Title Perinatal mortality in Pakistani, Bangladeshi and White British mothers, in Luton

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By

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Author's Declaration

"I, Rebecca Louise Garcia declare that this thesis and the work presented in it are my own and has been generated by me as the result of my own original research.

Perinatal mortality in Pakistani, Bangladeshi and White British mothers, in Luton.

I confirm that:

1. This work was done wholly or mainly while in candidature for a research degree at this University;
2. Where any part of this thesis has previously been submitted for a degree or any other qualification at this University or any other institution, this has been clearly stated;
3. Where I have cited the published work of others, this is always clearly attributed;
4. Where I have quoted from the work of others, the source is always given. With the exception of such quotations, this thesis is entirely my own work;
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Abstract

Addressing modifiable factors in perinatal mortality is a key priority for commissioners and service providers, aiming to improve birth outcomes and reduce preventable deaths (Department of Health, 2016; National Maternity Review, 2016). Luton, a town with a pleural population, experiences higher rates of perinatal mortality than the national average (CDOP, 2015). Figures show an ethnic variation; Pakistani and Bangladeshi mothers experience higher rates of perinatal mortality in England compared with White British mothers, and the reasons for this are unclear. Much of the existing literature approaches the problem by examining individual risk factors quantitatively or exploring South Asian women's experiences qualitatively. There is little research considering how Pakistani, Bangladeshi and White British women's health beliefs impact on their health behaviour through the maternity care pathway, in Luton, and how this might contribute to perinatal mortality.

This study takes an intersectional approach, using a convergent mixed-methods research design, reviewing retrospective secondary data (2008-2013) from the Luton and Dunstable Hospital NHS Foundation Trust's Circona Maternity information System, to identify risk factors for perinatal mortality in Luton. Additionally, focus groups were conducted with lay women (aged over 16, living in LU1-LU4, who had experienced a live birth, at 37 weeks of gestation in the previous 6-24 months), and face-to-face interviews were held with bereaved mothers (aged over 16, who suffered an infant bereavement in the preceding 6-24 months, living in LU1-LU4). Health care professionals working on the maternity care pathway also took part in focus groups or interviews, providing their views on the service needs of Pakistani, Bangladeshi and White British women.

The results/findings showed that risk factors varied according to ethnicity. Pakistani mothers had a greatest number of risk factors i.e. birthweight, diabetes, gestational diabetes, BMI <18kg/m^2, parity two, three and four and later booking (>12 weeks). Deprivation featured in 81% of all deaths in 2014. The findings with the mothers revealed mostly similarities among women, regardless of their ethnicity; the majority of women wanted more pregnancy-related information, especially in respect of stillbirth and adverse outcomes. Similarly, bereaved mothers regardless of their ethnicity also reported mostly similarities, which included experiencing intuition when things were not right with the pregnancy. A few differences according to ethnicity were also identified, which focused on cultural or religious needs, such as cultural therapies (mostly dietary restrictions) undertaken by Pakistani and Bangladeshi women.

The intersectional approach allowed simultaneous and aggregated factors (i.e. heritable, socio-economic status, structural factors and health beliefs and health behaviours) to be exposed; staff believed Pakistani and Bangladeshi women were not proactive in seeking pregnancy-related information, relying on verbal information and staff assumed mothers were literate and understood health messages. The intersected findings also revealed that few women took folic acid preconception, and many women co-slept with their baby. This study contributes new knowledge to the understanding of how Pakistani, Bangladeshi and White British women's health beliefs influence their health behaviour, and contributes to perinatal mortality in Luton.

Acknowledgements

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Publications to Date

Garcia, R. L., Ali, N., Papadopoulos, C. and Randhawa, G. (2015) ‘Specific antenatal interventions for Black, Asian and Minority Ethnic (BAME) pregnant women at high risk of poor birth outcomes in the United Kingdom: A scoping review’, *BMC Pregnancy and Childbirth*. doi: 10.1186/s12884-015-0657-2.

Garcia, R., Ali, N., Guppy, A., Griffiths, M. and Randhawa, G. (2016) ‘A comparison of antenatal classifications of “overweight” and “obesity” prevalence between white British, Indian, Pakistani and Bangladeshi pregnant women in England. An analysis of retrospective data’, *BMC Public Health*. BMC Public Health, pp. 1–7. doi: 10.1186/s12889-017-4211-1.

Garcia, R., Ali, N., Guppy, A., Griffiths, M. and Randhawa, G. (2017) ‘Differences in the pregnancy gestation period and mean birth weights in infants born to Indian, Pakistani, Bangladeshi and white British mothers in Luton, UK: a retrospective analysis of routinely collected data’, *BMJ Open*, 7(8), p. e017139. doi: 10.1136/bmjopen-2017-017139.

Garcia, R., Ali, N., Guppy, A., Griffiths, M. and Randhawa, G. (in review) ‘Prevalence of gestational diabetes in Pakistani, Indian, Bangladeshi and white British pregnant women in Luton, England: Analysis of routinely collected data’, *Maternal and Child Health Journal*.

Garcia, R. L., Ali, N., Griffiths, M. and Randhawa, G. (in review) ‘Understanding the consumption of folic acid during preconception, among Pakistani, Bangladeshi and White British mothers in Luton, UK: A qualitative study.’, *BMC Pregnancy and Childbirth*.

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List of abbreviations

ASR	Adjusted Standard Residuals
ANCOVA	Analysis of Covariance
BAME	Black Asian Minority Ethnic
BMI	Body Mass Index
BiB	Born in Bradford
CMACE	Centre for Maternal and Child Enquiries
CDOP	Child Death Overview Panels
CMiS	Circonia Maternity information System
DOH	Determinants of Health
DM	Diabetes Mellitus
EDD	Expected date of delivery
FG	Focus groups
FASD	Foetal alcohol spectrum disorder
FM	Foetal movements
GDM	Gestational Diabetes Mellitus
GTT	Glucose Tolerance Testing
GAP	Growth Assessment Protocol
HBM	Health Belief Model
HCP	Health Care Professional
HES	Hospital Episode data
HPA	Hypothalamic–Pituitary–Adrenal
IMD	Index of Multiple Deprivation
IMNST	Infant Mortality National Support Team
IMR	Infant Mortality Rate
IUGR	Intrauterine Growth Restriction
LMP	Last menstural period
LBW	Low birthweight
LSOA	Lower-layer super output areas
MLBU	Maternity led birthing unit
MCS	Millennium Cohort Study
MIS	minimum income standard
NHS	National Health Service
NICE	National Institute for Health and Care Excellence
NN4B	NHS Numbers 4 Babies
NS-SEC	National Statistics Socio-economic Classification
NICU	neonatal intensive care unit
NTD	Neural tube defects
ONS	Office for National Statistics
PMR	Perinatal Mortality Rate
PTB	Preterm birth
QOL	Quality of Life
SCT	Sickle Cell and Thalassemia
SGA	Small for Gestational Age
SPSS	Statistical Package for The Social Sciences
SSI	Semi structured interview
ST	Smokeless tobacco
SCM	Social cognition models
SES	Socio-economic status
SB	Stillbirth
TG	Topic guide
TPB	Theory of Planned Behaviour
UK	United Kingdom
WB	White British
WHO	World Health Organisation

Chapter 1: Introduction

1.1 Introduction

The United Kingdom (UK), continues to have one of the highest rates of stillbirth and neonatal mortality (hereafter referred to as 'perinatal mortality'[1]) in Europe (European Commission, 2016), despite England reporting a 20 percent decline over the last decade (HSCIC, 2016). In 2014 in England and Wales, 3,147 infants were delivered stillborn, and a further 1,376 infants died within the first 28 days after birth, resulting in approximately 12 families being affected with perinatal bereavement every day (Office for National Statistics, 2016a).

The existing evidence shows that there is an ethnic variation to perinatal mortality with statistics showing a disproportionately higher incidence of adverse birth outcomes[2] for Black Asian Minority Ethnic (BAME) groups[3]. In particular, Pakistani and Bangladeshi[4] families experience worse birth outcomes than White British (WB) infants (Gray, Hollowell, *et al.*, 2010; Raleigh, D. Hussey, *et al.*, 2010; Centre for Maternal and Child Enquiries, 2011b; Gardosi, *et al.*, 2013; National Child and Maternal Health Intelligence Network, 2014; Office for National Statistics, 2015b). On close inspection of the national statistics, there are patterns apparent in the adverse birth outcomes data[5], according to the mother's ethnic group.

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[1] Perinatal mortality is variously defined in the literature. For the purposes of this study it is defined as including stillborn infants delivered after 24 weeks of gestation and neonatal infant deaths up to seven days after birth. A fuller discussion of the terms and the decision how to use them is provided in Chapter Two, Section 2.

[2] The literature uses numerous terms to describe 'adverse birth outcomes'. These use different thresholds or umbrella terms. This study will use definitions consistent with the UK legal parameters and evidence base. This will be addressed in detail in Chapter Two, Section 2.

[3] Black African mothers suffer the worst birth outcomes in England, both in terms of maternal and infant health status.

[4] Indian mothers have been excluded from this study for the following reasons: figures show that Indian mothers have better birth outcomes than Pakistani and Bangladeshi women, in addition to a smaller number of Luton's residents being of Indian ethnicity.

[5] Data on stillbirth, neonatal mortality, infant mortality, low birthweight and preterm birth by maternal ethnicity.

Specifically, figures consistently show that Pakistani mothers have much higher rates of stillbirth than any other ethnic group while Bangladeshi mothers have higher rates of neonatal mortality and deliver infants that are considered small for gestational age (SGA) (Office for National Statistics, 2013b, 2013c, 2015d). These babies might also be categorised as low birthweight (LBW) which then carries a significant burden of mortality and lifelong morbidity (Cianfarani, Germani and Branca, 1999; Leon and Moser, 2012; de Wilde, van Buuren and Middelkoop, 2013; Wells *et al.*, 2013). Consequently, addressing inequalities in perinatal mortality continues to be a Government priority (Department of Health, 2014). The legal accountability to address perinatal mortality[6] has been passed from the Secretary of State to National Health Service (NHS) England and devolved to local commisioners and NHS providers (Department of Health, 2016; National Maternity Review, 2016). Thus making it a priority, particularly in geographic areas where figures show higher than national average perinatal and infant mortality rates.

Luton, where this study has taken place, has a high Black Asian and Minority Ethnic (BAME) population[7]; Pakistanis make up the largest proportion (14.4 percent) and when combined with Bangladeshis (6.7 percent), account for over one-fifth of Luton's population (Mayhew and Waples, 2011; Office for National Statistics, 2011c). Unsurprisingly then, Luton reports the highest perinatal mortality rate in the East of England (Office for National Statistics, 2014d; Child Death Overview Panel, 2015). The Pakistani and Bangladeshi ethnic groups contribute to over 50 percent of perinatal mortality experienced, compared with 26 percent in WB families (Child Death Overview Panel, 2013a, 2015). Perinatal mortality figures for Luton also show ethnic variance and area of residence/ward. Examination of data shows that the prevalence was focused predominantly in a few wards[8] within the town, which were also ranked as the most deprived (Research and Geospatial information, 2015). These wards include large numbers of Pakistani and Bangladeshi

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[6] Through the NHS Mandate; Objective 1 Through better commissioning, improve local and national health outcomes, particularly by addressing poor outcomes and inequalities.

[7] 55.4% of Luton's residents are BAME (Office for National Statistics, 2011c).

[8] Namely: Dallow, Biscot, Saints, which are also the top 10–20% most deprived areas, nationally (Research and Geospatial information, 2015).

families (Luton Borough Council, 2013; Luton Overview and Scrutiny Board, 2013; Public Health England, 2015a). Consequently, addressing inequalities in perinatal mortality is a priority in Luton, and a challenge for commissioners and maternity service providers to better respond to the needs of a diverse[9] community.

Clinical commissioners and service providers seek to deliver services that meet the needs of their communities, in line with government health and equalities legislation and priorities (*Health and Social Care Act*, 2012). Therefore, a sound understanding of the local population health needs is necessary to develop maternity services that meet government objectives and local requirements. Furthermore, there is a need to understand how individual health behaviours[10] also contribute to perinatal inequalities, before targeted interventions can be provided (Petherick *et al.*, 2016). However, understanding disparities in healthcare is protracted due to the complexity of combined mechanisms such as understanding the role of ethnicity absolute or relative poverty, social status and education attainment (Oliver and Nutbeam, 2003; Oliver and Mossialos, 2004; Marmot, 2010, 2013).

There is evidence showing the risk factors for perinatal mortality in the UK. The data has been retrieved from numerous sources including: National Statistics, hospital episode data (e.g. HES) linked with birth registration (e.g. NHS Numbers for Babies [NN4B]), Millennium Cohort Study (MCS), and Confidential Enquiries (Draper, Kurinczuk and Kenyor, 2015). The main focus of many epidemiological studies has been to understand how risk factors contribute to poor birth outcomes. Typically, scholars attend to one specific risk factor (e.g. maternal age or smoking status) however this approach obscures mechanisms that may be clustered (Spelman, 1990; Flay and Petraitis, 1994; Flay, Synder and Petraitis, 2009). Some of these studies do report ethnic differences,

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[9] Diverse community is defined as ‘difference’, but within the broader spheres of ethnicity, gender, marriage, religion, sexuality, geography, age, educational ability and income (Ingram, 2008).

[10] Health behaviours are discussed in Chapter Two, Sections 2.5.3 and 2.6.1.

(Margetts *et al.*, 2002; Balchin *et al.*, 2007; Moser, Stanfield and Leon, 2008a; Heslehurst *et al.*, 2010; Hossain *et al.*, 2011; Datta-Nemdharry, Dattani and Macfarlane, 2012; Leon and Moser, 2012; Bansal *et al.*, 2014); however, figures for Indian, Pakistani and Bangladeshi women are typically aggregated as 'South Asian' which obscures similarities and differences between them (Salway, *et al.,* 2009).

While a significant amount of evidence on risk factors for perinatal mortality is already available, this information is not specific to the Luton context. Demographic and socio-economic profiles, proximity and access to services in addition to service structure means that risk factors in one context may not be relevant in another (Kim and Saada, 2013). Therefore undertaking a detailed analysis of maternal factors specific to Luton is necessary to understand the salient risk factors associated with perinatal mortality (Boerleider *et al.*, 2013; UCL Institute of Health Equity, 2013; Garcia *et al.*, 2015).

The evidence base on the risk factors for perinatal mortality provides descriptive evidence on the factors contributing to poor birth outcomes. However, it fails to capture the influence of the mother's health beliefs, i.e. their knowledge, attitudes and perceptions[11], and subsequent health behaviour on the pregnancy and childbirth experience, which mediates perinatal mortality. In recent years there has been an increasing interest in the understanding of inequalities in health from a Determinants of Health (DOH) approach which presents important social categories to help describe inequalities in health, e.g. policy, social factors, health services, individual factors and genetic/heritable factors (Marmot, 2008; Marmot *et al.*, 2012). However, Salway and colleagues (2010) argue that social inequality is multifactorial, the intersection between these social categories is obscured, consequently the contribution health behaviour makes to the experience of perinatal

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[11] For this study, the term 'health beliefs' includes 'knowledge, attitude and perceptions' in respect of health-related issues (Ogden, 2012). Hereafter 'Knowledge, attitude and perceptions' is termed 'health beliefs'.

mortality and the explanations of ethnic differences in birth outcomes in maternity care is poorly understood (Szczepura, 2005, Salway, *et al.*, 2010).

Evidence suggests that health beliefs influence health behaviours (Conner and Norman, 1999, 2005); however, there is a paucity of evidence exploring how ethnicity influences health beliefs and health behaviours in pregnancy, which may affect birth outcomes (Lucas, Murray and Kinra, 2013). For example, identifying the health beliefs and health behaviour that contribute to delays in help-seeking (Lawn *et al.*, 2009). This may be a consequence of Pakistani and Bangladeshi mothers being perceived to be a 'hard to reach group'[12], therefore it is essential to ensure that Pakistani and Bangladeshi women's narratives related to perinatal mortality are heard (Spelman, 1990; Bowes and Domokos, 1996). Identifying modifiable factors are of particular interest to Public Health Luton and therefore a detailed exploration of health behaviour affecting perinatal outcomes will be undertaken as part of this study (Krieger, 1994; Nazroo, 2003; Conner and Norman, 2005).

The majority of previous research exploring Pakistani and Bangladeshi women's experiences has excluded WB women's views (or vice versa). Therefore, including WB women in the current study will facilitate an in-depth analysis of similarities and differences in health beliefs and health behaviours during pregnancy and childbirth between Pakistani, Bangladeshi and WB mothers (Almeida *et al.*, 2013; Wright *et al.*, 2013; Psarros, 2014). Also including WB mothers will help highlight discrepancies, further to gaining an understanding of how health beliefs and behaviours may contribute to birth outcomes, which together will contribute to the development of culturally competent services in Luton.

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[12] A great deal of empirical research refers to Pakistani and Bangladeshi women as 'hard to reach' (Flanagan and Hancock, 2010). This is a contested term that further promotes stigmatisation and wrongly assumes homogeneity in the 'hard to reach' group (Cook, 2002).

The need to deliver culturally competent services is now acknowledged in government policy and has been one of the responses in meeting the health needs of increasingly diverse populations (Nazroo, 2003; Owens and Randhawa, 2004; Mcfadden, Renfrew and Atkin, 2013; Horvat *et al.*, 2014). There is extensive evidence showing that culturally competent services lead to increased satisfaction and engagement with services, resulting in better health outcomes (Betancourt *et al.*, 2003, 2005; Mir, 2008; Paez *et al.*, 2009; World Health Organisation, 2013). The challenge for maternity services is to how best to deal with increasing diversity and reduce inequalities in perinatal mortality (Phillimore, 2014). Service providers are therefore central in transforming BAME women's experiences.

There is an extensive knowledge base on barriers and enablers to BAME groups accessing and utilising health services, but there is much less information on how health beliefs influence health behaviour which then, influences access and utilisation of services. This research seeks to address this gap by using an intersectional approach to examine the complex relationship of how health beliefs influence health behaviour and contribute to perinatal mortality in babies born to Pakistani, Bangladeshi and WB women living in Luton.

1.2 Research question, aim and objectives

1.2.1 Research question

How do health beliefs influence health behaviour and contribute to perinatal mortality in babies born to Pakistani, Bangladeshi and WB women living in Luton?

1.2.2 Aim

To explore how health beliefs influence health behaviour and contribute to perinatal mortality in infants born to Pakistani, Bangladeshi and WB women living in Luton.

1.2.3 Objectives

- To identify the current evidence of risk factors contributing to perinatal mortality in Pakistani Bangladeshi and WB women in Luton.
- To explore the similarities and differences in maternal health beliefs that influence health behaviours in perinatal mortality in Pakistani, Bangladeshi and WB women, through the maternity care pathway[13].
- To ascertain maternity health professionals' views on the service needs of Pakistani, Bangladeshi and WB pregnant women.

1.2.4 Research outcomes

- Provide a profile of risks factors for perinatal mortality specific to Luton to support planning and development of local maternity services.
- Provide empirical evidence of the similarities and differences in maternal health beliefs and how they influence health behaviours about perinatal mortality in Pakistani, Bangladeshi and WB women to support planning and development of maternity interventions and services in Luton.
- Provide empirical evidence on service provider perspectives on maternity care needs of Pakistani, Bangladeshi and WB women, to help develop culturally competent maternity services in Luton.

1.3. Outline of the thesis

This thesis is presented in eleven chapters. Chapter One presented the background and context, aims and objectives for this study. Chapter Two presents perinatal mortality in the context of inequalities in Luton. It moves on to discuss contentions with the current definitions surrounding

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[13] The maternity care pathway refers to preconception, antenatal, intrapartum and postnatal care. This is discussed further in Chapter Two, Section 2.5.4.

perinatal mortality and presents the current explanations of perinatal mortality, using the DOH approach, in addition to explanations of health beliefs and health behaviours as risk factors for perinatal mortality. Government and local responses are then provided, followed by limitations in the current approach looking at risk factors and health beliefs and health behaviours. Chapter Three discusses the conceptual foundations for this work. It provides the epistemological foundation of pragmatism and examines the contribution that an intersectional approach provides in conceptualising perinatal mortality. Chapter Four provides the rationale for using the chosen methodology of convergent mixed-methods and states the methods used in each objective. Chapters Five to Eight comprise the results/findings from the quantitative secondary *Ciconia Maternity information system (*CMiS) data, the qualitative findings from the 'lay[14]' mothers' focus groups (FG), and the findings from the bereaved mother's semi-structured interviews (SSI). Chapter Eight provides the findings from the health care professionals' FGs or interviews, while Chapter Nine converges the results from Chapters Five to Eight. Chapter Ten discusses the results and Chapter Eleven presents the limitations and reflections of the study and makes recommendations for future research.

1.4. Chapter Summary

This chapter has presented the background and context to the study and outlined the important key contextual issues that contribute to perinatal mortality. It has set the scene for why the focus of enquiry is the Pakistani, Bangladeshi and WB community living in Luton. The findings from this research will provide a profile of risk factors, relevant to Pakistani, Bangladeshi and WB women in Luton. Additionally, this study will provide empirical evidence on the similarities and differences of health beliefs and how they contribute to health behaviours in perinatal mortality in Pakistani, Bangladeshi and WB women. Additionally, exploring the health care professionals' views on the service needs of Pakistani, Bangladeshi and WB women in Luton. Findings from this research will

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[14] 'Lay' mothers refers to mothers who have had a normal birth outcome.

contribute towards the planning and development of maternity services for Luton’s diverse population and help reduce the ethnic inequalities in perinatal mortality.

Chapter 2: Perinatal mortality in the Luton context

2.1 Introduction

Chapter One presented the background and context for this study and highlighted that there are clear ethnic inequalities in perinatal mortality in England and Luton and identified that reducing inequalities in perinatal mortality for its diverse populations is of particular concern to national and local maternity services. Section 2.2 below begins with presenting the key definitions used in this study and highlights some methodological issues around the terminology and parameters which are applied in the maternity literature. Section 2.3 considers the causes of infant death; Section 2.4 presents a detailed account of ethnic inequalities in perinatal mortality in England and Luton using the DOH approach as a framework for understanding the risk factors for perinatal mortality. Section 2.5 presents the evidence of the current explanations of the determinants of perinatal mortality and Section 2.6 argues that while there is a wealth of understanding of the risk factors associated with perinatal mortality, there is limited information on understanding how health beliefs contribute to health behaviour and how these may be influencing the experience of perinatal mortality for Pakistani, Bangladeshi and WB women in Luton.

2.2 Key definitions in perinatal mortality

It is evident from the wider body of the global literature on perinatal mortality that there are several inconsistencies in the definitions and parameters applied. Given the complex and convergent terms, this section seeks to disambiguate the definitions and state the terms applied in this study. It commences with defining the ‘normal’ pregnancy to contextualise deviance from this norm, as seen in perinatal mortality (i.e. stillbirth and neonatal mortality). Additionally, it discusses the contribution of adverse birth outcomes that may result in perinatal mortality, demonstrating the complexity and interrelated nature of the problem.

2.2.1. The 'normal' pregnancy

Delivering a live infant weighing over 2500 g[15] between 37 and 42 weeks of completed gestation[16] is considered *normal* (The National Institute for Health and Care Excellence, 2010a; Macdonald and McGill-Cuerden, 2011). Labour is the process whereby the foetus is expelled from the uterus; onset is either spontaneous (i.e. naturally occurring) or medically induced (i.e. with the use of pharmacotherapy), delivery is assisted (i.e. with the use of instrumentation) or unassisted (World Health Organization, 1996; Lumley, 2003). The evidence base suggests that all humans have the same pregnancy gestation; however, a few studies have shown that South Asian, Mediterranean and African foetuses are developmentally more mature at an earlier gestation, challenging the idea of 37-42 weeks gestation being normal (Balchin *et al.*, 2007; Schaaf *et al.*, 2012).

2.2.2 Perinatal

There are numerous different definitions of *'perinatal'* in the global literature. The discrepancy is associated with legal definitions around *'viability*[17]' (House of Commons, 2007; Christoffersen-Deb, 2012; Mohangoo *et al.*, 2013). In England perinatal refers to 24 weeks of completed gestation, while the threshold value of seven completed days after birth remains the same (Office for National Statistics, 2012b). Perinatal mortality refers to death occurring within this timescale and is calculated as a rate per 1000 live births.

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[15] The arbitrary figure of 2500 g was determined by the World Health Organisation, as weight below this showed an increased mortality rate (Kramer, 1987).

[16] .'Gestation period' was originally an epidemiological concept by the World Health Organisation and International Federation of Obstetrics and Gynaecology, which is measured in weeks and days, from the first day of the last menstruation (LMP) (Steer, 2005). More recently, technological dating scans to confirm the gestation age and expected date of delivery (EDD) (The National Institute for Health and Care Excellence, 2010a). However, while menstruation dates have been found to be less reliable, they remain widely reported within the literature (Alexander *et al.*, 1995; Mohangoo *et al.*, 2013).

[17] Foetal viability refers to the age at which the foetus is considered to be able to survive external to the mothers' uterus and the precise age is contentious. There is an ambiguous area in vivo, whereby the viability of a foetus increases substantially after 24 weeks of gestation, however foetuses delivered at 22 or 23 weeks of gestation may be born alive and survive due to advances in medical technology (Irving and Ross, 1999; Hauck *et al*., 2011) although there is a higher rate of morbidity associated with preterm delivery (Parikh *et al*., 2014). Recent changes imposed by the Human Tissue Authority require all women delivering infants, including infanticide, to consider their options if the foetus is delivered with signs of life (Human Tissue Authority, 2014).

There are important issues around the application of inconsistent definitions. For instance, the Child Death Overview Panel (CDOP) reports on all neonatal deaths from 20 weeks of gestation[18], (Child Death Overview Panel, 2013b). Therefore, infants that are born with signs of life *and* before 24 weeks of gestation, (therefore with negligible chance of survival), are investigated and reported by CDOP[19]. Another issue around perinatal mortality figures is related to the proximity and clinical skill level of neonatal intensive care facilities (Claydon *et al.*, 2007; Neonatal Mortality Formative Research Group, 2008). Furthermore, advances in technology and foetal medical knowledge has resulted in increased numbers of preterm infants surviving, contributing to improved outcomes of perinatal, neonatal and infant mortality and morbidity (Seri and Evans, 2008; Christoffersen-Deb, 2012). Therefore, survival of preterm infants may increase; childhood morbidity may increase while neonatal death rates appear to decrease. Consequently, there is also a temporal perspective to consider. This research uses the definition applied in England for perinatal, using 24 weeks of completed gestation (in line with the legal definitions around viability) and seven completed days after birth.

2.2.3 Stillbirth

Stillbirth is the leading cause of perinatal mortality (Fretts, 2005; Flenady *et al.*, 2011) and is defined as a foetus that is born '*with no signs of life'*; however, there is a lack of international consensus on the precise working definition and parameters of stillbirth. In England, if an infant is born with no signs of life (i.e. dead) after 24 completed weeks of gestation, it is legally classified as stillborn[20] (*Still-Birth Act 1992*). Consequently, is required to be legally registered, have a formal burial/cremation and despite a fully formed infant being delivered at full term with no obvious

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[18] by definition this means that they were classified as live born, i.e. *'with signs of life.'*

[19] which was established in 2008, to work with the Infant Mortality National Support Team (IMNST) (Department of Health, 2010c; Korkodilos *et al.*, 2010)..

[20] In January 2014 Mr Loughton introduced a bill to Parliament recognise any delivery of a dead foetus as stillborn regardless of whether it had reached 24 weeks of gestation. To date this has not progressed through Parliament.

abnormalities, it does not undergo formal investigation (*Still-Birth Act 1992*; Fairbairn, 2014). Stillbirth is one of the main causes of perinatal mortality (Fretts, 2005; Flenady *et al.*, 2011). The literature frequently uses the terms perinatal mortality and stillbirth synonymously; however, there are clear distinctions and practical implications between the two terms. There are three further medical classifications of stillbirth which are as follows:

1. antepartum stillbirth – death before delivery
2. intrapartum stillbirth – death during childbirth
3. indeterminate stillbirth – unknown time of death.

Presently, there is also a lack of consensus in the classification systems used to determine causes of stillbirth, which are assigned using a coding system[21]. Regardless of the coding system employed, many stillbirths remained unexplained due to the lack of consistent or comprehensive data available (Gardosi *et al.*, 2005). As a consequence of the lack of a universal definition threshold, or classification system for stillbirth (Kramer, 1987; MBRRACE-UK, 2015b), there are methodological issues with comparing prevalence rates (Fretts, 2005; Neonatal Mortality Formative Research Group, 2008). The inconsistent classifications will have undoubtedly delayed progress in understanding the causes and contributors to stillbirth. This study will follow the stillbirth definitions applied in England: delivery of an infant with '*no signs of life'* between 24 and 42 weeks of gestation.

2.2.4 Infant mortality

Infant mortality is defined as death occurring in the infant within the first 12 months of life (Gray, Hollowell, *et al.*, 2010). This includes *neonatal* mortality, i.e. death occurring between zero and seven days, and *post-neonatal* mortality, i.e. death occurring between 7 and 28 days of life, although some authors do not always make this distinction clear (Swamy, Ostbye and Skjaerven, 2008; Kurinczuk *et al.*, 2010; Messer, 2011; Datta-Nemdharry, Dattani and Macfarlane, 2012;

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[21] For example, Wigglesworth (Wigglesworth, 1980), Aberdeen scales (Cole *et al*., 1986), Cause of Death and Associated Conditions (CODAC) (Frøen *et al*., 2009) and ReCoDe (Gardosi *et al*., 2005a).

Small, 2012; Phillimore, 2014). Interestingly, Luton’s CDOP identified that 40 percent of the neonatal deaths reported were infants born at early gestation (i.e. between 20 and 24 weeks of gestation), notably before the age of viability, which has implications for survival due to the developmental immaturity of the foetus.

Infant mortality rate (IMR) is defined as the number of deaths of infants aged under 12 months per 1000 live births, over a specified period (Reidpath and Allotey, 2003). IMR is an accepted proxy for population health status and is considered to be sensitive to temporal change and reflect distal determinants of health: general living standards, social wellbeing, illness rates, environmental factors in addition to a country’s economic resources (Reidpath and Allotey, 2003). Such changes may be evidenced in psychosocial contexts such as environmental factors, living conditions, access to healthcare resource and consequential stress effect (Srivastava, Singh and Jain, 2007; Nazroo, 2009; Kent *et al.*, 2013; Bircher and Kuruvilla, 2014). The term ‘*infant mortality’* in the current work will refer to the first 12 months of life, ‘*neonatal*’ is used to describe the first seven days of life, where ‘*postneonatal*’ refers to days 8–28 of life.

2.2.5 Low birth weight (LBW)

Low birthweight (LBW) is a significant contributory factor for increased risk of infant mortality and some contributing mechanisms have been identified. Preterm birth (PTB) (delivery before 37 completed weeks of gestation) may be the outcome of early spontaneous onset of labour or medically induced delivery and may be the result of comorbid complications in the mother or foetus (Han *et al.*, 2011). LBW may also occur after 37 weeks of completed gestation, typically referred to as SGA and are <10th percentile and may not have growth abnormalities or associated morbidities (Wilcox, 2002; Reidpath and Allotey, 2003; World Health Organisation, 2006b; Lausman and Kingdom, 2013). Finally, LBW may be the result of IUGR (section 2.3.4), whereby the normal growth and development of the foetus is hampered (Perinatal Institute for Maternal and Child

Health, 2011; Lausman *et al.*, 2013). Conversely, LBW does not always result in adverse outcomes and is not necessarily a consequence of preterm delivery; some preterm infants are heavier than 2500 g (Wilcox, 2002). Figure 1 shows the relationship between preterm birth, small for gestational age, intrauterine growth restriction and LBW.

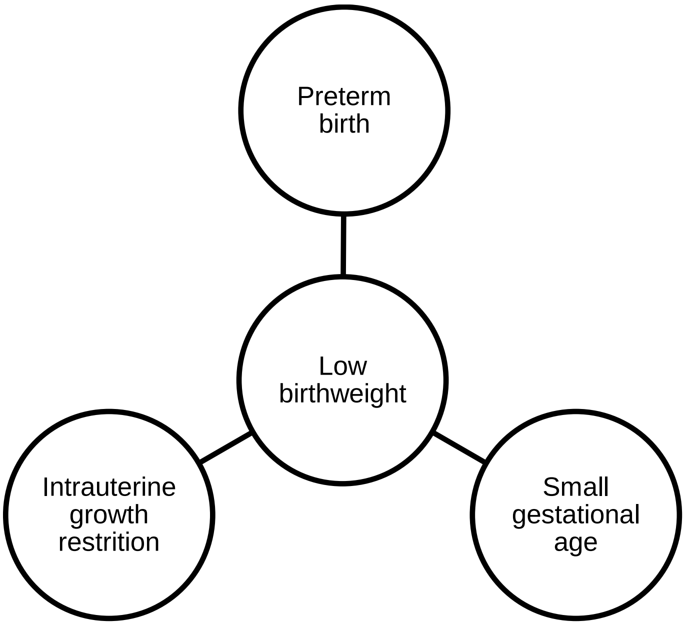

Figure 1: Diagram showing main contributors to LBW

Ethnic variation in birth weight is seen in national statistics and within the research literature. For example, it is widely known that South Asian women deliver infants of lower mean birth weights than their European counterparts, and this trend has been pervasive over time, although the mechanisms are poorly understood (Dhawan, 1995; Margetts *et al.*, 2002; Harding, Rosato and Cruickshank, 2004; Moser, Stanfield and Leon, 2008b; Leon and Moser, 2012).

2.2.6 Preterm Birth (PTB)

PTB accounts for 75 percent of infant deaths and it is estimated that 50 percent of preterm infants have consequential morbidities (Culhane and Goldenberg, 2011). PTB refers to birth before 37 weeks of gestation and may be the consequence of the spontaneous onset of labour or due to medical intervention as a result of maternal or foetal complications (Platt, 2014). It is a leading cause of LBW infant(s) and foetal immaturity, both being established contributors to perinatal mortality (Moser, Stanfield and Leon, 2008b; Kurinczuk *et al.*, 2009; Office for National Statistics, 2012b). Gestational age is correlated with birth weight whereby smaller weight infants and earlier gestation deliveries are at incrementally increased risk of morbidity and mortality within the first 12 months of life (Swamy, Ostbye and Skjaerven, 2008; Marmot, 2012; Platt, 2014). Surviving infants born with foetal immaturity can suffer increased morbidity across the lifespan, for example, chronic respiratory conditions as a consequence of immature lung development in utero (Messer, 2011; Joshi *et al.*, 2014). Figure 2 illustrates the PTB pathway to perinatal or infant mortality.

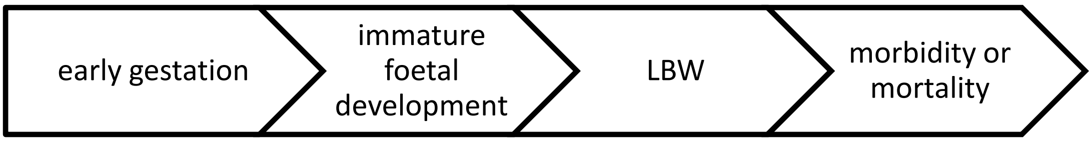

Figure 2: PTB pathway to infant mortality

Statistics show that PTB rates are slowly increasing (Goldenberg *et al.*, 2009; Office for National Statistics, 2011e, 2013f, 2014e). Figures also demonstrate higher rates of PTB in certain maternal ethnicities: Black Caribbean, Indian, Pakistani and Bangladeshi (Aveyard *et al.*, 2002; Office for National Statistics, 2015a). However, recent decades have witnessed increasing survival rates of PTB infants, due to advancing medical technologies (Lindsay *et al.*, 2000; Flenady *et al.*, 2011; Platt, 2014; West, *et al.*, 2014). Conversely, Wise (2003) argues that similarly to birth weight thresholds (see Section 2.3.5), a large number of infants are born around the gestational age of 37 weeks and do not suffer morbidity or mortality. Therefore suggesting that attention is made to the contributory factors *leading* to preterm birth rather than the arbitrary thresholds *per se* (Wise, 2003).

The exact mechanism behind PTB remains unclear. However, it is thought to be an accumulation of various interconnected proximal factors: inflammation or infection, ischemia or haemorrhage of the placenta or excessive uterine distension and stress (Behrman and Butler, 2007). The causes of PTB are broadly attributed to premature rupture of membranes (25 percent), maternal or foetal infection (30 percent) and spontaneous preterm labour (45 percent)(Goldenberg *et al.*, 2009). However, these causes only offer a late biological explanation why PTB occurred – not what triggered the cascade of bio-psychosocial events before the onset on PTB which, if better understood, could be addressed with interventions.

A large number of studies have considered the role of psychosocial factors and the role maternal stress may contribute to PTB. In general, the findings have shown a clear association between increased maternal stress and the onset of PTB (Behrman and Butler, 2007; Gungor, Oskay and Beji, 2011). However, there are various methodological issues with these studies, rendering the findings less informative than on first sight. For example, ‘stress’ is a broad term which represents biological pathways, such as lowered immune response and/or increased inflammatory responses (Wadhwa *et al.*, 2001; Hauck, Tanabe and Moon, 2011); psychological concepts, such as locus of control (Behrman and Butler, 2007), depression and anxiety (Federenko and Wadhwa, 2004; Grote *et al.*, 2010; Gungor, Oskay and Beji, 2011; Loret de Mola *et al.*, 2014; Mills *et al.*, 2014) and environmental stress factors such as poverty and racism (Krieger, 2001; Culley and Dyson, 2010; Hauck, Tanabe and Moon, 2011), making measurement of variables challenging and resulting in difficulty of comparison between studies

When combining ethnicity to the concept of stress, the measurement scales used in PTB research becomes problematic with validity issues. For instance, the perception of ‘stress’ in Western cultures may be different in other cultures. For example, in Urdu ‘*pereshaan*’ means tense, and in

Bengali ‘*oshanti’* means no peace. Consequently, interpretations and understandings of psychological constructs might change. Therefore the construct validity of measurement scales will vary across different cultures (Behrman and Butler, 2007). Moreover, if the scale is implemented within research using a diverse population, there may be erroneous results, under-reporting and difficulty in comparing study results across countries seeking consensus in findings (Triandis, 2010).

Therefore, while studies have collectively shown an association in maternal stress and PTB, studies highlight that migrant mothers have an increased prevalence of maternal depression (Falah-Hassani *et al.*, 2015). UK studies have found a high incidence of depression in South Asian women (Dhillon and Macarthur, 2010; Husain *et al.*, 2012; Traviss, West and House, 2012), in addition to more somatic symptoms (Bhui *et al.*, 2004; Kazi *et al.*, 2009; Traviss, West and House, 2012). However, because of the measurement issues surrounding perceptions of stress in other cultures, it remains unclear how maternal stress is influenced by maternal ethnicity and contributes to subsequent PTB.

Furthermore, several studies have shown that the longer migrant women reside in the UK the higher their chance of PTB (Aveyard *et al.*, 2002; Datta-Nemdharry, Dattani and Macfarlane, 2012). The MCS suggested that this was due to increasing adverse health behaviours, such as smoking (Dex *et al.*, 2005). Moreover, deprivation was independently associated with a higher risk of PTB in Black Caribbean and to a lesser extent for South Asian women (Aveyard *et al.*, 2002). However, in England, Pakistanis and Bangladeshis are the most deprived among all ethnicities. Subsequently, it might be that the association in Aveyard *et al*’s (2002) study between preterm birth and deprivation is simply a methodological artefact. What is clear is that Pakistani and Bangladeshi women are at higher risk of PTB and the distal determinants for PTB are multifaceted:

including migrant settler status, various forms of stress and maternal health behaviour mediate the outcome of PTB.

2.2.7 Intrauterine growth restriction (IUGR)

IUGR is a major determinant of LBW, stillbirth and perinatal mortality (Gardosi, Giddings, *et al.*, 2013). The definition for IUGR is a foetus whose growth is identified to be suboptimal in relation to the gestation age and <10th percentile and fails to reach its biological potential (Lausman *et al.*, 2013). IUGR and LBW has now replaced the term prematurity, to be more accurate and cease to obscure LBW (preterm) and SGA (at term) infants together, where mortality and morbidity risks may be differentiated (Wilcox, 2001; Lausman *et al.*, 2013). The cause of IUGR is associated with placental and vascular insufficiency (Lausman and Kingdom, 2013), and there are established risk factors including: smoking, low maternal weight gain, low maternal body mass index (BMI), comorbid maternal diseases such as pre-eclampsia, primiparity and short maternal stature (De Farias Aragão *et al.*, 2005; Ross and Beall, 2009; Lausman and Kingdom, 2013).

IUGR has been linked with chronic health conditions[22] in adulthood in both human (Roseboom *et al.*, 2001) and animal studies (Ross and Beall, 2009). Diabetes, hypertension and obesity are risk factors for adverse birth outcomes (Section 2.5.3), with higher risks of congenital anomalies associated with obesity (Stothard, Tennant and Bell, 2009; Heslehurst *et al.*, 2010), higher risk of stillbirth if mother has poorly controlled diabetes (Gardosi, *et al.*, 2013; Pintaudi *et al.*, 2015), and higher risk of IUGR found with maternal hypertension (Flenady *et al.*, 2011; Khalil *et al.*, 2013; Silverwood *et al.*, 2013) (although there is overlap between the comorbidities and outcomes). Studies have recently shown that individualised foetal growth charts have increased the

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[22] Diabetes mellitus, impaired renal function, hypertension, dyslipidaemia, obesity and cardiovascular disease in adulthood have been associated with LBW and IUGR (Ross and Beall, 2009; Silverwood *et al.*, 2013).

identification of pregnancies that are classified as IUGR, and therefore appropriate clinical management can be initiated during the pregnancy to prevent the foetus dying (Gardosi, *et al.*, 2013).

2.2.8 Congenital anomalies

Congenital anomalies are the second leading cause of infant death in England, following foetal immaturity (as a consequence of PTB, see Section 2.2.3), (Kurinczuk *et al.*, 2010; Office for National Statistics, 2015a). Across England and Wales, a centralised congenital anomalies register offers support, monitors the epidemiology of conditions and facilitates service provision[23] (Public Health England, 2016b). Statistics demonstrate approximately 93 percent of infants born with congenital anomalies survive. Conversely, 7 percent are affected by lethal anomalies which commonly include cardiac structural defects (of which there are 80 cardiac defects listed in the ICD-10[24]) (Kurinczuk *et al.*, 2010). Moreover, surveillance has shown that there is an increasing prevalence of neural tube defects (NTD) and this is one of the frequent reasons cited for termination of pregnancy in Europe (Khoshnood *et al.*, 2015). Furthermore, NTD are a potentially preventable anomaly by the consumption of preconception folic acid (Khoshnood *et al.*, 2015). Section 2.5.2 examines heritable factors further.

2.3 Causes of infant death.

There are trends within the explanations of foetal or infant death, which can be conceptualised along a death continuum and used to help understand the contributory factors to perinatal mortality. Moreover, several proximal determinants are typically used to ‘explain’ perinatal mortality, which include: LBW, PTB, IUGR and congenital anomalies. These explanations have been shown to cluster along particular timeframes on the death continuum, offering increased

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[23] Pre 15th March 2015 regional registers were in operation (Kurinczuk and Rashbass, 2015).
[24] International Statistical Classification of Diseases and Related Health Problems 10th Revision.

knowledge to the underlying aetiology behind perinatal mortality. However, while these proximal determinants may explain biological reasons for premature death, they fail to explain *why* the determinants occur in the first place. The next section explains the trends seen in the death continuum.

2.3.1 Trends in causes and time of death

There are patterns evident between the direct causes and indirect determinants of foetal death and the time of death. Death can occur at any time, from conception onwards. Therefore the classifications of ‘death’ vary according to the gestational age or birth age on a mortality continuum from conception to 12 months of life (see Figure 3). The classifications of death are as follows:

1. miscarriage: conception – 24 weeks of gestation
2. stillbirth: 24–42 weeks of gestation
3. neonatal mortality: Birth–7 days of life
4. post-neonatal mortality: 7–28 days of life
5. infant mortality: Birth – 12 months of life

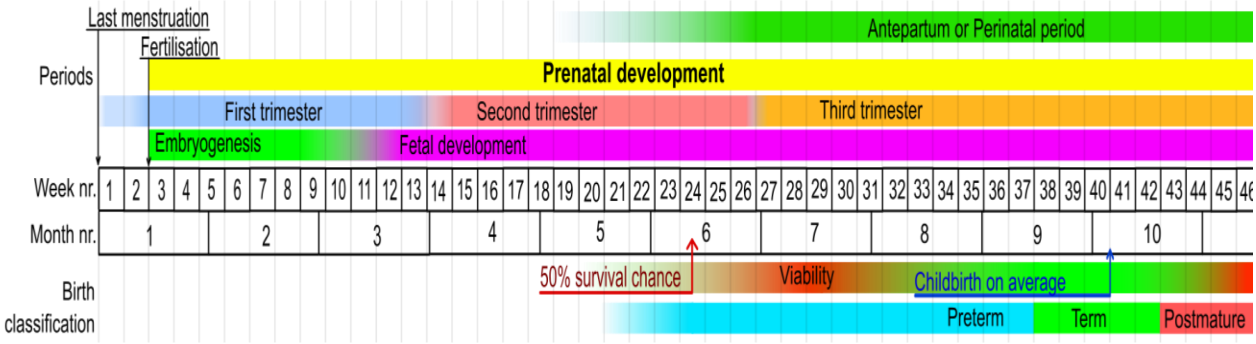

Figure 3: Depicts the developmental stages of pregnancy, with gestational age of viability shown at 24 weeks (Mikael Häggström, 2014)

There are different contributory factors to stillbirth[25] and neonatal death than the causes of infant and child death (World Health Organisation, 2006a). For example, stillbirth and neonatal deaths are the consequence of poor maternal health and complications at the time of delivery (Wise, 2003; Hollowell, Oakley, *et al.*, 2011; Office for National Statistics, 2015b). The majority of neonatal deaths are the consequence of preterm delivery (Section 2.2.6) and immaturity related conditions (Bowles, Walters and Jacobson, 2007; Messer, 2011; Office for National Statistics, 2011e; Child Death Overview Panel, 2013a; Parikh *et al.*, 2014). However, within communities of Pakistani origin around the world, the leading cause of death in the neonatal period is congenital anomalies[26] (Section 2.2.8) (World Health Organisation, 2012; Office for National Statistics, 2015b). Figure 4 depicts the trends in causes of life-death along the conception to 12-month continuum.

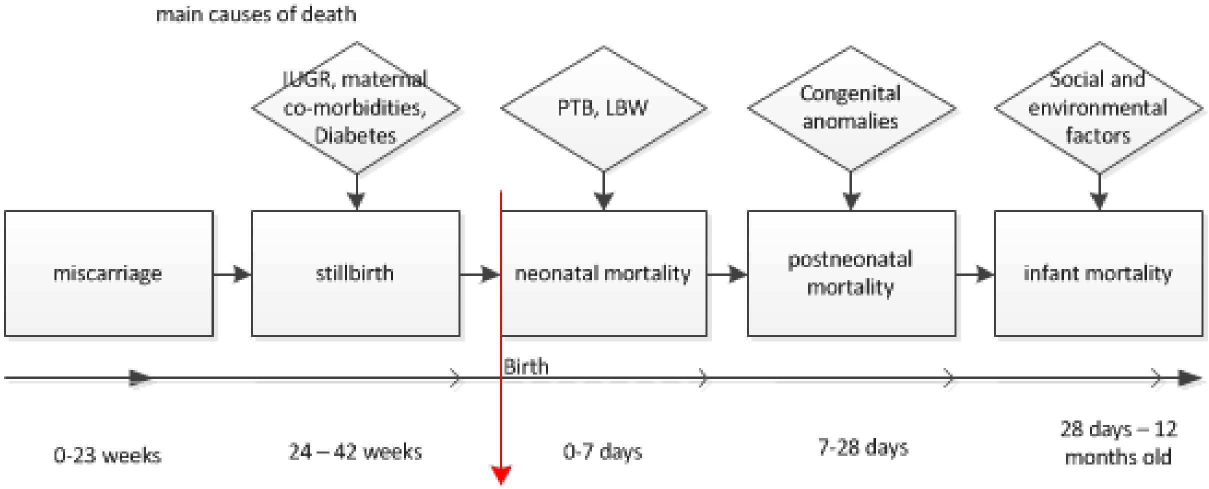

Figure 4: Mortality continuum

By contrast, post-neonatal causes of death are more commonly due to congenital anomalies, and are usually seen in term infants (Oakley, Maconochie and Doyle, 2010; Office for National

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[25] In England, a foetus that dies before 24 completed weeks of gestation is classified as 'early pregnancy loss' or 'miscarriage'; no formal burial or cremation is required. This legal definition is arbitrary and means that a foetus that is determined dead prior to 24 weeks, but might be delivered after 24 weeks would be classified as a miscarriage (Fairbairn, 2014). Conversely, a foetus delivered prior to 24 weeks that is born with life signs will warrant careful consideration by the neonatologist in consultation with parents regarding the chances of long-term survival and health consequence in determining the level of active clinical management (Seri and Evans, 2008).

[26] The International Classification of Diseases (ICD-10) Chapter XVII lists congenital malformations, abnormality and genetic disorders, according to body systems affected. There are over 150 disorders listed under disproportionately evidenced within the manual and routine socio-economic groups (Kurinczuk *et al.*, 2010).

Statistics, 2015b). Although congenital anomalies are the second leading cause of infant mortality (although some infants do survive) the causes remain largely unknown (Kurinczuk *et al.*, 2010). However diabetes mellitus, obesity and genetic disorders are known to contribute (Section 2.5.3) (Macintosh *et al.*, 2006; Stothard, Tennant and Bell, 2009; Kurinczuk *et al.*, 2010). The main causes of infant death (after two months and before twelve months of age) is usually attributed to the quality of care and environmental factors, such as hygiene, cigarette smoking (in the proximity of the infant) and bed sharing practices (Wise, 2003; World Health Organisation, 2006a; Ball *et al.*, 2012). These contributing mechanisms are important for public health interventions to address risk factors.

In England, no single cause of death is attributed to perinatal or neonatal deaths due to the use of the stillbirth and neonatal death certificate; introduced in 1986 to identify a sequence of contributing events resulting in perinatal death (Kurinczuk *et al.*, 2010; Office for National Statistics, 2011d). In response, the Office for National Statistics (ONS) implements a hierarchical classification system, facilitating the grouping of classifications and corresponding causes (Office for National Statistics, 2011d). The ONS death classification is listed below:

1. Congenital anomalies
2. Antepartum infection
3. Immaturity
4. Intrapartum causes
5. External conditions
6. Infections
7. Other specific causes
9. Sudden infant deaths
0. Unclassified

2.4 Ethnic variation in perinatal mortality

Section 2.2 has discussed the key definitions used in this study and Section 2.3 presented the causes of infant death. This section now presents the current situation and historical context to identify inequalities in perinatal mortality. Figures 5 and 6 show the current statistics on perinatal mortality, highlighting that rates in England and Wales are some of the highest in Europe. The figures also demonstrate a clear ethnic variation to the problem. The forthcoming paragraphs examine this in more detail, after a cautionary note regarding surveillance and monitoring, so that comparisons between studies are properly considered.

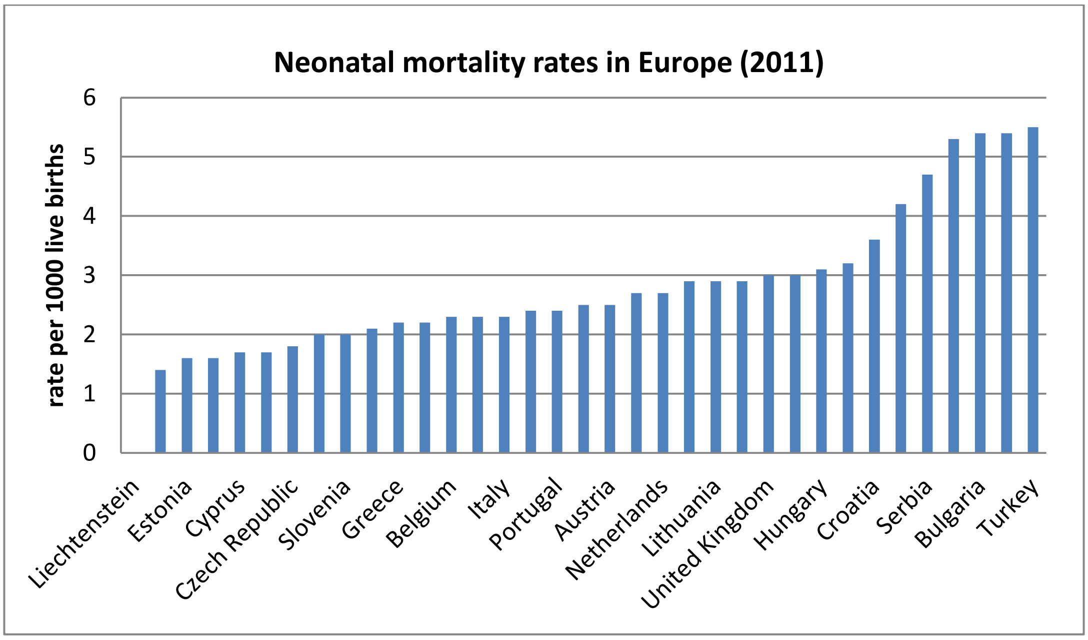

Figure 5: Graph[27] showing European neonatal mortality rates (2011)

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[27] **Source: Eurostat** http://ec.europa.eu/eurostat/data/database

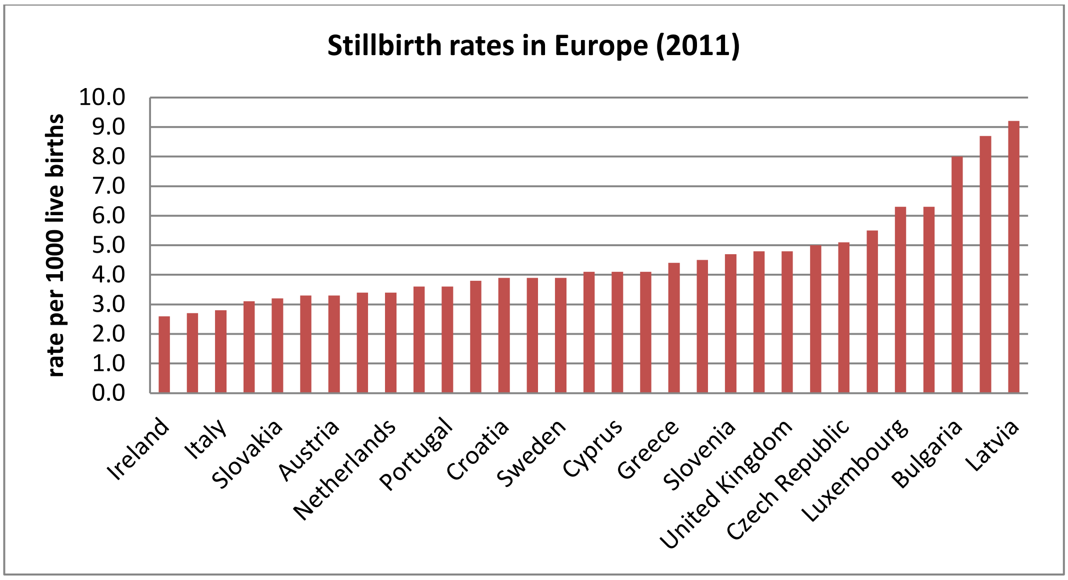

Figure 6: Graph[28] showing stillbirth rates in Europe, 2011

Surveillance is relevant for observing epidemiological trends in perinatal mortality and planning for maternity service provision, but it is important to contextualise the wider determinants that may have affected changes evidenced in the figures over time[29]. In other words, understanding declining figures over time needs to be considered more deeply than at face value. Current measurements and definitions of perinatal mortality are historically constructed and have changed over time, due to advances in technology, data collection techniques and more recently, linked hospital episode statistics with ONS Census data. This means that true like-for-like comparisons between countries and temporally within the UK are not possible, as the data sources are different. Nevertheless, the data has provided a rich source of information and knowledge regarding stillbirth and neonatal mortality (Moser, Stanfield and Leon, 2008b). Additionally the historical figures that have been recorded over the last 179 years in England have been useful to observe the declining

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[28] Ibid.

