

REPORT LAUNCH: Gypsy, Roma & Traveller community experiences of Infant Feeding information and support services

ROMA
SUPPORT GROUP

 **FRIENDS,
FAMILIES &
TRAVELLERS**



Agenda

- About us
- Intro to Gypsy, Roma & Traveller communities
- Maternal health inequalities
- Infant feeding
- Our methods
- Our findings
- Recommendations
- Q&A



About us



About us

This report was produced by Friends, Families and Travellers and Roma Support Group, as members of the [VCSE Health and Wellbeing Alliance](#).

Friends, Families and Travellers (FFT) are based in Brighton, and work to end racism and discrimination against Gypsy, Roma, and Traveller people 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.



Roma Support Group (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, we 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.



The VCSE Health & Wellbeing Alliance

VCSE = Voluntary, Community and Social Enterprise



The Health and Wellbeing Alliance is how:

- NHS England (NHSE),
- Department of Health and Social Care (DHSC), and
- Office for Health Promotion (OHP, was Public Health England)

work together with the VCSE sector to:

1. Facilitate integrated working between the statutory and voluntary sectors
2. Support a two-way flow of information between communities, the VCSE sector and policy leads
3. Amplify the voice of the VCSE sector and people with lived experience to inform national policy
4. Facilitate co-produced solutions to promote equality and reduce health inequalities

The HW Alliance is a network of national VCSE organisations that represent communities who share protected characteristics or experience health inequalities. www.england.nhs.uk/hwalliance/



Opening poll:

How would you rate your understanding of infant feeding issues impacting Gypsy, Roma and Traveller communities?



Introduction to Gypsy, Roma and Traveller Communities



Gypsy, Roma & Traveller Communities: An Introduction

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, Showmen and Roma.** Each of these communities have rich and distinct cultures and histories.

Use of the 'GRT' grouping is not always preferred, as it presents the same issues as the use of '[BAME](#)' by arguably failing to reflect the true diversity of the communities referenced - nevertheless, it is often used in policy and research contexts.

Gypsy, Roma and Traveller communities have traditionally lived nomadic lives in the UK, although members of these communities have increasingly moved into bricks and mortar housing. The 2011 census for England and Wales recorded 74% of Gypsies and Travellers as living in houses, flats, maisonettes or apartments.

This [video produced by Travellers' Times](#) provides a short, animated history of Britain's nomadic communities, while [this video produced by the European Roma Rights Centre](#) offers some important information about Roma communities.



Context: Maternal Health Inequalities



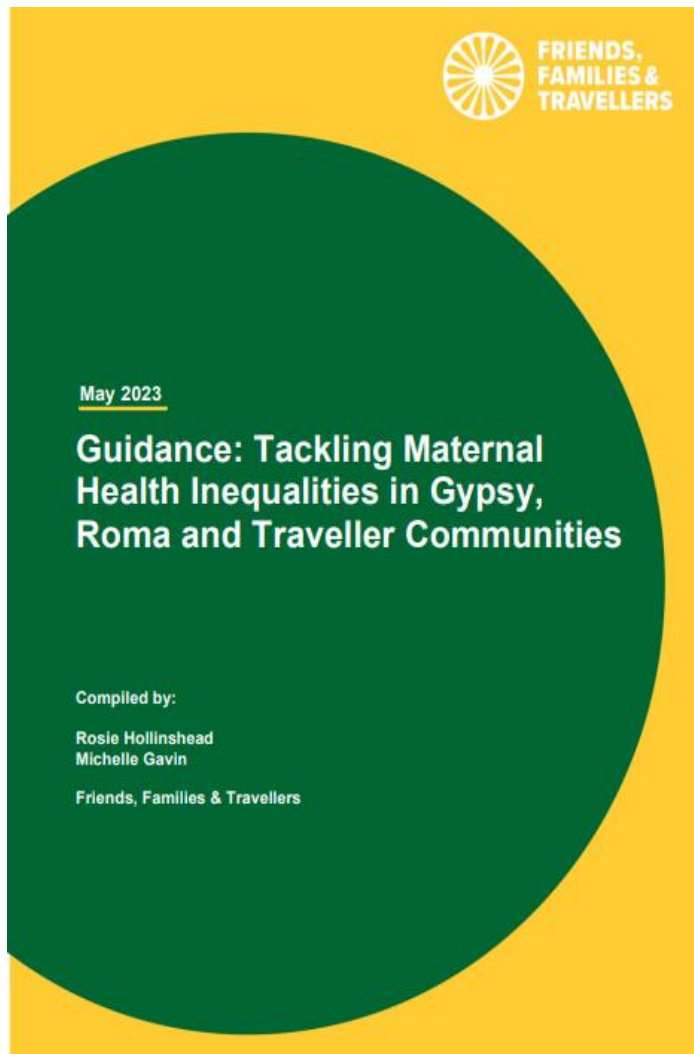
Maternal Health Outcomes

Members of the Gypsy, Roma and Traveller communities have the worst general health outcomes of any ethnic group in the UK, according to 2011 census data. These inequalities are also reflected in Gypsy, Roma and Traveller experiences of maternal health and care:

