

BMJ Open Experiences and outcomes of Gypsy, Roma and Traveller women in pregnancy: a scoping review protocol

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To cite: O'Brien M, Dempsey B, Higgins M. Experiences and outcomes of Gypsy, Roma and Traveller women in pregnancy: a scoping review protocol. *BMJ Open* 2022;**12**:e057788. doi:10.1136/bmjopen-2021-057788

► Prepublication history and additional supplemental material for this paper are available online. To view these files, please visit the journal online (<http://dx.doi.org/10.1136/bmjopen-2021-057788>).

Received 28 September 2021
Accepted 07 June 2022

ABSTRACT

Introduction Gypsy, Roma and Traveller communities are subjected to a specific form of racism fuelled by deep-seated prejudice and stereotypes. These groups have historically been the victims of school segregation, forced assimilation policies, hate speech and hate crimes. Persecution and displacement have resulted in high rates of unemployment, reduced access to education and poorer health in general, which places these groups at significantly increased risk of poverty. In pregnancy, they are at increased risk of adverse obstetric outcomes. There is a gap in the literature surrounding the experiences and outcomes of pregnant women within this group. A scoping review was chosen as the appropriate methodology to identify what is known about the experiences and outcomes of pregnant women in these communities.

Methods and Analysis The Levac *et al* guideline on conducting a scoping review will be followed. This six-step approach includes identification of the research question, identification of relevant studies, selection of studies, charting of data, summary of results and consultation with experiential experts. A comprehensive search of the following electronic databases from 1980 to 2021 will be conducted: CINAHL, Embase, MEDLINE, Scopus and Web of Science. Relevant grey literature and reference lists will also be searched. The Preferred Reporting Items for Systematic reviews and Meta-Analyses extension for Scoping Reviews (PRISMA-ScR) tool will be used.

Ethics and dissemination Ethical approval was not required for this protocol as all literature within this scoping review are publicly available. To facilitate dissemination of findings, the research team will present the findings to key stakeholders working with Gypsy, Roma and Traveller communities.

STRENGTHS AND LIMITATIONS OF THIS STUDY

- ⇒ Patient advocacy groups were consulted to inform the research question and search strategy.
- ⇒ Both published peer-reviewed and grey literature will be included to enhance the completeness of the review.
- ⇒ Studies will be limited to publications in English; note will be taken of the number of studies not published in English that are identified.
- ⇒ It is unfortunately possible that we may not identify all relevant data, given the limitations of searching the grey literature, especially if studies are published in non-English languages, including Roma, Sheita or Mincéir.

individual engages with healthcare but also extending to their communities at large.

Following an ancient way of life, Gypsy, Roma and Traveller groups have long been marginalised and discriminated against by larger society. The European Committee against Racism and Intolerance describes anti-Gypsyism as *a specific form of racism, an ideology founded on racial superiority, a form of dehumanisation and institutional racism nurtured by historical discrimination, which is expressed, among others, by violence, hate speech, exploitation, stigmatisation and the most blatant kind of discrimination*.¹ This is echoed in Ireland where Irish travellers face very significant and systemic discrimination in employment, private sector amenities and housing.²

The economic and social constraints of nomadic living include high rates of unemployment,¹ reduced access to education and poorer health in general.³ Such constraints place these groups at significantly increased risk of poverty compared with the general population.^{4 5} Pregnant women living in poverty have an increased risk of obstetric complications including preterm delivery, pre-eclampsia and stillbirth.^{6–8} The reasons for increased rates of poor obstetric outcomes within this population are multifactorial. There is, however, a responsibility on

INTRODUCTION

For many healthy women, pregnancy will often present the first time they access regular, continuous healthcare for a concerted period. These first encounters with the healthcare system are important for forming perceptions and building trust between healthcare providers and women. Failure to get these initial interactions right may have far-reaching implications, not only in how the



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healthcare providers to identify the unique barriers faced by nomadic women in their attempt to access healthcare in pregnancy and tailor medical care to these needs.