[29] The introduction of civil registration in 1837 facilitated the first recording of infant mortality. Prior to then, estimations were made from parish records. A steady decline has been observed, attributed to increased sanitation, advancing maternity and medical knowledge and improved nutrition (Oakley, 1982; Corsini and Viazzo, 1993). The recording of stillbirths commenced in 1927, with an estimated stillbirth rate of 38.3 per thousand live births (Office for National Statistics, 2013a). But caution is needed when comparing figures (or estimates) before and after 1993, as a consequence of the Still-Birth Act of 1992 (*Still-Birth Act 1992*; Office for National Statistics, 2013a).

trends in stillbirth and infant mortality. However, these have failed to offer any insight into the aetiology.

In 2014, England and Wales reported 695,233 live births and 3,254 stillbirths, equating to a stillbirth rate of 4.7 per 1000 live births (Office for National Statistics, 2014f). Moreover, in 2013 there were 1871 neonatal deaths (death in the first 28 days of life), a rate of 2.7 per 1000 live births (Office for National Statistics, 2014a). Stillbirth rates in the UK have remained fairly consistent for the last two decades (MBRRACE-UK, 2015b), although in recent years, neonatal survival has improved in response to advancing medical interventions and improved nutrition (Oakley, 1982; Wise, 2003; Cutler, Deaton and Lleras-Muney, 2006; Hollowell, Oakley, *et al.*, 2011). The stillbirth rate also remains high in comparison to other similar economic countries, which Penn *et al*. (2014) suggested may be an artefact of an ethnically diverse population, which also has a higher fertility rate than the WB (Penn *et al.*, 2014; MBRRACE-UK, 2015a).

Individual year cohorts show slight differences in the figures reported, in particular when reporting crude mortality rates, which may demonstrate chance occurrences which may be evidenced in small numbers (such as infant death), in addition to high-risk pregnancies occurring in some hospital settings due to the specialist facilities (MBRRACE-UK, 2015a). Research has shown that there is little change in adverse outcomes between generations (Margetts *et al.,* 2002; Malin and Gissler, 2009; Dhawan, 1995; Cross-Sudworth *et al.,* 2011). Nevertheless, figures have shown that Pakistani and Bangladeshi mothers have worse birth outcomes than WB mothers.

Disparities are evident in the perinatal mortality rates (PMR) when the rates are stratified by the mother's country of birth whereby mothers born in England and Wales have a PMR of 4.5 per 1000 live births, while mothers born in Pakistan have a PMR of 11.6 per 1000 live births and

Bangladeshi mothers have a PMR of 10.3 per 1000 live births (Office for National Statistics, 2014e). Similarly, the stillbirth rate of mothers born in England and Wales is 4.4 per 1000 live births. However, mothers born in Pakistan have a SB rate of 8.2 per 1000 and mothers born in Bangladesh have a SB rate of 6.6 per 1000 (Office for National Statistics, 2013b). Furthermore, the 2013 ONS figures demonstrate that Pakistani and Bangladeshi women have higher numbers of PTB infants (7.4 percent and 7.6 percent respectively) compared to WB (7.0 percent) (Office for National Statistics, 2014e).

It is noteworthy that figures for PMR also include live born infants to 7 days old, which is seen in many published figures in England. Importantly, these will include infants who have a poor survival prognosis due to malformations or fatal congenital anomalies[30] (Ahmed *et al.*, 2006; Ahmed, Green and Hewison, 2006; Bryant *et al.*, 2011). Furthermore, examination of the PMR prevalence literature typically excludes stillbirths or neonatal deaths that are a consequence of congenital anomalies, which serves to obscure the bigger picture, by ignoring foetal deaths that may have been otherwise inevitable - insofar as they were incompatible with life; however, exclusion of these deaths in terms of understanding the distal mechanisms hinders progress of our understanding of the aetiology.

Inspection of the national figures and research outcomes for Pakistani and Bangladeshi women delivering infants in England shows some distinct patterns. Research has shown that that LBW is commonly experienced in South Asian (i.e. Indian, Pakistani, Bangladeshi) mothers with babies on average being 280-350g lighter than WB infants (Jayaweera *et al.*, 2005; Kelly *et al.*, 2009). Similarly, Bangladeshi mothers are reported to have higher numbers of LBW infants than WB women, born after 37 weeks gestation and therefore considered SGA. Consequently, their mortality risk is better than for Pakistani mothers who, on the other hand, more frequently deliver

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[30] A congenital anomaly is a genetic defect, but not necessarily inherited.

preterm infants who are immature, have LBW or have congenital anomalies (Gray, Headley, *et al.*, 2010; Office for National Statistics, 2012b, 2014g). The reasons for the disparity remain speculative, although various risk factors for SB and neonatal mortality have been identified and will be discussed later in Section 2.5.

Conversely, mortality rates for infants delivered preterm are higher in Pakistani infants (31.4 per 1000 live births) compared to Bangladeshi infants (28.6 per 1000 live births) and WB infants (22 per 1000 live births) (Office for National Statistics, 2014e). This indicates that while a higher proportion of Bangladeshi mothers give birth before 37 full weeks of gestation (compared to WB), their offspring has improved survival rates compared to Pakistani infants. The reasons for this are presently unclear.

Poorer birth outcomes are clearly evident when comparing figures from the countries of Pakistan and Bangladesh to Pakistani and Bangladeshi migrant mothers delivering in England. For instance, in 2015, Pakistani mothers giving birth have a neonatal mortality rate of 64 per 1000[31] live births, and in Bangladeshi mothers have a neonatal mortality rate of 63 per 1000[32] live births respectively (World Bank, 2016). However, directly comparing England's figures with Bangladesh and Pakistan's figures does not translate to a like-for-like comparison, since the accuracy of national reporting and recording of births and stillbirths is claimed to be 'sketchy' – dependent upon whether the birth was in rural parts of each country (Fikree, Azam and Berendes, 2002) and whether there were trained birth attendants attending during delivery (Neonatal Mortality Formative Research Group, 2008; Choudhury and Ahmed, 2011; Garcés *et al.*, 2012) and whether the birth attendant (or birthing partner) had the knowledge for resuscitation and correct classification of a live born that

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[31] Data from 2015

[32] Ibid

was otherwise just slow to breathe (Fikree, Azam and Berendes, 2002; Moran *et al.*, 2009; Gogia and Sachdev, 2010; Gates *et al.*, 2013).

That said, these figures do lend support for the '*healthy migrant effect*' (Gissler *et al.*, 2009; Almeida *et al.*, 2013). However, despite improvements in the national figures in line with global trends, it is clear that there are ethnic inequalities between Pakistani and Bangladeshi women delivering infants in England and Wales, compared with WB mothers (Bartley *et al.*, 2005; Bartley, 2008; Gray, Headley, *et al.*, 2010). Furthermore, it is also evident that there are discrete differences between Pakistani and Bangladeshi infant outcomes which deserve closer inspection, in addition to understanding whether the risk factors intersect to determine the experience and subsequent outcomes in pregnancy and childbirth. The following section examines the situation in Luton.

2.4.1 Perinatal mortality in Luton

Section 2.3 above has discussed perinatal mortality in England and Wales and described the ethnic variation to perinatal mortality. This section moves the attention to explaining why this study was conducted in Luton. Luton is a unitary authority in the East of England, located just over 32 miles from central London and has approximately 210,800 residents (Geospatial Information Team & Department of Environmental and Regeneration, 2014) and is home to a diverse population. The town has recently been classified as plural, whereby no single ethnic group is classified as the 'majority' (ESRC Centre on Dynamics of Ethnicity, 2013). While 55 percent of residents are reported to be of 'White' ethnicity[33], 30 percent are of 'Asian' ethnicity (Office for National Statistics, 2011c). Specifically, 44.6 percent were reported as being WB, 14.4 percent were Pakistani and 6.7

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[33] Using 2011 ONS Census definitions, 'white' includes English or Welsh, Scottish or Northern Irish or British, Irish, Gypsy or Irish Traveller, and Any other White background. 'Asian / British Asian' includes: Indian, Pakistani, Bangladeshi, Chinese, and any other Asian background.

percent Bangladeshi (Office for National Statistics, 2011c). The town is currently ranked 59th most deprived (out of 326) in England with nine output areas ranked within the greatest 10 percent of the country's most deprived areas, which are located in the wards of Northwell, Biscot, Dallow, Farley and South (Research and Geospatial information, 2015). Figure 6 shows the map of Luton.

Figure 6: Map of Luton

In particular, Luton historically attracted migrants from Azad Kashmir[34] in Pakistan and Sylhet in North-Eastern Bangladesh[35]. The arrival of the majority of the town's South Asian migrants took place between the 1960s and the 1980s with male migrants being attracted by local industries, employment opportunities[36] and affordable housing[37] (Ballard, 1994, 2002; Ali, 1999; Ali, 2006; Meer and Modood, 2007). By contrast, recent migrants from Pakistan or Bangladesh are students, marriage partners or professionals (Communities and Local Government, 2009a, 2009b).

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[34] Azad Kashmir is the Pakistani administered region of Kashmir, which is almost as large as the UK, located in the Himalayas and has been disputed between India and Pakistan since 1947. After completion of the Mangla Dam in 1966 and the subsequent flooding of many villages in Azad Kashmir, migration was expedited (Richardson and Wood, 2009; Small, 2012).Many settlers who refer to themselves as Kashmiri are categorised as being Pakistani because they hold a Pakistani passport (Ali, 2009).

[35] Since 1947, migration was a consequence of political, environmental and economic reasons (Richardson and Wood, 2009).

[36] textiles, milliner and motor vehicle manufacture (Shaw, Dorling and Smith, 2006; Small, 2012).

[37] Typically economic migrants reside in poorer more affordable areas and purchase Victorian terraced houses, which was run down housing stock (Ballard, 2001, 2002; Communities and Local Government, 2009a).

According to figures in 2011, socio-economically, Pakistani and Bangladeshi communities have higher proportions of individuals in NS-SEC categories 5–8 in comparison with the White majority (NOMIS, 2016). Notably, the majority of Luton’s Pakistani and Bangladeshi families are concentrated within a few wards: Dallow, Biscot and Saints (Mayhew and Waples, 2011), which are also ranked in the top 10 percent most deprived in England (Research and Geospatial information, 2015). Figure 7 illustrates the electoral ward boundaries.

Figure 7: Map showing electoral wards in Luton

Statistics show that Luton has the sixth highest fertility rate in England (Luton Borough Council, 2013) and local figures have shown that in 2015, 56.4 percent of infant deliveries in Luton were from non-UK born mothers (Office for National Statistics, 2016d): the second highest in England (Office for National Statistics, 2014g). Luton is, therefore, a town with a plural population and is home to large numbers of Pakistani and Bangladeshi families; it has areas of high deprivation and reports a high fertility rate with the majority of births being from mothers born outside the UK.

Perinatal mortality in Luton is also higher than the national average (see Section 2.3). The perinatal mortality rate (PMR) in Luton is 9.7 per 1000 live births compared with the England and Wales average of 7.1 per 1000 live births (Office for National Statistics, 2016c). Specifically, there were 26 stillbirths reported in Luton for 2014, and this was the highest recorded in the East of England (Child Death Overview Panel, 2015; Office for National Statistics, 2016c). The CDOP reported that over 50 percent of the infant deaths that occurred in 2013 disproportionately affected Pakistani or Bangladeshi families (Child Death Overview Panel, 2013a). Furthermore, as mentioned above the Pakistani and Bangladeshi settlers reside in the wards with high rates of deprivation, which also report the highest rates of fertility and infant death (Luton Borough Council, 2013; Child Death Overview Panel, 2013c). Taken together, this demonstrates that there is ethnic variation to perinatal mortality in Luton, with Pakistani and Bangladeshi women having higher rates of PMR than the national average (Child Death Overview Panel, 2013b).

2.5 Explaining inequalities in perinatal mortality

The sections above have highlighted the extent of perinatal mortality for England and in Luton. This section uses the DOH approach as a useful starting point to understand the existing evidence base in explaining inequalities in perinatal mortality (Dahlgren and Whitehead, 1991; Whitehead and Dahlgren, 2007).

2.5.1 Describing the determinants of perinatal mortality

The DOH approach is currently the dominant way of describing the determinants associated with health inequalities. Applying the DOH approach to the experience of perinatal mortality provides a useful starting point to understanding the risk factors associated with perinatal mortality. The risk factors for perinatal mortality can be grouped as heritable factors (i.e. genetics, age, ethnicity, sex), lifestyle factors (i.e. health behaviour), structural factors (i.e. social support, government policy and services), and environmental and socio-economic status (SES) factors (i.e. education, employment, income, housing) (Dahlgren and Whitehead, 1991; Whitehead and Dahlgren, 2007).

The DOH approach emphasises related factors and recognises that the impact of the environments in which individuals function are mediated by politics, policies and economic factors (World Health Organisation, 2005; Whitehead and Dahlgren, 2007; Bircher and Kuruvilla, 2014). Additionally, it is widely accepted that over a person's lifespan, the accumulation of advantage or disadvantage creates a psychobiological response on health (Blane, 2006). In other words, understanding that the individual life experience and its cumulative effect, results in acute and chronic stress (Marmot and Wilkinson, 2003; Blane, 2006). Moreover, the contribution of individual health behaviour, which is mediated by environments and individual actions, resulting in positive, protective or risk factors, combine to modify health outcomes on an individual (Sallis, Owen and Fisher, 2010). Figure 8 illustrates that the DOH are related factors contributing to health status (McAlister, Perry and Parcel, 2008; Ogden, 2012).

The contribution of the life-course perspective to our understanding of DOH suggests early life exposures and accumulated contribution of SES factors, health behaviours, disadvantage and power dynamics in adult health status (Wadsworth and Kuh, 1997; Ravelli *et al.*, 1998; van de Mheen, Stronks and Mackenbach, 1998; Davey-Smith, 1999; Roseboom *et al.*, 2001). For example, studies have shown that many infants born of LBW, remain growth retarded through childhood and adolescence, and female children have a stunted growth spurt pre-menarche, resulting in a smaller stature woman in adulthood (Saigal *et al.*, 2006). Consequently, this has an impact on the size of the infant that they themselves go on to deliver (Sachdev, 2001; Saigal *et al.*, 2006; Collins, Rankin and David, 2011).

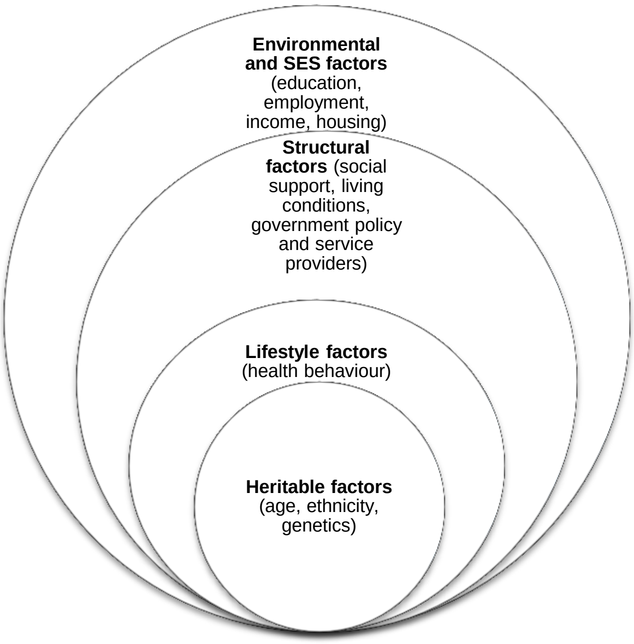

Figure 8: The DOH approach for perinatal mortality (adapted from the Dahlgren-Whitehead rainbow model (1992)

Research has also shown that although some growth catch up for LBW and SGA babies is made there appears to be a longer term consequence on adult health status, for instance, adipose distribution and insulin resistance in adulthood (Stanfield *et al.*, 2012; West *et al.*, 2013). Other birth cohort studies, e.g. West of Scotland Collaborative Study or British Birth Cohort studies (1946, 1958, 1970, and 2000) (Blane *et al.*, 1996; Wadsworth and Kuh, 1997; Blane, Smith and Hart, 1999; Silverwood *et al.*, 2013) have shown interesting trends, for instance, risk factors for adult cardiovascular disease (i.e. dyslipidaemia, obesity, and hypertension) are associated with the child's SES status and reduced child height in children aged 2–4 years is associated with higher rates of adult hypertension (Wadsworth and Kuh, 1997).

Additionally, there have been discussions advancing the '*foetal origins hypothesis*' (or early programming hypothesis) which suggests that there are critical periods of development in-utero that are mediated by nutritional factors, especially in the third trimester, rendering individuals more prone to endocrine and cardiovascular consequences in later life (Saigal *et al.*, 2006). Indeed, the high prevalence of LBW and preterm births evidenced in South Asian populations and the increased prevalence of diabetes and cardiovascular problems observed in this population lends support to this hypothesis. The determinants of perinatal mortality are discussed below, organised using the DOH approach.

2.5.2 Heritable factors (maternal ethnicity, genetics and age)

This section presents the heritable factors that are known to contribute to perinatal mortality. Heritable[38] factors contributing to perinatal mortality include maternal age, (i.e. young <20 years or older >35 years) (Kiernan and Smith, 2003; Freemantle *et al.*, 2009; Walker *et al.*, 2016), ethnicity (Penn *et al.*, 2014) and genetic factors[39] (Modell *et al.*, 2000; Pociot and Lernmark, 2016).

Ethnicity

This section addresses the contested term of 'ethnicity' and provides a brief overview to the problematic concept and subsequent application in research, ending with an explanation of how the term ethnicity is being used in this study. The concept of 'race' and 'ethnicity' as categories in research has resulted in years of scholarly debate (Bhopal, 1997; Saffron and Nazroo, 2002; Atkin, 2011) yet is still barely understood (Hale, 2004). Historically, attitudes involving persons from different ethnic and geographic backgrounds has been politically influenced – evidenced with differentiated behaviours and separation, racism, slavery, colonialism and apartheid (Bhopal and Donaldson, 1998; Bhopal, 2007). This served to highlight differences between the majority group and the minority group, whereby justification was made for the unequal treatment of minorities due

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[38] In the empirical literature often heritable and genetic factors are used interchangeably, however in this thesis heritable factors refer to genes being passed from parent to child (Downes, 2015).

[39] Genetic factors refer to mutations of the gene and are not necessarily heritable. Often the risk factors associated with hereditary and genetic factors get conflated (e.g. Down's syndrome is a mutation [genetic] whereas sickle cell thalassemia is heritable) (Downes, 2015).

to misrepresentation of fact and/or spotlighting problems in the minority group (i.e. with research focusing on the difference) (Bhopal, 2007; Chaturvedi, 2001). Within the scientific community, this was further confounded through research that was poorly designed, implemented and evaluated leading to erroneous and misleading findings (Bhopal, 2007; Gunaratnum, 2003). Therefore, the terminology and categories have been historically and politically influenced, consequently consideration needs to be given to the temporal changes of the political context of minority groups (Bradby, 2003; Gunaratnum, 2003; Patterson, 2004), and how they have been located in social, historical and current contexts (Gunaratnum, 2003).

The earlier concept of ‘race’ as previously applied in health research was argued to be biologically determined (Bradby, 2003; Karlsen and Nazroo, 2006). However, scholars now agree that research according to certain phenotype characteristics and cultural attributes (i.e. race) is artificial and socially constructed (Senior and Bhopal, 1994; Bradby, 2003; Karlsen and Nazroo, 2004; 2006; Clarke, 2006). On the other hand, ethnicity is a term which usually incorporates regional, language and religious differences, when compared to the majority (Bartley, 2008; Bhopal, 2004). Therefore, ‘race’ and ‘ethnicity’ are two separate concepts; ‘race’ being biological and heritable (Bradby, 2003), whereas ‘ethnicity’ implies social and cultural differences (Chaturvedi, 2001).

However, Hall (2000) argues that race/ethnicity is interrelated; he posits that while biological, the concept of race focuses on skin colour whereas ethnicity attends to cultural attitudes and behaviours. Furthermore, Hall (2000) also states that ethnicity is passed along generations, is stable and heritable through mechanisms including education, and cultural practice such as endogenous marriage unions (Hall, 2000). Despite the nuanced differences between the two concepts, the term ‘race’ is still used synonymously for ethnicity in research papers (Williams, 2002), and one explanation for this is that the term race is still widely used in popular lay language (Bradby, 2003).

Ethnicity has been variously defined (Bhopal, 1997; Bhopal and Donaldson, 1998; Atkin, 2011). The definitions are conceived according to four main explanations of phenomenon; primordial, epiphenomenon, situational or subjective[40] (Isajiw, 1993; Atkin, 2011). Furthermore, ethnicity can be defined by group parameters (e.g. shared culture, community or ancestors) or is defined by social-psychological path of self-identity and ascribing to belonging to group membership (Isajiw, 1993). Furthermore, Isajiw (2003) argues that definitions of ethnicity are abstract concepts that are reliant on collective experience and dependent on of the identity of self and others in a situational context. Additionally, Senior and Bhopal (1994) suggest ethnicity is ‘*shared origins or social background; shared culture and traditions that are distinctive, maintained between generations, and lead to a sense of identity and group; and a common language or religious tradition*’ (pg 327).

It is now widely accepted that ethnicity is a self-defined construct encapsulating common ancestry, shared territories, physical appearance and less tangible factors such as culture, language and religion (Chaturvedi, 2001; Salway *et al.*, 2009; Economic and Social Data Service, 2012). Moreover, it is a concept that is associated with personal identity (Nazroo, 2003; Atkin, 2011) and perceptions of group membership and social norms that may alter depending on circumstances, for example, Pakistani (ascribing to parental origins) or British Pakistani (ascribing to birth origins), or

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[40] The primordial approach claims that ethnicity is ascribed from ‘kin-and-clan’ and therefore is permanent and fixed (Geertz, 1963), whereas the epiphenomenon is the result of unequal economies (Nagel and Olzak, 1982). The situational approach states ethnicity is only relevant in certain situations that individuals find advantageous and the subjective approach suggests that ethnicity is a perception and depends on the psycho-social experience (Isajiw, 1993).

perceptions of identity being interlinked with family (i.e. seen in Asian tradition) or one's own physical body (i.e. seen in Western tradition) (Triandis, 1989), therefore is considered fluid (Markus and Hamedani, 2010). Consequently, the implications of using ethnicity as a category in research are not straightforward.

Much of the existent evidence in health research has focused on ethnic 'differences' between groups (Senior and Bhopal, 1994; Marmot, 2012), with health research variables frequently compared against host country outcomes as the comparator (Senior and Bhopal, 1994; Ali Hyder and Morrow, 2006). Furthermore Nazroo (1998) states that using ethnic categories fails to allow for in-group heterogeneity and the categorising of ethnicity is only valuable in a given social context. Bradby (2003) argues that differentiating against the majority population normalises the outcomes of the majority, while simultaneously racialising the results of the minority group and in using fixed-choice ethnic categories in health research, this implicitly lends weight to the notion of mutually exclusive groups and hence difference.

Subsequently, this exaggerates difference in minority groups and erroneously suggests that it is due to ethnicity that 'difference' occurs, with the consequence of obscuring other factors, such as deprivation (Gunaratnum, 2003). Moreover, Atkin (2011) argues that 'ethnicity' dominates the identity of BAME individuals, whereas it is seldom presented in the context of identity for White people. Consequently, this exemplifies 'difference' and 'otherness' (Hall, 1992) and simultaneously implies homogeneity within the ethnic categories, further perpetuating perceived ethnic homogeneity within groups and increasing stereotypes attitudes towards BAME groups (Atkin, 2011; Mcfadden, Renfrew and Atkin, 2013).

Research using ethnicity as a variable is conceptually and practically problematic (Bradby, 2003). Conceptually due to the diversity of classification systems available between different countries, which may utilise forced-choice, for instance the category of Asian in American literature broadly refers to individuals from the far east, China, south-east Asia, Japan, Thailand, the Philippines and Korea and White refers to origins from Europe, the Middle East, and North Africa, based on census classifications (Humes, Jones and Ramirez, 2011). Conversely, the UK currently uses fixed-choice census categories; Asian/Asian British categories to represent Indian, Pakistani, Bangladeshi, Chinese and 'Asian other' (Office for National Statistics, 2012a). In reality, however, there is heterogeneity between these ethnic categories, including SES factors, religion, culture, beliefs and behaviours. Moreover, further diversity also exists between migrant generations, dependent on the degree of cultural assimilation with the host country and the settler families (Núñez-de la Mora, Jesmin and Bentley, 2007; Hawkins *et al.*, 2008).

Culture

The contribution of culture in definitions of ethnicity is an important consideration. Culture (like ethnicity) is a disputed and complex concept (Geertz, 1973; Fuchs, 2001; Sewell, 2005), with two main perspectives, although the distinction between them is rarely provided (Sewell, 2005). Firstly, an external and defined category which can be delineated from human experience (and is therefore considered singularly) and secondly, referring to collective beliefs and practices that bind a group of humans together (and therefore is considered a society or sub-society) (Sewell, 2005). Consequently, there are many definitions of culture which have evolved over the last few decades (Patterson, 2000; Marsella and Yamada, 2010). These include culture being a learned experience, or a learned experience that attends to meaning-making, or culture being an institutional group, attending to meaning-making, or the dominant view from Geertz (1973): culture as a collective group of systems and subsequent meanings (Geertz, 1973; Sewell, 2005).

The current work defines '*culture'* as a shared, dynamic psycho-social construct that includes internal representations (i.e. attitudes, beliefs and behaviours) and external representations (i.e. social roles, social structures and objects) whereby internal and external cultural representations influence our culturally imbued reality and is evolving and self-reinforcing (Marsella and Yamada, 2010). Put another way, culture does not occur in isolation, but is part of a structural reality(i.e. material objects that signal cultural following, such as dress code) and conceptual reality (i.e. attitudes related to a cultural group), which also feedback into reinforcing these realities in a dynamic way (Markus and Hamedani, 2010). This, in turn, informs behaviours and this is multifaceted. Additionally, cultural practices, such as marital status – particularly single status and consanguineous unions also contribute to perinatal mortality (Grant and Bittles, 1997; Ali Hyder and Morrow, 2006; Ali, McLean and Rehman, 2012; Mir and Spicer, 2013; Ajaz, Ali and Randhawa, 2015; Knight *et al.*, 2015).

Culture influences the way in which individuals interpret their social world (which includes health status and pregnancy), elicits an emotional affect and defines a behavioural response (Bhui and Dinos, 2009). Moreover, there is a variety of symptom expressions and cultural contexts attached to illness that contribute to health beliefs, affective responses and health behaviours (Ali Hyder and Morrow, 2006). There are a few studies that have addressed how culture may influence Pakistani and Bangladeshi women's health beliefs and behaviours, however, these were conducted in their home countries in rural village settings, consequently the environmental contexts are too dissimilar to UK settler Pakistani or Bangladeshis, such that these findings aren't generalisable to the UK's Pakistani or Bangladeshi women (Chakraborty, 2003; Moran *et al.*, 2009; Choudhury and Ahmed, 2011). Moreover, there is very little research with Pakistani and Bangladeshi women in the UK context that considers how culture may influence health beliefs and behaviours (Lucas, Murray and Kinra, 2013; Yeasmin and Regmi, 2013a).

A series of social norms and expectancies surrounds the social experience of pregnancy. For example, within Pakistani and Bangladeshi families, pregnancy is a much anticipated and expected outcome following marriage (Koenig and Al Shohaib, 2014), in addition to providing women with an elevated social 'status' within their community (Choudhury and Ahmed, 2011). Moreover, Pakistani and Bangladeshi women typically hold the role of homemaker (following marriage and childbirth); consequently the expected social norm is that priority is made to attend to household matters and look after other children and older family members, in contrast to attending to their individual health needs (Dartnall, Ganguly and Batterham, 2005; Aston *et al.*, 2007b; Puthussery *et al.*, 2010; Jomeen and Redshaw, 2013). This is supported by the disproportionate numbers of Pakistani and Bangladeshi women who are not in formal employment (Communities and Local Government, 2009a). Language also contributes to the concept and experience of culture and ethnicity (Hale, 2004).

Language

Language is the means by which shared meanings of culture, religion, and practices (i.e. attitudes and behaviour) are communicated and exchanged between individuals and social groups (Markus and Hamedani, 2010). Language is deeper than the exchange of common linguistics, but includes having explicit knowledge of local dialect and slang (Ali, 2003) and may include non-verbal behavioural cues (Geertz, 1973). Furthermore, language is dynamic insofar as it evolves in the social world, and informs and constrains thinking[41] (i.e. cultural cognition) (Sharifian, 2017). Therefore, concepts in one language may not be present in another, or may be represented differently, resulting in miscommunication and misunderstanding of cultural contexts between speakers of different languages (Triandis, 1989; Chambra and Ahmad, 2000).

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[41] Known as linguistic relativity (Wolff and Holmes, 2011).

Limited English language proficiency of ethnic minority women, who are not born in the host country, is a commonly cited explanation for barriers to accessing services (Ali and Burchett, 2004; Dartnall *et al.,* 2005; Puthussery *et al.,* 2010; Jayaweera *et al.,* 2005). It is thought that language may further discriminate against knowledge of services within the locality, or poor awareness of entitlement, or become a barrier to information giving, which exacerbates disadvantage that may already be substantial due to low or no educational attainment of the women within the ethnic community, therefore perpetuating inequalities through reduced opportunities (Lu and Halfon, 2003).

The Confidential Enquiry identified poor communication as a factor in perinatal mortality (Rowe *et al.*, 2001; Ali, 2003; Draycott, Lewis and Stephens, 2011). A study that examined findings from a series of Confidential Enquiries identified that 52 percent of deaths had issues of 'poor communication' cited as a contributory factor; but the scope of 'poor communication' was poorly defined in the included studies and ranged from mothers' non-adherence to health advice, health advice not being explained or staff not listening to mothers (Rowe *et al.*, 2001). Although English language difficulties were not explicitly cited in the review, the authors believed that poor English language proficiency would exacerbate communication difficulties further (Rowe *et al.*, 2001). The NHS uses translation services to meet the needs of the diverse population; however, a review across three hospitals in the West Midlands has shown in the 83 percent of perinatal deaths, no professional translation service were offered to non-English proficient mothers, resulting in sub-optimal care (Cross-Sudworth, Williams and Gardosi, 2015).

Research evidence around the user's experience of using interpretation services shows there is more to translation than the simple conveyance of information between service user and healthcare professionals (HCP) (Regmi, Naidoo and Pilkington, 2010). There have also been questions raised in respect of the accuracy of professional translation in clinical practice, especially regarding ‘slang’ or dialects (Ali, 2003), concerns of subjectivity by the interpreter and how they may influence the health care professional and patient relationship and hence there are calls for medically trained interpreters (Temple and Edwards, 2002). Studies have also found that South Asian women have expressed concerns in using interpreter services for fears of stigmatisation and confidentiality in their community (Cross-Sudworth, 2007; Phillimore, 2015). However, there were also concerns expressed by HCP regarding using family members (i.e. children or husbands) as being ‘inappropriate’ to translate in a maternity setting (Ahmad, 2000), resulting in difficulty in asking sensitive questions, obtaining an accurate history and risking misinformation due to poor health literacy (Centre for Maternal and Child Enquiries, 2011b). Together, this shows that having limited English language proficiency is a barrier to receiving quality maternity care, and the solution is more complex than offering ‘interpretation’ services.

Religion

Religion is another important aspect when considering definitions of ethnicity and when conducting research that involves individuals who engage in distinct religious beliefs and practices (e.g. Muslims and Christians) and where religion may influence their health beliefs and health behaviours (Bahar *et al.*, 2005; Koenig and Al Shohaib, 2014; Raman *et al.*, 2016). Religion (like ethnicity and culture) is another contested term (Harrison, 2006). In lay language it often refers to a religious affiliation and may refer to a specific deity (e.g. God, as seen in Christianity or Allah in Islam), while others have no God (e.g. Buddism or Taoism) (Harrison, 2006). Consequently, operationalising religion is far from straightforward (Flannelly, Jankowski and Flannelly, 2014). There are three main clusters of definitions of religion, in respect of whether the religion is: monotheistic (e.g. belief in one God, Allah), has an affective element (i.e. expressive beliefs) or its functionality (e.g. a greater power than human) (Harrison, 2006). However, while the definition of religion is contested (Harrison, 2006), this study will use the following definition; ‘*An organised set of beliefs or practices designed to facilitate closeness to the sacred (e.g. God, Allah, Higher power* *or truth), and fostering an understanding of one's relationship and responsibility to others, living together in a community*' (Koenig, *et al,.* 2001; pg 18).

The two dominant religions in this study population are Christianity (WB) and Islam[42] (Pakistani and Bangladeshi). There are similarities and differences in health beliefs and health behaviours between Christians and Muslims as a consequence of religious and cultural influence (Bahar *et al.*, 2005; Koenig and Al Shohaib, 2014; Raman *et al.*, 2016). For instance, many Muslims believe the purpose of illness is a test from Allah, to help with purification following sin and provides opportunity for reward in the future. By contrast, the Old Testament states illness is God's punishment and some Christians believe illness is the result of God's will, while others think it is a test that leads to purification (Koenig and Al Shohaib, 2014). Islamic beliefs are quoted to explain pregnancy outcomes being the "will of God"[43] (Bryant *et al.*, 2011).

There is extensive literature on fatalistic attitudes in health (Alkhawari, Stimson and Warrens, 2005; Dartnall, Ganguly and Batterham, 2005; Ismail *et al.,* 2005; Grace *et al.,* 2008; McAlister, Perry and Parcel, 2008; Shaw, 2012; Lucas, Murray and Kinra, 2013). Several qualitative studies have shown that Muslim Pakistani and Bangladeshi women have fatalistic attitudes towards their pregnancies and pregnancy outcomes and this then is used to explain poor outcomes (Ali and Burchett, 2004; Dormandy *et al.*, 2005, 2010; McAlister, Perry and Parcel, 2008; Lucas, Murray and Kinra, 2013; Haddrill *et al.*, 2014). However, this attributes the responsibility to the mother and distances the role of providers. Fatalistic attitudes have not been widely reported for WB mothers, however this is most likely due to methodological artefact as a consequence of not including WB

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[42] Statistics show that just over 96 percent of Pakistani (Pakistan Bureau of Statistics, 2016) and 90 percent of Bangladeshi individuals identify as Muslims (the majority being Sunni) (United States Department of State, 2012). Similarly, 86 percent of WB identified with being Christian (Office for National Statistics, 2013d).

[43] This is better understood when the Islamic articles of faith are acknowledged: belief in God, Angels, Prophets, Divine books, Judgement day, and Destiny (*qudr*). Destiny means that everything occurs for a reason and it is "God's will", therefore rationalising that disease or bereavement must be accepted (Koenig and Al Shohaib, 2014).

groups in study designs, and implicit assumptions made by the authors. A paucity of in-depth exploration within the context of pregnancy outcomes has not discovered whether younger pregnant women have more fatalistic attitudes than older women, or whether there is a religious aspect to fatalistic attitudes.

Some literature suggests Muslims do not believe in abortion, unless there is a significant health risk to the mother, in which case it must then be completed within 120 days (Shaw, 2012). However, the Islamic fatwas[44] are often misunderstood or unknown; consequently, many Muslim women are reported to ascribe to the 'no abortion' attitude (Shaw, 2012; Koenig and Al Shohaib, 2014). This is reported to have an impact on the uptake of genetic screening, whereby Muslim women have been found to not utilise screening services, for a number of reasons (Section 2.5.3) (Irving and Ross, 1999; Dormandy *et al.*, 2005; Ahmed *et al.*, 2006; Rowe, *et al.*, 2008) and is a common explanation for increased rates of babies born with congenital anomalies (Section 2.2.8) (Koenig and Al Shohaib, 2014). This also demonstrates the inter-connected mechanisms of ethnicity (including religion), influences health beliefs and health behaviour and may contribute to birth outcomes.

Defining ethnicity for this study

Returning now to the issue of defining ethnicity, the above sections have shown the complexity of defining ethnicty, with the related concepts of langauge, religion and culture, and has shown how they are inter-linked and reciprocal (Patterson, 2014). Therefore, this study regards ethnicity as self-defined, dynamic in context, related to personal identity as well as social norms and therefore includes culture, religion and language (Triandis, 1989; Senior and Bhopal, 1994; Markus and

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[44] A fatwa is a religious rule, which becomes enmeshed in Islamic law (sharia) by religious scholars but is not explicitly mentioned in a Hadith or the Qur'an (Koenig, McCullough and Larson, 2001).

Hamedani, 2010). Consequently, for this study the concepts of language, religion and culture are encapsulated within an overarching definition of ‘ethnicity’.

This study uses the ONS (2011) census categories for self-declared ethnicity for WB, Pakistani and Bangladeshi women. Fixed self-report categories for ethnicity are acknowledged as being problematic (Aspinall, 1998), due to constraining people into selecting from a finite number of options, as their self-declared descriptor of ethnic affiliation (Burton, Nandi and Platt, 2008). For example, the major classification of ‘South Asian’ in the 2011 ONS census categories umbrellas the sub-groups of Indian, Pakistani, Bangladeshi and ‘*any other South Asian background’* into four homogenous groups, whereby ‘*any other South Asian background’* is a free-text box. Moreover, national identity[45] adds a further dimension to self-ascribed identity and the current ONS Census classifications do not fully capture the true essence of how individuals choose to define their identity, for example, self-identification as British Pakistani or Muslim. While acknowledging these limitations, implementing ONS Census (2011) categories does facilitate comparison of this research to other studies across England, the majority of which have used the census categories. In the context of the NHS, ethnicity is part of the ‘mandatory set’ – meaning it is mandatory information required in the records. The NHS uses 16+1 ethnic codes (Table 1) aligned with the ONS (2011) census categories (Department of Health, 2008; HSCIS, 2016).

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[45] National identity choices are: English, British, Scottish, Welsh, Northern Irish or other identity (free-text) (Office for National Statistics, 2011b).

Table 1: NHS Ethnic categories

NHS Ethnic categories	
White	
A	British
B	Irish
C	Any other White background
Mixed	
D	White and Black Caribbean
E	White and Black African
F	White and Asian
G	Any other mixed background
Asian or Asian British	
H	Indian
J	Pakistani
K	Bangladeshi
L	Any other Asian background
Black or Black British	
M	Caribbean
N	African
P	Any other Black background
Other Ethnic Groups	
R	Chinese
S	Any other ethnic group
Z	Not stated

An important principle behind gathering ethnicity data in the NHS is that the individual self-declares their ethnicity[46] and as such is not the interpretation of the HCP[47]. In theory, secondary data used in research from hospital records should, therefore, contain self-declared ethnic groups. In reality, whether this is the case may be questionable.

Evidence using ethnicity as a variable

Now that the concept of ethnicity has been discussed and defined for this study, the next few paragraphs will highlight how ethnicity has been used in the evidence base around perinatal

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[46] unless they refuse, in which case the Z category is used.
[47] with the exception of circumstances where a patient is unable to self-declare.

mortality. There are a growing number of studies in England that consider the role of ethnicity in adverse birth outcomes. National-level studies have been useful in showing certain patterning (Kiernan and Smith, 2003; Harding, Rosato and Cruickshank, 2004; Bradshaw *et al.*, 2005; Moser, Stanfield and Leon, 2008; Datta-Nemdharry, Dattani and Macfarlane, 2012; Dattani, Datta-Nemdharry and Macfarlane, 2012; Cresswell *et al.*, 2013; Henderson, Gao and Redshaw, 2013), such as higher prevalence rates of perinatal mortality in Pakistani women (Office for National Statistics, 2013b, 2015a), LBW in Bangladeshi women (Johnelle Sparks, 2009) and higher rates of smokers in WB women (Bansal *et al.*, 2014), however year-on-year there are discrete cohort differences (Office for National Statistics, 2013b, 2015a). Consequently, using data spanning several years helps to eliminate cohort effects.

Moreover, these studies typically utilise secondary data from hospital and/or civil records[48]. However, certain studies' results become limited by the lack of availability of confounding variables for adverse birth outcomes (e.g. maternal age, smoking status, the length of residency). Additionally, larger survey-based cohort studies[49] tend to be under-represented by BAME groups, which may be reflective of limited English language proficiency (Redshaw and Heikkilä, 2011; Henderson, Gao and Redshaw, 2013). It is quite likely that BAME respondents to paper-based survey methods are more likely to be British born or first generation British BAME, with a good level of English proficiency in addition to a solid understanding of maternity care systems in England (Section 2.5.4). Thus the perspectives of expectant migrants who were born overseas and who are less confident with navigating maternity services are not necessarily exposed.

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[48] see for example, Datta-Nemdharry *et al*, 2012; Cresswell *et al.*, 2013; or Moser *et al.*, 2008.

[49] Survey-based methods often use forced choice responses leading to some bias in the directionality of the research.

Furthermore, a review of the maternity literature demonstrates that quantitative studies using maternal ethnicity data and those that have included ONS data linked to either birth/death registrations or NS-SEC census data also uses self-defined ethnicity. Aspinall (1998) argues that this creates false homogeneity within groups. However, while this forced-choice ethnic assignment has value for public health level statistics (in addition to identification of certain patterning), the diversity found in factors such as SES, culture, religion, education and language within any ethnic assignment is not represented, consequently any aetiological mechanisms underlying any of these factors remain obscured (Bradby, 2003; Gunaratnum, 2003).

Within this body of evidence, often the category of South Asian is used, without further clarification to the breakdown of participants' ethnicity (i.e. Indian, Pakistani, Bangladeshi) (e.g. Dormandy *et al*, 2010), alternatively, authors do show specific ethnic categories and do not provide descriptive statistics (e.g. Ali, 2004), which has had the result of homogenising the narrative of Indian, Pakistani and Bangladeshi women into the broad category of South Asian, thus ignoring the diverse religious, cultural, language and SES factors that may have contributed to the participants' perspective. Moreover, commonly studies are specific to one ethnic group – epecially when looking at the narratives of South Asian women (e.g. Cross-Sudworth *et al.*, 2009 or Small, 2012). Consequently, accentuating differences contributes to 'othering' and uses an ethnocentric view (Crenshaw, 1991; Gunaratnum, 2003; Brah and Phoenix, 2004). It is also evident that Bangladeshi participants are particularly scarce within maternity qualitative research and with the exception of Woollett *et al*, (1995) and Homans (1980) no other studies have been identified that include the experiences of WB pregnant women. The consequence of this deficit within the current body of knowledge is that the similarities within the maternity experience among women of Pakistani, Bangladeshi and WB ethnicity are presently unclear.

Most of the existing research with Indian, Pakistani or Bangladeshi mothers uses the category of South Asian, despite heterogeneity between them. Furthermore, much of this existing research includes largely Pakistani mothers (Jessa and Hampshire, 1999; White *et al.*, 2006; Lowe, Griffiths and Sidhu, 2007; Shaw, 2011; Jafri *et al.*, 2015), with very few studies using Bangladeshi participants (Jayaweera, D'Souza and Garcia, 2005; Yeasmin and Regmi, 2013). The problem with the approach using a single ethnic group in one study design, is that it extenuates 'differences' in the participants of the study (Bartley, 2008). There are only two studies that have included WB women as a comparator to Pakistani or Bangladeshi women's experiences, which facilitates identification of similarities *and* differences (Homans, 1980; Woollett and Dosanjh-Matwala, 1990). While there are clearly important differences between Indian, Pakistani and Bangladeshi women in terms of their infant outcomes and SES contributing factors, (Katbamna, Bhukta and Parker, 2000; Baldwin and Griffiths, 2009; Stanfield *et al.*, 2012; Lucas, Murray and Kinra, 2013); consequently, aggregating data and outcomes for Indian, Pakistani and Bangladeshi families obscures subtle but significant differences, and in so doing will hinder the identification of distal and proximal determinants of perinatal and infant mortality within these communities.

The existing evidence has shown that there is ethnic patterning in perinatal mortality (Patel *et al.*, 2003; Gray, Hollowell, *et al.*, 2010; Kurinczuk *et al.*, 2010; Cantwell *et al.*, 2011; Draycott, Lewis and Stephens, 2011; Datta-Nemdharry, Dattani and Macfarlane, 2012). For example, Black Caribbean women have been identified as higher risk for maternal morbidity and infant mortality, attributed to single parentage that is observed within their culture (Feijen-De Jong *et al.*, 2012; Office for National Statistics, 2012b). Similarly, South Asian women (i.e. Indian, Pakistani, Bangladeshi) have been identified to be at higher risk of delivering smaller infants (Clarson *et al.*, 1982; Margetts *et al.*, 2002b; Kelly *et al.*, 2009; Khalil *et al.*, 2013), Pakistani mothers have been shown to have higher stillbirth rates, while Bangladeshi mothers give birth to more infants preterm (Freemantle *et al.*, 2009; Office for National Statistics, 2014b). Therefore some risk factors are more salient for Pakistani and Bangladeshi women than others.

Genetic factors

Heritability and genetic malformations contribute to congenital anomalies, in addition to the presence of certain health conditions during pregnancy, such as diabetes or obesity, with consequences to the morbidity and mortality of the foetus/infant (Macintosh *et al.*, 2006; Stothard, Tennant and Bell, 2009). Over 165 causes of congenital anomalies have been documented to contribute to stillbirth or infant mortality, which may be a consequence of genetic factors, including neural tube defects (NTD), chromosomal abnormalities such as Down's syndrome, single gene abnormalities as seen in autosomal recessive inheritance such as sickle cell and thalassaemia (SCT)[50] and Tay-Sachs, metabolic contributions evidenced when the mother has certain conditions such as diabetes and teratogens[51] (Kurinczuk *et al.*, 2010; Blackwell, 2015; World Health Organsiation, 2016b). There are two aspects when considering genetic factors; one is regarding identifying risk factors and the second in respect of screening. Screening during pregnancy helps to identify certain anomalies (although it is not always the case, as some anomalies might be identifed after birth) (Section 2.5.3) (Rowe, Garcia and Davidson, 2004).

Statistics show that the primary cause of death for perinatal mortality is immaturity related conditions (43.8 percent) followed by congenital anomalies (28.1 percent) (Office for National Statistics, 2013f). However, for babies delivered after 37 weeks, the most frequent cause of death was congenital anomaly (Office for National Statistics, 2013f). Families in routine and manual SES groups also experience approximately 33 percent more cases of congenital anomalies than more privileged SES groups (Kurinczuk *et al.*, 2010), demonstrating a social gradient. When ethnicity is considered, the figures then show that for WB infants the most frequent cause of death is

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[50] Found in people originating from Africa, Caribbean, Middle East, Asian or East Mediterranean.

[51] Pharmacological teratogens e.g. thalidomide, sodium valproate, warfarin, chemical teratogens, e.g. alcohol and infectious teratogens, e.g. rubella, cytomegalovirus, coxsackie and staphylococcus aureus (Kurinczuk *et al.*, 2010a).

immaturity related conditions, whereas for Asian[52] babies, it is congenital anomalies (Office for National Statistics, 2013f). Statistics have shown that globally and in England Pakistani infants have a higher prevalence of congenital anomalies compared with mothers of other ethnicities. Moreover, Pakistani families also experience high rates of perinatal mortality and have a high burden of morbidity associated with disabilities (Ahmad, 2000; Kurinczuk *et al.*, 2010; Office for National Statistics, 2014a). The reasons are unclear, but the typical explanation is that it is a consequence of consanguinity (Darr and Modell, 1988; Hamamy *et al.*, 2011; Child Death Overview Panel, 2013b; Gardosi, Madurasinghe *et al.*, 2013).

Examination of the wider literature on perinatal mortality shows that other risk factors have been identified contributing to congenital anomalies. For instance, the Born in Bradford (BiB) cohort study found that older maternal age was a factor (Sheridan *et al.*, 2013). Moreover, rates of congenital anomalies were found to be higher in mothers with diabetes (Macintosh *et al.*, 2006), and a systematic review and meta-analysis determined that maternal overweight was also a risk factor for congenital anomalies (Stothard, Tennant and Bell, 2009). Statistics have also revealed that SES factors play a role, with twice the risk identified for babies born in families in NS-SEC groups six and seven, in comparison to those born in families from NS-SEC one to five (Kurinczuk *et al.*, 2010). This shows that the mechanisms behind genetic risk factors are multifaceted.

During antenatal care, screening opportunities are offered to women to identify potential structural and genetic malformations of their foetus (Section 2.5.3). The aim of screening is for early identification and clinical management of identified problems which might include termination of pregnancy (or foeticide), if the problems are considered serious (Public Health England, 2014). These figures are not routinely considered alongside the statistics for perinatal mortality, however,

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[52] Defined as Indian, Pakistani Bangladeshi, and any other Asian background (Office for National Statistics, 2013f).

the 2014 statistics show that 51 percent of abortions were sought on medical grounds with only 2 percent (n= 3691) cited as a consequence of mental or physical disability to the child (Department of Health, 2015). The same year figures for stillbirth were 3284 and neonatal mortality was 4047, showing that a total 11,022 pregnancies ended in death (Office for National Statistics, 2015a).

Maternal age

Results from both the global evidence base and the UK literature, including Confidential Enquiries and cohort studies, consistently demonstrate that young (i.e. under 20 years of age) and older (over 35 years of age) maternal age presents a higher risk for adverse birth outcomes (Fretts, 2005; Draycott, Lewis and Stephens, 2011; Flenady *et al.*, 2011; Leon and Moser, 2012; Kenny *et al.*, 2013; Walker *et al.*, 2016). The findings repeatedly demonstrate a U-shaped curve (Gardosi, Giddings, *et al.*, 2013), although the proposed mechanisms are different between both extremes. For instance, younger mothers (<20 years old) are at increased risk of adverse birth outcomes for number of connected mechanisms including: inadequate maternal (and foetal) weight gain (Chen *et al.*, 2007; Harper, Chang and MacOnes, 2011), SES factors (Kang *et al.*, 2015), unplanned pregnancy (Behrman and Butler, 2007), health behaviours including substance misuse (Traviss, West and House, 2012; Bansal *et al.*, 2014), reduced engagement with antenatal services (Draycott, Lewis and Stephens, 2011; Ravelli *et al.*, 2011; Cresswell *et al.*, 2013; Nair *et al.*, 2014) inadequate nutritional consumption (Kramer, 1987), anaemia (Blomberg, Birch-Tyrberg and Kjølhede, 2014; Kang *et al.*, 2015), increased risk of IUGR (Gardosi, Giddings, *et al.*, 2013), psychosocial factors such as increased depression (Grote *et al.*, 2010) and the young women having immature reproductive organs (Kramer, 1987).

Conversely, older maternal age (>35 years old) has also been identified as a risk factor for adverse birth outcomes. In recent years, figures have shown that there is an increasing trend toward primipara in the later third decade; consequently, these women have a higher prevalence of comorbid pregnancy complications such as hypertension, diabetes and obesity (Heslehurst *et al.*, 2010; Draycott, Lewis and Stephens, 2011; Blomberg, Birch-Tyrberg and Kjølhede, 2014; Walker *et al.*, 2016). Furthermore, while fertility decreases with maternal age (i.e. over 35 years of age), there is an increased likelihood of the mother conceiving a dizygotic pregnancy (Beemsterboer *et al.*, 2006). Together, these factors present a more challenging clinical picture in addition to increased prevalence of perinatal mortality.

There are also differences between maternal age distributions and maternal ethnicity. The figures show that there are greater numbers of women from Pakistani and Bangladeshi origin conceiving at a younger age, compared to other ethnic groups (Moser, Stanfield and Leon, 2008b). For example, the North Western Perinatal Survey identified a higher proportion of WB mothers over the age of 35 giving birth; in contrast, a greater proportion of mothers of Pakistani and Bangladeshi origin were aged under 35 years old (Kenny *et al.*, 2013). Similarly, Leon and Moser (2012) identified 34.3 percent of Bangladeshi mothers as aged under 25 years of age, compared with 29.8 percent of Pakistani mothers and 27.7 percent of WB mothers.

2.5.3 Lifestyle factors (health behaviour)

The previous section (2.5.2) discussed the contribution of heritable factors (i.e. ethnicity, genetics and maternal age) on perinatal mortality. This section provides an explanation of health beliefs and health behaviour then presents the evidence of specific health behaviours that are currently addressed within the literature, with a focus on ethnicity. A growing number of qualitative studies in the UK have looked at experiences of South Asian women utilising maternity services (Homans, 1980; Woollett and Dosanjh-Matwala, 1990; Woollett *et al.*, 1995; Jessa and Hampshire, 1999; Katbamna, 2000; Ali and Burchett, 2004; Dartnall, Ganguly and Batterham, 2005; Ahmed, Green and Hewison, 2006; Lowe, Griffiths and Sidhu, 2007; Puthussery *et al.*, 2010; Raleigh, *et al.*, 2010; Dormandy *et al.*, 2010; Shaw, 2011, 2012; Twamley *et al.*, 2011; Bryant *et al.*, 2011; Cross-

Sudworth, Williams and Herron-Marx, 2011; Ali, McLean and Rehman, 2012; Jomeen and Redshaw, 2013; Psarros, 2014; Haddrill *et al.*, 2014). These studies have accessed the narratives of South Asian women at various stages along the maternity care pathway and provided valuable insight into their perceptions of their experiences.

