



# Experiences of Pregnant Migrant Women receiving Ante/Peri and Postnatal Care in the UK: A Longitudinal Follow-up Study of Doctors of the World's London Drop-In Clinic Attendees

## Authors

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## Abstract

### Title

Experiences of Pregnant Migrant Women receiving Ante/Peri and Postnatal Care in the UK: A Longitudinal Follow-up Study of Doctors of the World's London Drop-In Clinic Attendees

### Background

Access to adequate maternity care not only safeguards the pregnancy and facilitates good maternal health outcomes, but also is essential for communicable disease control. The National Institute of Health and Care Excellence's (NICE) guidelines for Antenatal Care<sup>1</sup> recommends that first contact with antenatal services should be made as early as possible, with full booking, interview and antenatal blood screening taking place by ten weeks' gestation. However, data from the Médecins du Monde<sup>2</sup> network has shown that across their 25 European projects vulnerable pregnant women are facing barriers to accessing healthcare with 65.9% having no access to antenatal care before attending one of their clinics, and 42.8% accessing care too late (first antenatal appointment after 12 weeks). Both of these factors are correlated with increased risk during pregnancy, as well as with poor maternal outcomes.<sup>1</sup> This study focuses in on the healthcare experience of vulnerable pregnant migrant women as seen in a London drop-in clinic. The care they received is compared with recognised standards for antenatal care and health inequalities in pregnancy are explored.

### Methods

A longitudinal follow-up study of all pregnant women presenting to the Doctors of the World (DOTW) drop-in clinic, between January 2013 and June 2014, was completed between June and October 2014. Baseline data was extracted from the DOTW database for potential participants. Participants were contacted by phone, using a three-way interpreter call if appropriate. Partici-

pants' antenatal and immediate postnatal experiences were ascertained using a pro forma questionnaire designed to determine access to antenatal care, barriers to accessing care and experiences during their pregnancy, labour, and the immediate postnatal period. These findings were analysed using a combination of quantitative and qualitative methodologies as appropriate.

### **Results:**

It was possible to follow-up 35 of the 85 pregnant migrant women who presented to DOTW's London drop-in clinic (response rate 41%). All but one did not have access to a GP. The average length of time in the UK prior to delivery was 4.6 years. Only 11/29 (38%) had their first antenatal appointment in the first 12 weeks of pregnancy with the rest booking late and 34% accessing antenatal care at greater than 20 weeks gestation. 50% of women had 5 or less antenatal appointments (less than the minimum level of antenatal care) and fear of costs and communication problems were cited as barriers. In this cohort there were two early neonatal deaths; both of the mothers received a bill for their hospital care.

### **Conclusion:**

This study finds evidence of the deterrent effect of entitlement checks and charging in a population with little access to primary care. Antenatal care is frequently received late and is often lower than the minimum standards for antenatal care and subsequently they and their unborn child are at increased risk of pregnancy-associated complications.

## **Plain Language Summary**

Access to good antenatal care is known to improve maternal and child outcomes and not having the correct standard of care can result in pregnancy associated complications for the mothers and their unborn children. We know from the general migrant population who access the clinic that fear of debt and being arrested are significant deterrents to accessing healthcare and we also know that people face administrative barriers by being asked to produce documentation that they do not have.

We found evidence that the pregnant migrant women who access our London drop-in clinic in the majority of cases did not have a GP despite being in the UK for on average 4.6 years at the time of delivery. In the majority of cases they were accessing maternity care later than is recommended and had fewer than the recommended number of antenatal appointments. This puts these women at increased risk of pregnancy-related complications. In our cohort two of the 35 women we were able to follow up have lost their babies soon after birth and in both cases they received a bill for their hospital care.

## Rationale & Background Information

Doctors of the World UK (DOTW) is part of the global Médecins du Monde (MdM) network, which delivers over 300 projects in more than 70 countries through 3,000 volunteers.

Their vision is of a world in which vulnerable people affected by war, natural disasters, disease, hunger, poverty or exclusion get the healthcare they need regardless of income or status. For over 30 years, they have worked to ensure excluded people overcome barriers to healthcare through targeted health programmes and advocacy work.

