Developing A Multi-Level Advocacy Framework for Roma Health at the Local Level

A dissertation presented by

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to my mother and father

Por el olivar venían,
bronce y sueño, los gitanos.
Las cabezas levantadas
y los ojos entornados.

Cómo canta la zumaya,
¡ay cómo canta en el árbol!
Por el cielo va la luna
con un niño de la mano.

Dentro de la fragua lloran,
dando gritos, los gitanos.
El aire la vela, vela.
El aire la está velando.

-Federico García Lorca, Romance de la luna, luna

"The engaged voice must never be fixed and absolute but always changing, always evolving in dialogue with a world beyond itself"

-bell hooks, Teaching to Transgress

Abbreviations and Acronyms

CBPAR	Community-based Participatory Action Research
EC	European Commission
EPHA	European Public Health Alliance
EU	European Union
IOM	International Organization for Migrations
FRA	European Union Fundamental Rights Agency
NGO	Non-governmental organization
NRIS	National Roma Integration Strategies
NRIS-H	National Roma Integration Strategies health component
OSF	Open Society Foundations
WHO	World Health Organization

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Abstract

Romani communities are Europe's largest ethnic minoritized group. The specific racism towards Romani communities—known as antigypsyism—has permeated historical socio-political structures that have denied Romani their rightful recognition as political subjects. Today, antigypsyism is reflected in the EU and national health policies known as the National Roma Integration Strategies Health Component (NRIS-H). It has been widely recognized that the NRIS-H was developed "for Roma, without Roma". The pre-established Eurocentric policy processes and traditional research methodologies have sustained Romani communities in marginalized conditions. The ramifications have been that Romani are blamed for their living conditions and deemed helpless, which has contributed to a negative stereotype that further excludes Romani from decision-making spaces. I propose that multi-level advocacy for Romani health justice can mediate a psycho-social-political empowerment journey with the objectives of: (1) building collaboration between multiple stakeholders at the local level, (2) building advocacy capacity among health professionals and organizational managers, (3) co-creating knowledge among a group of Romani neighbors, and (4) advocating for health justice of Romani communities. Inspired by community-based participatory action research tools, I address antigypsyism through (1) positionality and reflexivity, (2) interactive knowledge production, and (3) accountability to communities. The results are presented in a series of peer-reviewed publications. Finally, I present lessons learned to support the integration of multi-level advocacy phases as we move forward with new Romani social policies, for and with Romani communities.

Motivation

I am a first-generation, bilingual, Latina American, raised in the United States. My father is Cuban, he arrived in the United States when my grandparents fled Cuba in 1960 after the revolution. He became a successful engineer, a testimony of the renowned "American dream." My mother is from Caracas, Venezuela, she moved to the United States in her early 20s when she met my father. My mother chose to dedicate her life's work to her family and home, raising my two brothers and me. Our family comes from generation after generation of immigrants, some fleeing political upheaval and others because of a personal choice tied to new possibilities and opportunities. My story is an immigration of privilege. I was raised in the white, upper middle-class suburbs of Houston, Texas and later received my undergraduate Psychology degree from Boston University. In my early 20s, I chose to move to Spain to improve my Spanish and later stayed to continue my graduate studies. It was not necessarily an intentional choice that I immigrated to Spain, but rather inertia as I continued the pattern of the generations before me.

Looking back as I write this, this journey was catalyzed by my persistent need for meaning making, which still accompanies me today. It is important that I contextualize this for you because who I was and the perspective in which I began my research in 2015—the questions, assumptions, positionality—is drastically different to the perspective I have now. The research process was transformational for me, over and over again. My dissertation is a testament to that journey. It is also important that I highlight from the beginning that all of the knowledge in this document has been co-created between a group of Romani neighbors living in Sevilla, Spain and I—a white, upper middle-class Latina researcher from the United States.

Romani are Europe's largest minoritized ethnic community, with an estimated 12-15 million Romani people spread across the continent. It is estimated that about 80% of Romani people live in absolute poverty (FRA, 2018). In Spain, there are 750,000 Romani people with about 50% living in Andalucía, the context of my fieldwork. When I began my research in 2015, Europe had finalized what was known as the Roma Decade (2005-2015), a transnational political commitment that aimed to promote the inclusion of Romani. The National Romani Integration Strategies was an important outcome of the Romani Decade in which European member states developed Romani-targeted policies at the national level. These policies included goals within education, employment, housing and health. Member states, including Spain were involved in evaluating the impact of the National Romani Integration Strategies health component (NRIS-H). As a result, a report was published that showed that there had been little impact on improving Romani health status in Spain compared to non-Romani populations (La Parra Casado et al., 2016)).

About the time Europe had finalized the Roma Decade, I was enrolled in the Masters in Psychology of Social and Community Intervention at the Universidad de Sevilla, as well as volunteering at a non-governmental organization (NGO) in El Vacie, one of the oldest Romani settlements in Europe. I had little to no knowledge about Romani communities at that time except the unfortunate, persistent stereotypes that I had grown up with. Romani people are a significant part of Spanish history and culture, yet their impact has been ignored, hidden and diminished through the eyes of white Europeans. That was the only version I knew at the time—the untrue, harmful version.

When I moved to Sevilla, I was told stories about Romani people, usually from people who had no relationship to them and therefore recounted racist stereotypes and general disdain. I realized this was symptomatic of the real problem: people expected Romani people to live on the margins. It was clear—this fatalistic attitude helped people justify the abandonment of Romani people, making it easier to look the other way, to exclude them from the historical and cultural contributions that belonged to them too. In the eyes of the majority, the Romani people had no claim to a culture that they had helped create.

My role at the NGO was to provide extra educational support to three Romani children, ages 5-7 years old, in the after-school program. During these one-on-one sessions, the children told me their most intimate stories, the setting always the same: a prefabricated home next to a funeral home. I observed how young Romani mothers parked cars for money at the nearby funeral home as their sole form of income. These stories conflicted with my personal experience of Sevilla, a city that had been nothing but warm and welcoming since my arrival. I understood that the NGO was there to provide immediate services to the families—which they did—yet nothing had ever significantly changed. The El Vacie settlement was a symbol of the failure of the Roma Decade. During my time at the NGO, I wondered why El Vacie has been there for so long, with so little change. Why did private organizations undertake the responsibility of providing basic needs to these families? How had the municipal government not supported this community in a more sustainable way? I had met many people who blamed Romani for their living situation who said that "they choose to live this way." This marked an era of anger and urgency in my life, because what I saw in El Vacie were resistant Romani women and children living in circumstances that were impossible to escape, they did not have the privilege of choice.

The professionals I met at the NGO were kind, passionate, and sensitive people who spent years building meaningful relationships with the mothers and children, yet burnt-out from the lack of support and accountability of the local government. The white, non-Gitana professionals spent extra hours invested in providing responsive services to the families and carried an emotional burden that came from their sense of responsibility to El Vacie. The families and children looked to the professionals as their only form of help, dependent on them for many things. It was evident that something was not working—neither for the families or the NGO professionals. The NGO had been there for years. Was this NGO going to be there forever providing mothers with milk or children with shoes? Why was that acceptable? On my way home from El Vacie, I had to walk through the center of Sevilla to get to my apartment. Although the path was beautiful, the walk always felt heavy, because I knew I was crossing over and re-entering my privileged bubble where people chose to look the other way.

Parallel to my involvement at the NGO, I was taking the Fundamental Theories in Community Psychology class with Prof. García-Ramírez where he presented projects his research team at the Center for Community Action-Research at US (CESPYD) were undertaking. At the time, CESPYD was evaluating the NRIS-H to identify the methodological challenges that were impeding policies of having any real impact on the lives of Romani people. I began working with CESPYD with the goal of finishing my Master's thesis in this line of research. During the course of this class and while writing my Master thesis, CESPYD gave me the space to become a critical thinker and learn from colleagues whose research was guided by a sense of urgency as well. I learned to look at El Vacie from a critical perspective, and understand why policies were not working, why the NGO would continue to exist, why the Romani mothers and their children learned generation after generation to survive on the margins. I came to see the power dynamics that were at play. Most importantly CESPYD showed me how to channel my sense of urgency as a privileged student through meaningful research and understand the heavy walks home from El Vacie between two worlds. Since that moment what it meant to do my graduate studies changed, and it was now a deliberate choice to live between the two worlds. It is here where I begin to ask the more complex questions that guided my dissertation and that I continue to still ask myself today.

In 2016 CESPYD was granted funds for a pilot study titled "Follow-up Case Study: Strengthening Romani Participation through Romani Health Governance in Polígono Sur" from the International Organization for Migrations. Polígono Sur was different from what I had seen in El Vacie. Here there were consolidated, and powerful grassroots movements, and a government administration that was there to coordinate services provided by the network of NGOs. Despite the change in setting, the same pattern appeared: sensitive non-Romani professional, programs that had not made meaningful strides, and Romani neighbors that were not involved. I began defining the questions of my dissertation within the frame of this pilot study: How can we create conditions to collaborate between non-Romani health care providers, policymakers, Romani NGOs and Romani people living in marginalized contexts? By the end of this study, it was clear that Romani-targeted strategies were absent from local policies and programs, no one was monitoring the impact of the initiatives, NGOs were the service providers. An important outcome of this study was the relationships we had built between all those involved. These new relationships began to disrupt ways of working in the community, the old way was inadvertently maintaining Romani people in an inferior position and therefore, we had to change it.

The pilot study generated a new series of questions, in which I knew that talking about health equity was not enough, without addressing the social justice issues at hand: how can we change the deep-rooted racism that exists towards Romani? How can we build horizontal relationships between university-researchers and Roma NGOs in privileged positions with a group of Romani neighbors within a system that had obligated us to function within a set of power dynamics? What deliberate actions could we take where Romani neighbors could find strength individually and as a community to fight for their rights? These questions guided the proposal that received funding from the Open Society Foundations Romani Health Initiatives Office. It is in this setting where I began a journey to fully develop my dissertation fieldwork in which I aimed to respond to the following question: *How can Romani people be recognized as political subjects who advocate for transformative policy changes to enjoy health and prosperous lives?*

Language and Keyword Considerations

In my dissertation I will utilize the term "Romani" following the European Parliament document published in 2020. Romani is the umbrella term that refers to the heterogenous minoritized group of Romani population across Europe—from Travellers, to Sinti, Caló, Pueblo Gitano. In this dissertation I recognize that the Romani communities are richly diverse both in the wider European context and within the national contexts, and each have their own unique and specific experiences. In Spain, I have specifically collaborated with Spanish Romani, the Pueblo Gitano communities, who self-identify as *gitano/a*. Throughout the document I will refer to Romani when speaking of the diverse populations across Europe. When referring to the Spanish Romani community, I will utilize the following terms: (1) *Pueblo Gitano* when speaking of the group or

(2) *Gitano/a* (singular), (3) *Gitanos/as* (plural) when utilizing the name as a descriptor following the usage in Spanish.

Following the definition provided by the Alliance Against Antigypsyism (2017), *antigypsyism* is defined as the specific racism that Romani communities face in Europe. Not only does Antigypsyism refer to the negative attitudes in daily life and public sphere, but the systemic racism which is rooted in political neglect, discriminatory practices, and damaging stereotypes. According to the European Commission (EC), antigypsyism is widely recognized as a driver behind the health inequities of Romani communities (EC, 2018).

A *multi-level approach* refers to the ecological framework proposed by Bronfenbrenner (1986) which highlighted the interconnectedness of macrosystems, exosystems, mesosystems and microsystems and how they affect an individual's development throughout the life course. This also includes variables such as context and time that make the multi-level systems everchanging and dynamic. For the purpose of my dissertation, I will be utilizing multi-level to refer to an adapted version of Bronfenbrenner's model, both in regard to the institutions at each level as well as the key agents involved (Bronfenbrenner, 1992). The adaptation includes the following levels that will be echoed throughout the document: institutional (i.e. City Council or regional government, Mayor, government representatives, public housing officials), organizational (i.e. healthcare centers, social services, healthcare providers, nurses, non-governmental organizations), community (i.e. grassroots organization, churches, pastors, local leaders), and interpersonal (family, friends, neighbors).

Dissertation Structure

This dissertation is a compilation of scientific articles and is presented in four main chapters: State of the Art, Methodology, Results, Discussion and Final Conclusions (Boletín Oficial de la Universidad de Sevilla, 2020). In Chapter I I argue that antigypsyism is the underlying cause that sustains Romani health inequities. Next, I frame Romani health as a health justice issue which is linked to the multi-level advocacy framework that my dissertation proposes. The objectives are defined at the end of the chapter. Chapter II proposes a set of methodological implications that are transversal throughout my research. Chapter III presents a summary of the scientific articles presented and their relationship to the objectives, including other related publications. Finally, Chapter IV presents the discussion in which I contextualize the work in relevant policy and research, address limitations and propose recommendations

Table of Contents

Chapter I

State of the Art

Despite targeted Romani health policies enacted over the past 15 years, Romani health inequities remain unchanged. This is exemplified by data that show the life expectancy of Romani people is 10-15 years less than that of non-Romani people (European Commission, 2014). Available health data are an indicator of this (European Commision, 2018; Zaharaiva, 2020). Antigypysism is defined as specific racism towards Romani people. Antigypsyism is historically constructed and continues to be maintained today (Alliance Against Antigypsyism, 2016).

In this Chapter I will argue that antigypsyism is responsible for Romani health inequities. I will discuss the role antigypysism has played in denying Romani communities the opportunity to contribute as political subjects. In this dissertation, a political subject can be defined as an individual who actively construct the social order by connecting the personal dimension to the collective dimension (Arias-Rodriguez & Villota-Galeano, 2007). A political subject has the power to influence the social order, and therefore is deeply embedded within it. A political subject can also act as vehicle to ensure that the social order remains intact and unchanged, which can involve ignoring the dynamic nature of daily life and diverse experiences (Martín-Báro, 1993, p.16). As such, a political subject may contribute to jeopardizing a cohesive social order and inflict violence against those who remain outside of it (Moane, 2003). Romani people have survived on the margins of antigypsyist social orders throughout history. Instead of reaping the benefits of being a part of the social order, Romani people have developed an identity of resistance against the process of marginalization. From this perspective, the Romani identity is based on an ethnicizing intergroup dynamic that has taken place within historical and social-political contexts (Costache, 2018; Surdo & Kovats, 2015).

In the first section of this chapter I will discuss Romani people's continuous struggle against the political powers that have violated their rights as political subjects, which continues to be socially accepted in European culture and daily life (Cortés-Gomez & End, 2019; Zaharieva, 2020). I will also identify the narratives that are embedded in policies that aim to promote and protect Romani health, and I will discuss how policies homogenize the Romani experience across Europe. Homogenization constructs a reality of "others" and defines Romani experiences from a white European perspective. This homogenization results in an allocation of resources that have no real value to Romani communities, which both widens and deepens the health gap across all the domains of the social determinants of health.

The purpose of my dissertation is to build a multi-level advocacy framework that can ensure Romani self-determination in leading transformative changes in health policies. This will ensure that Romani communities can build healthy contexts with opportunities and resources to flourish across the lifespan. I will justify that through multi-level advocacy, Romani communities can resist antigypsyism through a psycho-socio-political political empowerment process, while gaining the recognition as political subjects that rightfully pertains to them.

1. Persecution of Romani People and the Struggle to be Recognized as Political Subjects

Romani people are the largest ethnic minoritized group in Europe. The term "Romani" is an umbrella term that refers to the heterogenous minoritized Romani population group in Europe—Travellers, Sinti, Caló, Pueblo Gitano (European Parliament, 2020). In the political context, the terminology has been debated and has evolved over the years as European and national governments continue to struggle with the recognition of Romani as political subjects. The Romani identity has been romanticized by white European culture through the social projection of a Romani nomadic way of life, a depiction that does not fully reflect the real historical damage inflicted on Romani people. Romani people have historically been treated as a threat to political powers. In this section I will discuss a series of key historical events to identify the many facets of antigypsyism. I would like to clarify that the objective of this section is not to provide a full, complex history of Romani people in Europe and Spain. Instead, I intend to show how the Romani identity was built in relationship to persecution and resistance throughout changing social political structures.

Romani history and identity dates back to the 9th century. It is believed that Romani people migrated from the northern parts of India and spread across the European continent up until the 14th century (Ringold et al., 2005). The date of their arrival in Europe is highly contested among historians and activists, as the primary sources of available documentation come from a Eurocentric perspective. Romani arrived in Spain in the 15th century, during the reign of the Catholic Monarchy (Fundación Secretariado Gitano, 2019). During this time, the church retained political power using religion to control lands and people. Romani people posed a threat to the established social order as they introduced new ways of life that reflected their contact with diverse communities throughout their journey to Spain. Romani people were quickly demonized under royal laws as they were considered a subgroup that did not fit the standards of mainstream cultural and social patterns (Cañadas-Ortega, n.d). The royal laws ordered that various ethnic and religious groups—such as Romani, Jewish and Muslim communities—abandon their ways of life and adopt Catholicism, or else they would be forced to leave. Jewish and Muslim groups left in masses to their "politico-religious allied countries", while Romani people had no homeland to turn to for asylum (Cortes & Fernandez, 2015). By the 16th and 17th centuries, laws that persecuted Romani communities spread across various modern-day European countries (Council of Europe, n.d.).

In 1749 the *Gran Redada* took place in Spain. This was one of the darkest moments in history of the Pueblo Gitano. Gitanos/as of all ages in Spain were internally displaced to engage in forced labor, and this now understood as ethnic cleansing, an attempt to control and forcibly assimilate Romani people (Agüero & Jiménez, 2020). The effort was approved by the King Fernando VI and implemented by security forces, who depicted the Pueblo Gitano as a godless and disobedient group. This strategy aimed to ensure that the Pueblo Gitano would eventually become socially fit for society. The internal diaspora of Romani people had resulted in the blending of the Romani language with Spanish—which is known today as Kaló (Council of Europe, n.d.). Similar overt, forced assimilation processes were enacted across the European continent over centuries (Mayall, 1992).

Towards the end of the 18th century, the French Revolution set a new precedent in the relationship between rulers and those they governed, uprooting the established social order and political power dynamics. The power of the people supported a transformation from feudalism and an absolute monarchy to the values that would become the pillars of modern day social orders in Europe. This created a new relationship between two newly defined actors: the nation and its citizens. During this period those most affected by poverty questioned the established social orders, encouraged collective critical thinking and began to take action to protect their rights (Wallerstein, 2003). Thus the French Revolution can be thought of as a historical turning point in Europe. Here, I aim not to reduce the complexity of its impact, but to emphasize how it supported a new social order: for example, as delineated in the Declaration of the Rights of Man and of the Citizen (National Assembly of France, 1789). This new social order recognized the capacity of the masses to bring about change. However, there was still differentiation between those who were recognized as citizens and those who were not. This instigated subsequent social movements and a new political culture (Hunt, 1996).

