Le Romneango Sfato

Roma Women's Voices: Experiences of Maternal Health Services in Ireland

Pavee Point
Traveller and Roma Centre

...Pavee Point has a long track record and competence in addressing Traveller and Roma health inequalities and the Right to Health....

Acknowledgements

We thank all those who helped with this report, particularly the Roma women participants who shared their experiences. We acknowledge all those who provided advice and support during the project – staff members of Pavee Point Traveller and Roma Centre and the Health Service Executive.

Researchers: Adriana Quinn, Bianca Tanase, Gabi Muntean and Jenny Liston

Edited by: Lynsey Kavanagh, Nuala Kelly

Photographer: Beta Bajgart

Designer: Angelia Fox

Citation: Pavee Point Traveller and Roma Centre (2023) Le Romneango Sfato. Roma women's voices: experiences of maternal health services in Ireland. Dublin: Pavee Point Traveller and Roma Centre.

Contents

Le Romneango Sfato

Roma Women's Voices: Experiences of Maternal Health Services in Ireland

Pavee Point Traveller and Roma Centre (Pavee Point) is a national NGO working to promote Traveller and Roma human rights in Ireland since 1985 through research, policy development, advocacy, and collective community action. Pavee Point works to address the needs of Travellers and Roma as minority ethnic groups experiencing exclusion, discrimination, and racism.

Pavee Point has a long track record and competence in addressing Traveller and Roma health inequalities and the Right to Health. Although Pavee Point has always worked on Roma health issues, we formally established a Roma health initiative in 2022. Our health work is guided by community work principles of participation, empowerment, human rights, equality, and social justice. Our initiative uses a targeted and mainstreaming approach in partnership with the Roma community to address health inequalities, and the social determinants of health through the promotion and prioritisation of Roma in local, regional, and national health policy and service provision.

Section 01: Background

There are approximately 5,000 Roma living in Ireland, with just under half residing in the Eastern Region (CHOs 6, 7 & 9). The Roma community, similar to Irish Travellers, has been recognised as one of the most marginalised and disadvantaged groups in Ireland, experiencing structural and systematic discrimination, prejudice and racism.

Findings from the National Roma Needs Assessment (RNA)[1] indicate that Roma in Ireland continue to experience poorer health outcomes, including higher rates of chronic health conditions, extreme poverty, poor housing and unemployment; and the lack of access to mainstream health services:

- Nearly half of Roma reported that they do not have access to medical cards and GPs.
- 1 in 4 (24%) Roma women had not accessed health services while pregnant and their first point of access was to give birth.
- Over half of Roma (51.3%) reported frequent mental distress;[2] with over 1 in 3 (34%) Roma reporting that they did not experience one day when their mental health was not poor in the previous month.

These issues are further compounded by difficulties Roma experience trying to establish the right to reside or to satisfy criteria as set out in the Habitual Residence Condition (HRC), which is prerequisite to accessing health services, including access to a medical card:

- 1 in 4 (25.7%) of Roma reported not having the right to reside or to be habitually resident.
- 1 in 5 (19.8%) Roma reported not having a PPS number.

Access to services is also affected by language barriers, lack of engagement with statutory agencies due to experiences of discrimination and lack of trust in the State and fear of the State, with 7 in 10 (70.5%) of Roma reporting discrimination in accessing health services.

1 Pavee Point and Department of Justice (2018) National Roma Needs Assessment https://www.paveepoint.ie/wp-content/uploads/2015/04/RNA-PDF.pdf
2 *Frequent mental distress (FMD) is defined as 14 or more days of poor mental health in the preceding one month.*

The COVID-19 pandemic and the ever deepening housing and homeless crisis have exacerbated challenges for Roma, especially those who are most vulnerable. In particular, Roma families who are living in severely overcrowded, unsafe and precarious accommodation, those who are unable to access social protections; and those without access to GP/health services.

Roma women's health needs are often not met by responses and strategies designed to confront and tackle gender inequality or ethnic discrimination alone. To best meet the needs of Roma women and girls, we must examine the intersection of ethnic and gender-based discrimination, acknowledging and addressing their experiences as women, as members of the Roma community, and as Roma women.

This paper builds on and updates Pavee Point's previous report[3] and research[4] on Roma women and maternal health and aims to include direct experiences of Roma women in order to identify key challenges and barriers in relation to maternal health care in Ireland. It is informed by interviews and focus groups with Roma women who delivered their babies in Irish maternity units.

The purpose of this report:

- Outline Roma women's experiences, key challenges, and barriers in relation to maternal health.
- Consider the findings in line with Commitments made at the national policy level (National Traveller and Roma Inclusion Strategy, Intercultural Health Strategy, National Maternity Strategy...)
- Provide key recommendations to the HSE and relevant stakeholders to address these challenges and improve Roma women's (and their babies) equality of access, participation, and outcomes in this area.

