Gypsy, Roma and Traveller access to and engagement with health services: a systematic review

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Abstract

Background

Gypsy, Roma and Traveller people represent the most disadvantaged minority groups in Europe, having the poorest health outcomes. This systematic review addressed the question of how Gypsy, Roma and Traveller people access healthcare and what are the best ways to enhance their engagement with health services.

Methods

Searches were conducted in 21 electronic databases complemented by a focussed Google search. Studies were included if they had sufficient focus on Gypsy, Roma or Traveller populations; reported data pertinent to healthcare service use or engagement; and were published in English from 2000 to 2015. Study findings were analysed thematically and a narrative synthesis reported.

Results

Ninety-nine studies from 32 countries were included, covering a range of health services. Nearly half of the presented findings related to primary healthcare services. Reported barriers to health service usage related to organisation of health systems, discrimination, culture and language, health literacy, service-user attributes, and economic barriers. Promising engagement strategies included specialist roles, outreach services, dedicated services, raising health awareness, handheld records, training for staff, and collaborative working.
Conclusion

This review provides evidence that Gypsy, Roma and Traveller populations across Europe struggle to exercise their right to healthcare on account of multiple barriers; and related to other determinants of disadvantage such as low literacy levels and experiences of discrimination. Some promising strategies to overcome barriers were reported but the evidence is weak, therefore rigorous evaluations of interventions to improve access to and engagement with health services for Gypsy, Roma and Traveller people are needed.

Key words

Gypsy; Roma; Travellers; access to healthcare; healthcare utilisation; systematic review.
Introduction

The Gypsy, Roma and Traveller population are the largest and most disadvantaged minority ethnic group in Europe. However, the difficulty of defining and identifying the target population in research is highlighted by variation in estimates of the population size. For example the Council of Europe estimate of population size of 6-16 million\(^1\) reflects a much wider in range than the European Union (EU) estimate of 10-12 million.\(^2\) These figures may be a significant under-estimation as many are reluctant to disclose their identity due to stigma. The term ‘Roma’ is used in EU policy documents to include heterogeneous groups with diverse histories, cultural, and linguistic backgrounds, such as Gypsies, Travellers, Sinti, Bargees/Boat dwellers and New Age Travellers.\(^2\) However, these terms are contested, assuming different meanings in different contexts.\(^3,4\) For instance the term ‘Gypsy’ carries pejorative connotations and is offensive to many Roma in Europe,\(^4\) \(^3\) while some Romany Gypsies in the United Kingdom (UK) are proud of being so identified.\(^3\) Across Europe large numbers of Roma are officially invisible because they lack citizenship and/or official documentation.\(^5\) In this paper we use terminology acceptable to most groups in the UK (i.e. Gypsy, Roma and Traveller\(^6\)), although the papers cited use a range of diverse (and inconsistent) terminologies, which we address when presenting our findings. Nonetheless, these population groups have two characteristics in common: one is self-ascription as Gypsy, Roma or Traveller along with a cultural tradition of nomadism, even if they no longer travel; the second is experiences of stigma, discrimination and social exclusion.

Previous reviews have identified that Gypsy, Roma and Traveller populations across Europe experience significantly worse health, when compared to majority populations.\(^7,8\) This includes
lower self-reported health and higher mortality risk;\(^9\) lower life expectancy;\(^9,10\) increased burden of communicable disease;\(^11-14\) increased morbidity from non-communicable disease;\(^11\) increased rates of suicide;\(^11\) and poorer infant and child health.\(^10\) However, the reviews also indicate a paucity of high quality evidence on Gypsy, Roma and Traveller health status\(^9,11-14\) and the need for further research, particularly on interventions to reduce health inequalities.\(^9\)

