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Gypsy, Roma and Traveller community experiences of infant feeding, information and support services



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About us

This piece of research was conducted by <u>Friends</u>, <u>Families and Travellers</u> (<u>FFT</u>) and <u>Roma Support Group</u> (<u>RSG</u>), through their work as <u>members of the VCSE Health</u> and Wellbeing Alliance.

FFT is a leading national charity that seeks to end racism and discrimination against Gypsies, Travellers and Roma, and to protect the right to pursue a nomadic way of life. We support individuals and families with the issues that matter most to them, at the same time as working to transform systems and institutions to address the root causes of inequalities faced by Gypsy, Roma and Traveller people. Every year, we support over 1,300 families with issues ranging from health to homelessness, education to financial inclusion, and discrimination to employment. Over half of our staff team, volunteers and trustee board are from Gypsy, Roma and Traveller communities.

RSG is a Roma-led charity based in East London, working to improve the quality of life for Roma refugees and migrants by helping them to overcome prejudice, isolation, and vulnerability. Every year, the RSG support around 2,000 Roma people with access to welfare, health services including mental health, education, financial inclusion, campaigning and policy, housing and cultural activities. Every year, about 120 Roma people benefit from one-to-one health advocacy. Since 1998, the RSG has worked with thousands of Roma families, offering them a variety of services, engaging the Roma community in all aspects of running and managing the organisation and promoting an understanding of Roma culture in the UK.



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Executive summary

Key findings

- **1. Cultural norms around infant feeding vary** across different Gypsy, Roma and Traveller communities.
 - i) Within Roma communities breastfeeding may be more typical.
 - ii) Formula feeding is more culturally expected among many Romany Gypsy, Irish Traveller and Travelling Showmen families.
 - iii) Research participants described a degree of **discomfort or stigma around breastfeeding** for some members of these communities.
 - iv) Modesty, privacy, health impact and family/community were cited by participants across all communities as major factors in infant feeding decision-making and practices.
- 2. A lack of culturally pertinent and accessible information and support on infant feeding was reported by participants, with many parents indicating that services did not feel tailored or suitable for their needs and experiences. This is linked to literacy and language barriers as well as a lack of cultural competency or awareness around structural issues accessing primary care for nomadic or migrant families, and families who live in insecure accommodation or shared housing.
- **3.** Accommodation and living circumstances were also highlighted as having a major impact on infant feeding experiences and ability to access services.
- 4. Parents described feeling stigma, pressure and judgement around their feeding choices, both from health professionals and from within their own communities. Some reported feeling that they 'couldn't win', as they would either face stigma from within their community for choosing to breastfeed, or shame from health professionals if they chose to formula feed.
- 5. Messaging from health professionals around infant feeding options was often deemed too rigid or pressurising by participants. Some participants felt pressured towards exclusive breastfeeding, despite expressing that more flexible strategies. such as combination or mixed feeding, would be more



suitable for their needs and living circumstances. In some cases, rigid 'all or nothing' messaging around breastfeeding put participants off from exploring breastfeeding at all, despite initial interest.

- **6.** A **lack of practical and hands-on support** around both breast and formula feeding was noted by many participants. A **lack of culturally relevant peer support opportunities** was also raised.
- 7. The timing of delivery for information around infant feeding was raised as an issue; participants pointed to a **need for more information and support before birth**, so that they felt prepared before their baby's arrival.
- 8. Experiences of discrimination and prejudice when accessing maternity or infant feeding services were reported by many participants, resulting in a sense of mistrust or fear of health professionals or institutions for some.

 Fear of social services involvement was a notable trend.
- 9. Concerns were raised by participants around the impact of NHS funding cuts and understaffing, particularly in terms of the consequences for service delivery and staff wellbeing.
- **10. The cost-of-living crisis and economic challenges** associated with maternity and infant feeding were a major concern for participants.
 - i) Maternity support payments were overwhelmingly considered insufficient. Moreover, many participants were unaware of the financial supports available to support maternity needs.
 - ii) The **cost of formula and feeding equipment** was raised as a major issue.
 - iii) Many participants felt it was 'better' or 'safer' for babies to be fed more expensive formulas. All formulas must meet regulatory requirements governing composition and there are no proven benefits of choosing a more expensive milk.
 - iv) Literacy barriers mean that some parents rely on verbal instructions from family or friends to prepare formula those who lack confidence around doing so correctly may rely on more expensive pre-prepared liquid formula to avoid mistakes in preparation. More professional



support and instruction should be provided around formula feeding, as well as breastfeeding.

- **11.Worry and shame around infant feeding** was consistently linked to poor wellbeing and **negative perinatal mental health experiences**. Stigma around mental illness and fear of state institutions/social services intervention were major barriers to accessing mental health support.
- **12.** This project was unusual in its inclusion of Gypsy, Roma and Traveller **fathers' and male partners' perspectives on infant feeding**. These participants shared their experiences and their views on roles and expectations for men in early stages of parenting:
 - i) In some communities, men are traditionally expected to take a secondary role in early stages of childcare. In some maternity contexts, it might not be seen as culturally appropriate for men to be present (e.g. during childbirth).
 - ii) These traditions are **not universally observed**, and many participants noted a **generational shift** toward young men being much more involved in infant feeding and early parenting.
 - iii) However, participants also expressed concern that health professionals from outside their community may sometimes misinterpret these cultural norms as a lack of engagement or interest in the wellbeing of their child or partner.
 - iv) Participants expressed a need for tailored information and support around infant feeding for fathers and male partners. Good practice suggestions for professionals included initially asking fathers and male partners how involved they would like to be in infant feeding discussions, without making assumptions about his parenting if he chooses not to be present for certain conversations.



Key recommendations

- 1. Maternity and infant feeding service providers should engage directly with members of Gypsy, Roma and Traveller communities to assess access needs, and adjust services accordingly. This process is best facilitated locally by collaboration with organisations or individuals who have existing relationships of trust with communities.
 - Services should be designed to accommodate for needs relating to literacy, language and digital barriers, accommodation-related challenges, as well as cultural norms and expectations common among Gypsy, Roma and Traveller communities. This is especially relevant for registration, booking and contact systems, which should be made as flexible and accessible as possible.
 - Culturally relevant peer support systems and opportunities should be created within infant feeding services for Gypsy, Roma and Traveller communities.
 - Members of Gypsy, Roma and Traveller communities should see themselves represented in the maternity and infant feeding workforce; NHS England should promote recruitment and training opportunities for community members.
 - Where possible, service providers should work with health mediators or community advocates from within Gypsy, Roma and Traveller communities. Ideally, this mediator would be able to provide language support in the service user's first language.
- 2. Gypsy, Roma and Traveller cultural competency and inclusive services training is recommended for all maternity and infant feeding service providers. Training services can be found via the <u>Cultural Awareness</u> <u>Hub</u>, which links to training offerings from <u>Friends</u>, <u>Families & Travellers</u> and <u>Roma Support Group</u>, among others. Relevant training topics for infant feeding and maternity services include:
 - Cultural norms and expectations around infant feeding;
 - Practical issues relating to infant feeding while living in culturally pertinent accommodation or insecure housing;
 - Effectively approaching culturally sensitive topics like gendered/sexual health issues and mental health (among others);
 - Cultural expectations around the role of father figures in some traditional Gypsy, Roma and Traveller families.



- 3. Culturally relevant and accessible infant feeding information resources should be provided to maternity and infant feeding service users. Where these are not currently available, steps should be taken to fund their development. One excellent example of culturally relevant infant feeding information materials is Pavee Mothers, a maternal health initiative by Ireland-based Pavee Point Traveller and Roma Centre. Developed by and for Irish Traveller women, this took the form of a website and printed information pack, as well as a text message campaign.
- 4. Infant feeding policy and support services must respect and support individual infant feeding choices. Effective, culturally pertinent and accessible support and advice should be available to all families, regardless of which feeding method they choose (including breastfeeding, formula feeding and combination feeding methods).
- 5. Suitable funding is critical to the delivery of safe, effective maternity and infant feeding services. Underfunding of maternity and infant feeding services must be viewed as an urgent political and economic priority. Budgets for maternity and infant feeding should be reviewed and increased in accordance with the Ockenden Reports' Immediate and Essential Actions and the latest Health and Social Care Committee Report on the Safety of Maternity Services in England, as a minimum starting point.
 - Commission and sustainably fund universal, accessible, and confidential infant feeding support, delivered by specialist/lead midwives, health visitors and suitably qualified breastfeeding specialists, which recognise the role of charitable organisations and community groups and their strong links with communities.
 - Ensure that health visiting services are properly funded and the number of health visitors is increased to ensure consistent and timely nutritional support for all families is provided, to better support both maternal and infant mental and physical health.
 - Ensure there are accessible and culturally competent children's centres or family hubs, disproportionately located in areas of disadvantage, offering joined-up universal services from pregnancy onwards, that include peer support.
- 6. Maternity service users must be made aware of economic, social and psychological support available to families by:



- Integrating broader help and advice services into healthcare settings. This could be delivered via a social prescribing system, and/or following a <u>health-justice partnership model</u>, which links new or pregnant parents with advice services through their midwife, enabling them to access benefit entitlements and exercise their rights.
- Advising migrant parents who may not be familiar with NHS care pathways on their NHS entitlements and typical maternity care pathways on first contact with services.
- Advising parents on what support is available to them as standard practice, to eliminate the need to ask for help or disclose a problem.
 Reluctance to do so is often associated with a fear of expressing vulnerability and/or a fear of intervention by social services.

7. Financial supports for families must be improved:

- Sure Start Maternity Grant should be uprated in line with inflation and eligibility expanded to second and subsequent children.
- Healthy Start should be uprated in line with inflation. Eligibility criteria should also be expanded to include those with No Recourse to Public Funds in order to reach some of society's most vulnerable families.
- The basic rate of Statutory Maternity Pay and Maternity Allowance should be raised to at least the level of National Minimum Wage.
- The current 8-week qualifying period for Statutory Maternity Pay should be extended to cover 12 weeks' earnings for those with variable hours, so that parents on casual contracts are not disadvantaged.
- The policy anomaly that treats Maternity Allowance as deductible from Universal Credit should be corrected and Maternity Allowance treated the same as Statutory Maternity Pay under Universal Credit rules.
- Administrative barriers to maternity payments (including both the maternity grant and the additional payments to pregnant women, babies and children under 3), such as the need for a separate application form, should be removed and payments made automatically after notification of pregnancy.

8. Measures must be taken to address the surging costs of infant formula:

 Infant formula should be recognised as an essential product for which there is no alternative and be treated in the same way as other essentials, such as energy or medicine.



- Pricing controls and caps should be explored as a matter of urgency by Government, alongside establishing a taskforce to evaluate the feasibility of commissioning a nationally or locally commissioned first infant formula milk.
- The Department of Health and Social Care should change its guidance to clarify that retailers are permitted to allow customers to buy formula with loyalty points, gift cards or vouchers.
- Healthy Start Vouchers should be increased so that they cover the weekly cost of formula feeding as a bare minimum. However, this needs to go hand in hand with longer term systemic change to secure access to an affordable product.
- o In all locations where formula is purchased or advice sought, clear public health information should be made available explaining that there are no established health benefits to babies of buying more expensive first formula products, since all first formulas must comply with regulations governing composition (meaning they are all comparable and nutritionally adequate). There is no need for families to buy more expensive infant formulas.
- 9. Perinatal mental health support services must be strengthened, suitably funded, and delivered in a culturally sensitive manner.
 - Service providers should be aware when supporting members of Gypsy, Roma and Traveller communities that there may be a reluctance to seek help with mental health issues due to cultural taboos and mistrust of healthcare/state institutions. This can also contribute to a lack of awareness about perinatal mental health issues and symptoms.
 - These barriers can contribute to a lack of awareness around what mental health services are available. It is therefore important to emphasise the availability of these services before need for them is expressed.
- 10. Decisions made by service providers around the involvement of social services should be handled with great care and sensitivity, as well as an understanding of the distress and harm to families that can be caused by unnecessary referrals.
 - Any referral to Children's Services should be made using recognised risk criteria.



