



Experiences of Pregnant Migrant Women receiving Ante/Peri and Postnatal Care in the UK: *A Doctors of the World Report on the Experiences of attendees at their London Drop-In Clinic*

Authors

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Abstract

Background

Access to adequate maternity care safeguards a pregnancy, facilitates good maternal health outcomes and is essential for communicable disease control. The National Institute of Health and Care Excellence's (NICE) guidelines for Antenatal Care¹ 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 Monde² 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 the 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.¹ This report focuses on the healthcare experience of vulnerable pregnant migrant women as seen in a London drop-in clinic.

Methods

This report looks at pregnant women who presented to Doctors of the World's (DOTW) drop-in clinic between January 2013 and June 2014. Participants were contacted by phone, using a three-way interpreter call if appropriate. Participants' 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. Further baseline data was then extracted from their DOTW record to ascertain their situation on accessing the clinic. 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 were approached after attending DOTW's London drop-in clinic (response rate 41%). All but one did not have access to a General Practitioner (GP) despite the average length of time in the UK prior to delivery being 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 five or fewer antenatal appointments (less than the minimum level of antenatal care). Fear of costs and communication problems were cited as barriers. In this cohort two women lost their babies, one at 42 weeks and the other in the early neonatal period. Both of these mothers received a bill for their hospital care.

Conclusion

This report 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 often does not meet the minimum standards for care and subsequently puts women and their unborn children 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. 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 the 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. Two of the 35 women we were able to follow-up lost their babies 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 service users 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 information 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*"³ 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 Europe² 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.⁴ 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.² All of these factors may further exacerbate the comparatively poor maternal health outcomes observed in migrant mothers within the UK.^{5,6}

Barriers to healthcare for pregnant women can have significant implications on both maternal and child health. Bollini et al⁷ showed that pregnant migrant women in Europe 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 that, if identified, can be addressed to improve the health of women and their families.⁸

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. Later in the postnatal period, such barriers can result in reduced uptake of immunisations.² 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.⁹ 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.¹⁰

Current NICE guidelines¹ 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 enquiry¹¹ 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 Guardian¹² 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.

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.² 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 service users 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.¹³

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.

Methods

This report looked at migrant women who presented pregnant to DOTW 's drop-in clinic, between January 2013 and June 2014. A total of 85 women were approached for inclusion in this report. Each was contacted by phone, using a three-way interpreter call if appropriate and interviewed to ascertain their antenatal and immediate postnatal experiences. The pro forma for this interview focused on access to antenatal care, barriers to accessing care and experiences during their pregnancy, labour and the immediate postnatal period. Data was then extracted from their DOTW records to ascertain their situation on accessing the clinic. All data was anonymised and any information that was felt to potentially identify a participant was removed.

Objectives

This report looks at:

- Access to antenatal care for pregnant migrant women attending the Doctors of the World Drop-in clinic.
- How pregnant migrant women accessing the Doctors of the World's London drop-in clinic view and experience antenatal care in the UK.
- The barriers and deterrents to accessing ante/peri and postnatal care for pregnant migrant women in the UK.

Analysis

Data was obtained from the service user's 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 a specially designed 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.

Results

Eighty-five women who presented pregnant to DOTW's drop-in clinic between January 2013 and June 2014 were approached. Thirty-five of these were successfully followed up, giving an overall response rate of 41%. Forty-four women were unreachable, five women were still pregnant at the end of the data collection period and one woman did not wish to participate.

Demographics

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

Immigration status

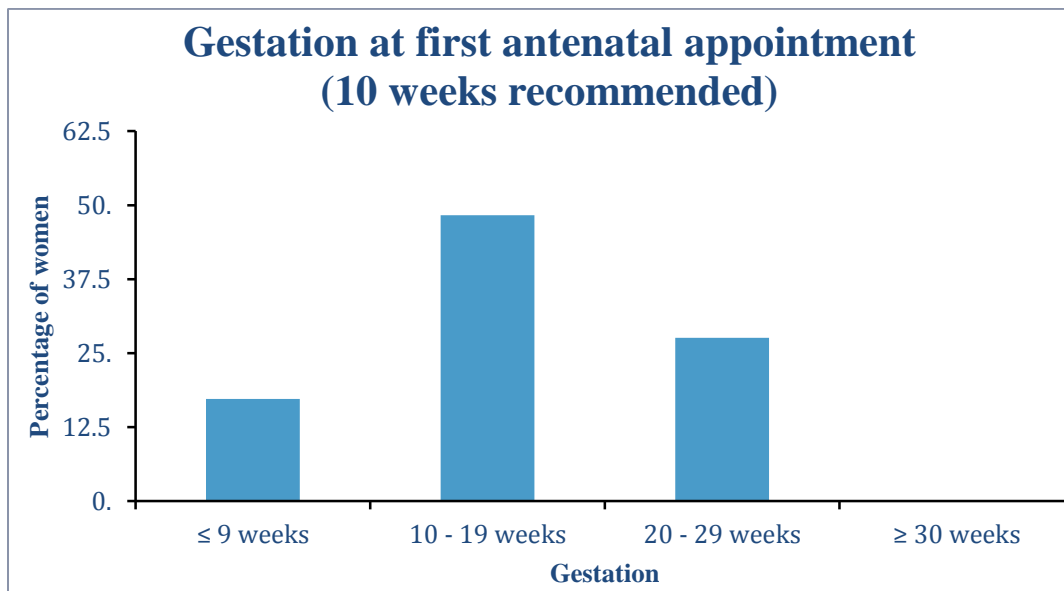
18 (53%) described themselves as undocumented migrants. Four (11.76%) were refugees, four (11.76%) were asylum seekers and one (2.9%) was a refused asylum seeker. One had a residence application in place at the time of delivery and another did not want to disclose her immigration status. Five (14.7%)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