The period following the end of the French Revolution marked a redefinition of the relationships of a people to their state. One of the shifts related to the protection of national boundaries against outsiders and the protection of citizens by the state. Romani people were still outside of the social order and exempt from protection by the state. For example, in the Austrian-Hungarian Empire (1890-1938), the Romani were perceived as a threat due to their way of life. After the end of the Empire, Romani people were forced to the live under persistent threat from both Austrian and Hungarian laws (Council of Europe, n.d.).

The 20th century, with all of its scientific and technological advances, did not bring benefits to Romani people, rather the industrial developments of this period were also used as a weapon against them. The social and political orders of contemporary Europe did not guarantee a better life for Romani people. The dictatorships in Europe that arose during this time repeated the laws of the politico-religious institutions of the past. During the Franco regime in Spain (1939-1975), laws were created that criminalized and stigmatized the Pueblo Gitano (García Sanz, 2018). Scholars estimate that during the Nazi regime between 300,000 and 500,000 Romani people were killed during the Holocaust (Lewy, 2000; Petrova, 2003). There still exists a widespread historical memory that does not recognize the Romani genocide that took place in concentration camps, for example, at *Zigeunerlager* (or the "gypsy camp") in Auschwitz-Birkenau (Joskowicz, 2016; Milton, 1992). It was not until the early 2000's that countries began to recognize this "forgotten Holocaust", however, it continues to be largely a silent history.

The end of World War II marked an important era for the recognition and protection of human rights following the Nuremburg trials in 1946. In 1948 the Universal Declaration of Human Rights widely recognized the rights and freedoms of all human beings. The implications of the Declaration would have impacted and improved the lives of Romani people, yet antigypsy mechanisms were still present in different laws and policies enacted throughout Western Europe. In Switzerland and the Czech Republic, Romani women continued to undergo forced sterilization (Albert & Szilvasi, 2017; Izsak, 2008). In Slovakia, Romani people lived without potable water (Harper et al., 2009). In France, Romani settlements were demolished by police and seen as illegal under French law. This eviction process left Romani people without a home, and they were forced to continue to move, building settlements from place to place and attempting to evade demolition (Rorke, 2020). The first International Romani Conference took place in London in 1979, amidst continued injustices around Europe. This marked a new era, as Romani people across Europe began to build a cohesive identity, with a flag and the anthem "Gelem, gelem". The word *rom* was adopted as a self-identifying term, and representatives at the conference established five commissions: social affairs, education, war crimes, language, and culture (Council of Europe, n.d.).

The new millennium was around the corner, with globalization on the rise and a shift in global powers, with the European Union playing an important leadership role. After the end of the Franco dictatorship in 1975, Spain committed to following European democratic principles. However, this abrupt shift to democracy was not inclusive of Romani people (Heredia-Ramirez, 1978). The democratic principles and ethical standards of Spanish laws - enacted as a part of the transition - have disguised the violence towards the Pueblo Gitano into subtle systemic racism that is difficult to identity and easy to normalize. The Pueblo Gitano has equal rights in the eyes of the law, but these rights are often not respected and, in most cases, ignored. This constitutes a modern-day dehumanization process that is hidden within daily culture.

Evidence shows that negative images of Romani people increase disgust towards them, which can lead to increased dehumanization (Dalsklev & Kunst, 2015). The word *Gitano* was defined as 'thief' up until 2015 in the official Spanish language dictionary (Real Academia Española, 2015) and the term still retains a negative connotation. A survey in 2015 showed that the most negative attitudes towards Gitanos were held by non-Gitanos, more so than immigrants or religious minorities, which demonstrates that, despite that Gitanos are citizens in Spain, there is deeply engrained antigypysism in Spanish (Instituto Nacional de Estadisticas, 2015). Gitanos are represented in the media as dangerous, which criminalizes their identity and instills fear of the neighborhoods where they reside, further isolating them from mainstream society (Cortes-Gomez, 2020). Another form of dehumanization occurs through silencing their realities. For example, the *Gran Redada* - the Gitano genocide of 1749 - is not included in Spanish history textbooks (Carrasco & Poblet, 2019; Gay y Blasco, 2016). This lack of recognition of Gitano history can be seen as a way of controlling the narrative, further isolating Gitanos.

Generation after generation of Romani people have had to resist persecution from different political powers. However, even forms of Romani resistance have been used to further criminalize and dehumanize them. This is well documented by Spanish researchers and activists in the story of flamenco music and dance (a source of identity, cohesion and political resistance and strength) in southern Spain (Cisneros-Kostic, 2010). Flamenco music has historically been a way of narrating Gitano history, experiences, and was also a way of recognizing Gitano historical memory. Yet Eurocentric, Spanish culture has adopted flamenco as its own, diluting the significance of Romani contributions and appropriating flamenco as a symbol of Spanish culture. For example, during the Franco Regime, flamenco music was celebrated as a Spanish cultural symbol, while at the same time Gitanos were demonized and persecuted. Today Romani activists and pro-Roma organizations help raise awareness of Romani history (Fundación Secretariado Gitano, 2006). However, the social representation of the Romani people is controlled by a one-sided narrative.

These historical and cultural examples are important in order to contextualize how Romani identity is currently projected and how a Eurocentric perspective attempts to control the Romani narrative. Figure 1 shows how historical processes are superimposed and influence the social representations of Romani people, which are reflected in the health policies of today.

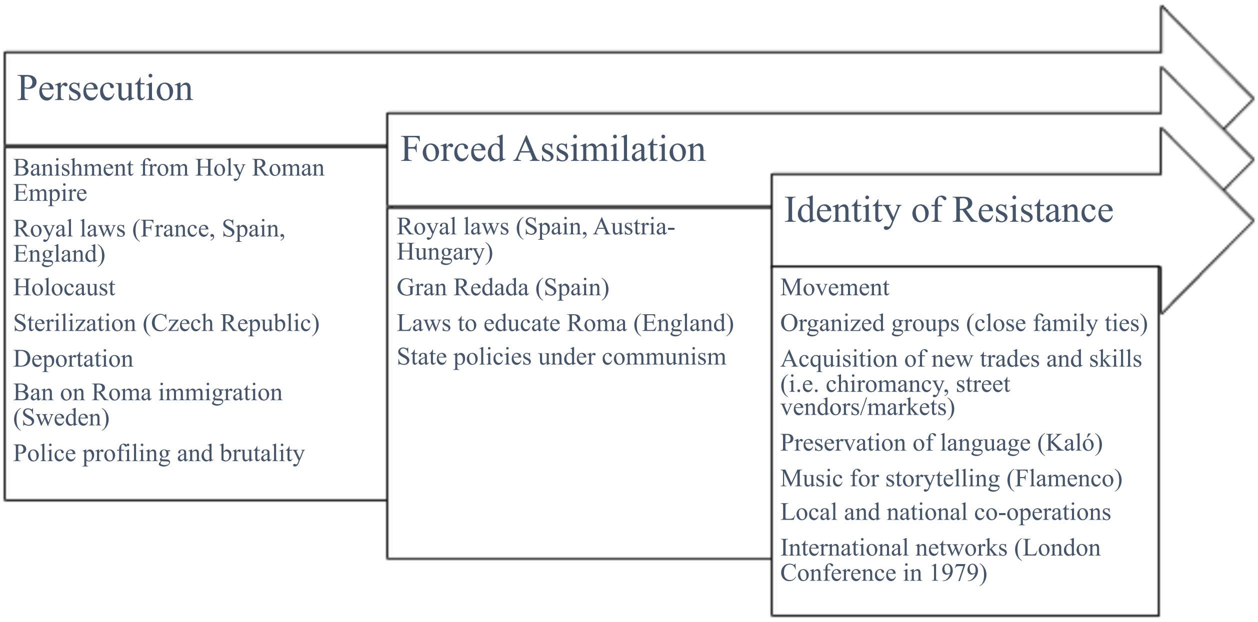

Figure 1. The Construction of the Romani Identity through Historical, Social, and Political Contexts.

Independent of the political system in place, Romani were not considered political subjects that had rights to shape social realities and reap the benefits as did other members of society. Despite a history of social and political persecution, Romani people have had the capacity to resist as a form of self-preservation (Filigrana, 2020). The Eurocentric perspective of the Romani journey has determined Romani representation in policies and interventions that are closely linked to poverty, helplessness, and social burden. In the next section, I will outline how the European policies that aim to promote inclusion, in practice re-affirm poverty, marginalization, and "othering" of the Romani people and fail to consider the many forms of Romani resistance that have been present throughout history.

2. Antigypsyism in Current Social Structures and Health Policies

Antigypysism is entrenched in European political efforts that aim to improve the health and lives of Romani people over the last fifteen years. As a result, the right to health of Romani people has been violated.

There are currently an estimated 12 million Romani people living on the European continent (FRA, 2018). In 2005 European Union member states committed to Decade of Roma Inclusion (henceforth referred to as Decade), a transnational platform that brought together government officials, civil society organizations and researchers to commit to improving the living conditions of Romani communities. A group of international partners including the United Nations Development Program (UNDP), World Bank, Open Society Foundations, United Nations agencies, the Roma Education Fund and the EC were among the supporters of the Decade. The objective of the Decade was to engage in dialogue to increase the economic capacity of Romani communities, improve housing conditions and prevent discrimination. Roma civil society, which included NGOs and activists, was expected to play a mediating role between the goals of the Decade and marginalized Romani communities. The Decade marked a turning point for Romani people in that they abruptly became recognized as political subjects that had equal rights under the law.

The main priority areas of the Decade were education, housing, health and employment, and the Decade also considered the core, cross-cutting issues of poverty, discrimination and gender. The cross-cutting issues played an active role within each priority area. An example of this is in the area of education and the cross-cutting issue of gender. Romani women have been said to experience double discrimination due to their ethnic and gender identities. Thus, in the area of education, Romani women experience high dropout rates due early motherhood in teenage years, which has the impact of excluding them from employment opportunities (UNICEF, 2011).

Albeit with recognition of the underlying issues faced by Romani people, the Decade was impacted by a series of challenges that still pose problems for Roma-targeted policy initiatives. One such challenge related to the role assigned to Romani communities. The Decade provided funding to individual Romani activists and Romani NGOs to assume the role of advocacy, implementation and monitoring of the Decade in their national contexts. Unfortunately, there was scarce Romani participation at the local level, and those involved did not have adequate resources or the capacity to mobilize and coordinate across multiple levels (Brüggemann & Friedman, 2017). Member states were also unable to effectively use European funds to target Romani needs (European Commission, 2011). Thus, during this period of the Decade, the Romani political subject was unable to take an active role in shaping national social structures and realities.

In response to the Decade’s challenges, the European Commission developed National Romani Integration Strategies (NRIS), a set of policies that set specific priorities in addressing the lessons learned from the Decade. Among other things, the NRIS committed member state governments to adapting policies to local realities and allocating sufficient funding from their national budgets (EC, 2011). The NRIS also identified key strategies to be considered in the Decade's four priority areas, with the additional inclusion of a social determinants of health perspective. This perspective recognizes that the contexts where people are born, grow and live influence their health and wellbeing, and that these factors must be considered in health policies (Gatti et al., 2016; Marmot, 2005). The NRIS proposed strong monitoring and evaluation efforts and strengthening the involvement of actors at the local level. However, according to an evaluation report commissioned by the European Parliament, serious gaps in implementation of the NRIS remained, leading to a situation that was similar to what had existed at the outset of the Decade (European Parliament, 2015).

In 2013 in Spain, the government developed an operational plan to implement the NRIS (Ministerio de Sanidad, Servicios Sociales e Igualdad, 2012) that aimed to identify specific actions and key actors responsible for implementing NRIS, such as government bodies at the national, regional and local levels, and NGO. A comparative study commissioned by the Spanish Ministry of Health & Social Policies compared data from the health surveys of 2006 and 2014 and showed that little progress had been made in the area of health. The study showed that some health indicators for non-Romani populations improved during the study period, while Romani people's health indicators stayed the same or in some cases worsened (Ministerio de Sanidad, Servicios Sociales e Igualdad, 2017). For example, Romani people had lower levels of perceived health than their non-Romani counterparts, independent of their socio-economic status (La Parra et al., 2015). This was especially true for Romani women, who showed an overall poorer health profile compared to non-Romani (Carrasco-Garrido et al., 2011). Despite this, Spain was celebrated as a prime example of successful NRIS resources allocation and implementation (Koska, 2015), which Ovalle and Mirga (2014) have called a “myth”.

In 2015 the International Organization for Migration (IOM) commissioned an National Roma Integration Strategy health component (NRIS-H) evaluation in member state countries within the framework of the EQUI-health project. The aim of EQUI-health was to evaluate the progress and impact of the NRIS-H through multi-stakeholder dialogue. The evaluation process implemented in Spain followed a participatory approach that brought together actors from multiple levels to evaluate how policy was designed and implemented at the national level. My colleagues developed the Roma Health Integration Strategy Index (RHIPEX) that evaluated national policies based on the indicators. The results of the evaluation are described in Table 1 (García-Ramírez et al., 2015; Escobar-Ballesta et al., 2018).

Table 1
The NRIS-H in Spain Through the RHIPEX

Dimensions	Results
Entitlement to the healthcare system	Insurance-based system has restricted entitlement (except: pregnant women, minors, emergencies). Bureaucracy and cutbacks (closure of services, staff shortage, co-payments, unemployment). Expulsion of the most vulnerable Romani people.
Accessibility of healthcare services	Ethnocentricism, stereotypes, biomedical perspective in the healthcare system Lack of Roma health mediators limit accessibility and navigation. Efforts by providers (e.g., informal census, navigation assistance).
Responsiveness of healthcare services	NRIS is not adjusted to Romani people's reality and needs. Many policies but with little implementation. Efforts by NGO mediators (e.g., training, workshops) and healthcare professionals (e.g., unofficially adapt practice and protocols - not recognized).
Capacity for achieving and sustaining change	Lack of budget, cutbacks, power decentralization, limited commitment. Romani NGO: low participation, bureaucracy, competition, subsidy-dependent, exclude foreign. Stakeholder collaboration difficult at hierarchic levels but flourishing at community levels.

According to Escobar-Ballesta et. al. (2018), the failure of the NRIS-H in Spain was due to the chain effect produced by antigypsyism, the fact that Romani people were excluded from participation at the local level, and health priorities that did not consider the realities of Romani people. For example, local family planning programs were not sensitive to the experience of Gitana women (Escobar-Ballesta et al., 2018).

In fact, national efforts related to the NRIS-H replicated oppressive structures by treating Romani groups as incapable of deciding upon their own needs and realities (Kóczé & Rövid, 2017). Romani were not involved in setting priorities, rather they were direct beneficiaries of services that had limited effectiveness, as shown in analyses of health data. Advances at the institutional level and coordination between organizations at the national level were successful, for example, the government's advisory body, the Roma State Council, played a decisive role at the national level. It should be highlighted that in terms of budget distribution, one Romani organization had received over 60 percent of the national funding consecutively over the years (EC, 2018). The significant control of funds by one powerful Romani network, with origins related to the Catholic church, suggests that contemporary social structures replicate those of the past (Fresno, 2001). However, grassroots movement efforts were coordinated amongst themselves through Khetane, a participatory platform established in 2013, and the Equi-Sastipen-rroma health mediator network (made up of the same organizations). Equi-Sastipen-rroma has been highlighted as a good practice in Spain, as it promoted collaboration among NGOs at the national levels, with coordinated regional and local level efforts (Equi-Sastipen-rroma, 2015). These platforms are independent of the Roma State Council, despite the presence of the same organizations across all three settings.

The chronic marginalization of Romani communities in Europe has stirred debate among activists and academics. Scholars have discussed the impact and challenges of NRIS related to its initial conceptualization, design, implementation and evaluation. The neoliberal nature of the NRIS policies has been widely criticized (Acton, 2005; Escobar-Ballesta et al., 2018; Kóczé, 2016). Romani-targeted policies have utilized the words "integration" or "inclusion", that suggest a paternalistic approach in which Romani communities would be helped to assimilate into mainstream society (Cortes Gomez & End, 2019). Koska and Rovid (2017) highlighted the double discourse of the NRIS. On the one hand, it recognized the discrimination experienced by Romani communities, yet it tried to make changes that functioned within exclusionary social and economic systems. This was clearly seen in the types of programs that were implemented. For example, programs were geared towards improving the employability of Romani people, without addressing the lack of personal or professional networks to access employment opportunities (Gatti et al., 2016). Family planning programs promoted contraceptives, without understanding the cultural implications of motherhood in the Romani community (Escobar-Ballesta et al., 2018). Programs aimed to address diversity training for teachers in school to support understanding of the language and cultural barriers faced by Romani students overlooked the engrained, negative attitudes non-Romani teachers had towards the Romani community and its culture (Kyuchukiv & New, 2016). These are examples of how policies and programs were developed for Romani people, but without their involvement.

Van Baar (2018) has argued that Roma policies in Europe were developed as a way to control development and security agendas linked to the mobilization of Romani communities, rather than as an effort to address their rights. The Decade as an unprecedented pact was considered a reaction to the geopolitical acquisition of Eastern European countries into the European Schengen space. The author highlighted that the political efforts were more about the burden that member state countries would assume during acquisition of these countries. This had the effect of the NRIS being used as a weapon against Romani communities. In fact, the policies utilized an umbrella term "Roma" that overlooked the heterogenous nature of communities of Romani people in Europe, a one-size-fits-all solution that missed the nuances of richly diverse communities, contributing to stereotypes. Thus it is argued that Romani people have little to no control over how they are perceived in political spheres (McGarry & Agarin, 2014).

Vermeersch (2012) highlighted that Romani-targeted policies were actually used by nationalist governments to further exclude them, by citing the lack of program impact to engage in victim blaming and pose Romani communities as being a burden, coined "assimilative warfare: by Giovanni (2018). Antigypsyist narratives supported negative attitudes towards Romani communities, building a case to justify their poor living conditions and painting the picture that Romani people were helpless. This racialization and ethnicization process created a "them versus us" situation, dehumanizing Romani people and creating a culture that strips them of their social value, and creating a situation of mistrust between Romani and non-Romani people. In turn, this had a direct impact on how policies were created and put into practice. For example, in healthcare settings Romani patients do not fully trust non-Romani doctors, due to interpersonal interactions that are rooted in antigypsyist attitudes and practices (Aiello et al., 2018). This "assimilative warfare" has forced Romani people to adjust to a system that has always excluded them.

