



Romani maternal and child health: moving from documenting disparities to testing progress and interventions to achieve equity

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I first became aware of the deplorable health disadvantage of Roma in 2006. I was working on a study that demonstrated the harmful effects of lead exposure from a smelter in Kosovo on childhood development. I came across the New York Times article “Displaced Gypsies at Risk From Lead in Kosovo Camps” that Romani children were severely sickened by the same lead smelter, in part due to political inaction to resolve the crisis. I quickly penned a Letter to the Editor expressing my outrage. Thirteen years later, news headlines now often feature “Roma” instead of the pejorative term “Gypsy,” a marker of some progress in international awareness of Roma identity and human rights. However, where have we come in advancing Romani maternal and child health, and what is next? We now have better documentation of the health disadvantage of Romani women and children, but we lack strategies to measure progress and evidence of successful interventions to meet the goal of health equity.

One key impediment to measuring progress is that surveillance of maternal and child health disparities in countries with sizeable Roma populations is inadequate. UNICEF’s Multiple Indicator Cluster Survey (MICS) is one of the few sources of data on Romani maternal and child health in non-EU countries. Since 2006, the number of countries that conduct Roma-specific MICS samples has grown, and researchers have increasingly used MICS data for in-depth analyses, which is a positive step (Petrovic et al. 2016; Djikanovic et al. 2018). However, MICS is necessary but not sufficient. First, it is not administered in EU countries making comparisons crossing EU boundaries difficult. Second, essential maternal and child health vital statistics such as infant mortality and low birth weight are not directly measured using household surveys such as

MICS, and therefore are not as reliable for monitoring trends as population-based rates calculated from vital statistics systems. Unfortunately, not all vital statistics systems collect information on ethnicity, and when they do, given the reluctance of some Roma to report their ethnicity, measures of ethnicity may not be valid. One plausible proxy is disaggregation by maternal education, given that Roma disproportionately represent women with a primary education or less. Another proxy is geographic region or neighborhood. For example, Rosicova reported that districts in Slovakia with the highest proportion of Roma had the highest infant mortality rates (Rosicova et al. 2011). This approach could be extended longitudinally to monitor trends over time, or to measure the impact of specific policies. Other potential data sources to monitor disparities are administrative data from national health insurance systems or electronic health records. Such approaches should parallel grass roots efforts to increase the number of Roma who self-identify as Roma in censuses, as well as efforts to dismantle institutional discrimination, including in the health care system.

A second impediment to moving beyond the documentation of maternal and child health disparities between Roma and non-Roma is that it is unclear what interventions may successfully reduce disparities, either because they do not exist or are not reported. For example, many studies have documented the disparity in smoking and smoking cessation during pregnancy between Roma and non-Roma women. However, no studies report culturally appropriate smoking cessation interventions among Romani women. A related issue described by the World Bank report “Breaking the Cycle of Exclusion in the Western Balkans” is that policies are not sufficiently evaluated. An exception is work by Sandor et al., which creatively used panel survey data to evaluate progress following the Decade of Roma Inclusion, although data shortcomings hampered inference of their findings (Sándor et al. 2017). A “Health in All Policies” approach incorporates health impact into cross-sectoral policy decisions and is an opportunity to integrate

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Romani health equity as policy concern across sectors (Hall and Jacobson 2018). Some public health scholars have embraced this framework (Molnar et al. 2010), but examples are rare.

A burgeoning area of research that may help to scale up evidence-based interventions to improve the health of Romani women and children is implementation science (Kroelinger et al. 2014). An example of where the implementation science approach may be helpful is Romani health mediator programs. Romani health mediator programs are one of the most promising interventions developed in the past two decades and have shown promise in terms of improving quality of care and health care communication (Roman et al. 2013). The World Bank report named Roma health mediation as a key policy recommendation. However, despite the profound potential of health mediators, evidence of the impact on Romani population health is lacking, possibly due to issues in implementation, including inadequate numbers and lack of systematization (Schaaf et al. 2016). Also supporting the implementation science approach is a recent qualitative study of segregated Roma in Slovakia identifying seven themes contributing to non-adherence to clinical and public health recommendations (Belak et al. 2018). Themes such as the socialization of Roma into their situation and racism of non-Roma toward Roma provide critical insight why clinical or public health interventions may not be successfully implemented without addressing contextual factors.

Finally, the lack of data to measure progress and evidence-based interventions must be considered in the broader context of structural racism as the root cause of Romani health disadvantage. Equity-responsive data systems and successful implementation of public health interventions must be supported by cross-sectoral policies advancing the position of Roma. Also essential is the involvement of Romani women across sectors, including health institutions and civil society organizations. Our work as public health scholars and practitioners will be much more impactful if we value the voice of Romani communities and think outside the box to overcome data

challenges and increase the evidence base to improve Romani maternal and child health and advance health equity.

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