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## **Taking stock of Roma health policies: Lesons for health governance**

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### **Abstract**

Roma health inequities are a wicked problem. Despite concerted efforts to reduce them under the Decade of Roma Inclusion initiative, the health gap between Roma and non-Roma populations in Europe persists. To address this problem, the European Commission devised the National Roma Integration Strategies (NRIS). This paper provides a critical assessment of the implementation of the NRIS' health strand (NRIS-H) in Spain and proposes an evaluation tool to monitor Roma health policies – the Roma Health Integration Policy Index (RHIPeX). It also makes recommendations to promote Roma health governance. To achieve these goals, four community forums, 33 stakeholder interviews and a scoping review were conducted. Results show that the NRIS-H implementation is hindered by lack of political commitment and poor resource allocation. This has a negative impact on Roma's entitlement to healthcare and on their participation in decision-making processes, jeopardising the elimination of the barriers that undermine their access to healthcare and potentially contributing to reproduce inequalities. These unintended effects point out the need to rethink Roma health governance by strengthening intersectional and intersectoral policies, enabling transformative Roma participation in policymaking and guaranteeing shared socio-political responsibility and accountability.

*Keywords:* Roma, health policy, policy assessment, governance, migration and health, Spain, wicked problem

## **Introduction**

The Roma have considerably poorer health outcomes when compared to non-Roma populations across Europe [1,2]. Studies point to a persistent health gap with Roma experiencing lower vaccination coverage, higher levels of communicable and non-communicable diseases, higher unmet health needs and higher infant mortality rates, while acknowledging definitional and methodological challenges that limit data comparability and impact the depth of the evidence base [1,3-8]. In 2005, twelve European countries joined efforts to promote Roma health equity through the Decade of Roma Inclusion – a political commitment to tackle the root causes of poor Roma health by enabling the participation of Roma representatives in health governance [9]. However, with the end of the Decade in 2015, it is clear that the health gap between Roma and non-Roma has not been closed [4,9-10]. Moreover, the persistent, interdependent and dynamic nature of Roma health inequities makes it a wicked problem [11], i.e. a problem over which there is little agreement on its causes and the best way to address them and that defies the capacity of any one organisation to solve it [12]. It is urgent thus to elicit innovative strategies to ensure Roma health governance, i.e. to assess and overcome the asymmetries in the distribution of the economic, intellectual, normative and political resources that affect Roma's health [13].

Foreseeing this challenge, the European Commission (EC) devised an EU Framework for National Roma Integration Strategies (NRIS) in 2011 [14]. The NRIS commits EU member states to monitor, share and strengthen Roma approaches in European policies by a) reducing the gap between policy planning and implementation; b) fostering intersectoral work and stakeholder leadership; c) engaging the Roma in decision-making and implementation processes; and, d) establishing evaluation systems to ensure the accountability and sustainability of political efforts. This paper takes stock of the implementation of the NRIS' health strand (NRIS-H) in Spain using a tool specifically

designed to enable stakeholder engagement in the evaluation process. In so doing, it allows drawing various lessons for Roma health governance.

In light of Spain's migratory context, a distinction is made between 'national Roma', i.e. Roma people born in Spain (Kale or *gitanos*), and 'foreign Roma', i.e. Roma immigrants in Spain who originate predominantly from Eastern European countries (e.g. Romania, Bulgaria). The term 'Roma' is used to refer to both groups [15].

### **Roma health in Spain**

In Spain, the Decade's National Action Plan aimed to improve Roma's access to and use of healthcare services, ensure Roma's health monitoring and reduce Roma health inequalities [16]. However, two national surveys on the health of national Roma conducted at the beginning and at the end of the Decade revealed little progress [17,18]. Roma people surveyed in 2014 continue to report poorer self-perceived health, higher rates of non-communicable diseases (e.g. cholesterol, hypertension, obesity, diabetes), mental health problems (e.g. depression) and tobacco consumption, and less physical activity when compared to non-Roma [18]. They also experience barriers in accessing services that are partially covered by the National Healthcare System (NHS) (e.g. oral care) [18]. Although the national surveys do not include foreign Roma, a study conducted in Catalunya shows that they also have a poor health status and appear to have even less access to healthcare than national Roma [19].