 Except in exceptional circumstances, where disclosure may carry the risk of acute harm, any potential referral should be discussed first with the person or family concerned, and their insight and opinion on the referral should be sought.

11. Service providers should be aware of cultural expectations about the role of father figures in traditional Gypsy, Roma and Traveller families.

- Adherence to more traditional expectations around male presence in certain maternity contexts should not be misinterpreted as a lack of interest or engagement on the part of fathers or partners.
- Opportunities should be provided for fathers and male partners to engage in maternity and infant feeding support should they wish to, although the choice not to engage directly should also be respected and not interpreted as a lack of interest in the wellbeing of their child or partner.



1. Introduction

Gypsy, Roma and Traveller communities are known to face some of the starkest inequalities in healthcare access and outcomes amongst the UK population, including when compared to other minority ethic groups¹. These inequalities are also reflected in Gypsy, Roma and Traveller experiences of maternal health and care. This piece of research builds upon work conducted by Friends, Families and Travellers (FFT) and Roma Support Group (RSG) which culminated in the publication of our 2023 <u>Guidance on Tackling Maternal Health Inequalities in Gypsy, Roma and Traveller Communities.</u>

This report focuses on infant feeding support and early information, offering maternal health professionals and policymakers an insight into the lived experiences of community members and guidance on how services can better meet the needs of Gypsy, Roma and Traveller families. The aim of this report is to amplify the voices of Gypsy, Roma and Traveller community members and to improve knowledge and understanding around the needs and experiences of these communities within the health and care system.

It is important to note that not all members of Gypsy, Roma and Traveller communities share the same life experiences. Some individuals will not necessarily experience all, or any, of the barriers outlined in this report. However, by increasing awareness around the experiences of the most marginalised patients, we can begin to create services that are accessible and welcoming to all.

1.A Background and context

Introduction to Gypsy, Roma and Traveller communities

The term Gypsy, Roma and Traveller (GRT) encompasses various communities, including Romany Gypsies (English Gypsies, Scottish Gypsy Travellers, Welsh Gypsies, and Romany people more widely), Irish Travellers, New Travellers, Boaters, Travelling Showmen and Roma². Use of the 'GRT' grouping presents the same issues as the use of 'BAME', as it arguably fails to reflect the true diversity of

¹ Friends, Families & Travellers (2022) <u>Briefing: Health inequalities experienced by Gypsy, Roma and Traveller communities</u>

² GOV UK (2022) Gypsy, Roma and Irish Traveller ethnicity summary



the communities referenced. For the purposes of this guide, we have avoided its use, however you may find the term used in other policy documents.

It should be noted that the 'Gypsy, Roma and Traveller' category grouping is not in universal use. Consequently, the below literature review includes various ethnonyms used in different sources. For example, authors in Europe may refer to some communities as 'Romany', 'Gypsies' or 'Romani' whereas from a UK policy context we would better understand these communities to be Roma. To avoid misinterpretation when citing external studies, we will remain true to original authors' terminology.

For further context, this <u>video produced by Travellers' Times</u>³ provides a short, animated history of Britain's nomadic communities, while <u>this video produced by the European Roma Rights Centre</u> offers some important information about Roma communities⁴.

The table below offers some basic background information on Gypsy, Roma and Traveller communities:

³ Traveller's Times (2019) Roads from the Past

⁴ European Roma Rights Centre (2019) <u>7 Things You Should Know About Roma People</u>



	Ethnicity	Arrival in England	Language	Accommodatio n type
Romany Gypsies	Historically originating in northern India, Romany Gypsies have been in the UK for many generations.	Before the 16th Century.	Romany Gypsies speak English and many also speak a Romani dialect to varying levels of fluency.	Around 75% of Romany people live in housing, and 25% live on Traveller sites, in caravans or chalets, or roadside.
Roma	Historically originated in Northern India and settled in Europe (including Romania, Slovakia, Czech Republic and Poland) before migrating to the UK more recently. Culturally, Roma individuals may belong to any of ~40 different groups/tribes.	Small numbers since 1945, with a number of Roma seeking asylum in the 1990s, and early 2000s, then a growth in population following EU expansion in 2004 and 2007.	The majority of Roma speak one of the many Romani dialects as a first language and their European origin country's as a second language. However the fluency in second language, as well as in English varies greatly.	The vast majority of Roma people live in housing, although there are disproportionate levels of homelessness and overcrowding.
Irish Travellers	Irish Travellers originated in Ireland as a distinct and separate ethnic group from the general Irish population recorded since the 12th century.	Recorded from the 18th century.	Irish Travellers speak English and some speak Gaelic/Irish. Many Irish Travellers also speak Gaelic derived Gammon or Cant.	Around ¾ live in housing and ¼ on Traveller sites in caravans or chalets. Of these, a small proportion live roadside or in public spaces.



Travelling Showmen	Anyone who travels to hold shows, circuses and fairs can be a Showperson. Many families have led this way of life for generations and many have Romany heritage.	According to the National Fairground Archive the first recorded charter was granted to King's Lynn in 1204.	Showmen primarily speak English.	Most Showmen live on yards in the winter months and travel during the summer months.
New Travellers	'New Traveller' can describe people from any background who chooses to lead a nomadic way of life or their descendants.	The New Traveller movement finds its roots in the free festivals of the 1960s, but people of all backgrounds have practiced nomadism throughout history.	New Travellers primarily speak English.	New Travellers lead a nomadic way of life – in vans, mobile homes, caravans and a small proportion are horse drawn.
Liveaboard Boaters	Anyone who lives on a boat, from all walks of life and backgrounds.	People have been living and working on boats since canals were built in England in the 18th Century.	Liveaboard Boaters primarily speak English.	Boaters live on narrowboats, barges or river cruisers, whether on a home mooring, a winter mooring or continuously cruising on a canal, or in a marina.

In the 2021 UK census, 172,465 people from 'Roma' and 'Gypsy or Irish Traveller' communities in England and Wales disclosed their ethnicity.⁵ However, census engagement is negatively impacted by a significant trust gap between Gypsy, Roma and Traveller communities and state institutions or public services. It is therefore likely that the official census record is an underestimate of the true population size;

⁵ Office for National Statistics (2021) Ethic Group (detailed)



other data sources estimate the UK's Gypsy, Roma and Traveller population to be in the region of 150,000 to 300,000,6 or as high as 500,000.7

Romany Gypsy and Irish Traveller communities have traditionally lived nomadic lives in the UK, although members of these communities have increasingly moved into bricks and mortar housing. The 2021 census for England and Wales recorded 78.4% of people who identified as Gypsy or Irish Traveller as living in houses, flats, maisonettes or apartments.⁸

Historically, Gypsy, Roma and Traveller communities have faced persecution across the UK and Europe, with every modern EU state having anti-Gypsy laws at some point. In the 16th century a law was passed in England that allowed the state to imprison, execute or banish anyone that was perceived to be a Gypsy. Historians estimate that during the Second World War, between 200,000 and 500,000 Roma and Sinti people were murdered by the Nazis and their collaborators in an act known as the Roma Genocide. Many Roma women were forcibly sterilised when accessing health services across parts of mainland Europe, with the last known case of this as recent as 2007, in the Czech Republic. This history is felt keenly by Gypsy, Roma and Traveller people and contributes to the lack of trust in state structures and bodies.

Today, the UK Government accepts that 'Gypsies, Travellers and Roma are among the most disadvantaged people in the country and have poor outcomes in key areas such as health and education'. 12

Health context for Gypsy, Roma and Traveller communities

Gypsy, Roma and Traveller communities are known to face some of the starkest inequalities in healthcare access, with the worst general health outcomes of any

⁶ Council of Europe (2012) Estimates of Roma Population in European Countries

⁷ University of Salford (2013) <u>Migrant Roma in the United Kingdom: Population size and experiences of local authorities and partners</u>, p.7

⁸ Office for National Statistics (2023) Gypsy or Irish Traveller populations, England and Wales: Census 2021

⁹ National Archives, 'Act concerning 'Egyptians', 1530'

¹⁰ Holocaust Memorial Day Trust, <u>The Roma Genocide</u>

¹¹ Hutt (2021) The shameful story of Roma women's forced sterilisation in central Europe

¹² UK Government (2017) (GRT0059)



ethnic group in the UK.¹³ ¹⁴ The reasons for these poor health outcomes are complex, but include the impact of discrimination and stigmatisation, the complicated nature of health systems and the effects of wider social determinants of health.

Visibility on health dynamics for Gypsy, Roma Traveller communities at population level in the UK is compromised by the historic <u>failure to include Gypsy</u>, <u>Roma and Traveller ethnic groups in the NHS Data Dictionary</u>. Nevertheless, health data which is available paints a striking picture of inequalities in access and outcomes.

The 2021 census for England and Wales revealed that 14% of Gypsy or Irish Traveller respondents described their health as "bad" or "very bad", more than twice as high as the White British group. ¹⁵ The Race Disparity Audit reveals that Gypsy and Traveller people are less likely to be satisfied with access to a GP than white British people (60.7% compared to 73.8%) and are also less likely to be satisfied with the service they receive (75.6% compared to 86.2% for white British) ¹⁶¹⁷. Other research shows that the health status of Gypsies and Travellers is much poorer than that of the general population, even when controlling for other factors such as variable socio-economic status and/or ethnicity ¹⁸; life expectancy for Gypsy and Traveller men and women is 10 years lower than the national average ¹⁹, and 42% of English Gypsies are affected by a long term condition, as opposed to 18% of the general population. ²⁰ Roma communities experience specific social exclusion factors and barriers in access to health and care services. ²¹ Roma individuals also have multiple overlapping risk factors for poor health and a life expectancy up to 10 years less than non-Roma communities in the UK. ²²

¹³ House of Commons Women and Equalities Committee (2019) <u>Tackling inequalities faced by Gypsy, Roma and Traveller</u> communities

¹⁴ Parry et al (2007) <u>Health status of Gypsies and Travellers in England</u>

¹⁵ Office for National Statistics (2023) Ethnic group differences in health, employment, education and housing shown in England and Wales' Census 2021

¹⁶ UK Government Ethnicity Facts and Figures, <u>Satisfaction with access to GP services</u> [These figures should be treated with caution, as sample sizes are small.]

¹⁷ UK Government Ethnicity Facts and Figures, <u>Patient experience of primary care - GP services</u>

¹⁸ Race Equality Foundation (2008) The health of Gypsies and Travellers in the UK

¹⁹ Equality and Human Right Commission (2017) Gypsies and Travellers: simple solutions for living together

²⁰ Royal College of General Practitioners (2013) <u>Improving access to health care for Gypsies and Travellers, homeless people</u> and sex workers

²¹ UK Government (2022) <u>Improving Roma health: a guide for health and care professionals</u>

²² European Public Health Alliance (2018) Closing the life expectancy gap of Roma in Europe



Maternal health inequalities in Gypsy, Roma and Traveller communities

These inequalities are also reflected in Gypsy, Roma and Traveller experiences of maternal health and care. Existing research published by FFT reveals barriers in accessing midwifery services and other maternal healthcare, particularly for nomadic parents (for example, a midwife may be unable to visit an expectant parent before they are moved on by a local authority)²³. Gypsy, Roma and Traveller people living in bricks and mortar accommodation may experience other barriers, linked to language, literacy, discrimination, or other structural issues can limit access to maternal healthcare services.²⁴

Research shows that inequalities in preventable maternal mortality and morbidity are greater for minority ethnic parents generally²⁵, and focused studies on Gypsy, Roma and Traveller communities have revealed specific inequalities faced by these groups. United Nations bodies have acknowledged that disparities in access to maternity care and family planning exist for Romani women in Europe²⁶. Romani women in Europe experience higher birth rates among adults and teenagers, higher rates of illegal or dangerous abortion services, and significantly higher instances of poor infant outcomes when pregnancy was carried to term.²⁷ Similar rates of poor infant outcomes were reported for English Romany women (12.8% compared to 6.9% for the general population), although this 1986 study is fairly dated.²⁸

In the UK, significantly higher rates of premature death have been reported among children of Gypsy and Traveller parents than the general population.²⁹ 1 in 5 Gypsy and Traveller mothers will experience the loss of a child, compared to 1 in a 100 in the non-Traveller community.³⁰ A 2009 study found miscarriage rates to be significantly higher for Gypsy and Traveller mothers, correlating this with reported

²³ Friends, Families & Travellers (2023) <u>Guidance: Tackling Maternal Health Inequalities in Gypsy, Roma and Traveller Communities</u>

²⁴ Ibid.