In a survey of 8735 Roma compared to 4572 non-Roma across 12 European countries,\(^15\) Roma were up to three times more likely to report unmet health needs. Cook et al\(^9\) found that Roma people were less likely to access dental services, cervical screening or immunisations; while identifying lack of documentation and affordability as barriers to accessing healthcare. The exclusion of Roma from health services across Europe was highlighted in 2006 by the European Roma Rights Centre.\(^16\) Furthermore, Gypsy, Roma and Traveller inequalities in health and health service engagement are set against a background of widespread disadvantage and discrimination in their day-to-day lives such as lack of adequate housing, poverty, restricted access to employment and low education and literacy levels.\(^15,17,18\)

The right to health, enshrined in the World Health Organisation (WHO) constitution, includes “access to timely, acceptable, and affordable healthcare of appropriate quality”.\(^19\) This underlines the importance of understanding Gypsy, Roma and Traveller peoples’ access to and engagement with healthcare services. The importance of research focussing on reducing health inequalities\(^9\) and on evaluating interventions to improve the health of Gypsy, Roma and Traveller people\(^20\) has been indicated. Aspinall\(^21\) explored interventions or service models to improve access to primary care and reduce avoidable hospital admissions in the UK, identifying elements of good practice including Gypsy and Traveller engagement in service development,
provision of adequate resources and building trust. However most of the examples were from the grey literature and lacked rigorous evaluation.\textsuperscript{21} Regarding outreach interventions, Carr et al\textsuperscript{20} found that the level of trust between communities and outreach workers - and the extent to which the focus of the intervention was negotiated with intended recipients - influenced the intervention’s success.

As part of a larger project focusing on enhancing trust between Gypsy, Roma and Traveller people and mainstream health services,\textsuperscript{22} we conducted a systematic review to examine empirical studies of Gypsy, Roma and Traveller access to and engagement with health services. The aims were to describe the range and nature of studies on how Gypsy, Roma and Traveller people access and engage with health services; and to identify the best evidence for ways to enhance Gypsy, Roma and Traveller peoples’ engagement with health services.
Methods

A review protocol is published elsewhere.\textsuperscript{22}

Search strategy

In May 2015, searches were conducted of the following databases: MEDLINE (via OVID), Embase (via OVID), CINAHL (via EBSCO), Cochrane Database of Systematic Review, Database of Abstracts of Reviews of Effects (DARE), Health Technology Assessment (HTA) database, CENTRAL, Social Science Citation Index (via Web of Knowledge), PsycINFO (via OVID), HMIC (via OVID), ASSIA (via Proquest), Social Policy and Practice (via OVID), Bibliomap (via the EPPI-Centre databases), DoPHER (via the EPPI-Centre databases), TROPHI (via the EPPI-Centre databases), the Campbell Library, Social Care Online and the British Nursing Index (via Proquest), Research Councils UK – Gateway to Research, OAIster and OpenGrey. In addition a focused search using the advanced Google interface, which allows a search to be constructed which focuses on the use of exact words or phrases and then allows results to be narrowed by a range of other parameters, was conducted to identify relevant research on NHS and UK Government sites. Search terms involved a combination of thesaurus and free-text terms, specific for each database. See Supplementary table S1 for the MEDLINE search strategy. In addition to searching the literature databases, the reference lists of relevant reviews were examined for publications meeting the inclusion criteria.

Eligibility criteria

Pre-defined eligibility criteria for inclusion included: (i) reported empirical, primary findings; (ii) adequate focus on Gypsy, Roma or Traveller populations (where other groups were included,
separate data had to be discernible for Gypsy, Roma or Traveller participants) worldwide; (iii) included data pertinent to healthcare service use or engagement; (iv) published in the English language from the year 2000 onwards. All study designs were included and we considered research studies, reports and assessments, provided they met the inclusion criteria.

Selection of studies

The search results were combined and duplicates removed. Titles and abstracts were screened independently by two reviewers and discrepancies discussed with a third reviewer until consensus was achieved. Full texts were retrieved for publications that appeared relevant or for which there was insufficient information to make a decision. Full texts were screened independently by two reviewers for inclusion, and discrepancies were discussed and resolved with a third reviewer.