The challenges undermining the creation of a robust evidence base on Roma health in Spain (e.g. constraints to survey undertaking, definitional inconsistencies) extend to other European countries [5,6,8,9,20-22]. Nevertheless, international evidence generally points to Roma being subject to greater vulnerability for social exclusion, unemployment, poverty and a low educational level that continue to hinder their access to the social determinants of

health [2,5,6,20] despite political commitment to address the problem. In its intersection with ethnicity, gender, age and migration status, limited access to the social determinants of health works to produce a gradient of vulnerability in which women, children and foreign Roma are at greater disadvantage [3,7,23-25].

The Decade's relative failure has led its signing members to agree on a new referent framework under the NRIS. In Spain, the NRIS-H and its Operational Plan [26,27] proposed a reorientation of healthcare services towards equity and cultural diversity, training of health professionals and community agents in cultural competence, and the establishment of mechanisms to promote intersectoral work and Roma participation. A key element of the NRIS-H is to ensure the monitoring of policies from a multiple stakeholder perspective by enabling all actors with a stake in Roma health to participate in policy assessment and reformulation on an equal footing.

### **Roma health inequities as a wicked problem**

Traditional policy approaches have sought to address Roma health inequities with quick and linear fixes that go from problem to solution uncritically [12]. However, Roma health inequities have persisted, not just because of the social shortcomings that are prone to arise when seeking to solve problems of great complexity but also due to the lack of a robust evidence base on which to ground policy. Research on Roma health is scarce, fragmented and often small-scale [5,8,9,20]. This constraints a thorough assessment of the mechanisms underlying Roma health inequities and the set up of effective health monitoring systems, causing policy to be produced in a piecemeal manner and with disregard to the various gradations of exclusion that impact Roma health. Acting toward an equitable distribution of the social determinants of health among the Roma requires participatory governance for

health, i.e. participation by all stakeholders in problem framing, priority setting and decision-making.

Roma health governance involves multiple stakeholders (e.g. Roma and non-Roma people, civil society organisations—CSO, health professionals, policymakers) with competing values and conflicting goals [11]. Moreover, both these stakeholders and evidence on Roma health inequities evolve at the same time that policymakers are trying to address the problem [11,12,28]. Having neither a definitive formulation nor a straightforward solution, Roma health inequities typically disallow for trial and error learning. As a result, ‘every solution to [this] wicked problem is a one-shot operation’ [11, p.163] that can lead to paradoxical and unforeseen consequences. The promotion of Roma participation in policy-making encouraged by the Decade and NRIS’ frameworks is a case in point of these unintended effects. Roma health stakeholders are not on an equal standing, to the obvious disadvantage of Roma people. As a result, policy has been developed and assessed by stakeholders working from within or closer to decision-making bodies (e.g. policy-makers, managers). The exclusion of health professionals, CSO and Roma from policy-making has caused policies to become disconnected from Roma’s needs and values and to fare poorly in terms of implementation [5,6,29]. Yet, where opportunities for Roma involvement in policy-making have arisen they have been often coopted by actors who claim to represent Roma’s interests but who are not acknowledged by Roma people as their legitimate representatives [9,22,30]. By failing to produce a response to Roma’s needs, while allocating Roma health resources to attend to the needs of other interest groups, participatory exercises of this kind risk contributing to reproduce existing health inequities. Dealing with Roma health inequities from a wicked problem perspective thus demands a tailor-made approach to Roma health governance [11-13,28] that can foster transformative policy change [31].