²⁵ Fernandez Turienzo et. al., (2021) <u>Addressing inequities in maternal health among women living in communities of social</u> <u>disadvantage and ethnic diversity</u>

²⁶ Colombini et. al., (2011) <u>Access of Roma to sexual and reproductive health services: Qualitative findings from Albania, Bulgaria and Macedonia</u>

²⁷ Watson and Downe (2017) <u>Discrimination against childbearing Romani women in maternity care in Europe: a mixed-methods</u> systematic review

²⁸ Pahl and Vaile, (1986) <u>Health and health care among Travellers</u>

²⁹ Parry et al (2007) <u>Health status of Gypsies and Travellers in England</u>

³⁰ Ormiston Children and Families Trust and Cambridgeshire Community Services (2008) An Insight into the Health of Gypsies and Travellers: A Booklet for Health Professionals in Cambridgeshire



poor living conditions and offering specific recommendations for improved accommodation provision to tackle this.³¹ In 2019, the House of Commons Women and Equalities Committee reported consistent failure by local and national policy to address health inequalities experienced by Gypsy, Roma and Traveller communities in the UK. The report offered specific recommendations around conducting enquiries and assessments to determine Gypsy, Roma and Traveller health needs and inclusion in health services, improvements for amenities and conditions on Traveller sites, as well as the implementation of training targeted at maternity and pre-natal staff to better support Gypsy, Roma and Traveller women.³²

Infant feeding and Gypsy, Roma and Traveller communities

Existing research on infant feeding in Gypsy, Roma and Traveller communities is fairly limited. However, published research indicates differing norms around breast or formula feeding, depending on the community in question. Among Gypsy and Traveller communities, breastfeeding rates are shown to be low, while breastfeeding has been shown to be more typical in Roma communities. Small-scale studies show that breastfeeding rates are extremely low among English and Welsh Gypsies, and Scottish and Irish Travellers, with one study finding a breastfeeding initiation rate of 3%, with none continuing to six weeks. 33 For many Gypsy and Traveller communities breastfeeding may not be typical and can be viewed by some as an 'immodest act'. 34 However, breastfeeding rates are much higher among European Roma communities, where breastfeeding is the cultural norm, with some mothers going as far as to describe the practice of breastfeeding as being an integral part of their cultural identity as Roma mothers. 35 Though more common among Roma communities, breastfeeding can be considered a very private process. 36

Research also indicates that Irish Traveller parents may be more susceptible to some metabolic ailments which can impact infant feeding, including Classical

³¹ Pahl and Vaile (2009) <u>Health Care Among Travellers</u>

³² House of Commons Women and Equalities Committee (2019) <u>Tackling inequalities faced by Gypsy, Roma and Traveller communities</u> p. 62-63.

³³ Pinkney, K. (2011). <u>The infant feeding practice of Gypsy and Traveller women in Western Cheshire Primary Care Trust and their attitudes towards breast and formula feeding.</u>

³⁴ Condon & Salmon (2014). "<u>You likes your way, we got our own way"</u>: <u>Gypsies and Travellers' views on infant feeding and health professional support.</u> Health Expectations

³⁵ Condon, L. (2015) Roma, Gypsies, Travellers and Infant Feeding

³⁶ Condon & Salmon (2014). "<u>You likes your way, we got our own way"</u>: <u>Gypsies and Travellers' views on infant feeding and health professional support.</u>" Health Expectations



Galactosemia. Approximately one in every 19,000 infants born in Ireland may have this condition, however, it is particularly common among infants born to Irish Traveller parents in whom the incidence is approximately 1 in 450 births compared to 1 in 36,000 births among the non-Irish Traveller, Irish community.³⁷ If infants with Classical Galactosemia are not treated promptly with a low-galactose diet, life-threatening complications appear within a few days after birth.³⁸ In Ireland, all babies born to Traveller parents are routinely screened for Galactosemia, with the test carried out soon after birth and babies given a soya-based formula until the results are received.³⁹ Use of soya-based formula will be continued if results are positive, but should be stopped if the child is found not to have the condition, as consumption could be harmful for the baby's development.⁴⁰ Test results can take between 6 hours and several days to be received and these delays can have a significant impact on initiating and establishing breastfeeding.⁴¹ Some mothers have reported that this practice made them feel they were being discriminated against, or expressed a lack of understanding as to why these practices were in place.⁴²

Studies have shown that although cultures around methods of infant feeding vary among different Gypsy, Roma and Traveller communities, outlooks are often passed down through generations, with new parents practicing the same methods as their own parents⁴³. Across different communities, infant feeding practices are often influenced by the dynamics of living in close proximity with large families, defined gender roles, as well as expectations around children participating in the care of younger children.⁴⁴

More in-depth qualitative studies have explored the centrality of family in views on and decision-making around infant feeding, as well as the impact of cultural ideas around the importance of modesty and body-covering, particularly for Irish Traveller and Romany Gypsy communities.⁴⁵ Infant feeding practices have been linked to

³⁷ Health Service Executive (n.d) Classical Galactosemia

³⁸ MedlinePlus (n.d) Galactosemia

³⁹ Taggart, E. (2021) 'Only 2% of Traveller women breastfeed due to a range of additional barriers', The Journal.

⁴⁰ Health Service Executive (n.d) <u>The Beutler test for babies in Travelling community</u>

⁴¹ Ibic

⁴² UCD School of Public Health and Population Science (2010) Breastfeeding is natural, but it's not the norm in Ireland

⁴³ Condon & Salmon (2014). "<u>You likes your way, we got our own way"</u>: <u>Gypsies and Travellers' views on infant feeding and health professional support.</u>' Health Expectations

⁴⁴ Condon, L. (2015) Roma, Gypsies, Travellers and Infant Feeding

⁴⁵ Condon & Salmon (2014). "<u>You likes your way, we got our own way"</u>: <u>Gypsies and Travellers' views on infant feeding and health professional support.</u> Health Expectations



community identity and can play a part in maintaining family traditions and values, contributing to community cohesion and resilience.⁴⁶ In one study, the identification of practices such as breastfeeding as something 'a Gypsy would not do' reflects the cultural and political weight of a parent's decision to feed in a way which differs from cultural traditions.⁴⁷

Gypsy and Traveller mothers who did practice breastfeeding frequently cited the health benefits as their reason for doing so. 48 Oft-cited challenges relating to breastfeeding for Gypsy and Traveller mothers include issues around modesty and finding privacy to feed, particularly when living in close proximity to large families and local communities, as well as managing feeding with multiple young children. 4950 Studies also outlined barriers to accessing culturally-appropriate professional and peer support for breastfeeding, indicating that cultural competency was underdeveloped and not prioritised by health professionals. 51 Crucially, research highlighted the futility of promoting the benefits of breastfeeding in the ante-natal period, while also failing to provide adequate practical support services postnatally. 5253

Notably, existing studies on Gypsy, Roma and Traveller infant feeding practices seemed to lack research into the role and influence of fathers and male partners in infant feeding. This is not unexpected, due to fairly widespread reluctance among Gypsy, Roma and Traveller men to discuss issues relating to maternity, as this is often perceived to be outside of typical male gender roles and expectations. In small-scale studies which did not specifically focus on Gypsy, Roma or Traveller communities, mothers' perceptions of their partners' support/responsiveness and fathers' reports of their own support/responsiveness predicted longer breastfeeding intentions and duration. ⁵⁴ The role and experiences of Gypsy, Roma and/or Traveller

⁴⁶ ibid

⁴⁷ ibid

⁴⁸ ibid

⁴⁹ Breastfeeding Berkshire (2019) 'Breastfeeding in the Gypsy, Roma and Traveller Community'

⁵⁰ Condon, L. (2015) Roma, Gypsies, Travellers and Infant Feeding

⁵¹ Condon & Salmon (2014). "You likes your way, we got our own way": Gypsies and Travellers' views on infant feeding and health professional support.' Health Expectations

⁵² Ibio

⁵³ Hoddinott et al. (2012) 'A serial qualitative interview study of infant feeding experiences: idealism meets realism'. British Medical Journal

⁵⁴ Rempel et al. (2016) Relationships between types of father breastfeeding support and breastfeeding outcomes



fathers' and male partners in infant feeding was identified as a gap in existing research.

Broader infant feeding policy context & the cost-of-living crisis

Current infant feeding policy in the UK promotes exclusive breastfeeding for the first six months of a baby's life. ⁵⁵ At an individual level, the policy promotes the initiation, duration and exclusivity of breastfeeding, as reflected in the <u>Public Health Outcomes Framework (PHOF)</u>, which categorises breastfeeding as an indicator of health improvement, and measures breastfeeding initiation and prevalence at 6-8 weeks. ⁵⁶ At population level, the policy aims to increase rates of breastfeeding, again reflected in the PHOF, which tracks the percentage of women initiating and continuing to breastfeed year on year.

The health benefits of breastfeeding for both parent and child are well-documented. ⁵⁷ However, there are many reasons why some families may choose not to, or may be unable to, breastfeed. Funding cuts to NHS infant feeding support ⁵⁸ and health visitor services ⁵⁹⁶⁰ mean that many families are unable to access the support they need to initiate and continue breastfeeding through the NHS, with private breastfeeding support services prohibitively expensive for many. As this report highlights, families from some Gypsy, Roma and Traveller communities will face specific barriers to breastfeeding, which is not considered the cultural norm in some communities. Regardless of the reasons behind infant feeding decisions, every parent's choice should be respected and well-supported.

The most recent data suggests that though 72% of women in the UK start breastfeeding, nearly two thirds (63.5%) of babies are being fed entirely or partially with formula milk at 6-8 weeks after birth. ⁶¹ The last national <u>Infant Feeding Survey</u>, conducted in 2010, showed that "by six months, levels of exclusive breastfeeding had decreased to one per cent, indicating that very few mothers were following the health department's recommendation that babies should be exclusively breastfed

⁵⁵ Public Health England (2021) Early years high impact area 3: Supporting breastfeeding

⁵⁶ Gov.UK (2024) Public Health Outcomes Framework

⁵⁷ NHS (n.d) Benefits of breastfeeding

⁵⁸ Unicef (2017) Cuts That Cost

⁵⁹ Institute of Health Visiting (2023) State of Health Visiting, UK survey report

⁶⁰ Nursing Times (2018) <u>Health visitor cuts negatively affecting breastfeeding support</u>

⁶¹ Gov.UK (2023) Breastfeeding at 6 to 8 weeks: comparison of NHS England and OHID data



until around the age of six months." ⁶² Based on the 2010 survey (supported by evidence from partial reviews since) the majority of babies will rely on formula milk, entirely or in combination with breastmilk, in the first six months of life.

The accessibility of high-quality, effective and culturally competent breastfeeding support, as well as safe and appropriate infant formulas for those who want or need them, are of crucial importance and must be considered in efforts to address maternal health inequalities. In the context of the ongoing cost-of-living crisis, the financial impact of infant feeding and the cost of formula is especially relevant.

