

UNIVERSIDAD AUTÓNOMA DE GUERRERO
CENTRO DE INVESTIGACIÓN DE ENFERMEDADES TROPICALES

MACEDONIAN AND KOSOVAN *ROMÁ* LIVING
IN “NOMAD CAMPS” IN ITALY:
HEALTH AND LIVING CONDITIONS OF CHILDREN
FROM BIRTH TO FIVE YEARS OF AGE

TÉSIS
QUE PARA OBTENER EL GRADO DE
DOCTOR EN EPIDEMIOLOGÍA

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ACAPULCO, GUERRERO, 26 DE OCTUBRE DE 2005

ABSTRACT

Epidemiologic research involving marginalized populations in urbanized societies faces two special challenges: the populations themselves often live in relatively small, widely dispersed groups and their conditions and needs are generally defined by outsiders – often inaccurately. In Italy, more than 18,000 foreign *Rom* who migrated from Eastern European countries live segregated in “nomads’ camps”, in unstable conditions. A sample of five camps of Kosovan and Macedonian *Romá* was selected, containing 137 families with 167 children under five years of age. The research focussed on the residents’ own priority: the health of their children and how it is affected by living conditions in the camps.

Confirming the concerns of the *Rom* parents, the study revealed a prevalence of asthma higher than documented in Italian children, high occurrences of diarrhoea and bronchitis and a high percentage of low birthweight babies. The results showed evidence of environmental factors affecting children’s health, often made worse by long periods the families spent living in the camps. Factors significantly associated with asthma, diarrhoea and bronchitis were: overcrowding of houses and camps, presence of rats, presence of stagnant water, structural conditions of the house, difficult access to toilet services, use of wood stoves and presence of industrial sites in the vicinity.

With no external funding available and despite its small numerical base, this thesis demonstrates that quantitative research among minorities dispersed in small groups is capable of providing reliable evidence that communities themselves can use to advocate for change – provided the design is based on the communities’ own priorities.

SINODALES

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*To the prejudice of people I care for,
without which I wouldn't have trodden this path*

“In the modern world, those whom we effectively hate are distant groups (...). We conceive them abstractly, and deceive ourselves into the belief that acts which are really embodiments of hatred are done from love of justice or some such lofty motive. Only a large measure of scepticism can tear away the veils which hide this truth from us. Having achieved that, we could begin to build a new morality, not based on envy and restriction, but on the wish for a full life and the realization that other human beings are a help and not a hindrance when once the madness of envy has been cured. This is not a Utopian hope (...). It could be realized tomorrow if men would learn to pursue their own happiness rather than the misery of others. This is no impossibly austere morality, yet its adoption would turn our earth into a paradise.”

Bertrand Russell
Sceptical Essays
1928

“(...) We should be able to see that cultural differences are superficial phenomena. In my experience, it is the similarities in man's many endeavours to control his reality – not the differences – that are impressive culturally. Each of us needs to act to rectify the social, economic and attitudinal disparities and prejudices which permeate the world. Posterity can muse upon whether our progress was made by science or by seeing.”

Andreas Fuglesang
About understanding
Dag Hammarskjöld Foundation, 1982

ACKNOWLEDGEMENTS

Firstly, I would like to thank the *Romá* from the camps covered in this study who accepted my presence and whom I hope will gain something positive from my work.

In the initial phase of this study, when I had few and unclear ideas, all those who helped me gave me their invaluable support: Carlotta Saletti, Giulio Taurisano from Turin local council, Piero Brunello, Sandro Costarelli, Piero Colacicchi of *ADM*, Pierangelo Bertoli and Radiana Grigoletto from *ETAM* in Venice, Rosanna Marcato, Pinuccia Scaramuzzetti from the *Gruppo Ecclesiale tra i Rom e i Sinti* in Verona, Tiziana Mori and Nicola Solimano of the *Michelucci Foundation*, Giovanna Lodolo, Anna Rota, Monica Rossi, Francesca Naldoni from *Doctors Without Borders*, Nando Sigona from *Com.p.a.re* and the members of the *Centro Sociale D.A.M.M.* in Naples.

Particular thanks go to those who introduced me and helped me get access to the camps. In Florence: Demir Mustafa, Rufat Edjevat, Giusy Baffè from *Quartiere 4*, Piero Colacicchi, the *Amenghià* Association, the workers from *Quartiere 4*, Ivan and all the watchmen. In Bergamo: Cristina Suardi, Anna Carrara, and Massimo Malachini from the *Migrantes* association. In Brescia my thanks go to Giovanni Valenti from the *Ufficio Stranieri e Nomadi*, Luigino Beltrami, Maria Majorana and Elena Nodalli. Thank-you also to the *Associazione Odar* in Bolzano, and in particular to Silvia Golino and Paola Dispoto. In Mestre/Venice, my thanks go to Federico Ballarin for his help when he was in charge of the *Ufficio Stranieri e Nomadi* and Sara Gomiero, former community worker at the *San Giuliano* camp. My thanks also extend to Dr. Maurizio Mauro and Maria Favaro from Venice local council, Vittoria Scarpa and Gianni Boeto from the *Associazione Caracol*.

With reference to bibliographic research, I must thank Paola Trevisan who pointed me in the right direction and gave me excellent advice and with whom there has been a fruitful exchange of material, and Beverly Shea for her support in tracing and reaching articles that I wouldn't have reached otherwise.

Precious information and readiness to help were offered to me by the staff of the health services in the cities I visited: Daniela Caselli from the *Consultorio Familiare* in *Quartiere 4* and Paolo Zagli from the *Presidio Sanitario "Le Piagge"* in Florence; Dr. Lorenzi from the *Dipartimento di Prevenzione* in Bergamo; Dr. Guizzi from the *Consultorio Familiare*, 7th health district, in Brescia; Amalia Vettore, health assistant at the *Consultorio Familiare* of *via San Marco* in Mestre.

I would have been at a loss without the generosity of Daniele Todesco and his family who, by lending me their camper van, enabled me to go and live at the *Poderaccio* camp for a month. The support of Alessandra Monasta was also invaluable in that she allowed me to take occasional warm baths to offset the freezing morning showers I took during the biting cold in that period.

My thanks go to Burhan Hasani for his friendship, for the work we carried out together and for all the things he has taught me.

Thank-you to my parents for having supported me, for their comments and the discussions which helped to think more clearly on issues that are not always easy to grasp.

I would like to thank my supervisors: Dr. Anne Cockcroft for her precious comments and Prof. Leonardo Piasere who guided me by supplying materials and advice without which I would not have gone very far. The opportunity to be part of the research group coordinated by Prof. Piasere has been of great value and thus I would like to extend my thanks especially to Michele Barontini, Stefania Pontrandolfo, Carlotta Saletti, Simona Sidoti, Elisabeth Tauber and Paola Trevisan. To the Director of the doctoral programme, Robert J. Ledogar, the Director of CIET, Neil Andersson, and to Dr. Christine Zarowsky and Dr. Nancy Gibson thanks for their useful comments in the final phase of this journey.

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DEFINITIONS AND ABBREVIATIONS

95% CI: 95% confidence interval. See the methods chapter for an extended discussion over confidence intervals.

CERD: Committee on the Elimination of Racial Discrimination.

CIET: CIET, Centro de Investigación de Enfermedades Tropicales, was born as a research center of the Faculty of Medicine at the Autonomous University of Guerrero, Mexico. As Community Information and Epidemiological Technologies, CIET developed into an international group of non-profit NGOs, academic institutes and charities dedicated to building the community voice into planning.

Confounder, confounding factor: Rothman (Rothman KJ, Greenland S. *Modern Epidemiology*. Lippincott-Raven, 1998) defines confounding as the confusion or mixing of extraneous effects with the effect of interest. “To be a confounder, the extraneous variable must have three necessary (but not sufficient or defining) characteristics: 1. It must be a risk factor for the disease among the unexposed (although it need not be a cause of disease); 2. It must be associated with the exposure under study in the source population (the population at risk from which the cases are derived); 3. It must not be affected by the exposure or the disease (although it may affect exposure). In particular, it cannot be an intermediate step in the causal path between the exposure and the disease.”

Effect modifier, effect-measure modification: “Effect-measure modification refers to variation in the magnitude of a measure of exposure effect across levels of another variable.

The variable across which the effect measure varies is called an *effect modifier*. Effect-measure modification is also known as heterogeneity of effect. Effect-measure modification is a finding to be reported rather than a bias to be avoided. In epidemiologic analysis one tries to eliminate confounding, but one tries to detect and estimate effect-measure modification.” (Rothman KJ, Greenland S. *Modern Epidemiology*. Lippincott-Raven, 1998).

Endogamy and Exogamy: From P.G. Solinas (*Popolazioni e sistemi sociali*. La nuova Italia scientifica, Roma 1992): “A norm prohibiting wedding outside a defined circle of people (a tribe, a cast, a village) is endogamic and defines an endogamic group. Evidently, the prohibition can accompany a more or less explicit prescription of the appropriate spouse or of the more appropriate spouse area of choice.” “Exogamy establishes that, for each of the members of a defined group of people, the choice of their potential wedding partners can not be included in their same group.” The *endogamy rate* (... *exogamy rate* ...) is, out of all people with a partner, the rate of people with a partner from inside (... outside ...) the group.

ERRC: European Roma Rights Center

Fisher Exact Test: For tables containing small numbers, the Cornfield approximations to the exact confidence limits for the odds ratio may not be accurate. Fisher exact test consists of evaluating the probability (derived from a hypergeometric probability distribution) of the observed fourfold table as well as of all the other tables having the same marginal frequencies. The hypothesis is rejected if the sum of the probabilities that are less or equal to the observed is less than or equal to the prespecified significance level (Fleiss JL. *Statistical methods for rates and proportions*. Wiley, 1981). See the methods chapter for a further discussion of this test.

Incidence proportion: Incidence proportion measures the proportion of people affected by an outcome event during a specified period of time. It may also be defined as the proportion of a closed population at risk that becomes “diseased” within a given period of time.

Prevalence: Prevalence is the proportion of cases at a specific moment in time in a population of individuals at risk.

Period prevalence: the period prevalence is the proportion of cases occurring in a prespecified period of time in a population of individuals at risk.

OR (Odds Ratio): The odds ratio is a measure of the degree of association between an antecedent factor and an outcome event. The odds ratio is based on the *odds*. The *odds* is a measure of the risk of experiencing the outcome under study (E) when the antecedent factor is present (A), which is the probability of the outcome (E) when the antecedent factor is present (A) divided by the probability of the outcome not occurring ($\bar{E}$) when the antecedent factor is present (A). For cross-sectional studies, F. Mosteller (*Association and estimation in contingency tables*. J Am Stat Assoc. 63, 1-28; 1968), A.W.F. Edwards (*The measure of association in a 2x2 table*. J R Stat Soc. Ser A, 126; 109-14; 1963) and J.L. Fleiss (*Statistical methods for rates and proportions*. Wiley, 1981; 61-75) illustrated the advantages of using the odds ratio as a measure of association for contingency tables.

Rom, Romá, Xoraxané: The term “*Romá*” (as plural noun) identifies populations originated in Central and Southern former Yugoslavia. In this study it is used for the Kosovan and Macedonian *Xoraxané* populations (i.e. of Muslim religious culture) who live in the five

selected camps. The term “*Rom*” is used as singular noun and adjective (both singular and plural) and, to simplify, to identify any other *Rom* group, Italian and foreign.

Test for interaction: in stratified analysis, the test used to measure the significance of heterogeneity is: $\sum \{ [\ln (OR_i) - \ln (OR_d)]^2 \} / [1/W_i]$

with: **ln** = natural log; **OR_i** = crude OR of each table = $(a_i * d_i) / (b_i * c_i)$;

OR_d = $(\sum W_i * OR_i) / (\sum W_i)$; **W_i** = $1 / (1/a_i) + (1/b_i) + (1/c_i) + (1/d_i)$

This test is commonly known as Woolf’s test, being based on Woolf’s log estimate of the common odds ration which is equal to $\ln(OR_d)$, where $1/(\sum W_i)$ is the variance of the $\ln(OR_d)$ (Breslow NE, Day NE. *Statistical methods in cancer research. Volume I – The analysis of case-control studies*. International Agency for Research of Cancer. IARC Scientific Publications No.32. Lyon 1980. pp.139-142).

SUMMARY

The situation of the *Rom* and *Sinti* populations in Italy is adverse from many points of view. Particularly worrying is the plight of many foreign *Rom* who arrived from Eastern and Southern Europe at different times during the 1990s. Thousands have lived ever since in camps built officially or unofficially throughout Italy.

Official camps are those which are formally recognised by municipalities and usually have basic facilities like water, electricity and toilets. Living in an official camp does not guarantee a decent standard of living or protection in the case of families without a regular residence permit, but it is usually a guarantee against eviction. Unofficial camps are tolerated illegal settlements, often with no facilities at all, where no protection is granted against eviction or expatriation.

The unstable conditions of life in the camps, the lengthy wait for regularisation of status, the lack of serious planning to deal with a situation that involves almost 20,000 people and the lack of co-ordination among policies adopted by various local administrations, generate a situation that lessens the possibility for integration of foreign *Rom* into Italian society. Thorough research is needed to investigate the potential social and health implications of this situation at a community level.

The general objective of this thesis is to demonstrate that quantitative research among marginalized urban populations widely dispersed in small groups, such as the foreign *Rom* living in camps in Italy, is capable of providing reliable evidence that communities themselves can use to advocate for change – provided the design is based on the

communities' own priorities.

Following a preliminary analysis of the existing problems inside the camps, the specific objectives arose from the main concern expressed by *Rom* living in camps in Italy: the health conditions of their children. This was also regarded as a problem by the local health authorities. An association between the conditions in the camps and the health status of children living there should provide ample motivation for improving the living conditions. The amount of resources already devoted to creating and maintaining these camps suggested that funds could be found to plan alternative, participatory and permanent solutions. It was therefore decided that the state of health of the children in the camps would be the main focus of this study.

As part of this work, a bibliographic analysis on the "health of Gypsies" was carried out. As well as reviewing previous relevant findings, this bibliographic analysis examined the approach taken by other researchers to the issue of Gypsies' health. Much of the published research does not take account of the great heterogeneity to be found among *Rom*, *Sinti*, *Kalè*, *Manush*, etc., from different countries, placed into different contexts and with distinct lifestyles.

All the foreign *Rom* camps in Italy were mapped in 2001, before the selection of the camps to be included in the present study. This task was carried out by the author as part of the European project *The Education of the Gypsy Childhood in Europe*. The mapping of the camps provided important contextual information (the geographical location, the number of residents and the nationality of the *Rom* who lived in camps in Italy) for the research carried out in five camps allocated to Kosovan and Macedonian *Romá*. The mapping study identified

155 settlements comprising a total of over 18,000 foreign *Rom*, with an average of 115 inhabitants per camp. Kosovans and Macedonians represent, respectively, 16% and 11% of this population, totalling some 5,000 people.

The number of foreign *Rom* not living in camps-like situations is extremely difficult to estimate. The lack of recognition of the *Rom* and *Sinti* minority in Italy and prejudice towards the Gypsies makes it more convenient, when possible, to hide their ethnic identity to the external world.

Before commencing the fieldwork, living in a camp was deemed necessary in order to strengthen contacts and knowledge from the inside, and in this way carefully prepare the approach to the research, the definitions and the instruments to be utilised.

The study design took into account the views and priorities of the people living in the camps. The study focused on five *Rom* camps situated in the centre and north of Italy. Only camps comprising Kosovan and Macedonian *Xoraxané Romá* were covered by the research, in order to have a homogeneous population and reduce as far as possible differences in habits and lifestyles among study participants.

The settlements chosen were: the camp in *Via del Poderaccio* in Florence, the camp in *Via Rovelli 160* in Bergamo, the farmhouse called “*Camafame*” in *Via Chiappa* in Brescia, the *San Giuliano* camp in Mestre/Venice and the *Castel Firmiano* camp in Bolzano.

The five selected camps had different historical backgrounds, were set up in different periods (ranging from 1990 for the camp in Florence to 1996 for the camp in Bolzano) and were

structured differently in terms of their location in the urban environment, their surface area (from 1500m² in Bergamo to 7500m² in Venice), the number of inhabitants (from over 300 in Florence to 80 in Brescia), the type of housing structure (brick structure in Brescia, self-built wooden bungalows in Bolzano and shacks in Bergamo, Venice and Florence), and the availability of sanitary facilities (unusable communal facilities in Bergamo, facilities for groups of families in Florence, and prefabricated units for individual families in Bolzano).

In gathering information various instruments were used. The main instrument was a household survey questionnaire enquiring into the health of the children, housing conditions and access to health services. All the instruments were fine-tuned and finalised during the month spent living at the *Poderaccio* camp in Florence between November and December 2001. The fieldwork in all the camps was carried out between December 10th 2001 and March 7th 2002 so as to reduce any seasonal variation in the diseases of interest.

The five camps comprised 137 families, totalling 737 people of which 167 were children from birth to five years of age.

Birthweight was recorded in 147 out of 167 children. Ten percent of these children had a birthweight of less than 2.5 kg (14/147) (95%CI 6%-15%). In Italy, according to data reported by UNICEF and the World Health Organisation (WHO), the percentage of children born underweight (<2.5kg) in the period 1995-99 was 5%. For comparison, countries with 10% children born underweight included Egypt, Iran and Zimbabwe.*

The percentage of children who suffered diarrhoea in the 15 days previous to the interview

* Unicef. *La condizione dell'infanzia nel mondo, 2001 – Prima infanzia*. Unicef 2000.

was 32% (53/165). The risk of diarrhoea was significantly higher in children from families that had been living at the camp for more than two years. Children living in overcrowded houses (more than 2.5 people per room) or in camps where water stagnated (due to damaged paving and inappropriate drainage) were more at risk if their families (and not necessarily the children) had been living at the camp for more than five years.

The percentage of children with cough in the two weeks preceding the interview stood at 55% (90/165). Children were more likely to have cough if the family did not have access to a shower and if there was stagnant water in the camp. Children of families living in overcrowded houses were more likely to have had cough if wood stoves were used for heating rather than gas cylinders or electric heaters.

The proportion of children who exhibited respiratory problems in the previous 12 months (17%, 28/165) was significantly associated with camp overcrowding (less than 25 square meters per person), conditions of the house and access to toilets with showers.

The prevalence of asthma recorded in the camps was higher than the nationally recorded rate (7% versus 5.2% for “respiratory problems with wheezing in the preceding 12 months”; 4% versus 1.4% for “at least four attack of wheezing in the last 12 months”). For the children of the camps, the prevalence of asthma was associated with the reported presence of rats in the camp, camp overcrowding, condition of the house and house overcrowding.

The camp inhabitants held clear views about the camp living conditions affecting the health of their children. From camp to camp, interviewees’ answers about causes of disease in the children varied in number and types of causes, according to the actual situation of the camps

they were living in. In camps with more unstable living conditions and more elements of concern for the health of the children, interviewees reported a higher number of causes of child illnesses linked with the camp environment.

The inhabitants saw the camps as squalid and unstable, making it difficult to raise a family and look after children. The poor quality of the housing, the damp, the difficulty in keeping children and the home clean, the lack of playing space for the children, and the difficulty in finding a permanent job while living in the camp were all mentioned as problems of daily living.

The following excerpt from *Table 6.3* shows the correspondence between the concerns expressed by the camp inhabitants and the statistical associations determined between child health conditions and the actual conditions observed.

Concerns expressed by the Romá

Main significant associations

Filth

Refuse, Dirtiness, Sewage outlets

Stagnant water

Cough (5 years living) $p=0.001$

Breathing difficulties (all) $p=0.026$

Unstable housing conditions

Structure and quality of the house

No air circulation

Heating, dry air

Difficult to warm up the house

Leaks and mouldiness

Condition of the house

Breathing difficulties (all) $p=0.010$

Asthma (in overcrowded camp) $p=0.016$

Wood stoves

Cough (in overcrowded households) $p=0.027$

Cold and humidity

Bathrooms outside

Lack of hot water

No warm bath for children

No heated bathroom

Lack of access to a toilet with a shower

Cough (all) $p=0.003$

Breathing difficulties (all) $p=0.007$

Presence of rats

Rats

Breathing difficulties (all) $p=0.027$

Asthma (all) $p=0.071$

Poor quality of air, unpleasant smell

Polluting industrial sites

Breathing difficulties (all) $p=0.003$

Overcrowding

Living space in the camp
Living space in the house

Home overcrowding

Asthma (day and night overcrowding) $p=0.014$

Camp overcrowding

Breathing difficulties (all) $p=0.001$

Asthma (+house conditions) $p=0.016$

Issues not explicitly mentioned:

Years spent living at the camp**Years spent (by parents) living at the camp**

Diarrhoea (all) $p=0.014$

Diarrhoea (in overcrowded household) $p=0.002$

Diarrhoea (in camp with stagnant water) $p=0.005$

Apparently contradicting:

Water inside the house**Water access inside the house**

Cough (children 0-3) $p=0.019$

The poor conditions of life inside the camps increased the degree of prejudice felt toward the *Rom* population by outsiders. Living in a “nomads’ camp” added an extra layer of discrimination to the fact of being a “Gypsy”; it increased instability made finding employment even more difficult and had an overall adverse effect on the possibility of integration.

The author concludes with the recommendation that *Rom* families presently resident in the camps should be helped to integrate into Italian society. In the meantime, the camps should be modified to conform to official health and safety norms. These requests come in first place from the *Romá* interviewed before and during field work, people who never lived in camp-like situations before coming to Italy. By no means do these camps represent something the *Romá* would like to safeguard.

These results can be achieved recognizing that prejudice has negatively affected the planning and realisation of permanent solutions. Prejudice, indeed, holds back the creation of a national policy that would take into account the reasons that induced the *Rom* to migrate to Italy and prevent them returning to their countries: such a policy is essential to facilitate the regularisation and integration of these people that are described, instead, as “nomads”.

While the prejudice towards the *Rom* is hindering the possibility of their involvement and participation in planning, this study confirms the reliability of their concerns, suggesting a participatory approach to research and emphasizing the importance of their involvement in the development of integration policies.

1. INTRODUCTION

The living conditions for thousands of non-Italian *Rom* in Italy are unstable, both for legally registered and illegal residents in the camps, who often live in seriously unhealthy and unhygienic situations. Many residents find it difficult to obtain documents that would allow them to integrate more fully into Italian society.

The camps, even the ones set up by local institutions, often lack basic amenities such as an adequate number of toilets and bathing facilities, and the majority are found on the run-down outskirts of cities. Often *Rom* live in improvised shacks built out of scrap materials, which are too hot in summer and too cold in winter.

This study tries to put the *Rom* at the centre of the research process by adopting an approach that starts from the perspective and concerns of those who are actually suffering from this situation. As analysed in the next section, one of the causes of marginalization of foreign *Rom*, and “Gypsies” in general, is the lack of credibility *Rom* have with institutions, preventing the latter from hearing the voice of the *Rom* communities and the formulation of a common strategy.

This study analyses different aspects of what makes this situation possible, moving from the concerns of the *Rom* communities and trying to give them the objectivity science can supply. The role of this thesis is to serve as a catalyst between the *Rom* and the institutions, offering information that can be understood and used by all stakeholders to implement a change. On one side, this study tries to verify if the concerns expressed by the *Romá* can be demonstrated with the help of quantitative research. On the other side, it is important to try and prove that

community based research can help bring their voice into planning. Both elements were important to establish a starting point towards the possibility of enhancing a community based participatory research process involving *Rom* communities, the academic world and institutions.

The study objective took shape over time, around one of the problems most deeply felt by the *Rom* as well as other interested parties, including institutional bodies and associations. Moving from the hypothesis that conditions of life in Italian authorised camps of foreign *Rom* can have a negative impact on the health status of children, the study analyses the relationship between the state of health of *Romá* children under the age of six years and the living conditions in the camps.

The study focuses on five camps that have been selected to represent the heterogeneity of the conditions in various camps in Italy. The camps in the study were inhabited mostly by Macedonian and Kosovan *Romá*. In contrast with the heterogeneity of conditions, the populations involved in the study were deliberately selected to be as ethnically homogeneous as possible.

It is mainly the *Romá* themselves who describe the health of their children and their living conditions. Because of the specific subject of the study, it focuses primarily on the views and experience of the mothers of children under the age of five years.

CONTEXT, BACKGROUND INFORMATION

The Macedonian and Kosovan *Romá* came to Italy mainly during the 1980's and 90's, forced to emigrate as a result of both economic pressures and the conflicts that have affected the Balkans. Signs of migrations to Italy were manifest even in the 1970's, but not of the magnitude of those that took place later, after the death of Tito (1980) and with the growing economic crisis – signs of which were evident in the mid 1980's – and the ethnic tension that led to the war and the collapse of the Yugoslavian Federation.

If one were to count all the non-Italian *Rom* – who came not only from the former Yugoslavian Federation but also from other parts of Eastern Europe – currently living in Italy in camps and other settlements, the number would probably exceed 20,000. Some 25% to 30% of these are Macedonians and Kosovans. These data come from a study carried out by the author as part of the *OPREROMA* project, co-ordinated by L. Piasere, which is described in Annex 1 (1, 2). The ERRRC report (European Roma Rights Center) for the year 2000 quotes NGO estimates of between 45,000 and 70,000 non-Italian *Rom* in Italy (3). The figure of 20,000 reported by the author refers to an actual count of *Rom* living in camps and other similar settlements. The majority of camp residents live in unstable conditions. Many, in fact, have the right to refugee status.

In March 1999, the United Nations *Committee on the Elimination of Racial Discrimination* (CERD) published a report in which the Italian government was accused of not making a serious effort to combat racial segregation and social discrimination against the *Rom*. It noted that the *Rom* were isolated from access to basic services and from participation in social and economic affairs (4). However, there is little epidemiological research about diseases in the

Rom living in camps, and into the possible relationship between such diseases and the crowded and unhygienic conditions in the camps. Nor is there work that suggests what health benefits might come from changing these conditions. There are no studies that analyse the link between health and living conditions in the camps from the point of view of the people who live in the camps.

The opinions of the *Rom* are seldom taken into consideration, although several authors have criticized the state of segregation and alienation in which the *Rom* live in the camps, and highlighted the legislative shortcomings and the discriminatory behaviour of various institutional bodies. This lack of consultation with the people concerned has led to the development of projects that do not take into account the perceived needs and the specific cultural make-up of these people. Often, decisions are taken over the heads of the interested parties, thus generating an attitude of apathy and suspicion on the part of the *Rom*. Frustration often rises from the lack of involvement in decision-making and the limited information that circulates in the camps about the decisions of local authorities.

In many cases, no planning takes place, and local institutions prefer to manage the camps by adopting emergency measures. Such measures are often more expensive than properly planned interventions but less visible and, therefore, less unpopular with the Italian constituencies.

The debate about the “*Rom* camps” in Italy

The debate about the *Rom* camps in Italy reveals several elements of irrationality. Rational solutions seem difficult to be sought due to prejudice and fear. The following review concerns

specifically the issue of foreign *Rom*; but much of it could also apply to Italian *Rom* and *Sinti*.

The Italian “nomads’ camps” for foreign *Rom* came into being mainly as a result of an emergency situation caused by the migration flow of the *Rom* from former Yugoslavia, due to the ethnic conflict and the war. In many cases, Italian local authorities set up “official” camps to house families that had settled in illegal camps or had occupied empty buildings. In the face of illegal settlements, the authorities deemed it necessary to do something to keep the problem under control.

As stated by Brunello in 1996, *“the objective shared by administrators and voluntary groups, and which eventually acts as a catalyst for discussion in newspapers, is the opening of camps with facilities. At the root of this request lie considerations of a health-related nature (closure of unhealthy structures and the guaranteeing of minimum hygiene standards) together with the need for social control (to prevent the ‘dispersion’ of Rom groups and keep them in one place).”* (5, p.15)

In many cases this approach seemed fair, especially when exceptions were made to house in the camps people without regular immigration documents. However, often these people had the right to political asylum or recognition of refugee status. The road to “officializing” their position, facilitating the integration process, did not run smoothly as the consequence of first reception policies. Rarely the authorities facilitated the process of recognition of the status of these people offering a true opportunity, an official status, and the possibility to look for a job and move freely in the Italian society. In addition, even in official camps, the lack of facilities, the below-standard living conditions and the lack of an effective reception policy led to very undesirable situations.

Ronald Lee, journalist and Canadian university lecturer of *Rom* ethnic extraction, points out that Italy does not apply the Geneva Convention on refugees (6), that there is a risk for a *Rom* who makes an application to regularise his situation of being expelled from the country, that apathy arises during the lengthy wait for a reply, and notes the difficulty in obtaining work permits that enable a person to avoid the unofficial economy and living off begging.

Compared with neighbouring European Countries, Italy is behind in the application of the law for granting asylum. According to UNDP's 2004 Human Development Report, in 2003 Italy had recognised approximately 12,000 refugees. France had recognised 132,000, United Kingdom 277,000 and Germany 960,000. Italy lacks a comprehensive asylum act implementing the Geneva Convention. Although the existing law provides a time limit of 15 days for the first decision of the Central Commission, the average length of the procedure is 12/14 months. During this period the asylum seeker is not allowed to work, while the law establishes a provision of 17.5 euros per day for the first 45 days only (7).

However, the lack of a national policy on asylum does not fully explain the Italian phenomenon of "nomads' camps" for the *Rom*. According to the anthropologist Piasere (1996), *"if one of the foundations on which a modern state is built is its counter-position to other states (whose members are therefore 'foreigners') another foundation is therefore necessarily constituted by anti-Gypsy and anti-nomad sentiments. Once the great majority of 'vagabonds' produced by European society in the modern era is forced to take upon itself the role of 'proletariat', Gypsies become the last in a line of those who were considered the 'dangerous classes' because, as Miriam Kapov writes, they constitute the 'last anarchists'."* (8, p.25)

Sigona, in 2002, complements this analysis by stating: *“the blanket of prejudice that covers Rom finds its architectural expression in the housing policies drawn up by the local councils and regional authorities in Italy. (...) The camp is not only an instrument of control (which it certainly is) but also the means by which a target group is created. Services become concentrated there, a special body of consumers is created so that, paradoxically, the final result is that being Rom becomes synonymous with living in the camp.”* (9, p.12)

The “nomads’ camps” for the *Rom* of former Yugoslavia are an outcome of prejudice. People who “temporarily” ended up in the camps are people considered unreliable, who should not be there, whose presence can be justified only for a limited period of time. The unstable nature of the camps serves as an implicit protection against the instability that is associated with the *Rom*, heir to the sad *Wandertrieb*, the gene for the instinct towards nomadism imagined by the Nazis to explain their unsociable behaviour and justify their extermination (10).

The camp becomes, therefore, a place outside time and space. After many years, people who have lived in camps and worked for years either in the unofficial economy or having managed to obtain a permit to stay, still run the risk of losing the small degree of legality acquired. Some have never had a permit to stay. The camp creates an anomaly (11), a place where rights no longer exist. Camps may be in places generally considered unfit for habitation, like in flood over-flow areas or next to toxic waste dumps, between electricity or ring-road pylons. In camps, illegal installations can be overlooked, hygiene standards can be unacceptable, emergency exits can be absent, and water and electricity connections can lie side by side.

In the words of Brunello, *“as in the case of the ghetto, the camp is a place of segregation which accommodates people who have been, up to that time, thrown out of the city and considered as undesirables; it strengthens the cultural identity of those who are enclosed there; it confers normality on a situation perceived as abnormal and exceptional.”* (5, p.17)

It is the lack of proper hygiene standards that is most often the reason given for dismantling unauthorised settlements. Yet such conditions also exist in the camps set up by the authorities. As stated by the ERRC, with reference to official and unauthorised camps: *“No camp was found to have an adequate drainage system.”* (3, p.19)

The situation can persist for many years. According to Colacicchi, there is *“(…) a complicated web of legal norms on one hand and stereo-types, prejudices, superstitions and groundless opinions on the ‘mysterious Gypsy population’ on the other. (...) Gypsies are considered en masse (the Gypsy) as ‘those who live in camps’, and are identified as ‘nomads’, incapable of living in one place.”* (12, p.29)

In 2000, ERRC accused the Italian authorities of blocking the efforts made by the *Rom* to improve their own conditions of life (3). This is often done through control and segregation, ignoring dialog, mutual collaboration and planning. According to ERRC, *“official camps in the majority of cases are surrounded by walls or perimeter fencing. In many cases a system of wardens ensures that access to the camps is controlled, thus violating the right to freedom of movement. (...) But in official camps, even those who do not have criminal charges pending are subject to some form of permanent control, while people in unauthorised camps are subject to periodic controls.”* (3, p.18)

Prejudice can be a relevant obstacle in the rational thinking process that could lead authorities to analyse the situation and find reasonable solutions together with the *Rom*. Carlisle, in 2002, declares that most *Rom* in Italy live in a physical state of separation from mainstream society, segregated from non-*Rom* Italians: *“Energy and resources spent on Roma are nearly always funnelled into a network of ghettos, government organized and sponsored. (...) How can we continue to term a society ‘nomadic’ when they lived in the same location, suffering the most horrific squalor, for more than 30 years? And how can they be accused of being anti-social when (...) we see that even in the worst of conditions, human dignity prevails and communities are formed?”* (13, pp.XIX-XXI)

The camps end up being more than the cause of physical segregation. The UN CERD, in the 1999 concluding observations on Italy, affirms that *“in addition to a frequent lack of basic facilities, the housing of Roma in such camps leads not only to physical segregation of the Roma community from Italian society, but a political, economic and cultural isolation as well.”* (4, par.D/11)

Hasani, 20 years old, after spending more than 10 years in a camp, declared: *“I think the idea of the camp is wrong for two reasons. Firstly because I have lived in a camp as well as in a house and I know what the differences are. Secondly, because it is difficult to keep a job when you live in a camp: the cold, the frequent lack of water, and other people keeping you awake... Life in the camp is always very precarious.”* (14, p.41)

This form of segregation goes even against the assimilation policies proposed by some political groups, which declare that the only possible solution to include Gypsies into Italian society is for the Gypsies to give up their culture and lifestyle. *Rom* are often accused of not

wanting to integrate, for example not sending their children to school. In some camps, families will be allowed to reside only if they send their children to school. Yet keeping a child in school is difficult in the conditions of the camps, if there is no hot water, if the camp is boggy and the home is a ten-year old shack made of scrap material. Integration of a child at school can be very hard if his/her family is segregated from society.

According to Colacicchi, *“men and women who look for regular employment are rejected because they are ‘nomads’, that is, because they live in camps. Living in camps, whether they be official or unauthorised, determines a whole second series of problems.”* (12, p.35) The first series of problems arises from the fact that *Rom* are rejected simply because they are *Rom* and so “Gypsies” and “nomads”. In many cases this determines the living conditions in which the *Rom* live. The second series of problems arises from the fact that the places and the living conditions in which the *Rom* find themselves living, defines them as being “Gypsies” and “nomads”. All this becomes consolidated over time, in years of institutional conservatism, so that efforts by the *Rom* to get out of such a situation require vast resources. In addition, more resources are usually then spent by the institutions to deal with the emergency of the camps.

In the words of Piasere: *“These camps, built on our excrement, constitute the real centre of the West, the centre in which contradictions entwine that are as huge as the world we have created, in which the right to citizenship and human rights clash in hard-headed combat, in which East and West Europe each reflect their own misery and their own remorse, and into which a city pours its own fragility and falsehoods and in which, despite everything, there are men, women and children who live their lives.”* (15, p.8)

OBJECTIVES

General Objective

The general objective of this thesis is to demonstrate that quantitative research among marginalized urban populations widely dispersed in small groups, such as the foreign *Rom* living in camps in Italy, is capable of providing reliable evidence that communities themselves can use to advocate for change – provided the design is based on the communities' own priorities.

The specific objectives arise from the main concern expressed by Macedonian and Kosovan *Romá* living in five “nomads’ camps” in Italy: the health conditions of their children.

Specific Objectives

- To measure the frequency of common health problems suffered by children from birth to the age of five living in the camps;
- To examine environmental factors in the camp that potentially affect the children's health;
- To describe habits and behaviours that may have health-effects on children;
- To analyse the relationships between environmental factors, habits and behaviours, and child health.
- To determine camp residents' access to and use of health services, especially in relation to child health.

2. LITERATURE REVIEW

CRITICAL REVIEW OF THE LITERATURE ON THE HEALTH OF “GYPSIES”

The objective of this literature review is to analyse how the health of various groups of Gypsies has been studied, what exactly has been studied and how the subsequent results have been presented.

The need to investigate these aspects arises from the conviction that research does not develop in a vacuum, and that science reflects, in positive and negative terms, underlying values and assumptions that guide the conceptualisation, choice and analysis of research problems (16). Given the prejudices affecting the Gypsy minority, it is important to understand whether these beliefs or the health need of specific groups of Gypsies influence health research on Gypsy issues. This will be important for the development of the methodology used in this thesis and to identify the priorities in research, in terms of what needs to be investigated and how.

The term “Gypsy” is used in the title of this chapter as a category of literature, not a category of people. There are many different groups of “Gypsies”, with different lifestyles and different living conditions. The word “Gypsy”, like the Italian “*zingaro*”, presents two problems. First of all, being a heteronym and a very general term, the word “Gypsy” has often been misused, leading to a deterioration of its meaning. The tenth edition of the Italian *Zanichelli* dictionary, 1977, reflects this problem in the two definitions it gives for “*zingaro*”: “1. Member of a population of Indian origin that migrated across Europe since the 12th century characterised by a nomadic lifestyle, casual work, and a wealth of ethnic traditions. 2. Derog: a dirty and badly dressed person” (author’s translation).

The Italian dictionary by G. Devoto and G. C. Oli (*Le Monnier*, 15th reprint, 1983) states: “1. Belonging to the migrant ethnic group of the *Zingari*, widely crossed with populations of different countries of adoption (Danubian and southern Europe, Egypt and Northern Africa), but originating from an Indian stock (north-western India), of which there are evident traces in the somatic features, contributing, together with a somewhat showy and ambiguous raggedness in the manner of dressing and with the traditional occupations of travellers (street-musicians, chiromancy, horse dealers, beggars), to distrust and folk superstition: *filthy, dressed in rags, black as a z.; live like a z.; astute as a z.* 2. as **adj.**: *z. music* (from Medieval Gr. *(A)tsinganoi*, tribe of Asia Minor)” (author’s translation). In the Oxford Advanced Learner’s Dictionary of Current English (A. S. Hornby, 21st impression 1986) two definitions are given for two different spellings¹: “**1 gipsy**, (playfully) attractive or mischievous person, esp. one with black, sparkling eyes. **2 Gypsy**, member of a wandering, originally Asiatic people, who move about in caravans and make camps from time to time, and earn living by collecting scrap material, horse-dealing, fortune-telling, basket-making, etc.”.

The second problem with the word “Gypsy” is that people are tempted to use this word – even though it includes people of very different ethnic origins – to draw generalising conclusions about the lifestyle, traditions and state of health of specific groups.

If the term “Gypsy” did not have a negative connotation, it could be used simply to define a group of populations with a number of features in common (and many differences).

The terms used by the various authors in their articles to define the people they are studying are reported as they were used, and in the language in which they were written.

Content Analysis

Generalisations about “Gypsies” are common. Many writers stated or implied that their findings from a study of a particular community could be extended to apply to all Gypsies. Such generalisations may encourage or stem from beliefs about people identified as “Gypsies” that lead Italian and other societies to marginalize these people.

References to “*zingari*”, “nomads”, “Gypsies”, “travellers”, “itinerants”, and “*gitans*” are common in the literature, especially in earlier studies, often without distinctions between peoples of different origin, nationality and lifestyles. Some authors make generalisations after contact with just one small group.

In some cases, the specific ethnic belonging could be irrelevant, but it could be helpful when no other element concerning living conditions and lifestyle of the studied group is given. “Gypsy” should not, by any means, be considered a risk factor without any further specification.

There are relatively few studies that specify which ethnic group was the subject of study. In Italy, for example, there are at least four different groups of Gypsies: Southern Italy *Rom*,

¹ Fowler’s *Modern English Usage* (Oxford University Press, 1985 reprint) clears up the double spelling issue: “In contrast with the words into which *y* has been introduced instead of the correct *i*, apparently from some notion that it has a decorative effect (*sylvan*, *syphon*, *syren*, *tyre*, *tyro*, etc.), there are a few from which it has been expelled for no better reason than that the display of two *y*s is thought an excessive indulgence in ornament. In *gypsy* and *pygmy* the first *y* is highly significant, reminding us that *gypsy* means Egyptian, and *pygmy* foot high (Gk.: elbow to knuckles). It is a pity that they should be thus cut away from their roots, and the maintenance of the *y* is desirable.”

Central and Northern Italy *Sinti*, Slovenian and Croatian *Rom* of Italian nationality, and foreign *Rom* from former Yugoslavia and other Eastern European countries. In big towns like Turin or Milan, all of these groups may be present. Different groups of Gypsies have very different lifestyles and living conditions. Even within a defined ethnic group there may be very different ways of life. People who are ethnically *Sinti* might live in mobile homes in camps, in brick houses in camps or in regular apartments. Different *Sinti* groups have different traditions and ways of life, they might speak their original language or not, be nomads or not, be more or less endogamous, have different beliefs and be German, French or Italian.

The simple fact of being a Gypsy does not imply a predisposition to certain conditions. As stressed by R. C. Gropper in 1982 (17), most diseases affecting specific groups of people are mainly attributable to the environment in which they live and their lifestyle, with only a small contribution from individual genetic characteristics. It is difficult to separate genetic causes of illness from environmental causes (that include social, cultural and political aspects). Therefore, in research into illness in “Gypsies”, it is important to specify which specific group has been studied and to describe their living arrangements.

Inappropriate generalizations are not uncommon (18, 19), and examples can be found of descriptions of specific ethnic groups by one author improperly used by other authors (“*The Sinti, in Piemonte since the XV Century, are more highly evolved*” than the *Rom Xoraxané* and *Kanjarja* (20, p.7)). Rabino Massa and Masali in 1987 (18) started out from a study by E. Marcolungo written in 1983 (21) that analysed different groups of Gypsies living in Turin, to engage in a study on the biological distance between *Sinti*, *Rom Xoraxané* and *Rom Kanjarja*, and found no significant differences between the groups. Biological distance should not be

confused with ethnic difference.

Generalisations about different groups of Gypsies, intended to be helpful, may fail in this intention. In an article by Bodner and Leininger, on American *Gypsies* and *Gypsies* from Northern Europe, published in 1992 and designed to help “*nurses understand this largely unknown culture, and to offer guidelines for providing culturally congruent nursing care*” (19, p.17), statements like: “*Gypsies believe in ghosts and miracles*”, “*they tend to use and often exploit the natural resources of others*” or “*women are trained in the art of fortune-telling*” (p.21) cannot be considered useful in serving the enunciated purpose. These features do not identify a culture, neither talking about a specific ethnic group nor referring to Northern European Gypsies. In terms of cross-cultural communication it would be more important to realise that cultural differences are superficial phenomena and to focus on understanding the similarities existing in man’s behaviours and accomplishments to control reality (22).

An interesting Italian article published in 2002 (23), about the activities carried out by the *Area Sanitaria* of the *Caritas Diocesana* of Rome in *campi zingari* (Gypsy camps), described the health status of the *zingari* and used bibliographic references to describe their health needs. The results showed precarious health conditions, with high rates of respiratory and skin diseases (mainly attributed to poverty) and hypertension and metabolic diseases (mainly attributed to their lifestyle), and with a higher risks in maternal and child health. The article reports data of the Epidemiological Observatory of Lazio Region, of a percentage of low birth weight babies of 18.4% for *nomadi* children compared with 5.7% for Italian children. The authors conclude that future interventions among *zingari* people should be aimed at improving their quality of life. However, the article does not distinguish in the analysis

between different groups and needs, offering to laypersons a generalised picture of *zingari/nomadi*.

The Gypsy “race”

It is not uncommon to encounter the term “race” being used inappropriately, even in relatively recent studies (24-30). De Amici and colleagues (26), in a letter published in 1998 by the title “*The influence of race on breastfeeding*”, compared 21 Gypsy women of unspecified origin, nationality and lifestyle with 23 Italian women (the implication being apparently that the Gypsy women were not Italian). The article included generalisations about Gypsy culture and lifestyle but did not provide any detail about the specific ethnicity or nationality of the 21 women in the study. Without any specification, the article included statements such as “*they spread all over the continent and live in nomadic isolation*”, “*they prefer to get married within their community for social and cultural reasons: this explains the high rate of consanguinity and the high rate of congenital abnormalities*”, “*we know little about their way of life and about dietary habits because of the language barrier*” (p.413). This type of background information renders any conclusion about breastfeeding practices questionable.

Cruz and colleagues, in 1998 (24), described the “Gypsy race” as a risk factor related to HBV (hepatitis B virus) infection in a prospective study “*to determine the relationship between this racial factor and HBV infection*” (p.314). The authors stated, “*the ‘Gypsy’ or ‘non-Gypsy’ characteristic was determined on the basis of the well-known anthropological features of this race and, in dubious cases, the person concerned was directly asked to furnish this information*” (p.315). No elements were given to justify why was “Gypsy race” considered to be a risk factor.

More recently, two Slovak and one Spanish article used the term “race” in the following statements:

- “*The purpose of this study was to investigate the underlying mutation in Gitelman syndrome patients of Gypsy race from different geographic origin*” (27, p.25).
- “*Romanies belong to Indo-European race*” (28, p.479).
- “*The Gipsy population is genetically related with Asian Indians because Romanies belong to the Indo-European race and their original home was Central Northern India*” (29, p.461).

In another Spanish article, the English term “gypsy race” was used in the English version of the summary, while *etnia gitana* was used in the Spanish version (30).

The origin of the Gypsies

Among the many articles on the genetic makeup of “Gypsies”, many present theories about their Indian origins and discuss their findings in the light of these theories (31-43). Few examples can illustrate the complexity of this field and the possible confusion that can result.

In 1979, Barstocas and colleagues (31) compared their results about genetics among Greek *gypsies* with those of other authors in studies carried out in India, Western Pakistan and other European countries. They described similarities and differences in the findings from different countries. They observed a similar distribution of ABO blood groups among Greek *gypsies* and among people studied in Indian and Pakistani populations, but were unable to conclude whether this supported theories on the origin of the *gypsies*.

In 1969, Galikova and colleagues (32) described a significant difference in Hp1 gene frequency comparing a sample of the Slovak *Gypsy* population with several samples derived from studies of the population of Czechoslovakia. The Hp1 gene frequency among their sample of Slovak *Gypsies* was similar to that described among populations in India and Pakistan. But significant differences also emerged on comparing the two groups of studied *Gypsies*, from Eastern and Western Slovakia. As the authors pointed out, the studied *Gypsies* were a mixed population for which was difficult to estimate the exogamy rate. The authors also declared that out of the 360 people studied, the “non-assimilated” (and therefore those who might have been more endogamous) were under-represented.

Kalaydjieva and colleagues (35), in an article published in 1996, stated that a disorder named “hereditary motor and sensory neuropathy - Lom” (HMSNL) was caused by a single mutation whose origin predates the divergence of the group studied from other groups that present the same disorder, but differ in terms of identity, language and history of migrations. However, only in later works by the same authors we found more specific references to the other populations not originally from Lom (north-western Bulgaria).

Ogawa et al. (36), in 1998, asserted that *Spanish Gypsies* are different from some East Asian (South Korean, Chinese Korean, Man, Northern Han, Mongolian and Buryat) populations in the distribution of HLA-B61 alleles and their association with HLA-C and DRB1. Rani and colleagues (39), in an article published in 1998 on the association between class II HLA alleles in the population of Northern India, found characteristics common to those of Czechoslovakian *Gypsies* and also suggested that Indians are Caucasoid with traces of Black and Mongoloid admixture.

R. C. Gropper made an interesting comment on the attention of researchers towards the genetic make-up of Gypsy groups (44, n.4 p.7): *“The question I wish to raise strikes more deeply at the issue of genetic (and, for that matter, linguistic) comparisons, even if the studies are conducted properly. What do they mean? What kind of an anthropological definition of a socio-cultural group is implied? If our focus is socio-cultural, why are we raising a biological (or linguistic) issue?”*

Studies on Gypsy health

Hajioff and McKee in 2000 (45) and Zeman, Depken and Senchina in 2003 (46) published two important reviews of the literature on health issues among *Roma* populations, leading to very similar conclusions.

Hajioff and McKee based their review on 110 articles on *Roma/Gypsies* published from 1966 to 1999 and excluded genetic studies in the count. In their review, the authors affirmed that the most striking finding was the almost complete absence of research on non-communicable diseases. Some suggested explanations were found in the difficulties of undertaking research on marginalized populations and in the fact that researchers may be regarded with hostility. But more serious explanations were also put forward, relating to the values underlying the research: *“the focus on communicable disease may reflect less a concern about the health needs of the Roma but more those of the majority population”* (p.868). Hajioff and McKee affirm that the health needs of the *Roma* population lack visibility, not only because of the absence of research, but also the absence of advocacy on their behalf.

Zeman and colleagues based their review on 129 articles published from 1985 to 2003 and

available in full-text English. Some 50% of these articles dealt with genetics, congenital anomalies and related concerns. The authors point out that “*genetic research and counselling is quite expensive and, while scientifically informative, if it is not applied it may do very little to enhance the health of Roma peoples in their daily lives*” (p.236). In their review, the authors found few studies on the health status of *Roma*, “*most of these being descriptive studies and only three being analytic or hypothesis testing in nature*” (p.232). Zeman and colleagues conclude affirming that “*the Roma peoples and other disenfranchised and impoverished groups would benefit from a concerted research and action focus on the part of health care scientists in regard to the factors of poverty, disenfranchisement, and oppression which contribute to an increased incidence of chronic and infectious health outcomes, poorer outcomes when these conditions occur, and poor health behaviours on the part of impoverished groups*” (p.243).

Ferrer, in 2003, carried out a review on Spanish *gitanos* (47). The review is based on 96 articles published in the last 20 years. Out of these, some 29 articles were the result of genetic studies. Despite the fact that 57% of the studies reported some social inequalities in health, the Spanish gypsy community is considered to be a health risk group mainly due to ethnic and genetic factors. The author affirms that despite a general awareness that the Spanish *gitanos* have a poorer health status because of strong socio-economic inequalities, there are relatively few articles concerning this matter.

Genetics and the health of Gypsies

In 2001, Kalaydjieva, Gresham and Calafell published a specific review on genetic studies (48). Out of 297 articles published from 1960 to 2000, some 124 were on genetic issues (41 in

clinical genetics, 44 were molecular studies on genetic disorders and 39 on population genetics).

The authors affirmed that very few articles dealing with population genetics suggested heterogeneity of *Romani* populations. Despite the fact that genetic analysis shows the internal diversity of the *Roma* – even within individual countries – who appear to be more heterogeneous than autochthonous European populations, *Roma* are the most studied European ethnic group in terms of genetic make-up. What is even more worrying is that although information on the characteristics of affected *Romani* populations could be important for public health interventions, genetic studies on *Roma* have often failed to take the immediate benefits of research back to the individuals and families that have been the object of research. In the review it is stated that *Roma* are still “objects” of investigations conducted by outsiders and that “*many publications display judgemental and paternalistic attitudes, that would be considered unacceptable if used with regard to other populations*” (p.3).

It is not intention of the author to deny the importance of genetic factors in the diseases that might concern groups of *Rom*, *Sinti* or *Kalè*. However, genetic explanations should not be considered as the only important factors. In 1966, R. Dubos stated (49): “*Whether they be of African, Amerindian, European or Oriental origin, and whatever the complexity of the racial mixtures of which they are constituted, human populations usually acquire the burden of diseases characteristic of the geographical area and social group in which they are born and live. Medically speaking, man is, in general, more the product of his environment than of his genetic endowment. The health of the people is determined not by their race but by the conditions of their life.*”

In the period between 2001 and 2005 two articles were published on the genetic make-up of *Roma*, stating that the collected information will be helpful for forensic purposes (50, 51), and two were published on anthropometrical differences between *Roma/Gypsies* and non-*Roma/Gypsies* (52, 53). In Bulgaria, the article by Zaharova and colleagues (50) analysed seven Y-chromosomal STR haplotypes showing a significant difference between Bulgarians, Bulgarian Turks and *Gypsies*, and suggesting that population differentiations could be taken into account in the analysis of forensic cases or for paternity testing in Bulgaria. In Greece, Deligiannidis and colleagues (51) analysed the allele frequencies of 13 STR loci, comparing a sample of Greek *Roma* with the Greek population. The results, considered by the authors to be relevant for forensic cases, showed significant differences in 11 out of the 13 loci. The same article presents a comparison between Greek *Roma* and a sample of Hungarian *Roma*, and showed significant differences in five out of eight loci. In Hungary, Nagy and Pap (52) analysed the dermatoglyphic traits of finger and palmar prints in samples of Hungarian and *Gypsy* children. Significant differences were found in most of the analyses that were carried out, suggesting, according to the authors, that admixture between Hungarians and *Gypsies* has been small despite having lived on the same territory for centuries. Mandadzhieva and colleagues (53) studied the differences in anthropometrical parameters and pulmonary function in Bulgarian and *Romany* children and found that Bulgarian children were taller, fatter, had higher birth weight, vital capacity, forced expiratory volume and transfer factor. The authors concluded that, besides genetic factors, some other factors, such as environmental and economic factors could significantly contribute to these differences, but that it would be difficult to weigh precisely the impact of each of them.

Congenital malformations among Gypsies

Some studies on congenital malformations in Gypsies seem to demonstrate preconceptions. In a Greek article published in 1979, the authors – who studied 200 *Azigani* in search for malformations and failed to find individuals with genetic malformations or hereditary diseases – speculated that children with health problems might have been abandoned in hospitals or in institutions and that during the 19th Century infanticide was practised on babies suffering from malformations (31). No evidence was given to support this statement.

Some studies concerning congenital diseases are difficult to interpret because they do not specify how the sample of people was selected (54, 55) or they mention selection methods not generally recommended (56, 57). In some cases the authors present conclusions that are not supported by the reported evidence (58, 59, 60).

The study by Diez and colleagues, published in 1998 (56), concerning the 185delAG BRCA1 mutation was based on a sample of 25 Spanish *Gypsy* and 25 non-*Gypsy* women: the authors affirm they did not know whether their sample of Spanish *Gypsy* women was representative of the Spanish *Gypsy* women's population. Only one *Gypsy* woman from the sample was found to be a heterozygous carrier of the mutation. The small numbers made it difficult to draw any conclusion about the proportion of heterozygous carriers in the Spanish *Gypsy* population, estimated by Stuewing (quoted by Diez) to be 1% in the *Ashkenazi* Jewish population. Nevertheless, the authors suggested that this mutation might have been transferred from the Jews to the *Gypsies* on their arrival in the Mediterranean. In 1989, Reddavid and colleagues (57), in Turin, randomly selected a group of 22 *Rom* for a study on polymorphism of β -globin genes. However, there are various groups of *Rom* in Turin very different from one

another and of different origins. Without information about which specific group or if more groups of *Rom* were studied, it is difficult to interpret the results. In the concluding paragraph, there is some confusion between “genetic origin” and “ethnic origin”, which can be a cause of ambiguity.

Several studies on the genetic make-up of the Gypsies and on congenital malformations were based on the assumption that Gypsy groups practiced some form of endogamy. However, endogamy needs to be clearly defined in terms of which groups practiced it, to what extent (in terms of definition of the inner group and rigour) and the estimated rate of consanguinity deriving from it. Other explanations of high rates of congenital deformities in members of single communities are also possible, including exposure to environmental mutagens.

Some studies recognise the multiple potential causes of genetic malformations and include epidemiological techniques to examine these. In 1998, Kalaydjieva and colleagues reported on the Hereditary Motor and Sensory Neuropathy-Lom (HMSNL) affecting 35 individuals from a *gypsy* community in northwest Bulgaria and four members of a *gypsy* family from northern Italy suggesting, after haplotype and linkage disequilibrium analyses, that it was caused by a single mutation that may have originated prior to the migration from India (59). Martinez and colleagues analysed the Medium Chain Acyl-Coenzyme A Dehydrogenase (MCAD) deficiency in the Spanish population showing a much higher frequency of the G985 mutation in the Spanish *Gypsy* population compared to the non-*Gypsy* population (60), suggesting that the mutation occurred out of Europe and was brought into Europe by Indo-European-speaking people. The authors justified this hypothesis with the evidence that the frequency of the mutation was higher in non-*Gypsy* populations of other northwestern European countries (Netherlands and Belgium) compared with Spain. In 1980, Varadi and

colleagues reported about six children from three *gypsy* families living in two colonies in eastern Hungary found to have a syndrome similar to the trisomy 13 and Mohr's syndrome (61). Although the authors could not prove consanguinity among the three families, they suggested the syndrome was probably autosomal recessive.

Among the numerous studies on genetic malformations in Gypsy populations, few of them discuss the possibility of improving the health of the studied groups through counselling or early diagnosis (62-66).

Preventive health care among Gypsies

Most of the articles on preventive health care among Gypsies focussed on childhood immunisation. In some cases the major concern seems to be that the rest of the population at large might be in danger due to the presence of unvaccinated Gypsies or else the authors consider being a Gypsy as a risk factor from a social, economic and health point of view without providing further explanations. Instances can be found in a letter by Antúnez Gálvez and colleagues on hepatitis B in *gitanos* children (67), in which the *gitanos* are considered a risk group without further specification of the reasons why an ethnic group had a higher prevalence of HBV infection and lower vaccination coverage. Aylward and colleagues carried out a study on members of a *Gypsy* camp in Italy, where a suspect polio case was notified in November 1994 (virologic studies did not detect evidence of a poliovirus infection), and stated that *Gypsies* (68) are at a particular risk of reintroducing wild polioviruses because of their low immunization coverage and often nomadic lifestyle.

Morales and colleagues (69), studying seroprevalence of anti-HAV antibodies in three socio-

environmental groups (white family unit, *Gypsy* family unit and orphanage), showed that seroprevalence was higher in children from *Gypsy* family units. However, no stratification was carried out to take into account socio-economic factors.

Other studies appear motivated by reasons such as the protection of the population being studied, or efforts to explain isolated cases or epidemics. Bell and colleagues (70), studying the “susceptibility of *itinerants* in Scotland to poliomyelitis” in eight separate sites, specified that *travelling* people who lived on well equipped sites did not pose a hazard to nearby settled populations. A study on 50 cases of poliomyelitis in Spain in 1998-1984 (71) revealed that, because of poor vaccination programmes, the *Gypsy* community contained a large group of susceptibles capable of transmitting poliomyelitis, maintaining wild-type virus strains in circulation. A study on an unspecified *nomade* community in Rome (72) showed a lower vaccination coverage compared with the Italian average, but a high prevalence of antibodies among the unvaccinated especially for polio and measles, probably due to “contact doses” and fostered by the poor hygienic status of the camp.

Still other studies on immunisation status or antibody prevalence in *Gypsy* groups ascribe economic disadvantage and reduced access to basic health services as accounting for the existing gap between *Gypsy* and non-*Gypsy* groups. Cilla and colleagues (73) explained the higher prevalence of HAV infection in Spanish *gypsy* children in San Sebastian (Basque Country) with the unfavourable living conditions of the Spanish *gypsy* population. Feder and colleagues (74) state that factors that reduce *Traveller Gypsies*’ access to immunizations in East London include involuntary mobility, lack of a general practitioner and lack of information about community health services. McKenzie identified the same factors as responsible for lower immunization coverage and poor health care in a study on under five

traveller children in Bradford (75).

Health problems among Gypsies in relation to living conditions and lifestyle

Most authors of studies on the relation between health problems and living conditions among Gypsies describe a situation that is well below the average for the general population in the area. However, Flynn in an article on *Irish Travellers* (76), published in 1986, described the good health status among these people, despite the identified risk factors (consanguinity, early marriages, large families, artificial feeding, illiteracy and poor housing). In particular he described low infant mortality and longevity. The only significant health problem was a high rate of congenital malformations, which was attributed to endogamy practised by this group. However, this author did not consider the possible role of environmental risk factors in the high rate of congenital defects, given that the latter did not seem to have affected either the infant mortality rate or the longevity. In a study published in 1988 on diseases relating to oral hygiene in a sample of the “*nomade*” child population in the city of Turin (20), the authors noted no particular difference between the prevalence of these diseases in the *nomadi* children compared with the rest of the population, even though, they said, the *nomadi* in their sample were “*by nature of habit and culture totally ignorant of the most basic notions of hygiene and oral preventative practices*” (p.9).

Many studies on the relationship between health and living conditions of Gypsies have been done in the United Kingdom. Several authors concluded that poor health in Gypsies is related to segregation generated by discrimination and by legislation that is either inadequate (Caravan Sites Act, 1968) or explicitly discriminatory (Criminal Justice and Public Order Act, 1994). Social alienation in turn creates insecurity, poverty and malnutrition, as pointed out by

J. Pahl and M. Vaile in 1987 (77), P.C. Walker in 1986 (78), I. Kargar in 1992 (79) and P. Van Cleemput in 2000 (80). Van Cleemput pointed out that ignorance and prejudice shown by medical staff render them unable to deal with the needs of *Gypsies* and *Travellers*. Pahl and Vaile, in a study carried out among all known *Travellers*' sites in Kent, reported an above average perinatal mortality, especially in sites with inadequate facilities, and insufficient immunisation and preventive care of children, especially among the more mobile groups. Walker, citing Pahl and Vaile and a study by Save the Children Fund carried out in East Anglia in 1983, expressed the need for local authorities to provide more and better-appointed sites for *traveller* families. Z. Matthews (81, p.26) stated: "*Social exclusion is a process. It does not develop in a vacuum but is rooted in systematic neglect... Most of the information, research and literature on marginalized groups such as travellers is rooted in the biomedical tradition and although this has provided an overview, it invariably ends up pathologising the culture itself, and, perhaps unintentionally, results in reinforcement of the misconceptions... More than 20 years ago the World Health Organisation advocated the hypothesis that health was primarily about politics, calling on governments to take responsibility for the health of their people... it is not merely the unfair distribution of resources that produces social inequalities, but rather powerlessness that emerges as a broad-based risk factor for disease.*"

Authors from outside the United Kingdom have also considered the relation between health and living conditions in *Gypsies*. In France, in an article published in 1988, J. C. Guiraud (82, p.11) claimed that: "*More than 20 years of discussions between Tsiganes: nomads and settlers, Romanies, Manouches and Gitans have afforded us the opportunity not just to carry out exhaustive scientific research, but to witness the assault on health inflicted by society at large on this hardy minority. There does indeed exist a pathology identifiable as exclusion, stress and forced idleness. The living conditions imposed on the Tsigans, still in 1988, in*

certain 'designated places', are a permanent assault on the minimum requirements for hygiene and respect for the individual."

In 1992, in Spain, J. M. Corretger et al. (83) stated that the most common paediatric diseases encountered in segregated groups that include ethnic groups of immigrants and *gitanas* communities were those fostered by shortcomings in socio-economic and health and hygiene conditions. Furthermore, the "imported" diseases of immigrants were at a low level, given their progressive integration into their adopted country. In 1991 in Hungary, K. Joubert (84) compared various socio-demographic factors with other variables relative to the conditions of a child at birth. His article is reviewed in the children's health section.