Transformative policy change refers to changes in policy that resort to the best available evidence and incorporate all stakeholders' views and values into decision-making. Transformative Roma health policy should therefore aim to: a) promote the strengthening of the evidence base to enable the identification of the underlying causes of Roma health inequities; b) ensure Roma participation in policy formulation, implementation and assessment through inclusive and reliable participatory exercises; and c) enable the involvement of all stakeholders in devising solutions, allocating resources and implementing actions to address Roma health inequities. To achieve this, both an evidence-based and a discursive approach need to be used [31]. The former focuses on the use of scientific evidence, while the latter recognises the power of discourse in translating particular groups' values and perspectives into courses of action. This paper aims to assess the implementation of the NRIS-H in Spain using a transformative policy change framework [31] with the final purpose of promoting Roma health governance. To do so, it draws on an evaluation tool specifically designed to incorporate both scientific evidence and stakeholder input – the RHIPLEX.

## **Methods**

This study entailed a recursive and iterative process to monitor the implementation of the NRIS-H in Spain through the development of a tool to assess Roma health policies – the Roma Health Policy Integration Index (RHIPLEX). In 2014, a partnership was established between two groups of stakeholders in the Spanish regions with the highest proportion of Roma people: a) researchers from the Centre of Community Research and Action at University of Seville (CESPYD) in Andalusia; and b) policymakers from the Public Health Agency of Catalonia (ASPCAT). This partnership developed the RHIPLEX inspired by the Migrant Integration Policy Index [32], a tool that evaluates and compares governmental

policies and actions aimed at promoting and improving the integration of migrant and ethnic minority populations across different policy sectors. RHIPEX also nourishes from the indicators proposed by the WHO's assessment recommendations for the NRIS-H [33] and the Decade's Roma Inclusion Index [10] and lays foundation on migrant health policy frameworks [34,35] and insights on how to improve Roma health policies' effectiveness [1]. As a result, RHIPEX consists of four dimensions: a) entitlement to healthcare, b) access to the healthcare system, c) responsiveness of healthcare services, and d) achieving and sustaining change. A set of indicators corresponds to each of these dimensions (see Table 1).

**Table 1.** Roma Health Integration Policy Index (RHIPEX): dimensions and indicators

<b>Dimensions</b>	<b>Indicators</b>
Entitlement to healthcare	<i>Requirements for obtaining entitlement:</i> formal and informal requirements for national and foreign Roma's access to the national healthcare system (NHS). Includes aspects related to the Health Card application process and other requirements related to forms of identification, registration, etc..
	<i>Co-payments:</i> frequency of out-of-pocket payments for medical care made by the Roma and cases of exemption from payment (e.g. low income, chronic diseases).
	<i>Coverage:</i> list of services to which the Roma population has access. Distinguishes between healthcare coverage for national and foreign Roma.
Access to healthcare	<i>Accessibility barriers:</i> barriers that hinder national and foreign Roma's access to the NHS. These barriers may be related to Roma's culture, derive from the system and its providers, etc.
	<i>Policies and adaptation strategies to suppress accessibility barriers:</i> policies developed and implemented through local, regional or national plans intended to tackle accessibility barriers. Also entails specific actions developed by providers of healthcare centres or civil society organizations to eliminate these barriers.
Responsiveness of healthcare services	<i>Health inequalities identified in the NRIS:</i> includes inequities described in the Operational Plan 2014-2016 and their critical appraisal.
	<i>Policies to make healthcare services more responsive:</i> includes aspects related to the training in cultural competence of service providers.
	<i>Healthcare services and providers' adaptation strategies:</i> measures adopted by healthcare providers and some healthcare centres to adapt to the characteristics and needs of national and foreign Roma population.
Achieving and sustaining change	<i>The political and economic context of the NRIS:</i> healthcare system's capacity to achieve the objectives of the Operational Plan of the NRIS. The focus is placed on how these objectives are shaped by current restrictions imposed on the NHS.
	<i>Organizational movement, participation and collaboration of the Roma community:</i> relationships between national and foreign Roma, Roma organizational movement and participation, as well as collaborative relationships between different organisations and how they contribute to improving Roma health.
	<i>Collaborative work among multiple stakeholders:</i> synergies between different organisations and how they contribute to improving Roma health and wellbeing. These organisations include local, regional and national institutional bodies, healthcare and academic institutions, Roma associations, social organisations and NGOs.