Data extraction and synthesis

Where available, data were extracted on: country and region; study type and methods; participants; types of health service; costs of services; engagement strategies (initiatives or pathways to promote engagement); study aims; and key findings related to Gypsy, Roma or Traveller participants. Information was extracted from the papers by one reviewer, then checked by a second reviewer.

Given the heterogeneous nature of this review, a meta-analysis was inappropriate, therefore a narrative synthesis was undertaken. To explore healthcare access and engagement thoroughly, we collated information on barriers to and facilitators of engagement in health services. This
information was analysed thematically by one reviewer then checked for consistency by a second reviewer.

**Quality assessment of core engagement strategy studies**

Only those studies that contributed a detailed account of engagement strategies were quality assessed. Qualitative studies were assessed globally drawing upon Critical Appraisal Skills Programme (CASP)\(^\text{23}\) and Consolidated Criteria for Reporting Qualitative Research (COREQ)\(^\text{24}\) criteria: triangulation of data, rigour, reflexivity, credibility, relevance, clear exposition of ethical issues, and methods of data collection and analysis. The nature and ‘typology’ of the qualitative evidence was also assessed.\(^\text{25}\) The use of the typology allows for classification of findings across a continuum of data transformation with topical surveys considered to be closest to the data. This is followed by thematic surveys, conceptual/thematic description and finally interpretive explanation, which is considered to be furthest from the data. Quantitative studies were assessed for risk of bias according to individual elements: whether an adequate sampling strategy had been employed; a participant response rate of over 60%; whether a validated instrument had been used to collect data; and whether statistical analyses had been appropriately conducted.
Results

The database search identified 6350 references and 74 additional records were identified through examining the Google search. Three additional records were identified though examining reference lists of review papers. See Figure 1 for details of the study selection process. After de-duplication, 3932 records were screened on title and abstract and 3548 were excluded. A total of 384 full-text papers were assessed for eligibility and 121 papers reporting 99 studies were included. See Supplementary table S2 for a list of included studies and references. Despite exhaustive attempts to locate all records, the full-texts for 13 papers were unobtainable. Based on the information available, we believe that many of these would not have met our inclusion criteria and are confident that inclusion of these records would not have changed the conclusions of our review.
Records identified through database search
(n = 6350)

Records identified through Google Scholar
(n = 74)

Additional records identified through reviews
(n = 3)

Records after duplicates removed
(n = 3932)

Records screened
(n = 3932)

Full-text articles assessed for eligibility
(n = 384)

Studies included in narrative synthesis
(n = 121, reporting 99 distinct studies)

Records excluded
(n = 3548)

Full-text articles excluded, with reasons
(n = 263)

No healthcare professional outcomes (25)
Not a breastfeeding education intervention (5)
Participants not healthcare professionals (5)
Not a RCT (1)
Mis-labelled duplicate study (1)
Range and nature of studies

Participants and settings

The 99 included studies were undertaken in 32 countries (31 European countries and Canada). Nine studies were carried out in multiple countries. Approximately half (n=49) were conducted in, or included, the UK. Figure 2 identifies countries included in the studies. Twenty-five studies contained findings related to groups other than Gypsy, Roma or Traveller, either as a comparator, or in studies involving several minority/disadvantaged groups. Thirty-six studies included health workers as well as Gypsy, Roma or Traveller participants; and seven studies involved only health workers or other professional participants.
Figure 2 locations included in the 99 studies

- Albania
- Austria
- Belgium
- Bosnia and Herzegovina
- Bulgaria
- Canada
- Croatia
- Czech Republic
- Finland
- France
- Germany
- Greece
- Hungary
- Ireland
- Italy
- Kosovo
- Latvia
- Lithuania
- Macedonia
- Moldova
- Montenegro
- Netherlands
- Poland
- Portugal
- Romania
- Serbia
- Slovakia
- Slovenia
- Spain
- Sweden
- Turkey
- UK
As anticipated, there was inconsistency in how the included studies used terms such as Gypsy, Roma or Traveller with many papers not describing how or by whom the labels were ascribed. National variations occurred alongside variations in individual papers, very few of which reported using self-ascription, while others classified participants according to defined templates such as census categories. Therefore we have taken a pragmatic but critical approach in presenting the literature and incorporated discussions of definitional heterogeneity when commenting on findings.

