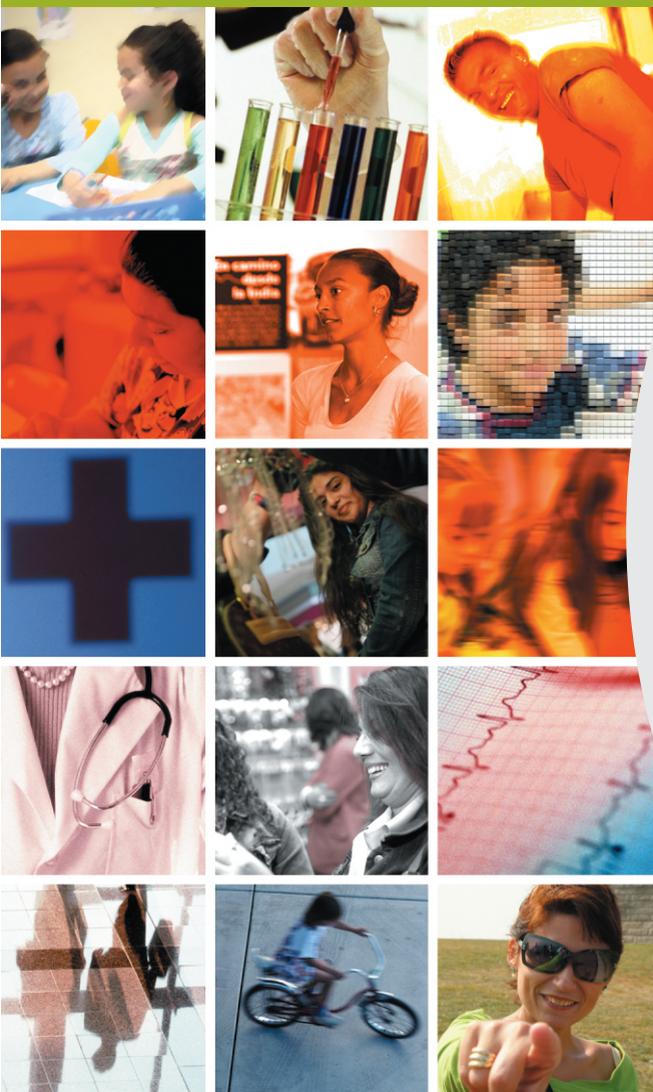


Handbook for Action in the Area of Health Services with the Roma Community



CONTENTS

INTRODUCTION

CHAPTER I

1. BACKGROUND INFORMATION REGARDING ROMA CULTURE

- 1.1 The Roma population in Europe
 - 1.1.1 Origin
 - 1.1.2 Current situation

- 1.2 The Spanish Roma population
 - 1.2.1 Demographic data
 - 1.2.2 Current situation
 - 1.2.3 Roma women
 - 1.2.4 Roma culture

2. HEALTH AND THE ROMA COMMUNITY

- 2.1 Basic premises
- 2.2 Perception of health
 - 2.2.1 Culture, Health and Disease
 - 2.2.2 Cultural aspects affecting the health-Roma community process
- 2.3 The health status of the Roma population in Spain

CHAPTER II

3. THE HEALTH-CARE SYSTEM AND THE ROMA POPULATION ACTION RECOMMENDATIONS

- 3.1. Introduction
- 3.2 Health Management Services
- 3.3 Primary Care Clinics and Specialised Centres
 - 3.3.1 Initial considerations
 - 3.3.2 Recommendations
 - 3.3.4 The clinical interview focused on the patient
- 3.4- Hospital and emergency services



4. GLOSSARY OF TERMS TO INCREASE AWARENESS OF THE ROMA CULTURE

CHAPTER III

5. ANNEXES

5.1 Best practices

- Intercultural mediation
- The experience at Madrid's San Carlos Hospital

5.2 Case Studies

- Best intervention practices through press news
- Self-analysis questionnaire to discover my prejudices or stereotypes towards Roma people

6. BIBLIOGRAPHY



INTRODUCTION

This Handbook was compiled as a contribution to the reduction of health inequalities in the National Health System, the goal being that all persons using these services be treated equally and in a way culturally suited to their specific needs. To that end, the Handbook lays down a series of action proposals designed to correct present inequalities having regard to the Roma population's access to the public health system.

The direct relationship between social inequalities and health inequalities has been clearly established by the main international bodies dealing with health issues. In this connection, if we bear in mind that a large number of individuals of the Roma Community find themselves in a situation of social exclusion or vulnerability, it should come as no surprise that the percentage of the Roma population affected by a lack of equality in health is also relevant.

Hence, the Ministry of Health and Consumer Affairs (MSC) and the Fundación Secretariado Gitano (FSG) have signed a Collaboration Agreement for the period 2003-2008 with the shared objective of "improving the health and living standards of the Roma community and encouraging more pro-active social policies to compensate for the inequalities endured by this group in the area of health".

One of the actions envisaged in the Agreement is the compiling of this Handbook for the purpose of raising the awareness and building the capacity of health-care providers concerning the specific characteristics of the Roma population, providing them with the tools they need to make their daily work easier, and the launching of a line of research to provide reliable data on the health status of the Roma community to be compared with the data on the majority society so as to be able to undertake more tailored initiatives with this group.

We would like to thank the members of the think-tank whose meetings in Madrid at the headquarters of the Ministry of Health and Consumer Affairs have coincided with the work sessions we have been conducting since 2003. Their contributions and comments have helped in making this Handbook as practical a tool as possible for health-care professionals. We would likewise like to thank the Area of Health Promotion of the Ministry of Health and Consumer Affairs and the Area of Health of the Fundación Secretariado Gitano for their constant support in the daily work undertaken in pursuit of health equality for the Spanish Roma population.

We trust that this material will be useful in helping health-care service providers to understand and gain insight into some of the social and cultural values of the Roma community, thus facilitating their daily work.

Ministry of Health and Consumer Affairs

Fundación Secretariado Gitano



Structure and use of the handbook:

The purpose of this handbook is to provide the different health-care providers with a series of socio-cultural recommendations to help focus their intervention in everyday health-care practice when dealing with patients from the Roma ethnic group. It is our intention to contribute to the development of health-care services which are culturally-tailored to the Roma population of our country in order to meet their health needs while recognising and respecting their cultural identity.

A number of different factors led us to compile this handbook. On the one hand, the situation of inequality faced by the Roma community with regard to health. Here we are referring to inequality mostly as concerns access to health-care goods and services. Despite having the same rights and opportunities as any other Spanish citizen, in practice this does not always hold true. It is also cause of concern to observe how recently disputes have arisen with the Roma population in health-care contexts. The importance of this issue, directly involving health-care personnel, calls for the development of measures and actions designed to prevent these types of situations.

Throughout this handbook we will suggest ways to focus actions which should be of use to all of those involved in providing health-care to the Roma community: health-care and other personnel at health centres, the Roma population, hospital administrators, primary care clinics, etc. All of these players will be the focus of the interventions set out.

We would especially like to focus on a series of preconceived ideas and generalisations which have a negative influence on the way the Roma population is treated. Some examples are:

- ⇒ The Roma are a marginalized group.
- ⇒ The Roma population poses a threat to health-care personnel.
- ⇒ Roma people cannot be given special treatment.

These prejudices and stereotypes, fruit of a lack of knowledge of the social and cultural values of the Roma community, are oftentimes the source of the sort of disputes that arise when Roma persons make use of health-care services. Throughout this handbook we will refer to know-how and resources which contribute to the elimination of these prejudices and will likewise offer a series of practical guidelines.

The material presented is structured around three clearly differentiated chapters:

- ⇒ **Chapter I:** provides a socio-cultural analysis of the existing situation and describes characteristics of the Roma population. Those cultural and environmental aspects related to the health of Roma persons are especially noteworthy.
- ⇒ **Chapter II:** provides an action proposal applicable to the different health-care services. This takes the form of guidelines which do not affect the therapeutic practices of health-care providers but which do have an important influence on the success rate of treatments and on the prevention of possible conflicts.
- ⇒ **Chapter III:** covers best practices gathered from accumulated experience.



Having regard to the use of this handbook, the following considerations must be borne in mind:

- ❑ This is global/integrated material and therefore proper use entails reading and understanding all of the different sections of the handbook.
- ❑ This should not be viewed as an extra burden for health-care personnel but rather as a tool leading to improvement in their professional practices in view of the influence that social and cultural factors have on disease and on users' relationship with the health-care system.
- ❑ This should not give rise to the idea of paternalism or favouritism towards the Roma community. The starting point is a situation of inequality facing Spain's largest ethnic minority which has the same rights and duties as the rest of the citizens of the majority society.
- ❑ We are aware of the limitations facing the health-care system and its service providers but we are equally aware that there are best practices which are possible to integrate.



CHAPTER I

1. BACKGROUND INFORMATION REGARDING ROMA CULTURE

1.1 The Roma population in Europe

1.1.1 Origin

The presence of Rom or Roma people in Europe goes far back in history. They settled in the 14th and 15th centuries mostly in Spain, Portugal, France, Germany, Russia, Romania and Hungary.

Despite having a common cultural identity, Europe's Roma population cannot be described as a single group but is rather comprised of diverse groups. This heterogeneity, noticeable in each of the countries and among the different regions as well, is largely due to the adaptation that this population group has made to the host countries throughout numerous migratory processes when they left their place of origin, the Punjab region in India. Some of their customs have also made their way into the culture of the host countries and include rhythms and folk dances as well as some words from their original language, Romany.

Regardless of their origin, a constant throughout the history of Roma in Europe has been the harassment and numerous persecutions to which they have been subjected. They have even undergone situations of slavery owing to their nature as a travelling and nomadic people and their cultural peculiarities. It suffices to remember the Medina Sidonia Order enforced by Isabel the Catholic Monarch in 1492 ordering the persecution of Roma together with Jews and Moors throughout Spain.

This history of discrimination over the centuries has meant that one of the common characteristics of this European ethnic minority is the great number of situations of poverty and social exclusion which they suffer and which situate them among Europe's most vulnerable groups. This exclusion is even more apparent in the continent's poorest countries and in the former Communist states.

The conflictive relations which have developed between Roma and non-Roma down through the centuries should therefore come as no surprise. Roma people are leery of anything from outside of their cultural circle while the non-Roma harbour many prejudices towards the Roma population.

1.1.2 Current situation

The Roma population is Europe's principal ethnic minority. An estimated seven to nine million Roma live in Europe today, close to two thirds in the Central and Eastern European countries.

The majority of this population is concentrated in the candidate or accession countries or in the most recent Member Countries: Romania with approximately 2.5 million, Hungary around 600,000, Bulgaria in the vicinity of 500,000, Slovakia close to 400,000 or the Czech Republic with close to 300,000.



Until the accession of the new countries to the European Union in May of 2004, Spain was the EU nation with the largest Roma population – over 650,000.

According to the report entitled “The Situation of Roma in an Enlarged European Union” published by the European Commission in November 2004¹, the general situation facing Europe’s Roma population in different spheres relevant to their social inclusion can be summarised as follows:

- ➔ **Education:** in many countries there is a tendency towards segregation of Roma with respect to the children of the majority society and where Roma children are admitted in mainstream schools, these often suffer a lack of resources or turn into ghettos. Moreover, hardly any attention is paid to the educational achievements of Roma children.
- ➔ **Employment:** few of the older European Union Member States target Roma communities in their National Action Plans for Employment despite the very high unemployment rate.
- ➔ **Housing:** The Roma population throughout all of Europe lives in sub-standard housing forming ghettos characterised by insufficient infrastructures and services which are segregated vis-à-vis other settlements. The disease rate is very high and the risk of eviction is always present.
- ➔ **Health-care Services:** the poverty and poor living conditions facing the Roma communities, considered jointly with persistent discrimination in the provision of health-care services, has led to a high rate of diseases such as tuberculosis and hepatitis. There is strong evidence showing that life expectancy of the Roma population is lower than for the rest of society. Several reliable indicators are needed to determine the rate of disease and the Roma community’s access to health-care systems.
- ➔ **Transversal Issues:**
 - Social protection systems in Europe often deny Roma access to the safety net system either deliberately or through negligence. Evidence shows that Roma social assistance seekers suffer discrimination.
 - A common problem throughout Europe is the lack of proper documentation in the case of Roma. This includes birth and marriage certificates, residency permits and identification documents. This has led to serious problems in gaining access to social services and in some cases has even given rise to stateless person status.
 - As for gender issues, many Roma women face dual discrimination and as a result decreased access to health-care, education and other services. In light of the role women play in the education of their children, this situation is of serious concern.