The NRIS-H's assessment involved a recursive data collection and analysis process between February and December 2014 from three sources: a scoping review of published documents, community forums and stakeholder interviews. The scoping review was used to identify evidence on Roma health and official perspectives about the NRIS-H implementation. The community forums and interviews were key in identifying evidence gaps, dissonances between official and stakeholders' perspectives of NRIS-H impact and strategies to overcome its fragilities.

The CESPYD-ASPCAT partnership created a stakeholder platform composed of 48 representatives from 25 institutions (e.g. Roma CSO, hospitals, primary healthcare centers, regional and local governments, universities) with relevant roles in the field of Roma health in Spain, including policymakers, managers, researchers, healthcare professionals, social workers, Roma representatives, mediators and technicians (see Appendix 1). Two community forums involving members of the partnership and the stakeholder platform were held in Andalusia and Catalonia at the beginning of the study to invite stakeholders to participate in the assessment. Following an interview guide based on RHIPEX's indicators, interviews with 33 stakeholders were later conducted with stakeholders in Andalusia (n=15) and Catalonia (n=18) by two researchers. The forums and interviews were audio recorded with participants' informed consent and transcribed verbatim.

At the same time, a scoping review of scientific literature, policies and plans on Roma health in Spain published between 2005 and 2014 was conducted. Materials from the beginning of the Decade, three research papers and four legal documents prior to 2005 were also included given their relevance for the assessment. Electronic databases (MEDLINE, PubMed, PsycINFO, Google Scholar) and 25 websites of organizations (e.g. national and regional health departments, Roma and non-Roma CSO, international and European

institutions) were searched using a combination of keywords following three topical areas: a) health policy (policy, strategy, plan); b) population (Roma, gypsy); and c) study setting (Spain, Andalusia, Catalonia). During the community forums and interviews, stakeholders suggested another 14 documents. From the 145 publications identified, 36 were included in the study following the WHO's analytic framework to review the NRIS-H [33] (see Appendix 2).

Data collected through the interviews and the scoping review were coded and content analysed using the Atlas.ti 5.0 software. RHIPEX's indicators served as *a priori* code system, to which were added categories derived inductively from the data. The analysis was conducted independently by two researchers assisted by a third who exchanged and compared results to eliminate discrepancies. Data quality was further ensured through two community forums organized at the end of the study in Seville and Barcelona to share and discuss the findings with the CESPYPD-ASPCAT partnership and the stakeholder platform.

## **Results**

Results concerned with the NRIS-H implementation are presented following RHIPEX's structure: entitlement to healthcare, access to healthcare, responsiveness of healthcare services, and achieving and sustaining change. They are illustrated by direct quotes drawn from the interviews (Table 2) and supported by literature from the scoping review.

