East European Roma Health Awareness Guide

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The East European Roma Health Awareness Guide provides essential information about Roma health in the context of history, culture and tradition. It aims to help health professionals engage with Roma families in a positive way, while also acknowledging that the Roma are a diverse group and that no one engagement strategy will be applicable to all patient-practitioner relationships. This guide gives special attention to the impact of culture, tradition and communication on health-related behaviours and use of services, providing a framework for identifying culturally sensitive methods for providing services to Roma individuals.

Contents

Introduction

This East European Roma Health Awareness Guide provides information about Roma history, culture and tradition, and aims to help health professionals engage with Roma families in a positive way. While this guide seeks to offer a multi-dimensional look at Roma culture, it is important to acknowledge that Roma community is very diverse and that it is impossible to describe all aspects of culture and tradition within this guide. The information provided should thus be used as a starting point in a learning process about this diverse community.

Effectively providing services for the Roma can be challenging within the framework of cultural differences and language barriers. Cultural conceptions of health and medical treatment may contribute to reluctance to use certain services, and limited knowledge of English may create problems in understanding health-related communications. It is also important to consider that the Roma have a long history of discrimination, and some may feel mistrust toward professionals.

This guide provides an overview of Roma health in the context of history and culture, and furthermore offers practical recommendations for engagement with Roma communities in your area. Throughout the guide, we give examples of situations you may encounter in your work with Roma, focusing on the issues of communication and methods for ensuring that your practice aligns with cultural values and expectations.

As you read this guide, consider:

- How the history of discrimination against Roma impacts their day-to-day behaviour
- How other socio-cultural factors (such as housing, education and employment) may affect health, health-related behaviour and use of services
- How Roma cultural traditions may impact their health-related behaviours
- How Roma service users may respond to your methods for communicating health information
- Which methods could be employed to facilitate communication across language barriers

History

The Roma left north-west India approximately 1000 years ago and went on to travel through Asia, North Africa, Europe and eventually the Americas. Since the 15th century, Romani groups have migrated to most countries in Europe. Some are – and have always been – settled and lived in permanent camps or housing, while others carried on their travelling lifestyle. Today, the European Roma in the UK predominantly live in permanent housing, and less than 20% of Roma throughout Europe are currently nomadic (European Commission, 2014).

Historical timeline

1100s - 1200s Romani language emerges among Indian emigrants in Anatolia and the Balkans. They include groups with a commercial-nomadic tradition and possibly mercenary soldiers.

1300s Roma begin to arrive in Europe beyond the Ottoman borders and are enslaved, especially in the Christian fringes of the Ottoman Empire in south-east Europe.

1530 The first laws expelling Roma from England, as well as strong anti-vagrancy laws, are introduced under Henry VIII.

1554 Queen Mary of England passes the Egyptians Act, which states that being a Gypsy is punishable by death. This act remained in place up until 1780, and follows a trend of legally mandated genocide throughout Western Europe.

1783 H.M.G. Grellmann's*Die Zigeuner* begins to apply European racism systematically to Roma.

1933 - 45 Figures from the US Holocaust Memorial Research Institute put the number of Roma lives lost at between 500,000 and 1.5 million.

1960s The few remaining nomadic Roma are forcibly settled in Eastern European countries. Intergroup tensions and lack of access to resources resulting from this forced settlement have had long ranging impacts on Roma communities.

1971 The First World Romani Congress is held in London, during which an international Romani flag, motto (***Opré Roma***- *Roma Arise*) and Anthem (***Gelem, Gelem***) are formally approved.

1989 Fall of socialism and migration of Roma from Eastern Europe towards the West. Many Roma fall deeper into poverty (Fesus et al., 2012).

2008 Gypsy Roma Traveller History Month,taking place in June, is established in the UK.[1]

[1] GRTHM started as a local initiative in LB of Brent. In 2008 DCSF awarded funding for the initiative to become a national event.

Population and Demographics

The Roma are the largest ethnic minority in Europe, and studies from across Europe report them to be among the most vulnerable and marginalised. UNICEF characterises the European Roma population as a young, fast-growing group comprised of approximately 10-12 million people and concentrated primarily in Central and South Eastern Europe (EU Agency for Fundamental Rights, 2012). The countries with the largest Roma populations are Bulgaria, Hungary, Romania, Serbia, Slovakia and Macedonia, with smaller, yet still sizeable, populations in the Czech Republic and Poland (UNICEF, 2010).

There are no official statistical data about Roma in the UK. This is partially attributable to the fact that the Roma do not constitute a nationality and may be reluctant to self-identify as Roma out of fear of discrimination. For these reasons, collecting reliable ethnic data on the Roma is difficult (Craig, 2011). Estimates of the number of Roma in the UK vary from 200,000 (not including the Gypsy and Traveller population, which is estimated to be between 200,000 and 300,000) to 1 million (Brown, Scullion & Martin, 2013; European Dialogue, 2009). The 200,000 estimate comes from a 2012 survey of local authorities conducted by researchers at the University of Salford, and is considered to be a conservative estimate (Brown, Scullion & Martin, 2013).

The majority of Roma in the UK come from Romania, Slovakia, Czech Republic and Poland, with smaller populations from Hungary, Latvia and Lithuania. Settlement patterns are generally based on family networks, prior knowledge of an area or access to accommodation (Brown, Scullion & Martin, 2013).

Although the literature often associates European Roma with Gypsies and Travellers, they in fact represent distinct groups with different history, culture and traditions.Unlike Irish Travellers, the European Roma and English Gypsies share a common ethnic origin, yet centuries of geographical separation have given rise to different cultural traditions. Most notably, English Gypsies adhere much more strongly to the tradition of travelling, while the Roma tend to live in permanent accommodation (Craig, 2011).