DOTW runs a clinic and advocacy programme in East London run by volunteer support workers, doctors and nurses that provides information and practical support to vulnerable people in order to help them gain access to regular health care services, as well as providing short-term healthcare to people who need it. The majority of the clinic's patients are undocumented migrants, but it provides assistance to anyone who has had difficulty accessing healthcare in the UK. Due to its status as both healthcare advocate and provider with an open door policy, DOTW is in a unique position to gather research on issues that are all too frequently under the radar. This report explores pregnant migrants' access to and experience with maternity care in the UK.

In Professor Marmot's 2010 report "*Fair Society, Healthy Lives*"<sup>3</sup> it was stressed that: "*tackling health inequalities was a matter of social justice, with real economic benefits and savings*". The costs cited for not addressing health inequalities were well in excess of £5.5 billion per year. One of the areas that demonstrates the most stark evidence of health inequalities is maternal and child health.

A 2014 MDM report across Europe<sup>2</sup> showed that migrants often faced barriers accessing health due to language difficulties (6.8%), a lack of knowledge and understanding (21.2%), fears of being reported or arrested (2.9%), treatment or consultation being too expensive (1.3%), administrative reasons (19.9%) or simply being denied health coverage (9.2%).

Within many vulnerable migrant groups, such as refused asylum seekers, trafficked people and undocumented migrants, pregnant women and children are identified as being more susceptible to ill health and mortality than other vulnerable groups, as well as their UK-born counterparts.<sup>4</sup> Furthermore, migrant women are more likely to face additional stressors, such as undocumented status, destitution, separation from families, threat of police involvement and homelessness. Many have also experienced other abuses, including trafficking for sex work or labour, violence,

or female genital mutilation (FGM). They can also be unaware of their rights to access healthcare, have been turned away, or are afraid of being charged.<sup>2</sup> All of these factors may further exacerbate the comparatively poor maternal health outcomes observed in migrant mothers within the UK.<sup>(5),(6)</sup>

Barriers to healthcare for pregnant women can have significant implications on both maternal and child health. Bollini et al<sup>7</sup> showed that pregnant migrant women in developed countries experienced worse pregnancy outcomes than their peers, with a 45% higher risk of low birth weight, 24% increased risk of pre-term delivery, and 50% increased risk of perinatal mortality. There was also evidence that the risks were significantly reduced for countries with strong integration policies. Pregnancy can be a prime time for intervention with midwives highlighting complex needs which if identified can be addressed to improve the health of women and their families.<sup>8</sup>

These barriers can result in not only poorer outcomes for mothers and babies, but can also have wider reaching implications through a failure to manage communicable diseases. Difficulties accessing antenatal care can result in missed opportunities for detection and unnecessary transmission of such diseases, then in the postnatal period, such barriers can result in reduced uptake of immunisations. Maternity services in the UK include a policy to screen all mothers for diseases that can be vertically transmitted and for whom transmission is preventable. The incidence of blood-borne infections, such as HIV and Hepatitis B, are higher in those who have lived in countries with increased prevalence of such diseases.<sup>9</sup> Therefore, antenatal screening provides a key opportunity for intervention, potentially reducing risk of transmission to the newborn, which can lead to a significant reduction in morbidity and mortality, as well as diagnosing the mother and reducing the risk to future pregnancies and partners.<sup>10</sup>

Current NICE guidelines<sup>1</sup> recommend that antenatal care booking, interview and blood screening should take place for women by 10 weeks gestation with no antenatal appointments missed. The minimum level of care recommended to achieve the national goals is booking by within the first 12 weeks of pregnancy and three or less missed appointments. In practice, there is a shortfall between the recommended guidelines and what is actually happening. The MBRACE-UK Saving Lives, Improving Mother's Care enquiry<sup>11</sup> into maternal deaths and morbidity, found that while there was a decrease in the overall numbers of maternal deaths (11/10000 in 2006-2008 to 10/100000 2010-2012), access to antenatal care remained an issue amongst the women who died. It found that maternal deaths were higher in older women, those living in the most deprived areas, and among some ethnic minority groups. This is reflected in a death rate in white UK-born women of 9 per 100,000 between 2009-2012, which increased to 26.9 among African

women and 20.5 among Indian women. The report found that, of those women who died, more than two thirds did not receive the nationally recommended level of antenatal care, while a quarter did not receive even the minimum level of antenatal care.