**Table 3.** Stakeholders' perspectives on the NRIS-H implementation

<b>1</b>	<b>Entitlement to healthcare</b>
1.1	'I can't prescribe them medicines because they are not in the system' (HP1)
1.2	'They have no documents at all (...) We have no information about their family structure' (PM1)
1.3	'The consulate charges them for the authentication of documents, a thing that shouldn't be doing' (PM3)
<b>2</b>	<b>Access to healthcare</b>
2.1	'In many centres they say 'no' straightaway to the Roma (...) minors, pregnant women, emergencies' (SW2)
2.2	'NHS isn't ready professionally to deal with exclusion, manage diversity, work in conflict areas...' (HM1)
2.3	'They are all equal so we don't have to implement positive discrimination with the Roma' (M2)
2.4	'[Roma] lack of compliance with basic codes of conduct [which] are irreconcilable with those of the mainstream population. So conflicts arise but not related to assistance or equity' (M3)
2.5	'A patient may come here with a backache and painkillers are prescribed, but the fact this person sleeps on the floor goes unnoticed' (HM1)
2.6	'There is not a mediator in the centre to be a referent for Roma patients (...) It is not compulsory' (PM2)
2.7	'The sure thing we know about foreign Roma is that we know nothing' (PM1)
2.8	'They don't keep their appointments, they use the emergency service a lot and they don't generally continue treatments' (HM1)
2.9	'We run a community project to include families in the system (...). Mediators call me [and] I accompany [Roma users] to the reception desk, we do all the paperwork, I clarify things for them' (SW4).
<b>3</b>	<b>Responsiveness of healthcare services</b>
3.1	'[NRIS-H's indicators] don't really fit our reality (...) a more global perspective is necessary to bring out the real needs of the Roma (...) It is extremely biomedical and it focuses on unrelated points' (M5)
3.2	'Regarding the integration of policies and allocation of resources (...) we miss the transversality of Roma within these' (M4)
3.3	'[NRIS is] a declaration of principles that would need to be implemented but remains up in the air' (M5)
3.4	'I have done some sort of visual collage (...) to smoothen the [communication] codes' (SW4)
3.5	'They don't really like doing things in groups (...) they are afraid or ashamed' (HP2)
3.6	'We proposed the mourning assistant since the Roma have specificities regarding death' (PM2)
3.7	'I've started to prescribe considering the price (...) They go to CSO Cáritas to get [the medicines]' (HP1)
3.8	'In the forty-day period after childbirth contraceptives are not generally prescribed. The Roma are [an exception because] some women get pregnant within one month of childbirth' (HP1)
3.9	'I call them if they miss an appointment and go to their places (...) so they have a proper follow-up' (HP3)
3.10	'The objectives set for doctors are linked to economic incentives and they aren't adapted (...) So if you refer patients four times and they miss the appointments, you're penalised' (HP1)
<b>4</b>	<b>Achieving and sustaining Roma health change</b>
4.1	'To implement [the NRIS-H] you have to provide a budget and see how it is articulated' (PM1)
4.2	'We see a lack of mobilization of the set of stakeholders responsible for [the NRIS] implementation' (M5)
4.3	'[The regional government] doesn't have orders from the State to make plans for the Roma (...) there is no obligation, neither administratively nor politically' (PM1)
4.4	'The Roma don't participate (...) Behind Roma CSO there are few Roma' (PM1)
4.5	'It has been easier to give them money than to empower them' (HM1)
4.6	'[The Roma organizational movement is not representative of] all the Roma but those who for one reason or another have been organized (...) its engagement within the community is quite limited' (M6).
4.7	'There are Roma who believe they are all equal (...) others feel more Spanish' (HM2)
4.8	'We can't give grants [to Spanish Roma CSO] if we want to help the foreign Roma [because] these are not going straight [to them]' (PM4)
4.9	'If it's hard to find people dealing with Roma health, imagine finding somebody working for foreign Roma's health' (HM2)
4.10	'There is no positive discrimination [unless] programs applying for funding contemplate this' (PM1)
4.11	'In the most institutional and political dimensions problems arise and collaboration is scant' (HM2)
4.12	'The Roma shouldn't be called just to attend meetings (...) Non-Roma need to partially manage [fundings, but] if the Roma have organizations why shouldn't we be responsible of it?' (PM2)
4.13	'We [providers] know each other and have good relationships, we speak the same language' (HM2)
4.14	'We aren't well coordinated (...) All Roma CSO requires you to do something [very similar]' (HP1)

*HP: healthcare professional; HM: health mediator; SW: social worker; PM: policymaker; M: manager*

### **Entitlement to healthcare**

The Spanish NRIS-H was designed at a time when the NHS provided universal coverage for both national and foreign Roma in the same grounds as for Spanish citizens [36]. In 2012, amidst the financial crisis, a right-wing government enforced Royal-Decree 16/2012 [37] arguing for the urgent need to guarantee the NHS's sustainability. This measure resulted in the transformation of the NHS from a tax-based system into an insurance-based system that restricted entitlement to healthcare to those affiliated to or insured by the Social Security System—except for pregnant women, children under 18 and emergency situations.

