Enhancing Gypsy, Roma and Traveller peoples' trust

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Enhancing Gypsy, Roma and Traveller peoples' trust: using maternity and early years' health services and dental health services as exemplars of mainstream service provision

Final Report

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Contents

List of Tables and Figures 6
List of Appendices 7
List of Abbreviations 8
Plain English Summary 9
Scientific Summary 10
  Background 10
  Aims and objectives 10
  Methods 11
  Results 12
    Stage 1 (Literature reviews). 12
    Stage 2 (Online consultation) 13
    Stage 3 (Case studies) 13
    Stage 4 (Cross-sectoral workshops) 13
  Recommendations 14
  Conclusion 14
Chapter1: Background 15
  Size of the Gypsy, Roma and Traveller population in the UK 15
  Health and health service uptake of Gypsy, Roma and Traveller people 15
  Trust and Community Engagement 16
  Policy context 17
Chapter 2: Study aims and overview of methods 19
  Study aims 19
  Study objectives 19
  Overview of methods 19
    Phase 1: Literature reviews 19
    Phase 2: National online consultation 20
    Phase 3: Case studies 20
    Phase 4: Cross-sectoral workshops 20
  Stakeholder Advisory Group 20
  Public and patient involvement in the research 20
Chapter 3: Literature reviews 23
  Review 1: Gypsy, Roma and Traveller access to and engagement with maternity, child health and dental health services 23
    Introduction 23
    Methods 23
    Findings 24
  Summary 32

Review 2: A systematic review of reviews of how trust has been conceptualised within health care contexts 34
  Introduction 34
  Methods 34
  Findings 35
  Summary 43
Review 3: Realist synthesis of approaches to community engagement involving Gypsy, Roma and Traveller people 45
  Aims 45
  Methods 45
  Findings 46
  Summary 54
Analytical framework 56
Chapter 4: National online consultation 57
Aims 57
Methods 57
Findings 57
  Respondents 57
  Trust and health service use 60
  Economic evaluation 72
Summary 72
Chapter 5: Case studies 74
Aims 74
Methods 74
Participants 75
Case study 1: Leeds 77
  Context 77
  Participants 78
  Findings 78
Case study 2: Fife 80
  Context 80
  Participants 81
  Findings 81
Case study 3: Sheffield 83
  Context 83
  Participants 84
  Findings 84

Case study 4: London 86
Context 86
Participants 87
Findings 87
Combined thematic analysis of case studies 90
Health status 90
Experiences of healthcare 90
Care that did not meet the mothers' expectations 93
Exercising autonomy 93
Influence of past experiences of services 94
Trust and engagement 94
Enhancing trust 94
Enhancing engagement 97
Summary 102
Chapter 6: Developing recommendations (cross-sectoral workshops) 104
Draft recommendations 104
Cross-sectoral workshops 105
Aims 105
Participants 106
Process 106
Workshop findings 107
Summary 113
Chapter 7: Economic findings 114
Background and objectives 114
Methods 114
Results 114
Costing top feasible strategy 115
Costing top acceptable strategy 116
Summary 118
Chapter 8: Discussion 120
Summary of findings 120
Experiences of Gypsy, Roma and Traveller people's experiences of maternity and early years' health services, and children's dental health services 120
Engagement activities used by health services and third sector organisations to enhance trust and increase uptake of maternity, early years' and children's dental health services by GRT people122
Principles of successful approaches to community engagement to enhance trust in mainstream services 124
Summary of recommendations 125

- Strengths and limitations 126
  - Strengths 126
  - Limitations 127
- Implications 128
  - Policy 128
  - Mainstream health services 130
  - Third sector organisations 131
- Applicability of findings to other socially excluded groups 131
- Further research 132
- Dissemination plan 133

Acknowledgements 134
References 220

List of Tables and Figures

Figure 1: Study flow chart 22
Figure 2: PRISMA diagram Engagement review 24
Table 1: Studies including findings related to maternity services, child health services, or dental health services and those providing detailed data regarding engagement strategies 25
Figure 3: PRISMA diagram 35
Table 2: Trust review included studies 36
Table 3 Assessment of methodological quality of the included reviews using AMSTAR 37
Table 4: Characteristics of trust 38
Figure 4: Conceptual model of trust 43
Table 5: Studies reporting contextual cross-cutting themes 49
Table 6: Programme theory 1: resource sub-themes and study references 50
Table 7: Short examples of C-M-O configurations relating to programme theory 1 51
Table 8: Programme theory 2: resource sub-themes and study references 51
Table 9: Short examples of C-M-O configurations relating to programme theory 2 52
Table 10: Programme theory 3: resource sub-themes and study references 53
Table 11: Short examples of C-M-O configurations relating to programme theory 3 54
Table 12: Analytical framework 56
Table13: Respondents' professional roles 58
Figure 5: 1: Location of respondents' work 59
Figure x.2: Gypsy and Traveller groups that respondents worked with 60
Table 14: Factors related to trust rated as important/very important 61
Table 15: Strategies to enhance engagement with health services rated as helpful/very helpful 65
Table 16. Barriers to engagement with health services rated as significant/very significant 69
Table 17: Cost areas of engagement 72
Table 18: Number of children for each mother participant 76
Table 19: Age of youngest child for each mother participant 76
Table 20: Origins of draft policy option/recommendations 104
Table 21: Participants in the cross-sectoral workshops 106
Table 22: combined acceptability and feasibility scores and ranking of top five priorities 108
Table 23: Implementation strategies for flexible services 111
Table 24: Implementation strategies for sustainable investment 111
Table 25: Combined scores from GT participation event on acceptability of strategies 112
Table 26. Staff costs 115
Table 27. Operational cost 116
Table 28: Activity times and costs for multi-agency forum 117

List of Appendices

Appendix 1: Published protocol……………………………………………………………………………………………134
Appendix 2: Stakeholder Advisory Group……………………………………………………………………………..143
Appendix 3: 4Rs Report………………………………………………………………………………………………………..144
Appendix 4: Published engagement review……………………………………………………………………..…..154
Appendix 5: Engagement review list of databases and search strategy……………………………………….162
Appendix 6: Trust review databases and search strategy……………………………………………………..172
Appendix 7: Online consultation……………………………………………………………………………………………..175
Appendix 8: Case study topic guides………………………………………………………………………………………..208
Appendix 9: Case study findings mapped to the conceptual model of trust…………………………….…211
Appendix 10: Cross-sectoral workshop hand-outs…………………………………………………………………..…213

List of Abbreviations

CEO	Chief Executive Officer
CS	Case study
DHSC	Department of Health and Social Care
EU	European Union
GP	General Practitioner
GRT	Gypsy, Roma and Traveller
Leeds GATE	Leeds Gypsy and Traveller Exchange
HCP	Health care practitioner
I	Interviewer
LGT	London Gypsies and Travellers
NHS	National Health Service
PHE	Public Health England
PPI	Public and patient involvement
R	Respondent
STAG	Southwark Travellers Action Group
TSO	Third Sector Organisation
UK	United Kingdom

Plain English Summary

The UK government wants to lessen differences in health between different groups. So far we do not know much about the needs of groups like Gypsy, Roma and Traveller people, whose health is worse than the rest of the population. We think the reasons why Gypsy, Roma and Traveller people have ill health is because many have poor housing and low levels of education, and experiences of marginalisation. They may even face prejudice and discrimination when they use health services.

We looked at how to improve trust and engagement between Gypsy, Roma and Traveller people and health services. We were especially interested in maternity services, health services for children, and dental care for children.

To do this we looked at other research and we talked to Gypsy, Roma and Traveller women, health professionals such as midwives, health visitors and dentists, and people who work in community organisations. We mostly talked to people in Leeds, Fife, Sheffield and London.

We found that some Gypsy, Roma and Traveller people have good experiences of health care but others have bad experiences. We also found that many children had problems with their teeth. Some had difficulty finding a GP or a dentist who will accept them in their surgeries. Some of the problems Gypsy, Roma and Traveller people face is because of discrimination, or because health professionals don't understand their lifestyle or needs. Everyone thought that trust was very important. However, it can be difficult for Gypsy, Roma and Traveller people to trust health services because of bad experiences they, or their families, or friends, have had.

We found these ways that health services can improve trust and engagement with Gypsy, Roma and Traveller people:

1. Make it easier to register with GP surgeries and dentists, and be less strict when people miss or are late for their appointments
2. Health services should treat everyone, no matter what their background, with respect and kindness
3. Make it easier for people to see the same health professional each time they need care, so that they can get know and trust each other
4. Make it easier for people to get health care when they need it e.g. walk-in services, and to have several problems and several family members dealt with at the same time
5. Health services should work together with community organisations who understand Gypsy, Roma and Traveller people
6. Provide enough funding so that new ways of providing health care for Gypsy, Roma and Traveller people can be tried for several years to see if they work.

We think that these changes to health care will not only improve experiences for Gypsy, Roma and Traveller people, but will also help other marginalised groups with poor health outcomes such as homeless people, vulnerable migrants and sex workers.

Scientific Summary

Background

In 2008, the World Health Organisation Commission on Social Determinants of Health called for 'closing of the gap' in health inequalities within a generation. Reducing health inequalities has been a priority for successive UK governments. The needs of the most marginalised groups have however, been neglected. Gypsies, Roma and Travellers (GRT) are a socially excluded group where evidence for improving health is weakest.

Although GRT communities are diverse, and robust evidence of health needs is lacking due to unknown population size and lack of systematic monitoring, there is consensus that GRT in the UK have poorer health and lower life expectancy than the general population and other disadvantaged groups. Some of the reasons why GRT are vulnerable to poor health outcomes include poor living conditions, high rates of homelessness, low educational achievement, social exclusion and widespread prejudice and discrimination. GRT also face many barriers to accessing healthcare. These multiple factors alongside poor quality care that does not meet healthcare needs may lead to low expectations and mistrust of health services and healthcare personnel. Trust in services and personnel is associated with increased utilisation of healthcare, and improved health behaviours and quality of care. Community engagement strategies have the potential to enhance trust and ensure services are tailored to the needs of specific populations.

This report provides an overview of a multi-component study conducted over four stages that aimed to strengthen the evidence regarding how to improve uptake and delivery of health services and thereby reduce health inequalities for GRT people.

Aims and objectives

This study aimed to investigate which approaches to community engagement are likely to enhance trust between GRT people and mainstream health services. The study focussed on maternity services, early years' health services and child dental health services. The objectives were to:

1. describe activities and methods used to engage GRT in health services and to assess the extent to which they focus on developing trust;
2. investigate the extent to which different engagement activities used by health services enhance trust and increase uptake of maternity services, early years' services and child dental health services by GRT;
3. examine the knowledge, attitudes/beliefs and experiences of GRT of maternity services, early years' services and child dental health services;
4. identify different approaches to enhancing GRT trust in maternity services, early years' services and child dental health services and explore the implications for policy and practice;

5. estimate the potential implementation costs of different approaches to enhancing GRT trust in maternity services, early years' services and child dental health services; and
6. explore whether community engagement approaches that work to enhance GRT trust in maternity services, early years' services and child dental health services are potentially applicable to other health services/vulnerable communities.

Methods

This multi-method 30-month study (June 2015 to November 2017) comprised four interlinked stages. A prior protocol for the study was published in the International Journal for Equity in Health (1) [ref]. The study team were advised throughout by two advisory groups; a Stakeholder Advisory Group comprising health professionals, policy advisors and academics, and a User Advisory Group, hosted by Leeds Gypsy and Traveller Exchange (Leeds GATE), comprising women representing Romany Gypsy, Irish Traveller and Eastern European Roma communities.

Stage one (a series of three literature reviews) [1 Engagement review] a systematic review of GRT peoples' engagement with health services, [2 Trust Review] a review of reviews regarding the concept of trust in healthcare settings, and [3 Realist Synthesis] a realist synthesis of engagement strategies for GRT people in health services.

Stage two (an online consultation). A semi-structured, web-based consultation delivered using the Bristol Online Survey Tool was designed to gather views on trust and engagement in health services for GRT people. The consultation focussed on maternity, early years and child dental services and aimed to elicit the views of three main groups: third sector organisations (TSOs) advocating for GRT; health and social care practitioners, policymakers, and health and social care service commissioners.

Stage three (case studies). We employed a case study methodology to generate in-depth, multi-faceted understanding of the complex issues surrounding enhancing trust and engagement between mainstream health services and GRT communities in their real-life context. Ethics approval was granted by the East Midlands - Leicester Central NHS Research Ethics Committee (16/EM/0028). We conducted four case studies in Leeds, Fife, Sheffield and London between June 2016 and August 2017. We selected the case study sites to reflect maximum diversity of GRT groups, living arrangements, service configuration and examples of good practice in terms of engagement and trust.

Stage four (Developing recommendation for policy with cross-sectoral facilitated workshops). Two cross-sectoral workshops (one in Leeds and one in Edinburgh) were held in September 2017 to sense check study findings and to develop recommendations for policy. In addition to the two workshops we also held a teleconference with participants from the South West of England. Invitations were sent to all those who had engaged with the study by circulating the online consultation, responding to the online consultation and agreeing to further contact, or facilitating recruitment to the case studies. We also invited those who had contacted the study team to express interest in the work, and through the health professional, third sector and academic networks of the research team and the Stakeholder Advisory Group. Stage four also involved considerations of the costs (economics) of providing health care interventions to improve accessibility of NHS services by and for GRT communities.

Results

Stage 1 (Literature reviews).

Review 1 (Engagement review) provides an inclusive account of Gypsy, Roma and Traveller people's access to and engagement with health services. Of the 99 studies included in the review, 49 studies (reported in 54 papers) contained findings relevant to one or more of our focus health services (Maternity; Child health, Dental health). Twenty four of the included studies were undertaken in the UK, five in Ireland and the remainder in 23 countries (22 European countries and Canada). The review has underlined the paucity of intervention studies or any considerations of cost in the literature. 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.

Review 2 (Trust review) provides an overview of the conceptual and theoretical understanding of "Trust" as it applies to any users of mainstream health and social care services. The analysis was based upon data contained in twenty systematic/literature reviews, five of which involved a form of evidence synthesis. All reviews had some deficiencies in elements of methodological quality and reporting. Data from the reviews was accounted for by three overarching categories: 1) overview and characteristics of trust; 2) conditions for and factors associated with trust (related to the patient, the healthcare provider or shared); and 3) outcomes of trust. The review extends existing knowledge and suggests a proto-conceptual model which can be used to understand conditions for and associations with trust between patients and providers and with regard to a number of important outcomes of trust.

Review 3 (Realist synthesis) drew primarily from twenty-six publications identified in the engagement review in which we had identified engagement strategies. Three candidate theories (i. Tailoring; ii. Participation; iii. Trust for promoting use of services) were identified. Twenty-five studies contributed information towards the first programme theory indicating that *tailoring* is of importance when working with the Gypsy and Traveller community given the contextual issues that interplay with services; Seventeen studies contributed towards the second theory indicating that the importance of promoting the *participation* of Gypsies, Traveller and Roma people is particularly important in service design and delivery; Sixteen studies contributed information to the third theory underlining the importance of *trust in promoting use of health services*.

From the three literature reviews, we developed an analytical framework to inform our analysis of the next two stages of the research: the online consultation and the case studies.

Stage 2 (Online consultation)

There were 196 respondents across a broad range of roles and who worked for a wide range of organisations: approximately half (47%) work in England, and approximately a third (32%) in Scotland. Trust was viewed as particularly important in engaging GRT in healthcare services in order to address previous negative experiences and to achieve healthcare delivery goals. A range of findings regarding the views and practices of respondents were gathered regarding: Factors that are related to trust; Barriers to developing trust in health services and how helpful they viewed a number of different strategies are to enhance engagement with mainstream, maternity, early years or child dental services. Respondents were also asked if they were aware of the costs, additional resources or cost-related issues associated with delivering engagement enhancing activities for GRT communities and whilst there were many responses, no specific costs associated with particular interventions were stated.

Stage 3 (Case studies)

Data was collected, analysed and summarized regarding: knowledge, perceptions and experiences of GRT with health services and how uptake could be improved; barriers to GRT accessing health services and how can these be overcome; activities/methods health services use to engage GRT and to what extent they focus on developing and negotiating trust; activities/methods TSOs use to engage GRT and to what extent they influence trust in and access to health services. Data regarding the costs of any activities/methods were also collected where possible but were limited in their nature and scope.

Stage 4 (Cross-sectoral workshops)

Of the total of 49 participants at both workshops (not including the research team), just over half were from the health sector including national policymakers, service commissioners, and frontline practitioners. Across all the participants there was representation from maternity, child and dental health services and primary care. Overall respondents agreed that the main study findings were consistent with their experiences and with previous research. Discussions with the participants indicated that the draft recommendations were largely acceptable, but that some may be less feasible than others or difficult to implement in certain sectors. The scoring exercise at the community participation event exercise was particularly valuable to ensure that recommendations make sense to community members. As a way of illustrating more in-depth cost analysis around recommendations, the most acceptable and feasible strategies from the two workshops were also considered. Based on an exploratory cost analysis, it is not possible to draw conclusions about whether the proposed strategies represent an efficient use of NHS resources. Cost-effectiveness decisions require taking into account all relevant outcomes of the strategies, mainly health benefits but possibly other non-health benefits as well. Although effectiveness analysis was not part of this exercise, evidence on cost-benefits analysis comparing current practice and improved pathways for Gypsy, Roma and Traveller communities suggest that up-front investment can pay for itself many times over in the longer term.

Recommendations

The key recommendations that were judged to be acceptable and/or feasible by our GRT, HCP and TSO participants are:

1. Sustain investment in projects and initiatives to allow relationships and trust to develop and continue;
2. Increase collaborative working with those that already have trusted relationships with GRT communities e.g. individuals from third sector organisations, individual health or other sector professionals;
3. Develop minimum standards of courtesy for all health service personnel including first points of contact e.g. receptionists, helpline staff;
4. Simplify GP and dentist registration e.g. allow c/o addresses, flexible requirements for proof of address; and develop less punitive approaches to dealing with non-attendance or arriving late for appointments;
5. Introduce literacy help cards throughout NHS (cards that can be presented to front line staff or receptionists to ask for discreet help with form-filling etc.) and provide alternatives to written information;
6. Enhance GRT people's health literacy: e.g. awareness of health service-user rights, tips on how to communicate with healthcare professionals and confidence to ask questions
7. Use engagement with routine maternity and child health services to deliver wider health messages, especially relating to child oral health
8. Provide flexible services e.g. flexible times/'drop-in' services/multiple access routes, one-stop shop

Conclusion

This study aimed to investigate which approaches to community engagement are likely to enhance trust between GRT and mainstream health services, and focussed on maternity services, early years' health services and child dental health services. It has involved the search, retrieval and analysis of a wide range of literature and consultation with a wide range of stakeholders. Existing literature in this area is limited but does provide some data to understand the key barriers to GRT people accessing health services, in identifying possible strategies and in understanding the conditions for and associations with trust between patients and providers. Our analysis indicates that whilst tailoring and trust in promoting use of health services is of importance when working with the GRT community, their participation in service design and delivery is particularly important. In this study we have captured a wide range of views and experiences regarding the best ways to promote, enhance and sustain trust and have distilled a number of key principles and recommendations to guide future policy development in this area. We have also highlighted how our findings related to GRT communities are applicable to other disadvantaged and marginalised groups.

Chapter1: Background

The research reported here focussed on community engagement to enhance trust between Gypsy, Roma and Traveller (GRT) communities in the UK and mainstream health services. To explore this, the study used maternity services, health services for children under the age of five and child dental health services as exemplars of mainstream health services. Throughout this report we use the nomenclature 'Gypsy, Roma and Traveller' to include groups with diverse histories, cultural, and linguistic backgrounds such as Romany Gypsies, Irish Travellers, Sinti, Bargees/Boat dwellers, New Age Travellers, and migrant Roma populations, who nevertheless have in common that they self-identify as Gypsy, Roma or Traveller, and have a cultural tradition of nomadism, even if they no longer travel. However, we acknowledge the contested nature of the terms recognising that they have different meanings in different contexts (2).

Size of the Gypsy, Roma and Traveller population in the UK

The challenges of defining and identifying the GRT population mean that precise figures for the size of the population living in the UK are not available. Gypsy and Traveller were included as census categories for the first time in 2011 and identified 58,000 Gypsy/Travellers living in England and Wales (3). Similarly, the Scottish census identified a population of 4,200 (4). However, these are considered to be gross underestimates due to the reluctance of many to self-identify because of the associated stigma (5). A survey undertaken by Brown et al (6) estimated that in 2012 there were at least 197,705 migrant Roma living in the UK. The Council of Europe estimate from 2012 (7) of between 150,000 and 300,000 GRT people living in the UK is probably also a conservative estimate and Brown et al (6) estimated the total population size to be 400,000 – 500,000. Thus the GRT population comprise a significant minority group in the UK.

Health and health service uptake of Gypsy, Roma and Traveller people

Despite the challenges highlighted above leading to a lack of robust evidence, numerous studies have found that GRT people have much poorer health outcomes leading to lower life expectancy than either the general population or other disadvantaged groups in the UK (8-13), including other minority ethnic groups. For example, in Leeds, average life expectancy for Gypsies and Travellers was estimated to be 28 years less than the general population (13). Poor health outcomes for women and children include increased maternal and child mortality (9, 12, 14). The All Ireland Traveller health study found that the infant mortality rate for Travellers in Ireland was almost four times higher than in the general population (15). Gypsy, Roma and Traveller children have the poorest health of any group in the UK with high rates of accidental injury and infections; high rates of accident and emergency department attendance (11, 16), low/variable uptake of childhood immunisations (17, 18), and significantly increasing risk of vaccine preventable disease (18, 19). Gypsy, Roma and Traveller people also have poor dental health, high unmet need and low dental registration (20, 21).

Reasons why GRT people are vulnerable to poor health outcomes, even when compared to other disadvantaged groups, include unsuitable accommodation and homelessness, low educational achievement, social exclusion and widespread prejudice and discrimination (22). Low uptake of preventative health services including antenatal and postnatal care, family planning, childhood developmental assessments and dental health services is a major contributing factor (14, 23).

Increasing uptake of maternity, early years and child dental health services can improve health and quality of life, reduce lifetime inequalities and improve health across the life-course, while delivering social and economic benefits (24-26). Poor childhood dental health impacts negatively on quality of life (27) including growth and cognitive development, by interfering with nutrition, concentration and school participation (28, 29). It has been suggested that increasing access to services for women and children may indirectly improve men's access (10).

There is evidence that GRT people face multiple barriers to accessing appropriate and responsive health services (11, 23), with particular problems when accessing maternity, early years and child dental health services (10). A mobile lifestyle contributes to underutilisation of healthcare (14). However, poor access is also experienced by settled GRT communities underpinned by complex factors including stigmatisation and lack of understanding by healthcare staff (10, 23, 30, 31). Furthermore, GRT people's health needs may be invisible due to lack of systematic monitoring (9, 32). Reported cultural barriers include normalisation of ill-health and pride in self-reliance (33), however it is unclear how these interact with social exclusion, poverty and poor living conditions (34).

Due to these complex barriers, interventions that work to increase the engagement of other disadvantaged populations may not work for GRT communities. Furthermore, poor quality care that does not meet healthcare needs may lead to low expectations and mistrust (23, 35).

Trust and Community Engagement

The role of trust between service-users, and health services/healthcare practitioners (HCPs) may be important for increasing uptake of health services and has also been linked to healthier lifestyle choices as well as improved quality of care (36-38). One approach to developing trust between service-users and health services is community engagement, which can also promote services that are tailored to the needs of specific communities (39-41). In this report we use the term "community engagement" to signify actions that aim to involve communities in making decisions that affect their lives. This includes design, delivery and evaluation of health services (39-41). Guidance from the National Institute for Health and Care Excellence suggested that community engagement can make services more effective, cost-effective and sustainable and increase uptake (42). However, evidence is lacking on how community engagement can enhance trust. Lessons from the Pacesetter Programme suggest that trust and confidence can be lost if community engagement is tokenistic (43).

Policy context

Reducing health inequalities through improving the health of the poorest is a government priority (44) and GRT communities have been identified as one of the most socially-excluded groups with the poorest health outcomes but where the evidence is weakest (45, 46). However, while the government commitment is clear, policy in this arena struggles to have an impact, especially on the lives of those who are most marginalised.

Public Health England (PHE), an executive agency of the Department of Health and Social Care (DHSC) has a remit to improve health and to reduce health inequalities. A 2017 report by PHE highlights the association between deprivation and inequalities in health particularly in life expectancy (47). The same report also indicates that as well as a social gradient in life expectancy there are also geographical differences whereby life expectancy is lower in the north of England compared to similarly deprived areas in the south. A health equity report by PHE focussed on ethnicity (46) emphasises the lack of data on health outcomes for GRT people. In fact the only indicator for which there is data is school readiness and this show that GRT children were twice as likely to not be ready for school compared to the average for all ethnic groups.

The Equality Act 2010 (48) is also of relevance to discrimination experienced by GRT people in their daily lives and when accessing service including health services. The Equality Act legally protects people from discrimination in the workplace and wider society and the related public sector Equality Duty, which came into force in 2011, requires public bodies (including the NHS and Local Authorities):

> *to consider all individuals when carrying out their day-to-day work – in shaping policy, in delivering services and in relation to their own employees. (49)*

It also requires public bodies to have due regard to eliminating discrimination and fostering good relations between different people in in everything they do (49, 50). The Equality and Human Rights Commission provides a measurement framework, which is applicable to England Scotland and Wales, to monitor progress against six domains, one of which is health (51). The health domain within the measurement framework specifically identifies: health outcomes; access to healthcare; mental health; reproductive and sexual health, and palliative and end-of-life care.

The social marginalisation and discrimination experienced by GRT people, both in accessing healthcare and in their everyday lives can also be set in the context of international human rights and equality frameworks increasingly employed to articulate the needs of those with ill-health and disability:

> *Disability results from the interaction between persons with impairments and attitudinal and environmental barriers that hinders their full and effective participation in society on an equal basis with others. (52)*

Here there is an emphasis on providing a facilitative environment and improved quality of life, thereby encouraging people to ‘flourish.’ More specifically related to health services, the World Health

Organization (WHO) enshrines a right to ‘access to timely, acceptable, and affordable healthcare of appropriate quality’ (53).

Also of relevance to the health of GRT people is the acknowledgement that most health inequalities are due to the social determinants of health i.e. the circumstances and conditions that impact on individuals across their life-course from birth, through childhood, adulthood and employment, and old age. The WHO identifies nine key concepts relevant to the social determinants of health (54), six of which are particularly relevant for our work: social exclusion; public health programmes and social determinants of health; women and gender equity; early child development; health systems; and measurement and evidence. Recognition of the social determinants of health underpins an approach to public health that supports change and is sensitive to context. Interventions tackling underlying causes of ill-health and health inequalities can transform lives by reducing social and environmental barriers and encourage people to take a proactive approach to health and well-being (55).

Chapter 2: Study aims and overview of methods

Study aims

The overarching aim of the research was to examine which approaches to community engagement are best at enhancing GRT peoples' trust in mainstream health services. To provide focus to this broad aim, we used maternity and early years' health services, and children's dental health services as exemplars of mainstream health service provision.

Study objectives

The specific objectives of the research were to:

1. Describe activities/methods that are currently used to engage GRT people in health services and assess the extent to which they focus on developing and negotiating trust;
2. Investigate the extent to which different engagement activities used by health services enhance trust and increase uptake of maternity and early years' and children's dental health services by GRT people;
3. Examine the knowledge, attitudes/beliefs and experiences of GRT people of maternity and early years' and children's dental health services;
4. To identify different approaches to enhancing GRT peoples' trust in maternity and early years' and children's dental health services s and explore the implications for policy and practice;
5. Estimate the potential implementation costs of different approaches to enhancing GRT peoples' trust in maternity and early years' and children's dental health services;
6. Explore whether community engagement approaches that work to enhance GRT peoples' trust in maternity and early years' and children's dental health services are applicable to other health service provision (e.g. mental health services) and/or other vulnerable communities (e.g. vulnerable migrants, homeless people).

Overview of methods

Based on the published study protocol (1) (Appendix 1), below is a summary of the multiple methods used along with signposting of where in the report details of the methods and findings of each component can be found. The study methods are represented in Figure 1.

Phase 1: Literature reviews

This phase comprised three related literature reviews:

Review 1: examined all available primary empirical literature regarding any aspect of GRT peoples' access and use of mainstream health-related services. This review has been published (56). It also included sub-sections that focussed on a) maternal and early years' health services; and b) child dental health services (Chapter 3);

Review 2: was a systematic review of reviews that examined how ‘trust’ has been conceptualised and theorised in any health care setting with a focus on primary studies that were informative about the relationship between vulnerable communities and mainstream health and social care services (Chapter 3);

Review 3: was a realist synthesis of community engagement approaches to enhance trust and increase participation of GRT peoples in health care services to provide a framework for explaining and understanding the complex and multi-faceted nature of engagement with health services. Reviews 1 and 2 provided a sampling frame for this review (Chapter 3).

Phase 2: National online consultation

A semi-structured web-based questionnaire sought views on how to enhance trust in mainstream services, the range of activities/methods used by maternity and early years’ health services, and children’s dental health services to engage GRT people and any associated costs; views of the success of different approaches to developing trust; and barriers to and suggested strategies for enhancing trust (Chapter 4).

Phase 3: Case studies

Four case studies comprising in-depth interviews; focus group discussions and telephone interviews with GRT people, healthcare practitioners and third sector organisations (TSO), and document analysis were conducted to explore in-depth community engagement and trust in health care for GRT people, and to understand experience of providing and receiving health services. The case studies were selected to reflect maximum diversity and examples of good practice (Chapter 5).

Phase 4: Cross-sectoral workshops

Stakeholders from backgrounds including health and social care practitioners, service managers and commissioners, policy-makers and TSOs attended workshops to add prioritise, and add context and explanation to the study policy options/recommendations, identifying barriers and positive strategies (Chapter 6).

Stakeholder Advisory Group

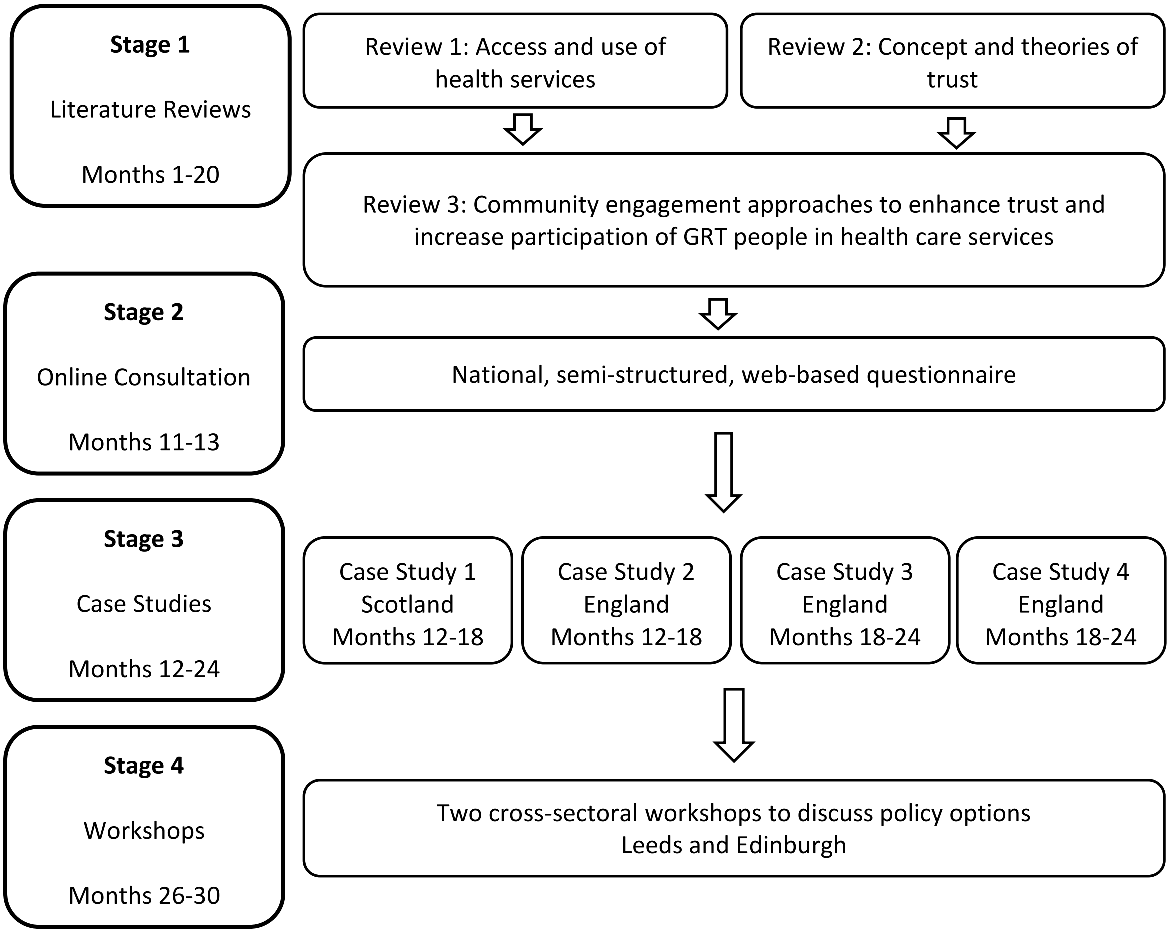
A Stakeholder Advisory Group guided the study team on all aspects of the research. The group comprised health care practitioners, and academics with expertise in community engagement, public and patient involvement in health services, and Gypsy, Roma and Traveller research (see Appendix 2 for list of members of the Stakeholder Advisory Group).

Public and patient involvement in the research

There has been public and patient involvement (PPI) throughout the conception, design, conduct and interpretation of this research following INVOLVE principles (57). We used four strategies to ensure this involvement:

1. The profile of the study team which included the Chief Executive Officer (CEO) of Leeds Gypsy and Traveller Exchange (Leeds GATE), a community members' organisation that works to improve the lives of Gypsies and Travellers in West Yorkshire and beyond. The CEO was involved in the study from its first conception to its completion and will remain involved in disseminating the findings. The CEO also played a critical role in facilitating relationships with three of the four case study sites;
2. A User Advisory Group comprising women representing the Romany Gypsy, Irish Traveller and Eastern European Roma communities and hosted by Leeds GATE met four times during the study and reviewed the documents submitted for ethics approval (participant information sheets, informed consent forms, and interview topic guides), and advised the study team on the conduct and interpretation of the findings, and disseminating the findings;
3. We held two advocacy training workshops to support the User Advisory Group and the wider GRT community to participate in research. The first, held in October 2015, brought together GRT people, members of TSOs, and academic researchers to discuss the four R's of research (Research, Rights, Respect, Results). The output of this event was a 'Do's and Don'ts' Guide to of Conducting Research with GRT communities (see Appendix 3). The second was held in November 2017 and brought together GRT people, members of TSOs and the research team to discuss experiences of participating in the research, to inform the recommendations of the research and methods of dissemination and to identify topics for future research that are important to GRT communities.
4. We included individuals from third sector organisations who represented and advocated for GRT communities in the online consultation, the case studies and the Stakeholder workshops. Further detail of how these representatives and advocates contributed their views to the research is detailed in the relevant chapters of this report.

Figure 1: Study flow chart



Chapter 3: Literature reviews

Review 1: Gypsy, Roma and Traveller access to and engagement with maternity, child health and dental health services

Introduction

We conducted an overarching review examining the range and nature of studies on how GRT people access and engage with a broad range of health services, and which describes the best evidence for ways to enhance GRT peoples' engagement with health services. The review is published in full in the International Journal of Public Health (56) and presented in Appendix 4. The overarching review included 99 studies. Here we report the findings of the subset of studies relevant to maternity services (23 studies); child health services (30 studies); and dental health services (20 studies).

Methods

Detailed methods are described in McFadden et al (56). In summary, in 2015 searches were conducted by York Health Economics Consortium (YHEC) in 21 databases along with a focused Google search to identify relevant research on NHS and UK Government sites. The reference lists of relevant reviews identified in the search was also examined for publications meeting the inclusion criteria. See Appendix 5 for the details of the search strategy and the list of databases searched. All study designs were included and we considered research studies as well as reports and assessments, provided they met the inclusion criteria: (i) reported empirical, primary findings (ii) adequate focus on Gypsies, Travellers or Roma populations (where other groups were included in the study, separate data must have been presented for GRT people); (iii) included data pertinent to health care service utilisation or engagement; (iv) published in the English language; (v) published from the year 2000 onwards. Publications were excluded if they did not report empirical, primary findings (review papers were excluded although reference lists of any reviews were searched for primary studies), methods and data, did not have a sufficient focus on GRT people, or health care.

Titles, abstracts and relevant full text papers were screened independently by two reviewers and discrepancies discussed with a third reviewer. Studies that had findings relevant to our focus on maternity, child health and dental health services were identified and relevant data extracted by one reviewer, then checked by a second reviewer. Data were analysed thematically to identify findings related to barriers to and facilitators of engagement with health services and are presented narratively. We selected papers that contained detailed examples of engagement strategies (defined as initiatives or pathways) which could facilitate Gypsies', Travellers' or Roma people's access to or use of maternity, child health or dental health services and data were extracted relating to the aims, procedures, and outcomes where available.

We conducted an assessment of study quality of those studies providing a detailed account of engagement strategies.

Findings

Of the 99 studies included in the overarching review (56), 49 studies (reported in 54 papers) contained findings relevant to one or more of our focus health services. Figure 2 shows the study inclusion process.

Figure 2: PRISMA diagram Engagement review

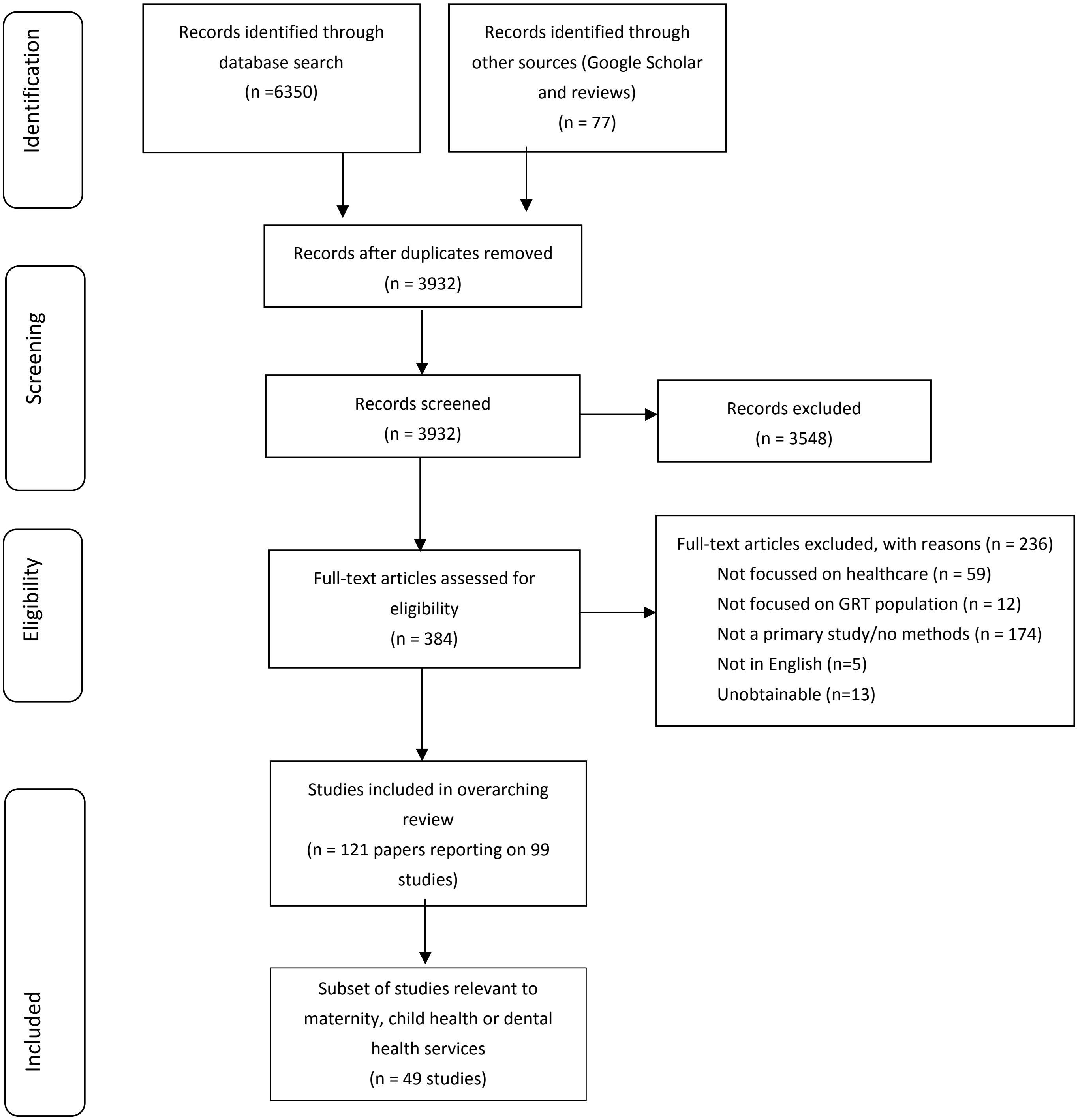


Table 1 lists the included studies. Twenty four of the included studies were undertaken in the UK, five in Ireland and the remainder in 23 countries (22 European countries and Canada).

Table 1: Studies including findings related to maternity services, child health services, or dental health services and those providing detailed data regarding engagement strategies

First author and year	Countries	MS	CHS	DHS	ES
All Ireland Traveller Health Study Team 2010, 2011 (15, 58)	Ireland, UK	√	√	√	√
Balazs 2012 (59)	Hungary	√			
Beach 2006 (16)	UK		√		
Colombini 2012 (60)	Albania, Macedonia, Bulgaria	√			
Cullen 2008 (61)	UK			√	
Dartnall 2005 (62)	UK	√	√		
Dental Department, HSE Dublin Mid-Leinster 2007 (63)	Ireland			√	√
Doyal 2002 (8), Gallagher 2011 (64)	UK	√	√	√	√
East Riding Local Strategic Partnership 2008 (65)	UK			√	
Ekuklu 2003 (66)	Turkey	√			
Ercoli 2015 (67)	Italy		√		
European Monitoring Centre on Racism and Xenophobia 2003 (68)	16 European countries including UK	√			√
Flecha 2013 (69)	Spain		√		√
Friends, Families and Travellers 2013 (70)	UK	√			
Gray 2013 (71)	UK		√		
Greenfields 2013 (72)	UK	√	√	√	√
Griffiths 2013 (73)	UK			√	√
Gyukits 2006 (74)	Hungary			√	
Idzerda 2011 (75)	Serbia		√		
Janevic 2011 (76)	Macedonia, Serbia	√			
Jarosova 2009 (77)	Czech Republic	√	√	√	√
Kanapeckiene 2009 (78)	Lithuania, Latvia		√		
Kipping 2013 (79)	UK			√	
Kosa 2007 (80)	Hungary			√	
Kraigher 2006 (81)	Slovenia		√		
Logar 2015 (82)	Slovenia	√			√
Lomax 2000 (83)	UK		√	√	√
Maltezou 2012 (84)	Greece		√		
Mellou 2015 (85)	Greece		√		
Monasta 2005 (86)	Italy	√	√	√	√
NHS Leeds West Clinical Commissioning Group 2015 (87)	UK	√			
Office for Public Management 2010 (88)	UK	√	√	√	
Papadopoulos 2007, 2005 (89, 90)	UK		√	√	
Parry 2004, Peters 2009 (12, 91)	UK	√	√	√	
Pavlovski 2008 (92)	Macedonia	√	√		
Rechel 2009 (93)	Bulgaria	√	√		
Reid 2007 (94)	Ireland	√	√		
Sedlecky 2015 (95)	Serbia	√			√
Short 2007 (96)	Bulgaria		√		
Sigerson 2013 (97)	UK		√	√	√
Sivic 2013 (98)	Bosnia & Herzegovina		√	√	
Smith 2013, Ruston 2013 (99, 100)	UK		√		
Tavares 2001 (101)	UK		√	√	√
Thomason 2006 (102)	UK			√	
Twiselton 2009 (103)	UK			√	
Van Cleemput 2010 (43)	UK	√			√
Van Cleemput 2010 (22)	UK		√		
Van Hout 2010 (104)	Ireland	√	√		√
Walsh 2011 (105)	Canada	√	√		

Key: MS – maternity services; CHS – child health services; DHS – dental health services; ES – provided detailed data regarding Engagement Strategies.

Twenty three studies provided data specifically regarding maternity services, 30 studies specifically regarding child health services, and 21 studies specifically regarding dental health services. In total 16 studies provided detailed data regarding engagement strategies: regarding maternity services (10 studies), child health services (7 studies), and dental health services (10 studies).

As there were many common themes across our three focus health services, we have mostly combined the findings in our narrative account and highlighted where there were differences.

Uptake of services

Overall it appeared that Gypsy and Traveller women in the UK are offered maternity care. However some studies found that Gypsy and Traveller women may access antenatal care late in pregnancy (58, 62, 106), and that this might be age-related with younger women more likely to attend at an earlier stage (62). Health professionals in the All Ireland Traveller health study felt that Travellers were as likely, or more likely to engage with antenatal and postnatal services than other groups (107). In contrast, Van Hout (104) found evidence of lack of uptake of antenatal care by Travellers in Ireland. There was anecdotal evidence of a woman who was not registered with a GP, using accident and emergency services instead (70). Peters et al (91) found that Gypsies and Travellers and African Caribbean participants had a higher use of midwife services than participants from the White population and Pakistani Muslim population; though the authors acknowledge that this may be due to higher fertility rates. Evidence relating to Roma women's use of maternity services in Eastern and Central Europe suggests that in general, Roma women engage less with maternity services than non-Roma women (59, 82, 93, 95). For example, in a study in Serbia, 6% of Roma women compared to 1% of non Roma women had no antenatal appointments (95), and in a study in Turkey (66), slightly more non-Roma than Roma women (92.9% and 82.9% respectively) had home visits from midwives.

For child health services, a number of Ireland- and UK-based studies indicated that parents place more importance on appointments for children compared to for their own health (22, 88, 89, 99, 107). The All Ireland Traveller health study (15) found that 59.5% of Traveller infants required additional contacts with a health visitor/public health nurse and that some Traveller children were not treated for health problems. Children's accident and emergency use rates were measured in a number of studies. Beach (16) found that Gypsy and Traveller children attended accident and emergency departments more than twice as often as non-Gypsy and Traveller children. The All Ireland Traveller Health study (58, 107) found that attendance rates in the last 12 months for Traveller children to accident and emergency were 41% in Ireland and 47.6% in Northern Ireland.

The All Ireland Traveller health study (58) found that rates of immunisation for five-year old Traveller children were 3% in Ireland and 6.6% in Norther Ireland. A study by Kraigher et al (81) in Slovenia reported lower levels of vaccination among pre-school aged Roma than the general population. In contrast, Maltezou et al (84) found that Roma mothers in Greece were more likely to accept the influenza vaccination for neonates than non-Roma mothers. Monasta (86) explored access to vaccination for Roma living in camps in Italy and found acceptance of vaccinations across study sites, and a request for the influenza vaccine in one site.

There was less information relating to use of dental health services but low rates of registration and uptake of services was the most common theme. In the UK, a study by Greenfields and Lowe (72) reported that of 66 Gypsy and Traveller people surveyed, less than half visited the dentist at least annually. While one survey reported that 68% of residents on three Traveller sites said they did not find it difficult to find a dentist (65), other studies reported low levels of registration (79, 102, 103). A study that examined the health and healthcare use of Travellers in Ireland found that, in the previous twelve months, 36.4% of five year olds, 60.9% of nine year olds, and 59.4% of 14 year olds living in the Republic of Ireland had seen a dentist; compared to 78.1% of five year olds, 76.9% of nine year olds, and 71.4% of fourteen year olds living in Northern Ireland (58). Qualitative findings pointed to Gypsy and Traveller children having poor teeth (88) as did a health needs assessment of Gypsy and Traveller people in Leeds (101). There were similarly low levels of uptake of dental services for Roma populations reported in Hungary (80) and Bosnia and Herzegovina (98). A study by Monasta (86), found that dental caries were a main issue for Roma children living in camps, even when very young.

Experiences of care

There were examples of positive experiences of maternity services (62, 72, 82, 88) and child health services, especially health visitors (83, 88). For example participants in Greenfields and Lowe (72) reported positive feelings towards maternity care staff, indicating that some are culturally aware and perhaps less prejudiced than staff in other services. There were reports that Gypsy and Traveller women felt positively about health visitors and child health services (88); and likewise Lomax et al (83) found that health visitors were regarded positively, mentioning flexible and non-interfering support. While there was very little information on experiences of dental health services, in one study, those registered with dental health services were happy with their dental care (88). There was indication of relationship building between doctors, dentists and health visitors and participants living in temporary accommodation in the study by Cullen et al (61), however transience affected the continuity of these relationships.

However, other studies indicated negative experiences of maternity and child services such as feeling ignored and neglect of emotional needs (71, 94, 100); being patronised or given orders rather than advice (62); and dissatisfaction the quality of care and staff competence (105). A study in Serbia and Macedonia (76) suggested that the level of care provided to Romani women was poor. Dartnall et al (62) found that some Traveller women felt that postnatal care was interfering and unnecessary. Papadopoulos and Lay (89) found a lack of trust between Traveller women and health visitors, where no previous relationship existed. Smith and Ruston (99) found that Travellers who were refused registration at a GP practice, indicated a fear of being thought overprotective or physically abusive towards children in attending accident and emergency.

Barriers to engagement with maternity services, child health services and dental health services

The barriers to engaging with maternity are very similar to those reported for all services (56) and included health system barriers, discrimination and attitudes of health care staff, cultural and language barriers, health literacy issues, service-user attributes; and economic barriers.

Health system barriers

Difficulties registering with a GP is a barrier in the UK, because mostly GPs are the gateway to maternity services (12, 62, 93, 94). Greenfields and Lowe (72) found that some Travellers did not have access to a health visiting service, while Tavares et al (101) reported that health visitor services were impacted by a high turnover of staff. Difficulties finding and/or registering with a dentists (e.g. due to lack of a postcode, difficulty completing forms or changing location) were reported in several UK studies (61, 72, 83, 88, 89, 102, 103). These difficulties resulted in some Gypsy and Traveller people travelling outside their locality to access dental health services. Five out of eighteen Gypsy/Traveller adults interviewed in Scotland by Griffiths and Caldwell (73) did not know how to get a dentist. Some of these respondents felt they had problems with their teeth. Access to emergency dental care was also found to be difficult (88). The All Ireland Traveller health study found that some Travellers had difficulties obtaining a medical card and that this could be a barrier to accessing private dentists (58). Greenfields and Lowe (72) reported that recording of ethnic status is not used in dentistry meaning there is little data to help monitor needs and plan services.

Lack of necessary documentation such as resident's permits or health cards was a common barrier to child health services for Roma people in some European countries (86, 93, 105). Idzerda et al (75) noted that accessibility of primary care is adversely affected by rurality for Roma in Serbia. A study in Bulgaria, (93) noted lack of availability of primary care to Roma children living in ghettoes, and that barriers exist in relation to travelling to a GP. Mellou et al (85) noted a lack of availability of resources to vaccinate Roma children living in camps.

Discrimination and attitudes of health care staff

Several studies indicated that perceived or experienced discrimination or racism influenced use of maternity services. The study by the European Monitoring Centre on Racism and Xenophobia (68) found contrasting opinions on whether healthcare for Roma was discriminatory, with non-government organisations and policy participants indicating that treatment is different for Roma, but health providers suggesting treatment is the same. The same study (68) reported segregation of some Roma patients in maternity wards which patients indicated was racism but health professionals suggested was for comfort.

Cultural and language barriers

Some of the findings pointed to lack of cultural and lifestyle understanding and awareness from health professionals (43, 94, 106). One study indicated tensions between health services and service users concerning the number of family visitors to the maternity ward (68), while Reid and Taylor (94) indicated that integrating a baby to the Traveller community may be easier if visitors are not restricted to family and friends. Some cultural beliefs, including those around purity, may be a barrier to some Roma women engaging with pregnancy-related care (68).

Some Travellers may prefer to rely on themselves or others in their communities rather than health services (62, 82, 94). Preference for same gender health care providers may be a barrier to some women attending appointments with male health providers (62). Similarly men may experience barriers to engaging with maternity or antenatal services where women's health issues are discussed as childbirth is considered an issue for women (62, 82, 94). Gender inequality may also impact women's ability to attend to their own health needs; Romani culture was described as patriarchal (76). Examples of this include families inhibiting women's access to abortion, lack of access to finances, and lack of autonomy to make choices about reproductive and sexual health (60, 76, 82). Reid and Taylor reported that women may rely on their husbands to attend antenatal appointments (94).

Health literacy issues

Communication issues may also impact on uptake of services. For example, Reid and Taylor (94) found that women could not read available health promotion literature, and the study by NHS Leeds West Clinical Commissioning Group (87) highlights challenges around use of touch screens in GP surgeries, as well as confusion around terminology that had serious medical consequences. Janevic et al (76) reported that Romani participants found it difficult to understand doctors, whereas gynaecologists assumed that Romani women did not listen or comply. Poor literacy (71), lack of knowledge about certain available services (72) and lack of understanding in relation to information provided (62) were noted and may affect ability or willingness to access services.

A study by the Office for Public Management (88) found a lack of understanding in relation to caring for teeth, while Papadopoulos and Lay (89) suggested that Gypsy and Traveller people may pull out their own teeth if they cannot find a dentist. Greenfields and Lowe (72) reported that 53% of 66 Gypsies and Travellers surveyed attempted to treat dental problems themselves, including by pulling teeth (men in particular), painkillers and herbal medicine. The same study also noted a preference to attend accident and emergency if experiencing dental problems, rather than an emergency dental service (72).

Service-user attributes

Several studies suggested individual reasons that services are not accessed. For example Rechel et al (93) found that GPs did not visit Roma newborns because the service was not requested. Fear may act as a barrier to attending services for some, including fear of being judged, discrimination or social service intervention (62) or fear of disease, particularly in the case of children (82). Embarrassment or shame may also influence use of health services, including antenatal class attendance (94). Janevic et al (76) found that low self-efficacy may affect use of maternal health care in that Roma women may not feel able to influence the interaction with health providers or their own health. Additionally, women may not complain about negative treatment they have received, and low self-esteem may influence women to feel responsible for being treated negatively.

Finally, the findings indicate that negative experiences such as those described above may impact on future use of services. Reid and Taylor (94) found that women who had felt intimidated by maternity service experiences wanted to delay any further involvement.

Economic barriers

Economic barriers were also evident in the findings, although mainly evident outside the UK where health care is not free at the point of delivery, for example poverty and inability to afford private healthcare in Serbia and Macedonia (76). Additionally, informal payments for services that should be free are requested by some providers (76). Need for childcare may affect women's ability to attend healthcare (82, 94). Greenfields and Lowe (72) found that cost of dental treatment in the UK could be a barrier. The All Ireland Traveller health study (58) reported economic barriers to children receiving healthcare. Walsh et al (105) also pointed to costs associated with healthcare in relation to paying for documentation to access services.

Strategies for enhancing access to health services

Consistent with McFadden et al (56), we grouped the findings related to ways of enhancing GRT engagement with health services by six categories of strategies: specialist roles; outreach services; dedicated services; raising health awareness; handheld records; and staff training.

Specialist roles

A number of the studies include information on specialist roles. Van Cleemput et al (43) described an initiative in England in which 30 Gypsy and Traveller community members received training to become Health Ambassadors. Their role included delivering training on Gypsy and Traveller culture to health staff, including student midwives. The training was evaluated positively by attendees and there was some evidence that practitioners had identified potentially useful ways of delivering care, such as ensuring community members have a named community midwife (43). Jarosova et al (77) reported an initiative in the Czech Republic in which 20 women who had a trusting relationship with the Roma community became Romany health and social assistants. The role included motivating and educating community members in relation to health practices, including in pregnancy. The outcomes of the assistant's work included increased preventative health appointments, including with the GP and gynaecologist, facilitating access to health information and increased trust in doctors. Sedlecky and Rasevic (95) included participants who held the role of Roma Health Mediators in Serbia. A main aim of this role was to improve Roma people's knowledge about accessing health services. The Mediators receive training and work with primary health care centres and within Roma settlements. In the study by

Dartnall et al (62), some Romany women had a health advocate who encouraged them to engage with the midwife for antenatal care. When there was no health advocate available this could make attending appointments more difficult. In Greenfields and Lowe (72) potential value was noted for health advocates. In Gray and Donnelly (71) participants increased their knowledge through the assistance of support workers but also other community members. An evaluation of a Romany health and social assistant course in the Czech Republic (77), the aims of which included educating and motivating community members around healthcare, found that positive outcomes included an increase in the number of Roma attending preventative dental examinations.