3 Pavee Point Traveller and Roma Centre (2013) Challenging Barriers and Misconceptions: Roma Maternal Health in Ireland https://www.paveepoint.ie/wp-content/uploads/2013/11/Roma-Maternal-Health-in-Ireland.pdf
4 Pavee Point Traveller and Roma Centre and Department of Justice (2018) National Roma Needs Assessment https://www.paveepoint.ie/wp-content/uploads/2015/04/RNA-PDF.pdf

Section 02:
Context - Policy

Roma Women's Maternal Health in Europe

Maternal health is a human right, and all women have the right to non-discriminatory and equal access to maternal and reproductive health, throughout their lives[5]. International literature has identified that many challenges exist for Roma women across Europe in terms of accessing reproductive and maternal health services. Roma women throughout Europe report experiencing physical and psychological abuse, discrimination, neglect, segregation, isolation and detention in maternity hospitals following childbirth because of their inability to pay[6]. This is further compounded by historical practices in some European countries of forced or coerced sterilization policies targeting Roma women[7], with cases of Roma women's forced sterilisation documented as recently as 2007. This has been highlighted by numerous human rights bodies and UN treaty monitoring bodies including the Committee on the Elimination of Discrimination against Women (CEDAW)[8]

Even when Roma women can access mainstream maternity care, they experience overt and covert racism, discrimination and mistreatment, leading to poorer health outcomes for Roma women and babies.[9] Here are some case examples in the European context:

5 UN CEDAW (1979) Article 12: States Parties shall take all appropriate measures to eliminate discrimination against women in the field of health care in order to ensure, on a basis of equality of men and women, access to health care services, including those related to family planning.
6 Khosla et al (2016) International Human Rights and the Mistreatment of Women During Childbirth https://www.ncbi.nlm.nih.gov/pmc/articles/PMC5394989/
7 Center for Reproductive Rights (2017) Speaking Out – Roma women's experiences of reproductive healthcare in Slovakia https://reproductiverights.org/wp-content/uploads/2019/04/GLP-SlovakiaRomaReport-Final-Print.pdf
8 See also; ERRC(2010) Coercive and Cruel, Sterilisation and its Consequences for Romani Women in the Czech Republic (1966-2016); Zampas and Lamačková (2011) Forced and coerced sterilization of women in Europe;
9 Watson, H.L., Downe, S. Discrimination against childbearing Romani women in maternity care in Europe: a mixed-methods systematic review. Reprod Health 14, 1 (2017). https://doi.org/10.1186/s12978-016-0263-4

Case Example Bulgaria[10]**:** *In 2019, the European Committee of Social Rights (ECSR) held Bulgaria responsible for Roma women's inferior access to reproductive healthcare. The Committee found that Bulgaria's failure to take proactive steps - including the much lower levels of health insurance coverage among Roma women, barriers to maternal care such as a lack of translation services, and significantly higher infant and maternal mortality rates - constituted a violation of the rights to health and non-discrimination under the Revised European Social Charter.*

Case Example Slovakia: *According to a Report in 2017 by the Center for Reproductive Rights and Slovak organization Center for Civil and Human Rights (Poradňa)*[11] *– Roma women living in Slovakia report facing discrimination and abuse when obtaining reproductive health services. Roma women spoke about humiliation, verbal abuse, lack of adequate healthcare, denial of information and even segregation in maternity wards.*

Roma Women's Maternal Health in Ireland

A previous Roma maternal health report published by Pavee Point[12] presented key issues in relation to poverty and lack of social protection; culturally appropriate and accessible information; and lack of interpreter services. The report also observed that the maternal health among many Roma women was comparatively poorer than among non-Roma women. A lack of access to preventative care can increase the risk of maternal mortality, infant mortality, premature birth and low birth weight. All of this points to an urgent need to gain more data on Roma women's experiences of maternal health, the impact of these experiences and urgent action to improve access to maternal health services for Roma in Ireland.

Recent research in Ireland[13] has highlighted several specific challenges facing migrant and minority ethnic women when accessing and engaging with maternal healthcare, including a higher proportion of maternal morbidity and mortality, unmet medical needs, poor mental health, and limited access to vital health information, which leads to under-utilisation of adequate maternity services. The Health Services Executive (HSE) report on perinatal statistics[14], published in June 2021 and covering 2018, shows women with a migrant background face higher risks surrounding pregnancy and childbirth.

While the collection of ethnic data amongst maternity units in Ireland varies, reporting of disaggregated data on the basis of ethnicity is not published nor used to inform service provision, making it difficult to monitor the experiences and outcomes for minority ethnic groups, including Roma women and their babies. However, in 2018 the National Roma Needs Assessment did report the following data on Roma women's maternal health across the country:

10 European Committee of Social Rights (2019) Complaint No. 151/2017 ERRC vs Bulgaria https://hudoc.esc.coe.int/eng/#{%22sort%22:[%22ESCPublicationDate%20Descending%22],%22ESCDcIdentifier%22:[%22cc-151-2017-dmerits-en%22]}
11 Center for Reproductive Rights (2017) Speaking Out – Roma women's experiences of reproductive healthcare in Slovakia https://reproductiverights.org/wp-content/uploads/2019/04/GLP-SlovakiaRomaReport-Final-Print.pdf
12 Pavee Point (2014) Challenging Barriers and Misconceptions. Roma Maternal Health in Ireland https://www.paveepoint.ie/wp-content/uploads/2013/11/Roma-Maternal-Health-in-Ireland.pdf
13 ESRI (2022) The integration of Non EU Migrant Women in Ireland https://www.esri.ie/system/files/publications/RS148_5.pdf
14 HSE (2021) Irish Maternity Indicator System National Report https://www.hse.ie/eng/about/who/acute-hospitals-division/woman-infants/national-reports-on-womens-health/irish-maternity-indicator-system-national-report-2020.pdf

- 24% of women had not accessed health services whilst pregnant and their first point of access was to give birth.
- 37.1% of Roma women respondents reported that they did not have adequate supplies for their baby after birth, with service providers identifying new-born babies living in houses with no heat, food, or basic supplies.
- Roma women's access to maternal health services was impacted by the additional barriers they face accessing primary care services, with 40% of Roma without a GP and 50% without a medical card.