The NRIS has also been criticized due to its "soft-policy" nature. Its provisions were non-binding for governments, and NRIS promoters were unable to leverage interests with national governments (Mirga-Kruszelnicka, 2017). This "vicious cycle" has ended in a lack of governmental accountability, scarce financial resources, and gaps between discourse and implementation (Matache, 2017). Also, the NRIS was transferred to agendas driven by governments' priorities as opposed to the real priorities of Romani people (Ryder & Taba, 2017). Governments outsourced the responsibilities of implementing the NRIS to NGOs, with limited funding available, thus promoting competition between NGOs to access grant money. NGO professionals worked overtime, depended on government funding as their main source of income, and had no evaluation capacity. Thus there were few programs informed by on-the-ground evidence (Fésüs, 2012). The competition among NGOs fragmented efforts among organizations and expected program results were based on the breadth of coverage, as opposed to the quality of services provided. This power dynamics and hierarchy created between smaller, grassroots organizations and larger, more influential NGOs made it difficult to engage in grassroots efforts (Acton & Ryder, 2013). In turn, paternalistic relationships contributed to ethnicizing the problem by attributing helplessness to the "Romani problem" and draining Romani people of their sense of agency.

Today it is estimated that 80 percent of Romani people in Europe live in extreme poverty (FRA, 2018). Romani housing has poor water quality, which increases the risk of communicable diseases (FRA, 2009). Romani people have a higher prevalence of communicable diseases, and Roma children have a higher prevalence of parasitic diseases (Tombat & van Dijk, 2020). In healthcare settings, providers still have overtly negative attitudes towards Romani people, in both their words and actions (Briones-Vozmediano et al., 2018; Fundación Secretariado Gitano, 2013). Environmental risk factors such as pollution result in an increased risk of adverse birth outcomes and chronic diseases for Romani people (Heidegger & Wiese, 2020). Romani populations have higher infant mortality rates and lower birth weights compared to non-Romani group (European Commission, 2014). Although there is a lack of consistent, rigorous data, studies suggest that Romani experience a higher prevalence of chronic diseases (Cook et al., 2013). Where people live, and the context in which they live, paves the way for how people thrive. This includes both physical marginalization and experiences of discrimination in daily life. For example, Romani youth experience discrimination in school systems, which leads to higher school dropout rates (FRA, 2012; FRA, 2014), and to being forced to begin their adult lives earlier. This is especially true for Romani girls, who have a higher chance of becoming mothers during their teenage years (UNICEF, 2016). As much as 56 percent of Romani children leave school before the age of 16 (Council of Europe, 2018). Due to poor school achievement, it is more difficult for Romani people to develop the networks that provide opportunities to access employment, thus they end up also being excluded from economic spheres. Furthermore, high unemployment rates and job insecurity are linked to higher rates of mental distress (Lê Cook et al., 2019). Mental distress can contribute to the narrative that a person is not capable of meeting their own needs and participate in daily life (Patel et al., 2018).

The 2018 12th European Platform for Roma Inclusion concluded that “Roma meaningful participation in all stages of the process, including decision making, efficient use of available funding, and political will at all levels, national, regional, local, are indispensable for interventions to bring tangible and long-lasting results” (EC, 2018). The Decade, the NRIS and the Spanish Operational Plan have been developed within a white Eurocentric culture, which has reinforced the domination of Romani people through laws, policies, programs, and practices. The Decade took a first step in bringing institutional recognition to Romani communities and putting Romani issues on public policy agendas. The NRIS created a network of actors committed to improving Romani living conditions and to dialogue across and within countries. However, political power disparities and dynamics were not addressed.

Agency, or self-determination, refers to a person's capacity to use their own voice and to make decisions regarding their lives with the optimal resources and opportunities to do so (Stronks et al., 2016). The political landscape in Europe, built on white Eurocentric values, has shaped how Romani people move within the political space and has meant that Romani depend on powerful actors—i.e., political parties or the church—to gain recognition. Romani people have been treated as passive agents, dependent on NGOs to represent them and provide basic services outsourced by governments. Over the last fifteen years, public policies have once again constructed the social realities of Romani people without considering their contributions to political dynamics. It is here that my dissertation aims to answer the following question: How can we develop processes that ensure that Romani communities are recognized as political subjects and have the capacity to influence political change?

3. Moving from Health Equity to a Romani Health Justice Approach

In this section I argue that the persistent exclusion of Romani people from political structures has contributed to sustaining oppressive conditions, which, among other things, has limited the impact of NRIS-H. Health equity principles in the NRIS-H have been defined by a dominant group, forcing Romani to adhere to established structures. I propose here that health justice is involves recognizing Romani people as political agents and respecting their right to health.

From a social justice perspective, governments and societies have the collective ethical and moral responsibility to create conditions that ensure individual and community health and wellbeing (Beauchamp, 1976). In order to approach Romani health as a social justice issue, I define conditions of justice as existing only when both distributive justice and procedural justice exist. Distributive justice refers to the recognition that goods in a society belong to you (Miller, 2001). Procedural justice refers to the deliberation process that instigates intersubjectivity and helps build a reality and structure that reflects multiple experiences. The NRIS-H focused on the distribution of resources defined by those in positions of power, national governments that did not commit to strong evaluation measures or budget allocations (Brüggemann & Friedman, 2017), non-Romani researchers who developed knowledge about Romani people without Romani participation (Matache, 2017; Silvernman, 2018), and NGOs that offered services to communities that replicated systems of power (Vrăbiescu & Kalir, 2017). Civil society organizations became the political structure that Romani people trusted, yet at the same time, these organizations defined a set of norms regarding how Romani people could interact with institutions and services (Martín-Baró, 1993, p.116-117).

Romani health policies have been informed by the dominant cultural narratives that have built the historical conditions of oppression for Romani communities. Thus Romani people exist on the margins of a political structure that is defined without considering them. Without procedural justice in the allocation of resources, Roma health policies based on principals of equality have replicated pre-existing power dynamics. Processes led by non-Romani people have decided upon the best means to address the public health challenges of Romani people, with the implicit assumption that Romani people are not in a position to decide for themselves. This unequal bargaining power further undermines individuals' perceptions that one is capable of participating (de Freitas & Martin, 2015). Since there has been a loss of trust between Romani and non-Romani people, Romani NGOs came to be representative of all communities. This has created a vicious cycle in which one group has dominated over the other, which has situated Romani people in a position of helplessness. This type of participation—whether in the form of coercion or tokenism—is a formality and not a distribution of real power (Gallagher, 2008).

Both distributive and procedural justice exist at multiple levels and are mediated by psychosocial processes—ranging from individual empowerment, relationships and interactions to how we exist in social, economic, political and cultural spheres (García-Ramírez et al., 2011; Prilleltensky, 2012). The deliberation process is a space where antigypsyism needs to be dismantled. The power dynamics that maintain antigypsyism must be understood as the control or domination of relationships between Romani and non-Romani people; both control and domination interact at multiple levels (Foucault, 1997; Prilleltensky & Nelson, 1997, p.5). Dominant antigypsyist narratives distort the realities of Romani people and contribute to victim-blaming, which threatens Romani people's right to define realities on their own terms. In fact, the historical marginalization of communities has involved removing the capacity for knowledge production and the legitimacy of decision-making about what works or does not work (Gaventa & Cornwall, 2006).

All of the above creates oppressive circumstances at individual, relational and collective levels. At the individual level, oppression is internalized, and Romani people assume the narratives that are told and develop expectations for what their circumstances are or will be (Palmer, 2018). Internalized narratives around traumatization subtly indoctrinate how historically oppressed communities utilize services, assimilate into the dominant group and negotiate their lives on the margins (Martín-Baró, 1993, p.75). At the relational level, the dichotomy of non-Romani vs. Romani people categorizes groups, furthers the creation of an in-group/out-group process and forces prescribed roles onto an inferior group (Hellgren & Gabrielli, 2021). At the collective levels, power oppresses through economic exploitation. This can be seen in the examples of criminalizing Romani work, eviction processes supported by the legal system and police forces, and early marriages and motherhood (García-Ramírez et al., 2020; Moane, 2003). The psychological implication of oppression is the interiorized form that leads to helplessness. Policies based on health equity inadvertently suggest that Romani people are helpless in adhering to established social norms, even though such policies do not actively include them in defining their realities and recognizing their rights.

I propose moving from a health equity approach to Romani health to a health justice approach. Health justice recognizes the political and ethical challenges engrained in health policy (Stronks, 2016). In my research, my use of the term health justice is inspired by the reproductive justice movement that was built on the relationships established between activists and scholars to influence change for the reproductive rights of Black women (Ross, 2017). The reproductive justice movement is an example of a movement in which people have been able to represent themselves, bring about change in the oppressive mechanisms of a dominant approach to reproductive rights, and built a movement through shared experience. A shift from health equity to health justice recognizes the rights of Romani people and their capacity to act as political subjects on the issues that are relevant to them.

4. Psycho-Social-Political Development through Multi-Level Advocacy

The complex nature of antigypsyism has called for new ways of working towards Romani health justice. The World Health Organization has highlighted that advocacy is a relevant tool to respond to institutional discrimination (WHO, 2000). Advocacy is defined as intentional, organized actions that aim to influence policy, practice, and attitudes (Aicher et al., 2010). According to Carlisle (2000), advocacy can be understood as a health promotion strategy that is concerned with equity, justice and protection. Advocacy enhances citizens' ability to influence policy while reinforcing the capacity for self-determination as proposed by a social justice framework (Pastor et al., 2018). Advocacy in the realm of public health can redefine how oppressed groups see themselves and challenge dominant narratives embedded in health policy. This implies that affected communities will demonstrate leadership in framing the issues that matter to them and build a network of relevant allies to mobilize for social change (Balcazar et al., 2012; Christens & Speer, 2015; Fals-Borda, 1988; Paloma et al., 2010; Rappaport, 1987; Zimmerman and Rappaport, 1988).

Oppressive contexts force groups to conform to unjust living conditions. Conforming is understood as an acritical view of the way things are, rather than a focus on the way things should be. There is no choice or possibility to envision another way of life. A critical view involves understanding the power dynamics that over time construct the world we know and in which we navigate our daily lives (García-Ramírez et al., 2011; Paloma et al., 2010). Moving from a health equity approach to a health justice approach implies a psycho-social-political journey, as described in Figure 2.

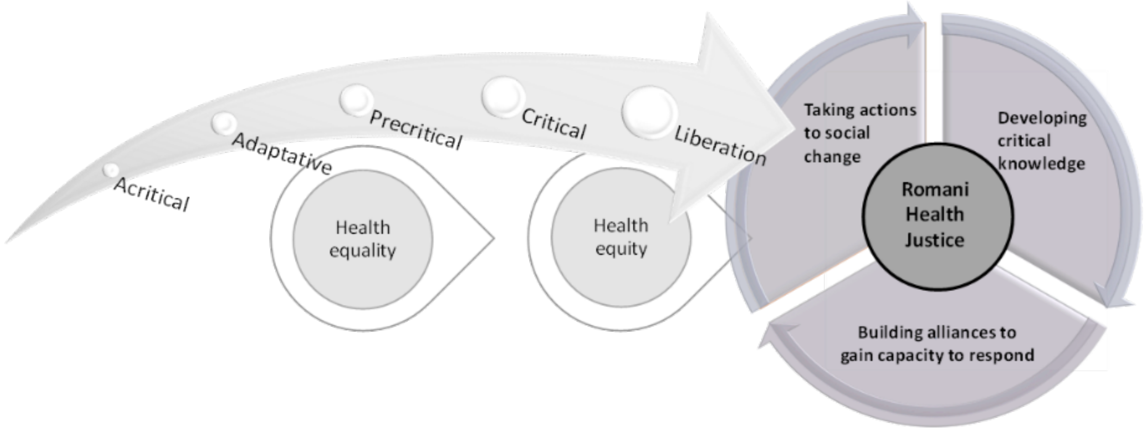

Figure 2. Psycho-Social-Political Development through Multi-Level Advocacy

Figure 2 reflects the psycho-social-political journey mediated through the advocacy process that ensures moving from principals of health equity towards principals of health justice. Advocacy supports psycho-social-political development that permits *building critical knowledge* around unjust living conditions. Socio-political development is defined as "a process of growth in a person's knowledge, analytical skills, emotional faculties, and capacity for action in political and social systems" (Watts, 2003, p.185,). For my dissertation, I refer to this process as psycho-social-political development; it is a process in which the individual develops the political capacity to influence change in their context (García-Ramírez et al., 2011).

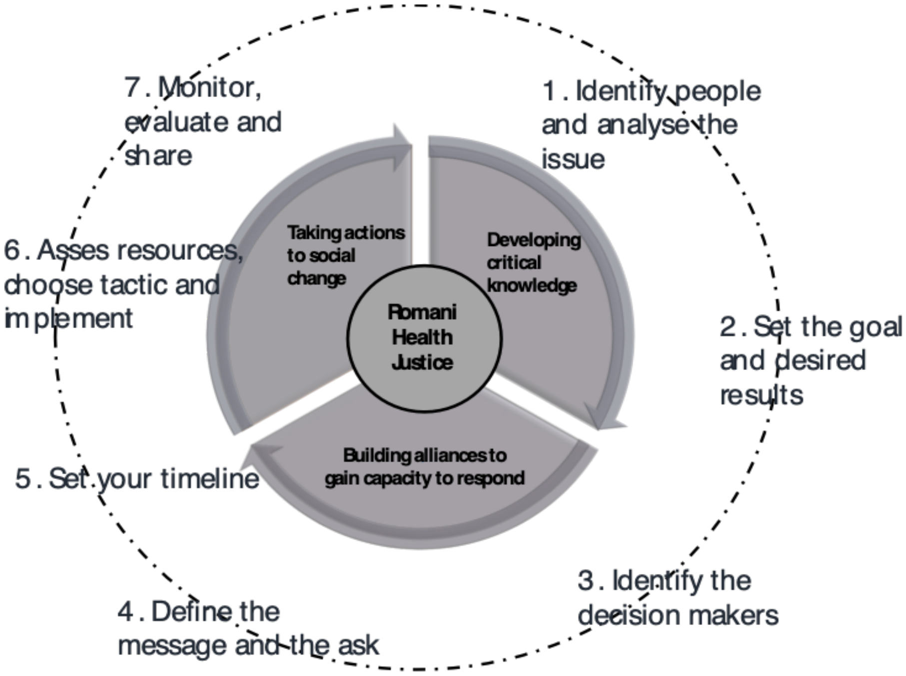

Figure 3. Psycho-Social-Political Development Mediated Through the Advocacy Process

This journey towards building a critical view of daily life and personal experiences is a process that is relevant for both Romani and non-Romani people (Cohen & Marshall, 2017; Farrer et al., 2015; Loftis, 2013; Wolff et al., 2016). Kieffer (1984) suggests that grassroots-level organizing and action can transform both the individual and group identity, recognizing them as political subjects who have the ability to shape the social structure over time. *Gaining alliances* with the involvement of multi-level stakeholders who exert power over resources. Multi-level stakeholders have the potential to shape the narrative embedded in public health should examine their positions in social and political structures as well (Bowen & Murshid, 2016; Briones-Vozmediano et al., 2018; Christoffel, 2000; Nixon, 2019). For my dissertation, health care providers, healthcare managers, civil society organizations, local policymakers and researchers are defined as “other actors”. From a health justice perspective, these actors have the responsibility to uphold the health rights of Romani people. However, relationships between Romani and non-Romani people have been built on norms that have been socially prescribed for generations. Mutual recognition between Romani and non-Romani people can help transcend in-group and out-group standards and work towards dismantling antigypsyism (Griffith et al., 2007). In summary, advocacy can mediate a psycho-socio-political empowerment process towards Romani health justice.

Finally, to influence change, Romani and non-Romani actors must engage in *taking actions for social change* that aim to build conditions of justice. Through coordinated actions, groups can gain legitimacy and power to make change (Chayinska et al., 2017). This action should be aimed at different settings at different levels. I propose that advocacy linked to community-based participatory action research is a form of self-determination and political action that aims to build conditions of justice for Romani communities.

5. Objectives

The objectives of my dissertation reflect four phases that put into practice a Romani health justice approach:

1. **To build collaboration between multiple stakeholders at the local level.** The first objective is to identify the challenges of involving minoritized communities in an ecological framework in order to understand the opportunities for collaboration. I aim to pilot a university-community partnership in the Polígono Sur area near Seville, Spain to map local policies, programs, Gitano/a leaders and other key stakeholders.

2. **To build advocacy capacity among health professionals and organizational managers.** The second objective aims to raise awareness of antigypsyism among health care providers with regards to their responsibility in advocating for Romani health within their respective institutions, and reach consensus regarding local health priorities.

3. **To co-create knowledge among a group of Gitano/a neighbors.** This objective aims to identify the health priorities of a group of Gitano/a neighbors through a co-production process, specifically Photovoice.

4. **To advocate for the health justice of the Pueblo Gitano.** The final objective is to co-produce knowledge regarding Romani health inequities through community-based

participatory action research methodologies in order to gain support from a wider to network for advocacy purposes.

Chapter II.

Method

The fact that Romani health policies have been shaped by knowledge built upon a Eurocentric, antigypsyist perspective on Romani communities has methodological implications. There are hidden, antigypysist power dynamics that have resulted in the narrative that Romani people are helpless outsiders, as opposed to insider experts who can narrate their own realities. In my work I assume that Romani communities and researchers can co-produce knowledge to work towards Romani health justice. I define the co-production of knowledge as a Romani-led creative process of community-based participatory action research (CBPAR) to influence health policy (Carcari-Stone et al., 2014; Durose et al., 2012.; Suarez-Balcazar, 2020). It is through this interaction that complex power dynamics are disrupted, and communities embark on an emancipatory journey (Gutierrez, 1990).

CBPAR provides a methodological toolbox for reflection, knowledge production and action (Lewin, 1946; Leung et al., 2004; Minkler, 2000; Wallerstein & Duran, 2010). CBPAR is a bottom-up approach to research in which communities are leaders of their own processes change and recognize their own capacity to articulate their needs. In this sense, CBPAR transforms a community into active political agents (Montero, 2010). CBPAR represents a journey towards acknowledging one's own responsibility as an active member of society, and as such, a person with rights. My research is guided by a series of methodological principals based on CBPAR, as shown in Figure 4: (1) positionality and reflexivity, (2) interactive knowledge production, and (3) accountability for communities.

