Pavee Mothering during COVID-19

Traveller women's experiences of maternity services with a focus on the COVID-19 pandemic period

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This research acknowledges the work of all Traveller Community Health Workers around the country who worked relentlessly during COVID-19 to protect Traveller health. In particular, the research is dedicated to Sheila Reilly (RIP) who was committed to Traveller rights and equality and dedicated her life to ensuring Traveller women's right to health.

contents

Executive Summary

Introduction

The Traveller community[1] experiences significant health inequalities, compounded by, the social determinants of health including, poor accommodation conditions, poverty, racism, and discrimination (AITHS Team, 2010). Maternal and perinatal outcomes for Traveller women are exceptionally poor as they experience higher parity, higher rates of miscarriage, stillbirth, perinatal death, and infant death, when compared to non-Traveller women (Leitao et al, 2021b) in addition to shorter intervals between pregnancies. Outcomes of pregnancies are also riskier for Traveller women and their babies – maternal morbidity and mortality is higher (Leitao et al, 2023) coupled with an infant mortality 3.5 times national rate and average birth weights much lower (Pavee Point, 2021b).

The COVID-19 pandemic created further challenges for Traveller women who were pregnant and in early motherhood. International data highlighted the disproportionate impact of COVID-19 on minority ethnic groups, including Travellers and Roma (Yaya et al 2020). Travellers were disproportionately affected by COVID-19 given significant increased risks of hospitalisation, ICU admission and/or death compared to the general population (Pavee Point, 2020b). This directly impacted pregnant women as well as impacting their support network. In addition, specific rules were imposed on service users of the maternity system regarding how they engaged with services throughout their pregnancy and how they gave birth. This posed additional challenges for Traveller women due to reliance on immediate family for social and family support. This research explores the experience of Traveller women in this context.

Research Aim and Objectives

The aim of the research was to explore the experiences of Traveller women who were pregnant or gave birth during the COVID-19 pandemic in Ireland. The objectives of the research were to:

- explore Traveller women's experiences of pregnancy during the COVID-19 pandemic and the years that immediately followed (2020-2022);
- explore Traveller women's engagement with mainstream maternity services during the COVID-19 pandemic;
- the personal, interpersonal and structural factors that mediate Traveller women's experiences of pregnancy during the COVID-19 pandemic.

1 *This report uses "Traveller" and "Irish Traveller" interchangeably to denote the ethnicity of women who participated in this research because these are the terms used by them in voluntarily self-identifying their ethnicity. According to the Equal Status Act "Traveller community" means the: Community of people who are commonly called Travellers and who are identified (both by themselves and others) as people with a shared history, culture and traditions including, historically, a nomadic way of life on the island of Ireland (Government of Ireland, 2015[2000], 7). While the European Parliament and of the Council of Europe (2013) use the umbrella term 'Roma' to refer to a number of groups such as Roma, Sinti, Kale and related groups in Europe, including Irish Travellers, this study focuses solely on Irish Travellers. 'Majority population,' 'non-Traveller' and 'general population' are used throughout the study to denote the distinction between Travellers and those in the majority population.*

Methodology

The starting points for the research were an acknowledgment of the social determinants of health (WHO, 2010) and a community development approach to the research (Banks et al., 2019). Using qualitative interviews with Traveller women across the country, in partnership with Pavee Point Traveller and Roma Centre, a leading national Traveller organisation, this research explored the lived experiences of pregnancy and birth with a particular focus on engagement with the maternity services during the COVID-19 pandemic. The research sought to document the experiences, the challenges and outline key service barriers and issues experienced by Traveller women. It also sought to identify good practice and recommendations for policy and practice development.

Research Findings

The research found that women did not always feel included in the maternity services or that services were for them. They reported that they did not always feel welcome in the service due to being a Traveller. They reported that they did not feel that they had all the information that they needed when they were engaging with maternity services and that this made it difficult to navigate the services. Literacy issues compounded this.

Women reported that they faced stereotypes and discrimination from staff in services. Women also reported difficulties in communicating with staff. This was felt more acutely during times of crisis as well as during labour/ the birth.

There were also issues specific to the COVID-19 context, for example, where partners' participation in appointments, including scans was limited. Participants also reported distress when the could not receive support from their partner or mother during early labour and sometimes, also during the birth. There were also many reports of postnatal struggles. Many challenges to breastfeeding were expressed including issues with the Beutler test, delays in breastfeeding support and ultimately little success in breastfeeding.

Overview of the Report

This report contributes to the timely discussion of maternity service provision during and after the COVID-19 pandemic where there were significant changes to service provision and how women are engaged with maternity services. The research also highlights challenges and outlines key service barriers and issues experienced by Traveller women and their partners post-pandemic.

This report has six sections. This first section serves as an introduction to the study. It briefly outlines the context, focus and overall aims and objectives of the study. Section 2 provides an overview of research pertaining to Travelers in Ireland with particular focus on health and the experiences and outcomes within the maternity services. Section 3 outlines the methodology of the study and provides information about the participants, their recruitment, the data collection, analysis and presentation of findings. Section 4 presents the findings of the study. Section 5 presents a focused discussion of the findings in relation to the literature and policy context presented in Section 2 as well as key recommendations for policy development and implementation.

Section 01
Introduction

1.1 Introduction

The Traveller community experiences significant health inequalities influenced by and compounded by the social determinants of health including, poor accommodation conditions, poverty, racism and discrimination (AITHS, 2010). Mortality rates are higher than the general population at all ages and for all causes of death. This is reflected in Travellers' overall demographic profile which is similar to that in developing countries, with a high birth rate and a young population (AITHS, 2010).

Maternal and perinatal outcomes for Traveller women are exceptionally poor as they experience higher parity, higher rates of miscarriage, stillbirth, perinatal death, and infant death, when compared to non-Traveller women (Leitao et al, 2021b) in addition to shorter intervals between pregnancies. Traveller women visit their doctor later in the early stages of pregnancy and book into maternity hospitals later than the general population (Pavee Point, 2018). 2.1% Traveller mothers did not have antenatal care (Pavee Point, 2018). Outcomes of pregnancies are also riskier for Traveller women and their babies - infant mortality is 3.5 times national rate and average birth weights are much lower (Pavee Point, 2018). COVID-19 has presented additional challenges, with international data indicating the disproportionate impact of COVID-19 on minority ethnic groups, including Travellers and Roma with more infections and worse outcomes (Pavee Point, 2020a). Travellers were disproportionately affected by COVID-19 given significant increased risks of hospitalisation, ICU admission and/or death compared to the general population (Pavee Point, 2020b).

Travellers (all ages and those aged 18-64 years) were noted to be at an elevated risk of infection, and in those aged 18-64 years there was an increased risk of severe disease (in terms of hospitalisation when considered as a proportion of cases, and hospitalisation, ICU admission and death when considered as a proportion of the population). Notably, these results are considered to underestimate the true prevalence, given limitations with the use of ethnic identifiers and the hard-to-reach nature of this population.

Evidence synthesis for groups in vaccine allocation group nine - those aged 18-64 years living or working in crowded conditions (Health Information and Quality Authority [HIQA], 2021)

"Members of the Traveller and Roma communities and people who are homeless are the only specific groups identified as being at significantly increased risk of hospitalisation ICU admission or death compared to the general population and should be prioritised for vaccination"

Updated Recommendations: Priority Groups for COVID-19 Vaccination (The National Immunisation Advisory Committee [NIAC], 2021)

Within the Irish maternity system, COVID-19 provided the impetus for the introduction of new restrictions across all health services, including maternity services. Many new rules were imposed on service users regarding how they engaged with services throughout their pregnancy and how they gave birth. These had impacts on visiting hours, accompanying appointments, online services, etc. This posed further challenges for Traveller women.

Working in partnership with Pavee Point, a leading national Traveller organisation, this research examines the lived experiences of pregnancy and birth for Traveller women, with a particular focus on their engagement with the maternity services, during the COVID-19 pandemic, documenting the experience, the challenges faced and outlining key service barriers experienced by Traveller women.

1.2 Research Aim and Objectives

The aim of the research was to explore the experiences of Traveller women who were pregnant or gave birth during the COVID-19 pandemic in Ireland. The objectives of the research were to:

- explore Traveller women's experiences of pregnancy during the COVID-19 pandemic and the years that immediately followed (2020-2022);
- explore Traveller women's engagement with mainstream maternity services during the COVID-19 pandemic;
- the personal, interpersonal and structural factors that mediate Traveller women's experiences of pregnancy during the COVID-19 pandemic.

