# Minority Health and Small Numbers Epidemiology: A Case Study of Living Conditions and the Health of Children in 5 Foreign *Romá* Camps in Italy

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Minority groups and socially marginalized populations often live in small communities, widely dispersed over both rural and urban areas.1 Their numbers can be statistically insignificant in relation to the rest of the population.<sup>2</sup> Routine data or large studies carried out to represent the total population are often of little help in identifying the problems of minorities and in designing appropriate responses to their needs.<sup>3</sup> However, minority health issues need particular attention, 4,5 especially those of marginalized groups<sup>6</sup> because social exclusion has distinctive effects on the excluded groups.<sup>7</sup> To reduce health disparities in a culturally appropriate and sustainable way, 8,9 these groups need to be involved in and contribute to 10 the gathering and analysis of evidence to support decisionmaking processes that affect them.11

Community-based participatory research has proved useful in such cases. <sup>12–15</sup> However, a full participatory approach needs time and funds to be developed to its full potential. <sup>12,16,17</sup> Alternative approaches are often needed as initial steps toward participatory research. <sup>18,19</sup> Sound methods should be designed to go with community-based participatory research approaches and to fit specific local needs. <sup>12,13,15,20,21</sup>

The distrust on the side of minority communities 21–24 caused by a long history of research on excluded groups being affected by prejudice and paradigms that often perpetrate exclusion, 15,25 the distance between researchers and communities, 23,26,27 the lack of funds, 12,23 the need to develop good relations, 28–30 and the need to share decisions and to balance expectations, resources, and impact, all require time and patience to be tackled.

In Italy, the living conditions of about 20 000 foreign *Româ* living segregated in so-called "nomad camps" present serious causes for concern. <sup>31–38</sup> Even if camps are in most cases recognized and managed by local

Objective. We sought to test methods for generating epidemiological evidence on health conditions of small, dispersed minority communities.

Methods. We used community-based mixed methods including a cross-sectional survey in 5 purposely selected settlements of *Khorakané Romá* (Gypsies of Muslim culture) in Italy to study the living conditions and health status of children aged from birth to 5 years.

Results. In the 15 days prior to the survey, 32% of the children had suffered diarrhea and 55% had had a cough. Some 17% had experienced respiratory difficulties during the past year. Risk factors associated with these outcomes included years spent living at the camp, overcrowding, housing conditions, use of wood-burning stoves, presence of rats, and issues related to quality of sanitation and drains. Qualitative information helped define the approach and the design, and in the interpretation and consolidation of quantitative results.

Conclusions. Guided by the priorities expressed by dispersed minority communities, small studies with little resources can provide a solid base to advocate for evidence-based participatory planning. Exact intervals appeared to be robust and conservative enough compared with other intervals, conferring solidity to the results. (Am J Public Health. 2008;98:2035–2041. doi:10.2105/AJPH.2007.129734)

institutions, they are often located in impoverished and isolated areas on the outskirts of towns, they do not generally meet minimum housing standards, and they present serious problems because of inappropriate drainage systems and insufficient sanitation and showers. According to a study conducted in 2001, <sup>39</sup> foreign *Romá* living in camps were mainly Bosnians, Serbs, Kosovans, and Macedonians; however, in recent years the number of Romanian *Romá* has increased and today probably represents the largest group. In 2001, Macedonian and Kosovan *Romá* represented 25% of the population of *Romá* living in camps.

Although these settlements are commonly called "nomad camps," foreign *Romá* are not nomads but simply migrants. The inappropriate heteronym or adjective "nomad," commonly used in Italy when speaking about *Romá* and *Sinti* (Italian Gypsies living in central and northern Italy) reflects the distance society at large tends to keep from the frequently mentioned "gypsy problem" (*problema zin-garo*). 40–42 This distance often ends up affecting the quality and the type of health research

carried out on  $Rom\dot{a}$  communities. <sup>43,44</sup> Research on nontransmittable diseases, for example, that affect  $Rom\dot{a}$  communities living in marginal contexts, remains underfunded, understudied, and a neglected public health concern. <sup>45–47</sup>

Our main objective was to develop and test a research method to narrow the gap between small dispersed minority communities (foreign *Româ* living in camps in our case) and social and health researchers and institutions. We proposed to do this by generating quality evidence that communities could use to advocate for change.