Outreach services

Participants in Greenfields and Lowe (72) suggested that increasing the number of health services, including midwife services, provided on sites would be 'culturally friendly' way to engage. Outreach health visiting services, sometimes incorporating breastfeeding support or immunisation services were reported by several studies (64, 83, 89, 97). Participants in Greenfields and Lowe (72) pointed to the value of health professionals, including dentists, attending the Travellers site to deliver health services. Text-reminders for dental appointments were also seen as a good idea. Papadopoulos and Lay (89) and Parry et al (12) suggested that Gypsies and Travellers would find outreach dental services beneficial. Indeed, Travellers in Lomax et al (83) found that a health clinic provided to site that involved dental service was helpful. The use of mobile dental care was also mentioned in Doyal et al (8) and Gallagher et al (64). Sigerson and Sayed (97) described an oral health promotion project delivered to a number of sites in Scotland. An oral health promoter working in Scotland (73) discussed collaborating with other professional colleagues such as the Child Smile initiative team to make introductions to the Gypsy and Traveller community.

Dedicated services

Some studies included examples of how services might be dedicated or tailored towards community members. In a study of health service provision within local authority/primary care trusts in England for Gypsy/Travellers, 13 out of 14 respondents indicated that there were specific services in relation to antenatal appointments (64). In Serbia, Romani women may access gynaecological services and a pregnancy counsellor via a non-governmental organisation as an alternative to mainstream services (68). In Greenfields and Lowe (72) potential value was noted for specialist health visitors. A study by Gallagher et al (64) in the South West of England found that some local authorities or primary care trusts provided dental health services specifically for Gypsy/Traveller communities. Greenfields and Lowe (72) surveyed health professional about ways to facilitate service delivery for Gypsies and Travellers, and participating dentists indicated there was some interest in GRT health consultants. In interviews with Gypsy/Travellers in Fife, Scotland it was suggested that a drop-in service involving dentists and other health professionals would be beneficial (73).

Raising health awareness

In Logar et al (82) Roma women participated in a reproductive health-based educational programme offered at the health centre and in the Roma settlement where participants lived. The findings suggest a positive attitude from the women towards the programme and an interest in discussing how to take the programme forward. They also offered advice on ensuring the success of the programme, including focussing on women's health, pregnancy, delivery, breastfeeding and child care, rather than on diseases; holding the programme in the settlement on a repeated basis; utilising different formats (discussion, workshops, presentations); and involving only women. A number of facilitators of engagement with services focussed on increasing knowledge and understanding in relation to health and provision of support to community members. Flecha (69) evaluated a study of education-related provision for Roma in Spain and found that participation in the project led to increased communication and awareness about children's health. Jarosova et al (77) described a course involving Roma in the Czech Republic that led to increase communication and cooperation between Roma patients and health care providers, including with the parents of young children. Indeed, participants in Rechel et al (93) felt that school education was tied to increased health knowledge and trust towards health services. An interviewee in Sigerson and Sayed (97) mentioned the value of explaining to people that dental treatment can be free to facilitate engagement. The need for commissioning services in relation to both promotion and prevention for oral health was also suggested (88).

Handheld records

Greenfields and Lowe (72) surveyed health professional about ways to facilitate service delivery for Gypsies and Travellers: dentists indicated most interest in hand-held records.

Staff training

In Greenfields and Lowe (72) potential value was noted for staff training. They surveyed health professionals about ways to facilitate service delivery for Gypsies and Travellers and dentists indicated there was some interest in GRT staff awareness training and culturally-relevant information.

Summary

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. Forty nine studies (reported in 54 papers) contained findings relevant to one or more of our focus health services. 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

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.

Review 2: A systematic review of reviews of how trust has been conceptualised within health care contexts

Introduction

The aim of this review of reviews was to examine how 'trust' has been conceptualised and theorised in any health care setting, and to report an overview of the conceptual and theoretical understanding of 'trust' as it applies to any users of mainstream health and social care services.

Methods

Search Strategy

The review searches were conducted by York Health Economics Consortium (YHEC) in 2015 in 15 databases. The search strategy comprised two concepts 'trust' AND ('literature reviews' OR 'systematic reviews'). See Appendix 6 for list of databases and an example of the full search strategy.

Eligibility

Publications were included if they met the following pre-defined criteria: (i) reported the findings of a review (systematic or non-systematic) of the literature, (ii) focussed primarily on understanding, describing or exploring the concept of trust, (iii) focussed primarily on healthcare (of any description), (iv) published in the English language, and (v) published from the year 2000 onwards. Publications were excluded if they (i) did not report review methods, (ii) did not have a main focus on trust, and (iii) did not have a main focus on healthcare.

Selection of studies

The database search results were imported to Endnote and de-duplicated. Two reviewers screened publication titles and records independently and any inconsistencies were discussed with a third reviewer. The full texts of all publications that appeared to meet the eligibility criteria, and those with insufficient information in the abstract, were retrieved. Two reviewers independently screened the full texts for inclusion and any inconsistencies were discussed with a third reviewer.

Study quality assessment

The included reviews were assessed for study quality using the items in the assessment of multiple systematic review checklist: AMSTAR (assessment of multiple systematic review) (108).

Data extraction and synthesis

For each eligible study, data related to the concept of trust were extracted by one reviewer and checked by a second reviewer. Only findings that related to trust in a health care context were extracted. The extracted findings were coded initially under six categories: (i) definitions, overviews or typologies; (ii) antecedents or pre-conditions; iii) influences; iv) characteristics; v) outcomes or consequences; and vi) measures or scales. As there was considerable overlap between the first five categories above, these were collapsed into three overarching categories: 1) overview and characteristics of trust; 2) conditions for and factors associated with trust (related to the patient, the healthcare provider or shared); and 3) outcomes of trust. These three categories are represented in a conceptual model of trust (see Figure 3).

Findings

The online database search produced 7929 original records. Of these 7780 were excluded on title and abstract screening. The full texts of 149 records were assessed for eligibility and 20 reviews were included. The 129 excluded reviews: did not have sufficient focus on the concept of trust, did not focus on health care, were not reviews, or were reviews without reported methods. See Figure 1 flow of studies in the review. Table 2 for an overview of the included reviews.

Figure 3: PRISMA diagram

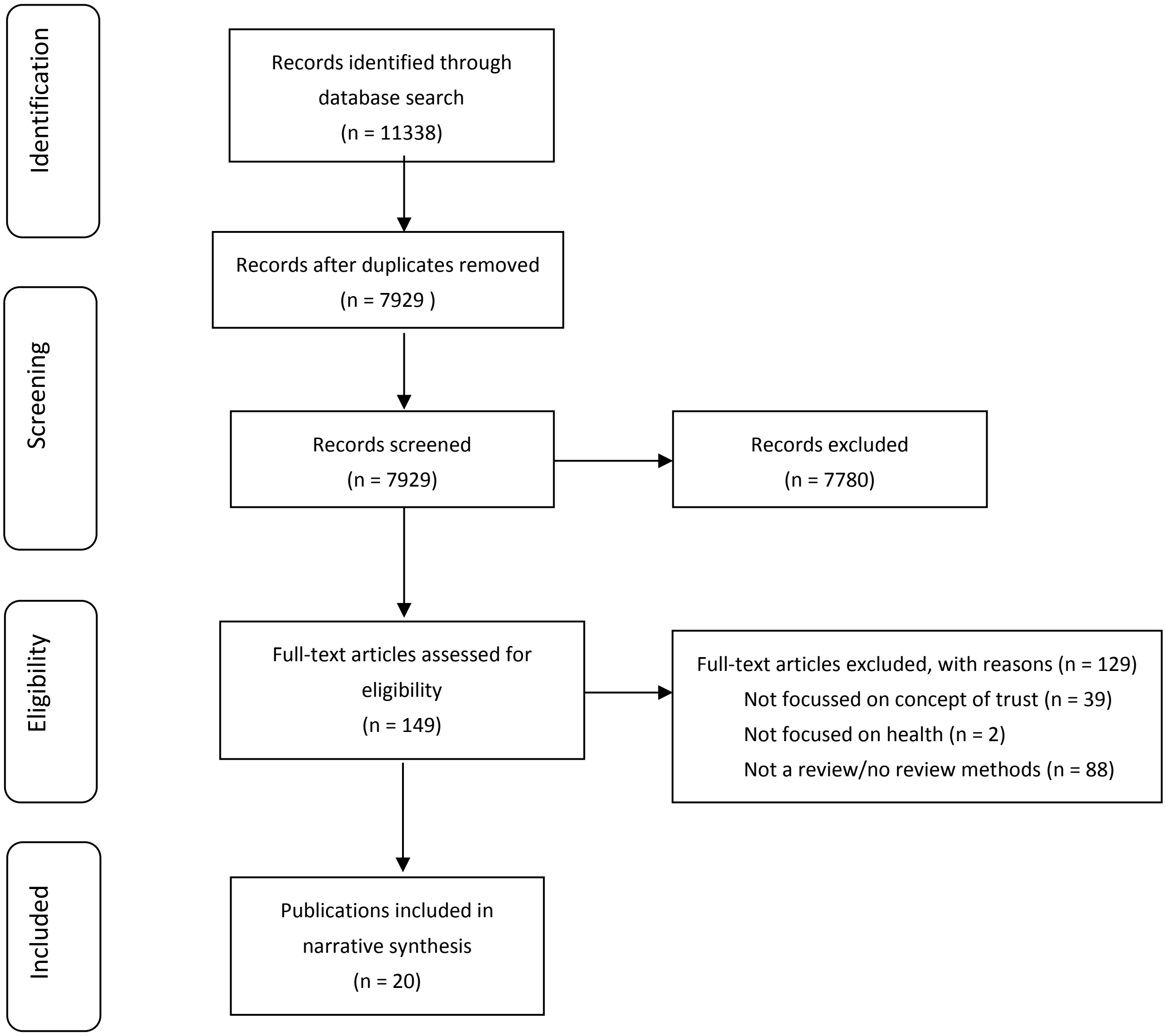


Table 2: Trust review included studies

Author/year	No. of included studies	Review type	Review question or purpose
Bell 2009 (109)	20	Concept analysis	To provide a greater understanding of the term ‘trust’ in relation to the nurse–patient relationship through the use of Rodgers’ concept analysis framework.
Carr 2014 (110)	38	Realist synthesis	To synthesise the evidence on outreach programmes to improve the health of Traveller Communities and to develop an explanation of how outreach works, for whom and in what circumstances.
Dinc 2012 (111)	17	Argument-based nursing ethics literature review	To explore the understandings and uses of the concepts of trust and trustworthiness within the field of nursing by reviewing argument-based nursing ethics literature.
Dinc 2013 (112)	34	Multimethod review (qualitative and quantitative)	To identify empirical studies on trust within the nurse–patient relationship and to analyse and synthesise the results.
Dy 2012 (113)	Unclear	Qualitative literature review	To develop a list of potential key concepts relevant to the quality of complex, shared medical decision-making.
Gaebel 2014 (114)	49	Multimethod systematic review	To elucidate the determinants of trust in mental health services, how trust may be modified and applied and if such modifications can improve not only trust, but also help-seeking and mental healthcare utilization in Europe.
Goudge 2005 (115)	Unclear	Multimethod review (qualitative and quantitative)	To review the methods applied in investigating trust. This review is not limited to the healthcare setting and also contains studies on trust within the community, in government, business and within organisations. The data extracted only pertains to the healthcare studies.
Hillen 2011 (116)	45	Multimethod review (qualitative and quantitative)	What is the strength, correlates and consequences of cancer patients’ trust in their physician?
Hsieh 2008 (117)	72	Concept analysis	To clarify the concept of social capital within a health context using Rodgers’s (2000) Evolutionary Method.
Hupcey 2001 (118)	107	Concept analysis	To assess the level of maturity of the scientific concept of trust, it was examined in four disciplines: nursing, medicine, psychology and sociology.
Laugharne 2006 (119)	21	Multimethod review (qualitative and quantitative)	Is there a research base for the influence of trust between patients and mental health clinicians? What is the evidence for the importance of choice in mental care? Has patient empowerment had an impact on mental health delivery?
Mullarkey 2011 (120)	20	Comprehensive literature review	To provide a comprehensive review of the topic of trust between nurses and nurse managers in the context of critical care units.
Murray 2015 (121)	47	Integrative review	What are the factors that promote trust in the patient and primary care provider relationship?
Ozawa 2013 (37)	42	Systematic review of scales and indices	How many trust measures are there? What relationships and populations do they study? What content areas do they capture? How rigorous are the measures?
Pearson 2000 (122)	Unclear	Synopsis of theories	To discuss current theories about trust and to weave together the early strands of empirical data on patient-physician trust into a practical update on state-of-the-art methods and results.

Author/year	**No. of included studies**	**Review type**	**Review question or purpose**
Phillips-Salimi 2012 (123)	28	Concept analysis	To provide an analysis of the concept of connectedness.
Ridd 2009 (124)	11	Qualitative literature review	To derive a conceptual framework of the factors that define patient–doctor relationships from the perspective of patients.
Seetharamu 2007 (125)	6	Thematic literature review	To enable the oncologist to better form a trusting relationship with the patient by describing four factors that influence patient trust
Tofan 2012 (126)	28	Selective narrative review	To contribute to the body of research on the effective governance of the physician–patient relationship in health-care markets.
Vega 2011 (127)	49	Meta-analytical review including experimental and theoretical studies	To examine the trust relationship between humans and health websites.

Quality assessment

See Table 3 below for the results of the quality assessment. All reviews had some deficiencies and notably, for all 20 reviews, none reported lists of both included and excluded studies. All five of the studies which had taken an approach to combining study findings were assessed as having used an appropriate method given their stated aims and purpose.

Table 3 Assessment of methodological quality of the included reviews using AMSTAR

First author (Year published)	**AMSTAR criteria***										
	1	**2**	**3**	**4**	**5**	**6**	**7**	**8**	**9**	**10**	**11**
Studies with an approach to combining study findings											
Dinc (2012)	No	Yes	Yes	No	No	Yes	Yes	Yes	Yes	No	No
Murray (2015)	Yes	Yes	Yes	No	No	Yes	Yes	Yes	Yes	No	No
Ozawa (2013)	Yes	Yes	Yes	Yes	No	Yes	No	No	Yes	No	No
Tofan (2013)	No	No	Yes	No	No	Yes	No	No	Yes	No	No
Vega (2011)	Yes	Yes	Yes	Yes	No	No	No	No	Yes	No	No
Studies with no attempt to combine study findings											
Bell (2009)	Yes	No	Yes	No	No	No	No	No	N/A	No	No
Carr (2014)	Yes	Yes	Yes	Yes	No	Yes	Yes	Yes	N/A	No	No
Dinc (2013)	Yes	No	Yes	No	No	Yes	No	No	N/A	No	No
Dy (2012)	Yes	No	Yes	Yes	No	No	No	No	N/A	No	No
Gaebel (2014)	Yes	Yes	Yes	No	No	Yes	Yes	Yes	N/A	Yes	No
Goudge (2005)	Yes	No	Yes	No	No	No	Yes	Yes	N/A	No	No
Hillen (2011)	Yes	Yes	Yes	No	No	Yes	No	No	N/A	No	No
Hsieh (2008)	Yes	No	Yes	Yes	No	No	No	No	N/A	No	No
Hupcey (2001)	Yes	No	Yes	Yes	No	No	No	No	N/A	No	No
Laugharne (2006)	Yes	No	No	Yes	No	No	No	No	N/A	No	No

Mullarkey (2011)	Yes	No	Yes	No	No	No	No	No	N/A	No	No
Pearson (2000)	Yes	No	No	No	No	No	No	No	N/A	No	No
Phillips-Salimi (2012)	Yes	Yes	Yes	Yes	No	Yes	Yes	Yes	N/A	No	No
Ridd (2009)	Yes	Yes	Yes	No	No	Yes	Yes	Yes	N/A	No	Yes
Seetharamu (2007)	Yes	No	No	No	No	No	No	No	N/A	No	No

***AMSTAR criteria**

1. Was an 'a priori' design provided?
2. Was there duplicate study selection and data extraction?
3. Was a comprehensive literature search performed?
4. Was the status of publication (i.e. grey literature) used as an inclusion criterion?
5. Was a list of studies (included and excluded) provided?
6. Were the characteristics of the included studies provided?
7. Was the scientific quality of the included studies assessed and documented?
8. Was the scientific quality of the included studies used appropriately in formulating conclusions?
9. Were the methods used to combine the findings of studies appropriate?
10. Was the likelihood of publication bias assessed?
11. Was the conflict of interest included?

The conceptual model of trust developed from this review is shown in Figure 4. The concept of trust has had, and continues to have considerable attention in the literature as evidenced by the number of reviews and studies identified. In terms of the health care context of the reviews, ten focussed on trust in general between patients and health care professionals and/or health care systems (37, 109, 111, 112, 115, 118, 121-124), six focussed on more specific health care contexts: mental health (114, 119); oncology (116, 125); complex medical conditions (113); and critical care (120); one focused on healthcare markets (126); one on websites (127) and one on trust as an element of social capital (117). Only one review focussed on a marginalised group i.e. Gypsies and Travellers (128). In the majority of cases trust was considered at an individual level between patients and healthcare providers. In addition, there was also some consideration of trust in the context of relationships between healthcare professionals and organizational management (111, 120).

There was no uniform definition of trust identified. However, Table 4 shows characteristics of trust that were reported across the included reviews.

Table 4: Characteristics of trust

Characteristics of trust	Studies
Complex	(109, 111, 122)
Indefinite	(112, 116)
Incorporates psychological aspects including beliefs, attitudes and emotions	(111, 115, 117, 119, 121, 122, 127)
May be fragile or broken	(112, 121)
Only noticeable by its absence	(109, 121)
Has boundaries	(111, 118, 121)
May develop, change or refine over time	(111, 112, 114, 115, 118, 121, 122, 124)

In addition to the characteristics of trust, some reviews suggested typologies of trust. The most common was the notion that there are two levels of trust: 1) interpersonal/micro level/individual and 2) impersonal/macro level/institutional (111, 119, 120). Interpersonal trust develops between two individuals – the service-user and the healthcare provider and is based on the trustworthy and moral character of the healthcare provider (111, 119, 120) whereas impersonal trust is based on trust in institutions or professions. According to Dinc and Gastmans (111), interpersonal trust is a pre-requisite of impersonal trust.

Conditions for and associations with trust

Patient focussed themes

There was some evidence of an association between belonging to a minority ethnic group and low trust (114, 116, 121). However, this was not clear cut as Murray and McCrone (121) found no significant differences associated with ethnic groups and trust. Trust may be affected by whether 'race' and language are shared between healthcare provider and patient (113) and similarity of outreach workers to programme participants (110).

There was a more consistent association between age and trust; in particular, older age and higher levels of trust (114, 116, 119). Conversely, Gaebal et al (114) also identified evidence of higher levels of trust in adolescents.

The association between gender and trust, and education and trust was mixed. Hillen et al (116) reported that women are more trusting than men; while Murray and McCrone (121) found contrasting evidence. There was contrasting evidence about the association between education level and trust, with some included studies reporting a positive correlation and others reporting a negative correlation (116, 121).

Gaebel et al (114) and Hillen et al (116) found evidence that type of health problem or healthcare used may affect trust; while Murray and McCrone (121) found contrasting evidence on the association between health status and trust. Laugharne and Priebe (119) reported that trust was more important to patients with mental health problems than patients with physical disease.

A consistent association between trust and beliefs was reported (111, 120, 122). Studies in Dinc and Gastmans (111) refer to this belief as the truster's belief in the good will of the trustee. Vega et al (127) argued that trust can be defined as an attitude as well as a belief. More specifically, trusting beliefs can be considered to be cognitive in terms of believing that the truster is competent and benevolent, whereas attitudes can be defined as feelings of security and reliance on the truster. Similarly, the sharing of similar personal beliefs between trustee and truster may foster trust (115).

Trust may be related to the patients' knowledge about healthcare or professionals (114, 118). As such, trust may be enhanced by enhancing knowledge about healthcare issues (114). Of note, an increase in knowledge due to the availability of online medical information may make patients less trusting in healthcare (126) though this was not found elsewhere (116). Previous positive or negative experiences may also influence trust levels (109, 111, 114, 116, 119, 120, 124, 125).

Patients must have a health care need that requires assistance related to their decision to trust (111, 118). Indeed it may be need rather than choice that determines whether trust is given (120). Feeling safe is also related to trust (123) including emotional and physical safety, and feeling valued (112), as well as being treated with dignity (114). Relatedly, shame or humiliation of the patient may affect trust negatively (125). There is an element of risk inherent in trusting another (109, 111, 118, 127); level of risk is assessed by the trustee/patient in the development of trusting relationships (111, 118).

Patient-provider focussed themes

Trust was identified as a key component that is necessary for the development of relationships between patients and health care providers (118). Within relationships there are both those who trust, and those who are trusted (120). This may also be thought of as partnership building (115, 118) or commitment (126). The length of the relationship between patient and provider may affect the level of trust in the provider (113, 116, 119). Continuity of carer is also related to developing trust (112, 114, 119), with Hillen et al (116), for example, finding evidence of less trust when there are frequent changes in healthcare provider. The development of the trusting relationship may be affected by comfort level (112) and rapport (112, 122) between patients and service providers.

There is power imbalance in the relationship between patients and healthcare providers (109, 111, 121, 125). A trusting relationship is described as one in which control is relinquished to the trusted party by the truster (126). This potentially makes patients vulnerable and open to exploitation (111). Conflicts of power within the relationship may influence trust levels (112), while the sharing of power, non-coerciveness, patient empowerment and participation in care may facilitate trust (111, 112, 114, 120, 121). Tofan et al (126) point to the need for balance between authoritativeness and egalitarianism in the relationship between patient and provider. Having a choice of healthcare provider may also promote trust (119).

Provider focussed themes

Commonly reported attributes of the provider that may affect trust include: willingness (118, 120, 121, 127); reliability (111, 113, 118, 120-123); following through on actions (112) consistency (111, 120), and confidence (37, 111, 117, 118, 121, 122, 127). Fulfilling patient expectations appeared important to patients' trust (109, 111-113, 116-118, 120, 121, 127). In order to trust, one party must determine that the other is trustworthy (121) and have a belief in that trustworthiness (119). Mullarkey et al (120) identified the following traits of a trustworthy individual: listening skills, respect, caring, honesty, confidentiality and reliability. Moreover, demonstrating trustworthiness then reinforces trust (120).

Professional competency of the service provider was consistently related to trust in health providers or healthcare (37, 111-114, 122, 125). This includes technical expertise or competence (109, 112, 114-116, 118, 119, 121, 122); training or qualifications related to occupation (37, 111, 112, 114, 115); and reputation (37, 116). Thus the performance of service providers may influence trust levels (120), and evidence in Ridd et al (124) suggested that providers' understanding of their own level of ability is related to their patients' trust in them. Vega et al (127) pointed to the importance of accuracy of information whereby feeling informed is related to forming trust (112). Trust and trustworthiness are negatively affected when providers lack knowledge and skills (112, 116). Thorough evaluations, appropriate and effective treatment are all related to trust (115) and might be thought of as specific examples of professional competence. Services and care that are comprehensive and coordinated are also associated with trust (121) and may similarly be thought of as competencies within the service. Murray and McCrone (121) also found evidence that patients felt positively about health staff who were attentive to the requests and expectations of their patients, and this in turn enhanced trust. Patients themselves may not feel trusted if they perceive that the provider does not recognise the seriousness of symptoms (124).

Interpersonal competency of the service provider is also part of trust in healthcare (116), including clear and complete communication (37, 110, 115, 118, 119, 121, 122), person-centred communication (121) and ability to listen (115, 116). On the other hand the use of overly technical language may be barrier to communication and may negatively affect trust (112). Reassurance and encouragement (112), benevolence (110), empathy (114), openness, and honesty (37, 112, 114-116, 119, 122-124) are all associated with trust. Respect from the service provider towards the patient is part of trust (112, 115, 121), as are cultural competence and acceptance (112, 113). Understanding the patient and their circumstances (125) as well as awareness of needs and distress (112) are also important. Goudge and Gilson (115) cite the importance of good bedside manner and Dinc and Gastmans (112) found evidence that knowing people aside from their status as a patient facilitates trust. Dinc and Gastmans (112) add that trust is affected negatively when service providers think of patients by diagnosis or bed number rather than as individuals.

The literature indicated that being caring (115, 116, 118, 121), genuine (120) and compassionate are important for developing trust (122). Providing assistance or acting out of goodwill are associated with the trustee in the relationship (109, 111, 118). There may also be an expectation that the trustee will act in the interests of the truster (37, 109, 110, 115, 118-121, 127), not exploit or harm the truster (111), and that their concern or assistance is genuine (113, 116). Concern for wellbeing (111, 115), obligation (109) and advocacy (116) are also linked to the trustee in the relationship.

Trust in healthcare and health professionals is associated with maintaining patients' confidentiality (112, 114, 115, 119, 122). Evidence in Goudge and Gilson (115) suggests that patient confidentiality is even more important when there is stigma associated with the health condition. Respecting patients' privacy may counter any shame that arises during the disease and treatment (125). However, Ozawa and Sripad (37) determined that confidentiality is less of a focus in trust in health systems than honesty, communication, confidence and competence. Fairness is part of the relationship between patient and provider (37) and a sense of justice plays a part in the development of trust (111, 120).

Related to the theme on developing relationships, accessibility of the provider to the patient may also influence trust (111, 114). This includes the availability of the healthcare provider or service (111, 114, 121) and the amount of time the provider spends with the patient (114, 119). High workloads and lack of time affect trust negatively (112), as does difficulty accessing services and long waiting times (112, 121).

Outcomes of trust in healthcare

The reviews suggested that the outcomes of trust include improved quality of care (111, 113, 117, 119, 120, 126) and responsiveness to patients (111).

Interpersonal trust between patients and healthcare providers was generally associated with the best clinical outcomes and healing (126), improvements in health status (109, 122), fewer medication side effects (119) and increased health screening uptake (116). Evidence in Hupcey et al (118) points to loss of trust as biologically unsettling. However, the relationship between trust and outcomes was not always consistent, with Pearson and Raeke (122) reporting that one of their included studies was not able to demonstrate a significant relationship between trust and positive health outcomes.

Trust may be associated with reduced patient anxiety (109, 111, 116), reduced perceptions of risk and fear of mistakes (116), and reduced shame linked to healthcare received (125). Trust may promote the patient’s sense of power or control (111). Patients may feel valued if their expectations are met (121). A loss of trust may be distressing (118) and patients may hold fears around their healthcare provider’s power if they do not trust them (125).

Trust levels may affect patients’ belief in or acceptance of their diagnosis (125) as well as compliance with treatment or recommendations (113, 115, 116, 122, 125, 126). Greater trust in the healthcare provider may mean patients are less likely ask for additional opinions on their health issue (116).

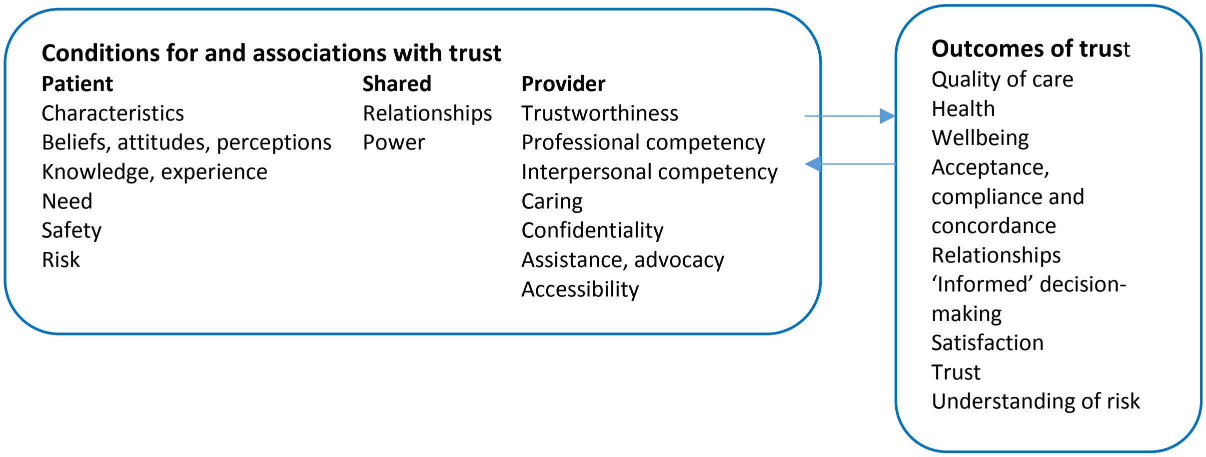
Trust was consistently linked to the building of the therapeutic relationship between patient and healthcare provider (109, 119, 122, 126). Trust enhances connections and co-operation between people (110, 126). Relationships may be both developed and stabilised if patients’ expectations are met (121). Hillen et al (116) found mixed evidence on whether higher trust levels were associated with increased communication with the healthcare provider. Similarly, Dinc and Gastmans (111) reported that this increase in communication can enable the collection of accurate information from the patient which is necessary for correct clinical diagnosis.

Trust was associated with decision-making (113, 116); patients who trust their providers may allow them greater control over decision-making (116, 126). A lack of trust may be associated with difficulties in shared decision-making (113). In addition to trust on behalf of the patient, Bell and Duffy (109) note that it is important for healthcare professionals to trust patients to make decisions about their own care and this is an important component of creating a successful relationship.

Trust was linked to with satisfaction with healthcare and/or provider (112, 114, 122, 126). Relatedly, trusting patients may return to the same provider should it be required, and recommend their provider to others (126). However, perceived quality of care was not associated with trust in all patients. Specifically, Tofan et al (126) reported that while trusting individuals who were insured reported better physician-patient relationships and higher levels of perceived quality of care than non-trusting individuals, trust did not exert a significant influence on non-insured individuals.

Placing trust in another leads to desirable or undesirable outcomes, depending on how the trustee responds (118). Trusting may lead to further or additional trust (117, 119, 121), and likewise with trustworthiness (111). If trustees do not meet expectations the patient may feel betrayed (119). Indeed, post-operative complications have been linked to lack of trust in surgeons (116). As such, in trust there is a 'feedback loop' (Laugharne and Priebe (119) p. 844) and the trust process can be considered somewhat circular.

Figure 4: Conceptual model of trust



This conceptual model of trust informed the realist synthesis reported next, and the analytical framework that underpinned analysis of the research material generated by the case studies reported in Chapter 5. Appendix 9 shows the case study research material mapped to this model of trust.

Summary

This review has provided an overview of the conceptual and theoretical understanding of 'trust' as it applies to any users of mainstream health and social care services. The analysis was based upon data contained in twenty systematic/literature reviews, five of which involved a form of evidence synthesis. All reviews had some deficiencies in elements of methodological quality and reporting. Data from the reviews was accounted for by three overarching categories: 1) overview and characteristics of trust; 2) conditions for and factors associated with trust (related to the patient, the healthcare provider or shared); and 3) outcomes of trust. A narrative descriptive account of the data in these three categories was provided. The review extends existing knowledge and suggests a proto-conceptual model which can be used to understand conditions for and associations with trust between patients and providers and with regard to a number of important outcomes of trust. This model was useful in guiding future aspects of the work reported in this document.

Review 3: Realist synthesis of approaches to community engagement involving Gypsy, Roma and Traveller people

Realist synthesis is an approach to the review and synthesis of evidence which focuses on understanding the mechanisms by which a complex intervention works or does not work (130). The methodology lends itself to the review of complex interventions since it can account for context and outcomes in the process of systematically and transparently synthesising relevant literature (131). We conducted a realist synthesis of community engagement approaches to enhance trust and increase participation of Gypsy/Travellers in health care services. This synthesis drew upon the data derived from reviews 1 and 2 already described in this report.

Aims

The aim of the realist synthesis was to explore which approaches to community engagement involving GRT people, and in what circumstances, lead to enhanced trust in mainstream health services

Methods

There are four main stages in the conduct of a realist synthesis: 1) define the scope of the review; 2) search for and appraise the evidence; 3) extract and synthesise findings; 4) draw conclusions and make recommendations (130).

Defining the scope

This stage involved describing and understanding the nature and content of interventions to enhance trust and facilitate participation of Gypsy/Travellers in health care services. It also involved understanding the context and circumstances of its implementation and use. At the outset of the whole project, in order to design a theoretically-based evaluative framework, we derived four hypotheses from the literature on community engagement:

1. Community engagement is a cost-effective strategy for enhancing the confidence and trust of GRT people in mainstream services (39);
2. Approaches to community engagement that work to enhance trust and increase uptake of services with some participants may not work with GRT people because of the longstanding experience of social exclusion and discrimination, low education and literacy levels and mistrust of authority (132);
3. Successful community engagement will be underpinned by genuine involvement of community members (i.e. not tokenistic), honest appraisal of what can be achieved (not raising expectations that cannot be met) and continuity of trusted personnel (43);
4. Community engagement between GRT people and mainstream health services can be facilitated effectively by GRT TSOs (132).

Search and appraisal

We drew primarily from a systematic review which explored Gypsy, Roma and Traveller engagement with health services, in which we had identified twenty-six core studies describing an engagement strategy with some detail (56). We aimed to exploring these strategies and their contexts in more detail in the current realist synthesis. For each strategy we aimed to explore 'how the programme was supposed to operate' to the 'empirical evidence on the actuality in different situations' (133, p2), in order to suggest which aspects of context and resources might lead to engagement and enhanced trust in health services. We were limited by the fact that only a sub-group of papers provided a sufficient detail about strategies; so we used incomplete context (C), Mechanism (M) and outcome (O) configurations to add to or contrast those that had more information. We secondarily drew upon a systematic review of how trust had been conceptualised in health care contexts (see Chapter 3, Review 2) in order to consider trust in the broadest sense within the current realise synthesis.

The included studies in the review of GRT engagement with health services were critically appraised as part of Review 1 based on the Critical Appraisal Skills Programme for qualitative studies, and assessing risk of bias in quantitative studies according to sampling strategy, response rate, use of a validated instrument, and appropriateness of statistical analysis (see McFadden et al (56) for further details). The studies included in the systematic review of trust were appraised for study quality using the AMSTAR systematic review checklist, as described in Chapter 3.

Extraction and synthesis

Findings on engagement strategies in the 26 core studies were extracted for CMO configurations to explore what did, and didn't work, in relation to each of the three programme theories. Under mechanisms, we identified both resources and responses (134). We also extracted recommendations within the papers for useful ways of working, to inform possible strategy design. We compared and contrasted findings from different studies to seek both confirmatory and contradictory findings, and used these to refine the programme theories (130).

Draw conclusions and make recommendations

The developing theories were taken to the project User Advisory Group and discussed for accuracy. They were also a key part of workshops to discuss recommendations for policy involving health, third sector, council and academic staff; and a participation event with Gypsies and Travellers (see Chapter 6: Developing policy options and recommendations). The final project recommendations are presented in Chapters 6 and 8.

Findings

Our realist synthesis drew on the two reviews reported above (in particular the twenty-six publications from review 1); discussion of developing theories with the project User Advisory Group; formed a key part of workshops to discuss recommendations for policy involving health, third sector, council and academic staff; and a participation event with Gypsies and Travellers (see Chapter 6: Developing policy options and recommendations).

The chief and primary source of data to inform the realist synthesis were 26 publications of 32 studies of engagement strategies (19 studies were qualitative, 13 were cross-sectional surveys). 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. 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. The quality assessment of trust review is described in chapter 3.

The included studies represented a wide range of contexts as evidenced by the range of countries where studies took place: Ireland (35, 58, 63, 104, 107); Northern Ireland (35, 58, 107); Scotland (73, 83, 97, 135, 136); England (8, 11, 43, 64, 72, 101, 137-140); Italy (86, 141); Spain (69); Czech Republic (77); Romania (142); across Europe (68, 143-145) and Serbia (95).

Candidate theory programmes

The initial four hypotheses were further developed and refined into candidate programme theories as the overall research project progressed and potential community engagement strategies were explored in detail; including through the previous literature reviews, discussions among the research team, and User Advisory groups. The original four hypotheses were developed as follows:

i) cost-effectiveness of community engagement with GRT people was widened in focus because we found little data on cost in the engagement review;

ii) interaction between GRT people's social experiences e.g. discrimination, and effect on community engagement success was evident in the wider context of many of the included studies;

iii) importance of involving GRT community members in community engagement became a focus of one programme theory. The honest appraisal of aims was too specific but featured in one programme theory. Continuity of trusted personnel became the focus of one programme theory;

iv) importance of involving civil society in engaging GRT in health services was explored across all the resulting programme theories.

The studies included this realist synthesis 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, and whilst this is a limitation of the evidence of what works best to enhance engagement, the study findings were able to inform the assessment of programme theories in this realist synthesis.

Following refinement of the hypotheses and the initial distillation of findings from the included literature, three candidate theories were identified. These theories focussed on three key ideas: i) the value of strategies that are tailored or flexible; ii) the value of involving community members in strategies; and iii) the value of focussing on trust as part of the strategies.

The three candidate programme theories were:

1. Health services/healthcare interventions that take into account the specific needs and circumstances of Gypsy, Roma and Traveller people (tailored and flexible) are important to enhance their engagement (including trust) with services;
2. Gypsy, Roma and Traveller people's participation in the design or delivery of health service/healthcare interventions is important to enhance engagement (including trust) with the service or intervention;
3. Trust in health care providers and/or institutions is an important feature of health services/healthcare interventions that aim to enhance Gypsy Roma and Traveller people's engagement in mainstream health services.

Analysis of the included studies indicated that there were three cross-cutting themes that provided the broad context that applied to all three candidate programme theories (i. Social disadvantage, marginalisation and/or discrimination or negative views about GRT communities; ii. Health problems or health inequalities; iii. Lack of health access or health knowledge) (see Table 5 below for an indication of which studies provided data regarding these).

Table 5: Studies reporting contextual cross-cutting themes

Contextual cross-cutting theme	Reference to papers that reported the theme
Social disadvantage, marginalisation and/or discrimination or negative views about GRT communities	(35, 43, 63, 68, 69, 82, 86, 95, 104, 136, 141, 143, 145, 146)
Health problems or health inequalities	(8, 11, 22, 35, 43, 63, 68, 69, 77, 95, 104, 140, 141, 146)
Lack of health access or health knowledge	(8, 11, 35, 68, 77, 95, 97, 104, 135, 137, 138, 141, 143, 145, 146)

The remainder of this results section considers each of the three candidate programme theories in turn. For each theory, first the theory is described, including an outline of: resource sub-themes, reference to studies that contributed information and examples of specific information from studies. This will then be followed by short examples of context – mechanisms- outcomes (CMO) configurations relating to the programme theory. We actively constructed CMO configurations in tables to examine what factors and settings (context) moderated adapted interventions (mechanism – including the resources required and reasoning for the mechanism) and to elucidate the configurations underpinning both success and failure (outcomes).

Programme theory 1: Health services/healthcare interventions that take into account the specific needs and circumstances of Gypsy, Roma and Traveller people (tailored and flexible) are important to enhance their engagement with services

We explored the idea that engagement in services or programmes by GRT may be enhanced by making the services or programmes either more flexible, or tailored towards the needs and experiences of the community members. Twenty-five studies contributed information towards this programme theory. As for all three programme theories, outcomes were considered to be positive ('what works') if it appeared that community members had engaged successfully with the services or interventions provided, or enhanced their health-related behaviours. The main resource sub-themes that were identified and the studies that contributed information to these are summarised in Table 6.

Tailoring is of importance when working with GRT communities given the contextual issues that interplay with services, namely the need to overcome social discrimination or marginalisation and health inequalities, as these may act as barriers to mainstream health access; as well as the fact that Gypsies, Travellers and Roma people have a unique culture that influences their lifestyle and choices. By focussing on the needs, culture or preferences of community members, individuals will respond more positively because they see the service as relevant or acceptable for them specifically. Using services that are tailored or flexible may also be more convenient, and it is possible that individuals may feel respected and valued by service providers because their specific needs are acknowledged/recognised. In these ways community members will engage positively with the service or intervention, which will then be able to fulfil its role as engaging with service users to enhance their health.

Table 6: Programme theory 1: resource sub-themes and study references

Resource sub-themes	Reference to studies that contributed information	Example information from studies
Preferences, needs and culture taken in to account **May include: general flexibility in working; involving organisations that have knowledge of GRT; developing and drawing upon cultural understanding; the development of dedicated GRT services or specific considerations for GRT e.g. specialist community roles e.g. mediators; taking services to the community (outreach)**	(8, 11, 35, 43, 63, 64, 68, 69, 72, 73, 77, 82, 83, 86, 95, 97, 104, 135-140, 143, 145, 146)	'…Travellers, Traveller culture and a community development approach on one side, and resources, health skills, health services and health knowledge on the other. This combination is essential…' (58) p24. 'the organisation uses a variety of methods to consult with our service users and to gather feedback from them in order to create services, which are tailored to meet the specific needs of the Roma community (137) p16 'We've got our own immunisations set up for Slovakian and Romanian and that's how we get the patients to come in…' (participant in (97) p. 23) 'take continued care to focus on the specific needs of the Slovak Roma' (136) p10
Avoiding further exclusion of GRT through service methods; and avoiding over-reliance on certain services or staff **May include developing improved services that benefit the whole community**	(43, 68, 86, 97, 104, 136-138, 141, 143, 145)	'the main effect of this service was to contribute toward everything that excludes Roma from the regular health facilities.' (141), p140 'Open access health visiting clinics in a sense can support or reinforce their kind of cultural beliefs that services are drop-in.'(NHS Greater Glasgow & Clyde Health Visitor)' (97) p23 '…not always through the development of Roma-specific initiatives. Indeed, there is clear scope here to also develop a range of services that would be of real benefit to the general community as a whole (136) p49

At the same time, information that contributed to this programme theory also points to the importance of balanced tailoring or flexibility so as to foster inclusion and acceptance of using mainstream services where possible, rather than facilitating isolation further. It is also important that staff members that work with GRT communities do not become over-relied upon or isolated, either by community members or other staff, because of any enhanced cultural understanding or previous experience working with communities. Enhanced services will be better not only for GRT, but for the wider population who may also face barriers.

Table 7: Short examples of C-M-O configurations relating to programme theory 1.

Context	Mechanism		Outcomes
	Resource	**Reasoning**	
Specific examples of short C-M-O configurations			
Sigerson & Sayed (97) **Roma in Glasgow, need to enhance engagement.**	Clinics for Roma mothers including baby clinic and immunisations. Includes local staff rearranging initial appointments with 24 hour waiting time.	Format received well; potentially culturally more similar to previous format in Eastern Europe.	Increase attendance service uptake.
Smolinska Poffley and Ingmire (147) **Lack of mental health advocacy for Roma and barriers to accessing services; existence of Roma Support Group.**	Mental health advocacy project for Roma including theatrical production; led by Roma Support Group who drew on relationships with community members. The project included bilingual advocates with understanding about the community. Consultation with community members on relevant information to be provided to health professionals.	Satisfaction from community members about advocate and volunteer work and positive feelings towards project.	Helped address issues around community member healthcare access; increased knowledge around mental health services; increased satisfaction with mental health services; increased trust in services and professionals.
Alunni (141) **Roma living in camps in Italy.**	Mobile medical unit visiting the camp.	Acceptance of alternative provision rather than mainstream provision.	Service is used but strengthening of exclusion from mainstream services and society.

Programme theory 2: Gypsy, Roma and Traveller community member participation in the design or delivery of health service/healthcare interventions is important to enhance engagement with the service or intervention and build trust

We explored the importance of GRT community members participating in services and interventions, in order to enhance engagement with the service or intervention. Seventeen studies contributed towards this theory. The main resource sub-themes that were identified and the studies that contributed information to these are summarised in Table 8.

Table 8: Programme theory 2: resource sub-themes and study references

Resource sub-themes	Reference to studies that contributed information	Example information from studies
Active participation of community members in service design or delivery May include: developing the resource; delivering the resource; training for community members in a resource role; effective communication; representation;(43, 95, 97, 101, 104, 136-138, 140, 146), shared power; collaboration; co-ownership; co-production	(35, 43, 63, 68, 69, 72, 73, 77, 95, 97, 101, 104, 136-138, 140, 146)	'…they decided on the aims of the project and on the format of the training that they wished to deliver.' (43) p48 'For Primary Health Care to be effective there must be close collaboration between the Traveller community, health workers, the health sector, the local authorities and a range of other statutory and voluntary agencies.' (58 p24) 'there is increasing scope to support and foster Roma-led initiatives' (136 p11)

Promoting the participation of Gypsies, Traveller and Roma people is particularly important in service design and delivery, given the context of historical and more recent social marginalisation and exclusion (68). The degree and consistency of community member participation may impact the success of the strategy, and a higher degree of involvement leading to better outcomes. Community members may have the opportunity to shape resources to reflect their thoughts, experiences and needs, thus they may feel resources are more relevant and useable. Community members may feel empowered, valued, useful, fulfilled or satisfied, and may also enhance their own learning, skills or confidence, through participation. Together these may foster ongoing participation in the health resource, which can then support individuals around relevant health matters.

Table 9: Short examples of C-M-O configurations relating to programme theory 2.

Context	Mechanism		Outcomes
	Resource	**Reasoning**	
Specific examples of short C-M-O configurations			
All Ireland study (58, 107) Ireland; Travellers, minority group with distinct culture.	Primary Health Care for Travellers Project. Aims include involving Travellers in health promotion; Traveller skill development; dialogue between Travellers and services. Working together with community members.	Community member capacity is built, empowerment, sense of partnership.	Enhancement around primary care, community participates in health strategy, focus on health improvement.
Flecha (69) Spain; focus on vulnerable groups, identified family participation.	School-based learning programme to bring Roma community members in to the classroom. Parents involved in learning activities with the children e.g. supporting the teacher, or participate in education programs themselves.	Parents feel increasingly valuable, self-confident and assertive. Participants are more interested in healthcare and illness and so become active agents in their families' health; Participant form more trusting networks with each other which translate into more trust in using services such as health.	Enhanced engagement with healthcare and health matters Improved communication and more informed relationships with healthcare staff; Increased trust in use of health services.
Smolinska-Poffley (137) England; Roma as migrants and asylum seekers; Roma Support Group involved who have history of advocacy.	Roma Support Group work. Consultation and collaboration with community members who guide strategies; focus on communication.	Community members' sense of ownership, sense of partnership, empowerment, shared control.	Effective continuous engagement with community members by organisation.
Van Cleemput et al (43) England; specialist services for Travellers exist; desire for change from community members,	Health ambassadors project; development, delivery and oversight by community members; high level of consultation; community member training; achievements recognised.	Commitment from community members; positive feelings about participating including interest and enthusiasm.	Community members successfully engaged in strategy.

Programme theory 3:Trust in health care providers and/or institutions is an important feature of health services/healthcare interventions that aim to enhance Gypsy, Roma and Traveller people's engagement in mainstream health services.

We explored the idea that trust is an important feature of, and should be considered within, health services and interventions that aim to enhance GRT engagement. Sixteen studies contributed information to this programme theory. The main resource sub-themes that were identified and the studies that contributed information are summarised in Table 10.

Table 10: Programme theory 3: resource sub-themes and study references

Resource sub-themes	Reference to studies that contributed information	Example information from studies
Trust as a key component of service or intervention **May include: drawing upon pre-existing trust with community members; developing trust during the intervention.**	(43, 68, 69, 72, 73, 77, 83, 97, 107, 135, 137-140, 143, 145, 146)	'Travellers were much less likely than the general population to trust health professionals and to feel respected in such encounters, based on the census data.' (107 p169) 'Overcoming that lack of trust was one of the greatest challenges faced by the project's advocates. It was crucial to address this in order to increase the service users' ability to access the help they needed in relation to their poor mental health and the process of empowerment.' (137 p59) 'The need to develop this trust and social bond is essential so that the GRT communities know you are serious about helping them.' (138 p13) 'Thus several important elements were in place before this project commenced: […]-complete trust in the person who was leading the project and that she would consulted them fully and involve them completely in the process' (43 p49) 'In the first stages of their involvement with the RSG projects new service users scrutinise and assess our work and engagement. Once trust is gained it is extended to all RSG projects and staff members. That factor helps all the new projects and project workers to engage with service users in a more meaningful and effective way.' (137 p11)

Building on or developing trust is particularly important to overcome previous negative experiences of discrimination experienced while using health services (e.g. 68). The importance of trust in promoting use of health services and interventions is evident not only from the studies included in this realist synthesis, but from Review 2 (page) which indicates that trust is associated with enhanced healthcare. By either drawing on or building trust, community members gain confidence in the service or intervention, and see health personnel as having their interests in mind. They may be more likely to take or adhere to health advice. Importantly, trust may be extended to others. Community members may also be more likely to trust in the future once trust has been established.

Table 11: Short examples of C-M-O configurations relating to programme theory 3.

Context	Mechanism		Outcomes
	Resource	**Reasoning**	
Specific examples of short C-M-O configurations			
Jarosova et al. (77) **Romany population; Czech Republic** **Assistants with history and trust with the community.**	Programme of health and social care assistants for Roma.	Trust in the assistants is drawn upon in the new project; community members trust the assistants and their work.	Community members' enhanced engagement in health matters; increased health knowledge, increased trust towards doctors.
Smolinska-Poffley and Ingmire (137) **England; Eastern European Roma** **Barriers to accessing services; existence of Roma Support Group with a history of advocacy.**	Mental health advocacy project; led by Roma Support Group; draw upon trusting relationships with community members; clear focus on building trust.	Trust from community members extends to project.	Good engagement with community members.
Van Cleemput et al (43) **England, Travellers** **Specialist health visitor for Travelling families with trusting relationships with community members.**	Health ambassadors project involving specialist health visitor who has a long history with community members.	Trust in staff member motivates community member participation in project, trust extended.	Successful engagement with community members.

Summary

This realist synthesis explored approaches to community engagement involving Gypsies, Travellers and Roma people, and examined what circumstances lead to enhanced trust in mainstream health services. The synthesis was based on data from twenty-six studies identified in a review exploring GRT engagement in health services. Study quality was generally poor across all of the included studies. We looked for information pertaining to context, mechanisms and outcomes around different engagement strategies within the studies, to explore what leads to engagement or trust in health services. Three candidate programme theories were identified.

Candidate programme theory one: Health services/healthcare interventions that take into account the specific needs and circumstances of Gypsy, Roma and Traveller people (tailored and flexible) are important to enhance their engagement (including trust) with services. We explored the idea that engagement in services or programmes by Gypsies, Roma or Travellers may be enhanced by making the services or programmes either more flexible, or tailored towards the needs and experiences of the community members. Twenty-five studies contributed information towards this programme theory. Tailoring is of importance when working with the Gypsy and Traveller community given the contextual issues that interplay with services, namely the need to overcome social discrimination or marginalisation and health inequalities, as these may act as barriers to mainstream health access; as well as the fact that Gypsies, Travellers and Roma people have a unique culture that influences their lifestyle and choices.

Candidate programme theory two: Gypsy, Roma and Traveller people's participation in the design or delivery of health service/healthcare interventions is important to enhance engagement (including trust) with the service or intervention. We explored the importance of Gypsy, Traveller and Roma community members participating in services and interventions, in order to enhance engagement with the service or intervention. Seventeen studies contributed towards this theory. Promoting the participation of Gypsies, Traveller and Roma people is particularly important in service design and delivery, given the context of historical and more recent social marginalisation and exclusion.

Candidate programme theory three: Trust in health care providers and/or institutions is an important feature of health services/healthcare interventions that aim to enhance Gypsy Roma and Traveller people's engagement in mainstream health services. We explored the idea that trust is an important feature of, and should be considered within, health services and interventions that aim to enhance GRT engagement. Sixteen studies contributed information to this programme theory. The importance of trust in promoting use of health services and interventions is evident not only from the studies included in this realist synthesis, but from Review 2 which indicates that trust is associated with enhanced healthcare.

Analytical framework

From the three literature reviews described we developed an analytical framework to inform our analysis of the next two phases of the research: the online consultation and the case studies. This is represented in Table 12 below.

Table 12: Analytical framework

1	**Knowledge, perceptions and experiences of health services**	**General health services**
		Adult dental health services
		Child dental health services
		Maternity services
		Child health services
2	Barriers and challenges to GRT accessing healthcare	General health services
	a) Health service issues	Adult dental health services
	b) Discrimination and negative attitudes of personnel	Child dental health services
	c) Culture and language	Maternity services
	d) Service-user attributes	Child health services
	e) Economic	
3	Improving uptake of and overcoming barriers to healthcare	General health services
		Adult dental health services
		Child dental health services
		Maternity services
		Child health services
4	Engagement strategies in healthcare	General health services
		Adult dental health services
		Child dental health services
		Maternity services
		Child health services
5	Engagement strategies used by TSOs	
6	Importance of trust	In health service work
		In third sector work
7	Information on costs	
8	Importance of tailoring and flexibility in strategies	
9	Importance of community member participation in strategies	
10	Importance of a focus on trust in strategies	

As well as the above analytical framework, we mapped our findings to the model of trust developed from the review of reviews (Figure 4) and the three programme theories arising from the realist synthesis (Chapter 3, review 3)

Chapter 4: National online consultation

Aims

There were two main aims of the consultation:

1) to gather the views of health and social care practitioners and members of TSOs with experience of working with GRT people in relation to trust and engagement in health services, and

2) to explore strategies that have been employed to increase engagement and trust in health services with GRT, to inform the selection of case studies.

Methods

A semi-structured, web-based consultation was designed to gather views on trust and engagement in health services for GRT people. The consultation focussed on maternity, early years and child dental services and aimed to elicit the views of three main groups: TSOs advocating for GRT people; health and social care practitioners, policymakers, and health and social care service commissioners.

The consultation included a combination of closed and open questions. The content of questions drew on the emerging findings of the three literature reviews described in chapter three of this report (the full survey can be found in Appendix 7). The Stakeholder Advisory Group and staff at Leeds GATE were consulted on the design and wording of the questionnaire.

The consultation was delivered using the Bristol Online Survey Tool. The survey link was disseminated by email through the professional and TSO networks of the research team and the Stakeholder Advisory Group, and recipients were asked to further circulate the link widely with colleagues. Additionally, we targeted dental health practitioners through a news bulletin in the British Dental Journal and the British Society of Paediatric Dentistry. The consultation was also promoted in the eBulletin of the National Child and Maternal Health Intelligence Network, Public Health England, and through social media (Twitter). Respondents were invited to complete the survey anonymously if they preferred. The survey was open between 27 May 2016 and 29 July 2016 which included a four-week extension to encourage additional responses from underrepresented sectors. The consultation was analysed using descriptive statistics for the quantitative questions and thematic analysis for the open-text responses.

Findings

Respondents

There were 196 respondents who worked for a wide range of organisations, including NHS maternity, child health and dental services, and TSOs advocating for Gypsies, Travellers and Roma. Over half (59%) worked in healthcare.

Respondents’ professional roles are presented in Table 13. A broad range of roles were represented. The largest groups were midwives (20%), health visitors (13%), dental practitioners (12.1%) and people working in public health/inequality focused posts (10.2%).

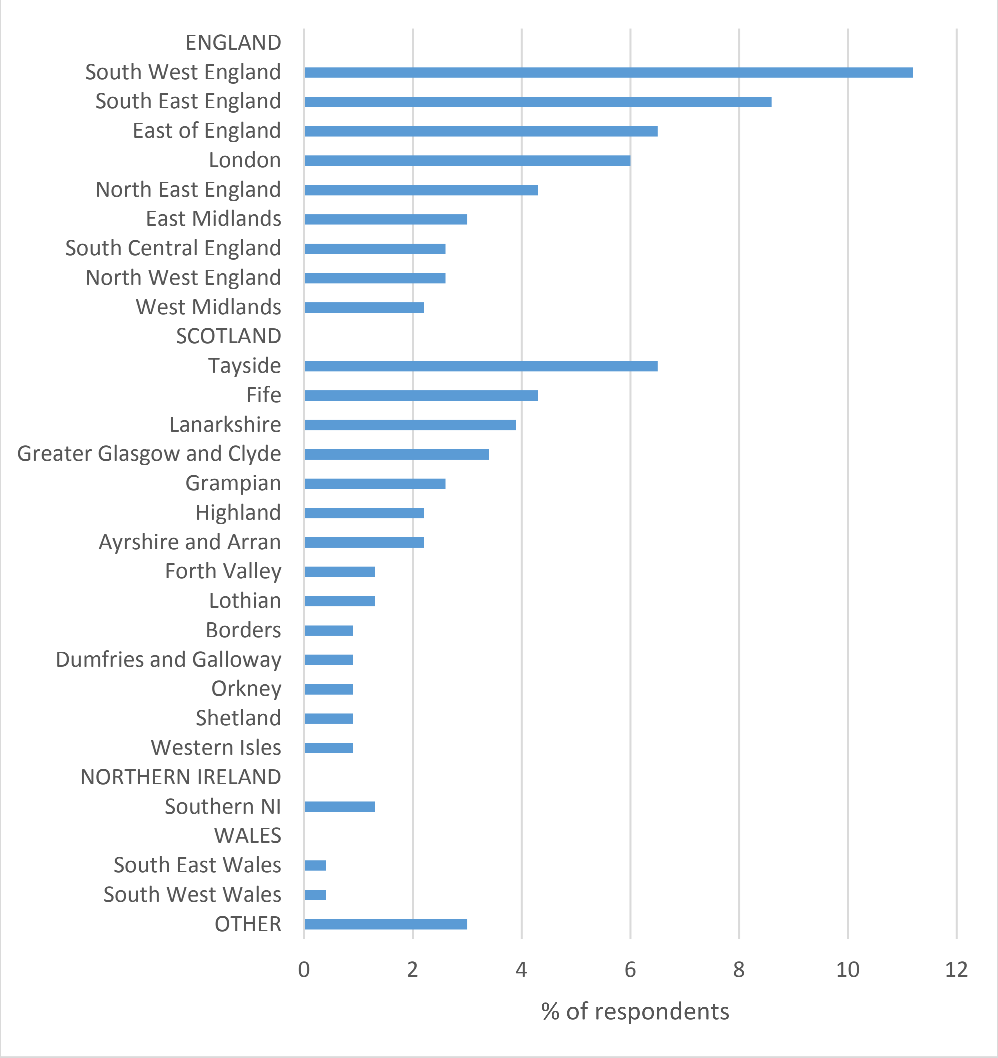
Table13: Respondents' professional roles

Role	%
Midwife	20.0
Health visitor	13.0
Nurse	6.1
Doctor (General practitioner/paediatrician/obstetrician)	1.5
Dental practitioner	12.1
Dental nurse	0.5
Oral health promoter	3.0
Support worker	4.5
Public health/environmental health/community development/health improvement specialist	10.2
Clinical Commissioner	1.0
Academic	5.0
Administrator	0.5
Service manager	6.5
Third/civil/voluntary sector manager	4.5
Volunteer	1.0
Other (e.g. mental health practitioners, GRT co-ordinator, podiatrist, paramedic)	10

Note: some respondents identified more than one role

The respondents worked cross the UK, with approximately half working (47%) in England, and approximately a third (32%) in Scotland (Figure 5). Other locations identified were Ireland and one participant worked across the UK and Europe.