From these aims and objectives the research project addressed two key research questions:

- what are Traveller women's experiences of pregnancy and maternity services generally?
- what are the experiences of Traveller women in engaging with maternity services, including with staff, during the antenatal, labour and birth and postnatal periods during the COVID-19 period?

1.3 Research Contribution

The research used qualitative interviews with women who were pregnant or had given birth; one expectant Traveller father; and focus groups with Traveller Community Health Workers. These were employed by Primary Health Care for Travellers Projects (PHCTPs)[2] in three areas across the country, the east, the west and north west.

The findings highlight particular challenges and outline key service barriers and issues experienced by Traveller women and their partners post-pandemic. The research contributes to the timely discussion of maternity service provision during COVID-19 where there were significant changes to service provision and how women were engaged with. The research considers the experiences of Traveller women in the context of current service provision and reflects on how services might better respond to the needs of Traveller women in the antenatal, birthing and postnatal periods, as well as explore how policy can best support services to do this.

2 *Primary Health Care for Travellers Projects (PHCTPs) are peer-led projects which use a community development approach to address Traveller health inequalities. PHCTPs train and employ Traveller Community Health Workers to identify and develop joint projects and initiatives with local health services. Using a social determinants approach to health, Traveller Community Health Workers undertake health advocacy in a range of health arenas, for example, perinatal health, health education, infant health, mental health, accommodation and environmental health issues, immunization and health alerts, addiction, etc.*

1.4 Overview of the report

This is the first of six sections in this report. This section has served as an introduction to the study. First, it briefly outlined the context, focus and overall aims and objectives of the study. Section 2 provides an overview of research pertaining to Travellers in Ireland with particular focus on heath and the experiences and outcomes within the maternity services. Section 3 outlines the methodology of the study and provides information about the participants, their recruitment and data collection and analysis. Section 4 presents the findings of the study. Section 5 presents a focused discussion of the findings in relation to the literature and policy context presented in section 2. The final section provides a summary of the study and considers the contribution to knowledge as well as its limitations. Key recommendations for policy development and implementation are also presented here.

Section 02
Literature and Policy Context

2.1 Introduction

This section presents a review of the international and Irish literature on the range of topics and themes relevant to this research project. It starts by exploring what we know about Travellers in Ireland in relation to demographics and health. We then examine the research on engagement by Travellers with health services. This is followed by a presentation of literature focused on Traveller women, pregnancy and birth and by a presentation of the research about Travellers and COVID-19, and COVID-19 and the Maternity Services. The final sections explore mental health, breastfeeding during this period. The final sections explore the policy and practice context.

2.2 Travellers in Ireland: Demographics and Health

According to Census 2022 (Central Statistics Office 2023) there are just under 33,000 Travellers in Ireland, up 6% since the previous Census in 2016. However, a Traveller family count by the Department of Housing, Local Government and Heritage (DHLCH 2022) reported 12,183 Traveller families which, given the average family size of 4, puts the count equivalent to 48,732 or 1% of overall population (as per CSO Census 2022).

In 2017, the State formally acknowledged Traveller ethnicity (Houses of the Oireachtas 2017). Despite this, Travellers continue to experience significant levels of discrimination and racism with over 50% of Travellers having experienced discrimination in their daily lives. 40% of people said they would not employ a Traveller, almost 80% said they would not want a Traveller to live near them and 18.2% said they would deny Irish citizenship to Travellers (AITHS, 2010).

Travellers experience significantly poorer health outcomes compared to the non-Travellers. According to Census 2022 , 36% of Irish Travellers are under the age of 15 made up compared with 20% of the total population, with over half of the Traveller population (55%) aged under 25 years compared to 32% of the general population (Central Statistics Office 2022). Only 5% of Travellers are over the age of 65 years, compared with 15% of non-Travellers (Census 2022).

There are also high rates of long-lasting conditions, accounting for 26% of the Traveller population. In comparison, 22% of the total population living in the State reported experiencing at least one long-lasting condition or difficulty to any extent.

From the All-Ireland Traveller Health study (AITHS Team, 2010) we know that only 41% of Travellers had complete trust in health professionals, compared to 82% in the general population. 7 out of 10 (66.7%) of service providers agreed Travellers experience discrimination in their use of health services. 53% of Travellers were "worried about experiencing unfair treatment"

" It does exist [...] there is that sentiment that Travellers are less deserving, hence give them substandard services." (AITHS Team, 2010: 84).

The social determinants of health have a particular impact on Travellers with, for example, 13.3% of female Travellers educated to upper second level compared to 69.1% in the general population; 80.2% of Travellers unemployed; 39% of Travellers are effectively homeless, this includes Travellers who live on the side of the road, who double up on sites, who are in emergency accommodation or sleep rough or in cars and represent 'hidden homelessness'[3] (Pavee Point, 2021; Central Statistics Office, 2016). In terms of the digital divide, Travellers also have less access to internet than the general population (Central Statistics Office, 2016).

Traveller women's mortality is three times the rate of women in the general population and their life expectancy is 12 years less (70 v 82) (AITHS, 2010). They have five times the rate of suicide compared to the general population (AITHS, 2010). In the AITHS, 62.7% of Traveller women reported that their mental health was poor for one or more days in the previous 30 days compared to 19.9% of women in the general population. In 2016, 30.4% of Traveller women aged 15+ reported looking after the home (CSO, 2016).

2.3 Engagement with health services

In their engagement with the health services, 41% of Travellers reported having trust in health professionals compared to 82% of general population (AITHS, 2010). Over half (53%) of Travellers were worried they would receive unfair treatment in those engagements and their worries would appear to be well founded as 7 out of 10 (66.7%) of service providers agreed that Travellers experience discrimination when using the health services (AITHS, 2010).

The majority of Travellers (83%) received health information from Traveller organisations and Primary Health Care for Travellers (PHCTPs) (AITHS, 2010). There are approximately 27 Primary Health Care for Travellers (PHCTPs) where Traveller Community Health Workers are employed to work within the community employed by regional Traveller Health Units (THU). The AITHS and the Consultation for the National Maternity Strategy highlighted that Traveller health workers filled gaps in information provision (AITHS, 2010; Keilthy et al., 2015). However, in recent years there has a been reduction in the number of Traveller Primary Health Care Projects and reduced numbers of Traveller Primary Health Care Workers employed which has impacted the service (Department of Health 2022). Nevertheless, the ongoing pandemic has demonstrated the value of a strong Traveller health infrastructure underpinned by community development, with the HSE (2021b) reporting that 86% of Travellers accessed COVID-19 information from Traveller Health Units and PHCTPs during this time.

3 *Approximately 39% of Travellers meet the European definition of homelessness (European Typology of Homelessness and housing exclusion-ETHOS) as this includes the large number of Travellers who are experiencing 'hidden homelessness' in overcrowded living conditions. This is compared to 6% of the general population. The ETHOS is a comprehensive framework that captures the complexity of homelessness and includes: rooflessness, houselessness, living in insecure accommodation, and living in inadequate accommodation. It captures people who are (1) sleeping rough; (2) in emergency accommodation, such as overnight shelters; (3) in accommodation for the homeless (e.g. hostels, shelters, refuges, transitional); (4) in institutions with no housing to which to go subsequently (e.g. release from prisons, medical institutions); (6) forced to live in temporary structures (including mobile homes/ trailers), due to lack of housing and/or appropriate provision of accommodation; (6) forced to live with family or friends due to lack of housing, not own residence (e.g. 'couch-surfing').*

2.4 Traveller women, pregnancy and birth

In the Traveller community, the average age of first-time mothers is 26 compared to 31.8 in the general population (AITHS, 2010). The average age of a Traveller mother has increased significantly over the past 30 years largely due to the work of PHCTPs, however, Traveller mothers remain younger, have higher parity rates and higher incidences of pregnancy loss and still births (Kavanagh, 2018). 98% of Traveller women access mainstream antenatal care services prior to giving birth albeit later booking with GP and with maternity hospital (AITHS, 2010, ix). 44.5% of Traveller women in the age category 40-49 have given birth to more than five children compared to 4.2% in the general population (CSO, 2016).

> *" Among Traveller women aged 40-49 (the age by which women have typically completed their fertility) 13.3 per cent had not given birth to a child - compared with 18.3 per cent of women generally. Nearly half had given birth to 5 or more children, in stark contrast to just under 1 in 20 (4.2%) of women overall in this age group."* (CSO, 2016).