#### **METHODS**

To define the specific topic of the study, L.M. visited approximately 30 camps to ask about residents' main worries and to understand what information could be helpful in supporting evidence-based advocacy. The link between living conditions and the health of people living in the camps came up repeatedly from *Romá*, activists, and social workers working with *Romá* living in camps. All 3 groups

## RESEARCH AND PRACTICE

requested a focus on the health of children as the most sensitive part of the population.

The distrust of *Romá* toward researchers investigating their problems "for money" made us decide not to seek funding for the research. For this reason the design had to fit with what could be achieved with limited personal resources, which is perhaps a common scenario with researchers who work with marginal minority health. We realize, however, that more than 1 research cycle—which implies more time and resources—is required to make an impact on health inequalities affecting minority groups, on the distrust of the *Romá*, and on the prejudice of the institutions.

The need to link perceptions, living conditions, environmental risks, housing standards, and child health made us opt for a mixed-method, cross-sectional, community-based but researcher-driven approach.<sup>23</sup>

Dealing with dispersed groups and lack of resources when studying minority health can significantly reduce the size of the sample researchers can count on, which requires the honing of statistical analysis suitable for small numbers. The lack of resources and of time availability and the precariousness of these settlements made us exclude the option of taking a longitudinal approach. We focused on variables that were not available for the total population (e.g., the period prevalence of diarrhea), also because of the extreme conditions of camps, which make it difficult to consider the universe of *Romá* living in camps as a subsample of the total Italian population. These considerations, together with the size of our sample, made us opt for stratified analysis, as explained in the main analysis section, excluding the recourse to simultaneous analysis in the form of both fixed and random effects models.

To limit the effect of culturally driven behaviors and attitudes, we focused the study on *Khorakhanê* (of Muslim culture) *Româ* from Macedonia and Kosovo. With a small sample, the likely heterogeneity introduced by major differences between communities could stretch the study power.

We purposely selected a cluster sample of 5 camps located in different provincial capital towns of northern Italy. The 5 camps do not represent the entirety of "nomad camps" in Italy, but they do illustrate the range of camp conditions that exist in Italy. A detailed mapping exercise of all foreign Roma settlements in

Italy<sup>39,48</sup> provided a sampling frame from which the 5 camps were selected. The camps selected were the camp of *via del Poderaccio* in Florence, the camp of *Via Rovelli 160* in Bergamo, the *Camafame* farmhouse of *Via Chiappa* in Brescia, the camp of *San Giuliano* in Mestre/Venice, and the camp of *Castel Firmiano* in Bolzano. The selected camps differed in several aspects (Table 1).

Before the design of the research tools was completed, L.M. spent 1 month living in 1 of the camps (the *Poderaccio* camp in Florence, from mid-November to mid-December 2001) in a camper van, with the purpose of fine-tuning the tools by getting more directly in touch with the environment and the problems of the *Romá*. This period also allowed L.M. to establish trust relationships with the residents, which was helpful for carrying out the fieldwork in all of the camps.

To further simplify the research tools for the gathering of quantitative information, we designed an analysis plan by dividing the variables into outcomes of child health, factors that could be associated with the outcome and acted upon (actionable variables), and factors that could not be modified but could influence the outcome and the actionable factors (conditioners). This plan helped us eliminate the variables that were not part of a coherent risk analysis structure.

We included all families living in the 5 camps in the household survey. The question-naire covered living conditions and the health status of children—in particular, the period prevalence of diarrhea and coughing in the past 15 days and of respiratory difficulties or wheezing in the past 12 months. Qualitative information was required to gather information about the adults' concerns and perceptions about the link between living conditions and health of children.

In each of the 5 camps, focus groups with mothers of children younger than 5 years followed the household interviews. We collected information about the location and characteristics of the camp with the use of a key informant's guide of questions.

#### **Main Analysis**

After reviewing the literature concerning the use of different statistical methods for calculating confidence intervals (CIs) based on the

odds ratio (OR), in the case of small samples and after comparing these methods with the help of P-value functions (Rothman's Episheet: http://members.aol.com/krothman/episheet. xls), we decided to limit the use of approximations and asymptotic estimates, and we opted for exact confidence limits. For single 2×2 tables, we used exact 95% CIs by Metha et al., 49,50 which coincide with the limits based on conditional maximum likelihood estimates of the OR and with the exact limits based on Fisher's exact probabilities. 51-53 We also used Fisher's exact simultaneous 2-tailed test, 54,55 instead of the more conservative 2 single 1-sided tests (as calculated by Rothman's Episheet). 56 In addition, we used Metha et al.'s limits for stratified 2×2 tables. Exact CIs are conservative on the nominal value, producing wider intervals than the asymptotic ones.<sup>57</sup> They guarantee, however, the inclusion of the nominal value. We opted for conservative but reliable intervals.

