MEANINGFUL ADVOCACY FOR ROMA HEALTH DURING THE COVID-19 CRISIS: THE YILÓ EXPERIENCE

epha european public health alliance

About EPHA

EPHA is a change agent – Europe's leading NGO alliance advocating for better health. We are a dynamic member-led organisation, made up of public health civil society, patient groups, health professionals, and disease groups working together to improve health and strengthen the voice of public health in Europe.

About EPHA's Health Inequalities Advocacy

We stand against discrimination, for inclusion and equal opportunities for all to live, work and age in sustainable, healthy environments. EPHA has called on researchers and policy analysts to submit research articles to help build knowledge about how the health of disadvantaged groups is affected by inequalities in areas such as employment, housing, education, healthcare, environment, and climate.

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Executive Summary

Public policies concerning health and economic recovery have ignored the specific experiences of Roma families and communities during the pandemic.[1] Scientific evidence warns that the health of ethnic minorities is exposed to greater risks than the rest of the population because of socio-political determinants.[2] Specifically, Roma communities are especially vulnerable because of antigypsyism, which leads to policies that deprive them of resources and opportunities for a healthy life.[3,4]

Several Spanish organizations and institutions developed urgent recommendations to reduce the impact of health and economic crisis on the Roma population.[5,6] Despite these efforts, the Roma population has reported worsening of their physical and mental health, increased discrimination, severe difficulties for the continuation of their children's studies and a significant income reduction, and harder access to basic food.[7] Under this scenario, international organizations such as EUPHA[8] called for action to involve the entire population and carry out advocacy actions in order to grant the same rights and responsibilities to all citizens and ensure that the measures established for majority populations also reached disadvantaged groups.

With this objective, advocacy processes led by 5 Roma women, specifically self-identifying as Gitanas (the Spanish Roma community), and researchers were promoted in various contexts in Seville (Spain). The aim was to create knowledge about health inequalities that emerged after COVID-19 and implement advocacy actions to defend Roma rights in Seville during the pandemic. A community-based participatory-action-research (CBPAR) was conducted. As a starting point, a partnership was formed between members of the research team of the Center of Community Research and Action (CESPYD) and five Roma women from various neighbourhoods at risk of social exclusion who had previously participated in other CBPAR projects.

1   Open Society Roma Initiatives Office (2020). Protecting Roma in Europe against COVID-19. Retrieved on July 26, 2021 from: https://www.opensocietyfoundations.org/publications/roma-in-the-covid-19-crisis

2   Pareek, M., Bangash, M. N., Pareek, N., Pan, D., Sze, S., Minhas, J. S., Hanif, W., & Khunti, K. (2020). Ethnicity and COVID-19: an urgent public health research priority. *The Lancet*, 395 (10234), 1421–1422. https://doi.org/10.1016/S0140-6736(20)30922-3

3   Matache, M., & Bhabha, J. (2020). Anti-Roma Racism is Spiraling during COVID-19 Pandemic. *Health and Human Rights*, 22(1), 379–382. https://www.ncbi.nlm.nih.gov/pmc/articles/PMC7348427/

4   Devakumar, D., Shannon, G., Bhopal, S. S., & Abubakar, I. (2020). Racism and discrimination in COVID-19 responses. *The Lancet*, 395(10231), 1194. https://doi.org/10.1016/s0140-6736(20)30792-3

5   Consejo Estatal del Pueblo Gitano (2020). Plan de Urgencia para las familias gitanas en situación de extrema vulnerabilidad. Propuestas de medidas y acciones ante la crisis del coronavirus.

6   Ministerio de derechos sociales y Agenda 2030 (2020). Documento técnico de recomendaciones de actuación de los servicios sociales ante la crisis por COVID-19, en asentamientos segregados y barrios altamente vulnerables. Retrieved on August 12, 2021 from: https://www.mscbs.gob.es/ssi/familiasInfancia/ServiciosSociales/docs/Covid19_Rec_asentamientos.pdf

7   Arza, J., Catala, L., Frances, F., Gil, D., Gonzalez, M. E., Parra-Casado, L., Rodríguez, M. F., Sanchis, M. J., Sanz-Barbero, B., & Vives-Cases, C. (2020). Informe Encuesta Impacto COVID19 Población Gitana 2020. Retrieved on August 1, 2021 from: https://repisalud.isciii.es/bitstream/handle/20.500.12105/11032/COVID-19_Impacto_PoblacionGitana.pdf