¹ Study entrusted to a consortium formed by the European Roma Rights Centre, Focus Consultancy Ltd. and the European Roma Information Office. This study furnishes information on the current situation facing Roma in the 25 EU Member States and analyses current policies aimed at improving that situation.



1.2 The Spanish Roma population

1.2.1 Demographic data

The Roma community has been present in Spain since the beginning of the 15th century. The Spanish Roma population is estimated at 650,000. The region with the greatest number of Roma is Andalusia (population estimated at 270,000) followed by other regions such as Catalonia (80,000), Madrid (60,000) or Valencia (with an estimated 52,000 Roma)².

The Spanish Roma population is very young in comparison with the non-Roma population. 45% are under the age of 16 and the birth rate is 64 per thousand while that of the non-Roma population is 14 per thousand³. Lately there has been a gradual decline in the birth rate and the number of children per family. The average age at which couples marry is rising although it is lower than that of non-Roma. In the case of Roma women, average marrying age is between 16 and 20 and for men is between 18 and 22.

1.2.2 Current situation

The multi-dimensional aspect of health is now recognised as comprising different aspects and spheres of influence which go beyond the purely physical. Education, employment and housing are issues of fundamental importance which determine the level of well-being and quality of life of a population group in a specific environment and, in turn, the levels of health of groups and communities. In this connection the most disadvantaged socio-economic groups which do not take part on an equal footing in education, employment or housing, are liable to suffer from poor health.

In general terms, there is a tendency towards improvement in the living conditions of the Roma population but there are still many barriers which stand in the way to their process of incorporation into the different spheres of public life. However, the Roma community is not immune to the transformation process characterising the society at large and this advancement process is being led by Roma women and young people.

The current situation of the Spanish Roma population in respect of the principle areas which exert an influence in their state of health can be summarised as follows:

→ Education

The educational level of the Roma population today is lower than that of any other social group of comparable size and makeup. Few Roma of the older generations have ever attended school on a regular basis and therefore the percentage of Roma over the age of 18 who are **totally and/or functionally illiterate is very high** (according to a recent survey conducted by the FSG, nearly 70% of Roma over the age of 16 have not completed their basic compulsory schooling). The illiteracy rate is even higher among women. This low educational level has the following principal consequences:

² OBSERVATORIO 02. Employment and the Roma Community. FSGG. Madrid 2003.

³ MONTOYA, Juan Manuel. Investigación sociológica, antropológica y demográfica sobre la Comunidad Gitana en España. Madrid, s.n, 1987 (Sociological, anthropological and demographic research on the Roma community in Spain).



- **Difficulty gaining access to professional and/or vocational training** and subsequently in finding gainful employment.
- They do not benefit from existing opportunities and social programmes because they cannot acquire adequate information.

According to the 2002 FSG study entitled “Evaluación de la Normalización Educativa del Alumnado Gitano en Educación Primaria” (Assessment of educational mainstreaming of Roma students at the primary school level), **Roma children throughout all of Spain are generally enrolled in school** (94% of Roma children enrol at the age of 6 or earlier). Despite all this, gains in terms of ongoing assistance, completion of compulsory schooling and improvement in academic performance are still lacking.

The causes are largely cultural, although it is also true that a growing proportion of Roma families does recognise the importance of their children starting school at an early age (74% of the children have attended day-care or nursery school and 85% of the families have taken the initiative to enrol their children in primary school⁴). Absenteeism also plays a part in the educational failure of Roma children and is basically due to the need help out with their parents’ trades and occupations (mobile trading especially), made even worse when the whole family must move because of work.

However, in tandem with these attitudes there is a growing trend towards greater appreciation of school and **education as the basic means of social advancement**, personal development and future opportunities.

Level of education is an indisputable factor contributing to how people take care of themselves. It has been observed, for example, that the notion of prevention, fairly foreign to the Roma population, has begun to gain importance in those sectors with a higher level of education.

→ Employment

Quality employment in the mainstream labour market is one of the main factors contributing to integration and health.

More and more Roma are moving into the mainstream labour market, leaving behind some of their traditional trades. However, the types of job posts filled by the Roma population are basically precarious which translates into short-term contracts, low salaries and low-level employment as labourers or auxiliary personnel. Gender is also a determining factor in employability and more Roma men make their way into the labour market than women.

→ Housing

Housing and habitat play a vital role in social exclusion/inclusion processes among the most disadvantaged population groups insofar as a dignified home in an accepting environment facilitates access to resources, services and rights and also opens the door to opportunities. Two issues have a bearing on the situation of the Roma minority as concerns housing⁵:

⁴ In line with the study mentioned earlier “Evaluación de la Normalización Educativa del Alumnado Gitano en Educación Primaria”, FSGG- Madrid, 2002.

⁵ The magazine entitled *Gitanos, Pensamiento y Cultura* (Roma, thought and culture) Focus on Housing, No 1. Madrid, FSGG, 2002.



- **The persistence of shanty towns and sub-standard housing.** Still today, between 10% and 12% of the Roma population continues living in segregated settlements in run-down neighbourhoods (shanty towns, pre-fab dwellings, neighbourhoods with special connotations, etc.). In 1991, 31% of all dwellings inhabited by Roma families were sub-standard (17.644)⁶. Still today, shanty towns and sub-standard housing continue to be a reality throughout practically all of Spain.
- **New problems are emerging.** The vulnerability of the Roma community in respect of housing has to do with aspects related to urban planning (concentration of the Roma population in certain locations), deterioration of housing and surrounding neighbourhoods and overcrowding in homes. Furthermore, in order to purchase a home one must fulfil a series of requirements (stable employment, ability to save, credit rating to gain access to a mortgage, etc.) which are often beyond the reach of many Roma families. Renting a home also poses problems for Roma not only owing to the expense but also due to the prevalence of discriminatory practices.

→ Religion

The evangelical churches (popularly referred to as “*El culto*” or worship) have recently grown in importance in the Roma community and now offer an alternative in terms of group support and conflict resolution. As concerns health, these churches constitute a protection factor for the Roma population insofar as they promote norms and behaviours related with taking care of personal health. Noteworthy examples are rehabilitation and assistance in the treatment of drug dependency or the efforts made to keep Roma women off tobacco and alcohol.

1.2.3 Roma women

Roma women play a key role within their communities. They are the educators, the ones that take care of the children and the elderly and are responsible for passing on the rules and values of Roma culture. They are more open to change in general, especially when it comes to health issues. To a large degree this is due to the fact that they have been the focus of the majority of the educational, social and health programmes implemented by institutions and associations.

Today, the leadership role of Roma women is increasingly recognised and not only within their home communities but also within the different sectors of public life. More and more women are breaking with the tradition of exclusive dedication to home and children and are making their way into the mainstream labour market or are taking training courses.

One should not lose sight of the fact that Roma women are traditionally in charge of health care and this means that all work targeting them specifically, has a multiplying effect with repercussions for the other members of the family. It is equally true, however, that they should not be the only focus of attention because that would spell even greater responsibility and demands. Men, therefore, merit special attention when it comes to personal care and health protection.

Roma youth are also a driving force contributing to the changes taking place in the lifestyle of the Roma community in the area of traditional values and redefinition of identity. The

⁶ Grupo PASS. Roma housing map in Spain. ASGG, 1991.



fact that they are remaining in school longer and are increasingly convinced of the importance of playing an active role in society, makes them generally more open to health promotion.

1.2.4 Roma Culture

The health-disease process and care of one's body are culture-specific meaning that each group or cultural minority will have their own set ideas regarding this process.

Working with ethnic and cultural minorities entails gaining insight into the most important aspects of their culture because these will play a decisive role in the therapeutic process.

When speaking of the Roma population we should always bear several key cultural aspects in mind which will determine the relationship established with the health-care system, with teachers or in terms of the proper or improper use made of the said services.

The Roma culture as we know it today has been evolving over time and adapting to the new reality facing Roma in all of the different places where they reside. However, over and above the heterogeneity of this population group, there is a series of commonly accepted elements that persist and form an essential part of the culture. It is an unwritten culture passed down over the generations where the Roma women play an important role as transmitters.

Cultural identity is omnipresent in the Roma community and is the source of great pride and community self-esteem as well as an important protection factor.

Community support, in this case closely linked with a feeling of cultural identity, also offers important protection to individuals. This is especially evident in extended family support offering material resources and both physical and emotional care which compensates for the risk factors to which broad sectors of the Roma minority are subjected. An important indicator in this respect is the low number of elderly Roma or those with a physical disability or mental disease who are institutionalised.

The following are some of the most characteristic **cultural features** of the Roma people which are essential in understanding their relationship with health and disease:

- Social organisation based on the **extended family**, the nucleus around which social and personal relations develop. That is why when a member becomes ill, the entire family and not just immediate family members accompany the infirmed or affected individuals
- Prevalence of the **group** over the individuality of each person.
- High value put on the **spoken word** which takes precedence over the written word.
- **Respect for elders**. The elderly are very present within the community and they are cared for at home.
- The influence that **older Roma** members have on the younger members. It is important to seek support from influential and respected Roma members who are capable of accepting new aspects of community life which benefit its development.
- **Mourning**: affects social and labour activities and imposes rules regarding personal appearance (black clothes and headscarf for women, beard for men, etc.) and community life



in terms of expressions of joy or entertainment activities.

→ The figure of the **deceased** is very important. It is important to bear possible reactions in mind when the death of a close family member is confirmed or when physicians order the removal of a corpse or call for an autopsy.

→ **Worship**: each church and pastor has a different influence on parishioners.

→ The **role of women**: women are responsible for know-how and treatment when it comes to illness and the sick.

→ **Overprotection of young women**. As of a very young age, girls are prepared for marriage and to assume reproductive functions. Sex is sometimes viewed as taboo, a factor that must be borne in mind when approaching anything having to do with sexual education, family planning or the prevention of gynaecological diseases.

The transformation process that the Roma community is currently undergoing has also been instrumental in loosening up some of the traditional Roma family rules and this has facilitated Roma access to different areas such as education, employment or health-care services, especially in the case of women.

2. HEALTH AND THE ROMA COMMUNITY

2.1 Basic premises

Health is conceived as a broad concept affecting different aspects of human life: physical, psychological and socio-cultural. In 1948 the WHO defined health as “*a state of complete physical, mental and social well-being and not merely the absence of disease or infirmity.*” The WHO considers health as a **fundamental human right** and therefore all people must have access to basic health-care resources.

Therefore, when we speak of health we are referring to the process of interaction between human beings and their social and natural environment, a process by which said human beings maintain physical and psychological well-being allowing them to contribute fully to their community’s social life⁷. Health is conceived as the result of all the factors affecting the lives of individuals: those that are virtually unsusceptible to modification (sex, age or genetics) as well as those that are potentially modifiable (behaviour, ways of earning a living, cultural and socio-economic aspects, etc.). Health, therefore, is not an exclusively biological phenomenon.

Inadequate housing, deficient education, insufficient income, etc. all have an important influence on health and are important factors determining the state of well-being and living standards of a population group living in a specific environment. The processes of exclusion and social marginalization limit people’s access to health-care services and the use they make of them. In this sense, the most disadvantaged socio-economic groups exhibit characteristics making them susceptible to poor health. Other variables such as gender, age, ethnic background, social class or geographical area are also **risk factors** when it comes to health.

⁷ “La población gitana en Andalucía: un estudio exploratorio de sus condiciones de vida”. Regional Government of Andalusia. Seville, 1996.