All of the analyses were carried out with free software: Epi Info 6.04d (Centers for Disease Control and Prevention, Atlanta, GA), Rothman's Episheet, and CIETmap 1.0 beta51 (Community Information and Epidemiological Technologies, New York, NY). The variability of the ORs when one is dealing with small numbers can be quite high. For this reason, we mainly focused on statistical significance and on the lower confidence limit, rather than on the magnitude of the significant associations found. The small sample imposed additional limitations on stratification of 2×2 tables, which was carried out as far as was possible. We attempted simultaneous analysis and modeling with logistic regression and regression trees. However, we finally decided to focus on stratified analysis. In fact, limits imposed on stratification, not allowing for a full understanding of the behavior of modifiers and conditioners, did not offer enough evidence of the dynamics of the variables to gain full control over simultaneous analysis. The choice was made with consideration that the problem we faced was attributable to the reduced size of the sample and not to overfitting or data being sparse in stratified tables.

In the 5 camps, we carried out fieldwork from mid-December 2001 to early March 2002 to reduce the possible confounding seasonal effects on the health of children. The survey covered 137 households for a total of

TABLE 1-Main Differences Among the 5 Selected Romá Camps: Italy, 2001-2002

	Bergamo	Brescia	Bolzano	Florence	Venice
Year of formation	1993	1993	1996	1990	1994
Square meters	1500	3000	3970	6100	7500
Number of residents	156	80	130	314	165
Distance from closest health service, km	1.7	8.5	3.0	6.0	4.0
Walking distance from closest public transport, min	5	35	15	10	12
Housing structures	Self-made shacks	Decrepit farmhouse	Self-made wood shacks,	Self-made shacks made of	Self-made shacks made
	made of scrap materials	with walled structure	in few cases connected to caravans	scrap materials, often connected to caravans	of scrap materials, often connected to caravans
Toilet facilities	Communal toilets in almost unusable conditions	Restructured old toilets in the walled structure, managed by groups of families	Outdoor prefabricated toilets assigned to single families	Outdoor prefabricated toilets, with no showers, assigned to groups of families	Communal toilets, divided for men and women
Availability of hot water	Only a few hours a day in the early morning	8 of 13 families had access to hot water	Yes, for all families	32 of 51 families did not have access to hot water	Yes, for all families

737 people, of whom 167 were children aged from birth to 5 years. We also held 5 focus group meetings, 1 in each camp, with mothers.

Most of the potential risk factors for children's health had been included in the questionnaire after L.M. had lived at the camp for 1 month and after observing and talking to the residents. Focus groups with mothers helped us formalize this information. Diarrhea, coughing, and respiratory difficulties represented for the mothers the main health problems children were facing, because of the impoverished environment, the inadequate insulation of the shacks, the presence of rats, the lack of access to proper toilets, the frequent lack of hot water, overcrowding, and the fact that camps did not have a safe place where children could play, especially those camps with insufficient drains and water stagnating throughout the year (Table 2). Most women pointed out that respiratory problems and coughing were more common during the winter, whereas diarrhea was more common during the summer. Not all women, however, agreed with this view and some affirmed that diarrhea and coughing were frequent the whole year round.

One third of the children covered by the study had had diarrhea in the 15 days prior to the interview (32%; 53 of 165). Environmental factors related to diarrhea occurrence were mainly linked to the years the family had spent living at the camp. If the family had spent more than 2 years at the camp, the child had a higher

risk of having had diarrhea in the previous 15 days (Table 3). Living at the camp for more than 5 years was barely significant (OR=2.05; exact 95% CI=1.00, 4.24; Fisher exact 2-tailed test P=.045; 33 of 83 vs 20 of 82), but 2 factors were significant modifiers in the relation between 5 years in a camp and diarrhea. Living in an overcrowded house (more than 2.5 people per room; test for interaction: P=.016) was a modifier, and although the relation between living for more than 5 years in a camp and diarrhea was significant for children living in overcrowded houses (Table 3), it was not for those not living in overcrowded houses (OR=1.04; 95% CI=0.41, 2.61). The second modifier was the presence of stagnant water in the camp (test for interaction: P=.045). As before, for children living in camps in which water stagnated, the relation between 5 years living at the camp and diarrhea was significant (Table 3), whereas it was not for children living in camps with no water stagnating (OR=0.78; 95% CI=0.21, 2.89).