Entitlement is strictly regulated through the Health Card: those who are not in possession of one are deprived of specialised services and drugs prescriptions (1.1) [37]. Regions such as Andalusia and Catalonia developed policies to alleviate the negative impacts of the Royal-Decree among the foreign population which resulted in several inconsistencies and unresolved questions [38,39]. Thus, the shift in entitlement took a toll on the most vulnerable members of the Roma community, causing many of them—mainly those without jobs or working in the informal economy—to be directly expelled from the NHS [40]. Stakeholders agreed with the report of the national Roma CSO Fundación Secretariado Gitano [40] which denounced the bureaucratic hurdles faced by foreign Roma in applying for a Health Card (e.g. registration at City Hall, dealing with consulates) (1.2-1.3); the provision of care to foreign pregnant Roma women only when it was directly related to pregnancy and the restrictions imposed to children even if they are covered by the Royal-Decree.

Besides, budget cutbacks and transference of health competences between institutions have led several primary and secondary healthcare services to close, causing Roma patients to quit treatments due to lack of information about or inability to move to other services [40]. Staff shortages have also caused the elimination of primary and pediatric care afternoon shifts

causing Roma children to miss classes and delaying vaccination schedules [40]. Also, co-payments for pharmaceuticals were imposed leaving many medicines out of coverage and patients in debt with the NHS have increased [40]. Roma's entitlement to care has thus been reduced both at the point of entry and in terms of the range of services available to them. The NRIS-H was not designed to anticipate and deal with these problems, nor was it revised in the meantime to overcome them.

### **Access to healthcare**

According to stakeholders, Roma people are exposed to various barriers that undermine their access to care, even in situations of emergency (2.1). Some stated that these accessibility barriers are linked to the NHS' lack of cultural competency (2.2), ethnocentrism (2.3) and outright stereotyping and discrimination (2.4) by some managers and professionals. Others noted that care provision tends to follow a biomedical model which disregards the social determinants that impact negatively on Roma's health (2.5). Other barriers pointed by interviewees include Roma's limited access to information due to the absence of health mediators that could facilitate their navigation of the NHS (2.6). Limited data on foreign Roma also makes it difficult to argue for policy aimed at adapting services to their needs (2.7). Stakeholders and the literature stated that the intersection of these barriers with cultural referentials, leads Roma to access the NHS through emergency services and to miss consultation appointments (2.8) [40-42].

Stakeholders explained that efforts to facilitate Roma's access to care are made on an *ad hoc* basis by some healthcare professionals and health mediators from CSO. These efforts include the use of informal census to locate potential users in settlements, navigation assistance and community health interventions (2.9-2.10). While this proves the potential of

intersectoral collaboration and health mediation regarding access at local level, it also exposes NRIS-H limitations in eliminating accessibility barriers within the NHS.

### **Responsiveness of healthcare services**

According to stakeholders, the NRIS-H prioritizes the effects (i.e. health problems) over the causes (i.e. social determinants) of Roma health inequities (3.1) and it should be updated toward the adoption of an holistic approach to Roma health. While our scoping review shows that regional and national plans intend to make the NHS more Roma-friendly through measures such as training professionals into cultural competence, publishing Roma health reports and guides, campaigning to adapt services to diversity and deploying mediators [16,43-46], stakeholders stated that most of these measures are neither transversal nor embedded within existing policies and find limited implementation on the ground (3.2-3.3).

For interviewees, where services have become sensitive to Roma needs that has been a direct result of local efforts. Health mediators from CSO have developed activities in healthcare centers such as trainings on Roma competence, translation services and workshops involving professionals and the Roma to increase mutual collaboration and understanding (3.4). In the absence of specific protocols for this population, some health professionals working in areas with a high density of Roma service users have unofficially adapted their practice to Roma's needs. According to stakeholders, the strategies employed include using collages to facilitate communication (3.5), talking privately about sensitive matters (3.6) and taking religious and cultural beliefs into account (3.7). Taking notice of economic deprivation when prescribing drugs (3.8) and adapting reproductive healthcare protocols (3.9) are also important in protecting the most vulnerable Roma. All these adjustments require professionals to be highly proactive, watchful and coordinated in engaging users, particularly where follow-up care is concerned (3.10). Stakeholders stated that overexertions like these

are not recognized by healthcare organizations, which may even penalize professionals for not achieving set performance goals that are incompatible with serving the Roma according to their contexts (3.11). The NRIS-H does not specify how to reconcile services' performance benchmarks with the additional demands associated with adapting care delivery to diverse populations.