Study design

Studies were categorised as qualitative, quantitative or combined quantitative and qualitative methods.

Forty-four studies used a range of qualitative methods to explore access to health services, healthcare experiences and support needs of Gypsy, Roma or Traveller people; and/or of experiences of healthcare providers or other expert informants of providing healthcare for these populations. Most studies were exploratory descriptive studies (n=27), six studies used participatory methods and four studies were health needs assessments. Other approaches included grounded theory (n=3), phenomenology (n=1), ethnography (n=1), feminist methodology (n=1) and case study design (n=1). All studies used some form of interviews or focus group discussions (or both) to generate research material. Other additional data collection methods included documentary analysis, observation and questionnaires with open-text responses.
There were 30 studies that used quantitative methods, of which 16 were cross-sectional surveys, eight analysed secondary data, two were retrospective cohort studies, two were before and after studies, and one was a consultation. Seventeen studies compared Gypsy, Roma or Traveller people’s engagement with health services with general populations or other disadvantaged groups.

Twenty-five studies combined qualitative and quantitative methods. The most frequent study designs were cross-sectional surveys with interviews or focus group discussions (n=9), or a survey that included open and closed questions (n=5). Four studies were mixed methods health needs assessments. The remaining seven studies used more complex mixed methods designs, including case studies, action research, and mixed methods evaluations (including a realist/participatory evaluation).

**Type of health service focus**

The studies incorporated a wide range of health services (summarised in Table 1), with primary healthcare, including general practitioner services, mentioned most frequently (n=46). Many studies highlighted lack of access to or uptake of services, most notably primary healthcare, immunisation, dental care and preventive services including screening.
Table \{ SEQ Table \* ARABIC \} Number of studies for each type of health service

<table>
<thead>
<tr>
<th>Type of health service</th>
<th>Number of studies</th>
</tr>
</thead>
<tbody>
<tr>
<td>Primary health care</td>
<td>46</td>
</tr>
<tr>
<td>Immunisation</td>
<td>29</td>
</tr>
<tr>
<td>Child health</td>
<td>29</td>
</tr>
<tr>
<td>Accident and emergency</td>
<td>23</td>
</tr>
<tr>
<td>Maternity</td>
<td>23</td>
</tr>
<tr>
<td>Sexual and reproductive health</td>
<td>22</td>
</tr>
<tr>
<td>Dental health</td>
<td>22</td>
</tr>
<tr>
<td>Mental health</td>
<td>20</td>
</tr>
<tr>
<td>Preventive health/screening</td>
<td>16</td>
</tr>
<tr>
<td>Unspecified or general health services</td>
<td>16</td>
</tr>
<tr>
<td>Health insurance</td>
<td>14</td>
</tr>
<tr>
<td>Addiction services</td>
<td>9</td>
</tr>
<tr>
<td>Helplines e.g. NHS Direct</td>
<td>8</td>
</tr>
<tr>
<td>Health records</td>
<td>5</td>
</tr>
<tr>
<td>End-of-life/palliative care</td>
<td>3</td>
</tr>
<tr>
<td>Ambulance services</td>
<td>3</td>
</tr>
<tr>
<td>Disability</td>
<td>2</td>
</tr>
<tr>
<td>Renal transplantation</td>
<td>1</td>
</tr>
</tbody>
</table>
Areas of cost

Little consideration was given to cost in the included studies. Consequently, there was little data on the cost-effectiveness of healthcare interventions. No study indicated total budget costs, which could have been used to estimate the total approximate costs of interventions, and no formal economic evaluations occurred. Costs were noted from the user perspective in one study. This study highlighted that when service and medicine costs are high, there is a low willingness to pay; which represents a barrier to healthcare uptake in countries where healthcare is not free at the point of delivery.