More than half of the children covered by the study had suffered from a cough in the past 15 days (55%; 90 of 165). If the family did not have access to a toilet with a shower, the child was more at risk of having suffered from cough (Table 3). This problem mainly affected the families in the camp in Florence, which was equipped with prefabricated toilets without showers. For a family to have access to water inside the house was also a risk factor, but only for children aged from birth to 3 years (test for

interaction: P=.028); if this association might seem contradictory, it needs to be said that the camps were not designed to allow families to have access to water inside the house, and in cases in which water was available inside the house, the plumbing had mostly been set up by the families and was not supported by appropriate drains. For children of families that had been living at the camp for more than 5 years (test of interaction: P=.023), the presence of stagnant water was a risk factor associated with coughing. For children living in overcrowded houses (test of interaction: P=.002), a significant risk was represented by the use of woodburning stoves for heating rather than electric or gas heating (Table 3).

Of all the children, 17% (28 of 165) had had episodes of respiratory difficulties or wheezing at least once in the past year. Several factors, concerning both household and camp conditions, were related to this outcome. A child was more at risk if he or she lived in a house that was in poor condition, as classified by the interviewer's direct observation (Table 3). As well as coughing, a child was more at risk of having had respiratory difficulties if the family did not have access to a toilet with a shower. Living in a camp with stagnant water was also significantly associated with respiratory difficulties or wheezing in the past year, as well as living in a camp in which the presence of rats had been reported and living in an overcrowded camp (less than 25 m<sup>2</sup> per person; Table 3).

TABLE 2—Potential Risk Factors for the Health of Children in *Romá* Camps Included in the Study and Mothers' Main Worries: Italy, 2001–2002

Risk Factors

Main Concerns Expressed by Mothers of Children

#### Camp-related factors

Presence of water stagnating because of ruined paving or inappropriate drainage systems

Size of the camp (number of people and square meters) Camp overcrowding (less than 25 m² per person)

Presence of rats in the camp

#### Household-related factors

Poor condition of house

House overcrowding (more than 2.5 people per room)

No access to a toilet with shower

Lack of access to water inside the house

Wood-burning stoves used for heating versus electric or gas heating

Family living at the camp for more than 2 or 5 years

Filth, dirtiness, insufficient sewage outlets, difficulties in keeping the place clean because of critical conditions of the camp and overcrowding

Unpleasant smells and poor air quality

Frustration generated by lack of privacy

Presence of rats because of the impoverished environment and difficulties

in keeping them out of the shacks

Unstable housing conditions, in terms of materials and overcrowding, and difficulties in keeping it clean

Difficulties in keeping the children clean and healthy because of the critical conditions of sanitation Not expressed as a problem

Problems related to poor insulation and air circulation, and the need to keep heating high during the day, but to turn it off at night for safety reasons

Frustration at not seeing any timely solution to their having to stay in the camp

#### **Sensitivity Analysis**

We analyzed some of the results to compare CIs calculated with different formulas. We compared exact CIs with intervals from Miettinen (asymptotic test—based method) and Cornfield (approximation to exact CIs; Table 4). Miettinen intervals were consistently narrower than exact intervals.

With Cornfield intervals, problems arise from different approaches to the approximation. Epi Info computes different intervals depending on whether Analysis or Statcalc are used. CIETmap generates a different result. In Table 4 we report Cornfield intervals as calculated by Epi Info Analysis and CIETmap. Furthermore, in the presence of small numbers, the upper limits may not be accurate, and we noticed fluctuations of the interval depending on the formula used and the distribution of frequencies in the contingency table.

#### **DISCUSSION**

Our main objective was to explore a research method that could contribute to narrowing the gap between dispersed minority communities and researchers and institutions. The epidemiological evidence generated supported the concerns expressed by the *Româ*. By validating their statements, these results can highlight the value of research and contribute to improving the dialogue with the institutions.

Evidence of the associations between living conditions and the health of children was simplified and summarized in a 1-page table. Such evidence was accepted and used by the communities and *Romá* and *Sinti* associations to demand change. Since the results were presented, the link between health and living conditions has acquired growing weight in *Romá* statements.