In 2010, the All-Ireland Traveler Health Study reported that Traveller women were having more spontaneous births and lower Caesarean births (AITHS, 2010). However, overall outcomes remain poor (AITHS, 2010). The miscarriage rate is 30.3% vs. 22.6% for the majority population. Stillbirth was 3.1 times higher. Perinatal mortality was 2.6 times higher and post-neonatal mortality rate was 6.7 times higher than the national average. IMR was 3.6 times the national rate. Premature births were higher and there was a lower-than-average birth weight (AITHS, 2010).

The National Perinatal Epidemiology Centre conducts audits and produces reports on perinatal mortality, severe maternal morbidity, home births, very low birth weight infants and pre-term rupture of membranes. Travellers are over-represented in all categories except home birth where none were reported in the Traveller community. Although accounting for 0.7% of the 15-49 year-old female population (CSO, 2016), in 2019 2.8% of mothers who experienced perinatal death were Travellers (O'Farrell et al, 2021); as were 3.7% who experienced severe maternal morbidity (Leitao et al 2021b). 1.4% of mothers whose babies experienced Neonatal Therapeutic Hypothermia were Travellers (Meaney et all 2021). Data for the Very Low Birth Weight Infants Report was not disaggregated because the data collection form used is for an American population and the ethnic categories do not reflect the Irish context (Leitao et al 2021a)[4]. Therefore, data on Travellers or other minority ethnic groups living in Ireland was not collected for this report. However, according to AITHS there was an excess number of newborns in lower birth weight categories among the Traveller community (AITHS, 2010, ix).

Women experiencing poverty and women from minority ethnic groups are at a higher risk of death during pregnancy and postnatally and their babies have higher mortality risk (Smart et al, 2003). They also experience inequitable and poorer maternity care. While at higher risk for mental ill health, they are less likely to be offered any support. Women from minority ethnic groups are more likely to present to the maternity services later in the pregnancies and are less likely to attend antenatal education classes. Furthermore, Traveller women reported experiencing macro and micro aggressions in their engagement with maternity services (Kavanagh, 2018).

4 *The collection form used is 'Vermont Oxford Network Data Collection Form'. The data collected is international. The maternal ethnicity/race question includes the following categories: 'Ethniciy of Mother: Hispanic /Not Hispanic. Race of Mother: Black or African American, American Indian or Alaska Native, White, Asian, Native, Hawaiian or Other Pacific Islander*

Kavanagh (2018) describes Traveller women's experiences of disrespectful and abusive treatment by health services during and after pregnancy loss in Ireland during a 30 year period. The experiences include neglect, abandonment, non-consented treatment and discrimination. Kavanagh argues that Traveller women's experiences of pregnancy loss are shaped and pronounced by gendered racism and suggests that these experiences are racialised obstetric violence on the basis of gender and ethnicity (Kavanagh, 2018).

2.5 Travellers and COVID-19

Irish Travellers were at greater risk of contracting COVID-19 and of suffering more severe symptoms due to poor living environments and higher rates of comorbidities (Villani, et al., 2021). A HIQA (2021) report found that difficulty in maintaining social distancing and self-isolation in overcrowded, inadequate conditions, often with limited or no access to running water, increased the risk of infection for Travellers. Travellers were at increased risk for severe disease as were people who were homeless and those with underlying medical conditions. Travellers are disproportionally impacted in both of those categories 39% of Travellers effectively experiencing homelessness (CSO, 2016) and experiencing more morbidities than the general population (AITHS, 2010). The Traveller experience of COVID-19 was in common with minority ethnic groups internationally who also experienced higher and more severe infection rates (Yaya et al., 2020). However, these numbers are considered underestimated both in the Traveller community in Ireland and in groups internationally as ethnicity data was not systematically gathered during the pandemic (HIQA 2021). Where data did exist, it was provided by local Traveller organisations, THUs, PHCTPs and groups working with Roma, who collected and monitored incidences of COVID-19 amongst Travellers and Roma (Pavee Point, 2020).

In a survey among the Traveller community regarding COVID-19, Travellers raised concerns about fear of stigma which was likely to be a barrier to early testing and diagnosis; about challenges faced attempting to maintain self-isolation, hygiene and sanitation on official and unofficial sites, and about difficulty accessing GP services. The survey noted that Travellers received the vast majority of their information about COVID-19 from THUs/PHCTPs (86%) and some information radio/TV news and social media (HSE, 2020b).

Villani, et al. (2021) explored the strategies adopted by community-health partnerships and NGOs to minimise the potential widening of Travellers' and Roma's health inequities during the initial response to the COVID-19 pandemic in Ireland. They found that the main pandemic mitigation interventions implemented were public health measures, culturally sensitive communications, lobbying for policy change and economic and social support. Villani et al argued that these interventions proved to be extremely important to reduce potential inequities in exposure to the virus and in access to healthcare and that community-health partnerships between minority groups' organi sations and healthcare professionals could mitigate the disproportionate effects of a pandemic on Travellers and Roma.

2.6 COVID-19 & Maternity Services

Ireland went into a full national 'lockdown' on 27th March 2020. Restrictions were slowly eased on 18th May 2020 but surges in infection rates resulted in second and third 'lockdowns' in October 2020 and January 2021 respectively. In maternity care, changes in the provision of services and care were implemented (HSE 2020a) such as reconfiguration of physical spaces in hospitals to accommodate suspected COVID-19 cases; redeployment of local outreach services back to the hospitals such as antenatal clinics; suspension of antenatal classes and strict no visiting policies in hospitals. This meant that partners were prohibited from attending antenatal scans and other appointments, and from visiting on antenatal or postnatal wards. Partners could only attend when labour was established and in a single room, or during a Caesarean birth and for recovery post-Caesarean in an operating theatre. A one-parent visiting policy also existed in neonatal intensive care units. Some antenatal and postnatal appointments took place by telephone or online, as did some educational classes and services. Postnatally, many Public Health Nurse (PHN) visits to homes ceased and some parents were instead asked to attend with their babies at local health centres. The staff in hospital and maternity services were also impacted during this time and experienced significant stress and pressure (Brady et al, 2022).

In a number of research studies in Ireland and internationally, common themes emerged about the experiences of pregnant people and their partners using the maternity services. They included the negative impact of restrictions and changes on partners attending antenatally, in early labour and postnatally, and its effects on the mental wellbeing of women and their partners; reductions in postnatal services particularly reduced visits from health workers such as PHNs; reduced supports for breastfeeding; problems with access to telehealth and internet access; poor communication and problems accessing information; lack of emphasis on pregnant women's mental health (Panda et al, 2021; Meaney et al, 2022; The Lancet, 2022).

2.7 Mental health in pregnancy during the pandemic

A systematic review found increased levels of mental health problems compared to pre-pandemic levels with increased postpartum depression (22% compared to 12%) and increased anxiety (37% compared to 15%) (Panda, 2021; Yan et al, 2020). It also found increased antenatal depression (31%) and psychological distress (70%). In a study of pregnant women's experiences in US, UK, Ireland and other countries, findings showed that stress in pregnancy was increased when there was a lack of access to antenatal care and reductions in social supports due to COVID-19 restrictions. They highlighted that 'higher pregnancy-specific stress and being a resident of Ireland … predicted lower satisfaction with maternity services' (Meaney et al, 2022).

2.8 Breastfeeding

Ireland has one of the lowest rates of breastfeeding in the world (HSE, 2016) with 45.5% of babies exclusively breastfed on discharge from hospital. By six months of age, 15% are exclusively breastfed in Ireland compared to 38% globally and 35% in Europe (WHO, 2013; HSE, 2021a). The WHO target is for 50% of babies to be exclusively breastfed for six months by 2025 (WHO, 2013). There is a dearth of research on breastfeeding in minority communities in Ireland. In other jurisdictions, such as the U.S., research had indicated minority ethnic groups are less likely to breastfeed. However, even among those groupings, the rates of breastfeeding at six months are higher than the general population in Ireland (Jones et al, 2015). In the Traveller community, the rate of breastfeeding is about 2% (Pavee Point 2021b; Hamid et al, 2011).