- **Gypsy and Traveller mothers are 20 times more likely than the rest of the population to experience the premature death of a child.**
- **29% of Gypsy and Traveller parents are likely to experience one or more miscarriages (compared to 16% among the non-traveller comparator group surveyed).**
- **Roma mothers experience higher rates of poor infant outcomes, such as preterm births and low birthweight, than the non-Roma population.**
- **Classical Galactosemia is particularly common among infants born to Irish Traveller parents: the incidence is approximately 1 in 450 births, compared to 1 in 36,000 births among the non-traveller Irish community. If not treated promptly, life-threatening complications can appear within a few days after birth.**



Previous HWA Research: Tackling Maternal Health Inequalities in Gypsy, Roma and Traveller Communities (2023)



Key Issues:

- Lack of effective communication and accessible information in health services. These relate primarily to **high rates of low literacy, language barriers, and digital exclusion.**
- Barriers to accessing and maintaining **continuity of care** for Gypsy, Roma and Traveller communities – particularly those who are nomadic.
- Issues relating to the **wider determinants of health**: often linked to housing and accommodation.
- **Discrimination**, both direct and structural, within public services in healthcare and beyond.
- **Fear and mistrust** of public services and state bodies.
- Lack of awareness and accommodation in services around **cultural norms.**
- **Stigma and taboo** relating to **perinatal mental health**, as well as **barriers to access** for mental health support.
- High rates of **Caesarean birth, miscarriage, pregnancy loss and/or child loss** reported by Gypsy, Roma & Traveller research participants.
- High rates of **Classical Galactosemia** among infants born to Irish Traveller parents.



Infant Feeding



Infant feeding and Gypsy, Roma & Traveller communities

We know through input from community members that **infant feeding is an important issue**. However, existing research on infant feeding in Gypsy, Roma and Traveller communities is very limited. Published research has shown:



Differing norms around breast or formula feeding, depending on the community

Importance of **family and tradition** in infant feeding choices.

Higher rates of metabolic ailments which can impact infant feeding, including **Classical Galactosemia**, experienced by Irish Travellers.



Our coproduced research process



Methodology

This 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.



Our findings



Theme 1: Cultural norms, expectations & 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; generally, 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.

Across the communities, participants referenced the **importance of family, health benefits** and issues around **modesty and the need for privacy** as key influences on feeding decisions.



Accounts from Romany Gypsy, Irish Traveller & Travelling Showmen participants

“[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.”

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

“Instead of health professionals judging me, my own community did! You can’t win.”

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

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



Accounts from Roma participants

“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.”

“There is a pressure from the community to breastfeed – because everyone talks about it as being the preferred method...”

“It would have been really helpful to be prepared and to know [about latching problems]. That’s our one advice when people are about to have babies! Don’t expect the baby to know how to do it.”

“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... It’s wrong!”

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



Shared factors in feeding choices across communities

Family & community

“I went to my family more for help – I felt very judged by professionals.”

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

Modesty & space

“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.”

Health benefits for mum & baby

– breastfeeding sometimes framed as “necessary” for unwell babies



Theme 2: Support, information and communication



Barriers to accessing support

- Wrongful refusal for primary care
- Nomadic living
- Insecure accommodation

Gaps in support available

- Lack of culturally pertinent peer support opportunities
- Reduction in information/support following the birth of second and subsequent children