8   EUPHA (2020). Statement by the EUPHA Migrant and Ethnic Minority Health Section on COVID-19 - Call for Action. Retrieved on August 31, 2021 from: https://eupha.org/repository/advocacy/MIG_statement_on_COVID19.pdf

The process was articulated in several phases following the model proposed by Miranda et al.:[9]

    (1) develop local knowledge about the problem
    (2) expand networks and build alliances, and
    (3) implement multilevel advocacy actions.

As a result, local knowledge was created on how inequities suffered in different social determinants of health were exacerbated by COVID-19 through interviews with the Roma population living in these neighbourhoods and analysing the narratives to identify common needs. Alliances were established with thirty-three grassroots organizations to learn about the concrete actions programmed to address the situation of Roma population. The organizations were representative of various grassroots efforts in Sevilla (i. e. migrant organizations, feminist organizations and other Roma organizations). Press releases were carried out in ten different media to disseminate the poor conditions Seville's Roma population was enduring among other advocacy actions. We provide a series of recommendations to ensure the implementation of the new EU Roma Strategic Framework 2020-2030.

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9   European Commission (2020). EU Roma strategic framework for equality, inclusion and participation. Retrieved on September 12, 2021 from: https://ec.europa.eu/info/sites/default/files/eu_roma_strategic_framework_for_equality_inclusion_and_participation_for_2020_-_2030_0.pdf

Introduction

The Roma community in Seville are suffering a new layer of health rights violations amidst the COVID-19 crisis. Rapid governmental actions were aimed at health protection and economic measures that have overlooked the pre-existing conditions of Roma communities across Europe.[10] Despite these efforts, the Roma population has reported worsening of their physical and mental health, increased discrimination, severe difficulties for the continuation of their children's studies and a significant income reduction, and harder access to basic food.[11] Research suggests that ethnic minorities are at-risk due to the political determinants that influence their health and in the case of Roma population in general, deeply embedded antigypsyism.[12] The systemic and structural nature of antigypsyism requires promoting strategies and mechanisms that establish flexible and transparent channels of communication between communities and institutional agents and ensure that the policies that concern them are sensitive to their situation and reflect their needs, desires and priorities.

The new EU Roma Strategic Framework (2020-2030) identifies as one of its key objectives the effective equality of the Roma population after the COVID-19 crisis its "participation through empowerment, cooperation and trust", especially in local, regional, national and European policies.[13] Following the new framework, our paper aims to shed light on how a university-community partnership built a critical counter narrative regarding the realities of Roma families during the pandemic and avocate for the resources they need at the local level. We present a series of recommendations to promote these types of participatory processes in new policy and program implementation.

10   Open Society Roma Initiatives Office (2020). Protecting Roma in Europe against COVID-19. Retrieved on July 26, 2021 from: https://www.opensocietyfoundations.org/publications/roma-in-the-covid-19-crisis

11   Arza, J., Catala, L., Frances, F., Gil, D., Gonzalez, M. E., Parra-Casado, L., Rodríguez, M. F., Sanchis, M. J., Sanz-Barbero, B., & Vives-Cases, C. (2020). Informe Encuesta Impacto COVID19 Población Gitana 2020. Retrieved on August 1, 2021 from: https://repisalud.isciii.es/bitstream/handle/20.500.12105/11032/COVID-19_Impacto_PoblacionGitana.pdf

12   Pareek, M., Bangash, M. N., Pareek, N., Pan, D., Sze, S., Minhas, J. S., Hanif, W., & Khunti, K. (2020). Ethnicity and COVID-19: an urgent public health research priority. *The Lancet*, 395 (10234), 1421–1422. https://doi.org/10.1016/S0140-6736(20)30922-3

13   European Commission (2020). EU Roma strategic framework for equality, inclusion and participation. Retrieved on September 12, 2021 from: https://ec.europa.eu/info/sites/default/files/eu_roma_strategic_framework_for_equality_inclusion_and_participation_for_2020_-_2030_0.pdf

Methodology

A community-based participatory-action-research (CBPAR) approach was adopted. This approach recognizes that people can assess their own needs and advocate for them, while valuing community partners as equal contributors to the research process.[14] The team at the Center of Community Research and Action at the Universidad de Sevilla (CESPYD) partnered with five Roma women, specifically self-identifying as Gitanas (the Spanish Roma community), from various neighbourhoods at risk of social exclusion who had previously participated in other projects (henceforth: partners). Between May and July 2020, we held daily 60–80-minute meetings online via Zoom.

