abandon their comfort zones to achieve a common discourse and  
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10 share goals; establish alliances and partnerships based on trust and respect; and engage in actions  
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12 for which they are accountable. Community psychologists are called to play a key role in this  
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14 global challenge.  
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Figure 1. A Strategy for Building Meaningful Community Advocacy

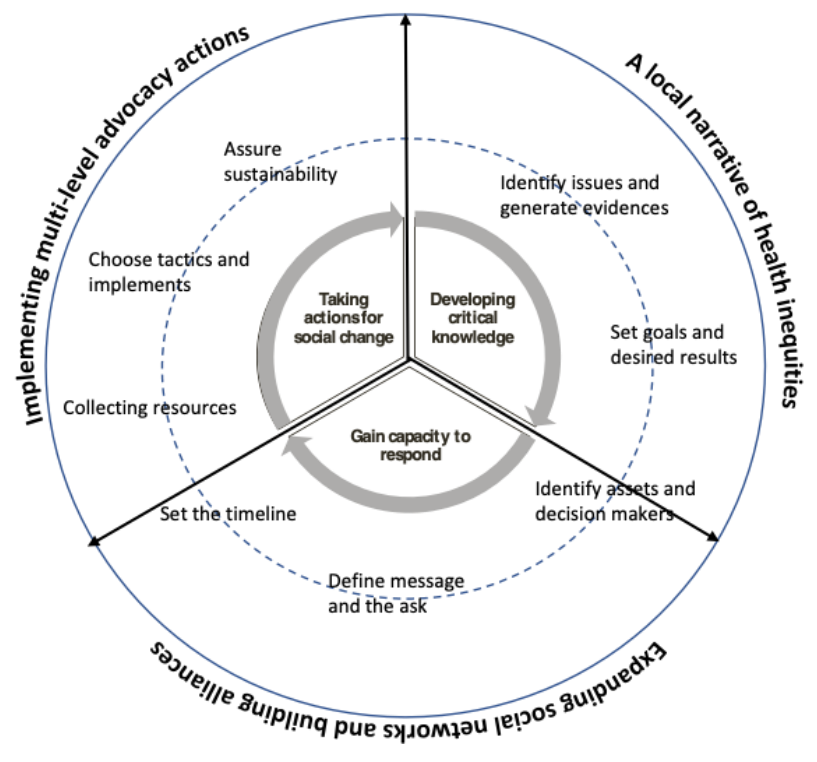




Table 1

*Results from the photovoice analysis*

|   | Themes  | Subthemes          | Ref | Photovoice Narratives (evidences)  | Example Photos*  |
|---|---|--------------------|-----|--|--|
| 1 | Neglect by public services                      | Abandonment        | 1.1 | <i>“The neighborhood is terrible because it is so dirty. You know? Here, they never clean, there is trash everywhere, sometimes you cannot even walk anywhere because of it...”</i> (Participant PS)   | Trash bags surrounding trees                                   |
|   |   | Unkept spaces      | 1.2 | <i>“...there are always so many insects, rats. They never come to fumigate here”</i> (Participant PS)  | A child’s hand with flea bites                                 |
|   |   | Lack of investment | 1.3 | <i>“I have to take my children to the other side of the neighborhood because our park is dirty and empty. It is a sad place for a child to play. In the other park where non-Roma live, there are slides, benches to sit on, and water fountains”</i> (Participant TB) | An empty park with a broken playground                         |
| 2 | Discrimination                                  | Unheard            | 2.1 | <i>“The shrubs are overgrown and have been for years. Like this, many things. We’ve called and asked, but they (public services) do not listen.”</i> (Participant PS)  | Shrubs grown over a bench                                      |
|   |   | Humiliation        | 2.2 | <i>“She (the principal) told us that we could not go inside the school the way we were dressed; at first we were all humiliated but one of the women went in and spoke to her later that day, asking her to apologize to us”</i> (Participant TB)                      | Broken glass and a dog lying in the middle of an unkept street |
| 3 | Normalized undignified living conditions        | Habitual           | 3.1 | <i>“There is so much trash, but it is normal for us. I have lived here my whole life. Until someone comes from outside the neighborhood and points it out, I do not even notice it anymore”</i> (Participant PS)   | A video of rats near piles of trash next to a neighbor’s home  |
|   |   | Self-blame         | 3.2 | <i>“Some neighbors are really dirty, especially other Roma neighbors. My street is the cleanest compared to the others in the area, because there are some non-Roma living there”</i> (Participant TB)   | A street near a neighbor’s home with broken infrastructure     |
| 4 | Lack of Roma presence in decision-making spaces | Silenced           | 4.1 | <i>“If we go speak to social services, we cannot complain too much because we do not know if this would put us at the end of the list for a new home”</i> (Participant EV)   | A broken waste container with piles of waste in and around it  |
|   |   | No representation  | 4.2 | <i>“Organizations only exist in the non-Roma part for the non-Roma, we do not have anything here except the Red Cross, which provides food and milk every once in a while...”</i> (Participant TB)   | Recycling bins from the non-Roma area of the neighborhood      |
| 5 | Psychological problems                          | Anxiety            | 5.1 | <i>“We are scared, living in tension. We cannot talk to our neighbors. Even when you ask for something nicely, you never know how angry they might be”</i> (Participant EV)  | Large piles of old garlic near neighbor’s home                 |

|            |     |  |   |
|------------|-----|--|---|
| Depression | 5.2 | <i>“Living here and seeing my neighborhood makes me depressed, our children have nowhere to go. I make sure that my daughter goes to school outside the neighborhood and spends the least amount of time here.”</i> (Participant PS) | Fecal waters in the entrance to a neighbor’s building |
| Fear       | 5.3 | <i>“As a child, I could not sleep at night because the rats would bite my fingers. My dad would stay awake at night to make sure that the rats would not come into our bed”</i> (Participant EV)                                     | A hole in the ceiling where a rat had fallen through  |

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