Analysis conducted by the <u>British Pregnancy Advisory Service (BPAS)</u> shows that the cost of infant formula has risen rapidly in the last two years; the cost of one box of the cheapest formula milk is now greater than the value of the Healthy Start Voucher families receiving qualifying benefits can claim, at £8.50 per week. ⁶³ Evidence suggests that branded suppliers of baby formula have increased their prices by more than their input costs over this period. ⁶⁴

Some parents are now resorting to unsafe practices like watering down formula milk or obtaining formula from unsafe sources⁶⁵. Unsurprisingly, formula milk has become one of the most commonly shoplifted items in the UK.⁶⁶

As part of measures to encourage breastfeeding, the UK has adopted aspects of the International Code of Marketing of Breastmilk Substitutes which is a set of recommendations designed to regulate the marketing of breastmilk substitutes, particularly infant formula and follow-on formula. Frovisions in this Code are written into regulation in the UK. While important in preventing harmful marketing and the commercialisation of infant feeding, in the context of the current cost-of-living crisis, these policies have created additional barriers to managing the cost of formula by banning discounted pricing or promotional activity. A <u>recent BPAS survey</u> revealed overwhelming support from participants for a review of regulations to enable the use

⁶² NHS England (2012) Infant Feeding Survey - UK, 2010

⁶³ BPAS (2023) The costs of infant feeding choices today

⁶⁴ Competition & Markets Authority (2023) Price inflation and competition in food and grocery manufacturing and supply

⁶⁵ Sky News (2023) <u>Desperate parents are stealing baby formula to keep their children fed</u>

⁶⁶ Ibid.

⁶⁷ WHO (1981) International Code of Marketing of Breast-Milk Substitutes



of supermarket points and vouchers in the purchase of formula, which is currently interpreted as prohibited under rules banning marketing or promotion⁶⁸.

Moreover, as Feed UK notes, "current UNICEF UK guidelines that recommend against direct provision of formula to formula fed babies by food and baby banks are creating barriers to access. This is causing problems at multiple levels: families face delays in getting formula for their babies, relationships between health care providers and third sector organisations are put under strain, and healthcare providers are prevented from accessing support for the babies in their care." Short-term measures could help to alleviate this problem: "formula can be provided safely by food/baby banks, alongside referring families to services that offer longer term support. It doesn't have to be one or the other. There are brilliant initiatives out there plugging the gaps left by the current system to ensure no baby goes hungry." But as Feed emphasise, "Obviously, food and baby banks are not the answer to formula poverty. We need systemic change."

As BPAS has pointed out, in policy terms, formula milk occupies an awkward and unique position between food and medicine⁷². Unlike other foodstuffs, families cannot shop around or adjust their babies' diets to cheaper alternatives without health consequences. As the CMA notes, families are "locked in" to purchasing formula – the only "alternative" is breastfeeding, which, as this report will highlight, may not be possible or pursued by women for a variety of reasons. While formula is more akin to medicine as an essential product for health, it is not subsidised in the same way.

Provision of a safe, non-profit, "national milk" or subsidised formula would be one means of securing consistent access for vulnerable families.⁷³ This would be a return to previous practice, remembered by older research participants; from 1940 until 1976, baby formula was either free, or heavily subsidised by the state. Parents of under ones were issued tokens which could either be swapped for formula directly at their local infant welfare clinic or, if they were wealthier, used to purchase formula at

⁶⁸ BPAS (2023) The costs of infant feeding choices today

⁶⁹ Feed UK (2022) Feed inquiry: access to infant formula for babies living in food poverty in the UK

⁷⁰ Ibid.

⁷¹ Ibid.

⁷² BPAS (2023) The costs of infant feeding choices today

⁷³ Cohen-Murray (2022) Why the UK needs a new National Milk



around a quarter of the market rate.⁷⁴ In a <u>recent BPAS survey</u>, the overwhelming majority of respondents were supportive of a national or subsidised milk: three quarters of those polled would consider using a free national formula if offered by the Government and/or local authorities, rising to 85% of the youngest mothers (16-24).⁷⁵

The decision in the 1970s to withdraw the provision of a National Milk in favour of breastfeeding promotion created an either/or narrative which does not reflect the needs and experiences of women today. Promoting and protecting breastfeeding does not need to come at the, quite literal, expense of failing to tackle the issues of access to an affordable, consistent supply of formula milk. As BPAS emphasises, "we do women a disservice by positioning breastfeeding as a public health issue, while failing to provide all women who want to breastfeed with the support they need to continue if that is their wish, while treating the issue of formula feeding as a privatised matter to be outsourced to commercial formula companies with a profit motive". ⁷⁶

1.B Our methods

This qualitative research project was shaped by the input and insights of Gypsy, Roma and Traveller community members at every stage. The project also benefitted from the expert advice of maternal health and infant feeding specialists, both clinical and non-clinical.

Initial research topics were identified by the research team through a scoping exercise and literature review. Research questions and data gathering methods were then developed in coproduction with working groups of community members, convened by FFT and RSG.

Research questions were presented to maternity and infant feeding professionals working in both healthcare and in academia, via a series of 1:1 interviews. This allowed the team to tailor the research to better meet the needs of policymakers and clinicians, as well as reflecting the lived realities of the Gypsy, Roma and Traveller community members who participated.

⁷⁴ Braughan (2023) Bring back National Milk

⁷⁵ BPAS (2023) The costs of infant feeding choices today

⁷⁶ Ibid.



Consulting academics with a background in infant feeding and/or research into Gypsy, Roma and Traveller communities, prompted the expansion of our research participants to include the experiences of fathers and non-birthing partners in the infant feeding process. This addressed a gap in existing research, and ultimately produced a more rounded and nuanced representation of Gypsy, Roma and Traveller families.

Our data gathering process included an online survey and a series of focus groups and 1:1 interviews. The design of these data gathering tools prioritised securing the input of as diverse a range of community voices as possible, by offering a variety of opportunities to engage. For participants who may not have been comfortable speaking openly in a group setting, 1:1 interviews made engagement more accessible. This was particularly true for participants who identified as men, some of whom would not have been willing to take part in the project if it required mixed-gender group work. FFT and RSG also offered in person and telephone support for community members to complete the online survey, in order to mitigate for issues around digital exclusion and low levels of literacy.

Our online survey solicited 125 responses total, of which 110 participants selfidentified as female and 4 as male. The cultural breakdown of these responses are as follows:

Romany Gypsy (44)
Roma (40)
New Traveller (16)
Irish Traveller (10)
Other Traveller (11)
Boater (7)
Scottish Gypsy/Traveller (3)
Showman (2)

Survey respondents mostly identified as female and living in settled accommodation. This aligned with the research team's expectations around gendered norms for discussing maternity and barriers to participation relating to high levels of digital exclusion – which become particularly acute for those living nomadically. It is therefore notable that survey data may not be reflective of the most marginalised and excluded members of Gypsy, Roma and Traveller communities.



A series of 5 online and in person focus groups were held by FFT and RSG, totalling 25 participants. Where possible, focus group sessions were separated by age group, in order to facilitate more open discussion (grandparents, parents with older children, parents with young children). Within Gypsy, Roma and Traveller communities, respect for older community members may restrict younger individuals from expressing contradictory or controversial views and experiences in mixed-age settings. Similarly, mixed-gender settings are not suitable for discussion relating to maternity issues, due to stigma and discomfort around discussing issues which are perceived as 'gendered'.

For this reason, the team included the option of participation via 1:1 interviews, in order to facilitate the involvement of parents and partners who identified as men. However, as the research process progressed, we found that 1:1 interviews produced much more in-depth and personal insights from all participants, regardless of gender. 16 total 1:1 interviews were held, with 11 mothers and 5 fathers.

Following data collection, further engagement sessions were held with the community working group and healthcare professionals to discuss findings and agree on good practice guidance outlined below.

Direct quotes have been included from anonymised research participants, to illustrate our findings and amplify the voices of community members.



2. Our findings

Every parent should feel equipped with all the information and support they need to make the best choice for them about how they feed their child. That support looks different for different individuals and communities, and health services have a responsibility to make sure support is accessible and appropriate for all.

Several key themes and findings emerged from our research process, which are outlined below. These are grouped under "cultural norms, expectations and influences", "support, information and communication", "experiences with infant feeding services", "economic challenges", "perinatal mental health" and "fathers' & partners' perspectives".

It should be noted that where particular experiences and trends are associated with particular communities, they should not be taken as universally true for every member of that community. Experiences shared in our interviews, surveys and focus groups were varied and nuanced – however, noting trends can be useful in highlighting important context for health workers and policymakers to be aware of when designing or delivering services.

2.A Cultural norms, expectations, and influences

Cultural norms and expectations around infant feeding were shown to heavily influence individual choices and experiences. Our research revealed tendencies which varied significantly between different ethnic and cultural groups; within Roma communities breastfeeding was considered the cultural norm, whereas participants from Romany Gypsy, Irish Traveller and Travelling Showmen backgrounds indicated that formula feeding was more typical within their communities.

i) Romany Gypsy, Irish Traveller and Travelling Showmen communities

Participants from Romany Gypsy, Irish Traveller and Travelling Showmen communities described bottle or formula feeding as the cultural norm. The reasons contributing to this ranged from the practical realities of life within the communities, to bonding aspects for families and friends. Bottle-feeding was seen as an important



tool for fathers and the wider family to bond with a new baby, and support mothers in the early stages of a child's life.

"[Bottle-feeding has a] bonding element with rest of family not just mum – everyone else feels left out when it's just mum doing the feeding."

Expressing breastmilk in order for other family members to feed by bottle was not a typical practice; most participants indicated that they had not heard of this as an option. The option to mixed or combination feed has not been offered or explained by health professionals, or in some cases had been actively discouraged.

Some participants also viewed bottle feeding as easier to monitor and manage than breastfeeding:

"Breastfeeding is always a worry because you never know if you have fed them enough - with a bottle you can manage it better."

Because formula feeding was more typical, knowledge and experience of breastfeeding within these communities has become limited. For parents who were interested in trying breastfeeding, there was sometimes little or no knowledge of how to manage breastfeeding within their family or immediate community – which for many would normally be their main source of advice and health information. This left some participants feeling lost and unprepared for difficulties when trying to breastfeed; compounded by barriers to accessing mainstream breastfeeding information and support, which will be addressed in more detail in Section 2.B.

Some participants from Romany Gypsy, Irish Traveller or Travelling Showmen backgrounds did choose to breastfeed, although they explained that this was unusual within their community. Some parents described experiences of cultural stigma around breastfeeding.

"I struggled a lot with other Travellers with my choice to breastfeed – they don't like it, they see it as unnatural. My friends thought I was completely mad! But the fact that I did it made it easier for my friends to try after. I'd already had all the arguments!"



"I felt very judged for breastfeeding, I didn't have any support in the community."

"My husband was very much 'whatever you want, I'll support you' but in the Showmen community that was a bit unusual – other men would say [breastfeeding is] 'disgusting'".

Participants described breastfeeding being viewed within their community as "not what we do" or "not normal", and in some cases even as "weird", "gross" – although these more hostile views were presented as less common.

Other participants described much easier experiences, having found that their choice to breastfeed was supported or accommodated with adjustments, such as feeding in a private space:

"There can be a big stigma around breastfeeding in site communities, but I didn't feel judged for choosing to do it."

"No one in the family would have judged you for feeding – as long as you didn't do it in front of anyone."

One participant explained that, while many mothers within her community felt judged by health professionals for choosing to formula feed, those who chose to breastfeed often faced judgement from within the community:

"Instead of health professionals judging me, my own community did! You can't win."

However, some participants pointed to a generational shift toward breastfeeding among younger people:

"The generation below me are more likely to give breastfeeding a go, but before that it was such a taboo. A lot of it goes down to modesty."

"Things are changing, lots of Romany Gypsies are starting to breastfeed more – even my mind changed between my first and second baby!"



"People can be so set in their ways – 'this is what we do, we've always done this' – but breastfeeding used to be normal, years ago, before formula. Now when people say, 'that's gammy', I just tell them to shut up!"

Those who did choose to breastfeed often pointed to the health benefits for both mother and baby as their primary reason for doing so, and in many cases their decision to breastfeed was influenced by their immediate family practices, regardless of broader community norms i.e. their own parents or older siblings had breastfed.