Of the 29 women that could recall, only five (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.



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

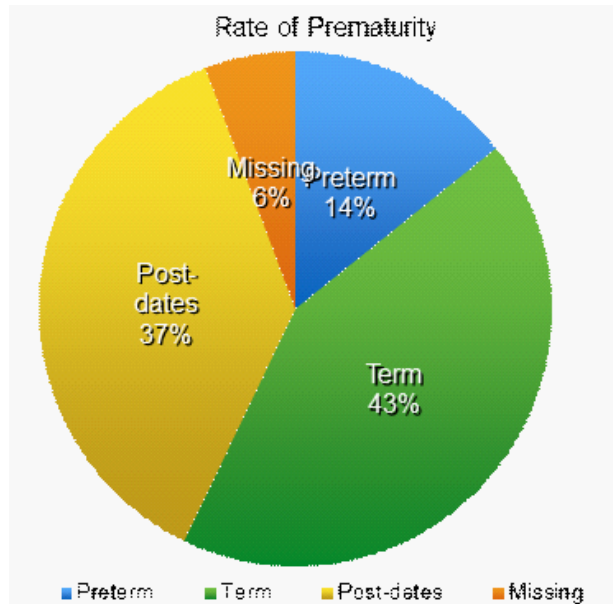
Only 18/35 (51.43%) managed to attend all of the antenatal appointments they were offered. For those that were unable to attend and were able to say why (15), commonly cited reasons for non-attendance included fear of cost, unaware of time/date of appointment or having to move after booking.

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).

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

43% of women had their babies at term, 37% of deliveries were post-dates, and 14% were pre-term.



2/35 service users contacted (5.5%) had lost their babies, one at 42 weeks and the other 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 28.57% staying for three 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.

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

Service User Experiences

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 prior to giving birth to her premature baby who died in the early neonatal period. This lady was billed £1,500 after losing her baby:

“Horrible - no one is helping, or has followed up.”

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 £2,620 after losing her baby.

One service user presented to the clinic after 20 weeks gestation. She had become temporarily 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 Home Office. She was referred to A&E by the DOTW clinician due to concerns about her health. This lady subsequently went into premature labour and devastatingly lost her baby in the early neonatal period. She received a bill for £1,500.

The variety in experiences appeared to be hospital dependent; with service users 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 report found that women were accessing 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.¹⁴ Women in our sample also tended to have fewer antenatal appointments with 50% having 5 or less appointments. There were also issues related to accessing antenatal appointments offered. The commonest reasons reported for non-attendance included fear of cost and communication difficulties, findings which are consistent with Phillimore et al's¹⁵ 2010 survey of migrant mothers in the West Midlands. This report is not a substitute for a full research study as this is a small biased sample and there was no access to their NHS hospital records. This was compounded with issues around not being able to identify all pregnant women who accessed the service during the time period. Therefore these findings are not generalisable and no conclusions can be drawn about the relationship between these women's access to antenatal care and maternal health outcomes. However, the national perinatal mortality rate (stillbirths and early neonatal deaths) for 2012 was 7 deaths per 1,000 total births¹⁷ and we have a cohort of 35 in which two mothers lost their babies in the perinatal period, a finding that at least prompts the need for further investigation.

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 opportunities for preventative measures and early interventions in complications. Aside from that there is evidence of a system in which women who have experienced the death of a child can be sent a bill for the care.

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 report is limited by the number of people included and the fact that only 41% of service users 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 so by definition those that attend represent those that 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 report indicates a need for an 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 service users with a subsequent thematic analysis enabling further exploration of the issues.

According to the latest Confidential Enquiry into Maternal Deaths and Morbidity¹¹, 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.¹⁶ This report 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.