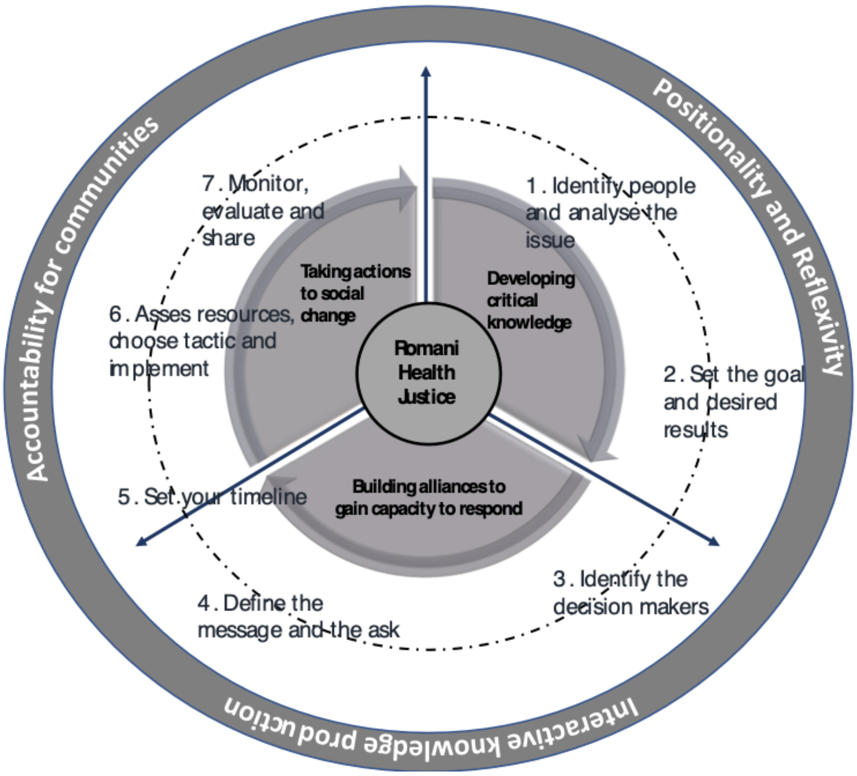

Figure 4. Community-Based Participatory Action Research to Advocate for Romani Health Justice

1. Positionality and Reflexivity

To address the systemic nature of antigypsyism, the issue of representation should be considered, and how actors relate to one another based on existing power dynamics. The radius of representation should be expanded to ensure that various voices are heard, especially those of Romani people living in the most marginalized conditions, as well as influential community leaders within civil society organizations and everyday neighbors. This brings into consideration a new horizontal model for collaboration (Lykes, 2017; Suarez-Balcazar et al., 2004). Horizontality challenges the service-user model of pro-Romani civil society organizations and the researcher-participant model of traditional research methods with Romani communities. Both current approaches place the community in an inferior position that must be disrupted within a health justice framework. Horizontality requires building horizontal relationships with multi-level actors that can provide diverse perspectives and resources to connect political debate to the realities on the ground (Ross, 2017). A space for collaboration allows for each actor to contribute to framing the problem and solution and promotes a collective sense of responsibility for addressing the issues.

Researchers and policymakers have considered Romani people a hard-to-reach population (Benoit et al., 2005; Condon et al., 2019), which poses the question: *hard to reach for whom?* The question of positionality is an issue created by traditional research methods that ask questions based on the social positions of pre-established social orders, which is known as a top-down approach. In my work, I follow the values proposed by feminist standpoint theory, which claims that our perspectives are determined by our position in the social order (Harding, 1991; Riger, 1992; Stein & Mankowski, 2004). From this perspective, university-based researchers are, in many ways, expressions of power and domination. When we imagine the top "one percent" of the population, we are usually looking at the socioeconomic status of a small group of people. Likewise, university researchers with a doctoral degree also make up 1.1 percent of the world's population (Hutt, 2019). Thus, researchers have the power of knowledge production.

Universities are powerful institutions that create standards that determine what is relevant, reliable, and valid. Their control over knowledge production influences how problems are framed and approached. For example, standards for rigorous research have been traditionally defined from a hegemonic viewpoint that approaches communities as a phenomenon of "others". This devalues community knowledge, as the research and analysis are given meaning by those other than the community itself. This is a form of subtle domination, as prestigious institutions value the replicability of knowledge that ignores the nuanced experiences of people with different viewpoints and silences them from the public sphere (Avery & Stanton, 2020). From this perspective, rigorous research is linked to reflexive practice and relevance to communities.

CBPAR has the potential to create a scenario where Romani communities and other actors can gain critical awareness and review their positionality, which can transform scholarship and support the development of a new status quo (Dutta, 2018; Garrido et al., 2019). The capacity to review positionality existent at each step of the co-production process is referred to as reflexivity (Dodgson, 2019 Soedirgo & Glas, 2020). Wolff et al. (2016) refer to reflexivity as explicitly naming systemic racism to ensure that no one is complicit. The co-production process embraces reflexivity and encourages further understanding social structures and power dynamics (Foster-Fishman et al., 2005; Suarez-Balcazar, 2020). Through this process, individuals reclaim their citizenship, and groups begin a journey that navigates civic life built on a new configuration of ideologies (Martin-Baro, 1990).

2. Interactive Knowledge Production

Interactive knowledge production refers to the dialectical practice of action-reflection, as proposed by Paulo Freire (1970), in which traditionally oppressed groups can develop theory while at the same time expressing these conditions and claiming what belongs to them. This ensures that people see themselves as citizens and see their issues as an integral part of the public sphere (Montero, 2010; Montero & Sonn, 2009). CBPAR shifts the nature of intersubjective processes, as people exchange experiences and identity their places within power structures, as opposed to conforming to existing norms (Christens, 2019). This considers nuanced experiences and builds new epistemological evidence that validates community experiences (Ross, 2017). Interactive knowledge production ensures that the community is relevant in influencing policy change. CBPAR has the potential to create a culture around critical exchange, to cross established boundaries and to develop political solidarity (hooks, 1992). In my disssertation I use a set of mixed methodologies that support interactive knowledge production, specifically, Photovoice, community mapping, and nominal groups.

Photovoice is a research method by which people can identify, represent, and enhance their community through a specific photographic technique (Catalani & Minkler, 2010; Foster-Fishman et al. 2010; Golden, 2020; Kovacic et al., 2014; Wang & Burris, 1997). In a Photovoie process, community members are first asked to identify the health priorities that matter to them through photographic representation. Over a period of time, the group takes photographs that represent the group members' priorities. Later, the photographs are shared among the group members. Through this dialogical exchange and categorization of information, groups can analyze the underlying power dynamics that sustain oppressive living conditions. Concurrently, the group solidifies and reaches a consensus on issues of insider and expert knowledge.

Community mapping is another form of interactive knowledge production. Community mapping aims to identify individuals and groups who are in positions of power and who have access to resources that are necessary to address health inequities (Cutts et al., 2016; Kretzmann & McKnight, 2005; Morgan & Ziglio, 2007). Community mapping identifies the resources in the community that have real social value to Romani people and evaluates the prestigious institutions that hold power and have access to these resources. Based on the community findings, a social network analysis of this situation can promote a deeper understanding, help identify opportunities for collaboration, and point to new actors who can ensure that health policies are responsive to the realities of Romani people (Nicaise et al., 2013).

Finally, consensus group approaches that are rooted in pragmatism have been used as a research instrument for health policy planning (Creswell & Plano Clark, 2011; Kaushik & Walsh, 2019). In my research we used a nominal group methodology that ensured that multi-stakeholder views were taken into consideration. This involved making use of a set of democratic principles that ensured that individuals had a voice in defining priorities, with sufficient time for reflection and deliberation (McMillan et al., 2014; Van de Ven & Delbecq, 1972). Debate was carried out with the goal of reaching a consensus that would simultaneously incite the responsibilities of each actor from a health justice perspective. This type of collaboration bridges the gap between researchers and practical knowledge from practitioners (Carney et al., 1996).

3. Accountability for Communities

The methodologies described above are methods that support gaining evidence and capacity for accountability. In the public health arena accountability refers to the process of ensuring that a duty-bearer fulfills obligations to ensure that health rights are fully met (London, 2008). Actors responsible for upholding health rights include health care providers, researchers, public service providers and civil society organizations. Researchers play an active role in ensuring that data and observations are given back to the community. Civil society organizations traditionally play an active role in accountability measures, however, they should also be held to specific standards of accountability by the communities they represent.

CBPAR ensures that community members develop the capacity to play a leading role in the accountability process and that all actors involved uphold their ethical obligations (Butterfoss et al., 1993; Fetterman et al., 1996; Foster-Fishman et al. 2001). This returns power to the communities, as political actors that evaluate resources and recognize themselves as right-holders (Hammonds et al., 2019). Mechanisms of accountability can include, for example, local coalitions where multi-level actors provide follow-up on a series of action-points in order to rebuild a sense of trust and promote new relationships based on mutual transparency (Joshi, 2007). Local coalitions can work to right wrongs and to develop Romani-sensitive policies and protocols. Thus, accountability is a multi-dimensional, ongoing process that gives power back to citizens (Baez-Camargo, 2011).

Finally, I would like to call attention to the ethical considerations that arise from a co-creation process that calls into question traditional ethical standards (Buchanan et al., 2007; Russel & Barley, 2020). Literally speaking, there is a transactional process that positions the researcher and the "researched" on different ends of a spectrum, from the outset of the process to during the consent process. This a way to ensure transparency and the self-determination that is necessary to uphold ethical standards, but it represents challenges for those of us who champion a co-production process. Buchanan et al. proposes that "the consent process must establish widespread community support, where residents agree that the proposed intervention is relevant and the methods of evaluation appropriate." (Buchanan et al., p.158, 2006). CBPAR recognizes the capacity of communities to lead their own change processes, which modifies the position of the researcher, and thus, the process of consent.

If we are concerned with issues of representation in social and political structures, then we must question how we approach confidentiality and anonymity. This includes, for example, the authorship of publications and who uses the co-created knowledge to influence policy, whether the external researcher or the community. Community-led change reimagines what confidentiality and anonymity should look like for research whose ownership is in the hands of the communities (Löfman et al., 2004). Roura (2021) explicitly sheds light on the "permeability of power dynamics" in participatory research and how the costs are greater for communities when participation is instrumental. The co-production process thus obligates us to redefine how we approach ethical aspects and to ensure that we are not silencing community voices by deciding on how the knowledge is best used. In Chapter III I share the results from a series of publications that address methodological implications.

Chapter III.

Results

This chapter presents the results of my dissertation available in the scientific articles presented. The first manuscript defines antigypsyism, and frames Roma health from a human rights-based approach. This article describes the results of the pilot study implemented in 2015 funded by the International Organization for Migrations (IOM) transnational project titled "Equi-health: Fostering health provision for migrants, the Roma and other vulnerable groups" financed by the DG Justice. This initiative aimed to evaluate the National Roma Integration Strategies health component (NRIS-H) across member states. In specific, our role was to implement a pilot study that aimed to evaluate and build conditions of collaboration for Roma health governance at the local level.

One of the main results of this pilot study was the continued funding received by the Open Society Foundations (2016-2019). This project aimed to develop multi-level advocacy processes to ensure the implementation of the NRIS-H at the local level in three neighborhoods in Sevilla. Two manuscripts were published in *Gaceta Sanitaria* that represented two main studies. The first *Gaceta Sanitaria* article describes the nominal group methodology with a group of healthcare professionals with the aim of developing a tailored action plans to advocate for Gitano/a neighbors. The first manuscript reflects a Photovoice study to co-create with a group of Gitano/a neighbors. Finally, in the fourth manuscript published in the *American Journal of Community Psychology,* I present the psycho-social-political model mediated through advocacy, and the main results of the larger initiative. All the manuscripts are available in Annex 1-5. Next, I will provide the abstract of each article linked to my research objectives.

Objective 1. To create conditions for collaboration between multiple local stakeholders at the local level.

Paper 1.

Authors: Miranda, D. E., García-Ramírez, M., Balcazar, F. E., & Suarez-Balcazar, Y.

Title: A Community-Based Participatory Action Research for Roma Health Justice in a Deprived District in Spain

Journal: International Journal of Environmental Research and Public

Year: 2019 **Vol.:** 16 (19). **Pages:** 3722

Doi: https://doi.org/10.3390/ijerph16193722

Quality indicators (JCR): 3.390 [Q1 in Public, Environmental & Occupational Health]

Abstract: Addressing health disparities and promoting health equity for Roma has been a challenge. The Roma are the largest disadvantaged ethnic minority population in Europe and have been the victims of deep social and economic injustices, institutional discrimination, and structural antigypsyism over many centuries. This has resulted in a much worse health status than their non-Roma counterparts. Current strategies based on ameliorative and top-down approaches to service delivery have resulted in paradoxical effects that solidify health disparities, since they do not effectively address the problems of vulnerable Roma groups. Following a health justice approach, we present a community-based participatory action research case study generated by a community and university partnership intended to address power imbalances and build collaboration among local stakeholders. This case study involved a group of health providers, Roma residents, researchers, Roma community organizations, and other stakeholders in the Polígono Sur, a neighborhood of Seville, Spain. The case study comprises four phases: (1) identifying Roma health assets, (2) empowering Roma community through sociopolitical awareness, (3) promoting alliances between Roma and community resources/institutions, and (4) building a common agenda for promoting Roma health justice. We highlighted best practices for developing processes to influence Roma health equity in local health policy agendas.

Contributions: The conceptualization of this article was developed by Prof. García-Ramírez and myself, in dialogue with my Co-Director Prof. Yolanda Suarez-Balcazar and Prof. Fabricio

Balcazar during my stay in Chicago (USA). While in Chicago, Prof. Suarez-Balcazar deepened my understandings of health inequities, university-community partnerships, and advocacy, which played an important role in guiding how I approached the rest of my fieldwork and publications. The initial draft of the article was written with their guidance based on the pilot study financed by the International Organization for Migrations. During the peer-review process, issues of ethical considerations and rigor regarding community-based participatory action research (CBPAR) arose. It is here where I begin to debate the methodological implications of CBPAR and the scientific value of co-created knowledge.

Other related publications:

Suarez-Balcazar, Y., Viquez, F., Miranda, D.E., & Early, A. R. (2020). Barriers to and facilitators of community participation among Latinx migrants with disabilities in the United States and Latinx migrant workers in Canada: An ecological analysis. *Journal of Community Psychology*, *48*(8), 2773-2788. https://doi.org/10.1002/jcop.22452

Quality indicators (JCR): 2.82 [Q2 in Psychology, Multidisciplinary]

Objective 2. To build advocacy capacity among health professionals and organizational managers.

Paper 2.

Authors: Albar-Marín, M. J., & Miranda, D. E.

Title: Advocacy for Roma health: In-service training of professionals from the Health District Sevilla

Journal: Gaceta Sanitaria

Year: 2019 **Vol.:** 34 (4) **Pages:** 411-414

Doi: https://doi.org/10.1016/j.gaceta.2019.07.010

Quality indicators (JCR): 2.139 [Q3 Health Policy and Services, and Public, Environmental & Occupational Health]

Abstract: This article describes a workshop whose objective was to build Roma health advocacy capacity among a group of health professionals. Health advocacy is recommended by international organizations and public health experts to overcome the health inequities that Roma populations suffer. Sixteen professionals from three health centers located in neighbourhoods with a high Roma population participated. The workshop was organized in three sessions aimed at raising awareness, sharing an advocacy framework and methodology and designing an advocacy plan. We highlight the utility of spaces for reflection and analysis, the need to advocate for Roma health with Roma leaders and community sectors, identification of opportunities and utilization of community resources. Future research should strengthen the development of intersectoral advocacy plans, disseminate them and facilitate their implementation in other contexts with similar characteristics.

Contributions: Prof. María Jesús Albar-Marín is an expert in public healthcare systems. We collaboratively designed the in-service training, and I worked on the preparation of the early drafts of this document. The in-service training followed consensus group methodologies and was recognized by the healthcare district as part of their professional in-service training program.

Objective 3. To co-create knowledge among a group of Gitano/a neighbors.

Paper 3.

Authors: Miranda D. E., Gutiérrez-Martínez, A., Vizarraga Trigueros, E., & Albar-Marín, M. J.

Title: Training for Roma health advocacy: a case study of Torreblanca, Seville

Journal: Gaceta Sanitaria

Year: 2020 **Vol**.: n/a **Pages**: n/a

Doi: https://doi.org/10.1016/j.gaceta.2020.09.002

Quality indicators (JCR): 2.139 [Q3 Health Policy and Services, and Public, Environmental & Occupational Health]

Abstract: *Objective.* The objective of this study is to build advocacy capacity among a group of gipsy Roma neighbours living in contexts of risk of social exclusion*.* *Methods.* A Community Based Participatory Action Research design was used, in which 4 members of the community participated in the process of collecting evidence by photo-voice, analysing it using the ReACT method and disseminating the results. *Results.* A total of 96 pieces of evidence were collected and analysed for qualitative data analysis. These were categorised according to (a) the type of unhealthy conditions and (b) the area of the neighbourhood where they were located. The subsequent thematic grouping made it possible to identify the causes: (a) the abandonment of public services; (b) discrimination; and (c) the lack of Roma presence in community spaces. The consequences identified were (a) mental and physical health problems and (b) the normalisation of undignified living conditions. The plan was designed to advocate for the presence of Roma in community spaces. *Conclusions.* Our study highlighted the relevance of the photo-voice to transcend the biomedical perspective and develop advocacy actions based on the knowledge created by the community. Future research should look more deeply into the impact of health advocacy on reducing inequalities and consider the importance of involving researchers, public health professionals and the community in addressing it.

Contributions: This paper reflects a snapshot of the fieldwork developed in one neighborhood in collaboration with our practicum student Ana Gutiérrez-Martínez and our community partner led by Emilio Vizarraga-Trigueros, an influential Gitano community leader. The three of us worked closely together daily to implement Photovoice and this document is evidence of our joint efforts. My role was to conceptualize the Photovoice methodology inspired by both public health and community psychology literature. Prof. Albar-Marín was a researcher on the *Road4health* project who led the work with health care professionals and supported developing the final drafts for publication.

Other related publications:

Miranda, D. E., Zhelyazkova, L., & Sladkova, J. (2021). A Photovoice Project for Ethnic Health Justice: Reflections from Romani Communities in Seville, Spain. *Global Journal of Community Psychology and Practice. 12* (2). https://www.gjcpp.org/pdfs/MirandaEtAl_Final-a.pdf

Objective 4. To advocate for health justice of the Pueblo Gitano.

Paper 4

Authors: Miranda, D. E., García-Ramírez, M., & Albar-Marín, M. J.

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

Journal: American Journal of Community Psychology

Year: 2020 **Vol.:** 66 (3-4) **Pages**: 347-357

Doi: https://doi.org/10.1002/ajcp.12443

Quality indicators (JCR): 3.554 [Q1 in Psychology, Multidisciplinary and Public, Environmental and Occupational Health]

Abstract: The pervasive failure of policies aimed at overcoming health inequities suffered by European Roma 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 prove 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 toward 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.