Barriers to Traveller mothers breastfeeding can include limited access to privacy due to overcrowded living accommodation, lack of sanitation and water facilities, lack of culturally appropriate and accessible information, lack of Traveller role models for breastfeeding and issues of cultural acceptance (Pavee Point, 2021b). An important barrier to breastfeeding in the Traveller community is the postponement of initiation of breastfeeding due to the need for specific high-risk screening for Classical Galactosaemia, a genetic condition which causes abnormal galactose intolerance (Fallon et al. 2019). In the Irish population generally Galactosaemia has an incidence rate of 1:16,200 but in the Traveller community the incidence rate is 1:450 (HSE, 2022). As breastfeeding must be postponed until results of the test are known, delays in initiation of breastfeeding can impact overall breastfeeding success (Welling et al, 2016). Galactosaemia is an autosomal recessive gene which means both parents must carry the gene for their baby to have the condition. In cases where both parents are carriers, there is a 25% chance of each of their babies having Galactosaemia. Pregnant Traveller women can now be fast-tracked for Galactosaemia carrier status genetic testing in Ireland (Pavee Point, 2023). While the issue of Galactosaemia is of importance in relation to breastfeeding in the Traveller community, Fallon et al (2019) contend that barriers to breastfeeding are more complex. They make several recommendations which include ensuring the Traveller community is involved in policy development which should explicitly address Travellers needs; specific staff training antenatally and postnatally and notably to support mothers to express milk while awaiting test results; recognition of the influence of families and the community on new mothers and so providing wider support and information; and more research to ensure policy is based on evidence (Fallon et al, 2019).

2.9 Policy Context

A number of national strategies recognise that Travellers face significant disadvantage in Ireland and some strategies also mention Traveller women's specific issues. However, there is minimal discussion about Traveller women's particular disadvantages and needs in relation to the maternity services in the various strategies relating to women such as the National Strategy for Women and Girls (Department of Justice and Equality 2017a), National Maternity Strategy (Department of Health 2016) and sometimes even in Traveller-specific strategies (HSE 2018; Department of Justice and Equality 2017b). At time of writing, a new National Traveller and Roma Inclusion Strategy (NTRIS) (Department of Justice and Equality 2017b) is under development which could provide opportunities to include maternal health issues. The National Traveller Health Action Plan (Department of Health 2022), recently published, has provisions for funding for Traveller health and incorporates the development of local plans. These positive momentums need to continue and need to include maternal health if perinatal outcomes are to be improved.

In Ireland's National Maternity Strategy however, there is only one named reference to Travellers – that they have an average lower age of mothers giving birth (Department of Health, 2016, 7). In addition, recommendation 7 (Department of Health, 2016:112) relates to the need for additional supports for women and families from disadvantaged and ethnic minorities and the first implementation plan recommends that a plan to support these groups be developed (HSE, 2017). The revised implementation plan notes that implementation of these recommendations, however, had yet to start (HSE, 2021a). At the end of 2022, this is 'yet to start' HSE (2021a).

2.10 Practice Context

Around the country, in each of the Traveller Health Units, PHCTPs have worked on the ground for decades directly with Traveller women who are pregnant and newly mothers resulting in higher uptake of antenatal care (AITHS 2010). At the national level,'Pavee Mothers' is an innovative maternal health initiative developed by Pavee Point in 2018. Working from a community development approach the Pavee Point Traveller Primary Health Care Project and Pavee Mothers, developed practical, accessible, and culturally appropriate resource materials to support Traveller women through the perinatal period. This included a comprehensive antenatal information pack for pregnancy and breastfeeding including a policy briefing document on breastfeeding and specific Pavee Mothers website (Pavee Point, 2018).

2.11 Conclusion

This section presented an overview of literature on the range of topics and themes relevant to this research project. A number of key points in relation to Traveller women's experience of pregnancy and birth in Ireland emerge from the literature:

- There is a distinct lack of robust disaggregated data in relation to Traveller women using maternity services and indeed the wider health services.
- Research highlights a lack of trust with healthcare providers broadly; the lack of culturally appropriate service provision (incl. literacy- 50% of Travellers have poor functional lit… compared to 9% of gen. population) and lack of engagement from service providers with Travellers and Traveller organisations.
- Research by Kavanagh (2018) highlights gendered racism which manifests both covertly and overtly on individual, interpersonal and structural levels[5] and racialised forms of obstetric violence on the basis of gender and ethnicity which is manifested on micro, meso and macro levels.

The next section introduces the methodology.

5 *Structural racism here refers to "structural and institutional arrangements, practices, policies and cultural norms, which have the effect of excluding or discriminating against individuals or groups, based on race, colour, descent, or national or ethnic origin." (Government of Ireland, 2023:8)*

Section 03
Methodology

3.1 Introduction

This section outlines the approach to the research. We start by introducing the research team and the approach to the work – community development led collaborative research with Pavee Point Traveller and Roma Centre. This is followed by a section that details how the research design developed and evolved. Section 3.5 describes how the team approached the literature review. Section 3.6 describes the recruitment of participants for the primary research. This is followed by a description of the data gathering and the approach to the analysis of survey, interviews and focus groups and the presentation and discussion of findings. The final part of this section looks at the limitations of the research.

3.2 The Research Aims and Objectives

The research sought to document the experience, the challenges and outline key service barriers and issues experienced by Traveller women. The aim of the research is to explore the experiences of Traveller women who were pregnant or gave birth during the COVID-19 pandemic in Ireland. The objectives of the research were to:

- explore Traveller women's experiences of pregnancy during the COVID-19 pandemic and the years that immediately followed (2020-2022);
- explore Traveller women's engagement with mainstream maternity services during the COVID-19 pandemic;
- the personal, interpersonal and structural factors that mediate Traveller women's experiences of Pregnancy during the COVID-19 pandemic.

From these aims and objectives the research project addressed two key research questions:

- what are Traveller women's experience of pregnancy and maternity services generally?
- what are the experiences of Traveller women in engaging with maternity services, including with staff, during antenatal, labour and birth and postnatal period during the COVID-19 period?

3.3 Approach to the Research

The starting points for the research were an acknowledgment of the social determinants of health and a community development approach to the research. The social determinants of health (SDH) are the non-medical factors that influence health outcomes. They are the conditions in which people are born, grow, work, live, and age, and the wider set of forces and systems shaping the conditions of daily life (WHO, 2010).

The community work approach to research values community knowledge alongside knowledge of the research process. Research used within the frame of community work is used as a practice tool for social change (Banks et al., 2019). Within the frame of community development, collaborative research is based on the principles of community development/ community work. These include:

- Collectivity - collection analysis and collective action
- Participation
- Empowerment
- Structural analysis of inequality
- Commitment to social change for equality and human rights

Community development led research can contribute to a deeper and more nuanced understanding of a range of social issues and provide a basis for taking research informed action within and alongside those communities as well as for policy makers.

3.6 Recruitment of participants

Communication about the research project was led by community workers at Pavee Point and local Traveller health projects. Participant information sheets were provided that outlined the following information: (Please see Appendix I) to interviewees (Traveller women) and focus groups (Primary Health Care workers).

- Description of the research project, its aims and objectives.
- Description of what was expected of the participants
- Description of how participant data was managed and used.
- Details on how to withdraw participation
- Contact details for the lead researcher.

Participants were sent information with sufficient time to read and consider the information in this leaflet, and to make contact the team with any questions concerning the research in advance of meeting the researchers.

3.7 Data Gathering

The research involved three data gathering strategies.

1. **Literature review:** the team undertook a structured review of relevant recent policy and academic literature relating to the research project. The literature review provided the context for the empirical research and informed the development of the research instruments to be used in the research. The review includes Irish and relevant international approaches.
2. **Primary data collection** was based on a multi-method strategy consisting of a) semi-structured interviews with Traveller women and b) focus groups with Primary Health Care Workers. Five Traveller women who were pregnant or gave birth during COVID-19 and one Traveller man whose wife gave birth during the pandemic were interviewed. 25 primary health care workers, in three focus groups in person in Galway, Donegal and Dublin, all women who worked directly with pregnant women in their communities as well as having experience of family members being pregnant or new mothers during the time. It was important to get a national perspective as antenatal and maternity services vary considerably across the country. Participants were recruited through the National Traveller Health Network. The interviewees were invited to choose the location of the interview. Due to the COVID-19 situation at the time of data collection, many of the interviews took place over the phone.

In the context of COVID-19 there were ongoing challenges facing the Traveller community. For these reasons, we had to be flexible with the timings of meetings, interviews, focus groups and workshops and change schedules accordingly. This meant that the research took longer than originally expected.