We adapted the advocacy process proposed by Miranda and colleagues, which aim is to build the capacities of communities and researchers to develop critical evidence to be used in actions across multiple settings [11]. First, partners developed local knowledge through semi-structured interview that were designed to evaluate the difficulties in complying with the sanitary measures. These were conducted by the participating Roma women by calling neighbours, using WhatsApp audio messages and phone recorders. *Annex 1* provides a table with the narratives and analysis.

Parallel to the interviews, the team monitored the narratives of institutions, organizations, and the media in regard to their depiction of Spanish Roma community. The media was identified by the partners as a key agent in influencing policies given the mobility restrictions imposed. Nineteen newspapers and six informative programs were monitored, considering their local and national relevance and representativeness of the different points of view within the political spectrum. We developed a set of indicators to define "good" versus "bad" practices in reporting Roma related news (*Annex 2*). *Annex 3* shows examples of news outlets that reflect good and bad practices monitored throughout the study.

Finally, alliances were established with thirty-three grassroots organizations to implement various actions to advocate for Roma rights.

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14   Minkler, M. (2005). Community-Based Research Partnerships: Challenges and Opportunities. Journal of Urban Health: Bulletin of the New York Academy of Medicine, 82, ii3–ii12. https://doi.org/10.1093/jurban/jti034

Main Discussion

Develop local knowledge about their health and socio-economic challenges

Our university-community collaboration identified the following elements that heightened existing circumstances:

1) Many families are living with limited access to basic resources, weak infrastructures that do not guarantee water and electricity. Segregated settlements throughout the city simply violate fundamental rights such as dignified living conditions and basic needs. Although some Roma families in the settlements have been allocated to new housing throughout the city, the segregated settlements continue to exist. Spain, as most European countries, adopted the World Health Organization recommendations to stay home, wash hands and practice physical distancing. These recomme dations overlook housing conditions such as overcrowding and access to water, therefore, putting Roma in a position to "not comply" with regulations. The confinement measures adopted aggravated the living conditions of women, because they were assigned not only all household chores, but expected to entertain children and adults living in the same household. This is in addition to already taking care of all the needs of the elderly, the young, and others in the family.

2) Unresponsive public services have abandoned Roma families living in marginalization. These homes are set in contexts of abandonment from the city waste management service, LIPASAM, which continues to ignore these neighbourhoods causing fear of the unsanitary conditions. Social services did not have the capacity to respond to families in need, some waiting weeks to be assisted. Non-governmental organizations assumed responsibility of providing resources to the families, however, the resources provided are not enough and not distributed evenly. Roma families living in uncertainty, distrusted public services, engraving the situation. This was true for other protective services (i. e. police) whose role is to protect their citizens and ensure the implementation of regulation measures sensitive to citizens' circumstances. Instead, Roma population of these neighbourhoods were criminalized and victims of police abuse of power. The misappropriation of police powers further engrained antigypsyism within protective institutions.

3) Roma entrepreneurs and workers were excluded from legitimized economic spheres prior to confinement. Therefore, they were not protected under governmental economic support during this time. In some cases, families have had to leave their homes in search for any informal opportunity to provide food for their families. This causes a risk of virus spread for all people in Sevilla and it is the government's responsibility to protect all citizens. While those working in industries—i. e. hospitality—that will have long lasting effects due to regulations, limit Roma capacity to engage in the formal economy.