The abandonment of the travelling lifestyle among the Roma has its origins in the Communist period in Eastern Europe, during which Roma populations were forcibly settled, often in areas lacking access to basic services. By restricting their ability to seek out better living conditions or employment, this forced settlement prevented the Roma from improving their socioeconomic position and heightened tensions between the Roma and other local groups. This in turn gave rise to a cycle of poverty, marginalisation and discrimination, which served as significant push factors driving the migration of Roma to Western Europe in the late 20th and early 21st centuries (European Dialogue, 2009).

Social Position and its Effects

The Roma identity is highly stigmatised in countries throughout Europe. Roma individuals are frequently denied access to public services, placed in segregated schools and restricted from many types of employment on the basis of ethnic identity. They are often forced to live in substandard, overcrowded accommodation, and many governments neglect infrastructure in predominantly Roma areas (Council of Europe, 2012).

Main non-health related concerns and problems experienced by the Roma Mental Health Advocacy Project's service users (2008-12, London, RSG)	
Concern/problem	**Percentage of service users***
Poor housing conditions and other housing problems	48%
No/very low income	35%
Debts	29%
Other family members with severe illness	26%
Welfare benefits issues	23%
Incapable of work	14.5%
Dependency on family	11%

Discrimination impacts all aspects of life in Roma communities. In the case of health, for example, social marginalisation not only limits Roma community members' use of health services, but can also discourage them from seeking out housing improvements or pursuing educational opportunities, both of which can have serious and long-term health impacts. Occupying a disadvantaged social position can thus influence health in a variety of ways, as is reflected in a statement from the European Commission:

> 'The WHO Commission on Social Determinants of Health (CSDH) regards processes of social exclusion as the major cause of health inequalities among migrants and ethnic minorities. It must also be observed that in this context health is a holistic concept. It is not considered only as health care, but it also includes disease prevention, health promotion and efforts to address concerns in the wide range of health areas – i.e. nutrition, physical activities, alcohol, and tobacco – as well as in other policy sectors - i.e. employment, housing and environment' (European Commission, 2014).

Under this model of health as a 'holistic concept,' health status is associated not only with physical and mental wellbeing, but also with access to suitable housing, education and employment. Poor

housing and environmental conditions can contribute to physical health problems, and can also lead to feelings of anxiety, depression and shame as a result of living in an isolated or dangerous environment. Knowledge that a person lives in an area with a large Roma population may, in turn, heighten discriminatory practices by employers and educators. When Roma individuals are unable to access education, they are less likely to gain the skills for understanding communications from health professionals (Rechel et al., 2009).This may then lead to the development of health problems that prevent Roma individuals from keeping their jobs or seeking out employment.

Although the above example describes only a subset of the consequences that can arise from poor housing, education, employment and health status, it nonetheless reveal show disadvantage in any one area can quickly produce a complex and interconnected set of barriers to social inclusion and participation. When working with Roma patients, it is vital to consider the full range of challenges that service users may be facing in their daily lives and to acknowledge that problems in one area likely have wider reaching effects than is outwardly apparent.

European Policy Context

In response to discrimination against Roma, the EU has issued directives and guidelines aimed at increasing access to public services in Roma communities. This is in line with the EU Charter of Fundamental Rights, which prohibits discrimination on the basis of ethnicity or social origin (EU Agency for Fundamental Rights). Responding to the prevalence of discriminatory treatment of Roma populations, the European Commission issued a communication in 2011 that called for improvements in access to education, employment, healthcare and housing by 2020. Although the European Commission makes recommendations for developing National Roma Integration Strategies and evaluates progress, Member States have primary responsibility for developing and implementing action plans.

Due to a lack of firm targets and guidelines for increasing Roma integration, however, there is substantial variation in national strategies. In the case of health policy, some countries have introduced health mediator programmes and additional training for health professionals in Roma-specific issues. Other countries have made little effort to institute specific programmes for addressing the Roma health situation, stating the mainstream policies are sufficient for addressing Roma health (European Commission, 2014).

UK Policy Context

In the case of the UK, the Human Rights Act 2000, the Race Relations (Amendment) Act 2000 and the Equality Act 2010 make general provisions for promoting and upholding the rights of minority groups, yet they do not specifically address the situation of the Roma (Brown, Scullion & Martin, 2013; European Dialogue, 2009). National health policy furthermore offers no direct guidelines for

improving health service provision to Roma communities, despite the fact that the Roma have routinely poorer health status and access to services (Craig, 2011; Tobi, Sheridan &Lais, 2010).

Recent health policy developments have instituted changes in the monitoring of local need and the development of service provision strategies. Under the Health and Social Care Act of 2012,local authorities take on greater responsibility for assessment of need and commissioning of services. At the centre of service development are health and wellbeing boards consisting of local commissioners, elected representatives and representatives of Health watch. They monitor local health and wellbeing to produce joint strategic needs assessments (JSNAs), which outline areas of health inequality and inform the development of joint health and wellbeing strategies. These strategies identify areas for action in improving health outcomes and set targets for community health promotion activities. Commissioning of NHS services falls to clinical commissioning groups, consisting of GPs and other clinicians, with resources allocated through the national NHS Commissioning Board(Department of Health, 2011).