Under the current charging regulations in the UK, pregnant women who do not have access to free NHS secondary care, have to pay for antenatal services. In an article for the Guardian<sup>12</sup> Professor of Complex Obstetrics at Kings College London, Susan Bewley, said that a policy of charging migrants for antenatal care was putting women in danger and that failure to access early antenatal care could result in poor outcomes for both mother and baby. The same article reported women turning up in labour with severe complications, which could have been prevented with proper access to ante/perinatal care.

In 2013, the Doctors of the World London Clinic saw 97 pregnant women in their mixed general clinic. Of these, 65% had not accessed any antenatal care and would be accessing care late, according to UK guidelines. This is reflected across the whole Médecins du Monde network, which runs 25 projects in eight European countries. Data collected on 285 pregnant women seen found 65.9% had no access to antenatal care before coming to one of the health centres, and 42.8% accessed care late.<sup>2</sup> Both of these factors are correlated with increased risks and poor maternal outcomes. On first medical consultation, the doctors decided that over 70% of these cases required that the individual receive urgent or semi-urgent care. Thus, clinics across Europe have found two-thirds of their pregnant service users to be at risk

Further barriers in accessing primary care have been observed in the DOTW London Clinic, with multiple cases of women being refused access to primary care because they were not able to provide various forms of documentation, despite not being required by the NHS to provide such documents. Moreover, one in five patients seen at the DOTW clinic feared being arrested if they tried to see a doctor - the disastrous consequences of which have been highlighted in the media.<sup>(13)</sup>

In addition to the current charging regulations causing fear and creating barriers to healthcare access, future changes in the entitlement policy are likely to further deter women from obtaining the maternity care they need and accessing services for their children.

This research aims to build on the existing studies that reflect the challenges facing migrant women trying to access antenatal care and their views and experiences of ante-, peri- and postnatal care in the United Kingdom.

## Study Design

This longitudinal follow-up study looked at all pregnant women presenting to Doctors of the World drop-in clinic, between January 2013 and June 2014. Baseline data on each participant was extracted from the Doctors of the World database, then participants were contacted by phone, using a three-way interpreter call if appropriate. A proforma questionnaire (see appendix 1) was used to ascertain their antenatal and immediate postnatal experiences. This document focused on access to antenatal care, barriers to accessing care and experiences during their pregnancy, labour and the immediate postnatal period.

## Objectives

This study sets out to contribute to the evidence-base on the experiences of pregnant migrant women accessing ante/peri and postnatal care in the UK. The objectives of this study are:

- To explore the views and experiences of pregnant migrant women receiving ante/peri and postnatal care in the UK.
- To establish access to antenatal care for pregnant migrant women attending the Doctors of the World Drop-in clinic.
- To identify barriers and deterrents to accessing ante/peri and postnatal care for pregnant migrant women in the UK.

## **The following research questions were formed to try and meet the objectives stated:**

- How do pregnant migrant women accessing the Doctors of the World's London drop-in clinic view and experience antenatal care in the UK?
- What are the barriers to accessing ante/peri and postnatal care for these pregnant migrant women?

## **Inclusion/Exclusion Criteria**

This study attempted to contact all pregnant women who attended the clinic between January 2013 and June 2014. The questionnaire was completed for women who had taken their pregnancy to full term. Excluded women were those who were still pregnant, terminated their pregnancy, or who miscarried.

## Analysis

Data was obtained from the patients DOTW record and from a follow-up telephone questionnaire. This data was descriptive in nature, and was collected and analysed using Google Sheets, Google Forms, MS Excel and STATA. Free responses, were documented by the interviewer in

the study pro forma. This qualitative data was extracted and analysed separately using a thematic approach. For these participants quotes were analysed and concepts, themes and possible interrelations or divergences between these themes were then derived. An exploratory mixed-method approach was used to synthesise the findings, and to produce recommendations.

## Results

85 pregnant women presented to the Doctors of the World drop-in clinic during this period. 35 of these were successfully followed up, giving an overall response rate of 41%. 44 women were unreachable, 5 women were still pregnant at the end of the data collection period and 1 woman did not wish to participate in the study.