It appears to be clear that belonging to a minority ethnic group has a bearing on the emergence of specific health inequalities. These inequalities are not only rooted in socio-economic variables but also in access to health-care services and the effective use made of such services affected by poor adaptation of the latter or even discrimination.

The processes of social exclusion and marginalization take a greater toll on these groups because, due to their condition as minorities, they do not actively participate in the different areas and facets of public life. The close relationship between social inequalities (economic, educational, housing, etc.) and health inequalities is clearly highlighted by international health organisations (WHO, European Commission, etc.).⁸ In this sense, if we bear in mind that a high percentage of the Roma population is in a situation of social exclusion or vulnerability,⁹ we should be able to understand that the percentage of the Roma population affected by the lack of equality in health is also very relevant.

In addition to these socio-economic variables, we have pointed out that cultural factors, habits and custom also have a bearing on the health of individuals and communities. The Roma community as an ethnic and cultural minority, features a series of culturally-rooted elements which also have an influence over the state of health of its members and condition the way they react and behave when faced with disease.

2.2 Perception of health

2.2.1 Culture, Health and Disease

The concept of “culture” refers to the values shared by members of a group, to the rules they obey and to the material goods they produce. The British anthropologist Tylor came up with the classic definition of culture as “that complex whole which includes knowledge, belief, art, morals, law, custom, and any other capabilities and habits acquired by man as a member of society.”

In the view of Teresa San Román, culture is not only the values and symbols of a people but also “*their way of organising themselves, their structures and institutions, shared habits or practices, the way or shared ways of viewing the world and of conceptualising the world and social relations*”.

Culture, therefore, viewed as a reality lived by people, their customs, laws, conceptions of the world and all that which allows them to live in society, is something that is learned and understood and the same holds true of one’s understanding of the body, health and disease. Disease is not viewed in the same way by different communities or within the same society and varies throughout different historical times within the same group.

Health and disease are socially constructed concepts which are defined and typified by each culture. In turn, each culture creates its own therapeutic alternatives as well as the steps to be followed to regain health. Therefore, disease must be viewed as an expression with a

⁸ European Commission “Conclusions and recommendations of the Studies Commission on social inequalities in the field of health in Spain.” 1.996.

⁹ The National Action Plan for Social Inclusion 2001-2003 estimates that over 30% of the Roma population is in a situation of social exclusion or vulnerability.



biological and cultural component. Independent of its biological component, it is always a form of cultural expression and if it is to be considered a disease, the society must label it as such.

If we consider culture in the health-disease process of ethnic minorities we can discover how:

- health-care information is received by patients;
- the rights and benefits that the health-care system offers are used;
- the symptoms, expectations and concerns regarding disease are expressed.

2.2.2 Cultural aspects affecting the health-Roma community process

There are different cultural models which establish different forms of behaviour regarding hygiene, sexuality, work, nutrition, physical exercise, sleep, etc., and which give rise to emotionally different reactions when it comes to assessing symptoms, perception of pain, etc.

The Spanish Roma community, as an ethnic and cultural minority also exhibits a series of cultural elements which determine their attitude and reaction to health and disease and likewise their relationship with the public health system.

If one is aware of these elements and is capable of handling them properly, they sometimes “strengthen” and lend greater credibility to the efforts of health-care providers. However, if they are ignored or one is not aware of them, they could be a potential source of conflict.

The following considerations should be kept in mind from the very outset:

- ➔ **In some sectors of the Roma community, health is not perceived as a top priority.** Housing, finances or employment all come before health in terms of this group’s perceived needs because in some cases they are not yet covered.
- ➔ **A large percentage of Roma conceive health as the absence of disease, and disease as an incapacitating phenomenon linked to death.** This unique perspective on health and disease leads to several consequences:
 - Health only becomes a concern in the presence of very dramatic symptoms and incapacitating consequences thus making it difficult to approach the concept of prevention.
 - Once the individual (and his family) perceive the presence of disease, action taken must be immediate and definitive in light of the direct link between disease and death.
 - The diagnosis is a matter of “*putting a label on one’s affliction.*” Thus, the attitude adopted is ambivalent. Complete avoidance prevails in the absence of symptoms and incapacitating consequences (in these cases the diagnosis may be perceived as a manifestation of a disease that previously did not exist).
 - The physician is an ambivalent figure: On the one hand s/he possesses the knowledge needed to cure the disease but, on the other hand, s/he is also the



one who diagnoses and discovers the disease. Reluctance to visit a physician is therefore common and accounts for lack of prevention.

- If symptoms disappear under treatment, all other therapeutic guidelines are generally ignored because from the perspective of this concept of health, the disease has vanished.

→ **Health care is the duty of women** and therefore women's health is usually at the bottom of the priority list. The next question is "who takes care of the caretaker?" The following consequences could result from this situation:

- Out-patient home-based care for women is usually very difficult; first of all because this means that homes must be properly equipped and second of all because it is very difficult for women to take on the role of "patient" at home.

In the case of mental health, women tend to abandon treatment prematurely.

→ **The perceived immediate need to cure illness as quickly as possible** is a product of the close association between disease and death. This means that the diagnosis of a health-care provider is urgently needed to determine the problem's degree of seriousness. On many occasions the result is the improper use of some health-care resources:

- Excessive use of emergency room services.
- Infrequent use of ambulance services; patients are generally transported by the family.
- Appointments at doctor's surgeries are not usually made.

→ **Certain traditional norms** such as prohibition on the use of tobacco and alcohol in the case of women or the limiting of sexual relations to marriage (especially with regard to women), **serve as health protection factors** (despite ethical issues involved).

→ Traditionally the Roma population has maintained **certain health habits** despite living in difficult conditions. An example is the fairly widespread use of bleach as a disinfectant.

→ The **individual's relationship with disease is a family affair**. Owing to the importance of the extended family, when a Roma individual becomes ill it is considered a problem of the entire family. Community support operates as a protection factor for the sick person.

In Roma culture, the co-existence of **different medical models** has been observed:

- ⇒ **Traditional model:** still in vogue but has lost a great degree of prestige. Often times it is relegated to the treatment of certain popular pathologies, mostly childhood diseases. Traditional health-care providers who, for many years, were responsible for the diagnosis, prevention and treatment of many diseases have increasingly been relegated to the treatment of ailments linked with "old-fashioned illnesses" or with problems not acknowledged by scientific medicine such as those related with "the evil eye", "sunburst" (*golpe de sol*) or "the ligament" (*ligamento*).
- ⇒ **Scientific model:** represented by the physician and pharmacist. Roma visit physicians when their ailment is not very serious and in the case of more severe problems they tend to



go directly to emergency health-care services. They often turn to private physicians. There is quite a bit of flexibility in the combined use of public and private medical institutions.

- ⇒ **Evangelical church:** the church treats all the pathologies which medicine is unable to effectively deal with such as terminal or social diseases (cancer, addictions, HIV, etc.). Faith-based cure is the principal recourse. An important element to keep in mind is that in its ideological discourse Pentecostal worship stresses health education guidelines such as the prohibition of drug use and in so doing lends support to the scientific medical recommendations thus becoming a vehicle for prevention.
- ⇒ **Self-diagnosis** is also a very important health-care method practiced by Roma women (mothers and grandmothers). They are the caretakers of all medical knowledge (scientific medicine, traditional medicine, etc.) and it is thus in the home environment where one may more clearly observe the relationship among the different health-care practices.

2.3 The health status of the Roma population in Spain

Very little specific scientific information is available to shed light on epidemiology and the Roma population thus making it difficult to gain insight into the incidence of diseases affecting this population group. However, some research and local analyses do offer the following data on the health situation of the Spanish Roma population.

- ➔ **Infant mortality** is 1.4 times higher than the national average and life expectancy for the Roma population is between 8 and 9 years below the average.¹⁰ In cases of extreme marginalization, life expectancy is estimated to be 10 years below the average.
- ➔ Higher incidence of **infectious disease**¹¹, mainly hepatitis B and C. Vertical or mother to child transmission has been observed frequently in the case of these diseases¹². A higher incidence of HIV is also observed, mainly among intravenous drug users.
- ➔ Deficient **child vaccination**,¹³ and generally inadequate follow-up on the “Healthy child” programmes, especially in areas with a low socio-economic level¹⁴.
- ➔ Deficient **eating habits and nutrition**, especially in the case of children (also affecting dental health).¹⁵ Adult diets are characterised by excessive consumption of coffee and fats.
- ➔ There is a higher incidence of **accidents and involuntary injury**¹⁶ such as: burns, falls, pedestrian traffic accidents, bone fractures, cuts, intoxications, etc.
- ➔ High-risk group for **congenital malformations**. The studies consulted make reference to genetic and cultural factors (endogamy).¹⁷
- ➔

¹⁰ *Las claves del racismo contemporáneo* (Key aspects of contemporary racism). Montoya, 1994.

¹¹ Cabedo, V.R. et. al. “Cómo son y de qué padecen los gitanos”. Publication *Atención Primaria*. Vol. 26, No. 1. 2000; Fos, E. et. al. “Elevado riesgo de infección por el virus de la hepatitis B en la población de raza gitana”. Publication *Atención Primaria*. Vol. 89, No. 13. 1.987.

¹² Delgado, A. “Resultados y análisis de la investigación de AgHBs en las embarazadas de un centro de salud durante 4 años”. Publication *Atención Primaria*. Vol. 7, No. 8. 1.990.



Turning specifically to the **health of Roma women**, special mention should be made of the incidence of certain diseases related to the role of mothers and wives traditionally assigned to them. The following relevant characteristics merit attention:

High **fertility** rate with pregnancies and births starting very young and continuing into older age.¹⁸

On occasion, sparse information with respect to **family planning**. Some birth control methods are not used because they are unknown and also because a number of myths and confused ideas still persist.¹⁹

Very little **gynaecological disease prevention**.²⁰

Premature **ageing** with incidence of diseases which are atypical for the age groups affected such as diabetes, bone ailments, cardiovascular problems, etc.

Excessive degree of **responsibility** both in and out of the home giving rise to symptoms of depression, anguish and anxiety in some cases.

In conclusion, and bearing in mind the indicators commonly used by the international scientific community to measure inequalities in the area of health,²¹ it can be said that the health-care status of the Roma population is clearly deficient. However, the opinion expressed in the scientific literature consulted tends to confirm that this health-care situation has more to do with a lack of equality in terms of life opportunities and access to and use made of resources

¹³ Regional Government of Andalusia. La población gitana en Andalucía. 1996.

¹⁴ Sastre, E. et. al. “*Situación de salud entre niños gitanos y no gitanos de una comarca granadina*”. Publication *Anales Españoles de Pediatría*. Vol. 53. No. 3. 2.000. Sánchez, F.J. et. al. “*Diferencia étnica en la actividad asistencial de urgencias. Aproximación a la realidad gitana*”. Publication *Anales Españoles de Pediatría*. Vol. 56. No. 1. 2.002.

¹⁵ Mora, L. et. al. “*Prevalencia de caries y factores asociados en niños de 2-5 años de los Centros de Salud Almanjáyar y Cartuja de Granada capital*”. Publication *Atención Primaria*. Vol. 26, No. 6. 2.000.

¹⁶ Sánchez, F.J. “*Diferencia étnica en la actividad asistencial de urgencias. Aproximación a la realidad gitana*”. Publication *Anales Españoles de Pediatría*. Vol. 56. No. 1. 2.002.

¹⁷ Martínez-Frías, M.L. “*Análisis del riesgo que para defectos congénitos tienen diferentes grupos étnicos de nuestro país*”. Publication *Anales Españoles de Pediatría*. Vol. 48. No. 4. 1998; Martínez-Frías, M.L., et. Al. “*Síndrome de Fraser: frecuencia en nuestro medio y aspectos clínico-epidemiológicos de una serie consecutiva de casos*”. Publication *Anales Españoles de Pediatría*. Vol. 48. No. 6. 1.998.

¹⁸ Dueñas, R. M. et. al. “*Influencia de factores socioeconómicos en la evolución y seguimiento del embarazo*.” Publication *Atención Primaria*. Vol. 19, No. 4. 1.997.