Within Europe, there are two predominant and ethnically distinct nomadic groups—Irish travellers and Roma. There are estimated to be 30 000 Irish travellers in Ireland³ and 1.8 million Roma within Romania.⁹ The population of these groups extends across the world with estimates of up to 320 000 Irish travellers living globally and 10 million Romani living in Europe alone.⁹ While Irish travellers and Roma have their own unique cultural identities, they face similar challenges of discrimination and racism from wider society. The displacement and persecution faced by these groups poses a significant threat to their sexual and reproductive health and rights.

In March 2017, the Irish government formally recognised Irish travellers as a distinct ethnic group in Ireland. This meaningful recognition was an effort to acknowledge the unique language, culture, history and traditions of Irish travellers. Despite this, travellers continue to be marginalised by society and encounter discrimination and stigmatisation in many aspects of their lives. There is a paucity of research around Irish traveller women and their experiences in the maternity services in Ireland. The All Ireland Traveller Health Study (AITHS), published in 2010, was a large-scale undertaking which sought to capture the health experiences and outcomes of all travellers living on the island of Ireland.⁴ This remains the premier document in traveller health, not least in part due to its enormous scope, but subsequent to its publication, there has been little in the way of further research. Uptake of maternity services and neonatal outcomes were included in the AITHS, but the specific experiences and outcomes of pregnant traveller women are not known. This is an oversight within the literature at large when we consider that 73% of the traveller population is aged <35 years, and in 2008, Irish travellers had the highest fertility rate in Europe (2.7 per 1000 population).^{3,4}

A similar report from the European Commission in 2014 was the Roma Health Report. This report acknowledged a *lack of research dedicated to understanding Roma women's health*.¹⁰ This is a concerning gap within the literature, particularly when Roma women are less likely to receive any antenatal care in pregnancy than their non-Roma peers and have higher rates of communicable diseases.^{10,11} The privation of antenatal care for Roma women is endemic across Europe with lack of documentation, accessibility and cost being cited as barriers to care.¹¹ Other postulated causes may be geographical access to healthcare, issues with language and/or communication, cultural beliefs and practices or the attitudes of healthcare providers towards Roma (and indeed, Gypsy and Traveller) women.

Government and non-government organisations are working to make meaningful change to address the inequalities faced by the Roma and Traveller communities. Implementation of the strategic framework set out by the governing bodies has made some limited progress

with improvements in education,¹² while much has been written about strategic planning for inclusion and participation, discrimination persists even at government level. In Ireland in 2019, the Irish Human Rights and Equality Commission found a consistent underspend of the Traveller-specific accommodation budget up to the amount of €68 million between 2008 and 2018.¹³

Within maternity care, Roma and Traveller women face higher rates of obstetric complications. It is the intention of this scoping review to collect what has been published in this area and synthesise the data to generate a comprehensive report.

SCOPING REVIEW OBJECTIVES

As highlighted, there is a lack of data around the experiences and obstetric outcomes of nomadic women. We will explore the breadth of the literature and map the available evidence. We will seek to identify and analyse gaps in the knowledge on this topic. We aim to systematically review literature for studies that have reported on pregnant women from Gypsy, Roma and Traveller communities.

Informed by Preferred Reporting Items for Systematic reviews and Meta-Analyses extension for Scoping Reviews (PRISMA ScR) reporting guideline for protocols, this protocol details a preplanned methodological and analytical approach to the research question. The scoping review will explore the experience and obstetric outcomes of women from Gypsy, Roma and Traveller communities.

METHODS AND ANALYSIS

A six-step approach based on the frameworks proposed by Arksey and O'Malley¹⁴ and Levac *et al*.¹⁵ will serve as the basis of this methodology, along with guidance from the Joanna Briggs Institute Reviewer's manual.¹⁶ A scoping review is the chosen methodology as the purpose of this review is to collate a comprehensive overview of the evidence in this broad topic. We will also use the PRISMA-ScR tool.¹⁷ This is the most up-to-date guidance on conducting scoping reviews.

The five steps of the guiding framework are outlined as follows: identification of the research question, identification of relevant studies, selection of studies, charting of data and summary of results. Finally, a sixth consultation step recommended by Levac *et al*.¹⁵ will be included to enhance the clinical value and to give perspective to the results of the review.

Identification of the research question

This stage seeks to select the specific research questions, which will guide the review, and to define the terms within it.

A pilot search of the literature specific to Irish travellers revealed a paucity of primary studies reporting on maternal and infant outcomes. As such, we expanded

the scope of this review to include other marginalised nomadic groups within Europe, that is, Roma gypsies.