Health service providers also highlighted what they saw as gaps in knowledge and information about services among Roma that they work with. Communication and language were also key concerns. Issues with interpreter services were raised in relation to maternity units. It was reported by midwives that language support was dependent on what was available in a particular hospital. Some also noted that this impacted on Roma women's attendance at appointments as well as understanding what was being said to them at their appointments.

Commitments in Irish Policy to Addressing the Maternal Health Needs of Roma Women

In recent years, commitments have been made to improve Roma maternal health in Ireland across a number of mainstream and targeted strategies relating to Traveller and Roma inclusion, intercultural health, and maternity services, including:

National Traveller and Roma Inclusion Strategy 2017-2021

Action 72 of NTRIS: Acknowledging the results of the National Roma Needs Assessment for Roma in Ireland, the Health Service Executive will support Roma women to access maternal health services in a timely and appropriate manner.

Second National Intercultural Health Strategy 2018-2023

Goal 1: Enhance accessibility of services to service users from diverse ethnic, cultural and religious backgrounds.

- Develop an evidence informed system of translating information.
- Much of the health promotion material and messages currently in use across the HSE is already utilised by members of diverse groups. In some instances, translation of this material may be all that is necessary to facilitate access to relevant information. However, certain material may need to be culturally adapted. In addition, and as with the indigenous population, some people from different minority ethnic and cultural groups may not be functionally literate, even within their own language. Addressing this issue will require a greater emphasis on visual and spoken messages. In some instances, health information may need to be targeted at specific groups, such as women and older people.

Creating a Better Future Together: National Maternity Strategy 2016

Action 5:

- Additional supports will be provided to pregnant women from vulnerable, disadvantaged groups or ethnic minorities, and will take account of the family's determinants of health, e.g. socio-economic circumstances

HIQA Maternity Standards

1.3.2: Service providers directly engage with women, particularly women from disadvantaged and minority groups and communities, for example members of the Traveller and Roma communities, through regular engagement with representative groups.

1.3.6: Staff respect individual values and beliefs, cultural norms, and ethnicity. The care provided is underpinned by the principle of autonomous choice in line with legislation and national policy.

Section 03: Findings

Demographics and Methodology

The purpose of this document was to gain an insight into the experiences and challenges that Roma women face during their pregnancy, birth, and postnatal care in mainstream Irish maternity services.

Through focus groups and semi-structured interviews, we spoke with 12 Roma women who received maternal healthcare in maternity units in Dublin. On average, women had 3.9 children, some were born here, and some born in other countries. The vast majority of women were originally from Romania, with the remaining women from Poland and Slovakia.

The interviews were conducted by Roma community workers to ensure that interviewees could speak in their preferred language and felt comfortable during the interview process. Thematic analysis followed, examining the participants' perception of their own needs, the services offered by the healthcare providers, and the implications on Roma women and their families.

Participants were approached according to the ethical requirements of Pavee Point, with prior explanations in the participant's native language on the purpose of the focus group/interviews and the purpose of the report. Privacy and confidentiality were ensured at all times, and upon signing the participation consent, the women were interviewed in a safe environment.

Overall Experience of Irish Maternity Services

Overall, the experiences of the women participants were mixed, with both positive and negative experiences reported. Some women noted that that they had received better care in Ireland than in their country of origin, some had positive experiences of the care they received for co-morbidities, and most had received some level of postnatal care.

P8: Everyone was so nice, compared to the racism in [country of origin]. There was a big difference between my country and here... Also, after delivery [in the hospital], they took care of the baby and paid attention to me, encouraging me to get some rest.

P10: [...] as a non-Irish, I was treated very well. Staff were very good even during and after labour, they allowed my mom and my husband in with me. Then the nurses would feed the baby with formula and give me a chance to rest.

Discrimination/Fair Treatment

However, Roma women also reported fear of mistreatment and experiences of racism and discrimination, this included women who reported not being treated fairly, that their pain/medical needs were not taken seriously, or they were afraid or couldn't ask for support.

P1: There was a difference, nurses gave out to me a lot. When I was in labour, I rang for an ambulance as I don't have a car and the nurses gave out to me when I arrived and were very angry.

P2: I just accept what I am given – trying to do it on my own, afraid to ask for something.

P5: When I was discharged, the nurses [knew that I am Roma] told me "we'll see you many times, for sure". I felt offended because they were assuming that Roma have loads of children.

Hiding Roma ethnicity and identity was reported by a number of Roma women who tried to blend in and not disclose that they were Roma for fear of racism, discrimination, and poor treatment, often based on previous experiences with health services in Ireland, or other European countries.

P9: They were very nice everywhere I went, but I had to hide my identity. If I go anywhere with Roma clothes, they think I'm from Romania and it's so different. When I say I'm not from Romania, they improve their attitudes.

P12: They don't ask my ethnicity, so I don't say anything.

P5: Had a good experience during the examinations, I always try to blend in and not show that I am Roma.

