

Hidden Health Crisis: Health Inequalities and Disaggregated Data

This report from the European Roma Rights Centre (ERRC) ties together two interrelated issues – health inequalities in Roma communities, and the duty on states to collect and publish disaggregated data in order to monitor these health inequalities. **The information on health inequalities in this report could only be revealed through the collection and analysis of disaggregated data, in this case disaggregated by ethnicity**, and also by age and sex. Without data, inequality remains hidden and the most vulnerable continue to face exclusion and discrimination.

Through a nationwide representative survey, this report highlights existing health inequalities between Roma and non-Roma in Romania, and the obligations on the state to provide for the health of all without discrimination. The survey was carried out in 1119 Roma households and 800 non-Roma households. The report then outlines the legal framework around data collection, including the safeguards that exist to protect individuals, and the good practice of States which collect and publish such data in order to inform public policy.

The best way to ensure that inequalities are addressed is through the collection and publication of disaggregated data, disaggregated by factors which can be grounds for discrimination, such as ethnicity and sex.

Health Inequalities

Some of the health inequalities which were highlighted by the survey are detailed here;

In relation to mortality

- A **16-year difference in the age at death** underlines the dramatic disparity between Roma and the general population in Romania in relation to health status and health outcomes.
- 21 deaths were recorded in the Roma population under the age of ten compared with three in the general population. This corresponds to 47 deaths per 1000 people under the age of 10 in the Roma population and 14 per one thousand in the general population – **the mortality rate in those aged under 10 is over three times higher in the Roma population.**
- **The average time between first diagnosis of a condition and death is 3.9 years in the Roma population while it is 6.8 years in the general population.**

Roma face greater obstacles and difficulties in accessing healthcare and paying for medication. **Roma are more likely to delay filling a prescription, or take less of the prescription, in order to save money.**

- 62% of Romani women responding to the survey had never heard of mammography, while only 20% of women in the general population reported the same. 39% of women from the general population reported high awareness of mammography compared to only 6% of Romani women.
- In relation to vaccinations and other preventive measures for children, clear health inequalities are revealed. The survey revealed that **almost 4 times as many Romani**

children had never been vaccinated when compared with the general population (6.4% compared with 1.7%).

- Results of the survey show that the **rate of diagnosis of TB among Roma respondents is more than double that of the general population**, while in the 55 – 64 age bracket diagnosis is four times higher among Roma respondents.
- In the 35 to 44 age group 2.7% of the Roma population have been diagnosed with some form of heart disease while for the general population the figure is 0.3%.

Disaggregated Data

Disaggregated data is statistical data which is further broken down into categories based on, for example, nationality, ethnicity, age, sex, or other indicators. The use of relevant and reliable indicators is crucial in order to assess human rights situation(s) and/or violation(s).¹ International human rights monitoring mechanisms have encouraged the disaggregation of data on the basis of the prohibited grounds of discrimination. Regarding discrimination against Roma populations, the Committee on the Elimination of Racial Discrimination indirectly asked for disaggregated data by ethnicity to measure the respect for the rights of Roma.² The Council of Europe has stated that due to a lack of collected statistics based on ethnicity and gender, the outcome of government policies and programmes cannot be accurately monitored, assessed and improved.³

It is sometimes claimed by European states that there is a prohibition on the collection of health data disaggregated by ethnicity. However, there is no blanket prohibition on collecting this kind of data, and there are examples of European states, such as the UK, which use such data to inform and shape public policy.

With respect to concerns about the collection and use of individually identifiable sensitive data, Directive 95/46/EC (on the protection of individuals with regard to the processing of personal data and on the free movement of such data) provides safeguards to address these concerns.

Recommendations

The ERRC calls on all states to monitor the status of Roma through the collection and publication of disaggregated data, and the use of such data to inform and shape public policy. Specifically, the ERRC recommends the following;

- Ensure that statistical data is collected and published by public authorities and disaggregated by all relevant factors including ethnicity, nationality, age, sex, and any other factor which may be a ground for either direct or indirect discrimination;
- Ensure that public policy in all areas, including health, education, employment and housing, is guided by disaggregated data and any inequalities which such data reveals;
- Ensure that public policy based on disaggregated data pays particular attention to Roma, who have been historically subjected to social exclusion and discrimination, and remain particularly vulnerable to social exclusion, poverty, and inequalities in health, education, employment, housing, and other areas.
- Introduce information campaigns to highlight the importance of data collection and the importance of registering one's self-identified nationality or ethnicity; address fears that minorities, including Roma, legitimately hold due to historic misuse of data on ethnicity and nationality;
- Provide disaggregated data in state reports to international human rights monitoring bodies and other relevant bodies on the enjoyment of human rights by all groups within the state;

¹ Office of the High Commissioner for Human Rights, *Human rights indicators: A Guide to Measurement and Implementation* (2012, UN Doc. HR/PUB/12/5), 21

² CERD, *General Recommendation No 27 on Discrimination against Roma*, para 46: 'States parties include in their periodic reports, in an appropriate form, data about the Roma communities within their jurisdiction, including statistical data about Roma participation in political life and about their economic, social and cultural situation, including from a gender perspective, and information about the implementation of this general recommendation.'

³ Council of Europe, Parliamentary Assembly, Resolution 1740 (2010), *The situation of Roma in Europe and relevant activities of the Council of Europe*, para. 15.7