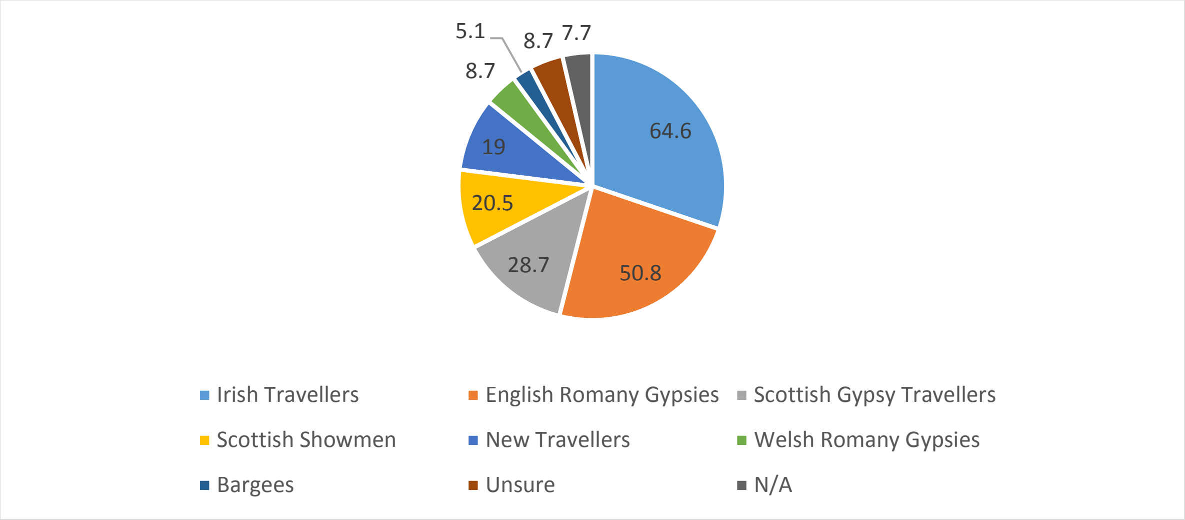
Figure 5: 1: Location of respondents' work



Note: some respondents identified more than one location

Respondents had a varied level of focus on Gypsies, Travellers and Roma people in their current and previous work roles, with more respondents having worked with Gypsies and Travellers than with Roma. Those working with Gypsies and Travellers, described this as their main focus (11.5%), high focus (13%), some focus (46.9%) and no focus (28.6%) in their current role. Figure x.2 presents the Gypsy and Traveller groups that respondents worked with. Nearly two thirds (64.6%) worked with Irish Travellers and approximately half worked with English Romany Gypsies (50.8%). Respondents working with Roma people described this as their main focus (3.2%), high focus (6.9%), some focus (47.1%) and no focus (42.9%) in their current role; and as their main focus (1.1%), high focus (7.8%), some focus (43.3%) and no focus (47.8%) in a previous role. We also asked participants to expand on which groups of Gypsies and Travellers their work had involved (Figure 6).

Figure x.2: Gypsy and Traveller groups that respondents worked with



Note: some respondents worked with more than one group

Trust and health service use

When asked about engaging Gypsies, Travellers and Roma people in healthcare services, 28.6% of respondents rated trust as the most important issue and 64.8% rated it as important or very important. When elaborating on their responses, a few respondents commented that while trust is important, there are other aspects of healthcare services that are as, or more, important; examples given were safe and effective care, culturally and clinically appropriate care, and health information and services that are adaptable to the needs of community members. Another view was that trust is important in engaging with everyone, not just with Gypsies, Travellers and Roma people; although it was felt that it may be particularly important for all groups who are vulnerable, marginalised and experience discrimination.

Two key reasons were offered as to why trust is particularly important in engaging Gypsies, Travellers and Roma people in healthcare services: (1) to address previous negative experiences of Gypsies, Travellers and Roma people (see section *Experience and fear of discrimination*); and (2) to achieve healthcare delivery goals. The delivery goals being to develop respectful relationships between Gypsies, Travellers, Roma people and health professionals, and to achieve open and honest communication about health, particularly sensitive health issues so people's needs can be understood and met.

> *Years of experience in working with GRT communities have convinced me that 'trust' coupled with high quality care are hugely important in terms of breaking down barriers. I've been repeatedly told by community members that even a clinically well-skilled practitioner who is not perceived of as culturally competent or trustworthy will be avoided with respondents frequently travelling long distances to see a practitioner whom they trust and know - either in person or by repute.* (Policy, academia)
>
> *As a nurse working with the community I realise that you have to build up the trust between yourself and the client before they will be happy to discuss medical issues comfortably. Taking*

> *the time to get to know your clients and build trust and confidence allows you to obtain all of the information needed to offer the health services they require.* (Nurse)

Factors that are related to trust

Respondents were asked to rate the importance of ten factors related to trust (Table 14.) in thinking about their work with Gypsies and Travellers. All the factors were rated as important or very important by the majority of respondents (range 89% to 96.7%). For work with Roma people, a slighter smaller proportion of respondents rated all factors as important or very important (range 75.4% to 83.3%).

Table 14: Factors related to trust rated as important/very important

Factor	% Gypsies & Travellers	% Roma
The development of a relationship between healthcare worker and service user	94.2[h]	80.5[d]
Service user feels safe using the service	95.8[i]	83.9[f]
Service user has confidence in the service	94.3[i]	82.2[f]
Accessibility of healthcare worker, including time to spend with the patient	94.2[i]	80.9[c]
Healthcare worker has the best interests of the patient in mind	93.7[h]	82.7[d]
Trustworthiness of healthcare worker	94.3[i]	83.3[d]
Shared power in the relationship between healthcare worker and service user	89.0[j]	75.4[e]
Confidentiality when using services	95.3[i]	81.3[c]
Competence of healthcare worker	95.8[i]	81.4[b]
Healthcare worker is caring/compassionate	96.8[g]	83.0[a]

Note. N responding to the factor = 176[a], 177[b], 178[c], 178[d], 179[e], 180[f], 189[g], 190[h], 191[i], 192[j]

Barriers to developing trust

Respondents were asked to list barriers to developing trust with Gypsies, Traveller and/or Roma people in relation to healthcare. There were 181 free text responses. Responses were classified either as (1) barriers associated with communities; or (2) barriers associated with healthcare services. The key barriers (those mentioned most often) are presented first for each category. Where the respondent specified if they were referring to Gypsies and Travellers or Roma people this is indicated.

Knowledge and beliefs about health

Health knowledge and health beliefs amongst GRT people were identified as important barriers to developing trust. In terms of knowledge it was suggested that some Gypsies, Travellers and Roma people do not understand the importance of preventive healthcare including dental care and maternity care; and may not understand when a health problem requires immediate attention. Health beliefs that threatened the development of trust were identified as cultural taboos around mental health, sexual health and cancer, beliefs that some health conditions are incurable leading people to be less likely or frightened to seek care, and a reliance on historic remedies and rituals.

> *There is very little knowledge within the [Roma] community of specific health conditions. In particular, mental health conditions are often related in terms of physical symptoms.* (TSO, focus on Roma)

Navigating the NHS

Limited understanding or misconceptions about the NHS was seen as preventing the development of trust. This included believing that the NHS charges for services, not understanding the roles of health professionals e.g. midwife, health visitor, or what the NHS can provide e.g. maternity services, dental services, or how to navigate services and book appointments. A few respondents commented that poor understanding can be because the NHS is different to the health services in people's countries of origin.

> *In the Roma group, the women are unfamiliar with the concept of seeing a midwife, not a doctor and therefore have reservations about the health care system. Once trust has been built and the UK system is explained and discussed, attendance is good.* (Maternity services, focus on Roma)

Literacy and language

Low levels of literacy amongst Gypsies, Travellers and Roma were seen to be a barrier to developing trust because this can lead the individual to feel embarrassed and worthless, prevent people from understanding written health information and appointment letters, completing paperwork to register for healthcare services and providing informed consent for procedures.

> *She attempted to fill in the forms but then had to admit that she was illiterate. I felt that this had a negative impact on the establishment of a trusting relationship and I have since adapted my care so that I complete the notes.* (Maternity services, some focus on Gypsies and Travellers)

Language was identified as a barrier to developing trust with Roma people, specifically the impact of having to rely on an interpreter or language line (and associated costs) to communicate.

> *As a dentist … one of the biggest challenges when working with a population which does not speak English (in my case) as their first language. Working with translators really reduces communication with my patients. Relationship building, key in dentistry.* (General dentistry, some focus on Gypsies, Travellers and Roma)

Community norms

Several community norms were suggested to be barriers to developing trust, for example, that one's health is private or an "*unclean*" topic not to be discussed with others, particularly not with healthcare staff of the opposite sex. Other comments observed that men do not typically have responsibility for health-related issues. The barrier of communities being "*closed*" to outsiders, reluctant to mix with non-Travellers and rejecting non-Traveller lifestyle choices, for example, registering with health services, were also identified.

> *A woman would not engage with male health workers as this is not culturally acceptable. Likewise, men would not want to discuss personal issues with female health workers.* (TSO, advocating for Gypsies and Travellers)

> *Often the community prefers to look after their family members themselves without outside assistance, any discussion of this subject needs to be dealt with very sensitively.* (Social care services, some focus on Gypsies, Travellers and Roma).

Discrimination, prejudice and cultural competence

Many respondents commented that a key barrier to developing trust was GRT experiences of discrimination, stigmatisation, negative stereotyping, prejudice and racism; in their daily lives, as well as when engaging with the NHS or health services in their countries of origin (particularly for Roma people).

> *Many Roma have faced severe discrimination and isolation in their countries of origin where interaction with any public service, including medical treatment, has left a negative experience and a deep fear and mistrust. There remains a lack of knowledge of who the Roma community is and how their experiences impact on their trust and engagement with health services.* (TSO, focus on Roma)

There was a perception that these experiences had led some Gypsies, Travellers and Roma people to be fearful or distrusting of authority/professionals, particularly those who wear a uniform. Respondents' comments suggested that some GRT people may fear that health professionals will judge their lifestyles, marginalise families and make life more difficult. A fear of social services, specifically removing children from families, was also identified.

Respondents suggested that a further service delivery barrier to developing trust was a lack of cultural competence and knowledge on the part of healthcare providers. Associated with this, and in line with the negative experiences of service users, were many comments about health professionals not communicating in a sensitive way, or worse, being discriminatory and exhibiting prejudice. Lack of training and resources were also mentioned, as were lack of time to spend with community members and a lack of specialist practitioners.

> *Lack of knowledge of the communities by service providers creates lack of understanding or empathy for the vastly different health experiences across the Travelling communities.* (Health promotion, focus on Gypsies, Travellers and Roma)

Continuity of care

Another important barrier to building relationships and developing trust was identified as a lack of continuity of care. Respondents noted that this can occur due to seeing multiple health professionals, high staff turnover, changes in services, not having a dedicated practitioner for Gypsies, Travellers and Roma people, and some GRT people's transient lifestyles.

> *Different person trying to engage with a piece of work each time. Therapeutic relationship extremely important and building a level of trust with the client. One-to-one working is essential to my job working with all my client base.* (Maternity and early years, some focus on Gypsies and Travellers)

Access to primary care

Accessing primary care was identified as a barrier to the development of trust. This was in terms of registering with a GP practice, specifically when GP practices close their lists to Gypsies, Travellers and Roma people or ask them to provide photographic ID to register, which many do not have. It also related to the limited capacity of primary care services, variation in service quality, long waiting lists, cuts to funding Specialist Health Visitor posts and limited capacity to do home visits.

Time

A lack of time for health professionals was identified as a barrier to developing relationships and build trust, to understand values of different Gypsy, Traveller or Roma cultures and to listen in appointments.

> *Not taking the time to get to know people. Having limited time for appointments can put people off as they feel that they are not important enough to warrant your time. (Nurse)*

Data sharing and record keeping

Data sharing was seen as barrier to developing trust because this is often done poorly across services and can threaten trusting relationships if the service user does not know who you are sharing their data with, and why. Capturing data e.g. recording ethnicity, from Gypsies, Travellers and Roma was seen to threaten trust if they are not consulted on this.

> *Data sharing requires appropriate data protection but also may run counter to the idea of a trusting patient provider relationship (i.e. if you don't know who will have access to your data and who controls this access) (Academia)*
>
> *Equality monitoring across the health service appears to be inconsistent, particularly in terms of service users. The Department of Health does not include Gypsy, Traveller and/or Roma communities within the ethnic monitoring categories. It is essential that across the NHS that Gypsies, Travellers and/or Roma communities are part of any data capture/monitoring arrangements. This will increase trust and confidence within the communities that there needs will be considered and services identified to specifically address any health needs. (Policy)*

Engagement in health services

Enhancing engagement

Respondents were asked to rate how helpful different strategies are to enhance engagement with mainstream, maternity, early years or child dental services (Table 15). All the strategies were rated as helpful or very helpful by at least three-quarters of respondents (range 76.8% to 94.5%). Developing a relationship between healthcare worker and service user, and developing trust were most frequently rated as helpful or very helpful (91.8%, 94.5% respectively). To facilitate engagement with Roma people, over two-thirds of respondents rated all strategies as helpful or very helpful (range 69.4% to 82.6%). Reaching service users via their established social networks e.g. word of mouth was most frequently supported (84.0%).

Table 15: Strategies to enhance engagement with health services rated as helpful/very helpful

Strategy	% Gypsies & Travellers	% Roma
Developing a relationship between healthcare worker and service user	91.8[i]	81.4[d]
Developing trust	94.5[k]	82.6[e]
Consulting with communities in developing interventions, services or programmes	85.6[h]	74.4[d]
Reaching service users via their established social networks e.g. word of mouth	82.8[i]	84.0[f]
Specialist (tailored) services for communities	79.6[i]	70.2[c]
Service outreach to communities	79.6[i]	72.3[b]
Reaching service users through family members and/or involving family in healthcare	84.0[j]	71.9[c]
Providing cultural awareness training for healthcare workers	90.1[i]	79.0[d]
Involving community members in the delivery of healthcare	80.7[j]	69.8[d]
Capacity building in the community	76.8[i]	67.4[a]
Providing health information to communities	77.3[g]	69.4[b]

Note. N responding to the strategy = 169[a], 170[b], 171[c], 172[d], 173[e], 174[f], 178[g], 180[h], 181[i], 182[j], 183[k]

Engagement strategies offered by respondents

Respondents were asked to describe activities or methods they knew of for engaging Gypsies, Travellers and/or Roma people in healthcare. There were 147 free text responses. They were also asked to describe those which they consider to be of particularly good practice, for which there were 129 free text responses. The following groups of strategies and good practice were offered. The strategies mentioned most often are presented first (outreach to communities, dedicated or tailored services, collaborative working, characteristics of services/projects and staff). Where the strategy was suggested to be specific to Gypsies and Travellers or Roma people, this is indicated. Notably two thirds of the strategies were consistent with those listed in Table 15.

Outreach to communities

The most frequently cited example of an engagement strategy was outreach to GRT people, or services provided in the community. Nearly all these examples related to health services visiting Gypsy and Traveller sites (private, council and unauthorised sites, as well as roadside). There were fewer examples of health services visiting Roma communities, one being outreach for immunisation. A wide variety of health professionals were mentioned as providing outreach, namely midwives, health visitors, nurses, dental services and primary care professionals. Mobile service facilities (general health, dental health and children's play) were frequently mentioned as a specific resource which supports outreach. These types of outreach services were frequently offered as examples of good practice.

Dedicated or tailored services

Many examples of engagement strategies were of dedicated or specialist services for Gypsies, Travellers and/or Roma, or services that had been tailored in some way to facilitate engagement with these communities. These were all offered as examples of good practice. There were slightly more examples of services to engage with the Roma community than with Gypsies and Travellers.

A wide range of professionals with a specific remit to work with communities (sometimes within a broader inequalities role) were mentioned including community development and health workers. A dedicated or specialist health visitor (both for Gypsies and Travellers, and Roma) was most commonly mentioned.

In terms of service provision, it was recommended that services and programmes are provided at times that are most convenient to service-users. Respondents gave examples of the ways that services were structured or adapted to encourage access including providing specific clinics for Gypsy, Traveller and Roma communities, drop-in and on-the-day services, out-of-hours services, one-stop-shops for Roma and avoiding booking appointments when families are travelling. There was mention of a forum in which professionals could share information related to Gypsies, Travellers and Roma people. Indeed, a number of respondents commented that dedicated health workers could be a great source of knowledge and understanding for other professionals to draw upon. Specific care pathways, as well as targeted antenatal and postnatal classes and care, and parenthood classes, were also mentioned. Clinics for Roma new arrivals, dedicated organisations for Roma to find information or meet each other, and a programme for Traveller men's health were other examples. More generally speaking some respondents recommending "*taking culture into account*" in service delivery.

> *Adapting our service and the service of partner agencies to meet the needs of the Roma community i.e. not expecting them to fit into the service we deliver but tailoring our service to meet their needs.* (Early years' healthcare, focus on Roma)

Collaborative working

Collaborative working was another commonly mentioned strategy. This referred to working with other organisations as well as with GRT communities. Respondents identified many multi-agency partnerships involving health, education, social care, local authorities and the voluntary sector (including groups with specialist knowledge of Gypsy, Traveller and Roma communities). They described making joint visits to community sites with other health professionals as well as a few examples of professional fora for discussion on Gypsy, Traveller and Roma issues. Several respondents stressed the value of accessing community members via other professionals who are already trusted. When identifying good practice for collaboration, examples were provided of health visitors, secondary healthcare, Child Smile, community-based organisations, Gypsy and Traveller liaison officers, site managers, council workers, government, Sure Start children's centres, and education.

> *… working with Gypsies and Travellers has taught us that the best way to enable mainstream organisations to engage is through the conduit of a trusted specialist organisation […] a bridge between the mainstream service provider and the community.* (TSO, focus on Gypsies, Travellers and Roma)

In providing examples of collaborating with community members, respondents used terms such as consultation, co-production, and described community members leading and "owning" pieces of work or delivering healthcare. They also mentioned peer support/mentoring and empowering community members and provided examples of creating roles for community members, specifically community health champions, health trainers, mediators and ambassadors where the individual has shared background, experiences, language and familiarity with the GRT community. These examples were offered as good practice for collaborative working, and seen as important to understanding community needs, providing mentoring, support or advocacy for the wider community, as well as developing trust by helping staff connect with the wider community. Some respondents mentioned the importance of drawing upon already established relationships with the community, to harness trust that has already been developed.

> *Forums and working alongside Traveller representatives appears to work well in the maternity setting. It […] opens channels of communication from which to start building trusting relationships. These groups provide an insight for both parties*. (Maternity and early years healthcare, some focus on Gypsies, Travellers and Roma)

Characteristics of services/projects and staff

The two most frequently mentioned characteristics of good services were providing a consistent approach and offering flexibility. Consistency was about commitment to delivering a regular service, over time, having clear roles and expectations, and ensuring continuity of care where staff have sufficient time to build relationships with people and deliver good healthcare. Flexibility to ensure services are accessible was described as allowing for GRT community members' preferences; for example, offering one-to-one or family interventions, and recognising that gender may need to be considered. Other features of good practice for services were helping with people's needs beyond health, providing a quick response, and having a mix of skills within the staff team. Using fewer text-based resources and avoiding a lot of paper and documents were also recommended.

> *Low level consistent engagement that is not related to healthcare (or indeed any other agenda) has been invaluable. This has brought about trusting relationships between ourselves and the community, which then gives us an opportunity to open up conversations about healthcare and how they might best engage with services.* (TSO, some focus on Gypsies and Travellers)

In describing staff who work with Gypsies and Travellers, and Roma people the most frequently mentioned valuable characteristic was having good understanding, knowledge or awareness about the local community. Importance was placed on being open and honest with community members, having good cultural awareness, respect, and being non-judgemental. It was also recommended that staff provide information about the service they are delivering, always have the best interests of the service user in mind, take an interest in community members and/or have experience of working with the community. Effective staff approaches to delivering services were seen to include listening, learning from and having empathy for the community; mediating and advocating; showing by action, delivering on actions, and being accountable.

Many of the examples of good practice were based on relationship-building between staff and GRT community members. Within this was acknowledgement of the importance of building of trust to facilitate engagement. Having adequate time together, both during meetings and in the long term, was seen as important.

> *Roma families. It works well to have a small team so they are used to seeing the same faces and this helps to build a trusting relationship and more effective interventions.* (Early years' healthcare, focus on Gypsies, Travellers and Roma)

Communication

There was also a focus on good communication. Respondents mentioned the use of interpreters, and translating information e.g. appointment letters, into the language of service users. They also cited using appropriate methods of communication, using verbal rather than written information for those with low literacy levels, and using simple language to explain concepts. Some reported using SMS messages and word of mouth to remind people about appointments. In more general terms, open discussion, listening, explaining and being clear were also mentioned, as was maintaining eye contact.

An important consideration for good practice in using interpreters was using in-house, block-booked and dedicated interpreters. One respondent pointed out that the use of unknown interpreters would affect confidentiality. Other activities offered as good practice were providing service users with a specific person as a contact point or a direct contact number.

Training or information for staff

Strategies focussed on providing cultural training or information for health and voluntary sector staff about Gypsies, Traveller and Roma people were also reported. In addition to an abstract sense of value of this, respondents offered real examples of training that they had been involved in delivering or had heard about, some of which had involved community members. It was seen as good practice to ensure that training focussed on cultural awareness and cultural sensitivity, and was provided to a range of professionals including GPs and reception staff.

Raising health awareness

Another engagement strategy used was to raise health awareness within the Gypsy, Traveller and Roma communities. Respondents mentioned addressing health literacy levels, providing information about services, offering workshops on health issues (including oral healthcare) for community members and hosting various types of health events such as fairs. In offering examples for good practice, a small number of respondents offered topics to focus on, specifically accessing the NHS, GP registration, immunisation, oral healthcare (for children in particular), first aid, fire safety and health values. Some answers pointed to the importance of delivering information in a culturally appropriate way.

Additional ideas

Less frequently mentioned examples of enhancing engagement included offering incentives e.g. a crèche, refreshments, equipment or advice to reach people. Related to this was the idea of providing health information for Gypsies, Travellers and Roma people through the events or activities that they enjoy, including local horse fairs, events for their children (Stay and Play) or celebrating GRT month.

> *Stay and play is successful because relationships of trust have been built it's a welcoming friendly environment and the children enjoy an activity, the families come and we address anything they want to talk about.* (Early years' healthcare, focus on Gypsies, Travellers and Roma)

A few respondents mentioned that there is nothing different in place for GRT people and that treatment would be the same as for any other member of the public.

Other ideas focussed on initiatives such as support for new mothers, financial incentives for breastfeeding and asset-based community development. Some participants highlighted the need to target patient registration issues, including for those with no fixed abode or a lack of documentation e.g. using 'mystery shopping' exercises.

> *Asset-based community development - recognising the skills and knowledge amongst communities and ensuring that health care professionals also appreciate and recognise this knowledge, cultural competence and available pool of talent and interest in health involvement.* (Policy, academia)

Barriers to engagement

Respondents were asked to rate the significance of different barriers to engagement with mainstream, maternity, early years or child dental services (Table 16). Just over half of the barriers were rated as significant or very significant by at least 80% of respondents (range 49.7% to 92.2%). Language/literacy of service user, cultural issues and health literacy of the service user were most frequently rated as significant or very significant (92.2%, 91.1%, 90.3% respectively). For barriers to engaging with Roma, smaller proportions of respondents identified barriers as significant or very significant (range 46.1% to 79.7%). The same three barriers were most frequently identified (language/literacy of service user 79.7%, cultural issues 77.1% and health literacy of service user 76.7%).

Table 16. Barriers to engagement with health services rated as significant/very significant

Barrier	% Gypsies & Travellers	% Roma
Discrimination, racism, prejudice or stereotyping of service users by professionals	81.1[j]	68.0[e]
Cultural issues	91.1i	77.1[b]
Previous experience influencing service users i.e. personal health or service use experiences or learning from others	87.1[h]	70.8[d]
Language/literacy of service user	92.2[j]	79.7[c]
Administration/bureaucracy in health services	85.6[k]	74.8[c]
Lack of trust in health services	88.2[i]	71.9[c]
Housing/accommodation of service users i.e. living circumstances or place of living	71.1[j]	61.0[c]
Fear associated with use of health services or receiving healthcare	87.8[j]	68.7[b]
Health literacy of service user	90.3[l]	76.7[c]
Stigma/shame associated with health issues	70.9[f]	60.2[b]
Transport needed to access health services	64.2[i]	59.8[c]
Self-reliance	73.6[h]	59.0[b]
Gender of service user	57.0[g]	48.2[b]
Lack of childcare	49.7[g]	46.1[a]

Note. N responding to the strategy = 165[a], 166[b], 167[c], 168[d], 169[e], 175[f], 177[g], 178[h], 179[i], 180[j], 181[k], 176[l].

Respondents were then asked to identify the most significant barrier. Those more commonly identified for Gypsies and Travellers were cultural issues (14.3%), followed by discrimination, racism, prejudice or stereotyping of service users by professionals (13.7%), and previous experience influencing service users (13.7%). For Roma, the barriers of discrimination (14%) and cultural issues (12.9%) were again highlighted as well as the language/literacy of a service user (13.5%).

Poor engagement strategies

Respondents were asked to describe activities or methods which they thought did not work well for engaging Gypsies, Travellers and/or Roma people in healthcare. There were 111 free text responses. The following ineffective engagement strategies were suggested. Those mentioned most often are presented first (characteristics of services and staff, communication, cultural awareness). Where the approach is specific to Gypsies and Travellers or Roma people, this is indicated. Not surprisingly often these were opposites of the good engagement strategies described above.

Characteristics of services and staff

The majority of responses focussed on service design that did not promote access or engagement. For example overly structured services with a focus on appointments that have to be booked and aren't flexible; and that take place at times when people have other commitments and in locations that easy to access (including far away or costly to get to). Inflexible attitudes to missed appointments, including removal of service users from registration lists, was raised, including the idea that this may exacerbate inequity. Respondents also raised appointment systems that are confusing (such as having to confirm appointment), needing a fixed address to use the services, a need to access care not only via the GP, a lack of certain services in some areas, and waiting lists. A number of respondents suggested not visiting Traveller sites without prior arrangement. Overall respondents felt that group activities or classes were not favoured. One respondent suggested not giving up on strategies too early. A lack of consistency in the service or staff was also highlighted as problematic. Other issues raised include overly theoretical or classroom-based activities, and a need for privacy around health matters.

> *I think consistency is important - too often an organisation decides it will do some work with Gypsies and Travellers but does not stay the course. Gypsies and Travellers then lose confidence in services and may be reluctant to engage with future projects as they can feel that organisations are just ticking boxes.* (TSO, focus on Gypsies and Travellers)

In terms of staff, the majority of answers focussed on staff exerting control over the service user; for example, telling people what to do, restricting behaviours, being overly prescriptive, not listening, following their own agenda, being demanding and not accepting alternative approaches.

Communication

The next most commonly identified issue was poor communication. Most respondents focussed on the use of letters or written materials to convey appointment times and health information which did not take in to account language or literacy levels of service users. The use of jargon and technical language, and too much information by leaflet, was also considered unhelpful. Difficulties in working with interpreters were also raised, including interpreters not being available, trained, or not knowing the Roma language.

Cultural awareness

Respondents also commented on a lack of cultural awareness, understanding and competence of staff in relation to the Gypsy, Traveller and Roma communities. This included not understanding cultural differences between Gypsy and Traveller groups, the impact of value judgements or the impact of poverty, and stereotyping. Respondents offered some specific examples, including health promotion materials that do not consider Roma customs or taboos; and rejecting cultural traditions without discussion.

> *Many of these issues in fact are simple good practice and courtesy for the majority of 'underserved' groups rather than GRT specific but there is a crying need for practitioners to have some awareness of the challenges faced by GRT people and also specific risk factors* .(Policy, academia)

Collaboration

Respondents felt that it was poor practice to not involve Gypsy, Traveller and Roma people through consultation which would allow community members' agendas and views to be heard. The challenges associated with working with partners were identified, including the need to avoid too many people visiting sites and not wanting to be associated with partners who may damage the relationship with the community. Consultations or partnerships which did not lead to any substantial outcomes or change were felt to be unhelpful.

> *Preconceptions that Gypsy and Traveller Community members don't want to engage with health may act as a barrier to practitioners having conversations with Traveller Communities about their health. (Academia)*

Accounting for differences among service users

Respondents discussed services that did not take into consideration differences among its users. This included mainstream services that were designed to be used by everyone in the same way. Inconsistent use of ethnic identifiers was also mentioned. Some respondents also suggested that it was unhelpful to group Gypsies, Roma and Travellers together, all Gypsies and Travellers together, or to provide one service for mixed groups of Travellers on a site. They also suggested the approach of grouping Gypsies and Travellers with other groups such as other minority ethnic groups and the homeless was unhelpful. A few respondents highlighted additional issues related to community background and policy that can affect engagement, including; the needs of highly transient people, gender issues, lack of education, discrimination, victim blaming, lack of recognition of Travellers as an ethnic group, and lack of recognition of LGBT Travellers.

Relationships and trust

Some respondents considered engagement with communities when relationships and trust have not been built, and the importance of both. Specific issues raised included a suggested preference for familiarity of health professionals, the difficulty communicating if there is no trust and difficulties involving sectors who are less trusted in health work. One respondent pointed out that trust in one person can lead to people only wanting to deal with that person.

> *Services that may have been set up for Gypsies and Travellers but there has been no thought given to building trust with this community first.* (Academia)

<u>Expectations of services</u>

Engagement may be affected by expectations of health and health services which are incongruent with healthcare service provision. This may include a preference to be seen when unwell rather than placing importance on preventative treatment; expectation of cultural insensitivity; and for Roma, a lack of understanding around the NHS and for which health problems there are potentially available treatments

> *The Roma communities lack of understanding of how the NHS works can make them feel frustrated as they do not get appointments when they want it. They therefore do not want to engage in the health service.* (Early years' healthcare, some focus on Roma)

Economic evaluation

No specific costs associated with particular interventions were stated. Respondents identified eight potential areas where additional resources and hence additional costs may be associated with delivering engagement activities and methods for Gypsies, Travellers and/or Roma people. The most widely cited additional resource was interpretation services (23.1%). Time was also considered an issue by 18.7% of the respondents in terms of additional or longer visits with health care professionals being required for this population. Costs around delivering specialist services were also identified as significant, as were dealing with missed appointments and travel cost.

Table 17: Cost areas of engagement

Area of cost	**N (%)**
Interpretation services	21 (23.1)
Time	17 (18.7)
Specialist services	14 (15.4)
Missed appointments (no shows)	13 (14.3)
Travel	13 (14.3)
Extra staff costs	5 (5.5)
Specific intervention costs	4 (4.4)
Remuneration for participation	4 (4.4)

N=91 responses

Summary

A semi-structured, web-based consultation delivered using the Bristol Online Survey Tool was designed to gather views on trust and engagement in health services for GRT people. The consultation focussed on maternity, early years and child dental services and aimed to elicit the views of three main groups: TSOs advocating for GRT people; health and social care practitioners, policymakers, and health and social care service commissioners. There were 196 respondents across a broad range of roles and who worked for a wide range of organisations: approximately half (47%) work in England, and approximately a third (32%) in Scotland. Trust was viewed as particularly important in engaging GRT in healthcare services in order to address previous negative experiences and to achieve healthcare delivery goals. A range of findings regarding the views and practices of respondents were gathered regarding: Factors that are related to trust; *Barriers to developing trust in health services* and how helpful they viewed a number of different strategies are to enhance engagement with mainstream, maternity, early years or child dental services. Respondents were also asked if they were aware of the costs, additional resources or cost-related issues associated with delivering engagement enhancing activities for GRT and whilst there were many responses, no specific costs associated with particular interventions were stated.

Chapter 5: Case studies

Aims

We chose case study methodology to generate in-depth, multi-faceted understanding of the complex issues surrounding enhancing trust and engagement between mainstream health services and GRT communities in their real-life context (148). We conducted four case studies in Leeds, Fife, Sheffield and London between June 2016 and August 2017.

The research questions for each case study were:

- What are the knowledge, perceptions and experiences of GRT people of maternity, early years' and child dental health services and how could uptake be improved?
- What are the barriers to GRT people accessing maternity, early years' and child dental health services and how can these be overcome?
- What activities/methods do maternity, early years' and child dental health services use to engage GRT people and to what extent to do they focus on developing and negotiating trust?
- What activities/methods do TSOs use to engage GRT people and to what extent do they influence trust in and access to maternity, early years' and child dental health services?
- What are the costs of these activities/methods?

Methods

We selected the case study sites to reflect maximum diversity of GRT groups, living arrangements, service configuration and examples of good practice in terms of engagement and trust. The selection of the case study sites was informed by knowledge of the research team and Stakeholder Advisory Group, and the findings of the online consultation. Ethics approval was granted by the East Midlands - Leicester Central NHS Research Ethics Committee (16/EM/0028).

Each case study included:

- Interviews with 8-12 mothers of pre-school children. Interviews explored perceptions of trust, views, experiences and awareness of maternity, early years' and child dental health services including barriers to service use, experiences of community engagement activities, ways of improving services and examples of good practice;
- One or more focus group discussions with 6–8 HCPs including midwives, health visitors, early years' practitioners, specialist/consultant paediatric and community dentists, service managers, commissioners and public health practitioners. Telephone interviews were offered as an alternative and for those where it was impractical to attend a focus group. The topic guide included experiences of service provision for GRT communities, barriers and facilitators to providing quality services and enhancing trust, training and education, and cross-sectoral working.
- Two - four interviews (telephone or face-to-face) with key informants from TSOs. The topic guide covered experiences of service provision for GRT communities, barriers and facilitators to

providing quality services and enhancing trust, and third sector approaches to community engagement
- Documentary analysis of relevant documents and web-pages materials, related to goals, and methods/activities used by health services/TSOs to engage GRT people.

We adopted a flexible, inclusive approach to interviews with mothers where other family members, such as husbands and grandmothers, could be included if they chose (or interviewed as an alternative), and we interviewed mothers (or other family members) either individually (15 occasions), in pairs (2 occasions) or in small groups (six occasions), depending on their preference. The interviews with mothers were held in the participants' homes, in TSO premises, or in communal areas on caravan sites. The focus group discussions with healthcare practitioners were held in NHS premise meeting rooms, and face-to-face interviews with members of TSOs were held in their organisations premises or in locations where they had organised meetings. We recruited all participants purposively, mainly through TSOs and health care practitioners. The topic guides are included in Appendix 8.

Most interviews and focus group discussions were audio-recorded and transcribed verbatim, and notes were taken for a small number of interviews with family members who preferred not to use the audio-recorder (three occasions). There was a large variation in the length of audio recordings from the discussions with mothers, depending on how much the participants wanted to say about each topic or their other commitments, from around eight to fifty-two minutes. Interviews and focus group discussions with health professionals and TSO participants lasted between twenty and eighty-one minutes, and thirty-two and seventy-three minutes respectively. The GRT participants each received a shopping voucher worth £15 as a thank you for taking part in the study.

NVivo software was used to manage and organise the data. We analysed data thematically using the analytical framework derived from the literature reviews (see Chapter 3). Consistent with case study methodology, the research material from each case study was analysed independently and then similarities and differences across case studies were compared (149). However, as the themes were remarkably similar across all four case studies, we provide a short summary of each case study first, providing the context and examples of specific barriers and engagement strategies. This is followed by an account of the combined thematic analysis, highlighting where there were differences between case study sites. Most of the differences were between case study three (Roma migrant population from Slovakia) and the three case studies that primarily included Irish Travellers but also Scottish Gypsy/Travellers, English Romany Gypsies, one Welsh Traveller, one participant who described herself as a Traveller, and one participant who had married a Traveller and lived on a Traveller site.

Participants

The participants were thirty-seven mothers, one father and five grandmothers. Most of the participants in the case studies in Leeds, Fife and London lived in caravans or chalets on sites (in some cases having lived there for many years), while some lived in housing. The Roma participants had been in the UK, or

Sheffield, for a number of years. The participants ranged in age from under twenty years to over sixty years. Almost all of the mothers (and the father) had more than one child, as shown in Table 18. The ages of the youngest children by each parent participant is shown in Table 19. The grandchildren of the grandmother participants included very young children. The mothers whose youngest child was slightly older than pre-school (aged 6-8 years) included some who were currently pregnant, or had younger grandchildren. Some of the Gypsy and Traveller mothers had children of a wide age range. We have chosen to present details about the participant in this combined way, across the case studies, in order to protect their anonymity.

Table 18: Number of children for each mother participant

Number of children	Pregnant	1	2	3	4	5	5+
Number of participants	3	6	6	9	6	3	7

N=37

Table 19: Age of youngest child for each mother participant

Age of youngest child (years)	<1	1	2	3	4	5	6	7	8
Number of participants	8	6	4	4	4	3	1	3	1

N=34

Case study 1: Leeds

Case study one was conducted in Leeds and focussed on Gypsy and Traveller communities. The case study site was selected because of our already strong relationship with Leeds GATE who provide a range of community engagement activities, and we were also aware of an example of good practice related to maternity services in the city. In addition, one study included in the engagement review (87) reported in 2015, a joint project between NHS Leeds West Clinical Commissioning Group and Leeds GATE that sought the views of Gypsies and Travellers on using primary health care services. The main finding was that Gypsies and Travellers had difficulties registering with GP practices and a series of recommendations were made including making registration with a GP of choice easier, providing clearer information about GP practices and the registration process, and providing more flexible and longer appointments.

Context

Although the Office of National Statistics Census (3) report 687 Gypsies and Travellers living in Leeds in 2011, a baseline census conducted in 2005 (150) estimated the population to be around 3000. Leeds City Council provides one overcrowded site of 41 pitches on the outskirts of the city, although two thirds of the Gypsy and Traveller community live in bricks and mortar housing, and an estimated 25 families live in unauthorised sites in the city.

Our documentary analysis revealed that Leeds City Council (LCC) and Leeds Clinical Commissioning Group (LCCG) have aspirations to reduce health inequalities in the city. For example Leeds Health and Wellbeing Strategy (151) includes ‘a relentless focus on reducing health inequalities in Leeds’. In terms of the foci of our study, the same document also lists the first priority to be: “A Child Friendly City and the best start in life” focussing on conception to age two. There is no mention of dental or oral health in this strategy.

The Maternity Strategy for Leeds 2015-2020 (152) includes a priority to:

> *“ensure that those families who need it, receive targeted support during their pregnancy and after the baby is born.”*

To fulfil this priority Leeds maternity care provision includes the Haamla service (153) which provides essential support for pregnant women and their families from minority ethnic communities and this includes Gypsy and Traveller women and babies. The maternity services also have developed specific pathways of care for women who need additional support and an integrated maternity care pathway for GRT women and babies was developed in 2013 (154). This care pathway incorporates joint working between the NHS maternity service and TSOs.

The key TSO working with Gypsy and Travellers in Leeds is Leeds GATE whose aim is to improve the quality of life for Gypsies and Travellers. Leeds GATE provides a range of activities and projects focussed on health including: telephone, drop-in and outreach advocacy support; community health educators training sessions; developing partnerships with other organisations to increase accessibility of services such as the Health Protection Agency and local GP practices; supporting health practitioners to develop cultural competence and engagement skills; and working with partners to conduct health-related research and consultation, both locally and nationally (155).

Participants

The participants in case study one were 10 mothers, eight HCPs, and four staff from a TSO. The mother interviewees lived in housing or on one Council site, and some had previous lived roadside.

Findings

While the mothers in this case study gave many examples of complex health needs for themselves and their children, they were mainly positive about the local maternity and health visiting services, although they did not comment on the Haamla service specifically. Sometimes this was compared to poorer experiences in other locations. In particular, site visits seemed to be appreciated, and this perception was supported by the health professional interview findings. One mother appreciated support when she experienced depression, while another was disappointed that health visitors no longer visited the site to weigh babies:

> *She [health visitor] was a lovely woman. She came out to see me not long ago, six months check-up. She come out to see me because I had bad depression. Last few months I had very bad depression. Like some days I'd sit and cry all day. So that's why I come to GATE as well. Because sitting at home all day I cry for nothing. But I told her, and she was there for me when I had depression. (Mother)*
>
> *There used to be a health visitor years ago. Years and years ago, but now if you want to get your baby weighed you've got to bring them to the doctor surgery on a certain day. (Mother)*
>
> *The services they engage with well, generally they're better with people that go to them. So for example midwifery. [Case 1] has quite a good model of midwifery where the team that works with Gypsy Travellers tends to do home visits rather than clinic visits. (HCP)*

The greatest barriers to accessing health services were related to registering with dentists and GP practices. While some families clearly were registered with dentists and had had good experiences, others reported access problems:

> *I think it's very hard to register with a dentist and if you miss one appointment then you're thrown out[…]Yes, I've had a dentist in [another location], but because I missed an appointment they fired me out, they were always going to fire me out because I was five minutes late, that's how I know (Mother).*

Accounts of mothers and TSO staff highlighted that many families could not register living on the authorised site could not register with the nearest GPs but had to travel some distance. This appeared to be a historical problem. Of note, there was previously an outreach mobile health service to the same site, and a participant noted that this may have exacerbated issues with mainstream GP registration.

> *With the doctors it's very hard to get an appointment. Where we should have a doctor's round this area. We shouldn't go all the way up there for a doctor's. (Mother)*

> *There used to be one [GP practice] in [name of area] but I was in it and they took us out of it. They said it wasn't in my name any more, and I was in there when I was a little girl. I was in there when my mum was in here. (Mother)*

> *[Name of TSO] had experience in the past with a health bus that used to go up onto [the site], and was a real sub-standard service. Sometimes it would have a doctor on it, sometimes it wouldn't, quite often it was just a nurse. It was supposed to go up twice a week and would end up going once a fortnight and things like this. But this health bus was used as a reason by lots of local GPs why they didn't need to register people at their surgery, because "you don't need registering, you've got the health bus". [….] And the reason a lot of our members are registered at a practice in [area], which is at least seven miles from the site. (TSO)*

In terms of successful strategies, the health care professionals and TSO staff spoke at length of the value of the Haamla maternity service and how it provided flexible and tailored care, and engendered trust. While the mothers did not name this service specifically, they were generally positive about their experiences with maternity care as described above. The service appeared to have originated from the vision and drive of an individual midwife who had moved on to a more senior position where she was able to incorporate the approach into policy, thus rendering it sustainable.

> *But there was a community midwife called [name] who runs a specialist midwifery service for vulnerable women, really, and she works largely with refugees and asylum seeking women. But she recognised that Gypsies and Travellers were also a group that were quite excluded from services and not getting great maternity services. So she worked with [TSO] members and staff to develop a maternity pathway that was better for Gypsies and Travellers. So that means if you are a Gypsy Traveller on site, on the roadside, or in a house in Leeds you can access a specialist midwife from the Haamla service, which is what her service is called. […] I'm pretty sure you get the same midwife throughout the process, which actually now is quite unusual because you just get seen by whoever in the general clinics, with the idea that building that consistency and trust is really important in providing healthcare to Gypsies and Travellers. But also the midwife has some flexibility in order to visit a roadside camp or follow women from that roadside camp around different camps, and then you're not always getting referred. (TSO)*

> *Like you've got [name of Haamla midwife] doing it out in the open, challenging minds. She's now moved on but she's left a team. Because otherwise it would have just been a quiet, "it's alright, I'm just going to do maternity stuff even though I shouldn't really be following the camp round." She finished her job, her replacement will not do that. But her replacement and her team do do that because she challenged the system. (TSO)*

Case study 2: Fife

Case study two was conducted in Fife in Scotland and focussed on Scottish Gypsy/Travellers. The case study site was selected because, unlike the other three case studies, it reflected an approach to community engagement that was led by the NHS, and the locality was mainly rural in contrast to the other three case studies which were in large cities. We were also aware of an oral health promotion initiative involving Gypsy/Travellers in the area. One paper included in our engagement review (73) reported a health needs assessment of Gypsy/Travellers in Fife. This assessment highlighted dental health and registration with GPs as areas of particular concern for Gypsy/Travellers in Fife; and recognised the 'Keep Well' programme as a good vehicle for improving health outcomes for Gypsy/Travellers. It recognised that the 'Keep Well' programme as a good vehicle for improving health outcomes for Gypsy/Travellers. The recommendations included co-ordinated working for roadside encampments, more flexible health services, creation of a multi-agency group to progress partnership working, and appointment of health inclusion workers specifically for Gypsy/Traveller communities.

Context

Fife is a large rural region with pockets of concentrated population. The 2011 Census reported 316 Gypsy/Travellers living in Fife, the fourth largest population of Gypsy/Travellers in Scotland. However, as previously described in this report, this is likely to be a significant underestimation of the true population size. Of these 316, 43% lived in a house or bungalow, 42% lived in a flat or tenement, and 12% lived in a caravan or other mobile structure. Accommodation for Gypsy/Travellers in Fife is provided by Fife Council on three sites with a total of 50 pitches. There are also variable numbers and size of unauthorised sites, especially during the Travelling season of March to October (73).

Documentary analysis found that NHS Fife places importance on engaging with the local community and others stating:

> *"NHS in Fife is working to improve services with the involvement and support of the public, our partners in other NHS Boards, Fife Council and voluntary agencies. We will continue to inform and consult local people at the earliest possible stages on all developments." (156)*

NHS Fife also has a corporate statement on equalities and human rights contained within its Equality Plan:

> *"NHS Fife is committed to making healthcare accessible by eliminating discrimination, promoting inclusion and ensuring a Human Rights based approach underpins all our functions and services" (157)*

As part of its equality and human rights work, NHS Fife convened a multi-sectoral Gypsy/Traveller Steering group that includes frontline health practitioners, service managers, TSOs, a local authority Gypsy/Traveller site manager, representatives from the local authority and education service, national policy, and academics. The purpose of the steering group is to improve health and reduce health inequalities for the Gypsy/Traveller population in Fife, through enacting the Gypsy/Traveller Action Plan that was developed in response to the Health Needs Assessment described above (73). One output of the Steering group was an e-learning module ‘Raising Awareness of Gypsy/Traveller Communities’ (158).

NHS Fife also has a Strategic Plan for Oral Health (159) that includes reducing inequalities in oral health and providing equitable access to primary dental health care. The plan mentions ‘tailoring and targeting support for disadvantaged groups’ but does not highlight Gypsy/Travellers specifically.

Critical to facilitating recruitment of mothers for our case study in Fife was a social prescribing project (160) that was implemented for 12 months from July 2016 to June 2017. The project was implemented in one Local Authority site and linked participants with non-clinical sources of support. There was an emphasis on building trust at the outset of the project and it had some successes (160) although it was only in operation for 12 months, at the end of which the funding was discontinued.

Fife Centre for Inequalities is a TSO whose mission is to “build a collective voice to champion equality, diversity, inclusion and social justice” (161).

Important to the context of this case study, at the time of conducting our research the residents on the site were unsure whether the Council were going to close it down. Subsequent to our research, Fife Council announced plans to spend £2 million upgrading its three Gypsy/Traveller sites.

Participants

The participants in case study one were six mothers, two grandmothers, 10 HCPs, and two staff from TSOs. The mothers participating in this case study all lived in one Council site.

Findings

Mothers’ reports of their experiences of maternity and child health services were mixed, with some satisfied with the care and others who felt they had experienced poor care. Some mothers were dissatisfied with the current maternity hospital (which is part of a general hospital) and spoke more positively about the previous (separate) maternity unit which appeared to have been more welcoming and flexible. One woman who described an experience in early pregnancy said:

> *I went down for to get seen because I didn’t know what was happening, and went into the maternity department, and because I wasn’t over twelve or thirteen weeks I wasn’t allowed to be seen at that bit, which I think is terrible because I thought that’s what a maternity hospital is for. They put me back out and I had to go through, what’s it called? A&E, to get booked in, which was a nightmare [….]when I had my girls at [previous maternity hospital] they were brilliant. If you had any issues or anything you could go down, they would give you a wee scan and make sure everything’s okay, put your mind at rest. (Mother)*

Although there were examples of children needing dental extractions, the mothers and grandmothers in this case study did not describe any problems with registering with a dentist and all seemed to be engaging with regular check-ups for their children or grandchildren. They also spoke about the importance of tooth-brushing that appeared to be reinforced at school:

> *Yes, we've all got our own regular dentist. As a matter of fact I've got an appointment tomorrow, check-ups […] our six month check-up for our teeth, yes […] One of the young ones, the three year old, yesterday he got four teeth out. […] They've all got their regular dentist and everything […] I think they're quite okay. (Grandmother)*
>
> *My kids brush their teeth in the morning before they go to school. When they're in school they get their dinner, teachers take them in, they brush their teeth […] at night time, they brush their teeth. I just keep brushing their teeth to make sure their teeth are all clean. (Mother)*

Health professionals also spoke about the importance of oral health and dental registration, and made reference to Childsmile (162), a Scotland-wide programme aimed at reducing inequalities in oral health through the distribution of dental packs and supervised tooth-brushing in primary schools serving deprived populations, and in all nurseries.

> *And that's spoke about in their six week check. You know, "are you registered at a dentist? Will you be registering the baby?" So then Childsmile, we can send them a card.* (Health visitor)

In terms of barriers, the location of the site, which was far from public transport, made access to services difficult. There were also reports of being treated badly when taking public transportation, consistent with broader experiences of social discrimination. Mothers also spoke of difficulty having services come to the site, such as taxis.

In terms of engagement strategies there were several examples of good engagement, most particularly the Keep Well social prescribing initiative which worked with the site residents to identify needs and solutions. A particular issue was the poor state of the accommodation (this was also noticeable to the research team when compared to sites visited in the other case studies), and the Keep Well nurses had invited the fire safety department and Cosy Kingdom (free and impartial energy and debt advice service available to all tenants and homeowners across Fife) to visit the site and advise residents. The Keep Well nurses had also responded to health needs such as providing a first aid course.

Case study 3: Sheffield

Case study three focussed on the migrant Roma community in Sheffield. We felt that a dedicated Roma case study would allow more in-depth focus on particular issues that might be different for Irish, English and Scottish Gypsy and Traveller people. We chose Sheffield based on existing contacts within the research team and Stakeholder Advisory Group, and responses to the online consultation. From the consultation, we identified a TSO, the Darnall Wellbeing Project who were willing to work with us and facilitate recruitment, and provide an interpreter for the interviews with mothers. The case study focused on maternity, early years' and dental health services.

Context

Migration of Roma people, mainly from Slovakia, began with small numbers of asylum-seekers in the early 2000s (163). After 2004, this increase significantly when Eastern European citizens gained the right to enter the UK as EU citizens to seek work (136). Similar to the case with Gypsies and Travellers, estimates of population size vary and in 2009, the Roma community themselves estimated the population size to be around 4,000 (164). In 2012 there were an estimated 2100 Slovak Roma living in three socio-economically deprived areas of Sheffield (165). Community tensions between the Roma and other communities has attracted national media attention (163).

The Public Health Strategy for Sheffield states an overall vision

> *"to improve healthy life expectancy, and to reduce inequality in healthy life expectancy between best and worst communities. (166)"*

The Sheffield Clinical Commissioning Group states the following on their website:

> *"We want to ensure there is equality of access and treatment for all people to the services that we commission, both as a matter of fairness and as an essential part of our drive to reduce health inequalities and increase the health and wellbeing of all our population". (167)*

Relevant to this case study, the maternity service in Sheffield offers interpreting services although it is stated that this is likely to be using the telephone 'language line' service during labour. The website identified a specialist midwifery team for 'vulnerable women' but does not provide any further information about the definition of 'vulnerable women' or the type of care offered (168).

Sheffield has a Community and Special Care Dentistry service whose mission is: *To be the leading provider of care and education in special care dentistry for vulnerable groups in Sheffield'* although Roma people are not mentioned specifically in the list of vulnerable groups (169).

Darnall Wellbeing is a not-for profit health organisation with an aim of helping people in socially-deprived areas of Sheffield to stay healthy (170). Among many other activities the organisation ran a Slovak Roma Health Project which comprised a holistic, targeted approach to improving the health and wellbeing of the Roma community in Sheffield. The project recruited, supported and trained a team of workers, including from a Roma background or who speak Eastern European languages and/or Roma, and tested a community development approach to improving health and wellbeing and increasing access to services. The project commenced in 2015 and, although it reported successes, at the time of our case study it was struggling to find funding to continue its activities.

Participants

The participants in this case study were seven mothers, one father, 25 HCPs and four TSO staff. One mother spoke English for her interview and an interpreter was present for the remainder of interviews (with two interviewees speaking English at certain points).

Findings

The complex needs discussed in relation to this case study were mainly focussed on the differences between health services here and in Slovakia, including in relation to our case study focus on maternity services. Mostly, the women reported that the service was better in the UK with more contact with midwives or doctors.

> *I start using the GP, then the GP gives me a midwife, and the midwife, I have a conversation with her every month or every two weeks. She's always asking me questions and looking my baby, how is she's growing, and the heart. This is okay. I feel happy (Mother)*

In terms of barriers, while the mothers did not highlight any specific barriers, transience was a significant issue for HCPs. For example it was reported that some women return to Slovakia to give birth. One HCP suggested the reason was because it was easier to get a passport for the baby in Slovakia and that they were entitled to a financial benefit:

> *I've just visited a family who told me that once social care got involved they did go back to Slovakia for two weeks but now they've hid in [case 3] for three months until eventually they're registered back at the GP. (HCP)*

There were issues around availability for dentists in certain area of Sheffield:

> *There are enough dentists in [case 3] but they're not in the right areas. So if you live in some parts of the city it's easily accessible. But I would say like one in twenty of the families I visit have a dentist, if that. (HCP)*

Several strategies for engagement were mentioned. There was description of a doula service that was offered to vulnerable women in Sheffield, where a doula can support a woman weekly during pregnancy, during labour, and then for six weeks following birth.

In terms of child health services, most women said they were happy with the service. A health visitor explained that although their service was for under-fives, they had to be flexible and often dealt with issues for school age children too:

> *We're often addressing the health needs and the needs of children in education or missing from education, off school and everything. (HCP)*

Also, because of the complex needs and challenges involved, a small team of heath visitors focussed on Roma families, even though this was not official policy:

> *the way that we know to meet the needs of the community is that it's probably best that a few of us within the bigger group just visit that community. (HCP)*

Health visitors described developing a specific pathway so that they could refer Roma children directly to the paediatric hospital for dental treatment, but that they had to modify it because of the high volume of referrals.

The TSO participants described how the Darnall Wellbeing Slovak-Roma health project worked in five geographical areas, focussing on GP practices with Roma patients on a sessional basis to deliver health messages, such as increasing the uptake of immunisations, and to refer patients to other services e.g. weight management and mental health services. The sessional workers also described how they sometimes acted as interpreters for receptionists, and contacted patients regarding missed appointments.

> *I do feel we are definitely making a difference […]it's the navigation, people don't know where to go and now they know we are there every Tuesday and every sort of day, each day, so they know exactly where to go. And they often come back to us with a piece of letter of a piece of paper […] whether it is to translate or whether it is to call and arrange an appointment. (TSO)*

However, at the time of the interviews the project was described as being scaled back due to lack of funding:

> *We're currently down to a sessional worker, a health link worker on 16 hours and recently recruited two health link workers on more of a sessional type lower key contract […] We're writing bids currently at the moment to enhance that and we're looking at bids that will go for three and five years. This is not a quick fix situation to the area. (TSO)*

.

Case study 4: London

The fourth case study focussed on Irish Travellers living in two boroughs in Southwark and Hackney, where there are relatively large numbers of Gypsy and Traveller people. We selected this case study because of the relatively large numbers of Gypsies and Irish Travellers living in London in the context of a much more diverse general population, and the particular pressures on accommodation and on health services within the capital city. We were aware of two TSOs working in the area both of which were known to Leeds GATE. The case study focussed on maternity and early years' health services.

