



Contents lists available at ScienceDirect

Health Policy

journal homepage: [www.elsevier.com/locate/healthpol](http://www.elsevier.com/locate/healthpol)



## Taking stock of Roma health policies in Spain: Lessons for health governance

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### ARTICLE INFO

#### Article history:

Received 7 June 2017

Received in revised form

19 December 2017

Accepted 28 February 2018

#### Keywords:

Roma

Health policy

Policy assessment

Governance

Migration and health

Spain

Wicked problem

### 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.

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### 1. 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 [9–11]. Moreover, the persistent, interdependent and dynamic nature of Roma

health inequities makes it a wicked problem [12], 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 [13]. 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 [14].

Foreseeing this challenge, the European Commission devised an EU Framework for National Roma Integration Strategies (NRIS) in 2011 [15]. 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

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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 [16].

### 1.1. 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 [17]. However, two national surveys on the health of national Roma conducted at the beginning and at the end of the Decade revealed little progress [18,19]. 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 [19]. They also experience barriers in accessing services that are partially covered by the National Healthcare System (NHS) (e.g. oral care) [19]. 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 [20].

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 [5,6,8,9,21,23]. 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 [2,5,6,21] 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 [4,7,24,25].

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 adopted in 2014 [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.

### 1.2. 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 [13]. 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 [5,8,9,21]. This constrains 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 [12]. Moreover, both these stakeholders and evidence on Roma health inequities evolve at the same time that policymakers are trying to address the problem [12,15,28]. 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' [12,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 [9,23,30]. 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 [12–14,28] 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 RHIPEX.

## 2. 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 (RHIPEX). 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 RHIPEX inspired by the Migrant Integration Policy Index [32], a tool that evaluates and compares governmental policies and actions

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