4) The digital gap caused by lack of technological resources and digital literacy is an important issue for Roma children and families. Families living in these neighbourhoods and settlements lack the infrastructure and economic means to access resources that are vital to stay connected to public life. Neighbours highlighted its effects on Roma children's access to educational platforms and families' access to governmental support. Internet, technology and overall digital literacy provided access to information, social support, educational platforms, work, governmental protective measures. Also, the digital gap created an extra duty for mothers and women in general, who acted as go-betweens for their children and the teachers. This gap also had a special impact on girls who are expected to help with child-rearing, home care, and serving the needs of males and elderly relatives in the home. Many girls did not attend online schooling for months, and when schools re-opened in Spain, they did not return. No specific measures have been designed to address the cause of absenteeism in this population. The long-term effects cause a bigger divide in educational outcomes and create future problems in a fair access to employment.

Building alliances to take multi-level advocacy actions

The establishment of alliances made it possible to disseminate the statement that reflected the analysis in various media and networks, and the implementation of multi-level advocacy actions. The identification of allies in the media highlighted the rise of the antigypsyist discourse in the media. This has consolidated negative attitudes and images, causing further generalization and bias towards Roma. We contacted 113 news outlets (radio, television and digital media) with a press release that reflected the counter narratives, of which 10 were published (see *Annex 4*).

To learn about the concrete actions programmed to address the situation of Roma population, alliances were established with thirty-three organizations. They expressed their collaboration with regional and local governments to build a coordinated network to respond to the urgent needs of these communities—for example, providing food and attending to individualized incidences. This burdened third sector organizations to protect Roma rights. The thirty-three organizations participated in the drafting of a document to expose the narratives collected by Roma population and monitor the actions implemented by the Seville City Council to address the situation.

As a result, the Mayor of Seville agreed to hold an online meeting with Roma women to hear their requests and recommendations via Zoom. Despite promises to establish communication channels to monitor actions aimed at promoting the socio-economic inclusion of these communities, the only response from the Mayor's Office was individual assistance to cover the basic needs of participating Roma women. Ultimately, the women decided to establish themselves as an advocacy group called YILÓ to continue advocating for policies that prioritize Roma needs in the aftermath of the COVID-19 crisis.

Policy Recommendations

The pandemic has provided an opportunity to effectively respond to challenges that require new forms of governance and political commitment. We propose a set of recommendations based on our experience, the best available evidence and the new EU Framework for Roma Equality, Inclusion and Participation:[15]

1. ***Frame the problems that Roma population experiences.*** The new EU Roma Strategic Framework (2020-2030) establishes as priority areas ensuring equal access to education, employment, health services and housing. Our experience and other available evidence[16,17] show the effectiveness of community-based-participatory strategies to ensure a correct analysis of the problems that encompass each of these areas, leaving behind paternalistic policies based on asymmetric power relations that maintain existing inequalities in social determinants of health. These actions would allow the development of various internal evaluations measures that ensure that they are adapted and sensitive to diverse circumstances faced by Roma.

2. ***Ensure the participation of Roma population in decision-making processes.*** The urban policies and plans should include a human rights-based approach. COVID-19 is providing an opportunity to promote democratic participation of Roma living in these neighborhoods. This entails monitoring the implementation of the plans and adjusting them. Local Governments should ensure that citizens are the central stakeholder actively involved in the decision-making process, building systems that ensure transparency and trust (Minkler, 2005).

3. ***Adopt measures with a gender approach.*** The EU Roma Strategic Framework calls for action to set targets and measures for specific groups, including gender-responsive and child age--sensitive measures. The confinement measures adopted by national authorities aggravated the living conditions of women and girls. Previous health crises affecting West Africa have revealed the special vulnerability of women and girls who see their options to decide about their own bodies diminish, increase the risk of suffering domestic violence, forced marriages and risky pregnancies and maternity hospitals.[18] A sexual and reproductive

15 Minkler, M. (2005). Community-Based Research Partnerships: Challenges and Opportunities. *Journal of Urban Health: Bulletin of the New York Academy of Medicine*, 82, ii3–ii12. https://doi.org/10.1093/jurban/jti034

16 Miranda, D. E., Gutiérrez-Martínez, A., Vizarraga Trigueros, E., & Albar-Marín, M. J. (2020). Capacitación de población gitana en abogacía para la salud: un estudio de caso en Torreblanca, Sevilla. *Gaceta Sanitaria*. https://doi.org/10.1016/j.gaceta.2020.09.002