The high period prevalence of diarrhea and acute respiratory illnesses was more similar to that found in marginalized urban communities in rich societies than in poor countries.  $^{58-62}$  This supports the theory of the social gradient: it is worse to be poor and marginalized in a well-off society than to live in an equivalently poor condition but to share it with the rest of the population.  $^{63-65}$ 

Most of the associated factors are known in the literature to be associated with health outcomes. Time was a key variable in our analysis, especially regarding diarrhea and coughing, for allowing us to distinguish, among children living in the same environment, between those whose families had had a higher "dose" of it and those who had a lower "dose." Spending time living in disadvantageous situations <sup>66</sup> and marginal communities is recognized as an important factor for health, <sup>67</sup> especially in those cases in which people feel unable to effect changes. <sup>22,68</sup>

Substandard housing can affect, in particular, children's physical and mental health. <sup>69,70</sup> Recognized factors defining poor housing and associated with the ill health of children are the

absence of hot water for washing, damaged or nonfunctioning toilets, water leaks, the presence of rats and cockroaches, overcrowding, the presence of dampness and mold, lack of ventilation, heating and insulation problems, and faulty building materials. 69,71-73 Overcrowding, especially in impoverished environments and poor housing conditions, is associated with psychological distress in children and mothers, which can affect the health status of children. 64,73,74 Rat allergens have been associated with respiratory problems. 75,76 Water stagnating on the camps' surface and inadequate water connections inside the houses caused humidity, dampness, and water intrusions. The lack of access to proper sanitation with showers and hot water generated a series of difficulties related to keeping the children clean without exposing them to cold weather, especially during the winter. It has been demonstrated that the use of woodburning stoves, together with poor insulation, lack of ventilation, and overcrowding problems, can increase the prevalence of respiratory problems.68,77,78

Methodological solutions were key to achieving our objective. Given the limited resources and the small sample, triangulation among quantitative data, qualitative information, and results from the literature about social determinants of health helped validate the results. The decision to select a culturally

TABLE 3—Risk Factors Associated With Prevalence of Diarrhea and Cough in the Past 15 Days and Respiratory Difficulties in Past 12 Months Among Children in *Romá* Camps: Italy, 2001–2002

Risk Factor	Had Outcome, n/N	OR (Exact 95% CI)	P <sup>a</sup>
Diarrhea in the past 15	days		
All children (N = 165)			
Living at the camp>2 y	48/131	3.35 (1.17, 11.77)	.01
Living at the camp≤2 y (Ref)	5/34	1.00	
Children living in overcrowded houses (n = 66)			
Living at the camp>5 y	13/27	6.31 (1.66, 26.32)	.00
Living at the camp≤5 y (Ref)	5/39	1.00	
Children living in camps with water stagnating on the surface (n = 110)			
Living at the camp>5 y	26/58	3.41 (1.34, 9.04)	.00
Living at the camp≤5 y (Ref)	10/52	1.00	
Cough in the past 15 d	ays		
All children (N=165)			
No access to a toilet with shower	48/73	2.34 (1.18, 4.68)	.01
Access to a toilet with shower (Ref)	41/91	1.00	
Children younger than 4 y (n = 119)			
Access to water inside the house	37/52	3.44 (1.49, 8.04)	.00
No access to water inside the house (Ref)	28/67	1.00	
Children of families that lived at the camp more than 5 y (n = 83)			
Stagnant water present	38/58	6.02 (1.88, 21.01)	.00
No stagnant water present (Ref)	6/25	1.00	
Children living in overcrowded houses (n = 66)			
Wood-burning stoves available for heating	10/12	7.27 (1.32, 72.52)	.01
Wood-burning stoves not available for heating (Ref)	22/54	1.00	
Respiratory difficulties in the pas	st 12 months		
Housing condition <sup>b</sup>			
House in poor condition	12/36	3.44 (1.29, 8.87)	.01
House not in poor condition	16/126	1.00	
Access to toilet with shower <sup>b</sup>			
No access to toilet with shower	22/91	3.56 (1.29, 11.34)	.00
Access to toilet with shower	6/73	1.00	
Stagnant water in camp <sup>b</sup>			
Stagnant water	24/110	3.56 (1.12, 14.81)	.02
No stagnant water	4/55	1.00	
Presence of rats in camp <sup>b</sup>			
Presence of rats	26/126	4.81 (1.10, 43.54)	.02
No presence of rats	2/39	1.00	
Overcrowding conditions <sup>b</sup>			
Camp overcrowding	23/90	4.81 (1.64, 16.99)	.00
No camp overcrowding	5/75	1.00	

*Note.* OR = odds ratio; CI = confidence interval.

homogeneous sample allowed us to limit the study power and to focus on environment and health. Furthermore, investigating an issue that was close to the hearts of the residents of the camps helped us strengthen the analysis. Exact intervals appeared to be robust and conservative enough compared with other intervals to confer solidity to the results.