As there is no mechanism for monitoring provision of services to Roma communities, local policies differ quite substantially. Some local areas (including Haringey, Cambridgeshire, Cumbria, Surrey, Central Bedfordshire, Kent, Hampshire, Suffolk and Norfolk) have JSNA chapters devoted specifically to Gypsy, Roma and Traveller populations. Others mention GRT health in broader discussions of the health status of marginalised groups, yet do not provide detailed discussions of the issues specific to these groups (Friends Families and Travellers, 2015). In some areas with known Roma populations, however, JSNAs do not mention Gypsy, Roma and Traveller health.

These local disparities point to the need to be particularly aware of local policy when providing services to Roma individuals. Levels of support for Roma communities vary from area to area, and a good understanding of local service provision can help to ensure that you are able to make appropriate referrals. When recommending services to your Roma patients, it is important to remember that Roma community members value realistic commitments to action on their behalf. Following up on referrals and promising action only when you know that you will be able to deliver on these promises can thus help to build respect and trust within the Roma community.

Roma Health Status in a European Context

Research on Roma health across Europe suggests that the Roma have poorer overall health than any other group, with life expectancies between 5 and 20 years lower than the majority population, higher infant mortality rates, higher prevalence of communicable disease and lower childhood immunisation rates (European Commission, 2014). In Spain, Hungary, Slovakia, England, Sweden, Greece and Serbia, the Roma report lower self-rated health status in comparison with the majority population (Cook et al., 2013).Poorer health status can be attributed to a range of factors, including substandard living conditions, lack of health-related information and limited access to health services. Limited access furthermore encompasses a complex, intersection set of social, economic

and cultural factors, all of which play varying roles in shaping health service use in Roma communities.

A survey conducted jointly by the EU Agency for Fundamental Rights and the UN Development Programme found that:

- One third of Roma respondents aged 35 to 54 reported health problems limiting their daily activities. (2011)
- Approximately 20 per cent of Roma respondents were not covered by medical insurance or did not know if they were covered. (2011)
- 66 per cent of Roma said they could not afford prescription drugs compared to 29 per cent of the majority population. (2004)
- 15 per cent of Roma children under the age of 14 are not vaccinated compared to four per cent of children from non-Roma households. (2004)

Access to care can be defined as provision of services in line with users' actual needs, yet in many cases the precise needs of Roma communities, as well as the best methods for addressing these needs, remain largely unknown (Rechel et al., 2009).International differences in health system utilisation suggest differences in services users' understanding of health systems. In England, for example, Roma are less likely to access specialist services and are less likely to be registered with a GP, which could be indicative of a lack of understanding of available services or appropriateness of services to particular health problems, as well as communication issues with service providers (Cook et al., 2013).

The European Commission highlights a set of common barriers to health care, including:

- Language and literacy
- Lack of knowledge of health systems
- Discrimination in health professionals
- Lack of trust in health professionals
- Physical barriers – mobility and distance
- Lack of identification and/or insurance

These factors can be divided broadly into two categories: barriers resulting from the structure of health systems and the nature of health policies, and those resulting from a wider set of sociocultural factors.

Systemic factors

One of the most common barriers to health care access is the lack of the proper identity documents required to register with health services or receive insurance coverage. According to a 2004 UN Development Programme survey of European Roma, 8% of Roma patients were denied medical services due to their inability to produce acceptable proof of identity, compared to 3% of the overall

population (United Nations Development Programme, 2014). Even when Roma are able to register with health systems, they may be unable to use necessary services due to the cost of insurance. While this is not the case in all countries, lack of funds for insurance can serve as a significant barrier to health care access (Kuehlbrandt et al., 2014).

Lack of understanding of health systems may also limit health service use. When Roma service users are unfamiliar with health system bureaucracy and procedures for making referrals, they may not feel confident in seeking out care or following up on health professionals' recommendations.

Sociocultural factors

While institutional barriers to health care access can have a substantial impact on Roma health outcomes, they account for only a fraction of the reasons for poorer health and limited service use in Roma communities. The European Commission emphasises how 'living conditions, health perceptions and behaviour, limited inclusion in prevention programmes such as immunisation programmes, and entrenched discrimination' have a pronounced impact on health and quality of life in Roma communities(2014).

In the case of housing, poorer access to quality accommodation can give rise to a complex and interconnected set of challenges to access to services and the maintenance of good health. Substandard accommodation and overcrowding can directly exacerbate health problems, and can furthermore increase anxiety levels. Additionally, the frequently isolated and segregated nature of Roma settlements can create physical barriers to service access (Council of Europe, 2012). Reaching areas where services are available can be expensive and time-consuming, especially when there is no provision for public transport.

Education and information can also have a substantial impact on Roma health. Roma individuals, many of whom are migrants, may not be aware of which services are available in receiving countries or how to access specialist services.In addition to a lack of health-related knowledge and information, the Roma often face barriers to educational attainment, which can create difficulties in understanding complex medical terminology and written communications from service providers.

Issues of poverty, discrimination and marginalisation lie at the heart of common barriers to health care access. It is important to be sensitive to the wider context of your Roma patients' experience of accessing health services and to understand that a wide array of interconnected factors likely influence their health seeking behaviours. In some cases this may involve gathering information on your patients' living situations, education levels and past experiences of discrimination and adjusting your care strategies accordingly. See the final section of this guide ('Examples of Positive Engagement') for examples of successful support and outreach strategies.

Roma Health Status in a UK Context

While Europe-wide research on Roma health status is in many cases applicable to the UK Roma population, reports on the national situation reveal a unique set of challenges to identifying and reaching out to Roma communities. The exact size of the UK Roma population is unknown, and the Roma tend to exhibit low levels of engagement with local services. These issues of identification, combined with reported high levels of mobility, make it very difficult to assess the precise needs of the Roma in the UK (Brown, Scullion & Martin, 2013).