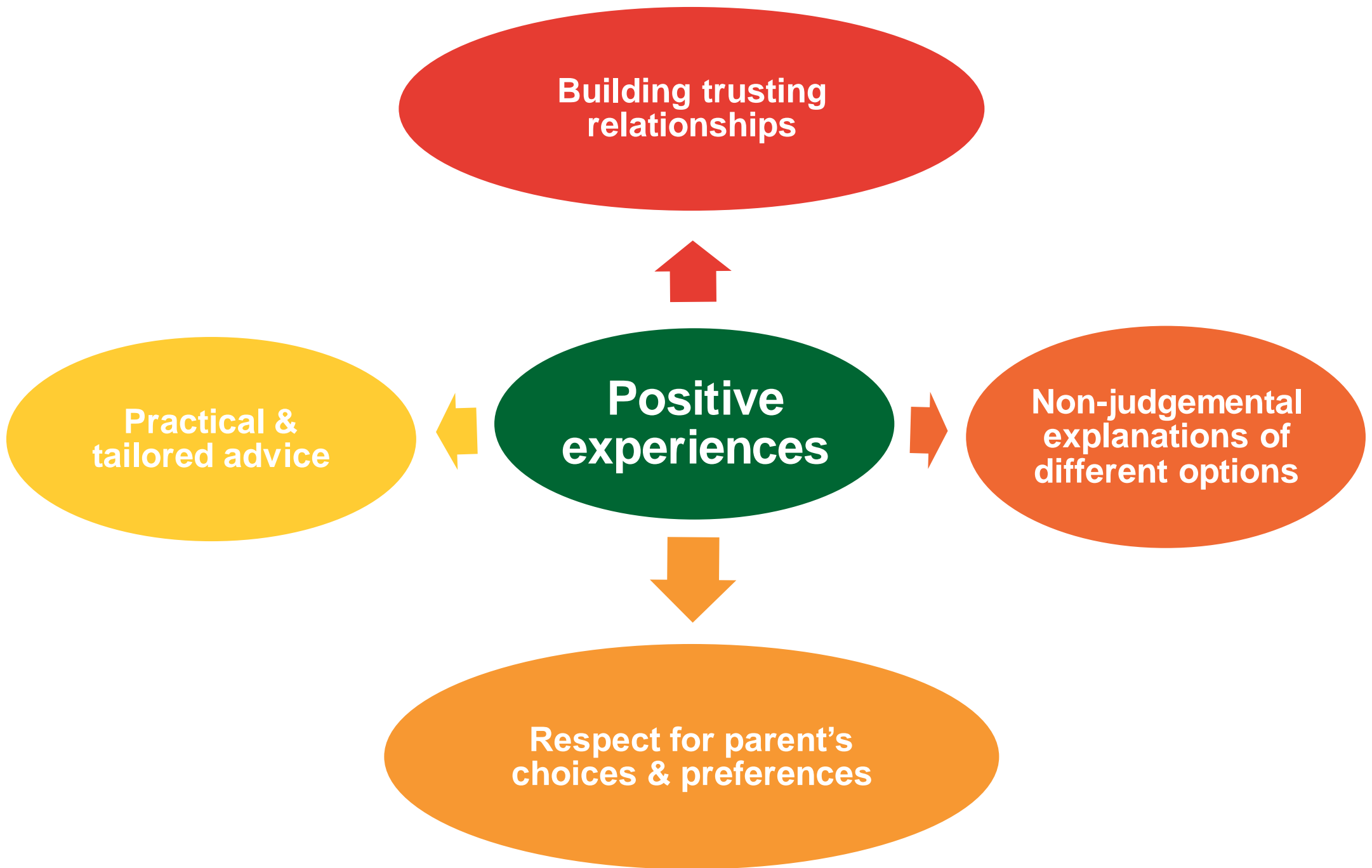
Information & effective communication

- Rigid messaging around infant feeding
- Timing of information delivery
- Roma postnatal 'purity period'
- Digital exclusion
- Language & literacy barriers
- Cultural relevance



Theme 3: Experiences with infant feeding services





Lack of cultural competency

- *“Lack of understanding of our culture is a big issue.”*
- *“We don’t trust authority figures; you’ll trust a doctor but then you get that prejudice...”*

Pressure to feed a certain way

- *“I felt really forced to breastfeed and looked down on for bottle-feeding.”*
- *The “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.”*

Lack of practical feeding support

- *“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.”*

Lack of support/info around formula feeding

- *“Although I wanted to breastfeed, more info and support about bottle feeding would have been good.”*

Concern around impact of NHS underfunding

- *“It’s not a reflection on staff, but a reflection on how underfunded they are.”*



Theme 4: Economic challenges



Economic challenges

Cost of formula

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

Lack of awareness around support available



Theme 5: Perinatal mental health



Fear of social services involvement

Cultural stigma around discussing mental health

Perinatal mental health

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

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



Theme 6: Fathers' & partners' perspectives



Fathers' & partners' perspectives

Traditional roles and expectations for fathers and male community members

- *“There’s certain things we don’t talk about, there’s women’s talk and there’s men’s talk.”*
- *“I would always leave the room for women’s conversations, they don’t want me there!”*

Concerns about perceptions of health professionals

- *“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!”*

Generational shifts

- *“It’s not standard 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.”*



Our 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.



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.



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.



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

Broader help and advice services should be integrated into healthcare settings. This could be delivered via a social prescribing system, and/or following a health-justice partnership model, which links new or pregnant parents with advice services through their midwife, enabling them to access benefit entitlements and exercise their rights.



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**.*

(cont...)



7. Financial supports for families must be improved:

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.***

(Cont..)



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

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.



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.



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



Closing poll:

How would you rate your understanding of infant feeding issues impacting Gypsy, Roma and Traveller communities?



Q&A





**FRIENDS,
FAMILIES &
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VCSE

health &
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Thank you

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