In many cases in which socio-economic factors are recognised as playing a role in the different health status of Gypsies and non-Gypsies, however, this is often not supported by evidence. In the last five years, only two studies made explicit use of socio-economic factors in studying the differences between Gypsy and non-Gypsy groups (85, 86). A 2005 Hungarian article (85) reports on the poor access to health services of people living in 767 marginal *Romany* settlements, where 138 thousand people live, including 21 thousand children from birth to five years of age. It presents information on the hygienic situation of these colonies – access to water, presence of rats, proximity of illegal refuse tips and house conditions – concluding that in most settlements the conditions endanger the public health and epidemiological safety of their inhabitants. Unfortunately the article does not look for associations between environmental risk factors and the health status of the inhabitants of the colonies. A Czech article (86) published in 2002, on vitamin C, E and A levels in maternal and cord blood sera, collected information on personal and social characteristics, health, ethnicity, and lifestyle of the mothers. The authors observed significantly decreased vitamin C

levels in *Gypsy* mothers and their babies compared to mothers and babies of the Czech ethnic group, suggesting that this could be attributed to unfavourable diet and smoking habits.

Anthropology and health of Gypsies

In the United States, A. Sutherland (87-89) and J. D. Thomas (90-93) are probably the major authors of articles written from a joint medical and anthropological point of view on this subject. In their articles, published respectively from 1977 to 1992 and from 1985 to 1993, they deal mainly with adult diseases and the explanations that should be given to medical staff to avoid misunderstanding and poor inter-personal rapport with *gypsy* patients. Two other relatively early American articles, one published by F. Mandell in 1974 (94) and the other by R.C. Wetzel and colleagues in 1983 (95), consider medical interaction with *gypsy* patients.

Mandell states (p.607): *“Delighted by stoic children and patients who intellectualise disease and glorify the physician, our appreciation of other cultural responses is often minimal... Medical cognisance of the meaning of various cultural practices and a willingness to accept their forms of communication can help to circumvent the phenomenon of alienation of the child and his parents from the physician.”*

In 1997, A. Ojanlatva and colleagues stated that the medical community's failure to effectively communicate with members of minority groups was a universal problem needing attention (96). B. Peck (97) and A. Streetly (98), respectively in 1983 and 1987, explained the importance of an integrated approach. Peck describes the work done by the Sheffield Gypsy Support Group and how, in Sheffield, enhanced cooperation between various agencies, including teachers, voluntary workers and a health visitor, improved the services for *gypsies*.

Streetly described the results of a year's work as clinical medical officer responsible of the provision of health care for travellers in Kent. After a study carried out in Kent in 1984-85, that showed a high prevalence of stillbirths, a low uptake of immunisation and that many sites for *travellers* lacked sanitation, electricity and water and were hazardous for children, the experience showed that it was important for all agencies to liaise to maximise any help provided, and for the health visitor to reach travellers of all ages and both sexes and to show respect for the travellers' cultural values.

E. Anderson (99) in 1997 analysed the perception of and concerns displayed by *traveller* parents of Leicestershire (UK) about the health of their children. *Traveller* parents were significantly more concerned than non-*traveller* parents regarding the risk of cough, colds, diarrhoea and asthma. The author stated that young children were at risk of ill health because of inadequate housing, poor facilities, poor water supply and overcrowding. According to the author, the attitude of *travellers* encountered in the study contradicted the negative views about *travellers* held by the general population.

D. M. Edwards and R. G. Watt (100, 101), in 1997, studied the perception and use of services by *Gypsy Travellers*, and found inequity in dental service use by *Travellers* living on unauthorised and transit sites in East Hertfordshire compared with the local population. As far as step-by-step take-up of medical treatment along normal channels is concerned, (specifically by the *Roma Harvati*), the Italian article by P. Trevisan (102), published in 1996, is particularly important. It describes the health beliefs and practices of a *Harvati* community of Northern Italy and analyses the relationship between the *Roma* and the health service, the fears, the opinions, the underlying attitudes, and the problems of communication and trust.

The health of children

The literature dealing specifically with the health of Gypsy children is sparse.

R. Porcu and colleagues (103), in 1996, dealt with the *zingara* population of the Milan area (Italy). In the article it was not clear which specific ethnic group was being targeted. The authors stated that *zingari* are divided into various ethnic entities – some settling long ago, some Italian and others foreign – and stated that *zingari* define themselves as *ROM*. However, Gypsies, or *zingari*, do not always define themselves as *Rom*; they define themselves in different ways, according to their ethnic origin. Furthermore, various groups of different origin define themselves as *Rom*, and if the *zingari* in the study defined themselves as *ROM*, it would still be necessary to specify which specific groups were being referred to.

The authors stated that “*zingari* are a young people” on the basis of the age pyramid and the fact that only 1% lived longer than 64 years. A specification as to which *zingari* were being referred to would have been needed in this case: whether they were camp dwellers or lived in houses, and whether they were Italian or foreign citizens. Foreign *Rom* and camp-dwelling *Rom* and *Sinti* cannot be considered closed populations. Recent immigration and permeability between camps and housed groups do not allow for an estimation of life expectancy from the age pyramid. Death and disease rates could indeed be higher in these populations, but it would be necessary to consider the differences between the various groups and their mobility before determining if this were the case or not.

While noting that “*encounters between zingaro patients and the SSN (National Health System) – also in the case of elderly zingaro citizens of Milan – mainly take place via*

Casualty, which patients turn to with all kinds of health problems, there practically being no other health structure available” (p.51), the authors concluded this was due to a lack of information on the part of workers about the conditions of *zingari* and their culture.

The admission rate for children aged 0 to 12 months was higher for *zingari* than for the rest of the population (from the data presented in the article, frequencies and percentages cannot be determined) and average in-patient treatment periods were much longer (8 days for *Rom* children and 5 days for all children). In-depth analysis would be required to look for the causes of these results: the different length of in-patient treatment could be an indicator that *Rom* children were taken to Casualty when they were in worse conditions compared with non-*Rom* children. The authors reported the most frequent causes of admission in paediatric departments of the Lombardia Region. The first four causes for *zingari* children appear to be all related to infectious diseases (acute bronchitis 15%, intestinal infections 11%, pharyngeal tonsillitis 7%, bronchial pneumonia 6%), whereas the four most frequently noted diagnoses for the infant population as a whole were lymphoid leukaemia 6%, observation for suspected disease 5%, bronchial pneumonia 4% and generic symptoms 3%.

S. ní Shuinéar (104) considered that one of the health risks faced by *zingare* communities is their unwillingness to place themselves in the hands of persons who are not *zingari*. She suggested that this is why *zingari* might request medical assistance late and via Casualty. Casualty departments are visible and accessible, and provide a degree of anonymity, whilst also providing immediate answers. In her work, published in 1994 by the UNICEF International Child Development Centre, she pointed out how the root causes of *zingari* high disease rate are basically environmental, related to housing problems and to the places in which they are often forced to live.

In 1974, F. Mandell (94), cited above, suggested that many of the conflict situations between the health system and *Gypsy* families arose out of an inability on the part of medical staff to come to terms with the point of view of patients (or of the parents of patients) with regard to the disease, and practises and exchanges of information relating to the disease.

An analysis of four years of interventions on a *Rom* settlement (the *S. Caterina* camp at Bologna) can be found in the work published in 1996 by M. Conti and F. Petri (105). The *Rom* are referred to as *nomadi* although they are not nomads, since the sedentary Bosnian *Rom*, at the time of writing the article, had been living in that camp for five years: 1991-1996. The work dealt with the important role of prevention, pro-breast feeding initiatives, performance of obligatory and facultative vaccination, and unsatisfactory hygiene conditions in the camp. Mention was made of problems in the past (Hepatitis B cases in 1991, frequent scabies and a measles epidemic in 1993). The authors provided an account of the work carried out by the *Poliambulatorio* health centre, the policy of which, over a period of five years, led to its becoming an acknowledged point of reference among the Slav and Albanian *Rom*. In this period, a general reduction in the incidence of all skin diseases and an increase in unsolicited requests for paediatric counselling, for vaccinations and for advice relating to correct feeding, were reported.

L. Gaspari and I. Pini (106), in 1996, also referred to *nomadi* and generically to *zingari* from former Yugoslavia. The authors describe a paediatric community health centre in Forlì, set up for this *Rom* group six years beforehand. In illustrating the work of the clinic, the authors wrote about the differences between what the *zingaro* understands as a health need and the pre-codified responses of the health services and the “*need for (health) services to restyle*

their approach to also take into account these perceived and expressed needs by focusing on the 'real' person requiring care, and to get rid of cultural and structural inflexibility in (health) services" (p.60). The clinic apparently had special arrangements for *Rom* patients and the authors stated that particular care was taken with regard to "*scrupulously applying hygiene norms in health centres after visits by nomads so that visitors arriving later would not be at all put out, or making specific facilities available*" (p.60). They also stated "*it goes without saying that preventive health measures are not readily understood by nomadic parents*" (p.61). This generalisation seems unjustified. The authors stated that all the mothers opted for hospital delivery and that newly-borns were often left in hospital care even when the mother left the hospital after the first day of life of the baby. This may be protective for the baby in view of the poor conditions in the camps and new mothers may take the decision to leave their newborn child in the hospital for this reason (12). Hospital delivery is sometimes humiliating for *Rom* mothers, as a result of widespread prejudice and the manner in which *Rom* mothers can be treated, and yet these obstacles are overcome in view of the benefits for the baby who will receive adequate hospital care.

G. Feder and R. Hussey (107) presented the results of the 1990 Maternity Alliance report on maternal and child health aspects of *Travellers* in Great Britain. They pointed out that the health conditions of pregnant women and their children were largely dependent upon the living conditions to be found in caravan sites. Areas of this kind were inadequate and far too few to accommodate the *Traveller* population. The report urged the health authorities to take the health needs of this population into account when planning services, and declared that integration of these communities was undermined by discrimination on the part of health service staff as well as by the mobility imposed upon this community as a result of the lack of caravan sites. McKenzie (75) cited this article, confirming that vaccination coverage for

traveller children under the age of five was lower than for children in Bradford within the same age range. McKenzie believed that one reason was the instability of the conditions of life of travellers due to repeated evictions, and did not consider that the beliefs of *travellers* were relevant factors.

The study by M. Gordon and colleagues (108), published in 1991, on the health conditions of 350 Northern Irish *traveller* children aged between 0 and 16 years is important in that it covered a population residing in areas with facilities provided as well as areas for which authorisation had not been granted, and flats. It is not clear from the paper whether the investigation was carried out on a household basis or whether respondents were selected from those who made use of health services. The study concentrated on the incidence of consanguinity, living conditions, congenital abnormalities, immunity status and reasons for in-patient treatment. Children aged between 2 and 5 years were selected for the immunity study in order to facilitate comparison with data from the rest of the population. However, this comparative study was neither included in the work nor cited in the bibliography. With regard to congenital abnormalities, only the consanguinity factor was considered. The very poor living conditions noted for a number of families were associated only with infectious diseases. The data on in-patient treatment revealed that *Traveller* children were more frequently admitted into hospitals with infectious diseases compared with the rest of the children. Out of 106 children aged below five, 42% were treated for respiratory infections and 25% for gastrointestinal infections.

K. Joubert (84), cited above, provided a detailed analysis of weight and length at birth and gestational age of Hungarian *gypsy* children. The author pointed out that the information was collected from birth records and that the children were declared *gypsy* if the mother spoke the

gypsy tongue. The author stated that *gypsies* who declared they spoke the *gypsy* tongue made up approximately 20% of the total *gypsy* population. Joubert collected data on 10,108 *gypsy* children born between 1973 and 1983, while the comparative data on the total Hungarian population concerned children born in 1978. He found that *gypsy* children were significantly smaller than the rest of the population (average difference: 377 g). The rate of underweight births (less than 2,500 g) was 26% among *gypsies* and 11% for the rest of the population. The premature birth rate (before 37th week) was 11% for *gypsies* compared with 5% for the rest of the population. Mothers' schooling was positively related to both infant weight and length at birth. Mothers who had undergone a longer period of schooling were also less prone to premature delivery and more likely to have fewer births.

Joubert considered that the higher rate of underweight births among *gypsies* compared with the national population might have been in part an inherited trait. However, the literature does not support an independent association between racial/ethnic origin and premature births nor is there published evidence of an independent association between racial/ethnic origin and low birthweight (109, 110). If they exist, the effects of genetic traits on birthweight are small. It is extremely difficult to separate environmental factors from true genetic differences (111). Maternal environment is acknowledged as the most important determinant of newborn weight (111, 112). Historically, the varied socio-economic conditions under which people have lived have caused great variations in the prevalence of low birthweight, even within the same population (113). Mothers' formal education level can be an important indirect factor affecting low birthweight (110). Isolation of an inherited trait effect requires control for other variables that could explain most of the observed difference in birthweight: differences in age at parity, birth interval, nutrition, incidence of health conditions such as systemic or genital tract infections, maternal height and weight, other socio-economic indicators such as

occupation or family income, antenatal care, potentially harmful habits such as smoking and drinking (109).

In an article on the *zingari* children of Milan, published in 1995, E. Sormani (114) cited K. Joubert, while noting that low birthweights were a frequent finding in Gypsies. Sormani also concurred with Gordon et al. on the high incidence of respiratory and gastrointestinal diseases. However, more information is needed to justify a comparison between Irish *traveller* children and the children of the vaguely defined *zingari* in Milan. By referring to *zingari* or *nomadi* children of Milan, the author was not supplying information on whether he was referring to Italians, foreigners, *Rom* or *Sinti*. More information would be needed to support the statements of the author on the studied group about lifestyle, low birthweight, poor vaccination coverage and high number of births, which are not common traits of all Gypsy groups.

One report published in 2003 (115) by Morrone and colleagues, described the approach followed in supplying health services to two camps of *Rom Khorakhané* and *Kaniarija* in Rome, Italy. It also presented clinical data on the outcome of the visits carried out at the camps by a group of medical doctors. The choice of collecting data on the access to the service – and not household data – was justified by the authors on the basis of the difficulty in gathering incidence and prevalence data due to the lack of population data. For children from birth to five years of age, 295 visits were carried out from October 1999 to July 2001. Some 29% of the visits were simple check-ups for healthy children, revealing a good preventive attitude of parents. Some 51% of the visits were for respiratory problems, 6% for gastrointestinal diseases and 5% for skin complaints. Unfortunately the analysis was descriptive, providing no evidence on the causes of the diseases.

Conclusions

There is a distinct lack of research focussing on well-defined Gypsy populations, or specifying what groups are being studied, and considering – as part of the epidemiological analysis – the context in which these populations live. More research covering extensive geographical areas and a greater number of communities would be necessary. In order to avoid perspectives of the “them-as-seen-by-us” type, more research is needed that includes the opinions and points of view of the Gypsies involved in the studies. Furthermore, with the exception of the United Kingdom, almost no studies have been carried out in other countries with Gypsy camps on the health of the populations who live there, and there is practically no research on the potential effects of legislation and behaviour of institutional bodies on the state of health of both “foreign” Gypsies and native groups.

In general, much of the literature is characterised by a defective analysis of the socio-economic context in which the studied groups live and of the cultural and anthropological dimension. This limits the usefulness of the research and in some cases it increases the obstacles in communication and understanding between the various studied groups of Gypsies and the health academy world.

To avoid the comparison between “Gypsies who are unhealthy because they are Gypsies” and “healthy majorities”, there is a need for studies that compare, within a homogeneous sample of a single Gypsy population, groups exposed to different potential risk factors and/or to different levels of risk. This way, the contribution to ill-health of specific studied factors could be disentangled from any putative weakness of the “Gypsy race”.

Considering that the Gypsies are the largest minority in Europe and generally the most discriminated and marginalized (116), it would be desirable to see more participatory research on the direct and indirect effects of forms of exclusion that, in many cases and in most countries, have an impact on their quality of life.

Unfortunately, most studies that advocate for the Gypsies were either descriptive or qualitative, and offered very little evidence on the effects of marginalization, living conditions and perceived racism (117) on the health of Gypsies. No examples of participatory research and few examples of community-based research were found.

As pointed out by Hajioff and McKee (45), previously cited in this review, the lack of advocacy on the behalf of the Gypsies was one of the most significant elements that appeared analysing the bibliography on the health of Gypsies. The systematic indifference toward Gypsies priorities, perceptions, and participation and the scarcity of research on the effects of prejudice and discrimination on the health status of marginalized groups needs to be taken into account.

However, recognizing that hypothesis and theories can be more or less subtly informed by societies' dominant ideologies (118, 119), and sensing the need to counterbalance the fact that those who are neither wealthy nor powerful are rarely consulted and informed about policies affecting them (120), should not induce to sacrifice the objectivity of science by appealing to emotion and morality (121).

In the words of Krieger, "*science (research on unsolved problems using defined, rigorous,*

and replicable methods to assess refutable propositions) and advocacy (recommendations for addressing unsolved problems, whether in the realms of practice, policy, or theory) mutually require critical assessment of competing theoretical and ideological explanatory frameworks and of the evidence they generate” (16, p.1152).

MARGINAL COMMUNITIES, ENVIRONMENT, HOUSING AND HEALTH

In this thesis most of the attention has been placed on factors identified by the *Romá* as risky for the health of their children. Before proceeding further it is necessary to consider the broader issue of the risk elements that confront any marginal population living in unstable housing conditions.

One of the problems affecting low income and ethnically discriminated groups living in urban contexts is the inequity in the siting of housing, which contributes to important disparities in health among population groups (122, 123, 124). In terms of exposure to environmental hazards affecting population groups unevenly, ethnicity tends to be a stronger determinant than socio-economic class (117). Evidence shows that neighbourhoods with higher percentages of minority residents tend to be closer to undesirable facilities, and be more exposed to air pollution (117, 125).

A growing body of scientific evidence demonstrates the relation between housing and health, uncovering increasingly new ways in which substandard housing affects physical and mental health - that of children in particular (124, 126). Having experienced poor housing conditions during childhood is associated with higher rates of admission to hospital and higher morbidity and mortality in adult life (127, 128, 129).

Characteristics of poor housing identified so far include: absence of hot water for washing, damaged or non-functioning toilets, water intrusion/leaks, ineffective waste disposal, presence of rats/roaches, overcrowding, presence of damp/mould, lack of ventilation, heating, and insulation problems, extreme temperature variations, and faulty building materials (122, 124, 130, 131).

Overcrowding can influence the level of psychological distress in children, and be related to developmental delay, heart diseases (131) and gastrointestinal infections (132). Overcrowding also affects mothers' mental health (124), which is considered an important factor in child health.

Not many studies have been conducted on the relation between asthma/allergic rhinitis and rat allergens. However, the presence of rat allergens in inner-city homes can be recurrent and it is proven that children are more likely to be sensitised to rats if there is visible evidence of rats in the home (133, 134).

Homes of people with low incomes are more likely to be less well insulated (124, 131). Homes with poor insulation tend to be too warm or too cold. Fluctuations in indoor temperature beyond a certain range are associated with a higher risk of cardiovascular disease (135), while living in cold houses is related to lower general health status (136), breathlessness and blocked nose (127).

Lack of ventilation and overcrowding, as well as poor materials and lack of maintenance, can increase the indoor level of humidity, generating problems of damp and mould (137, 138). It

is very complex to study home microclimates, as many factors need to be considered, like building materials, ventilation, water content and effects of heating and cooling (139). However, it has been proven that the presence of damp and mould is associated with the prevalence of wheeze, sore throat, runny nose, cough, fever and headaches in children (127, 139, 140). Dose-response relations have also been observed between increasing severity of dampness or mould, the mean number of symptoms (overall and per child), and general child health status (127).

In cases in which heating is kept high to compensate for poor insulation, health problems can arise due to the intense use of gas or wood stoves. In houses using gas stoves for heating, measurements showed levels of nitrogen dioxide (NO₂) 4 to 7 times higher than in houses using electric stoves (141). Indoor exposure to NO₂ has been associated with lung dysfunctions, such as asthma-related symptoms, lower levels of forced expiratory volume (FEV1) and forced vital capacity (FVC) in children (124, 138, 141, 142). The use of wood stoves can significantly increase the concentrations of carbon monoxide and polycyclic aromatic hydrocarbon particles. The effects of these occurrences on the prevalence of acute respiratory infections have been widely studied (131, 138, 143).

The effect of passive smoking on respiratory diseases in children has been well documented (124, 138). Parental cigarette smoking has been associated with different respiratory illnesses and symptoms, with significantly lower levels of FEV1 (142), and with low birthweight (144). It is important to take into account the social patterning of cigarette smoking, and consider that passive smoke suffered by children is a socially mediated factor (145). Social disadvantage, either material or social, is associated with high rates of smoking and very low rates of smoking cessation (146).

Some researchers have studied the psychological importance of the home, as a landmark and as a source of identity (147). The stress imposed by homelessness or unstable housing on children and parents increases the risk of physical and mental illness (147). Studies on homeless and poorly-housed children showed more frequent symptoms of illness (especially fever, cough, cold, vomiting, diarrhoea, bronchitis and wheezing), more frequent disability and bed days, and higher percentages of parents worried about their health, than in the general population (126).

In relatively well-off societies, the level of social and economic disadvantage within a society (relative disadvantage) is often associated with the increased risk of ill health of marginal groups, more than just the poor conditions alone (absolute disadvantage) (148). This finding is known as the theory of the gap or of the social gradient. Considering that health inequalities appear to be stronger in societies with higher income differences and higher levels of relative deprivation, in 1997 Wilkinson, citing Putnam's theory of social capital (149, 150), stated that "the importance of relative standards implies that psychosocial pathways may be particularly influential" (151, p.591) and that "psychosocial effects of social position account for the larger part of health inequalities" (p.591). A long debate originated mainly from a critique by Lynch and colleagues (152), on the definition of social capital to be applied to the public health field, on the role of social networks and the perception of inequality versus the structural causes of inequalities and its material manifestations (153-168). In 2004, Szreter and Woolcock (169) tried to reconcile the different perspectives, on the basis of "the volume and diversity of the empirical evidence indicating that social capital is likely to be a significant determinant of at least some important health outcomes" (p.652), and emphasizing that the debate was not "over whether inequality is highly significant in accounting for class

variations in health experience in economically advanced societies, but over the nature of the *principal* pathways of causation involved” (p.653). Szreter and Woolcock focussed on the definition of social capital, accounting for both a direct role of material deprivations and of the perception of “living in an unequal and unjust society” in determining ill-health outcomes.

Disadvantage can assume the forms of living in poor or temporary housing, living in difficult or unstable conditions or having an insecure employment (170). It also includes exposures to risky behaviours related to psychosocial stress, like smoking, eating and drinking “for comfort” (151). Time also needs to be taken into account: the longer people live in serious disadvantage, the greater their mental and physical health will suffer, with serious health consequences on the long-run (146).

In this thesis, given the decision of the author to focus on a sample of camps, some elements that would have been important in the comparison between *Rom* living in camps and *Rom* and/or non-*Rom* living in regular houses, were not considered. However, it is important to mention them here. The theory of the gap is one of these issues, which would need a sample including people living in better, more stable conditions. However, the time dimension will be taken into account in terms of years spent by the families living in the unstable conditions of the camps.

Another important element that should be considered, and that this thesis will not focus on, is the impact on health of racism and social exclusion (146), which is strictly linked with the theory of the gap (171). Ethnic minorities, refugees and homeless people are at a particular risk. People living in marginal communities feel – and are – often unable to effect changes (172). This sense of powerlessness causes frustration and stress, especially if people are

systematically excluded from the decision making process about their future perspectives. Comprehending racism is fundamental to understand ethnic inequalities in health, but the impact of racism on people would need to account for the complexity of the social and economic inequalities suffered (173). Racism can be attitudinal (prejudice – attitudes or beliefs that denigrate individuals or groups), behavioural (discrimination – acts denying equitable treatment to individual or groups), and can play a role as perceived racism (the way the individual perceives he/she is object of prejudice or discrimination) (174). Minority groups can suffer from multigenerational forms of oppression, disempowerment, forced relocations and assimilation (175). This complexity would require a specific study on the impact of various forms of racism on the health status of well-defined *Rom* groups.

COMMUNITY PRIORITIES AS A FORMAL ELEMENT OF RESEARCH DESIGN

The general objective of this thesis obliges the author to place community priorities at the centre of his research design. It becomes necessary, therefore, to examine research methods that formally incorporate community priorities into the design process.

We have found two methodological approaches in the literature that do this. One is called community-based participatory research and the other is referred to as CIET methods.

Community Based Participatory Research (CBPR)

CBPR can be defined as a collaborative research process in which researchers and community representatives work together in the identification of a problem affecting the community, in the collection of the data and in the interpretation of the results (176, 177). This can be

achieved by agreeing on a balance between developing valid generalisable knowledge, and benefiting the community that is being researched (178). Three fundamental elements in participatory research are collaboration, education and action (179). By education is meant a process involving all stakeholders, finalized to gaining better understanding of the shared environment, especially incorporating local knowledge and expertise in the understanding of health problems and the design of interventions. This can be done when community representatives and researchers share decisions and responsibilities (178, 180).

Because of its characteristics, CBPR approach tends to be less absorbed by the need of widespread generalisability and diffusion of results than other types of research, and more focussed on the empowerment of individuals and communities throughout the research process. For the same reasons, such an approach helps reducing the gap existing between researchers and community members (181). Importance is given to the active involvement and control by community participants in the process of creating knowledge and change (182, 183). The importance of community members' participation in the research process is expressed by the belief that community members are qualified experts in the understanding of the context and dynamics they live in (184). For this reason, such participation enhances the quality of the research process (185, 186).

The main difference with what is commonly known as “community based research”, which is research in a community place or setting, is that the latter usually implies limited, if any, involvement of community members throughout the research process, remaining basically investigator-driven (182).

The collaborative process enhanced by a CBPR approach, by engaging community members,

and employing local knowledge in the understanding of health problems and the design of interventions (176), is particularly useful when the focus of public health is on social, structural, and physical environmental inequities (182).

To achieve its objectives, CBPR needs time, trust, solid relationships among all partners, to be preferably a continuous process of repeated research cycles, to use a mixed methods approach, and to count on “special” funds. All of these elements, which will now be described, are linked to one another and are key issues to be considered in the definition of the methodology to be used in the context of *Rom* camps in Italy.

Time

It takes a long time to build trust and partnership’s relations, to establish a participatory type of project and to show reductions in social inequalities or improvements in health (187). CBPR involves a long-term process and commitment (176): time is needed to be able to transfer ownership (188), and strengthen research and teaching. A CBPR approach should consider the possibility of a gradual shift towards higher levels of participation of local people (189), always assessing the best affordable level of participation at each stage of the research process (190). Furthermore, even under optimal conditions, it takes time for action research to produce effects (188).

Action research is a complex long-term process that requires continued commitment from all partners involved (188). Especially for community members, the time they invest on research partnerships is time away from addressing other needs in their organization and communities (191). This issue is particularly relevant for individuals involved in CBPR projects, without

being relieved of other responsibilities (182) and in situations in which there is often scarcity of human and economic resources.

The reserved nature of Rom communities – Building trust

Some *Rom* communities are reluctant to accept the presence of people who are not part of their community and want to study them, their problems and their cultural dynamics. The author had to face this issue, when visiting the camps and involving camps' residents in the discussion on research priorities. This lack of trust is understandable, given that in the past there has often been some lack of tact on the part of researchers and some researchers may have displayed poor listening and inter-personal skills. As told to the author by *Rom* living in camps and by non-*Rom* researchers and activists, the *Rom* often feel they are being observed, as if in a "zoo".

As seen in the literature review on the "health of Gypsies", many studies conducted on *Rom* have been of little or no use in improving the *Rom*'s living conditions. Worse, because there may be anti-*Rom* prejudice among researchers themselves, their studies may be presented in a way that can emphasize negative traits of *Rom* and undermine the value of their culture.

Furthermore, prejudice towards *Rom* is often reciprocated by the *Rom*, so that they might hold negative views about *gadjo* (non-*Rom*) researchers.

The feeling of distrust of marginal groups towards academia is widely documented in the literature. In economically disadvantaged urban settings and for ethnic minorities, the lack of trust and the reluctance to participate in research studies is based on a history of research that

failed to address questions of practice or social use for communities, with little or no feedback of the results to the participants involved, and often leading to stigmatisation (179, 182, 192).

People in their communities do not want to be used as “research objects”, especially when research is secondary to developing interventions that benefit the communities (191). Even in participatory approaches, problematic relationships between researchers and communities can grow on mutual lack of understanding about priorities, values, responsibilities and perspectives (172).

CBPR approaches can have the potential to overcome the mistrust that often exists between members of economically or socially disadvantaged communities, and research institutions, by counterbalancing power and enhancing the quality, relevance, and application of research to more effectively address the needs identified by the communities (192, 176).

Mixed methods, triangulation and contextualization

Environmental and socio-cultural factors that have an influence on the health status of marginal urban communities need to be included in the research process, to increase the validity of public health research, by acknowledging and integrating all of the relevant information (179). In particular, the built environment has a considerable role in determining the health status of marginalized populations (175). A community-based, mixed methods’ research approach can be particularly helpful to understand the complexity of the marginal urban environment, and its influence on human health (175).

The use of a mixed method approach enhances validity by broadening the base for data

collection and inclusion of contextual factors (193). Qualitative methods can be very helpful to better understand the community and its environment (176). Content validity can be achieved in the variety of data collected, while reliability can be measured by triangulation of data from more than one source (179, 194). Results often validate, and are validated by, community residents' own perception of the risks existing in the context in which they live (193).

The participatory component is also needed to establish good relationships with the community, even outside a formal research context. Respect is required to enter the community, and this step should be done through recognized members of the community who introduce the researcher in an appropriate way (176). If understanding the complex and interconnected context of people's lives is part of what is required to reach the research objectives, work should be done to narrow the gap between researchers and communities, in terms of research methods and sincere relations.

Participatory research that uses a mixed methods approach can improve the validity of health research by ensuring that most of the factors that make up the context of people's lives are included (179).

If one of the objectives of CBPR is to understand underlying aetiologies, and identify strategies to reduce inequalities, it would be of little help to just focus on a single research priority. Given the complex situations in which marginal communities live, and of the interactions between political, social, environmental and health factors, it is difficult to imagine that a single research project can reduce health inequalities. An approach to research

that requires time to be developed, and a cyclical problem-solving process including diagnosing, action planning, action taking and evaluation (188, 192, 172) is recommended.

Funds

Because two of the central elements in CBPR are building a partnership between researchers and community members, and focussing on the causes of health disparities, funding should sustain the development of the infrastructure required to carry out this type of research. A long period of time would be needed even to carry out a single research and/or intervention on such issues. Building trustful relationships automatically implies raising the expectations of the communities, while working on complex relations between health and marginalization in community contexts requires time (182).

Funding agencies need to offer guarantees of long-term funding, of course in exchange of guarantees that the partnership itself should offer. We should expect CBPR program initiatives to entail at least five years funding, which could include a one year planning period (182). After this period, sponsors and reviewers will evaluate the achievements pre-specified in the CBPR agreement between the sponsors and the members of the partnership (researchers and community representatives). Given that the definition of priorities is part of the participatory process, funding agencies need to be more focussed on the process than on the specific topic of single research cycles (176).

Long-term funding is especially important in the context of marginal communities, in which the lack of resources is often chronic, and people can devote little time to community projects, having to struggle to sustain their families. For community members, dedicating a

significant amount of time to CBPR might mean having to drop other sources of income, and this decision can be made only if the process has the potential to be well funded and solid.

Final considerations

In an evaluation of health-related CBPR carried out on an extensive literature review, Viswanathan and colleagues (177) emphasize the fact that CBPR is an approach that can adopt different research methods: “to achieve the highest research quality, researchers” – together with communities – “must select the strongest possible study design, measurement approach, data collection plan, and analysis strategy to address their specific research question or specific aims” (p.81). The same authors underline how progress in the use of CBPR will be achieved by seeking, in each situation, the “best possible balance between research methodology and community participation” (p.130).

In their review of the literature on CBPR, Viswanathan and colleagues found very few studies “that represent a complete and fully evaluated intervention or an observational/epidemiologic study that can be generalised beyond the participants involved...” (p.96).

Given that the Macedonian and Kosovan *Romá* in Italy are widely dispersed in small groups, information that they can use for advocacy purposes must be generalisable across the camps into which they have been segregated. A refinement of CBPR capable of overcoming the limitation observed in the Viswanathan review and producing evidence that is comparable across different *Romá* communities is found in the literature on CIET methods.

CIET methods

CIET is a non-profit, non-governmental organisation dedicated to “building the community voice into planning and governance” (www.ciet.org) (Annex 2). The main goal of CIET is to stimulate communities’ participation in decisions that affect them, by bringing scientific research methods to the community level (195).

In the definition of CIET methods and to help define in which contexts these methods were developed and can be most useful, “evidence-based planning” represents a key concept (195-197). This can be better understood if we agree that, in evidence-based planning, “evidence should contribute to development” (195, p.9). CIET methods can also be described as a community-based research approach in which the process of managing the evidence is used “to promote increasing community participation through local research” (195, p.38).

Thus, to contribute to development, planning should not just be based on evidence, but should be helpful to and actively based on the specific evidence of those who are most in need of this development (198). Those who are most in need, however, are often marginal communities and minority groups excluded from decisions affecting them. Furthermore, exclusion often leads to take on a passive and fatalistic attitude (195). The distance between decision makers and communities can easily despoil any form of planning and development policy.

CIET methods are designed considering that, in itself, the process of gathering and managing evidence “can contribute to development also through its active dimension” (195, p.11). If people are actively involved in research and decisions about what concerns them, the evidence-based planning process will be more accurate and sustainable, and will have more

chances of contributing to development (199, 200).

In CIET methods, sampling is based on a selection of clusters (or sentinel sites) (195, 201). Stratification according to factors of interest to the research facilitates the selection of the sites. Representativeness is achieved either with a random sample of clusters (when enough information to stratify, enough resources and an adequate sampling frame are available) or purposively selecting sentinel sites with the support of all of the existing knowledge that can be used to reduce the selection bias (202).

In the specific micro-universe represented by a cluster/site, all the households are included in the survey. This solution strengthens the possibility of linking household data, institutional data, and discussions at community level, facilitating community participation and local planning (195, 203). This aspect can represent an advantage when dealing with a sample of several relatively small communities scattered on a wide territory, as in the case of foreign *Rom* camps in Italy. Logistically and economically, covering all households in a selected group of sites increases the possibility of covering more households reaching a bigger sample size, if compared with other forms of sampling (201).

Communities represent an ideal dimension as they form a relatively homogeneous universe in which changes can be monitored and social processes happen (195, 198). By measuring and discussing information at local level and comparing information between communities or at an aggregated level, the knowledge produced can stimulate community participation in the decision-making process (195).

Investing resources on clearly defined topics, concentrating the attention on specific issues,

helps “generate more detailed and reliable information” (195, p.18). To focus on specific development issues and produce actionable data, “no more and no less evidence should be collected than is required” (p.9). “The data should be kept simple and sparse, increasing in quantity and sophistication as the capabilities increase” (p.18). Hence, the questionnaire designed to collect quantitative epidemiological information is kept short, simple and focused. An analysis plan is defined once the research objectives are established, in order to design instruments that will only collect the necessary quantitative and qualitative information (198).

As Andersson stated, “getting beyond simple frequencies to the identification of *causality* is not only desirable. It is necessary” (195, p.27). What makes the information we collect actionable is the possibility to understand the links between factors we can act upon and the outcomes produced by these factors. In this logic, risk analysis can be a very helpful tool to measure dynamics of cause and effect (204). Risk analysis, and the use of stratified contingency tables, helps the investigator stay in direct contact with the data during the analysis, thus facilitating the interpretation and the communication of the results to communities, organizations and institutions (204, 195). Furthermore, the concepts of risk and differential risk are universal notions and, to be communicated, only need an appropriate translation into the cultural context we operate in (195).

Stratification is used to identify how risk factors impact on specific sub-groups of the population (205): for example, the incidence of diarrhoea in children could be associated with different factors in different sub-groups of children. This analysis permits the measurement of individual risk (Odds Ratios: a child in a defined situation is more at risk compared with a child not in that situation), and potential collective benefits of actions associated with the risk factor (Risk Difference: the benefit in terms of reduced incidence of a disease obtained by

taking away a risk factor from the portion of the population affected) (206).

This, however, is not enough. The use of a cross-design approach, mixing epidemiological and rapid anthropological techniques, is also needed if we consider that factors that might be associated with the outcome of interest could be part of a “complex situation-specific web of knowledge, attitudes and practices mediated by culture, education, environment, and climate” (195, p.27).

The concurrent use of quantitative and qualitative methods facilitates the understanding of dynamics at community level. When needed, information from several sources, including households, key informants, community profiles and focus group discussions, is collected. This “cross-design synthesis of methods” (195, p.7) helps incorporate local knowledge and strengthen the information at local level. It facilitates the interpretation of the evidence, the identification of sustainable solutions and enhances community participation in evidence-based planning. In CIET, this approach is called “meso-analysis”.

Qualitative information can be useful to explore points of view and opinions, in the design of quantitative instruments and in the interpretation of the results (203, 207-211). The importance of a mixed methods’ approach, for contextualizing and triangulating information, has been previously discussed in the description of the CBPR approach.

However, the main difference between meso-analysis and a mixed methods’ approach is the possibility of mixing the information in the micro-universes represented by the sites, where household data and information from the community or the local environment can be combined and discussed (195). Comparisons between homogeneous and heterogeneous sites

will then be possible, strengthening stratified analysis and planning.

CIET research methods are designed around this philosophy, bearing in mind that no blueprint exists that can be applied in all circumstances, and that the research method should always be defined and/or adjusted according to the context in which the actors involved operate (198).

CIET methods have been applied in developing countries and in well-off countries like the United States and Canada, with processes involving institutions, local organizations and minority groups. Community-based participatory research, using these methods, has been carried out in urban contexts, with marginal communities and minority groups (212-215).

3. METHODOLOGY, RESEARCH INSTRUMENTS AND ETHICAL CONSIDERATIONS

DEFINING THE METHODS, IN THE CONTEXT OF *ROM* CAMPS IN ITALY

In the case of *Rom* camps in Italy, both CIET methods and CBPR offered a good base to start defining what was needed and what could be achieved in terms of health research. This study attempts to start from priorities defined by the *Rom* living in the camps, and to provide information collected directly from the communities, including the opinions of the residents. The aim was to begin forming the base for discussions with planning authorities, and to suggest a possible approach towards participatory research with *Rom* communities.

While defining the project for the doctoral study, a decision had to be made about financial resources. In the first visits to the camps and in the discussions with the *Rom*, the level of distrust towards health research was evident in the idea that people who carry out such studies usually make money out of studying the health status of the *Rom*. The author also felt that the mistrust of *Rom* communities, and the distance between the academic world and the *Rom*, were serious obstacles towards the possibility of establishing a participatory research process and obtain funding for such a project.

For these reasons, this study was undertaken without any external funding. This decision had implications in terms of the approach and methods that could be applied. However, it served to build trust relationships in the camps, as it was clear that money was not part of what was determining the researcher's interests.

With no funding, the time the author could devote to the project was relatively limited. Involvement of community members in all phases of the research process, as established by the CBPR approach, would have been impossible, as the author could give no guarantees about future perspectives, and had no resources to cover up for the time devoted to the project by community members. Furthermore, at the time in which the study was designed and carried out, there were very few community members from the camps involved in *Rom* organizations, as the situation was particularly unstable. Even keeping in mind the ideal picture of participatory research, and a cyclic type of approach, the latter too had to be sacrificed, not being able to guarantee an extension of the project.

The decision to define a community-based researcher-driven approach was motivated by the idea that a first step was needed to start developing a health research approach that could be applied to marginalized *Rom* communities. With the belief that a CBPR approach using CIET methods would be the right direction to take, the author decided to start by taking into account the priorities of the *Rom*, spend time discussing with the *Rom* about their point of view, go live in a camp for a month to understand the difficulties and risks and establish a close relationship with the *Rom*, and use a mixed methods' approach to triangulate and contextualize the collected information.

The author's aims were, first to try and verify if the *Rom* perceptions about the link between health and living conditions could be, in a simple but effective way, proven right, giving more authority to the voice of the *Rom* expressing their priorities. Second, try to prove to the *Rom* in the camps that there are ways in which health research can be useful in validating and emphasizing their concerns. Third, with a method understood and shared by the academic world, try to demonstrate that, not only community based research was possible, but that *Rom*

could be active part and a precious resource in the research process. Last, and a consequence of the first three elements, narrow the gap existing between *Rom* communities, the academic world and local institutions.

The need to simplify the research instruments, while considering all of the most important factors related to the health status of children, was central for the sustainability of the process and to keep it closer to the community dimension. For example, the worry expressed by the *Rom* about wood and gas heating stoves and its relation with respiratory diseases in children in houses with little ventilation could have been studied, as seen in the literature review, by measuring the levels of NO₂, particles, carbon dioxide and polycyclic aromatic hydrocarbons. However, this was avoided considering that such measurements would have been very costly and intrusive, while measurements and results would have been more difficult to explain. Comparisons between the results of this study and those found in the literature will be carried out in the discussion chapter.

The author preferred to try and link the perceptions of the *Romá* about causes of risk with the factors included in the quantitative research instruments and, with the help of the literature, confirm the plausibility of the relations between environmental and behavioural factors and the health status of children. This helped triangulate and strengthen the qualitative and quantitative results.

CHOOSING THE RESEARCH TOPIC

The research topic was deliberately chosen to reflect a priority concern of the *Rom* living in the camps.

The theme of the study was chosen on the basis of:

- Priorities expressed by the *Rom*;
- Priorities of institutions providing services to the camps;
- The feasibility of achieving some change in the situation based on the study findings.

The theme (the health status of foreign *Rom* children living in camps in Italy) was initially identified by the author and talked over with Professor *Leonardo Piasere*, lecturer in Cultural Anthropology at the University of Florence, as a main concern for the *Rom*. Subsequently, the author talked to residents of the camps in different cities, as well as social workers from associations and institutions. This exchange served to confirm the theme as being of high priority for the *Rom* community and to start giving some pointers for designing the structure of the research.

Residents of the camps confirmed that the health of their children was very important to them. They pointed at the relationship between the living conditions in the camps and the health of the children; therefore they were interested in the possibility of a study focusing on this issue.

SELECTION OF CAMPS

The camps chosen for the study were not a representative sample, reflecting the conditions in which the non-Italian *Rom* live in Italy. The results obtained cannot be extended to include the entire *Rom* population in Italy.

The camps were purposively selected on the basis of having characteristics that illustrated the

range of camp conditions existing in Italy. The intention was to allow analysis of the relationships between living conditions and health status of children in different environments.

A comparison with *Rom* families of the same ethnic groups and not living in camps would have been useful, but was considered too costly and complicated to carry out, as it is difficult to identify foreign *Rom* families living in regular houses without being intrusive. The author knows several *Rom* families from Kosovo and Macedonia living in regular houses. In some cases these families accessed a regular house after living in a camp for some time. In other cases, they followed different integration routes and managed to avoid the camps. It is very difficult, however, to estimate the number of these families as, because of the prejudice against the Gypsies, these families tend not to declare themselves *Rom*.

A comparison with non-*Rom* families living in similar conditions was excluded: no Italian families really live in camps-like contexts, while other foreign groups living in similar contexts do not often share this situation with their families. Furthermore, the inclusion in the sample of other dimensions (camp/no-camp, *Rom*/no-*Rom*) would have implied the need of control over a more complex sample. Thus, more variables and a larger sample would have been required.

The detailed mapping exercise of all the non-Italian *Rom* settlements in Italy (see Annex 1) provided a list of possible camps from which the camps to be included in the study were selected. The criteria used for the selection of the camps are described below.

All the selected camps were located in Provincial capital cities of Central and Northern Italy.

The choice of restricting the study to Central and Northern Italy was dictated by the lack of resources and the need to cover the selected camps in a reasonable period of time. All the selected camps were inhabited by *Romà* of Macedonian and Kosovan nationality.

The five chosen camps were selected to have:

- Different years of formation (from 1990 of Florence, to 1996 of Bolzano),
- Different sizes (from 1500m² of Bergamo, to 7500m² of Venice),
- Different numbers of residents (from over 300 in Florence, to 80 in Brescia),
- Different housing structures (from the hard walls of Brescia, to the self made wood shacks of Bolzano, to the hovels of Bergamo, Venezia and Firenze)
- Different availability of toilets (the unusable ones of Bergamo, the communal ones of Venice, those for groups of families in Florence and the prefabricated or solid wall single family ones of Bolzano and Brescia).

The camps selected on the basis of these criteria, 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,
- The camp of *Castel Firmiano* in Bolzano.

A MONTH SPENT AT THE *PODERACCIO* CAMP

It was agreed with *Prof. Piasere* that it would be appropriate, before defining the final structure of the research and the instruments to be employed, that I should spend a month

living in the *Poderaccio* camp in Florence. The aim was to facilitate various elements, including:

- Reciprocal familiarity between the parties;
- Acquisition of appropriate behaviour on the part of the author;
- Understanding the general as well as the particular difficulties of life in the camps;
- Fine-tuning and simplification of the instruments of research bearing in mind both the information to be collected and the language to be used;
- Acquisition of confidence in carrying out the task of interviewer in this camp as well as in the subsequent camps.

Before moving into the camp, I contacted and asked for permission to do so from the representatives of the communities and from the institutional overseers of the camp (*Quartiere 4*: Ward n. 4). During the month spent at *Poderaccio*, I maintained contact and engaged in feedback with members of associations and in particular with the *ADM* (Association for the Defence of Minorities' Rights) and the *Amengià* Association, which is composed of *Rom* youngsters (some of whom were residents at the camp) and of non-*Rom*.

I moved into the camp in mid November 2001, with a camper van loaned by Daniele Todesco, an expert about *Rom* and *Sinti* issues and a friend from Verona. Giusy Baffè, from *Quartiere 4* in charge for the camp, had decided my location inside the area. I placed the camper van inside the wire netting, in front of the porter's lodge on the opposite side of the entrance gate. To access the "residential" area, the camp itself, you needed to climb fifteen meters uphill. The inhabited area was quite crowded and it was inappropriate for me to occupy precious spaces for the families. Even though I was not completely located inside the community, I found myself in an in-between situation that allowed me to be present without

being interfering. Moreover, the entrance to the camp was the place where almost everybody spent some time: mothers accompanying their sons and daughters to the school bus in the morning, children playing, adults hanging out and making conversation.

The month spent at the camp was, generally speaking, appreciated by the inhabitants, who regarded my presence as an opportunity to share certain difficulties and this brought about a sense of being “in the same boat”. I personally experienced no particular difficulties. I was treated with great hospitality. Whenever I have returned to the camp after completing the research, I have been greeted most affectionately.

Recent investigations into drug trafficking initially raised suspicions in some people that I might be a plain-clothes detective. However, over time, the matter became something of a joke. It is obviously not seen as “normal” that a *gadjo* should go and live in a camp and so some explanation had to be found.

The time I was in Florence also gave me the opportunity to get involved in other activities. Together with Burhan Hasani, a twenty years’ old *Romá* who has lived eight years at the *Poderaccio*, we planned and realised a photographic book (14) that tells how life in a camp can be, about the difficulties of conducting a normal life but also about how family life spaces are generated, despite all of the problems and discomforts. The camp is a place where nobody would like to raise his or her children but, nevertheless, it grows to be a home and a place to play, work and relate.

IN THE OTHER CAMPS

The fundamental experience gained during the month spent at *Poderaccio* enabled me to proceed with the research: particularly in terms of fine-tuning the research instruments and increasing my degree of self-confidence.

It was also useful as a guarantee. The fact that I had lived at *Poderaccio* and was familiar with the other camps and in some cases knew relatives and friends was a positive factor for the *Romá* and a point of interest.

On average, I spent a week in each of the other camps. It was not considered necessary for me to spend a month in each of the camps and, once started, there was the need to complete the fieldwork in a short time in order to guarantee the maximum homogeneity of the data.

The procedure outlined below was followed in all the camps before starting the research work:

- Contact with the non-*Rom* social workers who were well-known within the camp;
- A first, accompanied visit in order to explain the reasons for the study;
- Follow-up visits (always accompanied by social workers or members of the community) to continue the work.

The importance of my being accompanied was to testify that my presence in the camp was guaranteed by people known within the community.

I had already visited the camps in Bergamo, Bolzano and Venice to talk about the study. At

that time I had contacted *Romá* as well as staff from institutions and associations.

THE RESEARCH INSTRUMENTS

The study included a household questionnaire, guidelines for discussions in focus groups and record-cards used to collect observational data and information provided by key informants.

On the basis of the objectives, an analytical plan (Annex 3) was prepared before starting with the research instruments' design. The analytical plan is a tool that responds to the principle, taught in basic social and epidemiological research analysis courses, of optimising the information collected by defining *a priori* how it will be used. It helps identify what information is needed to cover the objectives of the study and the role each variable will play in the analysis. For this reason, it is a key element in the design of the research instruments.

Part of the information collected was quantitative and part qualitative. The intention was to obtain a complete picture of the interplay of factors and behaviours that impact on the relationship between health and environment.

The research instruments were deliberately kept as simple and short as possible, and followed a logical line of reasoning in the flow of the questions. All of the instruments were in Italian, as after visiting the camps and living at the *Poderaccio* for one month, it was clear to the author that the large majority of the people spoke a good Italian. Despite marginalization, there are many occasions for people living in the camps to interact with the “outside”. The language did not represent a problem during the interviews.

The author conducted all the interviews and facilitated and recorded all of the focus group meetings. Focus group meetings are usually recorded and facilitated by two different persons: the reason why the author acted both as facilitator and recorder is explained below.

The questionnaire

Epidemiological information on the state of health of the children, and data on the habits and conditions of life of families, was gathered with a household questionnaire (Annex 4), completed in a household survey with all the families in the five camps.

The interviews

In each family, when there were children under six years of age, the interviewer attempted to interview the mother of these children. If the mother was absent, the interviewer spoke instead to a proxy who could provide answers to the questions about the children, and to all of the other questions.

If there were no children of five years of age or younger in the family, the interviewer asked only the questions from the first part of the questionnaire.

In each city the interviewer completed all the interviews within two or three days so that the reference period (for example: for the period prevalence of diarrhoea) would be the same for everyone.

The author/interviewer was accompanied at all times by people who knew the families, who

were on good terms with them and who were trusted by them. In Florence, the author was accompanied by staff of the co-operatives managing the site and by those living on the site itself. In Bergamo and Brescia, community workers, from various groups and associations, accompanied the author. A woman go-between who once lived on the site introduced the author to the families in Venice. In Bolzano the author was accompanied both by staff of the association Odar and people living on the site.

An attempt was made, wherever possible, to verify the child birthweight indicated by the interviewee, using the records of the paediatric consultancy or the certificates held by the parents. For the sole purpose of examining the consultancy records, the interviewee was asked to give the name of the child, and this name was eliminated from the questionnaire once the verification had been carried out.

Direct observation during the household survey

During the household survey, the author made an evaluation of the internal condition of every living quarter. Although the evaluation was subjective, the author was the only person to make the evaluation and so one may consider the judgements to be, at the least, homogeneous. An effort was made to avoid being conditioned by the external environment and the general conditions of the camp.

In the evaluation of the internal housing conditions, a housing structure was considered “fair” where there were no signs of degradation or filth, but where there was also no particular attention to care and cleanliness, features which otherwise produced a different evaluation (“good” or “poor”).

Free and informed consent and confidentiality

At the beginning of each interview, the purpose of the research was explained. Anonymity of interviewees and their families was guaranteed and the assurance that the information would only be used in aggregated form and not to highlight single cases was given. It was explained that the interview would take ten to fifteen minutes, depending on the number of children up to five years of age and mentioned that, if necessary, the interview could be done later that day.

Taking leave of the interviewee, the interviewer thanked the person for the time, the kindness and the information given and underlined the importance of his/her collaboration in trying to gather information that could help to improve living conditions and the health of children.

The focus groups

The author facilitated a focus group discussion with mothers of children under six years of age in each city. A guide with eight questions was used (Annex 4).

These meetings were held in each camp after the interview work had been fully completed. The mothers of the children were identified during the interview and were then invited to take part in the meeting.

The intention of the discussions was to examine more closely mothers' definitions of good health and illness in the child and their behaviours in front of a child's illness.

The ideal number of participants in a focus group meeting is 8-10 people. This group size favours group dynamics and allows all to participate (195, 207, 216).

Before the fieldwork stage began, some people – both *Rom* and non-*Rom* researchers and activists the author had consulted – expressed concerns about the feasibility of conducting a focus group meeting at *Rom* camps. They considered that the persons concerned may not be accustomed to orderly group discussion, that impatience could become manifest and overall scepticism could arise. Because of these concerns, the author thought it would be better to have just one external person in the group and decided to both facilitate and record the meetings.

Description of meetings

Only two women attended the meeting in Florence. It took place on 19th December 2001 (14:30). In Bergamo the meeting took place on 29th January (16:00) and three mothers attended. The meeting in Brescia took place on 14th February 2002 (10:50) with four attending. Three women attended the Venice meeting, on 28th February 2002 (10:00). Five mothers attended the meeting in Bolzano, the 7th March 2002 (10:50).

The meetings lasted thirty minutes in all cities except Bolzano (40 minutes). They were generally conducted in the home of one of the participating women. However, the meeting in Venice was held in a prefab used by women “community teachers”. In Bolzano, the meeting was held in a room in the “*centro polifunzionale*” (multi-purpose centre).

Even though few mothers attended the meetings, it did not stop those who attended from taking part in the discussions.

Free and informed consent and confidentiality in the focus groups

All of the women who participated in focus group meetings had already answered the questionnaire.

On inviting the women to a focus group session, the interviewer explained that the purpose of the meeting was to discuss and gain a deeper understanding of issues already covered during the interview, with a small group of mothers. It was specified that the meeting would last from 20 to 40 minutes.

An appropriate time and place for the meeting were agreed upon with all of the invited participants.

Names were not asked for during the sessions. At the end of the session, the participants were thanked for their contribution and the importance of the elements that emerged during the meeting was specifically underlined.

The protocol for direct observation

A special form (Annex 4) was used to record information on the characteristics of the camp, the state of the facilities used in common, positive and negative circumstances in the neighbourhood, and ease of access to basic services.

These data were gathered by direct observation and with the collaboration of key informants (people from institutions, co-operatives or associations, and people residing in the various camps).

Considering that larger camps are more difficult to manage and most often present infrastructural problems, dichotomous variables about the number of people and the number of families living in each camp were created and used in risk analysis. To measure overcrowding in the camps, dichotomous variables were also developed using square meters per person.

Given the concerns of the residents of the camps, and taking into account that rats are dangerous not only from a hygiene point of view, but because they had also been known to bite children and adults, the presence of rats was recorded.

Interviews with the Health Services

The interviews with health services were based on a guide of issues to be approached: short summary of the relationship between the *Romá* and the health institutions, existence of specific services for the *Romá* (and in particular for children under the age of six), existing difficulties related to vaccination coverage, use of health cards and legal status of individual residents, access problems to health services, main pathologies found in under six children, opinion on the conditions of the settlement.

Every city had a different kind of organisation and a different approach. No interviews were

carried out in Bolzano due to the lack of a spokesperson for Health Services: the residents of the camp reported that they go to their family doctor or paediatrician or directly to hospital.

In Florence, beginning in 1999, the author contacted the staff of the Paediatric Health Centre in several occasions. The last interview took place on 30th November 2001, with a request to see the paediatric records in order to note down the birth-weight of the children involved in the study.

In Bergamo, information on health services was recorded on 29th and 30th January 2002 at the prevention department of the ASL (Local Health Unit) and from the community workers of the *Migrantes* co-operative, who managed health and welfare service issues on behalf of the local council.

The information recorded in Brescia is the outcome of two meetings held between January and February 2002 with Brescia Council's *Ufficio Stranieri e Nomadi* (Office for Foreigners and Nomads) and the staff of the 7th District of the ASL, Brescia.

In Mestre, initial contact with Health Services in the district dates back to November 1999. Information was collected over a period of time both from community workers and community educators who worked inside the camp as well as from medical staff from the Family and Paediatric Consultancy.

THE TIMING OF THE FIELDWORK

The fieldwork in all the camps was carried out during the winter so as to avoid possible confounding effects of season on the health of the children.

The work commenced in mid-November 2001 in Florence when I moved to the camp in a camper van. The interviews in Florence started on 10th December and the work was completed in the last camp – in Bolzano – on 7th March 2002.

Since the research was carried out during the winter the pattern of disease was typical of the season. In summer there would probably have been a lower incidence of respiratory diseases and possibly a higher incidence of gastro-intestinal problems.

ANALYSIS TOOLS

CIET methods are designed to deal with large samples, in terms of number of sites covered and people interviewed in each site. One of the limitations of this study, caused by the lack of funds, was the relatively small dimension of the sample. The small numbers and the fact that all the participants were living in camps limited the analysis to some extent. However, considering that lack of resources and difficulties in reaching small groups scattered on a wide territory can be common issues when dealing with marginalized groups, it is important to develop ways to carry out research in these conditions, and obtain good quality actionable data, including a quantitative component. For this reason, the author examined in detail the statistical aspects of the problem. The evaluation of what methods could be used to measure association and for calculating confidence intervals, in the specific context of this study, is

carried out below.

In risk analysis, the odds ratio was used as measure of association between outcomes of interest and potential causes. Since logistic modelling also gives rise to the odds ratio as a measure of association, it is convenient for probability functions and hypothesis testing, as well leading into logistic regression as the next step in the analysis. In this case, small numbers did not allow us to continue with logistic regression modelling.

Small sample measures of association and confidence intervals

Asymptotic estimates

Confidence intervals based on large-sample theory are much easier to compute than exact confidence intervals, but need to respect the conditions imposed by the asymptotic theory they are based on.

Mantel-Haenszel's (MH) estimator of the variance of the Odds Ratio (OR) – needed to calculate the standard chi square distribution – is consistent as k (the number of strata) increases and $2n$ (the sample size in each table) remains fixed (217). For stratified 2x2 tables, among the different candidates, the Mantel-Haenszel (1959) (205) point estimator of the OR in a series of 2x2 tables, together with the Robins and colleagues (1986) (218) variance estimator has been shown to have good coverage properties both when k is small but (m_i, n_i) are large or when k is large but (m_i, n_i) are small (219), that is both for the sparse data and large strata limiting models.

One drawback with the Mantel-Haenszel approach is that both OR and $var[\log(OR)]$ estimates are undefined when the conditional distribution S is equal to $s_{min} = \sum_i [\max(0, t_i - m_i)]$ or $s_{max} = \sum_i [\min(t_i, n_i)]$, thus in these extreme situations the Mantel-Haenszel procedure cannot furnish any interval at all (219).

In 1976, Miettinen (206) provided a simple and ingenious test-based method for constructing confidence limits using only the point estimate and the chi square test statistic (using preferably the MH chi square, calculated without continuity correction, otherwise the variance may be overestimated) (220):

- $\text{Chi square} = \log^2(OR) / \text{var}[\log(OR)] \Rightarrow OR_L, OR_U = OR^{(1 \pm Z_{\alpha/2} / \chi)}$

However, when case and control sample sizes are equal, the variance for other than 1 values of OR is systematically underestimated by this approach, the true average probability is less than the nominal $100(1 - \alpha)\%$, and the resulting confidence limits are too narrow (220). Nevertheless the test-based limits may be advocated on the basis of their simplicity.

Agresti, in 1999 (221), stated that unless the true odds ratio is very large, the asymptotic method (based on the fact that the estimator of $\log(OR)$ is asymptotically normal) based on the confidence interval obtained by exponentiating the end points of $\log(OR) \pm z_{\alpha/2} \text{var}[\log(OR)]$, where $z_{\alpha/2}$ is the $\alpha/2$ standard normal quantile (Woolf, 1955, cited by Agresti), seems to be acceptable even for small sample sizes.

However, considering that the probability of observing an extreme outcome with large underlying odds ratios (the very situation in which small studies are justified) can be substantial in small studies, we prefer to look for other solutions.

For single 2x2 tables, the “rule of 5” suggests that the approximations to significance levels in the neighborhood of 0.05 or larger are reasonably good, providing that the expected frequencies for all four cells in the 2x2 tables are at least 5 under the null hypothesis (222). For a series of 2x2 tables, Mantel and Fleiss (223) suggested the “rule of 5” for evaluating the adequacy of the approximation to the exact p -value obtained from the summary chi-square statistic. They first calculate the maximum and minimum values that the total number of exposed cases $sum(a_i)$ may take subject to fixed marginals in each of the 2x2 tables. These are $sum[\min(m_{1i}, n_{1i})]$ for the maximum and $sum[\max(0, m_{1i} - n_{0i})]$ for the minimum. Provided that the calculated mean value under the null hypothesis $sum(A_i)$ is at least five units away from both these extremes, the exact and approximate p -values should agree reasonably well for p 's in the range of 0.05 and above.

Exact Fisher test p -value

The basic conditional distribution theory for analysing independent binomial proportions was derived by Fisher in 1935 (224). Fisher calculated an exact conditional test, and derived the noncentral distribution as a function of the odds ratio. In 1956, Cornfield gave explicit expressions for confidence limits on the odds ratio (225). Thomas – 1971 for a single 2x2 table (226) and 1975 for stratified 2x2 tables (227) – implemented this method with computer algorithms.

Introduction to the exact confidence limits

Exact confidence limits are called “exact” because the procedure is based on exact distribution theory. Exact methods produce conservative confidence limits: that is the confidence interval will cover the true *OR* more frequently than is demanded of it. While, due to the discreteness of the distribution, coverage of the odds ratio exactly $100(1 - \alpha)\%$ of the time cannot be guaranteed, the advantage is that the actual coverage probability is bounded below by the nominal confidence level.

Ideally, one might always want to report exact confidence intervals, especially in situations in which the desired coverage probability – regardless of the sparseness or scarceness of the data – needs to be guaranteed. However, computing time is what made this approach not feasible for large samples.

To fight conservativeness, the *Mid-p* adjustment method reduces the width of the exact CI with a continuity correction and is popularly believed to preserve accuracy. However, there is no theoretical guarantee that the *Mid-p* approach will provide the desired coverage (219). It is called *Mid-p* because, the higher and lower *Mid-p*-value are defined as the probability under the test hypothesis that the test statistic Y is more (for the higher) or less (for the lower) than its observed value plus, for both limits, half the probability that Y equals its observed value (228).

Exact conditional tail method (approximate)

Exact confidence intervals by Cornfield (225) for the *OR* consist of the collection of OR_0

values for which the p-value exceeds $\alpha/2$ in conducting each exact one-sided test of $H_0: OR=OR_0$ using the nonnull hypergeometric conditional distribution derived from conditioning on row and column totals. The exactness refers to the conditional distribution being free of nuisance parameters (221). However, Cornfield is an approximate method.

To approximate the Cornfield $100(1 - \alpha)\%$ exact confidence interval, Cornfield (225) and Fisher (229) proposed the interval consisting of odds ratios resulting from expected frequencies having the same margins as the observed counts (for this reason it is called “conditional”).

Thomas (226, 227) algorithm uses an iterative technique to estimate the two one-tailed exact tests at the $\alpha/2$ significance level, where, given a in the first cell and m as the column marginal, the first equation is the sum of the hypergeometric functions, $f(i | m; OR)$ for $i = 0$ to a and $i = a$ to m , both equal to $\alpha/2$ (230).

The interval defined may be interpreted to contain all the values of OR not rejected by one-tailed exact tests at the $\alpha/2$ significance level. For this reason this method is called “tail method”.

The tail method yields a conditionally exact 95% Confidence Interval (CI) by Thomas’ method: the interval can come close to containing the null value of 1 even for small observed Fisher p -values. The apparent discrepancy between the exact p -value and the exact CI is explained by the marked asymmetry of the distribution of the test statistic. In many such cases, the one-sided Fisher’s exact p -value is the same as the two-sided Fisher’s exact p -value (Troendle and Frank, 2001) (231).

Although most authors call this method “exact”, because these limits provide a good approximation to the exact limits and come closest to achieving the nominal specifications, it is still calculated with a normal approximation of the mean and variance. For this reason it is still subject to the “rule of 5” and should actually be called “Cornfield approximation to the exact confidence limits”. For the limits as described by Thomas, the agreement is quite good (232). The Epi Info software applies the Mantel and Fleiss “rule of 5” and in cases in which this is not respected, the result is labeled as possibly “inaccurate”.