Contributions: This article reflects the "big picture" of the *Road4health* project in which I led the fieldwork under the guidance of Prof. García-Ramírez. I present the advocacy model linked to a psycho-social-political empowerment journey, as well as the strategies we co-designed with our community partners for health justice advocacy. This article reflects the relationships we built with various actors, especially the close collaboration with the groups of Gitano/a neighbors. The final reflections proposed by the article inspired the continued funding of the RoMOMatteR project, a transnational project aimed at addressing gender discrimination from a reproductive justice lens (For more information www.romomatter.org)

Other related publications:

Miranda, D.E., Escobar-Ballesta, M., Vizarraga-Trigueros, E., Albar-Marín, M.J., & García-Ramírez, M. (in press). Overcoming health inequities of silent Roma ranks from a social justice perspective. In C. Walker & A. Zolli (Eds.), *New ideas for new times: a handbook of innovative community*

Chapter IV.

Discussion

I present a multi-level advocacy framework for Romani health justice that provides lessons learned to improve the implementation of Romani health policies. The methodological implications permeated through multi-level advocacy process addressed the persistent challenges caused by antigypsyism. The intertwined nature of antigypysism and the historical resistance of Romani communities requires new ways of doing research to develop transformational health policies. Based on our experience in Sevilla, Spain, the multi-level advocacy phases offer a set of general contributions to improve the implementation of the National Roma Integration Strategies Health Component by (1) developing processes to ensure the co-production of knowledge, (2) advancing the role of civil society organizations as empowering political structures, and (3) recognizing that people have the capacity to influence change.

NRIS-H established a set of solutions to improve Romani health, “for Roma, without Roma”. The assumption that Romani communities need answers to persistent problems but should not be a part of the solution is a symptom of political structures that still consider Romani people as outsiders and inferior. The phases of multi-level advocacy in our work revealed that the NRIS-H was not recognized by the community at the local level. For example, in the case study of Torreblanca, we implemented a Photovoice methodology to support a psycho-socio political journey in which a group of Gitano/a neighbors asked questions that were relevant to them and identified the political dynamics that sustained marginalizing conditions. CBPAR tools can counter oppressive mechanisms by developing the political capacity of Romani communities. In this sense, the researchers recognized Gitano/a neighbors as co-producers of knowledge and, as such, as holders of Romani health rights. Shifting how knowledge is being produced and presented is important for disrupting power dynamics. It is also a mechanism for political accountability that gives power back to communities (Popay et al., 2020).

Also, the NRIS-H did not include legitimate representatives of local Romani communities. The development of policies was based on antigypsyist assumptions that Romani communities are disorganized, unqualified, nomadic, and lacking their own participatory structures. In fact, the Roma Decade and NRIS-H determined the Romani actors deemed to be legitimate (i.e. non-governmental organizations and influential activists) and how Romani would participate in existing political structures (yearly platforms and summits that take place in Brussels). It handpicked interlocutors with whom political leaders felt mutual understanding, to advance a Eurocentric health agenda. Therefore, participation and representation took place in the form of tokenism and co-optation.

In a 2017 study, Cohen & Marshall (2017) found that advocacy could play a role in furthering a neoliberal agenda if based solely on top-down approaches. Thus, in regard to the NRIS-H, this inadvertently duplicated a set of established power dynamics that generated efforts that supported Eurocentric, antigypyst political structures. The multi-level advocacy model unveiled the power dynamics between the influential NGOs and Gitano/a neighbors living in marginalized contexts. Roma NGOs were positioned to compete against one another for limited funds to implement programs that endorsed a paternalistic relationship with the community. The competitive nature that NGOs were obligated to assimilate contributed to a false narrative regarding their influence and power. In the community mapping studies I present, we found that Romani participated in their own well-established structures, for example, the Evangelical church or family networks. The model proposes legitimizing new local Romani actors and provide tools to develop their capacities to represent themselves. Thus, NGOs should be regenerated by using these tools to gain a real sense of political engagement on their own terms.

The trajectory of policies aimed at Romani inclusion is still rooted in established structures that need to recognize Romani as political subjects. There is extensive research on community engagement in health policy and systems, and it has been shown that participation exists on a spectrum of varying degrees (Crawford et al., 2002; Francés et al., 2016; Hahn et al.,

2017) For example, the type of participation we see at the E.U. and national levels mimics a one-off, “user” consultation process. Thus, it is a passive form of participation with no long-term transformational change for Romani communities. Romani communities that have been abandoned on the margins cannot be expected to engage with structures and actors that have violated their rights for hundreds of years. Successful public health initiatives incorporate the real involvement of local communities (Blas et al., 2008; de Freitas, 2017). In this sense, a multi-level advocacy framework is intentional in in that Romani people themselves consider who it is important to collaborate with, determine which methodologies will be utilized to co-produce knowledge, understand such knowledge, and determine how to act on it.

The COVID-19 pandemic unveiled a new era of collective uncertainty and a moment of public distrust in political and scientific institutions. The growing levels of uncertainty challenged the legitimacy of institutions for marginalized groups and have revealed gaps in public health (Madar et al., 2020). This has called into question the nature of knowledge production to inform policies and has elucidated a contrast between top-down and bottom-up perspectives (Parmet & Paul, 2020). During COVID-19 regulations and protocols were again reflective of a Eurocentric position, and Romani communities were expected to abide by those terms. The pandemic has given way to a new reality in which groups have their own agendas and must be necessarily involved in policy. The cost of policy making without involvement from Romani communities contributes to further advancing antigypysism, as populists will continue to narrate the Romani identity as outsiders. For this reason, it is important to build the political capacity of community leaders to be critical of the power dynamics at play.

Lessons can be seen in other transnational movements, such as Black Lives Matter or #MeToo. These movements have shown the power of self-representation as well as the power of interactive knowledge production via digital platforms (Mundt et al., 2018). The Black Lives Matter addressed systemic racist violence towards Black communities in the United States, while #MeToo denounced gender discrimination and violence. The co-production of knowledge via social media—for example from influencer platforms and crowdsourcing—can teach us that sharing similar experiences and democratizing information can create meaningful change and produce new leaders. CBPAR is a relevant approach in this new scenario of a globalized digital world, in which images can connect people and ignite a movement to keep political powers accountable for ensuring social justice. As we look forward, we must take into consideration that complex, shared problems (i.e., the pandemic, climate change) will require us to learn to work in a new, cooperative, and horizontal ways, in which we legitimize the experiences of various groups.

1. Limitations

The methodological implications I propose here have undergone a series of challenges that created tensions with traditional forms of qualitative research. First, project length is an important and influential component to consider. Projects of this political nature do not exist in a vacuum; that is to say, outside of European, national, and local contexts. Funding that is short-lived has consequences for communities, since it creates expectations and because funding often ends before the larger advocacy goals can be met. For example, during the time of the implementation of this project, the regional government in Seville changed, and a new wave of public service providers were put in charge. Staying abreast of the political agenda of a new cohort of professionals was not possible. This brings into question the sustainability of projects of this type in cases when they are not made into institutional protocol. It should be noted, however, that institutionalized protocol is not exempt from being pushed back by the political agendas of healthcare managers, and in the hands of the wrong professionals, protocol can become a tool for fulfilling institutional requirements (Roura, 2021). Thus, a project must be ready for a rapid response in terms of a change in relevant stakeholders.

It is also important to note the role of trust as it is mediated between non-Romani researchers, organizations, and the neighbors. As university-based researchers, our capacity to evaluate the impact of longstanding initiatives in the neighborhoods put into question the relevancy of Romani organizations. This created tensions between the university and the organizations, furthering a sense of mistrust. The community organization abandoned the project during the final implementation stage, as we called into question the user-service model that the organization employed. On the one hand, this was a key result of the project, as it shed light on the unjust conditions Romani organizations must endure as a part of the established political structures. They compete for resources, and in many cases are the only source of employment for Romani people living in marginalized neighborhoods. At the same time, we developed meaningful relationships directly with the neighbors, with whom we shared formal and informal spaces. We were able to cross longstanding boundaries to co-create knowledge and explicitly address the unjust power dynamics that exist between university-based researchers and neighbors. During these encounters researchers still played a role in controlling the expectations of the community, as we continued to navigate tensions between established structures and Romani structures.

2. Recommendations

The 2020 the European Commission published a document titled "EU Romani Strategic Framework for Equality, Inclusion and Participation" (EC, 2020). The new EU framework recognizes the low impact of previous policy initiatives. The elements I have previously highlighted are reflected in the document through horizontal objectives that prioritize Romani equality, inclusion, and participation. This document also recognizes the importance of an intersectional approach that takes into consideration the multiple voices within Romani communities, especially the role of Romani women and girls. Table 2 presents the type of objectives with the EU-level targets.

Table 2

Summary of the EU Romani Strategic Framework for Equality, Inclusion and Participation (2020)

Type of objective	Objectives	EU-level targets
Horizontal objectives are a renewed set of commitments to equality, inclusion and participation	Fight and prevent antigypsyism and discrimination	Cut the proportion of Roma with discrimination experience by at least half Decrease the proportion of general population who feel uncomfortable having Roma neighbors by at least a third
	Reduce poverty and social exclusion to close the socio-economic gap between Roma and the general population	Cut poverty gap between Roma and general population by at least half Cut poverty gap between Roma children and other children by at least half
	Promote participation through empowerment, cooperation, and trust	Capacitate and engage at least 90 NGOs in EU-wide coordinated Roma civil society monitoring Ensure participation of Roma NGOs as full members in national monitoring committees Double proportion of Roma who file a report when they experience discrimination Encourage participation of Roma in political life at local, regional, national and EU levels
Sectoral objectives define the social determinants of health in the areas of education, employment, housing and healthcare	Increase effective equal access to quality inclusive mainstream education	Cut gap in participation in early childhood education and care by at least half Reduce gap in upper secondary completion by at least one third Work towards eliminating segregation by cutting at least in half the proportion of Roma children attending segregated primary schools
	Increase effective equal access to quality and sustainable employment	Cut employment gap by at least half Cut gender employment gap for Roma by at least half Cut gap in NEET rate by at least half
	Improve Roma health and increase effective equal access to quality healthcare and social	Cut life expectancy gap by at least half
	Increase effective equal access to adequate desegregated housing and essential services	Reduce gap in housing deprivation by at least one third Cut gap in overcrowding by at least half Ensure that at least 95% of Roma have access to tap water

I present a series of recommendations based on the multi-level advocacy framework to guide the implementation of the new policy framework:

Redefine the role of Romani Civil Society and networks. Based on the premise that people have the capacity to represent themselves, organizations should challenge traditional hierarchical structures and strive to become a space that begins the psycho-social-political empowerment of other groups. The same organizational actors occupying the same positions of power over time loses relevance, as new priorities emerge. Sharing leadership roles is key to regenerating social movements. Understandably, there are moments organizations play a key role providing basic resources for communities—for example, during the pandemic--but this should be done as a parallel process that generates new local leaders as well (Wilson, 2020). Lessons can be learned from the various settings for resistance to injustices that immigrant groups have developed (Buckingham et al., 2021). As proposed by The Global Development of Applied Community Studies, local capacity building can be inoculated in various fields such as public health, urban planning, social work, and public administration (Lyew et al., p. 2, 2021). The focus should be on developing and recognizing locally based power and strengths (Council of Europe, 2018).

Expanding borders in research to recognize Romani policy agendas. Researchers are individuals who exist within political and social structures—both in our local communities as well as the wider national and global context. Therefore, it is imperative that we all develop our political capacities of standing in solidarity with traditionally marginalized groups and use our positions for transformative changes. Staying faithful to our research methodologies is a form of replicating the oppressive mechanisms that sustain health inequities, ironically the opposite of what our objectives intend to do. The top-down approaches that solely rely on the knowledge of outside experts contributes to pre-established structures that keep power in the hands of a few, further diluting the meaning of participation. Community power must be recognized and respected in the research process which implies a sense of humanity, a shared ethical responsibility and flexibility. Therefore, research paradigm must acknowledge the feedback of local actors and negotiate pre-existing methodological notions. The co-production of knowledge has the potential to rebuild trust between people and recognize our plurality.

Promote the political leadership of Romani women and youth. A human rights-based approach offers a new form of approaching solidarity that legitimizes the experiences of Romani women and girls. Supporting the leadership of Romani women at the forefront has the potential to create a unified resistance and not a form of confrontation or conflicting agendas. For example, Loretta Ross and her colleagues at SisterSong, are exemplary of how research and advocacy efforts can ensure transformative change, recognizing the nuanced experiences that exist among women (Ross, 2017).

The recent EU Rights of the Child document highlighted the development of youth capacity to participate in civic life (European Commission, 2021). In regard to Romani girls, a multi-level advocacy framework can help various actors create spaces from a young age to critically reflect and narrate their own experiences. Romani girls have the right to imagine their futures. This is a developmental process of mattering that can ensure psychological and collective wellbeing (García-Ramírez et al., 2020). The political capacity of youth ensures that rebuilding social and political structures includes connecting to diverse voices and understanding the mutual recognitions and influencing change. New technologies can help Romani girls connect to girls in other contexts who are experiencing similar issues and gain social support and see a world beyond the isolation of marginalized contexts that replicate oppressive structures generation over generation.

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Annex 1

Miranda, D. E., Garcia-Ramírez, M., Balcazar, F. E., & Suarez-Balcazar, Y. (2019). A community-based participatory action research for Roma health justice in a deprived district in Spain. *International Journal of Environmental Research and Public Health, 16*(19), 3722. https://doi.org/10.3390/ijerph16193722

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Article

A Community-Based Participatory Action Research for Roma Health Justice in a Deprived District in Spain

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Abstract: Addressing health disparities and promoting health equity for Roma has been a challenge. The Roma are the largest disadvantaged ethnic minority population in Europe and have been the victims of deep social and economic injustices, institutional discrimination, and structural antigypsyism over many centuries. This has resulted in a much worse health status than their non-Roma counterparts. Current strategies based on ameliorative and top-down approaches to service delivery have resulted in paradoxical effects that solidify health disparities, since they do not effectively address the problems of vulnerable Roma groups. Following a health justice approach, we present a community-based participatory action research case study generated by a community and university partnership intended to address power imbalances and build collaboration among local stakeholders. This case study involved a group of health providers, Roma residents, researchers, Roma community organizations, and other stakeholders in the Poligono Sur, a neighborhood of Seville, Spain. The case study comprises four phases: (1) identifying Roma health assets, (2) empowering Roma community through sociopolitical awareness, (3) promoting alliances between Roma and community resources/institutions, and (4) building a common agenda for promoting Roma health justice. We highlighted best practices for developing processes to influence Roma health equity in local health policy agendas.

Keywords: Roma; health inequities; antigypsyism; health justice; community-based participatory action research

1. Introduction

Roma poor health outcomes are a manifestation of the prevalent marginalization and discrimination they continue to suffer [1]. It is estimated that between 12 and 15 million Roma currently live in Europe, making them the largest ethnic minority group on the continent as well as the poorest and the unhealthiest [2]. The World Health Organization (WHO) and the EU Fundamental Rights Agency (FRA) have denounced that 80% of European Roma have a life expectancy up to 15 years lower than the non-Roma population as a consequence of living in marginalized communities under the poverty threshold [3]. After 14 years of sustained intergovernmental political efforts aimed at overcoming these inequities, there is a general consensus that this scenario—far from improving—has worsened, and the inefficiency of initiatives is due in part to the underestimation of systemic "antigypsyism" embedded in European society [1]. Antigypsyism is a historically constructed, persistent complexity of customary racism against social groups identified under the stigma “gypsy”. “Gypsy” homogenizes these groups and incorporates social structures and violent practices focused on reproducing structural disadvantages [1,4–7]. Antigypsyism has forced Roma to endure on the margins of society while preventing them from accessing the fundamental opportunities and resources required to enjoy a healthy life.

The WHO urges for a health justice approach in order to create an ethic of public affairs where every individual—regardless of ethnic origin—has the resources to be as healthy as possible according to their personal values and traditions [8]. Therefore, initiatives are encouraged to focus on creating opportunities for Roma to engage in decision making regarding the allocation of resources [9]. We present a collaborative action-research process involving Roma residents, academic researchers, and health and social care providers aimed at developing health justice in Poligono Sur, a disenfranchised district in southern Spain with a high Roma population [10].

In this section, we provide a general overview of how antigypsyism jeopardizes Roma people’s health, the theoretical components for Roma health justice, and the methodological approach of the initiative. In the following section, we present a case study for Roma health justice in Poligono Sur, Seville (Spain). Finally, we present lessons learned and recommendations to incorporate this framework for future initiatives. For the purpose of this paper, Roma refers to people living in a specific neighborhood (i.e., Poligono Sur) who identify themselves as “Gitanos/as”. Roma is the term adopted by the Council of Europe to refer to ethnic groups such as “Roma, Sinti, Kale and related groups in Europe, including Travellers and the Eastern groups and covers the wide diversity of the groups concerned, including persons who identify themselves as Gyspies” [11], p. 4.

1.1. Antigypsyism and Roma Health Inequities in Spain

Antigypsyism (also Romaphobia) is “defined as a form of dehumanisation, because prejudice against the Roma clearly goes beyond racist stereotyping whereby the Roma are associated with negative traits and behaviour. Through dehumanisation, the Roma are viewed as less than human; and, being less than human, they are perceived as not morally entitled to human rights equal to those of the rest of the population” [11], p. 12.

Antigypsyism in Europe has been forged over centuries. Since their arrival in Europe, the history of Roma has been forged by persecution, systematically fleeing from slavery, widespread intolerance, expulsions, genocide, racist attacks, and punitive laws on their traditions and ways of life [12]. They have—and are—being constantly forced to move or to settle in segregated neighborhoods where they suffer from discrimination, poverty, and substandard living conditions [13,14]. In Spain, Roma are the largest ethnic minority—between 700,000 and 900,000—and more than 40% live in the southern Spanish region of Andalusia [15]. Spanish Roma have paradoxically oscillated between fascination and repudiation to the point that they were the most disliked group in Spain in comparison to other minority and impoverished groups (e.g., migrants, Muslims, homeless people) [16]. Modern day practices of expulsion continue to occur, such as patterns of gentrification that obligate their displacement, perpetuating spatial segregation, living in unsanitary settlements and insecure, and overcrowded living conditions [2,17,18].