¹⁹ Reig, S., et. al. “*Anticoncepción : gitanas frente a payas*.” Publication *Atención Primaria*. Vol. 23, No. 2. 1.999.

²⁰ Dueñas, R. M. et. al. “*Influencia de factores socioeconómicos en la evolución y seguimiento del embarazo*.” Publication *Atención Primaria*. Vol. 19, No. 4. 1.997.

²¹ The most commonly used indicators are as follows: mortality rate, morbidity rate, perceived health, health-related behaviour, activity limitations and access to and use made of health-care services.



than with genetic factors intrinsic to the Roma minority (except in the case of congenital malformations).²²

KEY IDEAS

Regarding the Roma Community, Culture and Health

- Lacking education and income and sub-standard housing are factors which determine the degree of well-being and the living standard of the population.
- The processes of exclusion and social marginalization limit people's access to health-care services and the use they make of them.
- Culture also includes the way one views his/her body, health and disease.
- Both biological and cultural components should be recognised as playing a part in disease.
- Relevant aspects in the relationship that the Roma population has with health and disease:**
 - Health is not perceived as a high-priority need.
 - Concern begins when startling or invalidating symptoms emerge.
 - Health is conceived as the absence of disease and disease as an invalidating situation linked to death.
 - The diagnosis is a matter of "*putting a label on one's affliction.*"
 - Very little awareness of prevention.
 - Immediacy, i.e. the need to cure illness as quickly as possible.
 - Hygiene habits are prevalent.
 - Traditional rules often act as protection factors.
 - Women are entrusted with caring for the health of group members.
 - The physician is an ambivalent figure: On the one hand s/he possesses the knowledge needed to cure the disease but, on the other hand, s/he is also the one responsible for diagnosing and discovering the disease.
- Co-existence of different medical models:
 - Traditional: for the treatment of popular or folk pathologies.
 - Scientific: characterised by medical and pharmaceutical professionals.
 - Evangelical Church: for the treatment of terminal or social diseases (cancer, HIV, etc.).

²² Martínez-Frías, M.L. "Análisis del riesgo que para defectos congénitos tienen diferentes grupos étnicos de nuestro país". Publication *Anales Españoles de Pediatría*. Vol. 48. No. 4. 1.998.



CHAPTER II

3. THE HEALTH-CARE SYSTEM AND THE ROMA POPULATION ACTION RECOMMENDATIONS

3.1. Introduction

What follows is a proposal containing recommendations targeting the **different professionals working in the health-care system; guidelines to help in the provision of services which are culturally tailored to the Roma population and which meet their health-care needs from a perspective of respect for their cultural identity as an ethnic minority**. The final goal is to contribute to the elimination of health inequalities facing Roma and to prevent the emergence of possible conflicts in health-care contexts.

These guidelines should not be conceived as a “*cook-book*”. They cannot and should not be applied to the letter in any context given that a large number of very diverse factors exert an influence on this process such as: the service in which the health-care providers work (resources, organisation, department, etc.), the amount of time available to attend to each patient, the general characteristics of the territory and the population on which services focus as well as the motivation and rank of the professionals themselves.

It is also our intention to avoid “paternalistic” guidelines which could promote dependency of Roma patients on health-care institutions. We also advocate actions which help to build the capacity of the Roma population to be responsible in taking care of its own health and likewise to make proper use of health-care services.

Our aim is, therefore, to **offer a frame of reference for action** from a perspective of awareness of the Roma culture which allows us to understand their attitudes, lifestyles and behaviours in health-care contexts in pursuit of a **three-pronged objective**:

- To improve access to care and to foster quality care and success in health-care initiatives.
- To prevent the emergence of possible conflicts.
- To do capacity building work so as to gradually prepare Roma people to care for their own health.

We will address a series of practical recommendations focusing on the following health-care services:

- Administrative Services
- Primary Health Clinics and Specialist Centres
- Hospitals
- Emergency Room Services



3.2 Health Management Services

One of the challenges facing the organisation of the Spanish health-care system as concerns ethnic minorities is the “**acceptance of the concept of difference**”. This means care provision for the different cultures which live together in our country should be a transversal element in the planning of actions undertaken through health-care administrative services. We are **NOT** suggesting:

- setting up health-care services exclusively for Roma or for each ethnic group living in Spain;
- or interpreting equality as egalitarianism or “coffee for everyone”.

Lately a number of difficulties have been observed in our Public Health System which stand in the way to this acceptance of difference and we would propose the following recommendations to overcome this stumbling block:

SITUATIONS	RECOMMENDATIONS
<p>Lack of information regarding existing health inequalities within the population cared for in the field.</p> <p><u>For example:</u> differences in terms of percentages of children vaccinated, the prevalence of certain diseases or conflicts and difficulties arising at health-care centres, etc.</p>	<p>⇒ Set up a series of “<i>Alarm Systems</i>” which report on health inequalities and differences within the target population.</p> <p>⇒ The following management tools could be included in the health-care system:</p> <ul style="list-style-type: none"> ▪ “Active recruitment” of health-care users. ▪ Inter-sectoral coordination and collaboration: with Social Services, schools, intercultural mediation professionals, Roma associations, neighbourhood associations, etc. The aim is to set up coordination devices so that this tool is not left to the whim of the professionals. <p>⇒ Conduct “micro” surveys to gather information on health needs and behaviours.</p> <p>⇒ Construct large-scale “<i>maps</i>” in order to identify the areas most afflicted by health inequalities.</p>
<p>Inflexible management or procedural protocols</p> <p><u>For example:</u> vaccinations administered only in the morning. If one considers that many Roma work as mobile traders in the morning hours, a</p>	<p>⇒ Identify and add flexibility to those management or procedural protocols which exclude or make it difficult for the Roma population to gain access to the health-care system.</p> <p>⇒ Intensify and develop the “humanisation of care” process already under way in some hospitals.</p>



<p>vaccination schedule of that sort is limiting for many Roma families.</p>	
<p>Lack of protocols and actions tailored to diversity</p>	<p>⇒ Put together brochures and/or informative posters using simple language and visual supports to help Roma understand how the service works and what their rights and duties are as patients.</p> <p>⇒ Include action protocols in hospital “Reception Plans” suited to the Roma minority and which encompass the following initiatives:</p> <ul style="list-style-type: none"> ▪ Verbal and non-verbal information on patients’ rights and duties (rules, timetables, etc.) and hospital services and operational procedures. ▪ Facilitate the management of administrative formalities. ▪ Make referrals to other support services (social worker, psychologist) as needed. <p>⇒ Set up “Information points” where check-in, orientation and accompaniment activities are carried out.</p> <p>⇒ Implement pilot programmes which envisage intercultural mediation.</p> <p>⇒ Foster the presence of Roma professionals at health-care services. If this is not possible at the staff level it could be achieved through the engagement of external companies such as security or administrative services.</p> <p>⇒ Draw up protocols on how security services should perform according to the health-care context. It is important to note that the intervention of security officers arouses a great degree of mistrust among Roma and confirms the prejudices and stereotypes that they harbour about the way “payos” (non-Roma) treat the Roma people.</p>
<p>Lack of prevention and contingency plans to deal with potential conflict situations</p>	<p>Plans must be devised to prevent potential conflict situations by reinforcing the assurance of health-care services. Of the actions to be taken, we would stress the following:</p> <p>⇒ Make users aware of health-care services available so that their expectations are in tune with reality.</p> <p>⇒ Improve accessibility to health-care centres:</p> <ul style="list-style-type: none"> ▪ Provide training to administrative staff working at information desks, scheduling appointments and



<p>Lack of prevention and contingency plans to deal with potential conflict situations</p>	<p>patient services to sensitise them in accordance with the needs of each service.</p> <p>⇒ Reduce the waiting time associated with medical appointments, tests, emergency room services and in general for all health-care assistance.</p> <ul style="list-style-type: none"> ▪ Train professionals in the design, implementation and management of quality agendas at health clinics in order to adjust the time of the medical visit to the needs of patients. ▪ Primary care clinics should have the organisational measures by which to guarantee proper assessment and care for patients without an appointment and emergency cases while assuring that this “non-scheduled” care has the least possible repercussion on scheduled appointments. ▪ Optimise medical visits by preventing interruptions. ▪ Set up a personalised appointment programme at the external specialised care clinics. ▪ Establish quality criteria in the organisation and management of external appointment lists. <p>⇒ Make waiting rooms and other public areas as comfortable and peaceful as possible.</p> <p>⇒ Facilitate the check-in and stay of patients in health-care facilities.</p> <p>Assure that health-care rights are respected and information furnished to patients and family members.</p> <p>⇒ Reinforce security to prevent aggressions:</p> <ul style="list-style-type: none"> ▪ Identify citizens’ expectations of health-care services which do not correspond to reality and could cause them to react in an aggressive manner. ▪ Set up a protocol for professional action in the event of citizens whose behaviour is improper.
<p>Differences in terms of what are considered quality health-care services</p>	<p>⇒ Create a climate of respect, tranquillity and trust from the beginning of the relationship with the health-care system (this includes administrative staff, the appointment desk, etc.).</p> <p>⇒ Practice active listening.</p>

<p>In assessing the quality of health-care services, the Roma population places more emphasis on the way they are treated and a caring attitude from health-care staff.</p>	<ul style="list-style-type: none"> ⇒ Pay attention to the values, preferences and needs expressed. ⇒ Ask for feedback to make sure the message was understood. ⇒ Use simple language and avoid formalisms. ⇒ Explain clinical and administrative procedures clearly. <p>Indeed, these are the same elements that should be present in any relationship between health-care providers and patients regardless of ethnic background.</p>
<p>Lack of prevention and awareness heightening efforts made with the Roma community</p>	<ul style="list-style-type: none"> ⇒ Recruitment of Roma patients from primary care clinics to participate in prevention programmes or activities. For example, organise information sessions with local Roma women on pregnancy and birthing, prevention of the effects of menopause, nutrition, etc. ⇒ Conduct health education activities in the same surroundings where the Roma population resides. ⇒ Inform and train Roma leaders such as presidents of associations, evangelical pastors, highly regarded men or women, etc. on subjects related to health promotion. ⇒ Prevention and awareness heightening with Roma families in workshops and group activities. Bearing in mind the close relationship among extended family members, when one approaches the subject of health we should be aware that the relationship established is not usually between the individual and the health-care system but rather between the individual who is ill, the extended family and the health-care system. ⇒ Take advantage of the wisdom and “openness to change” characterising the Roma women of the family. ⇒ Furnish clear information regarding the effectiveness and effects of prevention measures and of some treatments such as vaccines, for example. ⇒ Get the Roma patients and community representatives involved in the design and implementation of prevention programmes.

Regarding the proposal to conduct surveys or research to gain insight into health inequalities, it is important to keep a few points in mind to assure effectiveness.



The following general criteria should be kept in mind when conducting surveys or research:

- Studies which constitute an affront to individual privacy should be avoided and efforts made to seek alternative techniques.
- Whenever Roma collaboration is requested for a study, they must be “rewarded” with the results.
- A number of questions must be posed prior to the start of any study: Are the expected results of the study going to be significant? In other words, is the information sought necessary for advancement in that sector? If the answer to the latter question is affirmative, do we have the necessary resources to carry out a sufficiently serious and high-quality study? If the answer to one or both of the above questions is negative, it would be better to dedicate our efforts and resources to other objectives.
- Regarding the subject of studies and research, the following useful ideas emerged which could facilitate the subsequent design of health promotion programmes:
 - Study of the factors which determine the health of the Roma community.
 - Study of the life expectancy of the Roma population.
 - Study of the traditional “healing” practices of the Roma community.

3.3 Primary Care Clinics and Specialised Centres

3.3.1 Initial considerations

Some of the difficulties arising in primary health clinics or specialists’ offices are related to a lack of awareness on the part of health-care personnel, administrative personnel or security officers regarding Roma culture. Occasionally conflicts arise which could be avoided if certain cultural codes are handled and interpreted correctly such as language, for example.