Researchers worked to establish a good rapport with all participants to create an environment for an empowering experience. Immediately before each interview each participant was introduced to the study. The researchers talked through the research information sheet and consent form with the participant to ensure that issues of literacy would not act as a barrier to informed participation. In all cases, consent forms were signed, and verbal consent was recorded at the beginning of each interview. Interviewers also discussed the right to stop the interview at any stage or indeed to withdraw from the research at any time without reason. They made it clear that the team were grateful for participants time and participation. These processes aimed to address the inherent issue of power imbalance that come with any research project. Power differentials in research do not simply dissipate just because a community development approach is used, ongoing dialogue and agreed actions are required between the researchers and participants to address these concerns throughout the research process.

3.8 Analysis of Survey, Interviews and Focus Groups

Interviews and Focus groups were transcribed and anonymised. The qualitative data was analysed thematically in response to the central research questions of the research project. The researcher undertook the first level analysis and presented the findings to the research team for feedback and input. This was followed by second analysis and presentation of the findings and contextualisation of these findings in relation to previous research and the Irish policy and practice context.

Data collection and analysis are spaces that inevitably result in some voices being enhanced "while others are silenced" (Mauthner and Doucet, 2003: 423). In this research we are concerned with parity of participation.

During the interview the researcher worked to create the conditions for these stories to be told and listened to. Conceiving participants as autonomous actors with agency, the researcher started by asked an open question, 'please tell me your story'. This aimed to encourage 'participant structured interviews' and create the conditions for informed participation which does not end with the start of the interview but is ongoing throughout the interview holding space for voice of the research participant. The interviews and focus groups were transcribed and analysed by the research team.

The interviews were analysed collaboratively within the research team. Thematic analysis was used. This involved individual readings and group readings and deep discussion about the themes and what they meant in the context of the research questions. The research team analysed the qualitative data together using thematic analysis. The final report was drafted collaboratively across the research team. The draft report was also shared with the wider team in Pavee Point, the Pavee Point Research Advisory Group as well as Traveller workers for checking and insights.

3.9 Presentation and Discussion of Findings

The research findings are presented in relation to the research questions set out at the beginning.

- What are Traveller women's experience of pregnancy and maternity services generally?
- What are the experiences of Traveller women in engaging with maternity services, including with staff, during antenatal, labour and birth and postnatal period during the COVID-19 period?

3.10 Research Ethics

Research Ethics approval was granted by the Social Science Research Ethics Committee in Maynooth University. The research was guided by key ethical principles of 'doing no harm' and gaining informed, voluntary consent for participation in the research. Community workers in the various community projects acted as gatekeepers in the recruitment process and supporters of the research and the participants, both peer researchers and survey/ interview/ and focus group participants.

There is potential for a power relationship to exist between the researchers and the research participants. This power relationship was addressed in a number of ways. The interviewers spent time with the interviewees in advance of the interview to take time to discuss the interview, the research and ensure informed consent. All those who took part in individual interviews were asked for and gave their consent. Participants were invited to speak with community workers in their project if they have any issues or concerns with the interview (as per the information sheet).

It is also important to note here that the interviews took place with participants who in some cases were in challenging life circumstances. Before starting the data collection the team identified potential risks and made a plan to mitigate these. For example, it should be considered that the experience of the interview may bring up sensitive issues and trigger distress in respondents, though these were minimised through creating a safe interview space for participants. As part of the data collection this was acknowledged in the interviews and contacts for support provided. The research team undertook training and mentoring in research and interview skills. A full risk assessment (also considering COVID-19) took place in advance of the interviews.

To protect the privacy of the participants, all of the interview transcriptions were anonymised, and all audio recordings deleted following verification of the audio recording or transcript.

3.11 Limitations

As noted above, systemic discrimination over generations means that Travellers face disproportionate health inequalities, higher than average suicide rates and lower life expectancies. Health inequalities, and other personal and family losses that the Traveller community experienced over the grant period were significant particularly in the context of COVID-19. For these reasons, we had to be flexible with the timings of meetings, interviews, focus groups and workshops and change schedules and outcomes accordingly. It also meant that the research took longer than we expected. We are thankful to the IRC for support throughout the project and during these delays.

This may have implications for the perspective and experience of the participants. The study is based on a small number of participants; thus, the findings of the study are limited in their transferability. Furthermore, the collected data were analysed based on the researchers' various epistemological, theoretical and with the starting points outlined above. We are mindful their impact cannot be ignored (Tufford and Newman, 2012) thus during the data analysis, we explicitly acknowledged and openly discussed these limitations and we have attempted to document this throughout the report.

This research focused on dimensions of the experience of COVID-19 and the time now since COVID-19, public health restrictions and lockdowns is growing. This may have implications for the perspective and experience of the participants of this research study.

3.12 Conclusion

This section outlined the approach to the research. We start by introducing the research team and the approach to the work – community development collaborative research in partnership with Pavee Point. The section details how the research design developed and evolved; the recruitment of participants for the primary research; how the data was gathered, the approach to the analysis and the presentation and discussion of findings. The final part of this section outlines the approach to ethics and the limitations of the research. The next section presents the findings of the research in relation to the research questions set out at the beginning of the research project.

Section 04
Findings

4.1 Introduction

The findings are drawn from analysis of the interviews and focus groups. The findings highlight specific experiences of pregnant and postnatal Traveller women. This section is presented in two parts. Section 4.2 describes the findings in relation to Traveller women's experience of pregnancy and maternity services generally. Section 4.3 describes the experiences of women in engaging with maternity services, including with staff, during antenatal, labour and birth and postnatal period during the COVID-19 period.

4.2 Engaging with Maternity Services as a Traveller

Women shared their experience of identifying as a Traveller in the maternity services. They expressed that they felt staff are uncomfortable asking the ethnicity question and they expressed that staff either assume or say nothing.

> *So it can be your appearance too because I have I would have a strong surname for a Traveller and my accent is strong anyway but I think it can be appearance too, that, if they don't assume who you are then they won't bother asking the question really unless you put it out there yourself.* FG2

> *oh staff sometimes don't feel comfortable asking that question...[...] there is training to be done in ethnic identifier.*FG2

Women want services to be responsive to need and want HCPs to engage directly to these issues

> *" ...found it actually good of her [PN ward midwife] then like she knew I was a Traveller obviously and she came back and she was like, oh these are the forms that you've to read and then she was like, 'can you read?', like the way she said it was a bit rude but her asking was still a good thing for her to ask d'you know that kind of way? And I was like 'oh yeah, I can read, yeah', and she was like, oh right, that's fine she goes, if there's anything that you need help with, she goes, for writing and stuff and I said, 'no look, I can read and write' like, I'm sound.... I think the way she was thinking that, d'you know the way like if I was too ashamed to tell her I couldn't read or write, she gave me a load of videos to look up on YouTube that explains stuff to you verbally which to me was good".* (3)

Participants reported many challenges in engaging with the maternity services during their pregnancy. Foremost, they that they did not feel that they had all the information that they needed when they were engaging with maternity services and that this made it difficult to navigate the services. The participants in this research noted that information about pregnancy and maternity services was most often given by Health Care Practitioners in written format such as leaflets and booklets as well as by links to 'apps'. All participants highlighted this as a barrier citing the low literacy levels in the Traveller community.

" ...anybody that has low literacy levels to be just gave the information like this without actually being explained to them... they have to be completely and utterly lost, because at one stage you've to give this big maternity book to people for people to read through, and I'd say Travellers if anything chucked it in the bin."

Two participants discussed the issue of shame attached to low literacy skills and while they themselves could read, one reported an incident she was aware of where a mother did not ask for information because she said she

"... was too embarrassed to say that I couldn't read" (I4)

Two participants suggested that the 'Pavee Mothers' leaflets being visible in the antenatal waiting room would be useful as well as Traveller Pride posters in these spaces to make them feel more welcoming. On the other hand, one participant described how she did feel comfortable in the GP waiting room because people waiting were a diverse group:

" I'm there like among an awful amount of people, like and an awful lot of people like from different minority groups like from marginalised disadvantaged areas, so it's very, it is diverse like, the waiting room alone is very diverse. Yeah, it's something that you would feel comfortable in" (I4)

4.2.1 Communication

Women also raised issues about receiving hospital communication and notices for appointments. Postal delivery was raised as a problem for some Traveller sites:

" ... but post didn't come out to our house out to our site for a long long time. And what was happening was, when appointments were coming out, you were either, you just got the post maybe a day or two days before your appointment or you'd probably get maybe a day after appointment was got so maybe they should look around how people, where people are living, what's their conditions like, are they receiving post or not receiving post..." (I4)

It was noted that text message reminders were sometimes received from some maternity units, but it was at short notice, often for next day appointments.