### Demographics

All participants were born outside the UK and had been in the UK on average 4.6 years prior to delivery.

#### **What was their immigration status on attending the clinic?**

18 (53%) described themselves as undocumented migrants. Four (11.76%) were refugees, four (11.76%) were asylum seekers and one (2.9%) was a refused asylum seeker. One had a residence application in place at the time of delivery and another did not want to disclose her immigration status. Five (14.7%) had a current visa.

### Access to Primary Care

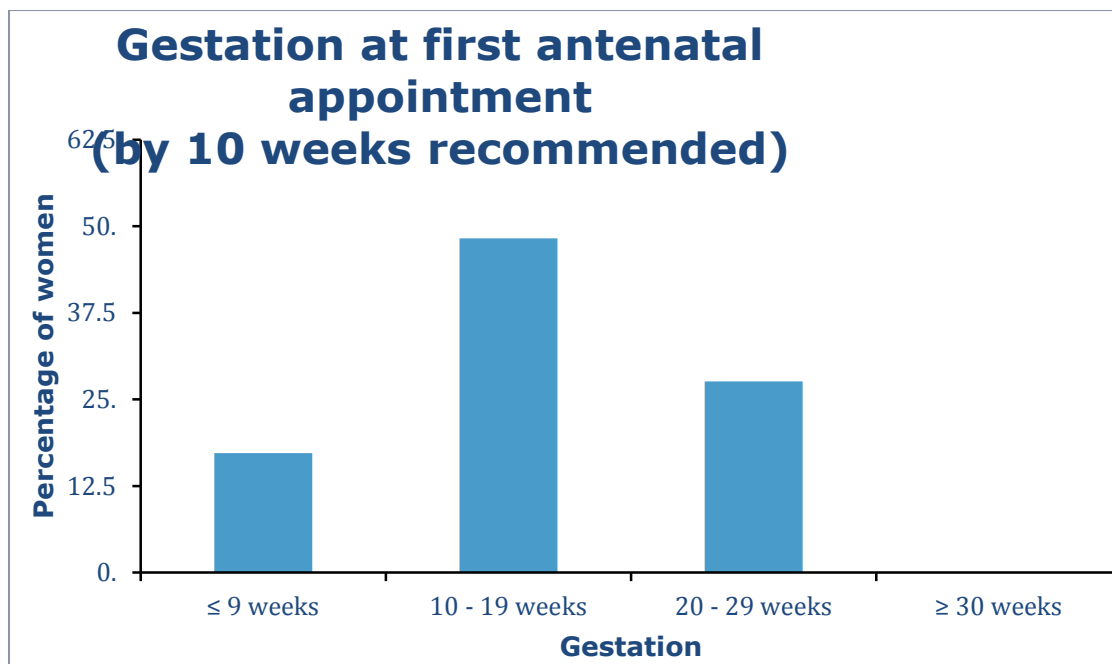
Only one woman was registered with a GP when she attended the clinic, and this was a temporary registration. 37.14% (13) of the participants had previously tried to register with a GP, but had been unable to do so.

### Antenatal Care

#### **How many weeks gestation at first antenatal appointment?**

Of the 29 women that could recall this information, only 5 (17%) women had their first antenatal appointment by the recommended 10 weeks' gestation. 11/29 (38%) had their first antenatal appointment in the first 12 weeks of pregnancy and 10 (34%) did not have their booking appointment until 20 weeks gestation or later.

*Fig 1. Gestation at first antenatal appointment*



**Number of antenatal appointments attended?**

Only 50% (17/34) of women had had 5 or more antenatal appointments prior to delivery, therefore 50% had less than the minimum level of antenatal care (3 or fewer antenatal appointments missed).

**If they did not attend all those offered why?**

Only 18/35 (51.43%) managed to attend all of the antenatal appointments they were offered. For those that were unable to attend and were able to say why (15), commonly cited reasons for non-attendance included fear of cost, unaware of time/date of appointment or having to move after booking.