No doubt some of these difficulties are also the result of the way Roma relate to health-care services and their professionals. Therefore capacity building work and commitment focusing on the Roma population is also necessary so that they become familiar with the way health-care services operate and make proper use of them. We should not forget that the relationship and perception that Roma people have of health-care services is mostly based on the information they receive from the experience that other Roma have had. That experience, positive or negative, passed on by word of mouth, is going to be a factor in the way they view the service.

The **Primary Health-care Clinics** are the first experience that one has of the health-care system. Professionals at this level of health care should view themselves as managers or counsellors of patients as the latter make their way through the health-care system. In the case of the Roma minority, this duty acquires special relevance because oftentimes they do not know



how to handle themselves in the different health-care services. Thus, these clinics play an essential role in initiating the “learning” process of Roma individuals in respect of caring for their health.

For a large portion of the Roma minority the **Specialised Care Centres** represent unchartered territory. In the case of serious illness oftentimes they turn to hospital emergency room services because this is the only place where they receive immediate care. It is therefore important to disseminate information about the existence of these centres and the medical areas they focus on with a view to fostering their use and preventing the collapse of emergency room services.

Special mention should be made of the following **medical specialities** when referring to the Roma population:

- ⇒ Paediatrics
- ⇒ Gynaecology
- ⇒ Mental Health

PAEDIATRICS	<p>Special emphasis should be put on the following issues:</p> <ul style="list-style-type: none"> ❑ Vaccination²³: although vaccinations are very standard among Roma children, we must keep stressing the importance of vaccines in protecting against serious disease. Special emphasis should be put on explaining the vaccination schedule, the importance of adhering to the latter and the places where the said vaccines are administered. ❑ Child nutrition: occasionally we find a lack of awareness as to the importance of a balanced diet for the proper development of children. ❑ Prevention of domestic accidents: a lack of awareness is also quite frequent in respect of injury from these types of accidents sometimes the result of homes which are not properly equipped and overall deterioration of the surrounding area.
GYNAECOLOGY	<p>The link between reproduction and sex, a taboo subject especially for women, means that monitoring and prevention actions as regards gynaecological matters is limited to pregnancy and birthing. The following aspects must be borne in mind:</p> <ul style="list-style-type: none"> ❑ Family Planning: is conditioned by cultural factors such as the wish to have a large family to guarantee ethnic group survival, the prestige and social status acquired by Roma women when they bear children, especially boys. While many Roma women are aware of the existence of different birth control methods, many avoid them because of the expectations that their community has of them as mothers. It is also true, however, that the younger

²³ See section 2.3. 2.3 The health status of the Roma population in Spain



GYNAECOLOGY	<p>generations are increasingly planning their pregnancies.</p> <ul style="list-style-type: none"> ❑ Gynaecological checks: are generally shrouded in mysticism and are the cause of anguish and fear for Roma women due to their lack of awareness. It is important that: <ul style="list-style-type: none"> - the gynaecologist doing the check is a women; - special care be taken with the doctor-patient relationship; - a climate of trust and understanding be created; - respect be shown for cultural aspects related with sex and reproduction. ❑ Menopause: Although this development process is becoming increasingly familiar to Roma women, there are still a large number who are caught unaware and find themselves facing a series of changes in their body which are improperly interpreted. The result tends to be an intensifying of the psychological disorder related with the onset of symptoms of depression and anxiety.
--------------------	--

MENTAL HEALTH	<p>The Roma population has not traditionally paid all that much attention to mental health care. One of the reasons for this is the typical connotation of mental disease as something “diabolical or transcendental” and treatment has been left to the traditional medical model.</p> <p>Lately, however, an growing number of Roma, especially women, are being treated through the mental health services. Generally, their problems or pathologies are directly related to the gender-specific roles assigned to them. Therefore, it is not uncommon to observe a pathology characterised by symptoms of anguish, anxiety, depression, etc. related to work overload and responsibility both in and outside of the home.</p> <p>In the case of Roma men, use of mental health services is generally limited to kicking the drug habit.</p> <p>We would therefore like to stress the importance of furnishing information on the need to take care of the psychological aspect of health and on the existence and operation of these services.</p>
----------------------	--

3.3.2 Recommendations

As regards the following recommendations it is important to remember that:

→ **It is not a matter of more work** but rather of incorporating new concepts, different ways of interpreting situations, new intervention methodologies, etc., allowing professionals to more efficiently carry out their duties thus obtaining better results in everyday work and reducing the possibility of emerging conflicts.

→ **A deeper awareness of the Roma population** will be useful in improving quality of work, will contribute to reducing existing inequalities and likewise to improving their



standard of living. **It will also help in focusing attention on diversity** in general, i.e. making headway towards more individualised care. In short, it is not an issue of going through a training course to learn how to approach each *different group*. It is more a matter of (over and above some specific, specialised content) honing one's tools of the trade such as empathetic communication, developing a mediator's mindset, dealing with conflict, etc., which are universally applicable.

AS REGARDS HEALTH-CARE PERSONNEL	
SITUATIONS	RECOMMENDATIONS
<p>Little understanding of the characteristics and culture of this minority among health-care providers</p>	<p>⇒ Gain insight into the cultural characteristics of the Roma community, identifying those which are decisive in terms of health; those exerting a negative effect and those others which can be taken advantage of to effect an improvement in health.</p> <ul style="list-style-type: none"> ▪ <u>For example:</u> solidarity among group members, respect for and care given to the elderly, certain traditional hygiene habits, the importance of the mourning ritual and its repercussions on daily activities, etc. <p>⇒ Training and capacity building of health-care personnel for work with ethnic minorities.</p>
<p>The prevalence of prejudices and preconceived stereotypes</p> <p>Generally no distinction is made between Roma culture and the “culture of marginalization” – characterising any group or individual living in a situation of social exclusion.</p>	<p>⇒ Avoid generalising the particular behaviour of a group of Roma or of a Roma family to the entire Roma community.</p> <p>⇒ Do away with the erroneous idea that “all Roma are the same”. Just as in the rest of society “they come in all shapes and colours”. The main characteristic of this minority is their diversity and heterogeneity depending on their economic and social background, family tradition, educational level, etc.</p>
<p>Lack of a mediator's mindset</p>	<p>⇒ Training of health-care personnel in conflict resolution skills.</p> <p>⇒ Activate negotiating and consensus-seeking skills. For example: “in order to comply with hospital rules and also to meet your need to know how your family member is getting on, I will inform you every 30 minutes as to his condition and in exchange, only one person will be allowed to stay with your uncle.”</p> <p>⇒</p>



Communication barriers	<p>Breakdowns in communication can be traced back to two specific factors: The lack of adaptation of messages communicated to the Roma population in terms of the sort of vocabulary employed,²⁴ and also rooted in health-care providers' predilection for the use of written communication while it is oral communication that prevails in the Roma community.</p> <p>In this connection, we would recommend:</p> <ul style="list-style-type: none"> ⇒ Use patient-centred clinical interview techniques. ⇒ Use clear, simple, everyday language and explain any technical terms employed. ⇒ Pay attention to gestures and other body language to gather information regarding the emotional state of the patient. ⇒ Repeat the diagnoses and treatments as well as the procedure to be followed in making appointments, etc, until you are satisfied that the message has been understood. Remember that written documents do not have the same validity for Roma patients. ⇒ Intersperse words that are part of their own vocabulary register to further close the communication gap.
-------------------------------	---

AS REGARDS THE ROMA POPULATION	
SITUATIONS	RECOMMENDATIONS
Reluctance to visit the physician	⇒ Separate the relationship with the doctor from death and disease. Teach the benefits of prevention and caring for one's health through health education activities.
Improper use of health-care services: either by deficiency or excess	⇒ Make service operation understandable. Mediators could play a role in this regard.
Unawareness of specialised health centres	⇒ Furnish information at the primary care clinics regarding the existence, access to and how the different specialised centres operate.

²⁴ Especially bearing in mind the lack of formal schooling in the case of a large sector of the Roma population.



<p>Mistrust of the public health-care services</p>	<p>⇒ Foster an individualised and flexible attitude. Professionals should be viewed as persons and not as rigid institutions.</p>
<p>Difficulty staying on the treatment</p>	<p>⇒ Be careful and act with moderation when requesting changes in lifestyles and habits.</p> <p>⇒ Furnish information regarding the positive and negative benefits of the medical prescription.</p> <p>⇒ Monitor patients closely and over time.</p>

3.3.3 Clinical interviews with the Roma population

The clinical interview is a tool used by health-care providers when initiating relationships with patients. A number of human relations factors come into play here together with other more technical issues from the health-care provider's side. Verbal and non-verbal communication both play an important role because they will be conditioning factors for future interaction. This should be approached like a negotiation process where opinions and alternatives go back and forth between patients and health-care providers.

Health-care literature indicates that a good health-care provider-patient relationship contributes to better results and satisfaction of the latter. Verbal and non-verbal communication skills such as attentive listening, two-way communication, expressions of empathy from the professional, etc., especially at the beginning, will largely determine the success of the therapeutic relationship.

In the case of ethnic minorities, we have already seen how cultural elements have a bearing on the relationship that these population groups have with health and disease. When talking about Roma, we should bear in mind the influence of elements specific to the Roma culture set out in point 3.2 of this handbook and how they affect the subjective component of disease. By means of the clinical interview, the health-care provider and the Roma patient can set the stage for a therapeutic relationship based on mutual respect and acceptance of differences.

Patient-centred communication

Lately, a new way of addressing communication in relations with patients has been developed where environmental aspects and life experiences having a bearing on the clinical situation are borne in mind.

The patient-centred communication model is based on 6 elements:

1. Exploration of the disease and the patient's related life experiences: in addition to exploring symptoms, the following aspects are considered:
 - The idea that the patient has regarding the disease.
 - The feelings the disease produces (anguish, fear, etc.).
 - The expectations that s/he has of the professional and the usefulness of the treatment.



- The impact that symptoms have on his/her daily life.
 - Non-verbal communication.
2. Understanding the whole person: this entails bearing in mind environmental, social and family factors such as the patient's living conditions, family relations and support structures, economic needs, etc.
 3. Reaching agreements with the patient: it is essential that the patient play an active role in the health-disease process. To that end, health-care providers should seek the patient's acceptance of the diagnosis proposed and the treatment.
 4. Incorporation of prevention and/or promotion: prevention and promotion are included in damage reduction, early detection of disease and the diminishing of its effect.
 5. Nurturing the professional-patient relationship: the professional should take advantage of each clinical visit to improve relations with the patient.
 6. Realism: All of the above should be undertaken while bearing in mind the realistic possibilities of the service where the health-care provider is working: available resources, time constraints, etc. It is a well-known fact that many health-care providers see an excessive number of patients and therefore will only be able to assess the aspects of this model which are most important for the process and for the patient.

The main objectives of the patient-centred clinical interview are:

- To issue a correct diagnosis;
- To guarantee follow-up on treatment;
- To prevent future health problems.