Access to information about maternity services

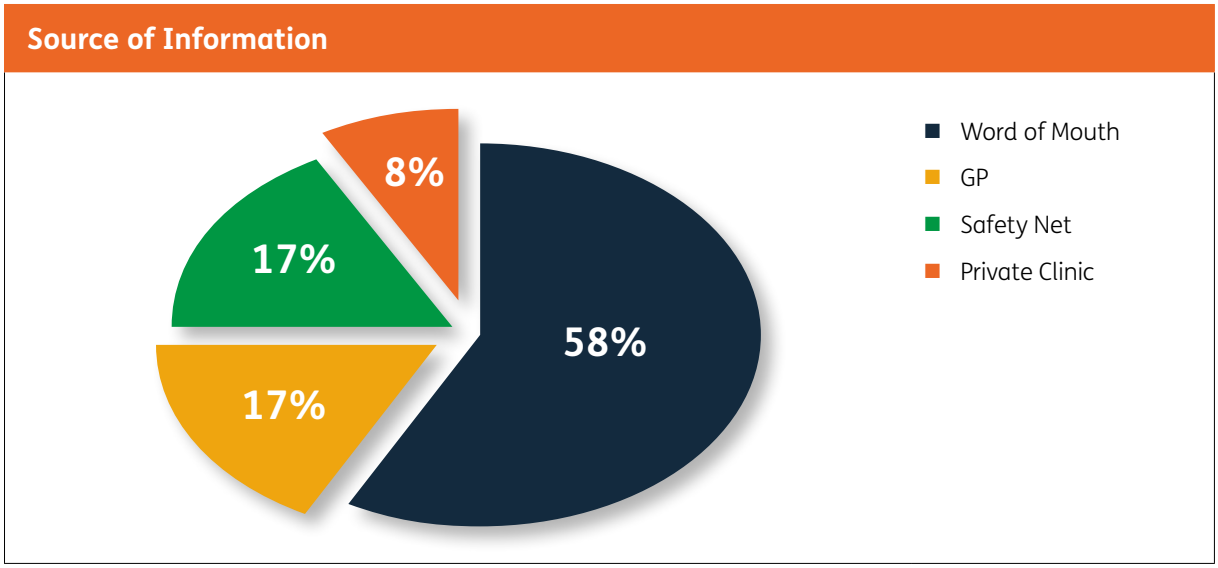
While just under half of Roma women reported receiving their maternal health information from health service providers, including mainstream health services, targeted health services (e.g Safetynet), and private clinics, most reported accessing information by word of mouth, from friends, family, Roma community workers or other support services.

Three participants did not have a GP and 4 participants did not have a medical card when they became pregnant, and this was reported as a significant barrier for these women when initially attempting to access primary care services and referrals to maternity services.

P5: At the beginning, for 10 years I didn't have a GP or medical card, now I have

P10: Many of my friends struggle now, with no GP, no medical card... Ireland was not like this before, I was very lucky.

Source of Information



Access to Free Health Maternal Healthcare

Under the HSE's Maternity and Infant Care Scheme, every pregnant woman who is ordinarily resident in Ireland is entitled to free maternity care. However, Roma women continue to report situations where they are asked to pay for maternity services if they cannot provide documentation to show they are ordinarily resident in Ireland (PPS number, proof of address, proof of employment). For example, one woman reported receiving a bill for €400 for her maternal healthcare.

Roma women reported that they were asked for proof of employment or address in order to register for pregnancy supports and women often didn't have these documents, due to precarious work situations or living in overcrowded conditions, something which has been extensively documented in a number or research and policy reports, including the National Roma Needs Assessment.

P8: GP refused me so I had to go private [...], as advised by a cousin. I paid the first consultation €100, then everything was free because I had proof of employment.

1 woman reported she was currently 5 months pregnant but did not have access to a GP or medical card; as a result, she was not receiving antenatal care and not registered with a maternity unit. Another woman reported that she didn't attend any antenatal appointments in her first pregnancy when she was a minor because she lacked health information and was reluctant to attend when she didn't speak English and didn't have a PPS number at the time. With her second pregnancy she attended appointments as she had linked with GP services with Safetynet Primary Care, who supported her with a referral.

P6: For first baby, I did not go to hospital until I got into labour. I had no GP, no English, no PPS, did not know anything about Ireland, even if I lived for a year here already.

Attending Maternal Care Appointments

Almost all participants reported attending all or some of their antenatal appointments, however, this was largely contingent on their family or living situation (access to transport, and childcare) and the health information they received. In some instances, Roma women reported not being clear on how to make appointments and/or the frequency of appointments and as a result, would delay their care and only present to the hospital when they thought something was wrong.

> *P1: I just turn up when I am worried, I do not know how to make appointments.*

> *P5. Yes, but only because my husband insisted.*

Literacy issues, lack of English and/or digital skills, or lack of awareness of health information led to women delaying access to care, for example, when they thought something was wrong, or when labour signs appear.

> *P5: And I didn't go to the GP appointments. I thought "what's the point, I'm OK and I have the hospital appointments anyway". Most Roma women think "Why go to GP when nothing's wrong?".*

Language/Literacy/Communication Barriers

Many participants encountered barriers with language/literacy/communication. Only 1 Roma participant reported being fortunate enough that her doctor spoke her national language. A small number of women reported that they understood and spoke English and had more positive experiences communicating with health service providers.

The participants facing language barriers had to rely on inappropriate means such as family members translating or communicated with a dictionary or Google Translate.