RSG casework suggests that Roma individuals in the UK encounter difficulties in accessing health services due to lack of documentation or lack of understanding of health system procedures. There have been situations in which Roma families have been unable to register with GPs because they were unable to provide official documents, including proof of address and children's immunisation records. In other cases, Roma families have been unsuccessful in registering with a GP because their nearest surgery was not accepting new patients, yet they did not understand that it was possible to register with a different surgery.

In terms of health issues, much of the research on theUK Roma population describes their health status in conjunction with that of Gypsies and Travellers.While these groups are culturally distinct, Gypsies, Roma and Travellers do exhibit certain similarities in health status, including:

- Higher rates of long-term illness, health problem or disability (European Commission, 2014; Parry et al., 2004)
- More problems with anxiety and depression (European Commission, 2014; Parry et al., 2004)
- Evidence of lower childhood vaccination rates, although these studies are too small in scale to be representative (European Commission, 2014)

Although these trends point to common challenges in accessing appropriate health services, general statements regarding Gypsy, Roma and Traveller health may oversimplify the unique challenges that each group encounters in interacting with health service providers. In the case of the Roma, their language, culture and length of residency in the UK differs from those of Gypsies and Travellers, making language barriers and lack of prior experience in UK health systems important factors in determining the ease with which they are able to access services. The next sections of this guide will provide an in-depth discussion of the impact of language and culture on health-related behaviours and use of services, as well as practical suggestions for addressing issues arising from communication barriers between Roma individuals and health care providers.

Language and Communication

Background

Most Roma speak a dialect of Romanes as their first language, and many later learn the language of their countries of origin. There are many dialects of Romanes, and although some are mutually intelligible, others are so different as to essentially constitute different languages. In addition to Romanes, many Roma also speak the language of their country of origin and are comfortable in carrying out conversation in this language. It is important to pay close attention to which language a Roma individual speaks and to ensure that communications are carried out in this language in as many cases as possible.

Communication basics

Direct and clear communication is highly valued in Roma culture. When speaking with Roma service users, it is very important to explicitly state what you are trying to accomplish through your work and what you intend the outcomes to be. Establishing and maintaining trust furthermore requires that you follow up on any referrals you may make. It is advisable not to promise to take action unless you are certain that you will be able to follow through.

In addition to these methods for building trust, there are other small steps you can take to show respect for Roma community members. It is important to make and maintain eye contact, and to avoid referring too frequently to notes or looking at a computer screen. Furthermore, there are various rules within Roma culture regarding appropriate clothing. Although you will not be expected to follow these rules, it is best to dress modestly when providing services in Roma communities.

Working with interpreters

In your work with Roma, it is likely that you will encounter individuals who do not speak English. One method for addressing this communication barrier is to employ an interpreter.

Working with interpreters is often essential in preventing miscommunication with Roma service users, yet it is always best to ask which language they are most comfortable using before requesting interpreter services. In assessments of children's language skills, for example, there have been cases in which evaluations were carried out in the national language of the parents' home country, but not Romanes, which was the only language spoken in the children's homes. This led to their incorrect placement in classes for children with learning disabilities. Such assessments would be best facilitated by interpreters and carried out in the first language of the child, and if no qualified interpreters are available, community members could be asked to provide interpretation services instead. In such cases, professionals can seek help through public or private agencies that offer interpreting services. Roma community organisations may also be able to recommend Roma people who speak fluent English.

As this example demonstrates, the decision to use interpreters can appear straightforward , yet it often proves to be a challenge in itself.

The key issues professionals should consider when working with interpreters are:

1. Linguistic problems and miscommunication

You may encounter Roma individuals who have received little formal schooling, and who therefore may have difficulties understanding health-related language, even when it is translated into their language. Data gathered in the UK and other European countries shows that the Roma community has the lowest educational achievement rates. This is due partly to institutional discrimination and partly to the perceived irrelevance of formal schooling to the Roma lifestyle (Department for

Education, 2010). In addition, there are still significant numbers of Roma who are either illiterate or semi-illiterate.

Case Study: Literacy and understanding

Anna, 56, was referred to psychological services and given the mental health related form to fill in at home. She asked for help from a person who spoke the same language as her. When this person was trying to explain the questions, it became clear that she did not understand the questions or the context. If she were to answer these questions in a health setting she would not have confidence to admit that she did not understand the questions (even when translated).

Low educational attainment rates and limited contact with public services has a great impact on the vocabulary of the members of the Roma community and the understanding of health-related concepts. As a result, certain forms of health communication – such as letters and text message reminders – may be ineffective in reaching Roma community members. There may also be situations in which certain health terminologies may be difficult to accurately translate into service users' languages. The word 'assessment,' for example, may be understood by some Roma to be equivalent with the term 'judgement.'

Therefore, professionals working with Roma families should be aware that many common terms and concepts – such as parenting mentoring, assessment, care plan, etc. – may need to be explained or rephrased in order to avoid any misunderstandings. It is important to consistently pay attention to Roma patients' reactions to your word choice and health advice and to explain concepts differently if service users seem confused or upset. In many cases, the most straightforward way to address this problem is to ask patients how they interpret what you are saying and to clarify in case of misunderstanding.

Case Study: Miscommunication

A Roma couple referred to Children's Services was offered parenting mentoring. They refused to attend and by doing so were seen as failing to engage with the services. Roma Support Group was commissioned to offer advice and guidance, and to assist Children's Services in improving engagement with the family.