Context

As in our previous case studies the precise size of the GRT population in London is unknown and estimates range between 8,196 in the 2011 census (3), to 13,500 (171), although both of these are suggested to be considerable under-estimates.

The documentary analysis for the London case study was challenging because of the size and complexity of service provision in London, meaning for example, that there was a wider choice of hospitals, GP practices and dental services. We focus therefore on two specific boroughs as examples: Southwark and Hackney, and on maternity and child health service provided by, or based from Kings College Hospital and Homerton University Hospital.

The Public Health Strategy for Southwark vision is that:

> *"Every child, family and adult has improved health and wellbeing and has access to high quality local services that meet their needs. Together we will invest to make a difference earlier in the lives of local residents, promoting resilience and self-management of health and giving everyone the best and fairest start. Working together to build a healthier future, we will tackle the root causes of ill health and inequality." (172)*

The Southwark Annual Public Health report 2017 'emphasises the role of place in influencing health and wellbeing and the role of regeneration in improving health and wellbeing and, in referring to where people are born, live, work, and age. The report states:

> *"How these places and spaces are designed, maintained and evolve is therefore vital to the health and wellbeing of the people and communities within them." (173)*

A Joint Needs Health Assessment for Southwark identified the diverse communities living in the locality but does not mention Gypsy and Traveller communities.

The Hackney Public Health Strategy identifies eight guiding principles, five of which have particular relevance for our case study:

- Outcomes: The Board will remain focused on areas where it can demonstrate the difference it brings for those people who need it most;
- Inequality: The Board will tackle the causes of inequality in health and wellbeing and focus its efforts where needs are greatest;

- Integration: The Board will ensure that service providers and care pathways will become more integrated, with relevant commissioners and providers working together to ensure improvements for residents;
- Equality: The Board will ensure that services meet the needs of Hackney's diverse communities. (174)

In relation to maternity services, there was evidence of work by the London Maternity Strategic Clinical Network to engage service-users in designing and improving services, but it was unclear whether any effort to include GRT people had been made (175).

Two TSOs facilitated recruitment to this case study: Southwark Travellers Action Group (STAG) and London Gypsies and Travellers (LGT).

Funded mainly by the Irish Government, STAG's aim is to "to address the multiple inequalities which Travellers in Southwark experience' (176). The organisation has several projects addressing specific issues that affect Travellers in Southwark.

Working in partnership with Gypsies and Travellers, LGT aims to "challenge social exclusion and discrimination' and to inform local, regional and national policy (177). It has four main areas of work: equality and inclusion, young people, work and skills, and homes.

Participants

The participants in case study four were 14 mothers, three grandmothers, 11 HCPs and three TSO staff.

Findings

A striking feature of this case study was that the mothers spoke about giving birth in three different hospitals (some women had experience of giving birth in all three), so that much of the conversation was around comparing their experiences in these different hospitals, and they were very clear about which one gave the best care. Aspects of care that women appreciated were being attended to constantly, especially when in labour.

> *It was the constant care, they made sure you kept up with every appointment and it was the care in the hospital when you were in labour that I liked, I found good. (Mother)*

Some mothers described experiences of discrimination in the past but thought this was getting better:

> *It's a lot better now though than what it was back then because [we] were highly discriminated back there, going back fourteen years ago, when you come into hospital and things like that. It's like "you're a Traveller, we'll just leave you at it." Blah, blah, blah. Now, it's like [….], not half as bad with us now. They're more open-minded, if it makes sense. So now [hospital] for me is the best. (Mother)*

One possible reason given for this was that the HCPs were more diverse:

> *years ago people wouldn't say they were Travellers and people wouldn't know. But I think because now not every doctor is an English doctor, they're all, there's a mix. (Mother)*

There was also a lot of discussion comparing two particular GP practices which gave very contrasting standards of care. However, it became clear that that practice that was described as being poor was from a single GP, and the mothers recognised the problems were for everyone attending that practice. Barriers to registration at GP practices were still in evidence and a TSO participant described having to challenge a GP practice receptionist who had asked a Traveller family for copies of bank statements as a pre-requisite for registration.

Another striking issue in this case study was the evidence of tensions around women's interpretation of the role of health visitors as a provider of support and healthcare, and in monitoring families safeguarding children. This tension was underpinned by previous vicarious experiences of children being removed from families. This issue was suggested to be making families less willing to attend hospital with their children.

> *R If you need them you've got to call upon them. But if you've been in a hospital with a child then they're on top of you. I know they have to, but that's the way I felt.*
>
> *R: I think that's a bit much, though. If you go to the hospital with a child, a child's fell over, you've got the health visitor the next day. […]*
>
> *R: It's making half the people frightened to go to the hospital. (Mothers)*

The mothers clearly found that some of the questions asked by health visitors were intrusive, and showed a lack of knowledge about Travellers.

> *R: The health visitor where I am now, she comes to me and says how comes I'm in a house? How comes I'm not on a site?*
>
> *I: Yeah, so they have some kind of pre…*
>
> *R: I was going to say to her it's none of her business, but I thought I won't. I'm going to be nice to you because you're new to me. But Travellers do live in housed accommodation as well. We're not just on the roadside or on site. So I think she might have had a bit of knowledge about Travellers, but not a lot. (Mother)*

Most of the mothers reported being registered with a dentist and taking their children for regular check-ups. A main barrier was receiving timely treatment for acute problems. One mother described ringing NHS 111 when her child had severe toothache, and having to take her child some distance for treatment. Another spoke of accessing emergency dental care for a child because of a long waiting time to receive treatment at her dental practice.

There were no examples of strategies to engage or increase access to health services specifically for Gypsies and Travellers. The two TSOs in the locality did not have projects focussed on health, although examples were given of advocacy work for example accompanying Travellers to hospital appointments or challenging discrimination e.g. refusal of registration at GP practices, and helping with reading letters and keeping appointments. One TSO provided skills training that included issues such as making online appointments, and recognising when letters were from health services e.g. awareness of NHS logo.

However, from both the mothers' and health professionals' accounts, the maternity service model of care that aimed to provide continuity of antenatal and postnatal care was valued by those mothers who received this service.

> *So we do have, I think there are about three caravan sites we have in [one locality], so obviously those women come to us. And so we do go to see them antenatally and postnatally. (HCP, midwife)*
>
> *I found it is good when you can go to see the midwife at the local children's centre, with the hubs they go to. I found that was better to use than going to the hospital. […] And then you see the one midwife all the time because it's an appointment, she's not based there [….] she wasn't rushed […] so I think it was better as more one-to-one support. (Mother)*

One HCP highlighted that a health visitor outreach service had been in place to engage with Gypsies and Travellers, and was a focal point for health visitors. The service had been decommissioned a year previous to our case study; though this HCP participant felt that the outreach approach had worked.

Combined thematic analysis of case studies

Health status

Although the focus of the case studies was on experiences of healthcare inevitably the mothers talked at length about their own, and their children's, health problems, which we briefly summarise here. It appeared there was a very high level of complex needs.

Maternity and child health

It was notable that across the three case studies with Gypsies and Travellers, many mothers described problems during pregnancy, childbirth and the postnatal period. This included pregnancy complications such as anaemia and gestational diabetes, difficult and/or long labours, caesarean sections and haemorrhage. There were several stories of loss, including miscarriages, stillbirths and death of a child. Some of the mothers described a serious health condition that one or more of their children experienced that required ongoing treatment or management, for example epilepsy, autism, and other disabilities. In contrast, the Roma mothers in case three did not generally describe complex pregnancies or births; instead a main themes was transitioning between or comparing healthcare systems. However, this may be partially due to the limitation of interpreted interviews.

Child dental health problems

Accounts of child dental health problems were given in all case studies, although this was least noticeable in case study two. Examples of problems included dental decay, misaligned teeth, and an apparently high rate of treatment including extractions, mass extractions and fillings.

Experiences of healthcare

Primary healthcare

While the focus of our research was on maternity, early years' and child dental health services, much of the discussion revolved around experiences of primary health care i.e. GP practices. This is not surprising as the GP practice is the first point of call for many health problems, and is the gateway to many other services.

The findings suggested that most of the families were registered with a GP, although in case study one, as already described, there was an issue about having to travel to find a GP practice that would register them. The majority of mothers seemed generally satisfied with the service provided by the GP, although there were many comparisons of good and not so good practices around being able to get appointments when needed. Positive comments included those doctors with nice manners, who listen, and who are good with children. The poorer experiences described by some included generally poor communication or understanding between the patient and health care professional, doctors who were patronising, expectations for care not being met, and questions around the health professional's competence.

> *Even if you tell them that they're poorly, they're really, really poorly and they need to see someone, they say, "well, we haven't got any more appointments". (Mother on GP service, CS1)*

> *The difference in the staff-wise is amazing because it's all about your child […] the specialist really, really was good with her (Mother, CS2)*

A few noted that they knew the surgery receptionists and that they were helpful, although others felt that receptionists had a poor attitude, including being rude.

> *I mean the doctors there are good. I know the receptionists very well and if it's one of the kids and she knows and she'll try and get me an emergency appointment and she'll ring me back. (Mother, CS4)*

In some cases the healthcare experiences were quite different for different children, and in different geographic locations

Participants in case three discussed their experiences of health services in Slovakia, and they generally appeared to feel more positive than negative about their healthcare experiences in the UK. Health professional participants who commented were not concerned about GP registration levels.

Maternity services

In all of the case studies the mothers were generally positive about their experiences of maternity care. Mothers talked about good care before, during, and after birth. Elements of the service that were particularly appreciated included watchful and supportive care, efficient services, staff who put them at ease and had time for them, and seeing the same midwife, either at home or in the GP practice. As an example, a group of mothers in case study four mentioned a hospital that they felt was particularly good because of the extra attention paid to the patients.

> *The midwives are very good women. When I had him they were the best in the world to me (Mother, CS1)*
>
> *It's better here [in UK] because there's like lots of doctors around when you're giving birth, like they sit with you and they help. Ask if you need anything. And her sister was with her during the birth as well. (Mother, interpreted quote, CS3)*

Some of the positive examples related to maternity care provision that had been ended, and the new set-up was less popular, for example a new maternity ward as was discussed in case two.

Less positive comments about maternity care related to being sent home from the hospital when they had attended in labour, not feeling adequately or consistently cared for or examined by staff on the maternity ward, leading to feelings of exclusion

The HCP and TSO staff generally thought that engagement with maternity services was positive, and that visiting women at home might facilitate this. A TSO participant in case study four noted that some mothers may want to go to those hospitals that they know are good. However, some HCP and TSO staff indicated that engagement could be mixed, especially if mothers were travelling. It was also reported that Gypsy and Traveller women were unlikely to attend antenatal or baby massage classes. The health professionals from case study three indicated that the health professionals needed to spend a lot of time following up with Roma women who did not attend for appointments, and that this was very challenging and time consuming. As noted previously, some women choose to return home to Slovakia to have their children; they may then return to the UK with their infants.

> *even if they engage when they're in the country, I don't think anyone's ever told me that they're going to leave the country. So then sometimes it's chasing around but they're actually just not here anymore. So it's not they're not engaging because they're not coming, they're just actually not here. And then you spend time trying to find out where are they. (HCP, CS3)*

There was discussion around heightened input for GRT from maternity and early years' professionals, one of the main issues being keeping up the engagement over the course of care, including when families move location. The importance of interpreters in providing healthcare to Roma women across the different services was apparent.

Early years' health services

Positive engagement with early years' health services was also described, including accessing a health visitor or baby clinics, and health visitors visiting homes. Positive elements of care described included health visitors who were supportive and who came when they said they would.

> *Generally nurses and health visitors are first class (mother, CS2)*

One mother talked about the specialist provisions she knew a child with complex health issues to be accessing, and was positive about the understanding of the health professional towards the parents. A few mothers felt that their babies could have been visited more often after birth. The main less positive aspects which arose in discussions with mothers around early years' health services, were perceiving that the health visitor was not interested in them, not seeing a heath visitor often enough, and not being up to date with immunisations.

As with maternity services, health visitor staff indicated positive engagement, especially when the babies were very young. In case study three, the health professionals pointed to mixed engagement of families with health visiting teams, with some being accepting and welcoming.

Dental health services

Generally, across the case studies, although high levels of dental problems were mentioned, the mothers reported accessing dentists, and taking their children for regular check-ups. Some families had been registered with the same dentist for years, although others used a walk-in service. In case study two, as described earlier, there was oral health provision brought to one of the sites, good engagement around this provision was described. Positive aspects of care included dentists who spend enough time with each child, who show understanding towards children, who have a calm attitude and being good with or nice to the children.

> *We've got a very nice lady and she really takes care of my kids (mother, on their dentist, CS2)*

One participant explained that the dentist takes their time, and a further positive aspect of care mentioned was being informed about what is happening:

> *They want to see you. Not just when you've got a problem. They make sure that you go back for your checks and everything. (Mother, CS1)*
>
> *It makes a big difference because you've got someone on a one to one level with you and he's talking to you […] letting you know what they're doing with you. That makes a big, big difference (MotherCS4)*

However, some mothers in case studies one, three and four had been unable to get a dentist for themselves or their children, found it difficult to get appointments, or travelled some distance for dental care. One mother explained that her children's teeth were not cared for adequately by a previous dentist; another felt very frustrated about the recommended course of treatment which she felt could be better; and another described a poor attitude and treatment towards her child during dental treatment.

In contrast to the mothers' reports of regular attendance for dental care, some health care practitioners felt that there was sometimes less than optimal engagement with dental services and/or a preference for a short course of treatment, as well as some missed appointments and a lack of recommended follow up care.

> *So a lot of the work that we have done when we're doing any sort of parent workshops is to try and get across to them that you will be seen but you have to make sure that you keep that appointment. And if you keep your appointment then it's not a problem at all. (HCP, dental, CS3*

However there was also reflection on positive engagement, for example in case study three, some dental health professionals reflected on some community members with whom they said they had developed relationships with over time.

Care that did not meet the mothers' expectations

As is evident in the negative aspects of care already described above , here was a good deal of discussion about what participants consider to be poor or unsatisfactory services, , across a large range of situations. This includes: inadequate or incompetent care from different providers; incorrect or delayed diagnosis of conditions; being given conflicting information; examinations that were not thorough enough and so did not put a participant's mind at rest; being inconvenienced by a service, for example having to wait; women who had a previous child were assumed to need less care because they had experience; and a sick child being sent home when the mother would have preferred care to have been provided in hospital:

> *I would have preferred it if they had to keep her in, but because the doctors were happy the way I was going with her, I was doing the right things (Mother, CS2)*

Exercising autonomy

One theme that was evident in the mothers' accounts of engaging with health services was that there were many interesting examples of mothers exercising autonomy when it came to their families' health, particularly their children's health. This was centred on seeking second opinions for a child when the mother was unhappy with the response of the GP around diagnosis or treatment plan. This included going to the accident and emergency department after, or instead of, GP appointments, especially if they could not get a timely appointment. The mothers often appeared to be drawing on their past experiences or on the experience of family or friends, or their own instinct about their child's health. There were also examples of mothers strongly voicing their concerns (or willingness to do so) if they felt treatment was inadequate.

> *I never, ever wait around […] Since that experience I had with my first child I'll always go to the doctor. (Mother, CS1)*
>
> *You don't want to go to the hospital but sometimes you have to because that's the only way you can get your kid seen to. (Mother, CS1)*
>
> *Sometimes you've got to go [to the hospital] on your own intuition. (Mother, CS4)*

Furthermore, the mothers gave examples that supported their instincts and decisions about their children's health.

> *And one time they [GP practice] go to me "we'll do call-back." I said "okay then." Waited, and she [child] was really sick, so I took her into the hospital, and two o'clock that afternoon they gave me a call-back, and she was on the hospital bed dripped up and everything because she was very sick. And if I had waited for that phone call anything could have happened to her. [Mother CS4)*

Conversely, there was one example where a mother had taken her child to the GP practice repeatedly, acting on her instincts, but her concerns had not been taken seriously with tragic consequences:

> *they never checked her properly and she died with pneumonia. they never checked her chest properly. Said it was clear. They never gave me antibiotics or anything. And she was there three times because I wasn't happy with her. (Mother CS1)*

Influence of past experiences of services

There was discussion across the case studies about how previous good or poor past experiences of health care influence subsequent expectations and experiences of care. For example the mothers spoke about knowing of good health care practitioners through word of mouth, and that encouraged them to want to see the same person. There were also examples of questioning whether it was worthwhile going to see certain health care practitioners because they (or others) had previously received treatment they were unhappy with. Mothers suggested they learned more about health issues from family or friends, and there were examples of when the mothers recognised the signs of ill health based on another person's previous experience.

> *I went to the doctor's and the doctor said "I'll bring you to the hospital" to get him checked out and they kept him in overnight. They were going to send him home, and I said no, because my mummy's sister's child she passed away with that, and that made me scared then. (Mother, CS2)*

Trust and engagement

Enhancing trust

We analysed ways to enhance trust as discussed during the interviews and focus groups, and mapped the analysis to the model of trust developed from literature review two. The most frequently mentioned themes across the case studies were the importance of getting to know individual practitioners; seeing the same HCP to allow trust to develop over time; the importance of confidentiality; and the influence of previous experiences. However, some mothers also indicated the importance of not trusting completely and using their own judgement in making decisions about health care. (Appendix 9 comprises a table showing detailed results of the mapping exercise). Below we provide selected specific examples from the mothers' accounts of trust and trusting.

A strong theme across the case studies was the critical role that trust plays in increasing the use of health services. For example, GRT participants felt that lack of trust affected both willingness to and anticipated value of engaging with HCPs. The findings from HCP and TSO participants also indicated that trust is a vital component of engaging people in health services.

> *Without trust, particularly with a community that are very sceptical about outsiders then the service you provide isn't going to be taken up to its fullest. (HCP, CS1)*

An English Romany Gypsy mother talked about the importance of trusting health professionals with your life, and the life of a child. She described feeling comfortable with and trusting a GP whom she had known for a number of years. She had been less trusting of doctors who had given her conflicting information when she had sought a second opinion. In discussing what could be done to build trust between health services and Gypsies and Travellers, she said that she never gets to see the same doctor again when receiving specialist healthcare:

> *You'll see them once, and that's it, you'll see another person […] and he could say a different thing altogether to what he said. (Mother CS1)*

One Irish Traveller mother recounted how trust was essential to keep on engaging with a HCP. She talked about knowing that she can trust a new dentist who she felt was better than the person she previously saw; and about a dentist who had to overcome the fear her child had of being treated:

> *that dentist there had to build his (child's) trust up because he was frightened of the other dentist […] And he built his trust up every time we were going in until he got things so he could start doing his teeth. (Mother CS1)*

An interview with three Traveller mothers highlighted the importance of trust in giving them the confidence to ask questions and disclose information. They described how Travellers are particularly concerned about confidentiality and sharing of information between services:

> *R: Because if you don't have trust in someone you're not going to be at ease, you won't confide in them, you won't ask them questions. And you don't want them there so you're on your tip-toes.*
>
> *R: Travellers, we're very private anyway. Very private. It takes a lot to confide in each other. Where that health professional, we should be able to relax and confide in them to the point where they won't take it anywhere else. (Mothers, CS4)*

In discussing what health services could do to build trust, the mothers gave an example of a midwife who used to visit the site and who had developed a relationship with people living there, and how people felt confident in her. She worked with the health visitor to facilitate a smooth transition between services. The role had since been discontinued. They also suggested that it was better to see the same GP, which they were not always able to do.

> *But I do think seeing the one person all the time is better. It's like my doctor, I see the one doctor now all the time and it's better. Because you don't have to go through your whole life story with them, they know you when they see you. They know everything about you so you don't have to keep telling them. (Mothers, CS4)*

They went on to talk about the importance, not only of trusting, but of their own intuition to guide interactions with HCPs. At times they did not trust the health guidance they had been given, and they questioned the professional competency of some of the health professionals they had encountered.

> *But to be honest with you all the doctors and midwives and health visitors, sometimes you've got to go on your own intuition. You can't trust them entirely. (Mothers, CS4)*

A number of Roma mothers interviewed also felt that their own instincts or intuitions were important, rather than trusting advice completely: 'You can trust, but not 100%' (Mother, CS3). One Roma mother gave an example of seeking an alternative opinion when she was dissatisfied around her child's diagnosis. A Roma father had received conflicting information about his child's health from different health professionals; and his trust was further negatively affected by both short appointment times and the language barrier.

A group of Irish Traveller mothers said that whether they trusted HCPs depended on whether they judged that the HCP had their best interests in mind:

> *It depends as she said, it depends because you don't know if they're out to get you or to help you. (Mothers, CS4)*

These mothers' accounts highlighted the extent to which they were affected by previous negative experiences, for example where an HCP had shared information with other services without permission.

> *R: It's a bad experience that we had in the past. Sometimes you're there and you're having a one-to-one and you think well that's a one-to-one that's the end of it, and before you know it you've got a lot of problems. They've been going behind your back and they're telling this one, telling that one.*
>
> *I: Right. Telling other health professionals?*
>
> *R: Yes. And you don't need that. (Mothers, CS4)*

These accounts also included vicarious experiences such as a case they had heard of where Traveller children had been taken into social care:

> *There's always a fear, your biggest fear is someone coming to take the kids off you. (Mothers, CS4)*

However they had also been influenced by previous good experiences and gave examples of HCPs they could talk to and rely on, or who were very helpful when they needed it; and there were examples of HCPs with whom they had built up relationships over years who had kept their confidence:

> *you build trust with somebody, when we build that up and we keep that trust* (Mothers, CS4).

These mothers felt that there was not much that health services could do to enhance trust, because Travellers are inclined not to trust people outside of their culture given years of discrimination.

Finally, a group of Scottish Gypsy/Travellers talked about whether they trusted HCPs, and why. One mother who trusted her doctor felt that he took his time, iss patient with her and is easy to sit with. Other mothers linked lack of trust to discrimination, both in their daily lives and in experiences with health services. A Gypsy/Traveller grandmother stated that she trusted her HCPs and had stayed with them for years. In discussing what could be done to enhance trust, she felt that HCPs were fulfilling their roles and that she trusted their judgement: '*If I didn't trust them I wouldn't be with them that long*' (Grandmother, CS2).

Enhancing engagement

In this section we present the main themes around approaches to engagement from the case studies. The findings are based on discussions about barriers to engagement, ideas for possible solutions, or examples of good practice around engagement and trust.

In addition to interpersonal characteristics of the provider (e.g. kindness, understanding, patience, attentiveness), all of which relate to our conceptual model of trust, the main approaches were: advocacy; collaboration; flexibility; tailoring services; specialist roles for community members; community support and outreach; education (including training) for professionals; providing information or education for community members; holistic care (dealing with a range of issues); relationships (including consistency and continuity); community participation; and health-based resources.

Advocacy

This discussion came mostly from TSO and HCP participants, and largely focussed on the roles of TSOs in supporting GRT community members, for example raising the profile or putting forward the voice of GRT; working for GRT rights; as well as more practical activities such as explaining health-related information, translating (Roma), and helping people to register with or engage with health services.

> *sometimes having another person, an advocate, in the room, could make that whole conversation go a lot better. (TSO, CS1)*
>
> *we are there for people, whether they just need a little chat or whether they need signposting to somebody else, we're there for them. (TSO, CS3)*

There were also examples of HCPs advocating for patients on various health and social issues, for example accessing additional healthcare, and a number of health professionals talked about being seen as someone who can help and is 'on the patient's side'.

> *she sees me as being somebody who will help her, which is a start to doing other things with her. (HP, CS2)*

Family members talked about how they had experienced being assisted or advocated for by TSOs or HCPs, including help with literacy or completing paperwork, and accessing health services.

> *she's happy of [the TSO staff]. They sorting out herself when she's been poorly. They take her to midwife. (Mother, CS3, interpreted)*
>
> *having a healthcare provider worker like her, when there's meetings about healthcare for certain communities she could go to them, put Travellers on the list, push forward the issues. If it's about immunisations, what's the girls' worries? (Mothers, CS4)*

Collaboration

There was a focus within the TSO and HCP interviews on collaborative efforts, including between TSOs and the health sector, between different health services, and between the health sector and local government, education or social services. This included disseminating information to the community together, joined-up approaches to care, combining services to offer them at the same time in the same place (e.g. on a Gypsy/Traveller site), and introducing new health professionals to community members through already trusted people.

> *[the advocates] are really, really good, so they actually go and chase people for me, because I just don't have the time. (HCP, CS3)*
>
> *I think integration is the key, without a doubt, we can't work separately in health […] I think we need to be a lot more joined up, particularly with this community. (HP, CS3)*

Flexible services

Discussions with both health professionals and TSOs pointed to the importance of flexible working. The issues addressed included flexible appointment times (including not turning people away if they are late); adapting procedures based on the needs of the community members; changing plans; responding quickly; accounting or preparing for community members' travelling or moving; and not being limited by geographical boundaries (mostly discussed in relation to health visitors).

> *with Scottish Travellers you have to be a wee bit more flexible. You have to understand that they might move on.' (HP, CS2)*
>
> *I think sometimes systems we have within the NHS of referral and processes are not flexible enough for people who don't appreciate them or can't navigate them. (HCP, CS1)*
>
> *if they are going to move on during the pregnancy that they know how to access services wherever they move on to, or they know who to ask […] putting them in touch with services in that area is really important in getting that confidence to reach out and ask for care. (HCP, CS1)*

Tailored or dedicated services

Tailoring services follows on from flexibility as the discussions focused on modifying procedures or refining practice in order to make them more accessible or relevant to community members. This includes recognising the specific needs of community members and making appropriate adaptations, for example communicating not only in writing, but verbally or pictorially if literacy is an issue, or providing information in different languages. This is relevant to both HCP and TSO practice. It may also include pathways or referrals systems or particular groups of people.

> *quite often because of the language barrier it is a little bit of extra work to get them to understand what it is they need to do, how to register their baby's birth and all that kind of stuff. But we've got things in place for that, we've got language line, we've got interpreters. (HCP, CS4)*

> *And we've altered. So I guess initially you think this is the service that we offer and we offer it to everybody and please can you fit into our service? Well I suppose that idea had to go really quickly because we've had to make special, I suppose, reasons as to how to send letters and how do we work with the community. (HCP, CS3)*

> *every client has individual needs […] we tailor make our service to all their needs anyway. And I think that come down to our advantage of getting to know our clients so well' (HCP, CS2)*

Services may also be developed specifically for, or with a main focus on, GRT. For example, participants talked about specialist nurses, midwives or health visitors. Health roles may have a wider remit, such as vulnerable, BME or migrant groups. These roles may allow practitioners to adopt some of the other approaches covered in this section, such as flexibility.

> *it's not the traditional form of care provision at a GP surgery. Because obviously these are women who can sometimes struggle to register with a GP and access care in what is seen as the normal route of care for the majority of women. (HCP, CS1)*

Mothers also talked about a healthcare worker they had known previously:

> *I think someone like that is very key. Because she didn't just touch on health things, it opened up doors for other areas as well, so she was involved in housing […] But because she was the first point of contact in [the area] as a healthcare provider everyone came through her. (Mother, CS4)*

Mothers also discussed the idea that they would like to see developed a supportive women's group where health professionals, such as their health visitor, could attend; and one mother expressed that she would only attend if it was for Travellers exclusively. Another mother felt that it would be helpful if there were maternity health provisions that Travellers could use to ensure care while travelling:

> *I think in my own opinion you should have, for Travelling people that travels, little caravans or something that they can walk in and be seen to by a midwife […] I think they should be able to do something like that for them. Because I do think there's a lot of women when they're having children, Travelling women, do get neglected. I think a lot of them do. I know in one way it's their own fault, but in another way it's not because if they have nowhere to go it's not their fault really they've nowhere to go. And then they pull into camp and get shifted the first thing in the morning, they don't get the time. (Mother, CS1)*

Importantly, there was also discussion about the importance of people using mainstream services where possible, rather than only accessing a tailored or dedicated service, as these may lead to further exclusion in the long term.

> *to make sure that the most marginalised don't get more marginalised, but also to make sure that the mainstream of society is getting good care in services as well. (HCP, CS1)*

Specialist roles

Participants mentioned a number of specialist roles which could focus on working with GRT. These included both actual examples in current practice, or ideas for good practice, such as health advocates (at Leeds GATE, for example); and Roma and Eastern European language workers, health trainers and health champions (as at Darnall Wellbeing, for example). This may also include roles to be taken on by community members, for example as peer health workers or Roma teaching assistants.

> *I do like an idea of health navigator stuff where you have community members that individually, obviously they work with [the TSO], but they are there within the community, that can help people. (TSO, CS1)*
>
> *It's giving them the oral health advice so that they can be an oral health advocate […] if we trained advocates and they could do the role, for us so that they could do regular delivery and awareness raising. (HCP, CS1)*

A group of mothers also felt that it would be beneficial to train someone to work with health professionals, and they felt they had already shared this idea in past consultations.

Community support and outreach

There were health professionals currently offering what might be considered an outreach or community support approach, in that care was taken to community members rather than accessed in a health service location. This included nurses, midwives, health visitors and oral health promoters visiting and working on sites. Although home visiting may be standard practice in maternity and health visiting services in the UK, we have grouped strategies by their design or methods, therefore we include midwife and health visiting with 'outreach' and 'community support'. Third sector organisation staff also visited community members in their homes. The community support and outreach approach appeared to be regarded positively across the case studies, sometimes because it was convenient to mothers and other times it ensured continuity of healthcare or focus on a particular health issue. Capacity issues around universally offering community support or outreach service for all appointments in relation to midwifery were noted.

> *I'm happy that [midwifery] come to my house, it's easier. (Mother, CS3)*
>
> *So for example midwifery […] the team that works with Gypsy Travellers tends to do home visits rather than clinic visits. So generally that's very welcomed and that's a really good service. Health visiting obviously goes to them, so their core contact, that's very valued. So services that would promote more of an outreach service tend to work very well. Services sometimes where you have to go different places it's much more difficult, particularly if it's an unfamiliar service. (HCP, CS1)*

Some mothers noted that they would prefer that health professionals do not arrive at their homes on site without an appointment, and/or that they would prefer to go to a clinic to be seen. There was also an example of a drop-in service delivered in a site porta-cabin that had not been used.

An approach that was mentioned across a number of case studies was a mobile health bus or health van, either as something that had taken place or an idea for engagement. There seemed to be mixed views however on how beneficial this would be, with some participants favouring the idea, and others explaining that they had seen poor versions of this in the past or that this may inhibit engagement with local health services (see Leeds case study for example). However, this approach did seem to be favoured by some mothers:

> *there used to be a big bus […] And it used to park there and there used to be a nurse and a doctor on this bus.[…] I think that was a great idea, fantastic idea to have a bus on here (Mother, CS1)*

Education and training for health professionals

Healthcare practitioners, TSO and family members talked about the importance of HCPs developing an understanding about GRT people and their cultures. Health and TSO participants also talked about training for professionals around GRT peoples' needs (offered either by TSOs or HCPs). Many had been involved in, or even offered, some kind of training, for example on equalities, cultural competence or GRT cultures. This approach generally seemed to be favoured, though some HCPs felt that learning by experience was also valuable.

> *the training was really useful. We helped put that together and gave a lot of information for that, but then I don't know how that's been received and whether people feel any differently towards the Gypsy Traveller community from doing it, but I think training is key. I think for people to understand the culture of Gypsy Travellers, but also to understand that the culture doesn't make them absolutely so alien and different that you can't deal with them. (TSO, CS2)*

Holistic care

Healthcare practitioners and TSO participants described an approach that could be considered 'holistic' in that they dealt with a broad range of issues that were important to service-users. For example in the case of TSOs this might mean covering health, accommodation, educational, or literacy issues, as and when required by families. A TSO participant explained how working through various topics and issues with people e.g. finances, could lead to discussions about health.

> *if you've got a hat on which is thinking around their health then it doesn't matter what you do. You could be helping someone do an oil change in the car, if you've got their health in your mind when you're working with them then… (TSO, CS1)*
>
> *If we've got a problem whether be it with our money, with our health, our kids, they would be with anything. We come [to the TSO] first because this is like the main core of everything to us. (Mother, CS4)*

There were also examples from health professionals of comprehensive approaches, such as dental practitioners asking about nutrition as well as dental issues; GPs that have whole family sessions, including for giving immunisations; and midwives being interested in the 'whole person' (not only their health issues), other family members, helping people access additional health services, and additional issues such as education:

> *we have to show that we're interested in them as a whole […] we get to know the kids and the family members and things like that. And they're the ones that are the most successful. (HCP, CS3)*

Relationships

The importance of good relationships between GRT people and service providers, and the positive effect this could have on engagement, was evident across the case studies. Getting to know people, and importantly the consistency and continuity of the relationship, all appeared to be important factors in developing trust with GRT people.

> *And then after a wee while the families started to get quite keen to get to know me a bit better and it's been fantastic. I am very much trusted on site […] having been on site now for many years I know the families quite well. (HCP, CS2)*
>
> *We spend quite a bit once we've got contact and had an opportunity to make a relationship, compared to if you talked to GPs, they've not got a GP or they've changed GP, or they've changed address so they can't be with that GP anymore. So it's not saying that GPs can't have those lovely ongoing relationships but it's just the reality of people's lives.' (HCP, CS4)*

Family members quite often said that they did not see the same HCP again for various health issues, and that they would prefer continuity.

Community participation

Some of the approaches taken across the case studies included GRT peoples' participation in developing health or TSO services. This approach was most evident in the TSOs where work is based on community member needs and/or participation; but there were also examples of health professionals whose work was shaped by community member.

> *So we had that group of young people who were able to inform us as well and keep us right. So it's always, always, I think, why we've succeeded as a project […] is that that we have always been driven by the agenda of the community. We've never done anything before we've been informed by their expertise. (TSO, CS2)*
>
> *[the TSO] is a members-led organisation and that's where the expertise and knowledge is, so it's really important to have those links and have that relationship with members as the experts and instigate ways into working with communities. (HCP, CS1)*
>
> *basically it's whatever they need […] So we're very much led by Gypsy Traveller (HP, case 2)*

Health-based resources

There were a few examples of using health-based resources as an engagement strategy. For example, in case two, it was felt that a previous approach to using hand-held health records might have been favoured by families because of their value when travelling. The development of health cards (a strategy used by Leeds GATE), indicating that the person carrying the card needed help with reading, was also highlighted as a method of helping to overcome literacy issues, for example when checking in at the GP surgery.

Summary

We employed a case study methodology to generate in-depth, multi-faceted understanding of the complex issues surrounding enhancing trust and engagement between mainstream health services and GRT communities in their real-life context. Ethics approval was granted by the East Midlands - Leicester Central NHS Research Ethics Committee (16/EM/0028). We conducted four case studies in Leeds, Fife, Sheffield and London between June 2016 and August 2017. We selected the case study sites to reflect maximum diversity of GRT groups, living arrangements, service configuration and examples of good practice in terms of engagement and trust.

Case study one was conducted in Leeds and focussed on Gypsy and Traveller communities. Participants were 10 mothers, eight health care practitioners, and four staff from a TSO. Case study two was conducted in Fife (a mainly rural locale) in Scotland and focussed on Scottish Gypsy/Travellers. The case study site was selected because, unlike the other three case studies, it was rural and reflected an approach to community engagement that was led by the NHS. Participants were seven mothers, one grandmother, 10 health care practitioners, and two TSO staff. Case study three focussed on the migrant Roma community in Sheffield. Participants were seven mothers, one father, 25 HCPs and four TSO staff. An interpreter was present for interviews with the mothers. Case study four focussed on Irish Travellers living in London in one of two boroughs: Southwark and Hackney. Participants were 14 mothers, three grandmothers, 11 HCPs from maternity and early years' services and three TSO staff.

Data was collected, analysed and summarized regarding: knowledge, perceptions and experiences of GRT people with health services and how uptake could be improved; barriers to GRT peoples' accessing health services and how these can be overcome; activities/methods health services use to engage GRT people and to what extent they focus on developing and negotiating trust; activities/methods TSOs use to engage GRT people and to what extent they influence trust in and access to health services. Data regarding the costs of any activities/methods were also collected where possible.

Chapter 6: Developing recommendations (cross-sectoral workshops)

We prepared draft recommendations based upon findings from the previous stages of this study and then fed these into two cross-sectoral workshops (one in Leeds and one in Edinburgh) held in September 2017 to sense check study findings and to develop recommendations for policy. In addition to the two workshops we also held a teleconference with participants from the South West of England. Invitations were sent to all those who had engaged with the study by circulating the online consultation, responding to the online consultation and agreeing to further contact, or facilitating recruitment to the case studies. We also invited those who had contacted the study team to express interest in the work, and through the health professional, third sector and academic networks of the research team and the Stakeholder Advisory Group.

Draft recommendations

The findings of each of the previous phases of the study (literature reviews, online consultation and case studies) were synthesised and a draft list of recommendation drawn up. These were categorised into four sections: community engagement, flexible services, mainstream service delivery, and knowledge and training. Table 20 lists the recommendations and provides the component(s) of the study from which they were derived. These 24 policy options/recommendations were taken forward for discussion at the cross sectoral workshops.

Table 20: Origins of draft policy option/recommendations

Draft policy options/recommendations

Strategies	**Main origins**
1. Community engagement	
Involve GRT communities in identifying assets for heath and designing services to meet their needs	Realist synthesis; online consultation; case studies (TSOs)
Focus health services on service-user priorities including referral/signposting for priorities beyond the remit of health services e.g. housing, debt advice, heating	Case studies (TSOs, HCPs)
Enhance GRT people's tools and skills to get what they need out of encounters with health services e.g. awareness of health service-user rights, tips on how to communicate with healthcare professionals and confidence to ask questions	Realist synthesis; online consultation; case studies (mothers, TSOs)
Increase collaborative working with those that already have trusted relationships with GRT communities e.g. individuals from third sector organisations, individual health or other sector professionals	Engagement review; trust review; realist synthesis; case studies (mothers, TSOs, HCPs)
Increase the role of third sector organisations in service design, commissioning and delivery	Realist synthesis; online consultation; case studies (mothers, TSOs, HCPs)
Optimise use of local authority site assets e.g. use space for health-related activities such as 'stay and play', develop the role of site managers to have a community development focus	Online consultation; case studies (TSOs)
2. Flexible services	
Provide outreach services to sites with the goal of encouraging access to mainstream services	Engagement review; realist synthesis; online consultation; case studies (mothers, TSOs, HCPs)

Strategies	**Main origins**
Increase flexibility of practitioners to cross geographical boundaries to provide continuity of care within reason (e.g. within same town/city)	Realist synthesis; case studies (TSOs, HCPs)
Develop specialist health professional and third sector roles that focus on developing trust and acting as a bridge to mainstream services	Engagement review; trust review; realist synthesis; online consultation; case studies (mothers, TSOs, HCPs)
Develop health advocacy roles for GRT people to work with communities to facilitate access to mainstream services e.g. health mediators, health champions, peer support	Engagement review; realist synthesis; online consultation; case studies (mothers, TSOs, HCPs)
Develop specific care pathways for GRT people for maternity, child health and child dental health services	Online consultation; document analysis; case studies (HCPs, TSOs)
Provide flexible services e.g. flexible times/'drop-in' services/multiple access routes, one-stop shops	Realist synthesis; online consultation; case studies (mothers, TSOs, HCPs)
3. Mainstream service delivery	
Simplify GP and dentist registration e.g. allow c/o addresses, flexible requirements for proof of address	Case studies (mothers, TSOs, HCPs)
Develop less punitive approaches to dealing with non-attendance or arriving late for appointments	Case studies (mothers, TSOs, HCPs)
Develop alternatives to written information	Realist synthesis; online consultation; case studies (mothers, TSOs, HCPs)
Improve access to professional interpreting services	Online consultation; case studies (mothers, TSOs, HCPs)
Introduce literacy help cards throughout NHS (cards that can be presented to front line staff or receptionists to ask for discreet help with form-filling etc.)	Documentary analysis; case studies (TSOs; case 1 specific)
Sustain investment in projects and initiatives to allow relationships and trust to develop and continue	Trust review; online consultation; case studies (mothers, TSOs, HCPs)
Develop minimum standards of courtesy for all health service personnel including first points of contact e.g. receptionists, helpline staff	Online consultation; case studies (mothers, TSOs, HCPs)
Provide holistic family-centred care that focuses on needs of all family members rather than fragmented services (e.g. different services for early years' and school-age children)	Online consultation; case studies (mothers, TSOs, HCPs)
4. Knowledge and training	
Use engagement with routine maternity and child health services to deliver wider health messages, especially relating to child oral health	Online consultation; case studies (TSOs, HCPs)
Involve GRT people and third sector organisations in health service staff training (pre-registration, post-registration, continuing professional development) to increase sensitivity to barriers to healthcare access; impact of wider experiences of prejudice and discrimination and effective ways of working with GRT communities	Engagement review; realist synthesis; online consultation; case studies (mothers, TSOs, HCPs)
Maximise opportunities for those involved in delivering health services for GRT people to reflect on their experiences and share their learning with mainstream service providers and commissioners	Engagement review; online consultation; case studies (HCPs)
Shape health service procedures through policies that relate to GRT communities e.g. collecting data on GRT health service use and outcomes	Documentary analysis; case studies (TSOs, HCPs)

Cross-sectoral workshops

Aims

The cross-sectoral workshops presented to a wide-range of relevant stakeholders, preliminary findings and draft recommendation/policy options based on the first three phases of the study. The purpose of this was to discuss the importance, feasibility and acceptability of the recommendations, along with any strategies for implementation. This ensured that the recommendations culminating from the research reflected the realities and constraints of policy and practice (178)

Participants

Two workshops were held in September 2017: the first in Edinburgh (19 participants) and the second in Leeds (26 participants). In addition to the two workshops, we held a teleconference with four participants from the South West of England who were disappointed that due to the distance involved, they were unable to attend a workshop in person. Invitations were sent to all those who had engaged with the study by circulating the online consultation, responding to the online consultation and agreeing to further contact, or facilitating recruitment to the case studies. We also invited those who had contacted the study team to express interest in the work, and through the health professional, third sector and academic networks of the research team and the Stakeholder Advisory Group. Several of those who were unable to attend because of the travel involved requested to join the event virtually, but the research team and facilitator felt this would be difficult to manage and risked disrupting the face-to-face discussions.

Table 21: Participants in the cross-sectoral workshops

Sector	Edinburgh workshop	Leeds workshop	South West England teleconference	Total
Health	13	11	4	27
Local Government	2	3		5
Third sector	2	9		11
University	2	3		5
Totals	19	26	4	49

Of the total of 49 participants (not including the research team), just over half were from the health sector including national policymakers, service commissioners, and frontline practitioners. It was notable that, at the Edinburgh workshop, nearly 70% of participants were from the health sector, whereas at the Leeds workshop, attendance by health sector and third sector participants was 42% and 35% respectively. Across all the participants there was representation from maternity, child and dental health services and primary care.

Process

The two workshops were moderated by an independent facilitator who contributed to the design of the activities prior to the workshops, and at the events, managed the process, encouraged participation and kept activities to time. The workshops commenced with short presentations giving an overview of the study including the methods, emergent findings and the role of GRT people in contributing to the conduct of the study. The handouts used to support the activities are presented in Appendix 10.

Participants were organised into small groups. Each group involved both a range of sectors and work locations; and had a facilitator and a note-taker who were either members of the research team or their colleagues, or, at the Leeds workshop, staff from Leeds GATE. Participants worked on three main exercises, as below. They remained in the same groups for the first two exercises, and then worked in self-selected groups for the third exercise according to their specific interests (maternity and child health services, dental services, general health services or third sector organisations). The three exercises comprised:

1. Discussion ('sense-checking') of the preliminary study findings relating to - (i) knowledge and experiences of health services (ii) barriers to health service use, and (iii) the concept and importance of trust. Participants were asked to comment on whether the findings were consistent with their own experiences and to add any important issues;
2. Participants were asked first to score individually the acceptability, feasibility and cost (as high, medium or low) of each of the draft recommendations (as highlighted in Table 20 above); and secondly to discuss their individual scores and reach a consensus score. Each table worked on one of the four categories of recommendations (community engagement, flexible services, mainstream service delivery, and knowledge and training), progressing to additional categories if they had time.
3. Each interest-based group focussed on one recommendation they thought was a top priority and discussed how it could be implemented in terms of who needed to be influenced, how they could be influenced, and any blockages to the strategy being adopted.

We complemented this exercise by asking the 20 participants at the second residential PPI event (see Chapter 2 for details), event to similarly rate statements (which were read out) as being acceptable to Gypsies and Travellers. The large majority of the invited participants were Gypsy and Traveller women, some of whom had experience of working in TSOs, and the remaining participants were third sector staff with knowledge of Gypsy and Traveller experience. Due to the depth of discussion and time constraints, we were unable to rate all of the statements.

Workshop findings

Sense-checking study findings

The discussions among the groups was very wide-ranging. Here we present only those themes that arose in more than one group discussion. Overall respondents agreed that the main study findings were consistent with their experiences and with previous research. One key theme that was raised by several groups was around the extent to which the findings based on experiences of using services and barriers to accessing services applied first to everyone regardless of background, and secondly to other marginalised groups such as homeless people or those with learning disabilities. Other issues that were emphasised included: the importance of confidentiality for trust; the risk of outreach or dedicated services becoming 'ghettoised'; the responsibility of health staff to overcome literacy challenges, for example by providing resources not only in written form; and the need for staff training on working with GRT people. We went on to discuss a number of additional key themes that participants brought up but that were consistent with our findings, namely different types of housing for Gypsies and Travellers; and different expectations of health services and health behaviours of Roma people. In terms of types of accommodation, respondents talked about ‘being forced to move on’ while others discussed how Gypsies and Travellers in houses might not be recognised by services and therefore may have more unmet needs. With regard to Roma people, the workshop participants talked about different expectations of health services in the UK compared to Slovakia; and health practitioners, particularly those involved in dental health services, discussed poor health behaviours such as high intakes of sugar among Roma children and cultural beliefs that ‘baby teeth’ are not important.

Scoring and ranking draft recommendations

The combined scores (high, medium or low) for the acceptability and feasibility of each recommendation are presented in Table 22. We have not included the scores for cost because it became apparent during the workshops that perception of cost was largely dependent on the participant’s sphere of responsibility within an organisation. For example the frontline practitioners or TSO staff who felt stretched for resource in their day-today work, tended to view any additional care to be high cost, whereas those responsible for large budgets viewed nearly all recommendations as low cost.

Table 22: combined acceptability and feasibility scores and ranking of top five priorities

Combined individual and group scores from all workshop participants

Strategies	**Acceptability** (Rank)*	**Feasibility** (Rank)
1. Community engagement		
Increase collaborative working with those that already have trusted relationships with GRT communities e.g. individuals from third sector organisations, individual health or other sector professionals	High	High **(4)**
Involve GRT communities in identifying assets for heath and designing services to meet their needs	High	Medium
Focus health services on service-user priorities including referral/signposting for priorities beyond the remit of health services e.g. housing, debt advice, heating	High	Medium
Enhance GRT people’s tools and skills to get what they need out of encounters with health services e.g. awareness of health service-user rights, tips on how to communicate with healthcare professionals and confidence to ask questions	High	Medium
Increase the role of third sector organisations in service design, commissioning and delivery	High	Medium
Optimise use of local authority site assets e.g. use space for health-related activities such as ’stay and play’, develop the role of site managers to have a community development focus	High	Medium
2. Flexible Services		
Provide outreach services to sites with the goal of encouraging access to mainstream services	High	Medium
Increase flexibility of practitioners to cross geographical boundaries to provide continuity of care within reason (e.g. within same town/city)	High	Medium
Develop specialist health professional and third sector roles that focus on developing trust and acting as a bridge to mainstream services	High	Medium
Develop health advocacy roles for GRT people to work with communities to facilitate access to mainstream services e.g. health mediators, health champions, peer support	High	Medium
Develop specific care pathways for GRT people for maternity, child health and child dental health services	High	Medium
Provide flexible services e.g. flexible times/’drop-in’ services/multiple access routes, one-stop shops	High **(5)**	Medium
3. Mainstream service delivery		

Strategies	**Acceptability** (Rank)*	**Feasibility** (Rank)
Simplify GP and dentist registration e.g. allow c/o addresses, flexible requirements for proof of address	High **(4)**	Medium
Develop less punitive approaches to dealing with non-attendance or arriving late for appointments	High **(2)**	Medium
Develop alternatives to written information	High	Medium **(5)**
Improve access to professional interpreting services	High	Medium
Introduce literacy help cards throughout NHS (cards that can be presented to front line staff or receptionists to ask for discreet help with form-filling etc.)	High	High **(3)**
Sustain investment in projects and initiatives to allow relationships and trust to develop and continue	High **(1)**	Medium
Develop minimum standards of courtesy for all health service personnel including first points of contact e.g. receptionists, helpline staff	High **(3)**	High **(2)**
Provide holistic family-centred care that focuses on needs of all family members rather than fragmented services (e.g. different services for early years' and school-age children)	High	Medium
4. Knowledge and training		
Use engagement with routine maternity and child health services to deliver wider health messages, especially relating to child oral health	High	High **(1)**
Involve GRT people and third sector organisations in health service staff training (pre-registration, post-registration, continuing professional development) to increase sensitivity to barriers to healthcare access; impact of wider experiences of prejudice and discrimination and effective ways of working with GRT communities	High	Medium
Maximise opportunities for those involved in delivering health services for GRT people to reflect on their experiences and share their learning with mainstream service providers and commissioners	High	Medium
Shape health service procedures through policies that relate to GRT communities e.g. collecting data on GRT health service use and outcomes	Medium	Medium

* The strategies were ranked by the number of participants who scored them as high and top five are shown here. The ranking was done separately for acceptability, and for feasibility.

It was notable that participants rated all but one recommendation as high for acceptability, but only four were rated high for feasibility. The most acceptable strategy was 'Sustain investment in projects and initiatives to allow relationships and trust to develop and continue' and the most feasible strategy was: 'Use engagement with routine maternity and child health services to deliver wider health messages, especially relating to child oral health'

Below we highlight the key themes from the discussion that took place during the scoring exercise.

Community engagement

Common themes in the discussions around the acceptability and feasibility of community engagement recommendations included: concerns that GRT people become fatigued with being consulted and then become disillusioned if there was no action resulting from their participation; there are risks to eroding trusting relationships between GRT community and TSOs and/or individual HCPs if referrals or collaborative working do not meet expectations; the idea of TSOs having a greater role was generally felt to be acceptable and feasible although there were concerns that some TSOs may have a specific agenda; costs were judged to be dependent on whether there was already ongoing community engagement, and were deemed high if starting from scratch.

Flexible services

Common themes under this set of recommendations were that outreach, specialist roles, and specialist pathways could result in other HCPs and services 'washing hands of' GRT people and/or of further discrimination. The costs were generally felt to be high because these roles would need additional staffing, but the cost could depend on the size of the population e.g. more cost-effective in larger populations. The feasibility of crossing boundaries differed for different services, e.g. more feasible for dental practices which do not work within geographical boundaries, or for midwives who are developing a caseload approach, but low feasibility for health visitors who were required to work within strict geographical boundaries. One participant at the Edinburgh workshop stated 'financial cost is low but the cultural cost is high' meaning it would need significant change in the way HCPs work.

Mainstream service delivery

The recommendations in this section were overwhelmingly judged to be high for acceptability, but views on feasibility were mixed. In terms of simplifying registration, this was felt to be more feasible for GP practices than for dental practices. It was also noted that access to health services was a basic right for everyone. Other common themes under this set of recommendations were concerns that practices (GPs and dental) would not 'take on board' a less punitive approach to missed appointments or minimum standards of courtesy for receptionists. Providing holistic family care rather than fragmented services was rated low feasibility because of funding arrangements, with one participant stating 'I can't imagine this ever working'.

Knowledge and training

The scoring appeared to be more variable under this section than the others. For example some were concerned that 'singling out' GRT communities might exacerbate stigmatisation. There was also concern that raising awareness of health issues had to be approached sensitively. The recommendation on using routine care episodes to deliver wider health messages was felt to be more feasible for health visitors because they have more flexibility within their roles, than for midwives. It was thought there may be some reluctance among GRT people to represent their communities in the context of delivering HCP training.

Implementation of strategies

In the tables below we provide the results of exercise three, for the two strategies that were most selected by three of the interest-specific groups.

Three groups (two maternity and child health; and one dental health) selected 'provide flexible services' as their priority strategy. One group also combined this with 'increasing flexibility of practitioners'.

Table 23: Implementation strategies for flexible services

Who to influence	How to influence	Blockages to influence
Recommendation: Provide flexible services e.g. flexible times/'drop-in' services/multiple access routes, one-stop shops		
TSOs **Service -commissioners** **Local authorities** **Hospital managers and clinical directors** **Nursing and Midwifery Council** **HCPs** **Higher Education Institutes** **Department of Health** **Other agencies e.g. housing, social services, education** **Service providers** **NHS executive teams** **Medics** **Pharmacists** **CDPH**	Data, evidence and research including costs to present to service commissioners Develop flexible policy Flexible working hours Challenge discrimination Bridge policy-practice gap Collaboration between health sector and TSOs: sharing knowledge, find common agenda Share good practice Remunerate practitioners for flexible/unsocial hours working Recognise complexity of needs Early intervention	Lack of data to justify change Lack of access to shared resources Fragmented IT systems Frontline HCPs lack confidence to diverge from pathways/set protocols and lack cultural competence Role divisions/ skill-mix- reliance on lesser-skilled practitioners for some tasks Inflexible care pathways Too much focus on risk management Incongruous with business and remuneration model – paid for coded activities Cost Tension between providing dedicated services and risk of further stigmatisation Lack of a channel of communication between frontline practitioners and service commissioners Geographical boundaries to service provision Cultural incompetence

Three groups (one maternity and child health, one dental, and one TSOs) selected 'sustain investment in projects and initiative' as their priority recommendation.

Table 24: Implementation strategies for sustainable investment

Who to influence	How to influence	Blockages to influence
Recommendation: Sustain investment in projects and initiatives to allow relationships and trust to develop and continue		
Department of Health **Service commissioners** **Local authorities** **Charitable and other funders** **Chief Dental Officers** **CDPH** **IJB**	Build trust and relationships Build engagement Long term investment Patience for outcome Provide evidence of cost effectiveness and return on investment Provide patient stories Senior managers/service commissioners to shadow frontline HCPs and TSOs to understand needs and issues Advocacy and assertiveness when asking for funding Funders need to understand need for long term investment to see improvement in outcomes National strategies needed Channelling allies	Not enough funding Fragmentation of services – silo working Access to communities Focus on cheapest option Measuring wrong outcomes too soon Targets too specific Midwives and health visitors employed differently - frequent organisational restructuring leads to lack of continuity in policy and loss of experience and 'intelligence' Disconnect between national and local government Not using data collected by local authorities Health needs assessments not published so information not shared Limited charitable trust funding

In addition to the cross-sectoral workshops and teleconference, we also asked the 20 Gypsy and Traveller participants at the residential advocacy event held in 2017 to score some of the recommendations for acceptability. There was not time to score all recommendation so we focussed on the community engagement and mainstream service delivery categories. The results are shown in Table

25 and demonstrate that, similar to the workshop participants, most of the recommendations were scored as high for acceptability. However, one was deemed medium and one of low acceptability as indicated in Table 25.

Table 25: Combined scores from GT participation event on acceptability of strategies

Combined scores from GT participation event

Strategies	**Acceptability** (Top 6 Rank)
1. Community engagement	
Involve GRT communities in identifying assets for heath and designing services to meet their needs	High (5)
Focus health services on service-user priorities including referral/signposting for priorities beyond the remit of health services e.g. housing, debt advice, heating	Medium
Enhance GRT people's tools and skills to get what they need out of encounters with health services e.g. awareness of health service-user rights, tips on how to communicate with healthcare professionals and confidence to ask questions	High
Increase collaborative working with those that already have trusted relationships with GRT communities e.g. individuals from third sector organisations, individual health or other sector professionals	High **(1)**
Increase the role of third sector organisations in service design, commissioning and delivery	High (5)
Optimise use of local authority site assets e.g. use space for health-related activities such as 'stay and play', develop the role of site managers to have a community development focus	Low
3. Mainstream service delivery	
Simplify GP and dentist registration e.g. allow c/o addresses, flexible requirements for proof of address	High
Develop less punitive approaches to dealing with non-attendance or arriving late for appointments	High
Develop alternatives to written information	High (1)
Introduce literacy help cards throughout NHS (cards that can be presented to front line staff or receptionists to ask for discreet help with form-filling etc.)	High
Sustain investment in projects and initiatives to allow relationships and trust to develop and continue	High **(1)**
Develop minimum standards of courtesy for all health service personnel including first points of contact e.g. receptionists, helpline staff	High **(1)**

Three of the four strategies that had been scored as acceptable and feasible at the workshops were also scored highly in this event and could be considered as 'quick wins' and for early implementation:

- Increase collaborative working with those that already have trusted relationships with GRT communities e.g. individuals from third sector organisations, individual health or other sector professionals;
- Introduce literacy help cards throughout NHS (cards that can be presented to front line staff or receptionists to ask for discreet help with form-filling etc.)
- Develop minimum standards of courtesy for all health service personnel including first points of contact e.g. receptionists, helpline staff

Summary

The findings of the workshop add depth to the findings that had so far been gathered through the literature reviews, online consultation and fieldwork. Discussions with the participants indicated that the draft recommendations were largely acceptable, but that some may be less feasible than others or difficult to implement in certain sectors. The scoring exercise at the community participation event exercise was particularly valuable to ensure that recommendations make sense to community members. As a way of illustrating more in-depth cost analysis around recommendations, the most acceptable and feasible strategies from the two workshops are taken forward to the next chapter on economic costings.