"My family breastfed more, my mum and my sisters too, so I always wanted to give it a go."

ii) Roma communities

Roma participants described breastfeeding as the cultural norm, although expectations around the duration of breastfeeding would vary. Most participants regarded breastfeeding for around a year as generally optimal, although some regional traditions expected a longer duration.

"Breastfeeding is seen as more natural and healthy – there are expectations about how long mothers should breastfeed for – at least a year if not longer."

"Usually, you would breastfeed for a year. The longer you breastfeed, the better."

Some participants mentioned feeling some pressure to breastfeed:

"There is a pressure from the community to breastfeed – because everyone talks about it as being the preferred method, you feel pressure that you should be doing it. There were discussions around doing it for a year as an accepted good period [...] – that's what everyone says! But at the same time, [...] if you don't breastfeed and blame it on the milk not being good enough, people are fine with that."

Participants also explained commonly held ideas around problems with breastfeeding being due to "bad milk" or not producing enough milk. Some



participants explained that there was not much awareness about common problems (like issues latching) and how they can be addressed, or techniques to help stimulate or increase breastmilk production. Breastfeeding was often framed in binary terms as either easy and natural, or just not possible for some people, with formula as an acceptable alternative in those cases.

"When the first baby was born we were in shock in those first hours, because my wife was trying to feed but [the baby] was just crying and crying and crying. We put that through the lens of people talking about not enough or not good enough milk [...], but all those things were misconceptions. We didn't understand what was happening, we didn't know it was because [the baby] wasn't latching properly."

The lack of awareness around breastfeeding problems and techniques experienced by some families was compounded by a lack of explanation from health professionals, leaving parents distressed and shocked if breastfeeding didn't go smoothly immediately:

"No professionals talked to us about latching before we gave birth – this wasn't talked about in Romania either, so our parents weren't aware either. It would have been really helpful to be prepared and to know. That's our one advice when people are about to have babies! Don't expect the baby to know how to do it."

Some participants felt that, because breastfeeding is the cultural norm for Roma families, health professionals would sometimes assume that families did not require in-depth breastfeeding information or practical support:

"There is an assumption that Roma women 'just know' how to breastfeed, like, 'that's what they do'. It's a misconception – professionals assume they don't have to talk about it with them, even if she is young, because 'her mother will tell her' and so on. It's wrong!"

This is compounded by the fact that migrant Roma community members may not be familiar with their maternity care entitlements through the NHS or a typical maternity care pathway. Because of this:



"Roma women might not expect professionals to come and give advice, they might not know what they are entitled to."

Some migrant Roma families were not aware of their healthcare entitlements under the NHS and would avoid interaction with health services due to worries about financial cost.

However, across the various community groups some commonalities emerged in participant responses around what elements influenced their infant feeding choices:

iii) Centrality of family and community

Across different communities, infant feeding choices typically reflected family feeding traditions, although not always. Generally, respondents who breastfed indicated that this was influenced by their immediate family (or a knowledge of the health benefits of breastfeeding), and those who formula-fed indicated that their choices around which brands or products for formula and equipment were heavily influenced by what other family members had used.

"Family influences a lot, that's the way it tends to be - what milk you use, all that kind of thing"

Respondents also referenced routinely seeking infant feeding information and help from family, friends and community knowledge – as well as independent research (often online) – rather than relying on professional help. If worried about an infant feeding issue, family and community would typically be the first and more trusted port of call, with professionals consulted at a later stage if deemed necessary. This is reflective of a broader trend of low engagement with health services and low levels of trust in health professionals, due in part to fear of and lived experiences of discrimination, as well as other access issues. See FFT's Health Inequalities Briefing and Tackling Maternal Health Inequalities Guidance for more on this.

"I went to my family more for help [...] – I felt very judged by professionals."

When asked 'where did you get most of your information about feeding your baby', 66.05% of total survey participants responded 'from my family and friends',



compared to 14.4% who responded 'from a health professional'. 11.2% of respondents chose 'from NHS websites or resources', while 8.35% selected an 'other' option and specified various non-NHS information sources, primarily online, including La Leche League or social media.

iv) Health benefits for babies and mothers

Across different communities, parents who breastfed typically referenced health benefits for babies and mothers as the primary reason for doing so, although levels of awareness around exactly what the benefits are varied.

Some participants, for whom breastfeeding was not a cultural norm, would attempt breastfeeding if their baby was premature or unwell – sometimes seen as 'needing to be done' for poorly babies, or more acceptable under extreme circumstances. Parents who experienced extended hospitalisation after the birth were more likely to breastfeed, even if only for the duration of their stay. More on this below, under Section 2.A.v.

v) Modesty privacy and space

Modesty, privacy and living space were themes raised by participants across various community groups, but these factors influenced participants' infant feeding experiences in different ways, depending on their context.

For various Gypsy and Traveller communities, modesty was an especially acute issue. Participants described a cultural stance that breastfeeding in public spaces was not appropriate, and many also felt that breastfeeding in front of family and friends was not acceptable.

"There's negative ideas about men seeing it (breastfeeding), and women either. And definitely not in public."

Again, some participants pointed to a gradual generational shift toward normalising breastfeeding in public:

"Modesty is a huge factor in the community, I wouldn't have breastfed in front of my mother, aunts - females, never mind men. You just didn't do that in those days, but times are changing and I think it's up to the woman if she's



comfortable breastfeeding, that's her choice and it should be respected. It wouldn't bother me if I saw someone breastfeeding."

However, for many participants, modesty and difficulty finding private space meant that breastfeeding did not feel like an option for them, regardless of health benefits.

"[I chose to feed by] bottle as I would not be getting my breast out in public to feed my child this is unheard of"

This was especially true for those who were travelling or living in culturally pertinent accommodation while feeding, as private space tends to be very limited:

"When travelling with a large group there's not much privacy, people are coming in and out of the trailer all the time so although I knew the breastfeeding was seen as the best for baby it was impossible to feed that way."

Although this was not a barrier for everyone, with some participants explaining that they were able to make arrangements with family that felt comfortable for breastfeeding at home:

"I just put a cloth over me. My dad isn't bothered, he leaves me to it, and my brothers are the same."

"I would hide to feed the kids, until with the last one I just insisted – this is what's happening, I'm sick of hiding, it's not my problem! Don't come in if you don't like it."

Some parents found ways of navigating the need for privacy by only breastfeeding at night or expressing breastmilk to be given by bottle in front of others.

One notable trend was an increased tendency toward breastfeeding among Gypsy and Traveller participants who experienced extended periods of hospitalisation with their newborn. Often, this would be a short window of breastfeeding while in the hospital, reverting to formula or expressing breastmilk to bottle-feed on returning home. This was linked to greater privacy for feeding in hospital, as well as more



information, practical support and advice from professionals. Additional time to get to know professionals and build a trusting relationship was also a contributing factor.

"It was okay in the hospital [but] there's no way I can do it at home around my family, and I can't do it out [in public]... It's not so much the feeding, but having a place to do it."

"There's nowhere in the trailer, there's [my partner's] mum, the other kids, me, my brothers – there's ten people in and out through the day! It's so hard to find space, you can't relax. So, when you're in the special baby unit, you've got that time and privacy."

Modesty is less of a barrier to breastfeeding in Roma communities, where breastfeeding is more normalised. However, modesty is still a factor, and for Roma participants who lived in shared, insecure or overcrowded accommodation, finding privacy to feed was raised as an issue.

"We were living with another family, I didn't want to feed in front of them. I had to feed in my bedroom, it felt awkward."

For participants who did not live in a traditional house or 'bricks and mortar' home, space and access to facilities like electricity and clean water sometimes impacted infant feeding.

"Living in a house, I had more space, it was easier to sterilise bottles and store everything...a lot of my friends and family don't have that, especially in a little trailer... I had it a lot easier than my friends and cousins who were travelling."

For Boater participants and participants who lived in smaller homes like caravans and trailers, access to sufficient space, electricity and water facilities was a challenge:

"[on the] canal boat, sterilizing was complicated as well as finding comfortable spots outside the bed to breastfeed"

"Narrowboat continuously cruising. Limits on water and power so used cold sterilisation. Had to move more frequently to ensure had enough water."



"Couldn't use hospital grade breast pumps because of not having mains power 24/7. Sterilising things was more of a pain because of no mains power or microwave and lack of space to store things."

"[I lived in a] caravan – issues with space to store things."

For participants across different community groups, living in culturally pertinent accommodation or insecure housing sometimes impacted access to services and support.

2.B Support, information and communication

Many participants described problems with accessing infant feeding support and information, as well as issues relating to effective communication from health service providers.

i) Accessing support

Participants outlined various barriers to accessing infant feeding support, which varied depending on cultural background and living circumstances. Members of Gypsy, Roma and Traveller communities often encounter problems accessing healthcare of any kind, due to wrongful refusal at the point of registration because they are unable to provide proof of identification, migration status or address.

Members of migrant Roma communities can face barriers to accessing care relating to migration status and may experience reluctance to seek help when needed, for fear of data sharing between the NHS and Home Office⁷⁷. Fear of being charged for healthcare and incurring crippling debt is another deterrent, often leading marginalised patients to put off accessing care until their condition reaches an acute stage⁷⁸.

⁷⁷ BMA (2019). <u>Delayed, deterred, and distressed: The impact of NHS overseas charging regulations on patients and the</u> doctors who care for them.

⁷⁸ Medact. (2020). Patients Not Passports: Challenging healthcare charging in the NHS.



Barriers to support associated with nomadic living

Participants who lived nomadically, travelled while pregnant/feeding or lived in culturally pertinent accommodation like a site or yard, experienced problems accessing infant feeding services.

Some participants indicated that health workers had refused to conduct on-site visits to Traveller sites. One participant described struggling to attend postnatal appointments because health visitors refused to visit her site and she was unable to drive herself following a caesarean birth and infection. Missed appointments prompted referral to social services:

"I got a call saying 'You've missed appointments so we're going to send social services'. It's like, you can send them down [to the site], but you didn't want to send anyone down to change my dressing or weigh the baby!"

Participants who moved around, by choice or by requirement, during pregnancy and the postnatal period, described the challenges this involved:

"I was 'moved along' regularly, it had a big impact."

"I moved a lot when my baby was born and when he was young. It was sometimes really difficult to access doctors and health visitors"

"We had health visitors visit us on the boat for the first month, then we moved the boat into a different HV jurisdiction, and no one visited after that - we got lost in the system as no one seemed to care about us."

"People who are travelling don't have consistent people [care providers], it's just whoever is available – it's hard to learn to trust anyone."

Barriers to support associated with insecure accommodation

Many Roma community members live in 'bricks and mortar' housing, but may live in insecure sublet tenancies or in temporary multiple occupancy housing. This can create barriers to primary care registration, as it can be difficult to provide proof of address. Some participants also noted fear of accepting home visits from health



workers for worry that their living situation will come under scrutiny. Home visits were feared by some as an opportunity for inspection, rather than care.

ii) Gaps in support available

Lack of culturally pertinent peer support opportunities

In maternity care generally and infant feeding particularly, peer support networks and 'mums' groups' can be a hugely important source of information, support and social connection for parents. This can have a positive impact on perinatal mental health and offer opportunities for signposting to support services if needed. For communities in which breastfeeding is not the cultural norm, opportunities to access networks dedicated to breastfeeding support can also be crucial in filling gaps in community knowledge or experience.

However, there is a severe lack of dedicated Gypsy, Roma and/or Traveller peer support opportunities. Overwhelmingly, participants indicated that they did not attend any kind of peer support group, because mainstream groups were seen as unwelcoming or inaccessible for Gypsy, Roma and Traveller parents – they were, simply put, "not for us". This was often due to fear of discrimination and judgement, or language barriers.

"I knew that they run groups, however this would be intimidating and culturally inappropriate for the majority of Traveller women."

"One Traveller parent of 9 children who did take the step of attending a specific breast-feeding group had a bad experience at her first session when she was told about a breast feeding bra and then a comment was made about her not being able to afford it because she was a Traveller and had so many children. In my experience breast feeding groups are quite elitist and middle class therefore alienating the Traveller community."