Stages and techniques of the clinical interview with the Roma population

Reception stage	<p>→ Objective</p> <p>To establish a therapeutic relationship based on empathy, warmth, respect and effective communication.</p> <p>→ Techniques</p> <ul style="list-style-type: none"> ▪ Cordial welcome. ▪ Relaxed visual contact. ▪ Deference and respect shown with older patients. ▪ A specific greeting should be given to Roma men (not to be considered as gender discrimination but rather as a small gesture which will affect the level of trust that the "head of the household" – and therefore the rest of the family – has in the health-care provider.
Defining the purpose of the visit	<p>→ Objective</p> <p>To establish the reason for the visit and obtain the data and information needed to gain insight into the nature of the problem and the patient's expectations and beliefs.</p>

<p>Defining the purpose of the visit</p>	<p>→ Techniques</p> <ul style="list-style-type: none"> ▪ Open questions intended to get the patient to provide information without undue prompting. ▪ Closed questions to obtain specific information to help clarify symptoms. ▪ Empathy: Verbal or non-verbal technique consisting of expressing emotional solidarity with the patient. For example: "I understand how important this is to Roma". ▪ Low-profile reaction: leave a little bit of time between the moment the patient stops talking and the interviewer reacts so as to avoid interruptions. ▪ Functional silence: intersperse moments of silence to leave time for the patient to think or to act as a catalyst for certain emotional reactions which may arise. ▪ Facilitate communication: verbal expressions from the interviewer ("please go on") or non-verbal (head nodding) which help the patient to continue speaking.
<p>Exploratory stage</p>	<p>→ Objective</p> <p>Make some sort of linking statement to prepare the patient for the exploration s/he will be subjected to explaining what it is you want him/her to do and the reason why this is necessary. This is especially sensitive when you are dealing with girls between the ages of 7 and 16 (known as "mozas" in Spain) or women if the professional is a man. It would be advisable to have a women professional.</p> <p>→ Techniques</p> <ul style="list-style-type: none"> ▪ Verbalise findings that are normal in order to reduce stress levels...
<p>Resolution stage</p>	<p>Different phases</p> <p>a) Information given to the patient: entails stating the problem detected, informing of its nature and agreeing on a prevention or treatment plan.</p> <p>→ Techniques</p> <ul style="list-style-type: none"> ▪ Use simple language avoiding technical medical jargon to the degree possible. ▪ Pay attention to the patient's non-verbal communication which could indicate lack of comprehension. ▪ Two-way communication: the patient should feel free to interrupt if there is something s/he does not understand. <p>b) Negotiation: it could happen that the patient has a different opinion regarding the diagnosis or treatment proposed by the professional. The following techniques can be used if this sort of dialogue arises:</p> <p>→ Techniques</p> <ul style="list-style-type: none"> ▪ Reverting ideas. Example: "the vaccination is not bad. It would be worse to contract the disease because you didn't take the vaccination and then infect one of your children."

	<ul style="list-style-type: none"> ▪ Give in intentionally. Example: “I think and x-ray <i>would</i> be a good idea but after we’ve finished with this treatment.” <p>c) Agree on a plan: a therapeutic plan should be agreed bearing in mind the beliefs, opinions and lifestyle of the patient so that s/he actually follows the treatment and recommendations.</p> <p>→ Techniques</p> <ul style="list-style-type: none"> ▪ Furnish information regarding the benefits of treatment and the possible negative consequences of not following it.
--	--

3.4 Hospitals and Emergency Services

The relationship that the Roma population has with health-care means that the experience of checking-in to a hospital will cause worry and stress which are shared by all of the members of the extended family. Moreover, a lack of awareness as to the organisation and operation of hospitals creates an added difficulty which very often gives rise to conflict. An attitude of negotiation and respect for the customs of the Roma people will help to resolve conflict situations.

It is well-known that the Roma population makes excessive use of emergency room hospital services. As has already been pointed out, this is directly related to the way in which Roma perceive disease: immediacy in diagnosis and cure and disease linked to death. Use of these services is prevalent when sick children are involved (especially when the symptoms include high fever) or in the case of accidents. In these circumstances perceived as “very serious” by the Roma family, members are usually in a desperate state of mind when they show up at emergency rooms.

SITUATIONS	RECOMMENDATIONS
<p>Lack of awareness as to how hospitals and emergency room services work</p>	<p>⇒ Set up clearly marked information points or desks to undertake the duties of receiving and providing verbal information to patients.</p> <p>⇒ When checking-in to the hospital, provide information in writing tailored to the cultural peculiarities of the Roma population as regards:</p> <ul style="list-style-type: none"> ▪ Hospital rules; ▪ Visitation hours and the scheduling of care and doctors’ rounds; ▪ List of patients’ rights and duties; ▪ Rules or instructions regarding visits, family members and those accompanying the patient. <p>⇒ Give a detailed explanation of:</p> <ul style="list-style-type: none"> ▪ Citizen’s rights and duties; ▪ The general organisation of health-care centres;

	<ul style="list-style-type: none"> ▪ Benefits and a list of health network services; ▪ Requirements which citizens must fulfil to gain access to Clinics; ▪ The proper use of health-care benefits and services. <p>⇒ Accompaniment, when appropriate, to the different hospital services.</p> <p>⇒ Qualify specific professionals (by way of training in dealing with diversity) entrusted with furnishing information.</p>
<p>The extended Roma family</p>	<p>⇒ Identify the maximum authority figure in the family group (generally the oldest men or, failing that, the oldest women to communicate messages: the patient's condition, hospital rules, the rights and duties of patients and relatives, etc. It is important to furnish information on the patient's condition, prognosis, evolution and, if relevant, treatment as soon as possible.</p> <p>⇒ The intervention of intercultural mediators fosters understanding between health-care personnel and Roma families by acting as an "interpreter" in these types of situations.</p> <p>⇒ Furnish waiting rooms and other public hospital areas to accommodate family members who may be staying. It would be advisable to implement control and monitoring actions to oversee compliance with hospital norms in these public areas.</p>
<p>Notice of death</p>	<p>⇒ Communicate this information to the most highly regarded members of the group.</p> <p>⇒ Demonstrate an attitude of understanding and respect towards expressions of pain.</p> <p>⇒ Furnish information regarding the next steps which need to be taken.</p>
<p>Timely diagnosis</p>	<p>⇒ Explain the need to run tests which will take an undetermined amount of time.</p> <p>⇒ Explain the rules of the service.</p> <p>⇒ Identify the maximum authority figure of the family group to transmit messages.</p> <p>⇒ Negotiate – if family members comply with the rules,</p>

	information will be furnished at regular intervals on the development of the patient's condition.
If a young Roma girl or adolescent is involved	<p>⇒ A detailed explanation must be made regarding the importance of running a test which could be perceived as a threat against some aspect related to the virginity of the child or adolescent.</p> <p>⇒ Demonstrate an attitude of respect and tolerance for these Roma customs.</p>
Security services	<p>⇒ Service rules and procedures should be explained by health-care providers because security services generate a large degree of mistrust among the Roma population.</p> <p>⇒ Negotiation and a tolerant attitude will facilitate conflict resolution.</p>

KEY IDEAS

Recommendations targeting health-care system services

Administrative Services

→ **Challenge: Acceptance of differences and attention to diversity**

Recommendations

- Active recruitment of health-care users
- Inter-sectoral coordination and collaboration
- Undertake studies and research at the macro level which shed light on health needs
- Draw up maps on the macro level
- Add flexibility to rigid protocols
- Identify those protocols which tend to exclude
- Include protocols suited to the cultural characteristics of the Roma minority in the "Reception Plan"
 - provide information on hospital procedure (rules, rights and duties);
 - help in the management of administrative formalities;



- make referrals to other services (social work, psychology, etc.).
- Work more intensely on “humanisation of care”
- Draft brochures and information posters tailored to the Roma population.
- Implement pilot programmes which envisage intercultural mediation.
- Create a climate of respect for Roma customs.
- Conduct health education activities in the same surroundings where the Roma population resides.
- Inform and train Roma community leaders.
- Work with families on group awareness heightening activities.
- Take advantage of the wisdom and openness of Roma women.

Primary Health Clinics and Specialised Medical Centres

- ➔ **Challenge facing the Roma population: to learn and build capacity in terms of taking care of their health and proper use of health-care services.**
- ➔ **Challenge facing professionals: learn about the Roma culture.**

Recommendations

- Inform the Roma population regarding the availability and operation of specialised medical services especially in the areas of paediatrics, gynaecology and mental health.
- Implement training and didactic actions targeting professionals as regards Roma culture.
- Avoid prejudices and stereotypes regarding the Roma population.
- Acquire mediation and conflict resolution skills.
- Implement patient-centred clinical interview techniques: clear language, consideration of the subjective and environmental aspects of the disease, non-verbal communication, etc.
- Monitor clinical cases closely and over time.



Hospital and emergency services

→ **Challenges:**

- ⇒ Peaceful conflict resolution.
- ⇒ Proper use of services.

Recommendations

- Communicate messages to the person of maximum authority in the group: usually an elder Roma man.
- Explain the rules of the service.
- Negotiate compliance with rules.
- Take extra care when communicating information about young Roma girls and be sensitive when reporting the death of a patient.
- Limit the scope of action of the security services.
- Provide a place for intercultural mediation.
- Prepare suitable places for the extended Roma family to stay.

4. GLOSSARY OF TERMS TO INCREASE AWARENESS OF THE ROMA CULTURE

CALÓ	<p>The language used by the Spanish Roma population. Spanish grammar is used as well as some Romany words (native language of the Roma population). The word “caló” or “calé” is also used to refer to Spanish Roma persons (the feminine forms are “calís” o “callís”).</p> <p>Some words in “caló” which are still commonly used: <i>camelar</i> (to want), <i>naquerar</i> (to speak), <i>chalenar</i> (to know), <i>jallar</i> (to eat). Also, some Romany words have been incorporated into Spanish such as <i>chaval</i> (young man), <i>currar</i> (to work), <i>parné</i> (money), etc.</p>
CLAN	<p>This term should NOT be used in reference to the traditional Roma family owing to its negative connotations related to its traditional association with criminal activities. The most appropriate terms would be “extended family” or “family group”. Another appropriate term to be used in reference to family relatives is “<i>linaje</i>” (which translates as “lineage”).</p>
CHAVORRILLO	Roma child
ETNIA	(Ethnic group, ethnic minority). A group of persons sharing a collective identity and a common history. They have their own culture, customs, rules, beliefs and traditions.
HOMBRE MUJER DE RESPETO	<p>This expression is used to refer to elder Roma persons who, owing to their life experience, have gained the respect and trust of the community. Their opinions and decisions have a strong influence on other Roma and they are key persons when it comes to resolving problems. This is the term which should be used in Spanish rather than <i>PATRIARCA</i> (patriarch) which is not a Roma word and is not accepted among the Roma population.</p>
LEY GITANA (ROMA LAW)	<p>Set of rules and customs traditionally determining the behaviour of the Roma population. This law is based on customs, the desire to belong to the group and oral tradition. There is no stable explicit structure guaranteeing its implementation, adaptation or enforcement. It is considered law insofar as it is respected by the Roma people and there is a sanction or negotiation between the parties involved.</p>
MOZA	Spanish Roma expression used to refer to unmarried girls, usually as of the age of 12.
PAYO/PAYA	A non-Roma person. This is not a derogative term.
PEDIMIENTO (engagement to marry)	<p>This refers to the traditional act where Roma couples introduce boyfriends or girlfriends to their respective families and a formal commitment is established. The <i>pedimiento</i> (also called <i>pidimiento</i>) implies that the families accept the future spouse chosen by their son/daughter. This</p>



	would be equivalent to becoming “engaged”. The expression “ <i>estar pedía</i> ” (to be engaged) is also common.
PRIMO PRIMA	This term (literally translated as “cousin”) is used by Roma to refer to one another. It does not denote belonging to the same family but rather to the same ethnic group.
PUEBLO GITANO	The expression “ <i>pueblo gitano</i> ” or “ <i>pueblo Roma</i> ” (Roma people) are colloquial ways of referring to all Roma people throughout the world. The Roma People is not, however, acknowledged as such under International Law despite sharing a common identity. The criteria applied to acknowledgement of a group as a “People” are very strict because this implies the right to claim self-determination.
ROMA (Rom/Romí)	The translation of the Spanish “ <i>gitano</i> ” in Romany is “Roma”, Rom (masculine) and Romí (feminine). The Spanish term “ <i>gitano</i> ” translates as “Roma” and is used to identify all Roma persons throughout the world who, depending on their region or country of residence, may identify themselves using other terms such as <i>Ciganos, Tsiganes, Gypsies</i> , etc.).
TÍO TÍA	This term (literally translated as “uncle” / “aunt”) is used to refer to highly respected men and women.
SASTIPEN	“Health” in Romany.
ROMA SYMBOLS	<p>The most well-known are the flag, the hymn entitled “Gelem, Gelem”, and the “cart-wheel” and “campfire” symbols.</p> <p>Festive dates: 8 April (International Roma Day), 24 June (the night of “San Juan”) and Christmas Eve (24-25 December).</p> <p>Important expressions: the greeting “<i>sastipen</i>” (literally “good health”) or “<i>sastipen ta lí</i>”, or “<i>sastipen thaj mesticen</i>” (“health and freedom”).</p>
VIRGINITY	A woman’s virginity before marriage is one of the mostly deeply rooted customs and symbols of the Roma culture.