Chapter 7: Economic findings

Background and objectives

The results of the engagement review emphasised the lack of evidence associated with the cost-effectiveness of health care interventions to improve accessibility of NHS services by GRT people. The review also 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. Therefore there is an urgent need for rigorous evaluations and economic evaluations of interventions to improve GRT communities' access to and engagement with health services. This analysis aims at providing a useful insight into costs of running a number of approaches to make NHS health services accessible by GRT people. This analysis does not provide insight into the cost-effectiveness - as outcome data were not available - but to increase the understanding of potential economic costs of improving the uptake and delivery of health services for GRT people.

Methods

The main data source used for cost estimation was scoring of draft recommendations described in the previous chapter. Respondents were asked to rate estimated costs of implementation for a number of pre-defined strategies aimed at enhancing GRT peoples' trust in maternity services, early years' services and child dental health services. Strategies were classified into four categories: (i) community engagement strategies; (ii) flexible services strategies; (iii) mainstream service delivery strategies; and (iv) knowledge and training strategies. Respondents were asked to rate implementation costs for each strategy as high, medium or low. Therefore no specific costs associated with particular interventions were stated. The strategies discussed during the workshops were also ranked in terms of acceptability and feasibility. We explored implementation costs for the top acceptable and top feasible strategies as an example of how much it would cost the NHS to improve access to GRT communities in terms of health and social care professionals' resource use. It was necessary to make assumptions about the type of activities involved in the delivery of each strategy, the health care staff involved and how long it would take to run activities. Assumptions were guided by the research team and expert opinion. We conducted a modest sensitivity analysis to explore the impact that changes in the assumptions have on cost estimates. Costs were analysed from the NHS and Personal Social Services perspective. Published Unit Costs of Health and Social Care (PPSRU 2017) were used for the analysis. Prices were inflated by the PSSRU pay and prices index.

Results

Respondents considered "mainstream service delivery" and "knowledge and training" as central priorities to improve the acceptability of NHS services to GRT people. According to stakeholders, the top acceptable strategy to these communities is to "sustain investment in projects and initiatives to allow relationships and trust to develop and continue"; whilst the top feasible strategy for health services and/or third parties to implement is to “use engagement with routine maternity and child health services to deliver wider health messages, especially relating to child oral health”.

Costing top feasible strategy

Using engagement with routine maternity and child health services to deliver wider health messages, especially relating to child oral health, was perceived as the top feasible strategy by stakeholders. During the group discussions the stakeholders identified the role played by health visitors and midwives as fundamental in order to target health messages and changing health related behaviours. Even though no specific costs associated with particular interventions were stated, the online consultation identified interpretation services and longer visits with health staff as additional resources that might facilitate engagement with these communities. Similarly the literature suggests that practice nurses are well placed to facilitate access to primary care and may represent a cost-effective resource (110). Furthermore interventions already in practice are predominantly delivered by health visitors or community health workers. It was also suggested that improving language access for patients who have limited English proficiency may lower the cost of their healthcare in the long run (179).

Based on the these recommendations and following similar approach of initiatives already in practice, we assumed that a programme involving a multidisciplinary health-team comprised of one Traveller Liaison Officer (e.g. to improve cohesion with maternity services); two clinical (nursing and dentistry) support workers (e.g. to allow the local community to gain confidence and build up trust and respect); one health visitor (e.g. to make assessment visits and help families with GP, immunisation and dentist appointments); and one midwife (e.g. provide health education, social care advice and providing care) could potentially improve engagement and improve health of the GTR communities. Using PSSRU as the main source for unit costs in this analysis the personnel costs of a potential programme to improve engagement with the travellers’ communities were estimated to be approximately £227,704 per annum. Assuming a catchment population of 1,000 travellers the costs of the programme are estimated as nearly £228 per traveller. Table 26 includes a breakdown of the costs and sources used in the analysis.

Table 26. Staff costs

Personnel costs	**Cost (£ 2017)**	**Source**
Traveller Liason Officer [a]	£16,536	NA
Clinical support worker - nursing [b]	£35,567	PSSRU 2017 (AfC Band 2)
Health visitor [c]	£70,017	PSSRU 2017 (AfC Band 6)
Midwife (community) [d]	£70,017	PSSRU 2017 (AfC Band 6)
Clinical support worker - dentistry [e]	£35,567	PSSRU 2017 (AfC Band 2)
Total personnel cost (per annum)	***227,704***	

[a.] No information available on unit costs for LTO. Evidence suggests that training costs for members of Traveller Communities might be expected to be high. Hence we assumed AfC Band 2 salary for the analysis. [b,c,d,e] Unit costs are estimated including salary and capital overheads.

Regarding operational costs (Table 27), the evidence suggests that setting up a GP enhanced service for Gypsy/Travellers including increased staffing to enable elasticity in appointments, increased doctor hours to enable extra consultation and employing and training a specialist practice nurse undertaking on site sessions cost approximately £113 per Traveller (180). The average cost of providing interpreter services has been estimated as £3.20 per patient (179). Similarly the training cost on cultural competency (e.g. online course) has been estimated £30 per session. Hence we estimated that operational activities for this potential programme would cost approximately £176.20 per traveller.

Table 27. Operational cost

Operational Costs	**Cost (£ 2017)**	Source
GP enhanced service (set up)	£113	NHS- Primary care service framework [a]
Interpreter	£3.2	Literature [b]
Training 2 health staff	£60	Friends Families and Travellers [c]
Total Operational costs (per case)	***£176.20***	

[a] Cost per traveller in the catchment population in the study. The study reports on 2009 prices that we inflated to 2017 using inflation rate by PSSRU.

b E. Jacobs, D. Shepard, J. Suaya and E. Stone, 2004, "Overcoming Language Barriers in Health Care: Costs and Benefits of Interpreter Services" American Journal of Public Health, 94:5, pp866-869. The study reports on 2004 prices that we inflated to 2017 using inflation rate by PSSRU

In order to take into account the uncertainty associated with our analysis we made some modifications in the assumptions. There is the potential for the cost of the programme to be further reduced if a clinical support worker rather than a health visitor undertook both nursing and dental assessment of the participant. Assuming a caseload of 1000 travellers the change in assumptions would indicate a programme cost as £122 per traveller in terms of personnel costs.

Costing top acceptable strategy

Sustaining investment in projects and initiatives to allow relationships and trust to develop and continue was perceived as the top feasible strategy by stakeholders, including "health professionals/management/academic" staff.

During group discussions there was an emphasis that projects that have a long term strategy (five years plus) and funding would lead to improved trust and relationships built and maintained. Likewise it is acknowledged that services should be commissioned for a minimum period of 3-5 years initially in order to ensure stability and continuity (181).

Published evidence suggests that multi-agency forums are a good approach to identify services for vulnerable migrants, and that concerns raised in those forums are transmitted to commissioners in order for actions to be taken (182). This type of approach not only helps to address trust, but also what services are effective and cost effective and therefore requires sustaining and funding. Based on these recommendations and assuming synergies between programmes, we considered that some members of the multidisciplinary health-team proposed to promote engagement might have also the potential to lead the forum. Therefore we assumed a multifaceted panel comprising a health visitor (e.g. lead professional) and a social worker plus a health ambassador (e.g. to carry on links already established between the GRT communities and health professionals) and an administrator. Unit costs are estimated as per PSSRU based on decision-making panels for the Commission Assessment Framework (CAF) for disabled children and families. Mirroring the CAF approach we assumed the forum to be involved in three types of decision panels: (i) assessment panel (e.g to select services that require a long term strategy and maintain a registry of GRT people thus trust and relationships are maintained); (ii) short-break panel (e.g. to re-assess needs and improve health outcomes); and (iii) joint commissioning panel (e.g. for commissioners to familiarise themselves with the population needs and ensure that procedures are maintained in place for maternity and oral health services to be commissioned). Total costs are estimated by multiplying the number of hours carried out for each panel (e.g. as estimated for CAF panels) by each type of personnel, by the relevant unit costs per hour as per PSSRU 2017. Based on our assumptions costs would be approximately £245 per assessment panel, £325 per short panel and £196 per joint commission panel; hence a forum approach based on three panels would cost £767 per annum (Table 28).

Table 28: Activity times and costs for multi-agency forum

Assessment panel	**Activity times[a]**	**Unit cost per hour[b]**	**Total cost**
Health visitor (lead professional) B6	5 hours	£44	£220
Clinical support worker – dentistry B2	1 hour 10 min	£23	£25
Administration	NA	NA	-
Health Ambassador	NA	NA	-
Total Assessment panel cost			***£245***
Short panel			
Health visitor (lead professional)	3 hours 20 min	£44	141
Clinical support worker - dentistry	1 hour 45 min	£23	33
Administration[c]	4 hours 40 min	£31	136
Health Ambassador[d]	1 hour 45 min	£10	15
Total Short panel cost			***£325***
Joint commissioning panel			
Health visitor (lead professional)	1 hour 45 min	£44	64
Clinical support worker - dentistry	1 hour 45 min	£23	33
Administration	3 hours 20 min	£31	99
Health Ambassador	NA	NA	-
Total Joint Commissioning panel cost			***£196***
Total Forum approach cost (per annum)			***£767***

[a] Activity times based on decision-making panels for the Commission Assessment Framework (CAF) for disabled children and families. [b] Unit costs as per PPSRU 2017 and based on Agenda for Change (AfC) including salary and capital overheads. [c] We assumed unit costs for the Administrator as for the Commission Assessment Framework (CAF) for disabled children and families. [d] No information available on unit costs for Health Ambassador hence we assumed AfC Band 2 salary (without including salary and capital overheads) for the analysis.

Assuming this forum approach will impact on the preventative and continuous care of 100 families the cost of relationships to be sustained based on this hypothetical framework would cost the NHS £77 per case per annum. Allocating a budget of £77,000 per year would potentially allow running a forum programme to sustain initiatives that increase trust for a catchment population of 1000 travellers. This is approximately the yearly costs of employing a health visitor. We cannot estimate if this spending actually saves money to the NHS from this analysis. However there is evidence that late presentation and poor management of maternal and child care can lead to higher costs to the NHS (183). For instance, the estimated average costs of an emergency caesarean section are £5,559 per birth compared with average costs of £1,608 per normal delivery without complications. In similar way, the unit cost of dental care for examination and advice is £21 per visit compared to £56 for treatment such as fillings or removal of teeth and £244 for any further treatment (e.g. crowns and bridges).

Based on this exploratory cost analysis, it is not possible to draw conclusions about whether the proposed strategies represent an efficient use of NHS resources. Cost-effectiveness decisions require taking into account all relevant outcomes of the strategies, mainly health benefits but possibly other non-health benefits as well. Although effectiveness analysis was not part of this exercise, evidence on cost-benefits analysis comparing current practice and improved pathways for GRT communities suggest that up-front investment can pay for itself many times over in the longer term (183). These included cost-savings in cancer and mental health, but also showed how important is a better understanding of their culture in order to improve outcomes for individuals and their families. It remains important that that cost and benefits related to the proposed interventions are properly assessed. In principle Randomised Control Trials are the most robust form of evaluation of interventions, as they eliminate biases that could lead to misleading results. Therefore from this analysis we conclude that there is a need for further trial research supporting decision makers to identify cost-effective services to improve GRT communities' health.

Summary

The aims of the cross-sectoral workshops were to present to a wide-range of relevant stakeholders, preliminary findings and draft recommendation/policy options based on the first three phases of the study with the purpose of discussing the importance, feasibility and acceptability of the recommendations, along with any strategies for implementation. This was intended to ensure that the recommendations culminating from the research reflected the realities and constraints of policy and practice. To this end, two workshops were held in September 2017, the first in Edinburgh (19 participants) and the second in Leeds (26 participants). In addition to the two workshops we also held a teleconference with participants from the South West of England. Invitations were sent to all those who had engaged with the study by circulating the online consultation, responding to the online consultation and agreeing to further contact, or facilitating recruitment to the case studies. We also invited those who had contacted the study team to express interest in the work, and through the health professional, third sector and academic networks of the research team and the Stakeholder Advisory Group.

Of the total of 49 participants (not including the research team), just over half were from the health sector including national policymakers, service commissioners, and frontline practitioners. Across all the participants there was representation from maternity, child and dental health services and primary care. Overall respondents agreed that the main study findings were consistent with their experiences and with previous research. Discussions with the participants indicated that the draft recommendations were largely acceptable, but that some may be less feasible than others or difficult to implement in certain sectors. The scoring exercise at the community participation event exercise was particularly valuable to ensure that recommendations make sense to community members. As a way of illustrating more in-depth cost analysis around recommendations, the most acceptable and feasible strategies from the two workshops are taken forward to the next chapter on economic costings.

Chapter 8: Discussion

This multi-phase study set out to examine which approaches to community engagement are best at enhancing GRT peoples' trust in mainstream health services. To provide focus to this broad aim, we used maternity and early years' health services, and children's dental health services as exemplars of mainstream health service provision. While we set out to focus on these three services, we inevitably found that our participants talked about primary care. This is not surprising as those associated with primary care are the gateway to other services (184). We have, therefore, included primary care throughout this report. In this chapter we first summarise the key findings of the study, drawing on results from the literature reviews, online consultation, case studies and cross-sectoral workshops. In presenting these findings, we outline the experiences of GRT people of using health services including barriers to accessing services. We then summarise specific examples of engagement activities and strategies and their potential cost, followed by highlighting key principles of approaches to engagement that enhance trust. Next we highlight the strengths and limitations of our work followed by discussion of the study's implications for health policy, mainstream health services and third sector organisations. Finally we explore the potential applicability of our findings to other socially excluded groups, discuss potential directions for future research, and set out our dissemination plans.

Summary of findings

Experiences of Gypsy, Roma and Traveller people's experiences of maternity and early years' health services, and children's dental health services

A prominent feature of our work was the seemingly high frequency and complexity of the health needs of the GRT population. This was evident in the accounts of both the GRT and the HCP participants, and is consistent with the literature on health outcomes for this population. This is typical of disadvantaged groups. Particularly striking in our work was the high level of dental issues necessitating complex treatment and multiple extractions in children. However, the lack of robust data on health outcomes for GRT populations was evident from our engagement review (review 1; chapter 3 and published review), from the HCPs and policymakers attending the cross-sectoral workshops, and from national policy documents (Public Health England Outcomes Framework).

Our work indicates great variation in the experiences of GRT people when accessing health services, including some very positive examples of care that was highly valued. The case study findings highlighted this most frequently in relation to maternity care by midwives, and early years' support from health visitors, but also provided examples of good care from dentists and GPs. In the GRT participants' accounts the key features of good care related mainly to the individual practitioners encountered and included kindness and respect, listening and being genuinely interested in the service-user, being reliable and non-judgemental. The important of developing relationships and consistency of provider were evident. All of these are consistent with the conceptual model of trust developed as part of this study (review 2; Chapter3). This is also a more general point that probably applies to everyone who uses health services, and almost certainly those from other disadvantaged and marginalised groups.

The many examples of poor care, or care that did not meet expectations, were linked to accounts of difficulty in accessing services, complex needs and a high number of narratives that involved apparent misdiagnosis or not recognising the severity of symptoms. It is not possible from our work to judge whether this level of clinical errors is greater than in the general population, but it could be explained by lack of appropriate communication, and health providers' assumptions underpinned by prejudice and discrimination, all of which are evident in our review findings (56).

There were consistent findings across all elements of our study of the difficulties GRT people face when accessing services. Much of this related to barriers to registration with GP practices and dentists, and the mothers, HCPs and TSO participants gave consistent accounts of practices refusing to register GRT people. This ranged from overt racism, as in the cross-sectoral workshop participant who was told by a GP practice that 'we don't accept Gypsies and Travellers here' to not registering those with no fixed address, or stating the practice was full. There seemed to be a particular issue with lack of capacity of dental care in the case studies in England. As the first point of contact with health services, receptionists in GP practices have a key role and, according to mothers, HCPs and TSO participants, they were not always welcoming or helpful. Other barriers in terms of primary care were the difficulty of making a timely appointment for what mothers assessed to be a serious problem (most often related to their children's health); and the punitive approaches to missed or arriving late for appointments, in both general and dental practices. While it is acknowledged that both of these apply to the general population, we suggest that the consequences are likely to impact on GRT people and other socially excluded groups disproportionately. One contributing factor to the high number of missed and late attendance at appointments was the miscommunication between health services and service-users, for example sending written letters with appointment times to people who cannot read and/or do not speak English. Both TSO and HCP participants described time-intensive strategies to helping GRT people to manage appointments.

Transience was an issue, although there was evidence from mothers' accounts and some of the cross-sectoral workshop participants that some HCPs hold stereotypical views and assumptions that GRT people always travel and/or live on sites, and that this is the main barrier to accessing services. As described above, our work shows multiple barriers to accessing services.

For the GRT mothers and TSO participants in our case studies, and from the engagement review, discrimination was a key barrier to accessing health services. Some HCPs were aware of this, although they were more likely to discuss discrimination in the wider context, for example in the media. It is interesting that in the online consultation, the top three barrier's identified by respondents were related to service-user attributes: i.e. language and literacy; cultural issues; and health literacy. While these barriers are indeed significant, they focus on behaviours of the service-user, rather than the barriers created by the health system, thus potentially shifting blame to community members. Linked to this, cultural assumptions about GRT people were evident in the engagement review, and in HCPs accounts, both in the case studies and the cross-sectoral workshops; for example that GRT people do not engage with health services because they are 'self-reliant', or prefer to take advice from families and their community. All of this is congruent with broader debates on health and ethnicity, in which a lack of engagement with service delivery is justified with reference to people's behaviour (185).

Frequent use of accident and emergency departments was an issue highlighted in the engagement review and case studies. In the mothers' accounts this was sometimes their choice; however often this was perceived to be the only option available, including because they could not be seen at a GP practice or were not satisfied with the action advised by the GP. In this sense the mothers were exercising autonomy and demonstrating resourcefulness. This also demonstrates that what might be termed as 'naïve trust' in health services is not desirable. This contrasted with HCPs accounts of GRT people waiting until symptoms were acute before presenting to health services, though this may apply to certain health issues only, like dental care.

In relation to trust and health services, there were several issues that undermined trust. One was mistrust of statutory agencies, including health and social services, how they are linked to each other and what information will be shared. Fear of having children removed was high and related to accounts of past experiences, or stories from others. Linked to this were multiple stories of poor past experiences of health services that undermined trust and heightened fear. The stories were often personal, having affected themselves or close family or friends, or were disseminated via social media. Within this frame of reference, some actions of HCPs were viewed with suspicion and considered to be over-surveillance, for example visiting families on sites without an obvious purpose, or visiting families at home the day after a child was taken to accident and emergency. This also undermines trust because it does not focus on the needs or priorities of individuals or their families. A theme that was apparent from some of the interviews with mothers, and from GRT people attending the PPI events, was the intrusive nature of some communication from HCPs, for example commenting on the décor of caravans. While from the perspective of the HCPs this might be an attempt at friendliness, or showing interest; in the context of mistrust, this was viewed at best as irrelevant, but also as intrusive and emphasising 'otherness'.

Engagement activities used by health services and third sector organisations to enhance trust and increase uptake of maternity, early years' and children's dental health services by GRT people

We found a range of strategies used by health services and TSOs to increase access and uptake of health services, including maternity, early years' and child dental health services. These included strategies provided mainly by health services such as flexible services; tailored/dedicated services; community support and outreach; education and training for HCPs and health-based resources. It also included services mainly provided by TSOs, or TSOs working in collaboration with health services, such as advocacy; specialist roles, for example health champions; and community participation in service design and development. In terms of advocacy, TSOs generally provided two functions: individual advocacy, such as supporting individuals to access services, including assistance with literacy or communicating with services; ; and collective advocacy, as in campaigning and advocating for the rights of GRT people, often at a strategic level. Other strategies were based on the principles of developing relationships between service providers and GRT people, of providing holistic care, by which we mean focussing on the priorities of the service-users including needs beyond healthcare, such as in the social prescribing approach (186), described in case study two.

We found examples of good practice in all of our case studies, including mainstream service delivery e.g. relationship building through continuity of care, such as by a small team of midwives in case study four; tailored/dedicated services, such as the Haamla maternity service in case study one, or oral health promotion work in case study two; cross-sectoral collaboration, such as between health, third sector and education, in case study two; and specialist roles, such as the Slovak-Roma health champions in case study three.

It is very clear that the successful strategies acknowledge the need to develop and negotiate trust, and while this may not have been explicit in their design, they link to our conceptual model of trust developed in review 2. Most of the strategies depended on developing interpersonal trust with one or a small number of practitioners. It was clear that the HCPs who participated in our study and described engagement strategies recognised that it takes time to build trust, and that reliability i.e. delivering on what is promised, being accessible, showing empathy and understanding individual circumstances, as well as sharing decision-making, are all critical to developing trust. It could be argued that successful strategies provide GRT people with safe physical, cultural and emotional spaces within which to express their needs and make choices about their care. Not surprisingly, we found that the relationship between engagement and trust is somewhat circular, in that engagement can lead to trust, but similarly trust is a prerequisite for engagement. We suggest that this is also a generic point that would be applicable to other disadvantaged and marginalised groups, as well as the wider population more generally.

One major theme related to many of the engagement strategies discussed in our study by all participants, was a lack of sustainability of health service provision. The strategies led by or delivered in collaboration with TSOs appeared to be particularly vulnerable to funding cuts, but this also applied to health service-led strategies such as the social prescribing approach described in case study two. It is therefore not surprising that one of the top priority recommendations from the workshops related to sustainable investment. Given the poor health outcomes of GRT people it can be projected that return on investment would be significant for strategies based on building trust and providing easier access to primary care, in terms of reduced use of accident and emergency departments and treatment of health conditions before they become serious (182).

Principles of successful approaches to community engagement to enhance trust in mainstream services

Drawing on our work on engagement and trust we propose some general principles of successful strategies. However, as this research was about mainstream services, our central argument is that these should be features of all services, and not viewed as additional for GRT people or other socially-excluded groups. Therefore we recommend using principles of proportionate universalism (187) which proposes that to reduce inequalities in health: ‘actions must be universal, but with a scale and intensity that is proportionate to the level of disadvantage’ (p9). This is also supported by the Social Value Act 2010 (50). Consistent with broader theoretical work on disadvantage and marginalisation, a proportionate universalism approach could also avoid seemingly patronising initiatives, which, although well-intentioned, may give offence and/or perpetuate stigmatisation (188, 189). Conversely, it could also address the view, relayed to us by some HCP and TSO participants, of resentment by users of mainstream services that GRT people or other groups are receiving extra services that are not available to the general population.

Our work suggests that developing and negotiating trust should be explicit in any approach to engagement, not just in acknowledging the time taken to develop trust but also strategising how interpersonal trust in one or a small group of practitioners can progress to impersonal/institutional trust. To some extent this requires a change in culture across the NHS to providing high quality services, including respectful care, for all, rather than viewing people from vulnerable or socially excluded communities as having additional needs. Without this approach, not only will GRT people continue to feel excluded and stigmatised, but those practitioners working with them are also at risk of being isolated. To achieve this, some of the engagement approaches described above should be viewed as strategies to develop trust and as a bridge to mainstream services; not as alternatives to mainstream services. Those practitioners and TSOs providing, for example, dedicated or outreach services, need to have strategic roles and to be integral to service commissioning, development and management, and not seen as a reason for mainstream services to not have to consider GRT people or other excluded groups. Health professionals in such roles should also be seen as role models and leaders within their professions; this would address the succession problem, where relationships and trust break down when an HCP changes role. Case study two provided an example of leadership by the health service, in the form of a cross-sector steering group chaired by a health professional with a strategic role within the NHS. We also argue that focussing on access to healthcare without simultaneously addressing the quality of care will not achieve improvement in health outcomes or reduction in health inequalities.

Further to the above discussion about sustainability, short-term funding of engagement strategies not only does not consider the time needed to develop trust and then achieve impact, but is likely to be counterproductive in that raising expectations that are not fulfilled creates disillusionment and cynicism, both of which undermine trust.

We have provided some estimation of cost of a number of priority strategies, albeit based on limited data, and wider evidence suggests the return on investment could be significant (182, 183).

In all of our work, the most successful model of community engagement and enhancing trust involved collaboration between health services and TSOs. It is often the TSO that knows the community, that has developed trust, and that has the expertise in community engagement and development. This knowledge and expertise should be harnessed, not just at the level of providing support and advocacy at an individual level, important though that is, but could make invaluable contributions at a strategic level, for example in service commissioning. This also requires time to develop trust and common understanding between TSOs and health services. Working with TSOs can also help to ensure that community engagement is meaningful and moves beyond repeated consultations or needs assessments without subsequent action.

Our work suggested that that overall there is more successful engagement with maternity services than with child or dental health services or with primary care. Therefore we propose that maternity services could be used as a conduit to other services, and possibly also to reaching families, and more particularly men. The engagement review and some views expressed by HCPs in our case studies suggested that men are more reluctant than women to access health services. Working with families more broadly rather than only focussing on the mother and baby, is likely to bring wider health benefits and to dispel ill-informed myths, for example regarding the role of men in parenting.

Summary of recommendations

The key recommendations that were judged to be acceptable and/or feasible by our GRT, HCP and TSO participants are presented below. We also indicate in parenthesis, examples of who could be responsible for implementing each recommendation:

1. Sustain investment in projects and initiatives to allow relationships and trust to develop and continue (National Government, Department of Health, NHS, Clinical Commissioning Groups, Local Authorities, TSOs and Charities);
2. Increase collaborative working with those that already have trusted relationships with GRT communities e.g. individuals from third sector organisations, individual health or other sector professionals (HCPs, service managers, TSOs, Local Authorities);
3. Develop minimum standards of courtesy for all health service personnel including first points of contact e.g. receptionists, helpline staff (NHS England, Public Health England, NHS Trusts, Local Authorities, professional regulators e.g. Nursing and Midwifery Council, General Medical Council, General Dental Council, Professional Associations e.g. British Medical Association, Royal College of General Practitioners, Royal College of Nursing, Royal College of Midwives, Community Practitioner and Health Visitor Association, British Dental Association);
4. Simplify GP and dentist registration e.g. allow c/o addresses, flexible requirements for proof of address; and develop less punitive approaches to dealing with non-attendance or arriving late

for appointments (Department of Health, NHS England, Public Health England, NHS Trusts, GP Practices, Dental Practices);

5. Introduce literacy help cards throughout NHS (cards that can be presented to front line staff or receptionists to ask for discreet help with form-filling etc.) and provide alternatives to written information (Department of Health, NHS England, Public Health England, Local Authorities, GP practices, Dental practices, NHS Trusts, TSOs) ;
6. Enhance GRT people's health literacy: e.g. awareness of health service-user rights, tips on how to communicate with healthcare professionals and confidence to ask questions (TSOs, Local Authorities, Public Health England, NHS Trusts)
7. Use engagement with routine maternity and child health services to deliver wider health messages, especially relating to child oral health (NHS Trusts, HCPs, Clinical Commissioning Groups, service managers);
8. Provide flexible services e.g. flexible times/'drop-in' services/multiple access routes, one-stop shop (NHS Trusts, Local Authorities, Clinical Commissioning Groups. Service managers, TSOs)

Strengths and limitations

Strengths

This study employed robust multiple methods and has achieved a comprehensive and detailed examination of how mainstream services can enhance trust with GRT people. The peer-reviewed publications of the protocol and the overarching engagement review (1, 56) are a starting point for demonstrating the methodological rigour of our work. The study triangulates findings and multiple perspectives from three literature reviews, an online consultation, four case studies and cross-sectoral workshops. Each component builds on the previous ones, and is underpinned by and further develops theoretical perspectives on trust and engagement. The choice of the foci of the work i.e. maternity services, early years' and child dental health services allowed us to develop in-depth understanding of the issues and lessons learned that can be applied more broadly to other services, and not only to other marginalised groups, but also to health services more generally. The inclusion of primary care in our work adds value to this.

Our selection of case study sites highlights a wide range of examples of good practice, both those led by TSOs and by health services, as well as highlighting strategies that don't work. This has facilitated synthesis of general principles for engagement to enhance trust. The case studies also cover a range of geographical areas and of different groups of GRT people. We reached all of our recruitment targets and included: 196 respondents to the online consultation; 110 participants in the case studies (43 GRT people, 54 HCPs, 13 TSO staff); 49 attendees at the cross-sectoral workshops; and GRT people were the main invitees at the PPI residential events.

Central to our work was the involvement of GRT people in the design, conduct, interpretation and dissemination of our work. Pivotal to this was the collaboration with Leeds GATE. The production of the

4Rs report (see Appendix 4) of conducting research with GRT people provides guidance that others can use. Mirroring the focus on trust in the research, we would not have been so successful in conducting the study without developing trusting relationships with Leeds GATE and building on the trust they had developed with other TSOs and GRT people.

We achieved excellent engagement from stakeholders from a variety of sectors including health, local and national governments in England and Scotland, education, TSOs and housing. This was particularly evident in the wide range of stakeholders who attended the cross-sectoral workshops and helped us to develop and prioritise the recommendations arising out of our work. We were also impressed by the number of people who wanted to contribute to our workshops but were unable to attend. Throughout the study, we have developed a large network of practitioners, policymakers and TSOs, that will support dissemination of the findings and development of impact. See below for a description of our dissemination plans.

We believe our study makes an original and significant contribution to the evidence of what works to enhance trust between GRT people and mainstream health services.

Limitations

It is important to acknowledge that our work is not without limitations. The literature in this field is limited and our engagement review found little evidence of what works. There was more focus on what doesn't work and on the barriers to access to healthcare. Furthermore, the included studies were mainly descriptive and had significant methodological limitations. Linked to this there was a dearth of data on which to base the economic evaluations.

It is also important to acknowledge that our approach to recruitment meant that the GRT participants were mostly from those engaging with TSOs (England) or already engaged with health services (Scotland), and largely those living on authorised sites or in bricks and mortar housing. We did not recruit anyone living in unauthorised/roadside sites, although many of those we spoke to had that experience in the past, or at different times of the year. While we achieved our target recruitment to the case studies, we acknowledge that greater diversity of TSOs and a larger sample of the GRT population would have strengthened the research. Within the financial constraints and time limitations of the research, we were unable to carry out further work to ascertain the extent to which the issues raised in our case studies reflect wider experiences and geographical differences. We acknowledge the gendered nature of the work in that all our participants were women, as were the members of the User Advisory group and the majority of those participating in the two advocacy training workshops. This was appropriate to the focus of the research, maternity, child health and child dental health services, however, the inclusion of men may have provided a different, but important perspective. A further limitation of the case study work was that most of the interviews with Roma participants were conducted with the aid of an interpreter which is known to limit the depth of the research material generated.

In relation to the participating HCPs, we are aware that many of these were those who are committed to working with and improving services for GRT people. This is inevitable in research, but means that we don't necessarily include the views of those in mainstream services who encounter very few GRT people in their daily roles. The approach of including the online consultation helped us to reach a wider range of HCPs but it is still unlikely that those who are not interested in or who have prejudicial attitudes towards GRT people would complete the questionnaire.

It is important to note that this research focussed on a specific research question asking which approaches to community engagement enhance trust between mainstream health services and GRT people. It did not address the health outcomes or the health needs of GRT people nor does it purport to provide solutions to the issues that might impact on health inequalities for GRT people. We also have not investigated whether increased engagement and trust do in fact lead to improved short- or long-term health outcomes or less requirement for treatment in GRT communities. However, inevitably we do raise some broader issues because they provide a context within which our work can be interpreted.

Implications

In this section we highlight the implications of our work for policy, health services and TSOs.

Policy

Broader context

It is critical that policy acknowledges and tackles the impact of the wider context of discrimination, prejudice and stigma within which GRT people live their daily lives. This is evident in for example the media, and statements by politicians. Reports of discrimination towards Gypsies and Travellers related to housing, employment and education are plentiful. It is beyond the remit of this report to go into details of these structural barriers to realising optimum health and wellbeing, however there is significant impact on the distrust that is evident between GRT people and public bodies and authorities, including the NHS. More specifically, previous poor experiences and collective cultural memory of current and past discrimination underpins mistrust of health services and fear of social services. Regarding the Eastern European Roma community in the UK, this extends to experiences in countries of origin. While there is policy rhetoric around reducing health inequalities at national and local levels, lack of action to tackle the social determinant and underlying structural barriers to health will undermine efforts within the health arena. Cross-sectoral action is needed at national and local levels. Many of these issues apply to other marginalised and disadvantaged groups (190), however, we would argue that few communities experience the level of overt prejudice and discrimination that GRT people are subjected to.

Health policy

The key tenet of health policy should be to enable everyone, including GRT and other marginalised groups, to be able to make genuine informed choices about their care and this would fulfil the individual's right to 'access to timely, acceptable, and affordable healthcare of appropriate quality' (53), as well as forming the basis for establishing trust. A central issue is the way in which diversity and difference are seen as problems by policymakers (191). One approach to addressing this would be to place those with greatest need at the centre of health policy and service commissioning, rather than as requiring additional or specialist services. If health policy meets the needs of the most vulnerable and/or marginalised, it will almost certainly meet the needs of everyone. This would be consistent with proportionate universalism. Current policy for maternity care in England and Scotland (192, 193) proposes continuity of carer for all women. Our findings support the notion that continuity of carer can be very effective in establishing trust. However, in implementing this policy, we propose that pilot/early adopter schemes focus on those with the poorest outcomes and greatest need, such as GRT people, rather than, as has happened in the past, new services are demanded first by those least in need.

It is also important that policy recognises that there is not quick solution; as we have demonstrated trust takes a long time to build, especially institutional trust. This needs a commitment to sustainable funding to recognise this, and evaluation needs to be long term to give interventions time to realise impact. We have demonstrated, as have others, that the role of the third sector is invaluable, but this should not be viewed as a cheap option; TSOs also need adequate and sustainable funding.

There needs to be recognition that lack of capacity and resource in the health service will always disproportionately affect marginalised groups with most need (55). This is particularly so when it places barriers to accessing services and results in punitive approaches to missed or late attendance at appointments; both of which undermine establishing trust. In terms of capacity, our work suggests there are particular issues for primary care and dental health services. It would appear there is need for a national and local focus on dental health care and an understanding of its relationship to general health. It was notable when analysing the plans of local Health and Wellbeing Boards that there was significant focus on maternal, newborn and child health, but there was no mention of oral or dental health.

There are also implications of the lack of robust data to inform policy. There is an urgent requirement to better understand the level of health need, to monitor outcomes, and to hold health and social care providers to account for delivering (or failing to deliver) on public health quality outcomes. Related to this is the proposal to bring together the information that is available through the myriad of local health needs assessments, surveys and consultations with GRT communities that have been conducted across the UK. This would provide a rich resource and reduce duplication of effort.

Patient safety is high on the international and national healthcare policy agenda (194, 195). Several examples of misunderstandings and misdiagnoses were apparent in the narratives of our participants, suggesting that patient safety is a particular issue for GRT people. We suggest that this both reflects and exacerbates mistrust between GRT people and HCPs, and is based on poor communication and provider assumptions about GRT people. Reflecting this, the patient safety agenda should include consideration of the interpersonal and cultural competence of HCPs as well as their clinical competence.

Our work has proposed some promising interventions that could have an impact on establishing trust and enhancing engagement between GRT people and mainstream health services. Three of these could be quick wins i.e. they were judged by our workshop participants to be both highly acceptable and feasible: increasing collaboration with those who already have trusted relationships; introducing NHS literacy help cards; and developing minimum standards of courtesy for all healthcare personnel.

Other policy options that were deemed highly acceptable included making it easier to register with a GP and dentist; developing less punitive approaches to missed/late attendance at appointments; and providing more flexible services, such as drop-in services and one-stop shops. Interventions that introduce specialist roles such as health champions as a link between mainstream health services and GRT communities may also be effective.

Mainstream health services

There are many implications from our work for mainstream health services, not least implementing the policies discussed above. In particular, this includes providing an environment which gives HCPs the freedom to cross boundaries, provide more flexible services, and ensure everyone has access to primary care and dental care.

In addition, our work suggests there is a need for health services to recognise and work with the strengths, resilience and autonomy of GRT people. We found examples in the literature and in our work of HCPs problematising self-reliance as a reflection of an ‘other’ culture, rather than seeing it as an asset. This is counter to the current policy emphasis on self-care (196) but reflects wider understandings of ethnicity (188).

Other implications for health services are related to making sure the information that service-users need is available in accessible formats, recognising the varying literacy levels of not only GRT people but also the general population. Additional resources are needed to meet the needs of those who do not speak English, including adequate interpreting services. It was notable that the NHS could not provide a Romani speaking interpreter for the participants in case study three.

A significant issue for the NHS is the cultural competence of its staff. We have highlighted throughout this report examples of subtle and not-so-subtle examples of lack of cultural competence (197). By cultural competence, we do not mean learning about other cultures as it is frequently understood, but that practitioners should understand how their own attitudes, assumptions and stereotyping impact on their interpersonal relationships. This encompasses being sensitive to the sources of mistrust, the influence of previous poor experiences and the fear of breaches of confidentiality. This is also an issue for higher education institutions that provide pre-registration and continuing professional development for health professionals, and for the regulatory bodies that set the standards for their education.

Linked to cultural competence is the need for all staff, including first points of contact such as receptionists, to provide respectful care for everyone, regardless of background, and to understand that apparent hostility is often an outward expression of mistrust, fear, stigma and the effect of poor previous experiences. Those who use NHS services are very familiar with and supportive of the ‘zero tolerance’ messages displayed in many premises; this has to be reciprocal and no service-user should ever have to experience lack of respect from NHS staff.

Third sector organisations

As we have demonstrated, TSOs have a significant role to play in working with health services and GRT communities to enhance engagement and trust. Funding is key to this role being realised to its full potential and this is discussed above under sustainability. We argue that to maximise effect, TSOs need to focus on two levels of advocacy; collective and individual. There were examples of both of these in our work, and in relation to health. Individual advocacy, for example, comprised helping GRT people to navigate health services, interpret communications from health services, challenge refusals of GP practices or dental practices to register GRT people, and accompanying individuals to appointments. This is all important work and can have significant impact on the experiences and outcomes of GRT people. At a collective level, there were examples of TSOs working with clinical commissioning groups to advocate for the needs of GRT people in the commissioning process. One way of strengthening this collective action could be for TSOs representing different disadvantaged and marginalised groups to collaborate on the many common issues we have identified. Developing trusting relationships with health providers and commissioners is critical to this, and progressing this collectively will strengthen all the individual relationships that already exist.

In conducting our engagement review (review 1) we found much of the most useful and detailed information came from reports of projects conducted or commissioned by TSOs. This grey literature can often be challenging to locate. Some reports that we found had to be excluded because they did not explicitly describe the methods used to collect the information reported. Therefore TSOs could combine efforts to create a repository of such information to avoid duplication and to ensure that everyone can benefit. We would also suggest there is a role for TSOs and academics to work together to strengthen the methodology used in research, and the reporting of it, to increase confidence in the findings.

Applicability of findings to other socially excluded groups

Throughout this chapter, we have commented on issues that could be applicable to other socially excluded groups, including vulnerable migrants, sex workers and homeless people, as well as GRT people. Trust is an issue that affects everyone using health services.

A common theme throughout our work was that many of our participants, including some GRT participants, suggested that problems faced in accessing healthcare were the same for everybody. While in one sense this is undoubtedly true, for example the challenges of making a GP appointment in some areas, we have argued that the impact of this is likely to affect those who are socially excluded disproportionately. In terms of trust, however, this has to be seen in the context of a history of mistrust between GRT people and authorities.

Aspinall (198) identified a spectrum of vulnerabilities that affect socially excluded groups (with a focus on Gypsies and Travellers, people who are homeless, vulnerable migrants and sex workers) with many similar complex needs. In this sense much of our work on trust and engagement will be applicable to groups that have similarly complex needs, poor health outcomes and are stigmatised. Other similarities may be lack of fixed address and transience. Our work with Roma people will reflect many of the issues faced by vulnerable migrants. There is a similar lack of data on health outcomes, and therefore lack of leverage for accountability, across many disadvantaged and marginalised groups.

It is also the case that there will be examples of potential solutions to the barriers and challenges highlighted in our work, that have been successful with other marginalised groups. An important step will be to bring this work together to inform and intersectional approach. We hope that our work will be used to strengthen evidence-informed intersectional advocacy.

Further research

Our detailed work has revealed a dearth of evidence to inform approaches to engagement that enhance trust between GRT people and mainstream health services. Here we highlight five potential areas for future research:

1. Studies that develop and assess the acceptability and feasibility of promising interventions, such as: more flexible service provision; specialist roles such as health champions; and collaboration between those who have developed trusted relationships with GRT communities. Such studies could also assess the feasibility of conducting rigorous evaluations of such interventions using experimental or other approaches.
2. Studies that explore the concept of cultural competence and what works best to strengthen and support knowledge, attitudes and skills of HCPs to work positively with diversity and difference. This could include investigating the most effective educational approaches as well as examining the impact of organisational context and policy on the implementation of culturally competent care.
3. Similarly detailed work is required with other disadvantaged and marginalised groups to identify the commonalities and differences and the implications of these for policy and practice. This intersectional lens could lead to a more critical and nuanced understanding of cultural context.
4. Innovative approaches to gathering data on the health outcomes of GRT and other marginalised communities to inform policy and hold health services to account for their progress on reducing health inequalities and tacking the social determinants of health.
5. Robust economic evaluations including cost-effectiveness studies to inform health policy and allocation of resources, although development work is needed first.

More broadly there is an urgent need for more work to be conducted with Roma communities from central and Eastern Europe. The impact of Brexit is unknown, but could be significant for the health status and experience of inequalities for these communities. In terms of geography, our studies focussed on England and Scotland, therefore further work could expand to include and compare finding in relation to GRT communities in Wales and Northern Ireland. Future work could broaden the focus in terms of health issues and services, for example mental health and care of older people. Finally the health needs and access to services for men have been neglected in studies and further work is needed.

Dissemination plan

We will disseminate the findings of our work through the following strategies:

- Write accessible summaries of the research to feedback our findings to all of our participants and network of interested stakeholders;
- Hold an event primarily for TSOs and GRT people to learn about the findings of our research – we would aspire to involve artist(s) who can convert our key messages into visual resources that could be used at a wide range of events such as Appleby Fair;
- Write policy briefings for politicians, health service organisations such as NHS Scotland, NHS England, Public Health England, Chief Medical, Nursing and Dental Officers in the four UK countries, and Professional Associations;
- Use social media, including writing blogs and writing for professional and TSO newsletters and publications, for dissemination to a wider audience of TSOs and HCPs;
- Present our findings/run workshops at professional and academic conferences.
- Continue to publish our work in peer-reviewed academic journals – our immediate plans include publishing the trust review, combining the findings of the realist synthesis with our primary data, and an analysis of lessons for cultural competence arising from our work.

Acknowledgements

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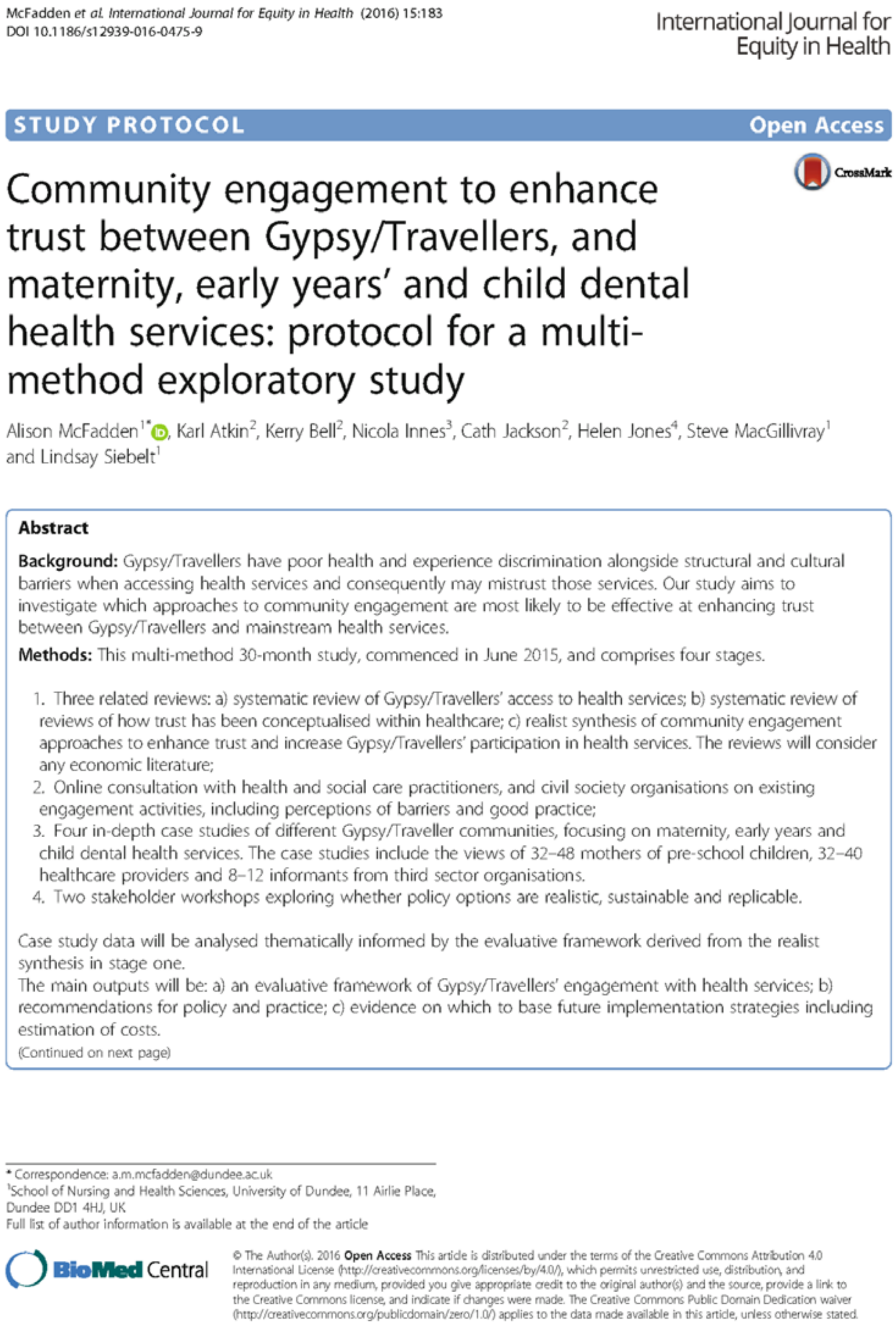
We would also like to thank everyone who disseminated and completed the online consultation; everyone who participated in the case studies, everyone who attended the cross-sectoral workshops or took part in the teleconference, and everyone who attended the PPI events.

Appendix 1: Published protocol



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STUDY PROTOCOL **Open Access**

Community engagement to enhance trust between Gypsy/Travellers, and maternity, early years' and child dental health services: protocol for a multi-method exploratory study

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Abstract

Background: Gypsy/Travellers have poor health and experience discrimination alongside structural and cultural barriers when accessing health services and consequently may mistrust those services. Our study aims to investigate which approaches to community engagement are most likely to be effective at enhancing trust between Gypsy/Travellers and mainstream health services.

Methods: This multi-method 30-month study, commenced in June 2015, and comprises four stages.

1. Three related reviews: a) systematic review of Gypsy/Travellers' access to health services; b) systematic review of reviews of how trust has been conceptualised within healthcare; c) realist synthesis of community engagement approaches to enhance trust and increase Gypsy/Travellers' participation in health services. The reviews will consider any economic literature;
2. Online consultation with health and social care practitioners, and civil society organisations on existing engagement activities, including perceptions of barriers and good practice;
3. Four in-depth case studies of different Gypsy/Traveller communities, focusing on maternity, early years and child dental health services. The case studies include the views of 32–48 mothers of pre-school children, 32–40 healthcare providers and 8–12 informants from third sector organisations.
4. Two stakeholder workshops exploring whether policy options are realistic, sustainable and replicable.

Case study data will be analysed thematically informed by the evaluative framework derived from the realist synthesis in stage one.
The main outputs will be: a) an evaluative framework of Gypsy/Travellers' engagement with health services; b) recommendations for policy and practice; c) evidence on which to base future implementation strategies including estimation of costs.

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Discussion: Our novel multi-method study seeks to provide recommendations for policy and practice that have potential to improve uptake and delivery of health services, and to reduce lifetime health inequalities for Gypsy/Travellers. The findings may have wider resonance for other marginalised populations. Strengths and limitations of the study are discussed.

Trial registration: Prospero registration for literature reviews: CRD42015021955 and CRD42015021950
UKCRN reference: 20036

Keywords: Gypsy/Travellers, Roma, Trust, Community engagement, Maternity services, Early years' services, Child dental health services, Case study, Multi-method research, Socially-excluded populations

Background

In 2008, the World Health Organisation Commission on Social Determinants of Health [1] called for 'closing of the gap' in health inequalities within a generation. Reducing health inequalities has been a priority for successive UK governments [2]. The needs of the most marginalised groups have however, been neglected. Gypsies and Travellers are one socially excluded group where evidence for improving health is weakest [3]. It is estimated that there are 150,000–300,000 Gypsy/Travellers in the UK [4], this however is likely to be an underestimate. Due to widespread stigma and discrimination, many Gypsy/Travellers do not disclose their identity [5]. This paper provides an overview of a multi- component study that aims to strengthen the evidence regarding how to improve uptake and delivery of health services and thereby reduce health inequalities for Gypsy/Travellers.

We use the term 'Gypsy/Travellers' to include all those with a cultural tradition of, and commitment to nomadism, including those who live permanently or temporarily in settled housing. This broad definition includes individuals from different socio-cultural backgrounds including Romany (English) Gypsies, Irish Travellers, Scottish Gypsy/Travellers and Eastern European Roma communities. However, there are contested definitions of Gypsy/Travellers reflecting complex cultural and/or linguistic differences between communities [6]. Therefore there are likely to be different health needs and experiences of health care between and within diverse Gypsy/Traveller communities [7].

Although Gypsy/Traveller communities are diverse, and robust evidence of health needs is lacking due to unknown population size and lack of systematic monitoring [8, 9], there is consensus that Gypsy/Travellers in the UK have poorer health and lower life expectancy than the general population and other disadvantaged groups [7, 8, 10–15]. This includes increased maternal and child mortality [8, 13, 16], and in children, high rates of accidental injury, infections and accident and emergency department attendance [11, 17]. Studies have found low uptake of preventative health services including childhood immunisations [18–21], significantly increasing risk of preventable disease [22, 23]. Gypsy/Travellers have poor dental health with high unmet need for dental care [24, 25].

Some of the reasons why Gypsy/Travellers are vulnerable to poor health outcomes, even when compared to other disadvantaged groups include poor living conditions, high rates of homelessness, low educational achievement, social exclusion and widespread prejudice and discrimination [26]. Gypsy/Travellers also face many barriers to accessing healthcare. For some, a mobile lifestyle is key [16], however, poor access is also experienced by settled Gypsy/Travellers. This is underpinned by complex factors including stigmatisation and lack of understanding by healthcare staff [10, 12, 27]. Reported cultural barriers include normalisation of ill-health and pride in self-reliance [28]. However, it is unclear how these interact with social exclusion and poverty [29].

These multiple factors alongside poor quality care that does not meet healthcare needs may lead to low expectations and mistrust of health services and healthcare personnel [27, 30]. Trust in services and personnel is associated with increased utilisation of healthcare, and improved health behaviours and quality of care [31–33]. Community engagement strategies have the potential to enhance trust and ensure services are tailored to the needs of specific populations [34–36]. "Community engagement" is one of several overlapping terms (others include "community involvement", "community participation", and "community development") used to describe activities that are aimed at enabling communities to participate in decisions that affect their lives and improve their health and wellbeing, including planning, design, delivery and evaluation of health services [34–36].

Aims and objectives

Our research investigates which approaches to community engagement are likely to enhance trust between Gypsy/Travellers and mainstream health services. The focus is maternity services, early years' health services and child dental health services. The objectives are to:

1. describe activities and methods used to engage Gypsy/Travellers in health services and to assess the extent to which they focus on developing trust;
2. investigate the extent to which different engagement activities used by health services enhance trust and increase uptake of maternity services, early years' services and child dental health services by Gypsy/Travellers;
3. examine the knowledge, attitudes/beliefs and experiences of Gypsy/Travellers of maternity services, early years' services and child dental health services;
4. identify different approaches to enhancing Gypsy/Travellers' trust in maternity services, early years' services and child dental health services and explore the implications for policy and practice;
5. estimate the potential implementation costs of different approaches to enhancing Gypsy/Travellers' trust in maternity services, early years' services and child dental health services; and
6. explore whether community engagement approaches that work to enhance Gypsy/Travellers' trust in maternity services, early years' services and child dental health services are potentially applicable to other health services/vulnerable communities.

Methods

Study design and overview

This multi-method 30-month study (June 2015 to November 2017) comprises four interlinked stages. See Fig. 1 for an overview.

The study team are being advised by two advisory groups; a Stakeholder Advisory Group comprising health professionals, policy advisors and academics, and a User Advisory Group, hosted by Leeds Gypsy and Traveller Exchange (Leeds GATE), comprising women representing Romany Gypsy, Irish Traveller and Eastern European Roma communities.

Stage one: literature reviews

Review one is a systematic review of all available primary empirical literature on how, why and where Gypsy/Travellers seek help from and engage with healthcare services.

Search

In May 2015, we searched 21 online databases: MEDLINE (via OVID), Embase (via OVID), CINAHL (via EBSCO), Cochrane Database of Systematic Review, Database of Abstracts of Reviews of Effects, Health Technology Assessment 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

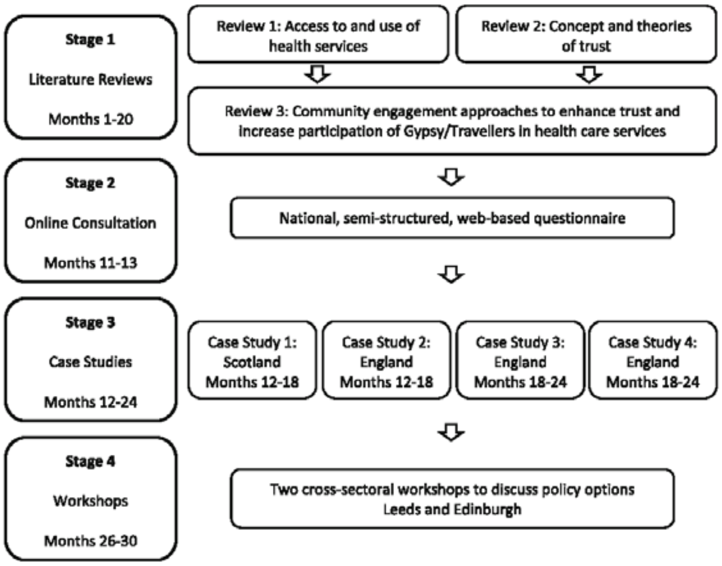

Fig. 1 Study flow chart

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, to identify work-in-progress and unpublished studies, a focused Google search was conducted. Reference lists of relevant literature reviews were examined to locate further studies. Search terms, developed with an Information Specialist, combined thesaurus and free-text terms. The search structure was (Gypsy/Traveller communities) AND (general healthcare services OR maternal and child healthcare services OR child dental health care services OR community engagement interventions).

Eligibility criteria

Publications were included if they reported methods and findings of a primary study, focused on Gypsy/Travellers, included data that illuminated how, why and where Gypsy/Travellers engage with health care services and were published in English after the year 2000. All study designs were included.

Selection of studies

Title and abstracts were screened independently by two reviewers and discrepancies discussed with a third reviewer. Full texts of publications appearing to meet the inclusion criteria were assessed independently by two reviewers and discrepancies discussed with a third reviewer.

Data extraction and synthesis

For each study meeting the eligibility criteria, data were extracted by one reviewer and checked by a second reviewer regarding methods, aims and specific findings related to the review question. A detailed narrative of the findings will be reported.

Output

An evidence matrix indicating key findings and the robustness of methodology, accompanied by a narrative synthesis is the key output of this review. Review one also provides a sampling frame to feed relevant studies into the realist synthesis of community engagement approaches [37]. Finally, we also conducted an appraisal of the economics literature applying focus to any economic evaluations or discussions of cost associated with engagement programmes. Economics literature was primarily identified via the first search though an additional search was also undertaken using NHS EED, the only remaining database for economic evaluations (published until 2014). Review one is in the write-up phase.