Reduction in information and support following the birth of second and subsequent children



A recurring theme raised by participants was a notable drop in infant feeding support and information offered to families after their first child. Participants indicated that for subsequent children, professionals seemed to have an:

"assumption that 'you're an expert now, you know what to do', but every pregnancy is different, still easy to feel lost."

"...because it was her third child, the health visitor only checked up on her quickly. They didn't offer a translator."

This was felt particularly by participants from Gypsy and Traveller communities where larger families with several children close in age are typical.

"More information and support is needed for later babies too. Professionals act like you don't need it after you've had one, but every baby is different, you have different feelings, it's a different experience."

"It's like, the more kids you have, the less support you get. But there might be big age gaps or different health circumstances, different living circumstances just a different baby!"

"As soon as you have another child, they don't even bother with you."

"It seemed like they thought I didn't need help or reassurance because it was 4th baby - 'she's had 4 it doesn't really matter'. We don't need to bother her – they didn't bother coming round. They just wanted to get me in and out – I didn't feel comfortable asking questions."

iii) Information and effective communication

The information made available to parents and the means by which this information is communicated can have a huge impact on infant feeding. Participants pointed to several issues with the type of information they received, and its delivery:

Rigid messaging around infant feeding



Many participants complained of receiving very rigid or "pushy" messaging about infant feeding from health professionals. This compromised relationships between parents and health professionals, and limited opportunities to explore different feeding methods in order to identify the most suitable strategy for different circumstances.

For example, some community members discussed wanting to breastfeed for health benefits, but feeling it was impossible in their living circumstances due to a lack of privacy. When combination methods like expressing and bottle-feeding breastmilk were mentioned, many participants were surprised, having never heard of this as an option:

"I didn't know you could do that! I would have tried that if they (health professionals) had said!"

'All or nothing' messaging around breastfeeding often gave participants the impression that exclusive, long-term breastfeeding or formula feeding were the only options available. For those who felt that breastfeeding in this way was not suitable for them, this shut down any exploration of adapted ways of breastfeeding that could mitigate for their living circumstance and cultural dynamics. Staff awareness and respect for the cultural elements that can be a barrier to breastfeeding for some in Gypsy and Traveller communities is key to holding engaging and informative dialogue with parents, in order to support them in finding the best feeding method for them.

More space needs to be given for parents to explore and determine how they can access the health benefits of breastfeeding in ways that feel comfortable and accessible in their specific circumstances.

"I never really had good support – I knew I wanted to do mixed feeding, but I always had pushback – didn't have good support in my decision, I always felt pushed to change it [to exclusive breastfeeding]. No one ever asked me why or tried to understand [why I wanted to combination feed]."

"They just wanted to push me to full breastfeeding, I thought you had to do one or the other."



"I remember breastfeeding being pushed on me. I felt very overwhelmed – they were just coming at me and coming at me... I was like no, I'm sick of this, I'll stick with what I've been doing, just leave me alone. It was just so much information."

In order to increase the levels of breastfeeding with Gypsy, Roma and Traveller communities, more flexibility and recognition of different experiences and requirements is needed in messaging from health professionals – with support and information provided around the different challenges that can be linked to non-exclusive breastfeeding.

Timing of information delivery

Participants from across different communities pointed to a need of practical information and support to be provided to parents before birth, as well as postnatally. This helps parents to anticipate and understand challenges they may face when first attempting to feed their baby, preventing unnecessary panic when issues do arise.

"I don't think there's nearly enough information before you have the baby – it seems like they wait till you're the most vulnerable you could be [after birth] before they attack you with info."

"Information is not clear about how hard it is. I found the experience a shocking surprise."

"We assumed the baby would know what to do! We expected that would be the case and it wasn't! That was a very difficult thing, especially in those first hours."

Roma postnatal 'purity period'

Another factor around timing is a custom observed by some traditional Roma communities after birth, often known as a 'purity period'. It is important to be aware of traditions associated with this custom, in order to factor them into postpartum service planning for patients who observe. After birth, observing mothers will not be expected to leave the home, and will be supported by female family or community members with tasks like cooking and cleaning, to allow time for mother and child to



bond. Male community members might not be present during this time, potentially including the child's father. The time periods involved can vary, typically ranging from a few weeks to around three months after birth.⁷⁹

This custom is no longer observed by most Roma families, following a generational shift away from this practice. However, this is important to discuss with families prior to birth, to ensure that key postnatal health information is delivered effectively, as families who observe this period may not be easily accessible after the birth.

Digital exclusion

Gypsy, Roma and Traveller communities experience <u>high levels of digital exclusion</u>. As such, it is important that infant feeding information and support is not 'digital by default', but is designed to be accessible for those who may not be able to easily view information or make appointments online.

Language barriers

Roma participants, for whom English was not their first language, explained the language barriers they experienced relating to infant feeding information.

"I struggled with breastfeeding for both children but I didn't know who to speak to. I needed an interpreter, but I didn't have one."

Many migrant Roma people have reported struggling to understand written material in English, or medical terms in both English and their first language (usually one of the Romanes dialects) or second language (often a Central or Eastern European language). Patients who cannot communicate effectively in English are entitled to an interpreter or health advocate, however, further barriers arise for Roma communities due to a lack of professionals who can speak and/or interpret Romanes. It is important to note that due to cultural taboos around discussing health issues, calling on family members to act as interpreters is not appropriate and can result in patients not disclosing important information about their symptoms.

⁷⁹ Roma Support Group (2022) Maternity Services

⁸⁰ Roma Support Group (2022) Language barriers and communication



Wording used in English is also relevant, as many members of Gypsy, Roma and Traveller communities experience inequalities in education⁸¹ meaning that health knowledge and public health messaging typically accessed in schools may have been missed.

Literacy barriers

Participants also discussed their experiences of barriers to accessing infant feeding information due to literacy. Low or no functional literacy levels can be more common in Gypsy, Roma and Traveller communities due to inequalities in education. For this reason, leaflets or webpages providing written information on infant feeding is not accessible for many parents and more tailored approaches need to be taken. This might include lengthier verbal explanations, or including audiovisual information options.

Some participants referenced staff not seeming to have a good understanding of how to work with literacy challenges:

"I struggle with reading and writing, booking stuff in... I don't think she [health worker] really understands needing help with literacy, she gives me all this paperwork..."

Cultural relevance

There is a lack of culturally relevant and specific infant feeding information available to Gypsy, Roma and Traveller families. A lack of culturally relevant imagery and examples in breastfeeding materials can compound a sense that breastfeeding *"isn't for us"*.

Participants indicated a need for infant feeding information relating specifically to nomadic living:

"Would have been good to have resources on how to sterilise with limited water/power and ways to store milk."

⁸¹ Friends, Families & Travellers (2023) Education inequalities facing Gypsies, Roma and Travellers in England



Participants expressed worry and confusion about the safety of breastfeeding, and explained that they did not have access to information that felt tailored to their experiences. More funding and opportunities from government need to be channelled into developing these kinds of resources.

One excellent example of culturally relevant infant feeding information materials was created by Ireland-based <u>Pavee Point Traveller and Roma Centre's</u> maternal health initiative, <u>Pavee Mothers</u>. Developed by and for Irish Traveller women, this took the form of <u>a website and printed information pack</u>, as well as a text message campaign.

2.C Experiences with infant feeding services

Generally, Gypsy Roma and Traveller communities have fairly low levels of engagement with health services, and it can be challenging for trusting relationships to develop between community members and health professionals.

Participants experiences with infant feeding services varied hugely by different geographic areas and with individual care providers. As previously mentioned, participants indicated very different experiences with subsequent children, compared to their first child.

Participants shared some positive experiences, outlined below, which have informed the good practice recommendations in Section 3.B. However, participants also shared more difficult experiences, including a lack of cultural competency in services, gaps in support provision, and other issues.

i) Positive experiences

The most positive experiences shared by participants were defined by professionals with whom they were able to build a trusting relationship. These professionals were able to take the time to listen and understand the participant's situation, concerns and culture, in order to provide nuanced, practical and tailored advice that prioritised the overall wellbeing of both mother and child.



Participants described professionals who explained the benefits of different infant feeding options in order to help parents to make their decision. Participants appreciated professionals who were non-judgemental and supportive, particularly when they could offer practical tips and advice.

"She listened to me and wasn't judgemental at all, then she showed me some different ways of holding [the baby] that worked much better for me. I thought I had to hold [the baby] a specific way, but she said as long as we are both comfortable and [the baby] is eating, then we're doing it right! I felt so much calmer."

"She explained all the health benefits to me, all the pros and cons of formula and breastfeeding, and just said, 'it's your choice'."

"The midwife I had with my youngest was wonderful... she explained everything in a friendly way. When I came across something I didn't really understand, she would explain it so clearly. She related as more of a friend. She was really caring. She went through everything with me, bottles, rashes, everything. I could not fault her in one way."

"They were brilliant, sat down with me and showed me how to hold the baby to feed, answered all my questions and asked me how I was feeling, made sure I was okay."

Participants particularly appreciated being able to access in-person support, as well as being given clear and accessible information to take away and process in their own time. Video calls were also seen as a good option for some, as were apps with trustworthy health information.

"At the hospital, after I gave birth, I had a short course about taking care of the baby and that helped me. The course was with 3-4 other women and a midwife. She was showing us what to do on a doll and we had our babies."

"The course after birth was very useful. It could be online, video, face to face, it doesn't matter. But a flyer won't work. It needs to be a course. Maybe the dads would also need the courses."



Thorough checks that feeding was going well, and that mother and baby were both healthy before leaving hospital were also valued:

"Before you leave the hospital, they should do all the checks, be certain the baby is feeding properly."

Unfortunately, many experiences did not look like this. Common aspects of more negative experiences are outlined below:

ii) Lack of cultural competency

Many participants felt that the infant feeding professionals they interacted with had very little understanding of their culture, living situations or needs. This made it very difficult to develop a trusting relationship.

"Midwives and health visitors have made comments about lack of space or facilities in trailers. I know that lack of understanding of our culture is a big issue."

"Professionals need to have a better understanding of us – travelling culture... We don't trust authority figures, you'll trust a doctor but then you get that prejudice... we're not an easy trusting culture, it stems from year and year of generational prejudice."

"They don't understand Roma culture."

"I felt very judged by professionals. You'd get a new health visitor and each one would be more interested in looking around the house, commenting on baby's clothes – they were very forceful about their views, acted like I was stupid. I'm not thick – I'm a Traveller but I'm not uneducated, you'd always feel quite down-trodden."

"They don't know anything about the differences between us, they make so many assumptions."



This was felt particularly in interactions with health visitors who did not seem to understand the basics of living on Traveller sites, or with professionals who did not seem to have an awareness of cultural sensitivities or stigmas around issues like mental health, gendered health issues or cancer. This often led to avoidable and unnecessarily uncomfortable experiences for participants.

Prejudice and discrimination

Some participants experienced incidents of prejudice and discrimination due to their ethnicity or background while accessing infant feeding services.

"The midwife made a discriminatory comment about Travellers leaving rubbish and mess and said she could see I wasn't like this as my home was pristine. It was a home visit in the last few weeks of my pregnancy and I was already feeling vulnerable and tearful. I have never forgotten this experience."

"[my health visitor] had a real problem with Travellers."

"They assume you're a low-life person."

iii) Feeling pressured to feed in a particular way, or judged for feeding choices

Many participants, particularly from Gypsy and Traveller communities in which breastfeeding is not the cultural norm, expressed that they felt judged by health professionals for their feeding choices or pressured to feed in a particular way.

"I felt really forced to breastfeed and looked down on for bottle-feeding."

"If you don't breastfeed they [professionals] do look down on you."

"I never felt like I was allowed to make my own decision as a mum."

"The messaging [in an infant feeding group session] was our bodies are made for this, everyone can do it – if you can't, you're weak, you're a bad mum'. I



was always planning to breastfeed, but I came out of that group feeling so angry, almost not wanting to do it!"