4.2.2 Negative Stereotypes and Racism

Participants spoke about ongoing issues in the maternity system, issues they experienced before COVID-19 and after the pandemic. All of the women reported facing stereotypes and discrimination in services. Traveller women reported negative interactions with staff during the antenatal appointments. They reported facing negative stereotypes about Travellers in these interactions.

> *" I just felt as if they thought that that I was your stereotype Traveller woman that has no education, that's in here having a baby just to have a baby, d'you know that kind of way? Like I just felt as if they put me down as another number, another woman, but after when I had the baby that first doctor, he was the head doctor that was in that night and I just found him very rude"* (I3)

This was also felt by another participant.

> *because I'm educated and because I've a full time job, people don't expect Travellers to have those things.*

Women also expressed that they felt that there was judgment based on the age of young Traveller mothers.

> *they're judged being young mothers and I think there's a lack of understanding or knowledge and very often because you're a young mother the first thing they would say to you, do you need a social worker, you know and that has happened as well, because they see you as young, that you're unexperienced, which is, you know because they don't really understand there's an element that Travellers get married young and have children young.* FG2

A Traveller Community Health Worker shared how a women described her interactions with a nurse where she felt the nurse was being condescending.

> *the nurse said to her, do you know how to pack a bag for the hospital? And the woman turned around and said, this is my fifth child, I think I would know how to pack a hospital bag, but the mother said to me, I could find her being condescending to me and trying to belittle me.* FG2

All of the interviewees and the focus group participants spoke of their experience of racism, their worry about racism and how it impacts them in the context of maternity services.

> *a lot of Traveller women, Traveller people, Travellers in general are afraid to speak up for what they know their rights are, because Travellers have been refused services in the past, I'm not saying specifically health services, but I do know at the moment what's happening in X is a load of Travellers and don't have a GP.* (I5)

> *the fact that I'm worried about protecting my daughter from discrimination before she's ever here says an awful lot about the society we're still living in.* (I5)

4.3 Experiences during the COVID-19 Period

COVID-19 highlighted the challenging living conditions for many Travellers. For pregnant women and new mothers this was particularly difficult during COVID-19.

> *there's a lot of Travellers as well that's living on the side of the road, right, so they have no running water, they have only the portaloos, and d'you know, there's families like that and the woman that's just after coming out with an open wound, it's ridiculous, d'you know what I mean, there's no electricity, they've to use generators and with the price of that and all going on you can't keep it going all day every day. So, it was very tough for a lot of Travellers.* FG1

In COVID-19 times this presented challenges for safety precautions and in particular isolating.

> *women coming out from hospitals going into a very small trailer, with maybe four or five children in it already and having to isolate, they found it very difficult to isolate, ... imagine being in a trailer with a tap outside, maybe five or six children in the trailer and bringing a new baby.* FG1

4.3.1 COVID-19: Engagement with Services

During COVID-19, restrictions were applied across the maternity services. This sections describes the experience of Traveller women during the ante natal period, during labour and birth and during the postnatal period.

During COVID-19, participants described negative experiences with staff and with their engagement with services in antenatal, birthing and postnatal services. Participants understood that hospital staff were under pressure but it still impacted on how they felt about their experience overall and for some it was very upsetting.

Participants described experiencing lack of listening and attention, and lack of kindness and sensitivity.

> *" [During labour] I felt I was getting no attention, like the nurses were just ignoring ya. Like when I was voicing me concerns to them like I just felt that they weren't listening.* (1)

This feeling was felt even stronger where there was something wrong or a pregnancy loss.

" ...but I just felt a little brushed aside what I was telling them, as if this was a normal [antenatal bleeding] oh sure look it happens to loads of girls and... as if what I was going through kinda wasn't a big deal to them

" I just I found it very insensitive even though I know God help them it happens every day but for me as a woman if I seen that happening to a hundred girls a day, to me it's still heart breaking to look at. And I wouldn't be so insensitive as to brush it off and say, 'look you're not the only person that this happens to'" (3)

understand the nurses are under an awful lot of strain in the best of times, I'm not taking that away from them, but I just think that when someone is in the Emergency Room, when they're asking questions, snapping at them is not the way to go, even if you're under stress.(5)

It was noted that local and GP services were generally a better experience as well as the Domino[6] schemes in the community given continuity of care and more time for appointments.

" I felt that doctors and nurses had more time for ya years ago, where this time during COVID-19 I understand it was difficult for them also but it just felt like, you know, appointments was rushed, and I felt then I couldn't really talk to me doctors or the nurses the way I would have with previously". (1)

One participant described **how** her experience was positive:

" she very, very polite, explains a lot, very clear so it's a warm welcome for me".(2)

4.3.2 Antenatal Appointments

Women described the loneliness of attending antenatal appointments on their own. They expressed a loss of the positive experience that they had anticipated sharing with their partners.

" Having to attend the antenatal classes and the appointments alone took me experience completely away. The exciting experience..." (1)

They also described fear and worry attending the appointments on their own.

"...you have to attend them [scans] alone made me worried..." (1)

6 *The Domino Scheme is a midwife-led maternity service in community-based clinics. On the Domino Scheme, pregnant people are cared for by experienced community midwives throughout their pregnancy, during labour (in hospital) and for the first week after their baby is born. This midwife-led care is combined with care from a GP (more info available at https://www.citizensinformation.ie/en/birth-family-relationships/before-your-baby-is-born/maternity-services-in-ireland/).*

4.3.3 Labour and Birth

The prohibition on partners attending scans as well as limited attendance during labour was raised by all interviewees. Interviewees described feeling upset, stressed and vulnerable without their support person.

> *" ...and while I was in there, I had to like video call [husband] and like [husband] met his son for the first time through a video call, d'you know that kind of way? ...they weren't allowed in but just to be as close as possible to the baby when he was being born".*

Men/partners also felt the stress of restricted access with one interviewee describing a conversation with a man they knew.

> *" He could only drop his wife to the hospital but couldn't go in with her and that caused him a bit of stress."* (2)

One participant described how she felt confident facing into birth but described how her experience in the hospital meant that she would feel more fearful of birth in the future.

Inconsistency implementing COVID-19 restrictions were described by a number of interviewees. For example, pregnant mothers were tested for COVID-19 but were sometimes admitted to hospital prior to test results and some partners were admitted to the labour ward without a test. A private clinic facilitated a partner to attend scans but the public hospital did not (for the same pregnancy).

Interviewees described relief once their birth partners could attend and for some it changed and improved the experience:

> *" I felt more at ease when [birth partner] arrived because I had somebody there for support and I felt then that if I had any concerns [birth partner] would vouch [voice] them to the doctors. [Birth partner] was my speaker d'you know...I felt the doctors was kinda listening to [birth partner] more than what had been listening to me."* (I1)

> *" ...everything went well [after birth partner arrived] like it was an exciting experience for me then. Like everything went smoothly".* (I1)

If the interviewees mothers were their birth partners – which is often the case in the Traveller community - this posed difficulty postnatally as only birth partners could visit. Therefore, partners/ husbands were unable to meet with their new baby until the mother was discharged. Some used a video call.

One woman described giving birth in a pre-labour ward:

" I was in a room [with six other women] where a woman actually had to give birth in the ward where I was... That was actually very frightening and very.. it was very traumatising" (I6)

Others described negative experiences.

" she had a very, very bad experience with her labour and her delivery. We weren't allowed to go in with her, you know the way even when they're in the ward you have to go out then at a certain hour, but once you're brought to the labour ward then she's, one of the women say, you're allowed to go up, but they left her down the stairs and she was in very, very, very, very, bad labour and I just said to her, put one of the doctors on to the phone to me till I try and explain like, and they told me not to ring the phone no more, that I was upsetting her". FG1

" It's a very emotional time for any mother, you know, who have hormones, you know, going in giving birth maybe the first time or any time, whatever,
*it could be the sixth child, it's hard enough to do that, especially through the pandemic never mind to be in a closed environment where you don't have access to family, and you experience discrimination within the services".*FG2

One of the Traveller Community Health Workers shared her own experience as a mother of a pregnant woman.