Understanding maternity health beliefs and health behaviours

In recent years, there has been a growing interest in the role of health beliefs (i.e. knowledge, attitude and perceptions[53]) and health behaviour (i.e. lifestyle factors) and in understanding subsequent health outcomes (Sutton, 2004; Ogden, 2007). Especially since health beliefs are understood to demonstrate plasticity and are considered modifiable (Ogden, 2007; Conner, 2013). Beliefs are informed by perceptions and can be judgements, interpretations, predictions and conclusions (Chaffee and Roser, 1986). There are many influences on health beliefs, including personal factors such as personality, emotions, symptomology, and perception of risk, social norms, self-efficacy, emotion and motivation (Conner and Norman, 1999; Abraham *et al.*, 2008; Degni *et al.*, 2012). Furthermore, social influences such as religion, culture and social learning through early parenting (Ahmed *et al.*, 2006; Degni *et al.*, 2012). In addition, demographic and environmental factors, such as poverty, physical access to health care services, education level and health literacy which may also impact health beliefs and behavioural outcomes (Lucas, Murray and Kinra, 2013). Figure 9 depicts the personal, social and SES factors that shape individual knowledge, attitudes and perceptions, which constitute health beliefs and influence health behaviour.

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[53] ‘Knowledge’ is defined as understanding of a subject, ‘attitude’ is refers to emotional affect and ‘perception’ is defined as information that is obtained through physical or cognitive sensory awareness (UNICEF, 2011; Shyamanta and Hemendra, 2013).

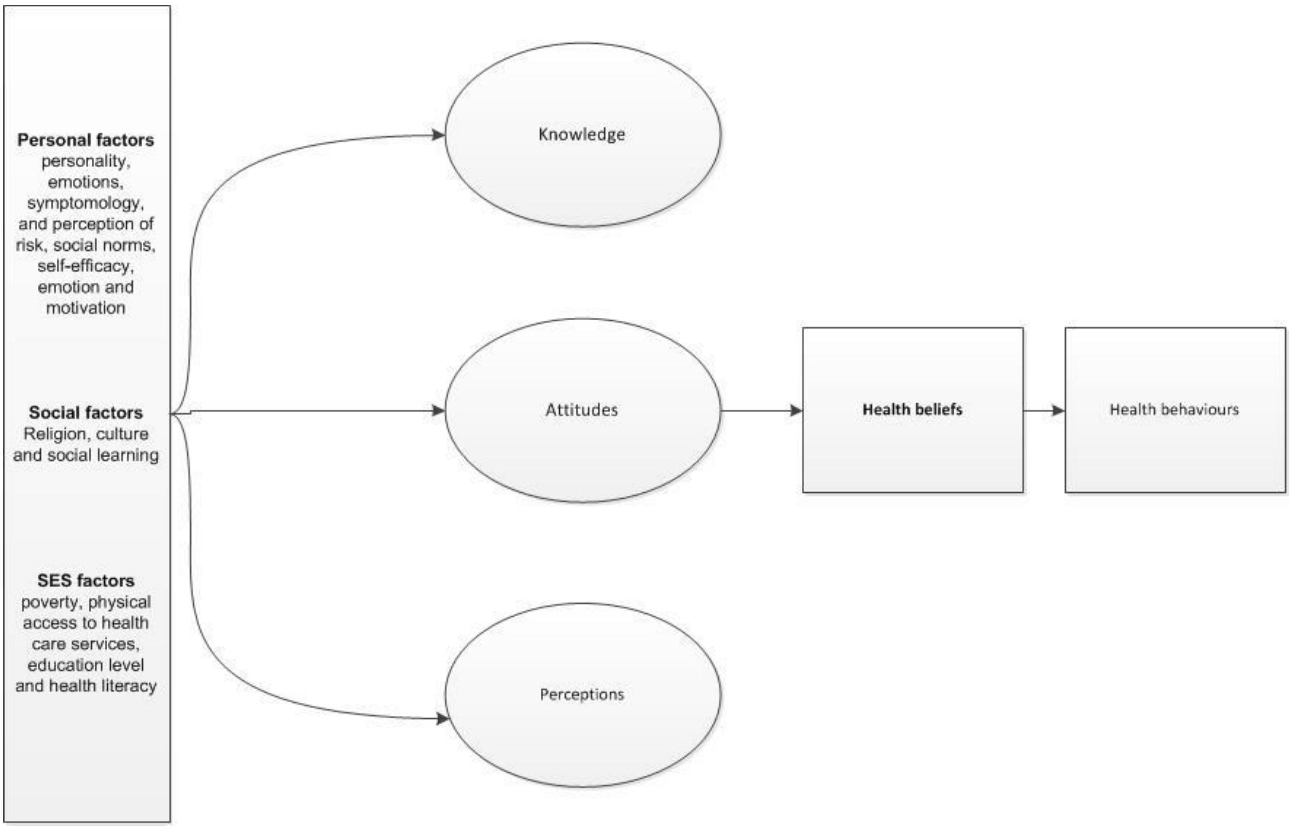

Figure 9: Diagram showing personal, social and SES factors that contribute to knowledge, attitude and perceptions, forming health beliefs.

Health literacy is variously defined in the literature, however this study will use the widely used definition proposed by Ratzan and Parker as '*the degree that individuals are able to process and understand health information, in order to make appropriate health decisions'* (Selden *et al*., 2000; pg 4). Therefore, on a practical level, education enables the use, navigation and implementation of maternity related information and together this promotes problem solving cognitions and healthful behaviours (Glanz, Rimer and Viswanath, 2008c). In other words, having a greater level of education will allow women to better understand health messages and be 'health literate' (Rubinelli, Kreps and Amann, 2014).

Moreover, the social gradient present in perinatal mortality, is influenced by health promoting behaviours that the mother undertakes (Hollowell, Kurinczuk, *et al.*, 2011). Mothers with less education will have less access to financial resource (such as high salary employment opportunities), more perceived life stressors (as a consequence of relative deprivation), less cognitive problem solving ability, and less understanding of basic health information (Benzeval *et al.*, 2014). Importantly, for women to make properly informed choices in their antenatal care[54], women need to understand the implications of their actions *and* inactions. Green and colleagues (2004) suggested that although women believed they had made ‘informed choices’ regarding their care, they failed to possess the degree of knowledge and understanding of the consequences of their actions (or inactions) to have actually made an informed decision (Green *et al.*, 2004). Interestingly, Sheridan and colleagues (2013) found maternal education at degree level was protective against congenital anomalies, in both WB and Pakistani mothers.

Several barriers to engaging in effective maternity care are related to maternal education and have been cited in the literature, salient for migrant mothers. For example, migrant mothers may not understand how the structure of the NHS maternity system works, or refugee mothers may be unsure of their entitlement or fearful of their legal status (Gissler *et al.*, 2009; Flanagan and Hancock, 2010), additionally with limited English language to understand the pregnancy information provided (Cross-Sudworth, Williams and Herron-Marx, 2011).

Therefore, the level of maternal education and degree of health literacy is clearly an important factor in birth outcomes, especially for non-English speaking or migrant mothers. However, education (and understanding) also interacts with other risk factors (e.g. individual, social or structural) mediating beliefs and behaviour and birth outcomes.

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[54] as advocated in the recent Maternity Review (National Maternity Review, 2016).

Health behaviour has been defined as '*activity undertaken for the purpose of preventing or detecting disease or for improved health and wellbeing'* (Conner & Norman, 2005; pg 2) and may include accessing information or remedies from several sources, including cultural therapies[55] such as: spiritual (e.g. through prayer) (Tarafder *et al*., 2013a), icons (e.g. rosary beads or charms) (Spector, 2004d), cultural beliefs (e.g. diet restrictions) (Grewal *et al*., 2008), herbalists (Tarafder *et al*., 2013a) and/or modern medicine (Small, 2012).

The current understanding of health belief to behavioural outcome process is multifaceted, whereby health beliefs are accepted as the foundation to which attitude develops (Hogg and Vaughan, 2008; Ogden, 2012). It is understood that if an attitude is strong it will be associated with a strong emotional affect; consequently, easily recalled and retrieved from memory (Maio and Haddock, 2010). This results in greater motivation to act in a particular way (Maio and Haddock, 2010). Also, the role of social norms[56] mediates belief systems, subsequent attitudes, which then influence behavioural outcomes, and are evidenced in a given series of behaviours (Taylor *et al.*, 2006; Maio and Haddock, 2010).

Therefore, health literacy, customs and cultural practice, past and peer behaviour, and vicarious learning combines and contributes to the complex mechanisms leading to health behaviours (Conner and Norman, 1999; Maio and Haddock, 2010). Together, these sources themselves are dynamic, dependent on evolving situational contexts between social actors, and are dependent on cultural context (Markus and Hamedani, 2010). For example, qualitative research exploring Pakistani and Bangladeshi women's barriers to using maternity services has shown that in Pakistani and Bangladeshi families, pregnancy is an expected and much-anticipated outcome

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[55] 'Cultural therapy' refers to knowledge and therapeutic health practices that are widely known and commonly practiced within a culture, and differs from biomedical health practices typically applied in the West. Cultural therapies may include: consuming herbs, prayer, icons, healers, and cultural concepts such as 'hot' and 'cold' (Singh-Bhopal, 1986; Spector, 2004b).

[56] Social norms are defined as the accepted group rules which constrain behaviour, (Bicchieri and Muldoon, 2014).

following marriage, in addition to providing women with an elevated social ‘status’ within their community (Choudhury and Ahmed, 2011).

Similarly, studies have shown that another normative belief in Pakistani and Bangladeshi families is surrounding the role of homemaker (following marriage and childbirth); consequently, the typical social norm is that women attend to household matters and look after children and older family members, in contrast to attending to their individual health needs (Dartnall, Ganguly and Batterham, 2005; Aston *et al.*, 2007b; Puthussery *et al.*, 2010; Jomeen and Redshaw, 2013). Consequently, different ethnic groups experience different perceived social norms, which exert greater or lesser pressure to comply with the perceived ‘normative’ situation within the particular ethnic group. Likewise, the norm in one ethnic group may be different to the majority norm; consequently, what is conceived as normal for each ethnic group may not converge, and may be perceived as deviant to each others norm.

Consequently, understanding how ethnicity provides various sources of dynamic information[57] which shape health beliefs, and differentially influences health behaviours in pregnancy, is an important consideration to understanding the experience of perinatal mortality, particularly since psychological and social contexts influence behaviour (Vaughn, Jacquez and Baker, 2009; Tarafder, Sultan and Rashid, 2013a). For example, attributing the cause of disease to the ‘will of God’ and not proactively seeking help from modern medical facilities (Bryant *et al.*, 2011) or utilising herbal therapy instead of pharmacotherapy, which will have an impact on women’s experience of perinatal mortality (Dartnall, Ganguly and Batterham, 2005). Despite the scope of

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[57] information or remedies from various sources: spiritual (e.g. through prayer) (Tarafder, Sultan and Rashid, 2013a), icons (e.g. rosary beads or charms) (Spector, 2004c), traditional beliefs (e.g. diet restrictions) (Grewal, Bhagat and Balneaves, 2008), herbalists (Tarafder, Sultan and Rashid, 2013a) and/or modern medicine (Small, 2012).

maternal health behaviours, the body of evidence on health behaviour in perinatal mortality is limited to specific behaviours which are mainly considered modifiable (Table 2).

Table 2: List of health behaviours in perinatal mortality

Health behaviour
Tobacco
Alcohol and substance misuse
Nutrition
Monitoring foetal movements
The booking appointment
Parity
BMI
Diabetes
Hypertension
Consanguinity

The existing evidence specifically on Pakistani, Bangladeshi and WB women's health beliefs and health behaviours during conception, pregnancy or the postnatal period in the UK is sparse. There are a growing number of studies that focus on specific health behaviours but treat the maternal population as a homogenous group, therefore understanding diversity in their health beliefs is obscured.

Evidence shows that specific health behaviours such as maternal smoking (Jayaweera *et al.*, 2005; Moser, Stanfield and Leon, 2008b; Traviss, West and House, 2012), maternal obesity (Heslehurst *et al.*, 2010; Penn *et al.*, 2014), comorbid diabetes mellitus or hypertensive disorders (Macintosh *et al.*, 2006; Khalil *et al.*, 2013; Penn *et al.*, 2014), maternal depression and women who are victims of domestic abuse (Price, 2007; Grote *et al.*, 2010; O'Reilly, Beale and Gillies, 2010; Loret de Mola *et al.*, 2014; Quispel *et al.*, 2014) can contribute to adverse birth outcomes. Furthermore, the quality of nutritional intake also contributes to optimal foetal development (Jessa and Hampshire, 1999; Rees *et al.*, 2005; Pittas *et al.*, 2007; Hossain *et al.*, 2011; Akhtar *et al.*, 2013). Additionally, health literacy also contributes to health behaviours through adherence to recommended care and engagement with healthcare services (Raatikainen, Heiskanen and Heinonen, 2007; Arntzen *et al.*, 2008; Yadav and Lee, 2013). Attention will now briefly turn to evidence on health behaviours in perinatal mortality, as presented in Table 2.

Tobacco

The contribution of maternal smoking on LBW is well understood, and studies have shown that smoking during pregnancy results in infants weighing 200g less (Bonellie, 2001; Chang *et al.*, 2013). Other documented complications include increased likelihood of IUGR, PTB, miscarriage and physical and cognitive developmental impairment (Lowry and Scammell, 2013). Additionally, teenagers are six times more likely to smoke than older women (Lowry and Scammell, 2013). Studies have also shown that there is a social gradient in smoking behaviour, with much higher numbers of women smoking from lower SES groups (Graham and Der, 1999; Lowry and Scammell, 2013). Moreover, Behrman and Butler argue that consideration of smoking prevalence in isolation without consideration of social context is misleading (Behrman and Butler, 2007).

The national prevalence of pregnant smokers is 12 percent. However, local figures have shown that Luton’s prevalence is 21.9 percent (Bedfordshire Clinical Commissioning Group, 2013). This equates to approximately 1000 maternities in Luton per year at risk of complications of maternal smoking. Figures have also shown that there is a clear ethnic variation in smoking behaviour, with high rates of WB smokers. Conversely, there are low rates of smoking behaviour in Pakistani and Bangladeshi pregnant mothers (Bedfordshire Clinical Commissioning Group, 2013).

Very few studies consider whether smokeless tobacco (ST) is used. ST is embedded within the social and cultural practices in south-east Asia (Gupta and Ray, 2003) and is a chewable form of tobacco, found in the form of *betal nut*, *quid*, *gutka*, or *paan* (Núñez-de la Mora, Jesmin and

Bentley, 2007). Studies have found that consumption was higher in older women and especially in Bangladeshi women and is utilised to reduce the symptoms of morning sickness (Núñez-de la Mora, Jesmin and Bentley, 2007; Messina *et al.*, 2013).

A number of studies have reported risks in ST use associated with stillbirth PTB, LBW and increased risk of miscarriage (Gupta, Subramoney and Sreevidya, 2004; Núñez-de la Mora, Jesmin and Bentley, 2007; Yakoob *et al.*, 2009; Inamdar *et al.*, 2015), although a recent systematic review assessing maternal ST use during pregnancy did confirm associations between ST use and adverse birth outcomes, although there were some doubts over methodological rigor (Inamdar *et al.*, 2015).

At present, there is little guidance on ST consumption in pregnancy. Consequently, maternity services are not specifically aware of its use, and unable to determine associated risk (The National Institute for Health and Care Excellence, 2012; O'Connor, 2015). Recent guidance on smoking cessation in pregnancy omitted the inclusion of ST products completely (O'Connor, 2015) and another publication sought only for more research on the use of ST in pregnancy (Lowry and Scammell, 2013). Moreover, although ST is legally required to have warnings on packages, 15 percent of ST packages fail to do so (Longman et al., 2010), consequently many users are unaware of the tobacco content and associated health risks (The National Institute for Health and Care Excellence, 2012). Clearly, ST is a risk factor and pregnant consumers are unlikely to be identified as being at risk, in addition to a lack of risk-reducing health information being provided.

Alcohol and substance misuse

The complications related to alcohol and substance misuse during pregnancy is well documented in the literature. Moreover, alcohol and substance misuse are associated with complex social environments (Grant *et al.*, 2014). Alcohol consumption, in particular during the first trimester contributes, to SGA, PTB, stillbirth and IUGR babies, in addition to foetal alcohol spectrum disorder (FASD) (Nykjaer *et al.*, 2014; Royal College of Obstetricians and Gynaecologists., 2015). FASD results in lifelong morbidity associated with cognitive, emotional and developmental disorders (Royal College of Obstetricians and Gynaecologists., 2015).

A recent study has shown that over 60 percent of women reported consuming alcohol above the recommended guidelines prior to conception and 50 percent of women during the first trimester (Nykjaer *et al.*, 2014). This may be a consequence of the high percentage of unintended pregnancies (Rashid, 2007; Dhillon and Macarthur, 2010), resulting in adverse maternal health behaviour. However, Nykjaer *et al*., (2014) did not collect data on maternal ethnicity. Studies including maternal ethnicity have shown that Pakistani and Bangladeshi pregnant mothers report not consuming alcohol during pregnancy, in contrast to WB women, where figures show that 8–50 percent of WB mothers consume alcohol in the first trimester (Hawkins *et al.*, 2008; West, *et al.*, 2014). Some caution is required in accepting self-reports of alcohol consumption at face value, particularly since it may be considered an invisible behaviour or taboo (Glanz, Rimer and Viswanath, 2008a). That said, these figures suggest that more WB women are at risk of complications from alcohol consumption during pregnancy than Pakistani or Bangladeshi mothers.

Nutrition

There are studies over the last two decades that have looked at the role of nutrition (e.g. folic acid, vitamin D, and micronutrients) in adverse birth outcomes. In the absence of robust experimental designs testing reduced nutrition during pregnancy on birth and subsequent morbidities (which are wholly unethical), the Dutch Famine cohort study offered a unique opportunity to study nutritional growth restrictions on the life-course development of chronic diseases (Roseboom *et al.*, 2001). Reduced glucose tolerance has been associated with LBW and associations with insulin dysfunction have been observed in adults originating from IUGR pregnancies (Roseboom *et al.*, 2001). Moreover, vitamin D deficiency has also been associated with insulin dysfunction (Pittas *et al.*, 2007; Robinson *et al.*, 2014) and has been found to be highly prevalent in South Asians living in the UK (Hyppönen and Power, 2007; Tahrani *et al.*, 2010). Together this suggests that maternal nutrition, specifically vitamin D, mediates birth outcomes as a distal determinant.

Moreover, the timing of maternal malnutrition during gestation has been shown to impact upon specific organ and cell development, critical to the corresponding developmental temporal window (Roseboom *et al.*, 2001). In other words, as the foetus develops during the gestation period in the uterus, there are critical periods where particular cells develop, and more recent studies have shown dysfunction in these developing cells which have consequences further along into the physical health status of the individual (Roseboom *et al.*, 2001; Silverwood *et al.*, 2013).

The benefits of the consumption of folic acid preconception and during the first trimester is now well established in helping to reduce the incidence of NTD (Jessa and Hampshire, 1999; Yakoob *et al.*, 2009; Lassi *et al.*, 2013; Hodgetts *et al.*, 2015); although a recent Cochrane review concluded that folic acid was not beneficial for reducing perinatal mortality or PTB, evidence was found to support improvement in mean birth weight (Lassi *et al.*, 2013). Studies have shown that the timing of ingestion of folic acid is crucial; it is required for embryogenesis (Royal College of Obstetricians and Gynaecologists, 2003). However, the prevalence of preconception intake of folic acid is reported to be between 10.4–31 percent (Tort *et al.*, 2013; Bestwick *et al.*, 2014), with the reported intake for South Asian women being less (20 percent) (Bestwick *et al.*, 2014). This may be due to the large numbers of unplanned conceptions and/or due to ineffective public health awareness (Wellings *et al.*, 2013).

Vitamin D deficiency is associated with a range of health problems including altered immune function, cardiovascular disease, insulin secretion and diabetes (Tahrani *et al.*, 2010; Robinson *et al.*, 2014). It is thought to contribute to pre-eclampsia, foetal lung development and hypocalcaemia (Robinson *et al.*, 2014). Moreover, there have been no studies to date showing the direct effect of vitamin D deficiency and perinatal mortality. However, while the research evidence in respect of the benefits of nutritional supplements is inconsistent and inconclusive (Eggemoen *et al.*, 2016; Palacios *et al.*, 2016) one study conducted in East London showed that antenatal vitamin supplementation in South Asian mothers appeared to increase the birth weight and infant developmental growth over 12 months (Brooke, Butters and Wood, 1981).

Vitamin D deficiency is more prevalent in younger mothers (Kwan *et al.*, 2007), South Asian communities (in Britain) (Toher *et al.*, 2014; Eggemoen *et al.*, 2016) and a social gradient has also been identified (Kwan *et al.*, 2007). Current explanations include the cultural practice of *purdah* (Holick, 2009), poor nutritional intake (Hossain *et al.*, 2011), and residence in northern European countries with restricted access to ultraviolet rays (Kwan *et al.*, 2007). In view of the paucity of supportive evidence clinical guidelines have recommended supplementation for women perceived at risk: South Asian women, low-income families, obese, women who practice purdah, women whose diets exclude dairy produce and fish, and women aged 19–24 years (The National Institute for Health and Care Excellence, 2010a). The extent to which the NICE guidance is followed in regard of vitamin D supplementation is unclear due to a lack of research evidence.

Monitoring foetal movements

Foetal movements (FM) are usually detected 18–20 weeks of gestation and are indicative of foetal wellbeing (Froen, Heazell, *et al.*, 2008). FM are perceived by the mother and may involve hiccups, vigorous or reduced movement (Linde and Rådestad, 2015). Reduction in FM is considered a significant clinical sign and has been observed in 55 percent of stillbirths (Efkarpidis *et al.*, 2004; Unterscheider *et al.*, 2009). Furthermore, it has been found to be a consequence of acid-base disorders resulting in reduced oxygenation to the foetal muscles (Darby-Stewart *et al.*, 2009), placental insufficiency (Froen, Tveit, *et al.*, 2008), sedating substances such as alcohol and opioid medication which cross the placenta and may temporarily decrease FM. Moreover, studies have shown that cigarette smoking may also contribute to decreased movements (Manning, Wyn Pugh and Boddy, 1975), in addition to elevations in plasma glucose levels (Robertson and Dierker, 2003) and perceptions of movements in obese mothers have also been identified as being unclear (Hofmeyr and Novikova, 2012).

A recent qualitative study involving mothers who had suffered perinatal bereavement showed that almost 66 percent of mothers had insight that something was wrong, either as a consequence of symptoms they experienced, such as reduced movements, or a feeling that things ‘weren’t right’ (Redshaw, Rowe and Henderson, 2014). The finding regarding ‘intuition’ that the Redshaw and colleagues (2014) study found was replicated with another recent international survey by Warland *et al* (2016), who found 73.4 percent of their respondents reported a ‘gut feeling’ that something was wrong. The authors also identified that the largest proportion of their sample (30.5 percent) also reported a reduction in FM, in addition to reports of increased FM prior to death (Warland *et al.*, 2015). What is interesting to note, is that FM is considered the best indicator for infant wellbeing (Froen, Heazell, *et al.*, 2008), yet the Linde *et al* (2016) study identified that women often mistook uterine contractions for foetal movements – suggesting that women aren’t really confident on what they are feeling and this might be especially true if this is a first pregnancy.

Mothers are encouraged to monitor their babies' movements; make time to do this each day and report any decrease in movements without delay for further investigation (Unterscheider *et al.*, 2009). However, a Cochrane review (Hofmeyr and Novikova, 2012) determined that formal movement charts were not found to be beneficial, which was supported by a recent systematic review (Winje *et al.*, 2015). While the evidence base remains unclear, educational messages to mothers are ambiguous and may result in delays in seeking help. Notwithstanding this, the evidence appears consistent with the findings that there are often 'changes' in the pattern of movements prior to infant death and the evidence suggests that the majority of women do appear to sense something is wrong.

The 'booking' appointment

Pregnant women are required to book into NHS maternity services ideally between 8 and 10 weeks of gestation[58], to access timely screening services, which aims for early identification of risks to the mother (e.g. gestational diabetes or pre-eclampsia) and foetus (e.g. IUGR) (The National Institute for Health and Care Excellence, 2010c). This booking appointment serves to fully assess the mother for potential risks and counsel her to make an informed decision for screening opportunities. Confidential Enquiries have shown that booking into services after the 12th gestational week of pregnancy[59] is associated with increased risk of maternal mortality and infant morbidity and mortality (Centre for Maternal and Child Enquiries, 2011b; Knight *et al.*, 2015).

Despite the UK Confidential Enquires showing how important early booking into maternity services is for maternal and foetal outcomes (Lewis, 2012), few studies have assessed late booking including maternal ethnicity or country of birth as a variable to determine the contribution in adverse outcomes (Rowe, *et al.*, 2008; Gardosi, *et al.*, 2013). However, these studies have

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[58] as recommended by NICE (CG62) (2008).

[59] 12 weeks and 6 days.

confirmed that BAME women often book later into maternity services (Rowe and Garcia, 2005; Rowe, *et al.*, 2008; Tucker *et al.*, 2010; Gardosi *et al.*, 2013; Redshaw and Henderson, 2014).

Furthermore, Black Caribbean mothers have been consistently identified as the highest proportion of mothers who book late into services; another study showed that Pakistani mothers have been identified as accessing antenatal services after 18 weeks of gestation (Kupek *et al.*, 2002). Cresswell and colleagues (2013) found that 71.4 percent of WB mothers were booked by 12 weeks, compared with only 64.9 percent of Pakistani mothers and 61.7 percent of Bangladeshi mothers. Several reasons have been cited for this, including limited English proficiency (Cresswell *et al.*, 2013), difficulties in understanding how to access and utilise the maternity service (compounded by non-English speakers or migrants) (Hatherall *et al.*, 2016), women born outside the UK or single mothers (Rowe and Garcia, 2005), younger maternal age, smoking and substance misuse and lower educational attainment (Raatikainen, Heiskanen and Heinonen, 2007).

There are inconsistencies in the literature regarding the precise timing and definition of late booking. Rowe *et al*. (2008) defined late booking as after 18 weeks of gestation, Cresswell *et al*. (2013) used 12 weeks, Gardosi *et al.* (2013) used <13 weeks of gestation, Schaaf *et al*. (2012) used 18 weeks. This study will use 12 weeks of gestation, determined by mothers' self-report or hospital records to define the threshold for early booking. Therefore, after 12 weeks will be considered as 'late' booking.

Screening uptake

The evidence assessing antenatal screening uptake in South Asian populations in England is limited (Modell *et al.*, 2000; Dormandy *et al.*, 2005, 2008, 2010; Rowe, *et al.*, 2008; Yu, 2012). Consequently, the reasons for poor uptake are not entirely elucidated. Some studies have suggested that women were not actually offered Down's syndrome screening (Rowe and Garcia, 2003; Rowe, Garcia and Davidson, 2004; Rowe, *et al.*, 2008) and poor uptake is evidenced in women from ethnic minority and socially deprived groups (Dormandy *et al.*, 2005). Aldedice *et al* (2010) found that women that were socially deprived and educationally disadvantaged were less likely to have antenatal screening tests. Taken together this is suggestive of inequalities in antenatal screening.

Some studies indicate inconsistency in SCT screening uptake by maternal ethnicity (Yu, 2012). For example, Dormandy and colleagues (2008), found a 67 percent SCT screening uptake in their cohort study across two Primary Care Trusts in deprived UK cities and this did not alter proportionally by the maternal ethnic group. Conversely, as part of the UK Confidential Enquiry into counselling for genetic disorders, Modell and colleagues (2000) found both regional and ethnic variation in uptake for the screening of major *β*-thalassemia, in addition to South Asian (Indian, Pakistani and Bangladeshi) mothers being substantially less likely to be offered screening during their first and all subsequent pregnancies. Nevertheless, the literature does indicate a trend of reduced uptake for antenatal screening uptake in South Asian women. A review of the qualitative literature reveals some insight into the reasons for this.

A small number of qualitative studies have explored the reasons for the low uptake of antenatal screening in South Asian women. Ahmed *et al.* (2006) interviewed 43 pregnant Pakistani women who had undertaken carrier status screening for *β*-thalassemia. The findings showed that the majority of women wanted to know the carrier status for practical reasons. Moreover, this would not influence the uptake of termination. Participants also revealed fatalistic attitudes and trust in God, which on the one hand represents religious attitudes, but may also correspond to deprived social and education backgrounds (Ahmed, Green and Hewison, 2006; Bittles, 2013). A further qualitative study has made a substantive contribution to the body of knowledge around the complexity of cultural practice of consanguinity and religious attitudes to screening (Ali, McLean and Rehman, 2012). Both studies' results showed that women were consensual to some screening tests but tended to decline others (i.e. Down's syndrome or other heritable conditions) due to perceptions of being coerced to undertake terminations which was not considered an option for Muslims (Ahmed, Green and Hewison, 2006; Ali, McLean and Rehman, 2012). Additionally, the contribution of Shaw (2012) highlights the lack of knowledge, understanding and practice of Muslim religion from both the perspectives of families and healthcare providers. Shaw (2012) identified that families would typically seek advice from authoritative figures regarding the ethically challenged decisions in addition to assumptions made by HCP regarding Muslims' reproductive decisions. Collectively, these findings suggest several factors including religious beliefs, social and educational factors, lack of informed choice and poor knowledge or understanding of fatwas contributing to reproductive decisions around screening uptake and terminations in British Pakistani families (Ali, McLean and Rehman, 2012; Shaw, 2012).

There is further contradictory evidence to reproductive behaviours when the termination rates for foetal anomaly were examined in the BiB study, showing that 59 percent of Pakistani mothers compared to 32 percent of WB mothers sought terminations for foetal abnormalities (Sheridan *et al.*, 2013). Furthermore, when national statistics (2014) are reviewed, considering the maternal ethnicity of mothers undertaking abortions, figures show nine percent of South Asian and 77 percent of white mothers access termination services, a difference to population statistics, suggesting that proportionally more South Asian women utilise termination services (Department of Health, 2015a). Therefore, contradictory to popular understanding that Pakistani and Bangladeshi women don't terminate pregnancies (due to religious beliefs), the national figures suggest otherwise. Although the exact reasons for their terminations remains unknown, the majority of terminations were classified as:

> *"the pregnancy has not exceeded its twenty-fourth week and that the continuance of the pregnancy would involve risk, greater than if the pregnancy were terminated, of injury to the physical or mental health of the pregnant woman"* (Department of Health, 2015: pg 8)

while only 2 percent of terminations are sought on the grounds of:

> "*There is a substantial risk that if the child were born it would suffer from such physical or mental abnormalities as to be seriously handicapped."*
>
> (Department of Health, 2015: pg 8)

This information, when taken together, suggests that there are barriers to screening uptake from both the staff and mothers' perspectives. For example, staff not offering particular screening tests (which may be due to false assumptions of women's religious beliefs), mothers misunderstanding the purpose of the screening (i.e. early identification of risk) and making their own assumptions and fears about being forced to abort their pregnancy if results identify an abnormal result and women not properly understanding the fatwas (Ahmed, Green and Hewison, 2006; Ali, McLean and Rehman, 2012).

Parity

Parity refers to the previous number of deliveries[60] a woman has experienced and is associated with increased risk of perinatal mortality, although the mechanism is not clearly understood (Shah, 2010). Monitoring through epidemiological studies has continually shown that parity is an independent risk factor for perinatal mortality; in particular, primipara, and women who have had in excess of four term pregnancies (Kiernan and Smith, 2003; Bollini *et al.*, 2009; Shah, 2010; Redshaw and Heikkilä, 2011; Penn *et al.*, 2014).

Parity as a risk factor is temporal across the reproductive life-course, and follows a similar U-shaped curve as evidenced in maternal age (Section 2.5.2). For example women aged <20 years of age may experience a number of complications including a higher risk of pre-eclampsia, IUGR

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[60] Referring to delivery of infant < 24 weeks of gestation.

and poor nutritional status (Kramer, 1987; Shah, 2010; Gardosi, Giddings, *et al.*, 2013). Conversely, older women who are more likely to have had previous pregnancies also experience (different) complications, such as hypertension, obesity and diabetes (Heslehurst *et al.*, 2010; Draycott, Lewis and Stephens, 2011; Blomberg, Birch-Tyrberg and Kjølhede, 2014).

Figures for England (2008–2014) also show that parity varies according to ethnicity: 67.9 percent of Pakistani mothers delivering infants during these years had more than three children, compared with 37.8 percent of Bangladeshi mothers and 11.4 percent of WB mothers (Office for National Statistics, 2016b). Similarly, studies identified that parity of 1 and ≥ 5 was associated with stillbirth (Gardosi *et al.*, 2005; Aminu *et al.*, 2014; Penn *et al.*, 2014), suggesting that Pakistani mothers (with a higher parity) are at risk.

BMI

Obesity has recently been identified as a significant contributory factor in stillbirth and congenital anomalies (Shai *et al.*, 2006; Stothard, Tennant and Bell, 2009; CMACE, 2010; Klebanov, Evans and Brooks-Gunn, 2014). Obesity is also a risk factor for diabetes (Shai *et al.*, 2006; Whincup *et al.*, 2010) and vitamin D deficiency (CMACE, 2010). Recently, Penn and colleagues (2014) identified South Asian ethnicity *and* obesity is a risk factor for stillbirth. However, what is unclear is how South Asian ethnicity may increase this risk.

Therefore, it is clear that maternal obesity increases a mother's risk profile during pregnancy, in addition to South Asian ethnicity. The World Health Organisation (WHO) categorises a BMI equal to or greater than 25 as 'overweight', equal to or greater than 30 as 'obese', and equal to or less than 18.5 as 'underweight'. Figures have suggested that Pakistani women are more likely to be obese than their Bangladeshi counterparts who are more likely to be underweight (Han *et al.*, 2011; National Obesity Observatory, 2011). Importantly, the clinical management and risks of overweight and underweight are different (National Institute for Health and Care Excellence, 2008; The National Institute for Health and Care Excellence, 2010b, 2010c, 2013; NICE (National Insitute for Health and Care Excellance), 2014).

In 2013, the National Institute of Clinical Excellence published new guidance on the BMI of South Asian populations (The National Institute for Health and Care Excellence, 2013), whereby the previous BMI anthropometrics are considered too high for South Asian people, and a BMI of $23kg/m^2$ is the threshold for overweight, and $27kg/m^2$ for ‘high risk’. Therefore, individuals previously classified as a normal weight range (i.e. $20kg/m^2$ to $25kg/m^2$) would now be considered as overweight/obese and interventions to reduce weight and the risk of other comorbid factors such as hypertension and diabetes need to be implemented (The National Institute for Health and Care Excellence, 2013).

Worryingly, these guidelines have not translated to the current NICE guidelines for pregnancy, antenatal care or diabetes in pregnancy. Correspondingly Pakistani women in particular remain at high risk of perinatal and infant mortality, by a number of compounded comorbid mechanisms: higher BMI (National Obesity Observatory, 2011) (especially if the new BMI anthropometrics for South Asian people is applied), higher risks of comorbid diabetes (Shai *et al.*, 2006; Gardosi, Madurasinghe, *et al.*, 2013) and not currently being identified as diabetic through the maternity care pathway (MBRRACE-UK, 2015a).

Despite the high risk of complications as a consequence of a raised BMI, the Centre for Maternal and Child Enquiries (CMACE) found that 20 percent of mothers did not have a BMI recorded in their records and only 31 percent of mothers had repeated measurements (CMACE, 2010). Maternal obesity also suggests a poor quality diet (and reduced folic acid intake) and reduced exercise-related behaviour and has been shown to be more restrictive of a natural birth process (Kerrigan and Kingdon, 2010).

Diabetes

Diabetes mellitus (DM) has been shown to contribute to maternal and infant complications including stillbirth and congenital anomalies, although the precise mechanisms are presently unclear. A systematic review by Baker and colleagues (2011) identified that women diagnosed with gestational diabetes (GDM) were more likely to be older, obese, less well educated and typically not employed; suggestive that health behaviour plays a role in GDM (Baker *et al.*, 2011).

The prevalence of GDM is increasing and it is estimated to affect 5 percent of pregnancies. The figure increases to 30 percent if the mother has previously suffered from GDM (Diabetes UK, 2015).The prevalence of GDM varies between mothers from different ethnic groups. Research has shown that South Asian women have an increased risk of developing GDM (Thorpe *et al.*, 2005; Ferrara, 2007; Makgoba, Savvidou and Steer, 2012; Bryant *et al.*, 2014a; Sanchalika and Teresa, 2015). Research has also shown that South Asian people are at a higher risk of developing diabetes through their life course (Shai *et al.*, 2006; Hawkes, Gomez and Broutet, 2013; Farrar *et al.*, 2015) and especially GD (Makgoba, Savvidou and Steer, 2012; Bryant *et al.*, 2014).

Research has suggested a number of factors that may be connected. For example, Pakistani infants have been shown to have greater central adiposity (West *et al.*, 2013), which is a risk factor for developing type II diabetes and cardiovascular disease (Barnett *et al.*, 2006). Additionally to accelerated weight gain in the first 12 months of life (Bansal *et al.*, 2008), which has been observed in the accelerated catch-up growth of PTB or LBW infants (Cianfarani, Germani and Branca, 1999). Furthermore, the early programming hypothesis suggests in utero environment mediates adult health and if a higher prevalence of South Asian mothers have GD or DM, then the foetus may also have higher blood glucose levels, resulting in a greater chance of developing adult obesity (although at present the these findings did not reach statistical significance) (Berglund *et al.*, 2016). Therefore, the process explaining the increased prevalence of DM and GD found in South Asians, maybe somewhat cyclical throughout the life-course as the diagram below illustrates (figure 10).

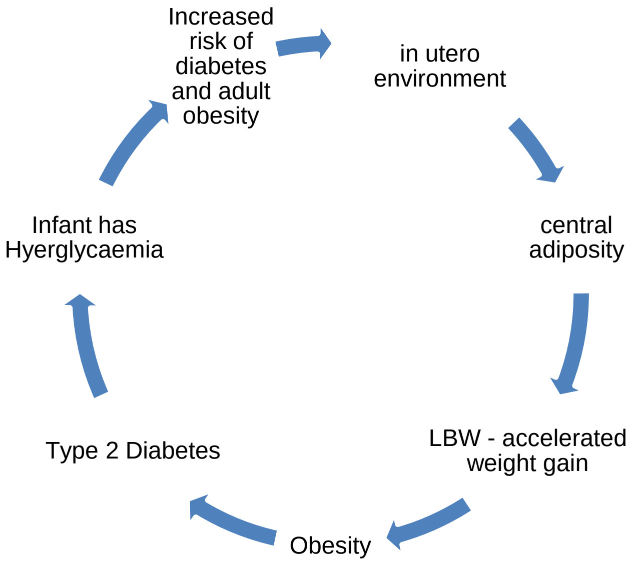

Figure 10: Potential cyclical risk of developing DM and GDM

There is a substantial evidence base on pre-existing diabetes in pregnancy, but there are only two UK based studies which have examined the prevalence of GDM comparing South Asian and White European/British pregnant mothers. Makgoba and colleagues (2012) used retrospective data which included over 15,000 pregnancies from South Asian women across North West London. They demonstrated that GDM had a prevalence of 1.9 percent in South Asian women compared with 0.7 percent in White European women, of which 25 percent of South Asian women required insulin treatment in comparison to only 14.7 percent of white European women (Makgoba, Savvidou and Steer, 2012).

This suggests that optimal blood glucose levels are not clinically achieved in South Asian women during pregnancy and the reasons for this are unknown. It may be a consequence of poor dietary management, low adherence to pharmacotherapy, poor treatment response or a combination of factors. The BiB cohort study has also published prevalence rates for diabetes (DM) in WB and South Asian women, showing similar rates between Pakistani and WB women. The authors of this study conclude that there were no real differences in DM prevalence in women from different ethnicities, including South Asian and WB women (Sheridan *et al.*, 2013). The BiB results for DM ranged from three to five percent, which were slightly lower than recently published national figures[61].

Prevalence rates across individual studies vary, as a consequence of researchers focusing on pre-existing DM (type 1 or 2) or GDM (Carolan, 2013). Furthermore, the lack of consensus in clinically relevant diagnostic thresholds has also contributed to heterogeneity between studies and subsequent research outcomes (Ferrara, 2007). Furthermore, sample sizes of South Asian populations included in the previous research are varied, and Pakistani and Bangladeshi women are aggregated into one homogenous group, i.e. South Asian, rather than recognising the separate ethnic groups making up the South Asian category, or alternatively the category of ‘South Asian’ has been used to report findings that are specific to Pakistanis (Nazroo and Williams, 2006; Sheridan *et al*., 2013).

Hypertension

Hypertension, gestational hypertension and pre-eclampsia are known risk factors for maternal and infant morbidity and mortality, with hypertension during pregnancy being one of the main causes of maternal death (Turner *et al.*, 2010), perinatal mortality and foetal syndrome[62] (Sibai, Dekker and Kupferminc, 2005). In 2010, the perinatal mortality report found that five percent of stillbirths

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[61] 5 percent for GDM and 6.2 percent for DM (UK average) (Diabetes UK, 2015).

[62] Reduction in amniotic fluid, IUGR and dysfunctional oxygenation (Sibai, Dekker and Kupferminc, 2005).

occurred in mothers with pre-eclampsia (Centre for Maternal and Child Enquiries, 2011a), while Penn and colleagues (2014) found a 50 percent increase in stillbirth with mothers who had hypertension. Moreover, more than 50 percent of preterm infants are born to mothers with pre-eclampsia and a further 20 to 25 percent of infants are born with IUGR (Turner *et al.*, 2010). Furthermore, concomitant risk factors for adverse outcomes include diabetes, renal disease, and autoimmune disorders with hypertension elevating the risk to high risk (Turner *et al.*, 2010). This shows that hypertension in pregnancy is an important risk factor in stillbirths.

In examining the existing literature on hypertensive disorders in pregnancy, ethnicity, and perinatal mortality or adverse birth outcomes it is clear that there are conflicting findings. For instance, one study has shown that South Asian ethnicity, combined with hypertension or pre-eclampisa were associated with preterm delivery[63], and SGA infants (Khalil *et al.*, 2013), while another study found hypertension was an independent risk factor for stillbirth in South Asian mothers (Penn *et al.*, 2014). Conversely, West *et al* (2014) found that Pakistani women were less likely than WB women to be hypertensive and the greater risk was gestational diabetes (West, *et al.*, 2014), similar to the findings from Bryant *et al* (2014). Similarly, Primatesta and colleagues (2000) found that South Asian mothers had equivalent rates of hypertension as White women, as did the recent BiB Study (Mceachan, 2012). It is highly likely that the differences are methodological artefacts. What is accepted is that hypertension is a risk factor for adverse outcomes for mother and infant.

Consanguinity

The cultural practice of consanguinity is the marriage of close biologically related family members (Grant and Bittles, 1997) and is more prevalent within the Pakistani community than the Bangladeshi community or Indian communities (Hamamy *et al.*, 2011; Bittles, 2015). It has been estimated that up to 49 percent of marriages in British Pakistani families are consanguineous (Public Health England, 2016) and it is widely understood that consanguineous unions have a

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[63] A risk factor for infant mortality and morbidity.

higher rate of autosomal recessive disorders (meaning that both parents need to be carriers in order for the gene mutation to become expressed as a disorder) (Darr and Modell, 1988; Grant and Bittles, 1997; Søgaard and Vedsted-Jakobsen, 2003). Furthermore, autosomal recessive genetic disorders are particularly prevalent in certain consanguineous populations such as the Ashkenazi Jews (Bittles, Grant and Shami, 1993; Morell *et al.*, 1998; Søgaard and Vedsted-Jakobsen, 2003). The literature documents high rates of congenital anomalies within Pakistani populations in the United Kingdom (Atkin, 2006; Ajaz, Ali and Randhawa, 2015).

The literature connects consanguinity and congenital anomalies (Sheridan, *et al.*, 2013; Hamamy *et al.*, 2011; Child Death Overview Panel, 2013b; Gardosi, *et al.*, 2013), resulting in obscuring other factors that may contribute to the higher rate of congenital anomalies (with mortal or morbidity outcomes). For example, a recent report by Public Health England (2016) suggested that mother countries of origin allows ‘inference’ of consanguineous union, taken from their findings of 49.9 percent of consanguineous marriages in Pakistani families (Public Health England, 2016a). Despite the focus on consanguinity to explain the higher incidence of congenital anomalies in Pakistani and Bangladeshi infants, studies have shown that the risk of anomalies is only 1.7-2.8 percent higher than in non-consanguineous populations (Hamamy *et al*., 2011).

The practice of consanguinity is typically used explain the high rate of stillbirth and infant death in Pakistani infants as a result of congenital anomalies (Grant and Bittles, 1997; Ali, McLean and Rehman, 2012; Child Death Overview Panel, 2013b). The recent BiB study, which to date is the largest prospective cohort study assessing the contribution of consanguinity to congenital anomalies (and infant mortality) in the UK, demonstrated that 31 percent of affected infants are the result of consanguineous unions and have a doubling of the risk of an affected infant (Sheridan *et al.*, 2013). In real terms, however, this equates to only 30 infants above the 60 that are affected. Similar results were seen in Tonks *et al*. (2014) study, which showed that 35 percent of the congenital anomaly deaths were ‘likely’ to be associated with autosomal recessive conditions (Tonks, Fowler and Williams, 2014).

Bittles (2013) argues that other detrimental mediating factors such as poverty and relative deprivation and marriage within the wider *biraderi* are likely contributors for the findings in the BiB study (Bittles, 2013). Furthermore, a review of the figures locally demonstrates that consanguinity only accounted for 20 percent of the deaths that occurred in the locality, despite 51 percent of the deaths affecting Pakistani and Bangladeshi families (Child Death Overview Panel, 2013b). Therefore, this suggests other factors contribute towards congenital anomalies in addition to consanguinity.

There is a prominent discussion within the literature regarding the lack of understanding around arranged marriages, and perceptions of forced kinship marriage that give rise to high incidences of congenital abnormalities (Shaw, 2012; CDOP, 2015; Salway *et al.*, 2012). Coincidentally, Pakistanis who practice high proportions of consanguineous unions appear to have reduced understanding regarding the associated risk of adverse birth outcomes (Ali, McLean and Rehman, 2012).

Consanguinity is framed as a modifiable contributory factor, insofar that screening and therapeutic terminations may reduce the incidence of delivering infants with fatal congenital anomalies (Spong, Reddy and Willinger, 2011; Child Death Overview Panel, 2013b). However, for religious reasons infanticide may not be acceptable, consequently many women refuse screening opportunities (Bryant *et al.*, 2011; Shaw, 2011). It has also been suggested that the high prevalence in Pakistani families is a consequence of the failure to take antenatal screening opportunities and subsequent terminations (Hollowell, Kurinczuk, *et al.*, 2011), and this is commonly explained to be the consequence of cultural and religious beliefs (Jaber *et al.*, 2005; Bryant *et al.*, 2011; Shaw, 2012; Koenig and Al Shohaib, 2014).

2.5.4 Structural factors (social networks, living conditions and service providers)

This next section reviews the contribution of social support, living conditions and service providers on perinatal mortality.

Social support

Social support has been variously defined including ‘*resources provided by other persons’* (Cohen and Syme, 1985; pg 4) and can include emotional support and practical and informational resources (Yali and Lobel, 2002) and can be from family, friends, community networks or public services (Shaw, Dorling and Smith, 2006, Reid and Herbert, 2014). Cohen and Syme (1985) argue that social support is dynamic and changes across the lifespan, in addition to fractured networks as a consequence of migration. Social support operates on a few levels individual and societial. On an individual level, the extent of recprocity is important, and it is likely that cultural convention ‘defines’ the principals of reciprocity (Stansfield, 2006). This suggests that the quality and quantity of social support between collectivist and individualistic cultures may vary, with demonstrable differences on health outcomes (Hofstede, 2003). Furthermore, religious networks (and religious beliefs) may also provide support but this is seldom discussed in the literature; the dominant theme is individual-level or societial-level support (Koenig and Al Shohaib, 2014).

Social networks (i.e. family and friends) are considered a resource (Unwin, 2014) and mediate birth outcomes through levels of social support (which may be perceived as either positive or negative) (Marmot and Wilkinson, 2003; Headley, 2004; Downe *et al.*, 2009; Cross-Sudworth, Williams and Herron-Marx, 2011), information sharing (Mir and Tovey, 2003; Betancourt *et al.*, 2005; Cross-Sudworth, Williams and Gardosi, 2015) and social exclusion (Bowes and Domokos, 1996; Atkin, Ali and Chu, 2009; Farooq, 2014).

There is substanstial research supporting the value of social support[64] in health outcomes, for example, social support has shown a buffering effect when migrant residents live in areas with others from the same ethnic group[65] (Halpern and Nazroo, 1999). However, there are few studies that have attended specifically to social support in South Asian, Pakistani or Bangladehsi families during the maternity care pathway in England. Moreover, there is increasing interest in levels of social support in ethnic minority families, as a means to explain differences in disease outcomes (Stansfield, 2006).

Social support is considered important for the wellbeing of the mother and has been shown to mitigate against the stress of pregnancy (Feldman *et al.*, 2000) in addition to decreasing complications (Glazier *et al.*, 2004). One study identified that South Asian women had a greater chance of receiving social support that appeared to buffer emotional symptoms compared with White women (Traviss *et al.*, 2013). No other studies were identified that considered the role of social support before perinatal mortlity – and only two studies assessed social support after the stillbirth (Surkan *et al.*, 1999; Cacciatore, Schnebly and Froen, 2009), and these were not explicit to ethnicity.

Studies over the last two decades have shown trends in South Asian families moving into nuclear family structures and less intergenerational living practices (Katbamna *et al.*, 2004). The literature has focused on support networks in South Asian communities being centred around kinship ties; consequently, this has led to stereotyped assumptions and inequitable levels of professional support, which exacerbates difference (Katbamna *et al.*, 2004). Katbamna and colleagues (2004)

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[64] Social support has been found to be positive, whereas social isolation has been found to be negative to health consequences (Stansfield, 2006).

[65] Referred to as the ethnic density effect (Halpern and Nazroo, 1999).

identified that while there is informal support by extended family for South Asian women, there is a paucity of formal support in health services. The challenges were attributed to language difficulties and poor knowledge of service provison (Katbamna *et al.*, 2004). This however, shifts responsibility to South Asian women, rather than focusing on how services may adapt to meet the deficit of adequate support.

Living conditions

This section describes how evolving government policies have shaped maternity services in response to a growing body of research and global initiatives[66], focusing on inequalities in perinatal mortality and then describes the maternity services structure in Luton. It then moves on to appraise the literature which discusses the service providers' role in contributing to women's experiences of maternity care, with a focus on Pakistani and Bangladeshi mothers in the UK.

Government response

The last few years has witnessed increased government attention on maternity services. A number of factors have contributed, including the Secretary of State for Health (2014) pledging to reduce the rate of stillbirths by one fifth before 2020, following the Morecombe Bay Investigation (2015), The Maternity Review (2016), Saving Babies Lives (2016) and key white papers[67]. Additionally, changes to legislation evidenced in the Health and Social Care Act (2012) address health inequalities, whereby government pledged to address inequality in access, service provision and quality of care (*Health and Social Care Act* 2012). Legal objectives have been set by government in '*The Mandate'* to the NHS to reduce deaths in neonatal mortality and stillbirth (outcome framework, domain 1c[68]) (Department of Health, 2015b), therefore making the NHS accountable

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[66] United Nations Sustainable Development Goals (3 & 10).

[67] 'Healthy lives, Healthy people' (Department of Health, 2010a) and 'Our Health and Wellbeing Today' (Department of Health, 2010b).

[68] 2015 NHS Outcomes framework, identified health priorities; domain 1 'preventing people from dying prematurely 'which includes 1c neonatal mortality and stillbirths.

for ensuring legal compliance to the outcome framework objectives. Moreover, in 2008 the Infant Mortality National Support Team (IMNST) was established, targeting disadvantaged localities aiming to reduce maternal and infant mortality and inequalities by sharing good practice through a collaborative and multidisciplinary team approach (Korkodilos *et al.*, 2010), including CDOP who review child deaths and address safeguarding issues locally. Reducing and addressing inequalities in birth outcomes is therefore a key government priority, whereby there are now legal objectives and extensive policy documents outlining government targets and associated interventions.

The maternity care pathway

The ‘maternity care pathway’ is referred to in only a few documents (Royal College of Obstetrics and Gynaecologists, 2008; Healthcare for London, 2009; Centre for Workforce Intelligence, 2015). It has not been explicitly defined, and has been typically used for data collection purposes to identify women using maternity services, following a pre-identified pathway (e.g. complex social factors or multiple pregnancy) which corresponds to the reimbursement scale for the NHS provider (NHS Digital, 2017). In the ‘Maternity care pathways for London’ (2009) report, and RCOG (2008) ‘Standards for maternity care’ (2008) it infers the stages between pre-pregnancy, antenatal, intrapartum and postnatal period. For the purposes of this study, the maternity care pathway will refer to the time period from preconception to postnatal (up to 12 months). This is depicted in Figure 11.

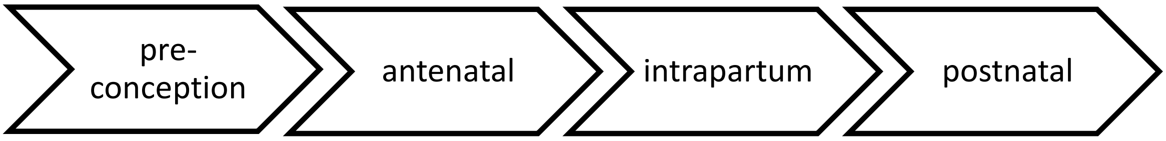

Figure 11: Diagram showing the time periods included within the maternity care pathway

Luton's maternity services

There is a broad range of maternity services available to Luton's population provided by the Luton and Dunstable University Hospital NHS Foundation Trust[69], GP surgeries and Children's centres[70].