> *P6: I had my brother with me, and they even accepted him in the delivery room to translate for me; it is a big culture shock, no way in my community men would be allowed to see women giving birth.*

> *P12: With Google Translate. So far, it's working OK. Not sure what will happen when I deliver...*

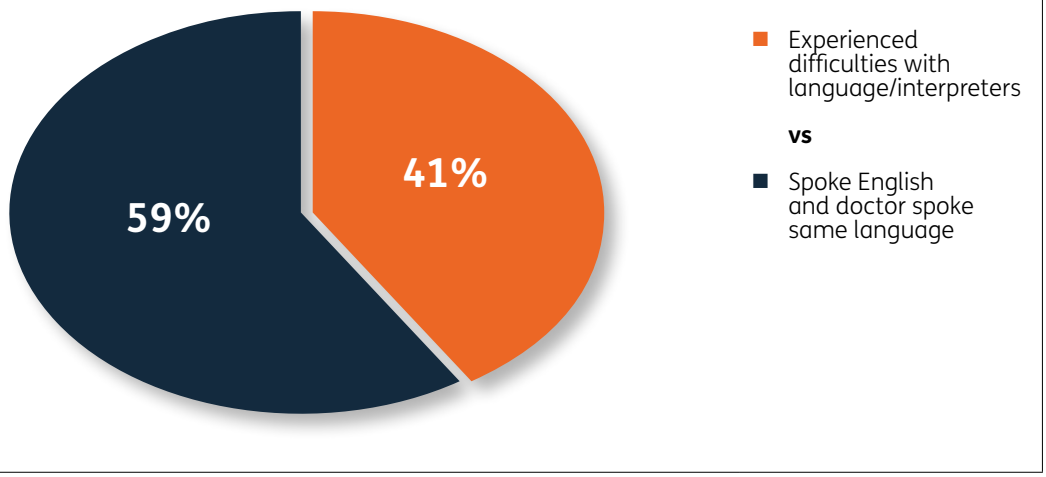
The communication barrier was a particular risk for women when there were health concerns/an emergency medical situation.

> *P2: My last birth on the day of release when doctor was checking the baby, the baby went blue and had difficulty breathing. They rushed away and no one explained what was happening.*

> *P4: There was no interpreter during birth, the baby had a cleft palate, and I could not understand. Very scary experience.*

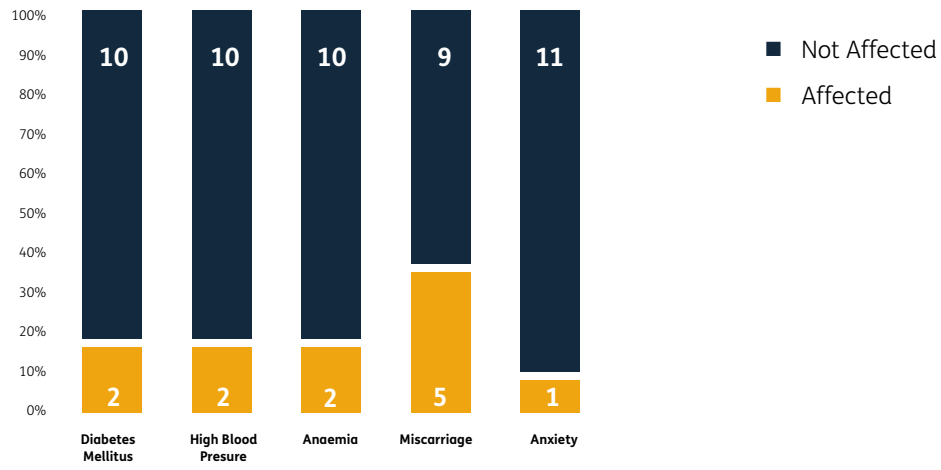
Official interpreter services were mentioned by 1 participant who at the time was a minor, and she received an initial consultation through an interpreter, but not for any follow up pregnancy appointments or during her following pregnancies.

Language Barriers



Health Issues while Pregnant

Reported Medical Issues



Many participants reported having health issues during pregnancy/labour, including gestational diabetes, high blood pressure, and anaemia. The women who attended antenatal care, reported receiving support and treatment for these conditions from health services. However, women also revealed that their experience of poor health was sometimes compounded by a lack of clear communication from healthcare providers or racism/discrimination.

> *P9: For the first baby I had epidural, and after, I had no idea how to take care of my back. [...] Nobody explained to me. [...] For the second one I had no epidural, because my back really hurt for a long time the first time.*

> *P6: They cut me by accident during delivery, and I was in pain for days without knowing what happened. When I went back, they refused to suture me and said "you're too smelly..."*

Just under half of participants reported that either they or other members of their immediate family experienced one or multiple pregnancy losses. All who reported experiencing pregnancy loss in Ireland, expressed significant barriers when seeking medical support. None of the women were offered counselling or mental health supports.

> *P3: I have had miscarriages, and no one offered support, just to come back if still bleeding.*

> *P6: I had a miscarriage during my third pregnancy, very traumatic. The baby was 3 months old, and I was bleeding, went to hospital twice but they sent me home without any explanations and any treatment for me or the baby. The Capuchin clinic was sending me back to hospital every time. [...] I went again in A&E (3rd time) with bad bleeding, and they didn't do anything, told I have to wait until everything comes out. I had to go back to my country to clean me and then the bleeding stopped. Moral support? Never.*

> *P9: In the hospital staff were nice, but they didn't help me, only pain killers and that was it, they were just waiting for everything to finish naturally. All they were asking was "OK? Feel OK?" but doing nothing to really help. [...] I had no clue if there is any support out there, I didn't look for it either.*

Postnatal Care

The majority of women reported meeting with a Public Health Nurse at some time after their pregnancies. A small number of participants had the Public Health Nurse visit for their first babies but not for subsequent babies. The language barrier was raised as an issue, as Roma women reported that Public Health Nurses did not have access to an interpreter for appointments.