Antigypsyism is also embedded within public service systems, including healthcare services. This is exemplified by accessibility barriers, negative attitudes of providers, exclusion from public health campaigns and programs, and absence of basic services in their neighborhoods [19]. National health surveys in 2014 reported worsening health conditions measured by indicators such as self-perceived health, chronic diseases, hearing and sight problems, dental cavities, obesity, and diabetes [20]. These surveys showed that an estimated 77% of Roma live in relative poverty, and their health status is significantly lower than that of low-income non-Roma. Roma health is also worse than non-Roma in all age segments [21]. The austerity measures implemented by the Spanish government from 2008 have exacerbated these health inequities while undermining measures taken to combat them [22].

Roma have developed a strong sense of agency in order to survive under these circumstances. This has been interpreted by non-Roma people as Roma's inability to live "integrated" into mainstream society [23]. For example, given Roma's values for extended family ties, it is typical for the extended family to be present and care for their sick loved ones when they are treated in healthcare services (e.g., primary health care centers, hospitals). Non-Roma Spaniards have a hard time accepting this cultural value. Dealing with a large number of extended family members makes communication between patient and providers challenging. This is commonly seen as unacceptable behavior by healthcare providers [24,25]. Daily interactions transform Roma protective factors into opportunities for discrimination in such a way that Roma are hostage to the antigypysist narratives, practices, and laws that are used against them [26]. Health care policies are habitually designed and implemented without Roma people's input, in part due to the belief that they are incapable of achieving a prosperous life [6,8].

In 2011, the Spanish Ministry of Health adopted the European policy framework—known as National Roma Integration Strategies (NRIS)—to respond to these inequities [27]. This framework assumes that Roma health inequities are a "wicked challenge" due to their pervasive character, the lack of consensus about causes, difficulties developing collaboration and commitment among stakeholders, absence of an intersectoral approach, and the absence of Roma influence [19]. This framework underscores the need for Roma organizations to be involved in the design, the implementation, and the assessment of the initiatives. However, recent reports indicate that, while Roma organizations are under pressure to implement programs, their voices are not being heard; thus, they are unable to represent the voices of the most vulnerable Roma people, and therefore the programs being implemented are not recognized by Roma communities [28–30]. In the 2018 12th meeting of the European Platform for Roma Inclusion, it was concluded that specific programs implemented in partnership between healthcare institutions and Roma organizations aimed at reducing the high rate of obesity among Roma, improving sexual and reproductive health, or increasing campaigns to promote awareness for vaccination have not achieved—and in some cases have worsened—their desired outcomes [31]. To challenge antigypsyism structures and to address its consequences in Roma health, this paper proposes a health justice approach

1.2. *Roma Health Justice*

A Roma health justice (RHJ) approach would allow us to understand that (a) Roma health inequities are determined by the negative influence of antigypsyism over all social structures and (b) the lack of opportunities in sociopolitical participation is one of the most concerning consequences of pervasive antigypsyism [32]. Adopting a RHJ approach requires highlighting and mobilizing Roma capacities to lead in changes that follow the needs and the *interests* of the locality/neighborhood through: (a) strengthening Roma health assets; (b) developing capacity to influence among silenced Roma neighbors; (c) articulating Roma first-hand influential participation in community spaces; and (d) meaningful involvement of Roma in the reallocation of significant resources [8,33,34]. This approach requires specific community-based methodologies capable of building shared critical knowledge while inspiring sociopolitical change.

1.2.1. Strengthening Roma Health Assets

An asset-based approach to health involves identifying strengths within the community and involving Roma in developing solutions to their health needs based on their own resources [35]. This approximation transcends traditional deficit-based approaches without the participation of Roma, thus developing systems in which Roma communities become dependent on professional and institutional resources [19]. Following community development literature, we define assets as individual, community, organizational, or institutional resources or characteristics that promote health and wellbeing for Roma [36]. Roma have shown resilience based on their traditions, family structures, sense of spirituality, solidarity, and commitment. These values have allowed them to remain cohesive in extremely adverse circumstances [37]. Over centuries of discrimination, Roma have maintained their collective mattering through insufflating their traditions, their collective values, and their artistic expressions [32]. This has contributed to an unbreakable capacity to build in-group identity and an extraordinary capacity of distinction from the out-group. In fact, the lack of a homeland has given them a strong ability to quickly transform the places where they arrive into their own; the lack of a state has led them to develop resilient standards for living together. The streets where they meet are important community spaces where they weave their social networks, and the households where they live become safe and empowering settings for children and elderly. For example, a recent study in Spain showed that the Evangelical church plays an important role for some Roma populations by providing a protective and supportive social environment [38]. These elements have a strong meaning for their living standards and—indeed—in the meaning of their health and in their culture of care [39]. The benefits of an asset-based approach highlights the capacity of Roma communities to guide change and reverse the misconception that they are helpless and dependent [35,40].

1.2.2. Developing Capacity to Influence among Silenced Roma Neighbors

The RHJ approach strengthens an intersectional perspective capable of integrating the multiple axes of vulnerability that Roma suffer in impoverished neighborhoods [41]. Narrower approaches have not only led to the invisibility of the most disenfranchised groups but have even worsened their health outcomes. RHJ overcomes assuming that all Roma share the same experience and recognizes the complexity of discriminatory intersections and its effects by including the voices of those who suffer multiple sources of inequities [42]. In order to challenge dominant discourses, RHJ aims to strengthen broad and effective participation of usually silenced groups by deconstructing and reconstructing individual and group narratives [33,43–47]. Based on self-construction theory, this implies facilitating processes that empower Roma communities to redefine their individual and group experiences as a violation of their health rights and recognize their strengths to defend them [48]. RHJ develops leadership of silenced Roma ranks by promoting socio-political awareness of their health rights, identifying discriminatory experiences, becoming aware of their agency, and developing capacity to take action [45,49,50].

1.2.3. Building Collaborative Capacity among Key Stakeholders

For Roma to influence change within their community, local key stakeholders who exert power over local resources and decision-making processes need to recognize them as legitimate stakeholders. Community organizing tactics that examine the power dynamics involved in contexts should be employed [34]. This consists of reexamining the role of mediating structures that maintain the status quo and institutions that comprise providers with negative attitudes towards Roma [51]. For example, at the organizational level, Roma community-based organizations (CBOs) are treated as mediating platforms between public institutions and silent Roma ranks. Roma CBOs assume responsibility of addressing Roma-needs but lack in dismantling dominant and antigypsyist narratives within prestigious organizational structures. The literature strongly proves that culturally sensitive providers can contribute to individual and community socio-political control to explicitly address discrimination [52,53]. Developing Roma sensitivity among non-Roma providers is required to deconstruct their unfair and oppressive narratives. This requires being aware that their performance could be biased by their social-cultural privileges while becoming necessary allies of initiatives led by Roma [54].

1.2.4. Meaningful Involvement of Roma in the Reallocation of Significant Resources

An RHJ approach aims to develop alliances in order to promote collaboration between different sectors and encourage systemic agreements and strategies [44]. This builds a sustainable and shared decision-making platform of overarching health priorities at the local level that can quickly mobilize stakeholders and resources [55]. Following community development strategies, HJA creates opportunities for dialogue between multiple stakeholders, promotes the leadership of Roma neighbors, and develops social solidarity through shared critical knowledge [56]. Creating participatory structures gives opportunities to silenced groups to articulate their priorities and translate their local knowledge to influential Roma organizations who do have political opportunities during the policymaking process [57]. This involvement leads to safe and empowering community spaces to exert real influence on the initiatives and the policies that affect them [58].

1.3. Community-Based Participatory Action Reserach

An RHJ approach requires being implemented through community-based participatory action research (CbPAR). Understood as an instrument for social change in the struggle against oppression, we conceive CbPAR as "a process through which members of an oppressed group or community identify a problem, collect and analyse information, [identify allies and create alliances] and act upon the problem in order to find solutions and to promote social and political transformation" [59], p. 17.

The implementation of CbPAR processes requires the appropriate time, multiple strategies (e.g., participatory observation, testimonials, narratives, advocacy, art-based performances), multiple stakeholders, and the meaningful involvement of people with different capabilities in order to gain a deep understanding of geographic contexts, use of space, the role of community resources, etc. [60].

CbPAR has proven to be a suitable methodology in addressing health inequities of ethnic minorities. It has shown its capacity to identify and address problems related to human immunodeficiency virus (HIV) infections, nutrition, obesity and diabetes, gender violence, mental health conditions, drug abuse, cardiovascular diseases, families with children with disabilities, as well as health promotion among ethnic-based groups [58,61–65].

Therefore, CbPAR supports RHJ because it targets the promotion of the leadership of Roma guided by Roma needs and resources and driven by their strengths and cultural patterns, ultimately building among participants a sense of belonging, skill development, and meaningful engagement and leadership. This approach gives real power to Roma participants to instigate system changes while incorporating the best available scientific evidence [61]. Researchers act as critical friends, providing technical assistance, guidance, training, and partnership with communities as a way to develop local-based evidence that highlights valuable resources, identifies and prioritizes their community concerns, and advocates for them in local agendas.

2. Case Study

2.1. Background

2.1.1. Community Context

There are an estimated 40,000 people living in the district of El Poligono Sur (PS), and approximately 20% identify themselves as Roma. Although there are no reliable data on the number of Roma living in the PS, as the census does not collect ethnic information, it is a well-known Roma enclave. In the 1960s, the Roma communities and families living in Triana, a historical and emblematic Roma neighborhood in Seville, were displaced to the PS as a result of gentrification and forced resettlements. PS is the poorest district in Spain, characterized by poor housing conditions, high unemployment rates, high rates of school absenteeism, and worse health status as compared to the rest of the city (Seville). Women have a life expectancy six years less than the rest of the population, and men have a life expectancy 10 years less [66]. These data are similar to those obtained by the Roma National Health Survey carried out in 2014 [67]. Today, the majority of Roma continue to live in the most precarious conditions and in the most excluded areas of the district.

PS has an extensive history of community-based activism that demanded from the City Council resources to improve the living conditions. As a result, in 2005, the City Council supported the development of a local plan [68]. This plan was supervised and implemented by a local public institution that promotes collaboration between organizations through intersectoral working groups that address health, education, housing, and employment. The local public institution has an important influence over local public services and community-based organizations, such as leading on coordination and collaboration. However, despite these efforts and the allocation of resources to PS, the Spanish National Institute of Statistics classifies PS as the most impoverished neighborhood in Spain [69].

A recent study evaluating the national Roma integration strategies health component in PS revealed that Roma populations are invisible in these local policies, plans, and participatory platforms [70]. For example, Escobar-Ballesta et al. (2018) [28] found that PS sexual and reproductive health programs focused on family planning have not been successful, in part because they ignore the Roma people's voices and their value towards large families and moral constraints in sexual patterns. Local policies and programs are ignoring other at-risk contextual factors. These previous studies highlight that PS continues to implement strategies that are based on mechanisms of equality, thus excluding the most at-risk groups, such as Roma, living in the most vulnerable areas.

2.1.2. The University-Community Partnership

This study was implemented by a university and community partnership, which followed the principles of mutual benefits and community engagement as articulated by Suarez-Balcazar, Harper, and Lewis (2005) [71]. University-community partnerships (henceforth partners) are considered reciprocal relationships in which university partners provide methodological tools for evaluation and identification of best practices as well as access to resources, while community partners provide in-depth knowledge of the community context, cultural sensitivity to decision-making processes, and access to hard-to-reach community members. The partnership of this study was composed by the Center of Community Action Research of the University of Seville (CESPYD, Coalition for the Study, Health, Power and Diversity; www.cespyd.org), which has experience developing and implementing action-research methods with communities. The community partner, FAKALI, (Federation of Roma Women's Association), is a Spanish platform of Roma women (www.fakali.org) who have experience working directly with communities and advocating for Roma rights and political representation in the Roma State Council. In the case of Polígono Sur, FAKALI was participating in health working groups in order to ensure that Roma health was included in local agendas. CESPYD led a previous study that evaluated Roma health policies at the national level in which FAKALI participated. This past collaboration consolidated the relationship between CESPYD and FAKALI. Lessons learned from this experience highlighted the strengths of this type of partnership for future Roma health policy evaluations at the local level [72]. We refer to FAKALI as the community partner and CESPYD as the research partner in this paper.

2.2. *Participants*

The community partner's initial contact with the local health policy coordinator, their participation in health working groups, and their experience with the primary healthcare center facilitated recruitment of health care providers. We invited providers from health working groups with semi-structured interviews and surveys (described below) to participate in the study. A total of eight sensitive providers from social services, primary healthcare centers, the public housing agency, and waste management services participated. These providers participated on the basis of their personal motivations and needs to improve their services through ensuring Roma-sensitive services. The providers' roles were to participate in workshops that support Roma health justice, be a reference within their organizations for Roma health, recruit other providers to participate in the study, and nominate local Roma community members (henceforth "neighbors").

Community partners and providers nominated Roma neighbors to participate in order to ensure a fair selection process. Research partners held face-to-face interviews with the nominees and invited neighbors to participate based on the following criteria: (a) identify themselves as Roma; (b) reside in the most impoverished areas of the district; (c) self-recognized as valuable members of Roma community; and (d) leadership capacity. A total of 20 neighbors were invited to create a parallel working group. A total of 15 neighbors participated in the study, 13 women and two men between the ages of 24–45. We intentionally chose neighbors from three of the most disenfranchised areas of the district in order to include multiple perspectives and reach the most silent groups. The Universidad de Seville and the Andalusian Health Council ethical board approved the implementation of this initiative, all participants signed informed content, and neighbors were given an economic compensation for their time in participating in this initiative.

2.3. Procedure

As depicted in Figure 1, we designed a four stage community-based participatory action research process focused on: (a) identifying Roma health assets, (b) empowering Roma through sociopolitical awareness, (c) promoting alliances between Roma and institutions and organizations and, (d) building a common agenda for Roma health justice. This study took place from February 2016 to January 2017.

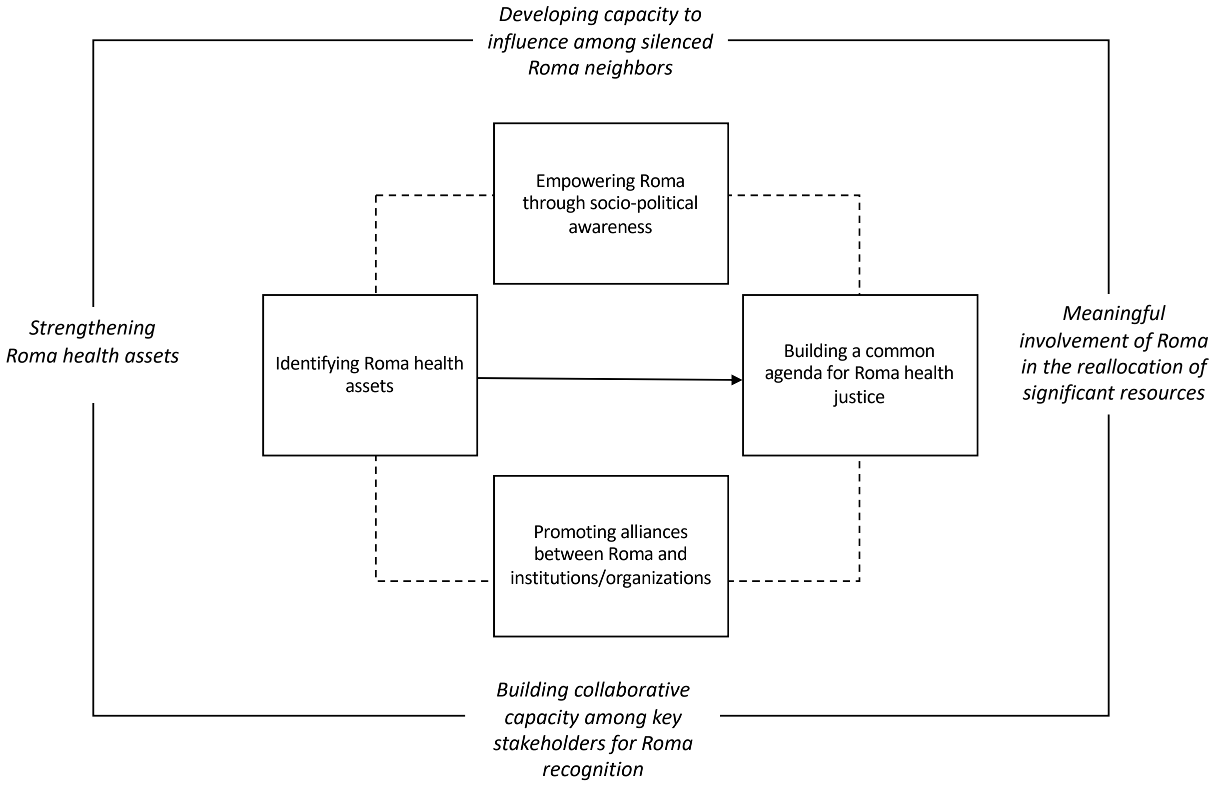

Figure 1. Community-based participatory action research process for Roma health justice at the local level.

2.3.1. Identifying Roma Health Assets

This was an iterative process targeted at identifying key stakeholders within the community. Key stakeholders included policymakers, representatives from public institutions, and Roma organizations. It was fundamental to identify Roma sensitive stakeholders in order to build a common language and purpose, to create spaces for constructive dialogue and reflection, and to develop systems of evaluation [73]. The objective of this stage was for partners and key stakeholders to build collective knowledge about the unfair Roma living conditions and the social determinants of Roma health inequities [65].

Initial semi-structured interviews with local providers were carried out in order to do a rapid community assessment of local Roma health and identify entry points into the community and potential providers to participate in the study workshops [74]. Interviews comprised the following questions: (1) "What experiences do you have working with the local Roma population?" (to better understand the background of each providers and their initial reactions towards Roma); (2) "Are there Roma-specific services?" (in order to identify existing resources and potential collaborators); and lastly, (3) "How would you describe the living conditions of local Roma population?" (to identify Roma and their relation to the most disenfranchised areas of PS). Two university partner researchers carried out eight interviews, which lasted 45–60 minutes and were recorded. Interviews were transcribed and triangulated with researcher's field notes to consolidate information.

The university partner designed surveys to identify and understand the relationship of Roma neighbors to their local health care resources, to identify potential providers to participate in the study, and to assess overall Roma sensitivity in the community. During August and September of 2016, a total of 200 neighbor surveys were collected. See Appendix A for survey questions. Neighbors were asked in what area of the district they lived and to identify services frequented by type (educational, health, social services, etc.) and then to specifically evaluate the frequented services of their choice. Partners collaborated with neighbors to conduct surveys with other neighbors who identified themselves as Roma. Surveys were intentionally carried out in local meeting points with high Roma populations such as local street markets, catholic and evangelical churches, plazas, and bars [75].