Review two is a systematic review of secondary (review) literature to examine how 'trust' has been conceptualised and theorised in any healthcare setting. Trust is a complex term, frequently used but rarely defined. We are particularly interested in describing frameworks/models that may be relevant in explaining the relationship between vulnerable communities and mainstream health and social care services. Trust is however, a challenging term to search for (a recently updated Cochrane review on interventions to enhance trust retrieved 14057 records for initial screening [38]). Since we were interested in understanding and describing the concept of trust within a health care context generally, we focused on secondary literature.

Search

We searched 15 online databases in May 2015: MEDLINE (via OVID), Embase (via OVID), CINAHL (via EBSCO), Cochrane Database of Systematic Review, Database of Abstracts of Reviews of Effects, Health Technology Assessment database, 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. The search structure was: "trust" synonyms AND "systematic review" synonyms.

Eligibility criteria

Systematic and non-systematic reviews were included if their primary focus was describing or exploring the concept of trust within a health care context, and were published in English after the year 2000

Study selection

Title and abstracts were screened independently by two reviewers and discrepancies discussed with a third reviewer. Full texts of publications appearing to meet the inclusion criteria were assessed independently by two reviewers and discrepancies discussed with a third reviewer.

Data extraction and synthesis

Data were extracted for each eligible study by one reviewer and checked by a second reviewer regarding: methods; review aims; and key findings specifically related to understanding, describing or exploring trust. A detailed narrative synthesis of the findings is currently under construction.

Review three is a realist synthesis of community engagement approaches to enhance trust and increase Gypsy/Travellers' participation in health services. Four hypotheses, derived from published literature, were developed to provide initial direction for the review:

1) Community engagement is an effective and cost-effective strategy for enhancing the confidence and trust of Gypsy/Travellers in mainstream services [34];
2) Approaches to community engagement that work to enhance trust and increase uptake of services with some participants may not work with Gypsy/Travellers because of the longstanding experience of social exclusion and discrimination, low education and literacy levels and mistrust of authority [39];
3) Successful community engagement will be underpinned by genuine involvement of community members (i.e. not tokenistic), honest appraisal of what can be achieved (not raising expectations that cannot be met) and continuity of trusted personnel [40].
4) Community engagement between Gypsy/Travellers and mainstream health services can be facilitated effectively by civil society Gypsy/Traveller organisations [8, 39].

Realist synthesis is appropriate for understanding complex interventions, in this case the interaction between trust and community engagement. Realist reviews focus on developing theories of what works for whom and in what circumstances thereby accounting for context, mechanisms and outcomes in the process of systematically synthesising relevant literature [41]. Our realist synthesis will draw on data derived from reviews one and two, but will also include purposive additional searching [37] for literature that focuses on engagement approaches with Gypsies, Travellers and Roma. The output of the realist synthesis will be an evaluative framework for explaining and understanding the complex and multi-faceted nature of engagement with health services. We plan to involve the study Stakeholder Advisory group in further stages of the review process. Review three is underway.

Stage two: online consultation

A semi-structured, web-based questionnaire will be purpose designed to elicit views on how to enhance trust in mainstream services; the range of activities/methods used by maternity, early years' and child dental health services to engage Gypsy/Travellers and any associated costs; perceptions of the success of different approaches to developing trust; and barriers to, and suggested strategies for, enhancing trust, including examples of good practice. The questions will be based on the aims of the study, findings of the literature reviews, and the views of the Stakeholder Advisory Group. The consultation will be delivered using the Bristol Online Survey tool [42], and will be disseminated by e-mail. We aim to include the views of three main groups, from across the UK, through purposive sampling:

1. Individuals working in civil society organisations who represent or advocate for Gypsy/Traveller communities. These include UK-wide organisations such as Friends, Family and Travellers; National Federation of Gypsy Liaison Groups; and local/regional groups such as Traveller Movement (London); Derbyshire Gypsy Liaison Groups; One voice for Travellers (Cambridgeshire); Roma Support Group (London); Romani Arts Company (Wales) An munia Tober (Northern Ireland) and Article 12 Young Gypsy Lives (Scotland). We will also include organisations who represent/advocate for users of maternity users (nct – formerly known as the National Childbirth Trust), and children (Save the Children UK; Children's Society). We were unable to identify any civil society organisations focusing on child dental health.
2. Health and social care practitioners delivering maternity, early years' and child dental health services (e.g. midwives, health visitors, general practitioners, and community dentists, who work with Gypsy/Travellers communities). We aim to include healthcare practitioners who have a specialist role regarding service provision for Gypsy/Travellers, and those who provide care for Gypsy/Travellers as part of mainstream services. We will reach these practitioners through professional organisations and networks such as Midwifery Supervisors network; Infant Feeding Leads network; Health Visitors Institute; Royal College of General Practitioners; Royal College of Paediatrics and Child Health; Faculty of Public Health; British Dental Association and British Society of Paediatric Dentistry.
3. Local policymakers and health and social care service commissioners (e.g. Directors of Public Health and Dental Public Health, health improvement specialists, health inequality teams, clinical commissioning groups and Local Authorities).

Analysis of the online consultation will include: proportions of respondents who agree/disagree with evidence–derived statements; and thematic analysis of free text questions including exploration of similarities and differences between different stakeholders.

The online consultation findings will: a) inform the selection of case studies, i.e. if a successful approach to community engagement with Gypsy/Travellers is identified, we may select the location as a case study site; b) provide a national context to locate the findings of the case studies; and c) provide a community of interest for dissemination of the study findings.

Stage three: case studies

Settings and participants

This stage comprises multiple case study design to explore in-depth community engagement and trust in healthcare for Gypsy/Travellers [43]. The unit of analysis is the approach to engagement between health services and Gypsy/Traveller communities within a locality. Each case study involves interviews, focus group discussions and documentary analysis. Four case studies will be selected purposively to reflect the diversity of Gypsy/Travellers communities, different approaches to community engagement, and examples of good practice regarding maternity, early years' or child dental health services (identified through the realist synthesis and online consultation). Three case studies will be in England and one in Scotland to reflect the larger population of Gypsy/Travellers in England and to meet the funders' remit of advising policymakers in England. The selection of a case study in Scotland strengthens the methodology because there are differences between healthcare structures and remuneration in England and Scotland that could be significant.

Overall, the case studies will include English/Romany Gypsies, Irish Travellers, Scottish Gypsy/Travellers and Eastern European Roma migrants. They will be conducted in two phases of six months. Lessons learned from the first two case studies, for example approaches to recruitment or revisions to interview topic guides, will inform the conduct of the second two case studies.

Our purposive sample strategy is designed to reflect the diversity of Gypsy/Traveller populations living in the UK. We aim to recruit mothers who live in permanent housing, and in authorised and unauthorised sites, and those following a nomadic lifestyle. Where the mother wishes, we will include other family members in interviews Health practitioners will be recruited purposively to include those working in maternity, early years' and child dental health services. Finally we will include key informants from civil society organisations that are involved in community engagement activities with Gypsy/Travellers. See Table 1 for an overview of the proposed numbers of participants and data generation methods.

The case studies will include analysis of documents, sourced through NHS and civil society organisations, websites, social media and from the research participants, related to methods and activities used by health services and civil society organisations to engage Gypsy/Travellers.

Access and recruitment

There are challenges in recruiting participants from marginalised communities. In each case study we will identify relevant civil society organisations, community workers, local authority or NHS frontline health and social care workers as gatekeepers who can identify potential participants. Leeds GATE will facilitate recruitment through their networks. We are developing relationships both for circulating the online consultation (stage two) and facilitating recruitment to case studies. We will liaise with individuals and organisations working with Gypsy/Travellers with whom we have established links and who are familiar with research process through a previous study [44]. The Stakeholder Advisory Group will identify additional organisations and specialist services to enahnce recruitment. The gatekeepers will facilitate recruitment of health and social care practitioners and key informants from civil society organisations.

Generating research material

Mothers of pre-school children We will conduct semi-structured, face-to-face interviews. The interview topic-guide will focus on perceptions of trust, views, experiences and awareness of maternity, early years' and child dental health services including barriers to service use, experiences of community engagement activities, and suggestions for ways of improving services.

Health and social care practitioners We will conduct focus group discussions with telephone interviews as a contingency for those unable to attend a focus group [45]. The topic guide will include participants' experiences of service provision for Gypsy/Traveller communities, barriers to providing quality services, organisational context, examples of good practice in terms of engagement and developing trust with Gypsy/Traveller communities and cost implications.

Key informants from civil society organisations We will conduct telephone interviews, focusing on views and experiences of different approaches to community engagement, barriers and suggested strategies for increasing trust between Gypsy/Travelers and mainstream health services.

Table 1 Target numbers of participants in case studies

Participants	Data generation method	Each case study	Total across four case studies
Mothers of pre-school children	Face-to face interviews	8–12	32–48
Health and social care practitioners	Focus group discussion	6–8	24–32
	Telephone interviews	2–4	8–16
Key informants from civil society organisations	Telephone interviews	2–4	8–16

The locations of interviews and focus group discussions will be negotiated with participants. All interviews and focus groups will be audio-recorded with the participants' written consent and transcribed for analysis. Where necessary, interviews with participants from Eastern European Roma backgrounds will be undertaken by a bilingual researcher who will transcribe and translate the audio-recording.

Analysis of research material

We will analyse data thematically, informed by the evaluative framework derived from the realist synthesis in stage one. The research material from each case study will be analysed and reported independently before comparing similarities and differences across case studies [46]. We will analyse diverse participant experience to avoid essentialist interpretations based on particular cultural groups [47]. NVivo 10 Software [46] will be used to manage the data.

Costs incurred by health and social care services will be estimated for each approach identified and represented as per family/per individual depending on the nature of the cost. All potential sources of costs will be identified, for instance cost of a visit from an appropriately trained practitioner. Cost data will be drawn from systematic review evidence and standard costing sources [47]. Although the results will only provide a conservative estimate of the costs associated with each approach, such knowledge is important to guide decision-making and future trials. If data is sufficiently rich, a theoretical cost-benefit analysis could be included using real life experiences of Gypsy/Travellers to estimate the potential benefits through cost savings.

The findings of the three completed stages of the research (reviews, online consultation and case studies) will be synthesised, using a triangulation protocol [48], to draw up a list of approaches to community engagement for enhancing Gypsy/Travellers' trust in mainstream services. This will be done at the data interpretation phase [49]. A 'convergence coding matrix' will be created to display the different sets of findings informed by the evaluative framework developed from the realist synthesis.

Stage four cross-sectoral workshops

Two cross-sectoral workshops will present the draft policy options/recommendations to diverse stakeholders. This approach ensures that options/recommendations culminating from research reflect the realities and constraints of policy and practice [50]. Furthermore, the workshops will create a community of interest for dissemination. Up to 40 stakeholders will be invited to attend (or nominate a deputy) including: representatives from civil society organisations; frontline maternity and early years' health services and children's dental health services staff, service managers and commissioners, national and local policymakers, representatives from Local Authorities, and members of the User and Stakeholder Advisory Groups. Detailed field notes along with materials from the groupwork and plenary sessions, will be synthesised and included in the final report.

Workshop participants will consider:

- the importance, acceptability, feasibility, replicability and sustainability of recommendations;
- barriers to and positive strategies for implementation of recommendations;
- possible consequences and costs of different policy options;
- how policy and practice options might work in different healthcare settings (e.g. mental health, adult dental services) and for other vulnerable populations (e.g. vulnerable migrants, homeless).

Public and patient involvement

It would not be possible to undertake this study without the involvement of Gypsy/Travellers. The study team includes the Chief Executive Officer of Leeds GATE, who is hosting the User Advisory Group whose involvement will include: input to the evaluative framework derived from the realist synthesis; development of participant information sheets and consent forms; advice on recruitment, topic guides for interviews and focus group discussions; interpretation of findings, and dissemination activities. In each case study location, we will identify two members of the local Gypsy/Traveller community to advise on the conduct of the research and any local issues of relevance, for example access, recruitment, and locally-tailored participant information sheets. We will support members of the User Advisory Group and local case study community members through two advocacy-training events in the first and second years of the project. The participatory events will bring together community members, researchers and members of civil society organisations.

Dissemination

The main output will be a report detailing: a) an evaluative framework of Gypsy/Travellers' engagement with health services; b) recommendations for policy and practice on how to enhance trust and improve the acceptability of health services to Gypsy/Travellers; and c) evidence on which to base future implementation strategies including estimation of costs of policy options. To increase impact, we will disseminate widely through written summaries, social media, and academic and professional conferences and publications. This will include: to Gypsy/Travellers communities led by the User Advisory Group; to research participants, and more widely through the network of civil society organisations developed from the online consultation and stakeholder workshops. Short articles will be written for magazines/newsletters. More detailed summaries will be prepared for health and social care organisations and disseminated to relevant professional organisations.

Discussion

This multi-component study seeks to explore ways of improving the uptake and delivery of health services and thereby reducing health inequalities for Gypsy/Travellers who are marginalised in the UK and across Europe [51]. The multi-method approach will combine data from a variety of perspectives including Gypsy/Travellers, health professionals and civil society organisations to provide policy recommendations to enhance trust and improve the acceptability of health services to Gypsy/Travellers

Although we have chosen to focus on maternity, early years' and child dental health services as exemplars of mainstream health services, the findings may have resonance for other health services. Issues of trust and engagement are likely to be determinants of differential uptake of health services for other marginalised populations such as homeless people and refugees/asylum seekers. Thus, our findings may have broader application. The robust methods of public and patient involvement will help to ensure that the research is conducted ethically. The involvement of stakeholders, particularly through the workshops will increase the likelihood that final recommendations reflect the realities and constraints of policy and practice. Through the online consultation and our approach to selecting the case studies we aim to provide best practice guidance.

Our study has several challenges and limitations. Trust and engagement are terms with multiple meanings. We planned the detailed literature reviews to develop theoretical understanding of these concepts which can then be explored in case studies and workshops. We anticipate that the explanatory framework will address different meanings of trust and engagement especially when these might differ between Gypsy/Traveller populations and health services. Within the constraints of the time and funding we are limited to four case studies which will be selected on the basis of good practice. This may reduce our ability to reflect on lessons-learned from approaches that have not worked. By the very nature of the marginalisation and discrimination experienced by Gypsy/Travellers in UK society, it is likely that recruitment to our study will be challenging and require multiple approaches. The ability of the researchers to develop trusting relationships first with gatekeepers and then with participants will be critical to the quality of the findings. We may not be able to recruit those who are most vulnerable e.g. those who do not engage with civil society organisations and/or those living in unauthorised encampments. Health professionals who participate are likely to be those who have an interest in this population group and therefore may not represent all mainstream practitioners. Despite these caveats, our study will add to the evidence-base of what works to increase trust and engagement between marginalised populations and mainstream health services.

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Availability of data and materials
Not applicable.

Authors' contributions
All authors contributed to the design and refinement of the protocol. AM drafted the manuscript. All authors contributed to revisions and approved the final version of the manuscript. Roles in the research: AM (PI) and LS will contribute to all stages of the study; KA and CJ will contribute to selection of case study sites, and analysis and interpretation of the data; SM will lead the literature reviews; NI will contribute to all stages of the study providing advice relating to dentistry; HJ will be responsible for PPI and facilitation of relationships with case study sites; KB will conduct the economic evaluation.

Competing interests
The authors declare that they have no competing interests.

Consent for publication
Not applicable.

Ethics approval and consent to participate
The study has been approved by the NHS Health Research Authority East Midlands - Leicester Central Research Ethics Committee (Ref: 16/EM/0028)

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Appendix 2: Stakeholder Advisory Group

Gail Findlay	Director of Health Improvement, Institute for Health and Human Development, University of East London
Sarah Bennett	Specialist Midwife, Leeds Acute Teaching Hospitals NHS Trust
Patrice van Cleemput	Honorary Research Fellow ScHARR University of Sheffield
Ruth Beattie	NHS England
Helen McAuslane	Public Health Specialty Registrar Consultant for Disease Control Kirklees local authority area
Jenny Harris	Consultant in Community Paediatric Dentistry Sheffield Salaried Primary Dental Care Service and Charles Clifford Dental Hospital Sheffield Teaching Hospitals NHS Foundation Trust
Rachel Humphris	DPhil (PhD) student, Institute of Social and Cultural Anthropology Research assistant, Centre On Migration Policy And Society (COMPAS) University of Oxford
Colin Clark	Professor of Sociology & Social Policy The University of the West of Scotland
Vijay Kumar	Chair Yorkshire and Humber RCGP

Appendix 3: 4Rs Report

Research
Respect
Rights
Results

LEEDS GATE
Gypsy and Traveller Exchange

In October 2015, Leeds Gypsy and Traveller Exchange in partnership with University of Dundee held an event to explore what RESPECT, RIGHTS and RESULTS mean in the context of RESEARCH into Gypsy and Traveller Communities.

A group of Gypsy and Traveller people, academic researchers and staff from civil society organisations from across the UK came together to try and answer the following questions:

- What is research and what can it be used for?
- Is there enough research about Gypsy, Traveller and Roma people or is there too much?
- How can we make sure that community members themselves can benefit from participating in research?
- What skills and assets can we bring to research we join in with?
- What makes good research and what is not so good?

Research
Respect
Rights
Results

The event was hosted by Leeds Gypsy and Traveller Exchange as part of our collaboration with Dundee and York Universities on a three year project to evaluate, and make recommendations concerning, the role of trust in patient/healthcare worker relationships involving Gypsy and Traveller people as patients. For Leeds GATE the event also contributed to our Lankelly Chase Funded project, exploring concepts of Asset Based Community Development and co-production in seeking to address severe and multiple disadvantage.

The purpose of the event was to explore Gypsy and Traveller people's participation in research and reflect on the experiences of all stakeholders in research—academics, communities, civils society, funders. The event sought to explore themes around equality in the transactions between researched and researchers, address issues of informed consent and fairness, communication barriers and managing expectations.

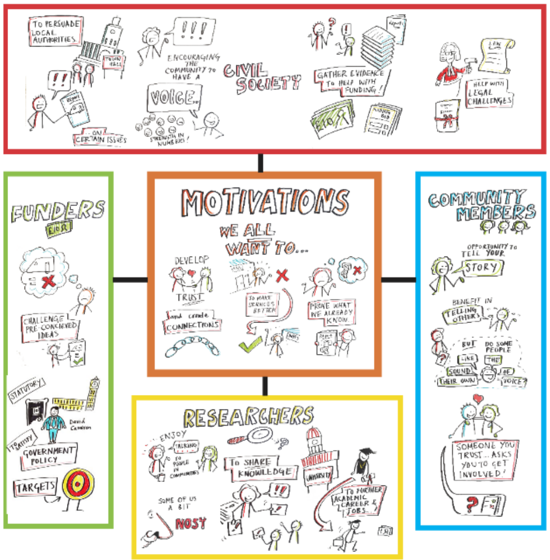
An agenda was loosely planned with the aim that sessions would be co-produced between all the candidates present. A photo voice activity was used as an opening session and from this we gathered research questions we aimed to address around our four key areas for exploration, Research, Rights, Respect and Results.

We were assisted in recording our findings by a Graphic Facilitator. This report consists of the graphics produced throughout our four sessions and aims to convey (in an easy read format) the key themes drawn out from our discussions. Initially we explored what had motivated us to put on the event, what we thought research was and our experiences of research.

We learnt about the research project at University of Dundee which had led to us exploring ideas around how people participate in research and this event. The project at Dundee is exploring the role of trust in health care delivery, with a particular focus on maternity, child health and child dental services.

We talked about our different experiences of research—what had been good and bad and what had made change happen...

We talked about different people's motivations for being involved in research and we made a map of these motivations...



Funders—want to challenge ideas, advise the government, make policy, help the government meet its targets

Civil Society—to influence local authorities, gather evidence for funding bids, help make legal challenges, encourage the community to have a voice

Researchers—enjoy talking to people, some of us are a bit nosy, we want to share knowledge and work on interesting projects in our careers

Communities—an opportunity to tell your story, someone you trust might ask you to get involved, it's good to tell your story but do some people like the sound of their own voice?

We all want to...develop trust and create connections, to make services better, to prove what we already know from our experiences.

We came up with Do's for Researchers—things for them to consider when working with Gypsies and Travellers...

And we came up with Don'ts for researchers. Things for researchers to avoid doing...

We talked about our rights in a research situation—what is respectful:

We all agreed people involved in research had a right to know what happened as a result of the research and too often this didn't happen.

We talked about how research should be shared and what it might be used for...

"If you end your research without telling people what happened , it's like ending a conversation without saying bye"

Appendix 4: Engagement review

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

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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 analyzed thematically and a narrative synthesis reported. **Results:** Ninety-nine studies from 32 countries were included, covering a range of health services. Nearly one-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.

Introduction

The Gypsy, Roma and Traveller population are the largest and most disadvantaged minority ethnic group 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 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,[3,4] while some Romany Gypsies in the 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 article, we use terminology acceptable to most groups in the UK (i.e. Gypsy, Roma and Traveller[6]), although the articles 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 and 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 with 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 with 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.[21] Regarding outreach interventions, Carr et al.[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 focussing on enhancing trust between Gypsy, Roma and Traveller people and mainstream health services,[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.[22]

Search strategy

In May 2015, searches were conducted of the following databases: MEDLINE (via OVID), Embase (via OVID), Cumulative Index to Nursing and Allied Health Literature (via EBSCO), Cochrane Database of Systematic Review, Database of Abstracts of Reviews of Effects, Health Technology Assessment database, CENTRAL, Social Science Citation Index (via Web of Knowledge), PsycINFO (via OVID), Health Management Information Consortium (via OVID), Applied Social Sciences Index and Abstracts (via Proquest), Social Policy and Practice (via OVID), Bibliomap (via the Evidence for Policy and Practice Information (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 National Health Service 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 and (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 articles 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 analyzed 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[23] and Consolidated Criteria for Reporting Qualitative Research[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.[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 articles. 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 articles were assessed for eligibility and 121 articles 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 articles 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.

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 one-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

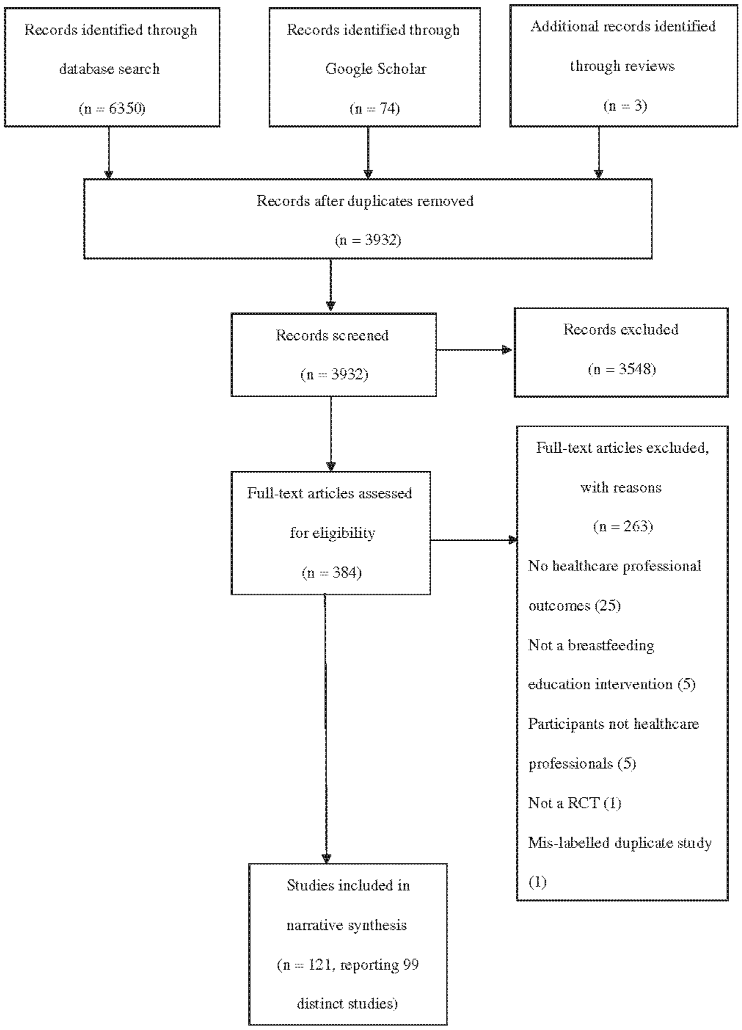

Figure 1 Preferred reporting items for systematic reviews and meta-analyses (PRISMA) flow chart

studies included health workers as well as Gypsy, Roma or Traveller participants; and seven studies involved only health workers or other professional participants.

As anticipated, there was inconsistency in how the included studies used terms such as Gypsy, Roma or Traveller with many articles not describing how or by whom the labels were ascribed. National variations occurred alongside variations in individual articles, 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 analyzed secondary data, two were retrospective cohort studies, two were before and after studies and one was a consultation. Seventeen studies compared

Figure 2 Locations included in the 99 studies

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.

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.[26] 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. Although we have presented the barriers/potential barriers in distinct categories, there is overlap and barriers in one theme compounded those in another.

Table 1 Number of studies for each type of health service

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

Table 2 Number of studies that include findings related to barriers

Category of barrier	Number of studies Total ($n = 99$)
Health service issues	62
Discrimination and attitudes of health service personnel	50
Cultural and language barriers	53
Health literacy	53
Service-user attributes	48
Economic barriers	18

Individual studies reporting barriers or potential barriers are shown in Supplementary table S3.

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 earlier 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 articles 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[9,18,27,28] 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[19]: 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[33] 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,[34] reflecting a strong concern with the 'other' in which cultural or ethnic difference are problematised 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, e.g. 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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Authorship

A.M., L.S., A.G., K.B. and S.M. contributed to conception and design, acquisition, analysis and interpretation of data and drafted the final article; N.I. contributed to conception and design, acquisition, analysis and interpretation of data; K.A., H.J. and C.J. contributed to conception and design and interpretation of data; H.H. contributed to acquisition, analysis and interpretation of data and all authors revised the article critically for important intellectual content, approved the final version and agree to be accountable for all aspects of the work.

Supplementary data

Supplementary data are available at *EURPUB* online.

Conflicts of interest: None declared.

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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Appendix 5: Engagement review list of databases and search strategy

Table A.2 Databases and information resources searched

Database / information source	**Interface / URL**
MEDLINE and MEDLINE In Process	OvidSP
Embase	OvidSP
CINAHL Plus	EBSCOHOST
Cochrane Database of Systematic Reviews (CDSR)	Cochrane Library / Wiley Interscience
Database of Abstracts of Reviews of Effects (DARE)	Cochrane Library / Wiley Interscience
Health Technology Assessment Database (HTA)	Cochrane Library / Wiley Interscience
Cochrane Central Register of Controlled Trials (CENTRAL)	Cochrane Library / Wiley Interscience
Social Sciences Citation Index	Web of Science
PsycINFO	OvidSP
HMIC Health Management Information Consortium	OvidSP
Applied Social Sciences Index and Abstracts (ASSIA)	Proquest
Social Policy and Practice	OvidSP
Bibliomap	http://eppi.ioe.ac.uk/webdatabases/intro.aspx?ID=7
Database of Promoting Health Effectiveness Reviews (DoPHER)	http://eppi.ioe.ac.uk/webdatabases4/SearchIntro.aspx
Trials Register of Promoting Health Interventions (TRoPHI)	http://eppi.ioe.ac.uk/webdatabases4/Intro.aspx?ID=12
The Campbell Library	http://www.campbellcollaboration.org/lib/
Social Care Online	http://www.scie-socialcareonline.org.uk/
British Nursing Index (BNI)	Proquest
Research Councils UK – Gateway to research	http://gtr.rcuk.ac.uk/
OAIster	https://oaister.worldcat.org/account/?page=searchItems
OpenGrey	http://www.opengrey.eu/
Google	https://www.google.co.uk/

A literature search was developed to identify studies on models of community engagement for enhancing the trust of gypsy / traveller communities in mainstream healthcare services. As requested, there was an emphasis on the specific services of maternal and child healthcare and child dental healthcare.

The strategy was developed in MEDLINE (Ovid interface). The strategy was devised using a combination of subject indexing terms and free text search terms in the title, abstract and keyword heading word fields. The search terms were identified through discussion within the research team, scanning background literature, browsing database thesauri and use of the PubMed PubReminer tool (http://hgserver2.amc.nl/cgi-bin/miner/miner2.cgi). The final MEDLINE strategy used is shown in **Error! Reference source not found.** below.

The revised strategy comprised five search concepts:

- Gypsy / traveller communities. Search lines 1 - 22;
- General healthcare services. Search lines 23 - 41;
- Child dental health care services. Search lines 42 – 57;
- Maternal and child healthcare services. Search lines 58 – 74;
- Community engagement interventions. Search lines 75 – 129.

The search was structured as follows:
(gypsy / traveller communities) AND (general healthcare services OR maternal and child healthcare services OR child dental health care services OR community engagement interventions).
The strategy also included 4 highly focused stand-alone search lines (search lines 132 – 135). These were included as an additional approach to identify relevant studies which might be missed by the combined five concept approach.
The search was limited to studies published in English language from 2000 to date. The strategy excluded records which were indexed as the following publication types: editorials, letters, comments and news items. The strategy also excluded animal studies using a standard algorithm.

Search strategy for Ovid MEDLINE(R) In-Process & Other Non-Indexed Citations and Ovid MEDLINE(R) 1946 to Present

1 Gypsies/ (643)
2 ((gypsy$1 or gypsies or gipsy$1 or gipsies) not (moth or moths or gypsyty3 or gypsy ty3 or ty3gypsy or ty3 gypsy)).ti,ab,kf. (1218)
3 (roma or romas or romany$1 or romani or romanis or romanies).ti,ab,kf. (896)
4 (arli or arlis or ashkali or ashkalis or aurari or auraris or balkan egyptian or balkan egyptians or bashalde or bashaldes or boyash$1 or churari or churaris or cigano or ciganos or erlide or erlides or gitano or gitanos or gitans or horahane or horahanes or kalderash$1 or lalleri or lalleris or lingurari or linguraris or lovari or lovaris or ludar or ludars or ludari or ludaris or luri or luris or machvaya or machvayas or manouche or manouches or manush or manushs or manushes or modgar or modgars or modyar or modyars or romanichal or romanichals or romanichel or romanichels or romanis?l or romanis?ls or romungro or romungros or rudari or rudaris or tsigane or tsiganes or ungaritza or ungaritzas or ursari or ursaris or yerlii or yerliis or zl?tari or zl?taris).ti,ab,kf. (45)
5 (sinti or sinta or sinte or sintis or sintas or sintes).ti,ab,kf. (15)

6 ceardannan$1.ti,ab,kf. (0)
7 (yenish$1 or yeniche$1 or jenische$1).ti,ab,kf. (0)
8 (quinqui$1 or mercheros$1).ti,ab,kf. (1)
9 kale.ti,ab,kf. not (exp Brassica/ or brassica$.ti,ab,kf.) (154)
10 (fairground$1 or fair-ground$1 or funfair$1 or fun-fair$1 or showmen$1 or show-men$1 or showwomen$1 or show-women$1 or showperson$1 or show-person$1 or showpeople$1 or show-people$1 or show communit$ or show travel?er$1 or forains industriel).ti,ab,kf. (84)
11 (circuses or circus men$1 or circus women$1 or circus person$1 or circus people$1 or circus communit$ or circus travel?er$1).ti,ab,kf. (37)
12 (bargee$1 or canal boat$1 or barge$1 or boat-dwell$).ti,ab,kf. (134)
13 (pavee$1 or minceir$ or lucht$1 or luchd$1 or itinerants).ti,ab,kf. (9)
14 (travel?er$1 and (communit$ or family or families or irish or ireland$ or eire or wales or welsh or scottish or scotland$1 or highland$1 or norwegian$1 or norway$1 or newage or new-age or itinerant$1 or minorit$ or ethnic$ or halting site$1 or caravan$1)).ti,ab,kf. (790)
15 (travel?er$1 adj1 (people$ or person or persons or children$1 or child$1 or men or mens or male$1 or women$1 or female$1 or population$1 or group$1 or site or sites)).ti,ab,kf. (176)
16 occupational travel?er$1.ti,ab,kf. (3)
17 (travel?ing adj5 (communit$ or family or families or irish or ireland$ or eire or wales or welsh or scottish or scotland$1 or highland$1 or norwegian$1 or norway$1 or newage or new-age or itinerant$1 or minorit$ or ethnic$ or site$1 or caravan$1)).ti,ab,kf. (213)
18 (travel?er$1 or travel?ing).ti,ab,kf. and ("Transients and Migrants"/ or "Emigrants and Immigrants"/ or Vulnerable Populations/ or Minority Groups/ or Ethnic Groups/ or Cultural Characteristics/) (283)
19 travel?er$1.ti. or travel?er$1.ab. /freq=2 (5463)
20 exp Travel/ or Travel Medicine/ or "travel medicine & infectious disease".jn. or (travel or (travel$ adj3 (oversea$ or abroad$ or international$ or vacation$ or holiday$)) or (return$ adj1 travel?er$)).ti,ab,kf. (37994)
21 19 not 20 (605)
22 or/1-18,21 (4285)
23 exp Health Services Accessibility/ (86801)
24 Health Services/ (19356)
25 Community Health Services/ (27370)
26 Community Health Nursing/ (18569)
27 Community Health Planning/ (4523)
28 Community Health Workers/ (3432)
29 Community Mental Health Services/ (16839)
30 Community Health Centers/ (6075)
31 Nurses, Community Health/ (137)
32 Community Medicine/ (1904)
33 Community Pharmacy Services/ (3025)
34 Health Promotion/ (55721)

35 Communication/ (64668)

36 education/ (18651)

37 exp health education/ (139003)

38 (community adj (health$ or mental or medicine$ or pharmac$ or service$)).ti,ab,kf. (28670)

39 healthcare.ti,ab,kf. (108744)

40 (health$ adj5 (care or service$ or promotion$1 or educat$)).ti,ab,kf. (419902)

41 or/23-40 (818325)

42 Dental Care for Children/ (3076)

43 exp Dental Health Services/ (30519)

44 exp Dentistry/ or exp Dentists/ or exp Dental Staff/ (351263)

45 Dentist-Patient Relations/ (7641)

46 Oral Health/ (10842)

47 exp Periodontal Diseases/ or exp tooth diseases/ (194579)

48 (dental$ or dentist$).ti,ab,kf. (210600)

49 (oral adj2 (health$ or care or hygiene or disease$1 or service$1)).ti,ab,kf. (29600)

50 ((teeth or tooth) adj3 decay$).ti,ab,kf. (2058)

51 (plaque$1 or caries).ti,ab,kf. (126753)

52 or/43-51 (595155)

53 exp Child/ or exp Infant/ or Adolescent/ (2938877)

54 (child$ or infant$ or newborn$ or new-born$ or neonat$ or neo-nat$ or baby$ or babies or pediat$ or paediat$ or schoolchild$ or preschool$ or adolescen$ or juvenile$ or youth$ or teenage$ or youngster$ or young people$ or young person$ or school$1 or kindergarten$1 or nursery or nurseries or early year$1).ti,ab,kf. (1905244)

55 52 and (53 or 54) (118959)

56 (brushathon or smile month or smile4life or smile 4 life or smile for life or brushing for life or designed to smile or national oral health plan or child-smile or child smile or childsmile or smile with a prophet or winning smiles or (smokefree adj2 smiling) or smileathon or creative smiles or city smiles or smile sack or bright smiles).ti,ab,kf. (44)

57 42 or 55 or 56 (118977)

58 exp Maternal Health Services/ (36403)

59 Maternal-Child Health Centers/ (2188)

60 maternal welfare/ (6196)

61 (mother$ or maternal$ or maternity or childbear$ or birth$ or pregnant or pregnanc$ or breastfeed$ or breast feed$ or breastfed$ or breast fed$ or lactating or lactation or conception or periconcept$ or preconcept$ or gestation$ or pregestation$ or prenatal$ or pre-natal$ or perinatal$ or peri-natal$ or antenatal$ or ante-natal$ or postpartum or post-partum or postnatal$ or post-natal$ or puerperium or puerperal).ti. (447813)

62 ((mother$ or maternal$ or maternity or childbear$ or birth$ or pregnant or pregnanc$ or breastfeed$ or breast feed$ or breastfed$ or breast fed$ or lactating or lactation or conception or periconcept$ or preconcept$ or gestation$ or pregestation$ or prenatal$ or pre-natal$ or perinatal$ or peri-natal$ or

antenatal$ or ante-natal$ or postpartum or post-partum or postnatal$ or post-natal$ or puerperium or puerperal) adj5 (service$ or care or promotion$1 or educat$)).ab,kf. (47867)

63 (maternal-child or maternal-infant or mother-child or mother-infant).ab,kf. (10291)

64 Midwifery/ (15278)

65 Nurse Midwives/ (6100)

66 (midwif$ or mid-wif$ or midwiv$ or mid-wiv$).ti,ab,kf. (17550)

67 or/58-66 (498284)

68 exp Child Health Services/ (19643)

69 Adolescent Health Services/ (4542)

70 exp child welfare/ or infant welfare/ (29621)

71 (child$ or infant$ or newborn$ or new-born$ or neonat$ or neo-nat$ or baby$ or babies or pediat$ or paediat$ or schoolchild$ or preschool$ or adolescen$ or juvenile$ or youth$ or teenage$ or youngster$ or young people$ or young person$ or school$1 or kindergarten$1 or nursery or nurseries or early year$1).ti. (1169696)

72 ((child$ or infant$ or newborn$ or new-born$ or neonat$ or neo-nat$ or baby$ or babies or pediat$ or paediat$ or schoolchild$ or preschool$ or adolescen$ or juvenile$ or youth$ or teenage$ or youngster$ or young people$ or young person$ or school$1 or kindergarten$1 or nursery or nurseries or early year$1) adj5 (service$ or care or promotion$1 or educat$)).ab,kf. (108806)

73 (sure start or surestart or new deal or newdeal or healthy start or healthystart).ti,ab,kf. (572)

74 or/68-73 (1219570)

75 exp Consumer Participation/ (32955)

76 community-institutional relations/ (9565)

77 hospital-patient relations/ (1820)

78 Professional-Family Relations/ (12310)

79 Professional-Patient Relations/ (22301)

80 Physician-Patient Relations/ (61626)

81 Nurse-Patient Relations/ (31300)

82 Community Networks/ (5714)

83 Community Integration/ (94)

84 Community-Based Participatory Research/ (2356)

85 Cooperative Behavior/ (31740)

86 exp Residence Characteristics/ (44803)

87 communit$.ti. (112064)

88 (engag$ or empower$ or mobilis$ or mobiliz$ or co-operat$ or cooperat$ or outreach$ or out-reach$).ti,ab,kf. (292717)

89 (participat$ or access$ or barrier$1 or facilitat$).ti,ab,kf. (1128950)

90 ((communit$ or citizen$1 or public or local$ or neighborhood$1 or neighbourhood$1 or area$1 or population$1 or resident$1 or user$1 or lay or consumer$1 or family or families) adj4 (develop$ or involv$ or collaborat$ or consult$ or partner$)).ti,ab,kf. (133228)

91 (health$ adj (champion$ or trainer$1 or communit$ or council$1 or determinant$1 or development$1 or impact$1 or improvement$ or inequalit$ or inequit$ or people$1 program$)).ti,ab,kf. (18364)

92 (agent$ adj2 chang$).ti,ab,kf. (1926)

93 (volunteer$1 or voluntary).ti,ab,kf. (192975)

94 stakeholder$1.ti,ab,kf. (16452)

95 (lay adj (person$1 or people$1 or communit$)).ti,ab,kf. (1549)

96 (delegat$ adj2 power$).ti,ab,kf. (23)

97 democratic renewal$.ti,ab,kf. (1)

98 (coproduc$ or co-produc$).ti,ab,kf. (2316)

99 (need$1 adj2 assess$).ti,ab,kf. (10435)

100 (rapid adj2 (appraisal$1 or assessment$1)).ti,ab,kf. (3456)

101 (service$1 adj2 (review$ or user$1)).ti,ab,kf. (4432)

102 (capacity adj2 build$).ti,ab,kf. (3534)

103 (priorit$ adj2 (set or sets or setting)).ti,ab,kf. (2984)

104 (strategic partnership$1 or LSP or LSPs or JSNA or JSNAs).ti,ab,kf. (1020)

105 (social adj (capital$1 or linking or cohesion or integration)).ti,ab,kf. (4209)

106 ((peer or peers) adj3 (led or leader$ or educat$ or train$)).ti,ab,kf. (2900)

107 ((neighbourhood$1 or neighborhood$1) adj (manager$1 or warden$1 or renew$)).ti,ab,kf. (21)

108 (social determinant$1 or determinant effectiveness).ti,ab,kf. (2841)

109 (local adj (government$1 or authorit$)).ti,ab,kf. (5076)

110 coalition member$.ti,ab,kf. (68)

111 (priorit$ adj2 setting).ti,ab,kf. (2288)

112 development approach$.ti,ab,kf. (440)

113 (partnership adj2 working).ti,ab,kf. (533)

114 social medicine$1.ti,ab,kf. (2003)

115 intervention guidance.ti,ab,kf. (18)

116 ((communit$ or citizen$1 or public or local$ or neighborhood$1 or neighbourhood$1 or area$1 or population$1 or resident$1 or user$1 or lay or consumer$1 or family or families) adj2 (alliance$1 or audit$ or orient$ or decision$ or support$)).ti,ab,kf. (30524)

117 ((communit$ or citizen$1 or public or local$ or neighborhood$1 or neighbourhood$1 or area$1 or population$1 or resident$1 or user$1 or lay or consumer$1) adj2 relation$).ti,ab,kf. (10795)

118 ((communit$ or citizen$1 or public or local$ or neighborhood$1 or neighbourhood$1 or area$1 or population$1 or resident$1 or user$1 or lay or consumer$1 or family or families) adj2 (survey$ or poll or polls or questionnaire$1 or interview$ or focus group$1)).ti,ab,kf. (32773)

119 ((communit$ or citizen$1 or public or local$ or neighborhood$1 or neighbourhood$1 or area$1 or population$1 or resident$1 or user$1 or lay or consumer$1 or family or families) adj2 (champion$ or mentor$ or leader$ or advoca$ or entrepren$ or represent$)).ti,ab,kf. (23634)

120 ((communit$ or citizen$1 or public or local$ or neighborhood$1 or neighbourhood$1 or area$1 or population$1 or resident$1 or user$1 or lay or consumer$1 or family or families) adj2 (coalition$ or

group$ or committee$ or council$ or workshop$ or forum$ or panel$ or jury or juries or network$ or organisation$ or organization$ or member$)).ti,ab,kf. (121910)

121 ((communit$ or citizen$1 or public or local$ or neighborhood$1 or neighbourhood$1 or area$1 or population$1 or resident$1 or user$1 or lay or consumer$1 or family or families) adj2 (input$ or perspective$ or view$ or opinion$ or contribut$ or perception$ or feedback$ or idea or ideas or contribut$ or dialogue$ or voice$ or articulat$ or verbalis$ or verbaliz$ or communicat$)).ti,ab,kf. (35134)

122 ((communit$ or citizen$1 or public or local$ or neighborhood$1 or neighbourhood$1 or area$1 or population$1 or resident$1 or user$1 or lay or consumer$1 or family or families) adj2 (plan or plans or activit$ or initiativ$ or path or paths or pathway$ or compact$1 or agreement$ or campaign$ or educat$ or inform$ or promot$ or action$1 or regenerat$ or re-generat$ or integrat$)).ti,ab,kf. (84910)

123 ((communit$ or citizen$1 or public or local$ or neighborhood$1 or neighbourhood$1 or area$1 or population$1 or resident$1 or user$1 or lay or consumer$1 or family or families) adj2 (based or control$ or led or driven or generate or generates or generated or owned or ownership$ or deliberat$ or governance)).ti,ab,kf. (202864)

124 ((communit$ or citizen$1 or public or local$ or neighborhood$1 or neighbourhood$1 or area$1 or population$1 or resident$1 or user$1 or lay or consumer$1 or family or families) adj2 links).ti,ab,kf. (635)

125 Trust/ (6223)

126 trust$.ti,ab,kf. (29109)

127 (mistrust$ or distrust$ or entrust$).ti,ab,kf. (3638)

128 ((communit$ or citizen$1 or public or local$ or neighborhood$1 or neighbourhood$1 or area$1 or population$1 or resident$1 or user$1 or lay or consumer$1 or family or families) adj2 (confiden$ or belief$ or believe$ or faith)).ti,ab,kf. (4769)

129 or/75-128 (2303479)

130 41 or 57 or 67 or 74 or 129 (4209739)

131 22 and 130 (1539)

132 (Gypsies/ or (gypsy$1 or gypsies or gipsy$1 or gipsies or roma or romas or romany$1 or romani or romanis or romanies or arli or arlis or ashkali or ashkalis or aurari or auraris or balkan egyptian or balkan egyptians or bashalde or bashaldes or boyash$1 or churari or churaris or cigano or ciganos or erlide or erlides or gitano or gitanos or gitans or horahane or horahanes or kalderash$1 or lalleri or lalleris or lingurari or linguraris or lovari or lovaris or ludar or ludars or ludari or ludaris or luri or luris or machvaya or machvayas or manouche or manouches or manush or manushs or manushes or modgar or modgars or modyar or modyars or romanichal or romanichals or romanichel or romanichels or romanis?l or romanis?ls or romungro or romungros or rudari or rudaris or tsigane or tsiganes or ungaritza or ungaritzas or ursari or ursaris or yerlii or yerliis or zl?tari or zl?taris or sinti or sinta or sinte or sintis or sintas or sintes or ceardannan$1 or yenish$1 or yeniche$1 or jenische$1 or quinqui$1 or mercheros$1 or kale or fairground$1 or fair-ground$1 or funfair$1 or fun-fair$1 or showmen$1 or show-men$1 or showwomen$1 or show-women$1 or showperson$1 or show-person$1 or showpeople$1 or show-people$1 or show communit$ or show travel?er$1 or forains industriel or circuses or circus men$1 or circus women$1 or circus person$1 or circus people$1 or circus communit$ or circus travel?er$1 or bargee$1 or canal boat$1 or barge$1 or boat-dwell$ or pavee$1 or minceir$ or lucht$1 or luchd$1 or itinerants or travel?er$1

communit$ or travel?er$1 family$1 or travel?er$1 families or irish travel?er$1 or welsh travel?er$1 or scottish travel?er$1 or highland$1 travel?er$1 or norwegian$1 travel?er$1 or newage travel?er$1 or new-age travel?er$1 or itinerant$1 travel?er$1 or minorit$ travel?er$1 or ethnic$ travel?er$1 or travel?er$1 halting site$1 or travel?er$1 caravan$1 or travel?er$1 people$1 or travel?er$1 person or travel?er$1 persons or travel?er$1 children$1 or travel?er$1 child$1 or travel?er$1 men$1 or travel?er male$1 or travel?er$1 women$1 or travel?er female$1 or travel?er$1 population$1 or travel?er$1 group$1 or travel?er$1 site or travel?er$1 sites or occupational travel?er$1 or travel?ing communit$).ti.) and (health$ or care$ or service$ or program$).ti. (189)

133 (Gypsies/ or (gypsy$1 or gypsies or gipsy$1 or gipsies or roma or romas or romany$1 or romani or romanis or romanies or arli or arlis or ashkali or ashkalis or aurari or auraris or balkan egyptian or balkan egyptians or bashalde or bashaldes or boyash$1 or churari or churaris or cigano or ciganos or erlide or erlides or gitano or gitanos or gitans or horahane or horahanes or kalderash$1 or lalleri or lalleris or lingurari or linguraris or lovari or lovaris or ludar or ludars or ludari or ludaris or luri or luris or machvaya or machvayas or manouche or manouches or manush or manushs or manushes or modgar or modgars or modyar or modyars or romanichal or romanichals or romanichel or romanichels or romanis?l or romanis?ls or romungro or romungros or rudari or rudaris or tsigane or tsiganes or ungaritza or ungaritzas or ursari or ursaris or yerlii or yerliis or zl?tari or zl?taris or sinti or sinta or sinte or sintis or sintas or sintes or ceardannan$1 or yenish$1 or yeniche$1 or jenische$1 or quinqui$1 or mercheros$1 or kale or fairground$1 or fair-ground$1 or funfair$1 or fun-fair$1 or showmen$1 or show-men$1 or showwomen$1 or show-women$1 or showperson$1 or show-person$1 or showpeople$1 or show-people$1 or show communit$ or show travel?er$1 or forains industriel or circuses or circus men$1 or circus women$1 or circus person$1 or circus people$1 or circus communit$ or circus travel?er$1 or bargee$1 or canal boat$1 or barge$1 or boat-dwell$ or pavee$1 or minceir$ or lucht$1 or luchd$1 or itinerants or travel?er$1 communit$ or travel?er$1 family$1 or travel?er$1 families or irish travel?er$1 or welsh travel?er$1 or scottish travel?er$1 or highland$1 travel?er$1 or norwegian$1 travel?er$1 or newage travel?er$1 or new-age travel?er$1 or itinerant$1 travel?er$1 or minorit$ travel?er$1 or ethnic$ travel?er$1 or travel?er$1 halting site$1 or travel?er$1 caravan$1 or travel?er$1 people$1 or travel?er$1 person or travel?er$1 persons or travel?er$1 children$1 or travel?er$1 child$1 or travel?er$1 men$1 or travel?er male$1 or travel?er$1 women$1 or travel?er female$1 or travel?er$1 population$1 or travel?er$1 group$1 or travel?er$1 site or travel?er$1 sites or occupational travel?er$1 or travel?ing communit$).ti.) and (disadvantag$ or disparit$ or equalit$ or equit$ or gap or gaps or gradient$1 or inequalit$ or inequit$ or unequal or variation$1 or exclusion or excluded).ti,ab,kf. (168)

134 ((gypsy$1 or gypsies or gipsy$1 or gipsies or roma or romas or romany$1 or romani or romanis or romanies or arli or arlis or ashkali or ashkalis or aurari or auraris or balkan egyptian or balkan egyptians or bashalde or bashaldes or boyash$1 or churari or churaris or cigano or ciganos or erlide or erlides or gitano or gitanos or gitans or horahane or horahanes or kalderash$1 or lalleri or lalleris or lingurari or linguraris or lovari or lovaris or ludar or ludars or ludari or ludaris or luri or luris or machvaya or machvayas or manouche or manouches or manush or manushs or manushes or modgar or modgars or modyar or modyars or romanichal or romanichals or romanichel or romanichels or romanis?l or romanis?ls or romungro or romungros or rudari or rudaris or tsigane or tsiganes or ungaritza or ungaritzas or ursari or

ursaris or yerlii or yerliis or zl?tari or zl?taris or sinti or sinta or sinte or sintis or sintas or sintes or ceardannan$1 or yenish$1 or yeniche$1 or jenische$1 or quinqui$1 or mercheros$1 or kale or fairground$1 or fair-ground$1 or funfair$1 or fun-fair$1 or showmen$1 or show-men$1 or showwomen$1 or show-women$1 or showperson$1 or show-person$1 or showpeople$1 or show-people$1 or show communit$ or show travel?er$1 or forains industriel or circuses or circus men$1 or circus women$1 or circus person$1 or circus people$1 or circus communit$ or circus travel?er$1 or bargee$1 or canal boat$1 or barge$1 or boat-dwell$ or pavee$1 or minceir$ or lucht$1 or luchd$1 or itinerants or travel?er$1 communit$ or travel?er$1 family$1 or travel?er$1 families or irish travel?er$1 or welsh travel?er$1 or scottish travel?er$1 or highland$1 travel?er$1 or norwegian$1 travel?er$1 or newage travel?er$1 or new-age travel?er$1 or itinerant$1 travel?er$1 or minorit$ travel?er$1 or ethnic$ travel?er$1 or travel?er$1 halting site$1 or travel?er$1 caravan$1 or travel?er$1 people$1 or travel?er$1 person or travel?er$1 persons or travel?er$1 children$1 or travel?er$1 child$1 or travel?er$1 men$1 or travel?er male$1 or travel?er$1 women$1 or travel?er female$1 or travel?er$1 population$1 or travel?er$1 group$1 or travel?er$1 site or travel?er$1 sites or occupational travel?er$1 or travel?ing communit$) and (develop$ or involv$ or collaborat$ or consult$ or partner$ or alliance$1 or audit$ or orient$ or decision$ or support$ or relation$ or survey$ or poll or polls or questionnaire$1 or interview$ or focus group$1 or champion$ or mentor$ or leader$ or advoca$ or entrepren$ or represent$ or coalition$ or group$ or committee$ or council$ or workshop$ or forum$ or panel$ or jury or juries or network$ or organisation$ or organization$ or member$ or input$ or perspective$ or view$ or opinion$ or contribut$ or perception$ or feedback$ or idea or ideas or contribut$ or dialogue$ or voice$ or articulat$ or verbalis$ or verbaliz$ or communicat$ or plan or plans or activit$ or initiativ$ or path or paths or pathway$ or compact$1 or agreement$ or campaign$ or educat$ or inform$ or promot$ or action$1 or regenerat$ or re-generat$ or integrat$ or based or control$ or led or driven or generate or generates or generated or owned or ownership$ or deliberat$ or governance or links or confiden$ or belief$ or believe$ or faith)).ti. (279)

135 ((gypsy$1 or gypsies or gipsy$1 or gipsies or roma or romas or romany$1 or romani or romanis or romanies or arli or arlis or ashkali or ashkalis or aurari or auraris or balkan egyptian or balkan egyptians or bashalde or bashaldes or boyash$1 or churari or churaris or cigano or ciganos or erlide or erlides or gitano or gitanos or gitans or horahane or horahanes or kalderash$1 or lalleri or lalleris or lingurari or linguraris or lovari or lovaris or ludar or ludars or ludari or ludaris or luri or luris or machvaya or machvayas or manouche or manouches or manush or manushs or manushes or modgar or modgars or modyar or modyars or romanichal or romanichals or romanichel or romanichels or romanis?l or romanis?ls or romungro or romungros or rudari or rudaris or tsigane or tsiganes or ungaritza or ungaritzas or ursari or ursaris or yerlii or yerliis or zl?tari or zl?taris or sinti or sinta or sinte or sintis or sintas or sintes or ceardannan$1 or yenish$1 or yeniche$1 or jenische$1 or quinqui$1 or mercheros$1 or kale or fairground$1 or fair-ground$1 or funfair$1 or fun-fair$1 or showmen$1 or show-men$1 or showwomen$1 or show-women$1 or showperson$1 or show-person$1 or showpeople$1 or show-people$1 or show communit$ or show travel?er$1 or forains industriel or circuses or circus men$1 or circus women$1 or circus person$1 or circus people$1 or circus communit$ or circus travel?er$1 or bargee$1 or canal boat$1 or barge$1 or boat-dwell$ or pavee$1 or minceir$ or lucht$1 or luchd$1 or itinerants or travel?er$1 communit$ or travel?er$1 family$1 or travel?er$1 families or irish travel?er$1 or welsh travel?er$1 or

scottish travel?er$1 or highland$1 travel?er$1 or norwegian$1 travel?er$1 or newage travel?er$1 or new-age travel?er$1 or itinerant$1 travel?er$1 or minorit$ travel?er$1 or ethnic$ travel?er$1 or travel?er$1 halting site$1 or travel?er$1 caravan$1 or travel?er$1 people$1 or travel?er$1 person or travel?er$1 persons or travel?er$1 children$1 or travel?er$1 child$1 or travel?er$1 men$1 or travel?er male$1 or travel?er$1 women$1 or travel?er female$1 or travel?er$1 population$1 or travel?er$1 group$1 or travel?er$1 site or travel?er$1 sites or occupational travel?er$1 or travel?ing communit$) adj4 (develop$ or involv$ or collaborat$ or consult$ or partner$ or alliance$1 or audit$ or orient$ or decision$ or support$ or relation$ or survey$ or poll or polls or questionnaire$1 or interview$ or focus group$1 or champion$ or mentor$ or leader$ or advoca$ or entrepren$ or represent$ or coalition$ or group$ or committee$ or council$ or workshop$ or forum$ or panel$ or jury or juries or network$ or organisation$ or organization$ or member$ or input$ or perspective$ or view$ or opinion$ or contribut$ or perception$ or feedback$ or idea or ideas or contribut$ or dialogue$ or voice$ or articulat$ or verbalis$ or verbaliz$ or communicat$ or plan or plans or activit$ or initiativ$ or path or paths or pathway$ or compact$1 or agreement$ or campaign$ or educat$ or inform$ or promot$ or action$1 or regenerat$ or integrat$ or re-generat$ or based or control$ or led or driven or generate or generates or generated or owned or ownership$ or deliberat$ or governance or links or confiden$ or belief$ or believe$ or faith)).ab,kf. (654)

136 (moth or moths or gypsyty3 or gypsy ty3 or ty3gypsy or ty3 gypsy).ti,ab,kf. (7996)
137 (132 or 133 or 134 or 135) not 136 (833)
138 or/131,137 (2001)
139 exp animals/ not humans/ (4041332)
140 (news or editorial or letter or comment).pt. (1562535)
141 138 not (139 or 140) (1754)
142 limit 141 to (english language and yr="2000 -Current") (1077)
143 remove duplicates from 142 (1064)

Key to Ovid symbols and commands

$	Unlimited right-hand truncation symbol
$N	Limited right-hand truncation - restricts the number of characters following the word to N
?	Wildcard symbol
ti,ab,kf	Searches are restricted to the Title, Abstract and Keyword Heading Word fields
adjN	Retrieves records that contain terms (in any order) within a specified number (N) of words of each other
/	Searches are restricted to the Subject Heading field
exp	The subject heading is exploded
*	The subject heading is searched as a major descriptor only
ab. /freq=N	Search is restricted to records where the terms occur at least N times in the abstract
pt.	Search is restricted to the publication type field
or/1-3	Combines sets 1 to 3 using OR

Appendix 6: Trust review databases and search strategy

Table A0: Trust review - databases and information resources searched

Database / information source	**Interface / URL**
MEDLINE and MEDLINE In Process	OvidSP
Embase	OvidSP
CINAHL Plus	EBSCOHOST
Cochrane Database of Systematic Reviews (CDSR)	Cochrane Library / Wiley Interscience
Database of Abstracts of Reviews of Effects (DARE)	Cochrane Library / Wiley Interscience
Health Technology Assessment Database (HTA)	Cochrane Library / Wiley Interscience
Social Sciences Citation Index (SSCI)	Web of Science
PsycINFO	OvidSP
HMIC Health Management Information Consortium	OvidSP
Applied Social Sciences Index and Abstracts (ASSIA)	Proquest
Social Policy and Practice	OvidSP
Bibliomap	http://eppi.ioe.ac.uk/webdatabases/intro.aspx?ID=7
Database of promoting health effectiveness reviews (DoPHER)	http://eppi.ioe.ac.uk/webdatabases4/Intro.aspx?ID=9
Trials Register of Promoting Health Interventions (TRoPHI)	http://eppi.ioe.ac.uk/webdatabases4/Intro.aspx?ID=12
The Campbell Library	http://www.campbellcollaboration.org/lib/
Science Citation Index Expanded (SCI-EXPANDED) / Conference Proceedings Citation Index- Science (CPCI-S)	Web of Science

Example search strategy

Source: Ovid MEDLINE(R) In-Process & Other Non-Indexed Citations and Ovid MEDLINE(R) 1946 to Present

Interface / URL: OvidSP
Search date: 21/05/15
Retrieved records: 2244
Search strategy:
1 Trust/ (6223)
2 (trust$ or mistrust$ or distrust$ or entrust$).ti,ab,kf. (32063)

3 or/1-2 (34859)
4 review.pt. (1980112)
5 literature review$.ti,ab,kf. (53665)
6 systematic$ review$.ti,ab,kf. (68205)
7 meta-analysis as topic/ (14250)
8 meta-analytic$.ti,ab,kf. (4063)
9 meta-analysis.ti,ab,kf,pt. (82568)
10 metanalysis.ti,ab,kf. (137)
11 metaanalysis.ti,ab,kf. (1164)
12 meta-synthesi$.ti,ab,kf. (296)
13 metasynthesi$.ti,ab,kf. (157)
14 meta-regression.ti,ab,kf. (2939)
15 metaregression.ti,ab,kf. (321)
16 (synthes$ adj3 literature).ti,ab,kf. (1577)
17 (synthes$ adj3 evidence).ti,ab,kf. (4626)
18 integrative review.ti,ab,kf. (1059)
19 data synthesis.ti,ab,kf. (7756)
20 (research synthesis or narrative synthesis).ti,ab,kf. (915)
21 (systematic study or systematic studies).ti,ab,kf. (8149)
22 (systematic comparison$ or systematic overview$).ti,ab,kf. (2061)
23 evidence based review.ti,ab,kf. (1412)
24 comprehensive review.ti,ab,kf. (7624)
25 critical review.ti,ab,kf. (11549)
26 quantitative review.ti,ab,kf. (506)
27 structured review.ti,ab,kf. (509)
28 realist review.ti,ab,kf. (80)
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30 qualitative review.ti,ab,kf. (506)
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34 cochrane.ab. (36134)
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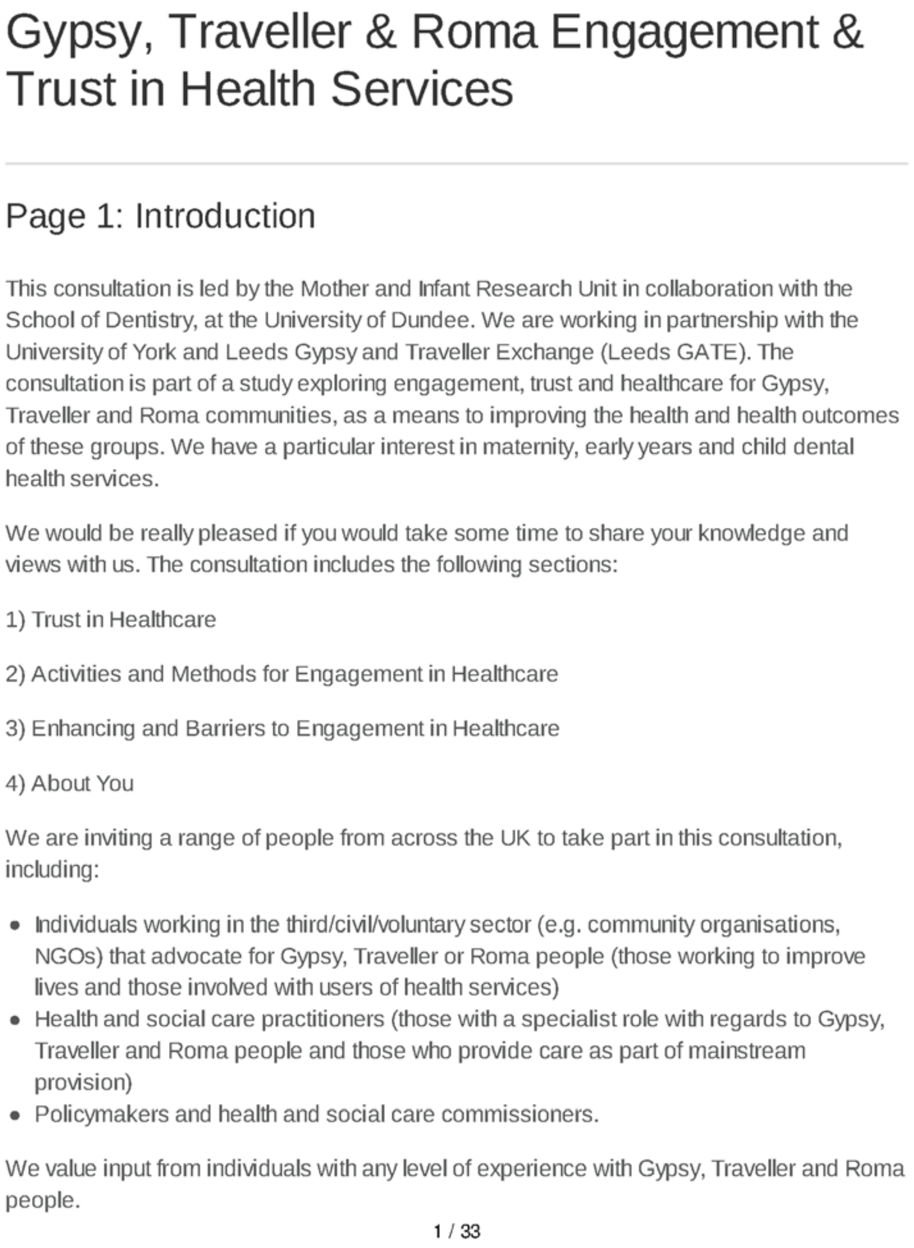
Appendix 7: Online consultation



Gypsy, Traveller & Roma Engagement & Trust in Health Services

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Page 1: Introduction

This consultation is led by the Mother and Infant Research Unit in collaboration with the School of Dentistry, at the University of Dundee. We are working in partnership with the University of York and Leeds Gypsy and Traveller Exchange (Leeds GATE). The consultation is part of a study exploring engagement, trust and healthcare for Gypsy, Traveller and Roma communities, as a means to improving the health and health outcomes of these groups. We have a particular interest in maternity, early years and child dental health services.