Preconception services

There are no specific NHS preconception services for women in Luton, unless they proactively access their GP or practice nurse for advice.

Antenatal services

The Luton and Dunstable University Hospital NHS Foundation Trust is a level 3 neonatal intensive care unit (NICU) provider, and as such takes complex case referrals from across the East of England. It offers a wide range of services, for example, teenage pregnancy unit, a choice of birthing venues such as facilities for home births, maternity led birthing unit, obstetrician led care for complex cases, antenatal screening services[71], slimming clinics for expectant and new mothers, smoking cessation clinics and neonatal intensive care facilities. In 2015, the Luton and Dunstable University Hospital NHS Foundation Trust implemented the *Growth Assessment Protocol (GAP*), using personalised foetal growth assessment for improved identification of IUGR foetus (Clifford *et al.*, 2013).

Luton has seven Children's Centres, offering a wide range of services to resident families, aimed at families with children aged from pregnancy to five years of age. Two Children's Centres have translation services available in Urdu (Meadow Way CC) and Sylheti (Beech Hill CC). Services relevant for pregnant or new mothers include: Bump2Babe Course (antenatal classes), yoga during pregnancy, parenting classes, fathers' group, one-to-one help and support, and support for

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[69] commissioned by Luton's Clinical Commissioning Group.

[70] Funded by Luton Borough Council.

[71] including the combined test for Down's syndrome, thalassaemia, rubella, SCT, glucose tolerance testing (GTT) hepatitis B and HIV.

perinatal mental health and domestic abuse. Qualifying[72] mothers have access to healthy start vouchers and multivitamins, encouraging expectant or new mothers to exchange vouchers for milk, fresh fruit, vegetables and vitamins.

A further initiative in Luton is 'Flying Start', aiming to provide evidence-based early intervention and support to babies and children, from pregnancy to aged 5, born in the areas of highest deprivation. Despite Luton having a high number of South Asian settlers, and figures from CDOP demonstrative of inequalities in birth outcomes (Child Death Overview Panel, 2013b), Luton does not offer specific maternity interventions for BAME expectant mothers (Garcia *et al.*, 2015).

Postnatal services

All the Children's Centres offer breastfeeding support, however, one specific Children's Centre (Dallow Ward) offers one-to-one breastfeeding support in the homes of South Asian mothers, to support continuation of breastfeeding practice. This is however, contradictory[73] to the centres' objectives, which promotes a group approach to breastfeeding advice clinics.

The next section considers how service providers (i.e. staff and services) influence the experience of pregnancy and childbirth and birth outcomes, both positively and negatively.

The provider role in the maternity experience

Research examining the role of health providers and their contribution to barriers and facilitators (Jordan, 2004; Downe *et al*., 2009; Degni *et al.,* 2012; Lakhanpaul *et al.,* 2014b) demonstrates that

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[72] Pregnant and in receipt of state benefits (ESA, JS, IS) or child tax credit with an income of less than £16,000 per year or aged under 18.

[73] The children's centre manager reported that the group approach did not work for a number of reasons including that South Asian mothers preferred to breastfeed in private, would be attending to other family needs as a matter of priority over attending clinic and as a consequence of South Asian women practicing the '40 day confinement'.

staff and services have a poor understanding of diverse cultural needs of their populations resulting in measurable differences in the delivery of care (Henderson *et al*., 2013; Hollowell *et al*., 2011). Literature also highlights service providers being central in determining women's maternity experiences (Henderson *et al*., 2013; vanRyn and Fu, 2003; Psarros, 2014). For example, attitudes and behaviours of healthcare service providers have been shown to be both a barrier and facilitator to ethnic minorities' levels of satisfaction and engagement with services (Puthussery *et al*., 2010; El Ansari *et al*., 2009).

During the1990s interest in BAME women's experiences served to highlight issues of racism (Woollett and Dosanjh-Matwala, 1990; Bowes and Domokos, 1996) and helped to increase cultural awareness (Cross-Sudworth, Williams and Herron-Marx, 2011). The main areas that were highlighted in this evidence are issues around effective communication (Rowe *et al.*, 2001; Degni *et al.*, 2012; Jomeen and Redshaw, 2013), not having appropriate information (Cross-Sudworth, 2007), feeling powerless and being invisible (Ellis, 2004), power imbalance between staff and mothers (Bowes and Domokos, 1996), and differing attitudes and perceptions to the standards of care received from midwives between 'indigenous' women and Pakistani mothers (Hirst and Hewison, 2002). The specific evidence of Pakistani and Bangladeshi women's experiences of maternity care in England is especially sparse (Ali and Burchett, 2004; Dartnall, Ganguly and Batterham, 2005; Jayaweera, D'Souza and Garcia, 2005; Puthussery *et al.*, 2008; Jomeen and Redshaw, 2013).

A recent review of the UK evidence identifying barriers and facilitators of timely engagement of maternity services by Hollowell and colleagues (2012) identified barriers faced by BAME women. These included women's poor understanding of how to navigate NHS services, or confidence to seek the information that they require; some women were found to be unclear of the value of maternity care, believing that pregnancy is natural and consequently undervaluing the contribution of antenatal surveillance. Moreover, there was misunderstanding and erroneous beliefs regarding screening – that it might be harmful. Hollowell *et al* (2012) also revealed that women had the desire to attend services that are localised and/or had the lack of means to physically access maternity services outside of their local area. Additionally there was a perception that health staff were not sensitive or respectful – which is the consequence of patients feeling disempowered through mechanisms of limited language proficiency, power imbalance and communication issues. This is then reinforced by the lack of availability of trained interpreters and the over-reliance on family members, the desire for a female practitioner, or misunderstanding that the women can see female staff (Hollowell *et al.*, 2012).

Dartnall and colleagues (2005) found that service providers were found to make assumptions of 'hard to reach' women's levels of language ability and knowledge of pregnancy; the staff provided health information leaflets that few mothers actually read, preferring to listen to the advice from elders in the community. Similarly, Ali and Burchett (2004) found that their participants reported that staff appeared reluctant to help non-English speaking mothers understand the information provided, especially when medical terminology was used. Consequently, many mothers perceived that they had insufficient information to make informed choices in their pregnancy care or birth plans (Ali and Burchett, 2004). While both these studies might be considered somewhat old, what is notable is similar findings in a more recent study of BME women's experiences in maternity services by Jomeen and Redshaw[74] (2013): poor communication issues were salient in the negative experiences reported, women felt a burden or perceived that they were ignored by uncaring staff, they did not feel that they were listened to, and weren't active in the decision making around their care. Furthermore, they reported perceptions of staff stereotyping their cultural needs and making assumptions regarding women's understanding of health messages (Jomeen and Redshaw, 2013).

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[74] where the majority of their participants were Pakistani.

It might be argued that some of the findings could apply to the experience of WB women since the studies mentioned above only include BAME. However, in 2013, Henderson and Colleagues published their findings that included 84.8 percent White, 2.5 percent Pakistani, 0.7 percent Bangladeshi, 2.4 percent Indian, 0.7 percent Caribbean and 2.7 percent African and Chinese living in England. Their results showed that most ethnic minority women reported a worse maternity experience compared with White mothers and concluded that little has changed since earlier studies (Henderson, Gao and Redshaw, 2013). Furthermore, it's hard to make direct comparisons between the sparse numbers of studies that do exist as the participants differ, due to methodological differences in the previous studies, for example the ethnic classification used or whether the study used qualitative (FG or interview) or quantitative (survey or secondary) data.

Cultural competence.

Many research and policy papers have called for '*culturally competent services'* to help resolve some of the inequalities in care experienced by ethnic minority women (Ali and Burchett, 2004; Grewal, Bhagat and Balneaves, 2008; Degni *et al.*, 2012; Garcia *et al.*, 2015). Cultural competence aims to develop services that deliver high standards of equitable care irrespective of ethnicity, and is of growing importance in an increasingly diverse population (Betancourt *et al.*, 2003; Mir, 2008). Betencorte (2003) argues that a poor understanding of cultural needs results in sterotyped behaviour by staff, and includes less information sharing (Betancourt *et al.*, 2003; Ellis, 2004). Furthermore, understanding differences in symptom expression, presentation and illness perceptions is an important contribution. Furthermore, bi-directional language barriers may also contribute to patient dissatisfaction, poor adherence and reduced outcomes (Betancourt *et al.*, 2003).

A closer examinaton of the literature on cultural competence however, fails to provide a clear idea as to what precisely staff might need to do to provide such a service. For example, there is no universally accepted definition (Horvat *et al.*, 2014), consequently, mainstream services 'essentialise' diversity (Witz, 1995) and focused services risk exacerbating difference and inequalities further by inadvertent streotyping (Cattaccin, Antonio and Domenig, 2013). Furthermore, a recent study by Phillimore (2016), contary to previous studies (Rowe and Garcia, 2005; Rowe, *et al.*, 2008; Tucker *et al.*, 2010; Gardosi, Madurasinghe, *et al.*, 2013; Redshaw and Henderson, 2014), identified that migrant women did not attend their antenatal care late, and engaged fully with maternity services and the degrees of service engagement were in fact influenced by institutional, legal and structural barriers. This indicates that understanding the contribution of institutional, structural and legal factors needs to be considered, in addition to diverse cultural factors at an individual level, in the development of culturally competent maternity services (Mir, 2008; Mir and Tovey, 2002; 2003).

2.5.5 Poverty, deprivation and socio-economic status factors

This section turns its attention to the role of poverty, deprivation and SES factors on perinatal mortality. This section starts by differentiating between poverty and deprivation and briefly highlights temporal changes in conceptualisations that are reflective of political and economic change (Davis *et al.,* 2014). It then presents SES as a measure of hierarchal position within society, shows the IMD measurement strategies that are applied in the UK and highlights those that are typically used in maternity research. This section concludes with an explanation of the measures applied in the current study.

Poverty and deprivation

This section disambiguates the concepts of poverty and deprivation, which have diverse conceptions within the wider literature (Townsend, 1979). For instance, poverty is typically associated with financial resource[75] and arguably one-dimensional whereby money is used to access other resources (e.g. education and social support) (Ayala, Jurado and Mayo-Perez, 2009), consequently impacting deprivation levels (Macinnes *et al*., 2015). Therefore, having access to certain resources is argued to assist families out of poverty and provide them with greater access to consumer options, including improved food choices or gym membership (Unwin, 2014; Tinson *et al.*, 2016). Deprivation refers to the challenges as a consequence of poverty and the use of various resources, hence is a multidimensional perspective (Ayala, Jurado and Mayo-Perez, 2009).

The association between poverty and deprivation with adverse birth outcomes is well-established (Acheson, 1998; Draper, Kurinczuk and Kenyor, 2015); a clear social gradient is evident both between and within countries (Bartley *et al.*, 2005; Bartley, 2008; Kelly *et al.*, 2009). Figures show that women living in areas of deprivation have the poorest birth outcomes, for example, the wards of Dallow and Biscot are the most deprived in Luton, and report the highest number of infant deaths (Child Death Overview Panel, 2015; Research and Geospatial information, 2015). Moreover, poverty does not contribute to poor outcomes in isolation but is part of a wider context dependent, socio-economic environment (Friedli, 2009; Bircher and Kuruvilla, 2014). For example, having adequate finance to access health promoting resources[76] such as healthy food choices is important for positive outcomes, in addition to protective factors (operating at different levels) such as environmental capital (communities), social capital (social and cultural norms) and emotional and cognitive capital (Friedli, 2009).

Relative poverty has been shown to be a worse indicator for poor health outcomes than absolute poverty (Elstad, 1998). The term ‘relative poverty’ is relative to comparisons with the majority population therefore a dynamic concept, consequently, malleable to wider political, economic or

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[75] The Joseph Rowntree Foundation (Tinson *et al*., 2016) uses several poverty measures, e.g. income, housing, life chances, employment and social security. However, these measures exclude wider psychosocial explanations of poor health behaviour, such as levels of social support, perception of stress or perceived control (Benzeval *et al.,* 2014).

[76] which includes health service provision, health behaviour, health literacy and practical resources.

commercial influences (Hirsch, 2011; Davis, Hirsch and Padley, 2014). Moreover, the experience of poverty in early life has been shown to impact health adversely in adulthood (Section 2.5.3) (Ravelli *et al.*, 1998; Marmot *et al.*, 2012). However, explaining the mechanism behind poverty and poor health outcomes is complicated. Currently, three explanations have been posited: firstly, the direct causes of poverty, (e.g. reduced material resources, including poor living standards and working conditions which contributes to deteriorating social relationships), secondly, differential health behaviour as a consequence of being in poverty (including increased life demands, greater perceived stress and more negative emotion) (Shaw, Dorling and Smith, 2006; Friedli, 2009; Bircher and Kuruvilla, 2014) and thirdly, reduced access to and utilisation of health services (D'Souza and Garcia, 2004; Small, 2012).

Combined with negative emotions, health behaviours such as alcohol consumption, smoking, poor diet and less exercise further exacerbate adverse health outcomes (Shaw, Dorling and Smith, 2006; Benzeval *et al.*, 2014). However, individual resources[77] fail to explain the mechanism of inequalities found in perinatal morality. While the social gradient is easily explained by a lack of resource in impoverished families (and countries), this does not explain why Pakistani or Bangladeshi women have worse birth outcomes than WB women in similar financial positions in England (Child Death Overview Panel, 2013a). Social exclusion has been suggested to advance the concept of relative poverty, to include the process of 'exclusion' to help explain the consequence of poverty. However, scholars cannot agree on a precise definition. Similar to deprivation, it is a multidimensional construct, which is context dependent.

Another concept that is frequently seen in the literature when considering poverty and deprivation is SES. SES refers to an individual's hierarchal position within society and is seen to influence access to resources within the home, community and employment (Friedli, 2009). SES typically

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[77] e.g. financial, education and social support.

incudes measures of income and/or occupation, social status, educational level and neighbourhood characteristics (Egerter *et al.*, 2005; Graham, 2011). SES is usually considered a multidimensional construct with different elements impacting across different time points across the life-course, and functioning at individual, social and environmental levels by means of distinctive mechanisms (Egerter *et al.*, 2005). It is frequently included as a variable in maternity outcomes research, and demonstrates a well-documented social gradient in perinatal mortality. This is shown in Table 3 (Marmot and Wilkinson, 2003; Marmot, 2010).

Table 3*:* 2013 PMR and NS-SEC classifications (ONS, 2013)

	NS-SEC	**Perinatal mortality**
England and Wales 2013	1.1	4.7
	1.2	4.9
	2	5.2
	3	6.3
	4	7.0
	5	7.3
	6	8.2
	7	9.9
	8	9.7

Moreover, while scholars accept SES is a multidimensional construct, normally only a few SES proxy variables are used in a single study, such as income (Wilkins, Sherman and Best, 1991; Flenady *et al.*, 2011), social class (Freemantle *et al.*, 2009; Kelly *et al.*, 2009), housing tenure (Dormandy *et al.*, 2005; Jayaweera, D'Souza and Garcia, 2005; West, *et al.*, 2014), education level achieved (Kiernan and Smith, 2003; Målqvist *et al.*, 2013; Yadav and Lee, 2013) or years of schooling (Johnelle Sparks, 2009). A possible reason for this is constraints on researcher resource, e.g. financial budget, time and feasibility and availability of variables, such that a pragmatic approach is utilised, although the explicit reasons for the limited SES variables is often not documented in the study (Egerter *et al.*, 2005; Ravelli *et al.*, 2011).

The wider research on SES as a determinant of health also has a number of noteworthy limitations which include a skew towards studies in high-income countries with white males, which has consequently reduced knowledge on other population groups, such as women, religious and cultural groups and ethnic minorities (Blane, Smith and Hart, 1999; Graham, 2011). Gray and colleagues (2010) suggest that understanding the relationship between ethnic differences in SES factors *and* SES factors on birth outcomes is essential, but presently this information is limited. A recent systematic review looking at SES factors on adverse birth outcomes found the precise contribution of poverty, deprivation and SES on adverse birth outcomes from high-income countries was contradictory (Blumenshine *et al.*, 2010). This is likely due to a methodological artefact of the type of measure(s) for SES or deprivation employed within each study, for instance ethnic differences in birth outcomes might be attributed to the measure of SES applied (Blumenshine *et al.*, 2010).

In the UK, figures show that SES varies by ethnic group (Leon and Moser, 2012). Pakistani and Bangladeshi families are consistently in receipt of lower incomes than other ethnic groups, with Pakistanis being worse off (Fisher and Nandi, 2015). Understanding the subtle differences in SES between ethnic groups is both important and challenging. For example, it has been suggested by some researchers that Pakistani and Bangladeshi people are found in similar SES categories (Small, 2012; Sheridan *et al.*, 2013), despite having differences in their birth outcomes. However, the discrete differences between Indian, Pakistani and Bangladeshi groups are not specifically identified in the SES measures, as a consequence of methodological reasons. For example, Indian mothers tend to have higher levels of education (Dale and Ahmed, 2011), Bangladeshi families are in receipt of more social security benefits and live in social housing (Jayaweera, D'Souza and Garcia, 2005; Office for National Statistics, 2011a), whilst Pakistani and Bangladeshi families are more likely to be living in homes that are considered overcrowded[78], in contrast to Indian families who are less likely to be living in conditions of overcrowding (Office for National Statistics, 2015c).

Poverty has been shown to operate differently between ethnic groups. The Early Childhood Longitudinal Study-Birth Cohort (USA) by Jonelle-Sparks *et al.* (2009), found that relative poverty was shown to function differently across ethnic groups and once all variables were controlled, the effect of relative poverty disappeared (Johnelle-Sparks, 2009). The authors concluded that this suggests that maternal access to antenatal care, health behaviour and health status have a greater influence on birth outcomes than relative poverty.

A systematic review of socioeconomic differences on adverse birth outcomes found the most common measure for SES was education, followed by occupation and lastly income (Blumenshine *et al.*, 2010). Moreover, they found that very few studies implemented all three measures, and some included paternal education. Their results found that typically occupation and area level deprivation was found to have an impact on adverse birth outcomes with income and education mediating outcomes respectively. Furthermore, ethnic variation was observed and found to improve outcomes (Blumenshine *et al.*, 2010). However, the difficulty of using education or income (or both) is seen in study analyses that show that at comparable education levels, some ethnic groups are in receipt of lower incomes, which might be suggestive of a number of combined factors; poorer educational experiences and reduced opportunities (Egerter *et al.*, 2005). Together, this shows that when considering the impact of SES factors on perinatal mortality, interpretation of the results is not necessarily straightforward.

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[78] refers to having fewer bedrooms than the ‘bedroom standard’, as set out in the Housing (Overcrowding) Bill (Love, 2003).

Educational attainment

Education[79] is a further measure for SES in research from high-income countries and is useful in studies looking to understand how SES contributes to future health outcomes (Graham, 2011). Several studies have used women's education level as a proxy for SES (Arntzen *et al.*, 2008; Blumenshine *et al.*, 2010; Baron *et al.*, 2015). Moreover, education is also a good proxy for cultural and environmental influences and higher levels of education achievements may operate on psychological levels to increase self-esteem and self-efficacy (Arntzen *et al.*, 2008). Interestingly, higher maternal education has been found to be an independent protective factor to mitigate against adverse birth outcomes (Arntzen *et al.*, 2008; Flenady *et al.*, 2011; Auger *et al.*, 2012; Juarez *et al.*, 2014).

There are a few possible explanations to why maternal education can contribute to birth outcomes (Cross-Sudworth, Williams and Herron-Marx, 2011; Yadav and Lee, 2013). Often in Pakistani or Bangladeshi households, the mother's primary role is caregiver to her children (and wider family), impacting on their financial position with a sole income, therefore access to resources is more limted (Jayaweera *et al.*, 2005; Jayaweera, D'Souza and Garcia, 2005; Aston *et al.*, 2007a; Hardin *et al.*, 2014; West, *et al.*, 2014). Similarly, some migrant women may not have had the same level of education depending on their country of origin, thus restricting employment opportunities, in addition to contributing to poorer health literacy levels (Ali Hyder and Morrow, 2006; Zanchetta and Poureslami, 2006; Zeh *et al.*, 2012).

However, education as a variable is not necessarily comparable between countries due to different school leaving ages, in addition to temporal and progressive changes in educational policies (Graham, 2011). For instance, the numbers of women staying in education have increased over time as a consequence of changing gender roles (Universities UK & Higher Education Statistics Agency, 2014). Consequently, caution is required when considering how education (as a temporal

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[79] academic level attained or years of education.

proxy for SES) may contribute to perinatal outcomes, which may correspond to temporal societal changes.

National Statistics Socio-Economic Classification

There are a number of ways in which SES is measured in the UK which have evolved over time[80]. Table 2.4 shows the different classifications since the 19th Century (Graham, 2011; Office for National Statistics, 2016e). The most recent measure, the National Statistics Socio-Economic Classification (NS-SEC), encapsulates eight categories and is the most detailed so far, but for research purposes, it does have a number of limitations. For example, studies that assess income data using NS-SEC, is only relevant for women in paid employment, and does not account for women who undertake unpaid caregiving roles to their children and other family members (Oakley, Maconochie and Doyle, 2010; Cabieses *et al.*, 2014). Similarly, well educated women (or men) may be full-time caregivers to their children, and the NS-SEC measure fails to capture this. Table 4 shows the changing classifications.

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[80] Since 1913, in the UK the most common measure of SES was related to occupation and linked with social class, known as the Registrar General social class, whereby women and their children were classified under the partners'/fathers' occupational classifications (Graham, 2011). From 2001, the system was substituted by the NS-SEC (Rose and Pevalin, 2005), which ceases to use employment skills as a one-dimensional SES measure but now incorporates 'employment relations' which reflect a broader array of employment situations and contexts (Office for National Statistics, 2016e).

Table 4: Summary of UK class classifications since 19th Century

	3 Great Classes (19th century)	**Registrar Generals Classification (1990)**		**NS SEC (2003)**	**NS-SEC (2016)**	
1	The gentry and professional people	Professionals		Professionals and managers	Professionals administrative and higher managers	1.1 Large employers and higher managerial and administrative occupations
						1.2 Higher professional occupations
2	Farmers and tradesmen	Managers and intermediate occupations		Intermediates	Lower managerial, administrative and professional occupations	
3	Artisans and labourers	Skilled	Non-manual	Small employers	Intermediate occupations	
			Manual			
4		Semiskilled		Lower supervisory and technical	Small employers and own account workers	
5		Unskilled		Semi-routine and routine	Lower supervisory and technical occupations	
6				Never worked/long-term unemployed	Semi-routine occupations	
7					Routine occupations	
8					Never worked and long-term unemployed	

Index of multiple deprivation

Area based information is another measure of SES, where individual data is shown at a specified area level. England uses the IMD which aggregates 37 indicators such as employment, income health and housing tenure into a relative deprivation score in lower-layer super output areas[81] (LSOA) (Department for Communities and Local Government, 2015). While far more comprehensive, it is still not without limitation. Although an LSOA may be ranked by IMD score, within the defined LSOA area there will be considerable heterogeneity. For instance, Luton is

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[81] There are 32,844 LSOA in England (Office for National Statistics, 2016). LSOA areas cover populations between 1,000 and 3,000 and households between 400 and 1,200 and implementation of the IMD across LSOA allows comparisons between small geographic areas (Office for National Statistics, 2016f).

ranked 59th out of 326[82] but across Luton's 121 LSOAs, IMD ranks between 871 (most deprived) and 28,788 (least deprived) showing diversity of wealth and deprivation (Department for Communities and Local Government, 2016).

Moreover, wealthy individuals reside in poor areas and vice versa, in addition to large populations of ethnic minorities who typically reside in areas classified as deprived while the residents may themselves not be poor (Graham, 2011). Furthermore, factors operating at local levels cannot be removed from factors operating on individual or family levels, e.g. impoverished women with poor health may reside in deprived areas, alternatively, residing in deprived areas may promote poorer health, or both mechanisms may be in operation (Bartley, 2008; Graham, 2011). Therefore, using IMD to reflect an area deprivation score fails to identify individuals who may have access to a number of health benefiting resources, despite residing in a deprived area.

Using household income or NS-SEC as a measure for SES is not straightforward in studies with female participants or participants from South Asian communities. For example, it has been suggested that in some cultures (notably South Asian), disclosing family income to outsiders is not acceptable, in addition to female members of the household who may be unaware of household income, particularly in an extended family setting where several members of the family may be in employment and contributing to the maintenance of the family (Shaw, 2000). Furthermore, it is noteworthy that in research contexts, authors seldom offer an explanation why particular SES measure were selected (e.g. income or education) in preference over, or in combination with, others (Egerter *et al.*, 2005). Consequently, careful consideration to avoid false representations of SES, in addition to explicit justification of the chosen and implemented SES measure is suggested (Egerter *et al.*, 2005).

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[82] where '1' is the most deprived.

Some studies have used linked hospital data[83] to determine SES factors (Moser, Stanfield and Leon, 2008; Datta-Nemdharry, Dattani and Macfarlane, 2012). However, NS-SEC data is only provided where fathers are registered on the birth registration, by which national statistics show that joint registration varies by ethnicity (Gray, Headley *et al.,* 2010). Moreover, since 2010, the linkage of hospital records with birth registrations facilitated the government to monitor inequalities in infant mortality targets but is completed on only 10 percent of actual records (Gray, Headley *et al*., 2010). Additionally, sole registered infants are known to be at increased risk of adversity yet the system designed to monitor infant inequalities, by virtue of recording fathers occupation status (rather than mothers), will exclude the very infants most likely to represent 'inequalities' at the poorest end of society (Gray, Headley *et al.,* 2010; Gray, Hollowell *et al.,* 2010).

As mentioned previously (Section 2.4), there are clear social gradients in perinatal mortality, between high and middle–low income countries (Central Intelligence Agency, 2015). These are easily understood as a consequence of clear discrepancies in access to sanitary conditions, medical facilities, antenatal screening and professional maternity care during the antepartum, intrapartum and postpartum period, explaining some of the differences in the figures[84] (Lawn *et al.*, 2009; Blencowe *et al.*, 2013). Similarly, in the UK, areas of high deprivation demonstrate higher perinatal mortality than affluent towns and cities, in addition to having larger populations of BAME settlers (Department of Health, 2010c; Korkodilos *et al.*, 2010; Cantwell *et al.*, 2011; Small, 2012; CHIMAT, 2014; Office for National Statistics, 2014b; Draper, Kurinczuk and Kenyor, 2015). Moreover, studies show that health behaviour is not limited to poverty or deprivation, but involves a host of other factors (Pampel, Krueger and Denney, 2010). Furthermore, few studies have explicitly addressed how poverty and deprivation interact with health behaviour to determine outcomes (Pampel, Krueger and Denney, 2010). Consequently, understanding how health beliefs

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[83] HES and birth registrations, known as NN4B.

[84] It is not within the scope of this work to discuss the contributory factors in middle–low income countries further, however it is recognised that some factors will indeed be similar.

and health behaviour are associated with the poverty, deprivation and the social gradient in perinatal mortality is less clear. Studies have shown certain health behaviour consistently shows a social gradient (e.g. smoking), while other behaviour such as fruit and vegetable consumption is inconsistent (Algren *et al.*, 2015).

Studies from rural Pakistan and Bangladesh have found that very poor and uneducated pregnant women have a higher propensity to follow cultural health beliefs, in the absence of formal knowledge and understanding (Choudhury *et al.*, 2012). For instance, normalising pregnancy so that they did not seek medical attention (which they could not afford) in early pregnancy (Rashid, 2007; Choudhury and Ahmed, 2011; Choudhury *et al.*, 2012). Furthermore, there is even less research that considers how numerous aspects of SES factors may intersect, accumulate and contribute to health behaviour and influence the experience of perinatal adversity (van de Mheen, Stronks and Mackenbach, 1998; Graham, 2011).

Measures of SES, poverty and deprivation in the current study

This section now outlines the measures used in the current study. It is clear that some SES measures (e.g. education or income level) are better suited to certain study designs or populations, and with systematic reviews showing ambiguous results in whether household income, area deprivation levels or education actually influences birth outcomes (Blumenshine *et al.*, 2010). Notwithstanding the limitations of the numerous SES variables as discussed above (Section 2.5.5), measuring the contribution of deprivation remains an important consideration in this study.

Consequently, similar to previous studies (Blumenshine *et al.*, 2010; Mceachan, 2012; Zeitlin *et al.*, 2016), this research will use maternal education level as a proxy measure for SES factors during the qualitative part of the study. Maternal education is ideal in this study population, as some women may be unaware of household income, or be uncomfortable disclosing personal information, in addition to education being independently associated as a protective factor against adverse birth outcomes (Arntzen *et al.*, 2008; Flenady *et al.*, 2011; Auger *et al.*, 2012; Juarez *et al.*, 2014). In addition, sector level postcode will be used to determine IMD for birth outcomes within the hospital data.

2.6 Critique of the DOH approach to understanding inequalities in perinatal mortality

Despite the successes of the DOH approach in understanding their contribution in morbidity and mortality (Nazroo and Williams, 2006), the mechanisms behind inequalities remain unclear and there are limitations to its conceptual and applied functionality. As a consequence of conceptualising and the subsequent application of DOH in studies, research tends to focus on proximal determinants, e.g. biological or behavioural factors which are considered modifiable. Hence, understanding the distal determinants contributing to biological or behavioural factors of perinatal mortality as a consequence of direct or indirect disadvantage/advantage are ignored (Atkin, 2011). Figure 12 shows the separation of the distal determinants of advantage or disadvantage, prior to psychobiological responses and behavioural responses at a proximal level to birth outcome.

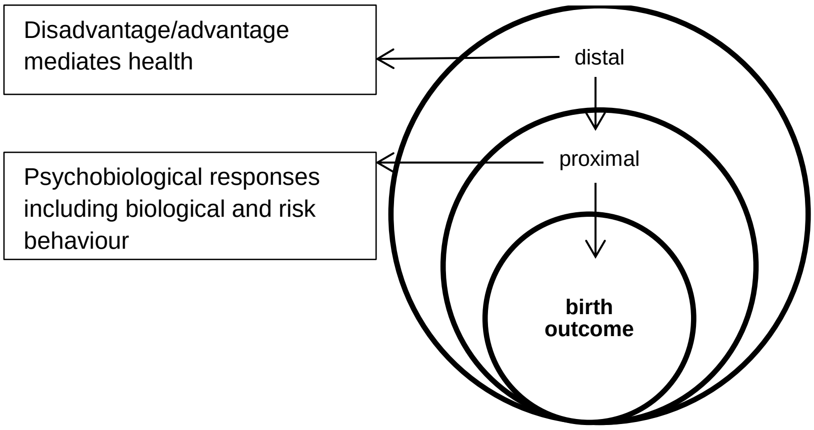

Figure 12: Diagram showing the relationships between distal and proximal determinants of birth outcomes

The DOH framework in explaining health inequalities acknowledges that interventions at one layer may impact outcomes on another layer and uses a systems approach incorporating policy, environment, community and individual levels (Dahlgren and Whitehead, 1991; Navarro, 2009). However, they are operationalised as separate layers; these layers are not understood to be merged or intersected. Furthermore, it is widely accepted that over a person's lifespan, the accumulation of advantage or disadvantage creates a psychobiological response on health (Blane, 2006). The contribution of the life-course perspective to our understanding of DOH suggests early life exposures and accumulated contribution of SES factors, health behaviours, disadvantage and power dynamics in adult health status (Wadsworth and Kuh, 1997; Ravelli *et al.*, 1998; van de Mheen, Stronks and Mackenbach, 1998; Roseboom *et al.*, 2001)

A substantial criticism of the model has been the deficit in acknowledging power dynamics (e.g. political, class, caste, racism and discrimination) which are present at all levels of society and not identified in the model (Navarro, 2009; Salway, *et al.*, 2010). Power dynamics will impact on the context and empowerment of factors on different layers (i.e. policy, environment, community and individual levels). For example, governments prioritise public health targets which will increase/reduce access, promotion and spending on specific interventions (Patterson, 2014). Consequently, perinatal mortality has not been a specific priority in the UK until 2015, following the publication of the United Nations Sustainable Development Goals (2015) and the subsequent government response (Section 2.5.4). A serious risk with priorities that are politically driven is that marginalised members of society are often further excluded (Atkin, Ali and Chu, 2009; Navarro, 2009) and the inequality gap becomes greater (Dahlgren and Whitehead, 2007; Whitehead and Dahlgren, 2007). The distinct lack of power dynamics may be the result of the DOH model being ethnocentric: contrived in the West and therefore homogeneous assumptions made on the experiences and beliefs of all humans (assumed the same) to which the model is supposed to apply. In turn, this links with the model's superficial attempt to account for ethnicity and culture (Navarro, 2009).

Ethnicity is observed at the heritable factors level of the model. However, ethnicity is a multifaceted construct and is not merely rooted in biological genetics, which is coincidentally paralleled to the outdated use of the term 'race' (Section 2.5.2) (Chaturvedi, 2001; Culley and Dyson, 2010). Consequently, interactions with ethnicity can be evidenced in all layers of the model. For example, considering the environmental tier – some ethnic groups (e.g. Pakistani and Bangladeshi) tend to cluster in areas of high deprivation and may be subject to segregation (Karlsen and Nazroo, 2002; Nazroo and Williams, 2006), whereby poor quality housing and increased exposure to environmental risks (which are more prevalent in areas of high deprivation) increase risks of perinatal mortality (Acheson, 1998; Sharp, 2010).

Similarly, although the model incorporates culture in the farthest layer away from the individual, culture itself is arguably present at every level of the model (i.e. policy, environment, community and individual levels). Culture is also a dynamic concept, incorporating socially learned and shared values which guide behaviour (Section 2.5.2) (Ali Hyder and Morrow, 2006; Patterson, 2014). It is dependent on context and in the case of multicultural societies, 'others' as well as one's culture impact on health outcomes, evidenced in inequalities: discrimination and racism (Karlsen and Nazroo, 2002; Navarro, 2009; Patterson, 2014). Consequently, culture also contributes to overall health outcomes.

Many determinants at each layer of the framework are context dependent – and this is not explicit. Aforementioned, disadvantage and discrimination may be experienced across all levels of the framework, whereby the quality of life[85] (QOL) (e.g. the internal and external experience of life) is

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[85] QOL is a multidimensional construct, including social, material, psychological and economic wellbeing (Felce and Perry, 1995; Fallowfield, 2009).

also affected but this is not explained by the framework's constructs (Ali Hyder and Morrow, 2006; Brunner and Marmot, 2006). Moreover, while psychosocial and psychobiological factors are accepted to mediate health (Brunner and Marmot, 2006; Hollowell, Kurinczuk, *et al.*, 2011) there is no explanation of psychobiological responses of the hypothalamic–pituitary–adrenal (HPA) axis (i.e. immune or endocrine dysfunction), or how this might impact pregnancy outcomes or indeed how positive factors such as resilience or personal agency may offer protection (Saffron and Nazroo, 2002). Indeed, national figures have consistently shown that Black Caribbean women are more prone to infectious diseases and South Asian women more frequently experience comorbid diabetes than WB women (Hauck, Tanabe and Moon, 2011; Khalil *et al.*, 2013; Draper, Kurinczuk and Kenyor, 2015).

The research focus on inequalities in perinatal mortality in BAME women has been mainly on access and utilisation (Woollett *et al.*, 1995; Bowes and Domokos, 1996; Ali and Burchett, 2004; Ellis, 2004; Szczepura, 2005; Puthussery *et al.*, 2010; Cross-Sudworth, Williams and Herron-Marx, 2011; Alshawish *et al.*, 2013; Cresswell *et al.*, 2013; Nair *et al.*, 2014). In particular, a number of explanations have been offered such as poor English language proficiency (Chambra and Ahmad, 2000; Jayaweera, D'Souza and Garcia, 2005; Szczepura, 2005; Downe *et al.*, 2009; Cross-Sudworth, Williams and Herron-Marx, 2011; Schachter, Kimbro and Gorman, 2012); recent migration resulting in poor awareness of services or unclear immigration status whereby women are fearful or unsure whether they have legal rights to use services (Evans and Bowlby, 2000; Bollini *et al.*, 2009; Gagnon *et al.*, 2009; Gissler *et al.*, 2009; Small, 2012; Aleksic, 2013; Almeida *et al.*, 2013); cultural and religious beliefs and health behaviours mediating utilisation of services (Jayaweera and Quigley, 2010; Hunt and Batty, 2011; Almeida *et al.*, 2013; Bansal *et al.*, 2014; Cabieses *et al.*, 2014); proximity of maternity service provision having financial and/or practical implications on service users (Spector, 2004a; Lurie *et al.*, 2005) and booking into services later than recommended (Ravelli *et al.*, 2011; Cresswell *et al.*, 2013).

Furthermore, studies have shown that staff and service providers have limited knowledge and understanding of the specific care needs of diverse populations, mediating quality of services provided (Hollowell, Oakley *et al.*, 2011; Degni *et al.*, 2012; Henderson, Gao and Redshaw, 2013). Coupled with insensitive service provision comes stereotyping, cultural and religious assumptions and covert racism, contributing to exclusion by staff (Nazroo and Karlsen, 2001; Saffron and Nazroo, 2002; Oliver and Mossialos, 2004; Cross-Sudworth, 2007; Jomeen and Redshaw, 2013), resulting in poorer perceptions of maternity experiences and reduced satisfaction (El Ansari *et al.*, 2009; Cross-Sudworth, Williams and Herron-Marx, 2011; Jomeen and Redshaw, 2013; Nair *et al.*, 2014). While this has contributed to our growing knowledge, studies have not properly considered how health behaviour may contribute to perinatal mortality.

2.6.1 Reconsidering the role of health beliefs and health behaviour in perinatal mortality

Section 2.5 provided the current explanations for perinatal mortality, using the DOH approach, while Section 2.6 highlighted how the DOH fails to go far enough to understand the simultaneous mechanisms behind inequalities in perinatal mortality. This section now reconsiders the role of maternal health beliefs in influencing health behaviour[86] and considers whether this will help in explaining inequalities in the experience of perinatal mortality for a sample of Pakistani, Bangladeshi and WB women in Luton. There is clearly a dearth of information specifically on maternal health beliefs in Pakistani, Bangladeshi and WB women and how health beliefs may influence subsequent health behaviour relating to perinatal mortality (Almeida *et al.*, 2013; Lucas, Murray and Kinra, 2013). This study argues that the current perspectives do not go far enough in examining or explaining women's health behaviour in pregnancy, especially when explaining the experience of perinatal mortality.

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[86] Health behaviour is defined as '*activity undertaken for the purpose of preventing or detecting disease or for improved health and wellbeing*' (Conner & Norman, 2005; pg 2).

As previously discussed (Section 2.5.3), several interrelated mechanisms influence health beliefs; for instance, religious prescription, customs and cultural practice, vicarious learning through peer behaviour, previous experience and health literacy (Conner and Norman, 1999; Conner, 2002; Spector, 2004a). Moreover, these mechanisms themselves depend on changing situational contexts and therefore are considered dynamic. Consequently, members of the same group will have varying levels of indoctrination both privately (e.g. psychologically/internally) and publicly (e.g. social situations/externally) (Nazroo, 2003; Roy, Torrez and Dale, 2004; Grewal, Bhagat and Balneaves, 2008; Cohen, 2010; Islamic Council for Queensland, 2010; Lucas, Murray and Kinra, 2013; Bansal *et al.*, 2014). Taken together, this implies that health beliefs are the result of several, complex influences, informing maternal health behaviour and contributing to the experience of perinatal mortality.

Lifestyle factors (or health behaviours) as evidenced in the maternity literature were presented in Section 2.5.3. However, the dominant focus in the literature has been on modifiable behaviour such as tobacco smoking, alcohol and substance use or monitoring of foetal movements. Jarvis and Wardle (2006) argue that individual health behaviours such as these, which involve a degree of personal choice, focuses on individuals and hence adopts a blame approach, subsequently failing to address why certain patterns of health bahaviour are more prevalent in some SES groups than others. Moreover, Gunderson and colleagues (2012) argue that religion does not feature in Western medicine, despite religion playing an important role in shaping behaviour.

There is a wealth of evidence for certain health behaviours, such as maternal smoking behaviour or BMI, on adverse outcomes but few studies consider other tobacco consumption practices, such as ST (Inamdar *et al.*, 2015), or how BMI risk might differ in South Asian populations (Bryant *et al.*, 2014). This exemplifies one of the significant limitations with the current maternity research, which has predominantly focused on an essentialised and homogenised group of women, often excluding minority women's behaviour. Furthermore, while there is a growing evidence base exploring South

Asian women's experiences of maternity care (Katbamna, Bhukta and Parker, 2000; Ali and Burchett, 2004; Puthussery *et al.*, 2010; Mcfadden, Renfrew and Atkin, 2013), there is little research that has also included WB women (Homans, 1980). Consequently, it is unclear whether these study findings are salient to *all* women or unique to certain ethnic groups.

The result of homogenising women of all ethnicities (or indeed, aggregating South Asian women together) (Bartley, 2008), means that there is little understanding of how ethnicity may influence health beliefs and health behaviour, which may then mediate the risk of perinatal mortality. It is also unclear which health beliefs and health behaviours are similar (in the context of a shared experience of pregnancy and motherhood) or diverse (as a result of ethnic influences) among women in Luton.

2.7 Chapter summary

This chapter has provided evidence showing ethnic variation in perinatal mortality seen in Pakistani, Bangladeshi families in Luton. Using the popular DOH framework used to understand inequalities, the framework was applied to understand risk factors for perinatal mortality. In addition it showed the role of health behaviour and considered how this contributes to inequality. Furthermore, the role of policy and maternity service providers and the contribution of environmental factors was also examined. The complexity of the risks of perinatal mortality coupled with the multifariousness of antenatal care has also been shown throughout this chapter. Pregnancy is a social experience – mediated by attitudes, behaviours, cultural expectancies, social norms, proximity to services, access and utilisation of maternity services and policy and power (Woollett *et al.*, 1995; Rezende, 2011). As such, it requires a conceptual approach that acknowledges and accounts simultaneously for the distal *and* proximal, interlinking and accumulating mediating factors to birth outcomes, such as the intersectional approach. The contribution that the intersectional approach can make to an understating of perinatal mortality is discussed in detail next (Chapter 3).

Chapter 3: Conceptual foundations

3.1 Introduction

Chapter Two presented the problem of inequalities in perinatal mortality in the context of England and then focused on Luton where this study is based. The DOH approach was used to highlight the current understanding of health behaviour in the determinants of perinatal mortality, including the structural[87] factors that may contribute to inequalities. However, it argues that there is a paucity of knowledge in understanding how Pakistani, Bangladeshi and WB women's health beliefs influence health behaviour during the maternity care pathway; consequently, current research does not go far enough to explain ethnic inequalities in perinatal mortality. This chapter discusses how the conceptual framework of pragmatism and an intersectional approach will help to understand how health beliefs influence health behaviour and contribute to perinatal mortality in babies born to Pakistani, Bangladeshi and WB women living in Luton.

3.2 Philosophical foundations

This thesis took a realist pragmatist philosophical approach to answering the research question and this influenced the study in two ways. Firstly, it contributed to decisions about theoretical positioning and methodology and secondly, understanding of the relationship between the researcher and the researched. These are discussed in Section 3.2.1 below.

3.2.1 Decisions about theoretical positioning

The existing wealth of knowledge on adverse birth outcomes shows that the research area is interrelated; certain conditions (such as IUGR or PTB) are themselves risk factor(s) for perinatal mortality (Chapter Two, Section 2.5) (Gardosi, 2006; Gardosi, Madurasinghe, *et al.*, 2013). While

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[87] Structural factors relate to social networks, living conditions and the service provider – see Chapter two, Section 2.5.4

the precise distal determinants for these risk factors (i.e. LBW, PTB, IUGR) are not well understood, the emerging evidence base typically focuses on one proximal risk factor (e.g. PTB). Moreover, research into perinatal mortality has been further hindered due to conceptual issues around terminology, and differences in legal and medical thresholds in defining concepts (Chapter Two, Section 2.2).

It also became apparent that there were dominantly epidemiological studies looking at risk factors (Krieger, 1994; Steer, 2005; Angelica and Fong, 2010; Leon and Moser, 2012; Blencowe *et al.*, 2013), which is descriptive and lacked context. Additionally there are some qualitative studies (Twamley *et al.*, 2011; Degni *et al.*, 2012; Kelley and Trinidad, 2012; Yeasmin and Regmi, 2013; Haddrill *et al.*, 2014; Redshaw, Rowe and Henderson, 2014) that contribute to our understanding of maternity experiences, but fewer studies that have focused on the opinions and experiences which include Pakistani and Bangladeshi mothers (Ali and Burchett, 2004; White *et al.*, 2006; Cross-Sudworth, Williams and Herron-Marx, 2011; Shaw, 2011). As mentioned previously, very few studies have included the opinions and experiences of WB mothers (Homans, 1980; Woollett and Dosanjh-Matwala, 1990) which would serve to help separate issues related to ethnicity and those related to motherhood, or maternity services. Similarly, a wealth of studies exist examining certain health behaviours, such as smoking in pregnancy (Bonellie, 2001; West, *et al.*, 2014; Marufu *et al.*, 2015) or BMI (Heslehurst *et al.*, 2008; Handisurya *et al.*, 2011; Kenny *et al.*, 2013; Bryant *et al.*, 2014), but few studies that have considered how health beliefs might mediate health behaviour in Pakistani, Bangladeshi and WB women (Lucas, Murray and Kinra, 2013; Yeasmin and Regmi, 2013). Consequently, the identified research gap leant towards a mixed-methods design to determine both the salient risk factors in Luton (indicative of health behaviour) and to explore how health beliefs influenced health behaviour and contribute toward perinatal mortality.

Consequently, while identifying risk factors and determinants is useful (i.e. the ‘what’ factors), understanding the context in which these risk factors operate is necessary to obtain a more comprehensive picture. In other words, the social and cultural context of this study needs to be properly considered. This means understanding how ethnicity contributes to the social and cultural influences that inform women’s health beliefs and their decisions about health behaviour, which then may mediate their risk to perinatal mortality, but in combination with the researcher’s prior assumptions (Kingdon, 2005), as there is an inherent risk of misleading or false information when interpreting findings (Maxwell, 2013a).

Women’s health beliefs are influenced by heterogeneous factors[88] and inform health behaviours, which potentiates or mitigates risk factors for perinatal mortality. This study seeks to identify the ‘what’ risk factors (using hospital data) suggestive of poor health behaviours that are in operation in Luton. Moreover, ‘how’ these might operate. By exploring health beliefs and health behaviours in Pakistani, Bangladeshi and WB women, in addition to exploring how structural factors contribute to women’s beliefs and behaviours; a pure positivist position is inappropriate due to the inability to contextualise the results within wider contexts (i.e. heritable, structural, lifestyle and SES factors) of the Pakistani, Bangladeshi and WB community, in Luton.

Different naturalistic methodologies implement techniques to increase the trustworthiness of study findings and conclusions, in contrast to validity evidenced in purist empirical work (Ravitch and Riggan, 2012).Therefore, the methods utilised in subjectivist positions are more naturalistic, lend

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[88] Health beliefs are influenced by numerous factors: personal factors (e.g. personality, emotions, symptomology, perception of risk, social norms, self-efficacy, emotion and motivation) (Abraham et al., 2008; Conner and Norman, 1999; Conner, 2013), social influences (e.g. religious interpretation, cultural expectancies, social learning) (Conner and Norman, 2005; Ahmed *et al.*, 2006; Degni *et al.*, 2012; Yeasmin and Regmi, 2013), demographic factors (e.g. poverty, education level, health literacy or physical access to health services) (Lucas *et al*., 2013).

themselves to qualitative methods – accessing the narrative and exploring ideographic (unique cases) and nomothetic (generalised) statements (Bryman, 2012c).

Consequently, the relevance of ontology and epistemology[89] extends to the methodology and specific methods chosen to answer the research question and meet the objectives of the study (Crotty, 1998). Simply put: how this research was planned and understood is influenced by the lens from which the researcher operates (Tov and Diener, 2010). Consequently, the fundamental beliefs of the researcher will invariably have implications for the design, interpretation and evaluation of exploring how health beliefs and health behaviour contributes to perinatal mortality (Rabe, 2003; Baca-Zinn, 2009; Maxwell, 2013a).

Objectivism and Subjectivism

Objectivist and subjectivist positions may be considered on a continuum with an objectivist (i.e. positivist) position on the one extreme representing absolute empirical rigour and subjectivism[90], and the subjectivist position at the other end of the continuum characterising constructionist and multiple realities. Positivists aim to test and falsify our current ideas of reality, assume an external reality position, claim objectivity through deductive reasoning and data driven theory testing, using externally observed hypothetico-deductive testing of reality, as seen in rigorous random controlled trials (Guba and Lincoln, 1994; Yardley and Marks, 2004). Positivist positions are considered as both mechanistic and empiricist and are evidenced in quantitative research (Krauss and Putra, 2005). Also, it is believed to be value-free and not subject to change through the process of repeated testing (Krauss and Putra, 2005). Hence, it is claimed there is greater validity and less

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[89] Ontology and epistemology are important considerations in health research, to promote detailed and complex questions and evaluations to explain the phenomena in question (Walsh and Evans, 2014). Without such attention, the research risks being inadequately considered or justified and will be absent of credibility (Walsh and Evans, 2014; Ravitch and Riggan, 2012).

[90] Subjectivist positions (i.e. relativism and constructionist) subsequently entered the philosophical debate in late 1980s, challenging the objectivist positions (i.e. positivist) through metaphysical arguments (Crotty, 1998; Bryman, 2012a).

bias to the results (Yardley and Marks, 2004; Krauss and Putra, 2005). Figure 13 depicts epistemological positions objectivist, subjectivist in relation to pragmatism.

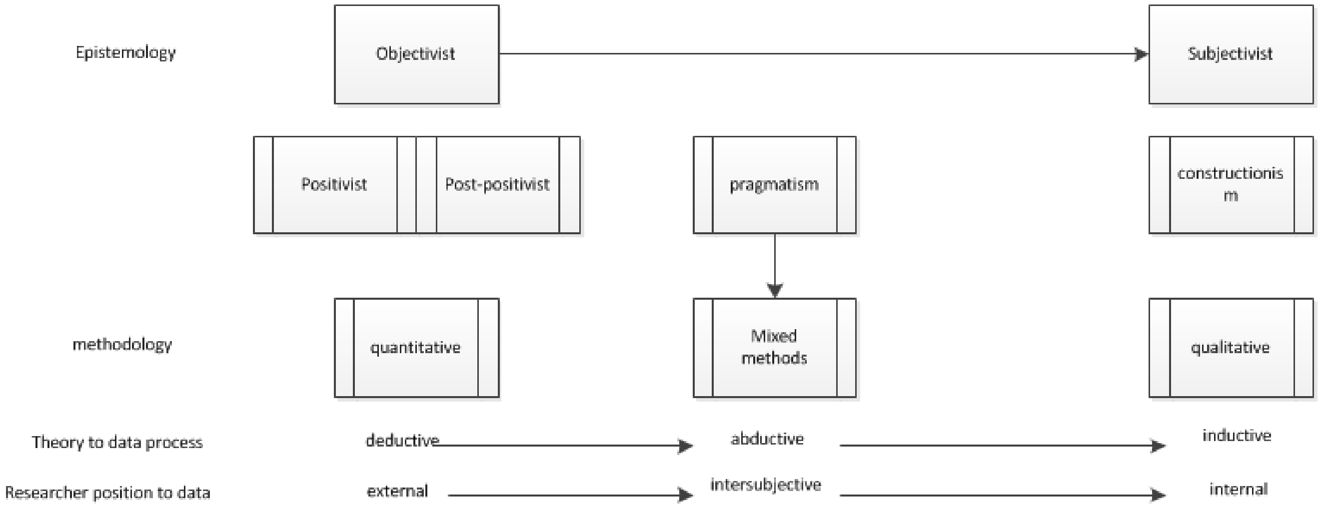

Figure 13: Schematic showing positions and elements of pragmatism compared to objectivist and subjectivist positions

The subsequent emergence of the post-positivist position retains a single reality orientation but acknowledges human limitation in research: claims reality is subject to extensive and critical examination to elucidate the best interpretation of reality possible, simultaneously accepting that this process is endless. Post-positivists are not as mechanistic as positivists, but retain a strong need for regulation and consider how the research in question supports previous work. Therefore supportive findings are ‘likely’ to represent reality (Guba and Lincoln, 1994).

Positivist and post-positivist positions are criticised for their inadequacy to consider contextual factors and assume that the researcher is external to the research process, while the data is represented in pure numerical form, with acceptance or rejection of the predicted hypothesis (Guba and Lincoln, 1994). Typically, positivists claim that numerical data is of higher quality than other naturalist data, and holds increased validity than subjective methods and whose superiority is further seen in the hierarchy of evidence whereby meta-analysis data drives evidence based medicine (Guba and Lincoln, 1994; Maxwell, 2011). Furthermore, positivist approaches fail to attend to outlier results adequately: results that do not fit the norm and are not explained through empirical methods, which are best served using subjectivist approaches and qualitative methods in small case study designs (Morgan, 2007; Bryman, 2012b). Furthermore, as the human contribution is removed in such rigorous positions, the meaning, purpose, understanding and explanations becomes impossible (Guba and Lincoln, 1994). Therefore, the data in perinatal epidemiological studies has absolutely no meaning on an individual level, as the mother has become diluted within the data in terms of reductionist statistics (Lawn *et al.*, 2009; Ravelli *et al.*, 2011; Blencowe *et al.*, 2013; Platts *et al.*, 2014; Draper, Kurinczuk and Kenyor, 2015). Consequently, understanding the ‘how’ behind significant statistics is impossible.

In an attempt to understand and obtain context to the ‘how’ behind significant statistical results, it was clear that accessing the experiences and opinions of mothers was also necessary to best address the research problem. Epistemologically, this approach is positioned on the opposite end of the continuum, as subjectivist positions (e.g. relativism and social constructionist). These claim there are no single realities, arguing that meaning is constructed by humans (as social actors) in combination with their culture and social interaction (Crotty, 1998).