The following research questions are proposed to include a wider breath of studies and capture data from similar marginalised groups:

1. What is the experience of Gypsy, Roma and Traveller women who access maternity care?
2. What are the obstetric outcomes within this group?

The authors acknowledge that nomadism is not a reality for many Gypsy, Roma and Traveller populations. More accurately these groups may be referred to as minority ethnic groups/indigenous groups.

Identification of relevant studies

Inclusion and exclusion criteria were defined to set clear guidance for reviewers to identify appropriate studies. Inclusion and exclusion criteria are outlined below.

Inclusion criteria

- ▶ Original, peer-reviewed articles.
- ▶ Studies published in the English language.
- ▶ Studies which focus on women from Gypsy, Roma and Traveller groups who are pregnant or recently pregnant.
- ▶ Literature published from January 1980 to 2021. The reason to restrict to these years is contextual, in that papers may be more applicable to current care. Obstetric care has changed so significantly since the 1960s and 1970s that including papers from these decades would not reflect practice at the current time. In addition, it is more socially unacceptable to discriminate openly based on social background, and clinical staff are more conscious of their previously unconscious biases.
- ▶ Review articles: systematic reviews, scoping reviews, meta-analysis and rapid reviews.
- ▶ Grey literature including government and non-governmental organisation reports and academic dissertations.
- ▶ Studies including qualitative, quantitative and mixed methods studies.
- ▶ All study designs will be considered, including cross-sectional qualitative and quantitative studies, randomised controlled trials and quasi-experimental designs and pilot studies.

Exclusion criteria

- ▶ Non-English publications will be excluded but will be noted.
- ▶ Studies published before January 1980, as discussed before regarding context.
- ▶ Studies which do not include pregnant people/women from Gypsy, Roma and Traveller groups.

Search strategy

Electronic databases

Assistance from a librarian was sought in this stage to develop and refine the search strategy. After first assessing electronic databases for their relevance and coverage of

Table 1 Population–Context–Concepts (PCC) strategy

Population	Gypsy, Roma and Traveller women
Context	The setting will be all pregnant women within this population. The location and environment will not be limited.
Concepts	Literature reporting on the outcomes of pregnant women will be reviewed. We will also consider the experiences of pregnant women in these populations.

the literature, we selected five electronic databases for searching:

- ▶ CINAHL
- ▶ EMBASE
- ▶ MEDLINE (OVID)
- ▶ Web of Science
- ▶ SCOPUS

There will be three strands to the search terms. These terms were used in a pilot search, which sought to capture the breadth of the literature. Search strategy and specific terms were chosen using the Population-Concepts-Context strategy proposed by Levac *et al.* This is displayed in [table 1](#). Relevant terms were included until searches returned no new relevant papers. Terms were cross-checked using Medical Subject Headings in MEDLINE, Excerpta Medica Thesaurus (Emtree terms) in EMBASE and CINAHL Subject Headings in CINAHL. A more detailed search strategy is given in online supplemental file 1.

Search 1: Pregnancy-related terms: “pregnan*” OR “antenatal” OR “postnatal” OR “maternity” OR “obstetric” OR “gravid*” OR “gestation” OR “parturition” OR “perinatal” OR “labor” OR “labour” OR “childbirth” OR “puerperal”

AND

Search 2: Population-related terms: “Irish traveller*” OR “roma” OR “romani” OR “roma gyps*” OR “pavee” OR “UK traveller*” OR “minceir” OR “gyps*” OR “gips*” OR “nomad*”

AND

Search 3: Experience and outcome-related terms: “pregnancy outcome*” OR “pregnancy complication*” OR “complication*” OR “outcome*” OR “experience*” OR “attitude*” OR “treatment outcome*” OR “clinical outcome*” OR “patient-reported outcome*” OR “puerperal disorder*” OR “labor complication*” OR “labour complication*” OR “fetal disease*” OR “fetal complication*” OR “fetal death” OR “maternal morbidity” OR “maternal mortality” OR “risk factors”

Hand searching

High yield journals are included for hand searching.