We would be really pleased if you would take some time to share your knowledge and views with us. The consultation includes the following sections:

1) Trust in Healthcare

2) Activities and Methods for Engagement in Healthcare

3) Enhancing and Barriers to Engagement in Healthcare

4) About You

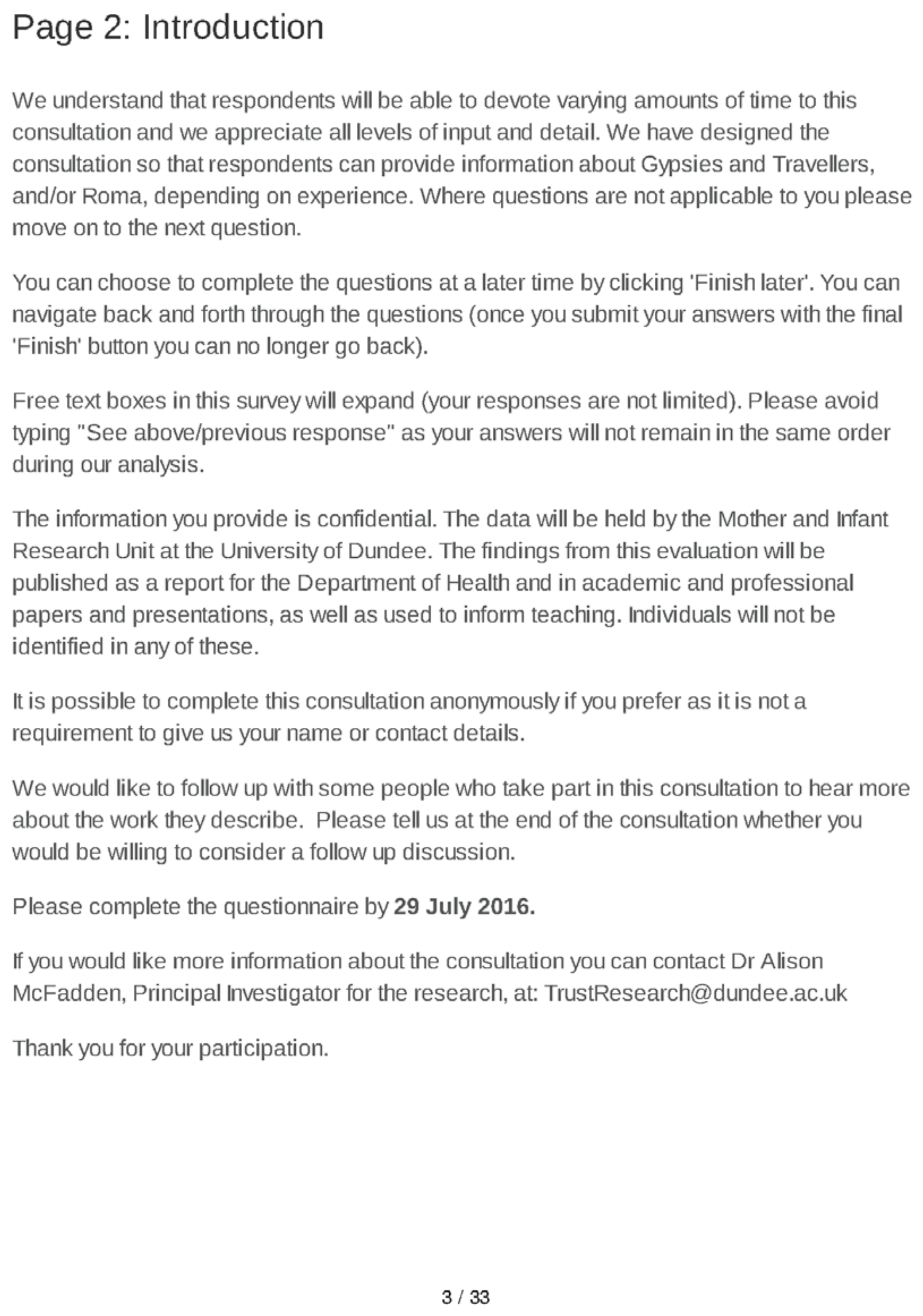
We are inviting a range of people from across the UK to take part in this consultation, including:

- Individuals working in the third/civil/voluntary sector (e.g. community organisations, NGOs) that advocate for Gypsy, Traveller or Roma people (those working to improve lives and those involved with users of health services)
- Health and social care practitioners (those with a specialist role with regards to Gypsy, Traveller and Roma people and those who provide care as part of mainstream provision)
- Policymakers and health and social care commissioners.

We value input from individuals with any level of experience with Gypsy, Traveller and Roma people.

1 / 33

In line with the Leeds GATE Ethnicity Briefing (2014), in this consultation the term 'Gypsies and Travellers' includes Romany Gypsies from England and Wales, Scottish Gypsy Travellers, Irish Travellers, Showmen, Bargees and New Travellers. 'Roma' refers to more recent arrivals to the UK from Europe. The Briefing can be found at: http://leedsgate.co.uk/sites/default/files/media/Ethnicity-Briefing.pdf



Page 2: Introduction

We understand that respondents will be able to devote varying amounts of time to this consultation and we appreciate all levels of input and detail. We have designed the consultation so that respondents can provide information about Gypsies and Travellers, and/or Roma, depending on experience. Where questions are not applicable to you please move on to the next question.

You can choose to complete the questions at a later time by clicking 'Finish later'. You can navigate back and forth through the questions (once you submit your answers with the final 'Finish' button you can no longer go back).

Free text boxes in this survey will expand (your responses are not limited). Please avoid typing "See above/previous response" as your answers will not remain in the same order during our analysis.

The information you provide is confidential. The data will be held by the Mother and Infant Research Unit at the University of Dundee. The findings from this evaluation will be published as a report for the Department of Health and in academic and professional papers and presentations, as well as used to inform teaching. Individuals will not be identified in any of these.

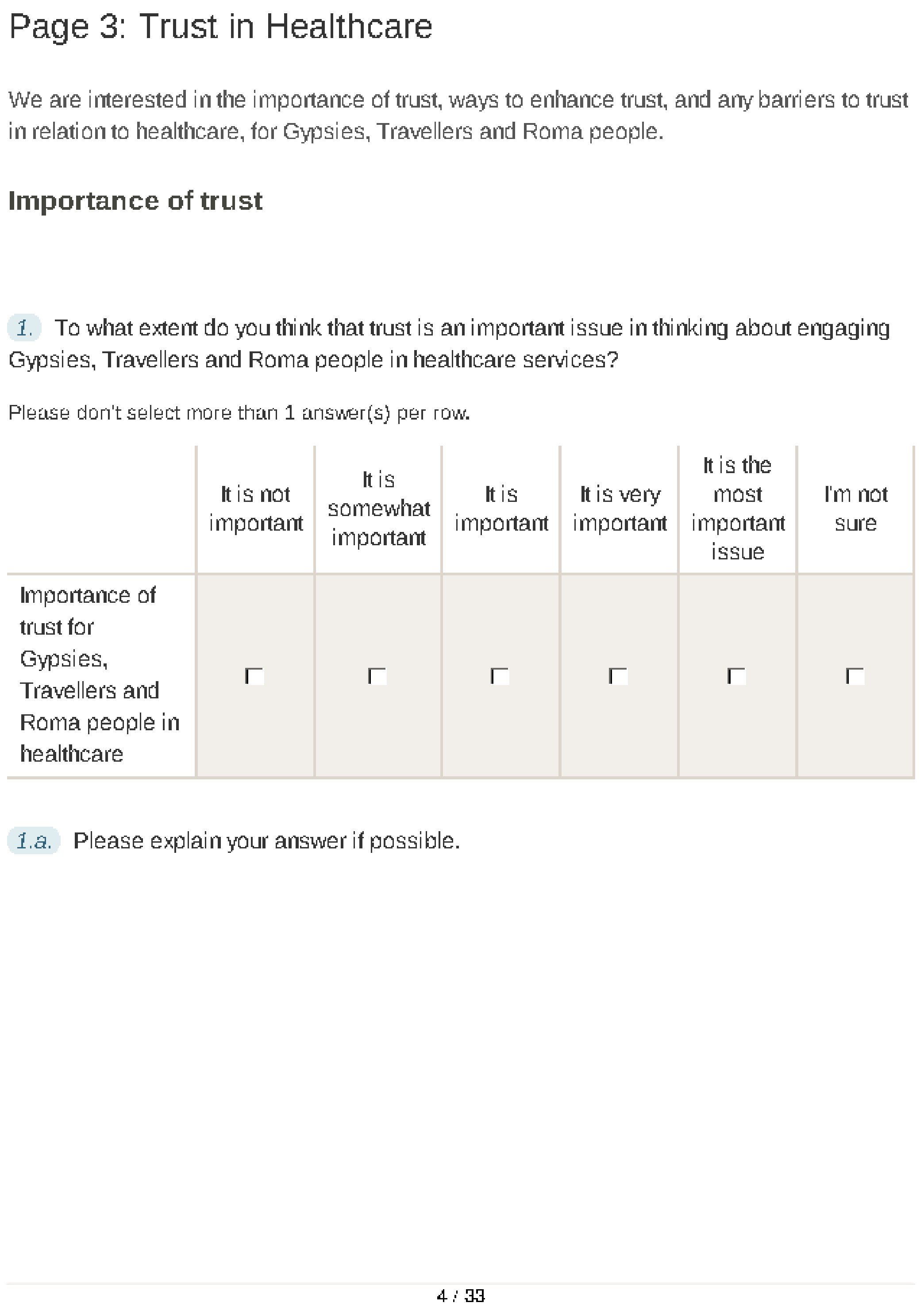
It is possible to complete this consultation anonymously if you prefer as it is not a requirement to give us your name or contact details.

We would like to follow up with some people who take part in this consultation to hear more about the work they describe. Please tell us at the end of the consultation whether you would be willing to consider a follow up discussion.

Please complete the questionnaire by **29 July 2016.**

If you would like more information about the consultation you can contact Dr Alison McFadden, Principal Investigator for the research, at: TrustResearch@dundee.ac.uk

Thank you for your participation.



Page 3: Trust in Healthcare

We are interested in the importance of trust, ways to enhance trust, and any barriers to trust in relation to healthcare, for Gypsies, Travellers and Roma people.

Importance of trust

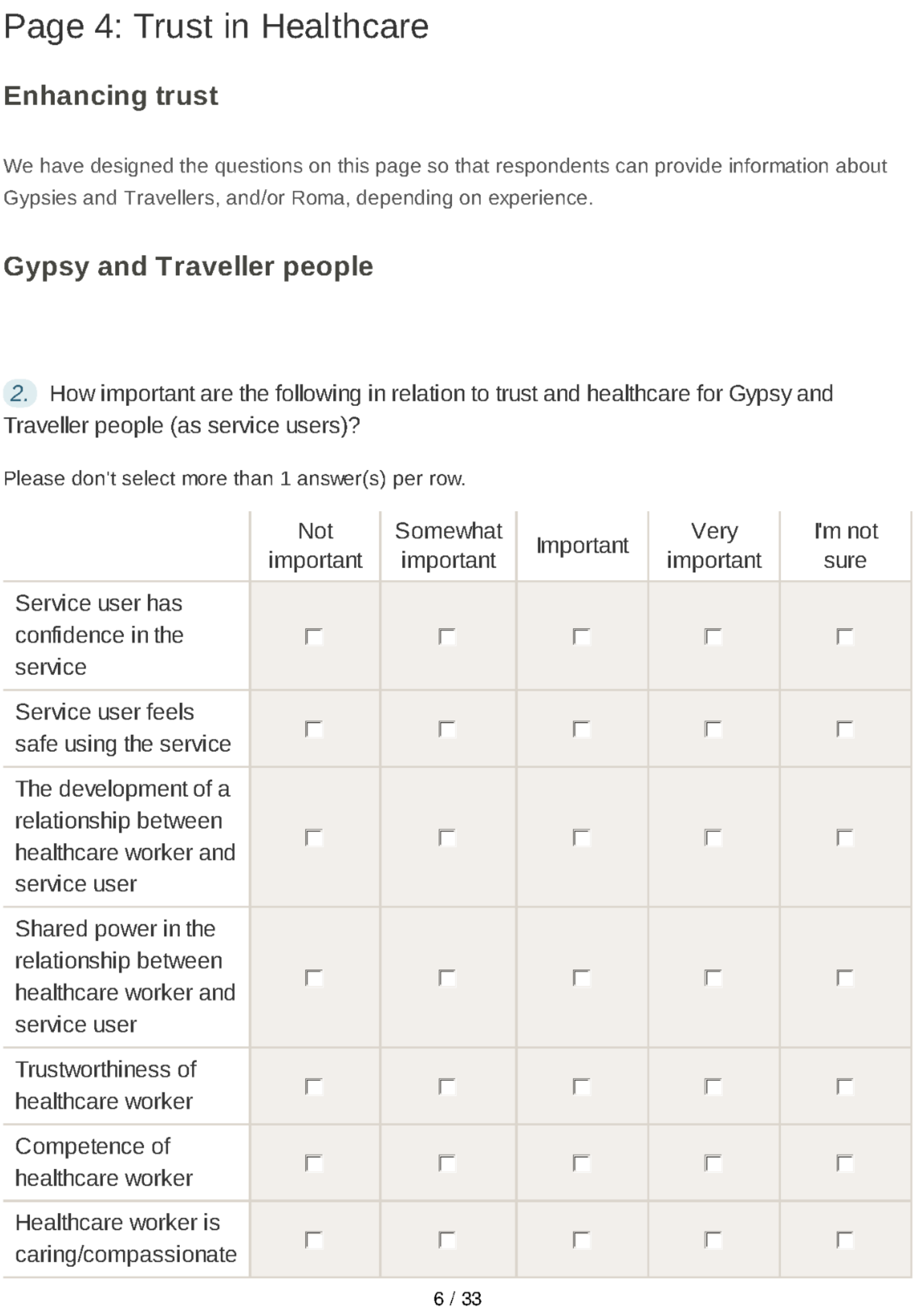
1. To what extent do you think that trust is an important issue in thinking about engaging Gypsies, Travellers and Roma people in healthcare services?

Please don't select more than 1 answer(s) per row.

	It is not important	It is somewhat important	It is important	It is very important	It is the most important issue	I'm not sure
Importance of trust for Gypsies, Travellers and Roma people in healthcare	☐	☐	☐	☐	☐	☐

1.a. Please explain your answer if possible.

(Box expands; please do not type 'see above')



Page 4: Trust in Healthcare

Enhancing trust

We have designed the questions on this page so that respondents can provide information about Gypsies and Travellers, and/or Roma, depending on experience.

Gypsy and Traveller people

2. How important are the following in relation to trust and healthcare for Gypsy and Traveller people (as service users)?

Please don't select more than 1 answer(s) per row.

	Not important	Somewhat important	Important	Very important	I'm not sure
Service user has confidence in the service	☐	☐	☐	☐	☐
Service user feels safe using the service	☐	☐	☐	☐	☐
The development of a relationship between healthcare worker and service user	☐	☐	☐	☐	☐
Shared power in the relationship between healthcare worker and service user	☐	☐	☐	☐	☐
Trustworthiness of healthcare worker	☐	☐	☐	☐	☐
Competence of healthcare worker	☐	☐	☐	☐	☐
Healthcare worker is caring/compassionate	☐	☐	☐	☐	☐

Confidentiality when using services	☐	☐	☐	☐	☐
Healthcare worker has the best interests of the patient in mind	☐	☐	☐	☐	☐
Accessibility of healthcare worker, including time to spend with the patient	☐	☐	☐	☐	☐

2.a. Which of these is the most important issue in relation to trust and healthcare for Gypsy and Traveller people (as service users)?

○ Service user has confidence in the service
○ Service user feels safe using the service
○ The development of a relationship between healthcare worker and service user
○ Shared power in the relationship between healthcare worker and service user
○ Trustworthiness of healthcare worker
○ Competence of healthcare worker
○ Healthcare worker is caring/compassionate
○ Confidentiality when using services
○ Healthcare worker has the best interests of the patient in mind
○ Accessibility of healthcare worker, including time to spend with the patient
○ I'm not sure

Roma people

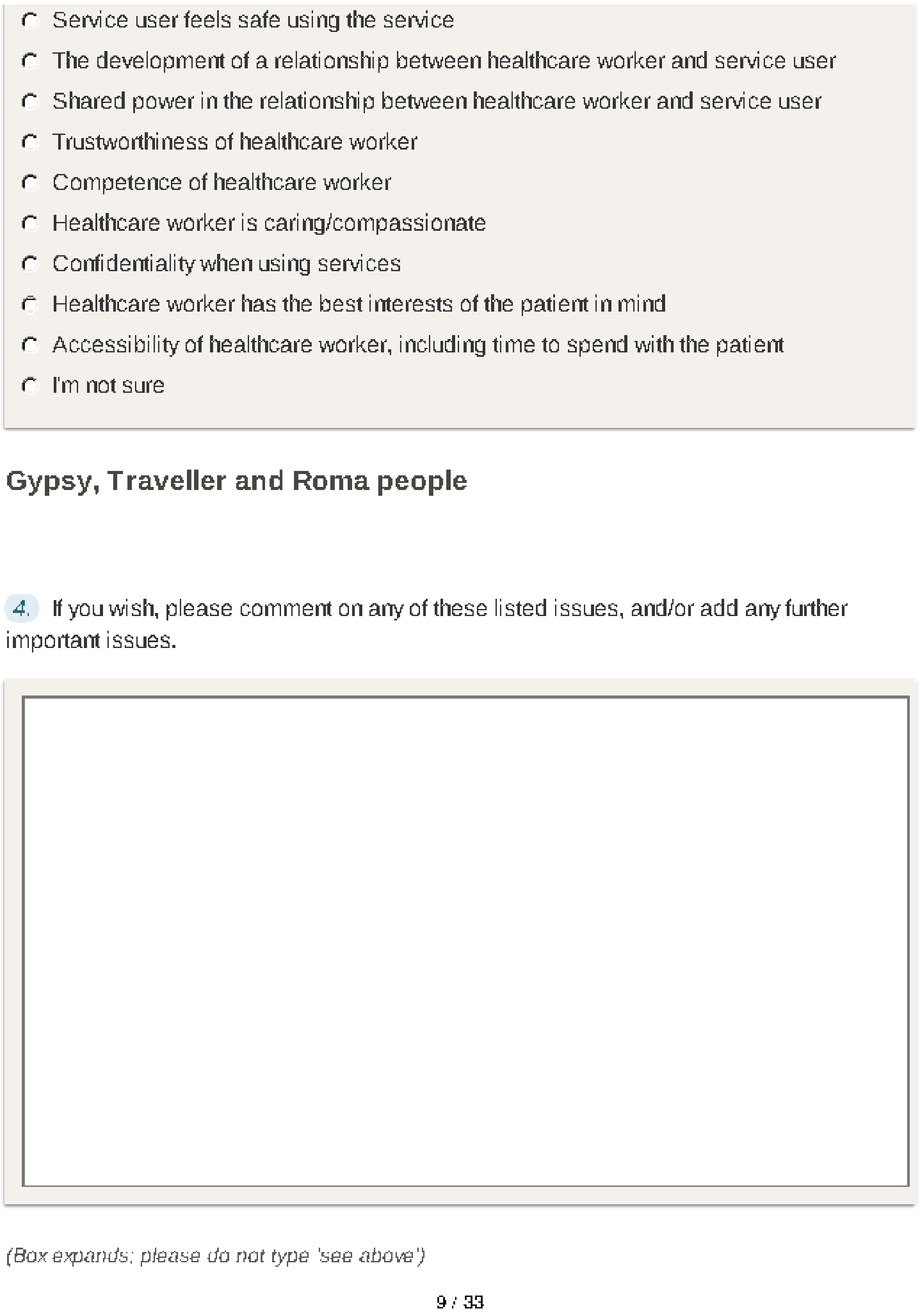
3. How important are the following in relation to trust and healthcare for Roma people (as service users)?

Please don't select more than 1 answer(s) per row.

	Not important	Somewhat important	Important	Very important	I'm not sure
Service user has confidence in the service	☐	☐	☐	☐	☐
Service user feels safe using the service	☐	☐	☐	☐	☐
The development of a relationship between healthcare worker and service user	☐	☐	☐	☐	☐
Shared power in the relationship between healthcare worker and service user	☐	☐	☐	☐	☐
Trustworthiness of healthcare worker	☐	☐	☐	☐	☐
Competence of healthcare worker	☐	☐	☐	☐	☐
Healthcare worker is caring/compassionate	☐	☐	☐	☐	☐
Confidentiality when using services	☐	☐	☐	☐	☐
Healthcare worker has the best interests of the patient in mind	☐	☐	☐	☐	☐
Accessibility of healthcare worker, including time to spend with the patient	☐	☐	☐	☐	☐

3.a. Which of these is the most important issue in relation to trust and healthcare for Roma people (as service users)?

○ Service user has confidence in the service



- ○ Service user feels safe using the service
- ○ The development of a relationship between healthcare worker and service user
- ○ Shared power in the relationship between healthcare worker and service user
- ○ Trustworthiness of healthcare worker
- ○ Competence of healthcare worker
- ○ Healthcare worker is caring/compassionate
- ○ Confidentiality when using services
- ○ Healthcare worker has the best interests of the patient in mind
- ○ Accessibility of healthcare worker, including time to spend with the patient
- ○ I'm not sure

Gypsy, Traveller and Roma people

4. If you wish, please comment on any of these listed issues, and/or add any further important issues.

(Box expands; please do not type 'see above')

9 / 33

Page 5: Trust in Healthcare

Barriers to trust

5. Please list any barriers to developing trust for Gypsies, Travellers and/or Roma people in relation to healthcare.

(Box expands; please do not type 'see above')

Page 6: Activities and Methods for Engagement in Healthcare

We are interested in learning about activities and methods used to engage with Gypsies, Travellers and Roma people in relation to healthcare (and maternity, early years and child dental health services in particular).

Examples include community outreach and involvement of community members in the delivery of healthcare.

Examples of activities and methods for engagement

6. Please tell us about any activities/methods for engaging Gypsies, Travellers and/or Roma people in healthcare that you know of (if possible please indicate whether these were associated with your place of work or elsewhere). It would be very useful if you could provide information on organisational issues, effectiveness and challenges; and indicate whether English or Welsh Romany Gypsies, Scottish Gypsy Travellers, Irish Travellers, Showmen, Bargees, New Travellers or Roma are/were involved.

(Box expands; please do not type 'see above')

Page 7: Activities and Methods for Engagement in Healthcare

What works well and why?

7. Please tell us about activities/methods that you consider to be of particularly good practice (i.e. "what works") in relation to engaging Gypsies, Travellers and/or Roma people in healthcare. This might be a programme, intervention, or the employment of a specific person for example. We would be particularly interested to know what you feel it is that makes this practice successful. (Again, it would be useful if you could indicate whether English or Welsh Romany Gypsies, Scottish Gypsy Travellers, Irish Travellers, Showmen, Bargees, New Travellers or Roma are/were involved).

(Box expands; please do not type 'see above')

Page 8: Activities and Methods for Engagement in Healthcare

What doesn't work?

8. Please tell us about any activities/methods of engaging with Gypsies, Travellers and Roma people that, in your opinion, do not work well. We would be particularly interested to know what you feel it is that makes this practice unsuccessful. (Again, it would be useful if you could indicate whether English or Welsh Romany Gypsies, Scottish Gypsy Travellers, Irish Travellers, Showmen, Bargees, New Travellers or Roma are/were involved).

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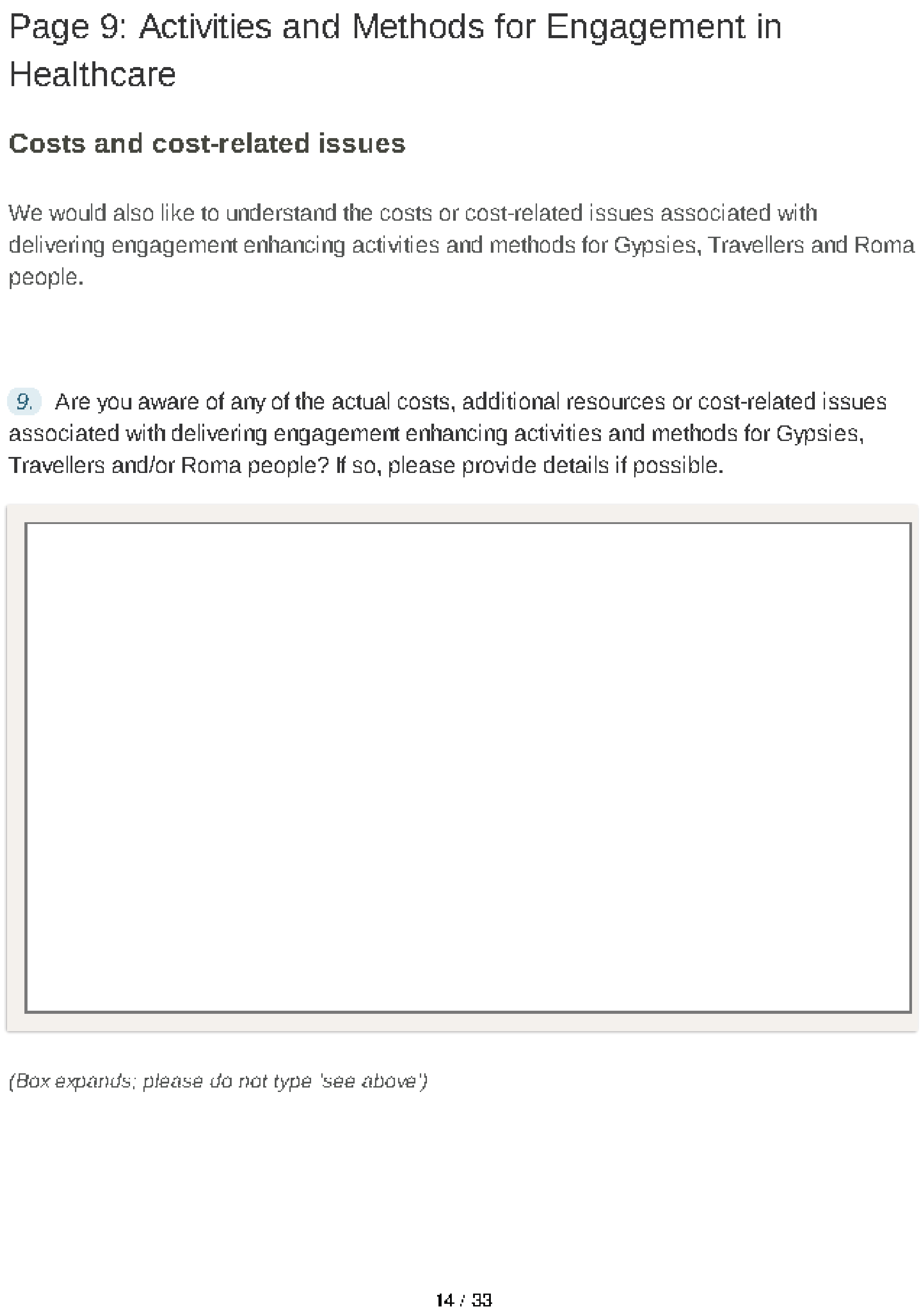


Page 9: Activities and Methods for Engagement in Healthcare

Costs and cost-related issues

We would also like to understand the costs or cost-related issues associated with delivering engagement enhancing activities and methods for Gypsies, Travellers and Roma people.

9. Are you aware of any of the actual costs, additional resources or cost-related issues associated with delivering engagement enhancing activities and methods for Gypsies, Travellers and/or Roma people? If so, please provide details if possible.

(Box expands; please do not type 'see above')

Page 10: Enhancing and Barriers to Engagement in Healthcare

Enhancing engagement

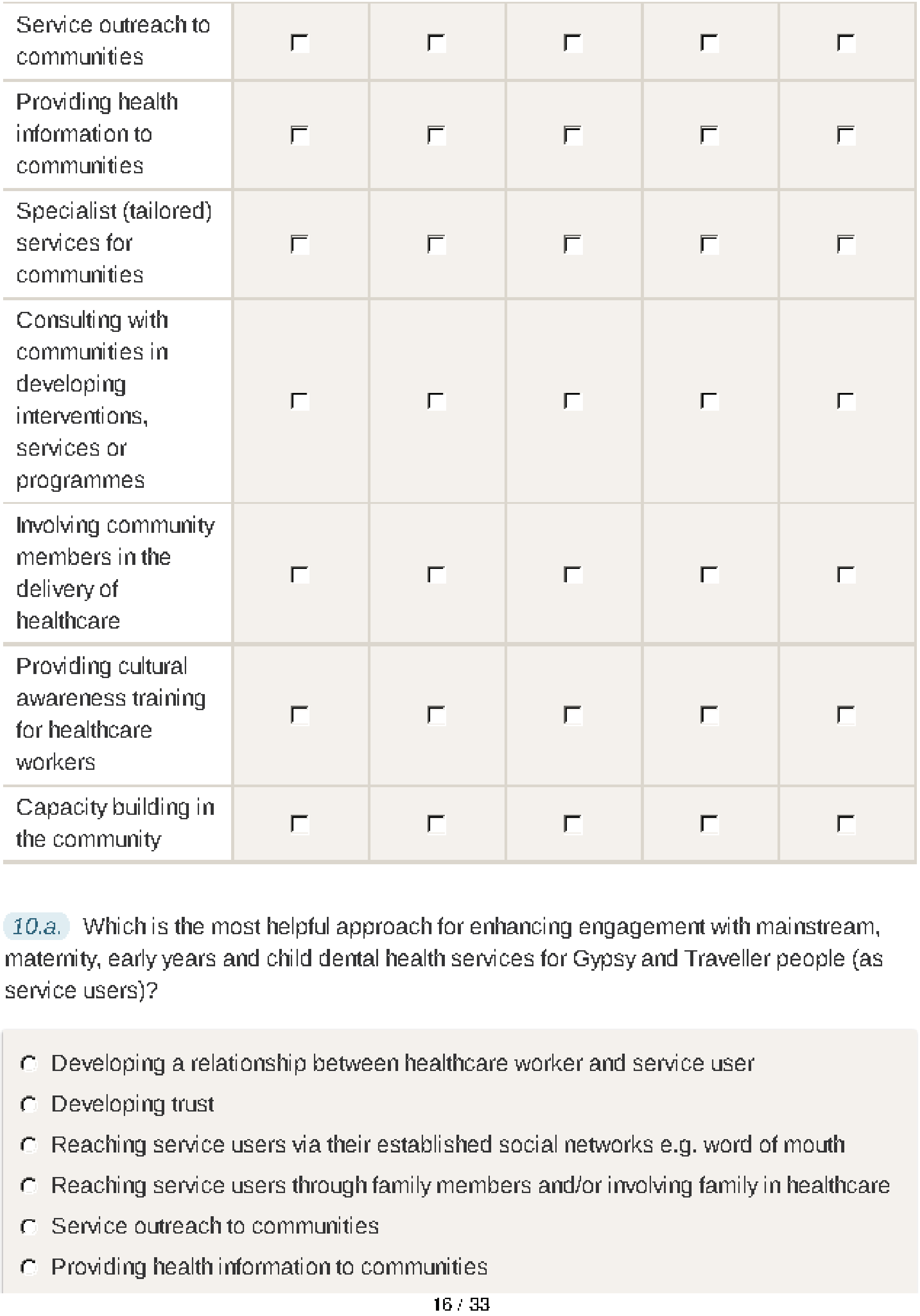
We have designed the questions on this page so that respondents can provide information about Gypsies and Travellers, and/or Roma, depending on experience.

Gypsy and Traveller people

10. How helpful do you think the following are in enhancing engagement with mainstream, maternity, early years and child dental health services for Gypsy and Traveller people (as service users)?

Please don't select more than 1 answer(s) per row.

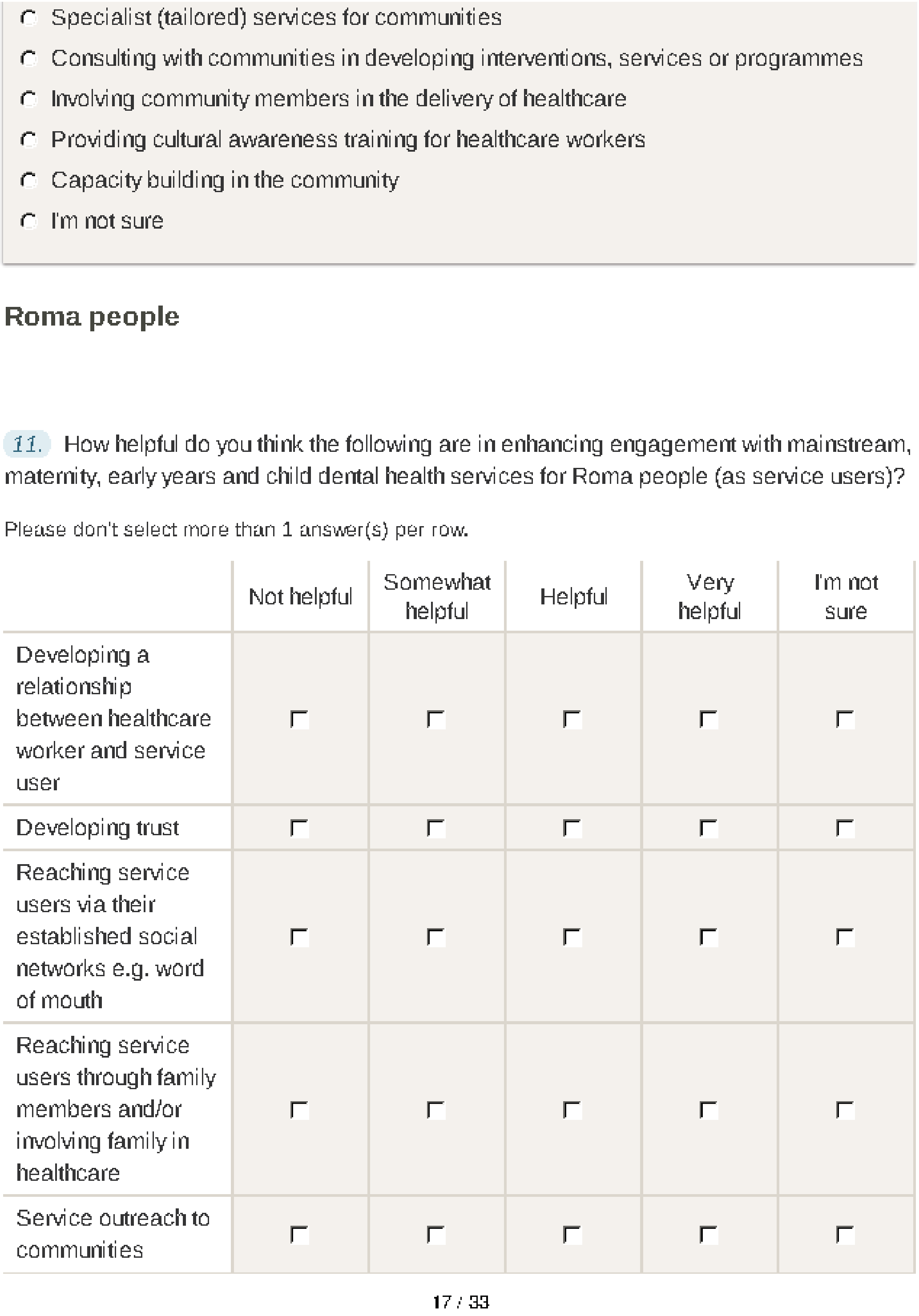
	Not helpful	Somewhat helpful	Helpful	Very helpful	I'm not sure
Developing a relationship between healthcare worker and service user	☐	☐	☐	☐	☐
Developing trust	☐	☐	☐	☐	☐
Reaching service users via their established social networks e.g. word of mouth	☐	☐	☐	☐	☐
Reaching service users through family members and/or involving family in healthcare	☐	☐	☐	☐	☐



Service outreach to communities	☐	☐	☐	☐	☐
Providing health information to communities	☐	☐	☐	☐	☐
Specialist (tailored) services for communities	☐	☐	☐	☐	☐
Consulting with communities in developing interventions, services or programmes	☐	☐	☐	☐	☐
Involving community members in the delivery of healthcare	☐	☐	☐	☐	☐
Providing cultural awareness training for healthcare workers	☐	☐	☐	☐	☐
Capacity building in the community	☐	☐	☐	☐	☐

10.a. Which is the most helpful approach for enhancing engagement with mainstream, maternity, early years and child dental health services for Gypsy and Traveller people (as service users)?

○ Developing a relationship between healthcare worker and service user
○ Developing trust
○ Reaching service users via their established social networks e.g. word of mouth
○ Reaching service users through family members and/or involving family in healthcare
○ Service outreach to communities
○ Providing health information to communities



○ Specialist (tailored) services for communities
○ Consulting with communities in developing interventions, services or programmes
○ Involving community members in the delivery of healthcare
○ Providing cultural awareness training for healthcare workers
○ Capacity building in the community
○ I'm not sure

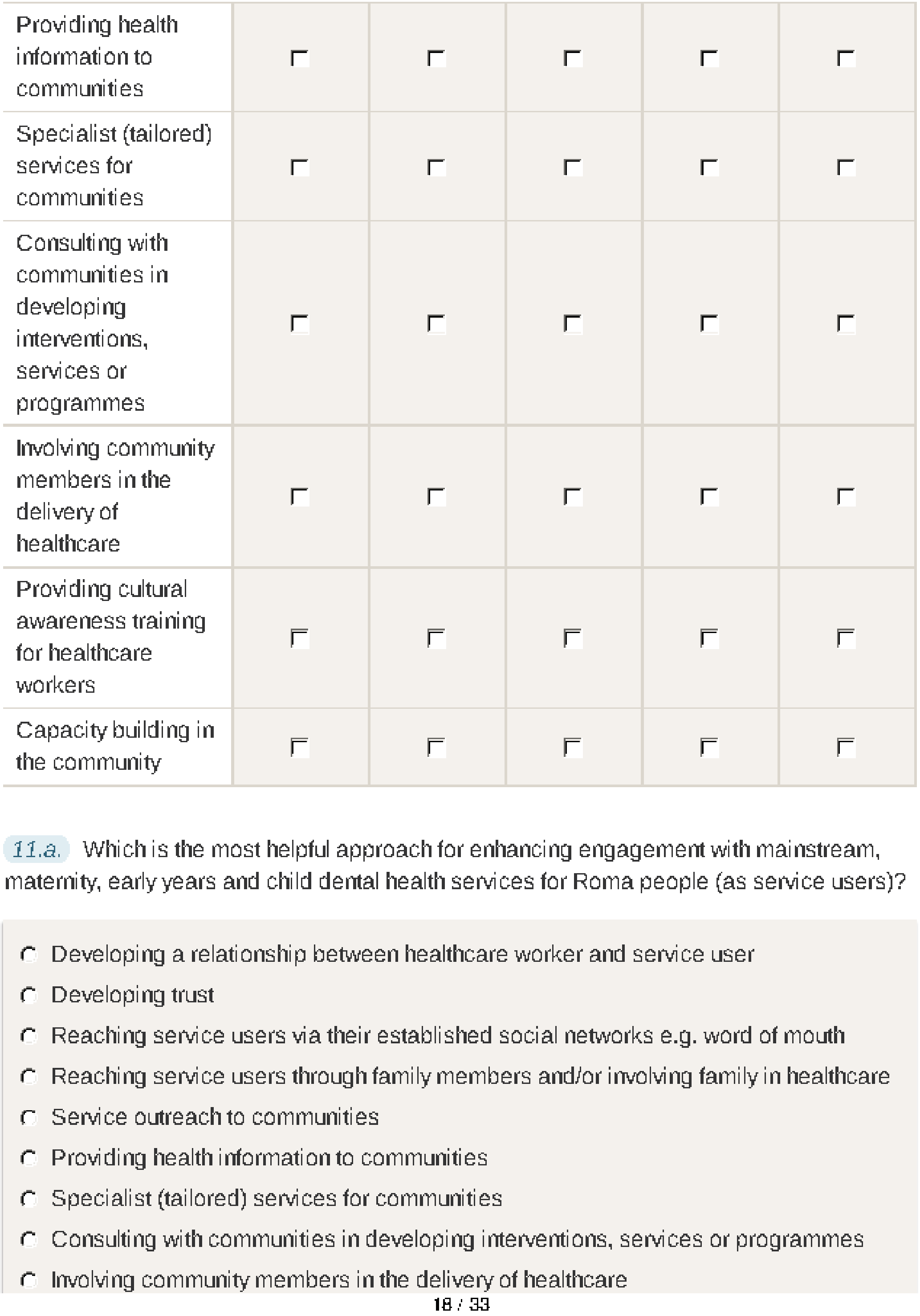
Roma people

11. How helpful do you think the following are in enhancing engagement with mainstream, maternity, early years and child dental health services for Roma people (as service users)?

Please don't select more than 1 answer(s) per row.

	Not helpful	Somewhat helpful	Helpful	Very helpful	I'm not sure
Developing a relationship between healthcare worker and service user	☐	☐	☐	☐	☐
Developing trust	☐	☐	☐	☐	☐
Reaching service users via their established social networks e.g. word of mouth	☐	☐	☐	☐	☐
Reaching service users through family members and/or involving family in healthcare	☐	☐	☐	☐	☐
Service outreach to communities	☐	☐	☐	☐	☐

17 / 33

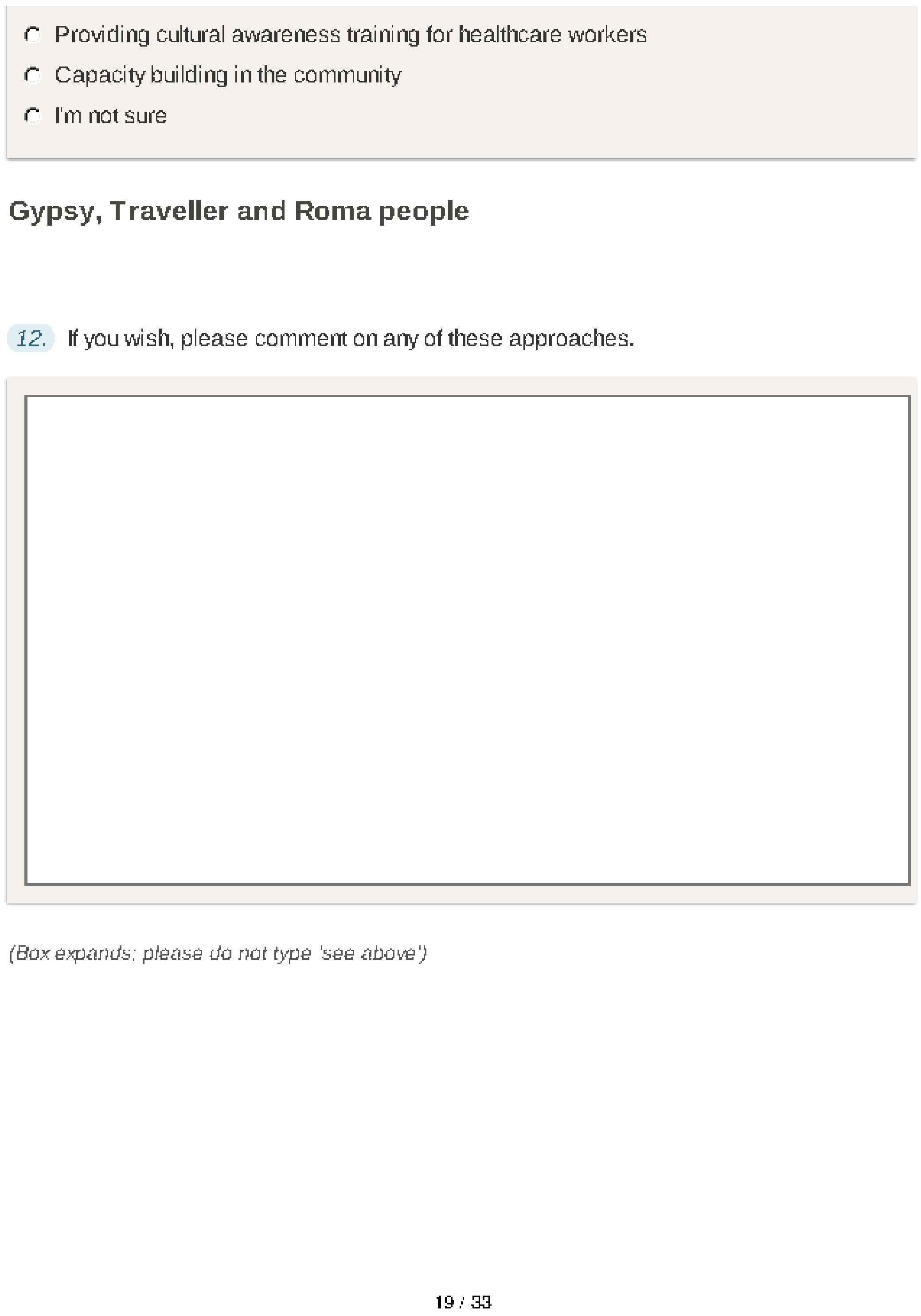


Providing health information to communities	☐	☐	☐	☐	☐
Specialist (tailored) services for communities	☐	☐	☐	☐	☐
Consulting with communities in developing interventions, services or programmes	☐	☐	☐	☐	☐
Involving community members in the delivery of healthcare	☐	☐	☐	☐	☐
Providing cultural awareness training for healthcare workers	☐	☐	☐	☐	☐
Capacity building in the community	☐	☐	☐	☐	☐

11.a. Which is the most helpful approach for enhancing engagement with mainstream, maternity, early years and child dental health services for Roma people (as service users)?