More accurate confidence limits are of course obtained if the mean and variance of the exact conditional distribution are used (220). These require the solution of polynomial equations of an even higher order, but are calculated by Metha, Patel and Gray (see below).

Exact conditional simultaneous method

In 2001, Agresti and Min (233), and Troendle and Frank (231) demonstrated that for constructing confidence intervals with discrete distributions, it is better to invert a single two-sided test than to invert two separate one-sided tests. “Better” meaning that intervals tend to be shorter and coverage probabilities tend to be closer to the nominal level. Of course this way the $1 - \alpha/2$ nominal level for the single tails is not guaranteed.

Based on Sterne’s approach (1954) (234), in 1977 Baptista and Pike elaborated an algorithm for an exact conditional simultaneous (two sided test) method (235).

Exact confidence limits by Metha, Patel and Gray

In 1985, Metha, Patel and Gray (236) improved the exact confidence limits suggested by Cornfield (1956) and implemented by Gart (1970) and Thomas (1975). Vollset, Hirji and Elashoff have further modified this method in 1991 (237).

Metha and colleagues suggest a recursive network algorithm for obtaining the exact confidence limits. The authors state the method could be used with relative ease for data sets up to $2nk=1000$, by which time one would expect the asymptotic results to hold.

Considering that the accuracy of the asymptotic *CI* would be questioned when only small proportions of the population fall in the exposed category, even for large k (strata) and n , as the skewness in the marginal configuration of each table become very pronounced (asymptotic distributions would fit very poorly in this situation, especially if *OR* were large), in these cases one would then prefer to report the exact *CI*.

Fortunately this is precisely the situation in which the underlying computational problem is easy. The more skewed the table marginals, the greater the savings in CPU time (236).

MLE – Maximum Likelihood Estimates, conditional and unconditional

The *MLE* of the common *OR* is found by equating the totals of the observed and expected numbers of exposed cases: $\sum(a_i) = E(a_i | \text{marginals}; OR)$.

For the *CMLE* (conditional maximum likelihood estimate of the common *OR*, derived from the hypergeometric model) the expectations $E(a_i)$ are calculated under non-central hypergeometric distributions (220), which are a high degree polynomial equation. The general use of this estimate is discouraged by the computational burden, but an algorithm is available by Thomas (227).

The *UMLE* (unconditional maximum likelihood estimate) is based on the distribution of all the data without assuming fixed marginals for each 2x2 table. The *UMLE* is a binomial-likelihood statistic, with a *MLE* of the *OR* derived from the two binomial model (228). The $E(a_i)$ are those of the approximating normal distribution. Thus the estimation procedure requires finding fitted frequencies for all the cells, such that the total of the observed and fitted numbers of exposed cases agree. While iterative calculations are also required here, they are less demanding than for the exact estimate and do not become more complicated when the numbers in each cell increase.

When there are many strata, each containing small numbers of cases and controls, the *UMLE* is biased in the sense of giving values for *OR* which are systematically more extreme (further from unity) than the true *OR* (220).

According to Rothman and Greenland (228), both the conditional and the unconditional *MLEs* require a “large” sample when numbers are summed across the strata, suggesting that only exact methods have no sample-size requirements at all. Because the *UMLE* of *OR* additionally requires large numbers within strata whereas *CMLE* does not, one may ask why is the *UMLE* used at all. According to Rothman and Greenland, there are two main reasons: 1) *CMLE* is computationally demanding, and when numbers in the strata are large ($N_{1i} > 10$ and $N_{0i} > 10$) the

two estimators will be almost equal; 2) Only the *UMLE* is widely available for estimation of quantities other than the *OR*.

Odds ratio's estimators for stratified 2x2 tables. In finite-sample cases, the *CMLE* of the odds ratio is superior to the unconditional. Asymptotically, the two *MLEs* are equivalent in the fixed-strata case, and the unconditional *MLE* is not consistent in the increasing-strata case (238, 239). According to Hauck (240), in finite samples, the *CMLE* is equal or superior to the MH estimator, while asymptotically the MH estimator is generally less efficient except at $OR=1$. Comparing *UMLE*, *CMLE*, and MH estimates of the odds ratio, the *CMLE* is superior both for bias and precision, in conditions with 5 and 10 strata and marginals of 10 to 50 in the strata (240).

Application to actual data

In Annex 5 we show different *CI*s calculated for a selection of tables using asymptotic, approximate and exact confidence intervals. For single 2x2 tables, we used *p*-value functions to compare the curves generated by Miettinen (asymptotic test-based method) and Exact 95% confidence intervals, as calculated using Rothman Episheet (241). For stratified tables, we compared *p*-value functions from Robins and colleagues and using the Exact method.

As reported, exact methods are more reliable for small samples. However, from the comparison of different *CI*s and from the *p*-value functions we can see how similar are most of the overall messages given by the different methods used, of course if we go beyond the simple idea of significance. The smaller the numbers involved, the more important is to try

and focus on the general picture. For this reason the p -value functions are useful in our case and especially to compare two different approaches to the CI s.

The Fisher exact 2-tailed test can be calculated in two different ways. Epi Info calculates it simultaneously, with the problem that in certain circumstances it ends being the same as the 1-tailed, due to asymmetry of the distribution of the test statistic (231). To avoid this problem, Rothman's Episheet calculates the 2-sided test using two single one-sided tests (228), yielding to more conservative p -values, and in some cases to p -values exceeding 1. In Annex 5 we reported both tests.

The exact limits by Metha, Patel and Gray, calculated with Epi Info 6.04d Statcalc, coincide with the exact limits for the MLE of the OR calculated by Epi Info 6.04d Analysis and with Rothman's limits based on Fisher exact probabilities calculated with Episheet (242). For this reason we just called them Exact CI s. Even if not explicitly so – apart of course for the CI s for the MLE of the OR – p -value functions based on exact methods are centered in the MLE of the OR , which should be a better estimation of the actual OR for small samples (240).

Cornfield confidence intervals present a problem caused by the approximation method and the use of the correction for continuity. Confusion is mostly caused by the numerous formulas existing in literature to deal with approximations and continuity corrections. Epi Info 6.04d presents different intervals depending on whether Statcalc or Analysis is used. CIET map 1.0 beta49 offers a third different result. For single 2x2 tables, in Annex 5 we report Cornfield intervals as calculated by Epi Info Analysis and by CIET map (in parenthesis). For stratified 2x2 tables, the reported Cornfield intervals were calculated using CIET map.

For single 2x2 tables, Miettinen *CI*s were calculated using CIETmap 1.0 beta49.

For stratified tables we reported the Robins, Breslow and Greenland (218) confidence intervals, based on the MH weighted odds ratio, calculated with Epi Info 6.04d.

With the help of *p*-value functions, for single 2x2 tables, in Annex 5 we can see that the exact *CI*s are, in general, more conservative than the Miettinen test-based asymptotic *CI*s. In some cases, as the exact confidence intervals are based on the hypergeometric non-central distribution, according to the distribution of frequencies in the 2x2 table, the exact limits can be shifted either towards the 1 or further from the 1 value. For stratified 2x2 tables, the comparison was made between Robins et al. and Exact *CI*s.

Choices made for the analysis

In the analysis of single 2x2 tables, Cornfield's 95% approximation to the exact confidence limits were used, unless inaccurate, as established by the "rule of 5". These limits were calculated with Epi Info 6.04d Analysis programme. Exact 95% confidence intervals by Metha, Patel and Gray, calculated using Epi Info 6.04 Statcalc, were used otherwise. As seen above, these exact limits coincide with the limits based on the maximum likelihood estimate of the *OR*, calculated with Epi Info 6.04d Analysis, and with Rothman's Exact limits calculated with Episheet. Fisher's exact 2-tailed test, calculated using Epi Info 6.04d Analysis and Eptable, was used when suggested by the "rule of 5".

For summary estimates of odds ratios from stratified 2x2 tables, asymptotic confidence limits by Robins, Breslow and Greenland were used supported, when needed, by Metha, Patel and

Gray exact limits. Both limits were calculated using Epi Info 6.04d Analysis and Statcalc.

Exact confidence intervals are known to be conservative on the nominal value, producing wider intervals than the asymptotic ones, but they guarantee inclusion of the nominal value. In this study, we preferred to have conservative rather than too narrow and unreliable intervals.

Given the small sample and the potential high variability of the odds ratio due to the small number of observations, the discussion focuses mainly on statistical significance and on the lower confidence limit, rather than commenting on the magnitude of the association.

Stratification of 2x2 tables was carried out as possible, within the constraints imposed by the small sample.

Simultaneous analysis and modelling was then attempted, using logistic regression and regression trees, but the final decision was made to stop at a simple stratified analysis. In fact, limits imposed to stratification, not allowing a full understanding of the behaviour of conditioners in a context involving more factors, did not offer enough evidence on variables' dynamics to gain full control over the simultaneous effect of conditioners in a model.

This choice was dictated by the consideration that the problem we faced was more due to the small sample and not as much to overfitting or data being sparse in stratified tables.

FEEDBACK TO THE COMMUNITIES, INSTITUTIONS AND ASSOCIATIONS

A key objective of this study was to provide information that could help improve the conditions of life for the *Rom* living in the camps. For this reason, it is essential that the results of this study find their way back to the *Rom* communities, and to the institutions and associations that may find useful elements for planning measures aimed at improvement. The author is involved in the feedback of information to all stakeholders, and Chapter 7 focuses on the different aspects of this process.

RESPONSE TO IMMEDIATE INDIVIDUAL NEEDS OF INTERVIEWED FAMILIES

Concerning the response of the author/interviewer to immediate individual needs (such as sick children) that were encountered in the course of the research, it was clear that families had a good knowledge of and access to available services. The author offered his help in the few cases where his support was needed and he was asked to intervene or give advice, for his knowledge or as an intermediary with the services.

4. HISTORY OF THE COMMUNITIES AND OF THE SELECTED CAMPS

This chapter presents information about the place of origin of the five communities involved in the study, and their living conditions, as well as bibliographic information on the history of the five selected camps.

THE *ROMÁ* OF THE *PODERACCIO* CAMP IN FLORENCE

The *Romá* that lived at the *Poderaccio* camp at the time the study was carried out were Kosovans and Macedonians of Muslim culture. Most of the families arrived in Italy in the period between 1989 and 1993, according to a census carried out by the Italian Council for Refugees (CIR) in 1994 (243).

Since 1989 the situation in Yugoslavia became particularly unstable, not only for the economic crisis, but also for the increasing tension between ethnic groups and the political changes in all Eastern European countries (244, 245). However, for the *Romá* of Yugoslavia the situation deteriorated gradually, in terms of ethnic tensions against them and access to services and resources, starting from the death of Tito in 1980 (244).

The majority of the Macedonian families used to live in *Skopjie*, in regular houses. The same can be said about the Kosovans families, most of which came from *Pristina* and *Mitrovica*. In any case, almost all were sedentary families coming from urban centres. In most Kosovan towns we could find a *Rom mahala*, a neighbourhood or street in which the majority of the population was *Rom* (245). It was the case of *Šuto Orizari* and *Maláva* in *Skopjie*, and

Moravska, Divagnoli, Velanija and Kolibarska in Pristina (246, 247). *Mahala* is a word of Arabic origin, which was probably introduced in the Balkans by the Turks, and that simply means “place” (247).

The men, both from Kosovo and Macedonia, used to practice all sorts of jobs, like factory workers, bricklayers, gardeners, drivers, tailors, butchers, traders and musicians (243). Most women used to work in their homes as housewives, but few worked as cleaning ladies. However, several people stated that there was a serious problem of unemployment (246).

According to CIR’s report, the main reasons for migrating to Italy, as mentioned by the family members, have been the economic crisis and the war. Italy was seen as a place where a job and better perspectives could be found, to improve the family’s living conditions.

From formal and informal comments collected by the author (14) and from interviews carried out by the *Fondazione Michelucci* (246), the impact with the camp of Florence, the caravans, and the general living conditions, was traumatic. People express the fact that they were not used to the lifestyle they found in the Italian camp, and that it took some time to get used and learn how to behave in, and survive to, such living conditions.

The *Poderaccio* camp had existed since 1990 and was set up to replace an illegal camp that was situated approximately 100 metres away. Consequently it was named the “*New Poderaccio*” or “*High Poderaccio*”. This camp was set up as a “stand-by” in the sense that the illegal camp which was set up in 1988 had to be converted and established with all the appropriate facilities to become an official camp.

When the “*High Poderaccio*” was established, it consisted of some containers and portacabins. As mentioned before, it housed two different groups: one from *Skopije* in Macedonia, and the other from the cities of *Mitrovica* and *Pristina* in Kosovo (248).

It is worth reporting Colacicchi’s description of the birth, in October 1988, of the first illegal camp, called “*Low Poderaccio*” (248, p.126): “*The area was fenced off all round and a central pre-fabricated building was erected to provide toilet and washing facilities, with a few taps for water and power points. The local council provided the Rom who came from ‘Ponte all’Indiano’ with a few caravans. The Civil Engineering department only gave its consent to this as a temporary arrangement, since the Poderaccio is a natural flood-overflow area for the Arno river. Next to the camp there was a dangerous hospital refuse tip, known as ‘red sacks’, which was removed about a year and a half later. It was one of the most dilapidated areas in the ‘quartiere’, ‘full of illegal refuse tips, breakers yards, wasteland’, as defined by the Officer in charge of Quartiere 4.*”

The *High Poderaccio*, a “transitory” solution that lasted 14 years, was finally demolished in June 2004.

THE ROMÁ OF VIA ROVELLI IN BERGAMO

The large majority of families, who lived at the camp of *Via Rovelli*, were originally from *Moravska*, as mentioned before, a neighbourhood in the southeastern outskirts of *Pristina*, in Kosovo. As pointed out in the analysis by Suardi (247), the *Rom* neighbourhoods like *Moravska*, did not have the form of a ghetto and were not shantytowns. Despite the

concentration of ethnic groups, before the war the different communities used to live together in fairly good accord.

Moravska had cultural and religious centres, a “bazaar”, and *Radio Pristina* had programmes and music in *Romanes*. *Rom* children going to Serb or Albanian schools could follow one hour of *Romanes* per week, and many youth studied in high school and university (247).

As mentioned in the previous paragraph, the *Romá* practiced all sorts of jobs. The unemployment was high, but it was caused by a deep economic crisis involving, more or less, all ethnic groups in Kosovo.

However, in the Yugoslavian Federation, the *Romá* were not considered as a “nation” but as an “ethnic group” and, for this reason did not have the right to schools in *Romanes*, television and radio programmes, and were in general more discriminated than other ethnic groups in the fields of access to housing, employment, social and health services (247).

In most cases, the *Romá* in *Moravska* lived in houses inhabited by single families, and often owned them. These houses were often aggregated around large courtyards and placed close to the father’s house, facilitating the relations within the extended family (247). *Moravska* was mostly destroyed during the war of Kosovo. After the war, Albanian families occupied the remaining houses left empty by the *Romá* and the Serbs.

The camp of *Via Rovelli* opened in 1993, without any real planning behind it but simply to provide accommodation for the first wave of *Romá* refugees from Kosovo. The first group consisted mostly of men. The majority was coming from the borough of *Moravska*, in

Pristina, as mentioned before. There used to be a smaller camp in the same street but this was closed down in 2001. The following description was given by D. Salvi (249): “*In 1993 a reception camp was set up in Via Rovelli 160: around 15 caravans were provided as part of a programme whose aim was gradual social integration. As a result, 36 people were housed, and amongst them only three women with their respective husbands.*”

In January 1998, the camp housed 94 people including 8 families, but with the end of the war in Kosovo in 1999 and the subsequent forced migration of *Romá* refugees from *Pristina*, the camp became home to more than 200 people in an area measuring just 1500m².

Overcrowding, lack of facilities and carelessness on the part of the local administration all contributed to very poor conditions in the camp. During the summer of 2001 there was a shigella epidemic: this disease found fertile breeding ground in the unsafe sanitary conditions in the camp.

Since 2002, there has been a slow process of allocation of public houses that partially solved the overcrowding problem.

THE *ROMÁ* OF THE FARMHOUSE OF VIA CHIAPPA, BRESCIA

Information on the *Romá* of Brescia was recorded from the families and with the help of the human rights activist Luigino Beltrami.

The 80 *Romá* living at the farmhouse at the time of the study came mostly from Kosovo, from the small town of *Gračanica*, in the immediate outskirts of *Pristina*, and from *Ulica Fabrica*,

a street of the industrial borough of *Mitrovica*. *Ulica Fabrica* was set on fire after the war, in 1999.

Although most families belonged to the *Xoraxané Shiftarija* group and had Albanian surnames, they were considered pro-Serb by the Albanians and, for this reason, persecuted after the war.

Most of the families arrived from Kosovo in 1989/1990, when the socio-economic situation became unstable, and the ethnic conflict became more harsh and violent. The adults used to work in factories, in the building trade, and in street cleansing and refuse collection services. Others had already migrated to Bosnia and Croatia, before coming to Italy, in search for better job opportunities.

The *Romá* were transferred to the farmhouse of *Via Chiappa* in June 1993. In the same year, the Local Council of Brescia set about legalising the status of these people in accordance with Law 390/92, which recognised them as refugees from Ex-Yugoslavia, thus revoking expulsion orders against them. A policy was also formulated to explain who these people were to the city's inhabitants. This became necessary as a result of an absurd but unfortunately common theory, as stated by G. Valenti (250, p.118): “*This was so as to provide a complete connotation, in a period in which it was being said ‘if they are gypsies, they cannot be refugees’, ‘if they are refugees, they cannot be gypsies’.*”

It is again Valenti who points out that when the authorities in Brescia set up this camp and another one in 1993, they did so “obviously” as a temporary measure.

The *Camafame* farmhouse in Brescia was closed at the end of 2002. It was declared uninhabitable after a fire. Some families were moved to another camp and some into regular apartments.

THE ROMÁ OF THE SAN GIULIANO CAMP IN MESTRE (VENICE)

Most of the *Romá* living at the camp of *San Giuliano* at the time of the study were from *Obilic*, *Kosovo Polje* and *Lipljan*. *Obilic* and *Kosovo Polje* are two villages five kilometres west of *Pristina*. *Lipljan* is a small town 15 kilometres south of *Pristina*. Some of the families had arrived three/four months before the fieldwork was carried out, from other small settlements in town and from another camp, *Zelarino*, which had been dismantled. Albeit the majority of the families in *Zelarino* were of Serb origin, mainly from *Šabac* (on the river *Sava*, between Beograd and the Bosnian Border), and Orthodox religious culture, those transferred to *San Giuliano* were mostly Kosovan.

The Kosovan families can be divided in two groups. The first arrived in Mestre in 1992 because of the growing tensions in Kosovo and the economic crisis, as reported above. The second group arrived in 1999, when the end of the war in Kosovo determined the break out of a systematic ethnic cleansing perpetrated by the Albanians against the *Romá*, with the destruction or the occupation of the houses owned by the *Romá*. A video published by *Razzismo Stop* and *Radio Sherwood* (“*Viaggio tra i profughi rom in fuga dal Kosovo*”, Padua, May 2000), documenting the consequences of the war in Kosovo, shows how the houses of the *Rom* village of *Obilic*, as well as of other *Rom* villages or neighbourhoods, were completely destroyed.

In Kosovo, the men used to work as miners in the *Golesh* mines, as factory workers and as peasants. Most of the women used to take care of the children and the home.

The camp of *San Giuliano* existed since September 1994. From November 1993 onwards, an illegal camp had established itself in the area of the *San Giuliano* refuse tip, considered to be of high-risk to health due to the presence of toxic industrial waste. The first inhabitants were Serbian refugees, but groups from Kosovo soon joined these. When the “refugee camp” was established, the majority of the 219 inhabitants were *Romá* from Kosovo (251).

In 1994, the idea of moving from the illegal camp to the official one was not greeted with eagerness by all the families, not because of a rejection of the undoubtedly improved living conditions, but because of distrust towards a place that had been chosen and organised using methods that were not their own (251).

The *San Giuliano* camp was finally closed at the end of 2002, concluding a project that found a sustainable way out from the logic of “nomads’ camps”, implementing a synergy among institutions, NGOs and the *Romà*. In two years, starting in 2001, two camps were closed in Venice and housing solutions – public, private, renting and loans for buying – were found for all of the families.

THE *ROMÁ* OF THE *CASTEL FIRMIANO* CAMP IN BOLZANO

The camp of *Castel Firmiano* existed since 1996 and offered shelter mainly to Macedonian *Romá*. The decision to set up facilities in this area was taken in the wake of a fire which destroyed 25 caravans in an area that had existed since 1993 and had been poorly set up at the

outset by the Provincial authorities (252). *Romá* were channelled into this area, too, nicknamed “container-land” (where the charitable organisation *Caritas* had housed non-European Community immigrants in containers). These *Romá* came from a settlement (that had existed since early 1992) located in the area of the building site of the future Trade Fair.

Most of the Macedonian *Rom* families that lived at the camp of *Castel Firmiano* arrived in Bolzano in 1992/1993.

Despite the fact that the *Rom* ethnic group was more protected in Macedonia than in other former Yugoslavian provinces (244), the economic crisis seriously affected Macedonia in those years. Politically, the *Romá* were recognised in the Constitution of the newly born Former Yugoslavian Republic of Macedonia (FYROM) with the same status as the other national minorities and, in contrast with all other former Yugoslavian provinces, at that time there was no nationalistic party sitting in the Parliament. Economically, the crisis that affected all of Former Yugoslavia was aggravated in Macedonia by the long dispute with Greece over the name “Macedonia” and by the embargo that resulted from it (244).

Thus, the *Romá*, being generally the more vulnerable ethnic group and those with the less qualified and more precarious jobs, were the first to suffer the consequences of the worsening of the economic crisis. For the above-mentioned explanations, the causes of the migration of the Macedonian *Romá* to Italy can be ascribed more to economic than to political reasons.

The majority of families were originally from *Šuto Orizari*, in *Skopje*. The situation concerning the housing and working conditions of the *Romá* in *Šuto Orizari* has been already described in the section about Florence.

The conditions of the *Castel Firmiano* camp did not change much from 2002 to 2004. In May 2004, though, a fire destroyed three bungalows and damaged one. The families that remained without shelter, received public housing apartments and one family got funds to repair the bungalow. In September 2004 a plan was made to intervene and restructure the camp following a proposal from the *Fondazione Michelucci* from Florence.

5. RESULTS

DIRECT OBSERVATION

The results presented in this section were collected via the information sheet called “Direct Observations: living conditions at the camp”.

Population of the five camps

The number of people in the five camps under consideration varied from 80 in the farmhouse in Brescia to 304 at the *Poderaccio* camp in Florence (Tab. 5.1). Because not all people living in the camps were officially registered, the official number of residents did not match exactly the actual number of people living in the camps. Although the actual figure was impossible to determine, the “official” and “actual” figures were very close to one another.

Altogether in the five camps, there were 160 families, totalling 845 people. The average size of the families varied from a minimum of 3.9 in the camp in Bolzano to a maximum of 6.6 in the camp in Venice.

The camp in Venice occupied the largest area, with 7500m², while the smallest was the camp in Bergamo with 1500m² (Tab. 5.2). Taking into account the camp populations, Bergamo was the most crowded (with 10m² per person), while the least crowded was Brescia with 50m² per person.

In Venice, the *San Giuliano* camp, that as reported earlier was finally closed down in March

2003, was already being slowly dismantled at the time of fieldwork. Many families had already been transferred to houses and more space had been made available despite the fact that new families had arrived from other camps that had been previously evacuated.

The calculation of the number of square metres available in Brescia was more complicated, as the area was not flat but based on a farmhouse with two floors. Therefore the calculation included the land surface (inside and outside), plus the number of square metres comprising the second floor. However, there is no certainty about the accuracy of the number of square metres reported by the “Office for Foreigners”.

Observations in the *Poderaccio* camp in Florence

The *High Poderaccio* camp was situated in the *Quartiere 4* (Florence is administratively divided into *Quartieri*), on the edge of *Isolotto*, just outside the city (Fig. 5.1). It was situated on a hill made of waste building materials from the demolition of the old *Officine Galileo* buildings. The camp was located in an area considered to be flood-overflow land for the *Arno* River: for this reason it was necessary for it to be located on higher ground.

The camp was enclosed all round. Only temporary access was granted to vehicles for loading and unloading purposes.

At the time of the study, more than 300 people lived in the *Poderaccio* camp.

Apart from the containers and the prefabricated toilets, the camp had a caretaker’s cabin located at the entrance to the camp. In December 2001 there were three bars run by families

living in the camp and a few other families used to sell odds and ends outside the shacks.

The housing at the *Poderaccio* camp consisted, fundamentally, of shacks, caravans, containers and the like (Fig. 5.2). As the camp had existed for many years, the containers provided at the beginning had been absorbed into more complex and liveable structures, even though the *Quartiere* never accepted the construction of walled buildings with the exception of the perimeter walls.

Observations in the camp in *Via Rovelli*, Bergamo

The camp was located in a former abattoir in the area of the city's fruit and vegetable market (Fig. 5.3, 5.4). Apart from its small size in relation to the number of people it contained, it was also sealed on all four sides by, respectively, a very high wall, net fencing, a wall of aluminium sheeting and by another wall with just one small door serving as the only exit.

About 150 people lived in the camp at the time of the study. Although new toilet facilities had been built towards the end of 2002, the hygienic conditions were still very poor in October 2004.

The situation in *Via Rovelli* was very insecure due to over-crowding and the scarcity of emergency escape exits in case of need.

Housing consisted of shacks built out of scrap materials and caravans. In most cases, the old caravans, emptied of their contents and only with the external structure left, were incorporated as part of the shacks and functioned as additional rooms.

Observations in the farmhouse in *Via Chiappa*, Brescia

The farmhouse was located in *Camafame* in an isolated position in relation to the residential centre (Fig. 5.5), as will be seen in the section on the measuring of distances. At the time of the study it gave shelter to 80 *Romá*.

The building was an old, country-style farmhouse on two floors with a central courtyard. It was in need of renovation and presented various problems, from decrepit door and window frames to structural weakness and water infiltration that caused damp and mould.

Some work had been carried out by individual families who refurbished the bathrooms, built verandas and mended the woodwork. The more impoverished families, though, lived in more unstable conditions.

Almost all the families lived in parts of the farmhouse, often enlarged by verandas that looked out onto the courtyard. Three families, however, lived in shacks built outside.

Observations in the *San Giuliano* camp, Mestre (Venice)

At the time of the study the camp housed 165 people.

The *San Giuliano* camp was situated near the car park bearing the same name, two kilometres from the town centre of Mestre (Fig. 5.6). It was practically unnoticeable from the outside also partly because very few cars used to arrive at the car park via the cul-de-sac.

The area allocated to the camp was large for the number of families living there at the time of the study, but this had not been the case a year before when the housing project had started (see chapter 4).

The major problem for the camp was the refuse tip that was closed down between 2000 and 2001. In summer 2000, various cases of eye irritation were reported, probably due to vapours emanating from the tip, as reported by the local Health Services.

The camp was enclosed all round. On the roadside of the camp there was a car park, and access to the camp was via the caretaker's cabin. It was flanked on the other three sides by uncultivated land. After the tip was decontaminated, and the camp demolished, the area became part of natural parkland.

In terms of facilities, apart from the caretaker's cabin, there was a container for the co-operative that ran the camp and another for the co-operative that was there to dismantle the camp. Additionally, there was a container that was meant for educational activities.

The homes consisted of shacks built out of scrap materials and caravans inserted into the structures. Only one family of recent arrival lived in a furnished container.

Observations in the *Castel Firmiano* camp in Bolzano

This camp offered shelter, at the time of the study, to 130 *Romá*.

The camp in Bolzano was by far the best of the five camps, in terms of conditions of the dwellings and quality of the structures (toilets, paving, electricity connections, etc.). It was situated outside the city on a hill, below *Castel Firmiano* (Fig. 5.7).

The area was previously set aside to be used as a refuse tip. After the land was reclaimed, it played host to a sports centre for wing shooting.

The area was divided into two parts with a car park and public facilities in the first and parking bays in the second.

The structure contained a large multipurpose hall, an office for the community workers, toilet facilities and a small room for meetings. The car park had allotted parking spaces, one per parking compound plus other unassigned spaces.

The 33 parking bays were set out along two rows, made of concrete and on a higher level than road level (Fig. 5.8). The toilet facilities were set in the middle of the area, between the two main rows of parking bays. The location of the toilets was questionable, as it hampered the possibility of using the central space for socializing purposes.

The residents themselves had built the small wooden houses, and the accommodation actually resembled small chalets. Only a few had a caravan that fitted into the structure and only one family lived in a caravan.

Comparative observations

The camps in Florence, Bergamo and Bolzano were built on an asphalt surface. Furthermore, in Bolzano the parking compounds that contained the little houses were on a raised level and built of concrete. In Bergamo, however, the surface was severely pot-holed and uneven. The courtyard of the farmhouse in Brescia was also made of asphalt, and was pot-holed and uneven, while the surface of the camp in Venice was made of gravel.

The problems – that will be described in a later section – relating to the uneven surface in Bergamo and Brescia and to the refuse tip in Florence meant there was often stagnant water in these three camps. As there was a lack of space available for children to play in, it was inevitable for children to play in that environment.

Problems with rats were reported in Florence, Bergamo and Venice, the three camps that were “classic” *Rom* camps, and where the housing was particularly poor. Wherever there were rats, they inevitably found their way into the shacks: it was easy for them to nibble their way through the materials used to build the shacks and to get in through the cracks.

In the same three camps (Florence, Bergamo and Venice), there were often materials piled up between one shack and the next. This was not refuse as such, but old, unused objects, tools, toys, chairs, tables and bric-a-brac of all kinds.

In Florence and Bergamo, there was also the problem of refuse building up outside the perimeter walls of the camp. While it was true that not much care was taken to deposit refuse inside the refuse bins, it was also true that they were often crammed to over-flowing, dirty and

in a poor state of repair. There were numerous complaints by the camp inhabitants in Bergamo about the mediocre service provided by the street cleaning service.

The camps in Florence, Brescia, Venice and Bolzano were situated near former refuse tips. In all four cases, the land had been decontaminated and reclaimed. In Bolzano, the land was reclaimed years before the camp was built, however, up to March 2006, the quality of the reclaim had never been ascertained. In Florence, the tip was a hospital refuse tip that was filled in with concrete before the camp was built. In Venice, the land was reclaimed after the *Romá* moved to the area. *Romá* had been present in Brescia since 1993 and the land that was previously used as the city's refuse tip was reclaimed in 1995. Both in Brescia and Venice, the hygiene office had reported health problems in the past related to the presence of these refuse tips.

Near the camp in Florence there was an asphalt-producing factory and a quarry producing building materials.

The camps in Florence and Venice were run by a co-operative that guaranteed round-the-clock surveillance. In Bolzano the association *Caritas* offered organisational skills and assistance during the day. No external body ran the camps or provided surveillance in Bergamo and Brescia, although at the Bergamo camp the local council-appointed co-operative managed all issues related to the camp residents.

The distance on foot was measured between each camp and the nearest means of public transport. The camp in Bergamo was only five minutes away from the first city bus stop. The camp in Florence was at a ten-minute distance, while the *San Giuliano* camp in Mestre was

12 minutes away and the *Castel Firmiano* camp in Bolzano was 15 minutes away. However, to reach the Bolzano camp from the bus stop, residents had to walk up hill. The farmhouse in Brescia was the furthest away, at 35 minutes from the nearest bus stop on foot.

The distance between the camps and the nearest hospital Casualty services was also measured. Once again, the Bergamo camp was the nearest, at 1.7km, followed by Bolzano at 3km and Venice at 4km. The *Poderaccio* camp in Florence was 6km from services, while the farmhouse in Brescia was 8.5km away.

Access to bathroom facilities and electricity supply

In Bolzano, each family had its own prefabricated bathroom outside the home, equipped with hot water, toilet, shower and a sink for washing dishes and clothing. In total, there were 33 bathrooms with a water heater. This enabled each family to manage its own needs in an independent fashion. The only negative point mentioned by the interviewees was the inconvenience of having an outside bathroom especially in winter. Washing children in winter without exposing them to the cold weather was no easy task.

In Florence each bathroom was assigned to two or more families, depending on the size of the families in question. There were 24 prefabricated bathrooms equipped with a water heater, a toilet and a washbasin. There were no showers or sinks and many of the water heaters did not work at the time of the survey. Some families had been assigned a bathroom containing just a chemical toilet. Maintenance of such chemical WCs was not optimal and during the authors' one-month stay at the camp there was no evidence of maintenance being carried out. A bathroom to be shared with other families was assigned to one of the new families that arrived

at *Poderaccio* from the *Masini* area, but the pre-existent families did not agree with the decision, and did not allow the new family to use it.

The absence of official shower units in Florence encouraged the residents to build illegal bathrooms inside their shacks. These “private” bathrooms discharged water down the slopes of the camp, as there was no way of connecting to the official sewage system. Having built themselves a shower unit, some families also decided to install a toilet for reasons of privacy, hygiene and self-management. The discharges from these unauthorised toilets, however, contributed considerably to the already poor state of the camp. There were eight of these unofficial bathrooms. The families who more fully respected the rules took showers in the outside bathrooms, using a jug and filling it from the washbasin. However, since the bathrooms did not have drainage canals connected to the sewage system, the water stagnated or flowed out and then around the camp. This stagnant water on the floor of the bathrooms had already caused some to cave in. The water flowing around the camp worsened hygiene standards, also because much of it ran down the slopes and formed a boggy channel that surrounded the camp.

The camp in Florence also lacked sinks where clothes or dishes could be washed. There was not a single area with a drainage system where clothes or rugs could be washed without the water flowing out and around the camp. The drainage pipes were so narrow that they easily became clogged. Again, all these problems led to water stagnating in a sort of boggy ditch that developed around the base of the camp. Soon after the author carried out the research into the problem, work commenced on the entrance side of the camp in an effort to channel this water away from the access road where it created problems. In winter, for example, there was a risk of the water freezing and the road becoming extremely dangerous.

In Bergamo, Brescia and Venice, there were sets of bathrooms and showers in common. In Bergamo and Brescia they were in an extremely decrepit condition that rendered them practically unusable. The number of available showers was very low: three in Bergamo, two in Brescia and four in Venice.

In Brescia, however, the majority of families (11 out of 13) also had a private bathroom, while the other two families had no choice but to use the communal bathrooms. These facilities had a WC, showers and sinks but in reality it would have been more hygienic not to use them and find alternatives instead. There was also no hot water. Of the 11 families that had private bathrooms, three used the same bathroom.

No families in Bergamo or Venice had their own private bathroom.

In Venice there were two sets of communal bathrooms: one for women and the other for men. They were equipped with hot water, WCs, showers, washbasins and sinks for doing the washing, and they were kept in a fairly good condition. Hot water was not available at all times.

The situation in Bergamo was very serious. There were two sets of bathroom facilities, one for men and one for women, but they were in such a highly unstable condition that the manager in charge of the hygiene office said he himself would not use those toilets for any reason. Because of the conditions of the toilets, many children defecated in the outside, worsening an already difficult situation created by the overcrowding. Because of the unreliability of the boiler system, hot water was only available in the early hours of the

morning. The bathrooms were equipped with WCs, showers and sinks but there were far too few of them to meet the demands of 30 families and so they had already become almost unusable. At the time of this study, new bathrooms were being built.

It is important to underline the importance of communal sinks for doing the washing, in Bergamo, Brescia and Venice. In Brescia they went unmentioned by interviewees and were probably not used because of the condition they were in and because residents had the opportunity to use private bathrooms. There were two sinks in Brescia, four in Bergamo and eight in Venice.

As far as the availability of toilet facilities is concerned, an important point is that it is clearly not the same if single families or groups of families use the bathrooms, as opposed to their being used communally. In fact, a single bathroom assigned to a defined group of families was more easily managed than communal bathrooms that everyone could use.

The electrical wiring systems, particularly inside the living quarters in the camps in Florence and Bergamo, represented a serious safety hazard. In Florence, the electrical system had been wired up to a point outside each shack, but the internal wiring had been installed by the families themselves and not according to law. In Bergamo, not only the internal, but also the external wiring, was not according to law, with wires hanging close to water sources and not well insulated.

Interviews with Health Services

Florence health services

In Florence there was a Paediatric Health Centre that offered assistance to the *Rom* children twice a week in the morning.

Many camp residents possessed a medical card since they were officially registered residents in the country. In that case, children up to the age of 14 had the right to be seen by a Family Paediatrician. However, many families preferred to use the services of the Health Centre or go to Casualty.

About 90% of the families used the Health Centre, whilst the hospitals most used were the *Mayer* and the *Torre Galli*.

Personnel from the Health Centre asserted that very few mothers in the camp practiced exclusive breast-feeding, even in the first months of life of the child. On the other hand, infants were often breast-fed for many months and for more than one year, almost more as a form of affection than for nutritional purposes. The health personnel's opinion was that the women in the camp believed their milk was not a rich enough source of nutrition and therefore preferred to introduce additional foodstuffs.

The *Distretto Sanitario* (Local Health Authority) had no health education programme for the *Poderaccio* camp.

Vaccination was the responsibility of the *Ufficio d'Igiene* (Hygiene Office), which employed the services of the *Assistente Sanitaria di Comunità* (Community Health Assistant). Immunisation coverage was almost total at the *Poderaccio* camp.

The Health Centre staff did not visit the camp but rather liaised with the community workers for appointments connected with vaccinations or for other appointments when children needed to be examined.

Community workers reported that *Romá* had difficulties remembering appointments, dates and treatment procedures.

Paediatricians reported that the biggest problem related to caries, which affected even the smallest children. Other diseases that they reported as common included gastro-enteritis in the summer and bronchitis in the winter, as well as frequent skin complaints. At the time of interview, two families in the camp had problems of scabies.

The Health Centre's paediatric records were up-to-date and well kept.

Bergamo health services

There were no Paediatric Centres or health centres available directly for the camp in Bergamo. Health Centres had been abolished and families referred directly to their family doctor or paediatrician.

There were no special services available for the *Romá*. Only those who were officially

registered had access to basic healthcare services and therefore to a family doctor. Other residents used Casualty, usually those of the *Seriata* and *Bergamo* hospitals. There was also a service available for those who did not have valid residence documents, *OICOS*, open twice a week in the evenings and on Saturday morning and run by volunteer doctors. This service was situated on the other side of town from the camp in *Via Rovelli* and as it was open in the evening it was not greatly exploited by the *Romá*. The STP medical card (for temporary foreign residents) only allowed for access to hospital services.

Depending on the seriousness of the disease, Casualty did not always provide the care requested: admittance to Casualty generally depends on the type and seriousness of the disease, and the staff on duty at the time. During a healthcare education course for the women in the camp, the excessive use of Casualty was also discussed. But, as stated by the community workers of *Migrantes*, given the living conditions in the camp, falling ill was common and recourse to some kind of medical treatment became a necessity.

All the children in the camp had a vaccination record-card. Appointments for boosters were made via *Migrantes* and the children were taken to the Vaccination Unit by mini-bus. Some mothers made their own way to the unit, while others accompanied their children, often making the task much easier to manage.

There were no problems with vaccinations, including the optional ones. At the end of November 2001, in a single morning, almost all the children were given the anti-flu vaccine, as requested by the mothers themselves.

The camp residents were almost all permanent residents in Italy and about 50% had a medical

card.

Ever since 1996, the ASL had alerted the local council to the poor conditions of the camp, referring to structural as well as health and welfare risks. The problems were linked to the following:

- the presence of faeces in the vicinity due to the extremely decrepit state of the toilet facilities,
- risk of electrocution due to the conditions of the electrical system,
- non-existent emergency exits,
- use of gas cylinders in the presence of highly flammable materials,
- risk of leptospirosis due to the presence of rats.

These warnings were followed by requests for help with structural work and rodent extermination. The last warnings were given just before the outbreak of a shigella epidemic.

When the outbreak of the shigella² epidemic occurred during the summer of 2001, the families did not understand the situation, believing that the diarrhoea symptoms were the ones the children were accustomed to getting in those conditions in the summer months. When, due to the epidemic, the children were prevented from returning to school, the parents were very unhappy and annoyed. The epidemic affected the two camps in *Via Rovelli*, one of which was dismantled in mid-October, 2001.

² Shigella are bacteria and they are more resistant to digestive acids than cholera. Transmission is by mouth via contaminated foods and causes dysentery. The bacteria multiply where foodstuffs are not refrigerated. Shigella can be treated with antibiotics. Anyone may be affected and the bacteria are fairly widespread, while epidemics and fresh outbreaks can more easily take hold in those whose immune system is weak and where standards of hygiene are poor. In children, apart from the dangers of dehydration caused by diarrhoea, there is also the danger of loss of blood via dysentery.

During the first 20 days of the epidemic, a camper van from the ASL, manned by doctors, visited the camp every day. This service slowly reduced the number of consultations needed and was then eliminated. Almost all the children underwent stool culture, and apart from cases of shigella (from two distinct strains), cases of salmonella and campylobacter were also found. In all, 22 children were affected by shigella.

The initial idea was to separate the *Rom* children from the others so that they could continue to go to school. The opinion of the ASL was that it was necessary to improve the hygiene conditions of the camp before allowing the children to go back to school. This position was motivated by the idea that it would be impossible to eradicate shigella unless the hygiene conditions in the camp improved. The ASL then abandoned this position although it continued trying to mediate with the school and the parents of the Italian children. The latter put up the greatest resistance. The *Rom* children were all allowed back at school only after the Christmas holiday.

Several times had the ASL requested measures to improve the condition of the toilet facilities, cleaning and decontamination of land both inside and outside the camp and the re-wiring of the electrical and safety system according to legal regulations.

Brescia health services

In Brescia there was a Family and Paediatric Consultancy that formerly offered its services one morning a week to two camps, including the one based in the farmhouse.

Health screening was carried out right from the beginning. The Paediatric unit was always

particularly active. The service was first offered to the *Romá* in so far as they were refugees, in possession of a green card.

All those who did not possess a residence permit were given STP medical cards, but minors and women in any case enjoyed right of access to health services. The ASL in Brescia ran a service for those foreigners who were in possession of an STP card.

During the first few years, each camp enjoyed a weekly health service for adults and minors. This commenced in 1992 with vaccinations that would allow the children to go to school. Then the programme went on to vaccinate starting with the newly-born. In 1992, screening was also carried out for TB and for dermatological diseases throughout the entire population of the camps.

During the first three years, volunteer nurses and doctors from The Red Cross offered a weekly service. Up until mid 2001 and for a period of eight years, there was a Community Health Assistant who covered both camps, visiting them in order to fix appointments for Thursday morning, the day set aside for *Romá*. The service was eliminated by the director of the Health District, the justification being that otherwise the *Romá* will not “stand on their own two feet”.

Since 1994, attempts were made to focus on the figure of the family doctor, choosing amongst those who showed most interest, based on a policy favouring legalisation of the *Rom* peoples’ status in the country. It was difficult at the beginning to persuade them to use the services of a family doctor and to follow the calendar of vaccination appointments. These problems were solved and only a few remained, relating to the new arrivals.

In 2002 services were being offered at the health unit, including those made available by family doctors and paediatricians. Healthcare workers no longer went on site.

The Paediatric Consultancy had been abolished in many areas. It was assumed that the family paediatrician would be able to provide the services of the Consultancy in the area covered previously by it. But in Brescia, the paediatricians were unable to cover specific areas as they had children spread out all over the district.

Moreover, not all the family groups went to the Family and Paediatric Consultancy. One explanation was that it was a long distance away from the farmhouse.

There have never been problems with vaccinations, although at the beginning medical personnel had to go to the camps to administer boosters and in this way everyone was vaccinated. All vaccinations were accepted, whether obligatory or optional.

On those occasions in which staff went to the camps to administer boosters, the children were also seen for other health problems. The demand for health services has therefore always been high.

Children who were ill were vaccinated in the Consultancy, while the others were vaccinated by the Local Health Services staff, that sent out a reminder when they fell behind with vaccinations.

The conditions of life in the farmhouse in Brescia were previously much worse than they

were at the time of the study, because of overcrowding as well as the poor state of the building itself. Old electric heaters were used to warm the rooms and because they were unprotected by fireguards, many children suffered burns.

The most serious problems were the death of a child who drowned in a ditch near the farmhouse, a cot-death in 1995, a child born in 1999 who died from a congenital heart condition and a baby girl who was born in 2000 with Ondine's syndrome.

Some years before the study was carried out, the problem of infections arose connected with the circumcision of children. Later the families were persuaded to have the operations performed in hospital, although this service was suspended in December 2001.

In 1997 there was a Hepatitis A epidemic. This led to the vaccination of all children up to the age of eight and then to the vaccination of all newborn babies.

The problem of head lice has been difficult to solve. The shampoo required to treat lice was expensive and it was difficult to explain the importance of removing the eggs and why a certain procedure had to be followed. In any case, nowadays, those families that have a bath and those who live in houses find it no longer difficult to solve this kind of problems.

Mestre health services

There was a Paediatric Consultancy that covered the *San Giuliano* camp in Mestre, but it only provided preventative medicine and not treatment. Children up to the age of one year were taken to the Consultancy for medical examination to have their development measured. The

Consultancy did, however, cover children up to the age of six. The Consultancy staff did not normally visit the camp.

The Hygiene Office took care of vaccinations and school health certificates.

Those who were in possession of a residence permit had the right to a medical card and therefore had access to a family doctor or paediatrician. In total there were about ten family doctors and five paediatricians assigned to the *Rom* families. Initially the community educators proposed doctors, but later it was the USL that assigned the doctors to the families.

All children underwent vaccination, although there were two separate calendars for those who were officially resident and those who did not have valid residence documents.

There was also a “mini” medical card, valid for three months, for those suffering from tuberculosis or for pregnant women who did not have a valid residence permit.

According to records dating back to 1999, there were often cases of bronchitis and skin diseases at the camp. In 1999 before a nearby refuse tip was decontaminated, almost all the residents had suffered problems of streaming and irritation to the eyes.

It was the opinion of the health workers that the attitudes of *Rom* families towards health services varied greatly. It was said that some were particularly mindful of healthcare issues and went more often to the Consultancy and to the doctor, while others were more neglectful.

RESULTS OF THE HOUSEHOLD SURVEY

During the fieldwork in the five camps under consideration, 137 families were interviewed (Tab. 5.3). The highest number of families interviewed was at the *Poderaccio* camp in Florence.

All but four families were covered in Florence. One missing family was away from the camp on the day of the interviews. Another family (made up of two parents and two children aged over five years) refused to be interviewed. A couple of families made up solely of one or more elderly people were not covered. In Bolzano the families not at the site on the days of the interviews were left out. One family with three children was absent at the time of fieldwork, and was left out. At the *San Giuliano* site in Mestre, only one family was left out (the children are no longer minors). The members of this family were out all day at work. Unfortunately, 21 out of 36 families were left out in Bergamo. This was due to an atmosphere of considerable tension and to the very unstable state of the site. It is difficult to hypothesise what difference the inclusion of the missing families would have made. As far as the author could verify, and by asking to the people that facilitated the contact with the families, those who refused to participate were not in better nor worse conditions than the ones covered by the study.

In total, 737 people were covered, totalling an average of 5.4 people per family ($SD=2.2$) (Tab. 5.4, Tab. 5.5).

The camps with the smaller families were Bolzano (with an average of 3.9 members, $SD=1.8$) and Bergamo (5.3, $SD=2.0$). As described in the following paragraphs, larger family size

(family with more than five members) was associated with bad conditions of the house, houses with composite type of structure and illiteracy of the mothers of children under six years of age.

Types of housing and overcrowding

As seen in the Direct Observation section, the housing structures varied from camp to camp, but they could be divided into four basic types and in combinations of the same: walled structured, shacks, containers and caravans (Tab. 5.6).

Some 91% of interviewees (125/137) lived in shacks or mixed structures that contained neither brick walls nor furnished containers. All but one of the containers in Florence were unfurnished and without windows.

Containers and caravans were important elements in housing structures in that they were isolated from the ground (and therefore from the damp) and could be sealed against rats.

As already stated, not all the shacks were of equal quality or all located in the same kind of environment. In Bolzano, for example, some could have almost been considered chalets and were constructed on a raised concrete surface. In Bergamo, on the other hand, they were all crammed into a small space and the ground surface of the camp was seriously pot-holed and uneven.

As a result of the evaluation of the internal housing conditions, done during the household survey, the worst camp was Florence, while the best camp was Brescia (Tab. 5.7). No housing

structures in Bolzano were considered to be in poor condition while in Brescia it was possible to maintain some housing in good conditions where brick walls formed part of the structure.

There was a significant association between the general conditions of a housing structure and its type, whether simple or composite. A simple structure was composed of a single element (a caravan, a shack, a container or a walled house), while a composite housing structure was composed of at least two of these elements. Out of “simple” structure houses, 61 out of 65 (94%) were judged to be in fair or good condition, whereas only 51 out of 68 (75%) of “composite” structures were judged to be in fair or good condition (OR 5.08; 95%CI 1.48 – 19.19*. Exact 95%CI 1.51 – 21.84; Fisher exact 2-tailed test $p=0.004$).

Although the composite housing structures were functional and demonstrated certain creativity in the use and adaptation of materials and units at hand, they were also probably indicative of a subsistence way of life that precluded planning and the stability that would allow for the construction of a “quality” home with better building materials.

A large family (more than five members) was more likely to live in a house in bad condition (14/21 families of more than five members living in a house in bad condition (67%), compared with 45/112 families of five or less members living in a house in bad condition (40%); OR 2.98; 95%CI 1.01 – 9.02). A large family was also more likely to be living in a composite type of house structure (43/69 families of more than five members living in a composite type of house (62%), compared with 17/68 families of five or less members living in a composite type of house (25%); OR 4.96; 95%CI 2.23 – 11.18). There was no interaction between the quality of the house and the structure in their association with size of the family.

By looking at the average number of people per room (Tab. 5.8, Tab. 5.9), the camp in Bergamo was the most overcrowded, with 3.4 people per room (SD=1.2). In Florence (2.5, SD=1.0), Brescia (3.0, SD=2.3) and Venice (2.7, SD=0.8) the situation was much the same, while in Bolzano the average was far lower. However, as described above, Bergamo did not have the highest average number of people per family (5.3); Venice (6.2), Florence and Brescia (5.8) had larger families. The overcrowding problem in Bergamo was not, therefore, due to an excessively large size of the families, but rather to the lack of living space available.

Each person interviewed was asked how the family members split up to occupy the separate parts of, and rooms inside, the house at bedtime. The term “bed space” is in inverted commas because one can rarely define the spaces as real beds: at night the family members slept on mattresses, rugs and sofas. Based on an average of people per “bed space”, Bergamo rated the highest with four people per space, while Bolzano had the lowest with two people per space (Tab. 5.10).

If one calculates the degree of overcrowding inside the camps on the basis of the relationship between the number of people actually present and the number of square metres, it can be seen that Bergamo had the lowest ratio, with 10m² per person, while Venice had the highest with 45m² (Tab. 5.11). As mentioned above, in Brescia the “camp” was actually a farmhouse on two floors with a courtyard, so the entire ground-level surface area was calculated plus the surface area of the second floor. In Venice there was considerable unused communal space, because of the gradual dismantling of the camp.

Access to water and bathroom facilities

In total, 39% (53/137) of families had access to water inside their homes (Tab. 5.12). In Bolzano, no families had water inside their homes, but each family had access to an outside bathroom. In Brescia, the farmhouse structure enabled each family to have access to water inside their home. In Venice and Bergamo, there were bathrooms and sinks in common and it would not, in any case, have been feasible to have a water connection to the shacks. In Florence, many families had water connected to their shacks even though no official wastewater drainage was set up inside the houses.

The issue of water connections must be seen alongside others, such as the presence of appropriate drainage systems, access to common bathrooms for the whole camp, for some families or for each family.

Access to and features of the bathrooms are important elements that could impact on the hygiene in the camps and potentially on the health of all the residents and on the children in particular (Tab. 5.13). Only 60% of the families in the five camps (81/136) had regular access to hot water, and 64% had access to a bathroom with a shower (87/136).

Electricity supply, fridge and heating system used in the house

All the families involved in the study (137/137) had electricity at home.

Almost all the families interviewed possessed a refrigerator, which is important for conservation of foodstuffs, especially in summer (Tab. 5.14). For this reason, this variable

was not used for the analysis.

Each family included in the study was asked what means was used to heat the home during the winter (Tab. 5.15). This variable was used to analyse whether a relationship existed between the diseases suffered by the children and the kind of heating system used.

Approximately 8% of the families interviewed (12/137) used more than one heating system.

In Bergamo and Venice, all the families used electric heaters (16/16). In Venice this was due to safety regulations, which prohibited the use of gas cylinders and wood-burning stoves. In Bolzano, the majority of families used wood-burning stoves (24/32), due both to the availability of wood and the availability of good quality traditional burners. In Florence, electrical heaters were the principle means used (33/52), but also wood-burning stoves (16/52) and gas heaters (6/52).

How and where cooking was carried out

Some 88% of families cooked inside the home (120/137) (Tab. 5.16). Brescia was found to have the lowest proportion of families that cooked inside the home (62%, 8/13), but many families cooked outside the walled structures of their home under a veranda almost entirely closed all round, like a kind of shack. In these cases cooking was considered to be “outside”, as it was in external conditions in relation to the presence of children.

Families employed different methods of cooking (Tab. 5.17): electric, gas-burning and wood-burning stoves. In some cases, in the same household more than one method was used. Not

just the type, but also the quality of the stoves varied. In Bolzano, for instance, many homes were equipped with efficient wood-burning heaters that also functioned as cookers and ovens. In cities like Florence and Brescia, the heaters and the wood-burning stoves were of a lower quality.

Demographics

For an easier understanding of the data according to age of the 737 people covered by the study, age groups have been used. Each age group comprises five years starting from birth. The age is expressed in terms of full years of life, so the first, counting from birth to the fourth year completed, includes from the first to the fifth year of life. The last group, from 65 years and upwards has been left open-ended but in reality includes very few people; there are two men (aged 65 and 66) and three women (two aged 65 and one aged 80).

Of the people covered by the study, 52% were females (380/737).

Looking at the age pyramid for the population under consideration (Fig. 5.9, Tab. 5.18), there is a rapid reduction from the first to the second section of the pyramid.

The average age of the population covered by the study was 20 years (SD=15.9) and varied from 21 in Brescia (SD=18.2) to 17 in Venice (SD=15.3) (Tab. 5.19).

Of the 137 families interviewed, 97 (71%) had at least one child of five years of age or younger. In Bergamo, 87% of families (14/16) had at least one child in this age range, while the lowest percentage was recorded in Bolzano (15/32, 47%) (Tab. 5.20).

The proportion of families with children of up to five years of age was significantly lower in Bolzano than in the other camps, all above 70% (82/105 families with children of up to the age of five in the other four camps (78%), compared with 15/32 families with children of up to the age of five in Bolzano (47%); OR 4.04; 95%CI 1.61 – 10.23).

In total, 167 children up to the age of five years were involved in the study. The data relating to the children is described below. Looking at the average number of children per family up to the age of five, it may be seen that Bolzano was the only city with less than one child per family (Tab. 5.21). All other cities had an average ranging from 1.3 to 1.5 children up to five years old per family.

Characteristics of the interviewees

Some 72% of the people interviewed were women (99/137) (Tab. 5.22). This percentage varied from one city to the next, ranging from a maximum of 79% at the *San Giuliano* camp and a minimum of 69% in Bolzano, Bergamo and Brescia. Among those families with children up to the age of five, the percentage of women interviewed was 75% (73/97) (Tab. 5.23).

An attempt was made to interview the mothers of children up to the age of five wherever such a situation existed. Where there were no children, it was of less importance who provided the information on the characteristics of the house or the habits of the family. In families with at least one child of up to five years of age, in 66% of cases the interviewee was the mother, in 24% the father and 8% the grandmother (Tab. 5.24).

The average age of interviewees was 31 years (SD=9.9), with a median age of 30 (Tab. 5.25). Some 39% of the interviewees were aged between 20 and 29 years, 32% were aged between 30 and 39, and 15% were in the 40-49 age range (Tab. 5.26).

The average age ranged from 38 in Brescia (SD=9.6) (where a high proportion of grandmothers was interviewed) to 25 in Bergamo (SD=6.3).

In the case of families with children, the average age of the interviewees was 29 (SD=8.5) (Tab. 5.27), ranging from 25 in Bergamo (SD=5.7) to 37 in Brescia (SD=10.4). The youngest person interviewed was 14 years old, while the oldest was 55.

Age of the mothers

The age of the mothers of children up to the age of five was recorder for 93 out of the 97 mothers in the study. Their average age was 27 (SD=6.9) (Tab. 5.28 and 5.29). Bergamo was the city with the “youngest” mothers, on average aged 24 (SD=5.8), while Venice had the “oldest” mothers, with an average age of 30 (SD=8.7). The youngest mother interviewed was 16, the oldest 49.

The age of the mothers at delivery was calculated for 159 out of the 167 children in the study (Tab. 5.30). The average age of the mothers at the time of birth was almost 25 years (24 years and 8 months, SD=6.4); the youngest was 15 while the oldest was 49. Some 84% of the children were born to women aged below 30 (134/159 between 15 and 29 years old).

It is noteworthy that in Bergamo, Brescia, Venice and Bolzano, a high percentage of women below the age of 20 gave birth in the past six years.

Moreover, in all the cities, the percentages for the groups after 29 years fall very rapidly. Only 12% (19/159) of children born in the last six years was born of mothers in the 30-39 age group.

To better picture the distribution of the age of the mothers at the moment of delivery, *Figure 5.10* shows a polynomial regression curve of the fourth degree.

Number of years spent living at the camp

Each interviewee was asked how many years he or she had spent at the camp (Tab. 5.31 and 5.32). On average, the 136 people who answered had lived at the camp for almost six years (Tab. 5.33). 10% had lived at the camp for over 10 years (14/136), while 45% had lived at the camp for between 6 and 10 years (61/136).

It should be noted that some people came from other camps, although this aspect was not explored in order not to complicate the analysis.

The camp in which residents had lived for the longest period of time was the *Poderaccio* in Florence, with 27% of interviewees reporting having lived there for more than 10 years (14/52) and with an average of over seven years. The interviewees in the farmhouse in Brescia also reported an average of over seven years, while the majority lived there for nine years (69%, 9/13). It appears that residents of the camp in Bolzano lived there for a much

shorter period, with 84% (26/31) having lived there for 6 years (since the camp opened). Many new arrivals, on the other hand, were recorded in the last year (9/24, 37%) at the *San Giuliano* camp in Venice, having arrived from other camps that had been dismantled. These were not, therefore, new arrivals in Italy but movements within the local authority of Venice.

Degree of literacy of the interviewees

Some 71% of interviewees claimed to be able to read and write a simple letter (Tab. 5.34). The ability of reading and writing referred to any language, and not specifically to Italian. The percentage was especially low in Venice (46%, 11/24) and relatively high in Brescia (85%, 11/13) and Bolzano (84%, 27/32).

Literacy was much higher among men compared with women (Tab. 5.35). Of the men interviewed, 97% (37/38) were literate as against 62% (60/99) of the women.

Literacy amongst the mothers

Unfortunately the literacy question was asked only about the interviewees. For this reason we only know the literacy of the mothers for two thirds of the families (64 out of 94 families with at least one child of five years of age or younger) and for 69% of the children (116 out of 167 children). This variable was nonetheless used in the analysis of associations with the health of the children.

Of the 64 interviewed mothers, 58% of them were able to read and write (Tab. 5.36). In Venice, only 3 out of 14 mothers interviewed were able to read and write and in Florence 15

out of 27.

Literacy of the mother was significantly associated with variables indicating overcrowding, meaning not only many people per square meter, but also many people living in the same camp or family. A mother was more likely to be illiterate if she lived in a family of more than five members (45/71 illiterate mothers living in families of more than five members (63%), compared with 12/45 illiterate mothers living in families of five or less members (27%); OR 4.76; 95%CI 1.94 – 11.87), in a house with more than 2.5 people per room (30/46 illiterate mothers living in a house with more than 2.5 people per room (65%), compared with 27/70 illiterate mothers living in a house with up to 2.5 people per room (39%); OR 2.99; 95%CI 1.28 – 7.05) or in a camp with more than 140 people living (56/100 illiterate mothers living in a camp with more than 140 people living (56), compared with 1/16 illiterate mothers living in a camp with less than 140 people living (6%); OR 19.09; 95%CI 2.44 – 409.07*. Exact 95%CI 2.68 – 817.65; Fisher exact 2-tailed test $p=0.000$).

There was not a significant difference in the literacy of the mothers depending on the age group (Tab. 5.37).

Finally, in a family where the mother was literate it was more likely that nobody smoked more than 10 cigarettes a day at home (15/19 literate mothers living in a house in which nobody smokes more than ten cigarettes a day (79%), compared with 21/44 literate mothers living in a house in which at least one person smokes more than ten cigarettes a day (48%); OR 4.11; 95%CI 1.04 – 17.56*. Exact 95%CI 1.05 – 19.32; Fisher exact 2-tailed test $p=0.028$).

The smoking of cigarettes

In order to find out how many people smoked inside the home, two questions were asked. The first asked how many people in the family smoked inside the home, while the second asked how many smoked more than ten cigarettes in the home per day.

Families in which nobody smoked amount to just 11% (Tab. 5.38, 5.39). In Brescia, all thirteen families interviewed had at least one person who smoked inside the home. Bergamo was the city with the highest number of families interviewed in which nobody smoked (4/12). In 15% (20/137) of the families there were more than two people smoking in the house.

If one takes into account only those families in which at least one person smoked, the average number of smokers per family was 1.9 (SD=1.0) (Tab. 5.40).

The proportion of families in which at least one person smoked at least ten cigarettes per day, including families in which nobody smoked, was 72% (98/136; Tab. 5.41). The highest proportion of families in which at least one person smoked ten cigarettes or more inside the home was found in Venice (20/24), while the lowest was found in Bergamo (8/15).

Amongst the families in which at least one person smoked, the average number of people who smoked at least ten cigarettes per day was 1.4 (SD=1.2) (Tab. 5.42).

Children from birth to five years of age: general information

Out of 137 families interviewed, there were 167 children up to five years of age, distributed between 97 families, and 40 (29%) families that had no children under the age of six.

The families with children under six years (97/137) each had, on average, 1.7 children up to five years of age (167/97, SD=0.9). Including all the 137 families interviewed, on average each family had 1.2 children up to the age of five (167/137, SD=1.1).

The distribution of the children in the study according to age (in months to be more exact; from birth to 71 months inclusive) was fairly regular (Tab. 5.43), even though there is a tendency towards a reduction in frequencies in the upper years (Fig. 5.11) (average age 33 months; 25° percentile at 16 months; median at 32; 75° percentile at 50). The cause of this reduction is difficult to interpret due to the small number of children.

Sex distribution of the children involved in the study was also regular, with 48% males (80/167) and 52% females (87/167) (Tab. 5.44). The sex variable has been analysed in order to ascertain what influence it might have on other factors included in the analysis.

In all cities, 78% of the children were born in Italy (129/166) with a variation ranging from a peak of 95% in Bolzano (18/19) to a low of 72% in Venice (26/36) (Tab. 5.45). Bolzano and Brescia had the highest number of children born in Italy.

Almost all of those born in Italy were born in the city in which they were resident (Tab. 5.46): the only other Italian city, apart from the five under consideration, where a child was born,

was Bologna, although this child lived in Bergamo at the time of the survey. All the camps reported the presence of children who were born in Kosovo, except Bolzano, which had a mainly Macedonian population.