Reference lists

Reference lists will be searched particularly looking at existing systematic and scoping reviews. Saturation will

**Table 2** Summary table for charting data from included articles

Charting themes	
Reference	Author(s)/organisation Title Year of publication Journal DOI
Study details	Aims/purpose Country Population/ethnicity
Methodology	Study design (qualitative, quantitative) Sample size Outcome
Key findings	Discrimination Patient experiences Systemic issues Barriers to care Adverse obstetric outcomes Non-engagement with antenatal care Successful interventions Other*
*Other denotes our intention to create new categories during the data charting process of unexpected findings and creation of new categories where deemed necessary.	

be defined when no new references are identified at this stage.

Selection of studies

Titles and abstracts will be reviewed independently by two reviewers (Maggie O'Brien and Brendan Dempsey). Papers identified by either or both reviewers will be included in the next phase. The same reviewers will screen full-text studies using the eligibility criteria mentioned above. Any disagreement will be resolved by either discussion or referral to the third author (Mary Higgins). PRISMA flow diagram will be presented to reflect the search process.

Charting of data

A charting form was developed to record key characteristics systematically and uniformly from the studies. One reviewer (MO'B) will conduct data extraction consisting of a summary table recording the key information of the selected studies (table 2).

Study reference (author, title, year of publication, journal, DOI (digital object identifier system), study details (aims, country, population/ethnicity), methodology (study design, sample size and outcome) and key findings will be entered into the charting form.

Summary of results

Collating and summarising: the concepts, aims and approaches in each study will be summarised. Themes shall be presented as a narrative summary as well as a qualitative thematic analysis of the results to illustrate key findings and themes. The experiences and outcomes of

Gypsy, Roma and Travellers will be reviewed and considered separately and compared where appropriate.

Reporting on results will be done using PRISMA-ScR guidelines.

Consultation

As per Levac *et al*'s recommendations, this stage will also be used to support knowledge transfer of preliminary data and identification of appropriate dissemination strategies. Following the completion of this review, we plan to re-engage with these groups.

PATIENT AND PUBLIC INVOLVEMENT

Three leading advocacy groups for Irish travellers—Pavee Point (<https://www.paveepoint.ie/>), Traveller Primary Healthcare Group and Pavee Mothers Group—were consulted early in the development stage of the research question to provide insight beyond the literature. Feedback given in this consultation step informed the research question. These organisations provided specific guidance regarding respectful terminology and research interests.

We will share the results with experiential experts and seek to understand if the findings in this review reflect their lived experiences or if there are any gaps in the literature which they identify.

ETHICS AND DISSEMINATION

Ethical approval was not required for the design of this protocol nor for the implementation of it. All literature within this scoping review are publicly available on the databases listed above.

We expect that the gathered data will identify gaps in knowledge to inform future research and policy change for these groups. To facilitate dissemination of findings, the research team will present the findings to key stakeholders working with the Gypsy, Roma and Traveller communities. These include the initial advocacy groups consulted—Pavee Point, Traveller Primary Healthcare Group, Pavee Mothers Group—as well as other groups including Nasc (the Irish Immigrant Support Centre) and Friends, Family and Travellers, a UK-based charity working to end discrimination against Gypsy, Roma and Traveller people. Pavee Point have also worked with Roma communities, most particularly in the Roma Needs Project.

We will also disseminate the results through publication in a peer-reviewed, academic journal and by presentation at academic conferences in the areas of discrimination, obstetrics and midwifery.

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Acknowledgements The authors thank Pavee Point, Traveller Primary Healthcare Group, Pavee Mothers Group for their contribution to the development of this research. We would also like to thank Mr Diarmuid Stokes at UCD Library for his support and assistance in development of the search strategy.

Contributors All authors contributed to the overall study design and specific methodologies. MO'B conceived and designed the study with MH. MO'B drafted the

manuscript and protocol with assistance from BD and MH. All authors have read, contributed with inputs and revisions and approved the final manuscript.

Funding The authors have not declared a specific grant for this research from any funding agency in the public, commercial or not-for-profit sectors.

Competing interests None declared.

Patient and public involvement Patients and/or the public were involved in the design, or conduct, or reporting, or dissemination plans of this research. Refer to the Methods section for further details.

Patient consent for publication Not applicable.

Provenance and peer review Not commissioned; externally peer reviewed.

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