CHAPTER III

5. ANNEXES

5.1 Best practices

This section features two actions considered models of best practices for work with the Roma population within the scope of health-care. These are actions intended to facilitate access of Roma to the health-care system and to keep them within that system as appropriate thus contributing to the reduction of health inequalities and the prevention of possible conflicts.

Intercultural mediation itself can be considered a resource in the fostering of quality health-care system benefits and its techniques and work methodologies serve to assure success of therapeutic interventions in the case of Roma patients.

The experience undertaken at Madrid's San Carlos Clinic is a project currently still under way which has been instrumental in bringing about a considerable improvement in the reception and information process for those entering this hospital. It targets the population at large and is especially useful in the case of individuals belonging to ethnic or cultural minorities.

In both cases this experience has proven that it is possible to implement specific actions within the scope of health-care which contribute to equal health opportunities for ethnic minorities.

Intercultural mediation

“Intercultural mediation is a resource available to individuals of different cultures and serves as a bridge with a view to promoting constructive change in intercultural relations. The main purpose of mediation in relations between culturally diverse individuals is to prevent cultural conflict by fostering recognition of differences, closing the gap between parties, fostering communication and mutual understanding, learning and developing techniques for coexistence, searching for alternative strategies for the resolution of cultural conflicts and community participation.”²⁵

Professional mediation is a resource bridging the gap between the Roma community and the majority society in order to promote constructive change in relations between the two. It is, therefore, a process and not a “fire extinguishing” tool to be used when conflicts arise.

Three types of intercultural mediation can be distinguished:

- PREVENTIVE mediation: the aim is to bridge the gap and facilitate communication and understanding among persons or groups with different cultural codes.
- REHABILITATING mediation: used to normalise and resolve intercultural conflicts.

²⁵ Several authors. *“La mediación intercultural: un puente para el diálogo”*. Desenvolupament Comunitari. Barcelona, 2000.



- TRANSFORMATION mediation: entails the implementation of a process by which rules, customs and individual points of view are set aside in order to establish new types of relationships and neighbourly relations between different cultures.

There is a widespread lack of awareness as regards the possibilities and benefits of intercultural mediation in health-care contexts. However, health education and access to health-care services is an important area of intervention for mediators.

The following duties form part of mediation with the Roma community in the field of health care:

- Enhance recruitment of the Roma population.
- Become aware of perceived needs.
- Facilitate communication between health care resource professionals and the Roma community promoting equal opportunity in gaining access to said resources.
- Break down cultural barriers.
- Advise Roma service users as to how to best relate to health care service providers.
- Advise health-care providers as to how to suitably meet the needs and interests of the Roma population.
- Promote community empowerment.
- Provide personal support to Roma service users.

The benefits of intercultural mediation filter down to health-care service providers as well as to the Roma population as users of the said services.

For health-care providers:

- Enhanced interpersonal relations by breaking down communication barriers.
- Improved interpretation and comprehension of some cultural guidelines, as in the case of adolescent Roma girls or widows.
- Prevents the emergence of conflicts in certain situations; for example the death of a Roma person.
- Leads to better results in medical treatment and prescriptions.
- Makes prevention and health promotion programmes more effective.

For the Roma population:

- Better understanding of diagnoses and therapeutic treatment increasing the success rate in the treatment of disease.
- Allows for greater understanding of the rules and procedures of the health-care system.
- Contributes to standardisation in the use of health-care services.
- Generates a feeling of greater safety and trust of health-care institutions and their health providers.

The fact that the mediator is Roma makes the initiative much more effective. While this is not a pre-requisite, it is important to point out that it has the following advantages: favours access to persons or situations that otherwise would be unreachable; helps close the gap and creates trust allowing Roma people to talk about their situation openly and clearly and, at the same time, the experience and action of the mediator serves as a reference model.

The incorporation of pilot intercultural mediation experiences in hospitals and primary care clinics would permit work with the Roma population covering aspects such as:



- Health education;
- The proper use of health-care services;
- Improvement in relations between health-care providers and Roma patients;
- Prevention of possible conflicts.

The experience at Madrid's San Carlos Hospital: "Information Area"

→ Background

In 1997 a meeting was held between the administration and worker representatives at Madrid's San Carlos Clinical Hospital to address the possible reform of the Hospital's Information Service.

A number of hospital service users had begun to demand their rights as concerns quality care and not only in terms of health care but also as regards administrative services and information. Therefore the hospital, as a public service focusing on addressing the needs of users, proposed a reform of information service activities and likewise a reorganisation of the processes and tasks employed to implement the said activities.

The argument was that if technological innovation played a fundamental role in improving the quality of our health-care system, this progress should go hand-in-hand with greater emphasis placed on the human factor, on citizens and their concerns, so that scientific development and the human component of health-care progress on an equal footing.

The purpose of the said reform was to implement a system by which to address users' doubts and solve their problems and likewise to channel their opinions and suggestions concerning the care provided. The idea was to focus hospital activities, as a public service and at all levels of its organisation, on the "humanisation" of care. This implied that:

- Attention should be personalised at all times and should address the needs of each person which will vary from case to case.
- Work techniques and methodologies had to be adapted to new social realities.
- It became necessary to foster a change of mentality and attitude of hospital personnel as regards the concept of public service in line with the following premises:
 - Adaptation to constant social change;
 - Consideration of the values and feelings of service users when providing professional services.

The reform was based on a global integrated project focused on addressing the problems and needs of hospital users as concerns information and communication.

→ Justification of the need for the new project "Information Area"

The following is a partial list of the **socio-demographic factors justifying** the restructuring of the Information Area:

- The growing number of elderly persons treated at the hospital.
- The growing immigrant population.



-
- The repercussions of gender violence cases in care provided at emergency room services.
 - Rise in the birth rate and culturally different practices among young women immigrants.

The **objectives** of this new project “Information Area” focused on improving the quality of care provided to users and acting as a communication link between hospital workers and users.

→ *Development of the Project*

At the project’s first stage it addressed the “**Reception of the patient at the hospital**”.

It is understood that hospital check-in is a situation producing needs which go beyond purely bureaucratic formalities. The communication process initiated within a health-care context implicitly entails aspects related with the feelings and emotions of the patient who **has come to the hospital because of a health problem**. Therefore, promoting a warmer environment and more personable treatment and offering better and more extensive information regarding the hospital, its resources and services will help patients to feel more confident, listened to and properly cared for.

To this end, a distinction should be made between the different types of patient situations:

- ⇒ Emergency room walk-ins
- ⇒ Patient checking-in to the hospital
- ⇒ Patient who comes for a test
- ⇒ Out patient office visit.

It is also important to distinguish among the different beneficiaries of the process who could be:

- ⇒ Patients
- ⇒ Relatives or friends
- ⇒ Service-providers

→ *Methodology*

In order to implement the activities developed, the so-called “**Information Work Posts**” were designed and located at the Emergency Room, X-ray service, Hospital Admissions, Out-patient visits and General Information. These posts were physically designed as “**Information Points**” which were clearly marked and identified with information panels.

These posts were operated by **information professionals** referred to as “green jackets” in reference to their uniform. Their duty depends on the location of the work post at the different POINTS OF INFORMATION situated in different areas of the hospital.

The following Information Posts can be found at the hospital:



AREA OR SERVICE	DUTIES
<p>OUT-PATIENT DOCTOR VISITS</p>	<p>Two posts are located at the Hospital's Out-patient area to take charge of reception, orientation and accompaniment of patients. The specific duties of the information specialists at this point include:</p> <ul style="list-style-type: none"> ▪ Organise of turn-taking based on patients' appointments. ▪ Inform users concerning: <ul style="list-style-type: none"> ▪ How the appointment service works ▪ How to gain access to the different hospital services ▪ The location of the office where they have their appointment. ▪ Provide information concerning: <ul style="list-style-type: none"> ▪ The existence of "waiting rooms" for use while at the service. ▪ The documents which are not provided at this service explaining the process to be followed. ▪ The need to donate blood (over the public announcement system) in collaboration with the Blood Bank. ▪ Distribution of the forms for tests and appointments explaining and highlighting date, time and place. ▪ Accompaniment of users with special difficulties to the different out-patient doctor's offices.
<p>CENTRAL SERVICES</p>	<p>This Information Point undertakes activities related with the operation and organisation of the hospital's central services. Its specific duties are:</p> <ul style="list-style-type: none"> ▪ To provide explanations regarding: <ul style="list-style-type: none"> ▪ The different hospital documents and how services operate. ▪ How to gain access to the different hospital services. ▪ The location of the places where patients should wait their turn and information on appointment timetables. ▪ Any incident arising in the service which could affect them. ▪ Reception of users with appointments at this service. ▪ Verification that the appointment is in order and indication as to where the user should wait to be called. ▪ Computer reception of all forms corresponding to tests to be carried out in the Service in order to improve the clinical management of the department.



<p>HOSPITAL ADMISSIONS</p>	<p>This information point was established to receive patients with programmed hospital check-in who are subsequently accompanied to the different in-patient wards. Generally access to this information point is through the General Information Points. Duties include:</p> <ul style="list-style-type: none"> ▪ Reception of patients upon arrival, accompanying them until check-in. ▪ Accompaniment and check-in and distribution of a toiletries bag, user's guide and other written information. ▪ To provide explanations regarding: <ul style="list-style-type: none"> · Rules, visiting hours and blood donations. · General hospital information. ▪ Accommodation of patients in their rooms and information regarding bathroom, telephone and television services. ▪ Show patient the location of the corresponding nurse's station. ▪ Submit documentation to nursing personnel: patient chart, diet, check-in documentation, ID stickers and proof of delivery. ▪ In-patients coming through the emergency room on Sundays.
<p>EMERGENCY ROOM</p>	<p>This information point is responsible for undertaking very specific activities which are difficult owing to the nature of emergency room services. Communication techniques and skills take on prime importance at this service. Duties include:</p> <ul style="list-style-type: none"> ▪ Information: <ul style="list-style-type: none"> · General information regarding the hospital · On how to gain access to the different hospital services · On the rules of the different emergency rooms · In writing concerning the location of the hospitalised patient · By telephone to patients (not clinical) · By telephone to address doubts about the health-care system and its organisation · Regarding when a patient was released. ▪ Contact <ul style="list-style-type: none"> · Contact family members upon request ▪ Information regarding <ul style="list-style-type: none"> · access to patients' rooms · the different health-care documents needed for subsequent formalities ▪ Checks <ul style="list-style-type: none"> · of how often medical information is provided to those accompanying patients by means of an incident report. · of the ambulances arriving to the emergency room informing

	<p>whether the patient is accompanied or not and the name of the ambulance service.</p> <ul style="list-style-type: none"> ▪ Public announcement call to patient family members upon request. ▪ Undertake to keep family members and friends as calm as possible. ▪ Furnish the service information brochure and other information documents. ▪ Keep track of the movements of ER patients and those checked-in to hospital wards providing the latter with the toiletries kit and reception guide. ▪ Collaborate as needed in extraordinary catastrophic situations.
<p>GENERAL INFORMATION POINTS</p>	<p>These information points are responsible for the undertaking of general information and reception activities. They are located at hospital entrances and duties basically include:</p> <ul style="list-style-type: none"> ▪ General information regarding the hospital and attached centres. ▪ Specific information on: <ul style="list-style-type: none"> · General rules such as visiting hours · Hospital documentation · How to gain access to health-care services · Channelling of complaints, suggestions and claims. ▪ Clarifications regarding the health-care system and its organisation. ▪ Access and verification of appointments and tests.

→ **Conclusion**

The effort made by Madrid's San Carlos Clinic Hospital to adapt to new social realities is a sign of the progressive trend towards attention to diversity. Proof of this is the signing of collaboration agreements with the following private entities:

- **Universidad de Alcalá de Henares** for translation and interpretation services to help with information duties in work with the immigrant population.
- **Fundación Secretariado Gitano** for the undertaking of activities related to:
 - The training of personnel in aspects related to the Roma population.
 - The development of materials such as the "Reception Guide for Service Users" adapted to Roma families.
 - Formation of a specific team of professionals to support hospital personnel in interventions with Roma patients and their families.