Engagement with health services

Barriers to engagement with health services

Findings related to one or more barriers, or potential barriers, to accessing or using health services occurred in 83 of the included studies. The factors acting as barriers to the use of health services were categorised under six key themes (Table 2). The reported barriers were similar across different populations of Gypsy, Roma and Traveller people, and across different national settings. Economic barriers were rarely mentioned in the UK studies where healthcare is mostly free at the point of delivery. While we have presented the barriers/potential barriers in distinct categories, there is overlap and barriers in one theme compounded those in another. Individual studies reporting barriers or potential barriers are shown in Supplementary table S3.
Table 2 Number of studies that include findings related to barriers

<table>
<thead>
<tr>
<th>Category of barrier</th>
<th>Number of studies</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Total (n=99)</td>
</tr>
<tr>
<td>Health service issues</td>
<td>62</td>
</tr>
<tr>
<td>Discrimination and attitudes of health service personnel</td>
<td>50</td>
</tr>
<tr>
<td>Cultural and language barriers</td>
<td>53</td>
</tr>
<tr>
<td>Health literacy</td>
<td>53</td>
</tr>
<tr>
<td>Service-user attributes</td>
<td>48</td>
</tr>
<tr>
<td>Economic barriers</td>
<td>18</td>
</tr>
</tbody>
</table>

*Health service issues*

The most commonly reported barriers/potential barriers encompassed difficulties registering with health services, especially for primary care. This barrier could originate from outside the health service i.e. lacking the necessary documentation to fulfil legal conditions for using health services or from within the health system as in the application of arbitrary rules such as declining to register those with no fixed address .. Consequently, some were refused further services because they were not registered, or were registered as temporary residents. Health service personnel also refused or were reluctant to visit sites or camps. The accessibility of services was also reported to be difficult, with barriers relating to the distance to reach services and inflexibility of services. Difficulty making appointments and waiting times for treatment were commonly reported. Concerns relating to quality of care were also reported e.g. lack of
thorough examination and fragmented care between different services. Lack of data on population size, health needs and service usage appeared to be barriers to providing appropriate healthcare for Gypsy, Roma or Traveller people.

**Discrimination and attitudes of health service personnel**

A prominent theme, and one that was interrelated with reported health service barriers, was Gypsy, Roma and Traveller people’s experiences or perceptions of discrimination when accessing and using health services, including attitudes of health service staff. The starkest example of discrimination was segregation; including Roma-only showers, eating rooms, and other facilities, most particularly in maternity wards, perceived by Roma women to be based on negative racial stereotypes. There were reports of hostile, patronising, judgemental, unsympathetic, and even abusive attitudes of healthcare staff, including health professionals and receptionists. These were said to be based on negative stereotypes. Poor communication and relationships between health service staff and Gypsy, Roma and Traveller service-users, such as not being listened to, not being taken seriously, or staff not taking the time to explain diagnoses and treatments, were also common themes.

**Cultural and language barriers**

The negative attitudes of health service personnel described above were linked to lack of cultural understanding with regards to the needs of Gypsy, Roma and Traveller communities; and the need for better cultural awareness and diversity training. The most commonly mentioned issue related to the importance of family was the tension caused between health service staff and service-users over the number of family members accompanying or visiting relatives receiving healthcare. Other issues include the importance of same gender healthcare
professionals, especially for gender-sensitive problems such as sexual and reproductive healthcare; understanding that some healthcare topics, such as mental health and substance misuse, may be considered taboo topics and thus need to be handled with privacy and confidentiality; and sensitivities around end-of-life/palliative care and cancer. Using health services for sensitive health needs was reported to be associated with stigma and a sense of shame. However, stigma and shame were also reported to be a consequence of devalued identity due to experiences of discrimination. It was suggested in some studies that people from Gypsy, Roma and Traveller communities may avoid health service use due to ‘fatalism’ or ‘belief in God’s will’, although such observations often reflected a lack of theoretical sophistication.