Of the 36 children born abroad, 5 were born at home, while 31 were born in hospital (Tab. 5.47). Only one of the six children born at home was born in Italy, in Florence. The other five were born in Kosovo. Three of the six born at home live in Florence, the other three in Venice.

Only two or three hospitals were used for childbirth across all the cities (Tab. 5.48 to 5.52).

Birthweight of the children in the study

The interviewees were asked to give the birthweight of the children in the study. However, the data collected were not always exact, due to lack of memory or absence of documents testifying to the facts. In 20 cases out of 167 (12%), the interviewees were unable to answer the question.

As mentioned in the methods section, wherever possible, the birthweight reported by the interviewer was checked using records of the paediatric consultancy or birth certificated held by the parents (Tab. 5.53).

There was no paediatric consultancy in Bergamo and none of the interviewees had any documents at hand showing the birthweight of the child.

The cross checking with records indicated that the average reported birthweight of the children (expressed in kg) did not differ greatly from the verified weight. Out of a total of 147 responses (to the questionnaire), 71 birthweights were verified and the average was 3.05 (SD=0.53). The other 76 non-verified birthweights gave an average of 3.10 (SD=0.52).

The comparison can be extended to the percentiles' distribution. With reference to verified birthweights, the distribution had a minimum of 1.850; the 25° percentile was at 2.740; the median was 3.050; the 75° percentile was at 3.440 and reached a maximum of 3.900. For unverified weights, the minimum stood at 1.900; the 25° percentile was at 2.800; the median weight was 3.010; the 75° percentile was at 3.500 and the maximum was 4.500. If one were to eliminate a single case of a birthweight of 4.500, the distributions would be practically identical.

Some 10% of children had a birthweight of less than 2.500 kilograms (14/147), varying from 8% of verified weights (6/71) to 11% of non-verified weights (8/76) (Tab. 5.54). Values of more than 10% were recorded in Venice and Bergamo, both for verified and unverified weights.

Two variables were significantly associated with low birthweight: age of the mother at delivery (considered to be a risk factor if the mother was younger than 19 or older than 34) and people smoking inside the house (more than two people smoking in the house). These two variables also interacted significantly with one another in their association with low birthweight (Test for interaction: $p=0.048$).

Looking at the variable about smoking, a child from a family in which more than two people

smoked was more at risk compared with a child from a family where no more than two people smoked (6/27 children who weighted less than 2.500 kg at birth from families in which more than two people smoked in the house (22%), compared with 8/120 children who weighted at birth less than 2.500 kg from families in which no more than two people smoked in the house (7%); OR 4.00; 95%CI 1.08 – 14.69. Exact 95%CI 1.02 – 14.58; Fisher exact 2-tailed test $p=0.023$). However, stratifying by the age of the mother at delivery there was no significant association between smoke and low birthweight in neither of the two groups.

Taking the age of the mother at delivery as the main exposure variable, and stratifying by smoking habits, if there were less than two people smoking in the house, a child born from a mother younger than 19 or older than 34 at the time of delivery was more at risk of being born underweight compared with a child born from a mother that was 19 to 34 years of age at delivery (in families with less than two people smoking in the house, 4/13 low birth weight children were born from mothers younger than 19 or older than 34 (31%), compared with 4/101 low birth weight children born from mothers between 19 and 34 years of age (4%); OR 10.78; 95%CI 1.82 – 66.13*. Exact 95%CI 1.64 – 66.37; Fisher exact 2-tailed test $p=0.006$). If there were more than two people smoking in the house, the proportion of children born underweight was 16% (4/25), with no significant difference according to the age to the mother (OR 0.75; 95%CI 0.06 – 9.81*. Exact 95%CI 0.05 – 12.37; Fisher exact 2-tailed test $p=1.000$).

The perception of the growth of the child by the interviewees

The interviewees were asked what opinion they had of the child in comparison with other children of the same age (whether bigger, normal or smaller). This question had to be used

alongside data from anthropometrical measurements of the children (weight and height), in order to examine the perception of the interviewees in comparison with the child's objective developmental stage. However, it was not possible to collect data on weight and height for logistical reasons and because it was felt to be excessively intrusive. After spending one month living at the *Poderaccio* camp, it was considered more appropriate not to carry out anthropometric measurements.

Overall, 21% of children were considered to be small for their age (34/165) (Tab. 5.55). This proportion varied from 28% in Florence (19/63) to 10% in Brescia (2/20). There was no difference in the percentages of small children according to age (Tab. 5.56) and sex (Tab. 5.57) of the child.

Symptoms of the children

The interviewees were asked whether, in the previous 15 days, the children had suffered from diarrhoea, coughing, skin complaints or other illnesses, and whether and where the children had been taken to see a doctor in relation to each symptom.

Interviewees were also asked if the children had had breathing difficulties or wheezing when breathing. If so, they were asked how many times the symptoms had recurred during the previous 12 months, if the child had been taken to a doctor and what diagnosis had been given. This set of questions was aimed at identifying children who suffered or had suffered from asthma, or recurrent episodes of "bronchitis".

Diarrhoea symptoms

Some 32% of interviewees (53/165) stated that the child had suffered from diarrhoea in the 15 days prior to the interview. The highest percentage was recorded in Brescia (50%, 10/20), while the lowest was in Bergamo (14%, 3/21) (Tab. 5.58).

In our study, in the case of diarrhoea in different age groups, it can be seen that period prevalence was higher in the three youngest years (11/33 in the first year of life (33%); 19/32 in the second year of life (59%); 8/24 in the third year of life (33%)) (Fig. 5.12), peaking in the second year. In successive years of age, the prevalence of diarrhoea diminished (7/30 in the fourth year of life (23%); 4/37 in the fifth year of life (15%); 4/19 in the sixth year of life (21%)).

Factors related to diarrhoea

There is a significant association between years spent living at the camp by the families and the period prevalence of diarrhoea. It is important to bear in mind that the variable “years spent at the camp” was referred to the family and not directly to the child, whose age might be less than the period of two or five years in which the variable has been dichotomised.

A child whose family had been living at the camp for more than two years was more at risk of diarrhoea compared with a child whose family had been living at the camp for two years or less (in families that lived at the camp for more than two years 48 out of 131 children had diarrhoea (37%), while in families that lived at the camp for two or less years 5 out of 34 children had diarrhoea (15%); OR 3.35; 95%CI 1.12 – 10.72*. Exact 95%CI 1.17 – 11.77;

Fisher exact 2-tailed test $p=0.014$). No confounders or significant effect modifiers were found to influence this association.

Among families that had spent more than five years living at the camp the direct association at the 95% confidence level is weaker (33/83 children with diarrhoea from families who lived at the camp for more than five years (40%), compared with 20/82 children with diarrhoea from families who lived at the camp for five or less years (24%); OR 2.05; 95%CI 0.99 – 4.25. Exact 95%CI 1.00 – 4.24; Fisher exact 2-tailed test $p=0.045$). However, considering the outcome of the exact confidence intervals and Fisher's test, the association between diarrhoea and more than five years spent at the camp by the family was further analysed.

To live in a camp for more than five years is a risk factor for diarrhoea if the family lived in an overcrowded house (with more than 2.5 people per room) (in families living in overcrowded houses, 13/27 children had diarrhoea in families who lived at the camp for more than five years (48%), compared with 5/39 children with diarrhoea in families who lived at the camp for five or less years (13%); OR 6.31; 95%CI 1.64 – 25.69*. Exact 95%CI 1.66 – 26.32; Fisher exact 2-tailed test $p=0.002$). Overcrowding of the house is not directly associated with period prevalence of diarrhoea, but the role of overcrowding in the association between diarrhoea and years spent by the family living at the camp can be justified by suggesting that overcrowding can become a problem in the long run. If the family lived in a less overcrowded house, there was no association between years spent living at the camp and diarrhoea (in families who lived in less overcrowded houses, 35/99 of the children had diarrhoea (35%); OR 1.04; 95%CI 0.41 – 2.61). House overcrowding was a significant modifier (Test for interaction: $p=0.016$).

To live in a camp for more than five years is a risk factor for diarrhoea if stagnant water was reported on the floor of the camp due to the damaged paving (in camps where stagnant water was reported, 26/58 children had diarrhoea in families who lived at the camp for more than five years (45%), compared with 10/52 children with diarrhoea in families who lived at the camp for five or less years (19%); OR 3.41; 95%CI 1.32 – 8.96). As before, stagnant water is not directly associated with period prevalence of diarrhoea, but children whose families had been living in a camp with stagnant water for more than five years were more likely to have had diarrhoea compared with children whose families had been living in a camp with stagnant water but for five years or less. If there was no stagnant water in the camp, there was no association between years spent at the camp and diarrhoea (in camps with no stagnant water, 17/55 children had diarrhoea (31%), no matter the number of years spent by the family living at the camp; OR 0.78; 95%CI 0.21 – 2.89). Presence of stagnant water interacted significantly (Test for interaction: $p=0.045$).

The age of the child was also associated with period prevalence of diarrhoea. A child under the age of four was more likely to have had diarrhoea in the 15 days prior to the interview compared with a four or five years old child (45/119 children under the age of four with diarrhoea (38%) compared with 8/46 four or five years old children with diarrhoea (17%); OR 2.89; 95%CI 1.15 – 7.46).

Coughing

Some 55% of children suffered from coughing in the fifteen days prior to the interview (90/165). The percentage was highest in Brescia (70%, 14/20) and lowest in Bolzano (37%, 7/19) (Tab. 5.59).

The age curve showing the period prevalence of coughing in the 15 days prior to the interview is very similar to the one plotted for the period prevalence of diarrhoea (Tab. 5.60, Fig. 5.13). An increase in period prevalence may be noted between birth and one year of age, at which point the curve reaches its peak. There is a subsequent decrease up to the age of three followed by a further increase that spans to include ages four and five. It should be noted that age refers to whole years completed.

Stratifying by sex of the children, the period prevalence of cough was almost identical for males and females (Tab. 5.61).

Factors related to coughing

The access of the family to a toilet with a shower was associated with the period prevalence of cough. A child whose family did not have access to a bathroom with shower was more likely to get cough, compared with a child whose family had access to a bathroom with a shower (48/73 children with cough in families with no access to a bathroom with shower (66%), compared with 41/91 children with cough in families with access to a bathroom with shower (45%); OR 2.34; 95%CI 1.17 – 4.69). This association did not seem to be affected by significant effect modifiers or confounders.

Type of access to water (inside or outside the house) was associated with cough. A child from a family with access to water inside the house was more likely to get cough compared with a child from a family with access to water outside the house (48/74 children with cough from

families with water inside the house (65%), compared with 42/91 children with cough from families without water inside the house (47%); OR 2.15; 95%CI 1.09 – 4.26).

The age of the child was a modifier (Test for interaction: $p=0.028$) on this association. For children under the age of four, family's access to water inside the house made the risk of cough higher than for a child whose family had access to water outside the house (among children under the age of four, in families with access to water inside the house 37/52 children had cough (71%), while in families with no access to water inside the house 28/67 children had cough (42%); OR 3.44; 95%CI 1.47 – 8.09). For children of four and five years of age, the association between access to water and coughing was not significant (among children of four and five years, 25/46 children had cough (54%), with no significant difference depending on access to water; OR 0.71; 95%CI 0.19 – 2.71).

Living in a camp with surface conditions that allow water to stagnate was a risk factor for coughing. A child living in a camp with stagnant water had twice the risk of cough compared with a child living in a camp without stagnant water (in camps with stagnant water 68/110 children had cough (62%), while in camps with no stagnant water 22/55 children had cough (40%); OR 2.43; 95%CI 1.18 – 5.01). Length of time living in the camps was a significant effect modifier on this association (Test for interaction: $p=0.023$):

- Selecting families that lived for more than five years at the camp, a child living in a camp with stagnant water had a higher risk of cough compared with a child who lived in a camp without stagnant water (among families who lived in a camp for more than five years, in camps with stagnant water 38/58 children had cough (66%), while in camps with no stagnant water 6/25 children had cough (24%); OR 6.02; 95%CI 1.85 – 20.44*. Exact 95%CI 1.88 – 21.01; Fisher exact 2-tailed test $p=0.001$). Such association was not

significant for families that lived at the camp for no more than five years (among families who lived in a camp for five or less years, 46/82 children had cough (56%), with no significant difference if they lived in a camp with or without stagnant water; OR 1.19; 95%CI 0.43 – 3.28).

Heating the house with wood stoves is not associated with period prevalence of cough in children. However, selecting families living in overcrowded houses (more than 2.5 people per room), we found a significant association between heating with wood stoves and coughing. Overcrowding in the house was a significant effect modifier (Test for interaction: $p=0.002$). For families living in overcrowded houses, a child had a higher risk of cough if only wood stoves were used for heating compared with a child from a house where other systems were used (among families living in more than 2.5 people per room, in houses exclusively using wood stoves for heating 10/12 children had cough (83%), while in houses not using exclusively wood stoves for heating 22/54 children had cough (41%); OR 7.27; 95%CI 1.27 – 54.32*. Exact 95%CI 1.32 – 72.52; Fisher exact 2-tailed test $p=0.010$). In families living in houses with up to 2.5 people per room such association was not significant (among families living in less overcrowded houses, 58/99 children had cough (57%), with no significant difference depending on the use of wood stoves; OR 0.44; 95%CI 0.17 – 1.12).

Breathing difficulties and asthma

In order to explore the theme of prevalence of asthma, the interviewees were asked if the children had ever exhibited wheezing in breathing or respiratory difficulties, how many times the problems had arisen, if the child had ever been taken to see a doctor and what diagnosis had been made.

Some 23% of interviewees stated that the child had had wheezing or respiratory difficulties during his or her lifetime (38/165). The highest percentage was recorded in Florence (29%, 20/69), followed by Bolzano (26%, 5/19) and Bergamo (24%, 5/21) (Tab. 5.62).

Of all the children, 17% (28/165) had had respiratory difficulties or wheezing at least once in the last year. Again, the highest percentage was recorded in Florence (28%, 19/69), followed by Bergamo (19%, 4/21) (Tab. 5.63). The distribution by age sees the highest period prevalence in the first two categories: first (21%, 7/33) and second year of age (28%, 9/32) (Tab. 5.64). There was no difference in the period prevalence according to sex (Tab. 5.65).

The period prevalence of children that had at least four “attacks” of wheezing or difficulties in breathing in the last 12 months was 5% (8/165) (Tab. 5.66). Because of the small number of cases, it is difficult to comment on the distribution by city (Tab. 5.67) and by age (Tab. 5.68). The distribution by sex (Tab. 5.69) shows a higher period prevalence for males (8%, 6/78) than for females (2%, 2/87) that, nevertheless, could be attributable to chance.

Starting with the risk analysis for respiratory difficulties or wheezing at least once in the last 12 months, four variables related to the condition of the camps were found to be significantly associated with the outcome. A child was more at risk of having had respiratory problems in the last 12 months if he/she lived:

- In camps with stagnant water (these are Florence, Bergamo and Brescia) (in camps with stagnant water 24/110 children had respiratory difficulties (22%), while in camps with no stagnant water 4/55 children had respiratory difficulties (7%); OR 3.56; 95%CI 1.07 – 13.02*. Exact 95%CI 1.12 – 14.81; Fisher exact 2-tailed test $p=0.023$). We did not find

confounders or factors interacting with this association.

- In camps with rats (camps with rats were also those with more than 150 people: Florence, Bergamo and Venice) (in camps with rats 26/126 children had respiratory difficulties (21%), while in camps with no rats 2/39 children had respiratory difficulties (5%); OR 4.81; 95%CI 1.02 – 31.28*. Exact 95%CI 1.10 – 43.54; Fisher exact 2-tailed test $p=0.027$). We did not find significant modifiers or confounders.
- In camps with less than 25 square meters per person (Florence and Bergamo) (in camps with less than 25m² per person 23/90 children had respiratory difficulties (26%), while 5/75 children had respiratory difficulties in camps with more than 25m² per person (7%); OR 4.81; 95%CI 1.59 – 15.59*. Exact 95%CI 1.64 – 16.99; Fisher exact 2-tailed test $p=0.001$). No significant modifiers or confounders were found. The camp in Bergamo had the highest density of population per square metre, 10m² per person, followed by Florence with 20m².
- In camps with polluting industrial sites near by (this identified the camp of Florence, the only camp with more than 200 people) (in camps with near by polluting sites 19/69 children had respiratory difficulties (28%), while 9/96 children had respiratory difficulties in camps without near by polluting sites (9%); OR 3.67; 95%CI 1.43 – 9.65). The *Poderaccio* camp in Florence was located near a gravel quarry and a factory producing asphalt.

Other simple variables associated with the outcome were the condition of the house (good or regular vs. bad) and the access to a toilet with a shower.

A child living in a house in poor condition had a higher risk of having had respiratory difficulties in the last 12 months compared with a child living in a house in regular or good

condition (in a house in bad condition 12/36 children had respiratory difficulties (33%), while in a house in regular or good condition 16/126 children had respiratory difficulties (13%); OR 3.44; 95%CI 1.31 – 9.01).

A child from a family with no access to a toilet with a shower had a higher risk of having had respiratory problems in the last 12 months compared with a child from a family with access to a toilet with a shower (in families with no access to a toilet with a shower 19/73 children had respiratory difficulties (26%), while in families with access to a toilet with a shower 9/91 children had respiratory difficulties (10%); OR 3.21; 95%CI 1.25 – 8.41).

Reported diagnosis of breathing problems

Of the children who had suffered wheezing or other respiratory problems, 35 out of 38 were taken to see a doctor: all the children in Bergamo, Brescia, Venice and Bolzano and 17 out of 20 in Florence had seen a doctor (Tab. 5.70).

Of the 35 children who were taken at least once to see a doctor because of respiratory problems, 14 received a positive diagnosis of asthma or asthmatic bronchitis while another 2 children were diagnosed with allergic bronchitis (Tab. 5.71). All the other children's respiratory difficulties were ascribed to occasional diseases.

Among the diagnosed pathologies, three cases of pneumonia were identified in Florence. Although the data does not indicate when these cases occurred, all three children had had respiratory problems at least once in the previous 12 months. The children were aged three, four and five years, respectively.

The percentage of *Rom* children aged 0-5 years who suffered asthma at some point during their lifetime was 9% (15/165).

Cross-referencing the variables on the diagnosis and on the number of times the child had had respiratory problems in the past year, one can obtain an indication of the prevalence of “active asthma”: this includes those who had had an asthma diagnosis and had had respiratory difficulties or wheezing in the past 12 months.

Bergamo was the city with the highest proportion of children with active asthma, with three cases out of 21, followed by Florence (6/69) and Venice (3/36) (Tab. 5.72). The frequencies are very low and thus do not allow for an easy analysis. However, an attempt was made to identify the principal tendencies that could help to give as clear a picture of the situation as possible.

The distribution of cases by age of the child showed that the highest percentages were in the first two years (Tab. 5.73). Although not statistically significant, there was a difference in the prevalence of active asthma between males and females (Tab. 5.74). Amongst the males, there were 8 cases out of 78 (10%), whilst amongst the girls there were 4 cases out of 87 (5%).

In risk analysis, the main difficulties were caused by the low number of cases of active asthma and by the fact that no cases had been recorded in two of the sites (Brescia and Bolzano).

Because of the small number of cases, in some occasions we used the exact Fisher test rather

than the odds ratio to evaluate the significance of the results. The use of the exact Fisher test is, in fact, suggested if at least one estimated frequency value in the 2x2 table cell is less than five.

The only simple variable to have a significant relation with the outcome, in simple 2x2 tables, was the variable identifying the camps where the presence of rats was reported. Because no cases of asthma have been reported in camps where there were no rats, the odds ratio could not be calculated. However, the p value of exact Fisher test could be used: in this case, the p value for the 2-tailed test was not significant (0.071), while the p value for the 1-tailed test was significant (0.034). If we accept the 1-tailed test, we could say that a child living in a camp with rats had a higher prevalence of asthma compared with a child from a camp where there were no rats. The prevalence of asthma was 10% (12/126) in camps with rats and 0% (0/39) in camps with no rats. Camps where the presence of rats was reported were also the ones with more than 150 people living: these camps were Bergamo, Florence and Venice.

Variables were created to analyse if the combination of characteristics related to living conditions, as overcrowding in the house or in the camp and conditions of the house, were associated to asthma prevalence.

The first composite variable combined overcrowding in the camps (if there were more than 25 square meters per person living at the camp) and condition of the house (if the condition of the house was regular or good). This composite variable had value “one” if both variables were 1, meaning the child was living in a house in regular or good conditions and in a camp with more than 25 square meters per person. The variable had value “two” otherwise.

A child living in an overcrowded camp or living in a house in bad conditions (or both) was more likely to have asthma compared with a child living in a less overcrowded camp and in a house in regular or good conditions (in camps with less than 25m² per person or in houses in bad conditions 11/98 children had asthma (11%), while in camps with more than 25m² per person and in houses in good or regular condition 1/67 children had asthma (1%); OR 8.34; 95%CI 1.06 – 180.20*. Exact 95%CI 1.15 – 364.52; Fisher exact 2-tailed test p=0.029).

The second variable combined house overcrowding (if the family lived in a house with more than one room per 2.5 people) and night overcrowding (if the family lived in a house with more than one bed every three people). The combined variable was “one” if either or both of the simple variables were “one”, and was “two” if both simple variables were “two”.

A child living in a house with less than one room for every 2.5 members of the family and with less than one bed every three members of the family had a higher risk of having asthma compared with a child living in a house with more than one room every 2.5 people or with more than one bed every three people (in houses with less than a room every 2.5 people and with less than one bed every three people 7/43 children had asthma (16%), while in families with more than one room every 2.5 people or more than one bed every three people 5/122 children had asthma (4%); OR 4.55; 95%CI 1.19 – 18.01*. Exact 95%CI 1.15 – 19.14; Fisher exact 2-tailed test p=0.014).

Dermatological diseases

Of all interviewees, 5% (8/165) stated that the child had suffered skin complaints in the previous 15 days (Tab. 5.75).

The skin complaints recorded were cases of non-specific dermatitis in the three camps, plus two cases of scabies and one of allergic dermatitis in Florence, one case of mycotic stomatitis in Bergamo and 1 of mycosis in Venice (Tab. 5.76).

The distribution of cases by age of the children showed a higher period prevalence in the first two years of life (Tab. 5.77), while stratifying by sex the percentage was the same for males and females (Tab. 5.78).

No skin diseases were reported at the camps in Brescia and Bolzano, which also did not have any cases of active asthma. Looking at variables related to conditions of the camps, we notice that there were three main differences between these two camps and the other three:

- Brescia and Bolzano were the only two camps with less than 150 residents (80 people lived in Brescia, 130 in Bolzano);
- In these two camps we did not observed piled up materials laying in common spaces;
- The presence of rats was not reported in Brescia and Bolzano.

These results cannot be considered statistically significant, not even considering the Fisher 2-tailed exact test that only reaches an 80% confidence.

With reference to skin diseases, the number of reported cases was too low to obtain sufficient results for a risk analysis. We did not find any factor associated with the outcome, neither considering the population of children from the five camps nor just selecting the three camps where cases of skin diseases were reported.

We also looked in stratified portions of the population, without finding significant

associations or interactions.

Seven out of the eight children had been taken to see a doctor (Tab. 5.79). Data as to where the children were taken for medical examination for skin diseases are reported in Tab. 5.80.

Other pathologies

The interviewees were asked if the children had had other health problems in the previous 15 days, apart from diarrhoea, coughing or skin complaints. 42% gave a positive answer (70/165) (Tab. 5.81).

Some 69 of the interviewees specified the types of symptoms the children had had, giving rise to 92 answers, since some children had had more than one symptom.

Table 5.82 shows that the symptoms were mixed with diseases such as chicken pox, hepatitis, influenza and roseola (exanthema subitum). Each of these diseases produces more than one symptom. These, however, were the replies as given by the interviewees.

The percentages were formed on the basis of the total number of children and the symptoms did not exclude each other. This explains why the percentages in Brescia are over 100%: for instance, a child with fever could also be counted amongst the children with vomiting.

About fever

Before carrying out a comprehensive analysis of all the diseases, a separate descriptive

analysis will be carried out on the cases of fever. Although no particular question was posed as regards fever, this analysis was necessary given the high percentage of children reported to have had this symptom.

The period prevalence of fever did not vary greatly from one camp to another, ranging from 5 out of 20 in Bergamo to 12 out of 36 in Venice with the exception of Brescia where 14 out of 20 children were affected (14/20) (Tab. 5.83).

The proportion of children suffering from fever in the 15 days prior to the interview varied greatly according to the age group of the children, reaching a peak in the second and third year (Fig. 5.14). The period prevalence of fever did not vary significantly depending on the sex of the child (Tab. 5.84).

Composite analysis of all reported symptoms

Looking at all the data together regarding diarrhoea, coughing and dermatological complaints and the data on other conditions, all in the 15 days prior to the interviews, it can be seen that only 33% of children were free of symptoms (54/165) while all the others had had at least one symptom (Tab. 5.85, Fig. 5.15).

Of the children who had suffered from some pathology in the previous 15 days (67%, 111/165), 48% had diarrhoea (53/111) as a symptom, 81% had coughing (90/111), 50% fever (55/110) and 14% vomiting (15/110). Of the 111 children whose parents said they had had health problems in the previous 15 days, 71% (79/111) were taken for medical examination.

As was seen earlier, of all the 165 children covered by the study, as many as 90 (55%) children suffered coughing in the 15 days prior to the interviews. Fever affected 33% of the children (55/165) and diarrhoea affected 32% (53/165). All the other symptoms or complaints listed recurred in less than 10% of children, and the only ones worth mentioning are vomiting (9% 15/165), skin diseases (5%, 8/165), rhinitis (4%, 6/165) pharyngitis (3%, 5/165) and otitis (25, 4/165). All the others were single cases.

In the case of coughing, of the 90 children who exhibited this symptom, 26% (23/90) had this symptom alone (Tab. 5.86). In the majority of cases, on the other hand, coughing was accompanied by fever (24%, 22/90), diarrhoea (18%, 16/90) or both 27%, 24/90). The period prevalence of coughing was strictly related to fever, vomiting and diarrhoea (Tab. 5.87).

As seen previously, 32% of children suffered diarrhoea. Of these, 11% had this symptom alone (6/53) (Tab. 5.88). But of the children who had diarrhoea, 49% also had coughing and fever (together with other symptoms), while those who had diarrhoea and coughing (but not fever) total 26% (14/53) and those who had diarrhoea and fever (but without coughing) total 13% (7/53). An initial analysis showed that the period prevalence of diarrhoea was linked to the period prevalence of coughing and vomiting (Tab. 5.89).

For a general over-view of all the combinations of diseases recorded and the relative percentages of children taken for medical examination, see *Table 5.90*.

Amongst the chronic conditions recorded, there were the following: one case of anaemia, two cases of heart murmur and a child born with a malformation (vaginal fistula), in one camp, a case of cleft lip in another camp and a child born with only one kidney in another camp.

During fieldwork carried out in one of the cities covered in the study, a baby girl born a few months previously was admitted to hospital due to serious malformations and later died. There had been no question specifically aimed at exploring this theme, but the parents of the children reported the conditions recorded spontaneously during the interviews.

Children taken for medical examination and symptoms exhibited

Children taken for medical examination in case of diarrhoea

Some 74% of all the children who had suffered diarrhoea in the 15 days prior to the interview had been taken to see a doctor (39/53). Use of health services was highest in Bolzano and Florence with 24 out of 29, while Brescia had the lowest use with five out of 10 children taken for a visit (Tab. 5.91).

Altogether, the number of children with diarrhoea who were taken to see a doctor stood at 39, and it became difficult to analyse the tendency across the cities as to where the children were taken. Nonetheless, in the next paragraphs, having analysed where the children were taken according to the various symptoms, it will be possible to acquire a clearer picture of the situation.

Analysing the proportion of children with diarrhoea who had been seen by a doctor, one can see a downward trend according to age (Chi square for linear trend, $p=0.000$): this means that as a child grew, the tendency to take him to a doctor diminished (Fig. 5.16, Tab. 5.92).

Risk analysis shows only one significant association: a child living in an overcrowded house

(with more than 2.5 people per room) was more likely to be taken for a visit compared with a child living in a less overcrowded house (in houses with less than one room every 2.5 people 17/18 children were taken for a visit in case of diarrhoea (94%), while in houses with more than one room every 2.5 people 22/35 children were taken for a visit in case of diarrhoea (63%); OR 10.05; 95%CI 1.15 – 226.03*. Exact 95%CI 1.23 – 451.51; Fisher exact 2-tailed test $p=0.020$). Unfortunately, the contingency table has only one datum in one of the cells and cannot be stratified in search for confounders and effect modifiers.

The paediatric consultancy only functioned in Florence and Venice: for this reason, in the tables showing take-up of health services, frequencies and percentages have been omitted for the cities of Bergamo, Brescia and Bolzano. In Florence, it was located near the camp and dedicated two mornings per week to seeing *Rom* children. In Venice, the consultancy was also near the camp but it was dedicated principally to preventative treatment. For information on health services available in each city, refer to the paragraph: “Interviews with Health Services”.

Despite the low frequencies, one notices consistent use of hospital services, whether paediatric or emergency services (Tab. 5.93). Some 28 out of 39 children were taken to these service points (72%). The paediatric consultancy was used extensively in Florence. In Bolzano, only on one occasion was a child taken to see the family paediatrician. It may be recalled that there were no Paediatric consultancies in Bergamo and Bolzano, while in Brescia it was located far from the settlement.

Children taken for medical treatment in case of coughing

In the case of coughing, the children were taken to see a doctor to a slightly lesser extent (71%, 64/90) (Tab. 5.94) than in the case of diarrhoea. Coughing was more common (55%, 90/165) than diarrhoea.

As age increases, a downward linear trend can be noted in the proportion of children with coughing who were taken for medical examination (Chi square for linear trend, $p=0.000$) (Fig. 5.17, Tab. 5.95). While in the first three years from birth the proportion remains high, as age increases, the proportion diminishes considerably.

Risk analysis revealed only one association: a child living in a house where no more than two people smoked was more likely to be taken for a visit in case of cough, compared with a child living in a house where more than two people smoked (in houses with two or less people smoking 58/77 children were taken for a visit in case of cough (75%), while in houses with more than two people smoking 6/13 children were taken for a visit in case of cough (46); OR 3.56; 95%CI 0.91 – 14.15. Exact 95%CI 0.89 – 14.37; Fisher exact 2-tailed test $p=0.047$). We did not find any significant effect modifier.

Although the numbers are rather low for carrying out a detailed analysis city by city, one notices (Tab. 5.96) that in the case of coughing, there was less recourse to emergency services and hospital services in general, and more use of the paediatric consultancy or the family paediatrician, wherever these services were present.

As in the case of diarrhoea, much use was made of the paediatric consultancy in Florence.

However, it should be noted how a reduced recourse to hospital services (paediatrician and emergency services) was at the expense of recourse to the family doctor and an increased use of the paediatric consultancy in the case of Florence.

Children with fever taken for medical examination

The proportion of children with fever who were taken for medical examination was higher than that of children with diarrhoea and coughing (75%, 41/55) (Tab. 5.97). This figure varied greatly from one city to the next, with a high of 94% in Florence (17/18) to a minimum of 50% in Brescia (7/14) and Bolzano (3/6).

In the case of fever, too, there was a downward linear trend, as age increased, in the tendency to take the child for medical examination (Chi square for linear trend, $p = 0.002$) (Fig. 5.18, Tab. 5.98). As in the case of coughing, the high percentage in the first three years of life fell dramatically in the following three years.

We found that a child living in a camp less than 15 minutes walking time from the closest public transport service was more likely to be taken for a visit in case of fever, compared with a child living in a camp that was 15 or more minutes away (in camps less than 15 minutes walking time from closest transport service 31/35 children were taken for a visit in the case of fever (89%), while in camps more than 15 minutes walking time from closest transport service 10/20 children were taken for a visit in the case of fever (50%); OR 7.75; 95%CI 1.67 – 38.96*. Exact 95%CI 1.69 – 39.97; Fisher exact 2-tailed test $p=0.003$). However, this association was not valid for children living in houses in good conditions, but only for those living in houses in regular or bad conditions (Test for interaction: $p=0.021$). Children with

fever, living in houses in good conditions, were taken for a visit in 83% of the cases (10/12). While for children living in house in regular or bad conditions, a child living in a camp that was less than 15 minutes away from the closer public transport service was much more likely to be taken for a visit in case of fever, compared with a child living in a further away camp (among children living in houses in regular or bad conditions, in camps less than 15 minutes walking time from closest transport service 28/31 children were taken for a visit in the case of fever (90%), while in camps more than 15 minutes away from the closest transport service 3/12 children were taken for a visit in the case of fever (25%); OR 28.00; 95%CI 3.73 – 276.08*. Exact 95%CI 3.78 – 236.34; Fisher exact 2-tailed test $p=0.000$).

The behaviour regarding recourse to health services in the case of fever was very similar to that for diarrhoea (Tab. 5.99).

In Bergamo and Brescia, all the children examined were taken to a hospital. In Florence, more than half of the children were taken to the paediatric consultancy (10/17). In Venice, five out of 10 children were taken to Casualty and four to hospital.

Children taken for medical examination in case of general sickness

Considering all the symptoms together, Brescia was still the city where least use was made of health services (53% 9/17). Most use was made in Bergamo (79%, 11/14), followed by Florence (76%, 38/50) (Tab. 5.100). In this case, however, there was no significant association between proportion of children taken for a visit and any variable.

The curve shows the decreasing linear trend towards taking children for examination as age

increases ($p = 0.000$), ranging from 20 out of 23 children in their first year to three out of 10 children in their sixth year (Fig. 5.19, Tab. 5.101).

Why children fall ill: the opinion of the interviewees

With regard to the most important causes in the camp of the children's illnesses according to the point of view of the interviewees, answers were analysed by category and listed in order of importance. The exact question was: "Here at the camp, what do you think are the main causes of illness for children?" Defining the categories, the author considered the respect of point of view of the respondents and the meaning attributed to the causes of illness as a priority.

The first category brought together perceived causes that were connected with the filthiness in the camp: the presence of refuse, dirtiness and bathroom sewage outlets and with the fact that the children had nowhere clean to play.

The second category of perceived causes incorporated those connected with the cold, with humidity, the lack of hot water and the fact that the bathrooms were situated outside the homes.

The third category grouped together perceived causes linked to the unstable housing conditions, to the fact that there was no air circulation in the shacks or that there were draughts, that there were leaks or mouldiness, that they were poor, old and unstable.

The fourth category of perceived causes was directly connected with the issue of rats, and the

fact that the presence of numerous rats was seen as a cause of illness in the children.

The fifth category included perceived causes linked to the poor quality of the air, to the unpleasant smell and poor air circulation in the shacks that were heated using gas or wood.

The sixth category concerned problems of overcrowding in the camps and living quarters.

The seventh category concerned the problem of stagnant water, and the fact that in the camp the ground was always waterlogged.

These categories were not determined in advance. They were created on the basis of the answers given by the interviewees.

Of the 137 who gave replies, 16% (22/137) said that nothing in particular inside the camp caused the children's illnesses (Tab. 5.102). Some 7% (10/137) said they did not know how to answer the question. In Bolzano, the interviewees who thought there was nothing in the camp that caused children's illnesses totalled 13 out of 32 and six out of 32 simply did not know how to answer the question.

The total frequencies and the percentages refer to the total number of replies given, up to four per person. Of the 137 who gave replies, 105 cited causes, in other words all of them except those who answered "nothing" or "don't know". Each interviewee therefore gave on average 2.2 answers (227/105). In Florence, the average number of replies of those who cited causes was 2.2 (107/49), 2.3 in Bergamo (34/15), 2.1 in Brescia (15/7), 2.3 in Venice (48/21) and 1.8 in Bolzano (23/13).

Most answers given by the interviewees cited filthiness and the cold as causes of illness in the children (Tab. 5.103). In Bolzano, the cold was an issue connected principally with the fact that the bathrooms were situated outside. No one in Brescia, where accommodation was in walled structures, referred to causes connected to the cold.

The problem of the presence of rats had been mainly reported in Florence, but was present also in Bergamo and Venice. Rats were not mentioned as a problem either in Brescia or in Bolzano. In Brescia, causes linked with water leaks, damp and mould in the rooms inside the farmhouse were mentioned, all structural problems that single families had difficulty in tackling by themselves. Poor air inside or outside the homes was attributed to a dirty and unhealthy environment. In Florence, the stench of rats was cited, but some families who lived near the bathrooms complained about the smell that came from the drains. In Bergamo the unpleasant smell was associated with the lack of bathrooms and overcrowding.

The problem of stagnant water was also reported in Brescia where, when it rained, a large puddle was created exactly in the middle of the internal courtyard, the only space where the children could play safely and undisturbed.

RESULTS OF MEETINGS WITH FOCUS GROUPS

The first question the mothers were asked during the Focus Group meetings was how they knew if their child was ill.

In Florence, the mothers replied that for them, a child was ill if he did not eat, if he/she was

weak, had a fever or a cough or when he/she isolated him/herself and kept to him/herself. In order to test for illness or fever, they placed a hand over the child's forehead. The mothers in Bergamo said a child was ill if he/she had fever or vomiting. They checked for fever by using a thermometer. In Brescia, the mothers said that if a baby cried or did not want to be cuddled except by the mother, or wanted to be breast-fed and slept a lot, then the child was unwell. They also said they could recognise illness in a child's face. In Venice, too, the mothers said that if a child was ill it could be seen in his/her facial features, by the fact that he/she cried and did not eat properly. In Bolzano, the mothers cited coughing, fever, tiredness and crying as signs of illness.

Therefore, apart from fever, common factors amongst the replies were tiredness, a certain irritability or pain that was revealed through crying, but also facial features and bodily gestures.

The mothers were subsequently asked how they determined if a child was well. They said a child was well if he/she did not have fever (Florence), but above all if he/she ran (Florence), walked (Bergamo), played (Bergamo, Brescia, Venice, and Bolzano) and went out to play (Brescia), talked (Bergamo), was hungry and wanted to eat (Florence, Brescia, Venice and Bolzano).

The opinions of the mothers, as to what should be done so as to keep the child healthy, varied considerably.

In Florence, it was thought that another living situation needed to be found unlike that of the camps, with rats, filth and nasty smells that came from the drains. They tried to take care of

their children but it was easy, given the conditions in the camps, for the children to fall ill.

In Bolzano, the mothers said they had to keep a very close eye on their children so that they did not catch a cold or some kind of infection. But they said this was difficult to achieve: a house is a house, but in the camps it was more difficult because the children could not be kept cooped up in a shack. The children also more easily fell ill at the camp because there was a lot of contact between the children.

In Bergamo, it was thought that the children needed to be looked after well, dressed warmly, kept clean and not left to play in dirty places.

In Brescia the mothers said that the children had to be kept well covered, especially in winter, not sent outside and not made to have a shower too often, particularly if the bathroom was not heated. It was important to keep the shack warm and keep the children entertained and looked after. The children had not, however, always to be kept indoors but sometimes taken out so as to get some fresh air.

In Venice, the mothers claimed that nothing much could be done because they did not know when a child was incubating an illness. They only found out when the child developed a fever or some other symptom.

The following questions, grouped together with their relative replies, pointed out the most common illnesses suffered by the children in the camps, the time of year in which they appeared most frequently and the perceived causes of these illnesses.

In Florence, the mothers' opinion was that the most common illnesses were bronchitis, coughing, skin complaints (scabies and fungal infections) and in certain cases, hepatitis. There were also other diseases perceived as being triggered by dirty conditions, such as asthma. Children suffered from coughing in summer as well as in winter. There was little difference between summer and winter as far as concerned the children's illnesses. As has been stated, a major problem was bronchitis, which affected the children both in summer and in winter. Diarrhoea was a lesser problem all year round. The main perceived causes of illness were the presence of rats and the poor quality of the air. When it was hot, it was difficult to stay inside the shacks and so one stood outside where, however, in summer there was a stench that came from the drains and from dead rats. The most difficult problem was where to give the children a warm bath: both in summer and in winter, bathing was done with cold water or not at all, and both situations were unsatisfactory. Some families did not even have access to a bathroom.

In Bergamo, the most common illnesses according to the mothers were fever, vomiting, stomach ache and coughing. They maintained that in the warm months, the children more often suffered from vomiting and diarrhoea, while in winter there was more influenza, fever and bronchitis, the latter they believed being triggered by the cold. In the summer, on the other hand, when it was too hot, children lost their appetite and consequently fell ill.

The major illnesses cited by the mothers in Brescia were bronchitis and fever, which appeared in winter. In the summer, on the other hand, no particular disease typified the season. Bronchitis arose because it was warm inside the home and cold outside. There was also a period in which the children had hepatitis A and doctors advised everyone to be vaccinated.

In Venice, mothers reported a number of “toilet diseases” (diarrhoea). Diarrhoea was especially common during hot spells whereas colds and coughing accompanied cold weather. Living in shacks meant that it was difficult to keep the cold out. The children could not be sent to school dirty or with dirty clothes, but it was difficult to keep them clean: washing clothing by hand when it was cold caused pain to the back, the hands and the legs. And if a mother fell ill, often the child fell ill too.

The most common diseases in Bolzano, according to the mothers, were bronchitis, colds and fever. When children had fever and a cold, they often also had diarrhoea. Bronchitis and flu appeared more commonly in winter, while in summer diseases varied greatly from child to child.

Amongst all the measures that could be taken to improve the health of the children, the mothers were asked first of all what they themselves could do. In Bergamo the mothers said they could keep a closer eye on the children, look after them well and keep them away from dirtiness. It was important that the people who lived in the camps kept them clean, an opinion also shared by the mothers in Brescia. In Venice, the mothers claimed they could not do anything; they tried to keep things clean as everyone else does, but having many children made the task difficult. In Florence and Bolzano, no answers were given along these lines.

Many answers were forthcoming in terms of what institutions could do to improve conditions at the camps.

In Florence, a request was being made, after 12 years of life in the camp, for alternative housing that would allow the children to grow up like Italian children. This request to leave

the camp was made with considerable force. The residents wanted a house with a garden where children could play: in the camp they played in the midst of rats and filth. When they had a house, even if they had to pay rent, they would have a shower, hot water and heating. They asked for help in finding work. Many women lived by begging, whereas if they had work they would be better able to look after their children. “If you don’t have work and you don’t beg, how can you get by? If you steal or sell drugs, you end up in prison. But people have to do something to survive. If you have a house, it is easier to find a job. If they know that you live at the *Poderaccio* camp, they think you live ‘like a gypsy’, spending one day here and one day there. When you look for work, and say you come from the *Poderaccio*, the reaction is ‘Good Heavens!’”

The women believed that if they were given a house, even having to pay, they would live in a better way. They wanted to pay and they wanted their children to grow up in better conditions and not at the camp living in the middle of filth.

In Bergamo, too, the mothers insisted on how important it was that the institutions help them by providing them with a house. They said nobody should be left to live in the conditions at the time obtaining in the camp. Even when the camp was cleaned every day, the same situation arose again and the children fell ill.

In Venice, the opinion was that while the camp existed, it could not be kept in the present conditions: rain leaks into the shacks and water in the presence of electricity was dangerous, and children were always nearby. The local council claimed that the camp was to be closed down within six months and alternative solutions found for the families, but some women believed they would be unable to find a house since they did not have a residence permit.

Meanwhile, said the mothers, children carried out their toilet functions outside the bathrooms for fear of rats and for the dirty conditions, and this produced a situation in which it was easy to get sick. In the meantime it would have been useful to have containers: the mice could not get in, there was a bathroom and washing machine and rain did not leak in (they were referring to the containers in the *Olmately* camp in Florence). In this way, the children would not have to perform their toilet functions outside.

Some women from Venice were afraid of not being given a house or of not being able to manage it. One woman's husband was in prison while another's husband had just been released but he did not have a residence permit. One woman claimed that she preferred to have a container with a bathroom rather than a house. It was difficult to grasp whether this was because she did not believe in the possibility of being given a house or because she did not see it as a manageable solution. Her request was certainly dictated by the need to find a solution right away. Another woman claimed she needed a house rather than a container. The first one replied she wanted a container first, and that she would like a house when she finally could obtain her documents.

The desire in Bolzano was much the same, that of moving to normal housing, such as a flat. In fact heating was seen as a problem: for safety reasons, at night when everyone was asleep, gas was used by a lot of families for heating rather than the wood used during the day. But gas heating created dry throat conditions in the children. Moreover, it was easier to maintain a stable temperature inside a flat, whereas in the shacks it was always either too hot or too cold. Finally, they had to go outside in order to wash the children because the bathrooms were located outdoors and so in winter the children caught cold and fall ill. Although it were the

mother who had to go out to wash the dishes or the baby's bottle, if she caught a cold she would pass it on to her children.

In Brescia, the *Romá* were already living in walled housing and therefore the requests they made were of a different order. They asked for a heating system to be installed in the homes so that heating via gas, wood-burning or electric heaters could be avoided. The mothers claimed that electric heaters in particular gave the children dry throats. They said the institutions should also repair the barnyard which flooded every time it rained. The roof was also in need of repair: the rain always leaked in until the families themselves undertook repairs. When the first families arrived at the farmhouse in 1993, the rooms were very damp and mouldy. Water leaked in through the roof and the ceilings on the first floor. There were still problems of mouldiness, leaks and damp, though less so after the families themselves had undertaken repairs at their own expense. In fact in many cases, the families had of their own initiative carried out repairs to render the farmhouse more liveable. In some cases, they had also built their own bathrooms so as to avoid sharing the communal bathrooms provided by the local council with other families, as these facilities were now in a pitiful state.

6. DISCUSSION OF RESULTS

In this chapter, the author will start with a balance between the strengths and the limitations of the study. Subsequently, the attention will be focussed on the elements that contributed, according to the author, to the achievement of the main objective of this thesis and, through the discussion of the quantitative and qualitative results on the living conditions and the health status of children, to each of its specific objectives (p.37).

CHARACTERISTICS AND LIMITS OF THE STUDY

The description of the five camps covered in this study shows how the various situations were heterogeneous in nature (mainly as regards the living quarters, overcrowding, and the differing availability of services from one camp to the next). The differences discerned, at the root of the selection process itself, offered the opportunity to analyse different contexts.

The decision, on the other hand, to choose a population that was the most homogeneous possible, and thus almost exclusively composed of *Romá* from Macedonia and Kosovo, allowed for an analysis of the differences between the various settlements on the basis of a uniform population, where individual differences (for example, their level of education, perception of the causes of diseases, or cigarette smoking), could be more easily identified and taken into account.

The decision to limit the study to a population living in camps, however, did not allow for a comparison with the population living outside. Despite the heterogeneity of the sample as regards environmental conditions, all the camps had a number of environmental factors

associated with more than one of the studied symptoms. Furthermore, as pointed out by the “theory of the gap” – referred to in the literature review chapter – the camps, as marginal and unstable living spaces in a wealthy society, can *per se* be considered among the causes of ill health. For these reasons, the author found it difficult to identify as many associations between environmental factors and symptoms as expected.

Fieldwork was carried out between mid-November 2001 and early March 2002, and this may have partially influenced the results, in that the series of symptoms may have been conditioned, to a certain extent, by the particularly cold winter of 2001-2002. In particular, this is the case of those symptoms, like diarrhoea and cough, whose occurrence was measured in the 15 days prior to the interview.

Problems were encountered due to the reduced amount of data in cases where further stratification would have been required or when statistical significance was sought from a certain set of data. The author tried to analyse in detail and in depth each situation, besides supporting the quantitative analysis with a detailed description of a situation that took into account many elements that set it in context, ranging from behaviour to perceptions, from the description of the camps to the health services, and from the history of the camps to the availability of basic services.

For the reasons mentioned above, the analysis appears to be more robust for pathologies studied on a longer period of time, like in the case of breathing difficulties in the last year and asthma prevalence. The fact that diarrhoea and cough were very common, and probably associated with factors linked to seasonal elements (e.g. influenza), complicated the analysis hiding to some extent the effect of environmental factors.

As described in the methods chapter, the small number of children involved in the study recommended the use of exact estimates for the calculation of the significance of the associations and the confidence intervals, especially in those cases in which approximate methods were inaccurate due to the small number of frequencies in the cells of the contingency tables. Stratified analysis has been thoroughly carried out, but modelling of data has been avoided, as the data did not deliver enough evidence to guarantee full control over simultaneous analysis.

The lack of resources has indeed limited the possibility to increase the sample size and, thus, the power of the study. As analysed in the literature review chapter, in many cases research on marginal groups faces this limitation, aggravated, as in our case, by the dispersion of small communities on a vast territory. Often marginal groups do not have the strength for their voice to get across their priorities and be heard by researchers. This is one of the reasons why resources for research and planning often do not reach these groups. However, in the case of this research, as specified in the methods chapter, undertaking the study without funding helped to establish trust relationships between the author and the camps' residents, as there was no ambiguity about what was drawing the researcher's attention.

As stated in the methods chapter, because of the very small number of participants, the meetings held with mothers after the household survey were not proper focus group meetings. However, as reported below, the information gathered in these meetings provided some valuable insights for the study. In a qualitative way, the participants expressed their main concerns and suggested links between environmental risk factors and the health of their children. This information formalizes the concerns gathered in the preliminary phase of the

research, and makes every quantitative result confirming these hypotheses more relevant.

GENERATING EVIDENCE FROM COMMUNITIES' OWN PRIORITIES

The general objective of this thesis was to demonstrate that quantitative research among marginalized urban populations widely dispersed in small groups, such as the foreign *Rom* living in camps in Italy, was capable of providing reliable evidence that community themselves could use to advocate for change – provided the design was based on the communities' own priorities.

The role of contextualization

In 1999 the author started interviewing *Rom* and people from the institutions and the associations and visiting *Rom* settlements in several Italian regions. This work, made of direct observation and preliminary discussions, together with the mapping out of all settlements of foreign *Rom* in Italy, conducted in 2001 (1, 2), offered relevant elements to start developing the research, in terms of approach and definition of objectives and hypothesis.

The literature review on the health of “Gypsies” revealed a series of issues that seemed to be in conflict with the aim of a better health for the Gypsies themselves. The distance between the researchers and the population studied often appeared too wide to stimulate a genuine interest in the health of this studied population. Even in circumstances in which it was manifest that they could play a role, living conditions were often not taken into account as risk factors in studies focusing on the causes of ill health of *Rom* groups. Many studies on Gypsies' health did not give enough elements to put the covered populations into context

culturally, ethnically and socially. Many studies could be interpreted in the light of a general diversity and weakness of Gypsies, instead of looking for factors linked to the marginal status of specific groups if compared with the society at large. In this attitude, the author perceived the risk of an implicit “new racist” tendency to justify a general weakness of groups of people, suggesting that this could be caused by inborn characters or self marginalizing behaviours, while excluding from the analysis social and environmental factors. Understanding what the literature on the health of Gypsies could offer in terms of approaches and results was crucial to define what was needed in order to try and contribute to the improvement of the existing situation.

The month spent living at the *Poderaccio*, in Florence, before starting fieldwork, gave a further contribution to the understanding of the camp dynamics, and helped shaping up the hypothesis and designing the instruments. This work helped simplifying the questionnaire, focussing on a limited number of specific factors to be studied. During fieldwork, a structured type of direct observation was used to gather information on environmental factors, helping to put more into context the people living in the camps.

From community priorities to epidemiological evidence

All the steps described above have been useful to better understand the priorities expressed by the *Romá* living in the camps and base the research on these priorities. The link between the worries of the *Romá* and the preliminary work done to understand the broader context contributing to the existence of “nomads’ camps” facilitated the collection, at community level, of specific quantitative and qualitative information focussing on the fulfilment of the objectives.

Considering the literature review on the CBPR approach and the participatory researches developed using CIET methods, the author believes that more direct participation of the *Romá* would have been desirable. However, the author is also convinced that this would have required time and funds that were not available. The choice to start producing good quality evidence to stimulate the attention of the communities, the institutions and the academia, with an investigator-driven community based research approach, gave satisfactory results.

This study shows that community based research focussing on marginalized urban populations spread in small groups is possible, even with very little resources. Furthermore, although in some cases they were less statistically significant than expected, the results presented in this thesis are relevant as they are strengthened by the way the study was designed, using information gathered in the preliminary phase of the design and focussing on the priorities and main concerns of the *Romá* residing in the camps. As mentioned in the literature review and methodology chapters, the use of a mixed methods' approach helped expand the information base, and allowed to better understand the contexts shared by these communities. The significance of the results is also strengthened by the confirmation of a general sensitivity of the data, attested in several occasions with the stratification by age and sex, and enhanced through the comparison with results from the literature.

As explored in the literature review, the relations between living conditions and the health status of children can be studied at different levels of complexity. However, the quantitative evidence generated by this study shows how these relations can be identified even with limited instruments, provided the research process takes into account the experience of the people living in such conditions, and is supported by the literature on the subject.

The author believes this study can provide useful information that can start stimulating a planning process and a different way of doing research together with *Rom* communities. Started from the priorities of the *Rom*, this study will hopefully serve as a first step in giving a scientific base to the concerns of the people living in camps in Italy, bringing their voice to the table of planners. The next chapter will specifically deal with issues related to the socialization of the results of this thesis.

DEMOGRAPHICS AND MORTALITY

Before discussing the results in terms of each specific objective of the thesis, it is necessary to discuss some of the demographic results.

In the age pyramids (Fig. 5.9 and Fig. 5.11), the reduction of frequencies from birth to the sixth year of life, and from the first to the second five years' category, could be explained by a high mortality rate accompanied by a high rate of fertility. But apart from taking into account that this reduction might be due to chance, it should be borne in mind that we were considering a limited group of foreigners with a certain degree of mobility and of "recent" migration.

A study of the rates and causes of infant mortality as well as of the general mortality of the *Rom* in the camps could make an interesting contribution to any effort to improve the quality of life of this population. Clearly, a study of this kind would require a very much larger number of participants and appropriate instruments, both from a scientific and from a socio-anthropological point of view. Tackling an issue such as death requires considerable and

sensitive preparation. As the flux of immigration is ongoing and recent, it would not be easy to use indirect estimating techniques.

This means it is very difficult to draw any conclusion as to the life expectancy of the population in our study. In the literature review on the “health of Gypsies” the author found articles drawing conclusions on the low life expectancy of the Gypsies. However, in some cases these articles are not based on closed populations, while in other cases references are made to studies carried out on different groups living in dissimilar contexts.

The fact that in our sample there were very few elderly people and that the average age was less than 20 years, may be explained by the fact that the elderly may have remained in their home country. Life in the camps in Italy is hard and it is reasonable to suppose that not everyone has the energy to try their luck by emigrating in another country. In some cases where the elderly have indeed emigrated, they might be living with other relatives in better living conditions. It is evident, in looking at the pyramid, that it is extremely squat. The fact that the middle age groups were quite numerous tends to support the hypothesis of “selective” immigration, or at least that most of the families living in the camps were young families.

The significantly lower proportion of families with children up to five years of age in Bolzano, compared with the other camps, could be related to the higher stability and standards of living in the Bolzano camp compared with the others. In terms of stability, looking at the number of years spent by families in the camps, Bolzano had the lowest standard deviation (SD 0.9; for Florence 4.6; Bergamo 2.2; Brescia 3.0; Venice 3.3) and was the only camp in which the mean number of years (six years) was equal to the mode and median. In terms of living conditions, Bolzano was the only camp where there were no houses in bad conditions,

all of the families had access to a private bathroom and to hot water. Bolzano shared with other camps other positive characteristics, but it was the only camp that combined most of them together: less than 140 people, more than 25 square meters per person, no polluting elements (like factories or gravel-pits) and no stagnant water. The same type of reasoning could be applied in considering the average size of the families interviewed city by city as recorded above.

A similar explanation could be given to the fact that Bolzano and Brescia had the highest number of children born in Italy (Tab. 5.45), probably due to more stability in better-consolidated situations and more acceptable conditions of life. Looking back at *Table 5.32* on the number of years spent at the present camp by the interviewee, one can see that Bolzano and Brescia had the highest modal value in percentage terms (Bolzano with six years, 84%, Brescia with nine years, 69%) and that it was the highest value, in that the other interviewees claimed they had been at the camp for fewer years. In the other cities, the frequencies were more evenly distributed across the years, demonstrating a lower degree of stability of the families in the camps.

FREQUENCY OF HEALTH PROBLEMS SUFFERED BY CHILDREN

The first specific objective of this thesis was to measure the frequency of common health problems suffered by children from birth to the age of five living in the camps.

The author published preliminary results on the health status of children in 2004, on *Roma Rights* (253).

Low birthweight

The percentage of children from the five camps born below weight (birthweight below 2.5 kg) stood at 10%.

In Italy, according to data recorded by UNICEF and WHO, the percentage of children born underweight (below 2.500 kg) during the period 1995-99 was 5%. As a means of comparison, in the same period, countries with 10% of low birthweight included Egypt, Iran, Lebanon and Zimbabwe (254).

In the literature review on the “health of Gypsies” we saw that some authors state that low birthweights are a frequent finding in Gypsy groups. However, we also reported that no evidence has been published of an independent association between racial/ethnic origin and low birthweight. If groups of Gypsies tend to have higher rates of babies born underweight compared to the rest of the population, environmental or behavioural factors should be identified to justify this difference.

Diarrhoea

For its impact on the wellbeing of the child, it is important to study the causes of diarrhoea, although it can be complicated due to the multiplicity of factors involved. “Diarrhoea is only the common symptom of a large number of intestinal diseases. The source of infection might be a virus, a bacteria, or a parasite, or, often, a combination of these. They all share the ability

to alter intestinal function, increasing fluid loss from the body and decreasing the retention of nutrients” (255, p.10).

As mentioned before, and especially in the case of diarrhoea, the analysis was limited by the lack of comparison with people not living in camps. The high level of period prevalence in all of the camps did not allow for an effective identification of the associations between environmental factors and diarrhoea.

In this study on *Rom* settlements, the percentage of children who had had diarrhoea in the last 15 days was 32%.

No comparable data were found on the paediatric population in Italy, but some examples can be provided, although not on the specific topic of “nomads’ camps”. All of these studies were carried out on children under the age of five and considering the period prevalence of diarrhoea during the past two weeks of the survey:

- A study carried out in 1996 in Nepal, on 13,338 children, showed a period prevalence of 18% (256).
- A study of more than 15,000 children carried out in Bangladesh in 1999 produced a result of 9% (1,424/15,321) (257).
- In 2001, a study on the nutritional status of children in Northern Iraq showed a period prevalence of 25% (from a sample of 2,745 children) (258).
- In South Africa, the 1998 Demographic and Health Survey reported an overall national period prevalence of diarrhoea in the two weeks previous to the interview in under five children of 29% (259).
- An article published in 1991 (260), estimating the morbidity for diarrhoeal diseases in

United States, stated that 16.5 million children under five had between 21 and 37 million episodes of diarrhoea annually. Of these, 2.1 to 3.7 million episodes led to a physician visit. To estimate the period prevalence of diarrhoea in a period of 15 days, from these data, the number of episodes per year and the duration of each episode need to be assumed. Keeping the numbers high, it can be assumed that each of the 16.5 million children had two episodes of diarrhoea annually (33 million cases in total) and that each episode lasted four days. In this case the period prevalence of diarrhoea in an interval of 15 days is 10% (number of episodes per year = $E = 2$; days an episode lasts = $D = 4$; days in a year = 365; interval = $I = 15$; $E [I + (D - 1)] / [365 + (D - 1)] = 2 (15 + 3) / (365 + 3) = 9.78$).

For a comparison with situations of marginality in urban contexts, it is also important to report the results of a study conducted on homeless and housed poor children in Los Angeles (U.S.A.) in 1987/1988 (126). In the past month, 34% of homeless children (67/194) and 29% of housed poor children (56/193) had diarrhoea or vomiting. Unfortunately the article does not specify the age of the children and the reference period is one month instead of 15 days.

The occurrence of diarrhoea appears to be higher in the three youngest years, reaching its peak in the second year, probably due as much to a change in the diet of the child as to being less often held in his/her mother's arms and walking around independently. The occurrence of diarrhoea diminishes in the following years, probably due to the strengthening of the body's immune defence system and the child's increased digestive capacity. In general, during the first six months of life, exclusive breast-feeding can help keep the incidence of diarrhoea low. After this period, maternal milk is part-substituted by other foods and diarrhoea can become commonplace in environments where adequate standards of hygiene cannot be guaranteed.

The age trend observed in this study was very similar to the ones reported in the studies cited above.

In general, the Italian word “*diarrea*” was used. Whenever necessary, the term used for a better understanding of “diarrhoea” was “*proliv*”, a word of Serb-Croat origin suggested by the mothers themselves. The term “*proliv*” has the same meaning as “diarrhoea”.

Furthermore, it would be difficult to imagine that the residents of the camps were more concerned than an Italian mother as regards diarrhoea. Since diarrhoea was very common in the camps it would be difficult to claim that they exaggerated the importance accorded to this symptom, and in fact, the contrary is more likely the case. Indeed, even when the children in Bergamo had shigella, the parents thought they were suffering from “normal” diarrhoea.

A simultaneous analysis of symptoms, taking into account diarrhoea only when accompanied by vomiting, gave rise to a percentage of 5% (9/165). Even allowing for a “problematic” definition of diarrhoea that might have given rise to a higher than expected percentage, counting diarrhoea and vomiting together generates a far more restrictive factor. Bearing these considerations in mind, a percentage of 5% of children with diarrhoea and vomiting should, nonetheless, be regarded as high.

In all the cities, the proportion of children with diarrhoea was high, ranging from 3 out of 21 in Bergamo to 10 out of 20 in Brescia, and 32% in the other cities.

Coughing

It is important to measure the period prevalence of coughing, as a symptom of bronchospasm and acute respiratory infections that are, as with diarrhoea, caused by a wide variety of disease agents. These infections range widely in terms of severity and their principal transmission factors are high population density, crowded living conditions, and seasonal changes that favour the spread of disease (255).

Some 55% of children suffered from coughing in the 15 days prior to the interview (90/165). Of these 90 children, 64 were taken to see a doctor. It should be pointed out that flu was rife amongst the children in the camps, giving rise to symptoms like diarrhoea, coughing and vomiting.

As with diarrhoea, the author did not find data on the prevalence of cough or acute lower respiratory infections in the Italian paediatric population. In a study conducted on homeless and housed poor children in Los Angeles, cited before (126), the percentage of children with cough/cold in the last month was 70% for homeless (136/194) and 79% for housed poor children (152/193). It is an important term of comparison although unfortunately, as already mentioned, the age of the children involved in the Los Angeles study was not specified and the prevalence was calculated over a one month period and not 15 days.

Studies conducted in poorer countries report, as in the case of diarrhoea, lower period prevalences. A study carried out in Bangladesh in 1999, on children under the age of five, reported a period prevalence of acute lower respiratory infections of 9% (1,329/15,321) in the two weeks before the interview (257). In Northern Iraq, a study on children under the age of

five, conducted in 2001, showed a period prevalence of acute respiratory infections in the last two weeks of 18% (from a sample of 2,745 children) (258).

Breathing difficulties and asthma

The author published preliminary findings on breathing difficulties and asthma in 2004, on *Epidemiologia & Prevenzione* (261).

With a view to making a comparison with Italian data on the incidence and prevalence of asthma, when feasible, the results of the Italian project “*Studi Italiani sui Disturbi Respiratori nell’Infanzia e l’Ambiente*” (262) (SIDRIA – Italian Study of Respiratory Difficulties in Childhood and the Environment, carried out in collaboration with the International Study of Asthma and Allergies in Childhood – ISAAC (263)) will be used. The SIDRIA data was collected during the academic year 1994-5 on a population of 18.737 primary school children (aged 6-7). It should be noted that the age referred to is different, and therefore some caution should be exercised in comparing the data.