" It was a horrible time to be a mother it was also a horrible time knowing that your child was in there and needing ya, I suppose, do you know what I mean, because we're used to being around but not just our experience, it's most of us, there was another woman in there as well and she actually had her baby in the bathroom. She had no partner with her, no nothing and the staff was ridiculous the same night. So, there was a lot of bad experiences". FG1

4.3.4 Pregnancy loss

The restriction on partner attendance was acutely felt for participants when things went wrong for them.

" ... and they [her husband and mother] were met by the security and told to get back out they weren't allowed in... they were just trying to explain, look we want to see what's wrong with her like, see how she is, see how the baby is, what's going on... They weren't even talked to like, they were literally kind of shoved kind of back out the door and to go away" (I3)

" a miscarriage to anybody is devastating. But I was alone for my appointments, I was alone in that Emergency Room when my husband was outside, you know" (I5)

" I'm sure it's difficult for every woman but particular challenge to Traveller women, you know, not having that support mechanism especially if there's literacy issues"(FG2)

The fear of restrictions had a potentially dangerous impact on Traveller women.

Some of the women probably sometimes would even delay going into the hospital, so they were putting themselves in danger as well, and when they were brought in they were isolating they had to be tested then straight away, every time they went, they were tested. So, they were left in so for a while to see what the results would be they would probably be checked over but they'd be, have to wait for the results to see did they have the Coronavirus, then they'd be locked in, so some of them were petrified to go to hospital. FG1

4.3.5 The Postnatal Period

In the postnatal period, mothers experienced a lack of support from both their own families but also from maternity and public health services.

" the restrictions [...] all impacted greatly on the mothers and the mother-in laws and stuff like that".

One grandmother describes her experience of having COVID-19 herself, the challenge it placed on her family, how she couldn't support her daughter in the way she normally would and the impact on her daughter who suffered from postnatal depression.

" I got COVID-19 meself, and I got it very bad at the very beginning of March, and me daughter had a new baby, she was two weeks old, and living on the site she was living out the back of a trailer, so I got it very bad, me daughter was sectioned, the baby was only two weeks old, and I had to try and keep them out of the house but we couldn't because she'd no running water or toilet or bathroom in the caravan, and she was sectioned so her immune system would have been low, and I got it very bad and I was terrified of her baby getting it with her immune system being low after being sectioned and the baby need help or two weeks, so I had to keep washing the place down with Dettol, let her use the bath because she had to take a bath because she was sectioned, so I found that very hard. The worry of it nearly killed me." FG1

COVID-19 meant that public health nurse visits and developmental checks were delayed.

" it was terrifying and now the baby got no six-week check-up, d'you that kind of way, no development check-ups cause they were all delayed over the COVID-19." FG1

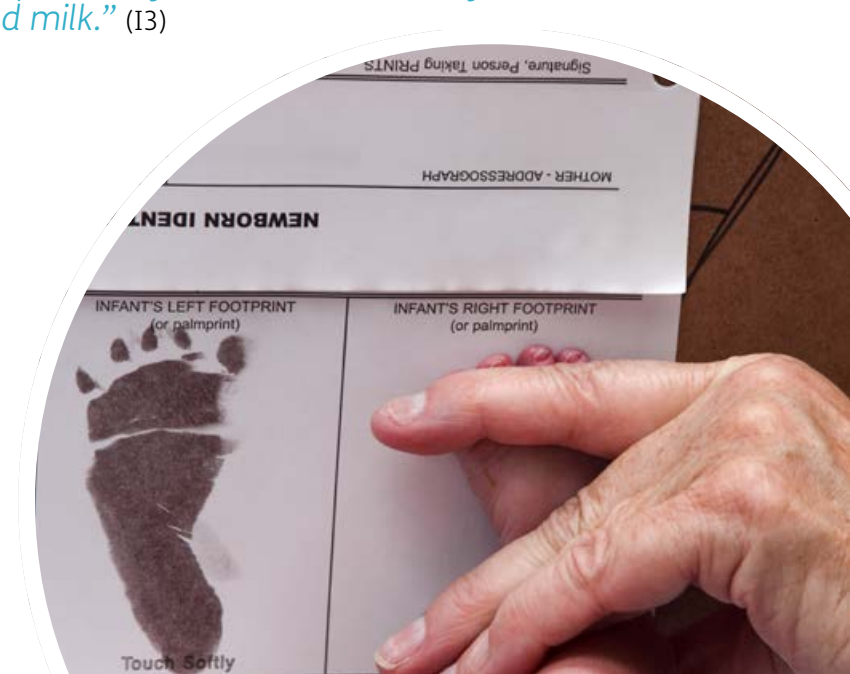
On halting sites, there was not space to facilitate social distancing, and this meant that undertaking a visit was difficult for the nurse.

" she would check the baby in the car so and there wasn't no right facilities even for her to go out to the sites, so that's what we kind of have a big problem with." FG2

This challenge also impacted on the experience of the visit for the mother and the baby. Mothers felt the absence of the support services when they needed support.

" And I don't know whether it was because of where I was living or not she just seemed very cold with him. I just felt that she didn't stay with him [baby] long at all [on a postnatal visit to her home]". (I1)

"I had to kind of remind the nurses a few bits, you know like the way our children have to have the soy-based milk." (I3)



4.4 Summary of Main Findings

Engaging with Maternity Services as a Traveller woman

- Participants spoke about ongoing issues in the maternity system, issues they experienced before COVID-19 and after the pandemic. All of the women reported facing stereotypes and discrimination in services. Traveller women reported negative interactions with staff during the antenatal appointments. They reported facing negative stereotypes about Travellers in these interactions. Women also expressed that they felt that there was judgment based on the age of young Traveller mothers.

- All of the interviewees and the focus group participants spoke of their experience of racism, their worry about racism and how it impacts them in the context of maternity services.

- Participants expressed that they felt staff are uncomfortable asking the ethnicity question and they expressed that staff either assume or say nothing.

- Participants reported many challenges in engaging with the maternity services during their pregnancy. Foremost, they that they did not feel that they had all the information that they needed when they were engaging with maternity services and that this made it difficult to navigate the services. The participants in this research noted that information about pregnancy and maternity services was most often given by Health Care Practitioners in written format such
as leaflets and booklets as well as by links to 'apps'. All participants highlighted this as a barrier citing the low literacy levels in the Traveller community.

- Women also raised issues about receiving hospital communication and notices for appointments. Postal delivery was raised as a problem for some Traveller sites.

- A number of participants discussed the issue of shame attached to low literacy skills.

- Two participants suggested that the 'Pavee Mothers' leaflets being visible in the antenatal waiting room would be useful as well as Traveller Pride posters in these spaces to make them feel more welcoming. On the other hand, one participant described how she did feel comfortable in the GP waiting room because people waiting were a diverse group.

- It was noted that text message reminders were sometimes received from some maternity units, but it was often at short notice, for example for next day appointments.

COVID-19 & Engagement with Services

- COVID-19 highlighted the challenging living conditions for many Travellers., including overcrowded accommodation.
- For pregnant women and new mothers this was particularly difficult during COVID-19.
- During COVID-19, participants described negative experiences with staff and with their engagement with services in antenatal, birthing and postnatal services. Participants understood that hospital staff were under pressure but it still impacted on how they felt about their experience overall and for some it was very upsetting.
- Participants described experiencing lack of listening and attention, and lack of kindness and sensitivity. This feeling was felt even stronger where there was something wrong or a pregnancy loss.
- Women described the loneliness of attending antenatal appointments on their own. They expressed a loss of the positive experience that they had anticipated sharing with their partners. They also described fear and worry attending the appointments on their own.
- The prohibition on partners attending scans as well as limited attendance during labour was raised by all interviewees. Interviewees described feeling upset, stressed and vulnerable without their support person. Men/partners also felt the stress of restricted access.
- The restriction on partner attendance was acutely felt for participants when things went wrong for them.
- Women stated that they would feel more fearful of birth in the future.
- Inconsistency implementing COVID-19 restrictions were described by a number of interviewees. For example, pregnant mothers were tested for COVID-19 but were sometimes admitted to hospital prior to test results and some partners were admitted to the labour ward without a test.
- It was noted that local and GP services were generally a better experience as well as the Domino[7] schemes in the community given continuity of care and more time for appointments.
- Interviewees described relief once their birth partners could attend and for some it changed and improved the experience.
- If the interviewees mothers were their birth partners – which is often the case in the Traveller community - this posed difficulty postnatally as only birth partners could visit. Therefore, partners/husbands were unable to meet with their new baby until the mother was discharged.
- In the postnatal period, mothers experienced a lack of support from both their own families but also from maternity and public health services.
- Participants reported that public health nurse visits and developmental checks were delayed.
- On halting sites, there was not space to facilitate social distancing, and this meant that undertaking a visit was difficult for the nurse.
- This challenge also impacted on the experience of the visit for the mother and the baby. Mothers felt the absence of the support services when they needed support.