### **Achieving and sustaining change**

Interviewees asserted that the lack of a budget for the NRIS-H has hindered the allocation of resources to implement its set goals (4.1). In addition, literature shows that NHS cutbacks have weakened the impact of previous achievements in Roma health [40]. Moreover, limited commitment from those responsible for the NRIS-H, together with the decentralization of health governance into national, regional and local institutions, has made it unclear who should be held accountable for implementing and monitoring it (4.2-4.3).

The leading role of national Roma CSO has been a key asset in keeping up the NRIS-H agenda. However, stakeholders recognized some challenges that urge to be addressed. First, the involvement of Roma people in CSO is very low (4.4). Second, national Roma CSO are becoming increasingly bureaucratized and prioritizing a run for resources to secure the continuity of their programs. Third, CSO promote a subsidy-dependent culture among users rather than empowering and representing the Roma community as a whole (4.5-4.6). Finally, some national Roma CSO deliberately exclude foreign Roma from their programs, contributing to make this population one of the most underrepresented and invisible groups in Spain (4.7-4.9).

Although regional and national bodies have been established to promote dialogue and collaboration for Roma health (e.g. National Roma Council, Regional Ministries for Roma Population) [44], stakeholders stated that there are no measures to ensure Roma's

participation in institutions (4.10) and reported difficulties in implementing intersectoral work at higher institutional levels (4.11). Some Roma representatives also argued for a more active role in policy formulation and implementation in decisions concerning their health (4.12). In contrast, intersectoral work at the community level (e.g. schools, primary healthcare centres, CSO) is flourishing (4.13): community roundtables, working groups and networks have been organised to promote Roma health locally. However, stakeholders feared that lack of coordination between independent programs with similar goals and catchment areas may lead to unnecessary wasting of meagre resources with potentially negative impacts for the sustainability of ongoing initiatives (4.14). Thus although NRIS-H offers an ideal framework to foster Roma participation and collaboration among stakeholders, it fails to ensure the resources and full-spectrum engagement necessary to achieve its goals.

## **Discussion**

This paper provides a critical assessment of the NRIS-H implementation in Spain and proposes an evaluation tool to monitor Roma health policies – the RHIPLEX, while arguing that Roma health inequities are a wicked problem. As this section unfolds, it also makes a set of recommendations to promote Roma health governance following a transformative policy change framework.

Results show that the NRIS-H provides a good referent to guide policy formulation at a national level. However, in the case of Spain, limited political commitment and insufficient resource allocation impede the full implementation of Roma health policy on the ground. This is evidenced by the limited investment made on building a robust evidence base on Roma health and the problems observed in guaranteeing Roma's representation in participatory policy-making, which resulted in the development of policies and services with low sensitivity to Roma's needs. NRIS-H poor enactment impedes the enforcement of



entitlement to healthcare among Roma' most vulnerable groups and defers the elimination of accessibility barriers within the NHS. Furthermore, it increases the burden endured by the professionals who act to overcome system inadequacies and reduces Roma's chances of representation in health decision-making processes. NRIS-H inadequate implementation appears thus to be paradoxically causing Roma health inequities in Spain to widen. These unintended effects point to the shortcomings of off-the-shelf approaches to wicked problems [47] and sets forth the need to rethink Roma health governance. In what follows, proposals are made to set this exercise in motion.

Roma health governance calls for an intersectional approach to health. As our results show, Roma health inequities are associated not only with Roma's ethnic background but also with other social identities (e.g. age, gender, class, migration status) that combine to place some Roma groups in a position of even higher vulnerability (e.g. foreign Roma teenage mothers) [48]. Policies that focus on one of these social identities while neglecting the others risk perpetuating power asymmetries and reproducing inequities [49]. It is necessary thus to imbue Roma health policies with intersectionality to enable an equitable distribution of resources and actions, particularly among the Roma at the lower rungs of the vulnerability ladder [20].