With the help of a Roma community member, we found that the reason the couple had refused the classes was that they thought parenting mentoring meant sexual education, and they were not interested in having more children.

Because of the cultural taboos related to certain life aspects (especially health), members of the Roma community also lack vocabulary related to certain emotions, body parts and illnesses. This can make diagnosis difficult. If you suspect that Roma patients do not know the words to fully explain their health issues, it may be best to adopt non-verbal strategies for conveying information.

2. Lack of Roma interpreters

Professionals should be aware that there are relatively few qualified interpreters in the Romanes language. For this reason, it is common to use interpreters who speak a Roma patient's second (or even third) language. In some cases, Roma may view non-Roma with distrust, but the lack of qualified Roma interpreters often necessitates the use of non-Roma interpreters.

To ensure a comfortable and productive consultation when using a non-Roma interpreter, it may be helpful to brief the interpreter on key issues in Roma health communication (i.e. the taboo subjects and the importance of simple language, which will be discussed in the next section of this guide) before meeting with the patient. This will help to ensure that non-Roma interpreters show respect for Roma culture and that they furthermore understand that Roma may not have the vocabulary to discuss certain health-related concepts and emotions.

When working with non-Roma interpreters, you should be aware of the fact that they may use a vocabulary that Roma patients could find confusing. It is thus helpful to explain the need for jargon-free language and, if necessary, outline strategies for explaining relevant health concepts. To further ensure that patients find your (and your interpreter's) communication to be clear and straightforward, it may also be necessary to repeat key points and check for understanding at the end of the consultation.

Due to the complexity of issues related to interpretation, Roma Support Group has designed training, *Working with Roma families through interpreters,* which further explores the challenges raised by linguistic barriers and cultural customs when working with Roma communities. More information is available from our website: romasupportgroup.org.uk.

Culture, Traditions and Taboos

Overview of purity laws and health taboos

When working with the Roma, it is important to remember that there are many cultural taboos that may influence their health-related behaviours and use of services. Although treatment of taboo subjects will vary from one person to another – with some adhering more strongly than others to traditional Roma culture – it is important to actively demonstrate respect for Roma beliefs when providing health services. As a general rule, a good way to show respect is to directly ask Roma service users what they expect from you.

Some of the most significant health taboos involve public discussion of sexual and mental health issues. This guide contains an overview of potential barriers to communication about sexual and mental health, as well as examples of successful engagement with Roma in these contexts. Furthermore, there are specific expectations related to appropriate treatment of terminal disease and end of life care.

Mental health

Mental health is considered a greater taboo than any other health problem, and for this reason it is very rarely discussed amongst the Roma. Often when talking about mental health Roma talk about being sad, feeling down and having a specific problem in their life; in situations like that it is acceptable to say that someone is depressed.

The Roma sometimes describe mental health issues as 'problems with the head' or 'being crazy' rather than recognising and naming mental health conditions. Some people will not be reluctant to talk about their mental health in front of others, but usually not in front of other Roma. The situation is changing amongst the young people who are more aware of various mental health problems but still reluctant to discuss them.

There is strong belief that mental health problems can be passed on genetically. This can jeopardise the prospect of marriage for the sufferer, as well as other family members, making mental health one of the most hidden and shameful issues in the community.

Based on the findings of the Roma Mental Health Advocacy Project[2], we know that the main mental health issues affecting migrant Roma communities in London are:

[2] The three-year Mental Health Advocacy Project funded by The King's Fund run by the Roma Support Group from 2008 to 2011. The research evaluation report was published in April 2012 and is available on the Roma Support Group's website.

Breakdown of all the mental health problems listed by the Roma Mental Health Advocacy project's service users and percentage of service users who suffered from them	
Mental health problem	**Percentage of service users**
Organic, including symptomatic, mental disorders due to brain damage	**1%**
Substance-related disorders (alcohol dependency)	**6%**
Schizophrenia and other psychotic disorders psychosis paranoid schizophrenia schizophrenia	**11%** 3% 2% 7%
Mood disorders Bipolar Disorder Depression	**61 %** 1% 61%
Anxiety disorders Anxiety (includes co-morbid anxiety: 2%) Panic attacks Posttraumatic stress disorder	**19 %** 11% 7% 2%
Disorders usually first diagnosed in infancy, childhood, or adolescence Autism Behavioural issues Emotional difficulties Learning disability	**17%** 4% 2% 2% 9%
Other mental health problems Suicidal thoughts and attempts Self-harm	**4%** 3% 1%

Accessing services

Often Roma try to hide the fact that they are suffering from mental health problems from their family and other community members. Once the family knows, they might also endeavour to hide the problem from others. This often creates a long delay in seeking medical help. In some cases health professionals are approached only when family members are no longer able to cope with the situation. Delays in seeking help may also result from a significant lack of knowledge amongst Eastern European Roma migrants about mental health services in the UK.