References

1. National Institute of Health and Care Excellence. *Antenatal care routine care for the healthy pregnant woman*. Clinical guideline, CG62. March 2008. Available at <http://www.nice.org.uk/cg62>. Accessed March 11, 2015.
2. Chauvin P, Simonnot N, Douay C, Vanbiervliet F. *Access To Healthcare for the Most Vulnerable in a Europe in Social Crisis 2014. Focus on women and children* London; 2014 p. 1–40. Available from: http://issuu.com/dotw/docs/mdm_2014_eu_report_access_to_care. Accessed March 11, 2015.
3. Marmot Review Team. Fair Society, Healthy Lives: strategic review of health inequalities in England post 2010. 2010. Available from: <http://www.instituteofhealthequity.org/projects/fair-society-healthy-lives-the-marmot-review>. Accessed March 11, 2015.
4. International Organisation of Migration. *Maternal and Child Healthcare for Immigrant Populations*. Brussels; 2009. Available from: [http://www.migrant-health-europe.org/files/FINAL_DRAFT_LISBON\(3\).pdf](http://www.migrant-health-europe.org/files/FINAL_DRAFT_LISBON(3).pdf). Accessed March 11, 2015.
5. Jayaweera H. *Health of Migrants in the UK : What Do We Know ?* Migration Observatory Briefing. University of Oxford, UK; 2014 p. 1–9. Available from: <http://www.migrationobservatory.ox.ac.uk/briefings/health-migrants-uk-what-do-we-know>. Accessed March 11, 2015.
6. Office for National Statistics. *Births in England and Wales by Parents' Country of Birth, 2013*. 2013 p. 1–10. Available from: <http://www.ons.gov.uk/ons/rel/vsob1/parents--country-of-birth--england-and-wales/2013/stb-births-by-cob-2013.html>. Accessed March 11, 2015.
7. Bollini P, Pampallona S, Wanner P, Kupelnick B. Pregnancy outcome of migrant women and integration policy: A systematic review of the international literature. *Soc Sci Med*; 2009;68(3):452–61. Available from: <http://www.sciencedirect.com/science/article/pii/S0277953608005406>. Accessed March 11, 2015.
8. Raisa M, Aquino J V, Mphil B, Edge D, Senior H, Smith DM. Pregnancy as an ideal time for intervention to address the complex needs of black and minority ethnic women : Views of British midwives. *Midwifery*; 2014;1–7. Available from: <http://www.sciencedirect.com/science/article/pii/S0266613814002617>. Accessed March 11, 2015.
9. Health Protection Agency. *Migrant Health: Infectious diseases in non - UK born populations in the United Kingdom. An update to the baseline report – 2011*. 2011. Available from: http://www.hpa.org.uk/webw/HPAweb&HPAwebStandard/HPAweb_C/1317131996733. Accessed March 11, 2015.

10. Department of Health. *Hepatitis B: Guidance, Data and Analysis*. Public Health England. 2014. Available from: <https://www.gov.uk/government/collections/hepatitis-b-guidance-data-and-analysis>. Accessed March 11, 2015.
11. Knight M, Kenyon S, Brocklehurst P, Neilson J, Shakespeare K KJ on behalf of M-U. *Saving Lives, Improving Mothers ' Care - Lessons learned to inform future maternity care the the UK and Ireland Confidential Enquiries into Maternal Deaths and Morbidity 2009-12*. Oxford Natl Perinat Epidemiol Unit, Univ Oxford 2014. Available from: <https://www.npeu.ox.ac.uk/downloads/files/mbrance-uk/reports/Saving%20Lives%20Improving%20Mothers%20Care%20report%202014%20Full.pdf>. Accessed March 11, 2015.
12. Diane Taylor. NHS charges putting pregnant migrant women in danger. *The Guardian*. 2013; Available from: <http://www.theguardian.com/society/2013/dec/27/nhs-charges-pregnant-migrant-women-danger>. Accessed March 11, 2015.
13. Aston J. Heavily pregnant immigrant carrying dead child wouldn't seek help as she was afraid she'd have to pay NHS under "health tourism" rules. *The Independent*. 2014; Available from: <http://www.independent.co.uk/news/uk/home-news/heavily-pregnant-immigrant-carrying-dead-child-wouldnt-see-help-as-she-was-afraid-shed-have-to-pay-nhs-under-health-tourism-rules-9205591.html>. Accessed March 11, 2015.
14. Health and Social Care Information Centre. NHS Maternity Statistics - England, 2012-2013 [Internet]. 2013. Available from: <http://www.hscic.gov.uk/catalogue/PUB12744>. Accessed March 11, 2015.
15. Phillimore J. *Delivering in an Age of Super-Diversity: West Midlands Review of Maternity Services for Migrant Women*. 2010. Available from: <http://www.wmemployers.org.uk/media/upload/Library/Migration%20Documents/Publications/Delivering%20in%20an%20Age%20of%20Super-diversity%20v5.pdf>. Accessed March 11, 2015.
16. Cantwell R, Clutton-Brock T, Cooper G, Dawson A, Drife J, Garrod D, et al. *Saving Mothers' Lives: Reviewing maternal deaths to make motherhood safer: 2006-2008. The Eighth Report of the Confidential Enquiries into Maternal Deaths in the United Kingdom. BJOG*. 2011;118 Suppl 1(March):1-203. Available from: <http://onlinelibrary.wiley.com/doi/10.1111/j.1471-0528.2010.02847.x/epdf>. Accessed March 11, 2015.
17. Office for National Statistics. Child mortality statistics: Childhood, infant and perinatal, 2012. Available from: <http://www.ons.gov.uk/ons/rel/vsob1/child-mortality-statistics--childhood--infant-and-perinatal/index.html>. Accessed March 11, 2015.