In this comparison we need to consider the possible impact of marginalization (“theory of the gap”) that adds on to the impact of difficult living conditions alone. However, we also need to account for the fact that *Rom* children covered by this study are “survivors” of particularly difficult living conditions and might be stronger than the average Italian child. Despite the fact that we compare data on a sample of Italian children and foreign children living in particular marginal conditions, and of a different age range, the author decided to present this comparison to describe some similarities in these two distributions.

The comparisons between the study on the five camps and SIDRIA's national data, analysed in this section are summarised in *Table 6.1*.

Some 23% of children covered by the study suffered from breathing difficulties or wheezing during their lifetime. Of all children, 17% suffered from this condition in the past 12 months with no difference depending on the sex of the child. Some 5% had at least four attacks of wheezing or had difficulties breathing in at least four occasions in the past year (8% for males and 2% for females).

For a comparison with Italian data regarding symptoms that were exhibited in the preceding 12 months, the SIDRIA study reported a period prevalence of dyspnoea with wheezing, for six and seven years old children, of 5.3%, affecting males (6.4%) more than females (4.0%). SIDRIA's period prevalence of wheezing attacks – at least four – was 1.4% affecting, also in this case, males (1.8%) more than females (1.0%).

The percentage of *Rom* children, living in the five camps, who suffered asthma at some point during their lifetime, was 9% (13% for males and 6% for females). Italian data reported the same percentage (9.0%, with 11.4% for males and 6.4% for females), but as the sample of the Italian study consisted of children of six and seven years old and the indicator we are using has cumulative life years as the denominator, the average lifetime of the Italian study is definitely higher than the average in our study of children up to the age of five.

This comparison may be taken as confirmation of the reliability of the data obtained in a study involving such small numbers and suggests that for the sample group of *Rom* children, with the number of years lived being equal, the incidence of asthma could well be higher than for

Italian children.

The reliability of the results is reinforced by comparison with data on sex distribution. The percentage of *Rom* children that have been diagnosed with asthma during their lifetime is 13% for males (10/78) and 6% for females (5/87), while for SIDRIA the figures are 11.4% for males and 6.4% for females.

In our study, active asthma incorporated all those who had had an asthma diagnosis in their lifetime and had had respiratory difficulties or wheezing in the past 12 months. In literature we found different definitions of “active asthma”. However, in general, these definitions are based on the presence of symptoms in the last 12 months and either a doctor-diagnosed asthma or the use of medicines for wheeze in the past year (264, 265).

The prevalence of active asthma in our study was 7% (10% for males and 5% for females).

Although it was not possible to obtain the figure for “active asthma” from the data in the SIDRIA article, comparing the data with that obtained for “dyspnoea with wheezing in the preceding 12 months”, a higher prevalence was recorded for the children in the camps: in the SIDRIA study, the period prevalence of dyspnoea with wheezing was 5.3% (6.4% for males and 4.0% for females), while in our study the prevalence of active asthma was 7% (with a 10% for males and 5% for females).

The percentages for *Rom* children were higher also in the case of a comparison between the percentage of children who suffered at least four attacks of dyspnoea with wheezing in the last 12 months reported by SIDRIA, and the period prevalence for the *Rom* children

calculated on the basis of at least four episodes of respiratory difficulties or wheezing in the last 12 months and an asthma diagnosis. For the *Rom* children the percentages were 4% (6/165) – 6% (5/78) for males and 1% (1/87) for females – while for the SIDRIA were 1.4% – 1.8% for males and 1.0 for females.

These figures revealed a greater period prevalence for the children in the settlements covered by the study, of asthma related symptoms which could, over time, impact on the prognosis of the asthma itself: in fact, it is claimed that 40% of children who manifest symptoms of asthma, such as respiratory wheezing, in the first three years of life, will also manifest them at the age of six and that this percentage increases significantly if the children have suffered from persistent asthma symptoms (266). Cohort studies have shown that the degree of persistency of asthma symptoms during childhood is linked to the extent to which the pulmonary function is reduced and to the quality of the asthma prognosis in the adult (267, 268).

Other symptoms and pathologies

Albeit the small number of children with dermatological diseases (8/165) was not sufficient to carry out risk analysis, it is important to underline that no cases were reported in Brescia and Bolzano, the only two camps with less than 150 residents and where no rats had been reported. The high recourse to medical treatment (seven out of eight children) was probably induced by the general discomfort caused by dermatological complaints and by the fact that, being visible, they could have been considered indicative of neglect or lack of cleanliness.

Regarding the chronic conditions recorded in the results section, we consider the issue to be

complex and to be looked at more in depth. The view of the author is that causes are to be sought mainly in environmental factors. This could be scientifically ascertained, but it appears that the *Romá* in our study did not practice forms of endogamy that could lead to high levels of consanguinity.

ENVIRONMENTAL FACTORS, HABITS AND BEHAVIOURS AFFECTING CHILDREN'S HEALTH

Albeit the second and third specific objectives required a description of “environmental factors in the camp that potentially affect the children’s health” and of “habits and behaviours that may have health-effects on children” (p.37), the author believes there is often an intimate link between the environment and the behaviours of people living in camp-like settings. This opinion, strengthened by the direct observation and the epidemiological analysis, is supported by the literature reviewed in “Marginal communities, environment, housing and health”.

Some examples of the link between behaviours and environment, with effects on the health status of children, can be briefly anticipated. Smoking habits, associated in our study with the low birthweight of children, are known in literature to be strongly associated with indicators of social disadvantage. The effects of the intense use of wood stoves on acute respiratory infections in children have been discussed in the literature review chapter. In poorly insulated homes, heating will be kept high during the winter, while families might not be able to afford a better heating system. As reported in the methods and results chapters, the house conditions, associated with respiratory difficulties and asthma, were determined by a combination of structural elements and family habits (care and cleanliness). For self-made shacks, even the structure itself reflects the capacity, possibility and will of the family members. However,

problems were also caused by space limitations due to overcrowding and limits imposed by the institutions on the materials that could be used and the interventions that could be made.

As stressed by Marmot (269), even when a behaviour can be considered the cause of a disease, we should “go further to examine the causes of these causes” (p.3), trying to understand the social determinant of that behaviour. This is particularly relevant if our final intention is to find ways to improving public health.

Below, before getting into the analysis of the relations between environmental and behavioural factors, and the health of children, the author focuses on the description of the main environmental and behavioural aspects requiring attention, and on the perception of the residents about the factors that influence the health of their children.

The camps’ environment

Starting from the broader environment, the description of the camps emphasized how almost all presented degrees of squalor. In the case of Florence, Brescia and Venice, the refuse dumps next to the settlements were cleared after the camps were set up. Even the camp of Bolzano was built on a refuse dump, cleared before its creation. The presence of rats was reported in Florence, Venice and Bergamo, indicating environmental degradation. The camps were often set up in neglected areas, adding weight over time to problems caused by poor planning, lack of basic services and overcrowding.

All the camps were equipped with electricity, although the wiring systems in the Florence and Bergamo camps were in an unstable condition.

The quality of the living quarters was particularly important in winter, for the possibility of retaining heat, reducing the effects of the cold outside. Often, however, draughts and lightweight materials meant that heating had to be kept high so as to maintain an acceptable temperature. According to the mothers, this made the air inside the shacks very dry and caused sore throats in the children. The limited amount of living space in the shacks forced the inhabitants to spend more time outdoors and therefore created the need for a warm place in which to recover from the cold. At night, unsafe heating systems had to be switched off, with the temperature inside the home dropping rapidly. In Brescia, structural problems of the *cascina* caused water to leak in, generating mould. Poor ventilation, poor insulation, inappropriate heating systems and moulds are known factors that can impact on the health of children, as mentioned in the literature review chapter.

In some cases, such as Florence, Bergamo and Venice, the problem of housing arose in summer too, when containers, caravans and lightweight structures made of plastic sheeting or with tin roofs became very hot during the day. According to the residents, during the summer, the presence of stagnant water, poor drainage and dead rats made the place unhealthy and the air outside smell particularly bad.

Access to proper toilets and showers was identified as a serious problem. Toilets outside the houses caused inconveniences for the washing of children, while self-made water connections inside the houses were often not supported by appropriate drainage systems. In Brescia, Florence and Bergamo the water often stagnated due to leaks, unsuitable drains, lack of places where people could wash their clothes, and the ruined floor of the camps.

Overcrowding

According to the Italian immigration Law (Legislative Decree 286/1998, modified by Law 189/2002), houses in which migrants live need to respect minimum standards in order for a foreigner to obtain a visa. Each Region sets these standards in terms of square meters per person. In Bolzano – part of the autonomous Region of Trentino Alto Adige – the standards are defined by the Provincial Authority. For a family of five, the minimum square meters per person range from 17.6 in Bolzano to 19.0 in Veneto. In the camp of Bergamo, the *Romá* lived in 10 square meters considering the whole camp area, and not just the shacks (Tab 5.2). In Florence, where the shacks covered about half of the total space of the camp (Fig. 5.2), each person lived in 19 square meters. According to the national census, carried out by ISTAT (Italian Institute of Statistics) in 2001, the national average number of square meters per resident in inhabited houses was 37. *Table 6.2* compares national and municipal data on house characteristics from the census and data from our study.

The national average number of rooms in houses inhabited by residents was 4.2. In the five municipalities involved in our study, Bergamo had the lower average – 3.1 rooms per house – and Florence had the higher with 4.3 rooms. In the camps the averages were much lower, ranging from 1.7 rooms per house in Bergamo, to 2.7 in Bolzano. In terms of rooms per residents, the Italian average of 1.6 is very high compared with the minimum of 0.3 in the camp of Bergamo and the maximum of 0.7 in the camp of Bolzano.

It is important to point out that all of the five camps had been set up and recognised by the local authorities. However, the overcrowding and substandard housing conditions often created problems to the *Romá* trying to obtain or renew regular working visas. In some cases,

the police and local authorities solved this issue informally, considering the camps as exceptions.

Overcrowding in the camps in Bergamo and Florence was not simply a problem of liveable space but also of safety. In limited spaces, in the presence of highly inflammable materials and poor wiring systems, any domestic accident, that would be fairly insignificant in a normal house, could turn into a serious issue involving several shacks and families.

Length of family residence in camps

There were two main reasons why it was important to determine the number of years the interviewees spent living in the camps. Often the camps were considered “provisional” and therefore little investment was made in terms of serious planning to either improve the living conditions in the settlements, or to find alternative housing solutions. Furthermore, spending many years in the unstable conditions of a camp could have a serious effect on residents’ motivation and change of attitude.

As already mentioned in the results chapter, the variable “years spent at the camp” refers to the family and not to the child. For this reason, the meaning of its association with the prevalence of specific health symptoms of the child needs to be examined for its potential impact on the environment the child lives in and, thus, its indirect impact on the child’s health.

On average, the people interviewed had lived in these settlements for almost six years. This was a lengthy period in which often the residents had reported living in a state of insecurity

and instability. It is time enough for a child to be born, grow and start to go to school. If it is difficult to get used to living in a camp, after several years people will have changed and accustomed to it, and will not be easy for the families to go back to a regular life and a regular house.

The association between number of years spent by the families in the camps and the prevalence of some of the investigated symptoms, discussed later on, confirms the role time can play either in worsening the impact on health of a poor environment or in weakening the family resilient behaviours that could partially protect the child from a hostile environment.

As previously mentioned, linked to the theory of the gap, living in conditions of disadvantage and marginality with respect to the society at large increases the risk of ill health, and the longer people live in these conditions the greater the risk (146). Lack of involvement in integration policies and political neglect can increase the feeling of frustration and resignation.

The perception of the residents of the camps

Where living conditions were more unstable, more causes of diseases were identified by the interviewees, and in most cases the perceived causes were the same as those identified in the analysis as being associated with symptoms like diarrhoea, coughing, fever and difficulties in breathing.

In Bolzano, we found the highest percentages of interviewees who thought there was nothing or could not say what in the camp could cause children's illnesses. This result suggests that

the residents found no elements that impacted negatively on the health of the children because the camp in Bolzano was in a condition such as to render it the least unstable of all the camps considered. In Brescia, too, where the situation was such that there were few shacks and nearly all the families were housed in walled structures, it is interesting to note the high number of interviewees who found no causes of the children's illnesses in the fact of living in the farmhouse.

In the literature review, no documentary analysis was found regarding the causes of diseases in *Rom* camps provided by the residents themselves. In order to understand where to begin in an attempt to improve the situation it is important to start with a description of the health status of children and their living conditions given by the *Rom* themselves.

In our study, the residents identified filth as the main cause of diseases in children. With a few exceptions, the interiors of the living quarters were extremely well looked after and clean. Maintaining the house and the camp clean was a very complicated undertaking that required constant mental and physical commitment.

Filth was followed by causes linked to the structural problems of the camps. The difficulties in keeping the shelters warm, fighting cold and humidity, the lack of hot water and the unstableness of the house structures were mentioned as causes of diseases in children.

Insufficient hygienic services and housing structures, and people living for long periods of time in overcrowding conditions, can end up having a serious impact on the environment, increasing the number of potential risk factors for the health of children. The presence of rats in three out of the five camps is an example of an element that can be the consequence of a

shattered environment and the cause of serious health problems.

Commitment was also required in looking after the children who, as pointed out by the mothers during Focus Group meetings, were difficult to keep inside the home. The mothers claimed that in living conditions such as those existing in the camps, it was very easy for a child to fall ill. Washing a child became problematic in view of the difficulties connected with the unavailability of hot water, of a shower or to the fact that the outside bathrooms were unheated.

The camp was seen as a source of squalor and insecurity that made it difficult to look after a family and bring up children. The residents of the camps mentioned the housing conditions, humidity, the difficulty in keeping the home and children clean, the lack of playing space for the children, and the difficulty in securing a permanent job while living in a camp as obstacles to be wrestled with every day.

As can be seen from a summary of the factors that the interviewees held to be the causes of illness in the children in the camps, there was a wide range of opinions and a good appreciation of factors that could potentially affect the health of children and adults alike. *Romá* clearly associated the features of the place where they were living with an impact on the health of their children. This was an important point as it underlined the fact that the residents had a good perception of the problems that existed in the camps and this should make it easier to promote efforts to improve conditions.

The mothers asked for the opportunity to bring up their children in a more dignified way, in a real house, like “Italian children”. This should not be interpreted as request to be assimilated,

but as the desire to live in a regular house as it was in former Yugoslavia. Other *Rom* and *Sinti* groups in Italy have different housing needs and requests.

In Italy, public opinion's general idea that Gypsies like living in camps is not supported by evidence. This opinion is one of the main reasons why local institutions set up "nomads' camps" for the *Rom* who fled from former Yugoslavia. Alternative solutions could be defined by setting up a constructive discussion with the residents of the camps.

RELATIONSHIPS BETWEEN ENVIRONMENTAL FACTORS, HABITS AND BEHAVIOURS, AND CHILD HEALTH

The fourth specific objective of this thesis was to analyse the relationships between environmental factors, habits and behaviours and child health.

Low birthweight

The analysis carried out on our data shows two main factors associated with low birthweight: early and late pregnancy (18 years old or younger and 35 years old or older) and smoking habits (if there were more than two people smoking inside the house).

In the relation between smoking and low birthweight, the variable of interest would have been primarily smoking habits of the mother during pregnancy, followed by the quantity of passive smoke inhaled by the mother during pregnancy. More than two people smoking in the house at the time of the interview is most probably a marker for these other two variables.

When facing the issue of smoking, and other behaviours like eating “for comfort”, one needs to take into account the social patterning of health related behaviours. Factors that predict smoking include stressful material and housing conditions. For this same reason, across marginal groups motivation to quit smoking, or to change harmful nutritional habits, is generally very low (145) and health education messages are very difficult to get through.

Diarrhoea

Risk analysis showed a significant association between period prevalence of diarrhoea and factors linked to the living conditions and length of stay at the camp. The risk of diarrhoea was higher if the family had been living at the camp for more than two years.

Following the idea that a long-lasting stay at the camps could also increase the impact of some environmental factors on the health of children, we tried to identify factors interacting with the association between diarrhoea and years spent living in the camps. The analysis revealed that for those families who had been living at the camp for more than five years, risk factors were overcrowding of the house and presence of stagnant water due to the ruined floor of the camp.

As we will see below, overcrowding and stagnant water are factors associated with other symptoms like cough and breathing difficulties.

Coughing

Significant associations were found between the period prevalence of cough and factors linked to access or presence of water. A child was more at risk of cough if the family did not have access to a toilet with a shower. This result is supported by one of the concerns expressed by the mothers of the children during focus groups meetings, about the difficulties of being able to take care of the hygiene of their children without exposing them to the cold, in a situation of difficult access to proper bathroom services and living in houses that were difficult to keep at a reasonable constant temperature.

The risk of cough was also associated with the access to water inside the house. In camps where some families had access to water inside their house (Brescia and Florence), this was not supported by proper wastewater drainage systems: in Brescia most of the water connections and drains inside the houses had been set up by the families with no professional supervision, while in Florence no drainage system existed in the shacks and water connections had been set up illegally. The association between bronchitis and inadequate water connections can be explained with a possible increase of humidity and mould. Bibliographic references on the link between damp, mould and respiratory diseases has been described in the literature review chapter.

Especially for those families that had been living at the camp for more than five years, if the presence of stagnant water was reported in the camp, the child was more at risk of cough. Stagnant water could be seen as a marker for the state of decay of the camp that, as in the case of diarrhoea, has an impact on the period prevalence of cough for children of families that have lived in these conditions for many years.

As mentioned in the case of diarrhoea, interaction between years spent at the camp and environmental factors in their association with period prevalence of cough can be an important element where, in this case, time seems to act as an “amplifier” on the effect of stagnant water on the period prevalence of cough.

For families living in overcrowded houses (more than 2.5 people per room), heating the house with wood stoves, rather than with electric or gas stoves, was a risk factor for coughing. Because of the type of structures and fixtures, most of the houses in the five camps were difficult to be kept warm. To maintain a constant temperature, families using wood stoves kept them usually on all day but needed to turn them off at night, for safety reasons. Overcrowding is probably a more serious problem during winter, when people tend to spend more time indoors. This situation is made worse by the use of wood stoves that need to be kept on all day. At night, overcrowding reaches its peak, while the temperature drops rapidly as wood stoves must be turned off.

As reported in the literature review chapter, in the analysis of risk factors linked to inadequate housing, the association between emissions of wood stoves (carbon monoxide, particles, polycyclic aromatic hydrocarbons) and acute respiratory infections in children has been well documented in the literature.

Breathing difficulties and asthma

Camp overcrowding was the strongest risk factor associated with breathing difficulties or wheezing at least once in the last year: a child from a camp in which people lived in less than

25 square meters per person had a higher risk of having had breathing difficulties in the past year. Furthermore, a child living in a house considered in bad condition was also more at risk.

The only variable to be associated with the prevalence of asthma was the presence of rats in the camps, but only if we accept the one-tailed exact Fisher test. Because of the small number of cases, the risk analysis was more complicated. The fact that there were no cases of asthma in camps without rats inhibited the possibility of a stratified analysis. Studies on the relation between presence of rats and asthma have been mentioned in the literature review chapter.

Combining variables about living conditions in the camps, we found that a child living in a less overcrowded camp (more than 25 square meters per person) and in a house in regular or good conditions was less at risk of asthma. Overcrowding within the house was also a risk factor: a child living in a house with more than 2.5 people per room and where people slept in more than three per mattress was more at risk of asthma.

CAMP RESIDENTS' ACCESS TO AND USE OF HEALTH SERVICES RELATED TO CHILD HEALTH

The fifth specific objective of this thesis was to determine camps residents' access to and use of health services, especially in relation to child health.

It was important to analyse the behaviour of the parents when they decided to take their children for medical examination after the appearance of specific symptoms. It was of interest in order to identify behaviours in the group studied, that led to their considering one or another symptom more or less serious, or more or less treatable at home in the family. For this

reason, even if this analysis is anecdotal if taken for just one symptom, it acquires more significance through the comparison of behaviours according to different symptoms.

A significant downward linear trend according to the age of the child was recorded for all symptoms: in the case of any symptom, the tendency to take the child for a visit diminished with the age of the child. This result is useful to confirm the sensitivity of the data, as it can be easily understood that, considering the same symptom, parents were less worried as the child got older.

Out of all the children who exhibited at least one symptom in the last 15 days, 71% were taken for a visit. In the case of fever the percentage reached 75%, while in the case of diarrhoea it was 74%. Some 71% of children with cough were taken for a visit.

Looking at the percentage of children taken to hospital services – including regular and emergency services – and not to a family paediatrician or a paediatric consultancy, we see that out of the children taken for a visit in the case of cough, only 59% were taken to hospital services, while in the case of diarrhoea and fever this percentage was higher (72% for diarrhoea and 68% for fever). As mentioned above, in the case of skin diseases, seven out of eight children were taken for a visit, and out of the seven, five were taken to hospital services.

In the studied communities, the high percentage of children born in hospital (96%) indicates a high resort to health services in the case of delivery.

The regular use of the family paediatrician could be implemented. However, we should take into consideration the fact that marginalized groups often feel less exposed accessing more

anonymous or *ad hoc* services, and unfortunately not all family doctors are free from prejudice and would easily accept foreign *Rom* living in camps as patients. In some cases, *ad hoc* services can be the first step to solve a problem of poor access and to narrow the gap between health services and marginal communities.

CONCERNS, EPIDEMIOLOGIC RESULTS AND POSSIBLE ACTIONS

Returning to the general objective of the thesis, it may be useful to summarise how the associations derived from the pursuit of the specific objectives demonstrate that quantitative research of the kind pursued here *is* capable of producing reliable evidence that communities themselves can use to advocate for change.

The following excerpt from *Table 6.3* summarises the main links between concerns expressed by the camp inhabitants and the associations found during the analysis.

As we saw, the concerns were formally collected during household interviews and meetings with the mothers of children under six year of age. However, they represent the same issues discussed in the design phases of the project.

The table tries to simplify the way concerns were translated into potential risk factors. Reality is more complex and one risk factor can reflect more than one concern, as well as one concern can be expressed with different risk factors. For example, poor quality of the air is not only caused by the proximity of industrial sites, but also by the place where camps are located, often in degraded areas, by inappropriate sewage systems, or by a mix of different issues.

Nevertheless, this table represents a convenient summary of the main findings of this thesis and their significance for the future health of the *Rom* children who participated in this study.

Concerns expressed by the Romá

Filth

Refuse, Dirtiness, Sewage outlets

Unstable housing conditions

Structure and quality of the house
No air circulation
Heating, dry air
Difficult to warm up the house
Leaks and mouldiness

Cold and humidity

Bathrooms outside
Lack of hot water
No warm bath for children
No heated bathroom

Presence of rats

Poor quality of air, unpleasant smell

Overcrowding

Living space in the camp
Living space in the house

Issues not explicitly mentioned:

Years spent living at the camp

Apparently contradicting:

Water inside the house

Main significant associations

Stagnant water

Cough (5 years living) $p=0.001$
Breathing difficulties (all) $p=0.026$

Condition of the house

Breathing difficulties (all) $p=0.010$
Asthma (in overcrowded camp) $p=0.016$

Wood stoves

Cough (in overcrowded households) $p=0.027$

Lack of access to a toilet with a shower

Cough (all) $p=0.003$
Breathing difficulties (all) $p=0.007$

Rats

Breathing difficulties (all) $p=0.027$
Asthma (all) $p=0.071$

Polluting industrial sites

Breathing difficulties (all) $p=0.003$

Home overcrowding

Asthma (day and night overcrowding) $p=0.014$

Camp overcrowding

Breathing difficulties (all) $p=0.001$
Asthma (+house conditions) $p=0.016$

Years spent (by parents) living at the camp

Diarrhoea (all) $p=0.014$
Diarrhoea (in overcrowded household) $p=0.002$
Diarrhoea (in camp with stagnant water) $p=0.005$

Water access inside the house

Cough (children 0-3) $p=0.019$

7. SOCIALIZING THE RESULTS AND THE EXPERIENCE

A study like the one presented with this thesis was needed because several stratified issues contributed, and still contribute, to create a complex situation of marginalization and lack of integration policies towards groups of foreign *Rom*. We shall now analyse how some aspects investigated in this thesis can be useful to *Rom* communities, to health services, to no-profit organizations and institutions to start a process of evidence based critical analysis. However, the same elements that contributed to the creation of “nomads’ camps” in Italy are the main obstacles we need to consider when defining how to disseminate findings, create partnerships, stimulate community based participatory research, and involve *Rom* associations in order to try and change the existing situation.

A discourse on how the information gathered through this study can have a positive impact on designing a strategy aimed at the improvement of the living conditions of foreign *Rom* in Italy, should take into account three main stakeholders: 1) *Rom* communities, 2) public and no-profit researchers and health workers, and 3) local, national and European institutions. This strategy should concentrate on three main issues: a) the critical review of the literature; b) the results of the relation between living conditions and health – what came out and what should be further explored; c) the need to implement a different type of research, more community based, more participatory, more focussed on the needs of the communities and the improvement of the existing conditions.

Considering that the camps are unstable by nature and can be easily modified or dismantled, a communication strategy should not focus on the five camps or on the population that lived in those camps, but on the mechanisms and consequences of physical exclusion affecting groups

of foreign *Rom* migrating to Italy. Even though some of the *Rom* families that lived in the camps managed to access regular houses, the situation in Italy is still unsolved, and the new migration flow of Romanian *Rom* is, in 2006, facing the same problems Kosovans and Macedonians faced some years ago.

This chapter was elaborated after discussing with Demir Mustafa, Macedonian *Romá*, founding member of the Florence based *Rom* association *Amalipé Romanó*, and Salvatore Geraci, Director of the *Area Sanitaria, Caritas Diocesana di Roma*, and member of the Scientific Direction of the *Società Italiana di Medicina delle Migrazioni* (SIMM). However, the opinions expressed in this chapter only reflect the point of view of the author.

To be able to spread the information and collect useful comments, part of the material of this thesis has already been presented and published. More information should be published and presented after the publication of the thesis. Apart from the publications, listed elsewhere, a paper on the critical analysis was presented at the annual conference of the Gypsy Lore Society, in Newcastle upon Tyne (England) the 3rd of September 2004. A presentation of the main results of the thesis was illustrated at the London Romani Studies seminar hosted at the London School of Economics the 29th of March 2004. Thomas Acton, professor of Romani Studies at the University of Greenwich, coordinated the seminar at the presence of Martin Kovats (consultant and researcher on the European Union's policies for *Roma* communities), Florina Zoltan (researcher and activist in a Romanian *Roma* refugee organisation), Lavinia Olmazu (project manager of a project on the representation of the *Roma* in the media) and Nidhi Trehan (Ph.D. researcher on European *Roma* Politics at the LSE). In both occasion the feedback by other researchers allowed to improve the analysis and establish good contacts to receive and channel useful information.

INVOLVING THE *ROM* ORGANIZATIONS

The main worry expressed by the foreign *Rom* living in camps was how the living conditions could impact on the health of the children. For this reason, the results of the thesis, in terms of risk factors for the health of the children, can be easily understood. However, the issue is not limited to the discussion of the results. The problem is more related to defining ways to involve *Rom* associations, and for *Rom* associations to find ways to change the actual situation.

Among the issues to be discussed with *Rom* organizations there is how can research be carried out with more involvement of *Rom* communities and focussing on priorities and issues of utility for the covered groups. It is important to involve *Rom* organizations in discussions with health researchers and operators in order to plan common approaches in terms of research and actions, and define how can evidence based research be useful in providing elements to advocate for change.

Among the priorities discussed with Mustafa:

- Design simplified charts exposing the information in *Table 6.3*, one chart for each significant result, and to spread this information among *Rom* associations;
- Define the terms of ethically correct research with *Rom* groups in Italy;
- Start discussing about partnerships, to stimulate participatory research, not only in the field of health but also, in general, to gather useful evidence to advocate for change.

Unfortunately *Rom* and *Sinti* are not recognised as a national minority in Italy, and resources

for this type of work are difficult to gather. Furthermore, the lack of recognition of the *Rom* and *Sinti* minority in Italy makes it difficult to involve foreign *Rom* who are living in regular houses and will tend not to declare themselves as *Rom*, to avoid prejudice. More integrated *Rom* would be in a better position to negotiate and establish partnerships with researchers and the institutions, while those living in camps are weaker and in a more unstable position.

After discussing with Mustafa, it was clearer that any process should not be carried out or stimulated only by *Rom* associations, but should rise from an agreement between researchers/health workers, institutions and *Rom* groups. Associations of foreign *Rom* in Italy are still weak and need support to be able to carry out such tasks. In many cases the negotiating power of these associations is still frail and their financial means are inadequate. However, albeit the author's opinion is that participation will need time, funds, and to be stimulated and supported, he also believes that it is worth starting to work in this direction.

THE RESEARCHERS AND THE HEALTH SERVICES

In many cases, data collected and published on the health of *Rom* living in camps in Italy come from the activity of institutional and no-profit health workers. In many cases, as explored in this thesis, the health services realise that the camps are inadequate and unhealthy places. However, the actions of the health services are often limited to the provision of health care and the description of the situation.

One of the main issues that should be discussed is the role of public health. As an example, a report published in 2003 by the Health Public Agency of Lazio Region (ASP) and the Lazio Region, documenting a vaccination campaign held in the camps of Rome, states in its

introduction that “one of the challenges of public health is to guarantee protection trails to the portion of population living in marginal situations, in unstable social, economic and cultural conditions” (270, p.9). The author’s point of view is closer to the idea expressed in the material used to define the methodological frame of this thesis. Krieger (16), Cohen and Northridge (120) state that public health professionals have the responsibility to ask whether the ways we think and work reflect or contribute to social inequality, and that public health and epidemiology need to explore and confront the effects of social and economic differences on health.

The information collected with this thesis shows how risk analysis in community based research, and the use of mixed methods, can produce good evidence to be used together with the *Rom* communities to gain negotiating power. In some cases, the health services and the *Rom* communities express the same concerns. Researchers and *Rom* associations should work together in gathering epidemiological evidence, and defining proposals to improve the existing situation. Such a process should stimulate a positive reaction from the institutions.

The dialogue with *Rom* communities is possible and very important in order to discuss about health behaviours, relations with the health services, and what can be changed and how in terms of living conditions.

The author feels that the focus should not be on educational programmes. As expressed by Fuglesang in his book on intercultural communication (22), “large amounts of pseudo-information are concentrated around the false fact that poverty and ill health are caused by ignorance”. What is needed is more involvement in the decision making process and in the definition of integration policies. Based on the results of this thesis, this process can start with

the discussion of what epidemiology can do to “explore and confront” the existing situation.

The author is a founding member and councillor of the association *Metis Africa*, a Verona (Italy) based no-profit organization aimed at the promotion of cross-cultural communication, which organises activities and courses in educational institutes with social and health workers. The critical review of the literature on the health of “Gypsies” (chapter 2) was presented in several occasions in lessons on cross-cultural communication. People that assisted to these lessons were in general not experts in cross-cultural communication and few had specific knowledge of *Rom* and *Sinti* cultures. Starting from this experience, the author realised that even people with no specific knowledge understood and identified the contradictions in the material. Even in exercises that included the reading of articles without any input from the trainer, the trainees were able to spot most of the elements of irrationality.

Keeping in mind the general ethical principles governing research involving humans, the author’s idea is that, in most cases, a positive attention towards the language and the approach used when dealing with distant groups is enough to make a first step towards a more rational and respectful research approach.

Defining a set of simple rules, when gathering and presenting data on *Rom* communities, can stimulate this positive attention. Furthermore, ethical principles for the conduct of research should be developed together with *Rom* and *Sinti* associations. Good examples of similar processes enhanced with and by minority groups throughout the world exist in the literature (271-273).

The author discussed this issue with Geraci and there is interest for the involvement of SIMM

in the discussion over for the development of a code of ethics for research with *Rom* and *Sinti* groups in Italy.

The socialization of the results of this thesis on the association between the living conditions in the camps and the health of the children cannot be separated from a more integrated approach. Hopefully, however, the spreading of these results could stimulate more researchers to investigate into the health consequences of segregation in camps, and motivate more funding partners to invest on this topic.

INVOLVING THE LOCAL AND NATIONAL INSTITUTIONS

The charts that should be designed for the *Rom* associations could also be used to disseminate information and start discussing with local and national institutions. However, the lack of information about the consequences of the living conditions in most of the camps for foreign *Rom* should be considered as one element of a more complex problem. The absence of a national policy concerning the *Rom* and *Sinti* minority affects Italian and foreign groups. Foreign groups, in addition, suffer from the consequences of being often not recognised as refugees, and from the difficulties of finding a job and a regular house, which impacts on the possibility of obtaining a regular visa.

The author's opinion is that the evidence needs to be supported by pressure applied by *Rom* and non-*Rom* associations, public health and international organizations.

Furthermore, evidence of the impact on health of the unstable living conditions in the camps should be supported by a cost analysis considering: 1) the cost of ill health on the individuals

and on the health system, 2) the costs of the camps (construction, maintenance and management), 3) the costs of alternative sustainable solutions. Such cost analysis was not carried out as part of this study as it required time and expertise the author could not rely on, but it could be elaborated in collaboration with local institutions. Alternative solutions and integration policies should always be defined together with *Rom* associations. A cost analysis that could demonstrate that alternative integration policies are more sustainable than “nomads’ camps” could strengthen the possibility of a change in the institutions.

8. CONCLUSIONS

This thesis showed how community-based research, using a combination of quantitative and qualitative methods, can produce useful evidence to demonstrate how living conditions in the particular context of “nomads’ camps” built for foreign *Rom* can impact on the health status of children.

The author believes that in such or similar conditions a researcher should try to develop a research approach that can be shared both by the communities and academia. The emphasis given to the priorities and points of view of the communities, in fact, should be integrated with good quality research, which should not be sacrificed.

The research approach ought to be developed to fit the needs of the communities and to accomplish shared objectives. In this context, for example, the use of a mixed methods’ approach applied to the micro-universes represented by the selected camps facilitated the inclusion of local knowledge and the understanding of local community and environmental dynamics.

Resources can often be a problem, especially in community-based research focussing on marginal groups. However, this study shows how, in particular circumstances, it is possible to start generating evidence and stimulate community participation despite the scarcity of funds. A balance between resource availability, achievable objectives, and quantity and quality of information to be collected, is required. Such a balance was particularly necessary in the case of this research.

Good quality analysis should fit the type of data available. Scarcity of data, in our case, made us avoid modelling, focus on stratified risk analysis and, in some cases, resort to exact estimates.

In community-based research, active participation of community members can improve the quality of research and stimulate evidence-based planning. However, exclusion suffered by marginalized communities can be a serious obstacle, and people cannot be forced to participate beyond their possibilities and will. As stated in CIET methods, the process of gathering and discussing evidence locally can, in itself, stimulate community participation and, in our case, serve as a starting point.

The discussion should now focus on whether and how the type of evidence produced with this study can be useful to *Rom* communities to advocate for change. In this context, the author feels some issues should be made explicit, not for the sake of advocating for the *Romá*, but in order to make sure that all the elements that contribute to the existing situation and those that can help improving it are taken into account.

SPECIAL TREATMENT

The first issue that should be taken into account deals with the consequences of prejudice, which is important while analysing how evidence based research can be useful for *Rom* communities. For this reason, it is necessary to address the unconscious paradigms generating tensions between groups (274). Prejudice, whether positive or negative, reduces people's ability to analyse the reality of a situation, gain knowledge, work together, search for just and sustainable solutions and take rational decisions.

In this sense, the author agrees with Sigona (9) who states that the housing policies developed by the local and regional authorities in Italy are the architectural expression of prejudice towards the *Rom* people. Often this attitude cannot be classified as racism in the form of explicit marginalization policies, but simply as the consequence of how Gypsies are represented. As part of this representation there is a certain fear of establishing relationships with people that are felt as distant and unreliable. This contributes to maintaining the gap between the society at large (and its institutional representatives) and the *Rom* and *Sinti* minority.

For this reason, even camps that are built and recognised by the institutions do not often comply with minimum housing standard regulations. Even when the conditions of these camps are visibly unsafe for the health, enquiry about the health of *Rom* and *Sinti* tends to bring about explanations that are based on their behaviour: cultural reasons, endogamy, the almost genetic predisposition towards filthiness (11). As stated by Fuglesang, “*to pronounce that people are unclean is inaccurate and immoral*” (22, p.178). In a community, filth is often a symptom of distintegration, in the sense that it can be almost exclusively seen in communities disturbed by external influences. In the thesis, we saw how the five camps are not the expression of a traditional way of life of the *Romá*. Thus, the external influence on the community and on the definition of the living space is strong. Furthermore, communities living in those camps are not made up of people who choose to live together, but of families forced to live together by the lack of alternatives.

The poor health conditions, where they exist, are mainly due to social segregation and not to an all-encompassing explanation in their “being Gypsies”. In the five camps, the quantitative

analysis showed how the period prevalence of diarrhoea, coughing, fever, respiratory difficulties and the prevalence of asthma were tied in different ways to the characteristics of the camps, the years spent living in such environments, the quality of the housing, the overcrowding and the type of access to toilet facilities.

The difficulties with the health services are often caused by lack of flexibility and knowledge of the services about how to deal with cultural differences. In defining new intervention programmes, the active involvement of the *Rom* communities is crucial to avoid offering services that do not fit with their needs and expectations (275).

The author does not deny that it is easier to identify the problems and connections between negative health outcomes and inadequate housing than it is to fix them (131). Marginal groups living in isolated communities have very little power and are often unable to effect changes (175). Furthermore, political factors can influence the ability of public health to respond to housing issues. Assuming that the housing situation of the camps reflects underlying power disparities, these disparities can also inhibit public health workers from confronting more powerful interests (124).

However, even if we cannot ensure reduced health inequalities just by identifying the problems and the connections alone, it is certainly a necessary condition to start developing participatory evidence based research and planning (123).

REGARDING HEALTH AND CULTURAL POLICIES

It is not the intention of this thesis to provide a blueprint for correct medical and cultural

policies to adopt for the *Romá* who live in settlements or for others groups of *Rom* or *Sinti*. Such useful blueprints, in fact, should not be associated exclusively with these groups. If there are conflictual relationships between health services and *Romá*, these are due to a more or less reciprocal absence of dialogue and listening skills. As mentioned above, to try to solve this problem, the health service should be trained to deal with the human side of the patient, the patient's family and the community, and in particular with "diversity". *Rom* associations should be involved in the definition of health programmes that could address the problems of ill health and access to the services, and *Rom* health workers should be trained to facilitate this process.

J.D. Thomas (91, p.134) claims that "*to those ignorant of Gypsy customs, their behaviour may often seem bizarre and capricious*" and that "*armed with an understanding of Gypsy society, one may hope for a more successful medical relationship*". This is certainly true, but a step forward would be to consider that everything that is different might appear bizarre and capricious if we lack the capacity to listen and understand. As stated by Fuglesang, what is impressive culturally are "*the similarities in man's many endeavours to control his reality – not the differences*" (22, p.13).

Suggestions, as proposed by some authors, regarding behaviour and relationships that should be promoted with reference to some specific groups of Gypsies may not be valid for other groups. Ojanlatva and colleagues (96) propose an insightful approach. Analysing the relationship between health services and Finnish *Romanies*, the article recommends measures to be adopted when dealing with minority groups: "*According to medical ethics, all patients must be treated equally. Cultural differences should not jeopardize this relationship. (...) In the process of explaining, it is assumed that a physician is believable, empathetic, and*

behaves matter-of-factly. A professional has to be skilled in verbal and non-verbal communication, including touch and listening skills, and being aware of cultural differences” (p.171).

Allocating specific health services to *Romá* may be a good or a bad idea depending on the circumstances. When groups of *Romá* arrived from former Yugoslavia after fleeing from the war and found themselves in a foreign country, concentrated in settlements on the outskirts of unknown cities, they were certainly in need of dedicated services or, at least, of integration and health education programmes so that the families could benefit from the services they needed. Once this first step had been taken, each family could have had access to the normal services available in the country. This process should have been undertaken together with all other processes allowing access to services and to the society in general, within the context of a comprehensive integration programme. To increase the sustainability and reduce the possibility of failures, these programmes should always be designed and carried out together with representatives of the target group.

RESPONSIBILITY AND PLANNING

Another fundamental problem that arises with reference to the camps seems to be the lack of openness to experiences of the same kind in other cities. Each local experience stands basically alone; thereby the same errors tend to be repeated.

Following the experience and the results presented in this thesis, local health services operating in areas with camps could start collaborating among them and with the *Rom* communities in order to establish partnerships and set up a discussion about community based

participatory research. In its first phase, such a network could be almost completely sustained by resources regularly available at the local health services. It would be of great help to generate data, compare different situations and stimulate evidence-based planning. Such process could help raise the awareness and the interest of local institutions. If *Rom* communities express distrust, such a process could start with an affordable degree of participation by the *Rom*, and such participation could be increased as the programme goes on and trustful relations are established. Among the literature cited in the review chapter, Macaulay and colleagues report good examples of participatory research in public health with minority groups in inner-city contexts (179). CIET can build on a positive experience in the same field (212-214).

However, the author considers that an obstacle lies in the lack of firm belief that alternatives to “nomads’ camps” exist and that the *Rom* can be a resource in the definition and realisation of these alternatives. The author hopes this thesis will give its contribution to overcome this obstacle. It shows how important it is to start from the *Rom*’s concerns, how risk analysis is possible, and how the use of mixed methods and triangulation can strengthen the analysis, even in the difficult context of the camps – facing the distrust of inner-city marginal groups, in small scattered communities and with no funds.

It is important to consider that the camps are not the problem, but the spatial manifestation of social exclusion and inadequate housing and integration policies (140). Thus, the solution is not to fight nor educate the people living in the camps, but lies in an improved and shared evidence based planning capacity.

THE COSTS AND THE CONSEQUENCES

As mentioned in the previous chapter, amongst a number of studies that should be carried out on the “camps”, it would be helpful to calculate the cost of maintaining the camps over the course of the past years, case by case, alongside the calculation of the cost of a project which, over the same number of years or less would have brought about the real social integration of these families. Social and health costs of living in the conditions of the considered camps should also be taken into account. Such evidence based cost analysis could help bring together *Rom* communities, institutions and health services with the common objective of defining a sustainable integrated programme.

It is true that many of these camps were set up to provide an alternative to far more serious situations of emergency or degradation. In many cases, the camp, in a sense, provided a guarantee of recognition. For this reason, too, the camp can become a cage from which it is difficult to exit. This static situation erodes the desire to achieve something on the part of these new citizens and often frustrates the opportunity for a sincere and constructive dialogue. Too often *Rom* have been considered incapable of analysing or reacting appropriately. Frequently we came across an inability to come together in order to find shared solutions. To work together in an attempt to exit from a stalled situation might sound difficult and, yet, setting the conditions for evidence-based productive dialogue could really be the turning point in the construction of an alternative model.

The project carried out in Mestre, that resulted in the closing of the *Zelarino* and *San Giuliano* camps, giving a chance to the families to rent regular houses, or even take on mortgages and buy houses, should be better considered in all of its positive and negative elements. The

project was carried out over two years with an amount of funds equal to those spent by the local administration in the management of the two camps. A solution was defined together with each family, which received financial support according to its particular situation. Support programmes followed the families for the first period of time. Unfortunately, living for many years in a camp-like situation makes it difficult to go back to real life and for some families the integration programme has been particularly arduous.

Some cities have already started a process to sustain the integration of *Rom* families in real bricks-and-mortar housing, both council and private. This is a fundamental process that should be undertaken together with the *Rom* families. Where this is happening, it would be important for the local health workers to collect evidence on the differences in health outcomes between the *Rom* who live in the camps and those living in better living environments (124).

PERCEPTIONS AND THE RESOURCES OF THE INHABITANTS OF THE CAMPS

The perception of the *Romá*, with respect to the life and the health consequences of living in the camps, made an important contribution to the analysis. The analysis made by most of the *Romá* interviewed – on the state of child health, the causes of the diseases and their seasonal recurrence, the use of services on the basis of a particular disease, the seriousness of the latter and the age of the child – demonstrated an awareness that should be taken into account. The people living in the camps know what makes the children fall ill and what should be done to improve the situation. Interviewees' answers about causes of disease in children varied in number and types of causes, according to the actual situation of the camps they were living in. The health services in the various cities underlined the attention and readiness most families

displayed in having their children vaccinated. It is very important to consider these positive elements to start building a different strategy based on dialogue. As stated by Wilkinson and Marmot, “*societies that enable all citizens to play a full and useful role in the social, economic and cultural life of their society will be healthier than those where people face insecurity, exclusion and deprivation*” (146, p.11).

Even the interviewed *Romá* living in better conditions would like to live in a real house. None of the foreign *Romá* interviewed preferred to live in a camp, with the sole exception of those who came from situations that were so unstable that they were unable to conceive of a “stable” solution such as a real house. The fear of losing everything was greater than the desire to improve their current situation.

Bigger numbers would be useful to fully substantiate some of the results produced by this study. However, the type of approach to research is what is even more important. More community based, house-by-house research is indeed necessary.

As seen from *Table 6.3*, the factors that are mainly associated with health outcomes describe a situation than could be easily solved with a minimum degree of combined analysis and planning which the communities and the authorities should conduct together. None of the elements described as risk factors should be present in regular housing solutions. After listening to the *Romá*, we are certain that those camps are a form of segregation. All the “nomads’ camps” we have visited are exceptions to the rules in terms of housing standards, safety and hygiene. For these reasons, the opinion of the author is that all actors involved should work together to replace the logic of the camps with solutions that are more respectful of human dignity.

TABLES

Table 5.1. Official number of people per camp at time of study and date of opening

City	People	Families	People per Family	Year of opening of the camp
Florence	314	51	6.2	1990
Bergamo	156	37	4.2	1993
Brescia	80	14	5.7	1993
Venice	165	25	6.6	1994
Bolzano	130	33	3.9	1996
Total	845	160	5.3	-

Table 5.2. Square metres per camp and per person

City	Square metres	M ² per person
Florence	6100	19
Bergamo	1500	10
Brescia	3000	50
Venice	7500	45
Bolzano	3970	31

Table 5.3. Number of families interviewed, city by city

City	Number	Percentage
Florence	52	38%
Bergamo	16	12%
Brescia	13	9%
Venice	24	18%
Bolzano	32	23%
Total	137	100%

Table 5.4. Number of people among interviewed families, city by city, and the average size of the families

City	Number	Percentage	Average size of family	SD
Florence	304	41%	5.8	2.5
Bergamo	85	12%	5.3	2.0
Brescia	75	10%	5.8	2.1
Venice	148	20%	6.2	1.8
Bolzano	125	17%	3.9	1.4
Total	737	100%	5.4	2.2

Table 5.5. Size of the families covered by the study

Family size	Number	Percentage
1	1	1%
2	8	6%
3	18	13%
4	25	18%
5	25	18%
6	23	17%
7	20	15%
8	4	3%
9	8	6%
10	2	1%
11	1	1%
14	2	1%
Total	137	100%

Table 5.6. Type of housing

City	Florence(%)		Bergamo(%)		Brescia (%)		Venice (%)		Bolzano (%)		Total (%)	
Shack	11	(21)	12	(75)	1	(8)	0	(0)	28	(87)	52	(38)
Shack and Caravan	13	(25)	3	(19)	1	(8)	19	(79)	3	(9)	39	(28)
Shack and Container*	23	(44)	-	(-)	-	(-)	-	(-)	-	(-)	23	(17)
Walled structure	-	(-)	-	(-)	9	(69)	-	(-)	-	(-)	9	(7)
Caravan	0	(0)	1	(6)	0	(0)	4	(17)	1	(3)	6	(4)
Shack, Caravan and Container	5	(10)	-	(-)	-	(-)	-	(-)	-	(-)	5	(4)
Walled structure and Shack	-	(-)	-	(-)	2	(15)	-	(-)	-	(-)	2	(1)
Container	-	(-)	-	(-)	-	(-)	1	(4)	-	(-)	1	(1)
Total	52	(100)	16	(100)	13	(100)	24	(100)	32	(100)	137	(100)

* Container = metal box

Table 5.7. General conditions and average conditions inside the housing structures, city by city

City	Florence (%)		Bergamo (%)		Brescia (%)		Venice (%)		Bolzano (%)		Total (%)	
Good	6	(12)	1	(7)	7	(54)	1	(4)	11	(35)	26	(20)
Fair	29	(57)	12	(86)	5	(38)	20	(83)	20	(65)	86	(65)
Poor	16	(31)	1	(7)	1	(8)	3	(12)	0	(0)	21	(16)
Total	51	(100)	14	(100)	13	(100)	24	(100)	31	(100)	133	(100)

Table 5.8. Housing structures and number of rooms and average number of rooms per house, city by city

City	Florence (%)		Bergamo (%)		Brescia (%)		Venice (%)		Bolzano (%)		Total (%)	
1	5	(10)	6	(37)	2	(15)	5	(21)	3	(9)	21	(15)
2	25	(48)	9	(56)	6	(46)	7	(29)	6	(19)	53	(39)
3	16	(31)	1	(6)	4	(31)	8	(33)	19	(59)	48	(35)
4	4	(8)	0	(0)	0	(0)	3	(12)	4	(12)	11	(8)
5	2	(4)	0	(0)	1	(8)	0	(0)	0	(0)	3	(2)
6	0	(0)	0	(0)	0	(0)	1	(4)	0	(0)	1	(1)
Total	52	(100)	16	(100)	13	(100)	24	(100)	32	(100)	137	(100)
Average	2.5		1.7		2.4		2.5		2.7		2.5	

Table 5.9. Average number of people per room (calculated house by house), city by city

	People	Rooms	Average	SD
Florence	304	129	2.5	1.0
Bergamo	85	27	3.4	1.2
Brescia	75	31	3.0	2.3
Venice	148	61	2.7	0.8
Bolzano	125	88	1.5	0.7
Total	737	336	2.4	1.3

Table 5.10. Average number of people per “bed space” (calculated house by house), city by city

	People	“Bed space”	People per “bed space”	SD
Florence	304	112	3.0	1.3
Bergamo	85	23	4.0	1.2
Brescia	75	31	2.4	0.4
Venice	148	52	3.3	1.6
Bolzano	125	70	2.0	0.9
Total	737	288	2.9	1.3

Table 5.11. Average number of people per square metre of camp space, city by city

	Square metres	People	Square meters x Person
Florence	6100	304	20
Bergamo	1500	156	10
Brescia	3000	80	37
Venice	7500	165	45
Bolzano	3972	130	31

Table 5.12. Families with access to water inside their home

City	Florence (%)		Bergamo (%)		Brescia (%)		Venice (%)		Bolzano (%)		Total (%)	
Yes	35	(67)	4	(25)	13	(100)	1	(4)	0	(0)	53	(39)
Total	52	(100)	16	(100)	13	(100)	24	(100)	32	(100)	137	(100)

Table 5.13. Families' access to toilet facilities and hot water, city by city

City	Florence (%)		Bergamo(%)		Brescia (%)		Venice (%)		Bolzano (%)		Total (%)	
<i>Average number of families per bathroom</i>												
Average	2.2		30.0		1.6		25.0		1.1			
<i>Availability of hot water</i>												
Yes	19	(37)	-	(-)	7	(54)	23	(96)	32	(100)	81	(60)
No	32	(63)	-	(-)	5	(38)	1	(4)	-	(-)	38	(28)
Not always	-	(-)	16	(100)	1	(8)	-	(-)	-	(-)	17	(12)
<i>Availability of bathroom facilities</i>												
W.c.	* 4	(8)	-		3	(23)	-		-		7	(5)
W.c. and washbasin	42	(82)	-		0	(0)	-		-		42	(31)
W.c., washbasin and shower	** 5	(10)	-		° 7	(54)	-		2	(6)	14	(10)
W.c., washbasin, shower and sink	0	(0)	16	(100)	3	(23)	24	(100)	30	(94)	73	(54)
Total	51	(100)	16	(100)	13	(100)	24	(100)	32	(100)	136	(100)

* Four families use chemical bathrooms, equipped only with a w.c.

** Five families use self-made bathrooms, built without authorisation, inside their homes

° Two of these families use the communal bathrooms, which supposedly also have washbasins, probably not mentioned because of the awful condition they are in.

Table 5.14. Families with at least a fridge in the home, city by city

City	Florence (%)		Bergamo (%)		Brescia (%)		Venice (%)		Bolzano (%)		Total (%)	
Yes	48	(92)	15	(94)	13	(100)	20	(83)	31	(97)	127	(93)
Total	52	(100)	16	(100)	13	(100)	24	(100)	32	(100)	137	(100)

Table 5.15. Means used to heat homes during winter, city by city

City	Florence(%)		Bergamo(%)		Brescia (%)		Venice (%)		Bolzano (%)		Total (%)	
Electricity	30	(58)	16	(100)	1	(8)	24	(100)	1	(3)	72	(53)
Wood	14	(27)	-		5	(38)	-		19	(59)	38	(28)
Gas	5	(10)	-		6	(46)	-		4	(13)	15	(11)
Wood & gas	-		-		1	(8)	-		5	(16)	6	(4)
Electricity & gas	1	(2)	-		-		-		3	(9)	4	(3)
Wood & electricity	2	(4)	-		-		-		-		2	(1)
Total	52	(100)	16	(100)	13	(100)	24	(100)	32	(100)	137	(100)

Table 5.16. Family cooking habits, either inside or outside the home, city by city

City	Florence (%)		Bergamo (%)		Brescia (%)		Venice (%)		Bolzano (%)		Total (%)	
Inside	49	(94)	15	(94)	8	(62)	19	(79)	29	(91)	120	(88)
Outside	3	(6)	1	(6)	5	(38)	5	(21)	3	(9)	17	(12)
Total	52	(100)	16	(100)	13	(100)	24	(100)	32	(100)	137	(100)

Table 5.17. Means used for cooking

City	Florence(%)		Bergamo(%)		Brescia (%)		Venice (%)		Bolzano (%)		Total (%)	
Electricity	29	(56)	9	(56)	-		22	(96)	2	(6)	62	(46)
Gas	8	(15)	6	(38)	10	(77)	1	(4)	14	(44)	39	(29)
Wood	10	(19)	-		2	(15)	-		9	(28)	21	(15)
Wood & gas	1	(2)	-		1	(8)	-		4	(13)	6	(4)
Wood & electricity	4	(8)	-		-		-		1	(3)	5	(4)
Electricity & gas	-		1	(6)	-		-		2	(6)	3	(2)
Total	52	(100)	16	(100)	13	(100)	23	(100)	32	(100)	136	(100)

Table 5.18. Age groups according to sex

Age group	Males		Females	
	Number	Percentage	Number	Percentage
0-4	69	19%	80	21%
5-9	54	15%	56	15%
10-14	47	13%	47	12%
15-19	30	8%	35	9%
20-24	31	9%	33	9%
25-29	24	7%	36	9%
30-34	35	10%	22	6%
35-39	24	7%	22	6%
40-44	17	5%	15	4%
45-49	7	2%	14	4%
50-54	8	2%	6	2%
55-59	5	1%	5	1%
60-64	4	1%	6	2%
65+	2	1%	3	1%
Total	357	100%	380	100%

Table 5.19. Average age of the members of the families interviewed, according to sex and city

City	Males	(SD)	Females	(SD)	Average total	(SD)
Florence	20	(16.5)	19	(16.1)	20	(16.3)
Bergamo	19	(15.7)	19	(16.5)	19	(16.0)
Brescia	23	(18.2)	20	(18.4)	21	(18.2)
Venice	17	(14.6)	18	(16.1)	17	(15.3)
Bolzano	21	(13.4)	21	(14.9)	21	(14.1)
Average age	20	(15.7)	19	(16.2)	20	(15.9)

Table 5.20. Families interviewed, with or without children

City	Florence (%)		Bergamo(%)		Brescia (%)		Venice (%)		Bolzano (%)		Total (%)	
With children	38	(73)	14	(87)	10	(77)	20	(83)	15	(47)	97	(71)
Without children	14	(27)	2	(13)	3	(23)	4	(17)	17	(53)	40	(29)
Total	52	(100)	16	(100)	13	(100)	24	(100)	32	(100)	137	(100)

Table 5.21. Number of children

City	Number of children	Average number of children per family	SD
Florence	71	1.4	1.1
Bergamo	21	1.3	0.9
Brescia	20	1.5	1.1
Venice	36	1.5	1.1
Bolzano	19	0.6	0.8
Total	167	1.2	1.1

Table 5.22. Sex of the interviewee

City	Florence (%)		Bergamo (%)		Brescia (%)		Venice (%)		Bolzano (%)		Total (%)	
Males	14	(27)	5	(31)	4	(31)	5	(21)	10	(31)	38	(28)
Females	38	(73)	11	(69)	9	(69)	19	(79)	22	(69)	99	(72)
Total	52	(100)	16	(100)	13	(100)	24	(100)	32	(100)	137	(100)

Table 5.23. Sex of the interviewee in families with children

City	Florence (%)		Bergamo (%)		Brescia (%)		Venice (%)		Bolzano (%)		Total (%)	
Males	7	(18)	4	(29)	4	(40)	5	(25)	4	(27)	24	(25)
Females	31	(82)	10	(71)	6	(60)	15	(75)	11	(73)	73	(75)
Total	38	(100)	14	(100)	10	(100)	20	(100)	15	(100)	97	(100)

Table 5.24. Role of the interviewee, in relation to the children, in families with children

City	Florence (%)		Bergamo (%)		Brescia (%)		Venice (%)		Bolzano (%)		Total (%)	
Mother	27	(71)	10	(71)	2	(20)	14	(70)	11	(73)	64	(66)
Father	7	(18)	4	(29)	4	(40)	4	(20)	4	(27)	23	(24)
Sister	1	(3)	0	(0)	0	(0)	0	(0)	0	(0)	1	(1)
Brother	0	(0)	0	(0)	0	(0)	1	(5)	0	(0)	1	(1)
Grandmother	3	(8)	0	(0)	4	(40)	1	(5)	0	(0)	8	(8)
Total	38	(100)	14	(100)	10	(100)	20	(100)	15	(100)	97	(100)

Table 5.25. Average age of interviewees, city by city

City	For all families			Only families with children		
	Number interviewed	Average age	(SD)	Number interviewed	Average age	(SD)
Florence	52	30	(8.7)	38	29	(7.1)
Bergamo	16	25	(6.3)	14	25	(5.7)
Brescia	13	38	(9.6)	10	37	(10.4)
Venice	24	33	(10.3)	20	31	(10.3)
Bolzano	32	32	(11.5)	15	27	(6.4)
Total	137	31	(9.9)	97	29	(8.5)

Table 5.26. Age groups of the interviewees

Age grp	For all families		Only families with children	
	Frequency	Percentage	Frequency	Percentage
10-19	13	9%	7	7%
20-29	53	39%	50	52%
30-39	44	32%	28	29%
40-49	20	15%	9	9%
50-59	7	5%	3	3%
Total	137	100%	97	100%

Table 5.27. Age group of the interviewees in families with children, city by city

City	Florence (%)		Bergamo (%)		Brescia (%)		Venice (%)		Bolzano (%)		Total	(%)
10-19	1	(3)	2	(14)	0	(0)	2	(10)	2	(13)	7	(7)
20-29	22	(58)	10	(71)	2	(20)	7	(35)	9	(60)	50	(52)
30-39	12	(32)	2	(14)	4	(40)	7	(35)	3	(20)	28	(29)
40-49	2	(5)	0	(0)	3	(30)	3	(15)	1	(7)	9	(9)
50-59	1	(3)	0	(0)	1	(10)	1	(5)	0	(0)	3	(3)
Total	38	(100)	14	(100)	10	(100)	20	(100)	15	(100)	97	(100)

Table 5.28. Average age of mothers of children

City	Number interviewed	Average age	SD
Florence	37	28	5.8
Bergamo	14	24	5.8
Brescia	8	27	8.2
Venice	20	30	8.7
Bolzano	14	26	6.2
Total	93	27	6.9

Table 5.29. Age group of the mothers in the case of families with children

City	Florence (%)		Bergamo (%)		Brescia (%)		Venice (%)		Bolzano (%)		Total (%)	
15-19	1	(3)	3	(21)	1	(12)	1	(5)	2	(14)	8	(9)
20-24	9	(24)	5	(36)	2	(25)	5	(25)	3	(21)	24	(26)
25-29	16	(43)	5	(36)	3	(38)	3	(15)	6	(43)	33	(35)
30-34	8	(22)	0	(0)	1	(12)	5	(25)	2	(14)	16	(17)
35-39	1	(3)	1	(7)	0	(0)	4	(20)	0	(0)	6	(6)
40-44	1	(3)	0	(0)	1	(12)	0	(0)	1	(7)	3	(3)
45-49	1	(3)	0	(0)	0	(0)	2	(10)	0	(0)	3	(3)
Total	37	(100)	14	(100)	8	(100)	20	(100)	14	(100)	93	(100)

Table 5.30. Age group at delivery of the mothers of children

City	Florence (%)		Bergamo (%)		Brescia (%)		Venice (%)		Bolzano (%)		Total (%)	
15-19	4	(6)	6	(29)	4	(27)	8	(22)	6	(35)	28	(18)
20-24	31	(44)	9	(43)	3	(20)	13	(36)	3	(18)	59	(37)
25-29	21	(30)	5	(24)	7	(47)	7	(19)	7	(41)	47	(30)
30-34	9	(13)	1	(5)	0	(0)	3	(8)	0	(0)	13	(8)
35-39	1	(1)	0	(0)	1	(7)	3	(8)	1	(6)	6	(4)
40-44	0	(0)	0	(0)	0	(0)	2	(6)	0	(0)	2	(1)
45-49	4	(6)	0	(0)	0	(0)	0	(0)	0	(0)	4	(3)
Total	70	(100)	21	(100)	15	(100)	36	(100)	17	(100)	159	(100)

Table 5.31. Number of years spent by the interviewees at the camp

Years spent at camp	Frequency	Percentage
Less than 1 year	13	10%
From 1 – 5	48	35%
From 6 – 10	61	45%
More than 10	14	10%
Total	136	100%

Table 5.32. Number of years spent by the interviewees at the camp, by city

City	Florence (%)		Bergamo (%)		Brescia (%)		Venice (%)		Bolzano (%)		Total (%)	
< 1	3	(6)	-	(-)	1	(8)	9	(37)	-	(-)	13	(10)
1	1	(2)	2	(12)	0	(0)	0	(0)	-	(-)	3	(2)
2	6	(12)	2	(12)	0	(0)	1	(4)	-	(-)	9	(7)
3	9	(17)	7	(44)	1	(8)	4	(17)	2	(6)	23	(17)
4	2	(4)	2	(12)	1	(8)	2	(8)	3	(10)	10	(7)
5	1	(2)	0	(0)	0	(0)	2	(8)	0	(0)	3	(2)
6	4	(8)	0	(0)	0	(0)	3	(12)	26	(84)	33	(24)
7	0	(0)	1	(6)	0	(0)	0	(0)	-	(-)	1	(1)
8	1	(2)	2	(12)	1	(8)	0	(0)	-	(-)	4	(3)
9	3	(6)	-	(-)	9	(69)	1	(4)	-	(-)	13	(10)
10	8	(15)	-	(-)	-	(-)	2	(8)	-	(-)	10	(7)
11-15	14	(27)	-	(-)	-	(-)	-	(-)	-	(-)	14	(10)
Total	52	(100)	16	(100)	13	(100)	24	(100)	31	(100)	136	(100)

Table 5.33. Average number of years spent at the camp by the interviewees, city by city

City	Interviewees	Average	SD
Florence	52	7.2	4.6
Bergamo	16	3.6	2.2
Brescia	13	7.4	3.0
Venice	24	3.3	3.3
Bolzano	31	5.6	0.9
Total	136	5.7	3.8