Even when Roma do use mental health services, theyare often afraid to disclose full details of their condition to mental health professionals. In our case work we often heard that professionals were not told about certain symptoms (e.g. hearing voices)out of a fear that it would lead to sectioning and forcible treatment in a mental health institution. Most of the service users who accessed the Roma Mental Health Advocacy Project were referred to appropriate medical services. However, they often had problems in accessing additional support, including social services, as illustrated in the table below:

Types of treatment/combination of treatments and other support offered to the Mental Health Advocacy Project's Roma service users in relation to their mental health problems*	
Type of treatment or combination of treatments offered	**Percentage of service users**
Medication	47%
Counselling	3%
Counselling and medication	10%
Counselling and education support	1%
Counselling, medication and self-help group	1%
Counselling, medication and special education support	1%
Medication and hospitalisation/mental health clinic	4%
Medication and social care services support	3%
Medication, hospitalisation, social care services support,	4%
Medication and other therapy (includes: psychotherapy 1, psychological care 1,	9%

psychiatric care 3)	
Medication, psychiatric care, special education and social care services support	1%
Medication and neurological treatment	1%
Psychiatric treatment	1%
Special education	1%
Speech therapy	1%

*Data as provided by service users, we were not always able to confirm it with mental health professionals or medical reports

Working with Roma affected by mental health problems

When working with Roma with mental health problems and their families, professionals need to make sure that Roma service users understand that all mental health information will be kept confidential and only passed on to third parties if the user agrees or if it has impact on others.

It is always important to make sure that Roma understand what is happening to them, the role and remit of work of the professional is to avoid misunderstandings. Professional jargon should be avoided when communicating.

Professionals should also ensure that Roma service users have a good understanding of the mental health problem they or family members are suffering from, as well as the long term prognosis/treatment. A diagnosis of autism in a child could, for example, create challenges for parents in effectively engaging with services, as they may not understand the nature of the condition, long-term prognosis, coping strategies and the services available to them.

It is also important to invest time, listen to the families' needs carefully and, where appropriate, be responsive to those needs (this could include providing more information about services, mental health problems, homelessness, debt, welfare problems, education, employment, etc.) in order to gain their trust. Once the trust is established, it is much easier to engage the families and address specific issues.

Gender

In traditional Roma culture, there are clear gender divisions in terms of responsibility within the family and appropriate social conduct. Women are traditionally in charge of cooking, cleaning and generally maintaining the household, whereas men are responsible for making a living outside the household. Both men and women take care of children, and responsibility for childcare often falls not only to parents but also to the extended family group (Matras).

There are specific rules related to women, many of which are associated with cultural conceptions of cleanliness. Some Roma, for example, will not wash men's and women's clothes together in order to avoid contamination. Women are furthermore considered unclean for one month after giving birth, which can influence their decision to seek out post-natal care.

Gender-related issues may arise in a health context when health problems are associated with sexual health, or even simply the lower half of the body. In these cases Roma patients may be unwilling to discuss symptoms with a health professional of the other gender, thus increasing the likelihood of misdiagnosis. Although the situation may vary based on the nature of the health problem, it is generally advisable to make sure that any consultations involving the middle and lower regions of the body only take place between Roma individuals, health professionals and interpreters of the same gender.

Case study: Family Interpreters and Gender Taboos

Eva, a 47-year-old Polish Roma woman, went to her GP with abdominal pains. Due to the lack of professional interpreters, she was asked to bring her own interpreter. The only person available was her adult son. Gender taboos prevented her from discussing the exact nature of her symptoms in front of him, and her health problem went undiagnosed. She eventually went to A&E, and it was found that she had cervical cancer. She died within three weeks.

Age

The Roma have a set of cultural rules related to age that may not be initially apparent to outsiders, yet can nonetheless have a significant impact on use of health services and disclosure of problems.

Case study: Health screening

A women's health screening took place after a dance class for Roma women aged 20-65. Although the women were informed in advance that the screening would take place and all health professionals were female, the mood in the group abruptly changed when the class ended and the screening began. The women were very uncomfortable and unwilling to discuss health-related concerns.

A Roma community member then explained that the age differences between the women in the group made it inappropriate context for discussing health matters.

When hosting group discussions of health issues, it is important to make sure that there is no more than a 10-year age difference between group members. It is also important to remember – particularly when family members are serving as interpreters – that it may not be possible to discuss

issues related to sexual health and certain areas of the body with people of different ages. In these cases it may be advisable to seek out a different interpreter or attempt to communicate directly with the person in need of care.

Working with elderly Roma

Elderly Roma are highly valued and respected members of the Roma community. They enjoy a great level of influence within their families and are often approached for advice and guidance.

Elderly Roma are most commonly supported and looked after by their families and Roma take great pride in this element of their culture.

"Our parents take care of us when we are children. We take care of them when they are old. This is like law for us. If somebody sends an elderly parent into a care home, other Roma disapprove of this action. Only in rare occasions, such as difficult mental health problems, elderly are placed in an appropriate care home but their children still visit them regularly."

- Roma Support Group client

Only a small number of the Roma Support Group's clients place their elderly in care homes. When this does occur, the most common reasons are either complex medical needs that cannot be met at home (such as difficult mental health conditions, dangerous or exceptionally challenging behaviour) or poverty. However, most Roma would prefer to look after their elderly themselves and would welcome medical staff at their homes, if needed.Research on this topic confirms this view:

'There is clear evidence of a wish for older/disabled people to remain living in their own cultural/community environment through the use of carers/support and adaptations where possible' (Greenfields & Lowe, 2013).

In addition, Roma Support Group's clients felt anxious about using day care centres/respite centres. They felt that change of care could be upsetting for elderly Roma and were also worried that if something happened they would not be able to be next to the elderly Roma person.

As was mentioned earlier in this guide, there are many taboos around gender and they are particularly important in health context. For instance, a mother can look after her husband or son but not after her father in law or her father.

When asked how medical professionals and social workers could engage positively with elderly Roma and their families, most of the Roma Support Group's clients stressed the importance of working with the whole family, i.e. be led by them, involve them in making decisions and ask for their suggestions regarding involvement.