The development of the constructivist and constructionist[91] perspectives were positioned against positivist or post-positivist approaches (Crotty, 1998). Constructivists and constructionists aim to gain an insight and ‘understanding’ of the context and interpretations of phenomena including their own, whereby socio-cultural meaning and values are acknowledged, and dialogue is used to uncover human belief and actions (Crotty, 1998; Yardley and Marks, 2004). Positivist perspectives,

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[91] The terms are often used interchangeably within the literature; however, the distinction between constructivist and social constructionist is important; *constructivists* claim to overcome the realism (external and objective reality) and idealism (internal thought-based reality) dichotomy, whereas in a *social constructionist* reality, objects do exist independently and externally from our internal conscious experience (Raskin, 2002).

on the other hand, consider ‘understanding’ irrelevant (Schwant, 2000). However, it is argued by Crotty (1998), that constructivist and constructionist positions are both objective and simultaneously subjective, making sense (i.e. constructions) of social or object interaction.

The literature demonstrates that proponents of constructivist or constructionist perspectives fail to agree on their ontological assumptions: how the diverse (social) integration reflects reality and the location of constructed meaning, in addition to not agreeing on the best methods to discover the truth in research terms (Raskin, 2002). Consequently, there are versions of constructivism and constructionism with different ontological assumptions (Raskin, 2002). Essentially constructionist and constructivist perspectives are metaphysical; that is, that they can never be proven or disproven and necessitates ‘faith’ – in direct contrast to realist perspectives that require observable evidence (Raskin, 2002; Yardley and Marks, 2004). Therefore, in understanding the human experience, proponents of subjectivist positions argue that no single truth could exist, as meaning is constructed between the ‘actors’ (Crotty, 1998; Bryman, 2012a). There are a small number of qualitative studies that have used this epistemological position.

Several small qualitative studies have been conducted exploring barriers and facilitators to maternity service engagement in ethnic minority women living in Britain (Ali and Burchett, 2004; Ellis, 2004; Dartnall, Ganguly and Batterham, 2005; Puthussery *et al.*, 2008). These studies enjoy explicit reasoning from participants to explain the research questions posed, offering insight and allowing researchers to forward tentative explanations to what may be happening. However, such studies are criticised for the inability to generalise their findings to the wider population, being contextualised in time and place within the individual study (Ravitch and Riggan, 2012). Therefore, while subjectivist positions offer a breadth of explanation through inductive means in diverse socio-cultural settings, they lose the objectivity of positivist positions.

Consequently, there is value for research in perinatal mortality to use both objectivist and subjectivist epistemological positions, to extract both rigorous and statistically significant data in addition to rich contextualised narrative data, which together provide breadth to the studies' insights and understanding (Morgan, 2007). This is especially salient in research from marginalised groups such as Pakistani and Bangladeshi women, who are under-represented in health research, therefore flexibility and practicality is necessary to meet the aims (Lakhanpaul, Bird, Culley *et al.*, 2014). Furthermore, utilising several data sources (numerical and narrative) within a single framework offers triangulation and convergence of the findings, and provides a substantive answer to the research question (Hammersley, 2008; Zhang and Creswell, 2013).

Some scholars argue that opposing epistemological worldviews are incompatible[92]; i.e. using both quantitative and qualitative methods in a single study (i.e. mixed-methods) (Morgan, 2007; Lincoln, Lynham and Guba, 2011). Each ontological and epistemological position and appropriate methods for each offers advantages and disadvantages, typically in antithesis to each other. However, due to the incompatibility of the extremist positions discussed above (i.e. objectivist and subjectivist), the epistemological position of the present study needs to satisfy the axiological position of the author in addition to the aims of the study (Morgan, 2007). Elucidating this led to an understanding that pragmatism was the epistemology that satisfied the worldview of the researcher and the study aims and is dicussed next.

Pragmatism

It is without doubt that the researcher's axiology influenced how the literature review informed the study; in other words, the worldview and value base of the researcher has focused on particular information during the early stages of the literature review, which in turn influenced how the current study took form (Kingdon, 2005). The interest in positivist medical facts derived from her nursing

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[92] This is known as the incompatibility thesis.

and pharmaceutical career and her personal (and subjective) curiosity in human health behaviours drew on her academic qualifications in psychology, in addition to her experience of pregnancy and childbirth. The apparent tension between objective reality and human subjective experience is naturally resolved through pragmatism. Figure 14 shows how the author's axiology influenced the literature review, development and refinement of the study[93] (Kingdon, 2005).

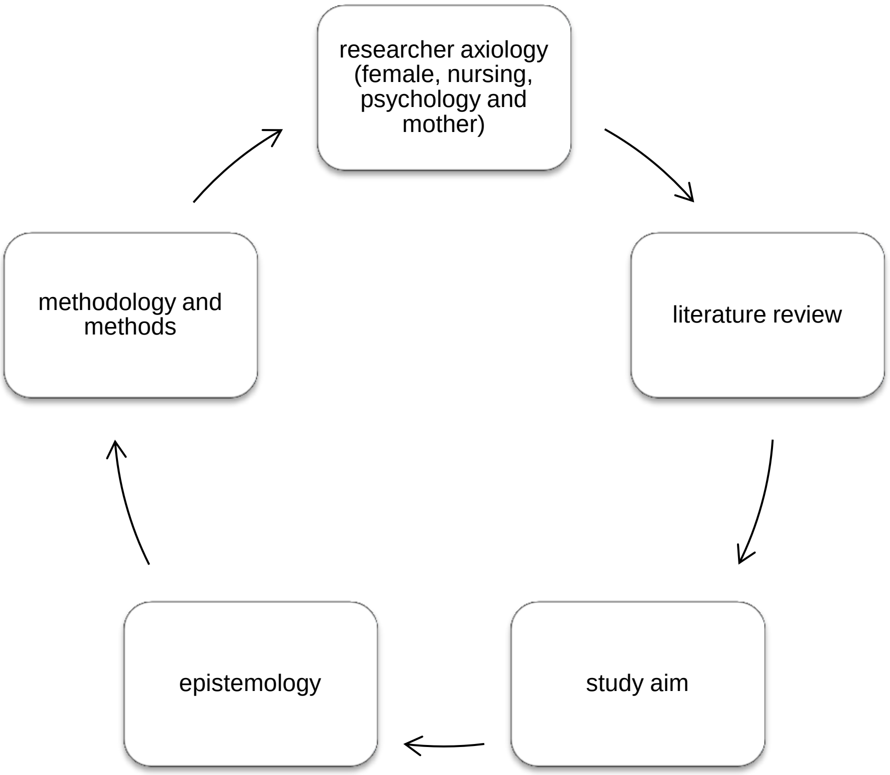

Figure 14: Diagram showing the related and evolving process of how literature review, epistemology and axiology informed the study methodology and methods

Pragmatism is placed between the objectivist and subjectivist positions and is advocated to manage the epistemological tension (Johnson, Onwuegbuzie and Turner, 2007; Morgan, 2007). Pragmatism holds value-orientated positions which consider moral issues within research, such as inequalities (Johnson and Onwuegbuzie, 2009), and state that truth is positioned in experiences as outcome-orientated – considering consequences of action. Therefore, pragmatism has a practical dimension including considerations of the next steps of research to further the understanding of

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[93] Although diagrammatically this is depicted as circular process, it is an iterative process (Lilford, Chard and Morrison, 1999).

knowledge (Morgan, 2007; Johnson and Onwuegbuzie, 2009; Bishop, 2015).This position also provides a logical and practical approach to seeking and evaluating knowledge claims, especially in complex research designs (Feilzer, 2009).

Furthermore, the researcher and participants become assimilated as the ontological and epistemological positions converge; the researcher becomes integral to the research processes, in contrast to objectivist positions, where the researcher is external to the research process (refer to Figure 13) (Crotty, 1998). Consequently, the researchers' relationship with the research process is neither externally orientated nor integral, but intersubjective, which permits a simultaneous understanding of the needs of participants *and* scholars who receive the published results (Morgan, 2007). This allows both a single reality perspective and multiple reality perspectives and undertakes the process of abstraction[94] that is compatible with the conflicting views such as universal and generalised results or context dependent with limitations on the generalisability of the findings (Morgan, 2007). As a result, more bias is expected but accepted; believing in multiple realities as opposed to a single reality (Guba and Lincoln, 1994; Crotty, 1998).

This study considers different factors that influence human health behaviours, including the role of ethnicity, (including language and religion), environment (including service structure) and how these create different dimensions within the same experiences of pregnancy and perinatal mortality between women of various ethnicities living in the same urban town. In other words, each ethnic group in the research is expected to have both differences and similarities in their risk factors and experiences. Consequently, a pragmatic epistemology and mixed-methodology (Chapter 4) are both logical and practical, and are, therefore, ideally positioned to attend to the complexity of

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[94] When applying theory to the data sources, pragmatism resolves the opposing processes by implementing an abductive process; in contrast to objectivism which applies deductive reasoning and subjectivism which implements an inductive reasoning process (Morgan, 2007)

variables, participants, mediators, researcher bias and research challenges (Holloway and Wheeler, 1996; Johnson and Onwuegbuzie, 2009).

Scholars continue to debate epistemology positions best placed to support knowledge and truth (Guba and Lincoln, 2001; Lincoln, Lynham and Guba, 2011; Teddlie and Tashakkori, 2011; Creswell, 2013). However, the outcome following this study is not to contribute to this theoretical debate, but to deliver tangible results that will promote changes in policy and practice within the local maternity services.

Reflecting on the researcher's axiology and the aims of this study, considering salient health beliefs and health behaviour for Pakistani, Bangladeshi and WB women that may contribute to inequalities in perinatal mortality, feminist perspectives naturally come to mind. The contribution of this worldview in this study is examined next.

Feminism

The foundations of feminist perspectives are found in feminist theory; exploring female oppression, exploitation, values and consciousness (Spelman, 1990; Stanley and Wise, 2002). Consequently, feminist perspectives are sensitive to political and ethical issues in research with disadvantaged minorities and includes examining 'power' (e.g. policies, practices and organisations), in addition to speaking against female oppression, providing a voice for marginalised women and to address challenges in methodological and conceptual frameworks (Stanley and Wise, 2002; Harding and Norberg, 2005; Mens-verhulst and Radtke, 2011).

Feminist positions stand against the dominant androcentric and positivist positions and therefore, provide marginalised and oppressed women with a 'voice' (Stanley and Wise, 2002).

Consequently, feminist researchers attempt to demonstrate cultural bias towards males, asserting the rights and control of women and promoting the value of interaction, relationships and daily experience and state that empathy is easily achieved when female researchers are dealing with predominantly female issues such as pregnancy and childbirth (Holloway and Wheeler, 1996; Crotty, 1998; Hudson, 2008). Therefore, feminist researchers are integrated with female participants, whereby shared experiences foster rapport and trust, which contributes to the richness of data that is generated through the study (Holloway and Wheeler, 1996).

Social structures contribute to how societies are governed, therefore understanding these mechanisms is essential before changes can be identified and implemented (Harding and Norberg, 2005). For instance, most feminist perspectives essentialise women into being White, middle class and Christian, therefore, women's identity is socially constructed and culturally bound (Spelman, 1990). Consequently, the dominant discourse positions Westernised White women as the 'subject' and they are anchored on top of the social construction of gender, where difference inevitably follows (Brah and Phoenix, 2004). This then assumes the same degree of oppression for all women who are found in different contexts and cultures. However, Spelman (1990) further argues that separation of gender and ethnicity is impossible.

Several scholars agree that there are several mechanisms of oppression on women: i.e. gender, race and poverty (Harding and Norberg, 2005; McGibbon and McPherson, 2010). McGibbon and McPherson (2010), suggest it is not necessarily an additive process, but likely a cumulative effect of gender, race and poverty contributing to the oppressive context. For example, women with a lack of education have lower levels of employment, or less senior management roles, leading to increased poverty. Gender inequalities exist for women at work; for instance, in 2015 the gender pay gap in the UK is reported as being 19 percent (Azmat, 2015). Consequently, poorer women will have reduced access to resources such as high-quality food and the ability to make healthy food choices, and poor condition housing, which is known to exacerbate health inequalities (Harding and Norberg, 2005). Discrimination and 'difference' contributes to this mechanism further for BAME women.

As mentioned above, the dominant discourse in feminist writing has focused on gender and poverty. However, discrimination through race (or colour) further contributes to disadvantage (Yuval-Davis, 2006). Frequently, the discourse separates women from their ethnicity (i.e. women *and* minority), implicitly implying that they are distinct categories rather than females who are also in an ethnic minority (Bowleg, 2012). The consequence of this is that it obscures any mechanisms which maintain the inequality (Bowleg, 2012). This study seeks to understand similarity between *all* women as mothers and identify differences in health belief and health behaviour that may contribute to perinatal mortality as a result of a mother's ethnicity. Also, understanding how maternity services respond to the needs of all women (Pakistani, Bangladeshi and WB women) will help deconstruct gender *and* ethnicity, similarity *and* difference.

There are some conceptual challenges for the current study in applying a feminist perspective. Typically, feminist researchers promote equality between researcher and participants and use awareness-raising methods to increase empowerment and simultaneously challenge value-free positions as biased (Holloway and Wheeler, 1996; Crotty, 1998). Therefore, when assessing differences in research, it means that the researcher has privileged the dominant group, and in so doing will have assumed the comparator group is homogeneous (Spelman, 1990). Harding and Norberg (2005) argue that researchers are implicit members of society, which has norms, values and assumptions. These shape the society and divergence then is seen as 'different'. Consequently, Harding and Norberg (2005) argue that value-free research is impossible, and suggest that power imbalances are present in research involving ethnicity, gender and social class, in addition to imbalance being present in the research questions and study focus, which is likely to be influenced by political contexts (Harding and Norberg, 2005; Bharj and Salway, 2008; Salway, *et al.*, 2010).

Within the context of the present study, the feminist lens of a WB woman's perspective providing a 'voice' to Pakistani and Bangladeshi women at first glance seems appropriate to examine how health beliefs influence health behaviour and contribute to perinatal mortality in Luton. However, there is a problem of power imbalance between the participants and researcher. There is a risk that the researcher will be perceived as in a position of power or authority, due to her professional (nursing) and academic qualifications, therefore, purely collaborated discussions are not being sought, and the researcher will not influence the conversations and reported experiences of the participants, or transfer her experiences into those being explored (Holloway and Wheeler, 1996).

Consequently, linked experiences between researcher and participants will not be actively pursued throughout the present study (although sometimes it may be appropriate to acknowledge shared understanding). Furthermore, feminist perspectives assume homogeneity between researcher and participant groups, which is not necessarily the case in this study, due to the relationship between the researcher and the participants, which is considered in detail in Section 3.2.2 (Crotty, 1998). While feminist perspectives are not being explicitly used in this work, they have influenced the use of the intersectional approach (Section 3.3), in particular, issues surrounding aggregated oppression(s) (i.e. gender *and* ethnicity) (Spelman, 1990) and structural factors that further perpetuate disadvantage and discrimination (Patterson, 2004; Cross-Sudworth, 2007; Bowleg, 2012).

3.2.2. The relationship between the researcher and the researched

An important conceptual consideration in the current study is how emic (insider), and etic (outsider) perspectives influenced both the design of the study and interpretation of the results (Maxwell, 2013b). To fully appreciate an emic perspective, Headland and colleagues (1990) argue that it need to be experienced as an outsider. Moreover, the etic perspective then increases as a consequence of increased emic perspectives which seek to understand similarity and difference (Headland, Pike and Harris, 1990).

Previous studies such as Shaw's ethnographic research on Pakistani *Biradari's* in Oxford (Shaw, 2000), clearly use etic approaches: a WB researcher conducting anthropological, ethnographic research on Pakistanis living in Oxford, England and Pakistan. The detail in her subsequent publication is a testimony to knowledge that was not taken for granted by herself (or by readers), so she carefully explained cultural concepts and observations that she made during her research which would be otherwise unknown to non-Pakistanis. This draws attention to differences.

Conversely, whereas it might be argued that Ajaz (Ajaz, Ali and Randhawa, 2015) and Ali (Ali and Burchett, 2004) use emic approaches as they are Canadian and British Pakistanis conducting research within their ethnic group. The benefit of an emic perspective is that there is implicit knowledge of religious and cultural nuances that may be missed by an outsider, yet understood by the researcher (Headland, Pike and Harris, 1990), although it might be argued that these nuances may not be reported by an emic perspective since they are assumed or taken for granted.

The present study brings an individualistic (researcher) and Westernised perspective (Luton as the setting) to the research problem, interpreting the world from an individualistic and Western perspective. By contrast, the Pakistani and Bangladeshi participants in this study reflect a collectivist perspective of the world (Kashima *et al.*, 1995), although British Pakistani and British Bangladeshi women have been influenced by the British society in which they live, therefore the degree to which they ascribe to individualistic and more Westernised cultures compared to Eastern collectivist values is unclear. This is salient for this study insofar as it is unclear to the extent in which British Pakistani and British Bangladeshi experiences are different to a WB woman's experience and are clearly outsider [95] and collectivist as opposed to insider[96] and an individualistic perspective and how these views shape belief and behaviour.

The nuances between individualistic and collectivist cultures can be appreciated using a White researcher whose framework is individualistic, so difference with Pakistani and Bangladeshi narrative that fails to ascribe to Western traditions will be clearly identified, and by contrast, the similarity of their narrative will also be identifiable. This is similar to Ellis's (2004) ethnographic research on Muslim South Asian women's experiences of maternity care which also took an intersubjective perspective, being a midwife Ellis was able to identify with service issues while being a White researcher exploring Muslim South Asian women's experiences of maternity services.

The current research is being conducted by a White female researcher; therefore, this uses an outsider perspective when considering Pakistani and Bangladeshi ethnicity and collectivist cultural matters. Conversely, an insider perspective will be present for awareness of individualistic cultural issues which may be present with British-born Pakistani or Bangladeshi mothers. Moreover, she is a registered nurse and has a good understanding of NHS services, which lends itself to both insider and outsider perspectives depending on the participant group (e.g. mothers or health professionals). Furthermore, she is also a mother and has had experience of pregnancy loss, and

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[95] to the researcher perspective

[96] Ibid

this provides emic perspectives. The combination of emic and etic perspectives within the current study contributes to the intersubjective view of the research problem (Maxwell, 2013b).

3.3 Social cognition models, ecological models and an intersectional approach

This section presents a brief overview of psychological and sociological health behaviour theories, which proffer a variety of models and conceptual frameworks, which were carefully considered and evaluated in relation to the current study. A collaborative approach was also considered (i.e. collating and adapting a few theoretical models into one) before the decision was taken to ground the work in an intersectional approach (Section 3.3.3) (Crenshaw, 1991; National Collaborative Centre for Health Public Policy, 2015).

3.3.1 Social cognition models (SCM)

In academic and clinical settings, social cognition models (SCM) have been used to help understand and test proximal and distal influences on health behaviour (Glanz, Rimmer and Viswanath, 2008). There are several theoretical approaches to understanding health beliefs and health behaviours, such as the Health Belief Model (HBM) (Hochbaum, Kegels and Rosenstock, 1952; Janz and Becker, 1984) or the Theory of Planned Behaviour (TPB) (Ajzen, 1991; Ajzen and Fishbein, 2005), to attempt to explain or predict health behaviour in specific health situations, such as smoking or screening behaviours (Janz and Becker, 1984). However, SCM do not adequately account for distal determinants of health, such as ethnicity, SES, or structural barriers.

SCM aim to describe the components of the main cognitive processes involved in behaviour and have been developed to help identify and test cognitive determinants of health behaviour (Glanz, Rimmer and Viswanath, 2008a). Attitudes and beliefs that influence behaviour are considered modifiable whereas gender, age or ethnicity is considered less modifiable (Morrison and Bennett, 2006; Conner and Norman, 2005). Consequently, implementing a SCM facilitates an exploration of cognitive health determinants, identifying modifiable factors for interventions to be developed, aiming towards behaviour change (Ogden, 2007; Conner and Norman, 2005). However, this does little to explain the contribution of the DOH, e.g. heritable, lifestyle or environmental factors.

The most common application of SCM is to develop or test predictive behaviour in the use of health promotion interventions and focus on consequences. Typically, studies use SCM to consider health-enhancing behaviours (e.g. exercise or nutrition) or health protective behaviours (e.g. screening behaviours and vaccination uptake) (Ogden, 2007). A few studies have implemented SCM to examine antenatal or postnatal behaviours, such as breastfeeding (Swanson and Power, 2000, 2005; Lawton *et al.*, 2012; Hirani and Karmaliani, 2013), antenatal care (Choudhury and Ahmed, 2011), smoking in pregnancy (Haslam and Lawrence, 2004; Kazemi *et al.*, 2011), or HIV screening (Mirkuzie *et al.*, 2011).

A much less common use for SCM is to use it as a theoretical framework to ascertain antecedent attitudes and beliefs before any intervention development (Conner and Norman, 2005; Ajzen, 2011). For example, a search in PubMed shows to date only six studies have employed the HBM and six studies using TPB on pregnancy-related health interventions including prediction and maintenance of breastfeeding behaviours and none include women from Pakistan, Bangladesh or South Asia in the study population, and no studies were identified using HBM or TPB as a basis for a theoretical framework (Cabieses *et al.,* 2014).

Ogden (2003) suggests that SCM have limited value as theoretical frameworks as typically authors have failed to refute the model(s), also, variables have been poorly aligned to predictive factors resulting in a misleading representation of the model's actual abilities. Therefore, during hypothesis testing, the model(s) themselves are not rigidly applied. Therefore, comparison between studies becomes challenging, and the robustness of the model is questioned (Ogden, 2003). This is further complicated by the fact that antenatal care is in itself a complex intervention (Ota *et al*., 2012), including education, screening and surveillance over a given period and varies according to each woman's perceived risk of complications (The National Institute for Health and Care Excellence, 2010, 2008). Therefore, aligning SCM with the distal determinants or multifaceted antenatal intervention is unfeasible.

An area of oversight in the SCM literature is that much of the social cognition research is based in the West, and focuses on a specific health behaviour (e.g. breastfeeding) with little attention to differences in health behaviour that may be evident in diverse populations (Swanson and Power, 2005). This has contributed to an obscuring of the role of ethnicity on health beliefs and behaviours. For example, Pakistani and Bangladeshi women may have different outcome expectancies from their engagement with maternity services, and may percieve regular attendance to be 'excessive' (Woollett *et al.*, 1995; Cresswell *et al.*, 2013), or utilise 'naturalistic' remedies during the natural phenomenon of pregnancy (The National Institute for Health and Care Excellence, 2008; Cresswell *et al.*, 2013; Tarafder, Sultan and Rashid, 2013).

3.3.2 Ecological models

This section looks at the suitability of ecological models as a theoretical framework in this study. Social sciences scholars recognised the limitations of SCM and pursued theoretical frameworks known as ecological models. Typically ecological models acknowledge levels which influence behaviour, commonly including individual, interpersonal, structural and policy level, and sociocultural physical environments interact across all levels (Glanz, Rimer and Viswanath, 2008c).

When considering inequalities in health, ecological models help incorporate contextual factors such as SES, gender, ethnicity and culture (Richard, Gauvin and Raine, 2011). Additionally epidemiologists state that dominant models take a linear or sequential perspective on explaining causation of individual risk factors. However, the role of converging environmental factors and biological factors on health outcomes is protracted, resulting in the need for conceptual models that utilise both cognitive factors at individual levels together with environmental, cultural and social factors (Richard, Gauvin and Raine, 2011).

Numerous scholars have posited slightly different conceptualisations of precisely how many influencing layers exist, in addition to questioning the terminology used to describe the layers (Sallis, Owen and Fisher, 2010). Academics have contributed and complicated the research field, with a mixture of specific models to guide interventions (Flay and Petraitis, 1994; Flay et al., 2009; Champion and Skinner, 2008) and those designed to explain behaviour (Andersen, 1995). Nevertheless, there is a rich evidence base supporting their use in health promotion (Naidoo and Wills, 2000; Rimer and Glanz, 2005).

Critics of ecological models state that it is unclear which factors may exert the greatest influence on a given health behaviour (McLaren and Hawe, 2005; Sallis, Owen and Fisher, 2010). Moreover, there is a lack of information regarding *how* distal determinants interact, mediating outcomes (Sallis, Owen and Fisher, 2010). A further criticism with ecological models, similar to SCM, is that it is unclear how potential variables interact, consequently ecological models widened perspectives but without being specific, in contrast to SCM which are likely to be more specific but without adequate consideration of the wider DOH (such as ethnicity, SES and environmental factors) (Reifsnider, Gallagher and Forgione, 2005; Richard, Gauvin and Raine, 2011).

Neither of these approaches (SCM or ecological models) adequately explains nuances that are found in ethnic differences, which impact on common beliefs, practices and behaviour (Spector, 2004a; Tarafder, Sultan and Rashid, 2013). Therefore a framework that encapsulates health beliefs (psychological), health behaviour, socio-economic factors (including education level and deprivation) and structural factors (such as physical location and environment) is required to expose the salient determinants of perinatal mortality (Cohen and Kitayama, 2010).

3.3.3 Intersectionality

The intersectional approach is increasingly being used in public health research and in women's health research, especially in Canada (Hankivsky, Cormier and de Merich, 2009; Hankivsky *et al*., 2010). This section overviews the current conceptual approach to inequalities in perinatal mortality and presents the intersectional approach as the lens through which will best reveal the similarities and differences in health beliefs and health behaviours of Pakistani, Bangladeshi and WB mothers in Luton. Figure 15 shows the concept map for the study, which tentatively maps a relationship between heritable factors (e.g. ethnicity), structural factors and SES factors linked to health beliefs, then to health behaviour, to explain the experience of perinatal mortality.

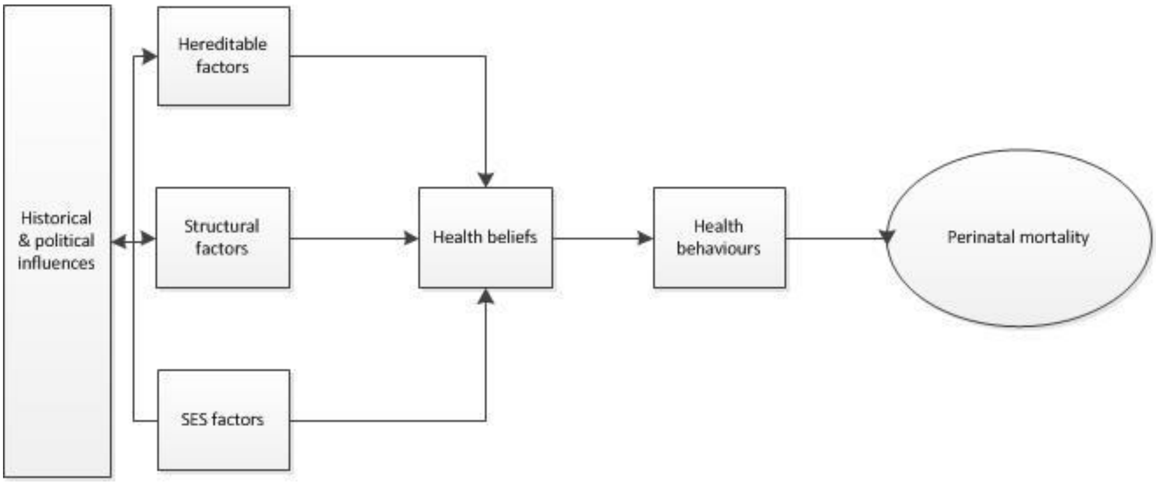

Figure 15**:** Diagram showing concepts contributing to perinatal mortality

As discussed in Chapter Two, Section 2.6, while the DOH approach in addressing determinants of perinatal mortality has been useful, it has both functional and conceptual limitations. Consequently, previous studies have focused on proximal determinants e.g. biological or lifestyle and behavioural factors. From a biological perspective, quantitative studies demonstrate population level prevalence or risk (Datta-Nemdharry, Dattani and Macfarlane, 2012; Leon and Moser, 2012; Bryant *et al.*, 2014), while studies that focused on specific behaviours typically report prevalence rates (Bryant *et al.*, 2014; Coton, Nazareth and Petersen, 2016) or attitudes and experiences from a specific perspective (e.g. Muslim women) (Ali and Burchett, 2004; Ellis, 2004; Sutan and Miskam, 2012; Shaw, 2014). Therefore, distal determinants for perinatal mortality have mostly been ignored, in addition to the contribution of disadvantage (Blumenshine *et al.*, 2010; Hollowell, Oakley, *et al.*, 2011). However, implementing an intersectional approach provides the ability to reveal simultaneous intersecting categories that contribute to the experience of perinatal mortality for Pakistani, Bangladeshi and WB women, in recognising that women's experience is influenced by a number of factors (e.g. ethnicity, SES, education) and power dynamics in operation between the intersecting categories (Hankivsky, Cormier and de Merich, 2009).

One of the most striking observations regarding the majority of current research with Pakistani and Bangladeshi mothers in the maternity literature, is the focus on identifying 'difference' in ethnic groups, whereby similarities in experiences have rarely been addressed (Homans, 1980; Woollett and Dosanjh-Matwala, 1990; Woollett *et al.*, 1995). Focusing on difference obscures important power dynamics in social relationships between ethnic groups that maintain 'othering' and health inequalities and further contributes to a lack of a critical perspective (Hall, 1992; Gunaratnum, 2003; Hankivsky and Christoffersen, 2008; Salway, Nazroo, Mir, Craig, Johnson, Gerrish, *et al.*, 2010).

A wealth of descriptive epidemiological research has highlighted salient risk factors for perinatal mortality, as discussed in Chapter Two, Section 2.4. Researchers use pre-identified health determinants to explore and explain risk and outcomes and are conceived as being additive, however, this fails to distinguish which (if any) risk category may be more important in contributing to health outcomes (Mens-verhulst and Radtke, 2011; Bowleg, 2012). Also, this fails to understand which determinants are more important than others or indeed, whether the list is comprehensive and not yet understood (Hankivsky and Christoffersen, 2008; Hollowell, Kurinczuk *et al.*, 2011). Furthermore, conceptualising risk categories in this way obscures new dimensions by not incorporating ubiquitous power dynamics, which may be evidenced at individual, social or environmental levels, and fails to reveal similarities and differences between *and* within disadvantaged groups, uncovering a core set of determinants for perinatal mortality (Mens-verhulst and Radtke, 1991; van Herk, Smith and Andrew, 2011).

In 1991, feminist writer Kimberlé Crenshaw published her paper on ‘intersectionality’, where she maps the intersection of gender and race and presents the argument of a new and previously unacknowledged social category for Black women. Crenshaw explains that by considering social identities (e.g. race, gender, social class and religion) converge and interact, a different socially constructed view is forwarded that accounts for oppression, power imbalance and discrimination. Consequently, she demonstrated that Black women had experienced disempowerment on several interacting levels: domestic violence, political sexism and racism, therefore their experience of overcoming domestic violence was far more complex than White women in the same abusive situation. Therefore, White women who had not experienced social racism had a different experience of sexism, which was consistent with the temporal and political climate at the time (Crenshaw, 1991).

Historically, ‘race’ (now ethnicity[97]) was used to ‘explain’ and justify social problems such as the (claimed) lower intelligence of Blacks, however, the historical and political context was never considered as a contributory factor to the underperformance of Black children in America

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[97] As discussed in Chapter two, ethnic identity is self-defined and incorporates facets of individual characteristics which include health beliefs and health behaviour. It corresponds to a shared belonging to a number of different social categories (including shared common language, regional territory, culture and customs) whereby individuals ascribe to different levels of indoctrination to each category (Saffron and Nazroo, 2002; Cohen, 2010).

(Herrnstein and Murray, 1994; Karlsen and Nazroo, 2002). However, applying an intersectional lens upon 'ethnicity' would have highlighted an ethnic and class intersection – showing a pattern of deprivation, disadvantage and exclusion as a result of historical and politic disadvantage (Spelman, 1990; Crenshaw, 1991; Patterson, 2000, 2014).

Most health research and policies fail to recognise the intersection of various social identities and therefore are unaware of how this conjuncture of multiple determinants at the individual level interacts with structural level health disparities (Bowleg, 2012). For example, how the combination of ethnicity, deprivation, low education attainment and poor health literacy interacts with rigid maternity services, which is aimed at homogenous middle-class White women, further excluding already marginalised women (Oakley, 1982; Witz, 1995; Hankivsky and Christoffersen, 2008). Consequently, the advantage of an intersectional approach is that it attends to power dynamics such as privilege and oppression and how this interacts with structural level services, which maintains inequality, in ways other theoretical models, such as SCM, fail to account for (Bowleg, 2012).

From a political and policy level, disempowerment may be unintentional; consequently, a situation may interact with existing vulnerabilities exacerbating disempowerment (Crenshaw, 1991; Hankivsky and Christoffersen, 2008). This can be seen when offering advice on screening in early pregnancy predominantly through communication in oral English (with or without translators present[98]) or leaflets written in English, assuming English language proficiency and health literacy, and disadvantages already vulnerable non-English proficient speakers and women with limited education and health literacy skills (Temple and Young, 2004; Regmi *et al.*, 2010). Moreover, some health concepts may not exist in their vocabulary and individual understanding of religious prescription will contribute to their overall decision-making processes (Shaw and Ahmed, 2004;

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[98] The problems of translation are discussed in Chapter Two, Section 2.5.2.

Cohen, 2010) thus exacerbating inequity further by allowing some women to inadvertently slip through gaps in the current services (McAlister, Perry and Parcel, 2008; Jayaweera and Quigley, 2010).

Moreover, Hankivsky and Christoffersen (2007) suggest that previous research with women has essentialised women's experiences and results in skewed knowledge of their experiences; hence implementing an intersectional perspective allows a number of determinants (i.e. variables) to be considered in an interactional and not additive format as seen in epidemiological work (Bowleg, 2012). Furthermore, public health typically examines risk categories separately which results in issues remaining invisible and an impaired understanding of the underlying dynamics thus maintaining inequalities (Mens-verhulst and Radtke, 1991; Bowleg, 2012).

The intersectional approach was successfully applied by Dworkin (2006), who identified that early HIV disease classifications excluded significant numbers of infected women, denying them access to diagnosis and therapeutic intervention as a consequence of excluding common female yeast infections from the official HIV classification. Moreover, previous surveillance categories used in HIV/AIDS did not identify the intersection of risk for women (due to homogenous and discretely defined categories) therefore factors such as poverty, gender and contextual factors contributing to risk was obscured (Dworkin, 2006). Consequently, women who were at high risk of contracting HIV were not identified as such; for example, self-identified heterosexual women who in reality practiced bisexual intercourse with self-identified homosexual partners engaging in anal intercourse (Dworkin, 2006), consequently, public health interventions failed to reach these ‘unidentified’ (and previously invisible) high-risk women.

As discussed in Chapter Two, Section 2.6 there is a need to look at the similarities (as well as difference) in maternity experiences and birth outcomes. This is illustrated when considering barriers for women accessing maternity services, whereby limited English language proficiency and health literacy have been identified as key factors for migrant women. However, language proficiency and health literacy are also problematic for poorly educated *non*-migrant women. Therefore, health messages need to be accessible to all women (Mens-verhulst and Radtke, 1991; The National Institute for Health and Care Excellence, 2010c; Hollowell *et al.*, 2012). Scrutinising *only* differences in maternity experiences and birth outcomes provides limited perspectives and does not lend much insight into how maternity care structures (e.g. policy and service provision) may further exclude vulnerable women (Mens-verhulst and Radtke, 1991, 2011).

Subsequently, implementing an intersectional approach will acknowledge power dynamics (i.e. privilege and oppression) and help to identify potential gaps in maternity provision which are currently invisible or inequity that is maintained due to interventions designed to meet the needs of a homogeneous White middle class society (Oakley, 1982; Mens-verhulst and Radtke, 2011; Bowleg, 2012). Recent, changes in legislation and policy impose health services to address inequity and inequalities (*Health and Social Care Act* 2012; Marmot, 2013; Bircher and Kuruvilla, 2014). Therefore, recognising previously excluded populations and identifying structural level (i.e. policy and service) factors that maintain inequality, while addressing individual level factors (e.g. ethnicity, age,) that may also exacerbate vulnerable women's situations, needs a different conceptual approach (Atkin, 2006; Dworkin, 2006; Bircher and Kuruvilla, 2014).

Recently, Lopez and Gadsden (2016) have suggested implementing an intersectional approach is well suited to understand health inequalities, arguing that an intersectional approach challenges the current conceptualisations in relationships between socially defined categories and therefore examines power dynamics. Additionally, it moves away from victim-blaming which is seen in many studies involving culture, genetics or ethnicity (López and Gadsden, 2016). Consequently, researchers reconceptualise existing issues, but implementing broader praxis, such that is necessary in current health services research (López and Gadsden, 2016). Moreover, the existing literature has shown that the (known) preceding mechanism(s) behind perinatal mortality are multi-factorial (Chapter 2, Section 2.5.2-2.5.5), including power dynamics across heritable, structural, SES factors and health beliefs and health behaviours. Therefore, utilising an intersectional approach in maternity research is not only well suited, but following recent Government attention to reducing perinatal mortality it is especially timely (National Maternity Review, 2016).

Implementing an intersectional approach is still relatively new in the UK and seldom seen in mainstream maternity research. Therefore, this is a novel undertaking in the present work. The intersectional approach is criticised for being poorly defined and inadequately operationalised, (Mens-verhulst and Radtke, 1991) and scholars lack consensus regards the optimum method to implement this approach; some suggesting complex research designs while others lean towards narrative work (Mens-verhulst and Radtke, 1991). Furthermore, it has also been suggested that language[99] itself is limited to properly explain the concept of 'intersectionality': how close the simultaneous relationships and intersecting mechanisms may be (Gunderson and Cochrane, 2012).

There are numerous versions of intersectional approach found in the literature. However there are commonalities between them; offering to understand the conjuncture between two (or more) intersections of social determinants and illuminating how broader social structures contribute to the maintenance of inequality (National Collaborative Centre for Health Public Policy, 2015). Nevertheless, the benefit of an intersectional approach is in facilitating the contribution of numerous dynamic social categories (e.g. SES or ethnicity) simultaneously (Hankivsky, Cormier and de Merich, 2009). Additionally, it accommodates pluralistic methods, such that it is well suited

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[99] 'Language' in the context of shared social meaning (Gunderson and Cochrane, 2012).

to mixed-method designs, identifying several data points and various decisions prioritising determinants, for instance, ethnicity or deprivation or both (Mens-verhulst and Radtke, 2011). Figure 16 depicts the approach used in this study.

Chapter Two, Section 2.5 previously detailed the available evidence and defined the following categories: heritable factors (ethnicity[100], genetics and age), structural level factors (social networks, policy response and Luton's maternity services), lifestyle factors (health beliefs and health behaviours) and SES factors (IMD and maternal education). These will be used in this study to determine the experience of perinatal mortality.

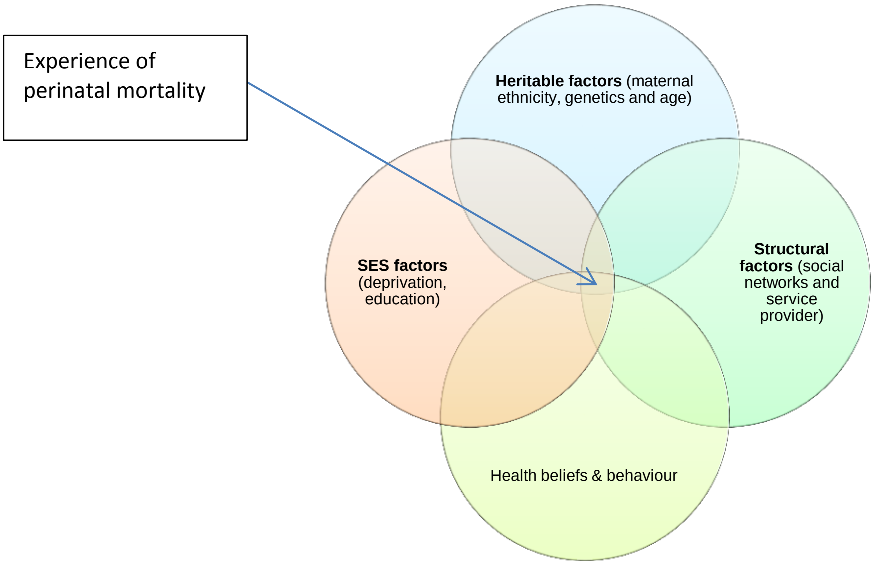

Figure 16 Diagram depicting experience of perinatal mortality in the conjuncture of determinants

3.4 Mixed-methods

This section now turns its attention to explaining why mixed-methods were deemed most appropiate to address the research question, situated within an intersectional approach

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[100] Ethnicity as described in Chapter Two, Section 2.5.2 is a self-defined construct encapsulating culture, religion, language, common ancestry, shared territories and physical appearance (Economic and Social Data Service, 2012).

(Hankivsky, Cormier and de Merich, 2009). Following on from Section 3.2.1, a pragmatist epistemological position was justified as most suitable, to resolve the natural tension between objectivist and subjectivist positions, and to utilise an intersubjective perspective (Geertz, 1993; Richie and Spencer, 2003). This will help identify similarity and difference in health belief and health behaviour in Pakistani, Bangladehi and WB women in Luton (Crenshaw, 1991), additionally, consider how aggregated determinants may influence the experience of perinatal mortality (Mens-verhulst and Radtke, 1991; Bowleg, 2012).

Mixed-methods offer flexibility which is necessary when conceptualising dynamic social categories (Hankivsky, Cormier and de Merich, 2009). In addition, triangulation of different data points provides confirmatory and/or contradictory outcome perspectives, supporting the conceptual foundations of this study (intersectional approach), which increases the validity and trustworthiness of the inquiry (Teddlie & Tashakkori, 2011; Hammersley, 2008), subsequently, convergence of several data points facilitates a comprehensive answer to a complex research problem (Zhang & Creswell, 2013).

Mixed-method research is an accepted methodology and is used increasingly in complex health research, such as in maternity research, whereby several integrated systems influence birth outcomes, such as biological, psychological and social factors (Haddrill *et al.*, 2014; Walsh and Evans, 2014). Therefore applying a mono-method research design in this instance would threaten the loss of valuable information that, if captured, can provide contextual insight to the research problem and meet the research outcomes (Johnson and Onwuegbuzie, 2009; Creswell and Plano-Clark, 2011a; Zhang and Creswell, 2013; Walsh and Evans, 2014). Therefore, to broadly address the research question, a convergent mixed-method design was considered the most suitable method (Creswell, Fetters and Ivankova, 2004; Meissner *et al.*, 2011; Zhang and Creswell, 2013).

However, mixed-method research is not without challenges. For example, overcoming the issue of where and when to blend the research methods to meet both the quantitative and qualitative research aims (Creswell, Fetters and Ivankova, 2004). In addition, researchers are required to establish if the study is dominated by quantitative or qualitative methods and determine the temporal sequence, which may have further implications on the study outcomes and in practical terms (Johnson and Onwuegbuzie, 2009). Chapter 4 attends to methodology applied to this study in more detail. Figure 17 depicts the conceptual framework for this work.

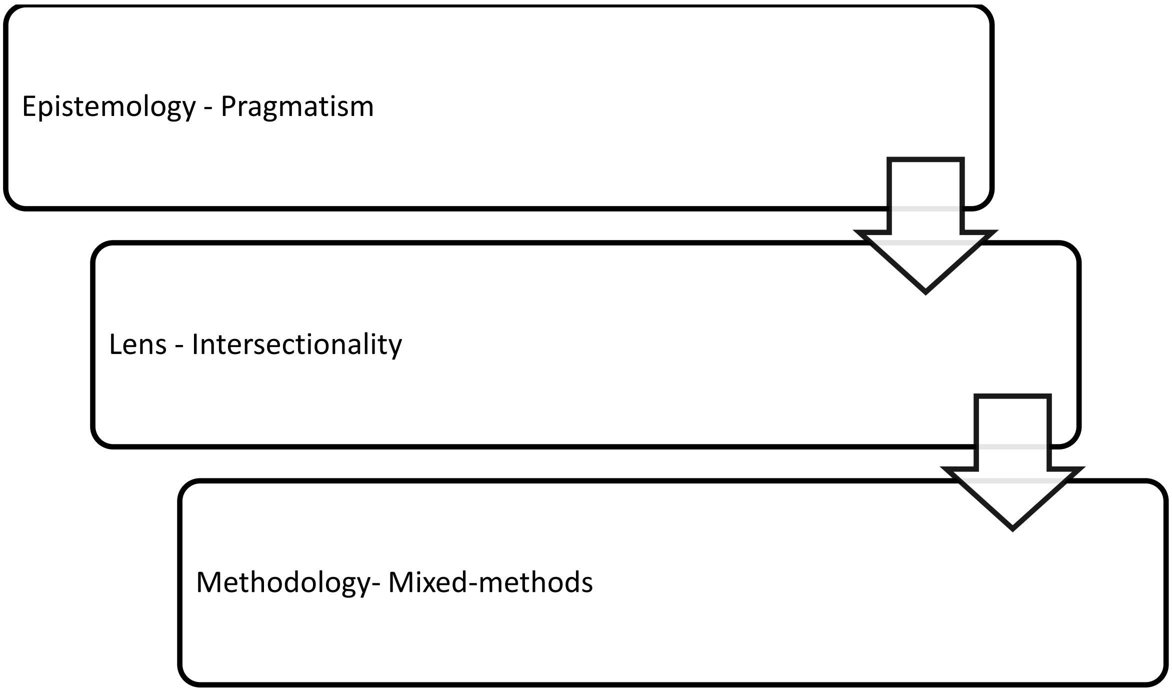

Figure 17: Conceptual framework: Overarching pragmatist philosophy with an intersectional lens, implementing mixed methods

3.5 Chapter summary

This chapter has presented the conceptual framework of the current body of work and explains why the paradigm of pragmatism is forwarded as the most suited epistemological paradigm to approach this study. Feminism was also critically discussed, and the rejection rationale was explained. Next, an intersectional approach was presented, explained and justified to show how this approach is salient within the current study on inequalities in perinatal mortality in Pakistani Bangladeshi and WB women in Luton. The chapter then discussed the limitations of using typical social and psychological approaches to conceptualising health beliefs and health behaviours, explained why these approaches would fail to identify the often obscured power dynamics and oppressions, which are found in health inequalities. Lastly, the use of mixed-methods was highlighted as the preferred method (rather than a mono-method) to address the complexity of the current research question.

Chapter 4: Methodology

4.1 Introduction

This chapter presents the methodology used in this study. The previous chapters have presented the research problem in context; showing ethnic variation in perinatal mortality, with higher rates in Pakistani and Bangladeshi infants in Luton (Chapter one), and described and explained the current explanations of perinatal mortality, while focusing on the ethnic inequalities, showing how the contribution of health beliefs that influence health behaviours have not been properly examined (Chapter two). This led to discussing the theoretical concepts in the present literature and examining the contribution of a pragmatist epistemology and intersectional approach, which is applied in this study (Chapter three).

This chapter restates the research question, aims and objectives, prior to providing an explanation of why mixed-method design was employed. Section 4.2 revisits the aim and objectives, while Section 4.3 provides rationale for utilising a mixed-method approach and a visual representation of the design. Each objective uses a different method, and this is detailed in Sections 4.4–4.6. Ethical considerations are discussed in Section 4.7. The chapter concludes with a summary.

4.2 The research question, aim and objectives

4.2.1 Research question

How do health beliefs influence health behaviour and contribute to perinatal mortality in babies born to Pakistani, Bangladeshi and WB women living in Luton?

4.2.2 Aim

To explore how health beliefs influence health behaviour and contribute to perinatal mortality in infants born to Pakistani, Bangladeshi and WB women, living in Luton.

4.2.3 Objectives

- To identify the current evidence of risk factors contributing to perinatal mortality in Pakistani Bangladeshi and WB women in Luton.
- To explore the similarities and differences in maternal health beliefs that influence health behaviours in perinatal mortality in Pakistani, Bangladeshi and WB women, through the maternity care pathway (preconception, antenatal care, intrapartum and postnatal care).
- To ascertain maternity health professionals' views on the service needs of Pakistani, Bangladeshi and WB pregnant women.

4.3 Choosing a mixed-method research methodology

This section presents the convergent mixed-method methodology applied within the current study. As mentioned in Chapter 3, the epistemological perspective of pragmatism is best suited for this study since it provides an outcome-orientated and practical approach to addressing the complexities of the aim and objectives of this study and answering the research question (Creswell and Plano-Clark, 2011a; Meissner *et al.*, 2011).

The purpose of convergent mixed-method design is to access a broad array of data points, which will facilitate identification of data patterns that may be evident between the three ethnically defined participant groups; accessing quantitative (secondary data) and qualitative data (i.e. narrative) in order to best answer the research question (Steckler *et al.*, 1992; Creswell and Plano-Clark, 2011a). Consequently, using both quantitative data, i.e. maternal and infant variables (objective one) and qualitative data, i.e. narrative exploring the similarities and differences of Pakistani, Bangladeshi and WB women's health beliefs and health behaviours during their pregnancy (objective two), and to qualitatively explore HCP understanding of the maternity needs of Pakistani, Bangladeshi and WB women (objective three). These combined will provide a rich and detailed understanding of the health beliefs and health behaviours that contribute to perinatal mortality in Luton's Pakistani and Bangladeshi infants (Creswell, 2009; Parahoo, 2006a; Creswell and Plano-Clark, 2011a).

Utilising different sources of data allows triangulation and convergence of the data points. Such as: quantitative secondary data analysis of pre-determined risk factors to identify significant factors and statistical associations in the data, compared and combined with qualitative findings from FG with mothers who had a normal birth outcome[101], face-to-face interviews with bereaved mothers and HCP who are currently involved in the maternity service delivery (Hammersley, 2008; Bryman, 2012b). Consequently, a convergent mixed-method design will facilitate a detailed understanding of the present situation in the Luton context (Figure 18) (Creswell and Plano-Clark, 2011a).

Few studies in the UK maternity literature have implemented mixed-methods, and most are mixed-method literature reviews or use survey data with few qualitative interviews (Kingdon *et al.*, 2009; Hollowell *et al.*, 2012; Cabieses *et al.*, 2014; Mumtaz, O'Brien and Higginbottom, 2014). Recently, one study looked at stillbirth bereavement care and implemented similar methods to this design; using localised statistical data, interviews with parents and staff FG (Chebsey *et al.*, 2015). Each objective has been influenced by numerous studies (e.g. Sachdev, 2001; Yeasmin and Regmi, 2013; Kelley and Trinidad, 2012; Ali, 2004; Ali *et al.*, 2012). A diagram of the convergent mixed-method design is seen in Figure 18.

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[101] Normal birth outcome is defined as delivery after 37 weeks of gestation, weighing over 2.5kg, and live born.

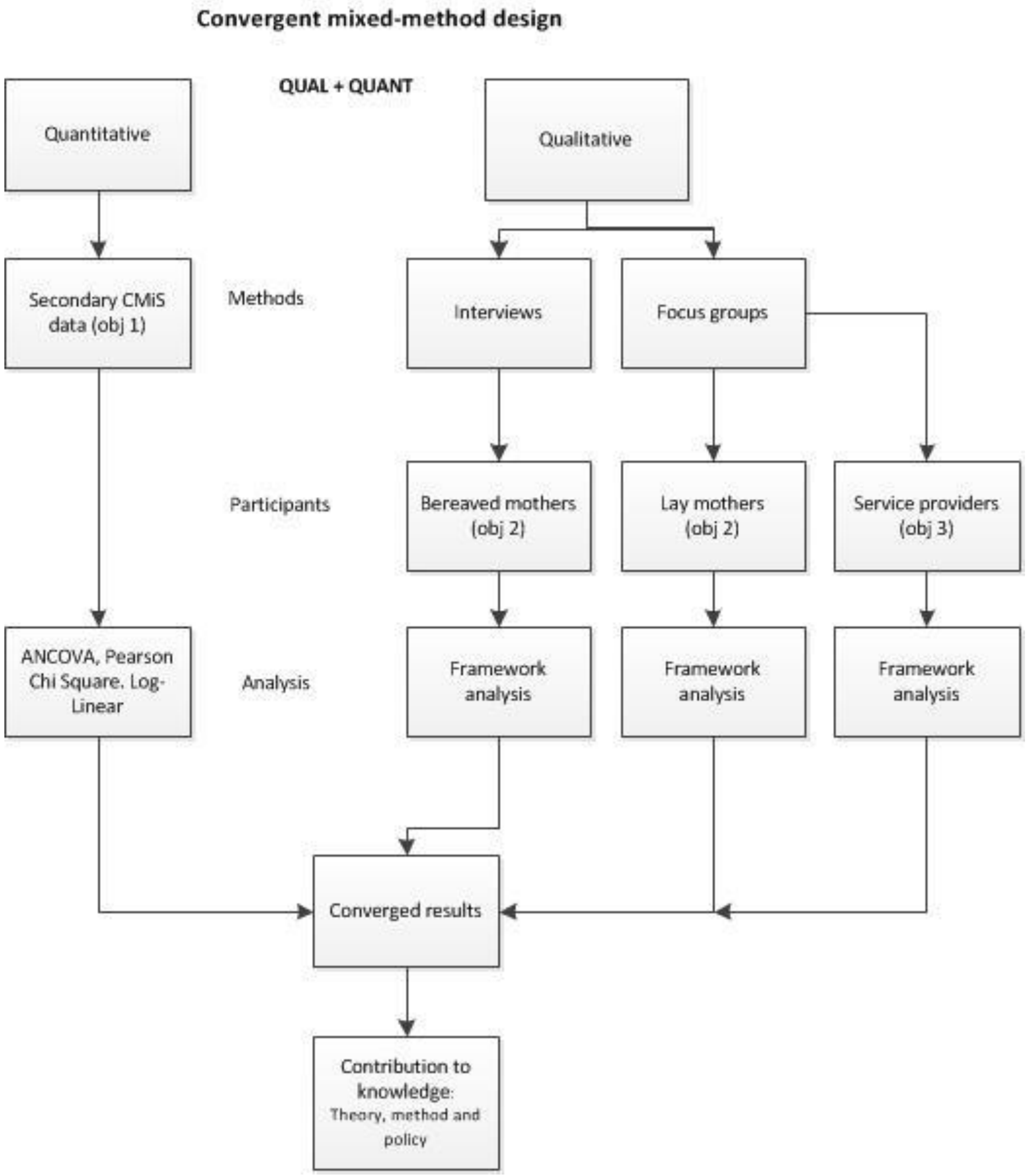

Figure 18: Diagram showing convergent mixed-method design process

4.4 Research methods

This section highlights the specific methods used for meeting the aims the research objectives .

4.4.1 Objective one

To identify the current evidence of risk factors contributing to perinatal mortality in Pakistani, Bangladeshi and WB women in Luton;

4.4.2 Method

A retrospective cohort design using routinely collected secondary quantitative data from the Luton and Dunstable University Hospital NHS Foundation Trust. Data was accessed from the *Ciconia Maternity information System*[102] (CMiS).