Table 5.34. Literacy of interviewees city by city

City	Florence (%)		Bergamo (%)		Brescia (%)		Venice (%)		Bolzano (%)		Total (%)	
Reads and writes	35	(67)	13	(81)	11	(85)	11	(46)	27	(84)	97	(71)
Total	52	(100)	16	(100)	13	(100)	24	(100)	32	(100)	137	(100)

Table 5.35. Literacy of interviewees according to sex

City	Men (%)		Women (%)		Total (%)	
Reads and writes	37	(97)	60	(61)	97	(71)
Total	38	(100)	99	(100)	137	(100)

Table 5.36. Literacy of the mothers interviewed

City	Florence (%)		Bergamo(%)		Brescia (%)		Venice (%)		Bolzano (%)		Total (%)	
Reads and writes	15	(56)	7	(70)	2	(100)	3	(21)	10	(91)	37	(58)
Total	27	(100)	10	(100)	2	(100)	14	(100)	11	(100)	64	(100)

Table 5.37. Literacy of the mothers by age groups

City	16-20 (%)		21-25 (%)		26-30 (%)		31-35 (%)		36-50 (%)		Totale (%)	
Reads and writes	6	(67)	10	(59)	14	(56)	5	(71)	2	(33)	37	(58)
Total	9	(100)	17	(100)	25	(100)	7	(100)	6	(100)	64	(100)

Table 5.38. Families in which nobody smokes and in which at least one person smokes, city by city

City	Florence (%)		Bergamo (%)		Brescia (%)		Venice (%)		Bolzano (%)		Total (%)	
Nobody	5	(10)	4	(25)	0	(0)	1	(4)	5	(16)	15	(11)
At least one person	47	(90)	12	(75)	13	(100)	23	(96)	27	(84)	122	(89)
Total	52	(100)	16	(100)	13	(100)	24	(100)	32	(100)	137	(100)

Table 5.39. Smokers per family, including families in which nobody smokes, city by city

City	Florence (%)		Bergamo (%)		Brescia (%)		Venice (%)		Bolzano (%)		Total (%)	
0	5	(10)	4	(25)	0	(0)	1	(4)	5	(16)	15	(11)
1	18	(35)	6	(38)	7	(54)	6	(25)	11	(34)	48	(35)
2	22	(42)	2	(12)	4	(31)	12	(50)	14	(44)	54	(39)
3	5	(10)	2	(12)	1	(8)	2	(8)	2	(6)	12	(9)
4	1	(2)	2	(12)	0	(0)	2	(8)	0	(0)	5	(4)
5	0	(0)	0	(0)	0	(0)	1	(4)	0	(0)	1	(1)
6	1	(2)	0	(0)	0	(0)	0	(0)	0	(0)	1	(1)
7	0	(0)	0	(0)	1	(8)	0	(0)	0	(0)	1	(1)
Total	52	(100)	16	(100)	13	(100)	24	(100)	32	(100)	137	(100)
Average	1.7		1.5		1.9		2.0		1.4		1.7	
SD	1.1		1.4		1.7		1.1		0.8		1.1	

Table 5.40. Number of smokers per family, in families in which at least one person smokes at home, city by city

City	Florence (%)		Bergamo (%)		Brescia (%)		Venice (%)		Bolzano (%)		Total (%)	
1	18	(38)	6	(50)	7	(54)	6	(26)	11	(41)	48	(39)
2	22	(47)	2	(17)	4	(31)	12	(52)	14	(52)	54	(44)
3	5	(11)	2	(17)	1	(8)	2	(9)	2	(7)	12	(10)
4	1	(2)	2	(17)	0	(0)	2	(9)	0	(0)	5	(4)
5	0	(0)	0	(0)	0	(0)	1	(4)	0	(0)	1	(1)
6	1	(2)	0	(0)	0	(0)	0	(0)	0	(0)	1	(1)
7	0	(0)	0	(0)	1	(8)	0	(0)	0	(0)	1	(1)
Total	47	(100)	12	(100)	13	(100)	23	(100)	27	(100)	122	(100)
Average	1.9		2.0		1.9		2.1		1.7		1.9	
SD	1.0		1.2		1.7		1.1		0.6		1.0	

Table 5.41. Number of people who smoke more than 10 cigarettes per day, including families in which nobody smokes, city by city

City	Florence (%)		Bergamo (%)		Brescia (%)		Venice (%)		Bolzano (%)		Total (%)	
0	13	(25)	7	(47)	5	(38)	4	(17)	9	(28)	38	(28)
1	21	(40)	5	(33)	4	(31)	6	(25)	16	(50)	52	(38)
2	13	(25)	1	(7)	2	(15)	11	(46)	7	(22)	34	(25)
3	3	(6)	1	(7)	1	(8)	2	(8)	0	(0)	7	(5)
4	1	(2)	1	(7)	0	(0)	0	(0)	0	(0)	2	(1)
5	0	(0)	0	(0)	0	(0)	1	(4)	0	(0)	1	(1)
6	1	(2)	0	(0)	0	(0)	0	(0)	0	(0)	1	(1)
7	0	(0)	0	(0)	1	(8)	0	(0)	0	(0)	1	(1)
Total	52	(100)	15	(100)	13	(100)	24	(100)	32	(100)	136	(100)
Average	1.3		0.9		1.4		1.6		0.9		1.2	
SD	1.2		1.2		1.9		1.1		0.7		1.2	

Table 5.42. Number of smokers who smoke more than 10 cigarettes per day in families in which at least one person smokes at home, city by city

City	Florence (%)		Bergamo (%)		Brescia (%)		Venice (%)		Bolzano (%)		Total (%)	
0	8	(17)	3	(27)	5	(38)	3	(13)	4	(15)	23	(19)
1	21	(45)	5	(45)	4	(31)	6	(26)	16	(59)	52	(43)
2	13	(28)	1	(9)	2	(15)	11	(48)	7	(26)	34	(28)
3	3	(6)	1	(9)	1	(8)	2	(9)	0	(0)	7	(6)
4	1	(2)	1	(9)	0	(0)	0	(0)	0	(0)	2	(2)
5	0	(0)	0	(0)	0	(0)	1	(4)	0	(0)	1	(1)
6	1	(2)	0	(0)	0	(0)	0	(0)	0	(0)	1	(1)
7	0	(0)	0	(0)	1	(8)	0	(0)	0	(0)	1	(1)
Total	47	(100)	11	(100)	13	(100)	23	(100)	27	(100)	121	(100)
Average	1.4		1.3		1.4		1.7		1.1		1.4	
SD	1.1		1.3		1.9		1.1		0.6		1.2	

Table 5.43. Age of children, city by city

City	Florence (%)		Bergamo (%)		Brescia (%)		Venice (%)		Bolzano (%)		Total (%)	
0	14	(20)	6	(29)	3	(15)	6	(17)	4	(21)	33	(20)
1	10	(14)	6	(29)	3	(15)	10	(28)	3	(16)	32	(19)
2	9	(13)	3	(14)	6	(30)	3	(8)	4	(21)	25	(15)
3	16	(23)	2	(10)	2	(10)	7	(19)	3	(16)	30	(18)
4	13	(18)	3	(14)	4	(20)	5	(14)	2	(11)	27	(16)
5	9	(13)	1	(5)	2	(10)	5	(14)	3	(16)	20	(12)
Total	71	(100)	21	(100)	20	(100)	36	(100)	19	(100)	167	(100)

Table 5.44. Sex of the children in the study, city by city

City	Florence (%)		Bergamo (%)		Brescia (%)		Venice (%)		Bolzano (%)		Total (%)	
Males	34	(48)	13	(62)	8	(40)	17	(47)	8	(42)	80	(48)
Females	37	(52)	8	(38)	12	(60)	19	(53)	11	(58)	87	(52)
Total	71	(100)	21	(100)	20	(100)	36	(100)	19	(100)	167	(100)

Table 5.45. Children born in Italy or abroad, city by city

City	Florence (%)		Bergamo (%)		Brescia (%)		Venice (%)		Bolzano (%)		Total (%)	
Italy	52	(74)	16	(76)	17	(85)	26	(72)	18	(95)	129	(78)
Abroad	18	(26)	5	(24)	3	(15)	10	(28)	1	(5)	37	(22)
Total	70	(100)	21	(100)	20	(100)	36	(100)	19	(100)	166	(100)

Table 5.46. Place of birth of the children, city by city

City	Florence (%)		Bergamo (%)		Brescia (%)		Venice (%)		Bolzano (%)		Total (%)	
Florence	52	(74)	-		-		-		-		52	(31)
Bergamo	-		15	(71)	-		-		-		15	(9)
Brescia	-		-		17	(85)	-		-		17	(10)
Venice	-		-		-		26	(72)	-		26	(16)
Bolzano	-		-		-		-		18	(95)	18	(11)
Bologna	-		1	(5)	-		-		-		1	(1)
Kosovo	16	(23)	5	(24)	3	(15)	10	(28)	-		34	(20)
Macedonia	1	(1)	-		-		-		1	(5)	2	(1)
Bosnia	1	(1)	-		-		-		-		1	(1)
Total	70	(100)	21	(100)	20	(100)	36	(100)	19	(100)	166	(100)

Table 5.47. Home or hospital births, in Italy or abroad

	Italy (%)	Abroad (%)	Total (%)
Home	1 (1)	5 (14)	6 (4)
Hospital	128 (99)	31 (86)	159 (96)
Total	129 (100)	36 (100)	165 (100)

Table 5.48. Home or hospital births, Florence

	Children	Percentage
Home, Kosovo	3	4%
Hospital, Kosovo	13	19%
Hospital, Macedonia	1	1%
Hospital, Bosnia	1	1%
Hospital "Torre Galli", Flor.	39	57%
Hospital "Careggi", Florence	12	17%
Total	69	100%

Table 5.49. Home or hospital births, Bergamo

	Children	Percentage
Hospital, Kosovo	5	24%
Hospital, Bologna	1	5%
Hospital "Seriata", Bergamo	10	48%
Hospital "Maggiore", Bergamo	5	24%
Total	21	100%

Table 5.50. Home or hospital births, Brescia

	Children	Percentage
Hospital, Kosovo	3	15%
Hospital "Civile", Bs	15	75%
Hospital "Fatebenefratelli", Bs	2	10%
Total	20	100%

Table 5.51. Home or hospital births, Venice

	Children	Percentage
Home, Kosovo	3	8%
Hospital, Kosovo	7	19%
Hospital "Umberto I", Venice	23	64%
Hospital "San Donà", Venice	2	6%
Hospital "Villa Salus"	1	3%
Total	36	100%

Table 5.52. Home or hospital births, Bolzano

	Children	Percentage
Hospital, Macedonia	1	5%
Hospital "S.Maurizio", Bolzano	15	79%
Hospital "Merano", Bolzano	3	16%
Total	19	100%

Table 5.53. Average birthweight, verified and unverified, city by city

City	Florence (%)		Bergamo (%)		Brescia (%)		Venice (%)		Bolzano (%)		Total (%)	
Verified	44	(70)	0	(0)	8	(42)	15	(56)	4	(22)	71	(48)
Average		3.01		-		3.08		3.07		3.30		3.05
SD		0.54		-		0.56		0.54		0.31		0.53
Not verified	19	(30)	20	(100)	11	(58)	12	(44)	14	(78)	76	(52)
Average		3.22		3.26		2.80		2.85		3.16		3.10
SD		0.41		0.59		0.33		0.58		0.52		0.52
Total	63	(100)	20	(100)	19	(100)	27	(100)	18	(100)	147	(100)
Average		3.07		3.26		2.92		2.98		3.19		3.08
SD		0.51		0.59		0.45		0.56		0.48		0.52

Table 5.54. Percentage of low birthweights (below 2.50kg), city by city

City		Florence (%)		Bergamo (%)		Brescia (%)		Venice (%)		Bolzano (%)		Total (%)	
Verified	Under-weight	3	(7)	-	(-)	1	(12)	2	(13)	0	(0)	6	(8)
	Total	44		-		8		15		4		71	
Not verified	Under-weight	0	(0)	2	(10)	2	(18)	3	(25)	1	(7)	8	(11)
	Total	19		20		11		12		14		76	
Total	Under-weight	3	(5)	2	(10)	3	(16)	5	(19)	1	(6)	14	(10)
	Total	63		20		19		27		18		147	

Table 5.55. Perception of the interviewee regarding growth of the child, city by city

City	Florence (%)	Bergamo (%)	Brescia (%)	Venice (%)	Bolzano (%)	Total (%)
Large	22 (32)	6 (29)	7 (35)	12 (33)	5 (26)	52 (32)
Normal	28 (41)	10 (48)	11 (55)	20 (56)	10 (53)	79 (48)
Small	19 (28)	5 (24)	2 (10)	4 (11)	4 (21)	34 (21)
Total	63 (100)	21 (100)	20 (100)	36 (100)	19 (100)	165 (100)

Table 5.56. Perception of the interviewee regarding growth of the child, by age of the child

City	0 (%)	1 (%)	2 (%)	3 (%)	4 (%)	5 (%)	Total (%)
Large	12 (36)	7 (22)	7 (29)	10 (33)	10 (37)	6 (32)	52 (32)
Normal	15 (45)	17 (53)	12 (50)	14 (47)	13 (48)	8 (42)	79 (48)
Small	6 (18)	8 (25)	5 (21)	6 (20)	4 (15)	5 (26)	34 (21)
Total	33 (100)	32 (100)	24 (100)	30 (100)	27 (100)	19 (100)	165 (100)

Table 5.57. Perception of the interviewee regarding growth of the child, by sex of the child

City	Male (%)	Female (%)	Total (%)
Large	26 (33)	26 (30)	52 (32)
Normal	36 (46)	43 (49)	79 (48)
Small	16 (21)	18 (21)	34 (21)
Total	78 (100)	87 (100)	165 (100)

Table 5.58. Children who had diarrhoea in the 15 days prior to the interview, city by city

City	Florence (%)		Bergamo (%)		Brescia (%)		Venice (%)		Bolzano (%)		Total (%)	
Yes	23	(33)	3	(14)	10	(50)	11	(31)	6	(32)	53	(32)
Total	69	(100)	21	(100)	20	(100)	36	(100)	19	(100)	165	(100)

Table 5.59. Proportion of children with cough in the fifteen days prior to the interview, city by city

City	Florence (%)		Bergamo (%)		Brescia (%)		Venice (%)		Bolzano (%)		Total (%)	
Yes	44	(64)	10	(48)	14	(70)	15	(42)	7	(37)	90	(55)
Total	69	(100)	21	(100)	20	(100)	36	(100)	19	(100)	165	(100)

Table 5.60. Proportion of children with cough in the fifteen days prior to the interview, by age of the child

Age	0	(%)	1	(%)	2	(%)	3	(%)	4	(%)	5	(%)	Total	(%)
Yes	17	(52)	24	(75)	13	(54)	11	(37)	16	(59)	9	(47)	90	(55)
Total	33	(100)	32	(100)	24	(100)	30	(100)	27	(100)	19	(100)	165	(100)

Table 5.61. Proportion of children with cough in the fifteen days prior to the interview, by sex

Sex	Male (%)		Female (%)		Total (%)	
Yes	43	(55)	47	(54)	90	(55)
Total	78	(100)	87	(100)	165	(100)

Table 5.62. Children who have had respiratory difficulties or wheezing during their lifetime

City	Florence (%)		Bergamo (%)		Brescia (%)		Venice (%)		Bolzano (%)		Total (%)	
Yes	20	(29)	5	(24)	3	(15)	5	(14)	5	(26)	38	(23)
Total	69	(100)	21	(100)	20	(100)	36	(100)	19	(100)	165	(100)

Table 5.63. Period prevalence of respiratory problems or wheezing in the past 12 months, city by city

City	Florence (%)		Bergamo (%)		Brescia (%)		Venice (%)		Bolzano (%)		Total (%)	
Yes	19	(28)	4	(19)	1	(5)	3	(8)	1	(5)	28	(17)
Total	69	(100)	21	(100)	20	(100)	36	(100)	19	(100)	165	(100)

Table 5.64. Period prevalence of respiratory problems or wheezing in the past 12 months, by age

Age	0	(%)	1	(%)	2	(%)	3	(%)	4	(%)	5	(%)	Total	(%)
Yes	7	(21)	9	(28)	2	(8)	4	(13)	3	(11)	3	(16)	28	(17)
Total	33	(100)	32	(100)	24	(100)	30	(100)	27	(100)	19	(100)	165	(100)

Table 5.65. Period prevalence of respiratory problems or wheezing in the past 12 months, by sex

Sex	Male	(%)	Female	(%)	Total	(%)
Yes	13	(17)	15	(17)	28	(17)
Total	78	(100)	87	(100)	165	(100)

Table 5.66. Number of times each child has had breathing difficulties in the last year, city by city

City	Florence (%)		Bergamo (%)		Brescia (%)		Venice (%)		Bolzano (%)		Total (%)	
Never in lifetime	49	(71)	16	(76)	17	(85)	31	(86)	14	(74)	127	(77)
Never in last year	1	(1)	1	(5)	2	(10)	2	(6)	4	(21)	10	(6)
1	13	(19)	2	(10)	1	(5)	2	(6)	0	(0)	18	(11)
2	2	(3)	0	(0)	0	(0)	0	(0)	0	(0)	2	(1)
4	2	(3)	2	(10)	0	(0)	0	(0)	0	(0)	4	(2)
5	0	(0)	0	(0)	0	(0)	1	(3)	0	(0)	1	(1)
6	0	(0)	0	(0)	0	(0)	0	(0)	1	(5)	1	(1)
Always	2	(3)	0	(0)	0	(0)	0	(0)	0	(0)	2	(1)
Total	69	(100)	21	(100)	20	(100)	36	(100)	19	(100)	165	(100)

Table 5.67. Period prevalence of at least four attacks of respiratory problems or wheezing in the past 12 months, by city

City	Florence (%)		Bergamo (%)		Brescia (%)		Venice (%)		Bolzano (%)		Total (%)	
Yes	4	(6)	2	(10)	0	(0)	1	(3)	1	(5)	8	(5)
Total	69	(100)	21	(100)	20	(100)	36	(100)	19	(100)	165	(100)

Table 5.68. Period prevalence of at least four attacks of respiratory problems or wheezing in the past 12 months, by age

Age	0	(%)	1	(%)	2	(%)	3	(%)	4	(%)	5	(%)	Total	(%)
Yes	2	(6)	5	(16)	0	(0)	0	(0)	0	(0)	1	(5)	8	(5)
Total	33	(100)	32	(100)	24	(100)	30	(100)	27	(100)	19	(100)	165	(100)

Table 5.69. Period prevalence of at least four attacks of respiratory problems or wheezing in the past 12 months, by sex

Sex	Male	(%)	Female	(%)	Total	(%)
Yes	6	(8)	2	(2)	8	(5)
Total	78	(100)	87	(100)	165	(100)

Table 5.70. Proportion of children with respiratory difficulties who were taken to see a doctor, city by city

City	Florence (%)		Bergamo (%)		Brescia (%)		Venice (%)		Bolzano (%)		Total (%)	
Yes	17	(85)	5	(100)	3	(100)	5	(100)	5	(100)	35	(92)
Total	20	(100)	5	(100)	3	(100)	5	(100)	5	(100)	38	(100)

Table 5.71. Diagnosis of respiratory problems, city by city

City	Florence (%)		Bergamo (%)		Brescia (%)		Venice (%)		Bolzano (%)		Total (%)	
Asthma	0	(0)	1	(20)	0	(0)	1	(20)	1	(20)	3	(9)
Asthmatic bronchitis	5	(29)	3	(60)	0	(0)	2	(40)	1	(20)	11	(31)
Allergic bronchitis	0	(0)	0	(0)	0	(0)	0	(0)	2	(40)	2	(6)
Bronchitis	6	(35)	1	(20)	1	(33)	1	(20)	1	(20)	10	(29)
Pneumonia	3	(18)	0	(0)	0	(0)	0	(0)	0	(0)	3	(9)
Catarrh	1	(6)	0	(0)	1	(33)	0	(0)	0	(0)	2	(6)
Due to heating	1	(6)	0	(0)	0	(0)	0	(0)	0	(0)	1	(3)
Respiratory difficulties	1	(6)	0	(0)	0	(0)	0	(0)	0	(0)	1	(3)
Don't know	0	(0)	0	(0)	1	(33)	1	(20)	0	(0)	2	(6)
Total	17	(100)	5	(100)	3	(100)	5	(100)	5	(100)	35	(100)

Table 5.72. Children with “active asthma”, city by city

City	Florence (%)		Bergamo (%)		Brescia (%)		Venice (%)		Bolzano (%)		Total (%)	
Yes	6	(9)	3	(14)	0	(0)	3	(8)	0	(0)	12	(7)
Total	69	(100)	21	(100)	20	(100)	36	(100)	19	(100)	165	(100)

Table 5.73. Children with “active asthma”, by age

Age	0	(%)	1	(%)	2	(%)	3	(%)	4	(%)	5	(%)	Total	(%)
Yes	3	(9)	5	(16)	0	(0)	2	(7)	1	(4)	1	(5)	12	(7)
Total	33	(100)	32	(100)	24	(100)	30	(100)	27	(100)	19	(100)	165	(100)

Table 5.74. Children with “active asthma”, by sex

Sex	Male	(%)	Female	(%)	Total	(%)
Yes	8	(10)	4	(5)	12	(7)
Total	78	(100)	87	(100)	165	(100)

Table 5.75. Children who have suffered skin complaints, city by city

City	Florence (%)		Bergamo (%)		Brescia (%)		Venice (%)		Bolzano (%)		Total (%)	
Yes	4	(6)	2	(10)	0	(0)	2	(6)	0	(0)	8	(5)
Total	69	(100)	21	(100)	20	(100)	36	(100)	19	(100)	165	(100)

Table 5.76. Types of skin complaint, city by city

City	Florence (%)		Bergamo (%)		Venice (%)		Total (%)	
Dermatitis	1	(25)	1	(50)	1	(50)	3	(38)
Allergy	1	(25)	0	(0)	0	(0)	1	(12)
Scabies	2	(50)	0	(0)	0	(0)	2	(25)
Mycotic stomatitis	0	(0)	1	(50)	0	(0)	1	(12)
Mycosis	0	(0)	0	(0)	1	(50)	1	(12)
Total	4	(100)	2	(100)	2	(100)	8	(100)

Table 5.77. Children who have suffered skin complaints, by age

Age	0 (%)	1 (%)	2 (%)	3 (%)	4 (%)	5 (%)	Total (%)
Yes	3 (9)	3 (9)	0 (0)	0 (0)	2 (7)	0 (0)	8 (5)
Total	33 (100)	32 (100)	24 (100)	30 (100)	27 (100)	19 (100)	165 (100)

Table 5.78. Children who have suffered skin complaints, by sex

Sex	Male (%)	Female (%)	Total (%)
Yes	4 (5)	4 (5)	8 (5)
Total	78 (100)	87 (100)	165 (100)

Table 5.79. Proportion of children with skin complaints who were taken for medical examination, city by city

City	Florence (%)		Bergamo (%)		Venice (%)		Total (%)	
Yes	4	(100)	2	(100)	1	(50)	7	(88)
Total	4	(100)	2	(100)	2	(100)	8	(100)

Table 5.80. Where children with skin diseases were taken for medical examination

City	Florence (%)		Bergamo (%)		Venice (%)		Total (%)	
Paediatric consultancy	1	(25)	-	(-)	0	(0)	1	(14)
School doctor	1	(25)	0	(0)	0	(0)	1	(14)
Casualty	0	(0)	1	(50)	0	(0)	1	(14)
Hospital, general	2	(50)	1	(50)	1	(100)	4	(57)
Total	4	(100)	2	(100)	1	(100)	7	(100)

Table 5.81. Other symptoms exhibited by the children, city by city

City	Florence (%)		Bergamo (%)		Brescia (%)		Venice (%)		Bolzano (%)		Total (%)	
Yes	24	(35)	10	(48)	16	(80)	12	(33)	8	(42)	70	(42)
Total	69	(100)	21	(100)	20	(100)	36	(100)	19	(100)	165	(100)

Table 5.82. Types of symptoms suffered in the previous 15 days, city by city

City	Florence (%)		Bergamo(%)		Brescia (%)		Venice (%)		Bolzano (%)		Total (%)	
Fever	18	(26)	5	(24)	14	(70)	12	(33)	6	(32)	55	(33)
Vomiting	2	(3)	3	(14)	10	(50)	0	(0)	0	(0)	15	(9)
Rhinitis	1	(1)	1	(5)	1	(5)	3	(8)	0	(0)	6	(4)
Pharyngitis	5	(7)	0	(0)	0	(0)	0	(0)	0	(0)	5	(3)
Otitis	2	(3)	1	(5)	0	(0)	0	(0)	1	(5)	4	(2)
Abdominal pains	0	(0)	1	(5)	0	(0)	0	(0)	0	(0)	1	(1)
Urinary-tract inf.	0	(0)	0	(0)	0	(0)	0	(0)	1	(5)	1	(1)
Hepatitis	1	(1)	0	(0)	0	(0)	0	(0)	0	(0)	1	(1)
Chickenpox	1	(1)	0	(0)	0	(0)	0	(0)	0	(0)	1	(1)
Roseola infantilis	0	(0)	0	(0)	1	(5)	0	(0)	0	(0)	1	(1)
Toothache	0	(0)	1	(5)	0	(0)	0	(0)	0	(0)	1	(1)
Influenza	0	(0)	0	(0)	0	(0)	0	(0)	1	(5)	1	(1)
Total no. children	69	(100)	21	(100)	20	(100)	36	(100)	19	(100)	165	(100)

Table 5.83. Children who suffered fever, city by city

City	Florence (%)		Bergamo (%)		Brescia (%)		Venice (%)		Bolzano (%)		Total (%)	
Yes	18	(26)	5	(25)	14	(70)	12	(33)	6	(32)	55	(34)
Total	69	(100)	20	(100)	20	(100)	36	(100)	19	(100)	164	(100)

Table 5.84. Children who suffered fever, by sex

Sex	Male (%)		Female (%)		Total (%)	
Yes	22	(28)	33	(38)	55	(34)
Total	78	(100)	86	(100)	164	(100)

Table 5.85. Children with at least one symptom, city by city

City	Florence (%)		Bergamo (%)		Brescia (%)		Venice (%)		Bolzano (%)		Total (%)	
Yes	50	(72)	14	(67)	17	(85)	17	(47)	13	(68)	111	(67)
Total	69	(100)	21	(100)	20	(100)	36	(100)	19	(100)	165	(100)

Table 5.86. Children with coughing plus other pathologies

	Frequency	Percentage
Only coughing	23	14%
Coughing, fever	13	8%
Coughing, diarrhoea	11	7%
Coughing, fever, diarrhoea	10	6%
Coughing, fever, diarrhoea, vomiting	6	4%
Coughing, fever, vomiting	4	2%
Coughing, fever, diarrhoea, skin diseases	4	2%
Coughing, fever, diarrhoea, rhinitis	3	2%
Coughing, diarrhoea, pharyngitis	2	1%
Coughing, fever, skin complaints	2	1%
Coughing, skin complaints	1	1%
Coughing, fever, rhinitis	1	1%
Coughing, fever, pharyngitis	1	1%
Coughing, fever, pharyngitis, rhinitis	1	1%
Coughing, fever, diarrhoea, vomiting, otitis	1	1%
Coughing, diarrhoea, otitis	1	1%
Coughing, diarrhoea, chicken pox	1	1%
Coughing, diarrhoea, vomiting, abdominal pains	1	1%
Coughing, vomiting	1	1%
Coughing, rhinitis	1	1%
Coughing, otitis, toothache	1	1%
Coughing, hepatitis	1	1%
<i>Cumulative coughing</i>	<i>90</i>	<i>55%</i>
<i>Other</i>	<i>21</i>	<i>13%</i>
<i>Nothing</i>	<i>54</i>	<i>33%</i>
Total	165	100%

Table 5.87. Relationship between occurrence of cough and other pathologies in the preceeding 15 days

	Fever		Vomiting		Diarrhoea	
	Yes (%)	No (%)	Yes (%)	No (%)	Yes (%)	No (%)
Coughing	46 (84)	44 (40)	13 (87)	77 (52)	40 (75)	50 (45)
Total	55 (100)	109 (100)	15 (100)	149 (100)	53 (100)	112 (100)
OR, 95% CI	3,1 < 7,5 < 18,7		1,2 < 6,1 < 41,0*		1,7 < 3,8 < 8,5	

* may not be accurate; Exact 95% CI 1.6 – 56.8; Fisher exact 2-tailed test p=0.012

Table 5.88. Children with diarrhoea plus other pathologies

	Frequency	Percentage
Only diarrhoea	6	4%
diarrhoea, coughing	11	7%
diarrhoea, coughing, fever	10	6%
diarrhoea, coughing, fever, vomiting	6	4%
diarrhoea, coughing, fever, skin complaints	4	2%
diarrhoea, fever	3	2%
diarrhoea, coughing, fever, rhinitis	3	2%
diarrhoea, coughing, pharyngitis	2	1%
diarrhoea, coughing, fever, vomiting, otitis	1	1%
diarrhoea, coughing, vomiting, abdominal pain	1	1%
diarrhoea, coughing, otitis	1	1%
diarrhoea, coughing, chicken pox	1	1%
diarrhoea, fever, vomiting	1	1%
diarrhoea, fever, otitis	1	1%
diarrhoea, urinary-tract infection	1	1%
diarrhoea, roseola infantilis	1	1%
<i>Cumulative diarrhoea</i>	<i>53</i>	<i>32%</i>
<i>Other</i>	<i>58</i>	<i>35%</i>
<i>Nothing</i>	<i>54</i>	<i>33%</i>
Total	165	100%

Table 5.89. Relationship between occurrence of diarrhoea and other pathologies in the previous 15 days

	Fever		Coughing		Vomiting	
	Yes	No	Yes	No	Yes	No
Diarrhoea	29(53%)	23(21%)	40(44%)	13(17%)	9(60%)	43(29%)
Total	55	109	90	75	15	149
OR, 95% CI	1.9 < 4.2 < 9.0		1.7 < 3.8 < 8.5		1.1 < 3.7 < 12.7*	

* may not be accurate; Exact 95% CI 1.1 – 13.3; Fisher exact 2-tailed test p=0.020

Table 5.90. Compendium of pathologies recorded and percentages of children examined by category

Pathologies	Freq.	%	Examined %	Cough	Fever	Diarrhoea	Vomition
None	54	33%	-----	-----	-----	-----	-----
Cough	23	14%	11 48%	•			
Cough, fever	13	8%	10 77%	•	•		
Cough, diarrhoea	11	7%	9 82%	•		•	
Cough, fever, diarrhoea	10	6%	10 100%	•	•	•	
Cough, fever, diarrhoea, vomition	6	4%	4 67%	•	•	•	•
Diarrhoea	6	4%	2 33%			•	
Fever	4	2%	2 50%		•		
Cough, fever, vomition	4	2%	2 50%	•	•		•
Cough, fever, diarrh., skin diseases	4	2%	4 100%	•	•	•	
Fever, diarrhoea	3	2%	1 33%		•	•	
Cough, fever, diarrhoea, rhinitis	3	2%	2 67%	•	•	•	
Cough, fever, skin diseases	2	1%	2 100%	•	•		
Cough, diarrhoea, pharyngitis	2	1%	2 100%	•		•	
Cough, fever, pharyngitis	1	1%	1 100%	•	•		
Cough, fever, pharyngitis, rhinitis	1	1%	1 100%	•	•		
Cough, fever, rhinitis	1	1%	1 100%	•	•		
Cough, fever, diarrh., vomit., otitis	1	1%	1 100%	•	•	•	•
Cough, diarrh., vomit., abdom.pain	1	1%	1 100%	•		•	•
Cough, diarrhoea, otitis	1	1%	1 100%	•		•	
Cough, diarrhoea, varicella	1	1%	1 100%	•		•	
Cough, vomition	1	1%	1 100%	•			•
Cough, rhinitis	1	1%	0 0%	•			
Cough, otitis, toothache	1	1%	1 100%	•			
Cough, hepatitis	1	1%	1 100%	•			
Cough, skin diseases	1	1%	1 100%	•			
Fever, diarrhoea, vomition	1	1%	0 0%		•	•	•
Fever, diarrhoea, otitis	1	1%	1 100%		•	•	
Diarrhoea, urinary tract infections	1	1%	1 100%			•	
Diarrhoea, roseola infantilis	1	1%	1 100%			•	
Vomition	1	1%	1 100%				•
Pharyngitis	1	1%	1 100%				
Skin diseases	1	1%	1 100%				
Influenza	1	1%	1 100%				
Total	165	100%	79/111 71%				

Table 5.91. Children with diarrhoea taken to see a doctor, city by city

City	Florence (%)		Bergamo (%)		Brescia (%)		Venice (%)		Bolzano (%)		Total (%)	
Yes	19	(83)	2	(67)	5	(50)	8	(73)	5	(83)	39	(74)
Total	23	(100)	3	(100)	10	(100)	11	(100)	6	(100)	53	(100)

Table 5.92. Children with diarrhoea taken for medical examination, by age of child

Age	0 (%)		1 (%)		2 (%)		3 (%)		4 (%)		5 (%)		Total (%)	
Examined	10	(91)	17	(89)	5	(63)	5	(71)	1	(25)	1	(25)	39	(74)
Total	11		19		8		7		4		4		53	

Chi square for linear trend, $p = 0.000$

Table 5.93. Where children with diarrhoea were taken for medical assistance, city by city

City	Florence (%)		Bergamo(%)		Brescia (%)		Venice (%)		Bolzano (%)		Total (%)	
Paediatric consultancy	9	(47)	-	(-)	-	(-)	1	(12)	-	(-)	10	(26)
Family paediatrician	0	(0)	0	(0)	0	(0)	0	(0)	1	(20)	1	(3)
Casualty	1	(5)	1	(50)	0	(0)	4	(50)	0	(0)	6	(15)
Hospital, general	9	(47)	1	(50)	5	(100)	3	(38)	4	(80)	22	(56)
Total	19	(100)	2	(100)	5	(100)	8	(100)	5	(100)	39	(100)

Table 5.94. Proportion of children with coughing who were taken to see a doctor, city by city

City	Florence (%)		Bergamo (%)		Brescia (%)		Venice (%)		Bolzano (%)		Total (%)	
Yes	33	(75)	6	(60)	8	(57)	11	(73)	6	(86)	64	(71)
Total	44	(100)	10	(100)	14	(100)	15	(100)	7	(100)	90	(100)

Table 5.95. Children with coughing taken for medical examination, in relation to age of child

Age	0 (%)		1 (%)		2 (%)		3 (%)		4 (%)		5 (%)		Total (%)
Examined	14	(82)	20	(83)	11	(85)	8	(73)	9	(56)	2	(22)	64 (71)
Total	17		24		13		11		16		9		90

Chi square for linear trend, $p = 0.000$

Table 5.96. Where children with coughing were taken for medical assistance, city by city

City	Florence (%)		Bergamo (%)		Brescia (%)		Venice (%)		Bolzano (%)		Total (%)	
Paediatric consultancy	20	(61)	-	(-)	-	(-)	1	(9)	-	(-)	21	(33)
Family paediatrician	1	(3)	1	(17)	1	(12)	0	(0)	2	(33)	5	(8)
Casualty	1	(3)	1	(17)	0	(0)	4	(36)	0	(0)	6	(9)
Hospital, general	11	(33)	4	(67)	7	(88)	6	(55)	4	(67)	32	(50)
Total	33	(100)	6	(100)	8	(100)	11	(100)	6	(100)	64	(100)

Table 5.97. Children with fever, taken for medical examination

City	Florence (%)		Bergamo (%)		Brescia (%)		Venice (%)		Bolzano (%)		Total (%)	
Yes	17	(94)	4	(80)	7	(50)	10	(83)	3	(50)	41	(75)
Total	18	(100)	5	(100)	14	(100)	12	(100)	6	(100)	55	(100)

Table 5.98. Children with fever taken for medical examination, in relation to age of child

Age	0 (%)		1 (%)		2 (%)		3 (%)		4 (%)		5 (%)		Total (%)	
Examined	5	(83)	15	(83)	9	(85)	4	(73)	6	(56)	2	(22)	41	(75)
Total	6		16		10		7		10		6		55	

Chi square for linear trend, $p = 0.002$

Table 5.99. Where children with fever were taken for examination, city by city

City	Florence (%)		Bergamo (%)		Brescia (%)		Venice (%)		Bolzano (%)		Total (%)	
Paediatric consultancy	10	(59)	-	(-)	-	(-)	1	(10)	-	(-)	11	(27)
Family paediatrician	1	(6)	0	(0)	0	(0)	0	(0)	1	(33)	2	(5)
Casualty	0	(0)	0	(0)	0	(0)	5	(50)	0	(0)	5	(12)
Hospital, general	6	(35)	4	(100)	7	(100)	4	(40)	2	(67)	23	(56)
Total	17	(100)	4	(100)	7	(100)	10	(100)	3	(100)	41	(100)

Table 5.100. Children with at least one symptom, taken for medical examination

City	Florence (%)		Bergamo (%)		Brescia (%)		Venice (%)		Bolzano (%)		Total (%)	
Yes	38	(76)	11	(79)	9	(53)	12	(71)	9	(69)	79	(71)
Total	50	(100)	14	(100)	17	(100)	17	(100)	13	(100)	111	(100)

Table 5.101. Children with at least one symptom, taken for medical examination, by age

Age	0	(%)	1	(%)	2	(%)	3	(%)	4	(%)	5	(%)	Total	(%)
Yes	10	(87)	25	(86)	11	(73)	11	(73)	9	(47)	3	(30)	79	(71)
Total	23	(100)	29	(100)	15	(100)	15	(100)	19	(100)	10	(100)	111	(100)

Chi square for linear trend, p = 0.000

Table 5.102. Answers regarding causes of children's illnesses at the camp, city by city

City	Florence(%)		Bergamo(%)		Brescia (%)		Venice (%)		Bolzano(%)		Total(%)	
Causes	49	(94)	15	(94)	7	(54)	21	(87)	13	(41)	105	(77)
Nothing	1	(2)	0	(0)	5	(38)	3	(13)	13	(41)	22	(16)
Don't know	2	(4)	1	(6)	1	(8)	0	(0)	6	(19)	10	(7)
Total	52	(100)	16	(100)	13	(100)	24	(100)	32	(100)	137	(100)

Table 5.103. Categories of answers regarding causes of children's illnesses at the camp, city by city

City	Florence(%)		Bergamo(%)		Brescia (%)		Venice (%)		Bolzano(%)		Total(%)	
Dirtiness	33	(31)	12	(35)	4	(27)	21	(44)	5	(21)	75	(33)
Cold	34	(32)	8	(24)	0	(0)	9	(19)	11	(48)	62	(27)
Unstable home	4	(4)	4	(12)	5	(33)	8	(17)	4	(17)	25	(11)
Presence of rats	20	(19)	1	(3)	0	(0)	2	(4)	0	(0)	23	(10)
Unclean air	8	(7)	4	(12)	1	(7)	3	(6)	1	(4)	17	(7)
Over-crowding	4	(4)	2	(6)	2	(13)	4	(8)	2	(9)	14	(6)
Stagnant water	4	(4)	3	(9)	3	(20)	1	(2)	0	(0)	11	(5)
Total	107	(100)	34	(100)	15	(100)	48	(100)	23	(100)	227	(100)

Table 6.1. Respiratory difficulties and asthma, comparison between SIDRIA national data and data from the five camps

	Total	Male	Female	Total	Male	Female
	Breathing difficulties and wheezing in last 12 months			Active asthma prevalence (diagnosed asthma + at least one attack in last year)		
Five camps, children 0-5	17% 28/165	17% 13/78	17% 15/87	7% 12/165	10% 8/78	5% 4/87
	Dyspnoea with wheezing in last 12 months					
SIDRIA study, children of 6-7	5.3%	6.4%	4.0%			
	At least 4 attacks in last 12 months			Asthma diagnosed during lifetime		
Five camps, children 0-5	5% 8/165	8% 6/78	2% 2/87	9% 15/165	13% 10/78	6% 5/87
	At least 4 attacks in last 12 months			Asthma diagnosed during lifetime		
SIDRIA study, children of 6-7	1.4%	1.8%	1.0%	9.0%	11.4%	6.4%

Table 6.2. Comparison between Italian 2001 census and study data on characteristics of inhabited houses

Istat, 2001 Census. Data on houses inhabited by residents			
City	Average number of rooms per house	Average number of rooms per person	Square meters per person
Florence	4.3	1.9	40.3
Bergamo	3.1	1.7	43.0
Brescia	4.1	1.7	41.1
Venice	4.1	1.7	38.2
Bolzano	3.7	1.6	34.8
Italy total	4.2	1.6	36.8
Data from the five camps			
City	Average number of rooms per house	Average number of rooms per person	Square meters per person, considering the whole camp area
Florence	2.5	0.4	19
Bergamo	1.7	0.3	10
Brescia	2.4	0.4	50
Venice	2.5	0.4	45
Bolzano	2.7	0.7	31

Table 6.3. Confirmation of main concerns on actionable factors

Concerns expressed by the Romá	Main significant associations	Comments	Considerations of feasibility
Filth Refuse, Dirtiness, Sewage outlets	Stagnant water • Cough (5 years living) p=0.001 • Breathing difficulties (all) p=0.026	In camps with very limited indoor and outdoor spaces, children are forced to live and play in these spaces, no matter the presence of risk elements.	The problem of stagnant water, due to the ruined paving and/or problems with the drainage system, is often caused by lack of serious planning.
Unstable housing conditions Structure and quality of the house No air circulation Heating, dry air Difficult to warm up the house Leaks and mouldiness	Condition of the house • Breathing difficulties (all) p=0.010 • Asthma (in overcrowded camp) p=0.016 Wood stoves • Cough (in overcrowded hh) p=0.027	Solid structures would also guarantee better insulation and, thus, solve most of the problems related to heating systems and safety.	Alternatives are more solid house structures in the camps or preferably inclusion of <i>Rom</i> families in regular housing schemes. The costs involved in this type of intervention should be assessed in relation to the benefits from reduced health costs.
Cold and humidity Bathrooms outside Lack of hot water No warm bath for children No heated bathroom	Lack of access to a toilet with a shower • Cough (all) p=0.003 • Breathing difficulties (all) p=0.007	Problems related to inadequate bathroom services are reflected here in the lack of access to showers and exposure to cold involved in trying to keep them clean.	The need for adequate places to wash children while keeping them warm should be considered as fundamental when planning any housing solution.
Presence of rats	Rats • Breathing difficulties (all) p=0.027 • Asthma (all) p=0.071	No cases of asthma were recorded in camps with no rats. Rats can be both a cause of diseases and an indicator of a degraded environment.	It is not enough just to eliminate rats, but also what fosters their presence. Improving housing conditions and the surrounding environment is a major part of the solution to this problem.
Poor quality of air, unpleasant smell	Polluting industrial sites • Breathing difficulties (all) p=0.003	In Florence, where the camp is close to an asphalt factory and a gravel pit, there is a significantly higher prevalence of respiratory problems.	Inclusion of <i>Rom</i> communities in more comprehensive urban planning would eliminate this problem.

Overcrowding Living space in the camp Living space in the house	Home overcrowding • Asthma (day+night) p=0.014 Camp overcrowding • Breathing difficulties (all) p=0.001 • Asthma (+house cond.) p=0.016	Overcrowding needs to be considered in its different aspects (house, camp, day, night).	Respecting existing housing codes when planning housing solutions for <i>Rom</i> families would solve this problem.
Issues not explicitly mentioned: Years spent living at the camp	Years spent living at the camp • Diarrhoea (all) p=0.014 • Diarrhoea (in overcrowded hh) p=0.002 • Diarrhoea (in camp with stagn. water) p=0.005	Time can play a role by generating a time-cumulative effect on risk situations for the health of children, and by leading to a sense of resignation and lack of reaction to risk situations.	Postponement of more stable solutions increases health and social costs. Families that spend many years living in a camp will find it more and more difficult to get used to managing life in a regular house.
Apparently contradicting: Water inside the house	Water inside the house • Cough (children 0-3) p=0.019	Families said bathroom services outside of the house were a problem. However, self-made water connections inside the houses, not supported by drainage systems, can be worse.	Water inside the house is a good advantage, but the house itself and the water connection need to be adequate. Provision of adequate housing would eliminate this problem.

We use Fisher exact 2-tailed test p-value to show significance of the associations.

- “All” => total population of children from birth to five years of age
- “5 years living” => population of children whose families lived at the camp for more than five years
- “In overcrowded hh” => population of children living in overcrowded houses, with more than 2.5 people per room
- “In camp with stagn.water” => population of children living in camps with stagnant water
- “Children 0-3” => population of children from birth to three years of age
- “Day+night” means the variable combined “more than 2.5 people per room in the house” and “more than 3 people per bed space in the house” as risk factor
- “In overcrowded camp” means the variable combined “bad house conditions” or “less than 25m² per person living at the camp” as risk factor
- “+ house cond.” means the variable combined “bad house conditions” or “less than 25m² per person living at the camp” as risk factor

FIGURES

Figure 5.1. City map of Florence and location of the camp of Via del Poderaccio

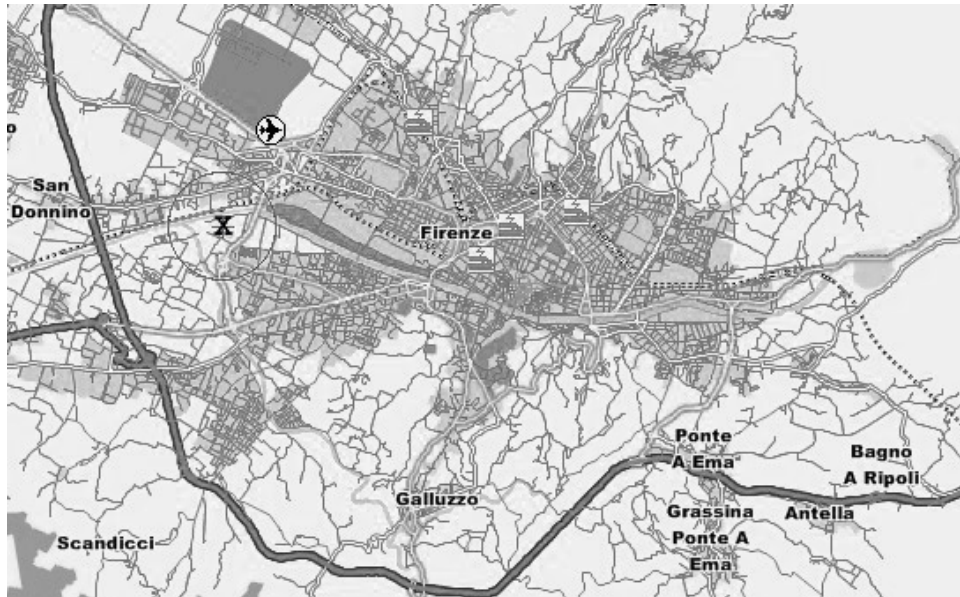


Figure 5.2. Camp of Via del Poderaccio, Florence

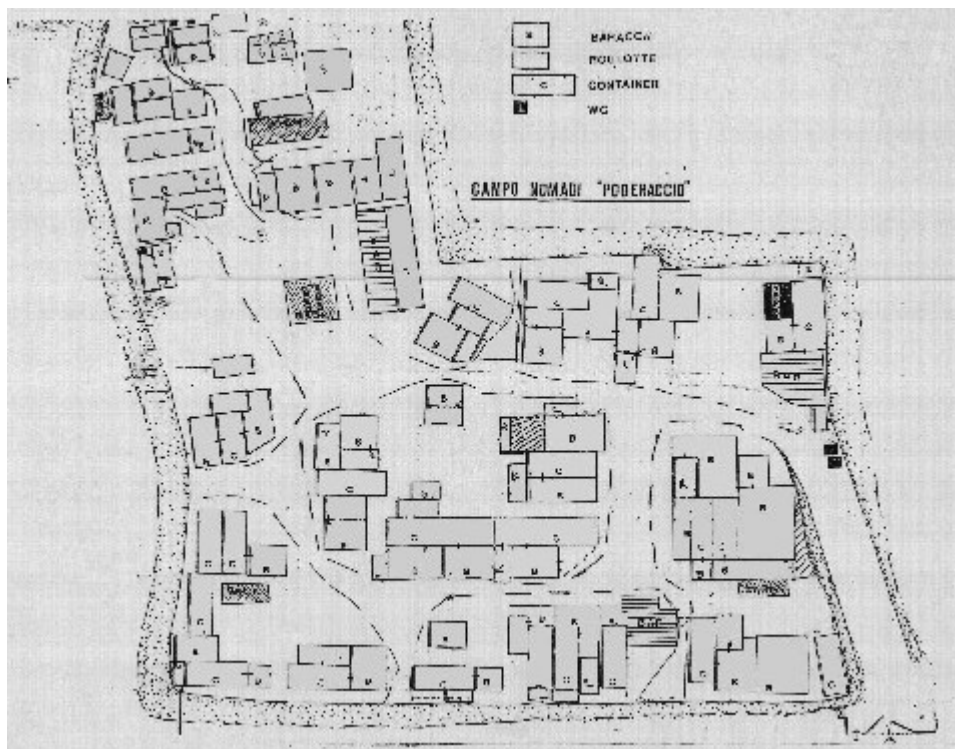


Figure 5.3. Bergamo city map and location of the camp of Via Rovelli 160



Figure 5.4. Camp of Via Rovelli 160, Bergamo

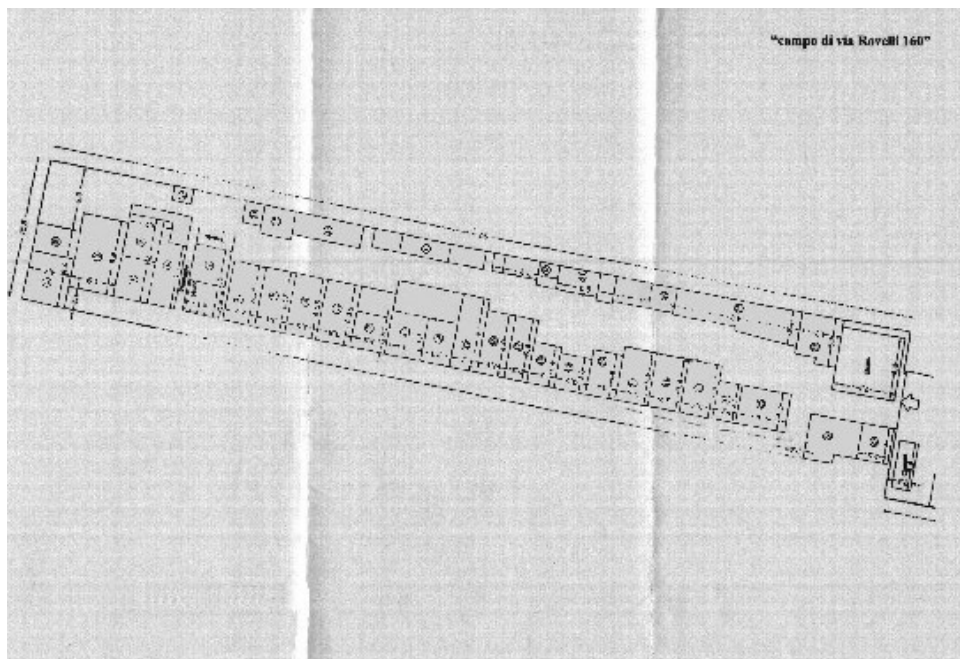


Figure 5.5. Brescia city map and location of the camp of Via Chiappa (Camafame)



Figure 5.6. Venezia/Mestre city map and location of the camp of San Giuliano

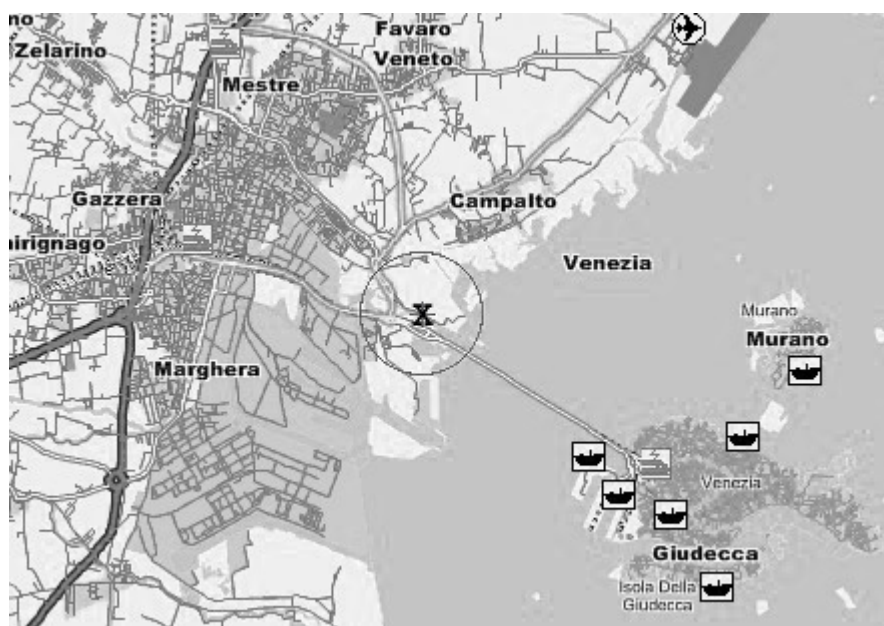


Figure 5.7. Bolzano city map and location of the camp of Castel Firmiano

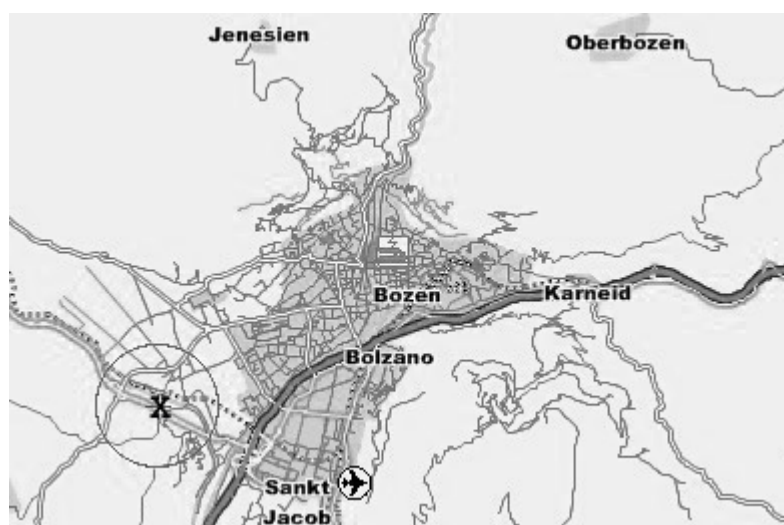


Figure 5.8. Camp of Castel Firmiano, Bolzano

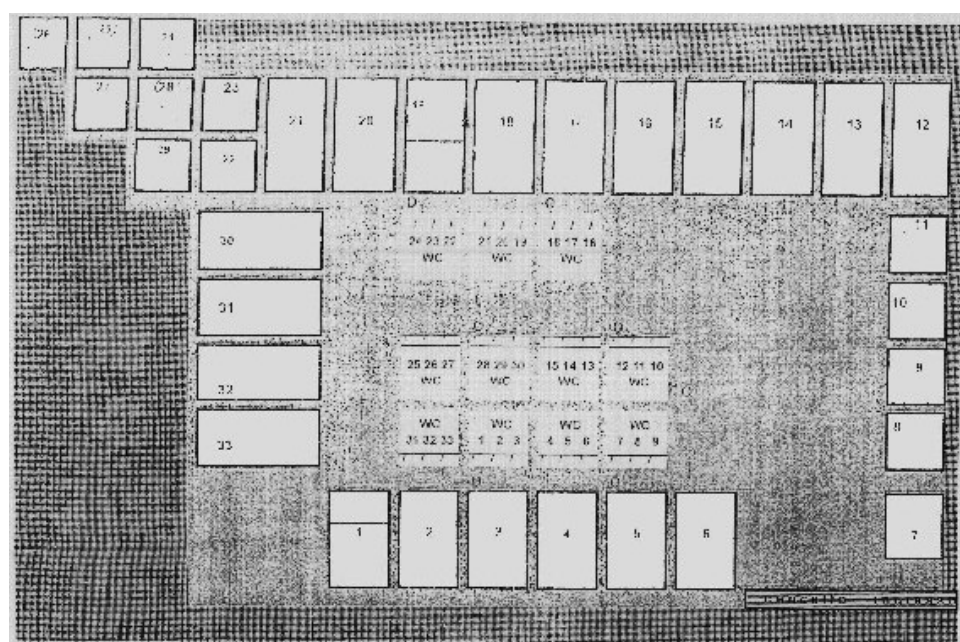


Figure 5.9. Age pyramid of members of families involved in the study, according to sex (n=737)

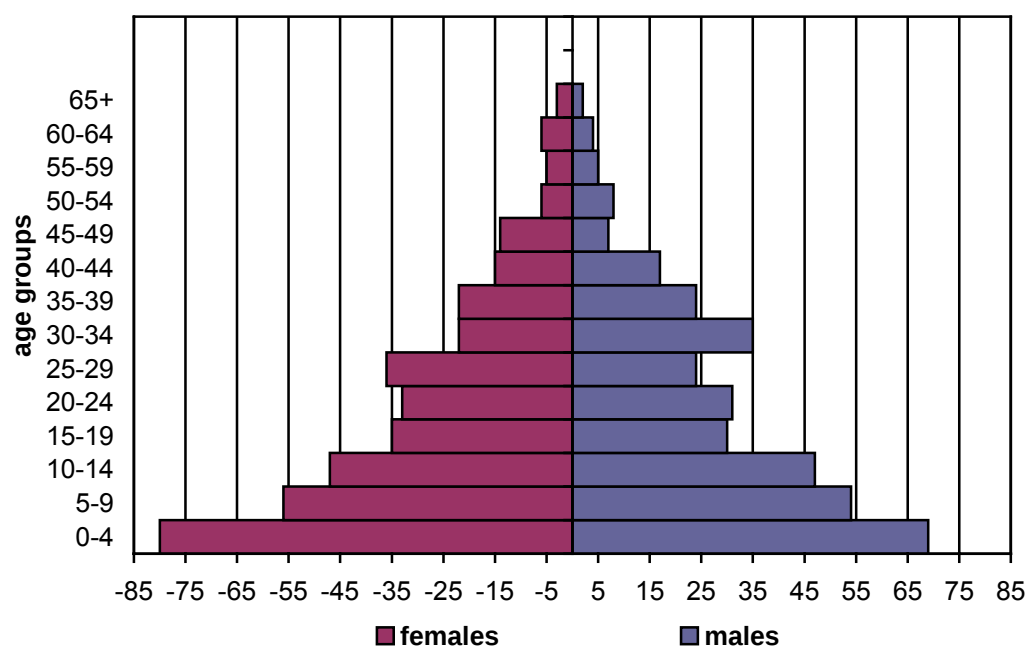


Figure 5.10. Mothers' age at delivery, for children from 0 to 5 years of age covered by the study; interpolation with a 4th grade polynomial regression (n=101)

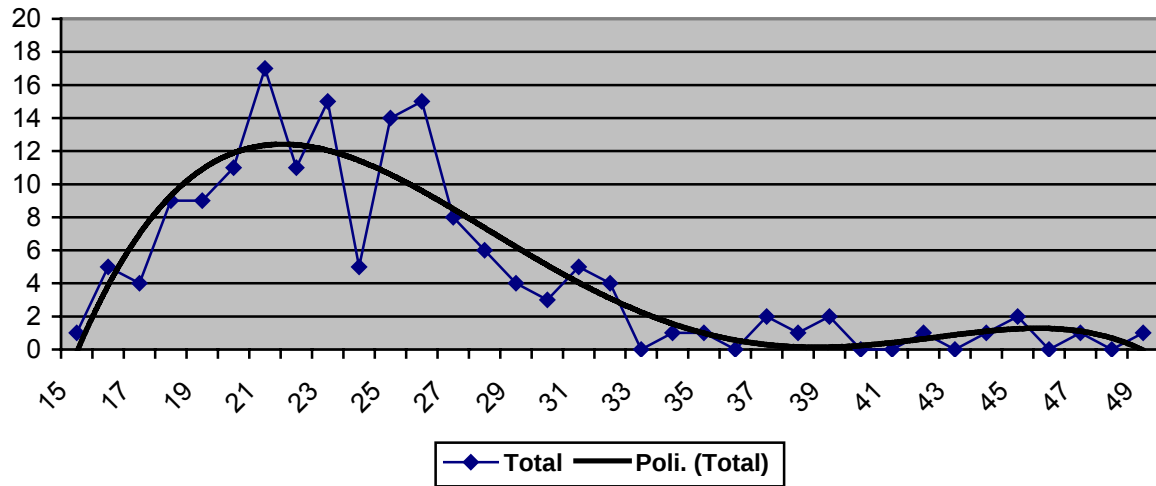


Figure 5.11. Age pyramid for the children, according to sex (n=167)

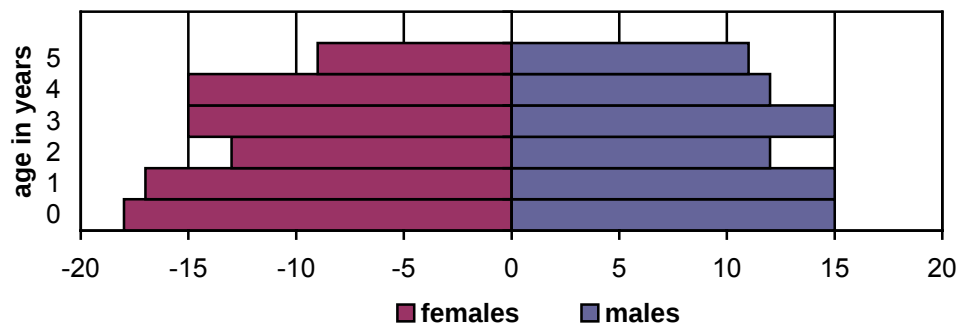


Figure 5.12. Period prevalence distribution of diarrhoea, in relation to age of child (n=165)

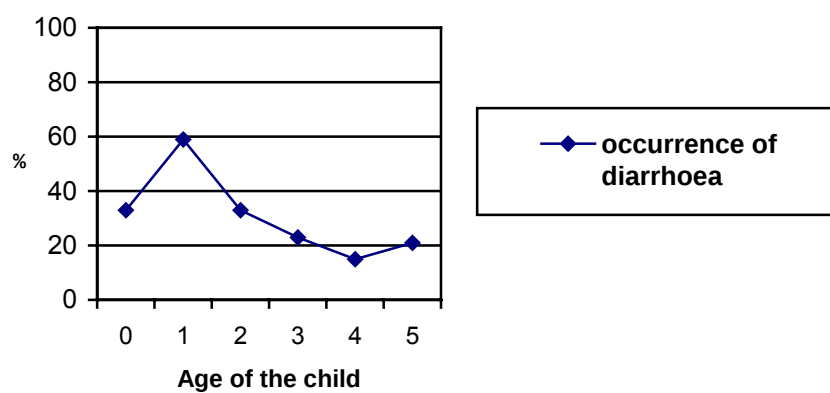


Figure 5.13. Period prevalence of coughing, in relation to age of child (n=165)