These initiatives undertaken show that within the rigid structure of the public health system there are viable strategies which contribute to meeting specific needs relating to the diversity of cultural groups living in Spain. Actions such as these make the public health system stronger as a quality service belonging to and serving everyone.



5.2 Case Studies

Analysis of real cases appearing in the press

NEWS CLIPPING 1²⁶

Altercation at La Paz (Madrid hospital) over the death of a young Roma man

Nearly fifty member's of the man's family intended to take away the cadaver

Anti-riot police were called in to deal with the situation.

A brother of the deceased brandished a knife and suffered a fractured skull in the ensuing scuffle

On Tuesday the entrance to the intensive care unit of the La Paz hospital was the scene of a pitched battle between the family members of a recently deceased young man and several anti-riot police.

It all began at mid afternoon with the death (by natural causes) of a young Roma man who was a patient at the said hospital. After announcing the death of the man of approximately 30 years of age, family members who were waiting inside the hospital (approximately 50 according to police sources) insisted on taking away the body. Tempers flared to such a point that doctors decided to call hospital security forces who were unable to contain the "fury" of the large Roma family.

In the end, police officers from the Fuencarral-El Pardo precinct were not enough either and the anti-riot police had to be called in. (...).

It seems that this is not the first time that this particular family has caused altercations such as this. A fortnight ago, hospital security guard forces were bolstered owing to the aggression demonstrated by some family members.

According to the medical director at La Paz, the problems began back on the 7th when the deceased checked-in to the hospital's intensive care unit. "Family members brought blankets to sleep in the lobby and used the entrance way as a bathroom" affirmed the medical director who also said that on one occasion a hospital worker had been threatened. (...).

New security plan

The health councillor yesterday described the situation as "unfortunate" and stated that despite the fact that these are exceptional situations motivated by "care-based emotion," this does not justify violent and aggressive attitudes against health-care personnel and against the hospital itself "which belongs to all of Madrid's citizens".

He also spoke of the drafting of a security plan with a €9 million budget to guarantee the security of patients and health-care personnel at hospitals throughout the region.

²⁶ Source. ABC Newspaper, Madrid. Page 32, 22.01.04.



REACTIONS

S.A.E. (Auxiliary Nursing Staff)

Yesterday the trade union called for the implementation of a security plan for health-care providers to increase both the active and passive security of the personnel, the creation of a support unit for workers who suffer aggression in the line of duty and another focusing on legal counsel.

C.E.S.M (Physicians)

The main trade union representing doctors yesterday called on citizens to come to their senses and respect health-care providers. In the view of the trade union, these types of conflict situations are becoming more and more prevalent. It therefore “pleads” with all citizens to understand that the physicians are the first to do everything in their power to remedy each situation as it arises.

NEWS ANALYSIS

If we take a detailed look at the information transmitted in this news clipping we can see that it is possible to implement a number of different initiatives to prevent the emergence of conflicts of this nature.

We will now analyse the body of the news clipping focusing on the sentences and paragraphs that have been underscored because they contain the key ideas needed to address the resolution and prevention of situations such as these.

→ “After announcing the death of the man, they insisted on taking away the body”

The concept of death and the figure of the deceased is very relevant in Roma culture. When an event such as this takes place or it is thought that it could take place, the following **strategies** must be implemented:

- ⇒ Communicate this information to the most highly regarded members of the group.
- ⇒ Prepare the family beforehand of the news to come.
- ⇒ Demonstrate an attitude of understanding and respect towards expressions of pain.
- ⇒ Furnish information regarding the next steps which must be taken.

→ “This is not the first time that this particular family has caused altercations such as this.” “The problems began back on the 7th when the deceased checked-in to the hospital’s intensive care unit.”

In the case of an already existing conflict situation, steps must be taken so that the situation does not get any worse. The participation of an **intercultural mediator** (of Roma background) would help in terms of:

- ⇒ Understanding between health-care providers and the Roma family;
- ⇒ The family’s understanding hospital procedure and rules;



- ⇒ A feeling of greater security and trust on the part of the Roma family towards the hospital and its care providers.

→ **“Family members brought blankets to sleep in the lobby and used the entrance way as a bathroom.”**

- ⇒ Compliance with the rules governing the use of public places can also be addressed through mediation.
- ⇒ The preparation of suitable areas where extended family members can stay, especially in the case of long hospital stays, would be advisable to prevent the improper use of other areas.

REACTIONS:

→ **“He also spoke of the drafting of a security plan”**

→ **S.A.E. (Auxiliary Nursing Staff)** Yesterday the trade union called for the implementation of a security plan for health-care providers to increase both the active and passive security of the personnel, the creation of a support unit for workers who suffer aggression in the line of duty and another focusing on legal counsel.

→ **C.E.S.M (Physicians)** The main trade union representing doctors yesterday called on citizens to come to their senses and respect health-care providers.

The drafting of a security plan is not enough. Prevention plans need to be drawn up with a focus on potential conflict situations envisaging:

- ⇒ Reinforcement of guarantees in the provision of health-care services.
- ⇒ The exercise of citizens' rights.
- ⇒ Reinforcement of the service user reception and information functions assuring that users understand rules and uses with specific attention paid to ethnic and cultural minorities.
- ⇒ Awareness heightening of the society regarding the work of health-care providers.
- ⇒ Training of professionals in conflict resolution.



**QUESTIONNAIRE TO IDENTIFY PREJUDICES AND STEREOTYPES
REGARDING THE ROMA POPULATION**

Tick a response

GENERAL QUESTIONS

1. Your contact with the Roma population is:

- Habitual and frequent
- Sporadic
- Rare or inexistent

2. The motive for this contact is:

- Family related
- Professional
- Friendship

3. Are stereotypes concerning Roma true?

- If that's how people see them, there must be a good reason for it.
- They often hold true
- No, they're usually clichés based on ignorance

4. The Roma community is:

- Diverse and heterogeneous; a wide array of people
- Marginalized
- Socially maladapted



5. The Roma community originally came from:

- Andalusia
- Europe
- India

6. The complaints lodged by the Roma population in respect of the treatment they receive from the majority society are:

- Exaggerated
- Logical and justified
- An excuse

7. Do you think that the Roma population makes sufficient effort to integrate and get on with the majority society?

- They do everything they can but suffer from acute discrimination
- They could do more
- They don't want to integrate

8. What degree of responsibility do you think Roma people have in situations of discrimination?

- They are not at fault
- Sometimes they provoke these situations
- Their attitude is the cause of racism

9. Do you think that the image of Roma persons portrayed in the media is accurate?

- Always
- Sometimes
- Almost never



10. What is your definition of racism?

- Violent outbursts against people of another race, culture, religion, ideology, etc.
- Rejection or marginalization against people of another race, culture, religion, ideology, etc.
- Positive or negative opinions of other persons based on race, culture, religion, ideology, etc.

11. Do you think that the Roma population suffers from racism or class distinction?

- Racism; they are rejected based on the colour of their skin and because they belong to a culture other than the majority one
- Class distinction; a famous Roma person with money is accepted
- Neither of the two

12. What do you think is the real underlying situation of the Roma minority with respect to racism?

- It's a problem that has always existed and has no solution
- It's a problem which could be solved if we all made an effort
- It's not as serious as people make it out to be

QUESTIONS CONCERNING PROFESSIONAL CONTACT WITH THE ROMA POPULATION IN THE CONTEXT OF HEALTH-CARE

13. Do you think that conflicts in health-care services with the Roma population is a problem which:

- Is very important and is getting worse
- Occurs in certain situations
- Is not as serious as people make it out to be



14. When you have to deal with the Roma population in your work:

- You go on alert because they are potentially conflictive people
- You try to adapt your approach bearing cultural differences in mind
- You proceed in the exact same way as you would with any other patient

15. Do you think that specific initiatives should be implemented for the Roma population as regards health-care services?

- No, because they're the same as all other Spaniards and have the same rights
- Yes, they must be helped in order to eliminate the inequalities they suffer and should be supported in their integration process
- Yes, specific services should be set up exclusively for Roma people

16. Would you find it useful for your profession to know something about the Roma culture?

- I don't think the Roma culture is all that different from ours
- Yes, that would help me understand attitudes and behaviours of Roma persons
- Yes, and the same should be done for all of the ethnic and cultural minorities living in Spain.

17. The training received by health-care service providers in conflict resolution and prevention is:

- Very important in addressing potentially conflictive situations
- Only useful for security personnel
- An extra work burden

18. Communication skills:

- Have nothing to do with the health-care therapist / patient relationship
- Are a useful tool when it comes to providing care to the Roma population
- Are equally important for the Roma and the non-Roma population



19. Concerning health-care providers, Roma people:

- Think that it is our duty to do everything they want us to do
- Have unrealistically high expectations
- Never do what you tell them unless the situation is extremely urgent

20. The presence of extended Roma families at health-care centres, especially hospitals:

- Is the cause of many problems
- bears witness to an important cultural value and ways must be found to incorporate this into the health-care system organisation
- Is unnecessary and they must be made to understand the rules

21. Specifically attending to the needs of Roma:

- Implies that the same must be done with other minority groups and that attention to cultural diversity should be a transversal characteristic in health-care services
- Is impossible
- Would contribute nothing to making things better

22. When Roma people come to a health-care service for treatment, do you think:

- They feel distrust towards the institution
- They trust in the effectiveness of the service
- It depends on each specific case and on their previous experiences

23. The incorporation of a cultural diversity plan in the health-care system:

- Is not the responsibility of the health-care system
- Would help to improve care provided to people of other cultures
- Would not change anything



24. My professional experience with Roma has been:

- Good, normal
- Negative in some cases and normal in others
- A cause of stress in my work

25. Which of the following population groups presents the most problems in their relationship with health-care services?

- Roma persons
- South-Americans
- People from the Maghreb



6. BIBLIOGRAPHY

- Reference Document “Salud y Comunidad Gitana” (Health and the Roma Community). Fundación Secretariado Gitano-Ministry of Health and Consumer Affairs. 2003.
- Discriminación y Comunidad Gitana. Claves y Estrategias para la promoción de la Igualdad de Trato. (Discrimination and the Roma Community. Key issues and strategies for the promotion of equal treatment). Fundación Secretariado General Gitano, 2003.
- Evans, S. Stopping Places. University of Hertfordshire Press, UK, 1999.
- Gitanos y Discriminación. Un estudio transnacional (Roma and Discrimination. A Transnational Study). Fundación Secretariado General Gitano, 2002.
- Kenrick, D. The Romani World. A historical dictionary of the Gypsies. University of Hertfordshire, UK., 2004.
- Manual de Atención Sanitaria a Inmigrantes (A Manual for the Provision of Health-care to Immigrants). 2nd edition. Department of Health. Government of Andalusia, 2004.
- Manual de Orientación Sociosanitaria para los inmigrantes de la Comunidad de Madrid (Social-health Guidelines Manual targeting immigrants in the Community of Madrid). Public Health Institute of the Community of Madrid. Department of Health, 2003.
- Plan de Calidad Integral de los Servicios Sanitarios de la Comunidad de Madrid (Integrated Health-care Services Quality Plan of the Community of Madrid). Department of Health of the Community of Madrid. 2003.
- Order 212/2004 of 4 March of the Department of Health and Consumer Affairs laying down the guidelines and general parameters for the drafting of prevention and care plans to address possible conflict situations in public health-care institutions and creating the central monitoring commission. Department of Health and Consumer Affairs of the Community of Madrid B.O.C.M (Official Gazette of the Community of Madrid) No 63.
- The role of the Healthcare Sector in Tackling Poverty and social Exclusion in Europe. European Health Management Association. December 2004.
- The Situation of Roma in an Enlarged European Union. Directorate General for Employment and Social Affairs. Unit D. European Commission. December 2004.