Conversely, other participants felt pushed into formula-feeding and unable to find sufficient support for breastfeeding under the NHS:

"Women's choice to breastfeed should be respected and well-funded. I had to pay privately for feeding support. I did go to council groups but there was no 1 on 1 support. I felt bullied by midwives after delivery into giving formula. This has caused me a lot of distress."

While it is essential that every mother is given all the information they need about the health benefits and practicalities of breastfeeding to make an informed decision, their individual choices must be respected. Parents should never feel shamed or judged for their choices around infant feeding.

iv) Lack of practical feeding support

Although many participants felt pushed towards breastfeeding, they also felt that they were not given sufficient practical support or information to breastfeed successfully.

"My wife had all the willingness and desire to breastfeed, but the problem was doing that practically. We missed getting practical support on how to properly latch and this created a very tense situation immediately after birth."

"Key information was missing about the practical way of breastfeeding, how you hold your baby... that was completely missed out of discussions and advice. We were very able to look online and read stuff to find out, but not everyone can. [...] Eventually when a health visitor came, she showed us some practical ways, but it felt like a long time."

Many participants shared that they were told about the benefits of breastfeeding but felt let down by services once their child was born. For parents who did not have family experience with breastfeeding or general knowledge of breastfeeding in their wider community, this was felt more acutely.



Several participants had never had any appointments with health visitors after their child was born and were unsure as to why – others attributed this to moving outside of a particular jurisdiction (see Section 2.B.i).

Multiple participants described being told to simply "push through" pain or difficulty breastfeeding by some health workers, before other workers were able to identify problems in need of treatment or technique changes, such as tongue-tie or mastitis.

"I was in agony, but she told me I just had to keep going. There was no consideration for my pain."

"I was really struggling... Eventually I had a different health visitor, and she suggested some different techniques, some different positions, helped me to relax. It wasn't working doing it the way I thought I was supposed to – but she said, 'if you're both comfy and it's working, that's fine!""

Parents who formula fed also pointed to a lack of practical support from professionals in terms of how to manage making formula and bottle feeding. One participant described the early days of making up formula as "nerve-wracking", as they felt inexperienced and unsupported. However, this was typically mitigated by a high level of community knowledge and experience of formula feeding, meaning that support and information could be sought from friends and family.

v) Reluctance to support or advise parents who have chosen to formula feed

Some participants indicated a lack of support provided for parents who chose to formula-feed, and an unwillingness from staff to give advice or practical support with this.

"Although I wanted to breastfeed, more info and support about bottle feeding would have been good."

Some participants shared a sense of abandonment, particularly if they had planned to breastfeed initially but struggled to do so in practice. One participant described turning to formula as an emergency measure when experiencing challenges with



breastfeeding while still in hospital after birth, and finding staff uncooperative and unsympathetic:

"I had to sterilise the new bottle I bought but I had no way of doing it in the hospital – but they said they couldn't help with sterilising 'we're not really allowed to help you with bottle feeding, we shouldn't really be doing this', but they did help in the end. But she never came to see what was going on and try to help in a practical way or advise."

Moreover, the same participant felt that staff were so opposed to formula feeding that he worried he would be reported:

"I understood they wanted us to breastfeed, it was clear, and I have to say I was thinking like 'okay, we want to as well, but we can't! Will this raise worries for them if I formula feed? Are they going to report this as a problem?' But I knew I needed to feed my baby. I understand they want [breastfeeding] because of all the benefits, but I was worried it would be reported."

vi) Concern around impact of NHS underfunding

Participants also shared their concern that much of the negative aspects of their experiences of infant feeding support services were linked to staff being over worked and under pressure, due to government cuts to the NHS. One participant explained that:

"It's not a reflection on staff, but a reflection on how underfunded they are."

"It's not the fault of the people struggling to do the job under horrendous conditions, a lot of people don't realise where the fault lies – with the government, not the staff."

For Roma families who experience language barriers, cuts to interpreting and translation services were a particular concern.



2.D Economic challenges

Existing research shows that Gypsy, Roma and Traveller communities face economic and financial exclusion generally, a dynamic only exacerbated by the cost of living crisis. The consequences of the current financial climate for mothers and families have been dire, as illustrated in more depth by Maternity Action's recent report 82 exploring the impact of the cost of living crisis on low-income mothers and families, and the British Pregnancy Advisory Service's report on the costs of infant feeding choices. 83 This broad trend was also reflected in the experiences shared by research participants.

Worries about the cost associated with having a child were felt by participants across different Gypsy, Roma and Traveller communities. Participants raised concerns relating to the cost of equipment associated with feeding, such as bottles, sterilisation tools and breast pumps, as well as the cost of formula. The cost-of-living crisis has meant that Statutory Maternity Pay and financial supports such as the Sure Start Maternity Grant or the Healthy Start Scheme payments are worth less and less for families in real terms. 84

"It was very difficult to buy everything we needed, even with the maternity grant."

i) Cost of formula

The cost of formula was a major worry particularly for participants who experienced cultural barriers around breastfeeding. Analysis shows that the cost of infant formula has risen rapidly since 2021; the cost of one box of the cheapest formula milk is now greater than the value of the Healthy Start Voucher families receiving qualifying benefits can claim, at £8.50 per week.⁸⁵

Moreover, many participants indicated that their choice formula brand or product was influenced by factors which would likely add additional expense. Some participants explained that they understood certain brands of formula to be a better or healthier

⁸² Maternity Action (2023) A perfect storm: pregnancy, new motherhood and the cost of living crisis

⁸³ BPAS (2023) The costs of infant feeding choices today

⁸⁴ Maternity Action (2023) A perfect storm: pregnancy, new motherhood and the cost of living crisis

⁸⁵ BPAS (2023) The costs of infant feeding choices today



choice. These brands were more expensive options that were either familiar brand names or marketed as meeting a particular need, such as "hungry baby" milks.

However, the NHS says there is no evidence these milks offer benefit over "normal" first infant formula ⁸⁶ and a recent study concluded "most products did not provide scientific references to support claims, and referenced claims were not supported by robust clinical trial evidence." ⁸⁷ First Steps Nutrition, an independent public health nutrition charity, notes there is little meaningful variation in the nutrient content of different brands of infant formula because they must all conform to the same compositional requirements which are controlled under The Infant Formula and Follow-on Formula (England) regulations. ⁸⁸ Once an ingredient is proven to be of benefit, the compositional regulations are amended to ensure it is added, meaning no formula has any proven benefit over another. ⁸⁹

A lack of information and awareness about the composition of formula contributed to a trend of parents believing that more expensive products or familiar brands were the 'better' or healthier choice, despite the fact that all formulas must meet regulatory requirements governing composition and there are no proven benefits of choosing a more expensive milk.

"I just got the most expensive [formula] as I thought price = quality."

"Decided based on family experience, big brands."

Participants indicated that their choices were mostly influenced by the brands or products that their family had historically used, unless their child had a particular requirement. Focus group participants indicated that some parents with low levels of literacy and limited experience with formula may prefer pre-mixed liquid options (to avoid issues with reading written instructions) which would also incur additional expense.

⁸⁶ DHSC (2022) Commission Delegated Regulation (EU) 2016/127 (supplementing Regulation (EU) No 609/2013): guidance

⁸⁷ BMJ (2023) <u>Health and nutrition claims for infant formula: international cross sectional survey</u>

⁸⁸ First Steps Nutrition Trust (2021) <u>Infant formula: An Overview</u>

⁸⁹ Which? (2024) Best baby formula milk brands and expert buying advice



ii) Lack of awareness around financial supports available

Additionally, most participants indicated that they had not been made aware of the financial supports available to families to support in the cost of having a child by health professionals any point in their maternity and postnatal care.

"I didn't know about child tax credits until the midwife who I bumped into at random told me. She was shocked I didn't know. Like 'hasn't your health visitor told you?!' – but I hadn't even had one!"

Some participants also noted that they felt too fearful to ask professionals about financial issues or support, in case this led to investigation by social services:

"No, they didn't tell me anything ever... You've got to go and find it all yourself online... And you don't want to ask. [My health visitor] didn't even want to come to my site anyway, so I thought if I start asking for help it might make it seem like I'm desperate, or I'm in need, and that might flag something up with social services. I just figured things out on my own, I felt like if I asked her... I mean, she was looking at me funny anyway. If she would have offered, I would have been like 'oh yeah!'"

2.E Perinatal mental health

Participants described the impact of infant feeding on their mental health, with the below main themes reoccurring:

i) Impact on mental health of feeling guilt, shame and worry around infant feeding

Several participants linked feelings of guilt, shame and worry associated with infant feeding to their own, or others' experiences of perinatal mental ill-health.

These feelings were most often associated with poor experiences when interacting with health professionals, although not exclusively so. Some participants linked experiences of postnatal anxiety or depression to more general worries around infant



feeding – feeling unsure as to whether their child was getting enough food, for example.

"I was in agony, and they kept saying 'it's you, you're doing it wrong' – I'd say, 'it's hurting', and their response was just 'well he needs to be fed'! I could see how people end up with postnatal depression. My friend puts her postnatal depression down to pressure from breastfeeding, she felt like the worst mum. I understood that, I felt like a terrible mum."

"It was all done on guilt, rather than listening to me – but you feel like to have to agree [with professional advice]. You're so hormonal and overwhelmed, and you just think 'well, they're the experts, they must be right'." (on professional infant feeding support).

"You're told that as a mum you should be able to do it [breastfeed], it should be easy, should be painless. It felt like admitting defeat to say there was a problem, it felt awful."

ii) Cultural stigma around discussing mental health

There is significant stigma and taboo around mental health within many Gypsy, Roma and Traveller communities. Awareness and openness around mental health issues is gradually improving, but there remains a significant reluctance to discuss mental health.

Specifically for some Roma groups, there is a belief that mental health problems are genetic and run in the family, meaning it is rarely discussed for fear of damaging the family's reputation or children's future chances of finding a marriage partner. The community's common language, Romanes, also lacks the vocabulary to describe mental health problems such as depression and anxiety attacks, as well as a range of different emotions, which can create barriers to accurate self-expression and diagnosis. When mental health is discussed, it may not be referenced as such. Many from Gypsy and Traveller communities will refer instead to having trouble with 'nerves' or having 'bad nerves'. There is some awareness of postpartum depression within these communities, but it may be referred to as bad nerves, 'the baby blues' or 'afterbirth stress'.



Many participants pointed to these cultural dynamics when sharing their experiences or thoughts on perinatal mental health, expressing worry that speaking out about their feelings may have negative consequences for their families.

"There needs to be more awareness and information about mental health. A lot of Travellers are only just in last 5 years getting to understand mental health as a thing. They wouldn't get help because it was embarrassing and really taboo in our culture."

iii) Fear of social services involvement

A recurrent theme among participants who had experienced perinatal mental health issues, or knew someone who had, was an unwillingness to disclose or seek help for fear of social services involvement.

"I was given a questionnaire about mental health stuff – tick if you felt this or that – I ticked no, because I was worried what they would say or think. My sister-in-law had postpartum but was too scared to say it in case they thought she couldn't look after the baby."

"I just felt like, 'you're not trying to help, you just want to report me', so I didn't want to say anything."

Participants worried that they would be perceived as 'needy' or 'not managing' if they disclosed any issues with their mental health. Many linked the fear of social services as a major source of anxiety which exacerbated their mental health struggles.

"You can see why women get down after having them [babies]... you're scared you're going to lose your baby - you've got that threat that someone's going to take them off you. They've got that power over you, at the end of the day."

One participant recounted her experience of being wrongly reported to social services after seeking a letter of support from her midwife to help secure independent housing:



"I had to do what they wanted, it was really scary and unnecessary – the midwife apologized and said she didn't mean for it to go that way – she said she was trying to help with housing but obviously... it really scared me, I'd never go back to that midwife. I put in a complaint about her, all I wanted was support with housing!"

iv) Lack of accessible, practical, culturally pertinent information on perinatal mental health

A lack of clear, practical information about perinatal mental health and the support available was evident in participant's accounts:

"They never explained what can happen, I didn't know what was normal."