4.4.3 Sample

Purposive sampling of women aged over 16 and *all birth outcomes* (i.e. stillbirth, perinatal mortality and low birth weight), who delivered 2008–13, residing in LU1–LU4, were included. The date range 2008–2013 was applied to represent the commencement of the latest National Institute for Clinical Excellence (NICE) guidelines on antenatal care (2008), in addition to policy level initiatives to reduce infant mortality in 2008 (i.e. Infant Mortality National Support Team).

4.4.4 Data collection

Ethical approval was provided by University of Bedfordshire Research Graduate School during the RS1 review process. NHS ethics were not required for this routinely collected data; however, an honorary contract was issued by the Luton and Dunstable University Hospital.

Accessing CMiS data

Scrutiny from the hospital's Information Governance Manager ensured adherence to patient confidentiality and data protection legislation.

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[102] CMiS is a computerised data management system produced by HD Clinical for maternity data, used by some maternity departments in UK. Clinical data is transposed from the paper medical records into CMiS by a midwife following delivery of the infant. Extracted data is in Microsoft Excel format. Typically each hospital has a CMiS 'midwife champion' who attends local meetings and training to optimally utilise the CMiS system.

Variables

Following the literature review (Chapter Two), the identified variables that were provided were:

1. maternal age (at booking in whole years)
2. marital status (single, married, divorced, cohabiting)
3. parity (1-10)
4. singleton or multiple
5. maternal height (cm) and weight (kg)
6. BMI (kg/m^2)
7. ethnicity (Pakistani, Bangladeshi or WB)
8. gestational age at delivery (in weeks)
9. birth outcome (liveborn, dead, stillborn [antepartum and intrapartum], and neonatal mortality)
10. birthweight (kg)
11. delivery method
12. infant gender (male, female or indeterminate[103])
13. Postcode at district level (LU1–LU4)

Challenges of data collection

There were some challenges experienced trying to obtain the CMiS data.

- There was no one within the Luton and Dunstable University Hospital NHS Foundation Trust who had the knowledge to undertake the extraction. The CMiS providers were contacted to establish if the extraction was physically possible, and advice was sought from the 'Midwifery Research Jiscmail' group. This resulted in identifying and meeting with an author who had published an article using CMiS data (and the research assistant who completed their extraction), who agreed to help with this study's extraction.

- Several requested variables could not be supplied; maternal age and district level postcode[104] (in conjunction with ethnicity) was considered potentially 'identifiable' and contravening data protection legislation. Instead, the Information Governance Manager

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[103] 'Indeterminate' is used when foetus is too young to establish the infant sex.

[104] the first three alpha-numerals

approved the supply of maternal age ranges (i.e. 16–21, 22–25, 26–30, 31–35, 36–40, >41) so as not to compromise patient confidentiality.

- The midwife had difficulty transforming the raw age data into the age ranges. The researcher developed a method in SPSS and Microsoft Excel to transform the data and then produced step-by-step instructions for the midwife to follow, who agreed to re-extract the data and complete the transformation task (with telephone guidance from the researcher) – so that the hospital CMiS data remained confidential and separate from the research team[105].

- At first, district level postcode data was provided (as requested). After initial analysis, it became apparent that this could not be mapped to electoral wards, and IMD data was available at whole postcode level. It was later agreed that a further data set[106] would be supplied (i.e. sector level[107] postcode).

4.4.5 Statistical analysis

Cross-tabulation using adjusted standard residuals (ASR) and Pearson Chi-Square was conducted to ascertain whether sampling distributions between sub-groups show independence. ASR is a useful and robust technique for categorical variables, especially when analysing groups with unequal sample sizes (Hinton, 2008; Field, 2013b).

The formula to calculate ASR is:

> Adjusted residual = (observed – expected) / √[expected x (1 + row total proportion) x (1-column total proportion)].

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[105] Satisfying the requirements of data protection, confidentiality and the Information Governance Manager.
[106] CMiS data for 2014, for LU1–LU4, birth outcome and maternal ethnicity.
[107] the first four alpha numerals.

The numbers within the cross-tabulation tables of significance are shown as ‘1.96’ (rounded to 2.0); within the counts of the sub-group, the ASR count shows above statistical significance (*p*=0.05) of the sub-group (Field, 2013a). To use Pearson Chi-Square, it is necessary that cell counts be above 5, therefore when looking at some variables with cell counts <5, the variable was transformed to ensure adequate cell counts, ensuring validity of the Pearson Chi-Square test. Frequency counts were conducted to determine cell counts before performing cross-tabs. Where variables were collapsed to account for small frequencies within the analysis, this is stated (Chapter 9) (Rindskopf, 2004; Field, 2013a).

An Analysis of Covariance (ANCOVA)[108] was used to determine if there was any significant difference between ethnic groups and to control for confounding variables (i.e. maternal age, smoking status, diabetes, gestation age at delivery, parity and maternal height and BMI), with birthweight as the outcome variable. Bonferroni posthoc analysis was used to determine where differences were, if present (Field, 2013b).

The Loglinear test of association was determined to be the most suitable test, to establish and model association and interactions between the variables, when applied in combination. Loglinear uses a using a multiway frequency table and has two approaches: general Loglinear and hierarchal model selection (Tabachnick and Fidell, 2014).The hierarchal model selection approach is most appropriate when the sequence of variable input or model is unknown and aims to identify the most parsimonious model (Tabachnick and Fidell, 2014). In the current study, there is no pre-identified model; consequently, the hierarchal model selection approach will be implemented. The equation for the hierarchal model is shown:

$$Ln(Fij) = \mu + \lambda i\ A + \lambda j\ B + \lambda k\ C + \lambda ij\ AB + \lambda ik\ AC + \lambda jk\ BC + \lambda ijk\ ABC$$

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[108] The equation to calculate an ANCOVA is: $E(Y \mid x1, x2) = \beta 0 + \beta 1 x1 + \beta 2 x2 + \beta 12 (x1 \cdot x2)$

Validity and reliability

Using secondary data sets has a number of benefits for issues surrounding validity and reliability; a large sample size, spanning over 6 years increases the representativeness of the data. In turn, this minimises bias from minimising missing data (Sarensen, Sabroe and Olsen, 1996). Additionally, there is a degree of consistency in data collection, as a consequence of understanding the information required to be input into CMiS (i.e. the variables). However, there are also some limitations, which should be noted; data collection is beyond the control and rigour of the researcher, which may raise questions of validity (Sarensen, Sabroe and Olsen, 1996). Furthermore, the raw data may not be in an optimum format for research purposes (Boslaugh, 2007). This is discussed further in Chapter Eleven. Notwithstanding the limitations, the results from objective one are generalisable to similar populations (Richie and Lewis, 2003, Mays and Pope, 2000).

4.5 Objective two

To explore the similarities and differences in maternal health beliefs that influence health behaviours in perinatal mortality in Pakistani, Bangladeshi and WB women, through the maternity care pathway.

4.5.1 Method

Two methods were used; FG and SSI with 2 distinct samples (lay mothers and bereaved mothers).

Lay mothers: FG discussions were conducted with lay mothers who have experienced a normal birth outcome. FG discussions would develop themes and concepts between the homogenous 'female' groups: i.e. '*pregnancy*' '*birth'* and '*motherhood'*. FG were stratified by ethnicity to provide a conducive space for the mothers to comfortably share their personal experiences, further allowing cross-comparison between ethnic groups (Kitzinger, 1994, 1995; Parahoo, 2006b;

Krueger and Casey, 2009). The topic guide was developed and piloted using themes evidenced in the current literature (see Section 4.5.4) (Appendix 1).

Bereaved mothers: Face-to-face semi-structured interviews were carried out to provide a sensitive and confidential environment for bereaved mothers (Parahoo, 2006a). Methodological and ethical considerations for this research have been aligned with the '*Framework for ethical decision making*' with research using bereaved families (see Sque *et al.*, 2014, and Appendix 2). The topic guide was developed by reviewing the existing evidence and designed to meet the research objectives (see Section 4.5.4) (Appendix 3).

4.5.2 Sample

Lay mothers: purposive sampling was used to recruit lay women, aged over 16, living in Dallow, Saints, South, Biscot, Farley, Leagrave and Lewsey[109,110], with a child aged under 24 months, singleton birth, ethnicity (Pakistani, Bangladeshi and WB). Exclusions include women who delivered a LBW infant (<2500g) or delivered preterm (<37 weeks), delivered multiples, or suffered an infant bereavement, gynaecological cancer and women who used assistive reproduction (Flenady *et al.*, 2011). Optimum numbers for FG are 5–8 individuals (Kitzinger, 1995; Krueger and Casey, 2009). Originally it was planned to run only English speaking FG, however, following strong objection from a Pakistani community representative before commencement of the FG, it was determined necessary to include the voices of non-English speaking Pakistani/Bangladeshi women, therefore FG facilitated by Urdu/Bengali speaker(s) were included. Moreover, there is an established body of research that shows that non-English speaking migrant women experience

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[109] A review of population by ethnicity density per ward was carried out to determine wards with higher ethnic populations.

[110] The above geographical wards were selected because they are the wards where the most infant deaths occurred in addition to being the most deprived and culturally diverse (Luton Borough Council, 2011; Child Death Overview Panel, 2013b).

language difficulties, less information sharing, worse outcomes and report poorer satisfaction to their maternity care (Oliver and Nutbeam, 2003; Cantwell *et al.*, 2011; Marmot, 2013; Psarros, 2014)

Bereaved mothers: Retrospective and purposive sampling of women identified a homogeneous group of women, who suffered a perinatal loss in the previous 6–24 months. Purposive sampling is necessary due to the specificity of the research question, resulting in a pre-determined and fixed sample strategy which is systematic and rigorous (Parahoo, 2006a; Teddlie and Yu, 2007; Bowling, 2009). The homogenous group was: '*mothers', 'pregnancy', 'birth', 'loss*' and '*motherhood'* all of whom have experienced an adverse birth outcome (defined as perinatal mortality or stillbirth), to provide insight into the similarities and differences of their maternal health beliefs, health behaviour and experience of adverse birth outcomes. Furthermore, purposive sampling will ensure that representation from the population of interest was achieved (i.e. Pakistani, Bangladeshi and WB women) (Lakhanpaul, Bird, Culley, *et al.*, 2014).

There is an established body of research that shows that migrant women experience worse outcomes and report poorer satisfaction to their levels of maternity care (Oliver and Nutbeam, 2003; Cantwell *et al.*, 2011; Marmot, 2013; Psarros, 2014). The evidence base suggests that BAME groups that have limited English language proficiency[111] have worse knowledge of health care services which leads to delays in help seeking and when they do reach services they report receiving inadequate information from healthcare staff, resulting in less informed decision making (Dormandy *et al.*, 2010; Schachter, Kimbro and Gorman, 2012;; Small, *et al.*, 2014). Language is frequently cited as a barrier to accessing services (Atkinson *et al.*, 2001; Cross-Sudworth, Williams

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[111] Language 'proficiency' in this instance refers to an accurate comprehension of the oral message(s) in English in contrast to English 'fluency', whereby comprehension may be imprecise and lead to subtle but important misunderstandings in the message conveyed (Johnson *et al.*, 2006; Schachter, Kimbro and Gorman, 2012).

and Herron-Marx, 2011; Redshaw and Heikkilä, 2011; Hollowell *et al.*, 2012) and receiving equitable levels of service (Szczepura, 2005; Mumtaz, O'Brien and Higginbottom, 2014). Moreover, migrant mothers are more likely to present to maternity services later resulting in fewer services being offered (such as early screening and risk detection) (Rowe *et al.*, 2008; Draycott, Lewis and Stephens, 2011; Cresswell *et al.*, 2013). Results from the Confidential Enquiry into maternal and child deaths has also shown that migrant mothers are at increased risk of adversity compared to the host country's mothers (Draycott, Lewis and Stephens, 2011; Lewis, 2012).

Consequently, including the perspectives of non-English speaking mothers who accessed maternity services and who have suffered a perinatal bereavement will contribute to the real understanding of the similarities and differences of maternity health beliefs and maternity health behaviours in non-English speaking mothers. Moreover, including women with limited English language proficiency will also capture women who have recently migrated to the UK for marriage[112]. Pakistani or Bangladeshi women who have settled in Luton for many years may have a low level of English proficiency, but a sound understanding of how local maternity services work, conversely recent migrants may be well educated but have a limited understanding of how local maternity services work (Schachter, Kimbro and Gorman, 2012). Therefore, the proposed sample frame aimed to capture the various perspectives of Pakistani and Bangladeshi women who accessed local maternity services, irrespective of their English language proficiency.

Mothers who suffered a perinatal loss retrospectively, of 6–24 months, were invited. A retrospective time frame, where bereaved mothers suffered their loss 6–24 months previously has been selected, following personal communication with a national infant bereavement charity (i.e. Stillbirth and Neonatal Death Charity [SANDS]) and to mirror previous timescales of studies

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[112] Although there is evidence showing that migration to marry UK citizens has declined, the large Pakistani and Bangladeshi community in Luton suggests that there may be some presentation of newly arrived women (Dale and Ahmed, 2011; Home Office, 2015).

including bereaved parents, therefore, being considered appropriate and sensitive, minimising undue distress but allowing accurate recall of their experience (Richies and Dawson, 1996; Stroebe, Stroebe and Schut, 2003; Dyregrov, 2004; Hynson *et al.*, 2006; Sque, Walker and Long-Sutehall, 2014).

Eligibility criteria

The inclusion criteria was: Pakistani, Bangladeshi and WB childbearing women, aged over 16 years (at the time of delivery) and residing in the LU1–LU4 postcode areas of Luton (which includes the wards of Dallow, Saints and Biscot which account for 33 percent of Luton's infant deaths and are the most deprived wards in the town), who have experienced a perinatal death with a singleton infant in the last 6–24 months. Non-English speakers were included in this sample. The reason for this is to ensure that the voices and experiences of all mothers regardless of English language proficiency were captured.

Exclusions included non-childbearing women aged under 16 (at the time of delivery) or post-menopausal women, not living in LU1–LU4, who had not experienced a perinatal death in the last 6–24 months, whose ethnicity was not Pakistani, Bangladeshi or WB. Further exclusions included multiple pregnancies, conception via assistive reproductive technology and women diagnosed with gynaecological cancer (Flenady *et al.*, 2011). The reasons for the exclusions are to ensure that these known factors that increase the risk of adverse outcomes were removed from the sample frame, reducing heterogeneity and confounds in the sample (Shevell *et al.*, 2005).

4.5.3 Recruitment

Lay mothers

Lay mothers who fit the eligibility criteria were recruited through local Children's Centres[113], situated within the wards of interest in Luton. Invitation to participate utilised several methods, to maximise recruitment outcomes (Roe, Minkler and Barnwell, 1994; Atkinson and Flint, 2001; Flanagan and Hancock, 2010). Recruitment methods were: poster advert (available on request), snowball sampling and face-to-face verbal invitation. Figure 19 shows the locations of the Children's Centres (in red) and their branch sites (in blue).

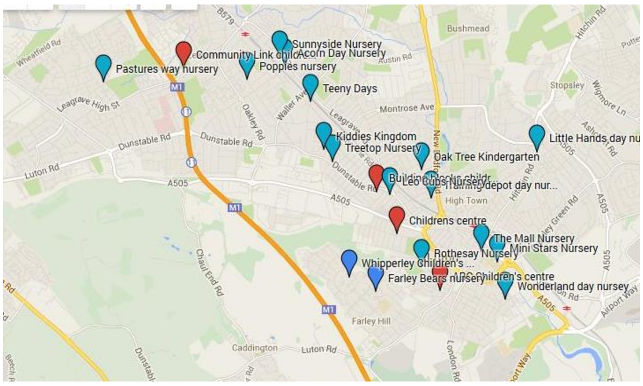

Figure 19: Map of located children's centres in wards (Dallow, Saints, South, Biscot, Farley, Leagrave and Lewsey).

Bereaved mothers

Potential participants who fit the eligibility criteria were identified from the Luton and Dunstable University Hospital Pursuing Perfection records (i.e. stillbirths) and Neonatal Intensive Care death records by Mr Griffiths and lead neonatal-nurse who assessed their suitability for inclusion, to determine whether the participants were medically fit to take part and to consider known mental health problems and levels of English competency. The participant was sent a cover letter from the consultant, a letter from the researcher, a study information sheet and an opt in/out reply slip, (herein referred to as '*the recruitment pack*') (Appendices 5–7) and was supplied with a postage paid return envelope (addressed to the researcher at the Institute for Health Research at the

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[113] A mapping exercise was undertaken to identify Children's Centres in each ward.

University of Bedfordshire[114]) thus, maintaining confidentiality for the mother. The recruitment letter approach has been used in research on bereavement and is regarded as the least intrusive recruitment strategy and one that empowers the participant to contact the researcher (Richies and Dawson, 1996). Before submission for ethical approval, the 'recruitment pack' was sent to The Child Bereavement Charity for their feedback. Further inclusions were ethnicity (i.e. Pakistani, Bangladeshi and WB).

Exclusions included women with a diagnosis of gynaecological cancer and women who used assistive reproduction technology, those who reside outside LU1–LU4, women who delivered multiples and mothers whose ethnicity is recorded as different to Pakistani, Bangladeshi or WB (Flenady *et al.*, 2011).

Recruitment of 'Hard to reach' communities

The term 'hard to reach[115]' is frequently cited in with Pakistani or Bangladeshi communities in the UK, and is typically used to explain under-representation of marginalised groups in research (Lakhanpaul, Bird, Manikam, *et al.*, 2014). Moreover, it has been suggested that addressing the complex and costly health inequalities in ethnic minority groups means that these populations are 'easy to ignore' (Salway *et al.*, 2016). However, by implementing recruitment strategies that are properly culturally sensitive to Pakistani and Bangladeshi communities, research including their valuable opinions is wholly achievable, without which, challenging inequalities in maternity care is protracted.

Key to the success of the recruitment of participants in this study is "trust".

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[114] Opt out replies (numerically coded) were collated and returned to the hospital so that, using the corresponding code, the target list was updated by hospital staff and no further contact will be made by the research team. This also maintains patient confidentiality.

[115] Described by the Health and Safety Executive (2004) as '*inaccessible to most traditional and conventional methods for any reason*' (pg 8).

- Supervisory team: the supervisory team have established trusting relationships with the community in Luton which facilitated access to participants.

- Gate keepers: the director of studies (Dr Nasreen Ali) introduced the researcher to several gatekeepers by organising a ‘get-together’ to discuss the study and recruitment. The invitees supported the researcher with access the wider community, and helped the researcher snowball lay mothers for the focus groups discussions. Additionally, they made recommendations that this study should include the voices of non-English speaking mothers, whose experience was thought to be different to English speaking Pakistani or Bangladeshi mothers.

- Face-to-face: a face-to-face recruitment method to recruit the hard to reach community, with supplementary snowballing. This allowed rapport, trust and familiarity to be established and key influencers within the community to be identified. By networking with key influencers the researcher was able to determine specific sessions where larger numbers of the target sample attended, consequently enabling more efficient recruitment. While this method was slow, it was important building broader relationships in the community, and both the researcher’s name and research is now recognised within the community.

- Insider/outsider: it is recognised that there are few studies using a White researcher within this community (others being Alison Shaw and Nicola Ellis). However, the broader themes of being a woman, motherhood and pregnancy are a shared experience with the researcher and therefore the issues become insider.

- The topic area is highly emotive in addition to being on the policy agendas of local Public Health initiatives; consequently, it has received broad support from Children’s Centre staff, mothers and community members alike.

The recruitment strategies for the English and non-English speakers varied and is described below in more detail.

Recruitment strategy for English speaking mothers

If prospective participants met the inclusion criteria, following screening of the list (Section 4.5.2) the midwife sent out a recruitment pack to the mother, (which contained a cover letter from the consultant [Appendix 4], a cover letter from the researcher [Appendix 5], a study information sheet [Appendix 6], and an opt-in/out reply slip [Appendix 7]). This was supplied with a postage paid return envelope (addressed to the researcher at the Institute for Health Research at the University of Bedfordshire [116]). This procedure maintained privacy and confidentiality for the mother and ensured that the research team did not have access to private and personal details of potential participants (including address and phone numbers) until this information was provided directly by the potential participant to the research team by means of returning the opt-in/out slip or contact directly from the participant to the researcher.

The recruitment packs were numerically coded by the hospital so that hospital staff clearly identified returned refusals and no further contact was made. Potential participants were invited to return the reply slip, either way, indicating consent to opt-in (and provide a name with a contact number) or indicating their wish to opt-out. Direct telephone contact with participants was only made by the researcher once the potential participant had returned the opt-in slip to the research team i.e. the participant providing their contact details to the researcher directly. The researcher then telephoned the potential participant to build rapport, answer any questions they may have and go through the information sheet.

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[116] Opt-out replies were collated and returned to the hospital so that, using the identifying code, the participant list was updated by hospital staff and no further contact was made by the research team.

If the potential participant agreed to participate, a venue of their choice was agreed (i.e. their home or a private room at the University of Bedfordshire Park Square Campus) and an interview date was agreed, (no sooner than 14 days after their initial telephone agreement), allowing for potential participants to change their minds and withdraw up to any point in the research process, (including during the interview process) (Richies and Dawson, 1996; Sque, Walker and Long-Sutehall, 2014). Non-responders were sent a second recruitment pack by the hospital staff, 2–3 weeks after the first recruitment pack was sent, following the same procedure as above. If the second recruitment pack failed to prompt a reply, it was taken as a refusal, and this was noted on the identified potential participant list held by Mr Griffiths. The recruitment process is shown in Appendix 8.

The recruitment letter approach has been used in research on bereavement and is regarded as the least intrusive recruitment strategy and one that empowers the participant to contact the researcher to take part in the research (Sque, Walker and Long-Sutehall, 2014). It also allows the prospective participant to communicate with the researcher for further detail on the research before consenting formally to take part in the face-to-face interview (Richies and Dawson, 1996; Dyregrov, 2004).

Recruitment strategy for Non-English speakers

It was anticipated that a small number of women would be identified by hospital staff as potentially suitable to be included in this study and known to be non-English speaking. After careful consideration, it was decided not to translate the research material for the reasons that follow:

Issues of literacy:

- The research supervisors Dr Nasreen Ali and Professor Gurch Randhawa have extensive experience of working with the South Asian community, specifically with Luton’s Pakistani and Bangladeshi Muslims. Research experience and existing published evidence highlights that the proposed sample may not be able to read their vernacular language or dialect (Ali, 2009; 2006).

- Other members of the family may be able to read and understand English and be able to convey the essential messages of the study to prospective participants (Shaw and Ahmed, 2004).

Issues of dialect/written dialect:

- The majority (approximately two-thirds) of the Pakistani community in Luton are from Azad Kashmir and are classified as Pakistani because of passport holding (Ballard, 2002; Ali, 2009) and speak either Urdu or a dialect of Punjabi called Pahari (Baart, 2003; Ethnologue, 2015). Punjabi is not formally taught or usually written (Baart, 2003; Shaw and Ahmed, 2004) and Pahari does not have a written script (Baart, 2003; Shaw and Ahmed, 2004; Stow, 2004).

- Although Urdu is the national language of Pakistan and is formally taught in schools, many 'Pakistanis' from Azad Kashmir have lower levels of formal education and are therefore less likely to read the Urdu text (UNICEF, 2015). Moreover, many Pakistani women in Luton are actually from Azad Kashmir and speak Pahari. The Bangladeshi community in Luton are mostly from Sylhet and speak Bangla or a regional dialect Sylheti (Communities and Local Government, 2009a). The Bangla Bureau of Statistics claims that only 52 percent of the Bangladeshi population are reported to be literate in their vernacular (Ethnologue., 2015).

Issues of translating:

- During translation, there is a challenge to accurately convey concepts that may not have literal equivalents in either host or home language (Shaw and Ahmed, 2004). Additionally, material may be reproduced by educated speakers of Urdu, therefore not reflective of the '*lay*' spoken version, or regional dialect of the spoken form (Shaw and Ahmed, 2004).

- It is also essential that cultural sensitivity is shown within any translated material to ensure that material is not offensive or shameful, especially when dealing with sensitive topics (Shaw and Ahmed, 2004). The result of poorly translated material leads to misleading and confusing information, for example “high-risk screen” translates to “too much dangerous screen” (Shaw and Ahmed, 2004; pg 331) implying the screening procedure is harmful.

- Consequently, translated material is reported as not being as effective as direct dialogue (Shaw and Ahmed, 2004). Therefore it is reasoned that reproducing the ‘recruitment pack’ in Urdu or Bengali is of questionable value for non-English speakers, to ensure accuracy and sensitivity of the material in addition to carefully conveying the purpose of the intended research, which will be best achieved in spoken form (Shaw and Ahmed, 2004).

A procedure was planned for follow-up telephone calls to identified non-English speaking bereaved mothers, to verbally inform them about the study using hospital translators. However, once staff had screened the list of potential participants, they were all identified as proficient in English; therefore telephone follow-up was not considered appropriate.

All participating mothers (i.e. Pakistani, Bangladeshi and WB) were offered a £20 high street voucher as a gesture of goodwill, at the end of the interview. Previous research with Pakistani and Bangladeshi women has typically reported a low response rate, compared to WB participants (Atkinson and Flint, 2001; Flanagan and Hancock, 2010). When considering the sensitive nature of this subject, reaching this hard to reach population (in particular non-English speaking mothers), the risk of becoming upset, the use of an incentive in this instance was considered an appropriate gesture (Grant and Sugarman, 2004).

Sample size

Lay mothers

The criteria for selecting women who had experienced a normal birth outcome was achieved through necessary a priori, purposive and snowball sampling of women, which was aimed at achieving context-rich data regarding their maternal health beliefs, health behaviour and experience of perinatal mortality. Additionally, purposive sampling was justified to ensure that representation from Pakistani, Bangladeshi and WB mothers was achieved (Lakhanpaul, Bird, Culley *et al.*, 2014). As in the previous sample structure (Section 4.5.2), the case sample of interest were Pakistani, Bangladeshi and WB women, aged over 16 years, who delivered a live infant in the preceding 24 months. The timescale of 24 months was selected to mirror the bereaved mother's sample framework, to reduce confounds such as hindsight bias, memory recall and psychological distortions due to subsequent pregnancy experience (Hynson *et al.*, 2006).

Context sampling requires that the women reside in the residential wards of interest: Dallow, Saints, South, Biscot, Farley, Leagrave and Lewsey. These wards were selected because they were the wards where the most infant deaths occurred in addition to being culturally diverse and having shown to be more deprived (Luton Borough Council, 2011; Child Death Overview Panel, 2013b). The decision of which ethnic group to target in each ward was derived from data on ethnicity population density per ward, whereby Farley, Leagrave and Lewsey wards had much smaller numbers of Pakistani and Bangladeshi residents compared to Dallow, Saints and Biscot where Pakistani and Bangladeshi are the majority ethnic population (Mayhew and Waples, 2011). Table 5 shows Luton’s wards, deprivation score, population by ethnic group and percentage of infant deaths, per ward.

Table 5: Table of Luton's wards, deprivation index and % of infant deaths.

Wards	Deprivation index*	Population			% of infant death
		Pakistani	**Bangladeshi**	**White**	
Dallow	52.68	5322	2906	5331	14
Saints	51.18	4523	1896	5496	10
South	33.64	397	288	9657	10
Biscot	51.18	4880	3630	5054	9
Farley	34.27	932	509	8805	8
Leagrave	31.51	1031	577	8367	8
Lewsey	27.51	603	455	9724	8
Reference and dates	(ONS, 2014c)	(Mayhew and Waples, 2011)			(CDOP, 2013)

* Figures taken from IMD2000 at ward level. This level of analysis is no longer available, and current statistics use smaller geographical locations. The rank data is 1 = most deprived – 8414 = least deprived. # Data from ONS census is considered inaccurate for Luton due to low response rate. Luton Borough Council and Migration Impact Fund undertook research to estimate population more accurately in 2011.

As above, a priori and purposive sampling were considered the appropriate method due to the specific research question, providing a fixed sample strategy (Parahoo, 2006; Bowling, 2009; Teddlie & Yu, 2007). Furthermore, purposive sampling was justified to ensure that representation from the population of interest (i.e. Pakistani and Bangladeshi) was met (Lakhanpaul, Bird, Culley *et al.*, 2014). While snowballing sampling is criticised for resulting in homogenous sampling, the use of mixed techniques will reduce this bias (Twamley *et al.*, 2009). Moreover, snowball sampling has been shown to be an effective way of reaching participants who are not typically public service users (Roe *et al*, 1994).

Table 6: Details the sample structure for normal birth outcomes

Ward	Ethnicity	Language	Age	Group size	Number of groups[#]
Dallow	Pakistani/Bangladeshi	English speakers	>16	5–8	1
		Non-English			1
Biscot	Pakistani/Bangladeshi	English speakers	>16	5–8	1
		Non-English			1
Saints	Pakistani/Bangladeshi	English speakers	>16	5–8	1
		Non-English			1
South	Pakistani/Bangladeshi	English speakers	>16	5–8	1
		Non-English			1[i]
Farley	WB	English speakers	>16	5–8	1
Leagrave	WB	English speakers	>16	5–8	1
Lewsey	WB	English speakers	>16	5–8	1
Total Women				35–56	

Bereaved mothers

In 2012, Luton reported 38 perinatal deaths (Office for National Statistics, 2013b). In 2013, Luton reported 31 infant deaths (birth to 12 months of age), whereby over 50 percent came from Pakistani and Bangladeshi families and of which 33 percent of the deaths were clustered across the town's most deprived wards: Dallow, Biscot and Saints, which also houses the largest numbers of Pakistani and Bangladeshi residents (Child Death Overview Panel, 2013b). Recruitment numbers were based on previous research with bereaved parents using semi-structured interviews which typically recruit 12–15 participants (Sanchez, 2001; Warland *et al.*, 2011; Sutan and Miskam, 2012). As far as possible the sample size was based on the principal of saturation, whereby no further interviews took place when no new themes emerged from the interviews or FG (Strauss and Corbin, 1994).

The aim of this objective is to identify similarities and differences between the bereaved mothers' verbal accounts. Consequently, it is argued that small numbers of face-to-face interviews will achieve rich and detailed description. While each participant story is unique, the main emergent themes are expected to be identified using a small number of participants. The sample structure for women who have experienced perinatal mortality is shown in Table 7.

Table 7 sample structure for women who have experienced perinatal mortality

Context/case	Ethnicity of women	Sample frame	Target participants
L&D Pursuing Perfection records	Pakistani/Bangladeshi/WB[1]		
NICU[#] death records	Pakistani/Bangladeshi/WB	38* per year	15

*Based on ONS figures for reported deaths in 2012 for Luton. [#] Neonatal Intensive Care Records (NICU). [1] The exact numbers are not known for each ethnicity.

4.5.4 Data collection

The information sheet and consent form were read to all English speaking participants to mitigate against poor literacy skills and ensured proper understanding of the mother's participation, which facilitated informed consent. If participants were not confident in English (speaking, listening or understanding), they were encouraged to take part in interviews speaking Bengali, Sylheti, Punjabi, Pahari or Urdu where they would feel more comfortable with the discussion. The approved translator(s) explained the nature and purpose of the research, using the original documents (consent and information sheets) as her topic guide.

Informed written consent was obtained (Appendix 6). For non-English speaking participants, the translator(s) went through the information sheet and consent form verbally so that the participant could complete the consent process. Explicit consent for the researcher to send a letter to the participant’s GP was also sought (Appendix 9) and this was documented on the consent form (Appendix 10). The letter advised the participant’s GP of their participation in the research, and detailed bereavement charities and provided a copy of the information sheet for the GP’s information. This letter was sent first class mail, the same day as the interview took place.

The face-to-face interviews were audio-recorded. Permission to record the interviews was sought before commencing audio recording, and this was documented on the information sheet and consent form. If, during the face-to-face interviews, participants were unwilling to sign the consent form or to be audio recorded, they were allowed to withdraw from the study. If the participant decided to withdraw after the recording had started, permission would have been sought to retain any audio material already obtained, however, had the participant refused, the audio material would have been deleted.

Before the interview commenced, the researcher checked the support procedures that were in place for later that day (i.e. a husband or visiting friend) and the researcher provided bereavement counselling information (page 2 of the debrief sheet) and arranged to telephone the participant 24–48 hours after the interview, to check on her emotional wellbeing. Following the initial consent process, a brief overview of the structure of the interview was provided to the participant so that they were clear on the process (as per section 1 of the topic guide). After this, relevant information seeking general questions were asked to establish a background framework of the mothers’ personal circumstances (e.g. is she partnered? does she have other children?). This served to ensure appropriate and sensitive questions were asked after that and helped establish rapport between the researcher and the participant. The mother was allowed to pause at any time during the interview process, (the recording may also have been paused) and this was guided by the participant and her levels of comfort/distress. If the mother became distressed, the researcher sought permission to continue; “Are you okay to carry on or would you like to stop?”

At the end of the interview, the participant was thanked, given their £20 goodwill voucher and issued with a debrief sheet and details of infant bereavement support services were highlighted again (Appendix 11). An open invitation to attend the ‘findings feedback’ presentation in the future was made. If participants expressed an interest in this, this was noted on their consent form.

Before leaving the venue, the researcher ensured that the mother was not unduly distressed and stayed for an informal debrief/chat (as long as the researcher was welcome to do so). A follow-up phone call (as mentioned to the participant before the interview took place) by the researcher was agreed and scheduled with the participant for the following 24–48 hours to check they were properly supported. If at 24–48 hours post interview, the participant was found to be distressed, they would have been invited to contact their GP.

Developing the topic guides

The topic guides were developed in the same way, (for objectives two and three) and were informed through a review of the existing literature and by the research objective(s). The topic guides are found in Appendices 1 and 3. They built on existing themes in the literature that could be utilised flexibly during the FG and analysis stage. Several iterations were produced and piloted, which highlighted the following issues:

Lay mothers

- Piloting the lay mothers’ topic guide revealed sequencing issues - for instance, questions around booking into maternity services and the gestational age at time of booking were originally situated at the end of the topic guide. This disrupted the natural flow of conversation and caused some confusion. Another issue was altering the terminology to be less formal and medicalised, so that the mothers properly understood what was being asked/discussed.

- Training for facilitating FG was undertaken during the researcher's role as a Research Assistant, on other projects holding FG and SSI and included feedback with the supervision team.

Bereaved mothers

- The pilot of the bereaved mother topic guide was undertaken with a bereaved Pakistani mother[117], who was consulted at various stages of this study, and was asked for her valued feedback and suggestions how to navigate the emotionally sensitive topic with cultural sensitivity. This was used as a training opportunity with the Director of Studies. During piloting of the bereaved mothers' topic guide it became apparent that the most appropriate direction for the conversation needed to be determined by mothers' personal experience, to avoid undue distress. Additionally, it became evident that commencing with an open-ended question extrapolated the mothers' personal story, which was both sensitive and pragmatic, providing a guide to the sensitivity and probing in the remaining interview. Piloting the TG was found to be a powerful learning opportunity.

Challenges of data collection

During data collection, some challenges were experienced. Recruitment challenges for hard to reach groups was aforementioned in Section 4.5.3.

Lay mothers

Recruitment

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[117] bereaved from ten years earlier.

- A recruitment plan was devised, targeting specific Children's Centres by ethnicity. Once the fieldwork commenced, it was evident that the attendees in the Children's Centres were not representative of the ethnicity of the residential area or that as is stated in the Migration Impact Report for Luton (Mayhew and Waples, 2011). Therefore, a decision was made to recruit all participating ethnicities from the target Children's Centres and stratify the FG at a later stage.

- Recruiting WB mothers was unexpectedly the hardest as they were dispersed in smaller numbers around Luton[118]. Recruitment for the WB mothers was finally achieved by the Children's Centre staff organising FG on the researcher's behalf.
- Recruiting Sylheti speaking Bangladeshi mothers was also challenging and succeeded after snowballing with two specific Bangladeshi gatekeepers from the community (who were met during field work).

- Recruitment methods – it was intended to recruit using posters, face-to-face and snowballing. Recruitment started in December 2014 and was naturally slow over the holiday period. To expedite successful recruitment, the researcher spent time attending play sessions in the Children's Centres, helping at a local Muslim community group on Saturdays, organised a toy donation to Bury Park Baby and Mums group and ran health talks to increase trust and rapport with the community. Children's Centre staff also identified other partner centres where the target mothers could be found.

- Baby clinic was attended by many potiential participants and it was suggested by several Children's Centre managers to use these sessions to recruit. Unfortunately the HV teams objected to this and despite the researcher's attempts to get permission from the HV team, her contact efforts were ignored.

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[118] WB mothers were reported to attend Children's Centres located in wards, outside of the wards of interest.

- Attendance to FG was poor if the weather was bad!

Logistical issues

- The majority of the mothers had young children, and childcare was a barrier to taking part. Consequently, children accompanied their mothers into the FG. When transcribing the interviews at a later stage, it became difficult to separate out the narrative from the background noise.

- Scheduling the FG was a challenge – the majority of the FG took place between 11 am and 2.45 pm to ensure that mothers were free to collect older children from school at 3 pm onwards. Additionally, the room provided was booked immediately after the FG; consequently, several FG were rushed at the end.

Issues with the topic guide:

- Some questions on the bio-questionaire were ambiguous and needed to be clarified to ensure consistency with responses.

- Some of the terminology used in the early sessions was too medicalised and needed to be rephrased so it was understood.

Bereaved mothers

Recruitment

- There were a series of unexpected delays by the hospital on sending the recruitment pack to the participants. NHS REC approval was granted in July 2015. However, the first recruitment letter was finally sent in November 2015.

- Contingency plans - Snowball recruitment using the gatekeepers and purposefully going through the original contact sheets of lay mothers potential participants and helpful Children's Centre staff, telephoning them to ask if they knew of any suitable mothers who fit the inclusion criteria. Additionally, CHUMS, SANDS, Sakoon and Children of Jannah bereavement charities[119] were contacted and agreed to help snowball and verbally advertise the FG to local women who may have been eligible to take part.

4.5.5 Data analysis

Demographic data from the bio-questionnaire (lay mothers) and interview transcripts (bereaved mothers) were entered into Microsoft Excel to determine participant characteristics (Chapter 6 Section 6.2.1 and Chapter 7 Section 7.1.1).

For the English speaking discussions, verbatim transcripts were produced by the researcher. For non-English speaking interviews, the first translation was conducted by the university approved translator. A second translator then listened to the non-English audio files and read the written translation to ensure consistency of transliteration[120] (Temple and Young, 2004; Regmi, Naidoo and Pilkington, 2010). A small number of transcripts were presented back to participants for further verification of the accuracy of the transcript, to ensure that trustworthiness was achieved (Shenton, 2004; Temple and Young, 2004; Stainton-Rogers, 2006). Transcripts were produced simultaneously with on-going focus groups and interviews, to identify the point of data saturation.

analysis Framework Analysis approach was used to analyse the transcripts. Framework analysis is considered an appropriate method in analysing qualitative data, offering a more structured approach than thematic analysis (Ritchie and Lewis, 2003), consequently is efficient in dealing with large amounts of data and contributes to the reliability and trustworthiness of the findings (Richie and Spencer, 1995). There are five key stages to using the Framework Analysis approach.

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[119] An amendment to the original Ethics Approval application was made to the Institute for Health Research, University of Bedfordshire, and subsequently approved.

[120] Gatekeepers from the community were approached to help with the transliteration. The university did not have stand-alone confidentiality agreements for non-employees; therefore one was drawn up by the researcher and signed by both parties.

using Microsoft Excel to organise the data (Gale *et al*., 2013). Framework analysis promotes five stages of analysis: submersion in the data, which ensures familiarisation of the narrative, identification of emergent themes to build a framework, indexing and schematic charting to organise data and interpretation of findings (Richie and Spencer, 1995; Srivastava and Thompson, 2009). In order to become submerged in the data, the researcher repeatedly listened to the audio outputs and reread the verbatim transcripts[121]. This process enabled the narrative to become more familiar and facilitated initial identification of emergent themes within the text. These early identified potential themes were noted (inductive themes). Additionally, themes driven from the existing literature, which had informed development of the topic guides, were also identified and noted (deductive themes).

Next, the early themes emerging from the transcripts were identified and named using relevant terminology from the existing literature and/or the transcripts (Richie and Spencer, 2003), then tabularised in Microsoft Excel to represent the emerging framework (or matrix), which facilitated the early indexing and subsequent charting of codes within the transcripts. The contents of the table were separated by each tab in Microsoft Excel so that each main theme was found on a single page; alongside related sub-themes. A related code (e.g. A1, B2ii, C3iii) was indexed into the verbatim transcript (as an annotation) so that all selected narrative (relevant to the identified framework code) could be identified, coded and tracked during the analysis stage (Mason, 2002). The corresponding narrative extract from each transcript was then sorted (i.e. copied, pasted and themes located together) into the related page and cell in Microsoft Excel, some with memos[122] added to an adjacent cell.

Once the initial framework (and codes) had been decided, the iterative procedure of indexing and charting the remaining transcripts took place (Richie and Spencer, 2003). Mason (2002) suggests this is an efficient way of processing large amounts of data and helps to identify outlier data. Indeed, during the process of indexing and charting, a number of extracts were identified that were not easily assigned to a single code, or

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[121] The transcripts for lay and bereaved mothers and staff (Section 4.6) were analysed using a separate coding framework.

[122] Where relevant to assist the research and Director of Studies agree any ambiguity or develop the coding framework further

failed to fit within the existing framework. A second coder[123] was consulted to help discern where best the data sat within the emergent framework. This resulted in reassessing the context of the narrative in question, to better understand the participants meaning behind their narrative. This was achieved listening and reading the transcripts and using post-it notes to document the context behind the text, aiming to remain true to the original narrative[124] (Richie and Spencer, 2003). This facilitated a broader overview of the growing volume of data. Consequently, the coding framework was revised, whereby certain sub-themes were better aligned with different main themes. Chapter Six and Seven provide the description of the findings and Chapter Nine presents the interpretation and Chapter Ten presents the discussion of the converged findings from this study.

Challenges of data analysis

- This study aimed to identify similarities and differences between Pakistani, Bangladeshi and WB mothers. Therefore, early in the analysis stage, it became evident that coding each piece of narrative that was extracted from every transcript and inserted into the Framework (in Microsoft Excel) was necessary to allow cross-comparison between extracts and to identify patterns in the data between ethnicities. This process generated large mounts of in-depoth information but overall the process was very time-consuming.

- During data sorting, the context of some narrative was lost (Richie and Spencer, 2003). Consequently, retrieval of the original narrative was necessary to make sense of the data. The use of additional memos assisted with this.

- Once the Framework required revising, this also proved to be time-consuming in Microsoft Excel as a consequence of the large volume of data that had been input. It was considered that a computer software package for qualitative data such as NVivo might be helpful in this context.

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[123] The Director of Studies

[124] Alternate approaches dissect the data further, resulting in deeper abstraction (Strauss and Corbin, 1994).

Trustworthiness of the data

Issues of 'trustworthiness' and 'applicability' are integral to qualitative data, due to the subjective nature of the data (Miles, Huberman and Saldana, 2014; Noble and Smith, 2015). Several processes were undertaken to ensure the data collection, analysis and interpretation of findings are trustworthy and applicable. These were: piloting the interview guide to ensure the questions asked the information that was being sought, a selection of transcripts were passed back to participants to validate as an accurate record of the discussion. Additionally, for non-English speaking FG, a process of transliteration and back-translation, listening to the original audio took place to ensure accuracy of the translated transcript (Temple and Young, 2004; Regmi, Naidoo and Pilkington, 2010).

Generalisability

The findings from this objective are representative of the local community, however, as previously stated (Chapter Two), due to subtle nuances in environmental influences on health beliefs and health behaviours, the degree to which these findings can be inferred to other towns and cities in England is questionable, without further research to confirm or dispute these findings (Richie and Lewis, 2003, Mays and Pope, 2000).

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4.6 Objective three

To ascertain maternity health professionals' views on the service needs of Pakistani, Bangladeshi and WB pregnant women.

4.6.1 Method

Qualitative methods using FG were used to generate rich data. FG are an effective way of gathering data with similar participant groups, in addition to the group constructing ideas together (Kitzinger, 1994; Krueger and Casey, 2009). Four FG with mixed HCP were sought. Moreover, the purpose of using FG is to create a debate among the participants and by incorporating medical and midwifery staff who represent all stages of the maternity care pathway within a single group should facilitate natural tension which may contribute to an active debate, while the group remains homogenous in their overall caregiving environment (Freeman, 2006).

4.6.2 Sample selection

The intention was to recruit a purposeful sample of maternity health professionals i.e. midwives, community midwives, health visitors (HV), support workers, neonatal nurses, community midwives, General Practitioners and hospital physicians). However, the actual sample obtained were hospital and community midwives, a GP, practice nurse and HV, all of whom were currently working on the maternity care pathway in Luton.

The staff at the Luton and Dunstable University Hospital working in the maternity department and GP surgeries located in the wards of interest (i.e. Dallow, Saints, South, Biscot, Farley, Leagrave and Lewsey) who were working with pregnant or new mothers were approached. Exclusions include staff not working in the maternity or neonatal intensive care departments at the Luton and Dunstable University Hospital, staff roles not defined as midwife, health care assistant, physician or HV, neonatal nurses and staff located in GP surgeries in wards other than Dallow, Saints, South, Biscot, Farley, Leagrave and Lewsey. Table 8 details the sample structure for staff working on the maternity care pathway in Luton.

Table 8 Sample structure of maternity staff

Maternity care pathway	**Location of staff**	**Sample frame Numbers of identified staff* employed**	**FG**[#]
Preconception	GP Surgeries	90	
Pregnancy	Hospital	350	4x FG 6–8 participants
Post-delivery	GP surgeries & Hospital	140	
		350	

*Doctors, Obstetricians (20), General Practitioners (90), Midwives (250), health care assistants (30), HV (50). The staff numbers were advised by the hospital and NHS Services.

[#] FG composite based on similar research by Kelley and Trinidad, 2012; Degni *et al.*, 2012)

4.6.3 Recruitment strategy

The staff at the Luton and Dunstable University Hospital working in the maternity and neonatal intensive care departments were identified through the Head of Midwifery and Audit Nurse at the hospital. Staff working within GP surgeries were identified through a mapping exercise, using the wards of interest (Dallow, Saints, South, Biscot, Farley, Leagrave and Lewsey) and GPs who were registered in NHS Choices at the time of recruitment. As the researcher is a nurse, understanding how to target the staff was thought to be easier, however there were challenges experienced (Section 4.6.4).

A poster flyer was displayed in the maternity and neonatal department restroom(s) and distributed for display in staff areas in the GP surgeries (Appendix 12). Hospital staff were invited to contact the researcher directly (by email/telephone), to register their interest (leaving a name, email and contact number) and to ask any questions. The staff working within GP surgeries, located within the wards of interest, were invited through letter and/or face-to-face verbal invitation (Appendix 13) and invited to register their interest in taking part by email/telephone or face-to-face. In the first instance, an information sheet was emailed to staff who expressed an interest in taking part, to provide supporting information and allow participants to make an informed decision whether to participate (Appendix 14). Once enough maternity staff were identified to form a meaningful group that was representative of the maternity care pathway in Luton (i.e. staff from GP surgeries and the maternity department), the date, time and venue were arranged, and participants were contacted using the contact details that they had previously provided. A minimum of 24 hours elapsed between issuing the study information and the FG taking place, allowing potential participants time to consider their participation carefully.

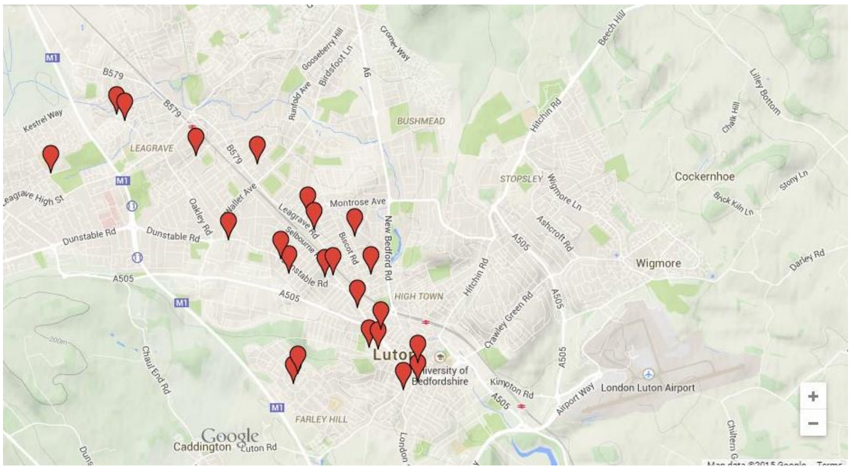

Figure 20: Map showing locations of GP surgeries in Dallow, Saints, South, Biscot, Farley, Leagrave and Lewsey

4.6.4 Data collection

A room at the hospital, GP surgery or community centre was identified to hold the FG discussions, and light refreshments were offered (tea, coffee and biscuits). At the beginning of the session, the information sheet was overviewed and any questions participants may have had, answered. Informed and written consent was obtained (Appendix 15). Participants were then asked to complete a bio-questionnaire (Appendix 16). The researcher conducted the FG. The verbal discussion was audio recorded and explicit permission to record the interviews was sought before recording, and this was documented on the consent form. If participants were unwilling to sign the consent form or to be audio recorded, they were allowed to withdraw from the study. It was explained that if the participant chose to withdraw once that recording had commenced, they may, however the recording thus far would be kept, as it forms part of a complex discussion and cannot be extracted separately. A brief overview of the FG format was made, as per section 1 of the topic guide (Appendix 17). At the end of the FG, all participants were thanked for their contribution and issued with a debrief sheet and an open invitation to attend the ‘findings feedback’ presentation in the future was given. If participants expressed an interest in this, this was noted on their consent form.

Developing the topic guides

The topic guides were developed in the same way as described in Section 4.5.4. The topic guide is found in Appendix 17. Several iterations were produced before the final draft was piloted, which highlighted the following issues;

- Piloting the topic guide revealed issues with the questioning, particularly as it was intended to have one topic guide for all staff disciplines. For instance, several questions on early drafts were only relevant for certain staff groups and attempting to incorporate the bio-questionnaire in the topic guide was unsuccessful, due to phrasing of questions regarding staff job roles and degrees of support to the women.

- There were also issues with phraseology of some questions, which were re-worded to ensure that questions were more explicit and used lay language to avoid any confusion.

Challenges of data collection

During data collection, some challenges were experienced.

Recruitment

- It had been planned to hold FG of mixed professions (to create debate). However, the majority of participants who volunteered were midwives; no one responded to the GP, Practice Nurse or HV invitation letters. It was then decided to try to achieve face-to-face interviews with at least one GP, PN and HV. Several meetings with local GPs took place, to try and identify a suitable solution and volunteers. One GP (and CCG commissioner) also obtained the support of the HV Lead[125], which encouraged participation from the HV team. This strategy was successful in recruiting a single HV who agreed to take part in a face-to-face interview.

- Although the majority of participants were midwives, recruitment was difficult. It was necessary to be resilient and persistent in attempts to gain staff participants. Unlike recruiting the lay community, the subject matter (perinatal mortality) did not generate enough support or interest. Through insider knowledge, the researcher identified sessions[126] where the staff could participate in the study, without feeling that they were giving up more of their already overstretched time.

- Recruiting PNs - efforts had been made to identify the PN by name, in each surgery, so that the invitation letter was more personal. However, this failed to recruit any interest. The researcher then contacted a colleague (a PN in the target area), where it became evident a

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[125] The HV team had not responded to any communication.

[126] The sessions identified were weekly team meetings and protected time for training.

PN did not typically see pregnant women. She agreed to participate, and attempted to recruit other PNs using snowballing, however this did not succeed.

Qualitative data analysis

Demographic data from the bio-questionnaire were entered into Microsoft Excel to determine participant characteristics (Chapter 8, Section 8.2.1). The FG were transcribed verbatim. A few transcripts were then passed back to a few participants to check whether they agreed that it was an accurate account of the discussion (Shenton, 2004; Temple and Young, 2004; Stainton-Rogers, 2006). As detailed previously in Section 4.5.5, the framework approach was used to analyse the data using Microsoft Excel to organise the data (Gale et al., 2013, Richie and Lewis, 2003). Framework analysis includes five stages of analysis: submersion in the data to ensure familiarisation of the text; identification of emergent themes to build a framework, indexing and schematic charting to organise the data and interpretation of findings (Srivastava and Thompson, 2009, Richie and Lewis, 2003). Themes emerging from the FG were identified and compared with existing themes from the current literature.

Trustworthiness of the data

A number of processes were undertaken to ensure the trustworthiness and applicability of the findings (Miles, Huberman and Saldana, 2014; Noble and Smith, 2015). These were: piloting the topic guide to check the applicability of the questions, a few transcripts were passed back to staff to ensure that the transcript was indeed an accurate record of the conversation and audio recordings were listened to and checked against transcripts by the supervisor. Additionally, when coding the transcripts and developing the framework, the researcher worked with the supervisor to disambiguate quotes and codes (Spencer, Richie and O'Conner, 2003).

Generalisability

It is likely the findings from objective three are generalisable, both representatively of the sample (i.e. HCP) and by inference, meaning other HCPs working in similar geographies and with similar population groups (Richie and Lewis, 2003, Mays and Pope, 2000).

4.7 Ethics

4.7.1 Ethical Approval

Ethics approval was provided by University of Bedfordshire Research Graduate School (March 2014), Institute for Health Research, University of Bedfordshire (reference IHRREC442, November 2014) (Appendix 18), Institute for Health Research, University of Bedfordshire (February 2016) and NHS ethics committee (reference: 15/EE/0181: 157751, June 2015) (Appendix 19). Research and Development approval was also sought from the Luton and Dunstable University Hospital Trust, before the commencement of the fieldwork.

4.7.2 Ethical considerations

The ethical considerations for this research were developed following both the British Psychological Society Code of Ethics and the Nursing Midwifery Council code of conduct, which were maintained at all times during the research (Nursing Midwifery Council, 2008; The British Psychological Society, 2009). During the planning stage of the research, local Pakistani community women (i.e. the gatekeepers) were consulted to ensure that the proposed procedures were culturally sensitive to the needs of the community, in addition to troubleshooting the potential barriers for Pakistani and Bangladeshi women participating in this study.

4.7.3 Risks and benefits

Before any recruitment of bereaved women, advice was sought from SANDS to determine the optimal recruitment time, post infant death, to avoid undue distress. Additionally the '*Framework for ethical decision making*' with research using bereaved families (see Sque *et al.*, 2014) was followed (Appendix 2).