> *P6. Yes, twice only, but because the baby was doing fine. For my surgery, they asked if I'm ok, but I was dressing my wound myself.*

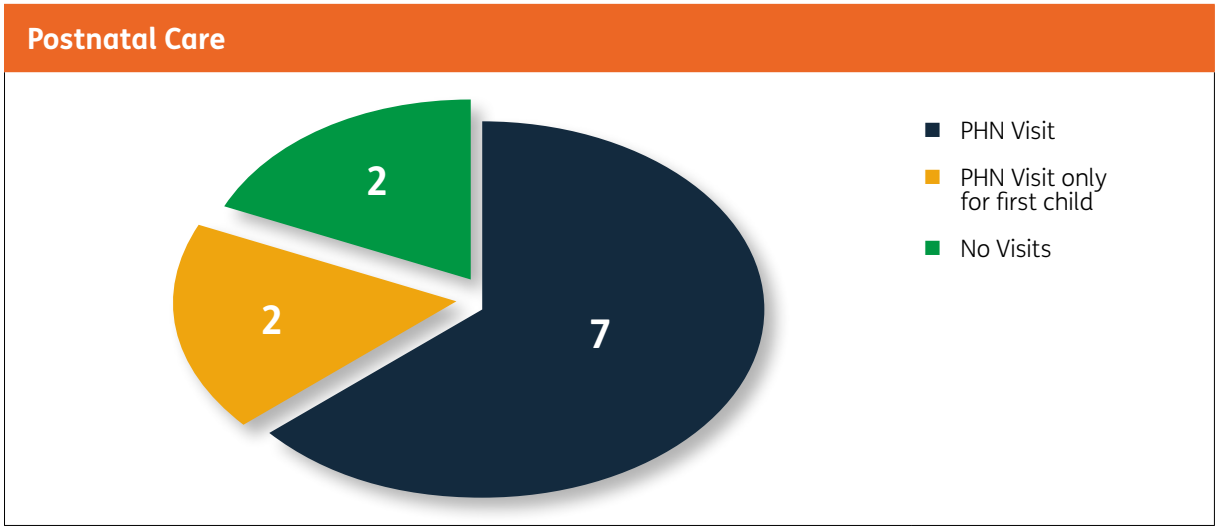
> *P10: Yes, first time after 1 week. I got a virus and I had to start bottle feed the baby, so the nurse checked the baby and the bottle feed. Then after a few regular visits, I was encouraged to bring the baby to GP if needed.*

A small number of women reported they had not had any visit from the Public Health Nurse following birth and 1 woman was not aware of the service.

> *P8: I stayed in hospital for 3 days and baby was fine, plus it was my second baby. But I didn't know anything about someone coming home to check on the baby.*

> *P7: Many mothers are so scared, especially the first time, but also every baby is different. We need support for every pregnancy and every baby.*

Postnatal Care



Breastfeeding Support

The majority of Roma women reported bottle feeding their babies with most women reporting that they did not receive information about breastfeeding, out of which 3 were asked if they wanted to breastfeed, with no further discussion. In one case for a breastfeeding mother, she was asked if she wanted formula instead.

> *P5: I was asked and given a leaflet about breastfeeding, but I chose bottle-feeding my baby. Nobody tried to convince me, they just gave me the leaflet and that was it.*

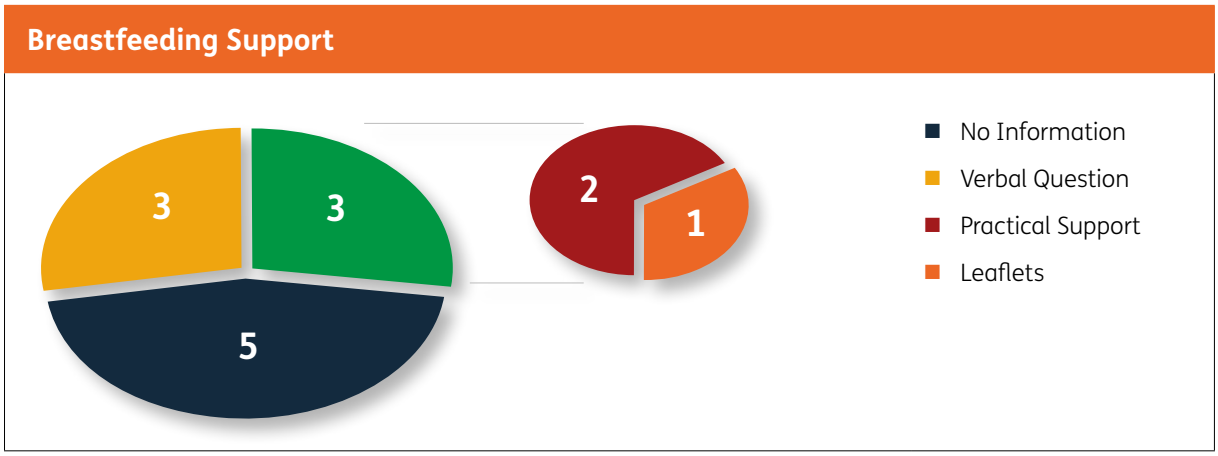
> *P6: They asked me if I know, but no information otherwise. But I knew already from my mother.*

> *P8: No, it was my 2nd baby, so nobody explained about breastfeeding, benefits or anything. They asked if I want the bottle, and I refused, I said I'll breastfeed, to give the milk powder to the women in poverty.*

In total, only 2 women reported breastfeeding. Other participants who bottle fed identified examples of feeding support including being asked questions about breastfeeding or were offered written information leaflets on breastfeeding (available in English). One Roma woman who did breastfeed, received breastfeeding information but felt it could have been delivered in a more positive way.