## The Perinatal Period

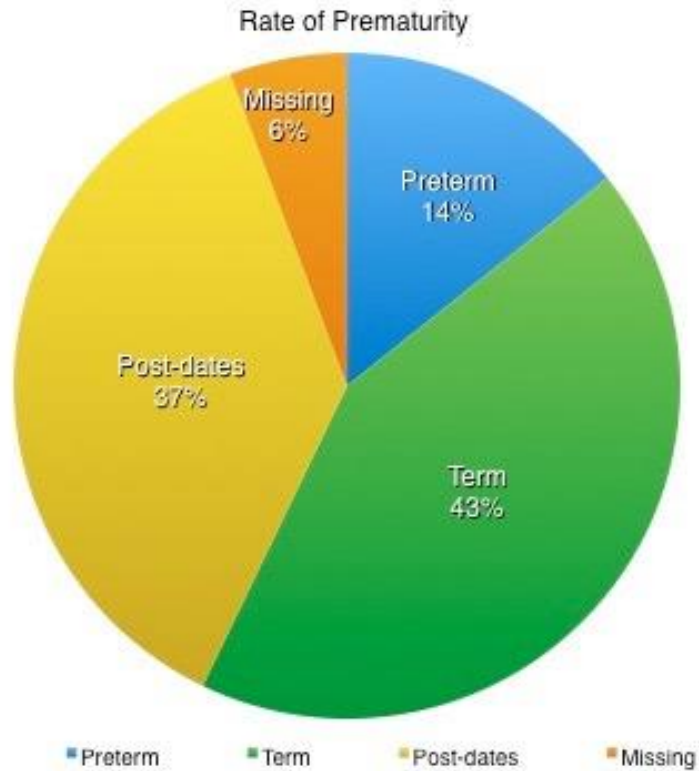
All the women that were asked had their baby in the hospital (n=35). Although the majority of deliveries were normal vaginal deliveries (58.82%), 29.41% of women had emergency caesarean sections (n=10).

*Table 1. Type of Delivery*

Type of Delivery	Frequency	Percentage
Elective (planned) Caesarean Section	1	2.9
Emergency Caesarean Section	10	29.4
Instrumental Delivery	2	5.9
Normal Vaginal Delivery	20	58.8

Forty-three per cent of women had their babies at terms 37% of deliveries were post-dates, and 14% were pre-term.

*Fig. 2. Proportion of mother who gave birth to their babies prematurely*



2 of the 35 patients contacted (5.5%) had lost their babies in the early neonatal period.

### Postnatal Care

24/35 (68.57%) of the women reported that they had to stay in hospital for longer than they expected. This involved a subsequent inpatient stay ranging from 2 - 11 days, with many (28.57%) staying for 3 days longer than expected. A range of reasons was given for this, and often participants only referred to an issue with the baby. In several cases, the mother made reference to the baby needing antibiotics, and in others it was due to maternal high blood pressure, post-caesarean section recovery and blood loss.

### Have you been billed?

Of the 35 women asked, 10 (28.57%) had been billed for their maternity care. 9 women reported being charged amounts ranging from £1,500 - £6,000.

## Service User Experiences

### PATIENT STORY:

*Patient X presented to the clinic at 23 weeks gestation. She had become temporally registered with her GP and was referred to her local hospital for antenatal care but was too scared to go as she was worried about being found by the UKBA (Home Office). She was referred to A&E by the DOTW clinician who assessed her due to concerns about her health. She was admitted to a nearby hospital and then discharged after a few days but sadly went into premature labour and lost her baby girl in the early neonatal period. She received a bill for £2,620*

The overall experience was positive for those who were not billed.

*"We have had a great experience - the nurses and doctors and midwife have been very, very helpful"*

However, some found that their GP was a barrier, and would check the baby, but would not attend to the mother's health.

Those that were billed tended to have a different experience:

*"...whole experience with NHS very very poor, puts mothers under pressure if you cannot afford charges. Really need to support these women. Now every single penny I get I have to pay back. Puts me in financial difficulty. When I got the hospital bill because I couldn't pay in one go I have to pay an extra £300. It seems unfair that the NHS will fund implants but not support pregnant women."*

Two of the 35 women contacted had lost their babies, and their experiences were universally poor. One mother reported having no antenatal appointments and gave birth prematurely at 28 weeks. Her preterm baby died from an overwhelming infection, and she felt this was the result of negligence.