Recruitment for bereaved mothers was achieved through a gatekeeper (Audit Midwife), who also screened the potential list of participants. Therefore vulnerable or medically unsuitable participants were not invited to participate. Participants were contacted using a cover letter by the hospital and a recruitment pack inviting potential participants to make contact with the researcher directly, consequently using a non-intrusive opt in/out system, which put control and choice with the participant. Furthermore, the Child Bereavement Charity reviewed the recruitment pack before use (Appendix 4–7).

While it is recognised that some topics may be distressing to participants (*and* the researcher) e.g. adverse birth outcomes, infant bereavement research has shown that disclosure and sharing of sensitive information within a research setting can be cathartic, empowering and therapeutic to women who have experienced adverse birth outcomes (Richies and Dawson, 1996; Statham, Solomou and Green, 2001; Stroebe, Stroebe and Schut, 2003; Hynson *et al.*, 2006; Redshaw, Rowe and Henderson, 2014).

The risk of becoming upset is clearly stated in the information sheet and on the consent form. If participants were to become upset during the FG or face-to-face interviews, they would be supported by the researcher and allowed to take the time to reflect/talk as needed. If they wished to stop the interview, this was respected. If this occurred, they were asked whether they wanted to continue and if they chose to stop, this was respected.

The researcher is a registered nurse, and has professional training to deal with sensitive issues, can recognise non-verbal signs of discomfort and distress and signposted all participants to counselling and professional services (e.g. SANDS or GP) for further support. At the end of the interview, the researcher stayed for a debrief talk (as required) and when arranging the interviews, established who was available after the interview to support the mother (i.e. friend or relative). If the mother was especially distressed, the researcher encouraged her to make contact with her GP and made sure she had supportive company. Also, she asked their permission to telephone the participant in a few days' time, to make sure they were managing their emotions and again, signpost them to the professional services for further support if they had not already done this.

All study participants were given information signposting them to specialist organisations, such as SANDS and Muslim Bereavement Support Service (MBSS). Contact details for further support was provided to each participant on the debrief sheet (Appendix 11). It was recognised that some sensitive issues might have needed to be shared with the research supervisor, in the context of direct support being required for the researcher. The researcher used a personal diary to help record and monitor her emotional responses during the interviews. This is recognised as a positive intervention (Frisina, Borod and Lepore, 2004; Pennebaker, 2013). External emotional support was also available from Bedfordshire University, and Royal College of Nursing counselling services.

The use of incentives is contentious. Pakistani and Bangladeshi women are recognised as hard to recruit (Grant and Sugarman, 2004; Twamley *et al.*, 2009). It is acknowledged that incentive may be considered coercive, however, when considering beneficence: taking part, the sensitive nature of the topic, risk of becoming upset and the benefits of revealing the voices of marginalised sector in Luton, the use of incentives are justified (Menikoff, 2001; Grant and Sugarman, 2004). Moreover, the recruitment packs did not advertise an incentive, and therefore this is not overtly coercive, whereby the £20 voucher was mentioned at the end of the information sheet and framed as a ‘thank you’ for their time. £20 was considered an appropriate sum for compensating their time and has been used by University of Bedfordshire Institute for Health Research in similar populations and demographics and has found to promote successful recruitment (Menikoff, 2001; Grant and Sugarman, 2004). Participants who elect to withdraw within the first 30 minutes of the interview (including the consenting process) would not receive the £20 gratuity, however, if they were to pull out after 40 minutes, they would. This is commensurate with the time and commitment they have provided toward the study.

4.7.4 Informed consent

Each participant was issued with a research information sheet which detailed the nature, purpose, confidentiality, risks and benefits associated with participating in the research (Appendices 6 and 14). It also explained how results would be disseminated and included contact details for the researcher and supervisor for obtaining further information about the study if required. For non-English speaking potential participants, the hospital and University translator(s) used the information sheet and consent form as their topic guide to ensure mothers were giving informed consent. Potential participants contacted the researcher directly and provided the researcher with a contact name and number. The interview or FG session was scheduled following a minimum period of 14 days for bereaved mothers and 24 hours for health care staff, allowing adequate time to consider their participation. For the English speaking interview participants, the information sheet was read verbatim. However, the translator used the information sheet and consent form as her topic guide to obtain informed consent for non-English speaking participants and this helped to mitigate against poor literacy. Once each participant had been allowed to ask questions, voluntary, informed and signed consent was obtained from each participant on individual paper consent forms (Appendices 9 and 15). Permission to record the interviews was sought before audio recording, and it was explained that they were allowed to withdraw and were asked their permission to keep the audio recording thus far. Participants refusing to be recorded were allowed to withdraw from the study.

4.7.5 Confidentiality

All information gained from the research was de-identified and treated in confidence and in accordance with data protection legislation. The hospital staff handled potential participant personal information (e.g. names and addresses), and the recruitment packs were coded by the hospital staff to match the list of potential participants so that refusals were clearly identifiable. The research team had access to a first name, contact number and email only if and when provided by the participant, for the purposes of further contact by the research team to discuss possible participation. For the interviews with bereaved mothers, if mothers chose to be interviewed in their homes, the participant's address was known to the research team for the purpose of conducting the interview and informing Dr Nasreen Ali of the researcher's safe exit from the premises. Careful handling of this information ensured that the address detail was not paired with output data at any time. Codes were used at the point of transcribing for any verbal text. For example, P1, P2 will refer to participant one, two, etc. Identifiable factors such as names, places, dates were expressed as follows: [name] [date] [place] therefore retaining privacy and confidentiality.

Participants were welcome to withdraw at any time. Should they have expressed this, permission was sought to keep any audio data gathered thus far; this would be documented on the consent form, countersigned by the researcher and participant and if they refuse, this would be respected, and the audio would be deleted. For the FG, it was explained before the start of the session, that while participants were free to withdraw at any time, data collected in the FG setting up to the point of withdrawal could not be removed, due to the difficulty of excluding individual data in a shared conversation, however the participant was free to withdraw at any time. All information shared by the participants is treated in confidence and only shared with the research team for the current study.

The hospital translator(s) will already have a confidentiality agreement in place with the Luton and Dunstable University Hospital. However, a confidentiality agreement was drawn up with the assistants who also undertook the task of transliteration (Appendix 20).

4.7.6 Data storage

All audio recording, transcriptions and descriptive data was stored on an encrypted USB stick, in addition to password protected and encrypted digital files, stored on a University issued password protected computer. Paper consent forms and bio-questionnaires were stored in a secure locked facility (i.e. locked filing system), located in a locked and alarmed facility on the University Putteridge Bury Campus. Data was only shared with the research team (researcher, supervisory team and approved translator). Data will be kept for a maximum of 5 years, as per Royal College of Nursing research ethics (Royal College of Nursing, 2009) and current data protection and by the University regulations (Data Protection Act, 1998). The safe destruction of digital or paper files will follow the University procedures at that time.

4.8 Chapter summary

This chapter presents the methodology and methods employed in the current study. The objectives were to review secondary data from the hospital identifying risk factors that contributed to perinatal mortality, to explore similarities and differences in the health beliefs and health behaviours around perinatal mortality and to understand maternity health professionals’ views on the service needs of Pakistani, Bangladeshi and WB pregnant women. Together, these objectives address the main aim of this research, which is to determine how health beliefs influence health behaviour and contribute to perinatal mortality in babies born to Pakistani, Bangladeshi and WB women in Luton.

This study employs a convergent mixed-method design, to utilise both quantitative and qualitative sources of data, providing context and depth to the findings. The design uses three methods: retrospective cohort design, using secondary data, FG and semi-structured interviews in three distinct participant groups (i.e. lay mothers, bereaved mothers and health care professionals working on the maternity care pathway). The results will be merged to provide both triangulation and 'convergence' of the findings. The following chapters will present the results (Chapter 5) and findings (Chapters 6–8) of this research and Chapter 9 converges these results and findings.

Chapter 5: Quantitative results: Factors contributing to perinatal mortality in Luton

5.1 Introduction

This chapter presents the quantitative results which addressed objective one: To identify the current evidence of risk factors contributing to perinatal mortality in Pakistani Bangladeshi and WB women in Luton. The secondary data from the CMiS was extracted for years 2006 to 2013 and women who resided in LU1 to LU4 at the time of their infant delivery. The chapter begins with presenting the hypotheses and then progresses to an overview of how the data was cleaned and transformed into a workable database using IBM SPSS®, addressing key issues such as missing values and transformation of variables. It moves on to systematically present the results of each hypothesis (Section 5.3.2) and then summarises the main results (Section 5.4).

5.1.1 Hypotheses

Following a review of the literature (see Chapter Two) risk factors for perinatal mortality in WB, Pakistani and Bangladeshi women were identified, ten hypotheses were developed which were tested using the extracted CMiS data:

H1. There will be a difference in birth outcomes (i.e. stillbirth and neonatal death) between WB, Pakistani and Bangladeshi infants.

H2. More Pakistani and Bangladeshi infants will be delivered preterm than WB infants.

H3. Pakistani and Bangladeshi mothers will have lighter birthweight infants than WB mothers.

H4. More Pakistani and Bangladeshi women will have diabetes than WB women.

H5. More Pakistani and Bangladeshi women will be overweight, compared with WB women.

H6. There will be more smoking WB mothers compared with Pakistani and Bangladeshi mothers.

H7. Pakistani and Bangladeshi mothers will have a greater parity and give birth to infants at younger maternal age, compared with WB mothers.

H8. WB mothers will book into maternity services earlier than Pakistani and Bangladeshi mothers.

H9. There will be more infant deaths associated with more deprived areas.

H10. There will be an interaction between ethnicity and birth outcome, BMI, PTB, birthweight, diabetes and smoking.

5.1.2 Reporting significance values and clinical importance

There is a recognised debate regarding significance reporting in statistical analysis. It is understood that whilst statistics may suggest ‘significance’ on a predetermined value (which is typically pre-defined at $p<0.05$), this translates to a 95% chance that the statistical results are ‘true’, therefore there is always a small chance (5%) that the results that appear ‘significant’ are indeed erroneous (type I error) or results that appear insignificant are in fact important (type II error) (Field, 2013b). More importantly within health research, statistical significance may not necessarily be reached (hence rejecting the hypothesis) while conversely, clinical importance and tangible differences may be observed, i.e. the threshold of viability at 24 weeks of gestation and >500g (Spicer, 2005; Field, 2013b). This factor needs to be borne in mind with the current study, as small differences that may not reach significance value may have tangible outcomes in perinatal mortality and morbidity.

5.2 CMiS data

Twenty-four Microsoft Excel files were extracted from the hospital CMiS system, containing the raw de-identified data of women who had delivered infant(s) during 2008–2013 and who resided in postcode areas of LU1 to LU4 (N=21,264). The raw data files contained between 740 and 1081 individual cases of data[127]. These were extracted separately for each year and district level postcode (e.g. 2008, LU1). Due to restrictions in data protection, district level postcode data only was supplied with the data 2008–2013. However, a separate raw dataset for 2014 data was provided, which included sector level postcodes, maternal ethnicity and birth outcome. Table 21 shows frequency of cases in each year/postcode.

Figure 21*:* Cases of infant delivery shown by year and area

Frequency counts by date and postcode

		Postcode				**Total**
		LU1	**LU2**	**LU3**	**LU4**	
Date	**2008**	756	779	1003	1048	3586
	2009	797	701	1038	979	3515
	2010	779	737	1081	942	3539
	2011	800	815	1015	929	3559
	2012	784	740	1066	987	3577
	2013	831	774	961	922	3488
Total		**4747**	**4546**	**6164**	**5807**	**21264**

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[127] Each case of data pertained to one mother and infant delivery.

The Excel files were each imported into IBM SPSS 21® to create a master database of raw data. The data was cleaned (Section 5.2.2) and the variables filtered by the coding variable ‘maternal ethnicity’ to extract the raw data of WB, Pakistani and Bangladeshi cases. This selected data was then transferred to a further master database called ‘*ethnic3*’.

5.2.1 Variables

The variables were: maternal age (at booking), marital status, parity, singleton or multiple, maternal height and weight, BMI, ethnicity, gestational age at delivery, birth outcome, birth weight, delivery method and infant gender. Several variables were recoded to provide meaningful analysis as the cell counts for some sub-categories were too small. For example, in the raw data birth outcome consisted of five categories: ‘live born and still living’ (L),’ neonatal death (N), antepartum stillbirth (A), intrapartum stillbirth (I), indeterminate stillbirth (X), however these were collapsed into two new variables, binary birth outcome (e.g. dead/alive) and stillbirth (e.g. stillbirth/alive/neonatal death), which ensures that cell counts are greater than 5[128]. The following variables were transformed into re-coded variables[129]: booking, birth outcome, smoking status, stillbirth, ethnicity, birthweight, maternal BMI and gestation age at delivery.

5.2.2 Data cleaning

Initial visual inspections were conducted on each variable to identify obvious data entry errors, outliers and output parameters. This revealed that height and weight data had been entered using both imperial and metric measurements. Therefore it was necessary to convert imperial measurements. This was achieved using SPSS syntax and transforming new height and weight variables. Next, values were assigned and defined for nominal data, to mirror the CMiS coding systems.

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[128] This is a requirement for accepting Pearson Chi-Square test of association results.

[129] Using accepted thresholds and definitions from the UK literature.

5.2.3 Dealing with missing values

Visual inspection of the frequency counts of individual variables identified missing values. Little's Completely at Random (MCAR) test (Little, 1988) was used to ascertain whether the missing values were indeed random i.e. Missing at Random (MAR) or systematically[130] missing (MNAR). Little's MCAR test was found to be significant, indicating that some data was systematically missing i.e. MNAR ($\chi^2 = 32882.04$, df = 177, $p = .00$). There is no clear or known rationale or method for dealing with non-random data entry, which may be the consequence of numerous reasons (deliberate or not) and as such this is problematic in increasing bias and error in the analysis (Schafer and Graham, 2002; Baguley, 2012).

More recently, scholars debated the accuracy of the MNAR test due to the possible reasons for the missing values. Currently, it is recommended that researchers use several methods[131] to check their data, which helps identify the context of missing values (Nakagawa and Freckleton, 2008; Osborne, 2013). Historically, researchers would delete cases with missing values (complete case analysis), but this has been shown to result in erroneous reporting of results and significantly reducing power in the sample (Ibrahim, Chu and Chen, 2012; Osborne, 2013). Alternatively, median figures have been used but this has also been shown to introduce bias, especially when larger percentages of data are missing (Schafer and Graham, 2002; Ibrahim, Chu and Chen, 2012; Osborne, 2013).

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[130] Systematically missing data implies deliberate non-response by the participant.

[131] A further possible technique is expectation–likelihood modelling (EM), but this is only suitable when the missing values are considered to be random (i.e. MCAR or MAR). Consideration is necessary regards the context and type of design and missing-ness of data (Baguley, 2012); this study uses secondary computer data taken from maternity paper records, whereby a number of extraneous situations may result missing values.

Current thinking to deal with missing data is to use a multiple-imputation method (MI), which substitutes the missing value for the most likely missing value, based on the data in the current series. This likely missing value is not static and is randomly generated from an advancing repetition of values in the series (Osborne, 2013; Ware *et al*., 2012; Ibrahim *et al*., 2012). However, studies have shown that when MNAR data has used MI results can be biased even more than by complete case analysis (Sterne et al., 2009).

In line with current thinking (i.e. Osborne, 2013 and Ware *et al*, 2012) multiple imputations (MI) were carried out to determine further whether there were clear patterns evident within the missing data. MI showed that 67.74% of data was complete in 21 variables and 10 variables had incomplete values of 32.26%. It is typical in large secondary data sets that there will be large numbers of missing data. In the CMiS data, 99.97% of cases of the reported missing values (Ware *et al.*, 2012), consequently missing-ness of >5% should, therefore, be considered MAR and/or MNAR; in other words all large datasets will inherently be a combination of missing at random and not random, and understanding the context behind the missing data is a useful task, especially when data is derived from manual data entry (as in CMiS), and can be subject to a number of failings (Baguley, 2012; De Goeij *et al.*, 2013; Osborne, 2013). De Goeij and colleagues (2013) suggest it is a combination of random and non-random factors which contribute to missing data in health research.

Using SPSS, visual patterning of the CMiS data was checked and missing values were found in the variables of height (16.3% missing) and weight (14.5% missing); suggesting that missing-ness may be a consequence of a number of unrelated mechanisms, such as poor data recording, no access to measurement instruments, failure to transfer information from paper record to CMiS system, while in truth, the actual reasons are unknown (Baguley, 2012; De Goeij *et al.*, 2013). No further significant patterns were found in the extracted data (Ware *et al.*, 2012; Osborne, 2013). Figure 22 shows the variables and frequency of missing data, marked in red.

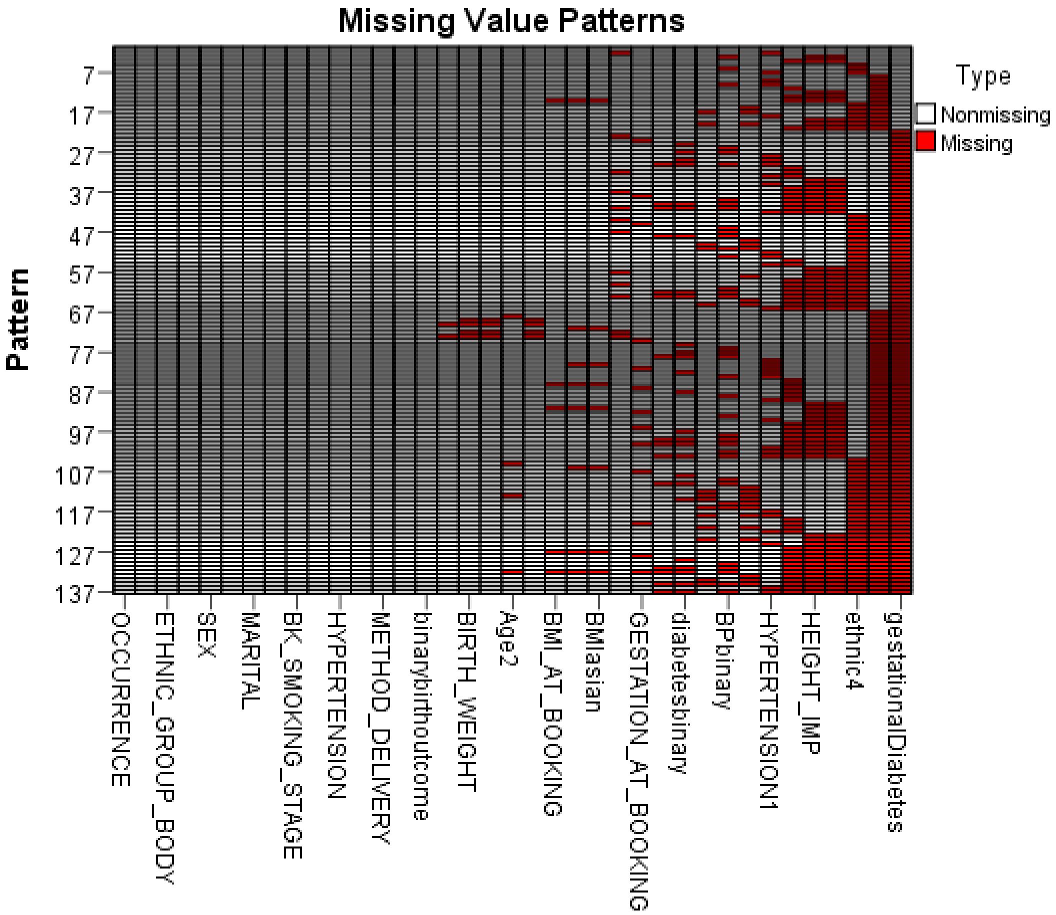

Figure 22: Grid showing missing values across variables

This study used complete case analysis and deleted cases where values were missing. Inspection of similar studies demonstrated that they also deleted missing and incomplete cases (Redshaw and Heikkilä, 2011; Sheridan *et al.,* 2013; Makgoba *et al.,* 2012; Ravelli *et al.,* 1998). Discrete missing values (i.e. 999 and 9999) were input into SPSS to explicitly code missing values across numeric variables. SPSS uses default list-wise deletion of missing cases in the majority of the analysis, and this default was maintained. Total sample size for each analysis is reported in the forthcoming sections (N).

5.2.4 Statistical analysis

Analyses were conducted using IBM Statistics Package for the Social Sciences (SPSS) ® v21. The raw data contained data on all ethnicities (N=21,264), however for the purposes of this study, data was selected for only WB, Pakistani, and Bangladeshi outcomes (N = 14,220).

Cross-tabulation using ASR and Pearson Chi-Square test of association was performed to ascertain whether categorical groups are statistically associated (Agresti, 2013). Additionally, to control for co-variables that are known to mediate outcomes, ANCOVA was used, using Bonferroni as the posthoc analysis.

An exploratory loglinear analysis was selected as the most appropriate statistical analysis to test the categorical and polynominal or dichotomous recoded variables. The aim was to identify how the variables might be associated in an ‘intersectional’ way – mediating risk positively or negatively in a given model. No pre-determined models were therefore assumed from the data, specifically, consequently, hierarchal model selection was chosen[132].

5.2.5 Confounds

There are several known confounds to perinatal mortality and morbidity. For example, maternal smoking is well documented to contribute to lower birthweight. Other recognised contributors are

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[132] The highest order interaction is identified through the analysis, in progressive and descending order, through to the lowest order interaction, while removing interactions that fail to contribute to the model.

parity, maternal age, maternal height, weight and BMI, diabetes, and gestation age at birth (Sebire *et al.*, 2001; Patel *et al.*, 2004; Platts *et al.*, 2014). These have been controlled where SPSS analysis permits and this is reported accordingly.

5.3 Results

5.3.1 Cohort descriptive statistics

The cohort (N=21,264) mean and standard deviations are shown in Table 9. This showed a cohort mean for gestational age at delivery was 39.06 weeks, birth weight equalled 3232.8 g, parity was 1.96, and maternal height and weight were 161.68 cm and 67.7kg respectively.

Table 9: Descriptive statistics for whole cohort# LU1–LU4 cohort 2008–2013

Descriptive Statistics

	N	**Mean**	**Std. Deviation**	**Minimum**	**Maximum**
Parity	21264	1.96	1.23	1.00	14.00
Gestation at delivery	21264	39.06	2.21	18.00	46.00
Maternal Height	17041	161.78	7.07	100.00	191.00
Maternal weight	18190	67.70	15.8	30.45	191.00
Infant birth weight	21259	3232.8	597.44	145.00	6960.00
Infant(s) delivered	21264	1.01	0.12	1.00	3.00

N =21,264 included all ethnic groups.

The database was then filtered by cases of WB, Pakistani and Bangladeshi ethnicity (N= 14,220), and the means and standard deviations for parity, gestation age at delivery, birthweight, maternal height and weight were calculated (Table 10).

The numbers of mothers in each ethnic group sized ranged between 7020 (WB) and 2057 (Bangladeshi). The mean for gestational age at delivery ranged between 39.96 weeks (Pakistani) and 38.9 weeks (Bangladeshi). Infant birthweight ranged from 3316.62g (WB) to 3066.52g (Bangladeshi). Parity ranged from 1.43 (Pakistani) to 0.93 (WB), maternal height and weight ranged from 155.1cm (WB) to 150.89cm (Bangladeshi) and 70.33kg (WB) to 60.26kg (Bangladeshi).

Table 10: Mean and standard deviations in WB, Indian, Pakistani and Bangladeshi mothers in LU1–LU4, 2008–2013

Descriptive Statistics

Ethnicity	Variable	N	Mean	Std. Deviation	Minimum	Maximum
WB	**Parity**	7020	.93	1.17	.00	10.00
	Gest at delivery	7020	39.14	2.31	19.00	46.00
	Birth weight	7017	3317.62	611.01	180.00	5925.0
	Maternal weight	6094	70.33	16.7	30.45	191.00
	Maternal height	6011	155.10	48.33	1.00	999.00
Pakistani	**Parity**	5143	1.42	1.30	.00	7.00
	Gest at delivery	5143	39.96	1.96	18.0	44.0
	Birth weight	5141	3127.64	578.65	32.95	141.00
	Maternal weight	4037	65.72	14.19	32.95	141.00
	Maternal height	4127	153.55	41.31	1.50	1655.00
Bangladeshi	**Parity**	2057	1.43	1.29	.00	9.00
	Gest at delivery	2057	38.9	1.97	21.00	42.00
	Birth weight	2057	3066.52	538.64	350.00	4970.00
	Maternal weight	1736	60.26	12.84	35.00	166.00
	Maternal height	1736	150.89	34.03	1.52	999.00
Total		15, 211				

Next, frequency counts and percentages for the categorical variables (i.e. maternal age, smokers, diabetic, maternal BMI at booking and gestational age at delivery) were calculated in SPSS using ‘ethnic 3’ data (Table 11). This shows that WB mothers have the highest percentages of younger and older age mothers, in addition to 21.5% of mothers reported to smoke and the highest percentage of mothers who delivered preterm (7.3%). Conversely, 49% of mothers with diabetes (inclusive of pre-existing diabetes and gestational diabetes) were Pakistani. Moreover, a higher percentage of Pakistani mothers (25.2%) had a low BMI (<18.5kg/m^2) whereas a higher percentage of WB mothers (2.7%) had a BMI greater than 40kg/m^2.

Table 11: Frequency and percentages for WB, Pakistani and Bangladeshi deliveries 2008–2013

Ethnicity	**n**	**Maternal age n (%)**						**Smokers n(%)**	**Diabetic n(%)**	**BMI# n(%)**					Delivery age at gestation n(%)	
		16-20	**21-25**	**26-30**	**31-35**	**36-40**	**>40**			**<18.5**	**19-24.9**	**25-29.9**	**30-39.9**	**40-60**	**24-37**	**37+**
WB	7005	1012 (14.4)	1729 (24.8)	2047 (29.2)	1515 (21.6)	617 (8.8)	99 (1.4)	1490 (21.5)	54 (22.6)	1367 (19.5)	2540 (36.2)	1747 (24.9)	1173 (16.7)	188 (2.7)	512 (7.3)	6493 (92.7)
Pakistani	5130	217 (4.3)	1496 (29.1)	1886 (36.7)	1099 (21.6)	386 (7.5)	40 (0.8)	73 (1.4)	117 (49)	1296 (25.2)	1644 (32)	1313 (25.5)	807 (15.7)	81 (1.6)	334 (6.5)	4796 (93.5)
Bangladeshi	2053	93 (4.5)	587 (28.5)	808 (39.3)	437 (21.2)	123 (6)	9 (0.4)	18 (0.9)	68 (28.5)	488 (23.7)	762 (37.1)	553 (26.9)	228 (11.1)	25 (1.2)	135 (6.6)	1918 (93.4)
Total	**14188**															

BMI standard measure

5.3.2 Hypothesis 1: Birth outcome

Hypothesis 1 states: There will be a difference in birth outcomes (i.e. stillbirth and neonatal death) between WB, Pakistani and Bangladeshi infants.

Descriptive statistics for birth outcomes (i.e. antepartum stillbirth, intrapartum stillbirth, indeterminate stillbirth, neonatal death and livebirth) and maternal ethnicity were calculated using the cross-tabulation function in SPSS. This showed that there was a total of 128 deaths in WB, Pakistani and Bangladeshi infants. Antepartum stillbirth was the most common cause of death (Table 12). Within the three ethnic groups, Pakistani mothers had 41.5% of the antepartum stillbirths and 66.7% of intrapartum stillbirths; WB had 66.7% of indeterminate stillbirths and 42.5% of neonatal deaths.

Table 12: Shows frequency and percentage of birth outcome by maternal ethnicity

		Birth outcome					Total
		Ant s/b[1] n(%)	**Int s/b[2] n(%)**	**Inde s/b[3] n(%)**	**Liveborn n(%)**	**Neonatal death n(%)**	
Ethnicity	**WB**	32 (39)	1 (33.3)	2 (66.7)	6968 (49.4)	17 (42.5)	7020
	Pakistani	34 (41.5)	2 (66.7)	1 (33.3)	5090 (36.1)	16 (40)	5143
	Bangladeshi	16 (19.5)	0	0	2034 (14.4)	7 (17.5)	2057
Total		**82**	**3**	**3**		**40**	**14220**

[1]Antepartum stillbirth, [2]Intrapartum stillbirth, [3]Indeterminate stillbirth

ASR and Chi-Square test of association were used to determine whether there was a significant association between maternal ethnicity and birth outcome. Due to small cell counts in the various stillbirth categories, (i.e. <5), the birth outcome variable had to be condensed into a binary variable (i.e. live/dead). Pearson Chi-Square test of association was not significant (χ^2= 4.076, *df*=2, *p*=0.130).

5.3.3 Hypothesis 2: Preterm birth

Hypothesis 2 states: More Pakistani and Bangladeshi infants will be delivered preterm than WB infants.

Frequency counts and percentages of the numbers of infants born according to gestation age (i.e. pre-viable <23.9 weeks, 24-36.9 weeks or after 37 weeks gestation) are shown in Table 13 and birth outcome (i.e. dead or alive) is shown in Table 14. In total, 27 of the 32 infants born before the age of viability died. A slightly higher percentage of Pakistani infants were delivered before 24 weeks, although a higher percentage of WB infants were born before 24 weeks of gestation and died.

Table 13: Frequency and percentage of gestation age at delivery by maternal ethnicity

		Gestation age at delivery n(%)			Total
		<23.9	**24-37**	**>37**	
Ethnicity	**WB**	15 (0.2)	512 (7.3)	6492 (92.5)	7019
	Pakistani	13 (0.3)	334 (6.5)	4796 (93.3)	5143
	Bangladeshi	4 (0.2)	135 (6.6)	1785 (93.2)	2057
Total		32 (0.2)	981 (6.9)	13206 (92.9%)	14220

Table 14: Frequencies and percentages of birth outcome, gestation age at delivery and maternal ethnicity

Birth outcome			Gestation age n(%)			Total
			<23.9	**24-37**	**>37**	
Live	**Ethnicity**	**WB**	2(33.3)	858(45.3)	6108(46.3)	6968(46.2)
		Pakistani	3(50)	635(33.6)	4452(33.8)	5090(33.8)
		Bangladeshi	0	258(13.6)	1776(13.5)	2034(13.5)
	Total		**6**	**1551**	**12336**	**14092**
Dead	**Ethnicity**	**WB**	13(46.4)	30(39)	9(33.3)	52(39.4)
		Pakistani	10(35.7)	35(45.5)	8(29.6)	53(40.2)
		Bangladeshi	4(14.3)	10(13)	9(27)	23(17.4)
	Total		**27**	**75**	**26**	**128**

Pearson Chi-Square test of association was used to determine whether there was a significant association between mothers' ethnicity and PTB. The result was not significant (χ^2= 3.67, *df*=2, *p*=0.452). To control for confounds, a second analysis was done, which included only primipara, live singleton births born after 24 weeks were included the Chi-Square analysis (Table 15). However, Pearson Chi-Square test of association was not significant (χ^2= 3.36, *df*=2, *p*=0.186).

Table 15: Frequency count of primipara, live singleton births, delivered >24 weeks by ethnic group.

		Gestation age at delivery		Total
		24-37	**>37**	
Ethnicity	**WB**	229	2967	3196
	Pakistani	120	1688	1808
	Bangladeshi	54	655	709
Total		403	5310	5713

5.3.4 Hypothesis 3: Birthweight

Hypothesis 3 states: Pakistani and Bangladeshi mothers will have lighter birthweight infants than WB mothers.

ANCOVA was conducted to establish the effect of ethnicity on birthweight, and adjusting for confounders to birthweight (i.e. maternal age, smoking status, diabetes, gestation age at delivery, parity and maternal height and BMI). Birthweight is reported as unadjusted, and adjusted mean(s), and is shown for each maternal ethnicity (Table 16). The adjusted mean birthweight results found Bangladeshi mothers had the lightest mean birthweights (3055.4g) compared to WB mothers who delivered infants with a mean birthweight of 3269.04g, showing a difference of 263.64g. The adjusted results showed a significant difference mean infant birthweight by maternal ethnicity; *F*(2, 4440) = 112.8, *p*<.0005. The partial Eta-squared for maternal ethnicity was η^2= .047.

The covariates of BMI; F(1, 4542) =33.79, $p<.005$, partial η^2 =.006), maternal smoking; F(1, 4542)= 65.6, $p<.005$ partial η^2 =.014), maternal height; (F(1, 4542) = 4.34, $p=0.037$ partial η^2 =.001), diabetes; F(1, 4542) = 8.33, $p=.004$, η^2 =.003), parity; F(1, 4542) = 43.99, $p<.005$, partial η^2 =.003), and gestation age at delivery; F(1, 4542) = 3034.77, $p<.005$, partial η^2 =.003), all had a significant effect on birthweight.

Bonferroni posthoc analysis revealed adjusted mean birthweight was statistically significantly lower in Pakistani infants (mean difference of -161.508g, 95% CI [-196.96—126.05] $p<.00$), *and* Bangladeshi infants (mean difference of –197.89, 95% CI [-148.26- -247.53] $p<.005$).

Table 16: Adjusted and unadjusted mean and standard error for birthweight by ethnicity

Ethnicity	**N**	**Unadjusted Mean**	**Std. Error**	**Adjusted Mean**	**Std. Error**	**95% Confidence Interval**	
						Lower Bound	**Upper Bound**
WB	2623	3320.83	11.1	3269.04	9.15	3251.10	3286.98
Pakistani	1365	3092.12	14.21	3118.1	12.55	3093.50	3142.69
Bangladeshi	566	2992.72	22.17	3005.40	28.21	2950.09	3060.71
Total	4554						

5.3.5 Hypothesis 4: Diabetes

Hypothesis 4 states: More Pakistani and Bangladeshi women will have diabetes, than WB women.

Cross-tabulation was performed to determine associations between ethnicity and diagnosis of diabetes (i.e. diabetes, gestational, on insulin, not diabetic). A Pearson Chi-Square test was conducted to determine independence between the categories. All cell counts were above 5. The result was highly significant (χ^2=103.94, *df*=10, *p*<.005) and suggests strongly that diabetes diagnosis is significantly associated with maternal ethnicity. ASR was estimated for each ethnic group in the Chi-Square analysis to reveal significant areas of over and under-representation[133]. The results (Table 17) show that Pakistani mothers are over-represented in the diabetes category (ASR= 2.3) and gestational diabetes (ASR = 3.2), and Bangladeshi mothers are over-represented in the gestational diabetes category (ASR =5.0) and insulin category (ASR = 2.5). WB women were under-represented in the gestational diabetes category (ASR = -5.4).

The diabetes categories were collapsed into a binary variable (diabetic or non-diabetic). Cross-tabulation was repeated to test associations between ethnicity and diabetes diagnosis. A Pearson Chi-Square test was conducted to determine independence between the categories. All cell counts were above 5. The result was highly significant (χ^2=79.5, *df*=2, *p*<.005).

ASR was then estimated for each ethnic group to determine over and under-representation. The results (Table 18) show that Pakistani mothers are over-represented (ASR= 3.3) and Bangladeshi mothers (ASR =5.7) in the diagnosed with diabetes category. Percentages also show that 49% of mothers diagnosed with diabetes are Pakistani.

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[133] ASR values of >2 or <-2 mean that the observed value in any crosstabs cell is statistically different to that occurring by chance (Field, 2006)

Table 17: frequencies, percentages and ASR for diabetes (all categories)

			Diabetes n(%) **diabetic**	**gestational**	**insulin**	**non**	**n/s#**	**Total**
Ethnicity	**WB**	Count	5 (0.1)	25 (0.4)	24 (0.3)	6938 (98.8)	12 (0.2)	7020
		Std. Residual	-2.8	-5.4	-1.4	.8	-1.6	
	Pakistani	Count	20 (0.4)	74 (1.4)	23 (0.4)	5006 (97.3)	13 (0.3)	5143
		Std. Residual	2.3	3.2	.0	-.4	-.2	
	Bangladeshi	Count	8 (0.4)	43 (2.1)	17 (0.8)	1973 (95.5)	13 (0.6)	2057
		Std. Residual	1.5	5.0	2.5	-.9	3.2	
Total		Count	33	142	64	13917	38	14220

Table 18: frequencies, percentages and ASR for diabetes (binary variable)

			diabetes binary n(%) diabetes	non-diabetic	Total
Ethnicity	**WB**	Count	54 (22.6)	6938 (49.9)	6992
		Std. Residual	-5.9	.8	
	Pakistani	Count	117 (49)	5006 (36)	5123
		Std. Residual	3.3	-.4	
	Bangladeshi	Count	68 (28.5)	1973 (14.2)	2041
		Std. Residual	5.7	-.7	
Total		Count	239	13917	14156

5.3.6 Hypothesis 5: BMI

Hypothesis 5 states: More Pakistani and Bangladeshi women will be overweight, compared with WB women.

Descriptive statistics for maternal height and weight is shown in Table 19. The cohort mean weight was 67.25kg, and cohort mean height is 153.95cm. When stratified by ethnicity, WB mothers have the tallest mean height (155.10cm) and heaviest mean weight (70.33kg), above the cohort mean(s).

Table 19: Descriptive statistics for height and weight

Ethnicity		N	**Mean**	**Std. Error**	Std. Deviation	Minimum	Maximum
WB	height	6011	155.10	.623	48.33	1.00	187.00
	weight	6094	70.33	.214	16.7	30.45	191.00
	Valid N (listwise)	5879					
Pakistani	height	4127	153.55	.643	41.31	1.50	165.50
	weight	4307	65.72	.216	14.19	32.95	141.00
	Valid N (listwise)	4034					
Bangladeshi	height	1736	150.89	34.032	34.03	1.52	187.00
	weight						
	Valid N (listwise)	1736	60.26	12.843	12.84	35.00	166.00

Table 20 depicts descriptive statistics for BMI by ethnicity, showing WB women have highest mean BMI (21.84kg/m^2).

Table 20: Descriptive statistics for BMI

Ethnicity		**N**	**Mean**	**Std. Dev**	**Min**	**Max**
WB	BMI	7019	21.84	11.12	0.00	77.00
	listwise	7019				
Pakistani	BMI	5141	20.21	11.7	0.00	52.00
	listwise	5141				
Bangladeshi	BMI	2057	20.26	10.85	0.00	99.00
	listwise	2057				

Frequency counts and percentages were calculated for BMI categories by ethnicity. The greatest percentage of mothers with a BMI <18kg/m^2 were Pakistani (25.2%), 19-24.5kg/ m^2 and 25-29.9kg/ m^2 were Bangladeshi (37.1%, 26.9% respectively), 30-39.9kg/ m^2 and 40-60kg/ m^2 were WB

(16.7% and 2.7% respectively). Pearson Chi-Square test of association was used to determine independence between the BMI categories and ethnicity (Table 21).

Table 21: Frequency, percentage and ASR for BMI thresholds by ethnicity

			BMI standard n(%)					Total
			<18.5	**19-24.9**	**25-29.9**	**30-39.9**	**40-60**	
Ethnicity	**WB**	Count	1367 (19.5)	2540 (36.2)	1747 (24.9)	1173 (16.7)	188 (2.7)	7015
		Adjusted Residual	**-7.6**	**3.5**	-1.4	**3.9**	**5.1**	
	Pakistani	Count	1296 (25.2)	1644 (32)	1313 (25.5)	807 (15.7)	81 (1.6)	5141
		Adjusted Residual	**6.6**	**-5.3**	.2	.4	**-3.1**	
	Bangladesh	Count	488 (23.7)	762 (37.1)	553 (26.9)	228 (11.1)	25 (1.2)	2056
		Adjusted Residual	1.8	**2.3**	1.7	**-6.0**	**-2.9**	
Total		Count	3151	4946	3613	2208	294	14212

Bold = significance p<0.05

Cross-tabulation was performed to determine associations between ethnicity and BMI. A Pearson Chi-Square test was done to test independence between the categories. All cell counts were above 5. The result was significant (χ^2=126.32, *df*=8, *p*<.005), suggestive that BMI is significantly associated with maternal ethnicity. ASR was estimated for each ethnic group in the Chi-Square analysis to reveal significant areas of over and under-representation. The results (Table 21) show that Pakistani mothers are over-represented in the category 18kg/m^2 (ASR= 6.6), but under-represented in the 19-24.5kg/ m^2 (ASR=-5.3), Bangladeshi mothers are under-represented in BMI categories 30-39.9kg/ m^2 and 40-60kg/ m^2 (ASR =-6.0 and ASR = -2.9 respectively), WB women were under-represented in the 18kg/m^2 category (ASR = -7.6), but over-represented in the 30-39.9kg/ m^2 and 40-60kg/ m^2 categories (ASR = 3.9 and ASR = 5.1 respectively). Figure 23 displays the BMI distributions by mothers' ethnic group.

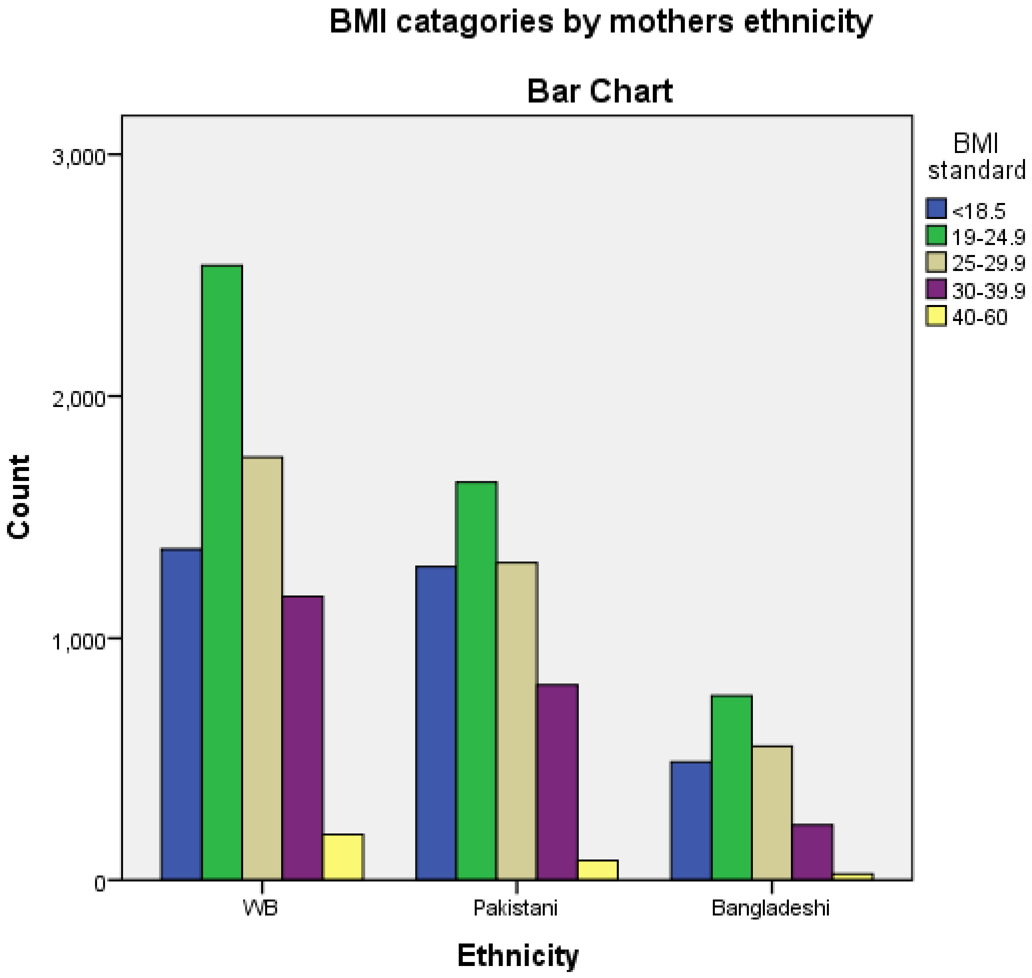

Figure 23: Bar chart showing BMI distributions by mothers' ethnicity.

5.3.7 Hypothesis 6: Smoking

Hypothesis 6 states: There will be more smoking WB mothers compared with Pakistani and Bangladeshi mothers.

Frequency and percentages were calculated for maternal smoking[134] (as a binary variable). This showed that 21.5% of WB mothers were recorded as being smokers, compared to 1.4% of Pakistani and 0.9% of Bangladeshi mothers.

Cross-tabulation was performed to determine associations between ethnicity and smoking. A Pearson Chi-Square test was done to test independence between the categories. All cell counts were above 5. The result was significant (χ^2=1457.98, *df*=2, *p*<.005), suggestive that smoking is significantly associated with maternal ethnicity. ASR was estimated for each ethnic group in the Chi-Square analysis to reveal significant areas of over and under-representation. The results (Table 22) show that WB mothers are over-represented in the smoking category (ASR = 38.2), while Pakistani and Bangladeshi mothers are under-represented (ASR = -27.9 and ASR = -16.1, respectively).

Table 22: Frequency, percentages and ASR for smoking by ethnicity

			Smoking		**Total**
			Non-smoker	**Smoker**	
Ethnicity	**WB**	Count	5496	1508	7004
			(78.5)	(21.5)	
		Adjusted Residual	**-38.2**	**38.2**	
	Pakistani	Count	5063	73	5136
			(98.6)	(1.4)	
		Adjusted Residual	**27.9**	-**27.9**	
	Bangladeshi	Count	2036	18	2054
			(99.1)	(0.9)	
		Adjusted Residual	**16.1**	-**16.**1	
Total		Count	12595	1599	14194

5.3.8 Hypothesis 7: Parity and maternal age

Hypothesis 7 states: Pakistani and Bangladeshi mothers will have a greater parity and give birth to infants in younger maternal age, compared with WB mothers.

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[134] There is currently no code in CMiS for recording smokeless tobacco consumption

There were 8993 cases where parity was recorded in CMiS and n=5227 missing cases, and 14,219 cases of age data (n=1 missing). The frequency and percentages were calculated for each ethnic group. Figure 24 displays the frequency of parity by ethnicity and Figure 5.6 shows age bands by ethnicity.

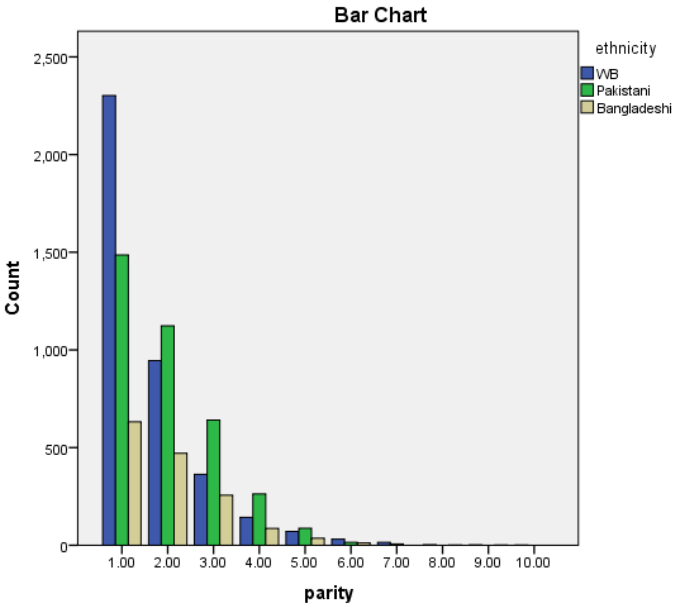

Figure 24: Graph showing frequency of parity by ethnicity

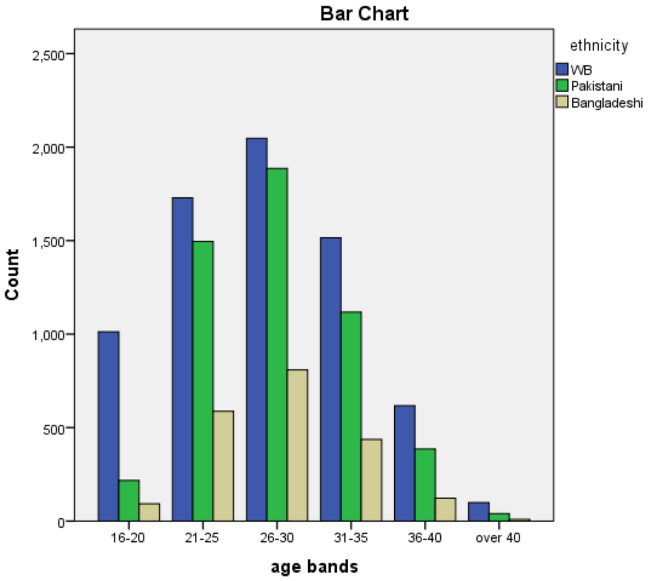

Figure 25: Graph showing age distribution by ethnicity

Cross-tabulation was used to assess the parity distributions. The percentage calculation showed that WB mothers had 59.4% of parity 1, compared with 33.6% Pakistani and 14.3% Bangladeshi mothers (Table 23). A Pearson Chi-Square test was done to test independence between the categories. All cell counts were above 5 (except parity 8, 9 and 10, n=8). The result was significant (χ^2=352.47, *df*=18, *p*<.005), suggestive that parity is significantly associated with maternal ethnicity.

ASR was estimated for each ethnic group in the Chi-Square analysis to reveal significant areas of over and under-representation. The results show that WB mothers are over-represented in parity 1 (ASR = 16.9). Conversely, Pakistani mothers were over-represented in parity 2 (ASR = 4.8), parity 3 (ASR = 8.3), parity 4 (ASR = 6.1) and under-represented in parity 6 (ASR = -2.2).

Next, maternal age was assessed using cross-tabulation and Pearson Chi-Square test of independence. Frequency and percentages showed that 14.4% of WB women were aged 16–20, whereas 36.7% of Pakistani women were aged 26–30, and 8.8% of WB were aged 36–40. Pearson Chi-Square results were significant (χ^2=528.92, *df*=10, *p*<.005), suggesting that there were associations between parity and maternal age. ASR showed areas of over or under-representation. This showed that WB were overly represented in ages 16–20 (ASR = 14.4) and 36–40 (ASR = 8.8), whereas Pakistani mothers were over-represented in ages 21–25 (ASR = 4.6) and 26–30 (ASR = 6.3). Bangladeshi mothers were under-represented in ages 16–20 (ASR = -8.1), 36–40 (ASR= -3.5) and over 40 (ASR=-2.9). Table 23 shows the frequency count and percentage by ethnic group.

Table 23: Frequency, percentage and ASR by ethnicity

			Age bands **N (%)**					
			16-20	**21-25**	**26-30**	**31-35**	**36-40**	**over 40**
Ethnicity	**WB**	Count	1012 (14.4)	1729 (24.6)	2047 (29.2)	1515 (21.6)	617 (8.8)	99 (1.4)
		Adjusted Residual	**20.8**	-5.8	-10.4	.0	**3.8**	**4.3**
	Pakistani	Count	217 (4.2)	1496 (29.1)	1886 (36.7)	1118 (21.7)	386 (7.5)	40 (0.8)
		Adjusted Residual	**-15.7**	**4.6**	**6.3**	.3	-1.4	**-2.3**
	Bangladeshi	Count	93 (4.5)	587 (28.5)	808 (39.3)	437 (21.2)	123 (6)	9 (0.4)
		Adjusted Residual	**-8.1**	1.9	**6.2**	-.4	**-3.5**	**-2.9**
Total		Count	1322 (9.3)	3812 (26.8)	4741 (33.3)	3070 (21.6)	1126 (7.9)	148 (1)

5.3.9 Hypothesis 8: Booking

Hypothesis 8 states: WB mothers will book into maternity services earlier than Pakistani and Bangladeshi mothers.

Gestation age at booking was recoded into a binary variable (before 12 weeks and after 12.1 weeks). Cross-tabulation was used to determine frequency counts and percentages and establish whether there were any significant associations between the groups (Table 24). All cell counts were above 5. Within the cohort, 82.1% of mothers were booked by 12 weeks of gestation. Pearson Chi-Square was significant (χ^2=51.62, *df*=2, *p*<.005), suggestive that booking is significantly associated with maternal ethnicity.

ASR was then estimated for each ethnic group in the Chi-Square analysis to reveal significant areas of over and under-representation. The results show that WB mothers are over-represented in the booking category by 12 weeks (ASR = 7.2). Conversely, Pakistani and Bangladeshi mothers were under-represented in the booking category by 12 weeks of gestation (ASR = -5.6 and ASR = -2.6).

Table 24: Frequency, percentage and ASR for gestation age at booking.

			Booking n(%)		**Total**
			<12 weeks	**>12.1 weeks**	
Ethnicity	**WB**	Count	5909 (84.4)	1089 (15.6)	6998
		Adjusted Residual	7.2	-7.2	
	Pakistani	Count	4088 (79.9)	1040 (20.3)	5128
		Adjusted Residual	-5.6	5.6	
	Bangladeshi	Count	1642 (80.1)	409 (19.9)	2051
		Adjusted Residual	-2.6	2.6	
Total		Count	11639 (82.1)	2538 (17.9)	14177

Table 25: Frequency and percentages of parity by ethnicity

			Parity										Tota
			1.00	**2.00**	**3.00**	**4.00**	**5.00**	**6.00**	**7.00**	**8.00**	**9.00**	**10.00**	
Ethnicity	**WB**	Count	2302 (59.4)	945 (24.4)	363 (9.4)	143 (3.7)	71 (1.8)	31 (0.8)	15 (0.4)	3 (0.1)	2 (0.1)	1 (0.4)	3876
		Adjusted Residual	**16.9**	**-7.1**	**-11.0**	**-6.5**	-1.8	1.6	**2.4**	1.3	.8	1.1	
	Pakistani	Count	1486 (33.6)	1123 (44.2)	641 (50.9)	263 (53.9)	87 (44.8)	15 (25.9)	7 (0.2)	0	0		3622
		Adjusted Residual	**-12.7**	**4.8**	**8.3**	**6.1**	1.3	**-2.2**	-.8	-1.6	-1.4	-.8	
	Bangladeshi	Count	632 (14.3)	471 (18.6)	256 (20.3)	86 (17.5)	36 (18.6)	12 (20.7)	0	1 (0.1)	1 (0.1)	0	1495
		Adjusted Residual	**-5.8**	**3.1**	**3.8**	.5	.7	.8	**-2.1**	.5	.8	-.4	
Total		Count	4420	2539	1260	492	194	58	22	4	3	1	8993

5.3.10 Hypothesis 9: Deprivation

Hypothesis 9 states: There will be a greater number of infant deaths associated with more deprived areas.