#### **Limitations**

Almost all of the families in the camps agreed to participate, except in Bergamo where the situation was tense because of the particularly precarious living conditions and where only 15 out of 36 families agreed to participate in the study. Despite attempts, we were unable to approach the nonparticipating families to look for differences between them and those who took part in the research. Instead, we asked the *Romá* who participated some questions regarding the other families. Their responses suggested that there were no important differences between participating and nonparticipating families in terms of living conditions, family composition, and time spent living at the camp.

High prevalence in small data sets caused problems in the analysis of associated factors. Living in camps seemed to be a risk factor for children, and, for diarrhea, acute respiratory illnesses, and respiratory difficulties, a comparative study between children living in camps and children not living in camps would have given better results. We did not find data on the prevalence of diarrhea and acute respiratory illnesses either in Romá children or in non-Romá children not living in camps in Italy. Similarly elusive comparisons are likely with other marginalized populations. This interpretation explains why we found more risk factors to be associated with breathing difficulties in the past year: this outcome defined a more specific and less recurrent pathology.

#### **Conclusions**

Even though our initial idea was to adopt a community-based participatory research approach, we realized that the same problems that contribute to marginalization and lack of participation of minority groups were obstacles to conducting participatory research and to trying to tackle the burden affecting minority health. For these reasons, we deemed it important to try anyway to elaborate alternative methods to start gaining good-quality information that could be used to advocate for evidence-based participatory planning.

In this way, our study should be seen as a first step on the way to full participatory research, adopting methods that can be used to carry out studies with dispersed groups, little resources, and a small sample. The evidence generated from putting the priorities of

<sup>&</sup>lt;sup>a</sup>By exact 2-tailed Fisher simultaneous test.

<sup>&</sup>lt;sup>b</sup>For all children (N = 165).

TABLE 4—Comparison Between Different Confidence Intervals (CIs) for Matches Calculated on all Children in *Romá* Camps: Italy, 2001–2002

	Exact 95% CI	Miettinen 95% CI	Cornfield (Epilnfo <sup>a</sup> ) 95% Cl	Cornfield (CIETmap <sup>b</sup> ) 95% CI
Diarrhea				
More than 2 years living at the camp	1.17, 11.77	1.27, 8.89	1.12, 10.72 <sup>c</sup>	1.33, 31.18
Respiratory difficulties				
House in poor condition	1.29, 8.87	1.48, 7.97	1.31, 9.01	1.23, 9.20
No access to toilet with shower	1.29, 1.34	1.41, 8.98	1.25, 10.62 <sup>c</sup>	1.42, 19.41
Stagnant water	1.12, 14.81	1.23, 10.31	1.07, 13.02 <sup>c</sup>	1.32, 368.57
Presence of rats	1.10, 43.54	1.22, 18.92	1.02, 31.28 <sup>c</sup>	1.48, 11.10
Camp overcrowding	1.64, 16.99	1.84, 12.54	1.59, 15.59 <sup>c</sup>	1.87, 43.20

<sup>&</sup>lt;sup>a</sup>Epi Info 6.04d (Division of Surveillance and Epidemiology, Epidemiology Program Office, Centers for Disease Control and Prevention, Atlanta, GA).

marginal communities first can help validate the voice and the worries of these communities with hard data. If research is driven by people's priorities and designed to include their perceptions and points of view and has the objective of increasing their direct participation in future research and addressing issues of interest for the improvement of living conditions, we consider that even small community-based studies that use risk analysis and mixed methods' techniques can raise useful data for advocating for change.

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#### **Contributors**

L. Monasta originated and conducted the research and wrote the article. N. Andersson followed the process of writing the article and made suggestions and corrections. R.J. Ledogar supervised the final part of the research work and the editing of the final article. A. Cockcroft supervised the initial part of the survey work and all of the epidemiological aspects and contributed to framing the objectives and methods.

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L. Piasere oversaw the anthropological aspects of the work and contributed to framing the objectives and methods.

#### **Human Participant Protection**

This study was approved by the ethical review board of Community Information and Epidemiological Technologies.

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<sup>&</sup>lt;sup>b</sup>CIETmap 1.0 beta51 (Community Information and Epidemiological Technologies, New York, NY).

<sup>&</sup>lt;sup>c</sup>May be inaccurate.

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