4.5 Conclusion

This section presented the research findings. These findings are presented thematically incorporating the data from the interviews and the focus groups. The following section discusses these findings and provides conclusions and recommendations.

7 *The Domino Scheme is a midwife-led maternity service in community-based clinics. On the Domino Scheme, pregnant people are cared for by experienced community midwives throughout their pregnancy, during labour (in hospital) and for the first week after their baby is born. This midwife-led care is combined with care from a GP (more info available at https://www.citizensinformation.ie/en/birth-family-relationships/before-your-baby-is-born/maternity-services-in-ireland/).*

Section 05
Discussion, Conclusion and Recommendations

5.1 Introduction

The section discusses focuses on the main themes which emerged from the research findings. It then draws conclusions from the research project and presents some recommendations.

5.2 Discussion

The research documented the experiences of women in engaging with maternity services including with staff during antenatal, labour and birth and postnatal period during the COVID-19 period. Traveller women had many different experiences in the maternity service, some positive but many negative.

Participants reported that they faced stereotypes and discrimination from staff in services. The research found that women did not always feel included in the maternity services or that services were for them. They reported feeling that they did not have all the information that they needed when they were engaging with maternity services and that this made it difficult to navigate the services. Literacy issues compounded this. A significant issue expressed was how staff engaged with them as Traveller women regarding their ethnicity. Women reported a difficulty for staff or awkwardness in asking the ethnicity question at booking and coming back to this in relation to the women's care in terms of the effective communication of appointments, information about pregnancy and about the maternity services themselves. Women expressed that they wanted the services to be responsive to need and want HCPs to be confident and engage directly with them. This challenge in communication was felt more acutely during times of crisis as well as during labour/ birth.

These findings contribute to the reported lack of trust in health professionals compared to the majority population (AITHS, 2010). They mirror the reported fear of receiving unfair treatment in those engagements in the AITHS (AITHS, 2010).

There were also issues specific to the COVID-19 context, for example, where partners participation in appointments, including scans, was limited. Participants also reported distress when the could not receive support from their partner or mother during early labour and sometimes, also during the birth. There were also many reports of postnatal struggles. Many challenges to breastfeeding were expressed including issues with the Beutler test, delays in breastfeeding support and ultimately little success in breastfeeding. Several studies in Ireland and internationally highlighted similar experiences of pregnant people and their partners using the maternity services including the negative impact of restrictions and changes on partners attending antenatally, in early labour and postnatally, and its effects on the mental wellbeing of women and their partners; poor communication and problems accessing information; reductions in postnatal services particularly reduced visits from health workers such as PHNs; as well as reduced supports for breastfeeding (Panda et al, 2021; Meaney et al, 2022; The Lancet, 2022).

In the COVID-19 context, women described the loneliness, as well as worry and fear of attending antenatal appointments on their own. They expressed a loss of the positive experience that they had anticipated sharing with their partners. The prohibition on partners attending scans as well as limited attendance during labour was raised by all interviewees. Interviewees described feeling upset, stressed and vulnerable without their support person. One participant also described how partner and family were fearful for her during appointments and during the labour and birth. Participants found the inconsistency of the implementation of the COVID-19 restrictions stressful and frustrating. In the postnatal period, mothers experienced a lack of support from both their own families due to the COVID-19 travel restrictions and illness in the community, as well as from maternity and public health services. Participants also experienced delays for public health nurse visits and developmental checks. This also mirrors findings from other studies focussed on this time period – for example study of pregnant women's experiences in US, UK, Ireland and other countries, findings showed that stress in pregnancy was increased when there was a lack of access to antenatal care and reductions in social supports due to COVID-19 restrictions (Panda, 2021), highlighting that 'higher pregnancy-specific stress and being a resident of Ireland … predicted lower satisfaction with maternity services' (Meaney et al, 2022). Furthermore, a systematic review found increased levels of mental health problems compared to pre-pandemic levels with increased postpartum depression (22% compared to 12%) and increased anxiety (37% compared to 15%) with increased antenatal depression (31%) and psychological distress (70%) (Yan et al, 2020).

This research further illuminates findings by Kavanagh (2018) showing examples of the experience of gendered racism and obstetric violence at the individual, interpersonal and structural levels within the maternity system, further compounded by the event of COVID-19.

The interviews with the Traveller women and focus groups with Traveller Community Health Workers revealed the challenges Traveller women face but also provided some insight into how supports might be provided. The issues faced by the community in accessing and using pre and postnatal maternity care are multifaceted and interconnected and thus the interventions must also be targeted and integrated.

This report contributes to the timely discussion of maternity service provision during and after the COVID-19 pandemic where there were significant changes to service provision and how women are engaged with in maternity services. The research also highlights challenges and outlines key service barriers and issues experienced by Traveller women and their partners post-pandemic.

5.4 Conclusion

This research was developed in partnership with Pavee Point Traveller and Roma Centre based on emerging and identified needs by Travellers and Traveller organisations during COVID-19. The research undertook a community work approach built on the principles of social justice, participation, empowerment, collectivity. The research created the conditions for original research in partnership with Traveller women, contributing to new understanding, advancing experiential knowledge in the field of health, maternity services, postnatal services and supports and service delivery of these.

Very little research has been conducted by and with Travellers/ Traveller organisations, in collaboration/ partnership with academics/researchers/ universities. Working with NGOs that work directly with and in communities is a way of creating the conditions for this to happen. The project reinforced the need for collaborative research with and alongside communities. The research findings directly inform the organisations' policy, advocacy and direct work with Traveller women and their partners, providing impact and added value to this collaborative and participative research. This project also created the conditions and made it possible for the organisation to undertake this important research, something which is a challenge for many NGOs given the need for additional resources and support required. It creates the conditions for dialogue between Traveller women, Traveller organisations, service providers and policymakers.

5.5 Recommendations

The findings point to the need for immediate direct action. First of all, without an ethnic identifier we know very little about the participation, access or outcomes of Traveller women and their babies. Clear pathways to services are needed, with specific supports to navigate the system and the digital divide is essential.

Trust is crucial in any intervention or service development. Clearly mapped mechanisms to address racism must be developed in all public services particularly where service users are potentially vulnerable, such as pregnant women. In the medium to longer term, a specific action plan must be developed and resourced to draw learning for how mainstream maternity services can become accessible and effective for Traveller women and their families.

5.5.1 Recommendations: National Level

- Fully implement and resource the National Traveller Health Action Plan (NTHAP) at national and local levels, this includes investment in the Traveller health infrastructure to undertake special measures to address Traveller perinatal health inequalities.
- Ensure that any Review of National Maternity Strategy is underpinned by a human-rights based approach, is co-designed and includes direct engagement with women, including Traveller, Roma and other minority ethnic women.
- Ensure a commitment to Traveller and Roma inclusion and the intersectional experiences of Traveller and Roma women are included in the upcoming Independent Pandemic Evaluation established by the Department of the Taoiseach to support future proofing for future pandemics.

- Ensure full implementation of ethnic equality monitoring (in line with human rights standards) across all maternity units. This must be consistent and data published promptly and used to equality proof policy and services.
- Ensure that Traveller and Roma women are mainstreamed into existing and forthcoming health policy.

5.5.2 Recommendations: Engagement, training, service provision and development

- Anti-racism and discrimination training should be part of all health-related training programmes, including initial and in-service training as per NTRIS, NTHAP and the NAPAR.
- Resourcing and development of a Traveller specific perinatal mental health initiative to address poor mental health of Traveller mothers.
- Midwifery and nursing representation on all Traveller Health Units to support partnership working and service integration.
- Visibility of Traveller and other minority ethnic women in mainstream maternity services, including maternity units and primary care settings

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Working in partnership with Pavee Point, a leading national Traveller organisation, this research examines the lived experiences of pregnancy and birth for Traveller women, with a particular focus on their engagement with the maternity services, during the COVID-19 pandemic, documenting the experience, the challenges faced and outlining key service barriers experienced by Traveller women.

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