Roma health governance calls for a health-in-all policies approach. Roma people experience lower educational levels, higher long-term unemployment, higher exposure to poor living conditions and higher rates of at-risk and absolute poverty and discrimination [5,10,50]. Successful public policies on education, sanitation, social services and discrimination are likely to have a positive impact on the social determinants of health with spillover effects to Roma health outcomes [1,44,51]. Roma health policies thus need to be developed from a systems-thinking perspective and foster multilevel partnerships between representatives of the various policy, professional and civil society sectors to jointly devise

and implement intersectoral strategies to address Roma health inequities [52]. This requires building stakeholders' capacity to frame and communicate the problems at hand, procure resources and engage in participatory decision-making processes directed at improving Roma health [52,53].

Roma health governance calls for an advocacy approach. Policy making and implementation have traditionally been top-down processes led by decision-makers, where lay citizen participation is often used as a 'technology of legitimation' for *a priori* made decisions [54]. Conversely, Roma health governance advocates for transformative participation [55], i.e. for a process of engagement through which dominant discourses are challenged, and transformative change is produced, by enabling dialogic relationships that allow disempowered minorities such as the Roma to become involved in the decisions that affect their lives on a more equalitarian standing [56]. Enabling such a process in Spain will require local institutional stakeholders who are known to and respected by the Roma (e.g. academics, professionals) to work together with both national and foreign Roma communities to identify legitimate representatives, discuss their problems and establish priorities for action, and foster the skills necessary to advocate for their needs and influence decision-making (e.g. argumentation skills) [52,57]. Acting in this way, will require the creation of participatory mechanisms specifically designed to foster Roma participation in policy formulation, implementation and assessment, i.e. set up locally, resourced with translation services where needed, and mindful of cultural differences both within Roma groups and between Roma and the host society [58]. But above all, it will demand a redistribution of power among stakeholders and the incorporation of new roles: stakeholders who are not recognized as Roma legitimate representatives need to be replaced by advocates selected by Roma communities themselves. At the same time, institutional stakeholders will have to show openness to hearing Roma's concerns and to join them in advocating for responses to

their needs (e.g. policy change, services reform, needs-based interventions). By embracing the role of Roma health advocates, institutional stakeholders will fare a better chance in building trust and support from Roma communities, acting as liaison between Roma and the NHS, and fostering change toward Roma participation equitable policy and service development. This, in turn, is likely to enhance Roma's access to the social determinants of health, increase their policy literacy and enable them to become more empowered advocates [13,59,60].

Roma health governance calls for a social accountability approach. The NRIS-H assessment highlights the need for strengthening the evidence-base on Roma health and promoting a systematic and equity-focused health impact assessment at local level [61]. For that to take place, the type of questions asked and the methods used to collect and analyse data need to be reconsidered [20,21,23,49]. Moreover, stakeholders need to be aware of the importance of monitoring, reporting and evaluating both capabilities and fragilities, and to embed that routine into their practices [62,63]. Simultaneously, public institutions and healthcare services need to promote leadership for assessment and to allocate resources to support these processes. These actions are crucial to guarantee shared socio-political responsibility, proactivity and accountability for Roma health governance among all stakeholders [13,61].

## **Conclusion**

The WHO European policy framework for the twenty-first century [64] aims 'to significantly improve the health and well-being of populations, reduce health inequalities, strengthen public health, and ensure people-centered health systems that are universal, equitable, sustainable, and of high quality.' This is particularly challenging for voiceless ethnic minorities at high risk for vulnerability as are the Roma. This paper draws attention to the

need for transformative Roma health policies based on a critical understanding that can challenge the unjust structures that act to maintain the *status quo* of this population [31]. Involving the Roma, and all the other stakeholders, in policy planning, implementation and assessment can help strengthen the evidence-base, infuse policy with people's values and enhance their sense of agency in promoting Roma health [22,59]. It may also foster Roma's empowerment [14,60]. In sum, Roma health governance requires a multilevel approach that acknowledges the importance of intersectionality, intersectoriality, advocacy, participation and social accountability in advancing a fair distribution of rights and opportunities through Roma communities.

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