As might be expected, a mobile lifestyle exacerbated difficulties in accessing health services, developing relationships with staff, and achieving continuity and follow-up care. This was a particular problem for those living in roadside encampments who experienced forced evictions. Communication difficulties and cultural misunderstandings were compounded when service-users did not speak the same language as the healthcare staff. Shortages of interpreters in health services was reported. For Roma migrants there was an additional barrier of having to communicate through interpreters in a second language because of a lack of Romani interpreters. For some healthcare staff working with interpreters was reported to be frustrating and compounded issues around privacy and disclosure of health concerns.

Health literacy barriers

A key barrier to accessing and using health services for Gypsy, Roma and Traveller communities was knowing how to access and navigate health systems and being able to access and understand health information. Studies reported particular difficulties with understanding how
to access dental, mental health, and sexual and reproductive health services (including family planning). Lack of understanding of medical jargon was another commonly reported barrier, and reported poor functional literacy compounded the difficulty of accessing information. Consequences of these issues included not being able to read written medication instructions, appointments, or health promotion information. Using information technology (such as making or checking-in for appointments) was reported to be challenging and to cause embarrassment for some service-users.

Service-user attributes

The service-user attributes reported as barriers to accessing health services for Gypsy, Roma and Traveller people fit three broad themes: individual characteristics (age and gender); individual preferences (such as consulting with family, using alternative therapies and self-reliance); and concerns about health services (such as lack of trust). There were contradictory reports regarding the effect of age and gender on health service use. Common themes were lack of autonomy among women to make decisions about health and that women were more likely to use health services for children rather than themselves. It was frequently reported that men have more difficulty talking about health and are more likely to present late in disease progression. Fear associated with use of health services was reported often, and included the expectation of discrimination or being judged, fear of removal of children by statutory services or fear of diagnosis, illness, or treatment. Mistrust of health services was reported to be a major issue for many. Fear and mistrust were often based on personal or vicarious previous poor experiences of health services.
Economic barriers

The economic barriers reported in the included studies related to either the charges made for services or the lack of financial resource to afford transport to health services or to be able to use a phone to make appointments. Inability to afford care included not having health insurance to cover costs and inability to make informal payments demanded for services that were supposed to be free of charge.

Enhancing or facilitating access to health services

Forty of the included studies mentioned at least one form of engagement strategy that may enhance or facilitate access to health services, however the level of detail on the different strategies varied. Twenty-six studies provided a greater level of detail pertaining to 47 different strategies. We regarded these as core studies (see Supplementary table S4 for details) and provide a thematic description of the strategies and, when available, outcomes.

Specialist roles

Eight strategies were grouped under the theme of developing a specialist role to work with community members. This included for example the involvement of community members as links between healthcare and the community, facilitating relationships or providing health information. The study findings suggest that these roles are positively received by those who take them on and by health professionals, and that there are positive outcomes in relation to increasing community members’ engagement with health services.

Outreach

Seven strategies focussed on outreach to communities (or taking care to the community), largely by a range of health practitioners. The importance of positive relationships between
providers and communities was highlighted. Some findings, however, raised the idea that outreach services may reinforce disengagement from mainstream health services by providing an alternative means of care.

**Dedicated services**

Eleven strategies could be described as ‘dedicated services’ with a focus on Gypsies, Travellers or Roma people. This included for example specialist staff, services to improve the health of the community and health policies. The studies point to a wide range of professionals engaging with or considering these communities in a number of different ways, and provision of healthcare featured strongly. Again, one study pointed to disengagement from mainstream services if an alternative was available.

**Raising health awareness**

Nine strategies focussed on raising health awareness within the community. A variety of methods were reported, including educational and training programmes delivered in schools, health centres and settlements, and public events, including in relation to health service use, oral health and reproductive health. The strategies included input from health practitioners and third sector organisations. There is evidence of positive feedback from community members involved in the initiatives and a number of the studies reported that these initiatives were associated with increased knowledge and awareness around various health issues.