17 Miranda, D. E., Garcia-Ramirez, 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

18 Davies, S.E. and Bennett, B. (2016). A gendered human rights analysis of Ebola and Zika: locating gender in global health emergencies. *International Affairs*, 92(5), pp.1041–1060. Retreived on September 14, 2021 from: https://doi.org/10.1111/1468-2346.12704

justice framework can guide how policies can better monitor and respond to the social, health and gender inequities effecting Roma women and girls living in conduits of exclusion.[19]

4. ***Organizational networks should be given the space to advocate for Roma population.*** Organization and associations working in segregated neighbourhoods should be supporting evaluation efforts and not supplementing governmental responsibility. A human-rights based approach recognizing the role of organizational networks involving Roma population can strengthen Roma participation in advocacy. Faced with the risks of coaptation, the nationals' Roma strategic frameworks[20] must adopt commitments and effective monitoring systems that allow Roma and pro-Roma civil society to remain independent systems of political consultation to defend the rights of Roma population.

5. ***Combat antigypsyism in the media, structures and policies.*** Antigypsyism during times of crisis increased public health challenges for all and defies the dignity of Roma living in segregated neighbourhoods. According to the Spanish national Royal Decree Law 7/2010 discriminatory discourses that violate people's dignity on the basis of ethnic origin is forbidden .[21] Therefore, local, regional and national institutions should promote inclusive cities by denouncing the negative images of the press and promote strategies that raise awareness of the realities of Roma living in these neighbourhoods. Without this, governments are naturalizing the unjust circumstances that jeopardizes effective social inclusion.

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19 World Health Organization & Human Reproduction Programme (2020). Addressing Human Rights as Key to the COVID-19 Response. Retrieved on September 16, 2021 from: https://www.who.int/publications/i/item/addressing-human-rights-as-key-to-the-covid-19-response

20 European Commission (2020). Guidelines for planning and implementing national Roma strategic frameworks. Retrieved on September 23, 2021 from: https://ec.europa.eu/info/sites/default/files/guidelines_for_planning_and_implementing_national_roma_strategic_frameworks_en.pdf

21 Ley 7/2010, de 31 de marzo, General de la Comunicación Audiovisual. Boletín Oficial del Estado, núm. 79, (01 April 2010). Retrieved from: https://www.boe.es/buscar/pdf/2010/BOE-A-2010-5292-consolidado.pdf

Conclusion

This paper offers an understanding of how the application of one-size-fits-all policies have negatively impacted the Roma population living under conditions of vulnerability during COVID-19 pandemic, providing analysis of qualitative data that shows the inequality of rights and access to resources this community faced during this global health crisis. The exclusion of Roma population from policy definitions limits the possibility of transformative change in effective resources to meet their needs. Disregarding their unjust living conditions, access to services, gender inequalities, the digital gap that affected children and adults alike and their struggle to access fair working increase the risk of further injustice and inequities in the future. However, we aim to provide an example of how Roma communities can get effectively involved in advocacy, working together to influence local policies through integrative and participatory practices, such as CBPAR, in order to reclaim their rights. The new EU Roma Strategic Framework offers the opportunity to include the Roma population in policymaking processes and creating effective changes.

Annexes

Annex 1. Narratives collected during the national state of emergency by Roma neighbors