2.F Fathers' & partners' perspectives

This piece of research is the only available project (identifiable by the FFT research team), which includes direct input from Gypsy, Roma and Traveller men on their experiences and perspectives relating to infant feeding. This topic is not often openly discussed by men in these communities as, like other issues relating to maternity, infant feeding can be seen as an inappropriate area for men's input:

"There's certain things we don't talk about, there's women's talk and there's men's talk."

Male participant's views on different types of infant feeding generally reflected the cultural trends outlined in section 2.A.

Each family and individual experience is different, however some common themes which emerged in conversation with participants are outlined below.

i) Traditional roles and expectations for fathers and male community members

Across most Gypsy, Roma and Traveller communities, men are often expected to



take a secondary role in the early stages of childcare. In some instances, it may not be seen as culturally appropriate for men to be present. These may include the birth, when breastfeeding or during conversations about gendered health issues and maternity care – although this is not universal for every family. Most of the male participants touched on this topic, explaining that their perceived role in caring for their families during pregnancy and postnatally was often heavily influenced by gender expectations, and an awareness that male presence in certain spaces and conversations may not have been viewed as appropriate by their partner, family or wider community.

"It's not seen as a macho thing, not a man's thing to do... a lot of people won't ask questions, they feel too awkward, like it's a shameful thing."

"I would always leave the room for women's conversations, they don't want me there!"

"I knew whatever questions I had I could have the conversation with my wife afterward. There were things the professionals would talk about that would make me uncomfortable."

"The [Roma] community is still quite conservative – this is seen as the role the mother should have."

ii) Concerns about perceptions of health professionals

However, this cultural norm can become layered with fears around the misconceptions of health professionals who do not fully understand the sociocultural dynamics at play.

Some participants expressed worry that men's absence from spaces and conversations relating to birth and maternity care may be interpreted by health professionals as a lack of engagement or interest in the wellbeing of their child, partner or family. It should be stressed that this would be a profound misinterpretation of a traditional cultural model.



Conversely, in one case, when asked if he ever felt judged by professionals for his choices around being involved in infant feeding conversations, one father explained that professionals seemed as though they would have preferred he were not involved:

"Yes, definitely, I feel like they would have been happier if I was out of sight and out of mind! I don't think they liked me asking questions."

"Health professionals didn't seem to like my involvement – they were not interested in my questions or what I wanted to say. I got a sense of 'please stay out of it' – but it's my wife and my child too!"

iii) Generational shifts

All of the fathers interviewed noted that they see a generational shift in men's behaviours, with younger men becoming more practically involved in the early stages of childcare, including infant feeding.

"Quite a few Travellers don't agree with breastfeeding, or don't get involved with breastfeeding and things like nappy changing – but we shouldn't be embarrassed about it."

"With my extended family, [men] would get involved more when it comes to solid food, not so much in the breastfeeding period. Even if that includes formula, families aren't so involved. Personally, I was quite a lot, and I can see it changing – others are starting to do it too."

"It's not standard for Irish Travellers for men to be involved [with feeding]. I help, and my brother does with his child, but my father never really helped – it's changing as time goes on."

"I never thought I'd do feeding when I grew up, but when my child was in front of me I wanted to help."

iv) Need for tailored support and information for fathers and male partners



Some male participants expressed that, although they wanted to be more involved in infant feeding, they felt that there wasn't an opportunity for them to be involved in conversations with professionals, or they didn't feel confident enough to ask to be involved. Participants suggested that good practice for professionals would include initially asking fathers and male partners how involved they would like to be in infant feeding discussions, without making judgements about his parenting if he chooses not to be present for certain conversations.

For male participants, most information on infant feeding came from family and partners, rather than professionals:

"My wife taught me everything I know, I can make a bottle and feed the child, wind them, all that. I was taught it all by my wife, I never spoke to a professional about any of it."

Some participants raised the need for more tailored informative materials for fathers and male partners:

"Actually no, no [health professionals] involved me [in infant feeding discussions]. Yes, I would have liked them to – not details necessarily, but general things to have some idea! Practical advice, how to support my wife – I think there should be an option maybe. With communities being more or less conservative or traditional and so on, not wanting to be involved should be respected - but it should still be offered! Like if they asked at the start."

"Maybe midwives or GPs could have some info, some resources about it about how dads could help and give support, or maybe groups where people can get together and talk."

"There's space for maybe a leaflet for fathers, to help support and teach them. I would have taken that away and had a look."



3. Our recommendations

Based on the above findings we have worked with community members and organisational partners to develop the below recommendations to support better infant feeding and maternity experiences for Gypsy, Roma and Traveller families.

- 1. Maternity and infant feeding service providers should engage directly with members of Gypsy, Roma and Traveller communities to assess access needs, and adjust services accordingly. This process is best facilitated locally by collaboration with organisations or individuals who have existing relationships of trust with communities.
 - Services should be designed to accommodate for needs relating to literacy, language and digital barriers, accommodation-related challenges, as well as cultural norms and expectations common among Gypsy, Roma and Traveller communities. This is especially relevant for registration, booking and contact systems, which should be made as flexible and accessible as possible.
 - Culturally relevant peer support systems and opportunities should be created within infant feeding services for Gypsy, Roma and Traveller communities.
 - Members of Gypsy, Roma and Traveller communities should see themselves represented in the maternity and infant feeding workforce; NHS England should promote recruitment and training opportunities for community members.
 - Where possible, service providers should work with health mediators or community advocates from within Gypsy, Roma and Traveller communities. Ideally, this mediator would be able to provide language support in the service user's first language.
- 2. Gypsy, Roma and Traveller cultural competency and inclusive services training is recommended for all maternity and infant feeding service providers. Training services can be found via the Cultural Awareness
 Hub, which links to training offerings from Friends, Families & Travellers
 and Roma Support Group, among others. Relevant training topics for infant feeding and maternity services include:
 - cultural norms and expectations around infant feeding;
 - practical issues relating to infant feeding while living in culturally pertinent accommodation or insecure housing;



- effectively approaching culturally sensitive topics like gendered/sexual health issues and mental health (among others);
- Cultural expectations around the role of father figures in some traditional Gypsy, Roma and Traveller families.
- 3. Culturally relevant and accessible infant feeding information resources should be provided to maternity and infant feeding service users. Where these are not currently available, steps should be taken to fund their development. One excellent example of culturally relevant infant feeding information materials was created by Ireland-based Pavee Point Traveller and Roma Centre's maternal health initiative, Pavee Mothers. Developed by and for Irish Traveller women, this took the form of a website and printed information pack, as well as a text message campaign.
- 4. Infant feeding policy and support services must respect and support individual infant feeding choices. Effective, culturally pertinent and accessible support and advice should be available to all families, regardless of which feeding method they choose (including breastfeeding, formula feeding and combination feeding methods).
- 5. Suitable funding is critical to the delivery of safe, effective maternity and infant feeding services. Underfunding of maternity and infant feeding services must be viewed as an urgent political and economic priority. Budgets for maternity and infant feeding should be reviewed and increased in accordance with the Ockenden Reports' Immediate and Essential Actions and the latest Health and Social Care Committee Report on the Safety of Maternity Services in England, as a minimum starting point.
 - Commission and sustainably fund universal, accessible, and confidential infant feeding support delivered by specialist/lead midwives, health visitors and suitably qualified breastfeeding specialists, recognising the role of charitable organisations and community groups and their strong links with communities.
 - Ensure that health visiting services are properly funded and the number of health visitors is increased to ensure consistent timely nutritional support for all families to better support maternal and infant mental and physical health.
 - Ensure there are accessible and culturally competent children's centres or family hubs, disproportionately located in areas of disadvantage, offering joined-up universal services from pregnancy



onwards, that include peer support.

6. Awareness among maternity service users around economic, social and psychological support available to families must be improved:

- O Broader help and advice services should be integrated into healthcare settings. This could be delivered via a social prescribing system, and/or following a <u>health-justice partnership model</u>, which links new or pregnant parents with advice services through their midwife, enabling them to access benefit entitlements and exercise their rights.
- Migrant parents who may not be familiar with NHS care pathways should be advised on their NHS entitlements and typical maternity care pathways on first contact with services.
- Parents should be advised on what support is available to them
 as standard practice, to eliminate the need to ask for help or disclose
 a problem. Reluctance to do so is often associated with a fear of
 expressing vulnerability and/or a fear of intervention by social services.

7. Financial supports for families must be improved:

- Sure Start Maternity Grant should be uprated in line with inflation and eligibility expanded to second and subsequent children.
- Healthy Start should be uprated in line with inflation. Eligibility criteria should also be expanded to include those with No Recourse to Public Funds, in order to reach some of society's most vulnerable families.
- The basic rate of Statutory Maternity Pay and Maternity Allowance should be raised to at least the level of National Minimum Wage.
- The current 8-week qualifying period for Statutory Maternity Pay should be extended to cover 12 weeks' earnings for those with variable hours so that parents on casual contracts are not disadvantaged.
- The policy anomaly that treats Maternity Allowance as deductible from <u>Universal Credit</u> should be corrected and Maternity Allowance treated the same as Statutory Maternity Pay under Universal Credit rules.
- Administrative barriers to maternity payments (including both the maternity grant and the additional payments to pregnant women, babies and children under 3), such as the need for a separate application form, should be removed and payments made automatically after notification of pregnancy.



8. Measures must be taken to address the surging costs of infant formula:

- Infant formula should be recognised as an essential product for which there is no alternative and be treated in the same way as other essentials such as energy or medicine.
- Pricing controls and caps should be explored as a matter of urgency by Government alongside establishing a taskforce to evaluate the feasibility of commissioning a nationally or locally commissioned first infant formula milk.
- The Department of Health and Social Care should change its guidance to clarify that retailers are permitted to allow customers to buy formula with loyalty points, gift cards or vouchers.
- Healthy Start Vouchers should be increased so that as a bare minimum they cover the weekly cost of formula feeding, however this needs to go hand in hand with longer term systemic change to secure access to an affordable product.
- Clear public health information must be available in all locations where formula is purchased or advice sought that all first formulas must comply with regulations governing composition, are nutritionally adequate and comparable, and there are no established health benefits to babies of buying more expensive products. There is no need for families to buy more expensive infant formulas.
- 9. Perinatal mental health support services must be strengthened, suitably funded, and delivered in a culturally sensitive manner.
 - Service providers should be aware when supporting members of Gypsy, Roma and Traveller communities that there may be a reluctance to seek help with mental health issues due to cultural taboos and mistrust of healthcare/state institutions. This can also contribute to a lack of awareness about perinatal mental health issues and symptoms.
 - These barriers can also contribute to a lack of awareness around what mental health services are available. It is therefore important to emphasise the availability of these services before need for them is expressed.
- 10. Decisions made by service providers around the involvement of social services should be handled with great care and sensitivity, as well as an



understanding of the distress and harm to families that can be caused by unnecessary referrals.

- Any referral to Children's Services should be made using recognised risk criteria.
- Except in exceptional circumstances, where disclosure may carry the risk of acute harm, any potential referral should be discussed first with the person or family concerned, and their insight and opinion on the referral should be sought.

11. Service providers should be aware of cultural expectations about the role of father figures in traditional Gypsy, Roma and Traveller families.

- Adherence to more traditional expectations around male presence in certain maternity contexts should not be misinterpreted as a lack of interest or engagement on the part of fathers or partners.
- Opportunities should be provided for fathers and male partners to engage in maternity and infant feeding support should they wish to, although the choice not to engage directly should also be respected and not interpreted as a lack of interest in the wellbeing of their child or partner.



About us

Friends, Families and Travellers is a leading national charity that seeks to end racism and discrimination against Gypsies, Travellers and Roma, regardless of ethnicity, nationality, culture or background, whether settled or mobile, and to protect the right to pursue a nomadic way of life.

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