Additionally, 40 provider surveys were collected with the objective to rapidly assess provider and organizations with Roma sensitivity. We used a set of indicators selected from the Community Cultural Competence instrument. This instrument was developed to assess the equity and the cultural competence and sensitivity of healthcare providers and organizations working in multi-ethnic communities [53]. At the organizational level, questions fall under the following dimensions: (a) values and goals of the organization (e.g., social justice is an important value in my organization), (b) accessibility of services (e.g., my organization actively identifies accessibility barriers specific to the Roma community), (c) sensitivity towards the Roma community (e.g., my organization evaluates Roma user satisfaction), and (d) participation (e.g., my organization includes participatory mechanisms for Roma). Personal level dimensions include: (a) personal value of work (e.g., my work is important to me), (b) personal level of adaptation (e.g., I can adapt my work for Roma needs), and (c) sensitivity towards Roma (e.g., I value and respect Roma and/or other groups). Appendix B shows both organizational and personal level questions answered on a 5-point Likert scale.

2.3.2. Empowering Roma through Sociopolitical Awareness

This was a creative process that elicited higher-order thinking in which Roma discussed and reflected about power imbalances in their community lives, built critical knowledge around their health rights, and activated their involvement in addressing them [33,76]. To operationalize this process, Photovoice was facilitated by academic partners in order for Roma to identify concerns, share personal discriminatory experiences, and build self-determination to defend their health rights.

Photovoice workshops were designed to be spaces for reflection, dialogue, and gathering of local evidence. First, two 2 h workshops were implemented to discuss and share neighbors' health concerns. Next, neighbors agreed on a health priority and took photographs to represent it. An innovative feature of our Photovoice method was converting everyday resources, such as the personal smartphone application *WhatsApp*, to be used as a tool for health promotion and community evaluation. Each neighbor chose one priority to photograph and sent relevant photographs through the *WhatsApp* group between sessions. Two 2 h sessions were designed to share their individual photographs with the larger group. We displayed photographs on the projector to instigate dialogue. In order to facilitate discussion and identify forms of discrimination that were affecting their daily lives, we utilized the Photovoice showed methodology of Wang and Burris (1997) [63,64,77]: (a) What do you see here?; (b) What is really happening here?; (c) How does this relate to our lives?; (d) Why does this concern, situation, strength exist?; (e) How can we become empowered through our new understanding; and (f) What can we do? Data analysis consisted of identifying themes with neighbors as proposed by Foster-Fishman, Law, Lichty, and Aoun (2010) [78]. This process included individual reflections to brainstorm local Roma health problems and group dialogue to analyze causes and effects in order to categorize photographs into overarching themes and to develop recommendations.

2.3.3. Promoting Alliances between Roma and Community Resources/Institutions

We worked in parallel with health service providers from public institutions and community agencies (henceforth "providers"). The workshop objectives were to improve providers' understanding of the Roma communities through Roma health awareness and discussion of local health challenges, to create a collaborative environment, and to collect and examine data [51].

Eight workshops were scheduled on providers' availabilities and motivations to include Roma health as a priority within their work objectives. Based on problem-based learning methods, each session encouraged dialogue and reflection among participants and partners to explore Roma health inequities [79]. Partners prepared content to develop providers' sensitivity, facilitated dialogue, and, at the end of each meeting, providers committed to a follow-up action. Research partners took field notes and developed workshop minutes to follow-up with providers.

2.3.4. Building a Common Agenda for Roma Health Justice

This phase included community organizing and development strategies such as (a) a field visit of European health mediators for feedback; (b) planning a meeting between partners; (c) participating with providers and neighbors in order to consolidate their work towards Roma health justice; (d) sharing tools for community evaluation; and (e) negotiating problem definitions and potential solutions.

First, a field visit was organized in PS for health mediators from across Europe to share good practices and feedback and to develop recommendations to include Roma health justice in health mediation agendas. Next, a workshop was organized between partners, providers, neighbors, and other key stakeholders in order to share and negotiate priorities, resources, and actions. This new space for collaboration was a horizontal infrastructure that acted as an empowering community setting for negotiating local resources and increasing accountability among stakeholders [80]. Partners planned the workshop with the following content: (1) share evidence; (2) identify allies; (3) identify opportunities for Roma engagement; (4) plan for implementation and sustainability of actions. Research partners took field notes and developed workshop minutes to follow-up with providers.

2.4. Results

2.4.1. Identifying Roma Health Assets

Interviews and surveys allowed us to understand PS context, identify Roma sensitive providers to participate in workshops, and raise awareness regarding significant Roma resources. Initial interviews from community partners' existing contacts allowed for partners to understand providers' concerns as professionals working in PS and illustrate the bigger picture of Roma living conditions from non-Roma providers' perspectives. The respondents included: two social services coordinators, two center for addiction workers, two community-based organization coordinators, one rehabilitation center coordinator, and one local policy coordinator. As it is possible to see in Table 1, providers identified Roma as a significant part of PS but were implementing an equality model based on a provider–user relationship to neighbors, for example, health mediation programs by Roma organizations. Providers expressed how organizations were playing a role in health mediation but were not enough to access or understand the PS Roma community. Roma-specific actions were not included within their protocols despite being a majority of their users and the most challenging ones. Providers expressed their lack of knowledge in responding to Roma-specific needs and identified this gap in knowledge as a contributor/barrier to accessibility of services.

Table 1. Sample quotes from stakeholder interviews for Poligono Sur (PS) rapid assessment.

Question	Quotes
What experiences do you have working with the local Roma population?	"We try to work with the Roma community because it is a priority in the Poligono Sur, and we understand that they have particular needs [. . .] we are conscious that we lack mediation to better understand them, it is challenging." "The 'I am a social victim' is a persistent problem of the population here. 'By being a gypsy I have a right to everything', and this is not the reality. Because there are non-Roma people who have much greater needs and we have to be provider in a wide spectrum. We are familiar with the Roma handicaps and obviously need to help [. . .]"
Are their Roma-specific services?	"There are many local Roma non-governmental organizations however they are exclusive to only part of the Roma community so their services are not accessible to everyone who could be taking advantage of them" "[. . .] coordination is good with all community-based organizations, but many Roma organizations do mediation. When there is a real problem [with Roma] there is a lot of personal involvement then there can be no impartiality"
How would you describe the living conditions of local Roma population?	"There are many houses that are overcrowded, meaning that 3 or 4 generations are living together. They have done extensions to the original house [. . .] they are looking for, as it is logical and normal, a way to survive." "And here that happens very often [. . .] many children with substance abuse problems use the pension [of elderly family member] for consumption." "Because although these are apartment building, we consider them as vertical settlements [. . .]"

Figure 2 displays the density of Roma population represented by a color gradient separated by PS neighborhoods. The six neighborhoods were identified and defined in initial stakeholder interviews. The darker shades show a higher density of Roma population. Neighbor surveys revealed that 80% of Roma live in the worst areas of the district and confirmed that areas with high Roma population are hidden between large highways and a railroad track. Also, Figure 2 displays the services that were identified (represented by type of resources—healthcare services, faith-based organizations, Roma community-based organizations, etc.). Overall, areas with high Roma populations were lacking formal health services, and proximity to other community-based organizations (CBOs) were furthest from areas of high Roma density, except for a small Roma CBO and two evangelical churches.

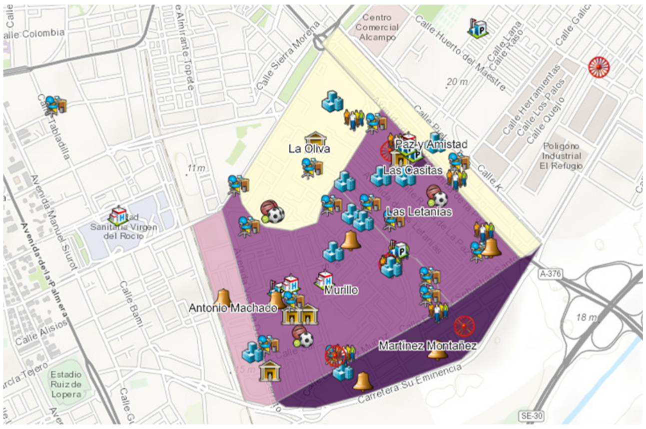

Figure 2. Screenshot of PS resources through a Roma sensitivity lens. This image shows density of Roma population (represented by darker shades) and identifies resources represented by type. For example, the bell icon represents faith-based organizations, blue centers represent educational services, and red circles represent Roma CBOs. This screenshot reveals that 80% of Roma live nearest two Evangelical churches and furthest away from formal health care services.

Surveys revealed that public services such as the Housing Agency and the Employment Office scored lowest in both user satisfaction and organizational/provider Roma sensitivity. Informal services such as CBOs and faith-based organizations scored highest in user satisfaction and organizational/provider Roma sensitivity. Specifically, two Roma-led CBOs and one evangelical church located within the area with the highest Roma population scored highest. Roma-led CBOs provided activities for Roma youth in the area, mental health services such as family counseling and workshops to increase employability, and literacy workshops. Meanwhile, the Evangelical church was identified by more than half of the respondents and frequented by most more than twice a week. This specific church is led by Roma pastors and provides spiritual and emotional support. Educational settings that identified collaboration with Roma mediation programs and implemented programs adapted to Roma needs scored highest across both provider and neighbor surveys. Health mediation programs were implemented by larger Roma organizations that were not community-based. Surveys revealed that external places out of the Poligono Sur—such as parks and squares, bars, and shopping malls—were frequented and important in the community life of Roma neighbors. This wider use of services outside the neighborhood strongly suggests the relevance of open spaces in the Roma community life and an expression of the lack of these spaces and services in their surrounding spaces and neighborhoods.

In conclusion, provider interviews recognized that health mediation was useful in bringing Roma users to services; however, these respected health mediation programs in educational and healthcare settings were being implemented by Roma organizations without the collaboration of smaller Roma CBOs. Meanwhile, Roma-led faith-based organizations and CBOs assumed the role of providing resources that were recognized by the community as their own.

2.4.2. Empowering Roma through Sociopolitical Awareness

Photovoice workshops began with neighbors defining what health meant to them as a group. Neighbors then discussed and brainstormed a list of their community health concerns. The health concerns were then categorized in the following series of priorities: (a) plazas (open outdoor spaces), (b) lack of spaces and opportunities for leisure, (c) abandoned commercial spaces, (d) lack of trash bins near their homes, (e) absence of public services (e.g., public transportation), and (f) domestic risk factors. A total of 99 photographs were taken between May and June of 2016 that were representative of these environmental factors. Photographs were taken in different areas of PS near neighbors' homes and surrounding communal spaces. Utilizing the photographs, partners facilitated discussion. Neighbors reflected on the discrimination and the abandonment they felt on a daily basis. Based on these causes, the photographs were categorized into three main overarching themes: (a) unhealthy public spaces, (b) neglect from public services, and (c) unlivable housing conditions. Figures 3–5 are examples of each of these themes with photographs and neighbors' narratives. For each theme, a series of recommendations/actions were proposed.

(**a**) (**b**) (**c**)

Figure 3. Unhealthy public spaces. (**a**) ¨There are around 40 or 50 homes and only one trash bin trash is left near the trees, the rats, mosquitos, insects, the situation is unbearable, the neighborhood is very dirty". (**b**) "There used to be two football fields. People used to play football here. I would look out the window and watch. They were going to begin construction here and took away the field and now it has turned into this". (**c**) "There are limited places for leisure. Perhaps three or four. They accumulate trash and things are left broken".


(**a**) (**b**) (**c**)

Figure 4. Neglect from public services. (**a**) "The local waste management office is only 20 meters away. They clean this area ever eight or nine days, the trash does not fit inside". (**b**) "Here we can see the neglect of the city council in regards to parks and gardens. They never come to garden and trash just accumulates". (**c**) "A big problem we have here in the Poligono Sur is the vegetation, here we do not have gardeners or anything with the consequences of fleas, rats, mosquitos, spiders, and it is incredible. You cannot see anything . . . you cannot see the plaza".


(**a**) (**b**) (**c**)

Figure 5. Unlivable housing conditions. (**a**) "There was a rehabilitation plan, they took the people out for construction and it was left half done". Despite local rehabilitation plans, "These buildings have been like this for ten years . . . homeless people and drug addicts occupy the building . . . when they are cold they build fireplaces and the building goes up in flames constantly". (**b**) "There is a hole where a wash sink was that was torn out and now it is full of trash. Next door there are people who live with the trash and smell". (**c**) This was a photograph a neighbor sent to the Whatsapp group after we finished the formal Photovoice sessions. After a day of rainfall in Sevilla, neighbors were unable to leave their homes because of the poor sewage system.

Unhealthy Public Spaces

The photographs presented under unhealthy public spaces showed the accumulation of trash everywhere, overgrown vegetation, construction left unfinished, sewage in spaces where children played, infestation of rats and insects near their homes, and commercial spaces that have been left in poor conditions. Figure 3 below represents photographs and narratives of unhealthy public spaces. Neighbors then developed the following recommendations/actions: (a) increase the number of waste bins, (b) increase frequency of waste collection, (c) raise awareness among neighbors to maintain clean spaces, and (d) improve the installations of commercial spaces.

Neglect from Public Services

Neighbors expressed an overall sense of abandonment from public services such as the waste management, parks and gardening, mail, public transport, and the local policy committee responsible for coordinating actions in the district. The conversation oscillated between blaming other neighbors for the poor conditions of common spaces to the complete neglect from those responsible of providing services in the neighborhood. It was highlighted that, in parts of the neighborhood where non-Roma lived, the living conditions were drastically different. Figure 4 below represents photographs taken in different public spaces in PS and narratives of unhealthy public spaces. Neighbors then developed the following recommendations/actions: (a) petition for an increase in the frequency of trash pick-up, public transport, and gardening, (b) request a local post office, and (c) implement city bike stations.

Unlivable Housing Conditions

The housing conditions of the areas where participating neighbors and most other Roma neighbors lived were the worst areas of the district. Government funded housing was abandoned, and projects had been left halfway done. Infrastructure (e.g., elevators, mailboxes, sewage systems, burnt homes) was left broken. Figure 5 below represents photographs and narratives of unhealthy public spaces. Neighbors then developed the following recommendations/actions: (a) restore housing conditions and (b) assess and fix the sewage system.

These results and recommendations were to be shared to the group of providers in a joint workshop described in Section 2.4.4.

2.4.3. Promoting Alliances between Roma and Community Resources/Institutions

Based on needs and gaps detected in the survey (see 2.4.1.), partners were responsible for improving providers' understanding of the Roma communities through raising awareness regarding antigypsyism, discussion of local health challenges, creating a collaborative environment, and collecting and examining data [54]. Topics discussed followed recommendations from the Spanish National Health Mediation network [81]. Each workshop ended with commitments from providers such as attending the next meeting, identifying two influential Roma neighbors, identifying other health providers as allies, and organizing a meeting to be held at the end of the study with Roma neighbors. Workshops were not recorded due to the sensitive issues being addressed. University partners took field notes and consolidated main ideas prior to developing minutes (logistics, content, and commitments) for each workshop and were then transferred back to providers.

As shown in Table 2 below, initial provider reactions were blaming Roma culture for their poor health outcomes. As the workshops progressed and new information was provided, providers' narratives transformed into the identification of contextual factors (education, housing, employment) and the healthcare system exclusion of Roma as factors influencing Roma poor health outcomes. Lastly, providers committed to collaborating with Roma neighbors in a joint workshop in order to design actions forward.

Table 2. Content of provider workshops with excerpts from research partner's field notes.

Modules	Topics	Field Notes of Provider Discussion
History and culture of Roma population	Roma history Cultural identity Social demographics	Providers attribute Roma health problems to culture and health practices, homogenizing group needs.
Roma health	Health diagnostics Health inequities	Providers begin to discuss marginalization as the main problem, questioning initial attribution to culture. Neglect of public spaces as a general concern for health issues.
Roma health and Spanish healthcare system	Cultural differences between Roma and healthcare system Structure and coverage of the healthcare system National Roma integration strategies health component	Blaming individualized habits of Roma. Structural issues are identified (e.g., lack of provider continuity in healthcare center) and no available resources to improve services for Roma. Providers did not have knowledge about Roma health policies.
Strategies to facilitate intervention	Peer mentoring Mediation Cultural competences*	Providers identified their own good practices when responding to local Roma needs. Identified frustrations due to lack of organizational support and the need to adapt their practices to local needs.
Health promotion with Roma community	Health education for Roma community Health accompaniment Intersectoral work Community networking Roma participation	Agreed that collaboration with Roma organizations and Roma neighbors was an action that could help improve local health outcomes.

2.4.4. Building a Common Agenda for Roma Health Justice

A meeting was organized in PS between mediators from across Europe (Bulgaria, Romania, Macedonia, Spain), partners, neighbors, providers, and Roma CBOs. This consisted of sharing good practices between Roma health mediators from different European countries (Belgium, Bulgaria, Frane, Moldova, Romania, Slovaki, Spain, and Ukraine). The meeting was an opportunity for participating local providers and neighbors to share and disseminate the process and the work they had been doing. A general consensus of the meeting was that, in order to move forward in improving Roma health, it was necessary to transform the provider–user model that mediation programs apply towards processes that empower Roma populations living in marginalized communities. This was an important contribution for the wider-European agenda for Roma health [82]. (For more information: https://eea.iom.int/sites/default/files/publication/document/Equi-Health-Final-report.pdf).

Finally, a meeting was held at the local primary healthcare center. A total of 21 participants attended the meeting, comprising five neighbors, eight providers, and eight members of the university-community partnership. All providers that Roma had previously identified as relevant and important for them, representatives of social services, primary healthcare centers, the public housing agency, waste management services, and the chair of the Local Public Authority of Poligono Sur were invited. Partners facilitated discussion and ensured a climate for neighbors as protagonists of the meeting. For example, one neighbor reflected that the services that were available were not recognized by the neighbors and shared Photovoice results with providers in order to develop a common, shared understanding of the health concerns that were important to them. Providers who had been working in the neighborhood had not attributed health outcomes to the environmental issues that neighbors shared. Existing services were not recognized or utilized by neighbors: "There are a lot of services in PS but the people do not know them or do not know how to use them". In response, providers recognized that local plans did not reflect the complexity of the context: "It [local policy plan] is a small, reduced vision of the dynamics in the PS." This has caused the development of well-intentioned initiatives to not be sustainable over time. Neighbors expressed their sense of burnout: "We can all agree, that all of the people are tired of unfulfilled promises that begin and never finish." Overall providers felt a need to work with neighbors to transform the living conditions and improve their own services: "Without the PS people, we will not change anything, it is necessary to create strategies with neighbors."