Themes	Narratives
Unjust living conditions	"the truth is we are struggling, we are too many and the house is too small" (Roma Woman 21. Torreblanca)
	"the housing is not adequate to be inside, because as I said, the poor people we don't have many resources" (Roma Woman 3. Polígono Sur)
Unresponsive public services	"Today at 2pm the lights went off, and it came back when you called me, around 4h50pm, it came back, and it was off since 2pm" (Roma Woman 23. Torreblanca)
	"But here the water is just a trickle… and it's not hot really, it's hot now and then after that there's no more. The water heater will not work. I have to heat water in the cooking pot to take a shower" (Roma Woman 25. Torreblanca)
	"And the light, well, now it's back, but then it goes out again, and it comes back really weak. And the worst is not that the light goes out, it's the fact that food spoils" (Roma Woman 24. Torreblanca)
	"the electricity goes up and down, and when it goes up and you have the TV on or something it breaks the TV, or the refrigerator, and you…die of sadness" (Roma Woman 7. Polígono Sur)
Roma entrepreneurs and workers	"Also, economically, in this neighbourhood we live a lot the street life" (Roma Woman 9. Polígono Sur)
	"Of course, we are street vendors and now we can't go out to work, so of course there's no money coming in the house, zero" (Roma Woman 13. Polígono Sur)
	"Half of the people here don't work, and those who would go out to sell, well they can't so it's bad" (Roma Woman 24. Torreblanca)
	"Of course, of course, because we had to stop working, because we work in street markets and, sure, when you close the street markets and other workplaces, well… it's a sector, I think it's the sector that has taken the biggest blow, because of course, peddling is an everyday activity" (Roma Woman 2. Polígono Sur)
Digital gap	"We have to do a lot of homework and it's harder because we need to hand it through the internet, through email… it's a mess. There are things we don't understand well" (Roma Woman 29. Torreblanca)
	"Yes, she does her homework, but I can't send it to her teacher because I don't have a computer nor the app" (Roma Woman 15. Polígono Sur)
	"They send the homework through email so I go to the parlor and the attendant downloads it for me. You know what I mean? Because I don't have a computer at home. It's how she does her homework" (Roma Woman 16. Polígono Sur)
	"My daughter does nothing all day long, honestly. I don't know…it's through email and I don't get it, the teacher called me on the phone and I told them that I don't know, I told them I would tell my husband, but he doesn't know about it either…And now I'm waiting for them to call me back, because I don't have their number, so when they call me we will see what to do with my daughter, you know?" (Roma Woman 21. Torreblanca)

Annex 2. Indicators used to analyze good and bad praxis

Categorization	Indicators	Code
Good Practices	Complaints in defence of vulnerable neighbourhoods or Roma community	1
	Practical assistance in neighbourhoods or settlements	2
	Objection to hegemonic/discriminatory news	3
	Information on the situation in the neighbourhoods or the Roma community	4
	Requests for help/assistance	5
	Complaints about human rights violations	6
Bad Practices	Discriminatory comments towards Roma community or target neighbourhoods	7
	Manifestations of hatred towards the Roma community or target neighbourhoods	8
	Prejudices towards the Roma community or target neighbourhoods	9
	Stigmatization towards Roma community or target neighbourhoods	10
	Generalization in Roma community or target neighbourhoods	11
	Labelling of Roma community or target neighbourhoods	12
	Blaming the Roma community or target neighbourhoods	13

Annex 3. Messages transmitted by the media

Headline	Code
Las Tres Mil Viviendas in Seville: how to survive lockdown in the poorest neighborhood of Spain	1, 2, 3, 4, 9
Volunteers bring food to families in Las Tres Mil Viviendas, Seville, during lockdown	1, 2, 4, 9, 11, 12
We ask for water supply and that solidarity not be conspicuous by its absence	2, 4, 5
How the confinement in Las Tres Mil Viviendas neighborhood is being breached	10, 11, 12, 13
Bretón asks the Military Emergence Unit to "patrol" Polígono Sur of Seville	2, 4, 10, 11, 12, 13
Coronavirus: The lockdown aggravates the educational gap for Roma students	1, 4, 5
What happens to 700 families in Polígono Sur when schools are closed for COVID-19?	2, 3, 4, 9

Annex 4. Media that echoed narratives analysed by university-community partners

Newspaper and headline	Screenshot
Spanish Revolution The drama of shantytowns: lack of decent housing prevents the most vulnerable groups from protecting themselves from COVID-19	 El drama de las chabolas: la falta de una vivienda digna impide a los colectivos más vulnerables protegerse de la COVID-19
Canal Sur Roma in precarious situation due to the state of alarm	 La población gitana, en precario por el estado de alarma
Europa Press Andalucía More than 20 groups request information on social "measures" in the shantytowns of Seville from Covid	Más de 20 colectivos piden información sobre las "medidas" sociales en los poblados chabolistas de Sevilla ante el Covid
El Correo Web The lack of decent housing prevents the most vulnerable groups in Seville from protecting themselves from COVID-19	La falta de una vivienda digna impide a los colectivos más vulnerables de Sevilla protegerse de la COVID-19

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The drama of shantytowns: lack of decent housing prevents the most vulnerable groups from protecting themselves from COVID-19

La Giganta Digital

Situation in the shantytowns: "If the virus doesn't kill us, hunger will kill us"