**Handheld records**

Three strategies are based on handheld or personal health records. All three relate to Gypsies and Travellers. The findings point to positive feedback and interest about this method from professionals as well as Gypsies and Travellers. There were, however, indications that these
records are underused by both. Further, a number of potentially negative issues, including around efficacy and confidentiality, were raised.

*Cultural awareness training*

Six strategies from three studies focussed on cultural awareness training for staff (although a number of additional studies included this as an element of their engagement strategy). There was evidence of collaboration between health services and third sector or community groups, as well as community members, in the delivery of the training.

*Collaborative working*

Finally, three strategies from three studies offered examples of collaborative working between health services and community members, however, a number of other studies included collaboration as an element of their work. These studies showed a varied level of collaboration, from community members overseeing and delivering projects, to consultation with community members around needs. The study that looked at community members overseeing projects found evidence of disengagement over time through a lack of regular contact.

*Quality of Engagement Strategy Papers*

We conducted an assessment of study quality of the 26 studies providing a detailed account of engagement strategies. Thirteen studies were qualitative, seven were cross-sectional surveys and six studies included both.

The 19 studies involving qualitative methods were subject to a global assessment of study quality according to the following criteria: triangulation of data, rigour, reflexivity, credibility, relevance, clear exposition of ethical issues, and methods of data collection and analysis. Strong studies were deemed to be those that were assessed to have adequately employed all of these
criteria. Five studies were assessed as strong and 14 studies as weak (see Supplementary table S5 for details). In terms of the nature and ‘typology’ of the qualitative evidence: eight studies were assessed as being topical surveys; seven studies were thematic surveys and four studies provided a conceptual thematic description. No studies were assessed as having achieved a level of data transformation that was at the level of interpretive explanation.

Assessment of the quantitative studies was hindered by poor reporting and it was not possible to assess the sampling strategy in seven studies or the response rate in nine studies. Of the studies where data were available, only four studies were assessed as having an adequate sampling strategy and only two studies had a response rate of over 60%. Only two studies used a validated instrument and two studies reported application of appropriate statistical analysis. Thus study quality was generally poor across the different methodological components (see Supplementary table S6 for details).
Discussion and conclusions

This review highlights that Gypsy, Roma and Traveller peoples’ access to and engagement with health services has been the focus of extensive research. The 99 studies included in this review are from diverse countries and settings, and cover a wide range of health services. Despite this diversity, there are common themes, particularly in relation to the confluence of barriers that Gypsy, Roma and Traveller people face when accessing and using health services. Key barriers include health systems’ bureaucratic processes, discrimination and negative attitudes of some health service staff, cultural misunderstanding and language barriers, low levels of health literacy and affordability. In addition, some barriers relate to service user attributes of Gypsy, Roma and Traveller people, although this may be underpinned by fear and mistrust.

Our review highlighted diverse approaches that might successfully facilitate Gypsy, Roma and Traveller communities’ engagement with health services, such as outreach and specialist roles, cultural-awareness training for health service staff and collaborative working between health services and members of Gypsy, Roma or Traveller communities.

Our review confirms findings of other literature reviews that Gypsy, Roma and Traveller communities face significant obstacles to exercising their rights to healthcare. Whilst health services may generally be available, our review suggests that four dimensions of accessibility of services: non-discrimination, physical accessibility, affordability, and information accessibility, need to be addressed. Further, there was evidence that health services are not culturally sensitive or acceptable, and that Gypsy, Roma and Traveller people experience widespread overt (or more subtle forms of) discrimination. Twelve studies in our
review reported lack of data on the size of Gypsy, Roma or Traveller populations and/or on their health outcomes, needs or use of health services, which renders it difficult for governments and statutory service providers to be held to account for meeting the healthcare needs of this disadvantaged population group. Although the 12 studies were all from the UK or Ireland, lack of data has been found elsewhere.13,29

The barriers to accessing healthcare, reported in the studies included in this review, may not be specific to Gypsy, Roma and Traveller communities. For example experiences of discrimination and lack of cultural awareness of health service staff have been reported for other minority ethnic groups.30,31 Health system barriers are also widely reported. However, in the case of Gypsy, Roma and Traveller populations, this has to be set against the background not only of widespread prejudice and discrimination in accessing healthcare, but also in housing and education.18 In this context, the consequences of barriers to accessing healthcare may be more significant.32