- ○ Developing a relationship between healthcare worker and service user
- ○ Developing trust
- ○ Reaching service users via their established social networks e.g. word of mouth
- ○ Reaching service users through family members and/or involving family in healthcare
- ○ Service outreach to communities
- ○ Providing health information to communities
- ○ Specialist (tailored) services for communities
- ○ Consulting with communities in developing interventions, services or programmes
- ○ Involving community members in the delivery of healthcare

18 / 33



○ Providing cultural awareness training for healthcare workers
○ Capacity building in the community
○ I'm not sure

Gypsy, Traveller and Roma people

12. If you wish, please comment on any of these approaches.

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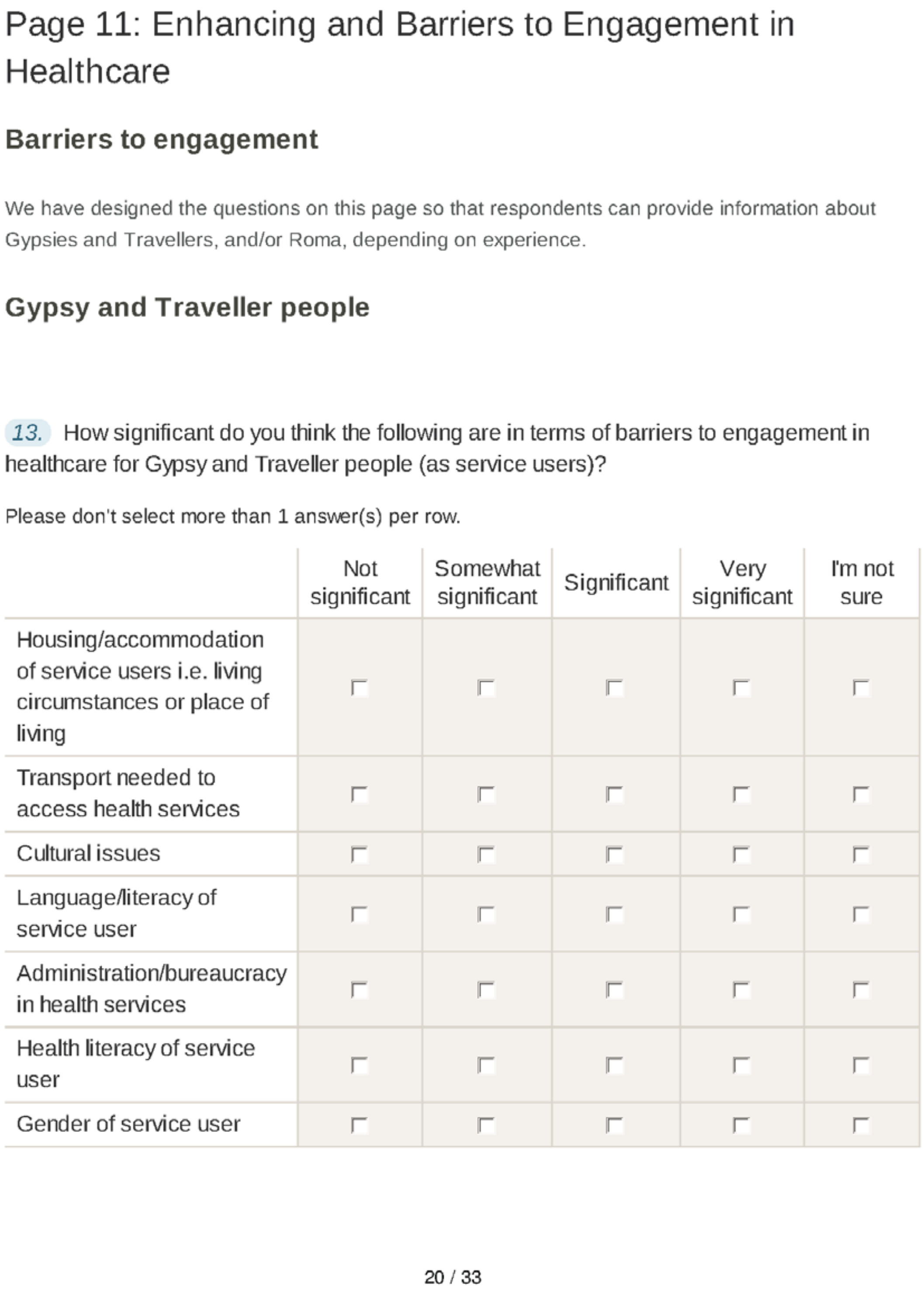


Page 11: Enhancing and Barriers to Engagement in Healthcare

Barriers to engagement

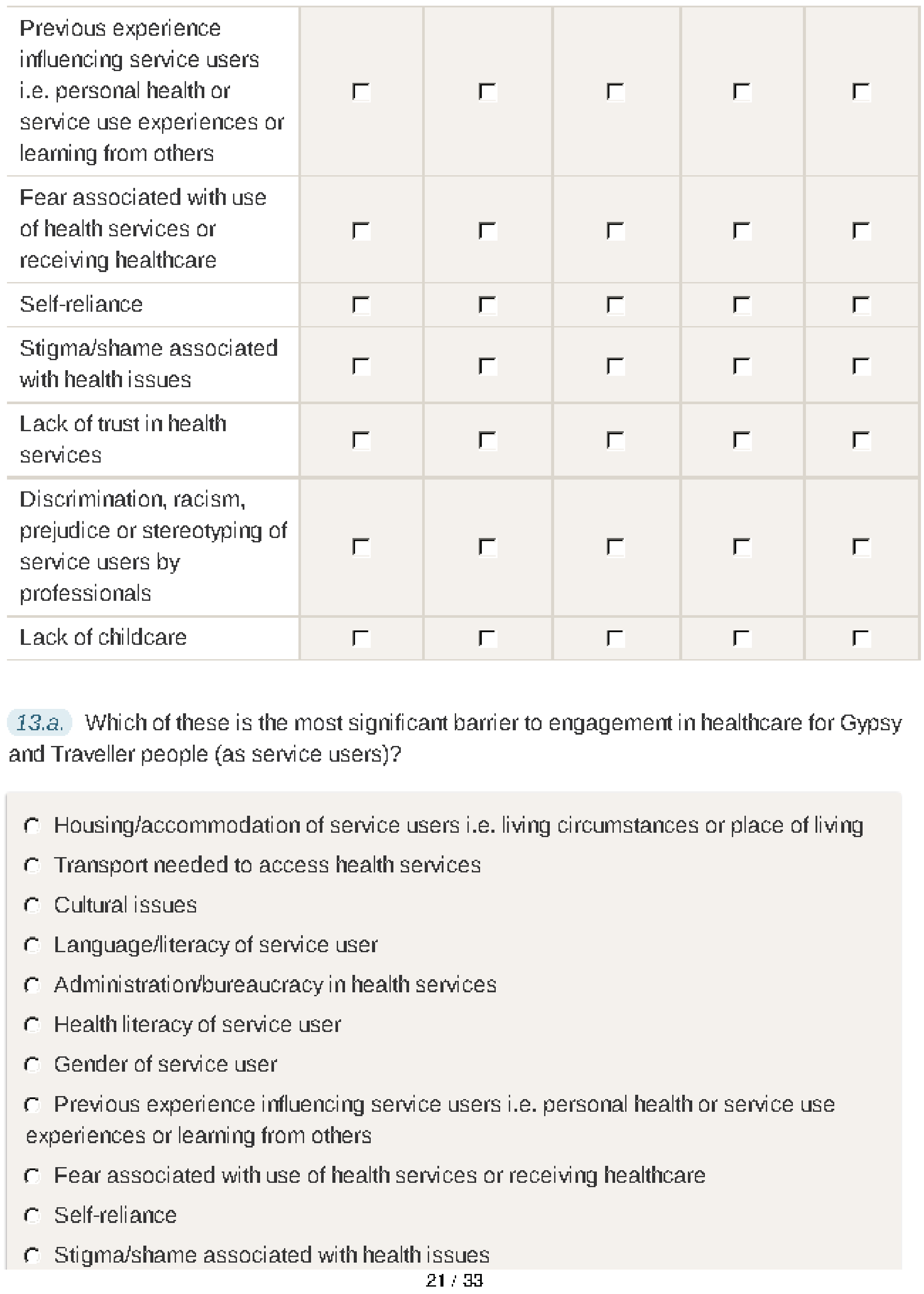
We have designed the questions on this page so that respondents can provide information about Gypsies and Travellers, and/or Roma, depending on experience.

Gypsy and Traveller people

13. How significant do you think the following are in terms of barriers to engagement in healthcare for Gypsy and Traveller people (as service users)?

Please don't select more than 1 answer(s) per row.

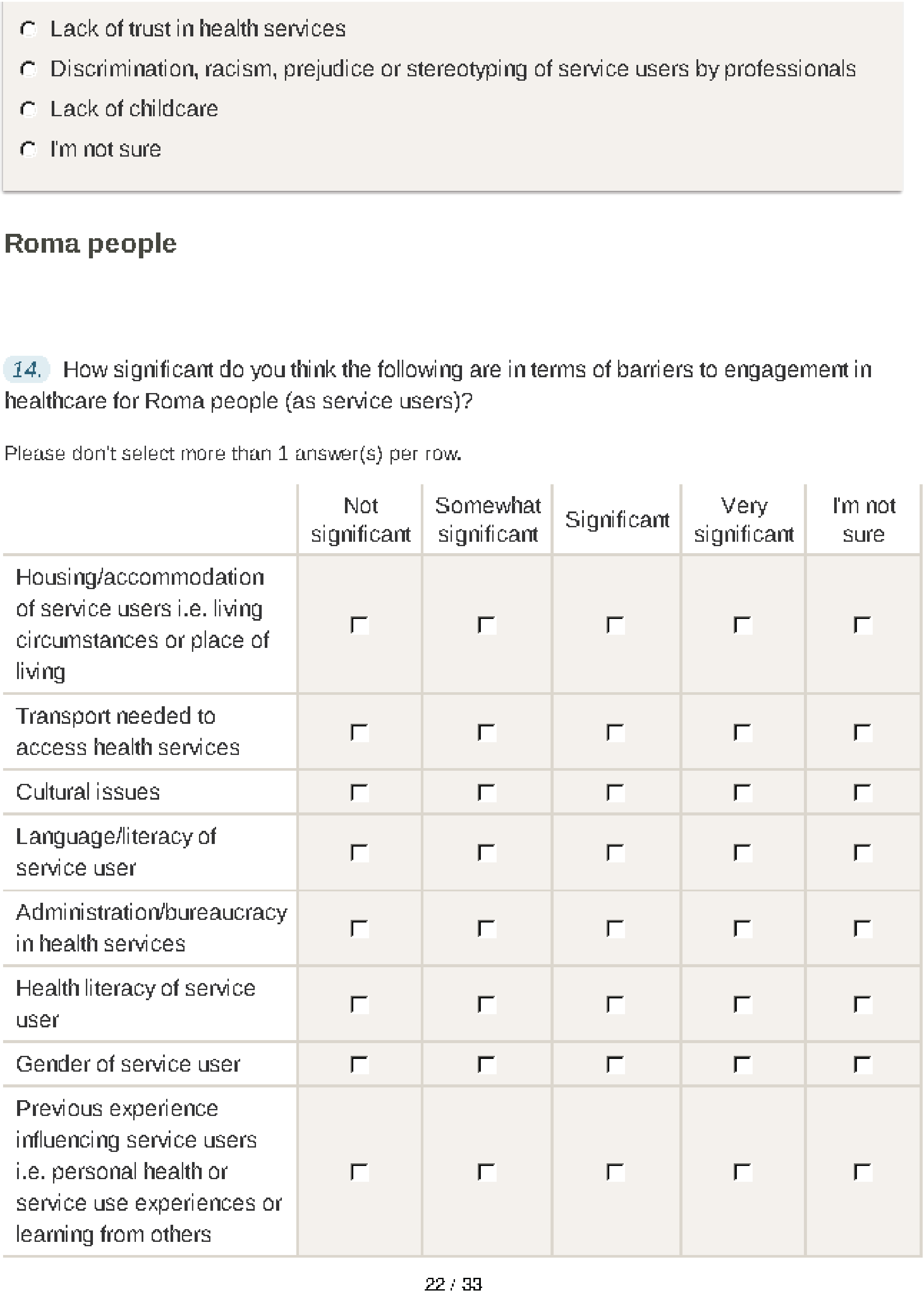
	Not significant	Somewhat significant	Significant	Very significant	I'm not sure
Housing/accommodation of service users i.e. living circumstances or place of living	☐	☐	☐	☐	☐
Transport needed to access health services	☐	☐	☐	☐	☐
Cultural issues	☐	☐	☐	☐	☐
Language/literacy of service user	☐	☐	☐	☐	☐
Administration/bureaucracy in health services	☐	☐	☐	☐	☐
Health literacy of service user	☐	☐	☐	☐	☐
Gender of service user	☐	☐	☐	☐	☐



Previous experience influencing service users i.e. personal health or service use experiences or learning from others	☐	☐	☐	☐	☐
Fear associated with use of health services or receiving healthcare	☐	☐	☐	☐	☐
Self-reliance	☐	☐	☐	☐	☐
Stigma/shame associated with health issues	☐	☐	☐	☐	☐
Lack of trust in health services	☐	☐	☐	☐	☐
Discrimination, racism, prejudice or stereotyping of service users by professionals	☐	☐	☐	☐	☐
Lack of childcare	☐	☐	☐	☐	☐

13.a. Which of these is the most significant barrier to engagement in healthcare for Gypsy and Traveller people (as service users)?

○ Housing/accommodation of service users i.e. living circumstances or place of living
○ Transport needed to access health services
○ Cultural issues
○ Language/literacy of service user
○ Administration/bureaucracy in health services
○ Health literacy of service user
○ Gender of service user
○ Previous experience influencing service users i.e. personal health or service use experiences or learning from others
○ Fear associated with use of health services or receiving healthcare
○ Self-reliance
○ Stigma/shame associated with health issues



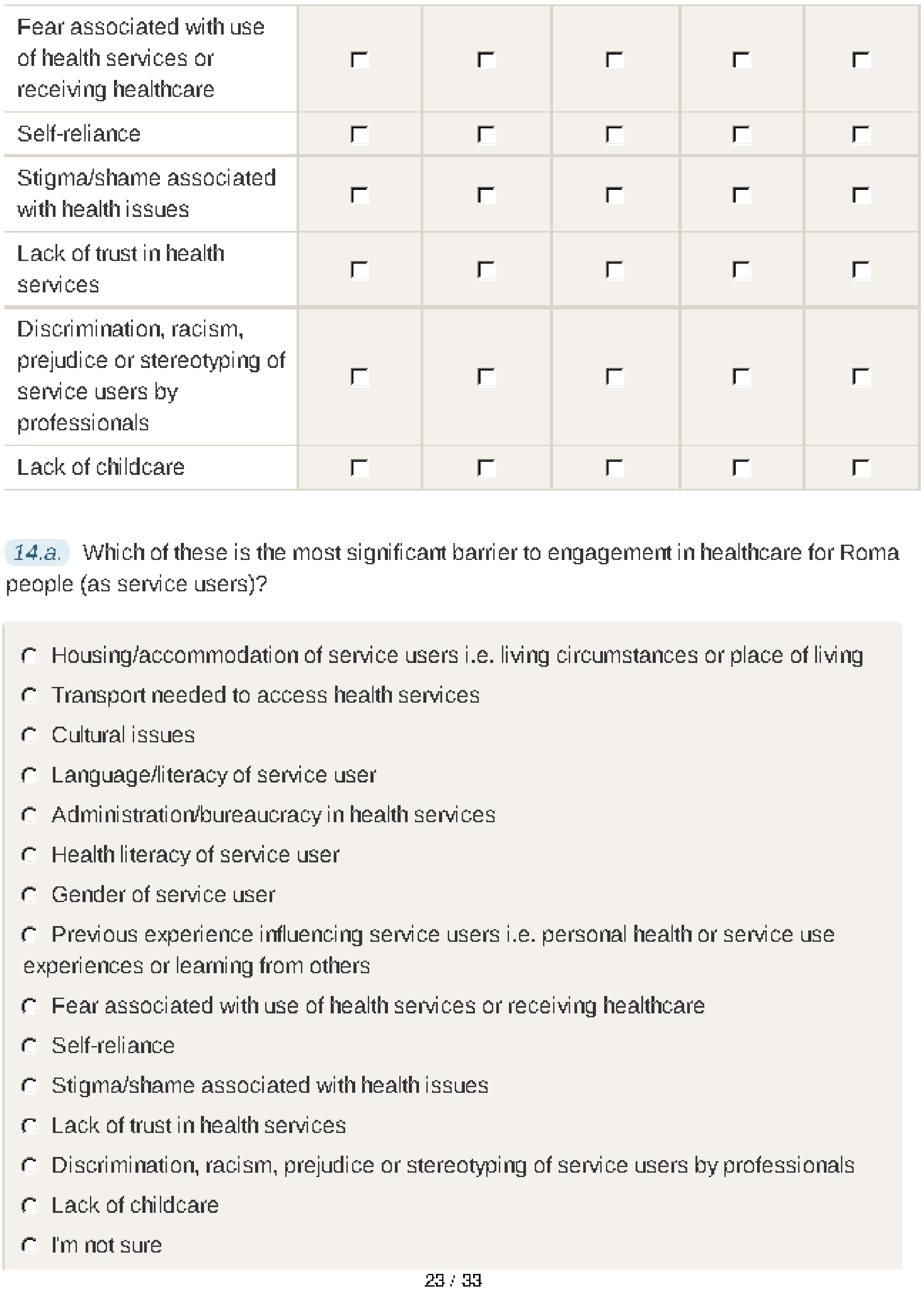
○ Lack of trust in health services
○ Discrimination, racism, prejudice or stereotyping of service users by professionals
○ Lack of childcare
○ I'm not sure

Roma people

14. How significant do you think the following are in terms of barriers to engagement in healthcare for Roma people (as service users)?

Please don't select more than 1 answer(s) per row.

	Not significant	Somewhat significant	Significant	Very significant	I'm not sure
Housing/accommodation of service users i.e. living circumstances or place of living	☐	☐	☐	☐	☐
Transport needed to access health services	☐	☐	☐	☐	☐
Cultural issues	☐	☐	☐	☐	☐
Language/literacy of service user	☐	☐	☐	☐	☐
Administration/bureaucracy in health services	☐	☐	☐	☐	☐
Health literacy of service user	☐	☐	☐	☐	☐
Gender of service user	☐	☐	☐	☐	☐
Previous experience influencing service users i.e. personal health or service use experiences or learning from others	☐	☐	☐	☐	☐



Fear associated with use of health services or receiving healthcare	☐	☐	☐	☐	☐
Self-reliance	☐	☐	☐	☐	☐
Stigma/shame associated with health issues	☐	☐	☐	☐	☐
Lack of trust in health services	☐	☐	☐	☐	☐
Discrimination, racism, prejudice or stereotyping of service users by professionals	☐	☐	☐	☐	☐
Lack of childcare	☐	☐	☐	☐	☐

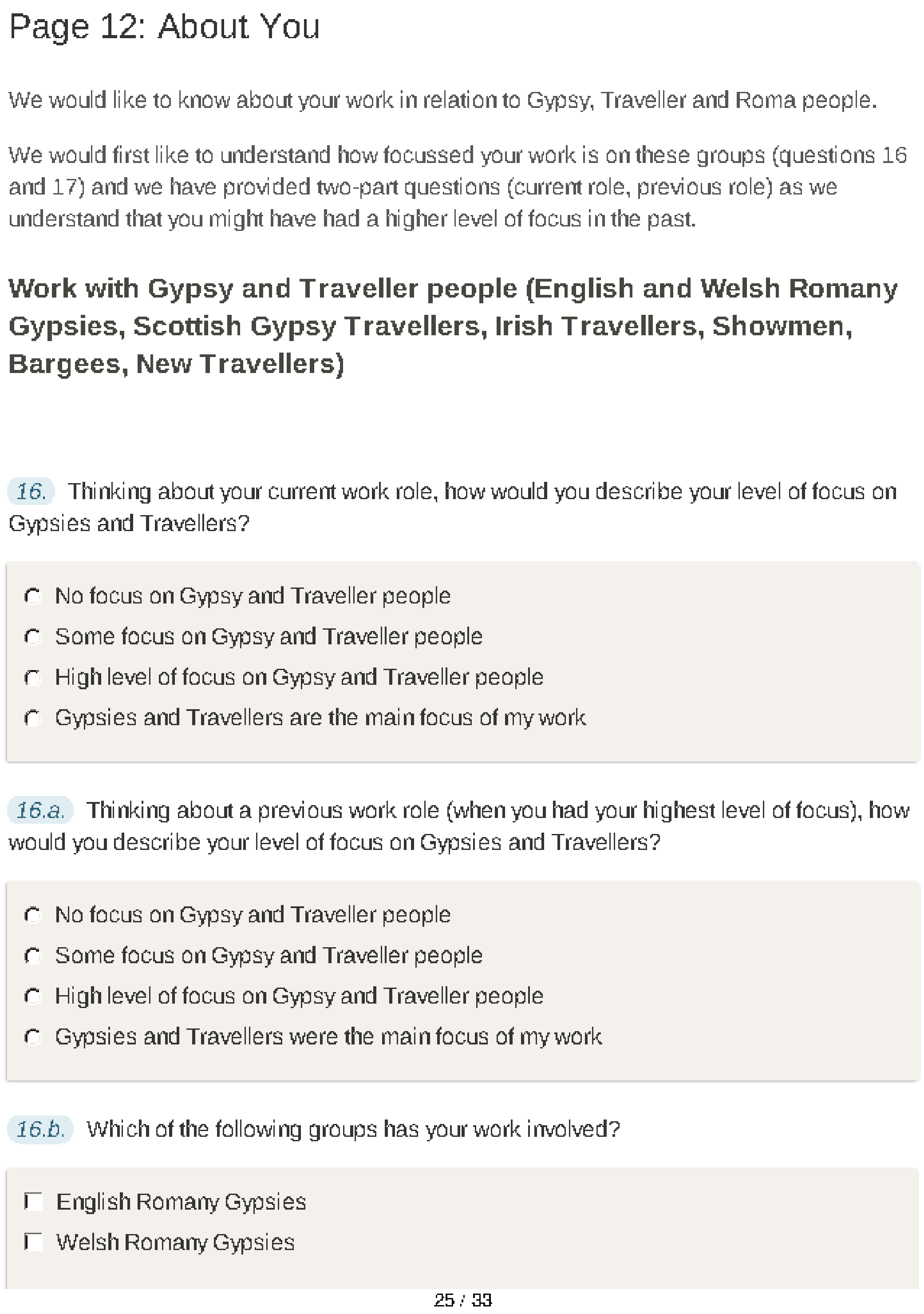
14.a. Which of these is the most significant barrier to engagement in healthcare for Roma people (as service users)?

○ Housing/accommodation of service users i.e. living circumstances or place of living
○ Transport needed to access health services
○ Cultural issues
○ Language/literacy of service user
○ Administration/bureaucracy in health services
○ Health literacy of service user
○ Gender of service user
○ Previous experience influencing service users i.e. personal health or service use experiences or learning from others
○ Fear associated with use of health services or receiving healthcare
○ Self-reliance
○ Stigma/shame associated with health issues
○ Lack of trust in health services
○ Discrimination, racism, prejudice or stereotyping of service users by professionals
○ Lack of childcare
○ I'm not sure

Gypsy, Traveller and Roma people

15. If you wish, please comment on any of these barriers and/or add any others.

(Box expands; please do not type 'see above')



Page 12: About You

We would like to know about your work in relation to Gypsy, Traveller and Roma people.

We would first like to understand how focussed your work is on these groups (questions 16 and 17) and we have provided two-part questions (current role, previous role) as we understand that you might have had a higher level of focus in the past.

Work with Gypsy and Traveller people (English and Welsh Romany Gypsies, Scottish Gypsy Travellers, Irish Travellers, Showmen, Bargees, New Travellers)

16. Thinking about your current work role, how would you describe your level of focus on Gypsies and Travellers?

- ○ No focus on Gypsy and Traveller people
- ○ Some focus on Gypsy and Traveller people
- ○ High level of focus on Gypsy and Traveller people
- ○ Gypsies and Travellers are the main focus of my work

16.a. Thinking about a previous work role (when you had your highest level of focus), how would you describe your level of focus on Gypsies and Travellers?

- ○ No focus on Gypsy and Traveller people
- ○ Some focus on Gypsy and Traveller people
- ○ High level of focus on Gypsy and Traveller people
- ○ Gypsies and Travellers were the main focus of my work

16.b. Which of the following groups has your work involved?

- ☐ English Romany Gypsies
- ☐ Welsh Romany Gypsies

☐ Scottish Gypsy Travellers
☐ Irish Travellers
☐ Showmen
☐ Bargees
☐ New Travellers
☐ I'm not sure
☐ Not applicable (my work has not involved Gypsies and Travellers)

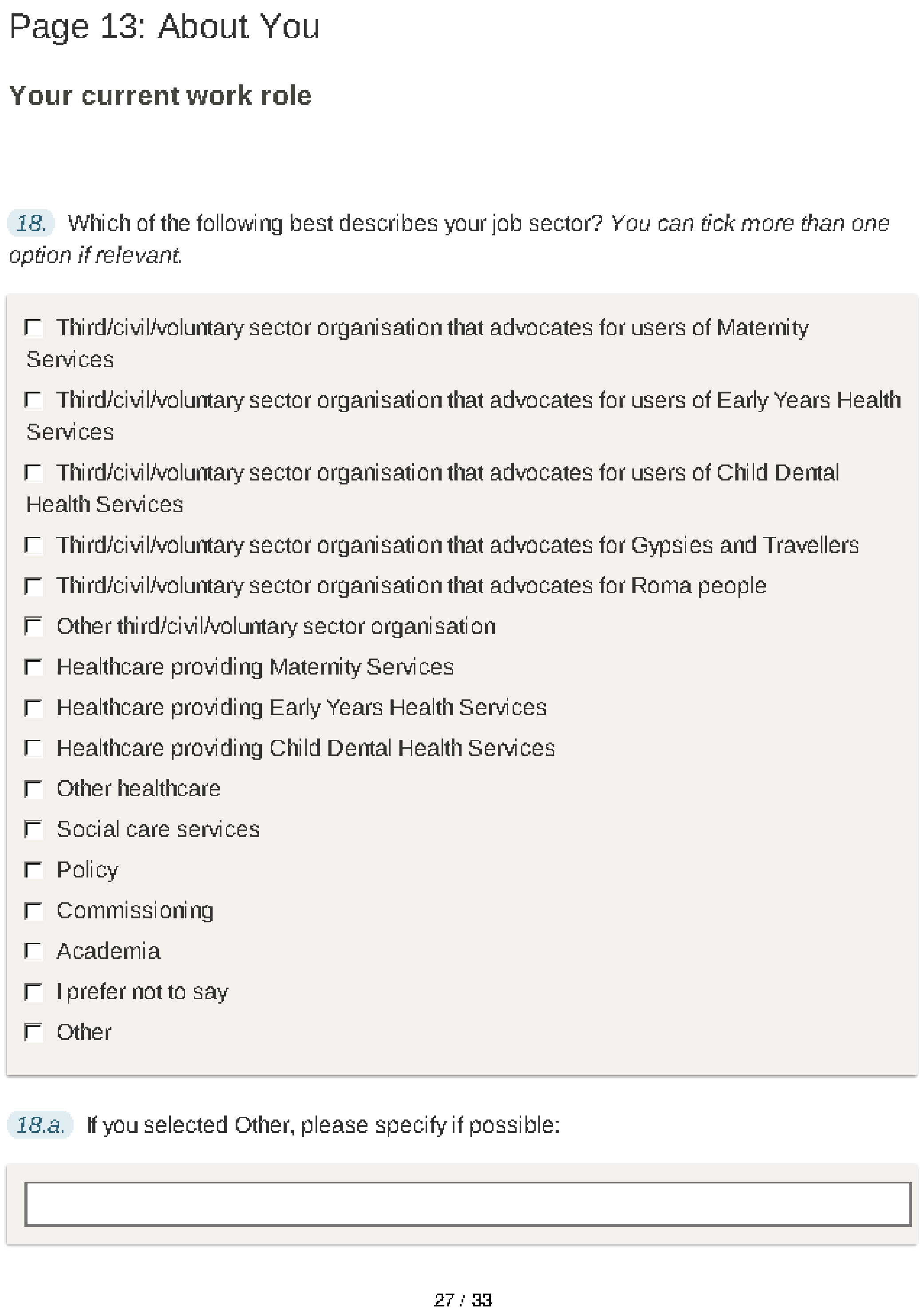
Work with Roma people (from Europe)

17. Thinking about your current work role, how would you describe your level of focus on Roma people?

○ No focus on Roma people
○ Some focus on Roma people
○ High level of focus on Roma people
○ Roma people are the main focus of my work

17.a. Thinking about a previous work role (when you had your highest level of focus), how would you describe your level of focus on Roma people?

○ No focus on Roma people
○ Some focus on Roma people
○ High level of focus on Roma people
○ Roma people were the main focus of my work



Page 13: About You

Your current work role

18. Which of the following best describes your job sector? *You can tick more than one option if relevant.*

- ☐ Third/civil/voluntary sector organisation that advocates for users of Maternity Services
- ☐ Third/civil/voluntary sector organisation that advocates for users of Early Years Health Services
- ☐ Third/civil/voluntary sector organisation that advocates for users of Child Dental Health Services
- ☐ Third/civil/voluntary sector organisation that advocates for Gypsies and Travellers
- ☐ Third/civil/voluntary sector organisation that advocates for Roma people
- ☐ Other third/civil/voluntary sector organisation
- ☐ Healthcare providing Maternity Services
- ☐ Healthcare providing Early Years Health Services
- ☐ Healthcare providing Child Dental Health Services
- ☐ Other healthcare
- ☐ Social care services
- ☐ Policy
- ☐ Commissioning
- ☐ Academia
- ☐ I prefer not to say
- ☐ Other

18.a. If you selected Other, please specify if possible:

19. What is your job role?

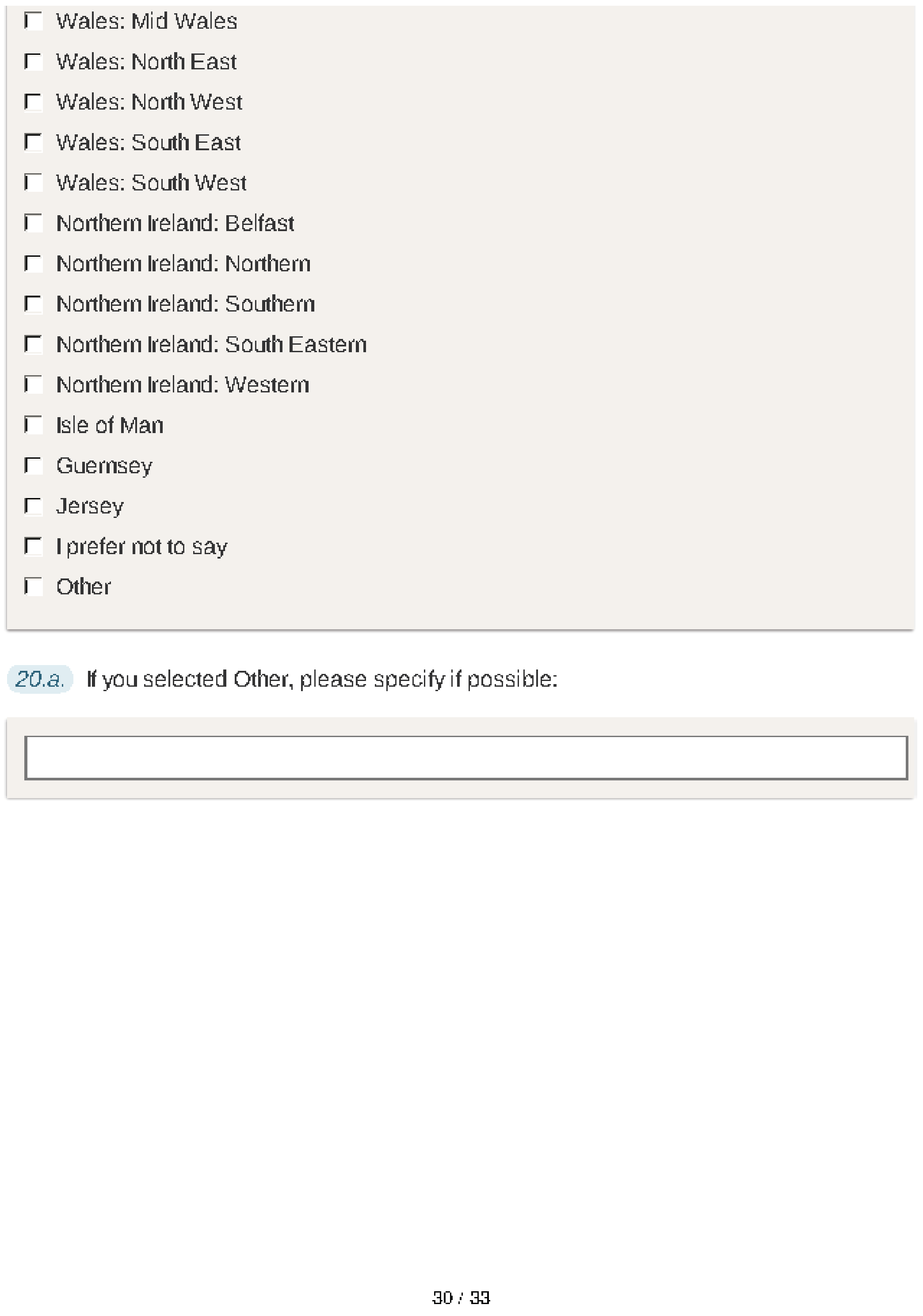
☐ Midwife
☐ Health Visitor
☐ Early Years Practitioner
☐ Infant Feeding Specialist
☐ Obstetrician
☐ Paediatrician
☐ General Practitioner
☐ Nurse
☐ Public Health Specialist
☐ Non-salaried General Dental Practitioner
☐ Salaried General Dental Practitioner
☐ Specialist or Consultant in Paediatric Dentistry
☐ Dental Nurse
☐ Dental Therapist
☐ Dental Hygienist
☐ Childsmile or other oral health promotion/preventative programme
☐ Clinical Commissioning Group/Service Commissioner
☐ Health Inequality Team
☐ Health Improvement Specialist
☐ Support Worker
☐ Administrator
☐ Service Manager
☐ Manager within a third/civil/voluntary sector organisation
☐ CEO/Director of a third/civil/voluntary sector organisation
☐ Academic
☐ Volunteer
☐ I prefer not to say
☐ Other

19.a. If you selected Other, please specify if possible:

☐

20. Where is your work based?

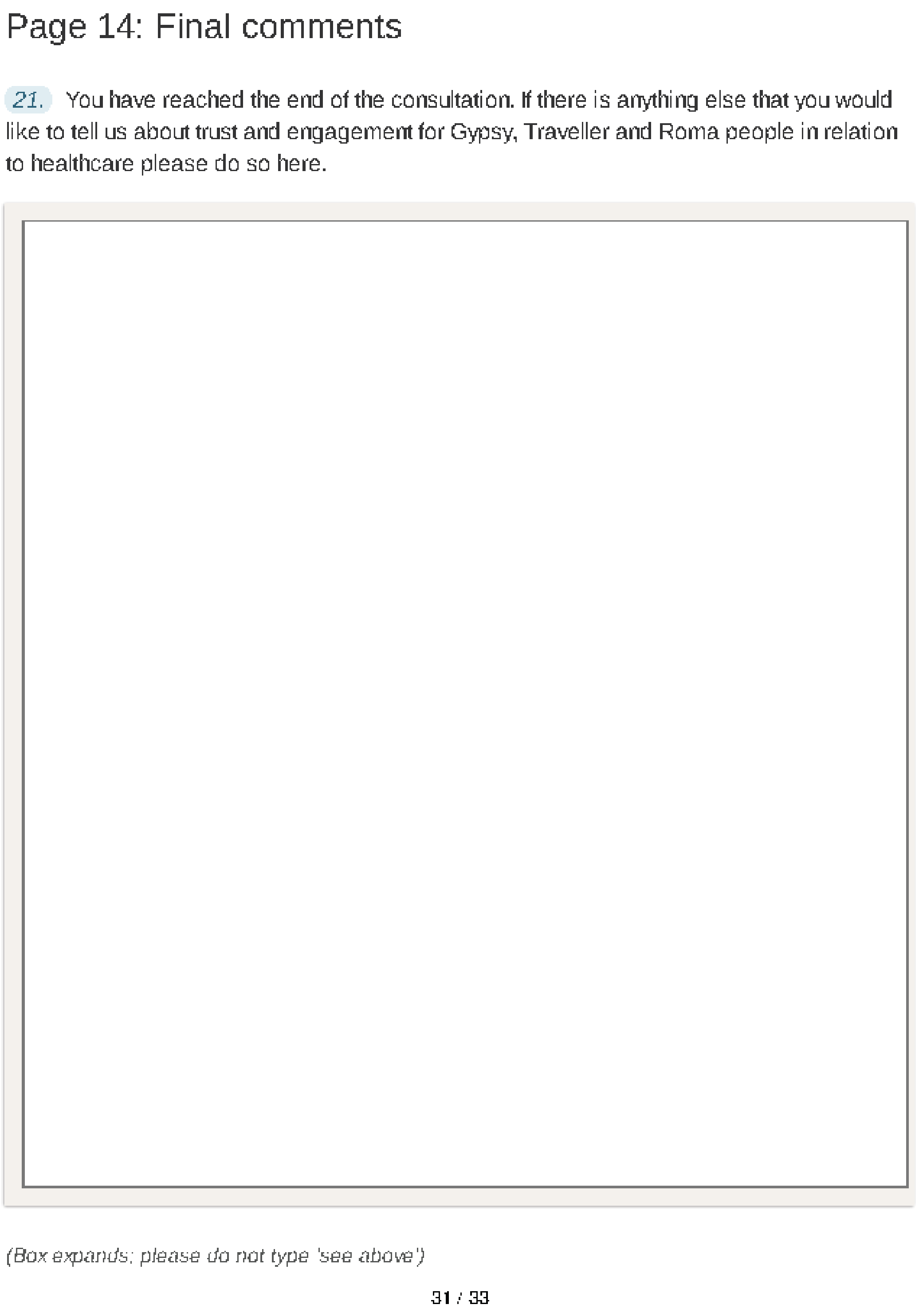
☐ Scotland: Ayrshire and Arran
☐ Scotland: Borders
☐ Scotland: Dumfries and Galloway
☐ Scotland: Fife
☐ Scotland: Forth Valley
☐ Scotland: Grampian
☐ Scotland: Greater Glasgow and Clyde
☐ Scotland: Highland
☐ Scotland: Lanarkshire
☐ Scotland: Lothian
☐ Scotland: Orkney
☐ Scotland: Shetland
☐ Scotland: Tayside
☐ Scotland: Western Isles
☐ England: East of England
☐ England: East Midlands
☐ England: London
☐ England: North East
☐ England: North West
☐ England: South Central
☐ England: South East
☐ England: South West
☐ England: West Midlands
☐ England: Yorkshire and the Humber



☐ Wales: Mid Wales
☐ Wales: North East
☐ Wales: North West
☐ Wales: South East
☐ Wales: South West
☐ Northern Ireland: Belfast
☐ Northern Ireland: Northern
☐ Northern Ireland: Southern
☐ Northern Ireland: South Eastern
☐ Northern Ireland: Western
☐ Isle of Man
☐ Guernsey
☐ Jersey
☐ I prefer not to say
☐ Other

20.a. If you selected Other, please specify if possible:

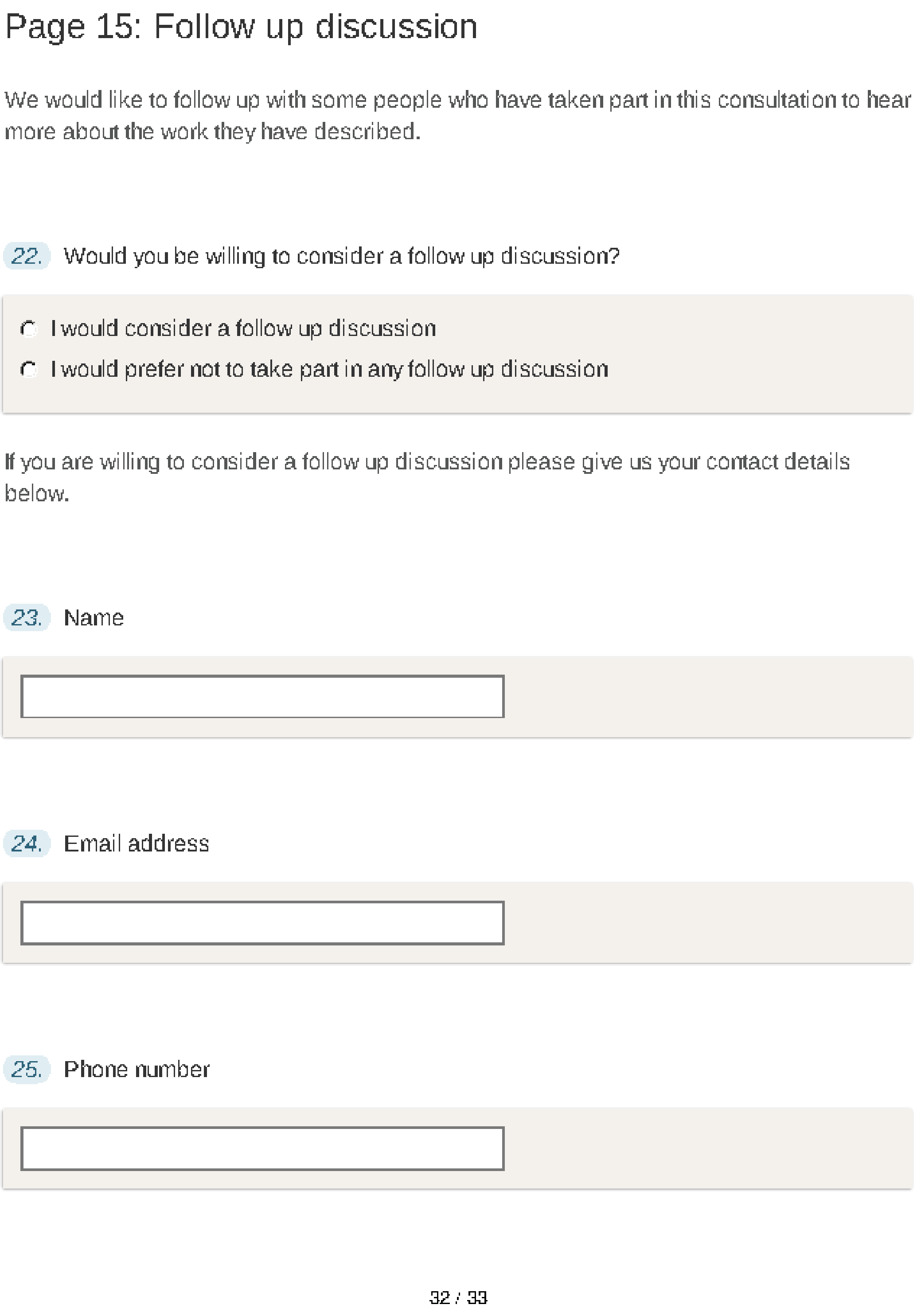
30 / 33



Page 14: Final comments

21. You have reached the end of the consultation. If there is anything else that you would like to tell us about trust and engagement for Gypsy, Traveller and Roma people in relation to healthcare please do so here.

(Box expands; please do not type 'see above')



Page 15: Follow up discussion

We would like to follow up with some people who have taken part in this consultation to hear more about the work they have described.

22. Would you be willing to consider a follow up discussion?

○ I would consider a follow up discussion
○ I would prefer not to take part in any follow up discussion

If you are willing to consider a follow up discussion please give us your contact details below.

23. Name

24. Email address

25. Phone number

32 / 33

Page 16: Thank you

Thank you very much for taking the time to complete this online consultation. Your responses have now been submitted.

The study will be completed in December 2017.

If you would like to receive a summary of the findings please click on the link below to leave your contact details. These contact details will not be linked to your consultation responses.

https://dundee.onlinesurveys.ac.uk/engagementandtrustcontactdetails

Appendix 8: Case study topic guides

Interview Topic Guide: Mothers of pre-school aged children

Experiences of maternity and child health services

1 We are interested in your experiences of maternity care. How many children do you have?
2 Is your child a boy or girl/Are your children boys or girls?
3 What age is your child/are your children?
4 Can you tell me a story about using maternity services? Prompts – during pregnancy, birth, after the birth)
5 What services did you use during pregnancy/giving birth/after the birth?
6 What was good about the services/not so good/how could they be improved?
7 Were there any barriers to using maternity services?
8 Can you tell me a story about using child health services for your child(ren) e.g. health visitor developmental checks; using health services when you child was ill
9 How could child health services be improved? What advice would you give to other Gypsy/Traveller, Roma women about maternity services and health services for children?

Child dentistry

1 What about your use of child dentistry services? Have you seen the child dentist and can you tell me a story about that?
2 Are you registered with a dentist/ is it easy to register with the dentist/is it easy to use the dentist?
3 Are there barriers to accessing the dentist for your children?
4 How could dentistry services for children be improved? What advice would you give to other Gypsy/Traveller, Roma women about dentistry services for children?

General health services

1 Can you tell me about your experiences of engaging with/using different health services?
2 Which health services are easier to engage with than others? [Prompts: If so, why? Are there health services that do a particularly good job of engaging with Gypsy/Travellers/Roma? What is good about them? Are there any that are difficult to engage with or use? If so, why?]
3 Are there any barriers or things which make it difficult for you to engage with or use health services? Do you think your experiences of using health services are different from other women who are not Gypsy Travellers?
4 Are you registered with a GP? Are your other family members (husband, children)?

Trust

We are interested in the importance of trust when it comes to engaging with different health services.
1 Do you think that trust is important when it comes to accessing health services?
2 Could anything be done to build more trust between health services and Gypsy/Travellers/Roma?
3 What could maternity services do to build more trust?
4 What could the child dentist do to build more trust?

Engagement

1 Have you ever been involved with any health services to increase engagement or trust (such as asked your opinion about what's good or bad)? Have you been involved in any projects that aim to increase engagement or trust?
2 Are there other community projects or services [e.g. voluntary sector] going on that help people access health services? What do they do well? What else could they do? [Prompt: Involvement with organisations]

Demographics

1 What age are you?

2 What kind of accommodation do you live in?
3 How long have you lived in your current location?
4 Where are you originally from?
5 Are you Romany Gypsy, Irish Traveller, Roma?

Final points

1 What would you like us to tell health professionals about providing services for Gypsy/Travellers, Roma? What would you like us to tell the Department of Health/Government about providing health services for Gypsy/Travellers, Roma?
2 Is there anything else that you would like to tell me about?

Topic Guide: Health Care Professionals (focus groups and individual interviews)

A. Focussed discussion on participants' roles and the work they do with Gypsies, Travellers or Roma

Could you briefly describe your role for me please?

Could you summarise your work with Gypsies, Travellers or Roma people? How many Gypsies, Travellers, Roma people live in your catchment area?

B. General discussion about health services, maternity, dentistry

As you know, we are interested in how Gypsy/Traveller/Roma families engage with different health services. Can you tell me about your thoughts on this?

Are some of the health services easier to engage with than others? [*Prompts: Are there health services that do a particularly good job of engaging with Gypsy/Travellers/Roma? Are there any that are very difficult to engage with?]*

As you know, we are particularly interested in services related to maternity, children's health and children's dentistry. Could you tell me about Gypsy, Traveller and Roma people's engagement with these services? *(Participant to discuss their particular area of knowledge)*

Are there any barriers or things which make it difficult for Gypsy/Travellers or Roma people to engage with health services?

What, if anything, could services do to enhance Gypsies, Travellers and Roma people's engagement?

What, if anything, could maternity/child's health/child's dentistry do to enhance engagement?

Are you aware of any examples of good practice in terms of working with/engaging with Gypsy/Travellers elsewhere? (prompts – could they be replicated in your services?)

How does working with Gypsy/Travellers compare with working with other BME groups/vulnerable populations/majority population? Why do you think this is?

C. Trust

We are interested in the importance of trust when it comes to engaging with different health services. Do you think that trust is important? To what extent does trust exist between your services and Gypsies, Travellers or Roma people?

What, if anything, could be done to build more trust between health services and Gypsy/Travellers/Roma?

What could maternity/child's health/child's dentistry do to enhance trust?

Are there other factors, aside from trust, that are important when it comes to engaging with services?

D. Training and education

Have you had any training/education related to working with Gypsy/Traveller communities/BME groups/vulnerable populations?

Did the training meet your needs/could it be improved?

What training would you like?

E. Cross-sectoral working

Do you work with any other sectors/disciplines to deliver services to Gypsies, Travellers and Roma people? E.g. Local authority, education, third sector/voluntary/charities?
How does this help you to engage with Gypsies, Travellers and Roma people? How could you work better with other sectors?
F. Other issues the participant would like to discuss
Is there anything else that you would like to discuss?

Interview Guide: Third Sector

A. Focussed discussion on participant's role and the work they do with Gypsies, Travellers or Roma
Could you briefly describe your role for me please?
Could you summarise your work with Gypsies, Travellers or Roma people?
B. General discussion about health services, maternity, dentistry
As you know, we are interested in how Gypsy/Traveller/Roma families engage with different health services. Can you tell me about your thoughts on this?
Are some of the health services easier to engage with than others for Gypsy/Travellers? [*Prompts: Are there health services that do a particularly good job of engaging with Gypsy/Travellers/Roma? Are there any that are very difficult to engage with?]*
As you know, we are particularly interested in services related to maternity, children's health and children's dentistry. Could you tell me about Gypsy, Traveller and Roma people's engagement with these services? *(Participant to discuss their particular area of knowledge)*
Are there any barriers or things which make it difficult for Gypsy/Travellers or Roma people to engage with health services?
How does your organisation engage with health services (if at all)? [Is there anything that could improve your relationship with health services? Is there anything more that your organisation could do to improve engagement between health services and Gypsy/Travellers?]
What, if anything, could services do to enhance Gypsies, Travellers and Roma people's engagement?
What, if anything, could maternity/child's health/child's dentistry do to enhance engagement?
C. Trust
We are interested in the importance of trust when it comes to engaging with different health services. Do you think that trust is important?
What, if anything, could be done to build more trust between health services and Gypsy/Travellers/Roma?
What could maternity/child's health/child's dentistry do to enhance trust?
Are there other factors, aside from trust, that are important when it comes to engaging with services?
D. Community Engagement
What approaches to community engagement do you use with Gypsy/Travellers/Roma people? [What approaches do you think work best? Are there lessons from other sectors (e.g. local authority, education) that could apply to health services in terms of engaging with Gypsy/Travellers/Roma communities?]
Are you aware of any examples of good practice (in terms of developing trust or engagement with Gypsy/Travellers by health services) in other areas that could be used in this area?
D. Other issues the participant wants to discuss
What would you like us to feedback to health services in our report?
What would you like us to feedback to the government?
Is there anything else that you would like to discuss?

Appendix 9: Case study findings mapped to the conceptual model of trust

<table>
<tr><th><u>Patient-provider trust themes</u></th><th><u>Key issues discussed</u></th></tr>
<tr><td>Relationships</td><td>-Building relationships between provider and patient
-Consistency of provider
-Length of relationships and building trust over time
-The relationship with any interpreter
-Comfort and rapport</td></tr>
<tr><td colspan="2"><i>Examples from discussion:</i>

‘The midwifery service is a good model […] the midwife […] will access them wherever they are and is very well known within the community. […] It’s always the same person, they know what to expect, and she’s very well trusted within their community.’ (HCP, case 1)

‘I’ve got quite a large caseload of Roma ladies that I see […] if you get to know them, if you spend the time to get to know them they build up a bit of a trust with you and then they do want to come and see you. So it’s just odd ones that don’t always engage’ (HCP, case 3)

‘once you have a trusted individual who is able to keep plugging away and go back onto the site and becomes known and maybe set up whatever they need to set up there, that’s when the trust starts to happen’ (TSO, case 2)</td></tr>
<tr><td>Power</td><td>-Balance of power
-Patient’s power as important in their care
-Patient able to share views and contribute</td></tr>
<tr><td colspan="2"><i>Examples from discussion:</i>
‘It’s like “you’re you and I’m me and I’ve got my uniform on and I’m in charge”. And the way you get people to trust you is to not do that, and to talk to them like, “I’ve got some knowledge but we’re equals”’ (HCP, case 1)</td></tr>
<tr><td colspan="2"><u>Provider trust themes</u></td></tr>
<tr><td>Professional competency</td><td>- Being dissatisfied or feeling lack of professional competency
-Comprehensive and coordinated services as positive (and reverse)
-Attentiveness as important, and experiences of lack of attentiveness</td></tr>
<tr><td colspan="2"><i>Examples from discussion:</i>
‘I changed my doctor because I didn’t seem to be getting anywhere with him’ (Mother, case 1)

‘I went down to that hospital to try and get seen, try to get appointments, try to get answers, and it was like you were just blanked and you didn’t know what was happening. That’s how I felt at the time […] They never gave me the care or anything that I think I needed (Mother, case 2)</td></tr>
<tr><td>Interpersonal competency</td><td>-Clear, complete, open communication; listening
-Communication affected by lack of shared language, involvement of interpreters
-Attitude, manner
-Importance of respect
-Discrimination in healthcare
-Understanding the patient, their circumstances, cultural competence and acceptance</td></tr>
<tr><td colspan="2"><i>Examples from discussion:</i>
‘if they’ve got an attitude that they don’t like you […] and just doing it because it’s their job, no, I don’t want to see them again. But if they really are genuine and nice …’ (Mother, case 1)

‘there used to be a Traveller education service […] it was cut […] I think that was really good because they had someone that everybody trusted and respected who was going up to the sites talking to families and made a difference’ (TSO, case 4)</td></tr>
</table>

<table>
<tr><td colspan="2">‘I think it’s probably better that you have somebody who understands and has a good dialogue with them because then that way they can dictate what’s more important’ (HCP, case 2)</td></tr>
<tr><td>Caring</td><td>-Caring, patient’s interests in mind, kindness, compassion</td></tr>
<tr><td colspan="2"><i>Examples from discussion:</i>
‘we had to have some quite difficult discussions around his child’s oral care […] And so there the way I approached it was just to try to communicate to him that I had his child’s interests at heart, that we weren’t trying to … I think he thought we were criticising […] Over subsequent appointments we built up really a very friendly, amicable relationship’ (HCP, case 3)</td></tr>
<tr><td>Assistance, advocacy</td><td>-Third sector or health professionals providing advocacy around accessing health services</td></tr>
<tr><td colspan="2"><i>Examples from discussion:</i>
‘It changes weekly as to which dentists are accepting NHS patients. It relies upon someone being able to access that information, usually online. So usually it does need somebody, some sort of advocate, to find that information out and then to translate that information to the community […] And then there’s the added difficulties of having to go up and complete all the paperwork, usually there’s people that struggle with filling forms in. So that’s generally another service that requires somebody in a supporting role […] ’ (HCP, case 1)</td></tr>
<tr><td>Accessibility</td><td>-Ability to access: registration difficulties; punitive measures to remove people from registration lists, around being late for appointments
-Availability of the HP: inability to get appointments
-Amount of time to spend with patient during consultation, or patient is rushed
-Long waiting times or lists</td></tr>
<tr><td colspan="2"><i>Examples from discussion:</i>
‘It’s not a very good doctor’s […] I just wouldn’t recommend them. They rush you in and out and sometimes you have an appointment, say for eleven, and they don’t see you until about twenty past, twenty-five past […] sometimes you can’t get an appointment.’ (Mother, case 1)
‘if they do arrive late we do try and accommodate to see, they’re here…’ (HCP, case 3)</td></tr>
</table>

Appendix 10: Cross-sectoral workshop hand-outs

Gypsy, Roma and Traveller Trust & Engagement Research Stakeholder Workshop Group discussion 1: Knowledge and experiences

Complex needs and poor health outcomes

Mixed satisfaction;
Varied expectations?

Good experiences linked to good relationships with certain practitioners

Reports of engagement with dentists but difficulties experienced and high level of treatment

KNOWLEDGE AND EXPERIENCES OF HEALTH SERVICES

Examples of misdiagnosis by healthcare practitioners

Not meeting expectations of care

Influence of past experiences of services (own, other's) affects engagement

Not being listened to, dismissed

Exercising autonomy: seeking additional/alternative care

Gypsy, Roma and Traveller Trust & Engagement Research Stakeholder Workshop Group discussion 1: Barriers

BARRIERS TO ACCESSING AND ENGAGING WITH HEALTH SERVICES

- Broader social issues e.g. discrimination, immigration, inequality…
- Transience
- Lack of understanding to navigate services
- Difficulties registering/accessing regularly e.g. practices full, travelling for care, address needed, waiting lists
- Emphasis on written word
- Language and interpreters
- Lack of communication, explanation, support when using some services
- Punitive approach to appointments (late, missed)
- Costs associated with engaging with services
- Concerns about discrimination and hostility
- Concerns over monitoring, confidentiality, information being passed between agencies
- Balancing HP and service user priorities
- Services not integrated; Slow, complex referrals
- Consultations without result
- Short-termism including funding

Gypsy, Roma and Traveller Trust & Engagement Research Stakeholder Workshop Group discussion 1: Trust

Trust is important

Mixed experiences and thoughts regarding trusting HPs

Cyclical nature of trust and mistrust; and engagement

Importance of working with already trusted people

Importance of feeling that practitioner has patient's best interests in mind.

Misplaced trust can lead to acceptance of incorrect diagnosis

CONCEPT AND IMPORTANCE OF TRUST

Takes time and persistence

Sharing of power: acknowledging service user's instincts and knowledge

Needs communication (especially listening) and relationship building

Importance of interpersonal and professional competence

Group discussion 2: Group score sheet Table ……….

Instructions

Please rate each strategy as **HIGH** or **MEDIUM** or **LOW** for:

a) **Acceptability** to Gypsy, Roma and Traveller (GRT) people
b) **Feasibility** for health services and/or third sector organisations to implement
c) **Estimated cost** of implementation

1. COMMUNITY ENGAGEMENT	**Acceptability**	**Feasibility**	**Cost**
Involve GRT communities in identifying assets for heath and designing services to meet their needs			
Focus health services on service-user priorities including referral/signposting for priorities beyond the remit of health services e.g. housing, debt advice, heating			
Enhance GRT people's tools and skills to get what they need out of encounters with health services e.g. awareness of health service-user rights, tips on how to communicate with healthcare professionals and confidence to ask questions			
Increase collaborative working with those that already have trusted relationships with GRT communities e.g. individuals from third sector organisations, individual health or other sector professionals			
Increase the role of third sector organisations in service design, commissioning and delivery			
Optimise use of local authority site assets e.g. use space for health-related activities such as 'stay and play', develop the role of site managers to have a community development focus			
2. FLEXIBLE SERVICES			
Provide outreach services to sites with the goal of encouraging access to mainstream services			
Increase flexibility of practitioners to cross geographical boundaries to provide continuity of care within reason (e.g. within same town/city)			
Develop specialist health professional and third sector roles that focus on developing trust and acting as a bridge to mainstream services			
Develop health advocacy roles for GRT people to work with communities to facilitate access to mainstream services e.g. health mediators, health champions, peer support			
Develop specific care pathways for GRT people for maternity, child health and child dental health services			
Provide flexible services e.g. flexible times/'drop-in' services/multiple access routes, one-stop shops			
3. MAINSTREAM SERVICE DELIVERY			
Simplify GP and dentist registration e.g. allow c/o addresses, flexible requirements for proof of address			
Develop less punitive approaches to dealing with non-attendance or arriving late for appointments			
Develop alternatives to written information			
Improve access to professional interpreting services			
	Acceptability	**Feasibility**	**Cost**
Introduce literacy help cards throughout NHS (cards that can be presented to front line staff or receptionists to ask for discreet help with form-filling etc.)			

Sustain investment in projects and initiatives to allow relationships and trust to develop and continue			
Develop minimum standards of courtesy for all health service personnel including first points of contact e.g. receptionists, helpline staff			
Provide holistic family-centred care that focuses on needs of all family members rather than fragmented services (e.g. different services for early years' and school-age children)			
4. KNOWLEDGE AND TRAINING			
Use engagement with routine maternity and child health services to deliver wider health messages, especially relating to child oral health			
Involve GRT people and third sector organisations in health service staff training (pre-registration, post-registration, continuing professional development) to increase sensitivity to barriers to healthcare access; impact of wider experiences of prejudice and discrimination and effective ways of working with GRT communities			
Maximise opportunities for those involved in delivering health services for GRT people to reflect on their experiences and share their learning with mainstream service providers and commissioners			
Shape health service procedures through policies that relate to GRT communities e.g. collecting data on GRT health service use and outcomes			
OTHER (please add)			

Exercise 3: Influencing policy - priority strategies

STRATEGY 1

Who to influence	**How** to influence	**Blockages** to influence

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