When speaking to Roma about placing elderly in care homes, it is important to provide a lot of reassurance and in-depth information. Most Roma we consulted on this topic felt uncomfortable about this option and said they would be frightened of professionals offering them this service. This option appears to be in conflict with their cultural beliefs and they struggled to understand how

elderly Roma or their families would benefit from this service. For this reason, involuntary placement of elderly Roma into care homes could potentially have a negative impact on their mental health.

Cancer and terminal illness

Most Roma are fearful of serious illness and death and avoid discussing serious illness, especially cancer and dying. There is no clear consensus about diagnosis disclosure. Some Roma prefer to know full diagnosis in order to prepare themselves for the end of life. Others prefer that terminal diagnosis is not disclosed to a person in question, in order to protect them from distress and enable them to remain hopeful about their recovery.

There is a general lack of awareness about cancer, its symptoms and nature of its treatment. In addition, some Roma also have beliefs and misconceptions related to cancer. For instance, many of our clients believe that cancer can "get angry" if touched (through biopsy, surgery, radio therapy or chemotherapy or any other treatment). In the only qualitative study of Gypsy/Traveller bereavement care and end of life experience,Jesper recorded similar understanding about effectiveness of various cancer treatments:

'But there is a certain cancer once it's touched (operated on), you can die with it… But if you don't tamper with it, if you don't put a knife to cancer it cannot bust or it can't grow. I do believe in that and a lot of the Gypsy people believe not to touch a cancer' (Jesper, Griffiths & Smith, 2008).

For this reason, some Roma delay discussing symptoms or seeking help and usually approach medical services when the illness is at a very advanced stage. The treatment is then likely to be unsuccessful, thereby confirming their belief about the treatment.

End of life care

Most Roma prefer spending their last days of life at home, with their families. Immediate and extended family members would visit the dying person on a daily basis; this could amount to 30-40 people. Some of the family members stay with the dying person throughout day and night. Very important dying rituals take place during this time which enables the dying person to 'depart calmly.'

Despite the desire to die at home, there are cases in which end of life care occurs in a hospital or care home. As health care providers may not be accustomed to dealing with large numbers of visitors in the context of end of life care, traditional dying rituals may create tensions with health service staff (Jesper, Griffiths & Smith, 2008).

When asked how hospital staff could improve their services in order to cater more sensitively for Roma, Roma community members we consulted suggested the following:

- Hospital staff should be more understanding about family members visiting the ill person.

- Hospital staff should offer prayer room facilities to Roma families, as many Roma organise prayer sessions, including priests and pastors.
- Family members prefer to take the deceased person home for a wake.
- Identifying key people in the family and providing clear and jargon-free information can help health care staff and Roma families to cope.
- Hospital staff should be aware that older Roma patients might feel threatened in a hospital/hospice setting, in part because many of them might be illiterate and are sometimes reluctant to admit this. Therefore, assistance should be offered with reading medical material, ordering food and any other issues which require literacy skills.

Drug addiction and substance (mis) use

There is very little published information about drug use within the Roma community, with no official statistics on drug prevalence or the nature and extent of problematic drug use. Despite anecdotal evidence that this problem is rapidly increasing in this community, drug misuse within the Roma community remains a taboo subject, which contributes to general lack of knowledge about drugs, their effect on individuals and their families and drug services available.

Based on findings from the Roma Mentoring Programme (2006-2009) and the Drug Awareness Research carried out in 2010, the drugs most commonly used within the community are cannabis, skunk, hashish, heroin and crack cocaine. Most recently, drug services reported prevalence of pervitin users amongst newly arrived Czech and Slovak Roma migrants. In our work with Roma with substance misuse problems,we found that the average age for beginning to use drugs was 13. Young Roma drug users commonly receive treatment only after referral to drug services as part of the provision with youth offending teams or probation. Their drug use is often very serious by this point, and they are in need of high levels of support.

Domestic violence

Although a 2008 European Commission report suggests that domestic violence is considered an acceptable practice within Roma society, evidence from Roma community members reveals it to be a taboo topic. The taboo nature of this subject may be attributable to dynamics within Roma families, which causes women to feel as though they are unable to discuss family problems. There is also a fear that exposing tensions within the Roma community could lead to further stigmatisation.

Even when women do seek out help in cases of domestic violence, evidence has shown that support services are not in line with their needs. In Hungary, for example, only 20% of Roma domestic violence victims sought out police assistance, and in these cases, only one out of seven women reported an adequate response (UN Refugee Agency, 2012).

When domestic violence victims are in a vulnerable position with regard to immigration or employment status, they may fear that seeking out help will alert authorities to their situation. If you are working with a Roma individual who you suspect may be a victim of domestic violence, it is important to offer clear descriptions of what services are available, what actions can be taken and to

offer assurance that support services for domestic violence victims will not make them more vulnerable. There may be additional challenges associated with providing support for domestic violence victims while also showing respect for Roma family structures.

Examples of Positive Engagement

RSG Drug Awareness Project

In December 2009, the Roma Support Group ran a Drug Awareness Project for the Roma community. As part of this project, we ran community consultation meetings with Roma parents and young people (60 participants) and conducted individual-focused interviews with young people who were/are affected by the substance misuse (5 participants). The Newham SSMT (Specialist Substance Misuse Team) and CSSS (CAMHS Specialist Substance Misuse Service) supported the project by offering specialised advice and guidance.