The studies in this review reported a range of strategies developed to encourage Gypsies, Travellers and Roma people to address health issues and engage with health services, delivered by both the health system and third sector organisations. In some cases community members had been meaningfully involved in the design and implementation of the strategy, although in others the community voice was lacking. Detailed discussion or evaluation of many of the strategies was not reported, limiting the evidence of what works best to enhance engagement. It is notable that many of the detailed strategies were in the grey literature which partially explains why the methodological quality was generally weak. This further highlights the need
for rigorous evaluations of interventions to improve access to and engagement with health services.

It is important to consider whether engagement strategies may in fact discourage the use of mainstream services and lead to further marginalisation and stigmatisation. This is most evident in Alunni who noted that a mobile health unit successfully delivered health services to Roma people living in camps, while at the same time discouraging them from accessing mainstream health services. It is possible that these strategies are most valuable for those who face multiple barriers to accessing services, thereby providing a pathway to accessing mainstream services rather than an alternative service.

This review provides an inclusive account of Gypsy, Roma and Traveller people’s access to and engagement with health services. It is based on a comprehensive search of 21 databases and was conducted using rigorous and transparent methods. The review mapped published and grey literature from across Europe and Canada to provide an overview of the range and nature of studies in this field, and has focussed on both barriers and engagement strategies to present evidence on ways to enhance health services use, since both must be taken in to account. The review extends existing knowledge by focussing on all types of health services, and all population groups under the broad classification of Gypsy, Roma and Traveller populations.

The review is limited by the exclusion of non-English language publications, and we anticipate that there will be studies published in languages other than English that we have not included. However, the review has underlined the paucity of intervention studies or any considerations of cost in the literature. Particularly within a UK context, decision-making around the delivery of healthcare provision and interventions is largely driven by cost and the ability to demonstrate
cost-effectiveness. Future research would, therefore, benefit from the inclusion of clearly defined costs and resource use.

The results of this review echo findings on ethnicity and health inequalities more broadly, reflecting a strong concern with the ‘other’ in which cultural or ethnic difference are problematized and reified. Debates about culturally competent care highlight that, while cultural awareness training can be helpful, it also risks reproducing stereotypes and failing to take account of the multiple identities and social realities in which Gypsy, Roma and Traveller people live their lives. When viewed from this perspective, ideas of cultural difference, for example about God’s will and fatalism are demonstrated to be far more nuanced, and reflect the myths held by healthcare practitioners rather than the individual’s experience. This highlights a need for further research that uses a more sophisticated understanding of diversity and difference.
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Conflicts of interest

None declared

Authorship

AM, LS, AG, KB and SM contributed to conception and design, acquisition, analysis and interpretation of data and drafted the final manuscript;

NI contributed to conception and design, acquisition, analysis and interpretation of data;

KA, HJ and CJ contributed to conception and design, and interpretation of data;

HH contributed to acquisition, analysis and interpretation of data;

All authors revised the manuscript critically for important intellectual content, approved the final version, and agree to be accountable for all aspects of the work.
Key Points

- Gypsy, Roma and Traveller communities across Europe and Canada face significant obstacles to exercising their rights to healthcare in relation to non-discrimination, physical accessibility, affordability, and information accessibility;
- Key barriers to Gypsy, Roma and Traveller people accessing health services include health systems’ bureaucratic processes, discrimination and negative attitudes of some health service staff, cultural misunderstanding and language barriers, low levels of health literacy and affordability;
- There are promising strategies to enhance Gypsy, Roma and Traveller communities’ engagement with health services such as specialist roles, outreach and dedicated services, but the evidence base for this is weak;
- Therefore there is an urgent need for rigorous evaluations and economic evaluations of interventions to improve Gypsy, Roma and Traveller communities’ access to and engagement with health services.
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