*"Horrible - no one is helping, or has followed up."*

This lady was billed £2,620 after losing her baby.

Another lady who had three antenatal appointments also reported a negative experience:

*"Experience at hospital has been bad. Went to hospital at 40 weeks pregnancy. Was feeling weak and tired - said doctors made her feel bad. She ended up losing the baby at 42 weeks, and she felt very unsupported at the hospital."*

This lady was billed £1,500 after losing her baby.

The variety in experiences appeared to be hospital dependent; with patients reporting that moving to another area, and therefore booking at a different hospital, could result in a very different experience. Parents reported being:

*“Scared to have baby at hospital with having to pay before baby was born.”*

Some mothers who were billed found that this was the main problem and not the care per se.

*“Everything was fine in pregnancy. She felt that care was adequate - her main problem is the bill. She is having to pay £300 every month and it is really difficult to do this and look after a new baby.”*

## Conclusion

DOTW London clinic has a unique group of service users who have previously been too afraid or denied access to healthcare in the UK. Following up the pregnant service users provides some insight into the health outcomes for this vulnerable group and their unborn children, as well as their experiences of accessing maternity care in the UK.

The first shocking statistic from this cohort is that the majority of women did not have access to a GP, although this is a biased sample as help with GP registration is commonly the reason women attend the DOTW clinic. However, this does mean that as well as not being able to access timely medical advice and referral to maternity services, they are unlikely to have had screening such as cervical smears and blood-borne virus testing.

Regarding antenatal care, this study found that women were accessing antenatal care late with only 11/29 (38%) having their first antenatal appointment in the first 12 weeks of pregnancy and 34% having it later than 20 weeks gestation. This is much lower than 2012-2013 England wide statistics which found that 72.3% of pregnant women had their first antenatal appointment within the first 12 weeks of pregnancy.<sup>14</sup> Women also tended to have fewer antenatal appointments with 50% having 5 or less appointments. There were also issues with access to antenatal appointments offered, the commonest mentioned reasons for non-attendance, including fear of cost and communication difficulties, findings which are consistent with Phillimore et al<sup>15</sup> 2010 survey of migrant mothers in the West Midlands. This study is too small to show a link between these participants' antenatal care and their outcomes. However, the national perinatal mortality rate (stillbirths and early neonatal deaths) for 2012 was 7.0 deaths per 1,000 total births and we have a cohort of 35 in which two mothers lost their babies in the perinatal period.<sup>16</sup>

Charging in all these contexts seems counterintuitive, this is a setting in which families are living below the poverty line and barriers to accessing maternity care are likely to have real human costs as well as financial costs to the NHS due to the knock on effects of reduced preventative measures and opportunities for early interventions in complications. Aside from that there is evidence of a system in which a woman who experienced the death of her child could be sent a bill for her treatment.

There is also evidence that although maternity care is classed as '*immediately necessary treatment*' and cannot be refused on any grounds, the subsequent charges, which vary according to each NHS Trust, frighten many women into not attending.

This study is limited by its size and the fact that only 41% of patients who attended the clinic could be reached, but it is possible that those who were not able to be contacted are an even more vulnerable population e.g. phones lost, stolen, confiscated. The clinic aims to facilitate access to healthcare, therefore by definition those that attend represent women who have had difficulty accessing healthcare, so are not generalisable to the population as a whole. However, for a population that does not have a voice and on which there is often very little data, especially in the case of undocumented migrants, any insight gleaned is incredibly valuable.

This study indicates a need for a larger more in-depth study of the needs of this vulnerable and complex population and the barriers that they face accessing healthcare. This could be done via in-depth interviews with patients with a subsequent thematic analysis enabling a more in-depth exploration of the issues.

According to the latest Confidential Enquiry into Maternal Deaths and Morbidity,<sup>11</sup> poor access to antenatal care is a major issue amongst women who died and in the 2011 Saving Mothers' Lives report, black african women had a mortality rate four times that of white women in the UK.<sup>17</sup> This study finds evidence of the deterrent effect of entitlement checks and charging in a population with little access to primary care. Antenatal care is frequently received late and is often lower than the minimum standards for antenatal care and subsequently they and their unborn child are at increased risk of pregnancy-associated complications.

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