This was a radical move, given the taboo nature of this topic for the community. For the first time, many older Roma people were able to hear at first-hand how hard some young people were finding the battle against illegal drugs. Young people were also reminded how much some older members of the community wanted to help them and try to understand the nature of drug use. Consultation between drug treatment providers and Roma also helped demystify some of the problems in providing appropriate substance misuse services. Following recommendations were outlined:

- Raising awareness about Roma amongst professionals involved in supporting clients with substance misuse problems
- Raising awareness about drugs, services available and the nature of treatment
- Multidisciplinary approach
- Involvement of wider family in supporting an individual with substance misuse problems (where appropriate and requested by service users, a family member should be involved in sessions with professionals)
- Involvement of community organisations, community leaders or local Roma churches can help in outreach to the community and promote awareness of local drug services, promotional events, etc.
- Importance of outreach services as some community members either may not know of specialised services or may not recognise that they have a problem with substance misuse
- Commissioning comprehensive research about substance misuse in Roma communities in the UK so that appropriate services can be established

Following this research, the Roma Support Group, in partnership with the East London CAMHS Specialist Substance Misuse Service, organised two drug awareness events for the Roma community: one for young people and one for their parents. Both events were attended by approximately sixty people and Roma were involved in every stage of organising and running of the events.

Redbridge Specialist Health Visitor Project

A health visitor-led project explored how access to health provision could be improved for Roma children living in Redbridge. The team developed a model which allowed this vulnerable group to access a full spectrum of primary care services, delivered by a specialist health visiting team in their homes and at a clinic in a children's centre. The team focused on immunisations, developmental checks, breastfeeding support, general health advice and supporting families to register with a GP. The team worked with children up to 19 years of age and their families, always using an interpreter.

Innovative ways of working were used including offering immunisations and developmental checks at home rather than in a clinic or GP setting. The weekly clinic was held in a children's centre, which offered parents a unique opportunity to access a health visitor, who was supported in her work by an interpreter. The children's centre proved to be an excellent venue, as the centre was able to offer a Roma group running in an adjacent room at the same time as the clinic. This group was run by a Romanian speaking family support worker who was able to offer play activities and advice on accessing education services.

The project ran for a year in 2011 and saw a significant improvement in the uptake of immunisations, developmental checks and GP registration.

Roma Health Champions

Through the Roma Health Champions programme, Roma volunteers were trained in techniques for managing health and wellbeing. The Health Champions then hosted community health promotion activities, including healthy eating classes, mental and sexual health information sessions, Zumba classes and women's health programmes. Not only did these activities increase community members' knowledge of healthy behaviours and available services, but they also helped health care providers to better understand the needs of local Roma communities (Roma SOURCE, 2013).

By involving Roma volunteers as community Health Champions, this project made culturally sensitive health information readily accessible to Roma community members. Furthermore, service user-led delivery of health outreach programmes increased their sense of control over personal and community health. In this way Roma community members gained confidence in using health services and seeking out health information, and some Health Champions used the skills developed through their volunteer work to gain paid employment in health promotion.

While the Roma Health Champions programme was largely successful in engaging Roma community members, there were challenges associated with retaining volunteers for long-term and regular involvement, as they often had to work around family and work commitments. Language barriers created additional issues with successfully recruiting and engaging volunteers, though engagement with the programme ultimately helped volunteers to improve their English language skills. Despite these issues with volunteer recruitment and retention, the Roma Health Champions programme nonetheless offers a highly effective model for improving health communication within the Roma community.

RSG Forum Theatre

From 2009 to 2012 the RSG sponsored a forum theatre programme, in which Roma and non-Roma participants explored health and wellbeing issues through the medium of theatre performance.

This project reached a large number of Roma community members, and the involvement of Roma volunteers helped to ensure that issues would be addressed in a culturally sensitive way. The project's success can furthermore be attributed to the fact that participants discussed causes of mental distress, as opposed to taking a formal diagnosis-based approach to mental health issues. In this way the forum theatre programme allowed Roma community members to overcome some of their reluctance to discuss mental health issues by providing an open and accepting environment for working through problems.

After the conclusion of this project, participants continued to be involved in other forum theatre activities, as well as other types of creative projects focusedon health promotion and training for professionals.

RSG project's service users and volunteers, Forum Theatre rehearsal, Trinity Centre, December 2009

Recommendations for Working Successfully with Roma Families

See a referral through from start to finish. Too often a much needed referral is made and then not followed up by the referrer. If an appointment letter is sent in English the family may not understand it, and failure to attend can result in them being discharged from the service. Even if somebody calls the family with details of an appointment it does not mean they will know how to find the address. Some Roma families do not travel very far from their homes. They may need some basic support planning their journey.

Try not to use jargon and medical terminology, as this can be confusing for the family. Some Roma individuals will want to be polite, and therefore may not tell you if they are not following the conversation. If you keep language jargon-free, it prevents any unnecessary confusion or misunderstanding of what is happening.

Chase up letters you may have sent with a phone call (or home visit if possible). Try to have correspondence translated into the family's language. If there is no budget for translation, you can consider that your letter may not be read at all.

When working with Roma "BE"

- Positive
- Respectful of traditions and customs
- Open and honest
- Aware of language issues (interpreting, first/second language issues, lack of vocabulary, illiteracy)
- Be mindful of age, gender, cultural taboos (consult the community if in doubt)

When working with Roma "DO"

- Make eye contact when talking
- Maintain eye contact when talking
- Involve Roma representatives in your work
- Engage with family members and explain what is happening
- Invest time
- Work in a multidisciplinary way
- Use word of mouth to spread information as it is often more effective than written information
- If appropriate, behave in an informal way
- Raise the community's awareness about relevant issues through individual and group meetings
- Use cultural references
- Explain why you are asking questions and what you will do with answers
- Dress modestly

When working with Roma "DO NOT"

- Don't promise what you cannot deliver
- Don't use professional jargon

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