> *P9: Yes... they told me I am a bad mom if I don't breastfeed.*

> *P10: I received booklets on breastfeeding and its benefits, plus there was a group in the hospital where they were teaching us how to feed the babies, how to burp them, change nappies and how to bath.*



Roma Women's Recommendations for Change

During interviews and focus groups, Roma women were asked for their recommendations on how Irish maternal health services can improve supports for Roma women. Some women suggested the need for culturally appropriate and accessible maternal health information that is visual, rather than written. This included information on how to care for themselves and for baby, and how to access and use interpreters. Also, participants emphasised the importance of how information is communicated, ensuring information is shared in a way that Roma women understand, with services taking the time to ensure they know what they are being told.

> *P9. Through interpreters. To be able to ask anything. I felt like blind and deaf throughout my pregnancies, especially in emergencies and delivery. There should be someone to translate, so many things can happen, you sign and you have no idea what you sign...*

> *P7. To teach us verbally, not through writing and reading. To talk to us and teach us about baby, how to dress, how to feed.*

> *P10. Through translated leaflets in different languages, and a person that speaks Roma to translate face to face. It's so important if one of your own is there, it calms the woman, changes the entire mental situation, and then the patient will understand also the importance of the medical information that is told to her.*

> *P8. But perhaps more explanations are needed, for each appointment what is the purpose of it. Very important to go for check-ups during pregnancy. The child grows, could have an illness that grows with it, the doctor can help in time, very important to go regularly.*

Roma women also expressed their right to be treated fairly, with dignity and respect, without any discriminatory or exclusionary attitudes, as well as having their pain and healthcare needs taken seriously.

> *P7. I want the nurses and doctors and everyone in the health system to know that we want to be treated like everybody else. Everyone stares at us, everywhere, some are very mean especially when I was in pain.*

> *P4: I am 5 months pregnant and 3 times I am bleeding – I go to the hospital, and they tell me to go home and you will receive an appointment but it's never come.*

Section 04: Discussion

All women have a right to maternal and reproductive health services. The 12 participants in this report were asked about their experiences as Roma women accessing maternity services in Ireland, their experiences of using these services, and the continuity of their postnatal care.

All Roma women interviewed identified barriers to accessing maternal healthcare at all stages - these included a lack of accessible information, language barriers, and the impacts of racism and discrimination. This resulted in unmet medical needs, and under-utilisation of services similar to the findings identified by the recent ESRI report on migrant women's experiences of maternal care in Ireland. This also reflects the findings of the National Roma Needs Assessment which identified Roma women's access to maternal healthcare as a key issue, as well as our 2013 report on Roma maternal health.

During the COVID 19 crisis, there was an increasing awareness and identified need for a strong Roma health infrastructure (similar to the Traveller health infrastructure) to strategically respond to the health needs of the Roma community. This resulted in the allocation of Roma/Migrant health worker positions in every HSE CHO area. This provides an opportunity for mainstream health services to work closely, and in collaboration with Roma and organisations working with Roma to address Roma health inequalities, inclusive of Roma women's maternal health.

Access to Healthcare Services

Social Determinants of Maternal Health

Roma women reported many challenges related to the social determinants impacting their maternal health, these included racism, discrimination, poverty, insecure accommodation, low educational attainment, lack of transport support and lack of childcare support. This impacted women's ability to attend appointments, and their ability to raise concerns about their treatment in services. This reflects the findings of the National Roma Needs Assessment where 37% of Roma women did not have the basic supplies for the babies, as well as significant concerns about suitable housing conditions with 46% experiencing homelessness at some stage in their lives and 45% living in overcrowded accommodation. These social determinants of health need to be taken into consideration in the provision of maternal healthcare for Roma women.

Documentation/Access to Medical Cards

Although maternal healthcare is free for all women ordinarily resident in Ireland, some hospitals require PPS numbers and proof of address when registering for their antenatal services. This was reported as a significant barrier for some Roma women making the initial booking appointment and resulted in one woman receiving a bill for her maternity care from the hospital. These processes have the potential to further marginalise Roma women from accessing mainstream maternity services, particularly at early stage in their pregnancy. This could potentially place Roma women and their babies at risk of delaying their care as we saw in one case illustrated in the findings of this report.

At policy level, some Roma women raised the issue of accessing primary care services, including GPs and medical cards. Although a medical card is not needed to access maternal care, exclusion from primary care services impacted on Roma women's access to maternal health information and in some instances, timely referrals to maternity units.

In total, 4 women reported not having a medical card and others reported difficulties and long waiting times to receive their medical card. Roma women eligible for a medical card, often cannot access one due to language and literacy barriers, as well as difficulties producing proof of income and proof of address due to precarious working and living conditions. This reflected the findings of the National Roma Needs Assessment where almost half of participants reported not having a medical card.

Accessible/Culturally Appropriate Information

Participants identified that they lacked clear information on maternity services – how to make appointments, how to access interpreter services, and how to look after their health during pregnancy. Information that was shared with them was often not culturally appropriate or in accessible language or format. Women often received health information through word of mouth in their own community, from trusted family and friends, or organisations/services working with Roma. It is important that targeted and culturally appropriate information is developed and disseminated in partnership between health services, Roma women, and Roma health and community workers.

Experiences of Roma Women When Using Health Services

Racism and Discrimination

Roma participants also identified racism and discrimination as impacting on their experiences of maternal health care in Ireland. Some women reported that pain wasn't taken seriously, or staff made discriminatory comments. Women also noted that due to past negative experiences, in Ireland and in their countries of origin, they felt it necessary to hide their ethnicity as Roma women in order to receive a fairer service. This supports broader literature and findings of the National Roma Needs Assessment, where 70.5% of respondents reported that they had been discriminated against in health care services. Roma women reported significantly higher levels of discrimination at 84.1% compared to 52.9% of men.