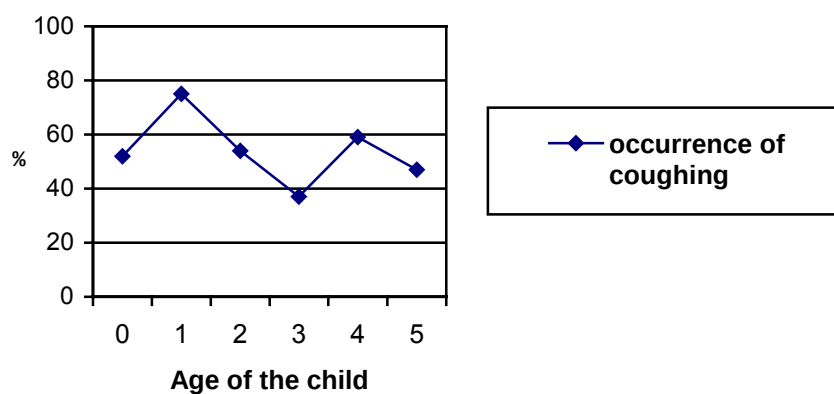


Figure 5.14. Period prevalence distribution of fever according to the age of the child (n=164)

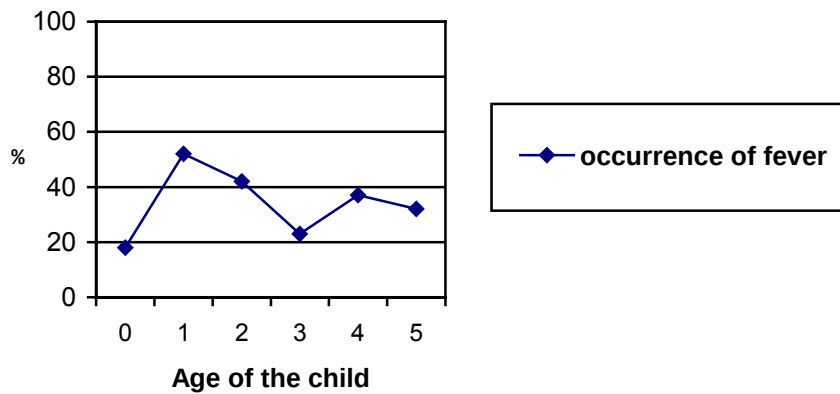


Figure 5.15. Occurrence of at least one symptom exhibited in the previous 15 days, and the age of the child (n=165)

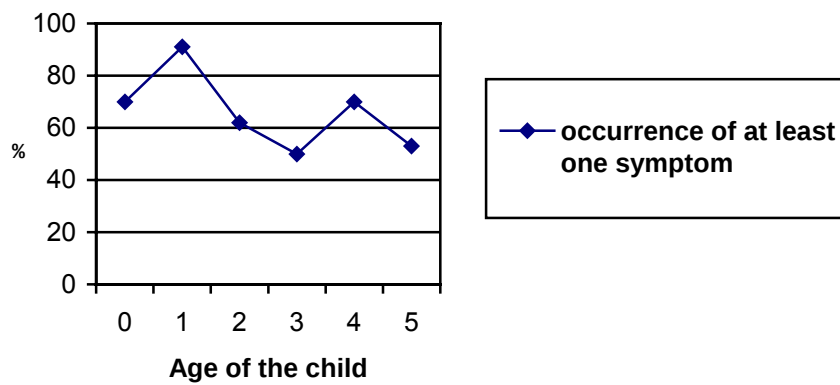


Figure 5.16. Children with diarrhoea taken for medical examination, by age of child (n=53)

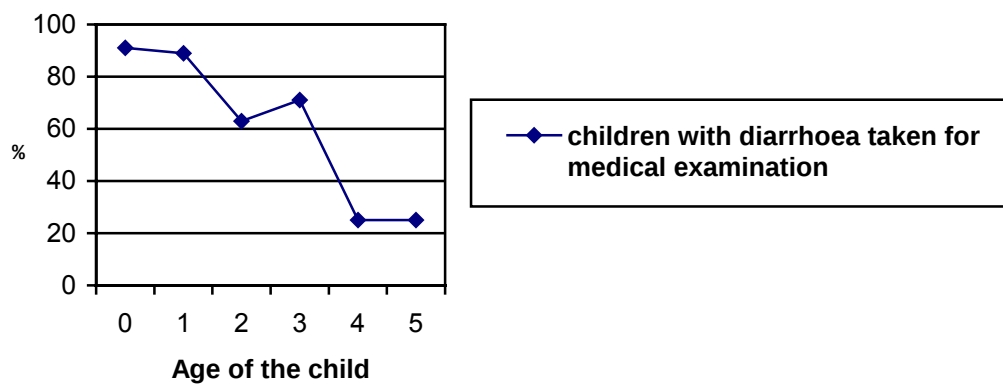


Figure 5.17. Children with coughing taken for medical examination, in relation to age of child (n=90)

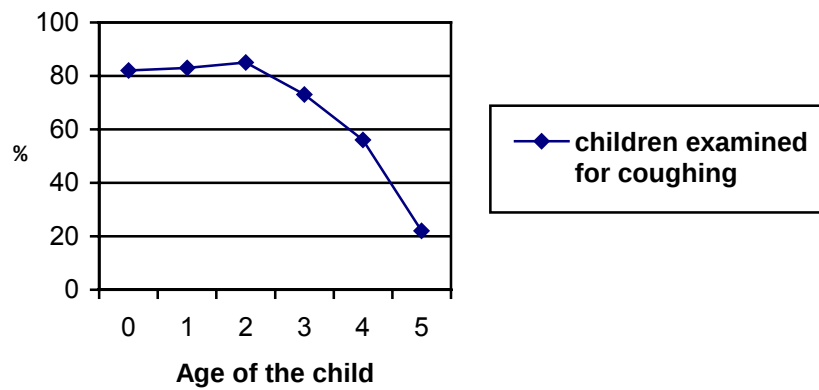


Figure 5.18. Children with fever taken for medical examination, in relation to age of child (n=55)

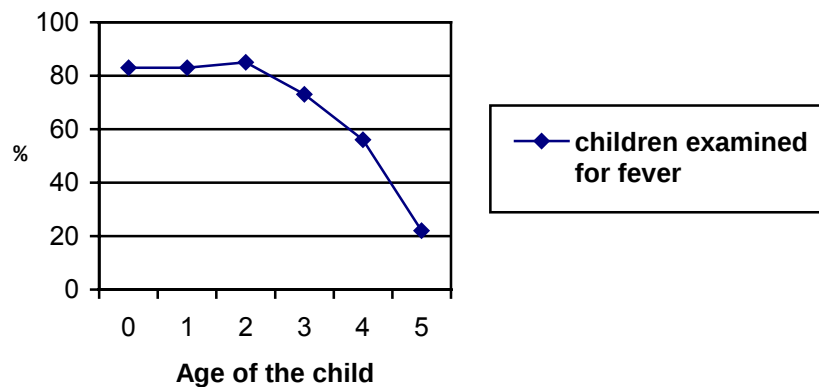
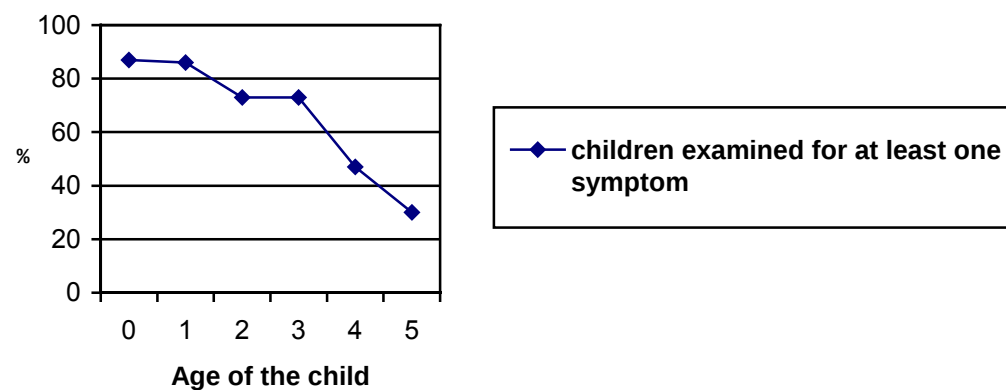


Figure 5.19. Children with at least one symptom taken for medical examination, in relation to age of child (n=111)



REFERENCES

1. Monasta L. *Mappatura degli insediamenti di cittadini non italiani di etnia rom sul territorio nazionale*. Report of the research project "The education of the Gypsy childhood in Europe". Dipartimento di Studi Sociali, Università di Firenze, 2003.
2. Monasta L. Note sulla mappatura degli insediamenti di Rom stranieri presenti in Italia. In: Saletti Salza C, Piasere L. eds. *Italia Romani Vol. IV*. CISU. Roma 2004: 3-16.
3. ERRC, *Il paese dei campi. La segregazione razziale dei Rom in Italia*. I Libri di Carta. Oct. 2000.
4. CERD (Committee on the Elimination of Racial Discrimination). *Concluding Observations, Italy*. 54th Session, 1-19 March 1999. 18 March 1999.
5. Brunello P. Introduzione. In: Brunello P. ed. *L'Urbanistica del Disprezzo*. Manifestolibri. Roma 1996: 11-21.
6. Lee R. I rom nel limbo 'Kalisferia'. In: Montesi S. *Terre sospese, vite di un campo rom*. Prospettiva Edizioni. Roma, 2002.
7. School of Planning, Oxford Brookes University. *Survey on policy and practice related to refugee integration*. Commissioned by the European Refugee Fund Community Actions 2001/2. Dec. 2002
8. Piasere L. Stranieri "e" nomadi. In: Brunello P. ed. *L'Urbanistica del Disprezzo*. Manifestolibri. Roma 1996: 23-27.
9. Sigona N. *Figli del ghetto. Gli italiani, i campi nomadi e l'invenzione degli zingari*. Nonluoghi libere edizioni. Trento 2002.
10. Boursier G. Lo sterminio degli zingari. In: Boursier G, Converso M, Iacomini F. eds. *Zigeuner, lo sterminio dimenticato*. Sinnos Ed. Roma 1996.
11. Piasere L. *Popoli delle discariche*. CISU. Roma 1991.
12. Colacicchi P. Discriminazioni. In: Brunello P. ed. *L'Urbanistica del Disprezzo*. Manifestolibri. Roma 1996: 29-38.
13. Carlisle K. Tenere i rom alla larga. In: Montesi S. *Terre sospese, vite di un campo rom*. Prospettiva Edizioni. Roma 2002.
14. Hasani B, Monasta L. *Vite costrette, un viaggio fotografico nel campo Rom del Poderaccio*. Ombre Corte. Verona 2003.
15. Piasere L. Prefazione. In: Hasani B, Monasta L. *Vite costrette, un viaggio fotografico nel campo Rom del Poderaccio*. Ombre Corte. Verona 2003.
16. Krieger N. *Questioning epidemiology: objectivity, advocacy, and socially responsible science*. Am J Public Health. 1999; 89(8):1151-3.
17. Gropper RC. *Gypsies and the health professions*. Newsletters of the Gypsy Lore Society, North American Chapter. 1982 Autumn; Vol. 5 (4): 1-8.
18. Rabino Massa E, Masali M. *Gli Zingari. Note antropologiche*. Federazione medica. 1987. XL, 3:247-252.
19. Bodner A, Leininger M. *Transcultural nursing care values, beliefs, and practices of American (USA) Gypsies*. Journal of Transcultural Nursing. 1992 Summer; 4(1):17-28.

20. Rabino Massa E, Viterbo S, Mina M, Giordano M. *Indagine epidemiologica su caratteristiche di interesse odontostomatologico di un campione di popolazione nomade in età pediatrica*. Minerva Stomatologica. 1988 Jan;37(1):7-12.
21. Marcolungo E. *Zingari a Torino: i Rom slavi fra la tradizione e mutamento*. Tesi di Laurea della Facoltà di Scienze Politiche, Torino. 1983.
22. Fuglesang A. *About understanding – Ideas and observations on cross-cultural communication*. Dag Hammarskjöld Foundation. Uppsala, 1982.
23. Geraci S, Motta F, Rossano R. *Il bisogno di salute nelle popolazioni zingare*. Ann Ig. 2002 Jul-Aug;14(4 Suppl 4):17-31.
24. Cruz M, Dieguez A, Fos E, R-Hierro F. *Epidemiologic survey of Hepatitis B in Gypsy women*. European Journal of Epidemiology. 1988 Sep; 4(3): 314-317.
25. Camara Medina C, Perez Garcia A, Quesada Lupianez P, Sanchez Cantalejo E. *Intervención con agentes de salud comunitarios en programas de inmunizaciones en la comunidad gitana*. Atencion Primaria. 1994 May 15;13(8):415-8.
26. De Amici D, Gasparoni A, Chirico G.& Bogliolo O. *The influence of race on breast feeding*. European Journal of Epidemiology. 1998; 14: 413-415.
27. Coto E, Rodriguez J, Jeck N, Alvarez V et al. *A new mutation (intron 9 +1 G>T) in the SLC12A3 gene is linked to Gitelman syndrome in Gypsies*. Kidney Int. 2004 Jan;65(1):25-9.
28. Ginter E, Krajcovicova-Kudlackova M, Kacala O, Kovacic V, Valachovicova M. *Health status of Romanies (Gypsies) in the Slovak Republic and in the neighbouring countries*. Bratisl Lek Listy. 2001;102(10):479-84.
29. Krajcovicova-Kudlackova M, Blazicek P, Spustova V, Valachovicova M, Ginter E. *Cardiovascular risk factors in young Gypsy population*. Bratisl Lek Listy. 2004;105(7-8):256-9.
30. Sanchez Serrano FJ, Zubiaur Cantalapiedra A, Herrero Galiana A, Gallart Martinez MD et al. *Diferencia étnica en la actividad asistencial de urgencia. Aproximación a la realidad gitana*. An Esp Pediatr. 2002 Jan;56(1):17-22.
31. Bartsocas CS, Karayanni C, Tsipouras P, Baibas E, Bouloukos A, Papadatos C. *Genetic structure of Greek gypsies*. Clinical Genetics. 1979; 15: 5-10.
32. Galikova J, Vilimova M, Ferak V, Mayerova A. *Haptoglobin types in gypsies from Slovakia*. Human Heredity. 1969; 19: 480-5.
33. Harper PS, Williams EM. *Genetic disorders in Gypsies*. (lettera). The Lancet. 1975 May 3: 1; 1041.
34. Harper PS, Williams EM and Sunderland E. *Genetic markers in Welsh gypsies*. Journal of Medical Genetics. 1977;14: 177-182.
35. Kalaydjieva L, Hallmayer J, Chandler D, Savov A et al. *Gene mapping in Gypsies identifies a novel demyelinating neuropathy on chromosome 8q24*. Nature Genetics. 1996 Oct;14(2):214-7.
36. Ogawa A, Tokunaga K, Lin L, Kashiwase K et al. *Diversity of HAL-B61 alleles and haplotypes in East Asian and Spanish Gypsies*. Tissue Antigens. 1998; Vol. 51: 356-366.
37. Rabino Massa E, Reddavid M, Monchietto MJ, Siori MS. *Risultati preliminari e caratteristiche dell'emotipo di due comunità di Zingari*. Antropologia Contemporanea. 1987. Vol. 10, N 1-2: 149-153.
38. Rabino Massa E, Revello D, Merelli R. *Analisi delle emoglobine e delle sieroproteine di una popolazione nomade (Zingari Rom) presente nell'area torinese*. Antropologia Contemporanea. 1993. Vol. 16, N. 1-2-3: 277-283.

39. Rani R, Fernandez-Viña M A, Stastny P. *Associations between HLA classes II alleles in a North Indian population*. Tissue Antigens. 1998; 52: 37-43.
40. Tauszik T. *Human and medical genetic examinations on the Gypsy population in Hungary*. Newsletter of the Gypsy Lore Society, North American Chapter. 1986 Autumn; Vol. 9: Number 4. New York.
41. Gresham D, Morar B, Underhill PA, Passarino G et al. *Origins and divergence of the Roma (gypsies)*. Am J Hum Genet. 2001 Dec; 69(6): 1314-31.
42. Morar B, Gresham D, Angelicheva D, Tournev I et al. *Mutation history of the roma/gypsies*. Am J Hum Genet. 2004 Oct;75(4):596-609.
43. Chaix R, Austerlitz F, Morar B, Kalaydjieva L, Heyer E. *Vlax Roma history: what do coalescent-based methods tell us?* Eur J Hum Genet. 2004 Apr;12(4):285-92.
44. Gropper RC. *What does blood tell?* (Three-part series) Newsletters of the Gypsy Lore Society, North American Chapter. 1981 Spring, Summer, Autumn; Vol. 4: N. 2, 3 & 4. New York.
45. Hajioff S, McKee M. *The health of the Roma people: a review of the published literature*. J Epidemiol Community Health. 2000; 54:864-869.
46. Zeman CL, Depken DE, Senchina DS. *Roma health issues: a review of the literature and discussion*. Ethn Health. 2003 Aug;8(3):223-49.
47. Ferrer F. *El estado de salud del pueblo gitano en España. Una revisión de la bibliografía*. Gac Sanit. 2003;17 Suppl 3:2-8.
48. Kalaydjieva L, Gresham D, Calafell F. *Genetic studies of the Roma (Gypsies): a review*. BMC Medical Genetics. 2001;2:5. <http://www.biomedcentral.com/1471-2350/2/5>
49. Dubos R. *Man and his environment – Biomedical knowledge and social action*. Perspectives in Biology and Medicine. 1966; 9:623-36.
50. Zaharova B, Andonova S, Gilissen A, Cassiman JJ, Decorte R, Kremensky I. *Y-chromosomal STR haplotypes in three major population groups in Bulgaria*. Forensic Sci Int. 2001 Dec 27;124(2-3):182-6.
51. Deligiannidis P, Triantaphyllidis C, Psaroulis D, Kouvatsi A. *Forensic evaluation of 13 STR loci in the Roma population (Gypsies) of Greece*. Forensic Sci Int. 2005 Jun 2; [Epub ahead of print].
52. Nagy AS, Pap M. *Comparative analysis of dermatoglyphic traits in Hungarian and Gypsy populations*. Hum Biol. 2004 Jun;76(3):383-400.
53. Mandadzhieva S, Marinov B, Kostianev S, Turnovska T. *Anthropometric and cardiopulmonary parameters in Bulgarian and Romany children: cross-sectional study*. Croat Med J. 2005 Apr;46(2):294-301.
54. Plasilova M, Feravoka E, Kadasi L, Polakova H et al. *Linkage of autosomal recessive primary congenital glaucoma to the GLC3A locus in Roms (Gypsies) from Slovakia*. Human Heredity. 1998; 48: 30-33.
55. Barry J, Kirke P. *Congenital anomalies in the Irish traveller community*. Irish Medical Journal. 1997 Oct;90(6):233-4.
56. Diez O, Domenech M, Alonso M et al. *Identification of the 185delAG BRCA1 mutation in a Spanish Gypsy population*. Human Genetics. 1998; 103: 707-708.
57. Reddavid M, Rabino Massa E, Camaschella C. *I polimorfismi dei geni β -globinici in Zingari Rom*. Antropologia Contemporanea. 1989. Vol. 12, N. 4: 207-211.

58. Martinez-Frias ML, Bermejo E. *Prevalence of congenital anomaly syndromes in a Spanish gypsy population*. Journal of Medical Genetics, 1992; 29 (7): 483-6.
59. Kalaydjieva L, Nikolova A, Turnev I, Petrova J et al. *Hereditary motor and sensory neuropathy - Lom, a novel demyelinating neuropathy associated with deafness in Gypsies*. Clinical, electrophysiological and nerve biopsy. Brain. 1998; 121: 399-408.
60. Martinez G, Garcia-Lozano JR, Ribes A, Maldonado MD, Baldellou A, De Pablo R, Nuñez-Roldan A. *High risk of medium chain acyl-coenzyme A dehydrogenase deficiency among Gypsies*. Pediatric Research. 1998; Vol. 44: N.1: 83-84.
61. Varadi V, Szabò L, Papp Z. *Syndrome of polydactyly, cleft lip/palate or lingual lump, and psychomotor retardation in endogamic gypsies*. Journal of Medical Genetics. 1980; 17: 119-122.
62. Diego Nunez MA, Cortijo Gonzalez C. *Familial hypobetalipoproteinemia: Report of a family and review of Spanish contributions*. An Esp Pediatr. 2002 Jan;56(1):64-7.
63. Hunter M, Heyer E, Austerlitz F, Angelicheva D et al. *The P28T mutation in the GALK1 gene accounts for galactokinase deficiency in Roma (Gypsy) patients across Europe*. Pediatr Res. 2002 May;51(5):602-6.
64. Giros M, Boveda MD, Vazquez de la Cruz A, Lazaro P et al. *Mutation P28T in gene GK1 as the cause of a familial galactokinase deficiency*. Arch Soc Esp Oftalmol. 2003 Feb;78(2):111-4.
65. Vazquez-Lopez ME, Martinez-Regueira S, Somoza-Rubio C, Gonzalez-Gomez FJ et al. *Hypotonia and lethargy: initial manifestations of a new case of galactosemia*. Rev Neurol. 2004 Aug 1-15;39(3):240-2.
66. Georgieva B, Todorova A, Tournev I, Mitev V, Kremensky I. *C283Y gamma-sarcoglycan gene mutation in the Bulgarian Roma (Gypsy) population: prevalence study and carrier screening in a high-risk community*. Clin Genet. 2004 Nov;66(5):467-72.
67. Antunez Galvez JM, Aguilar Heredia Y, Castaño Carracedo MA, Orihuela Cañadas F. *Hepatitis B en niños y adolescentes de etnia gitana*. Medicina Clinica (Barcelona). 1993 Nov; 101 (15): 596-7.
68. Aylward R B, Porta D, Fiore L, Ridolfi B, Chierchini P, Forastiere F. *Unimmunized Gypsy populations and implications for the eradication of poliomyelitis in Europe*. The Journal of Infectious Diseases. 1997; 175 (Suppl. 1): S86-8.
69. Morales JL, Huber L, Gallego S, Alvarez G, Diez-Delgado J, Gonzalez A, Aguilar L, Dal-Re R. *A seroepidemiologic study of hepatitis A in Spanish children. Relationship of prevalence to age and socio-environmental factors*. Infection. 1992 Jul-Aug;20(4):194-6.
70. Bell EJ, Riding MH, Collier PW, Wilson NC, Reid D. *Susceptibility of itinerants ("travelling people") in Scotland to poliomyelitis*. Bulletin WHO. 1983; 61 (5); 839-843.
71. Bernal A, Garcia-Saiz A, Liacer A, de Ory F, Tello O, Najera R. *Poliomyelitis in Spain, 1982-1984: virologic and epidemiologic studies*. American Journal of Epidemiology. 1987 Jul;126(1):69-76.
72. Porta D, Chierchini P, Bruno L, Fiore L, Cristofaro G, Amato C, Catone S, Gentili G, Sangalli M, Forastiere F. *Studio seroepidemiologico sul livello di copertura immunitaria in una comunità nomade a Roma*. Epidemiologia e Prevenzione. 1997 Jan-Mar; 21(1):48-53.
73. Cilla G, Perez-Traliero E, Marimon J M, Erdozain S and Gutierrez C. *Prevalence of hepatitis A antibody among disadvantaged gypsy children in northern Spain*. Epidemiol. Infect. 1995; 115: 157-161.
74. Feder G, Vaclavik T, Streetly A. *Traveller Gypsies and childhood immunization: a study in east London*. British Journal of General Practitioners. 1993 Jul;43(372):281-4.

75. McKenzie AB. *Traveller mothers and babies*. BMJ. 1990 Jul 14;301(6743):123.
76. Flynn M. *Mortality, morbidity and marital features of Travellers in the Irish Midlands*. Irish Medical Journal. 1986. 79: 308-10.
77. Pahl J, Vaile M. *Health and health care among travellers*. Journal of Social Policy. 1988 Apr;17(2):195-213.
78. Walker PC. *The health of travellers*. BMJ. 1986 Nov 22;293:1322
79. Kargar I. *Tales of travail*. Nursing Times. 1992 Sep 16-22;88(38):22.
80. Van Cleemput P. *Health care needs of travellers*. Arch Dis Child. 2000 Jan;82(1):32-7
81. Matthews Z. *The outsiders*. Nursing Times. 1998 Sep 16-22;94(37):26-7.
82. Guiraud JC. *Pathologies tsiganes? Études Tsiganes*. 1988; 2: 11-16.
83. Corretger JM, Fortuny C, Botet F, Valls O. *Marginalidad, grupos étnicos y salud*. An Esp Pediatr. 1992 Jun;36 Suppl 48:115-7.
84. Joubert K. *Size at birth and some sociodemographic factors in gypsies in Hungary*. Journal of Biosocial Science. 1991 Jan;23(1):39-47.
85. Gyorgy U, Andrea O, Maria B, Sandor B, Eva S. *Roma colonies in Hungary--medical care of children and hygienic conditions*. Orv Hetil. 2005 Apr 10;146(15):691-9.
86. Dejmek J, Ginter E, Solansky I, Podrazilova K et al. *Vitamin C, E and A levels in maternal and fetal blood for Czech and Gypsy ethnic groups in the Czech Republic*. Int J Vitam Nutr Res. 2002
87. Sutherland A. *Gypsies and health care*. Western Journal of Medicine. 1992 Sep;157(3):276-80.
88. Sutherland A. *Health and illness among the Rom of California*. Journal of the Gypsy Lore Society. 1992; 5(2),1: 19-59.
89. Sutherland A. The body as a social symbol among the Rom. In: Blaching J. ed. *The anthropology of the body*. Academy Press. London 1977: 375-390.
90. Thomas JD. *Gypsies and American medical care*. Annals of Internal Medicine. 1985 Jun;102(6):842-5.
91. Thomas JD. *Health care of American Gypsies: social and medical aspects*. Papers from the eighth and ninth annual meeting. Gypsy Lore Society, North American Chapter, (C. DeSilva, J. Grumet, D. J. Nemeth (eds)) 1988. pp. 128-138. Gypsy Lore Society, North America Chapter, publications No. 4, New York.
92. Thomas JD. *Tales of a gypsy doc: perspectives on social and medical aspects of care of the American Gypsy population*. Cleveland Clinic Journal of Medicine. 1993 Nov-Dec;60(6):427-8.
93. Thomas JD, Doucette MM, Thomas DC, Stoeckle JD. *Disease, lifestyle, and consanguinity in 58 American Gypsies*. Lancet. 1987 Aug 15;2(8555):377-9.
94. Mandell F. *Gypsies: culture and child care*. Pediatrics. 1974 Nov;54(5):603-7.
95. Wetzel RC, Dean JM, Rogers MC. *Gypsies and acute medical intervention*. Pediatrics. 1983 Nov;72(5):731-5.
96. Ojanlatva A, Vandenbussche C, Heldt H, Horte A et al. *The use of problem-based learning in dealing with cultural minority groups*. Patient Education and Counseling. 1997 Jun; 31(2): 171-6.

97. Peck B. *Gypsies - A Sheffield experience*. Health Visitor. 1983 Oct;56(10):365.
98. Streetly A. *Health care for travellers: one year's experience*. BMJ. 1987 Feb 21;294:492-4
99. Anderson E. *Health concerns and needs of Traveller families*. Health Visitor. 1997; 70: 148-150.
100. Edwards DM, Watt RG. *Diet and hygiene in the lives of Gypsy Travellers in Hertfordshire*. Community Dental Health. 1997 Mar;14(1):41-6.
101. Edwards DM, Watt RG. *Oral health care in the lives of Gypsy Travellers in east Hertfordshire*. British Dental Journal. 1997 Oct 11;183(7):252-7.
102. Trevisan P. Fra medici e santi: itinerari terapeutici di una comunità di Roma croati. In: Piasere L. ed. *Italia Romani, Vol. I*. Ed. CISU. Roma 1996: 205-26.
103. Porcu R, Cottatellucci T, Sormani E, Trevisan P et al. *I problemi di salute dei bambini zingari*. Atti del convegno APeC: "Dalle Ande agli Appennini", Pediatria di comunità e salute del bambino tra nomadismo e immigrazione. Forlì 26 Ottobre 1996.
104. Ní Shuinéar S. Crescere zingaro: riflessioni sul seminario ICDC-UNICEF. In: UNICEF-ICDC. *Crescere Zingaro*. Ed. Anicia. Roma 1994:31-54.
105. Conti M, Pietri F. *Esperienza di un consultorio pediatrico: attività a favore di una popolazione nomade*. Atti del convegno APeC: "Dalle Ande agli Appennini", Pediatria di comunità e salute del bambino tra nomadismo e immigrazione. Forlì 26 Ottobre 1996.
106. Gaspari L, Pini I. *La pediatria di comunità e i bisogni di salute del bambino nomade: esperienza di operatori dell'azienda USL di Forlì*. Atti del convegno APeC: "Dalle Ande agli Appennini", Pediatria di comunità e salute del bambino tra nomadismo e immigrazione. Forlì 26 Ottobre 1996.
107. Feder G, Hussey R. *Traveller mothers and babies. Health authorities need to provide better care*. BMJ. 1990 June 16; 300:1536-37.
108. Gordon M, Gorman DR, Hashem S, Stewart DGT. *The health of travellers' children in Northern Ireland*. Public Health. 1991; 105: 387-391.
109. Kramer MS. *Determinants of low birth weight: methodological assessment and meta-analysis*. Bull WHO. 1987; 65: 663-737.
110. Kramer MS. *Socioeconomic determinants of intrauterine growth retardation*. Eur J Clin Nutr. 1998 Jan; 52 (Suppl 1):S29-S33.
111. Prada JA, Tsang RC. *Biological mechanisms of environmentally induced causes of IURG*. Eur J Clin Nutr. 1998 Jan; 52 (Suppl 1):S21-S27.
112. WHO. *The World health report 2005: make every mother and child count*. World Health Organization, 2005.
113. Steckel RH. *Birth weights and stillbirths in historical perspective*. Eur J Clin Nutr. 1998 Jan; 52 (Suppl 1):S16-S20.
114. Sormani E, NAGA. *Il bambino zingaro*. RMP. 1995; 495: 20-23.
115. Istituto Superiore di Sanità. *Immigrati e zingari: salute e diseguaglianze*. Edited by Morrone A, Spinelli A, Geraci S, Toma L, Andreozzi S. 2003, Rapporti ISTISAN 03/4.
116. UNDP. *Faces of poverty, faces of hope – Vulnerability profiles for Decade of Roma Inclusion countries*. Bratislava, 2005.

117. Brown P. *Race, class, and environmental health: a review and systematization of the literature*. Environ Research. 1995; 69:15-30.
118. Proctor RN. *Value-free science? Purity and power in modern knowledge*. Harvard University Press. Cambridge, Mass, 1991.
119. Ziman J. *An introduction to science studies: the philosophical and social aspects of science and technology*. Cambridge University Press. Cambridge, England, 1984.
120. Cohen HW, Northridge ME. *Getting political: racism and urban health*. Am J Public Health. 2000; 90(6):841-842.
121. Savitz DA, Poole C, Miller WC. *Reassessing the role of epidemiology in public health*. Am J Public Health. 1999; 89(8):1158-61.
122. Stafford M, McCarthy M. Neighbourhoods, housing, and health. In: Marmot M, Wilkinson RG. eds. *Social Determinants of Health, II ed*. Oxford University Press, 2006:297-317.
123. Northridge ME, Sclar ED. *Housing and health*. Am J Public Health. 2002;92(5):701.
124. Krieger J, Higgins DL. *Housing and health: time again for public health action*. Am J Public Health. 2002;92(5):758-768.
125. Northridge ME, Shepard PM. *Environmental racism and public health*. Am J Public Health. 1997;87(5):730-732.
126. Wood DL, Valdez RB, Hayashi T, Shen A. *Health of homeless children and housed, poor children*. Pediatrics. 1990;86(6):858-66.
127. Platt SD, Martin CJ, Hunt SM, Lewis CW. *Damp housing, mould growth, and symptomatic health care*. BMJ. 1989;298:1673-8.
128. Folmer-Anderson T. *Persistence of social and health problems in the welfare state: a Danish cohort experience from 1948 to 1979*. Soc Sci Med. 1984;18:555-600.
129. Britten N, Davies JMC, Colley JRT. *Early respiratory experience and subsequent cough and peak expiratory flow rate in 36 years old men and women*. BMJ. 1987;294:1317-20.
130. Sharfstein J, Sandel M, Kahn R, Bauchner H. *Is child health at risk while families wait for housing vouchers?* Am J Public Health. 2001;91(8):1191-2.
131. Bashir SA. *Home is where the harm is: inadequate housing as a public health crisis*. Am J Public Health. 2002;92(5):733-738.
132. Kieltyka A, Szafraniec K, Jedrychowski W. *Environment and child health – Environmental factors and Helicobacter pylori infection in children and youth in Poland: population-based study*.
133. Phipatanakul W, Eggleston PA, Wood RA, and the National Cooperative Inner-city Asthma Study Group. *The prevalence of mouse allergen in inner-city homes*. J Allergy Clin Immunol. 1999;103:S235.
134. Phipatanakul W, Eggleston PA, Wright EC, Wood RA, and the National Cooperative Inner-city Asthma Study Group. *Mouse allergen. II. The relationship of mouse allergen exposure to mouse sensitization and asthma morbidity in inner-city children with asthma*. J Allergy Clin Immunol. 2000;106(6):1075-80.
135. Collins KJ. *Low indoor temperature and morbidity in the elderly*. Age Aging. 1986;15:212-220.
136. Evans J, Hyndman S, Stewart-Brown S, Smith D, Petersen S. *An epidemiological study of the relative importance of damp housing in relation to adult health*. J Epidemiol Community Health. 2000;54:677-686.

137. Markus TA. Cold, condensation and housing poverty. In: Burridge R. Ormandy D. eds. *Unhealthy housing: research, remedies and reform*. NY, Spon Press, 1993:141-167.
138. Samet JM, Spengler JD. *Indoor environments and health: moving into the 21st Century*. Am J Public Health. 2003;93(9):1489-1493.
139. Peat JK, Dickerson J, Li J. *Effects of damp and mould in the home on respiratory health: a review of the literature*. Allergy. 1998;53:120-128.
140. Sclar ED, Northridge ME. *Slums, slum dwellers, and health*. Am J Public Health. 2003;93(9):1381.
141. Speizer FE, Ferris B, Bishop YMM, Spengler J. *Respiratory disease rates and pulmonary function in children associated with NO₂ exposure*. Am Rev Respir Dis. 1980;121:3-10.
142. Ware JH, Dockery DW, Spiro A, Speizer FE, Ferris BG. *Passive smoking, gas cooking, and respiratory health of children living in six cities*. Am Rev Respir Dis. 1984;129:366-374.
143. World Health Organization. *Global estimates of burden of disease caused by the environment*. WHO, Switzerland, 2002.
144. Wadsworth M, Butterworth S. Early life. In: Marmot M, Wilkinson RG. eds. *Social Determinants of Health, II ed*. Oxford University Press, 2006:31-53.
145. Jarvis MJ, Wardle J. Social patterning of individual health behaviours: the case of cigarette smoking. In: Marmot M, Wilkinson RG. eds. *Social Determinants of Health, II ed*. Oxford University Press, 2006:224-237.
146. Wilkinson RG, Marmot M. eds. *Social determinants of health: the solid facts, II ed*. World Health Organization, 2003.
147. Fullilove MT, Fullilove RE. *What's housing got to do with it?* Am J Public Health. 2000;90(2):183-184.
148. Wilkinson RG. Ourselves and others – for better or worse: social vulnerability and inequality. In: Marmot M, Wilkinson RG. eds. *Social Determinants of Health, II ed*. Oxford University Press, 2006:341-357.
149. Wilkinson RG. *Unhealthy societies: the afflictions of inequality*. London: Routledge, 1996.
150. Putnam R. *Making democracy work: civic traditions in modern Italy*. Princeton, NJ: Princeton University Press, 1993.
151. Wilkinson RG. *Socioeconomic determinants of health: health inequalities: relative or absolute material standards?* BMJ. 1997;314:591.
152. Lynch J, Davey Smith G, Kaplan G, House J. *Income inequality and mortality: importance to health of individual income, psychosocial environment, or material conditions*. BMJ. 2000;320:1200–04.
153. Muntaner C, Lynch J. *Income inequality and social cohesion versus class relations: a critique of Wilkinson's neo-Durkheimian research program*. Int J Health Serv. 1998;29:59–81.
154. Wilkinson RG. *Income inequality, social cohesion and health: clarifying the theory. A reply to Muntaner and Lynch*. Int J Health Serv. 1999;29:525–43.
155. Wilkinson RG. *Inequality and the social environment: a reply to Lynch et al*. J Epidemiol Community Health. 2000;54:411–13.

156. Lynch J. *Income inequality and health: expanding the debate*. Soc Sci Med. 2000;51:1001–05.
157. Leon DA, Walt G, Gilson L. *International perspectives on health inequalities and policy*. BMJ. 2001;322:591–4.
158. Marmot M, Wilkinson RG. *Psychosocial and material pathways in the relation between income and health: a response to Lynch et al*. BMJ. 2001;322:1233–36.
159. Lynch J, Davey Smith G, Hillemeier M et al. *Income inequality, the psychosocial environment, and health: comparisons of wealthy nations*. Lancet. 2001;358:194–200.
160. Muntaner C, Lynch JW, Hillemeier M et al. *Economic inequality, working-class power, social capital, and cause-specific mortality in wealthy countries*. Int J Health Serv. 2002;32:629–56.
161. Rodgers GB. *Income and inequality as determinants of mortality: an international cross-section analysis*. Int J Epidemiol. 2002;31:533–38.
162. Wilkinson RG. *Liberty, fraternity, equality*. Int J Epidemiol. 2002;31:538–43.
163. Porta M, Borrell C, Copete JL. *Theory in the fabric of evidence on the health effects of inequalities in income distribution*. Int J Epidemiol. 2002;31:543–46.
164. Deaton A. *The convoluted story of international studies of inequality and health*. Int J Epidemiol. 2002;31:546–49.
165. Lynch J, Davey Smith G. *Income inequality and health: The end of the story?* Int J Epidemiol. 2002;31:549–51.
166. Séguin L, Xu Q, Potvin L et al. *Effects of low income on infant health*. CMAJ. 2003;168(12):1533–8
167. Pearce N, Davey Smith G. *Is social capital the key to inequalities in health?* Am J Public Health. 2003;93:122–29.
168. Sacker A, Firth D, Fitzpatrick R, et al. *Comparing health inequality in men and women: prospective study of mortality 1986–96*. BMJ. 2000;320:1303–7.
169. Szreter¹ S, Woolcock M. *Health by association? Social capital, social theory, and the political economy of public health*. Int J Epidemiol. 2004;33:650–667
170. Blane D. The life course, the social gradient, and health. In: Marmot M, Wilkinson RG. eds. *Social Determinants of Health, II ed*. Oxford University Press, 2006:54–77.
171. Shaw M, Dorling D, Smith GD. Poverty, social exclusion, and minorities. In: Marmot M, Wilkinson RG. eds. *Social Determinants of Health, II ed*. Oxford University Press, 2006:196–223.
172. Fisher PA, Ball TJ. *Balancing empiricism and local cultural knowledge in the design of prevention research*. J Urban Health. 2005;82(2 supp3):iii44–iii55.
173. Nazroo JY, Williams DR. The social determination of ethnic/racial inequalities in health. In: Marmot M, Wilkinson RG. eds. *Social Determinants of Health, II ed*. Oxford University Press, 2006:238–266.
174. Clark R, Anderson NB, Clark VR, Williams DR. *Racism as a stressor for African Americans: a biophycosocial model*. American Psychologist. 1999;54(10):805–816.
175. Srinivasan S, O'Fallon LR, Dearry A. *Creating healthy communities, healthy homes, healthy people: initiating a research agenda on the built environment and public health*. Am J Public Health. 2003;93(9):1446–1450.

176. Agency for Healthcare Research and Quality. *Community-based participatory research. Conference summary*. Rockville, MD, USA. June 2002. <http://www.ahrq.gov/about/cpcr/cbpr1.htm>
177. Viswanathan M, Ammerman A, Eng E, et al. *Community-Based Participatory Research: Assessing the Evidence*. Evidence Report/Technology Assessment No. 99. Agency for Healthcare Research and Quality. Rockville, MD, USA. July 2004.
178. Macaulay AC, Commanda LE, Freeman WL, Gibson N, McCabe ML, Robbins CM, Twohig P. *Participatory research maximises community and lay involvement*. BMJ. 1999;319:774-8.
179. Macaulay AC, Freeman WL, Gibson N, McCabe ML, Robbins CM, Twohig, PL, NAPCRG. *Responsible research with communities: participatory research in primary care – a policy statement for the North American Primary Care Research Group*. 1998. www.napcrg.org/exec.html
180. Litt IF. *Research with, not on, adolescents: community-based participatory research*. J Adolesc Health. 2003;33:315-316.
181. Minore B, Boone M, Katt M, Kinch P, Birch S. *Addressing the realities of health care in northern aboriginal communities through participatory action research*. J Interprof Care. 2004;18(4):360-8.
182. Israel BA, Schulz AJ, Parker EA, Becker AB. *Community-based participatory research: policy recommendations for promoting a partnership approach in health research*. Education for Health. 2001;14(2):182-197.
183. Macaulay AC, Gibson N, Freeman WL, et al. *The community's voice in research*. CMAJ. 2001;164(12):1661-2.
184. Batalden PB, Cronenwett LR, Brown LL, et al. *Collaboration in improving care for patients: how can we find out what we haven't been able to figure out yet?* Jt Comm J Qual Improv. 1998;24(10):609-18.
185. Macaulay AC, Delormier T, McComber AM, et al. *Participatory research with native community of Kahnawake creates innovative Code of Research Ethics*. Can J Pub Health. 1998;89(2):105-8.
186. Stern G. *Research, action, and social betterment*. Am Behav Sci. 1985;29(2):229-48.
187. Fisher B, Neve H, Heritage Z. *Community development, user involvement, and primary health care*. BMJ. 1999;318:749-50.
188. Israel BA, Schurman SJ, Hugentobler MK. *Conducting action research: relationships between organization members and researchers*. J Appl Behav Sci. 1992; 28:78-101.
189. Townsend E, Birch DE, Langley J, Langille L. *Participatory research in a mental health clubhouse*. Occupat Ther J Res. 2000;20(1):18-44.
190. Macleod C. *Research as intervention within community mental health*. Curationis. 1997;20(2):53-6.
191. Lantz PM, Viruell-Fuentes E, Israel BA, Softley D, Guzman R. *Can communities and academia work together on public health research? Evaluation results from a community-based participatory research partnership in Detroit*. Journal of Urban Health. 2001; 78(3):495-507.
192. Lewis TC, Robins TG, Joseph CLM et al. *Identification of gaps in the diagnosis and treatment of childhood asthma using a community-based participatory research approach*. J Urban Health. 2004;81(3):472-88.
193. Schulz AJ, Israel BA, Parker EA, Lockett M, Hill Y, Wills R. *The East Side Village health worker partnership: integrating research with action to reduce health disparities*. Public Health Reports. 2001;116:548-57.

194. Murray SA, Graham LJ. *Practice based health needs assessment: use of four methods in a small neighbourhood*. BMJ. 1995;310:1443-8.
195. Andersson N. *Evidence-based planning: the philosophy and methods of sentinel community surveillance*. CIETinternational/EDI World Bank. Washington 1996.
196. Andersson N, Arostegui J, Lainez O, Irigoyen L et al. *Sitios centinela: la experiencia de Centroamérica y Guerrero (México) en la descentralización de planificación*. CIET - Prioridades de Salud. 1990; 1&2:18-29.
197. Andersson N, Villegas A, Paredes S. Microregional planning: measurements and mobilisation in Guerrero, Mexico. In: Andersson N. *Four essays on community-based research in planning*. CIETinternational. New York, 1995.
198. Andersson N, Morelli R, Ledogar RJ. Principios orientadores de medición en la salud. CIET – Prioridades de Salud. 1990;1&2:1-17.
199. Andersson N, Martinez E, Cerrato F, Morales E, Ledogar R.J. *The Use of Community-based Data in Health Planning in Mexico and Central America*. Health Policy and Planning. 1989; 4(3):197-206.
200. Ledogar RJ, Andersson N. *Impact estimation through sentinel community surveillance: An affordable epidemiological approach*. Third World Planning Review. 1993; 15/3:263-272.
201. Andersson N. *Los problemas con el muestreo probabilístico en la selección de sitios centinela*. CIET - Prioridades de Salud. 1990; 1&2:30-35.
202. Andersson N. A monitoring option for development in “data poor” countries. In: Andersson N. *Four essays on community-based research in planning*. CIETinternational. New York, 1995.
203. Andersson N. Meso-analysis: quantifying qualitative data from communities and services. In: Andersson N. *Four essays on community-based research in planning*. CIETinternational. New York, 1995: 51-59.
204. Andersson N. *La estimación del riesgo*. CIET - Prioridades de Salud. 1990; 1&2:57-66.
205. Mantel N, Haenszel W. *Statistical aspects of the analysis of data from retrospective studies of disease*. J Natl Cancer Inst. 22 (1959). 718-748.
206. Miettinen O.E. *Estimability and estimation in case-referent studies*. Am J Epidemiol. 103 (1976). 226-235.
207. Monasta L. *La mesoanalisi in paesi in via di sviluppo: un'esperienza nello stato di Guerrero (Messico)*. Tesi di Laurea in Scienze Statistiche e Demografiche. Università degli studi di Padova, Facoltà di Scienze Statistiche, Demografiche ed Attuariali. A.A. 1993-1994.
208. Stange KC, Miller WL, Crabtree BF, O'Connor PJ, Zyzanski SJ. *Multi-method research: approaches for integrating qualitative and quantitative methods*. J Gen Intern Med. 1994;9:278-282.
209. Goering PN, Streiner DL. *Reconcilable differences: the marriage of qualitative and quantitative methods*. Can J Psychiatry. 1996;41:491-497.
210. Tashakkori A, Teddlie C. *Mixed methodology: combining qualitative and quantitative approaches*. Thousand Oaks, Calif: Sage Publications; 1998.
211. Cresswell JW, Fetters MD, Ivankova NV. *Designing a mixed methods study in primary care*. Ann Fam Med. 2004;2:7-12.
212. Ledogar RJ, Acosta LG, Penchaszadeh A. *Building international public health vision through local community research: the El Puente-CIET partnership*. Am J Public Health. 1999; 89(12):1795-7.

213. Ledogar RJ, Penchaszadeh A, Garden CC, et al. *Asthma and Latino cultures: different prevalence reported among groups sharing the same environment*. Am J Public Health. 2000;90(6):929-35.
214. Research Team – Children of the Earth High School. Risk and resiliency within the urban Aboriginal \ First Nations youth context – The report of the research team. Draft Report, Health Canada-CIETcanada-Medicine Fire. Victoria (BC), 1996.
215. Ledogar RJ, Iglesias-Garden C, Miranda A, Monasta L. *Evidence Based Planning by a Community Organization: Preparing to Combat Asthma in Brooklyn, New York*. Draft Report, CIETinternational-El Puente. New York, 1998.
216. Scrimshaw S, Gleason R. *Rapid assessment procedures: qualitative methodologies for planning and evaluation of health related programmes*. International Nutrition Fundation for Developing Countries. Boston 1992.
217. Breslow NE. *Odds ratio estimators when the data are sparse*. Biometrika. 1981; 68:73-84.
218. Robins J, Breslow N, Greenland S. *Estimators of the Mantel-Haenszel variance consistent in both sparse data and large-strata limiting models*. Biometrics. 1986: 42;311-323.
219. Metha CR, Walsh SJ. *Comparison of exact, mid-p, and the Mantel-Haenszel confidence intervals for the common odds ratio across several 2x2 contingency tables*. The American Statistician. 1992: 42/2;146-150.
220. Breslow NE, Day NE. *Statistical methods in cancer research*. Vol. I – The analysis of case-control studies. IARC n.32. Lyon, 1980.
221. Agresti A. *On logit confidence intervals for the odds ratio with small samples*. Biometrics. 1999: 55;597-602.
222. Armitage P. *Statistical methods in medical research*. Blackwell Scientific Publications. Oxford, 1971.
223. Mantel N, Fleiss JL. *Minimum expected cell size requirements for the Mantel-Haenszel one-degree-of-freedom chi-square test and a related rapid procedure*. Am J Epidemiol. 1980: 112;129-134.
224. Fisher RA. *The logic of inductive inference*. Journal of the Royal Statistical Society, Ser A. 1935; 98,1:39-54.
225. Cornfield J. *A statistical problem arising from retrospective studies*. Proc. 3rd Berkeley Symp. Math. Statist. and Prob. University of California Press. 1956: Vol. 4; 135-148.
226. Thomas DG. *Algorithm AS 36 – Exact limits for the odds ratio in a 2x2 table*. Applied Statistics. 1971: 20/1;105-110.
227. Thomas DG. *Exact and asymptotic methods for the combination of 2x2 tables*. Computers and Biomedical Research. 1975: 8/5;423-46.
228. Rothman KJ, Greenland S. *Modern Epidemiology*. II Edition. Lippincott-Raven, 1998.
229. Fisher RA. *Confidence limits for the cross-product ratio*. Australian Journal of Statistics. 1962: 4;41
230. Thomas DG, Gart JJ. *A table of exact confidence limits for differences and ratios of two proportions and their odds ratios*. J.A.S.A. 1977: 72/357;73-76.
231. Troendle JF, Frank J. *Unbiased confidence intervals for the odds ratio of two independent binomial samples with application to case-control data*. Biometrics. 2001: 57;484-489.

232. CDC. *The Epi Info Manual, version 6.02*. Brixton Books. London 1994.
233. Agresti A, Min Y. *On small sample confidence intervals for parameters in discrete distributions*. Biometrics. 2001; 57:963-71.
234. Sterne TE. *Some remarks on confidence or fiducial limits*. Biometrika. 1954; 41:275-278.
235. Baptista J, Pike MC. *Exact two-sided confidence limits for the odds ratio in a 2x2 table*. Applied Statistics. 1977; 26:214-220.
236. Metha CR, Patel NR, Gray R. *Computing an exact confidence interval for the common odds ratio in several 2x2 contingency tables*. J.A.S.A. 1985; 80/392:969-973.
237. Vollset SE, Hirji KF, Elashoff RM. *Fast computation of exact confidence limits for the common odds ratio in a series of 2x2 tables*. J.A.S.A. 1991; 86/414:404-409.
238. Gart JJ. *Point and interval estimation of the common odds ratio in the combination of 2x2 tables with fixed marginals*. Biometrika. 1970; 57:471-475.
239. Gart JJ. *The comparison of proportions: a review of significance tests, confidence intervals and adjustments for stratification*. Review of the International Statistical Institute. 1971; 39(2):148-169. Addenda and errata in 1972; 40(2):221.
240. Hauck WW. *A comparative study of conditional maximum likelihood estimation of a common odds ratio*. Biometrics. 1984; 40:1117-1123.
241. Poole C. *Beyond the confidence interval*. Am.J.Pub.Health.1987; 77(2):195-199.
242. Rothman KJ. *Computation of exact confidence intervals for the odds ratio*. Int. J. Biomed. Comp. 1975; 6:31-39.
243. Consiglio Italiano per i Rifugiati. *Relazione sul censimento di cittadini provenienti dall'ex-Jugoslavia presenti nei campi di Poderaccio (Alto, Masini, Basso), Olmatello (Dentro e Fuori) e Nave Brozzi (Firenze)*. CIR. Roma, 1995.
244. Golino S. *Popolazione e identità rom: strategie di sopravvivenza. I romá in provincia di Bolzano*. Università di Trento, Facoltà di economia - Corso di laurea in economia politica. Tesi di laurea AA 1998/99.
245. Lapov Z. *Vačaré romané? – Diversità a confronto: percorsi delle identità Rom*. Franco Angeli. Milano, 2004.
246. Fondazione Giovanni Michelucci. *Osservatorio sugli insediamenti rom e sinti in Toscana – Rapporto Conclusivo 2004*. Fondazione Giovanni Michelucci. Firenze, 2004.
247. Suardi C. *Rom Khorakhané, un'identità oltre i confini*. Università di Milano, Facoltà di Lettere e Filosofia - Corso di Laurea in Lettere Moderne Indirizzo Geografico. Tesi di laurea AA 2001/02.
248. Colacicchi P. *Rom a Firenze*. In: Brunello P. ed. *L'Urbanistica del Disprezzo*. Manifestolibri. Roma 1996: 125-136.
249. Salvi D. *Alla periferia del villaggio globale. Strategie di adattamento di due comunità zingare a Bergamo*. Tesi di Laurea. Facoltà di Sociologia, Università degli studi di Trento. A.A 1999-2000.
250. Valenti G. *Campi rom a Brescia*. In: Brunello P. ed. *L'Urbanistica del Disprezzo*. Manifestolibri. Roma 1996: 117-124.
251. Baldoli C, Brusò F, De Palma A, Marcato R. *Rom della ex Jugoslavia a Mestre*. In: Brunello P. ed. *L'Urbanistica del Disprezzo*. Manifestolibri. Roma 1996: 179-196.

252. Carli S. I Rom a Bolzano. In: Brunello P. ed. *L'Urbanistica del Disprezzo*. Manifestolibri. 1996: 107-116.
253. Monasta L. *The Health of Foreign Romani Children in Italy: Results of a Study in Five Camps of Roma from Macedonia and Kosovo*. Roma Rights - Quarterly journal of the European Roma Rights Center. Health Care, N. 3-4, 2004: 46-55. <http://www.errc.org/cikk.php?cikk=2061>
254. Unicef. *La condizione dell'infanzia nel mondo, 2001 – Prima infanzia*. Unicef. 2000.
255. Demographic Data for Development Project. *Child Survival: Risks and the Road to Health*. Institute for Resource Development/Westinghouse. March 1987.
256. National Planning Commission Secretariat, Kathmandu. *Diarrhoea, water and sanitation – Nepal multiple indicator surveillance*. Nepal, June 1997.
257. Cockcroft A, Monasta L, Onishi J, Karim E. *Baseline service delivery survey – Final Report*. Health and population sector programme, 1998-2000. Bangladesh. June 1999.
258. UNICEF. *Nutritional Status of Children Under Five, Northern Iraq*. IRQ 2001/007. http://www.unicef.org/evaldatabase/index_14460.html
259. Department of Health, Medical Research Council & Measure DHS+. *South Africa Demographic and Health Survey 1998, Full Report*. Department of Health, Pretoria 2002.
260. Glass RI, Lew JF, Gangarosa RE, LeBaron CW, Ho MS. *Estimates of morbidity and mortality rates for diarrheal diseases in American children*. J Pediatr. 1991 Apr;118(4 (Pt 2)):S27-33.
261. Monasta L. *Difficoltà respiratorie e prevalenza d'asma in bambini da zero a cinque anni in cinque insediamenti Rom*. Epidemiol Prev. 2004 Jul-Oct; 28 (4-5): 258-64.
262. SIDRIA (Gruppo collaborativo). *La frequenza dell'asma pediatrico in diverse aree italiane. I risultati di SIDRIA*. Epid Prev. 1997; 21: 235-242.
263. International Study of Asthma and Allergies in Childhood (ISAAC) Steering Committee. *Worldwide variations in the prevalence of asthma symptoms: the International Study of Asthma and Allergies in Childhood (ISAAC)*. Eur Respir J. 1998; 12: 315-335.
264. The National Asthma Control Task Force. *The Prevention and management of asthma in Canada: a major challenge now and in the future*. Canada 2000.
265. Thorne P. *Exposure intervention in a rural pediatric asthma cohort*. www.niehs.nih.gov/translate/cbpr/grantees/project.cfm?id=369
266. Martinez FD. *Recognizing early asthma*. Allergy. 1999; 54: 24-28.
267. Weiss ST. *Epidemiology and heterogeneity of asthma*. Ann Allergy Asthma Immunol. 2001; 87 (1 Suppl 1): 5-8.
268. Sears MR. *Consequences of long-term inflammation. The natural history of asthma*. Clin Chest Med. 2000; 21: 315-29.
269. Marmot M. Introduction. In: Marmot M, Wilkinson RG. eds. *Social Determinants of Health, II ed*. Oxford University Press, 2006:1-5.
270. Agenzia di Sanità Pubblica della Regione Lazio, G.R.I.S Area Zingari, Regione Lazio. *Salute senza esclusione: campagna vaccinale per i bambini rom e sinti a Roma*. Agenzia di Sanità Pubblica della Regione Lazio (ASP). Rome, 2003.

271. Association of Canadian Universities for Northern Studies. *Ethical principles for the conduct of research in the north*. ACUNS. Ottawa, 1997. (www.yukoncollege.yk.ca/~agraham/ethics.htm)
272. Macaulay AC, Delormier T, Cross EJ, et al. *Participatory research with native community of Kahnawale creates innovative code of research ethics*. Can J Public Health. 1998;89:105-8.
273. The Australian Institute of Aboriginal and Torres Strait Islander Studies. *Guidelines for Ethical Research in Indigenous Studies*. AIATSIS, May 2000.
<http://www.aiatsis.gov.au/library/assets/pdfs/policies/EthicsGuideA4.pdf>
274. Bass E, Korn D, Whitehead T. Academic incentives and capacity building for CBPR. In: *Community-based participatory research*. Conference summary. June 2002. Agency for Healthcare Research and Quality, Rockville, MD. <http://www.ahrq.gov/about/cpcr/cbpr/cbpr1.htm>
275. Dirección General de Salud Pública – Ministerio de Sanidad y Consumo, Área de Salud – Fundación Secretariado Gitano. *Salud y comunidad gitana - Análisis de propuestas para la actuación*. Ministerio de sanidad y consumo. Madrid 2006.

ANNEX 1. NOTES ON THE MAPPING OF NON-ITALIAN ROM SETTLEMENTS IN ITALY

Much of the data presented here comes from a study carried out by the author between the end of February and the beginning of August 2001. As part of the European project “The Education of the Gypsy Childhood in Europe” under the supervision of Prof. Leonardo Piasere, this study consisted in mapping all the settlements comprising at least three families of non-Italian *Rom* in Italy (1).

It is therefore more than simply a mapping of camps, since some settlements consisted of families or groups of families who lived in “proper” houses or who had purchased or rented land, with or without bricks-and-mortar housing.

Concerning settlements on private land, one should also note that a good number of *Rom* families have unknowingly (or underestimating the issue) acquired land from Italians that is subject to limitations in its use. Apart from land with building and land use restrictions, it is often a question of land that is flood-prone and land subject to environmental and landscape conservation regulations.

Many cases were identified of families who had independently purchased houses or land in a particular area. In the municipality of *Zagarolo* (in *Valle Martella*) in the province of Rome, for example, there were various non-Italian *Rom* families as well as *Sinti* families and Italian *Rom*. A similar situation was found in the province of Turin, in Catania and in the province of Lecce. Where such situations were identified, they were duly described in the study but not included in the actual mapping, as they could not really be considered settlements in the true sense, rather they were groups of individual families living in the same neighbourhood or rural area. These families were of varying size, each with their own house, but tended to live in the same area.

The map did not include families occupying council houses or flats. Some local councils had adopted a policy of bricks-and-mortar housing for *Rom* families, to good effect. In other cases, the choice of living in a house or flat was taken spontaneously by the families themselves without the assistance of institutional bodies or associations.

This mapping study will not have identified groups who live incognito in urban outskirts or in the countryside as they tend to court invisibility and do not declare themselves to be *Rom*.

Of course, since the study concerns foreign *Rom*, the map did not include Italian *Rom* or *Sinti*. Reference to Italian *Rom* is not limited to those in the south of Italy such as in Abruzzo, Molise and Campania, but includes groups such as the *Lovara*, *Kalderash*, *Harvati* and *Slovénsko*.

The study was carried out over a period of about five months. Most of the contacts were made by means of telephone, email, fax and letter. “On-the-spot” observations would have taken a very long time, also bearing in mind that many settlements are by nature extremely mobile. It was therefore necessary to obtain a “snapshot” of the situation in as brief a period as possible. Many of the settlements identified in this study have already ceased to exist: these include *Bressanone*, *Zelarino* (Mestre), and one of two camps in Bergamo; and evictions have

occurred at the camp in *via Barzaghi* (Milan). In March 2003 the *San Giuliano* of Venice was closed and in June the *Masini* (Florence) was completely destroyed by fire.

In some cases, such as in the Tuscany and Emilia Romagna regions, the situation was better organised and therefore it was easier to carry out the study and collect the necessary information. In Tuscany the Regional Observatory managed by the *Michelucci Foundation* monitors the presence of *Rom* and *Sinti* in the territory. In Emilia Romagna, the regional authority operates its own monitoring activities. On its web site, Rome City Council presents some data regarding settlements. In the latter two cases, verification was carried out case-by-case. The *Michelucci Foundation*'s information was taken at face value.

In numerous instances, several sources were used to verify the data provided. This was especially the case where data were approximate or contradictory.

Several different sources were used. Social Services sometimes had a more accurate understanding of the situation. In other cases, information was gathered from specific associations such as *Opera Nomadi*, *AIZO* (Italian Association Gypsies Today) and *Caritas*, or other associations or bodies, such as the Municipal Police, or Aldermen and offices responsible for "Foreigners and Nomads". The Social Services best informed about the situation were not always those at the local council level. Occasionally, these were at a Provincial or Regional level. It was found at times that single individuals either inside or outside institutional bodies understood the situation well, whether out of personal interest or because they had held longstanding positions of authority in such matters.

It should be borne in mind that the number of occupants in a camp is almost always an approximate number. This is because these situations are by nature unstable. The nationality of *Rom* was also established on the basis of an approximate estimate, where no "official" institutional data were forthcoming. Associations or institutional bodies frequently declared that in a particular camp there was "x" number of people, of which half were of "y" nationality while the other half were "z". In cases where no other sources of information were available, these data were taken at face value.

Several factors contribute to the imprecision of information about number of occupants in a camp and nationalities. Many of these settlements were temporary, unofficial or in very unstable conditions, and for these reasons families might move to find more stable and safer conditions. Inhabitants of unauthorised settlements are often evicted. On occasion, the settlements themselves are dismantled or reduced in size. In some localities, local administrative bodies had started policies of placing families in public or private housing. In a number of settlements, regular families hosted more or less temporary guests who were not officially registered.

THE MAIN MIGRATORY FLOWS AND NUMBERS REPORTED BY OTHER AUTHORS

L. Piasere (2) refers to four great migratory flows of *Rom* and *Sinti* to Italy, and a fifth will need to be added that took place after 1988, the year in which Piasere publishes his paper.

The first of these flows took place between the 10th and 15th centuries. Two separate stocks reached Italy. The *Sinti* mainly came to Northern and Central Italy, and the *Rom* to the south. The present-day estimated populations of these *Rom* and *Sinti* groups are approximately

30,000 each (3). The migration to Southern Italy probably originated from Greek-speaking areas of the Balkans, as it seems from the analysis of their language, which does not have German or Slavic influences (2). Both groups might have been pushed towards Italy by the expansion of the Ottoman Empire that brought “new” groups to the Balkans, while inducing the existing ones to escape from the conflict and move towards Western and Northern Europe. The first groups who settled in Northern Italy arrived later from Northern Europe through the Hungarian Empire.

The second flow started from the mid 19th century with the arrival in Italy of *Rom* (*Kalderash*, *Lovara* and *Čurara*) roughly from what is now Hungary and Romania. The flow of these latter *Rom* was the result of the migrations probably generated by the final decline of a 500-year reign of slavery in Valachia and Moldavia (up to 1856) (2).

The 7,000 *Rom* estimated by Brunello (3) and S. Geraci et al. (4), who are the children and grandchildren of migrants from northern Yugoslavia between the First and Second World Wars, are considered to be the third flow. They are mainly German, Slovenian and Croatian groups (*Slovénsko Roma*, *Hrvansko Roma* and *Istrijani Roma*) (2).