Table 3 depicts the contents of the meeting, the collaborative set of proposals, and the outcomes of meeting negotiations. For example, during the identification of potential allies to address health concerns, neighbors and providers committed to identifying other neighbors and providers in working towards a collective goal, and this led to exchanging contact information between neighbors and providers.

Table 3. A workshop was held between neighbors and health providers. During this workshop, partners organized content and participants developed a series of proposals that were negotiated into the agreements/recommendations presented below.

Content	Neighbor Proposal	Agreement/Recommendations
(1) Share evidence (resource map and Photovoice)	Increase number of trash bins Raise awareness among others regarding clean spaces Improve frequency and quality of public service	Develop plan to meet with waste management representatives Providers offering navigational support of different institutions and resources within the community
(2) Identify allies	Commit to working with health providers and other Roma	Exchange of contact information between Roma and providers
(3) Identify opportunities for Roma engagement	Open channels for collaboration with local institutions	Invitation to participate in local health working groups by local policymaker
(4) Plan for implementation and sustainability actions	Offer support as Roma advocates within institutions and organizations	Follow-up meeting Continued funding from the Open Society Foundations Roma Initiatives Office

We present results by short-term outcomes and actions directed towards structural changes. Short-term refers to tangible actions that were seen on the ground, while structural changes refer to actions incorporated at the institutional and organizational level.

A short-term outcome following this meeting was that partners continued funding by the Open Society Foundations *Road4Health* (2016–2019) initiative in which interested participants—health providers and neighbors—maintain collaboration and are consolidating these initial spaces for formal local coalitions in PS and other neighborhoods with high Roma populations. Participating neighbors have continued working in this direction by involving other neighbors, developing other strategies to collect evidence (i.e., surveys and interviews), disseminating results within their neighborhood, and gaining support from organizations and institutions. Local community-based organization *Estudio 41013* collaborated with the research team as a community expert and incorporated a health justice approach into their initiatives. *Estudio 41013* organized meetings with pastors from faith-based organizations and representatives from small Roma community-based organizations in order to begin collaborating in future initiatives.

In regards to structural changes, the primary healthcare center director supported partners in meeting with the Sevilla healthcare district directors to support institutionalizing workshops within the healthcare districts continuing education programs in order to raise awareness and identify strategies to support Roma neighbors in defending their health rights [54]. With the support of the community partner and the healthcare district, research partners formalized a continuing education program in the university for the following year. This continuing education program's overall objective was to develop advocacy capacity among a group of Roma neighbors to incorporate a health justice approach in their respective communities. Health care providers have been supportive throughout the follow-up discussions and have maintained a collaborative relationship with both university and community partners. Following this study, partners formalized their relationship by signing a collaboration agreement with the University of Seville, and this included Roma health in academic agendas.

3. Discussion

The overall purpose of this paper was to implement a Roma health justice approach for transformative change in a deprived neighborhood with a high Roma population. We presented a case study of a community-based participatory action research process (CbPAR) that intended to increase sociopolitical control in order to deconstruct structural antigypsyism in local health care settings. We can work towards restoring Roma rights by developing individual and collective Roma sociopolitical awareness about discriminatory experiences. Through the Photovoice methodology, neighbors were given the opportunity to articulate their concerns individually, engage in dialogue around their rights as citizens to enjoy healthier living conditions, and to then advocate together for their rights in front of a group of providers. Our study provides lessons learned for future CbPAR to advance towards healthcare systems that recognize the rights of the diversity within our society.

Our findings confirm that current ameliorative interventions that focus on providing services or assistance may paradoxically contribute to reinforcing negative attitudes towards the Roma and attributing problems to a homogenized group instead of recognizing the multiple forms of discrimination that affect them [32]. For example, providers' discourse was contrasted by their commitment when neighbors shared Photovoice results regarding unhealthy public spaces coinciding with health provider's concerns. Photovoice results showed that neighbors were being ignored by public services and therefore challenged providers' existing perceptions of Roma as a helpless community. This act of recognition or making Roma voices heard—both individually and collectively—shifted the traditional user–provider relationship to that of Roma as an equal collaborator that is capable of defining policy and interventions that directly affect community needs.

During the identification of resources, we generated evidence that distinguished between resources with institutional prestige and resources that engaged Roma communities while exposing institutions and organizations perpetuating Roma health inequities. For example, providers had difficulty accessing different layers of the Polígono Sur Roma community, yet smaller community-based organizations were able to have active participation and high satisfaction from them. Faith-based organizations, for example, the Evangelical church, provide services that are defined and sustained by the community themselves. These types of services are employing community-based approaches that include neighbors' voices in designing resources, ensuring collective ownership and creating a network built on trust. Larger organizations and institutions should engage the Roma community from the beginning in order to gain a new sense of trust and make services their own. Future work should include collaboration on the ground with those resources recognized by Roma communities and develop a relationship based on mutual benefits and trust. Including Roma communities only as users of services perpetuates mistrust, lack of engagement, and discriminatory attitudes that maintain health inequities [39]. Gaining a real understanding of the Roma community context can stimulate change among providers' attitudes and practices towards Roma and organizational equity [53]

Our initiative also highlights that Roma organizations have to ensure the voices of at-risk Roma without replacing them to advocate for health rights and to ensure that diverse and real needs are met. This challenge is complicated by organizations' reliance/dependence on funding by governments whose plans tend to maintain the status quo. However, by engaging at-risk Roma, we can challenge these mechanisms as a form monitoring and accountability [83]. Including health justice principles in interventions that recognize Roma community knowledge enables us to dismantle asymmetrical power relations and deconstruct essentializing Roma health inequities [61]. Roma health justice requires evolving from efforts that focus on purely remedial solutions towards transformative policy changes that bring about systemic change and the balancing of power dynamics. Our CbPAR experience instigated Roma community members' engagement in prioritizing local agendas and negotiating local resources. In this vein, we must build the capacity of Roma organizations to include Roma health justice approaches in their current interventions. Community-based organizations should develop policy-influencing skills and identify allies that can translate their collective knowledge to the policymaking arena in order to ensure access and quality of health services [65,84]. This would create less distance between influential spaces and hard-to-reach Roma communities.

Finally, our case study presents a set of limitations and challenges in regards to CbPAR. First, we specifically worked with Roma Kalo. We suggest that upcoming studies diversify and explore with other ethnic groups since CbPAR processes require sensitivity to complex contexts in which new community settings are formed [85,86]. As external experts, we acted as catalysts that instigated the process of shaping new relationships and redefining old relationships by organizing workshops between multiple stakeholders. Intersubjective dialogue and bidirectional learning processes between researchers, providers, neighbors, and other stakeholders can improve problem framing for influential policy changes [52]. However, this requires research and community partners to build relationships with different stakeholders of the community, which entails a large investment in time. Challenges regarding time can influence momentum and expectations and contribute to an overall sense of burnout among participants. Working with public services means that we depend on outside influences such as changes in funding, institutional protocols, and governments, which can then mark the time and the sustainability of these efforts. Another challenge is the history of collaboration between community stakeholders, which includes competition for similar resources. This can create fragmentation between resources and duplicity of services, which in turns makes the entry point into communities segmented and favor coverage for one part of the community. We suggest reinforcing alliances with university researchers who are not competing for the same resources. University-community relationships are optimal as they can reinforce each other to obtain both private and common goals for real social changes to social justice. University access to resources and evidence-based knowledge complement organizations' experiential knowledge. In turn, this can ensure transparency and evaluation by documenting outcomes and revisiting health justice values.

4. Conclusions

A health justice approach requires us to respect and highlight these community characteristics, utilizing community codes as sources of collaboration and not as barriers that create weak alliances and lack of trust. Lessons learned from this experience can be transferred to other contexts with communities with other Roma ethnic communities. Despite Polígono Sur being a neighborhood with a long history of activism and the subject of university research of Roma organizations and community-based organizations, our initiative created new and empowering community settings that promoted Roma leadership [80]. Initiatives as the one described in this paper require the development of trusting relationships, the inclusion of all local stakeholders as experts, and participatory analyses that revisit policy commitments. Locally-based coalitions, action groups, and tasks should be recognized as legitimate actors.

These mixed methods allowed us to access legitimized Roma community leaders and learn to respect community entry points, time-frames, and processes in order to build trust within the community to build effective alliances and a true sense of collaboration. This was reflected in the commitment to continue working collaboratively between neighbors, university partners, and other community stakeholders. By instigating new alliances and collaboration between multiple community stakeholders in spaces for equal collaboration, it was possible to negotiate priorities and resources to be shared towards a collective goal. Our findings suggest that a community-based participatory action research model follows a Roma health justice approach by organizing new local settings that give a voice back to neighbors to readjust community agendas and resources based on real priorities with the support of a group of sensitive providers. In this direction, we believe that future initiatives are obligated to incorporate processes that engage Roma communities in leading meaningful efforts that influence equitable policy changes.

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Appendix A

Table A1. Roma neighbor survey for resource identification and evaluation.

Dimension	Questions
Use of community resources	How often do you attend these services (list of formal and informal services provided)
Level of satisfaction with services	I feel respected My opinions are taken into consideration I have the opportunity to participate in activities Activities with Roma are organized I feel understood I have problems receiving services I am satisfied with the service I receive Professionals are ready to work with Roma community It is easy to commute to from Poligono Sur

Appendix B

Table A2. Organizational and health care provider survey for local Roma equity.

Level	Dimension	Questions
Organizational	Values and goals of the organization	Social justice is an important value in my organization
		My organization provides opportunities for Roma well-being
	Accessibility of services	My organization actively identifies accessibility barriers specific to Roma community
		My organization provides mechanisms to overcome these barriers
	Sensitivity towards Roma community	My organization evaluates if its practices are Roma-sensitive
		My organization registers Roma-specific information
		My organization provides Roma-specific training
		My organization adapts its practices to Roma needs
		My organization evaluates Roma-user satisfaction
		My organization provides its providers with Roma-specific resources
	Participation	My organization includes participatory mechanism for Roma
		Providers can influence within the organization
		My organization responds to Roma complaints and/or ‘proposals
		My organization participates in Roma community activities
		My organization provides health mediation/mediation services
		My organization has formal relations with other organizations (if so, which ones)
Personal	Personal value of work	My work is important to me
		My role is important for organizational functioning
	Personal level of adaptation	I can adapt my work for Roma needs
		My organization provides me with information specific for adapting work with Roma
		My organization provides me with Roma-specific training
		I am competent when providing services to Roma
		I have support of other community resources
		I show appreciation towards Roma when providing services
	Sensitivity towards Roma	I value and respect Roma and/or other groups
		I effectively communicate with Roma users

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Annex 2

Suarez-Balcazar, Y., Viquez, F., Miranda, D.E., & Early, A. R. (2020). Barriers to and facilitators of community participation among Latinx migrants with disabilities in the United States and Latinx migrant workers in Canada: An ecological analysis. *Journal of Community Psychology*, *48*(8), 2773-2788. https://doi.org/10.1002/jcop.22452

Annex 3

Albar-Marín, M. a J. & Miranda, D. E. (2019). Advocacy for Roma health: In-service training of professionals from the Health District Sevilla. *Gaceta Sanitaria. 34* (4), 411-414. https://doi.org/10.1016/j.gaceta.2019.07.010

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Nota de campo

Abogacía por la salud de la población gitana: capacitación de profesionales del Distrito Sanitario Sevilla

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RESUMEN

Se describe la experiencia de un taller cuyo objetivo fue capacitar a profesionales para abogar por la salud de la población gitana. La abogacía por la salud es recomendada por organismos internacionales y expertos en salud pública para superar las inequidades en salud. Participaron 16 profesionales de tres centros de salud de barrios con una alta densidad de población gitana, en riesgo de exclusión social. El taller se organizó en tres sesiones dirigidas a sensibilizar, dar a conocer el marco conceptual y metodológico de la abogacía, y diseñar un plan de abogacía. Se pone de manifiesto la utilidad de este espacio de reflexión y análisis, y la necesidad de abogar por la salud de la población gitana, junto a otros agentes gitanos/as y sectores comunitarios, identificando oportunidades y utilizando los recursos comunitarios. Futuras investigaciones deben profundizar en el desarrollo de planes de abogacía intersectoriales y difundirlos, para facilitar su implementación en otros contextos de características similares.

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Advocacy for Roma health: in-service training of professionals from the Seville Health District

Keywords:
Advocacy
Health inequities
Roma
In-service training

ABSTRACT

This article describes a workshop whose objective was to build Roma health advocacy capacity among a group of health professionals. Health advocacy is recommended by international organizations and public health experts to overcome the health inequities that Roma populations suffer. Sixteen professionals from three health centres located in neighbourhoods with a high Roma population participated. The workshop was organized in three sessions aimed at raising awareness, sharing an advocacy framework and methodology and designing an advocacy plan. We highlight the utility of spaces for reflection and analysis, the need to advocate for Roma health with Roma leaders and community sectors, identification of opportunities and utilization of community resources. Future research should strengthen the development of intersectoral advocacy plans, disseminate them and facilitate their implementation in other contexts with similar characteristics.

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Introducción

Las persistentes inequidades en salud en la población gitana y la evidencia de la influencia que ejercen los determinantes sociales obligan a redefinir el papel del profesional de la salud en la abogacía[1]. La abogacía por la salud se define como un intento organizado de cambiar las políticas, las prácticas o las actitudes, presentando evidencias y argumentos, para sustentar cómo y por qué debería suceder el cambio[2]. La Organización Mundial de la Salud[3] y la Comisión Europea[4] identifican la abogacía por la salud como el medio para conseguir cambios en las políticas que reduzcan las inequidades, lo cual implica que el profesional trabaje desde un marco de derechos humanos y adquiera un compromiso político y de transformación que impulse cambios legislativos.

En la revisión de la literatura realizada por Farrer et al.[5] se señala el cometido que debe desempeñar la salud pública, en estrecha colaboración con organizaciones u otros sectores comunitarios, en la abogacía por la salud de las poblaciones más vulnerables. Aunque los programas de capacitación en abogacía han mostrado efectos positivos a corto plazo, son escasas las iniciativas llevadas a cabo en este sentido[6].

A pesar de que la abogacía por la salud requiere la participación de diversos agentes vecinales, así como de profesionales de servicios públicos y políticos, la capacitación de profesionales de la salud se considera fundamental por la responsabilidad ética que tienen en defensa de la salud pública[1]. El objetivo de este trabajo es describir la experiencia de un taller de capacitación en abogacía

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Annex 4

Miranda D.E., Gutiérrez-Martínez A., Vizarraga Trigueros E., Albar-Marín M.J. (2020). Training for Roma health advocacy: a case study of Torreblanca, Seville. *Gaceta Sanitaria*. https://doi.org/10.1016/j.gaceta.2020.09.002

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Original

Capacitación de población gitana en abogacía para la salud: un estudio de caso en Torreblanca, Sevilla

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RESUMEN

Objetivo: El objetivo del presente estudio es crear capacidad de abogacía entre un grupo de vecinos/as gitanos/as que viven en contextos de riesgo de exclusión social.
Método: Se ha utilizado un diseño de Investigación Acción Participativa Basada en la Comunidad, en el que el que 4 miembros de la comunidad participaron en el proceso de recogida de evidencias mediante fotovoz, análisis de estas siguiendo el método ReACT y diseminación de los resultados.
Resultados: Se recogieron un total de 96 evidencias que fueron analizadas para el análisis de datos cualitativos. Estas fueron categorizadas atendiendo a (a) el tipo de condiciones insalubres y (b) la zona del barrio donde se encontraban. La posterior agrupación temática permitió identificar como causas: (a) El abandono de los servicios públicos; (b) la discriminación y (c) la falta de presencia de población gitana en los espacios comunitarios. Las consecuencias señaladas fueron (a) problemas de salud mental y física y (b) normalización de condiciones de vida indignas. El plan diseñado tuvo por objetivo abogar por la presencia gitana en los espacios comunitarios.
Conclusiones: Nuestro estudio puso en evidencia la pertinencia del fotovoz para trascender la perspectiva biomédica y desarrollar acciones de abogacía basadas en el conocimiento creado por la comunidad. Futuras investigaciones deberían profundizar en el impacto de la abogacía para la salud en la reducción de las desigualdades y considerar la importancia de implicar a investigadores/as, profesionales de salud pública y la comunidad en su abordaj.

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Training for Roma health advocacy: a case study of Torreblanca, Seville

ABSTRACT

Keywords:
Participatory action-research
Health advocacy
Roma
Health inequalities
Social determinants of health

Objective: The objective of this study is to build advocacy capacity among a group of gipsy Roma neighbours living in contexts of risk of social exclusion.
Methods: A Community Based Participatory Action Research design was used, in which 4 members of the community participated in the process of collecting evidence by photo-voice, analysing it using the ReACT method and disseminating the results.
Results: A total of 96 pieces of evidence were collected and analysed for qualitative data analysis. These were categorised according to (a) the type of unhealthy conditions and (b) the area of the neighbourhood where they were located. The subsequent thematic grouping made it possible to identify the causes: (a) the abandonment of public services; (b) discrimination; and (c) the lack of Roma presence in community spaces. The consequences identified were (a) mental and physical health problems and (b) the normalisation of undignified living conditions. The plan was designed to advocate for the presence of Roma in community spaces.
Conclusions: Our study highlighted the relevance of the photo-voice to transcend the biomedical perspective and develop advocacy actions based on the knowledge created by the community. Future research should look more deeply into the impact of health advocacy on reducing inequalities and consider the importance of involving researchers, public health professionals and the community in addressing it.

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Introducción

En España, la población gitana sigue sufriendo desigualdades en salud, tal como se constata en la *Segunda Encuesta Nacional de Salud Gitana* realizada en 2014[1] y más recientemente en el *Informe del Relator Especial de Naciones Unidas*[2]. En este último se

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Annex 5

Miranda, D. E., García-Ramírez, M., & Albar-Marín, M. J. (2020). Building meaningful community advocacy for ethnic-based health equity: The *RoAd4Health* experience. *American Journal of Community Psychology*, *66*(3-4), 347-357. https://doi.org/10.1002/ajcp.12443

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ORIGINAL ARTICLE

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

Daniela E. Miranda, Manuel García-Ramírez, and María J. Albar-Marín

Highlights

- Global health challenges require to shift our strategies regarding ethnic minorities inequities.
- Roma living conditions are deeply rooted in discriminatory structures that produce health inequities.
- Social determinants of health inequities require evidence-based transformative policies.
- Community advocacy promotes critical knowledge and alliances in order to take political actions.

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Abstract The pervasive failure of policies aimed at overcoming health inequities suffered by European Roma 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 prove 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 toward 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.

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Keywords Ethnic minorities · Community advocacy · Roma · Health inequities · Transformative policies

Introduction

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. Rome is 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 (García-Ramírez et al., 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