Language and Literacy Barriers

Only a small number of participants reported positive experiences with communication while accessing maternity services. The women with positive experiences reported that they spoke English, or on one case, the doctor spoke their national language. Those who could not communicate with health professionals, reported negative experiences, as interpreter supports were not always available, leaving women feeling scared and ill informed. This reflects our 2013 report as well as the findings of the National Roma Needs Assessment where only 4.6% of respondents reported using professional interpreters, and 68% using family or friends – resulting in women not attending appointments and/or not fully understanding health information at their appointments.

Health Inequalities

Across Europe, life expectancy is estimated to be between 10-15 years shorter[15] for Roma when compared to the non-Roma population, with higher prevalence of cardio-vascular disease and diabetes, similar to Travellers. As outlined above, 1 in 3 of Roma women stated having high blood pressure or diabetes during their pregnancy and they received care for this, which is positive. This reflects the ESRI report on migrant women facing higher risks in pregnancy and childbirth, and it is important that health inequalities are a consideration when health services aim to improve access and provide additional supports for Roma women as committed to in National Traveller and Roma Inclusion Strategy, the intercultural health strategy, and the National Maternity Strategy.

Continuity of Care

Participants identified barriers to accessing postnatal care. Some women reported not feeling adequately supported when they experienced traumatic births or experienced pregnancy loss. None of the participants had accessed mental health supports when facing these issues, due to lack of information, referrals, or language supports. This is concerning when levels of reported poor mental health were extremely high in the Roma Needs Assessment, with 51.3% of respondents reporting more than 14 days of the previous month when their mental health was not good.

9 out of 12 women had some contact with a Public Health Nurse after pregnancy, this is to be welcomed, however, some identified difficulties with communication and consistency, for example due to lack of interpreter support. This reflects findings in the National Roma Needs Assessment where 66.1% of Roma women reported receiving support from a public health nurse. Public health nurses reported in the Roma Needs Assessment that they experienced challenges contacting young mothers post-discharge as they may have moved or been evicted. It also emerged in focus groups that some mothers avoided public health nurses for fear of children being taken into care due to poverty and poor living conditions.

15 The European Public Health Alliance (2014) Closing the Life Expectancy Gap of Roma in Europe https://www.reyn.eu/wp-content/uploads/2019/03/closing-the-life-expectancy-gap-of-roma-in-europe-study.pdf

Section 05:
Recommendations

This report shows that Roma women continue to face barriers to realising their right to maternal health in Ireland. Targeted and mainstream measures are needed in order to address racism and discrimination, as well as the specific needs of Roma women.

Recommendations previously made by Pavee Point in the National Roma Needs Assessment, as well as a dedicated Pavee Point publication in 2013 on Roma Maternal Health[16] remain relevant today, as implementation of actions to address Roma women's maternal health inequalities has been slow. Also given the emerging health needs and changes in health services since the COVID 19 pandemic, the movement to digital health, and ever worsening housing and homeless crisis, the maternal health needs of minority ethnic women, including Roma women, need urgent attention.

16 Pavee Point (2014) Challenging Barriers and Misconceptions. Roma Maternal Health in Ireland https://www.paveepoint.ie/wp-content/uploads/2013/11/Roma-Maternal-Health-in-Ireland.pdf

Pavee Point recommends:

Integrate and align policy actions relating to Roma maternal health *in the upcoming National Traveller and Roma Inclusion Strategy, National Strategy for Women and Girls, Intercultural Health Strategy, and National Maternity Strategy. Ensure all strategies have clear actions, targets, indicators, timelines, and allocated resources to ensure full implementation.*

- Ensure a **human rights-based approach** to maternal health services in Ireland, which guarantees provision of care, which is non-discriminatory, respectful and culturally appropriate.
- The National Women and Infants Health Programme to support the **development of a care pathway for Roma women** accessing maternity services in Ireland in partnership with groups working with Roma. This pathway will include addressing significant barriers outlined in this report in relation to registering and accessing mainstream antenatal care services.
- Mandatory **anti-racism and intercultural training** for all health care providers (both at induction and CPD levels), inclusive of anti-Roma racism, among healthcare practitioners.
- To equality proof maternity services, implement **Ethnic Equality Monitoring** (in line with human rights standards), including a standardised universal ethnic identifier across all relevant maternal health data sets with additional training for health professionals.
- Ensure appropriate **interpreter services** are available to all Roma women accessing maternal health care who need it, and women are informed on their right to access this service.
- HSE, in collaboration with organisations working with Roma, to **provide clear, accessible information about the Irish healthcare system**, including care pathways (e.g. where and how to access care, rights and entitlements) to Roma women.
- Building on the model of Pavee Mothers, establish a **National Roma perinatal health initiative**, focusing on key issues such as breastfeeding, and perinatal mental health, and ensuring active participation and involvement of Roma women in the development and implementation of effective maternal health policies, strategies, and initiatives.
- Support and resource local organisations working with Roma to work collaboratively with HSE maternal health services to deliver **targeted Roma maternal health supports**.
- **Building on the positive work of Public Health Nursing, support** partnerships/ integrated responses with organisations working with Roma, and provide **accessible postnatal information and services for Roma women**
- Department of Social Protection and Department of Housing, Local Government, and Heritage to r**eview the application of legislation and policy, such as Habitual Residence Condition, and Housing Circular 41/2012,** and its impact on Roma women's access to necessary supports for them and their children.

Pavee Point Traveller & Roma Centre
46 Charles Street Great
Dublin 1 DO1 XC63 Ireland

www.paveepoint.ie

Pavee Point
Traveller and Roma Centre