The fourth flow involves *Rom* from the various countries of the former Yugoslavian Federation whose destination was Western Europe. This migration started from the end of the 1960's. The manner in which these flows took place and the reasons involved varied. The flows of those defined in 1988 by Piasere as “of recent origin”, because of the developments in the former Yugoslavian Federation are to be considered ongoing right up to 1999, the time of the war in Kosovo and thereafter (5). P. Brunello estimates that 35,000 Yugoslav *Rom* (Slovenians, Croatians, Serbs, Macedonians and Kosovans) reached Italy between the mid-1970's and 1992. We may add to this estimate 10,000 who arrived from Bosnia during the war there. Brunello's publication dates back to 1996 and therefore could not include arrivals determined by the war in Kosovo. It is thought that 120,000 *Romá* migrated from Kosovo to other countries after mid-June 1999 (J.A. Dérens, 1999, cited by N. Sigona (6)) and, out of these, about five thousand could have settled in Italy.

The fifth flow resulted from the fall of the *Ceausescu* regime in Romania in 1989 (as stated by S. Costarelli (7)). At the time in which Costarelli was writing, this flow had not reached Italy, and was mainly toward France and Germany. At present-time, it represents the main migration flow of foreign *Rom* to Italy. Due to the worsening of living conditions in Romania, and to intolerance and marked ethnic discrimination, an increased number of arrivals from Romania is reported. ERRC (European Roma Rights Center) denounces serious human rights violations perpetrated against the *Rom* population (8) of Romania, in every social, political and institutional context. These problems are confirmed by the European Union, which considers this issue amongst the priorities to be solved before the acceptance of Romania into the Union (9).

All those who arrived during the first and second flows – and in part, i.e. up to the 1980's, during the third flow – are now Italian citizens. Estimates of foreign and Italian *Rom* and *Sinti* reported by Brunello, Costarelli and Geraci et al. are in the order of 110-120,000. However, these estimates are limited to 1995. According to ERRC data (10) there are 60-90,000 Italian *Rom* citizens. Foreign-born *Rom* and *Rom* born in Italy whose parents are immigrants total 45-70,000 persons.

As pointed out above, the mapping work conducted personally only concerns foreigners (not having Italian nationality) residing in settlements.

DATA DERIVED FROM THE MAPPING EXERCISE

Complete data concerning the numbers of non-Italian *Rom* and their countries of origin identified in the mapping work, alongside charts showing each settlement case-by-case, plus additional information, appear in the “The education of the Gypsy Childhood in Europe” official Report. A summary is provided here. Tables of the data, together with a general map of Italy showing the settlements, illustrate this information.

Settlements and Regions

The mapping process identified 155 settlements containing a total of 18,125 non-Italian *Rom*. The average camp consisted of 115 people. If the population of Italy comprises 56,778,031 inhabitants, we found 3.2 non-Italian *Rom* in camps per 10,000 inhabitants. The distribution of *Rom* and settlements on the Italian territory was uneven (Fig. A.1, Tab. A1.1, Tab. A2.2).

In the north of Italy (Piedmont, Val D’Aosta, Liguria, Lombardy, Veneto, Trentino-Alto-Adige, Friuli-Venezia-Giulia), the mapping recorded 45 settlements and approximately 4,000 non-Italian *Rom*. The average size of a camp was 90 people. Comparing northern, central and southern Italy and the islands, this was the lowest figure for camp occupancy. This could be due to a planning policy aimed at smaller camps, a more even geographic distribution of camps or smaller towns. The number of non-Italian *Rom* residing in camps per 10,000 inhabitants was also lower in the north of Italy. In a population numbering 21,419,682, there were 1.9 non-Italian *Rom* per 10,000. Thus in northern Italy there were approximately two non-Italian *Rom*, living in camps, per 10,000 inhabitants.

In central Italy (Emilia Romagna, Tuscany, Umbria, Lazio, Marche, Abruzzo, Molise), mapping out revealed 74 settlements comprising a total of 8,100 inhabitants. The average camp contained 110 people. In this region, there were five non-Italian *Rom* per 10,000 inhabitants (total population: 16,400,819). This is the highest relative number of non-Italian *Rom* in Italy. This was due to the large concentration of camps in the city of Rome and in Tuscany.

In the south of Italy (Campania, Puglia, Basilicata and Calabria), 23 camps were recorded with an average of 178 people per settlement. This was the highest average and indicates a higher degree of agglomeration. In the province of Naples alone, there were at least three camps with more than 600 inhabitants, two in *Scampia* and one in *Giugliano di Campania*. The camps were usually smaller in Puglia, but in Foggia one camp comprised 500 people. In the south there were 3.3 non-Italian *Rom* in camps per 10,000 inhabitants (total population: 12,342,896).

In the islands (Sicily and Sardinia) a total of 1,850 non-Italian *Rom* occupy 13 settlements. The average size was 142, with a figure of 3.2 non-Italian *Rom* per 10,000 inhabitants. Of these 13 settlements, 9 were located in Sardinia. These average 80 people. Since the population of Sardinia totals 1,648,248, this translates into 4.4 non-Italian *Rom* in camps per

10,000 inhabitants. In Sicily the four settlements recorded comprised a total of 1,130 people with an average of 282 people per settlement.

After Lazio, with 10.5 *Rom* per 10,000 inhabitants (due principally to the concentration in Rome), other regions with the highest number of *Rom* were Tuscany (4.5), Campania (4.5) and Sardinia (4.4), followed by Puglia (3.4).

In the area covered by Rome City Council, more than 5,100 non-Italian *Rom* lived in 23 settlements with an average of 226 per settlement. There were 225 residents in two settlements in the rest of the Lazio region (in the provinces of *Frosinone* and *Latina*).

The Campania and Sicily regions had the highest average in terms of numbers per settlement - both with 282 - followed by Lazio (217), Lombardy (135) and Puglia (124).

Place of origin

As indicated above, in some cases the data shown on nationalities are based on approximate percentages provided by institutional bodies and associations. These data should therefore be treated with caution, although they do provide a useful general guide. Data on place of origin, by geographic area and by every single region, can be found in Tab. A1.3 to A1.7.

Of the 18,125 non-Italian *Rom* present in the settlements identified in the mapping survey in 2001, some 28% appeared to be of Bosnian origin, 21% were Serbs, 16% Kosovan, 11% Macedonian, 9% Croatian, 9% Romanian, 5% were from Montenegro, 0.5% were Albanian and 0.5% were Polish.

At the time of finalising this thesis in 2005, we realise that amongst *Rom* as a whole, in 2001 it was the Romanians who tended to render themselves more unidentifiable or less visible, because of their relatively recent immigration to Italy. Therefore, the proportion of Romanians may have been under estimated.

The number of *Rom* according to nationality varied between geographic areas of Italy and between regions. It is difficult to know why there were more Bosnians and Macedonians in central Italy, or more Croatians in the north, or Serbs in the south, etc. but there does seem to be a vague geographical correspondence along latitudinal lines between the states of the former Yugoslavian Federation and the regions of Italy.

Among an estimated 5,100 Bosnians, 3,000 lived in the central regions of Italy (37% of all the non-Italian *Rom* in camps in these regions). Fewer than 1,000 lived in the south, about 650 in the north, and about 500 in the islands.

The 3,800 Serb *Rom* living in settlements were concentrated in central Italy (1,150), and the south (1,250), although considerable numbers were recorded in the north (850), and islands (550). In the islands, Serb *Rom* accounted for 30% of all the non-Italian *Rom* living in camps, this being the highest percentage, followed by Bosnians who comprised 27% and Kosovans who totalled 20%.

Of the approximately 2,900 Kosovan *Romá* found living in settlements, about 1,000 lived in camps in central Italy, about 800 in the north, 750 in the south and 350 in the islands.

Kosovans accounted for about 20% of *Romá* living in northern and southern Italy and in the islands. They made up about 12% of the *Rom* population living in central Italy.

Slightly more than 2,000 Macedonian *Romá* were recorded as living in settlements. About 1,100 Macedonians lived in the central regions, 500 in the south, 300 in the north and about 100 in the islands.

About 4,000 *Rom* were recorded in the regions of northern Italy. Of these, 730 were Croatians: this amounts to almost half of all the 1,600 Croatian *Rom* present in camps in Italy in 2001. An additional 700 were located in the regions of central Italy.

Romanian *Rom* totalling approximately 1,600 were concentrated mainly in northern and central Italy, with about 650 people for each of the two areas. Slightly more than 200 Romanians were recorded as living in the southern regions and slightly more than 50 lived in the islands.

The regions of northern Italy appeared not to have attracted any *Rom* from Montenegro. The almost 900 *Rom* from Montenegro lived in the following regions: 450 in central Italy, 230 in the south and 200 in the islands.

Polish *Rom* were recorded exclusively in Piedmont, and totalled approximately 80 people. There was approximately the same number of Albanian *Rom*, although the true figure was probably higher and was likely to increase. Of those located, 50 were recorded in camps in Tuscany, and others were spread around Emilia Romagna and Calabria.

References

1. Monasta L. *Mappatura degli insediamenti di cittadini non italiani di etnia rom sul territorio nazionale*. Rapporto di ricerca del progetto "The education of the Gypsy childhood in Europe". 2003, Dipartimento di Studi Sociali, Università di Firenze.
2. Piasere L. "Parte Antropologica". *Il fenomeno della migrazione in riferimento alle difficoltà di adattamento sociale delle componenti nomadi*. Istituto Internazionale di Studi Giuridici, Ente di Diritto Pubblico. Roma 1988.
3. Brunello P. "Introduzione". *L'Urbanistica del Disprezzo*. Brunello P. (a cura di). Manifestolibri. 1996: 11-21.
4. Geraci S, Maisano B, Motta F. (a cura di). *Salute Zingara*. Caritas Diocesana di Roma. Edizioni Anterem. 1998: 23-27.
5. Sigona N. *Figli del ghetto. Gli italiani, i campi nomadi e l'invenzione degli zingari*. Nonluoghi libere edizioni. Dicembre 2002.
6. Sigona N. *L'Italia dei campi. Leggi regionali e "tutela" di Rom*. Tesi di Laurea in Antropologia Economica. Facoltà di Scienze Politiche, Istituto Universitario Orientale. Napoli. A.A.1998-99.
7. Costarelli S. *I bambini zingari in Europa: una panoramica*. In "Crescere Zingaro". UNICEF-ICDC. Ed. Anicia 1994: 55-72.
8. www.errc.org/publications/reports/index.shtml
9. www.romanothan.ro/documents/reports/rap_ue_romania_eng.htm
10. ERRC, *Il paese dei campi. La segregazione razziale dei Rom in Italia*. I Libri di Carta. Ottobre 2000.

Tables

Table A1.1. Numbers of foreign Rom in settlements, by geographic area

Area	Numbers in settlements	Numbers of settlements	Average numbers per settlement	Total population	Numbers per 10,000 inhabitants
Northern	4,050	45	90	21,419,682	1.9
Central	8,133	74	110	16,400,819	5.0
Southern	4,090	23	178	12,342,896	3.3
Islands	1,852	13	142	6,614,634	2.8
Total	18,125	155	117	56,778,031	3.2

Table A1.2. Numbers of foreign Rom in settlements, by Region

Region	Numbers in settlements	Numbers of settlements	Average numbers per settlement	Total population	Numbers per 10,000 inhabitants
Piedmont	1,238	16	77	4,302,565	- 2.9
Valle d'Aosta	20	1	20	115,938	- 1.7
Liguria	285	4	71	1,676,282	- 1.7
Lombardy	1,895	14	135	8,856,074	- 2.1
Trentino A.A.	160	2	80	890,360	- 1.8
Veneto	431	7	62	4,380,797	- 1.0
Friuli V.G	21	1	21	1,197,666	- 0.2
Emilia Romagna	904	20	45	3,909,512	- 2.3
Tuscany	1,591	21	76	3,529,946	+ 4.5
Umbria	70	4	17	811,831	- 0.9
Marche	78	2	39	1,429,205	- 0.5
Lazio	5,414	25	217	5,140,371	+ 10.5
Abruzzo	76	2	38	1,249,054	- 0.6
Molise	0	0	X	330,900	- X
Campania	2,535	9	282	5,630,280	+ 4.5
Puglia	1,365	11	124	4,031,885	+ 3.4
Basilicata	0	0	X	610,528	- X
Calabria	190	3	63	2,070,203	- 0.9
Sicily	1,130	4	282	4,966,386	- 2.3
Sardinia	722	9	80	1,648,248	+ 4.4
Total	18,125	155	115	56,778,031	3.2

Table A1.3. Origin of foreign Rom in settlements, by geographic area

Origin	Northern Number - %		Central Number - %		Southern Number - %		Islands Number - %		Total Number - %	
Albania	0	0%	60	1%	20	0.5%	0	0%	80	0.5%
Bosnia	646	16%	2,986	37%	970	24%	495	27%	5,097	28%
Croatia	729	18%	709	9%	109	3%	52	3%	1,599	9%
Kosovo	804	20%	994	12%	760	19%	378	20%	2,936	16%
Macedonia	318	8%	1,102	14%	515	13%	117	6%	2,052	11%
Montenegro	0	0%	457	6%	232	6%	190	10%	879	5%
Poland	73	2%	0	0%	0	0%	0	0%	73	0.5%
Romania	633	16%	677	8%	216	5%	65	4%	1,591	9%
Serbia	847	21%	1,148	14%	1,268	31%	555	30%	3,818	21%
Total	4,050	100%	8,133	100%	4,090	100%	1,852	100%	18,125	100%

Table A1.4. Origin of foreign Rom in settlements, in Regions of Northern Italy

Origin	Piedmont Number - %		Val d'Aosta Number - %		Liguria Number - %		Lombardy Number - %		Trent.A.A. Number - %		Veneto Number - %		Friuli V.G. Number - %		Total Number - %	
Albania	0	0%	0	0%	0	0%	0	0%	0	0%	0	0%	0	0%	0	0%
Bosnia	189	15%	0	0%	230	81%	140	7%	9	6%	68	16%	10	48%	646	16%
Croatia	671	54%	11	55%	0	0%	35	2%	0	0%	12	3%	0	0%	729	18%
Kosovo	0	0%	0	0%	0	0%	600	32%	4	2%	200	46%	0	0%	804	20%
Macedonia	101	8%	5	25%	5	2%	60	3%	147	92%	0	0%	0	0%	318	8%
Montenegro	0	0%	0	0%	0	0%	0	0%	0	0%	0	0%	0	0%	0	0%
Poland	73	6%	0	0%	0	0%	0	0%	0	0%	0	0%	0	0%	73	2%
Romania	82	7%	0	0%	50	18%	500	26%	0	0%	1	0%	0	0%	633	16%
Serbia	122	10%	4	20%	0	0%	560	30%	0	0%	150	35%	11	52%	847	21%
Total	1,238	100%	20	100%	285	100%	1,895	100%	160	100%	431	100%	21	100%	4,050	100%

Table A1.5. Origin of foreign Rom in settlements, in Regions of Central Italy

Origin	Em. Rom. Number - %		Tuscany Number - %		Umbria Number - %		Lazio Number - %		Marche Number - %		Abruzzo Number - %		Molise Number - %		Total Number - %	
Albania	10	1%	50	3%	0	0%	0	0%	0	0%	0	0%	0	x%	60	1%
Bosnia	360	40%	223	14%	0	0%	2,385	44%	18	23%	0	0%	0	x%	2,986	37%
Croatia	17	2%	9	1%	0	0%	623	12%	60	77%	0	0%	0	x%	709	9%
Kosovo	176	19%	717	45%	0	0%	25	0.5%	0	0%	76	100%	0	x%	994	12%
Macedonia	101	11%	446	28%	70	100%	485	9%	0	0%	0	0%	0	x%	1,102	14%
Montenegro	33	4%	0	0%	0	0%	424	8%	0	0%	0	0%	0	x%	457	6%
Poland	0	0%	0	0%	0	0%	0	0%	0	0%	0	0%	0	x%	0	0%
Romania	12	1%	79	5%	0	0%	586	11%	0	0%	0	0%	0	x%	677	8%
Serbia	195	22%	67	4%	0	0%	886	16%	0	0%	0	0%	0	x%	1,148	14%
Total	904	100%	1,591	100%	70	100%	5,414	100%	78	100%	76	100%	0	x%	8,133	100%

Table A1.6. Origin of foreign Rom in settlements, in Regions of Southern Italy

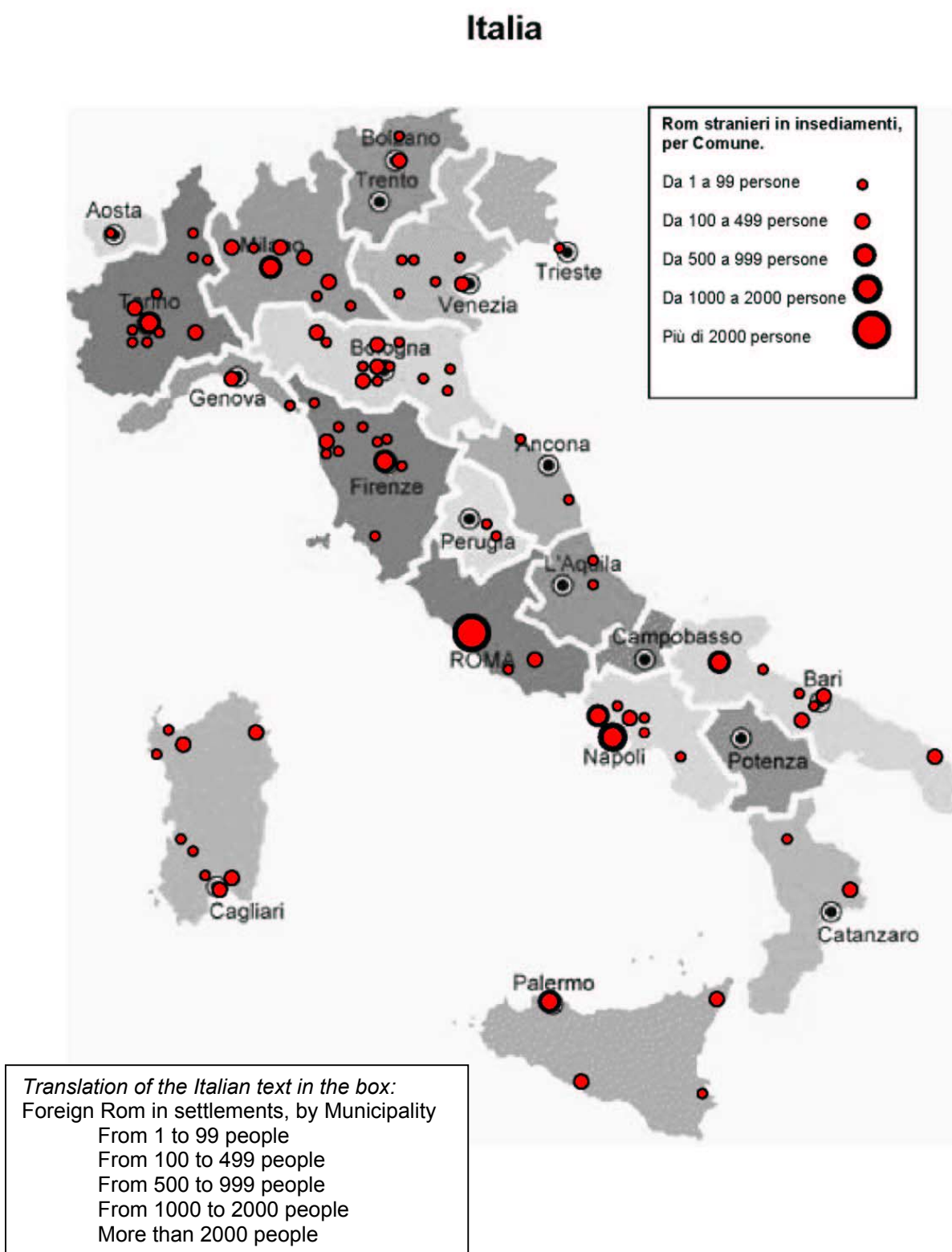
Origin	Campania Number - %		Puglia Number - %		Basilicata Number - %		Calabria Number - %		Total Number - %	
Albania	0	0%	0	0%	0	x%	20	11%	20	0.5%
Bosnia	950	37%	20	1%	0	x%	0	0%	970	24%
Croatia	13	0.5%	96	7%	0	x%	0	0%	109	3%
Kosovo	83	3%	507	37%	0	x%	170	89%	760	19%
Macedonia	208	8%	307	22%	0	x%	0	0%	515	13%
Montenegro	13	0.5%	219	16%	0	x%	0	0%	232	6%
Poland	0	0%	0	0%	0	x%	0	0%	0	0%
Romania	0	0%	216	16%	0	x%	0	0%	216	5%
Serbia	1,268	50%	0	0%	0	x%	0	0%	1,268	31%
Total	2,535	100%	1,365	100%	0	x%	190	100%	4,090	100%

Table A1.7. Origin of foreign Rom in settlements, by Island Regions

Origin	Sicily Number - %		Sardinia Number - %		Total Number - %	
Albania	0	0%	0	0%	0	0%
Bosnia	0	0%	495	69%	495	27%
Croatia	5	0.5%	47	7%	52	3%
Kosovo	378	33%	0	0%	378	20%
Macedonia	100	9%	17	2%	117	6%
Montenegro	125	11%	65	9%	190	10%
Poland	0	0%	0	0%	0	0%
Romania	65	6%	0	0%	65	4%
Serbia	457	40%	98	14%	555	30%
Total	1,130	100%	722	100%	1,852	100%

Figure

Figure A1.1. Map of the number of foreign Rom in settlements, by Municipality



ANNEX 2. THE CIET METHODOLOGY

The CIET methodology¹ was originally conceived to build capacities while producing accurate, detailed and actionable data rapidly and at low cost. Ordinarily, the focus is on the use of epidemiological data in local or national planning². This may be at the level of a municipality, a city³, a state, a number of provinces⁴ or an entire country⁵.

The approach permits community-based fact finding through a reiterative process, addressing one set of issues at a time. CIET methodology is a cross-design of qualitative and quantitative techniques that permits a holistic picture of – and locally designed solutions to – a particular problem. It is a cost-effective way to collect community data, presenting them in an appropriate form for planning at local, regional and national levels.

CIET methodology has been used in community surveys in many countries and specifically in Service Delivery Surveys in a number of different countries⁶. Some of the key features of the methodology are shown in the box.

Features of CIET methodology

- Data collected from cluster sites, selected to be representative of a district, a region or a country.
- Repeated cyclical process, each cycle including planning and instrument design, data collection, data analysis and interpretation, and communication of results.
- Each cycle focuses on a particular area or problem, not trying to collect data on a wide range of problems.
- Quantitative data from household questionnaires combined with qualitative data from focus groups, key informant interviews and institutional reviews *from the same communities* (that is, the data are coterminous) allow a better understanding of the issues addressed. This combined analysis is called mesoanalysis¹.
- Data analysis is not only in terms of indicators (for example, rate of childhood measles) but also in terms of *risk* (for example, the risk of measles in an unvaccinated child compared with a vaccinated child).
- Analysis gives results in a form that assists planning at household, community, district and national levels.
- The same sites are revisited in subsequent cycles of data collection, allowing easy estimation of changes over time or as a result of intervention.
- Each cycle of data collections and analysis requires a communication strategy to get the information to those who need it for planning.
- Transfer of skills of data collection, analysis and communication over a number of cycles is an explicit aim.

1. Andersson N. *Evidence-based planning: the philosophy and methods of sentinel community surveillance*. CIETinternational/EDI World Bank: Washington, 1996.

2. Ledogar RJ and N Andersson. *Impact estimation through sentinel community surveillance: An affordable epidemiological approach*. Third World Planning Review 1993; 15/3:263-272.

3. Arostegui J. *Los Sitios Centinela en Managua, Nicaragua*. UNICEF, Managua, 1992.

4. McTyre L. *Assessment and analysis of progress towards National Plan of Action goals in Mozambique*. UNICEF 1993.

5. Munroe L. *Sentinel community surveillance in Zimbabwe*. Evaluation News, UNICEF, Sept 1993.

6. CIETinternational and World Bank EDI. *Service delivery surveys: applying the sentinel community surveillance methodology*. Country overviews. EDI/World Bank, 1997.

ANNEX 3. THE AOC TABLE

The AOC table is the main link between the variables needed in the analysis and the instruments used to gather information, like the questionnaire. It is very important because in defining the research instruments we want to ask questions that will give us information that is already part of an analysis plan. This prevents us from asking questions that are not part of the general picture and that will end up giving us only a simple frequency.

AOC stands for Actionable variables, Outcome variables and Conditioners:

- Outcome variables are those variables that we think are to some extent influenced by other variables. They could be identified as the “effect” in the cause-effect model, but at this stage we don’t want to give for granted that a possible association between variables is part of a cause-effect relation.
- Actionable variables are those variables that we consider as part of what we can change to finally change the Outcome. They could be identified as the “cause”, but again this can only be proven after in depth analysis.

Conditioners are variables that might influence Outcome variables and/or the association between Actionable and Outcome variables. In general, these are variables we can’t change but we need to take into consideration to better understand reality. Conditioners could act as effect modifiers or confounders:

- A confounder is a factor explaining or producing confounding, which is a discrepancy between a desired counterfactual risk or rate (which the exposed would have had, had they been unexposed) and the unexposed risk or rate that was its substitute*. To act as a confounder a variable needs to be a risk factor for the disease (outcome) among the unexposed and be associated with the exposure variable in the source population. Confounding needs to be avoided, or adjusted for stratifying on confounders.
- An effect modifier is not a bias. A variable can be identified as an effect modifier if it shows a significant heterogeneity in the relation between an exposure and the outcome stratified by this variable. Effect modifiers need to be included in the analysis because they help us understand better the relation between the exposure and the outcome and plan specific interventions: if an actionable variable has an effect on the outcome only in a particular portion of the population, I will need to focus my attention on that portion.

The AOC table is designed before and helps defining the research instruments. This initial version evolves during analysis with the addition of dichotomised and combined variables. For example, the variable “number of years spent by the family living at the camp” will be dichotomised for its use in risk analysis. To calculate overcrowding within the house in terms of how many people live in how many rooms, two variables will be combined – number of family members and number of rooms – and later dichotomised.

In the household questionnaire most variables are AOC variables. The remaining ones are needed for other purposes: there are questions about behaviours that will help us understand what is the perception and the reaction to a certain situations. For example, if a child had diarrhoea, we asked if he/she was taken to see a doctor, and where. By doing this for several diseases, we can understand what is the general perception of the gravity attributed to each disease, and get an idea of the so called “recourse model”, limited to the step associated with the access to health services.

* K.J. Rothman, S. Greenland. “Modern Epidemiology”. Lippincott-Raven, 1998.

AOC table

Actionable Variables	Outcome Variables	Conditioners
Areas and variables related to living conditions in the camps, relative to the family of the child. Years spent living at the camp by the family. Type of structure and quality of the house. Overcrowding: Living space in the house. Space available for the night (beds, couches) Access to water. Access to hot water. Access to showers. Type and quality of toilets. Families per toilet. Connection to electricity. If the family owns a fridge. Areas of interest and variables more related to family behaviour. Literacy of the mother. Number of people smoking in the house and quantity of cigarettes smoked. System used for heating the house. System used for cooking. If the family cooks inside of outside of the house. Mesovariables: elements that could identify living conditions common to the whole camp People and families living in each camp Overcrowding (square meters per person living in each camp) Ground (floor) of the camp Only collective toilets Presence of potential risk factors: rats, former dumps, uncollected garbage, piled up materials, stagnant water, and others identified. Measures of degree of isolation of the camp: Walking time to the closer public transportation. Distance in km to closer Hospital/Emergency Room.	Underweight at birth (below 2.5kg), that could be influenced by living conditions suffered by the mother. Interviewee's perception of normal growth of the child. Period prevalence of diseases and symptoms that can be related to unstable living conditions: generally those involving the epithelia. In the 15 days prior to the interview: Period prevalence of diarrhoea Period prevalence of coughing Period prevalence of skin diseases Other reported symptoms occurred in the 15 days prior to the interview. Difficulty breathing or wheezing in the last 12 months. Prevalence of active asthma (difficulties breathing or wheezing in the last 12 months+clear diagnosis of asthma).	Number of people in the family. Age and sex of the child. Country of birth of the child. Age of the mother at delivery of the child.

ANNEX 5. EXAMPLES OF SMALL SAMPLE MEASURES OF ASSOCIATION AND CONFIDENCE INTERVALS

Tables used in the analysis of low birthweight

We will start looking at the table of people smoking inside the house (more than two people smoking in the house), by age of the mother at delivery (if the mother was younger than 19 or older than 34). As we will see, both variables are associated with low birthweight.

Table A1. Age of mother at delivery and number of people smoking in the house

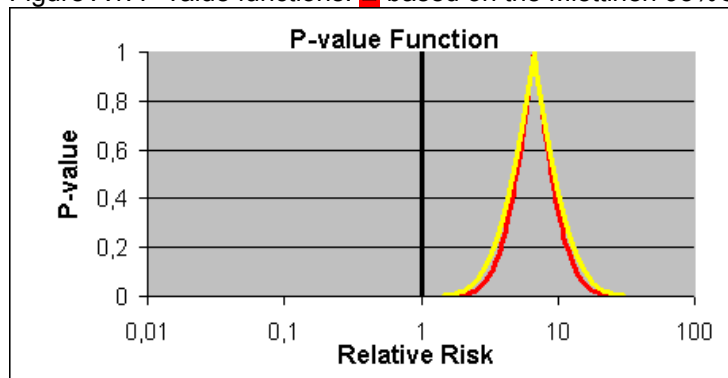
Smoke	Age of mother at delivery		
	19-34	<19 or >34	
2 or less	114	17	131
More than 2	14 (11%)	14 (45%)	28 (18%)
	128	31	159

Fisher exact 2-tailed test: Epi Info $p=0.000$, Rothman Fisher exact 2-tailed test: $p=0.000$

OR 6.71 *Miettinen 95% CI* 2.91 – 15.43
 Cornfield 95% CI 2.48 – 18.37 (2.47 – 19.76)

MLE of OR 6.59 *Exact 95%CI* 2.46 – 18.04

Figure A1. P-value functions: ■ based on the Miettinen 95%CI, ■ based on the Exact 95%CI



In this case, all the estimates show the significance of the association for $100(1 - \alpha)\% = 95\%$. Miettinen's CIs are narrower than Cornfield's and Exact CIs.

Given the strength of the association, we cannot see the difference between the two ways of calculating the Fisher exact 2-tailed test.

Taking the age of the mother at delivery as the outcome variable, and stratifying by smoking habits, if there were less than two people smoking in the house, a child born from a mother younger than 19 or older than 34 at the time of delivery was more at risk of being born underweight compared with a child born from a mother that was 19 to 34 years of age at delivery.

Children from families with less than two people smoking in the house

Table A2. Age of mother at delivery and birth weight of children

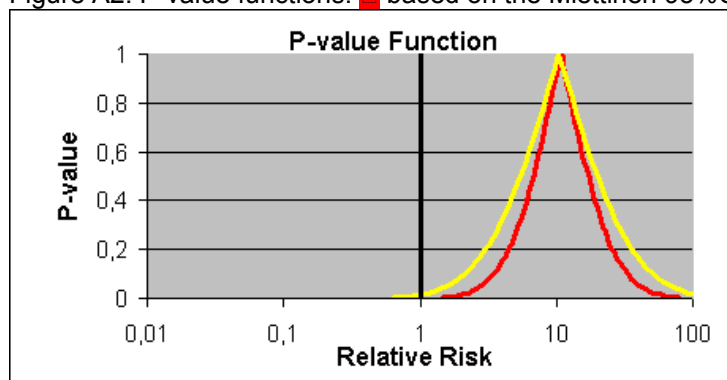
Birthweight	Age of mother at delivery		
	19-34	<19 or >34	
≥2.500	97	9	106
<2.500	4 (4%)	4 (31%)	8 (7%)
	101	13	114

Fisher exact 2-tailed test: Epi Info $p=0.006$, Rothman $p=0,011$

OR 10.78 Miettinen 95% CI 2.90 – 40.11
 Cornfield 95% CI 1.82 – 66.21* (1.14 – 114.60)

MLE of OR 10.35 Exact 95%CI 1.64 – 66.37

Figure A2. P-value functions: ■ based on the Miettinen 95%CI, ■ based on the Exact 95%CI



Again, Miettinenen's CIs are narrower than Cornfield's and the Exact CIs. In this case, this is very clear looking at the p-value functions.

We can see a big difference between Cornfield's intervals calculated with Epi Info Analysis and with CIET map: Exact limits are closer to the ones calculated with Epi Info, and slightly more conservative than these.

The MLE of the OR is shifted to the left, "closer" to the 1 value. However, looking at the p-value functions, the centre of Miettinen's function seems to be closer than the centre of the Exact function to the unity.

Rothman's Fisher exact test, although more conservative than the Epi Info, is still significant.

Children from families with two or more people smoking in the house

Table A3. In families with two or more people smoking in the house, age of mother at delivery and birth weight of children

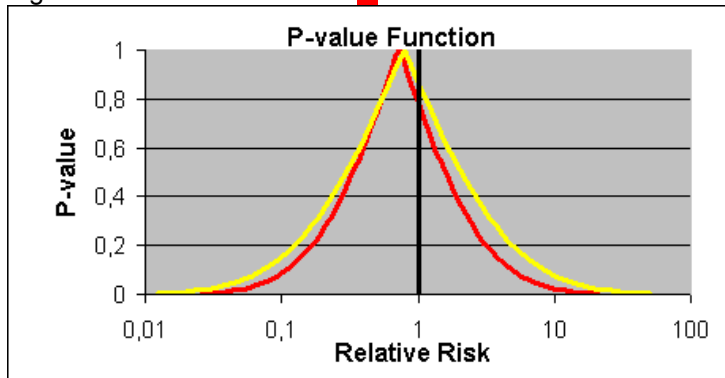
Birthweight	Age of mother at delivery		
	19-34	<19 or >34	
≥2.500	9	12	21
<2.500	2 (18%)	2 (14%)	4 (16%)
	11	14	25

Fisher exact 2-tailed test: Epi Info $p=1.000$, Rothman $p=1.209$

OR 0.75 Miettinen 95% CI 0.08 – 6.65
 Cornfield 95% CI 0.06 – 9.81* (-0.03 – 17.03)

MLE of OR 0.76 Exact 95%CI 0.05 – 12.37

Figure A3. P-value functions: ■ based on the Miettinen 95%CI, ■ based on the Exact 95%CI



In this case, Rothman's Fisher test exceeds 1, and the lower Cornfield's limit calculated using CIET map is negative. This might not seem very relevant, apart in terms of coherence, considering that nothing would make us look for significance in this circumstance.

Miettinen's intervals are once again narrower than Cornfield's and Exact intervals, with the exact limits being the most conservative.

Looking at the summary estimates for the stratified tables, we notice a relevant difference between the two p-value functions. The function based on Robins et al. does not seem to be centred in the MH weighted OR.

Crude OR 5.05

MH Weighted OR 3.23

Miettinen 95% CI

1.16 – 9.03

Robins, Greenland, Breslow 95% CI

0.91 – 11.44

Cornfield 95% CI

0.94 – 22.98

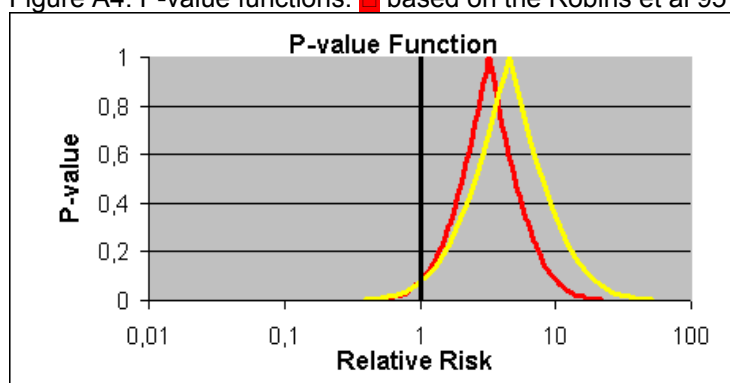
MLE of OR 4.54

Exact 95%CI

0.90 – 22.66

Chi square for evaluation of interaction 3.91 (P-value 0.048)

Figure A4. P-value functions: ■ based on the Robins et al 95%CI, ■ based on the Exact 95%CI



The difference between the MH weighted OR and the MLE of the OR is relevant. Looking at the p-value functions, and especially at the upper limit, Robins et al. CIs appear to be narrower than the Exact CIs. Miettinen's limits are the only ones to show significance, but probably not reliable given the circumstances.

Tables used in the analysis of diarrhoea

A child whose parents had been living at the camp for more than two years was more at risk of diarrhoea compared with a child whose family had been living at the camp for two years or less.

Table A4. Years spent by family at the camp and occurrence of diarrhoea in children

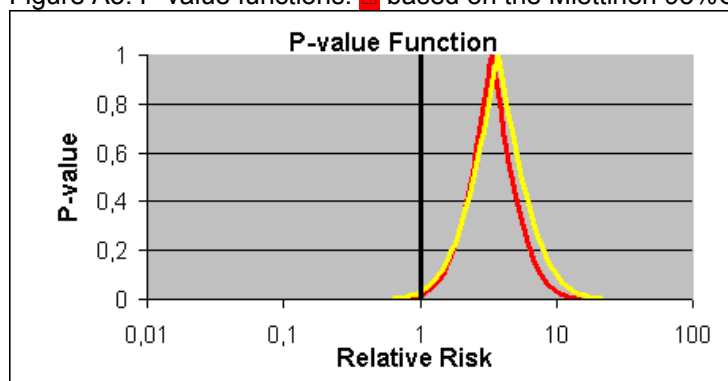
Diarrhoea	Years spent by family at the camp		
	2 or less	More than 2	
No	29	83	112
Yes	5 (15%)	48 (37%)	53 (32%)
	34	131	165

Fisher exact 2-tailed test: Epi Info $p=0.014$, Rothman $p=0.020$

OR 3.35 Miettinen 95% CI 1.27 – 8.89
 Cornfield 95% CI 1.12 – 10.72* (1.33 – 31.18)

MLE of OR 3.33 Exact 95%CI 1.17 – 11.77

Figure A5. P-value functions: ■ based on the Miettinen 95%CI, ■ based on the Exact 95%CI



Cornfield's approximation to the exact confidence limits appears to be inaccurate. From Miettinen to Exact CIs, all limits show a significance association. Both methods used to calculate Fisher's exact 2-tailed test are also significant.

The association between incidence of diarrhoea of the child and whether the family had spent more than five years living at the camp is not significant according to Cornfield as calculated by Epi Info Analysis. It is significant according to Cornfield as calculated by CIETmap. It is significant considering a simultaneous Fisher test, but not if we take the more conservative test calculated by Rothman.

Table A5. Years spent by family at the camp and occurrence of diarrhoea in children

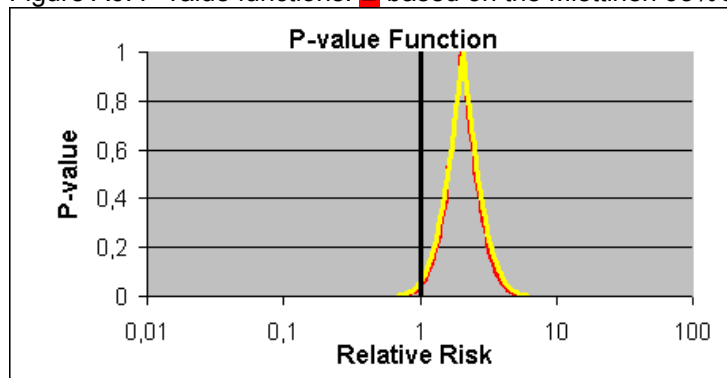
Diarrhoea	Years spent by family at the camp		
	5 or less	More than 5	
No	62	50	112
Yes	20 (24%)	33 (40%)	53 (32%)
	82	83	165

Fisher exact 2-tailed test: Epi Info $p=0.045$, Rothman test: $p=0.051$

OR 2.05 Miettinen 95% CI 1.05 – 3.98
 Cornfield 95% CI 0.99 – 4.25 (1.01 – 4.45)

MLE of OR 2.04 Exact 95%CI 1.00 – 4.24

Figure A6. P-value functions: ■ based on the Miettinen 95%CI, ■ based on the Exact 95%CI



Even though, in this case, significance is not confirmed by all of the different methods used, it is interesting to note how the p-value functions are almost identical. This is probably due to the good distribution of frequencies in the 2x2 table and the relatively small OR.

Overcrowding of the house is not directly associated with incidence of diarrhoea, though the role of overcrowding in the association between diarrhoea and years spent by the family living at the camp can be justified by suggesting that overcrowding can become a problem in the long run.

Families living in overcrowded houses

Table A6. In families living in overcrowded houses, years spent by family at the camp and occurrence of diarrhoea

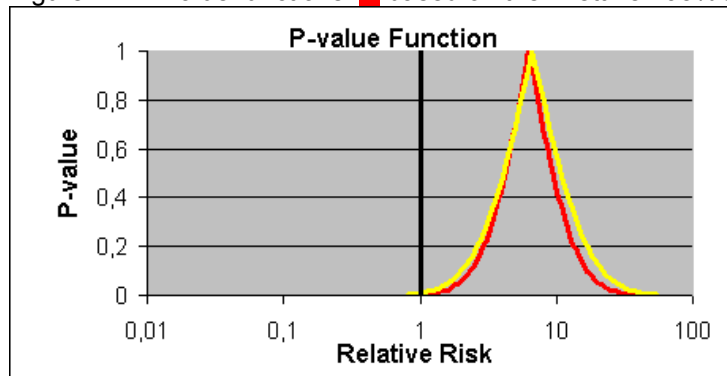
Diarrhoea	Years spent by family at the camp		
	5 or less	More than 5	
No	34	14	48
Yes	5 (13%)	13 (48%)	18 (27%)
	39	27	66

Fisher exact 2-tailed test: Epi Info $p=0.002$, Rothman $p=0.004$

OR 6.31 Miettinen 95% CI 2.00 – 19.92
 Cornfield 95% CI 1.64 – 25.69* (1.84 – 46.53)

MLE of OR 6.12 Exact 95%CI 1.66 – 26.32

Figure A7. P-value functions: ■ based on the Miettinen 95%CI, ■ based on the Exact 95%CI



Despite the small number of frequencies in this table, all the methods used show a 95% confidence. In this case, Exact CIs seem to behave even better than the Cornfield's CIs, in terms of accuracy and conservativeness.

Families not living in overcrowded houses

Table A7. In families not living in overcrowded houses, years spent by family at the camp and occurrence of diarrhoea

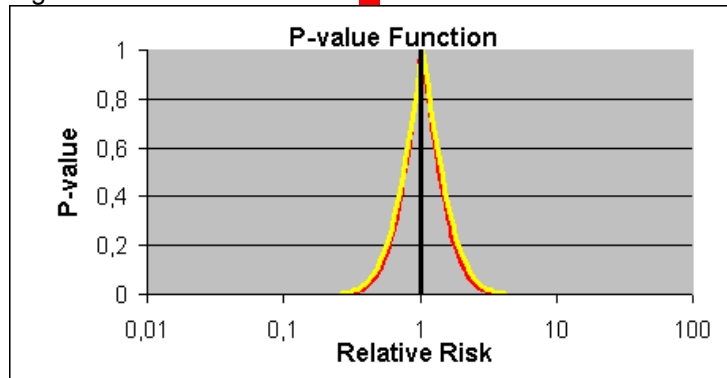
Diarrhoea	Years spent by family at the camp		
	5 or less	More than 5	
No	28	36	64
Yes	15 (35%)	20 (36%)	35 (35%)
	43	56	99

Fisher exact 2-tailed test: Epi Info $p=1.000$, Rothman $p=1.103$

OR 1.04 Miettinen 95% CI 0.45 – 2.39
 Cornfield 95% CI 0.41 – 2.61 (0.41 – 2.73)

MLE of OR 1.04 Exact 95%CI 0.42 – 2.60

Figure A8. P-value functions: ■ based on the Miettinen 95%CI, ■ based on the Exact 95%CI



The good distribution of frequencies in the table, and the OR being almost one, make the different CIs very close to one another. To be reported that the Rothman's Fisher exact 2-tailed test is more than 1.

Summary estimates for the stratified tables.

Crude OR 2.05

MH Weighted OR 1.90

Miettinen 95% CI

1.00 – 3.59

Robins, Greenland, Breslow 95% CI

0.98 – 3.66

Cornfield 95% CI

0.95 – 4.10

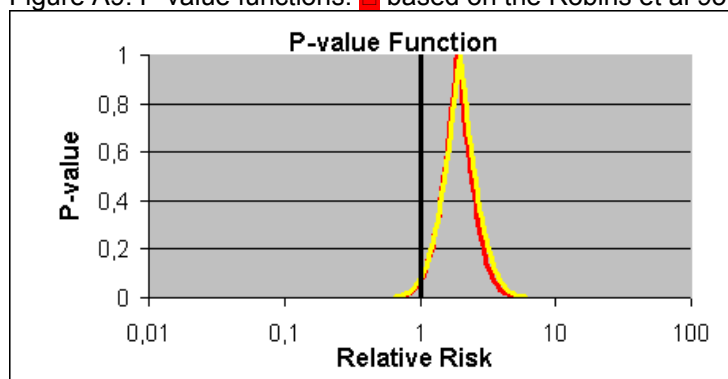
MLE of OR 1.95

Exact 95% CI

0.95 – 4.08

Chi square for evaluation of interaction 5.85 (P-value 0.016)

Figure A9. P-value functions: ■ based on the Robins et al 95%CI, ■ based on the Exact 95%CI



The p-value functions show how Robins et al. and Exact CIs are very close. Also Miettinen's CIs, albeit narrower, are near to the other estimates.

To live in a camp for more than five years was a risk factor for diarrhoea if stagnant water was reported on the floor of the camp due to the damaged paving. If there was no stagnant water in the camp, there was no association between years spent at the camp and diarrhoea.

Families living in camps with stagnant water

Table A8. In camps with stagnant water, years spent by family at the camp and occurrence of diarrhoea in children

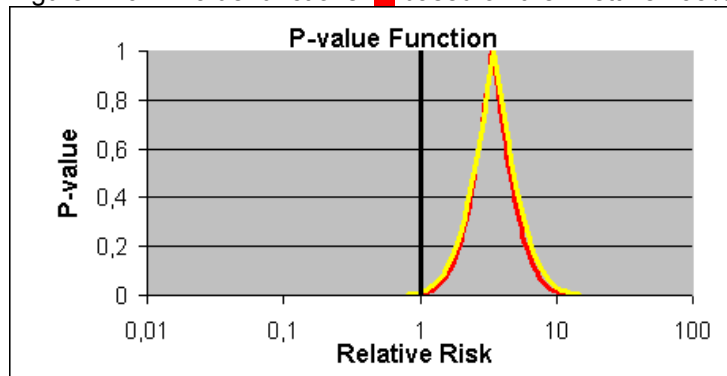
Diarrhoea	Years spent by family at the camp		
	5 or less	More than 5	
No	42	32	74
Yes	10 (19%)	26 (45%)	36 (33%)
	52	58	110

Fisher exact 2-tailed test: Epi Info $p=0.005$, Rothman $p=0.007$

OR 3.41 Miettinen 95% CI 1.46 – 7.95
 Cornfield 95% CI 1.32 – 8.96 (1.41 – 10.65)

MLE of OR 3.37 Exact 95%CI 1.34 – 9.04

Figure A10. P-value functions: ■ based on the Miettinen 95%CI, ■ based on the Exact 95%CI



Cornfield (as calculated with Epi Info) and Exact limits are almost identical. Miettinen's CIs are narrower but still very close, as shown by the p-value functions.

Families living in camps with no stagnant water

Table A9. In camps with no stagnant water, years spent by family at the camp and occurrence of diarrhoea in children

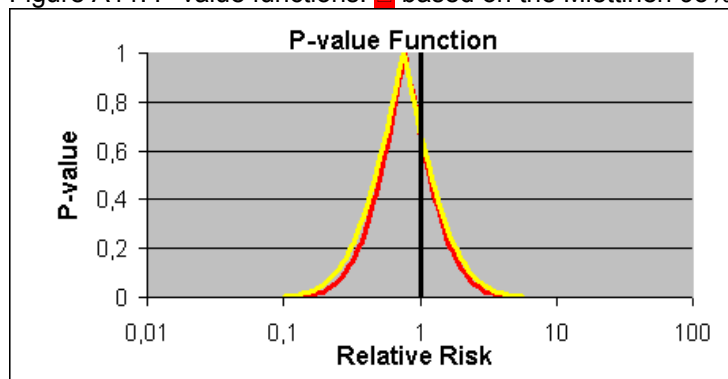
Diarrhoea	Years spent by family at the camp		
	5 or less	More than 5	
No	20	18	38
Yes	10 (33%)	7 (28%)	17 (31%)
	30	25	55

Fisher exact 2-tailed test: Epi Info $p=0.773$, Rothman $p=0.897$

OR 0.78 Miettinen 95% CI 0.24 – 2.50
 Cornfield 95% CI 0.21 – 2.89 (0.17 – 2.94)

MLE of OR 0.78 Exact 95%CI 0.20 – 2.85

Figure A11. P-value functions: ■ based on the Miettinen 95%CI, ■ based on the Exact 95%CI



In this case, the association is definitely not significant. All CIs are relatively close to one another, probably due to the regular distribution of frequencies in the 2x2 table.

Considering the summary estimates for the stratified tables, we can see how Miettinen's test-based and Robins et al. asymptotic CIs are significant, but very close to value 1. Cornfield's approximation, calculated using CIET map, and the Exact CIs are not significant, but again, very close to value 1.

Robins et al. and Exact p-value functions are almost identical.

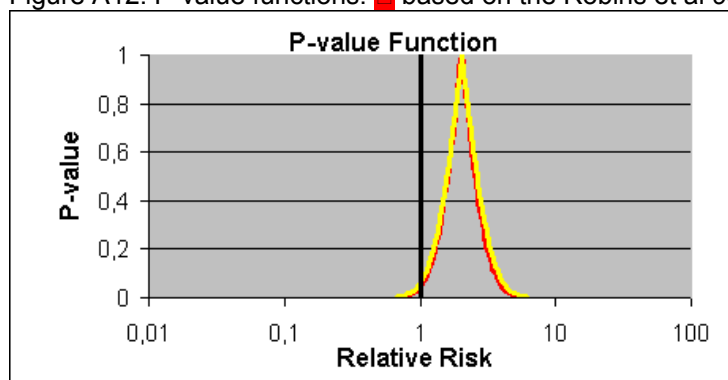
Crude OR 2.05

<i>MH Weighted OR 2.02</i>	<i>Miettinen 95% CI</i>	<i>1.04 – 3.90</i>
	<i>Robins, Greenland, Breslow 95% CI</i>	<i>1.04 – 3.92</i>
	<i>Cornfield 95% CI</i>	<i>0.99 – 4.22</i>

<i>MLE of OR 2.02</i>	<i>Exact 95%CI</i>	<i>0.99 – 4.21</i>
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Chi square for evaluation of interaction 4.04 (P-value 0.045)

Figure A12. P-value functions: ■ based on the Robins et al 95%CI, ■ based on the Exact 95%CI



Factors related to cough

Selecting families that lived for more than five years at the camp, a child living in a camp with stagnant water had a higher risk of cough compared with a child who lived in a camp without stagnant water. Such association was not significant for families that lived at the camp for no more than five years.

Families who lived at the camp for more than five years

Table A10. For families who lived at the camp for more than five years, presence of stagnant water and occurrence of cough in children

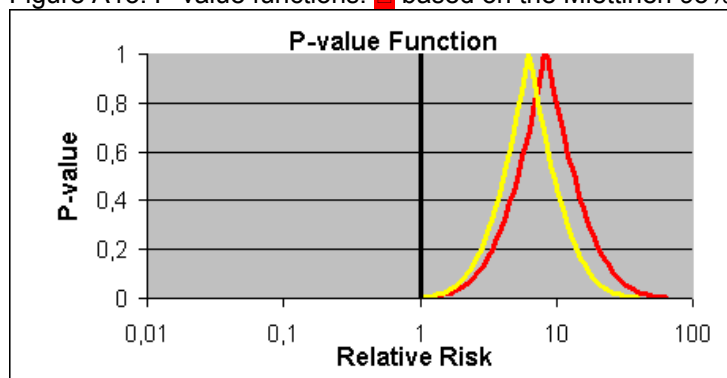
Cough	Presence of stagnant water		
	No	Yes	
No	19	20	39
Yes	6 (24%)	38 (66%)	44 (53%)
	25	58	83

Fisher exact 2-tailed test: Epi Info $p=0.001$, Rothman $p=0.001$

OR 6.02 Miettinen 95% CI 2.17 – 32.30
 Cornfield 95% CI 1.85 – 20.44* (2.07 – 32.30)

MLE of OR 5.88 Exact 95% CI 1.88 – 21.01

Figure A13. P-value functions: ■ based on the Miettinen 95%CI, ■ based on the Exact 95%CI



The way frequencies are distributed in the 2x2 table, also reflected in a relatively high OR, generate clearly different estimates. The two p-value functions (Miettinen and Exact) are visibly dissimilar.

However, all estimates agree on the 95% significance of the association and the p-value functions are also explicit about the association.

Families who lived at the camp for five years of less

Table A11. For families who lived at the camp for five years of less, presence of stagnant water and occurrence of cough in children

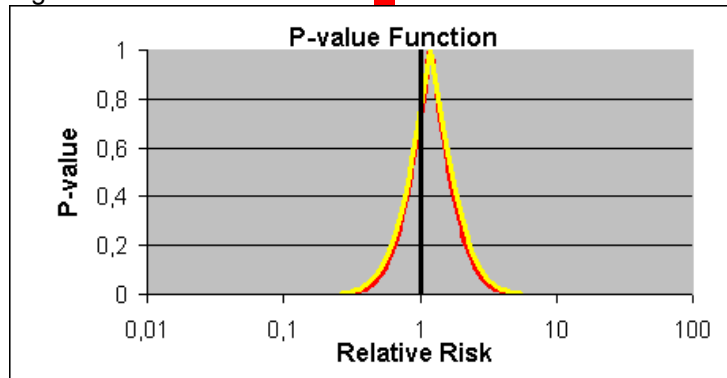
Cough	Presence of stagnant water		
	No	Yes	
No	14	22	36
Yes	16 (53%)	30 (58%)	46 (56%)
	30	52	82

Fisher exact 2-tailed test: Epi Info $p=0.818$, Rothman $p=0.877$

OR 1.19 Miettinen 95% CI 0.48 – 2.96
 Cornfield 95% CI 0.43 – 3.28 (0.42 – 3.36)

MLE of OR 1.19 Exact 95%CI 0.44 – 3.24

Figure A14. P-value functions: ■ based on the Miettinen 95%CI, ■ based on the Exact 95%CI



The distribution of frequencies is more regular in this case, with an OR very close to value 1. All of the CIs are very close and the p-value functions are almost identical.

The significance of the association is not as relevant, considered the significance of the test for interaction.

We can still report a “classic” situation in which the CIs are very close to one another and ordered from top to bottom, from the narrowest to the widest.

Crude OR 2.43

MH Weighted OR 2.41

Miettinen 95% CI

1.26 – 4.59

Robins, Greenland, Breslow 95% CI

1.25 – 4.65

Cornfield 95% CI

1.20 – 5.08

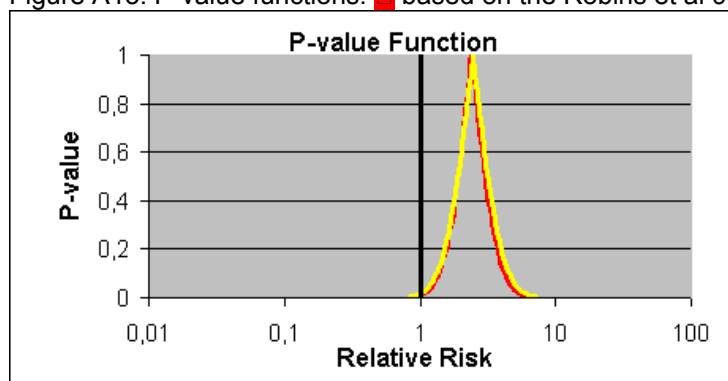
MLE of OR 2.44

Exact 95%CI

1.20 – 5.04

Chi square for evaluation of interaction 5.15 (P-value 0.023)

Figure A15. P-value functions: ■ based on the Robins et al 95%CI, ■ based on the Exact 95%CI



Heating the house with wood stoves is not associated with incidence of cough in children. Though, selecting families living in overcrowded houses (more than 2.5 people per room), we found a significant association between heating with wood stoves and coughing, irrelevant in the case of families not living in overcrowded houses.

Children of families living in overcrowded houses

Table A12. In families living in overcrowded houses, heating with wood stoves and occurrence of cough in children

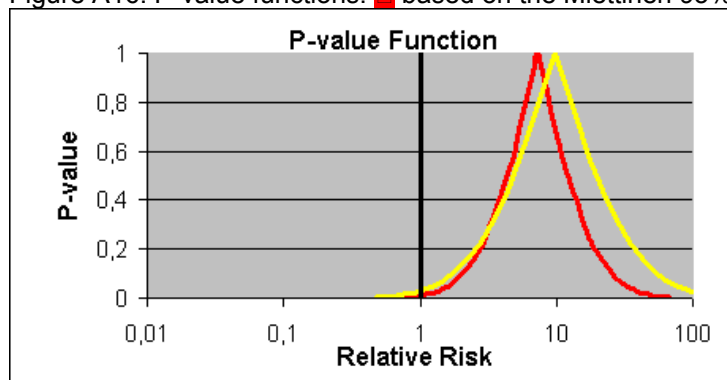
Cough	Heating with wood stoves		
	No	Yes	
No	32	2	34
Yes	22 (41%)	10 (83%)	32 (48%)
	54	12	66

Fisher exact 2-tailed test: Epi Info $p=0.010$, Rothman $p=0.017$

OR 7.27 Miettinen 95% CI 1.68 – 31.55
 Cornfield 95% CI 1.27 – 54.32* (1.71 – 26.63)

MLE of OR 7.07 Exact 95%CI 1.32 – 72.52

Figure A16. P-value functions: ■ based on the Miettinen 95%CI, ■ based on the Exact 95%CI



Skewness of the frequencies in the 2x2 table, reflected in the high value of the OR, makes the CIs very different from one another. The Epi Info evaluation of the Cornfield CIs establishes they are inaccurate.

On the other side, the level of the OR guarantees significance of the association, no matter the method used.

Children of families not living in overcrowded houses

Table A13. In families not living in overcrowded houses, heating with wood stoves and occurrence of cough in children

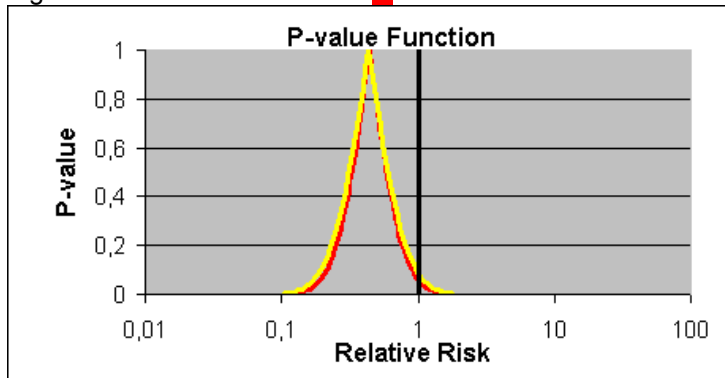
Cough	Heating with wood stoves		
	No	Yes	
No	22	19	41
Yes	42 (66%)	16 (46%)	58 (59%)
	64	35	99

Fisher exact 2-tailed test: Epi Info $p=0.060$, Rothman $p=0.088$

OR 0.44 Miettinen 95% CI 0.19 – 1.02
 Cornfield 95% CI 0.17 – 1.12 (0.16 – 1.11)

MLE of OR 0.44 Exact 95%CI 0.17 – 1.11

Figure A17. P-value functions: ■ based on the Miettinen 95%CI, ■ based on the Exact 95%CI



Despite a level of OR distant from value 1, none of the methods used show any significance in the association between no cough and heating with wood stoves. All of the CIs are very close, including Miettinen and Exact, as shown by the p-value functions.

As in the previous summary table, with a weighted OR close to the unity, the CIs reported in this case are close to one another and arranged from the narrowest to the widest.

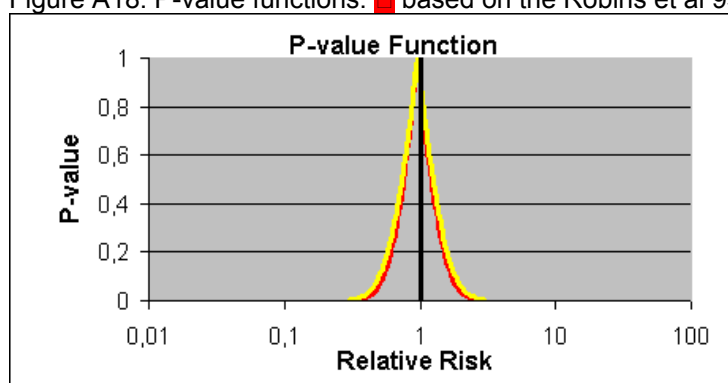
Crude OR 1.04

<i>MH Weighted OR 0.96</i>	<i>Miettinen 95% CI</i>	<i>0.50 – 1.84</i>
	<i>Robins, Greenland, Breslow 95% CI</i>	<i>0.49 – 1.88</i>
	<i>Cornfield 95% CI</i>	<i>0.45 – 2.04</i>

<i>MLE of OR 0.96</i>	<i>Exact 95%CI</i>	<i>0.45 – 2.04</i>
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Chi square for evaluation of interaction 9.12 (P-value 0.003)

Figure A18. P-value functions: ■ based on the Robins et al 95%CI, ■ based on the Exact 95%CI



Tables used in the analysis of breathing difficulties and asthma

A child was more at risk of having had respiratory problems in the last 12 months if he/she lived in a camp with less than 25 square meters per person.

Table A14. Camps' overcrowding and breathing difficulties in children

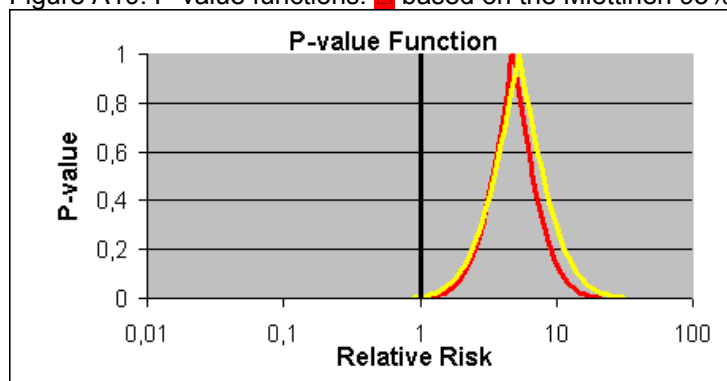
Breathing difficulties	Children in overcrowded camps		
	No	Yes	
No	70	67	137
Yes	5 (7%)	23 (26%)	28 (17%)
	75	90	165

Fisher exact 2-tailed test: Epi Info $p=0.001$, Rothman $p=0.002$

OR 4.81 Miettinen 95% CI 1.84 – 12.54
 Cornfield 95% CI 1.59 – 15.59* (1.87 – 43.20)

MLE of OR 4.76 Exact 95%CI 1.64 – 16.99

Figure A19. P-value functions: ■ based on the Miettinen 95%CI, ■ based on the Exact 95%CI



From this example, as well as from others before (i.e. Fig.A5 and Fig.A16), we see how the p-value function based on the 95%CI is not centered in the actual OR: in fact, the p-value function calculated from the Exact CIs, centered in the MLE of the OR, which is closer than the actual OR to the unity, is instead further from the unity with respect to the center of the Miettinen p-value function.