The 2014 raw data[135] was imported into SPSS. The ethnicity variable was recoded so that only Pakistani, Bangladeshi and WB outcomes were shown. Next, the dataset was filtered by deceased cases. This showed that in 2014, there were 16 perinatal deaths for Pakistani, Bangladeshi and WB mothers in LU1–LU4. Table 26 shows the frequencies of deaths in each postcode sector. This shows that ‘LU3 2’ ‘LU3 3’ and ‘LU4 9’ each had three perinatal deaths, and LU2 7 had four perinatal deaths. WB mothers had 8 deaths (50%), Pakistani mothers had 7 (44%) and Bangladeshi mothers only 1 (6%) death. The sector level postcode deaths were mapped to IMD decile data, which showed 13 out of 16 (81%) deaths occurred in the most deprived IMD deciles (4 and 5).

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[135] For reasons of confidentiality this 2014 dataset contained only maternal ethnicity, sector level postcode and birth outcome.

Table 26: Postcode and frequency of perinatal mortality by ethnicity

Postcode	Ward(s)#	Ethnicity	Birth outcome	IMD decile
			dead	
LU1 1	Dallow/South /Biscot	Bangladeshi	1	5
LU1 5	Farley/South	Pakistani	1	4
LU2 7	Barnfield/ Bramingham/ Hightown/ Icknield	WB	2	4
LU3 1	Barnfield/Biscot /Hightown/ Limbury/Saints	WB	1	5
		Pakistani	1	
LU3 2	Barnfield/ Icknield/ Limbury/Saints	Pakistani	3	4
LU3 3	Bramingham/ Nortwell/ Sundon	WB	3	3
LU4 8	Biscot/Challney /Dallow/Saints	WB	1	5
LU4 9	Leagrave/ Challney	WB	1	4
		Pakistani	2	

Full postcodes are necessary to map directly onto Parliamentary wards.

5.3.11 Hypothesis 10: Exploratory analysis

Hypothesis 10 states: There will be an interaction between ethnicity and birth outcome, BMI, PTB, birthweight, diabetes and smoking.

To conduct the test, the raw data was input into SPSS. The variables entered into the model were: maternal ethnicity, diabetes (coded as a binary variable yes/no), smoking (coded as a binary yes/no variable), BMI standard (classified by 5 groups as <18.5, 19-24.9, 25-29.9, 30-39.9, 40-60), PTB coded as a tertiary variable (<23.9 weeks, 24-36.9 weeks and >37 weeks of gestation) and birth outcome which was re-coded as a binary variable (dead/alive).

The nature of the raw data output and re-coded variables has restricted analysis to crosstabs and Loglinear, due to violations of homogeneity, unequal sample sizes and failing to meet the criterion of a normal distribution. When inspecting the assumptions for the Loglinear analysis, the output for cell counts and residuals showed that counts were below five as a consequence of too many sub-groups[136] when using all the variables in one model. The model was reconfigured, using ethnicity, BMI and diabetes, then again for ethnicity, PTB and birth outcome, but again numerous cell counts were below five which violate the assumptions for a reliable output.

5.4 Key results

This section highlights the main findings. Each hypothesis is stated followed by the result and acceptance or rejection of the hypothesis.

- H1. There will be a difference in birth outcomes (i.e. stillbirth and neonatal death between WB, Pakistani and Bangladeshi infants.

  41.5% of Pakistani women who had an antepartum stillbirth were Pakistani, whereas 42.5% of WB women experienced a neonatal death. However, the result was not statistically significant. H1 is rejected.

- H2. More Pakistani and Bangladeshi infants will be delivered preterm than WB infants.

  0.3% of Pakistani mothers delivered before 23.9 weeks, whereas 7.3% of WB mothers delivered between 24 and 37 weeks of gestation. Additionally 50% (n=3) of the pre-viable Pakistani infants survived, compared with 33% (n=2) WB infants. However, Pearson Chi-Square was not significant. H2 is rejected.

- H3. Pakistani and Bangladeshi mothers will have lighter birthweight infants than WB mothers

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[136] Groups were: birth outcome + ethnicity + BMI + diabetes binary + Age + smoking binary + PTB

The adjusted mean birthweight for Pakistani (mean difference of -161.508g, 95% CI [-196.96—126.05] $p<.00$) and Bangladeshi (mean difference of –197.89, 95% CI [-148.26- -247.53] $p<.005$) infants was significantly lighter than WB infants. H3 is accepted.

- H4. More Pakistani and Bangladeshi women will have diabetes than WB women.

  49% of women with diabetes were Pakistani. Pakistani women were overly represented in the categories of diabetes and gestational diabetes, while Bangladeshi women were over-represented in gestational diabetes and insulin categories. The result was statistically significant, showing associations between ethnicity and diabetes. H4 is accepted.

- H5. More Pakistani and Bangladeshi women will be overweight, compared with WB women.

  19.4% of WB women had a BMI >30kg/m^2, 25.2% of Pakistani women had a BMI < 18.5kg/m^2, WB women had the highest mean BMI (21.84kg/m^2), 44.3% of WB, 42.8% of Pakistani and 39.2% of Bangladeshi women had a BMI >25kg/m^2. The results were statistically significant. H5 is rejected.

- H6. There will be more smoking WB mothers compared with Pakistani and Bangladeshi mothers.

  21.5% of WB women were smokers. The result was statistically significant. H6 is accepted.

- H7. Pakistani and Bangladeshi mothers will have a greater parity and give birth to infants at younger maternal age, compared with WB mothers.

  59.4% of deliveries by WB mothers were parity 1. WB mothers were also over-represented in parity 7, whereas Pakistani mothers were over-represented in parity 2, 3 and 4. Additionally 14.4% of deliveries by mothers aged 16-20 and 10.2% of deliveries after the age of 36 were WB women, whereas 69.8% of Pakistani women were in ages 21-30. The results were significant. H7 is rejected.

- H8. WB mothers will book into maternity services earlier than Pakistani and Bangladeshi mothers.

  82.5% of all mothers were booked into antenatal services by 12 weeks. However, only 79.9% of Pakistani and 80.1% Bangladeshi mothers booked, compared with 84.4% WB mothers, before 12 weeks. H8 is accepted.

- H9. There will be a greater number of infant deaths associated with more deprived areas.

  81% of perinatal deaths occurred in IMD deciles 4 and 5. H9 is accepted.

- H10. There will be an interaction between ethnicity and at least one of the following: birth outcome, BMI, PTB, birthweight, diabetes and smoking.

  The analysis could not be reliably conducted using inferential statistics.

Table 27 details the results salient to each ethnicity. This shows that Pakistani mothers have the greatest number of risk factors.

Table 27: Identified risk factors by ethnicity

WB	**Pakistani**	**Bangladeshi**
Parity 1, 7	Birthweight	Birthweight
Maternal age (16–20, 30+ years)	Diabetes	Gestational diabetes
Smoking	Gestational diabetes	Insulin
BMI >30kg/m^2	BMI < 18.5kg/m^2	Booking
Deprivation	Parity 2,3,4	Deprivation
	Booking	
	Deprivation	

5.5 Chapter summary

This chapter has presented the results of the statistical analysis of secondary CMiS data, which aimed to identify risk factors for perinatal mortality in WB, Pakistani and Bangladeshi mothers. The results show that ethnicity (i.e. WB, Pakistani or Bangladeshi) is associated with different risk factors, although not all the results reached statistical significance.

No associations in ethnicity and birth outcome or PTB were found; however, Pakistani and Bangladeshi infants were shown to have a (lighter) adjusted mean birthweight, compared with WB infants. Moreover, significantly, there was an association between Pakistani and Bangladeshi women who were diabetic. Conversely, more WB were found to be overweight (BMI>25kg/m^2), 21.5% of WB women were smokers and 59.4% were parity 1, with 14.4% aged between 16–20 years and 10.2% aged over 36 years, while Pakistani women were more likely to be aged 21–30 and parity 2, 3, and 4 and the results showed less Pakistani and Bangladeshi mothers were booked into maternity services by 12 weeks of gestation, compared with WB mothers. Additionally the results showed a social gradient, whereby 81% of perinatal deaths occurred in families with an IMD decile of 4 or 5. Unfortunately, the exploratory Loglinear could not be performed due to small cell counts, once all the variables had been placed in a crosstab matrix.

Chapter 6: The lay mothers’ perspectives of perinatal mortality

6.1 Introduction

This chapter presents the qualitative findings following the FG that took place with lay Pakistani, Bangladeshi or WB mothers (stratified by ethnicity). The FG was designed to meet objective two:[137] To explore the similarities and differences in maternal health beliefs that influence health behaviours in perinatal mortality in Pakistani, Bangladeshi and WB women, through the maternity care pathway. The narrative themes have been described, and participant quotations have been provided in Sections 6.1.2–6.1.4. Participants’ identifying information was removed to maintain anonymity; otherwise, the quotations have been reported verbatim and were coded to the origins of the FG. The participants’ ethnicity has only been mentioned in this chapter, where differences have been observed, otherwise the results refer to the participants, regardless of their ethnicity. The sample structure for each FG and the FG codes are shown in Table 28. The coding framework is found in Appendix 22.

Table 28: FG sample structure and FG codes

FG	FG code	Participant ethnicity	Participant number	Coding example
1	FG1WB	WB	P1-5	
2	FG2WB	WB	P1-5	
3	FG3P	Pakistani	P1-4	FG1WB-P5
4	FG4P	Pakistani	P1-6	
5	FG5B	Bangladeshi	P1-4	
6	FG6P	Pakistani	P1-3	
7	FG7B	Bangladeshi	P1-4	
8	FG8B	Bangladeshi	P1-8	
9	FG9P	Pakistani	P1-7	

Chapter Two, Section 2.5.1 discussed the literature on health beliefs and how these contribute to health behaviour. This section now presents the findings from the lay mothers’ FG and wherever relevant, discusses the similarities and differences between Pakistani, Bangladeshi and WB mothers’ health beliefs and how these influence their health behaviour in relation to perinatal mortality. It begins with describing the characteristics of the FG (Section 6.1.1) and proceeds to present the main themes: knowledge and information of pregnancy and perinatal mortality,

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[137] in combination with the findings from bereaved mothers: Chapter Seven

attitudes and perceptions to pregnancy and perinatal mortality and experience with maternity services. These will be presented and described separately in Sections 6.1.3–6.1.4. Figure 26 shows the themes and sub-themes that emerged from the group discussions.

6.1.1 Participant characteristics

There was a total of nine FGs, stratified by participant self-identified ethnicity (see Chapter Two Section 2.5.2). The FG took place between December 2014 and January 2016, in community centres or Children's Centres located in the wards of interest (Dallow, Biscot, Leagrave, Saints, Farley, Lewsey) in Luton. The FG participant numbers ranged from 3–8 and the duration of the FG ranged from 62 minutes to 134 minutes (Appendix 21).

The individual participant characteristics from each FG are found in Appendix 21 (Tables A.3 to A.11). Participants' ages ranged from 23 to 49 years of age, and length of time spent resident in the UK ranged from 2 to 39 years. The highest level of academic achievement was master's level (reported in two of the Pakistani FG); conversely, the lowest level of academic achievement was reported to be equivalent to year eight education, also found in the Urdu speaking Pakistani group. The majority of participants lived with their partner/husband and children, and nine women reported living with extended family. Three WB women reported living alone with their children and not their partner and another three WB women referred to their 'partner' as opposed to the husband. The numbers of existing children ranged from 1–6. The first contact with their GP (to report the pregnancy) was reported ranged from 6–17 weeks of gestation[138].

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[138] It was explained that the late booking (i.e. 17 weeks) was the consequence of an unplanned pregnancy and the GP consultation was intended to discuss termination of the pregnancy.

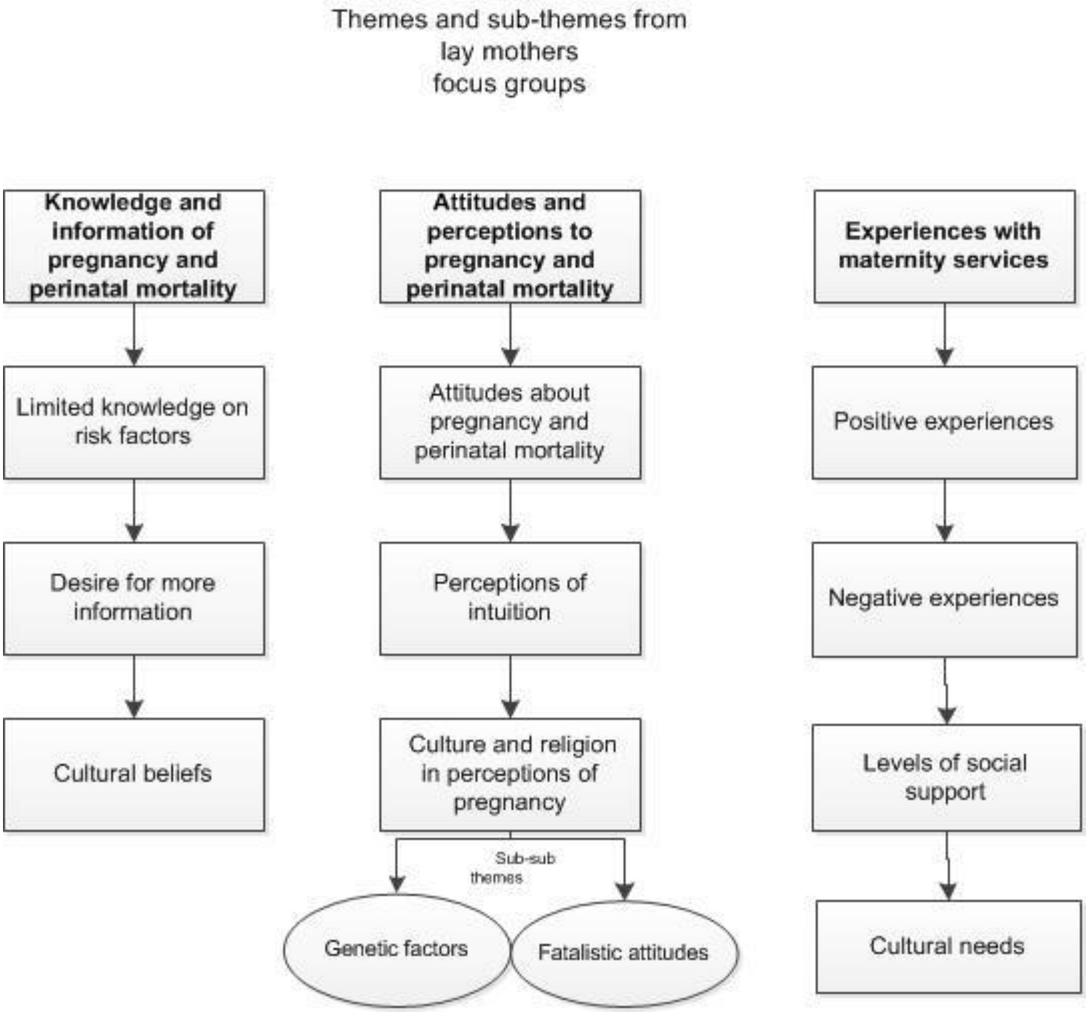

Figure 26: Themes, sub-themes and sub-sub themes identified from lay mothers' FG

6.1.2 Knowledge and information of pregnancy and perinatal mortality

In respect of the theme ‘knowledge and information of pregnancy and perinatal mortality’, three sub-themes emerged; limited knowledge on risk factors, the desire for more information and cultural beliefs. These findings represent similarity between all the mothers in the focus groups, unless differences were identified, whereby the mothers’ ethnicity has been explicitly stated.

Limited knowledge on risk factors

The mothers discussed their knowledge and their understanding of risks associated with pregnancy and perinatal mortality. This section is presented sequentially, by knowledge and understanding of risks through the maternity pathway, commencing with preconception care.

<u>Preconception</u>

The subject of taking folic acid during pregnancy was discussed in all the FG sessions, however, only three mothers were aware of the importance of taking folic acid before conception, to reduce the risk of NTDs and promote healthy neural development of the foetus. This is evidenced in the following narratives:

> I felt, well you hear in the media that taking folic acid, that is not just the first 12 weeks but the recommend that you take it 3 months prior to conception, as well …so I had been taking folic acid for 12 months before falling pregnant this time, cos I was taking it previously and I just carried on taking the folic acid and bearing in mind that folic acid is found in leafy green vegetables anyway …(FG2WB-P5).
>
> Vitamins, folic acid they say is very important - important for the baby’s mental development. Before conceiving and after, we should continue taking it, as the mother’s and baby’s body becomes stronger (FG9B-P1).

Conversely, several mothers explained that they were completely unaware of the benefits of taking folic acid at all:

> However, it [folic acid] is not something that for example for my first one that was ever discussed or, there is a possibility that you might have a child, taking folic acid or something like that … That was the thought that never crossed my mind (FG3P-P2).

> It [folic acid] is not something that for example a 16-year-old would even think about; I don't think there's that much information out there (FG13WB-P2).

However, the majority of mothers across all the FGs explained that they started taking folic acid but only after receiving advice from their GP or midwife during their first pregnancy appointment.

> You find out, as soon as you register yourself really, that is when they prescribe it [folic acid] when you take it is the first three months isn't it? (FG7B-P2)

> I started taking it [folic acid] as soon as I found out I was pregnant. I spoke to the midwife, and they gave me like a prescription to go and get erm, folic acid (FG1WB-P3)

Additionally, several WB mothers described their reluctance to take folic acid, as they were confused about health advice that prohibits pregnant women from taking medicine during pregnancy and so avoided folic acid:

> I was a bit scared taking folic acid tablets and all the tablets for pregnancy; I was a bit scared of that, just in case like, I dunno, like there are all these scary (FG2WB-P2).

> I think, psychologically I can't take any medication when I'm pregnant I just feel is better for the baby if (FG1WB-P5).

A minority of mothers explained why they purposefully did not take folic acid at all. One mother associated her mother taking folic acid with the stillbirth of her sibling and another mother explained that she was unsure how to get hold of the tablets using the voucher system:

> Yeah, everything was fine. Because my mum took folic acid and she lost her baby so you can't really say can you? Do you know I mean? There is people that take it and they have problems (FG1WB-P1).

> No, I mean I could get the vouchers for it [folic acid] because I get the appropriate benefits, but I just never, I didn't really know how to do it or how to apply for it. So I just didn't bother it seemed pointless (FG1WB-P4).

Several mothers described their experience of being unaware that they were pregnant, until the pregnancy had progressed into the later stages. This is seen in the following:

> For me I didn't know [I was pregnant], I had a fall, went to the hospital. They asked me if I was pregnant I said I don't know if I had missed my periods…They checked – I was pregnant! My mum had figured it out by me being reluctant to eat certain foods. I was happy but felt embarrassed too (FG8B-P5).

> Well I didn’t know I was pregnant, actually, I just felt that this was my first time, and I felt really sick…but I feel a kind of bit sick, and I had this sort of rash on my hand, and she said “Oh” … to be honest I wasn’t even expecting to be pregnant, even though my period was late, I just thought it would be stress, or something so I went along to the doctor’s and he said that take a pregnancy test and I just thought he probably doesn’t know what he’s talking about, but we will just take it, but I was quite surprised when I did take it and … I said to him “But I would know if I was pregnant?”, but he said to me ... “No … some don’t actually until they’re just about to give birth”, and I didn’t believe him – but that’s what my GP was telling me so for me it was a surprise, I wasn’t expecting it, and I didn’t really believe the doctor when he said he’d take a pregnancy test (FG4P-P2).

Antenatal

Several mothers described their confusion over what constituted pregnancy signs, and which symptoms might be considered an indication that the pregnancy is progressing normally. The following narrative is a good example of this:

> Well morning sickness, is one of them [symptoms] - but I think that it is seen as a negative thing, but I just had a conversation with someone, and I see it as a positive thing, it’s a good thing it kind of shows the baby is healthy, but in some cultures is seen as being negative I think (FG4P-P2).

When discussing things that might go wrong, the majority of mothers explained that they had little knowledge in respect of risk factors for perinatal mortality:

> I don’t know about risk factors... [for stillbirth] (FG5B -P1).
>
> But I didn’t know until this pregnancy that there was a lot of stuff … well basically, I never knew you could get blood clots when you are pregnant then obviously she told me they were caused through smoking (FG1WB-P3).

Several mothers explicitly discussed their lack of awareness around stillbirth. This is evidenced in the following narratives:

> I don’t know much about it [stillbirth], but it’s probably developmental, isn’t it? Whether things are formed properly whether they are affected by the weight - so yes (FG6P-P1).
>
> …because the only information that I got is after going through it … the horrific experience of my cousin going through it [stillbirth] (FG3P-P2).

When the mothers discussed their understanding of risk factors, one participant explained that she thought stillbirth was the result of being lazy:

> Those that are bed bound, lazy, lazy [when things go wrong] (FG9B-P3).

Another mother suggested stillbirth may be the consequence of taking up unfamiliar exercise:

> I think that [exercise] would only contribute to it [stillbirth] if you didn't normally do it and if your body is not used it (FG1WB-P3)

In contrast, the majority of mothers were aware of the adverse consequences of maternal smoking, drug taking and drinking alcohol during pregnancy. This is shown in the following:

> Yes but drinking and smoking. Is a big … and drugs is a big risk factor, and if you avoid that then that causes it I remember reading that. (FG6P-P2).
>
> I have always associated low birthweight; they would say that smoking in pregnancy can result in low birthweight (FG2WB-P5).

It was only in the WB FG that several participants discussed their smoking behaviour during their pregnancies:

> I probably wouldn't have given up smoking if I hadn't got the DVT because obviously they said it can cause it, erm that can happen, or be one of the main factors that cause it, so I stopped that [smoking] and I didn't go back (FG1W- P2).
>
> … I still smoke, but I've cut right down, a right lot, I use my inhaler as well and that now, so I don't, I try and cut it right down as much as I can, sometimes I have about five fags a day at the moment … I would give up if I could …(FG1WB-P5).

Tobacco consumption in the form of ST was only discussed by Bangladeshi mothers; whereby they described it as a common practice used by Bangladeshi women; although more typically in older generations.

> There's a lot [betal nut] out there … Well you know how bad it is … Well it is bad (FG8B-P3).
>
> Chewing ... chewing yes disgusting! It is more of a, it happens a lot back home, and some people would bring that back with them, and you can buy it here, but it's a lot of the older generation do it don't see many young women chewing tobacco (FG5B P1).

However, while the majority of mothers recognised it was harmful, some admitted that they craved it during their pregnancy.

> Sometimes you crave for it [betal nut] during pregnancy (FG8B-P1).

It was only in the WB FG that the mothers shared their understanding of the effect of high blood pressure having an impact on the infants' size.

> You see, my blood pressure was put down to, stress related hypertension erm, just because of the amount of pain I was in and I worked full time right up until literally, I had him, so I would get high blood pressure so it would come back down again by itself, and I would get these like, peaks of it, so I was never medicated for it, so when he came out, he just looked so small, erm … (FG2WB-P4).

All the FGs discussed monitoring of foetal movements as a sign of the baby's wellbeing. This is seen in the following:

> I think they [staff] do tell you though, if you feel any kicking or movements, or if you don't feel any movements then do notify us. And I will be honest – I have used the system when it comes to that especially when they are so big, and there has been days when I haven't felt anything … (FG3P-P2)

<u>Postnatal</u>

Several mothers discussed the benefits of breastfeeding; however, one Pakistani mother concluded that there was no added benefit to breastfeed over bottle-feeding:

> So I compare the two, and now she is doing the same as what he was doing at the same age. But he was bottle-fed, and she is breastfed. So to me I cannot see the difference, I think it is whatever the child likes as long as they eat and drink and are healthy that is all that matters (FG4P-P1).

Several Pakistani mothers described the conflict they experienced with other family members around their decision to breastfeed. This is seen in the following:

> I don't live with my in-laws … but … I had my mum to help me and she did give me lots of advice and I wanted to breastfeed and she didn't want me to breastfeed and that was a real battle. … I think it was just her generation – she was educated to bottle-feed, that was back then you know? [Laughing] (FG4P-P4).

Despite the mothers having been provided health information that their babies were supposed to sleep in the supine position, several participants explained that they didn't believe in the safety of the baby lying on their backs, and they described placing their babies 'on their side', so in the event that if their babies vomited, they would not choke.

> I have always laid him on his side, but to me, that was more because he was more a sicky baby, I always thought, if he was on his back and he was sick I'd rather have him on his side ... despite the guidance being laying them on their back …(FG2WB-P5).

Moreover, one Pakistani mother explained how her mother-in-law would try and sleep the baby on its stomach:

> But I won't allow because I have read books on it [sleeping position], so like you can't put a baby sleeping on his belly, especially when it's not rolling. But they [mother-in-law] try to do it, and I try to grab hold of her but I am criticised for that, and I have had quite a hard experience (FG4P-P1).

A large number of mothers, regardless of their ethnicity, discussed co-sleeping with their child, which they explained made feeding through the night easier and enabled the participants to have more sleep – although they were aware of the risks. This is seen in the following extract:

> Co-sleeping, I was aware of that because I did a risk assessment, I was not a smoker I didn't drink and I think that where I had had a C-section I just needed to rest and unfortunately I didn't have anyone around me, they were literally bringing her in to feed her, but I do remember telling my midwife, not my midwife sorry my health visitor, and is getting reprimanded quite badly (FG6P-P1).

The majority of mothers described how their previous experience of pregnancy informed their current understanding and influenced their health behaviours in subsequent pregnancies. This is found in the following extracts:

> If you have had children before I think that it is easier because you know what's right (FG3P-P1).

And mothers who had conceived more than once discussed that while each pregnancy was similar, they were also very different and that although a previous pregnancy experience gave the mothers knowledge and insight into symptoms during pregnancy and labour about what to expect from services, each pregnancy was indeed unique, that participants remain inexperienced in regards to the current pregnancy.

> But the second is different from the first. I was quite scared with my first. Lots of pain, very long labour. Hospital time, everything was different (FG9P-P2).

> Everybody's different, everybody's had different things everybody's pregnancy is different, and you experience your pregnancies

> different; I've noticed that my two pregnancies were slightly different (FG4P-P5).

The mothers described how family and friends provided knowledge and information about pregnancy and risk factors:

> My elder sister-in-law told me [about pregnancy] ...Yes – once they know that you are pregnant … But before pregnancy, there is nothing [information] (FG8B-P2)
>
> I think for me again it was because I had somebody at home to tell me, and she said you don't really get looked at until about 12 weeks (FG4P-P3).

Desire for more information

The sub-theme of 'desire for more information' emerged from the main theme. The majority of mothers expressed the desire for more pregnancy-related information:

> Because you want to know it doesn't matter whether it's your first or your sixth, or your seventh you still want to know what's happening to your baby on a daily basis (FG3P-P4)
>
> When you are really keen you want to know what's going on [laughing] (FG3P-P2).

Similarly, the majority of mothers expressed a desire for more information on risk factors for adverse outcomes, including stillbirths. This is evident from the following:

> I would say more awareness on stillbirths. What to look out for it doesn't matter whether you were born or bred here or whether you came from you know somewhere else; I just think you know there is just not enough information on stillbirths and what to look out for (FG3P-P1).
>
> But I think there needs to be more awareness of what to look out for, like is your baby moving or not? I think there is not enough to stillbirths out there (FG3P-P1).

Moreover, the mothers described having to be proactive in seeking pregnancy-related information, in order to be properly informed. This is seen in the following narratives:

> … because obviously I had moved from [city] and not knowing anything we did have to do a lot of our own searches to see what was there (FG6P-P1).

> I had to make a list before I went to each appointment about everything that I wanted to ask. And then I took it with me because every time when I go I forget what I wanted to ask (FG8B-P3).

> I did research off my own back, rather than someone telling me that it is this, this, this and this, because there is no cause for miscarriage really … (FG6P-P1).

They also described a large amount of the pregnancy-related information being provided in leaflet format, by the midwives. The responsibility was given to the expectant mother to read the material provided. This is evident in the following narratives:

> I think that they [midwives] give you more leaflets instead of talking with you and making you understand what is going on but they say go and read it (FG5B-P3).

> I think it depends on your midwife as well, you know, like when I came here, I was bombarded with so much stuff [leaflets], you know, I wasn't told any of this stuff before (FG2WB-P1).

> I think the dependence is on you reading the literature, isn't it? (FG2WB-P4).

The mothers explained that it was not always easy to find the information:

> It [the information] could be better, even I think that educated or not educated; I speak English and I couldn't [find information] … You have to really go out of your way to look for what you want (FG6P-P2)

And they discussed obtaining pregnancy-related information from several sources: paper-based leaflets, 'Emma's Diary', 'Bounty Pack', and the internet. This is seen in the following:

> What I really loved was the booklet that we got … Emma's diary I loved that. Every pregnancy I had I went through that I would read as my bedtime reading I would read it to my husband and keep reading, reading … so I really appreciated Emma's diary and the Bounty packs that was great (FG4P-P3).

> I read like a lot of Bounty books, I think they were really useful (FG3P-P2).

> Oh, I know, but I did it [Google'ed health information] anyway! (FG6P-P1).

> Yes is a good website I think it's American, no is not an App it's just a website and weekly, if you sign our weekly they give you updates on what your baby should be doing. So I used to think, is my baby doing that? (FG7B-P2).

Cultural beliefs

Several cultural beliefs emerged from the FG discussions, which influenced women's health behaviour in pregnancy. All the mothers discussed the value of eating well during pregnancy, although a minority of mothers thought that they needed to eat more. This is evident in the following narrative:

> But if you're eating healthily and you don't have an eating disorder I think the baby just takes what it needs, I also think that you know, that some people have the ideology that I am pregnant so I have to eat double the amount of food (FG3P-P2).
>
> I don't know about healthy I just eat more! (FG8B-P1).

One Pakistani mother explained that she believed babies ought to be 'chubby' and that this was a sign of good health:

> Yes, they [healthy babies] should be fat and chubby – everyone wants a fat chubby baby. Just feed, feed, and feed. Feed them loads (FG9P-P2).

The majority of the cultural beliefs involved guidance on prohibitive foods, which are thought to have detrimental consequences during pregnancy. For example: bone marrow, beef, papaya, pineapple and tamarind. This is evident in the following narrative:

> For the first three months, the midwives tell you not to eat the dairy foods too. They tell you not to eat certain foods – uncooked meats (FG3P-P3).
>
> Calcium from bones isn't it? What do you call it ... you know – the bones they have lots of calcium in it … Bone marrow … (FG7B-P3).
>
> I don't know if that's medically proven or not? Beef? ... she said lamb brain is not allowed to eat during pregnancy (FG7B-P1).
>
> Don't have pineapple – otherwise you miscarriage and don't have tamarind – Yeah – tamarind and pineapple (FG8B-P3).
>
> Papaya – yes. They say that it kind of dries you out … I have always been told not to eat papaya. And liver. Because it has so much vitamin A, and it is not good for your baby (FG9P-P2).

All the Pakistani mothers described a cultural therapy of buttermilk (a warm milk drink made with butter or ghee), that is purported to help the baby 'slip' out of the participant's birth canal more easily and make the birth easier.

> It's [buttermilk] an Asian culture thing, where people think that if you have buttermilk, your baby will slip out, but I'm sorry I don't believe in that (FG3P-P1).
>
> … [laughing], drink that [buttermilk] and your baby will slip out! (FG4P-P2).

The Pakistani mothers also described health promoting foods during pregnancy such as *'punjari'*[139] although they were unclear as to the precise ingredients of the food:

> My mother made me a whole box of it! [punjari][Laughs] – it was going to stay in the cupboard, I couldn't eat it, but it was like yes have some of this … [Laughs] (FG6P-P1).
>
> And they make loads of it [panjari]! And they want you to have it every day, forget the fact that is highly calorific, and God knows what is in it is full of butter and sugar (FG6P-P3).

Furthermore, the Pakistani and Bangladeshi mothers described further beneficial cultural beliefs, such as eating fish to promote the production of breastmilk, milk with raw egg for backache and chicken soup for strength. This is seen in the following narratives:

> But I don't like to eat a lot of fish anyway; I don't have any problems with breastmilk … My son was about seven months and my breastmilk was reducing … but my mum was like have a lot more fish it will help … (FG5B-P2).
>
> Mmm, my mother-in-law said to me take raw egg with milk and this helps your back pain (FG4P-P5).
>
> But I do know that my mum and my sister-in-law is prepared like the chicken soup I think it is? ... which is seen as being strengthening, especially after when you start to have your contractions and things like fennel seeds and all sorts of things that they grind up … [Laughing] (FG4P-P2)

The Pakistani mothers explained that turmeric was believed to have antibiotic properties

> Turmeric and milk as well, because that has healing properties it is supposed to help once you had the baby (FG6P-P2).
>
> Yes it [turmeric] is an antibiotic (FG6P-P2).

In one Bangladeshi FG[140] the women described the practice of being tied up around the hips and lower abdomen after birth. They explained that the belief was it stopped the vagina from falling out.

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[139] Punjari is a sweet dish traditionally made from: whole wheat flour, chickpea flour, semolina, dried coconut, gum, white poppy seeds, almonds, pistachios, powdered sugar, fennel seeds, dry ginger, cardamom and ghee.

[140] FG5B

> My mum had it done when she was … The first two I did it, I tied myself up, because it helps … It helps in the sense that once you tie yourself up you are able to carry on do housework and look after the children and the in-laws … (FG5B P4).
>
> Yeah, when you have a baby, they tie you round your hips … [gestures] because they say that your vagina area is going to come out, so they tie you up [laughing] (FG5B-P3).

Additionally, there was a belief described by Pakistani mothers[141] that pressing a date on the roof of the baby's mouth would help regulate its blood sugar levels;

> … but we just squished a tiny bit of date … and sometimes just sometimes and especially if you have that diabetes during pregnancy your baby is dependent on sugar anyway isn't it? So apparently it does help (FG4P-P3).

It was also explained that using henna while pregnant was thought to result in an orange baby;

> … henna so culture says don't put henna on when you are pregnant but religion doesn't say anything about it … maybe somebody by accident got henna on their hand and then they become anxious … Oh my god I got henna on my hand my baby is going to be orange … [Laughs] (FG8B-P1).

There were some differences between the FGs. Notably there was no reference made to health enhancing beliefs or health harmful food beliefs, in the WB FGs. Only one WB FG[142] discussed cultural beliefs, limited to to the use of charms. This is seen in the following:

> … of my friends … they swear by the amber bracelets, for teething and things like that they say about amber bracelets, you put them around the ankle, most people put them around the ankle, of babies and they are supposed to assist and reduce the symptoms of teething (FG2WB-P4).
>
> I heard about the key, you know, if it swings one way it is a girl and if it swings the other way it is a boy … there is another one with the keys, if you drop the keys on the floor and they land one way it is a boy … (FG2WB-P3).

About half the Pakistani and Bangladeshi mothers made reference to their preference for scientifically-based therapeutic practices, in contrast to cultural beliefs, seen in the following:

> There are a lot of old wives tales … And they tell you do this, take this, you'll have an easy pregnancy … you have a easy labour and, I'll be honest, I am just sort of, just more not logical, but I like to be aware of the facts, so I actually do my research, so what medication

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[141] FG4P
[142] FG2WB

> will help for what reason, and I'd rather not take anything extra than what is necessary (FG3P-P4).

Moreover, within the narrative, it is evident that while the majority of Pakistani and Bangladeshi mothers were aware of the cultural beliefs, there was mixed opinion whether women engaged with the beliefs or not. This is seen in the following extracts:

> I don't know but I did listen to our parents, only because I enjoyed it as well, I enjoy the pampering and I enjoyed joining in with those things. I have still got this thing that my mum sends me, my baby is seven months old and I still haven't finished, but just to please them I have still been doing them, and to not hurt their feelings. But if I thought there was any harm to my baby I would not take it, I would not take random potions and I guess even in this … In the west you still there is stuff that you are supposed to eat towards the end (FG4P-P3).
>
> I haven't tried it [turmeric and milk], but I think I would consider it because even now I feel quite reluctant, having been on antibiotics, and touch wood, he has been okay, but you know I would rather try herbal medicine than to go for something off the shelf, and if it doesn't work and I have to go to the doctor's then that's fine do it (FG6P-P3).

While participants' cultural beliefs influenced their behaviour in earlier pregnancies, the mothers were less complicit in following the suggestions in later pregnancies. One FG[143] (Bangladeshi mothers) had a quick-paced conversation, which was interspersed with laughter where most of the group contributed their opinions regarding cultural beliefs or behaviours. It included 'going out after sunset' (P1), not going to the zoo, for 'fear of evil spirits' (P4), 'to drink coconut milk so that the baby's eyes will be light!' (P5), drinking milk to make the skin fairer, while butter makes it 'nice and moist' (P2) and henna causes large birthmarks (P1).

6.1.3 Attitudes and perceptions to pregnancy and perinatal mortality

There were three sub-themes within the main theme of attitudes and perceptions to pregnancy and perinatal mortality. These were attitudes about pregnancy, personal intuition and culture and religion in perceptions of pregnancy.

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[143] FG8B

Attitudes about pregnancy and perinatal mortality

The majority of the participants described their fear and anxiety during their pregnancy. This is evident within the following excerpts:

> I was scared, and I was scared about the pain and that I was scared that I was going to be a mum (FG2WB-P4).
>
> With my daughter, I did have anxiety problems, panic attacks, vomiting, so that was the worst pregnancy (FG7B-P1).

In particular, it was evident within the narratives that participants felt especially anxious about the potential complications that may occur during pregnancy or at the time of delivery. This is seen in the following extract:

> Well before I fell pregnant I was really scared. Because I had heard so many stories and one of my friends, she had a stillbirth just about a couple of years before that, so that thing that scared me, one of my sister-in-laws … I have witnessed a lot through nieces and nephews … I was so scared to have a child myself … (FG7B-P2).

All mothers described concerns about the wellbeing of their unborn child, in addition to themselves during pregnancy and childbirth:

> … and you think the safety of my baby… And I am fine, I think you are thinking more about a baby at that time so long as we are all okay … and all the other issues drown out (FG7B-P2).
>
> But it’s always in your heart what if I die? Not even the baby, I never even thought about him … If anything happened to me … (FG3P-P3).

The narratives revealed that the majority of women typically held idealised attitudes toward their first pregnancies:

> With my first one … I just thought it would be easy, and nobody said to me it was going to be painful and that you’re going to have so much sickness, no one ever said about the horrible things (FG5B-P2).
>
> I thought it was going to be a walk in the park, I’ll be honest, erm, but that was prior to having my daughter (FG6B-P1).

Other women made references to the normalisation of pregnancy; a natural human process and normal life-event. This is evident in the following extracts:

> And it [pregnancy] is not an illness – I once heard somebody say that pregnancy is not an illness, and that’s when it got to me and I thought – no it’s not an illness, you have to get on with your life and there something good to look forward to the end, so with illness you don’t

> know when it's gone and, but this does and when it does you have something at the end so … You just get on with it (FG4P-P5).
>
> I think I just knew it [pregnancy] as a normal thing like you are just pregnant (FG2WB-P2).
>
> I think before pregnancy I didn't really know what I was going into at all, I didn't really ask anyone I just didn't really think about it – it was just something natural (FG4P-P3).

The majority of women described how they perceived their experience(s) of pregnancy and their emergent identity as a mother. They explained how it changed their status as a woman in society and their roles in life. However, while this was verbalised more explicitly in the Pakistani and Bangladeshi FGs, it was also described in the WB FG.

> I think that when you have children they [other family members] have more respect for you, you know, when they see you raising your children and how you raise children, if they are happy with it then obviously the respect grows a bit more ... (FG5B-P3).
>
> Yes it [your role as a woman] changes (FG9P-P2).
>
> Wow! So much respect … For all these women … (FG4P-P6).
>
> [Pregnancy] is such an amazing I love that feeling … It's so exciting you are going to be a mum you can't believe it … (FG7B-P2).

Perceptions of intuition

A further important sub-theme that emerged from the narrative was that of perceptions of intuition. Many mothers (regardless of their ethnicity) explained how they had 'gut feelings' and sensed when something was not right with their pregnancies. This is found in the following extracts:

> I hope nothing's gonna go wrong, but it's like with your gut feeling straightaway doctor or midwife or hospital and get checked that up, especially if you know that something is wrong you're usually right as well … (FG3P-P2).
>
> If you had experience of previous pregnancies, you know sometimes what's wrong, you know what's right and what's wrong, and you also get a feeling inside as well when you know that something is not right and you should always go with that feeling (FG3P-P1).

In addition to their personal intuition, the majority of women identified physical symptoms that might suggest something was wrong; however, they also understood what was unusual for them during their pregnancy but may have been considered normal for other women. This is seen in the following:

> I say bleeding, but I know so many women who have had bleeding throughout their pregnancies but have had healthy babies, but er, for me – because I never had any bleeding at all in my previous pregnancies, there was the tiniest tiniest spot of blood in my last one, that to me, I just straight away knew that something was wrong, even though it was only the slightest amount, so for me, I sort of knew it was the end (FG2WB-P5).

Culture and religion in perceptions of pregnancy

Pakistani and Bangladeshi mothers spoke about the preference for a boy child. They pointed out that this preference was driven by the cultural expectation that boys look after parents in their older years, through economic support, whereas girls marry and leave home and support their in-laws. However, they acknowledged that while this attitude existed within the wider community, conversely most mothers expressed the desire for a female baby or were unconcerned about the baby's gender. Furthermore, a small number of participants across separate FGs spoke of the personal distress that the gender preference attitude caused them at the time of their pregnancy.

> And they addressed me in a Bengali way [Sylheti] Meaning that you got the son, that I got a boy, that is something that they get excited about! I personally think, nowadays I think that girls are much better for the parents. They do more for their parents than what the boys would do (FG7B-P1).

Within the sub-theme of 'culture and religion', a number of sub-sub themes emerged. These were awareness of genetic factors and fatalistic attitudes.

Awareness of genetic factors

Each FG discussed the understanding of genetic influences on adverse birth outcomes. Pakistani, Bangladeshi and WB women spoke about how they believed specifically, Down's syndrome was heritable, but they did not discuss genetic reasons, showing any further understanding of the syndrome. The following extracts show this:

> It's [Down's syndrome] in your genes as well, isn't it? (FG3P -1).

> Back in Bangladesh, like quite a few members of my family are disabled and they have Down syndrome, and all of that, so you do … You do think it could become passed down (FG5B-P1).
>
> Yes there is a higher risk, because my [inaudible] is married to my cousin, and we got problems (FG8B-P4).

Participants in the Pakistani and Bangladeshi FGs also discussed how consanguinity might contribute to adverse birth outcomes. The narrative extracts below highlight a good awareness of genetic anomalies related to cousin marriages.

> They [cousin marriage] tend to have a Down syndrome I know a couple that have a Down syndrome baby, and they are related, it is to do with genetics in our religion it says try and avoids to marry to close in your family … It's to do with the genetic makeup it's like there's a chance of them becoming physically or mentally disabled … Especially in Pakistani culture, lots of Pakistanis get married into related. In our culture [Bangladeshi], we do as well, but it is not as much as them (FG7B-P2).
>
> Yes my husband's sister, this is back home because he's got stepsiblings so his sister is married to his cousin, his first cousin so we made sure that she had a blood test to make sure she wasn't the carrier, so yes … it is first cousin marriage and she has lots of epileptic fit and she needs a bone marrow transplant to overcome that (FG6P-P1).

Several Pakistani and Bangladeshi mothers described how staff assumed that they were in a consanguineous marriage. This is seen in the following:

> Yes if something happens they automatically think that it is related to your husband and that you are related to your husband (FG8B-P5).

Women in one of the Pakistani FGs discussed how they believed there was a high rate of consanguineous marriages in Luton, due to the smaller numbers of Asian residents in the town, compared with other larger cities with greater populations of South Asian settlers. Additionally, they stated that many of the migrants in Luton originated from a specific region in Pakistan (Kashmir), and this was thought to explain the high rates of consanguineous unions locally.

> Yes, I speak to the mums in the other groups and they got married to their cousin whether it is second or third or whatever and they all sort of lived on the same road, it's just seems like that which seems more prominent here, it probably happens in [city], but because [city] is so much bigger you don't notice or see it as much … (FG6P-P1).

> I think so. Because the [town] community it appears to be from a certain area of Pakistani and they all seem to know each other (FG6P-P1).

Fatalistic attitudes

The majority of women, regardless of their ethnicity, demonstrated fatalistic attitudes to experiencing adversity in pregnancy. They explained that they believed adversity was down to fate or God's will, however, from a religious perspective, it was only Pakistani and Bangladeshi participants who made direct references to God and God's will.

> Yeah, yeah, to be honest, I think that is either meant to be or it's not meant to be, do you know what I mean? (FG1WB-P1).
>
> First time, they told me they do the test at this many weeks, to see if everything is ok. That it was my choice. But you know we believe whatever is from God. God willing (FG9P-P1).
>
> Yes we do think like that [God's will] God says if you try you will get, but for example, if you have the flu, you can't as God's done that. And that because it is from God, we are not going to take anything for it – but we still do take medication for it (FG9P P4).

6.1.4 Experiences with maternity services

Four sub-themes emerged from the main theme. These were: positive experiences, negative experiences, levels of social support and cultural needs.

Positive experiences

The mothers described both good and bad experiences with the local maternity services. Most women expressed positive experiences and opinions of the maternity services.

> I have had three children here … and I had good experience ... And I have lost three children here … I have had good experience … I did definitely prefer the support they used to get when they came to your house … (FG3P-P3).
>
> But they have been brilliant, and they said "You need to come" and they put me on a monitor until I am satisfied (FG3P-P1).

A minority of non-English speaking Pakistani mothers described how maternity services had attended to their language needs very well. `

> They do give a lot of information, they ask. I think that it is become so multi-cultural that when we do go to the midwife, there tends to be two. One of them is very approachable for us, one maybe English, and one Pakistani, or Bangladeshi. They can understand our language. Whenever I have gone, there have been two, one of which was Pakistani. If I wasn't comfortable in speaking English, then I could speak to them in my own language (FG9P-P1).
>
> They do ask, when you fill in forms, they do ask which language you would prefer. They do offer help and ask about your home language (FG9P-P3).

The majority of mothers recognised that their pregnancy experience was influenced by the level of rapport that they established with maternity staff, especially the midwife that delivered the baby. This is seen in the following:

> Your midwife should be friendly – I went one time the baby wasn't moving, I went in before my labour time and I think I saw a senior midwife, but they weren't very friendly, but I had another midwife who was very nice (FG4P-P5).
>
> My first one – I was really lucky to have had a really good midwife – she was with me throughout my pregnancy, right through until delivering the baby and taking me up to the ward. She worked extra hours to take me up to the ward … (FG8-P1).
>
> It [the midwife] makes a big difference it really does, just to have someone there that you know (FG8B-P1).

Negative experiences

A number of Pakistani, Bangladeshi and WB women reported negative experiences of maternity services. One Pakistani mother explained that she experienced long delays before the maternity services made contact for her first appointment.

> I've always found that I've had to chase them up, for them to get in touch with me to say, you know what? I am pregnant you need to commandeer your notes or whatever because usually, they say they will contact you in a couple of weeks but you are normally waiting 4 to 6 weeks before anybody contacts you, so you are thinking is there something wrong? Have they taken me off the record or whatever? (FG5B-P3).

Another Bangladeshi mother described how she felt that the maternity nurses were cold and not as understanding as the midwives.

> I remember asking them to bring the baby to me because they wouldn't let me leave the bed … But the nurse comes and says "When you get up and do it yourself" – but I said "I can't because I've got a catheter stuck up inside me", and she said "Oh, okay then … fine", then she brought my baby to me, and you know what? Then they told me not to keep the baby in the bed … Some of the midwives are okay, and they say "Don't worry about it, just ignore them", but the nurses … they can be quite cold not so understanding (FG5B-P4).

A minority of mothers explained that they did not feel that the HCP gave adequate explanations around the screening tests, to allow women to make informed choices:

> Like the people I know with Down's syndrome test, like I didn't opt in for it, but like my friend kind of explained it more than the midwife or the consultant or anyone else did. They [staff] just kind of expect you to know I think (FG2WB-P1).

One mother felt that the health visiting (HV) service was very critical:

> And I was holding [name] like that, she [HV] said "You need to support her head like this" … And I said "I am, my fingers are bare around her head", and she really upset me and my mother-in-law. Because I was living with my mother-in-law, and my mother-in-law was saying "Don't worry, don't worry" … they [HV] try and put you down, and I was a bit upset, but then I sort of snapped myself out of it … (FG1WB-P2).

Moreover, other women described how inaccessible the health visiting services were:

> … you have to go and get the baby weighed, and that I found a bit difficult because I had quite quite heavy bleeding during my last labour and then was having breastfeeding issues and at that time if you've got other children as well, you don't want to really … want to be taking your little baby out to another centre in the community. I remember I had it in December when there was snow everywhere and that I found though very difficult (FG4P-P3).

The WB mothers described situations where they did not feel that they were listened to. One WB mother spoke about being forced to breastfeed despite having blisters on her nipples; another participant explained how the midwives did not listen to their pleas of being in pain.

> They [staff] did try and pressure me into doing it … and I had blisters and it just wasn't working out right … they were still pushing me to do it, I carried on and I ended up getting more blisters and it was just so painful (FG1WB P1).

> Yeah…like I was 8cm dilated, and they are telling me, "Oh, no you are not in pain", like trust me I am, [laughs] I nearly had my boy on the toilet [laughs] (FG2WB-P1).

The majority of mothers described long waiting times to see HCP at the hospital, which for one mother was a problem since she was breastfeeding.

> Yes mine was consultant led, but it was just the timings … you would spend hours and ages … That they're in the waiting room, that's what I didn't enjoy at all, I know it is the way that it is but the waiting time was ridiculous (FG6P-P3).
>
> Well, I didn't go. You have to feel right within yourself, you have to feel healed for you to be able to move because you're taking this baby out and if you're not feeling right yourself, and like you said, it can be a two-hour slot so you could be waiting … And I thought she breastfeeds every half an hour so what am I gonna do? [Laughing](FG3P-P1).

One non-English speaking Bangladeshi mother felt that the HCP were not as attentive to the Pakistani or Bangladeshi women as they were to white women using maternity services. This is seen in the following:

> What they're trying to say is that where they do ask the help, I may try and explain something, and they do understand it, they do pick it up … That is quite good, but they feel that because the Asians they don't put that much attention towards them. That's what they said … they feel that they're not really bothered about them because they are Asian. They are saying that there is a white person next to them, and then they help them but while she [Bengali mum] is calling for help they [staff] are not attending to her ... they say that if they knew how to speak [English] they would have said more … They would have said that you are not helping me you know? … They would have stood up a bit more been a bit more assertive (FG7B-P1).

All the mothers believed that not being proficient in the English language was thought to be a disadvantage for non-English speaking women during pregnancy and when using maternity services. It was also believed that a good command of English provided women with more confidence in communicating their needs during their pregnancy and while using maternity services. This is evident in the following:

> You are just a bit, what shall I say disadvantaged, that's the only thing really because language does give you a lot of confidence being able to speak the language – but if you don't have it you know what you want to say within your own language but she can't and at that moment in time, if you don't say it and it loses its value doesn't it? (FG7B-P1).
>
> And if you don't speak the language and if you don't know you would never be made aware of that, and if you don't see it or you're not told about it, I can imagine how hard it would be for them [non-English speakers] (FG6P-P2).

However, in this next example, the mother sensed a change in the attitude of the HCP, once they realised the lady concerned could speak English well.

> I think that it is because, at one point I did think that one woman did discriminate against me, I think I did say something to her but I can't quite remember what it was and she probably realised that she did know how to speak … I'll be a bit more careful with her that's how I felt with her because of her behaviour … It changed towards me … But I think it's because I can speak proper English and I could tell, look I can see what's going on, you know, why are you being rude? She did change a bit (FG7B-P2).

The other Bangladeshi mother explained how she was ignored and felt that her inability to speak English resulted in her being disempowered and feeling discriminated against, resulting in her needs not being met.

> So basically, after the baby was born she was vomiting, and she was pressing the bell and nobody was attending to her as she had vomited all over the bed, …and she said that was a horrible experience for her ... they are saying that because of their culture they are not – you know how like for example if you are outspoken with your English, you can stand up for yourself, that kind of thing. They felt a bit … discriminated against because that they looked at others and that they weren't getting the attention that the staff were giving to compared to others around. So they did feel that because of the lack of language, and their inability to speak out that they weren't given the quality of service … And that she wasn't getting it … (FG7B-P1).

One Pakistani mother described being offended and felt that she had been pre-judged as not being British or educated because she wore a hijab:

> I think that something that automatically if you're from a certain background you are automatically judged on that background than you are, just because you having a child because you may want to have a child, it is not because someone pressurised me to have a boy, it is not because I have nothing else to do with my time … I get a bit offended; you know they do asked me "How many years have you been in the country?" just because I wear a headscarf. I was born British (FG3P-P2).

The majority of mothers also described being discharged home too quickly after the delivery. They explained that they believed this was a consequence of the maternity department at the hospital being short of beds.

> Nowadays they discharge the mother straight away but before they used to keep the mother for a few days for observation regardless, but now the babies go home straightaway … But the next day you

> come back because she's got all I don't know means … But I don't think they current thoroughly check you (FG7B-P2).
>
> It is disgusting, they send women home on the same day now, and if you and the baby is healthy then they say right, you are all right to go home then (FG1WB-P1).

Levels of social support

The mothers described their experiences of social support that they encountered during their pregnancies. All the mothers had support from family and friends during their pregnancy. However, the extent to which this occurred and who was involved differed according to the ethnicity of the women in the FG. For example, the majority of the Pakistani and Bangladeshi mothers received support from their mother-in-law and spoke of sisters or sisters-in-law in addition to their husbands who also supported them during their pregnancy. This is seen in the following narratives:

> I had my mum and my midwife was great, and I had my sister-in-law who had her baby; he was nine months old by then so I had a lot of advice from her so it was mainly friends and family (FG6P-P2).
>
> Mine [support] was my husband, my sister and my antenatal class. I really liked them, we still meet up, and my yoga teacher because I did postnatal yoga and that really helped, because she was able to relax me a bit and calm me down, she was really good (FG6P-P1).

The following narratives demonstrate Bangladeshi fathers getting involved in their wife's care.

> My partner, now he does everything … He absolutely does everything from the cleaning to the cooking, and I absolutely love it! (FG5B-P2).
>
> Yes, they [husbands] want to get more involved, they don't distance themselves or anything … (FG5B-P1).

WB participants confirmed that they were supported by their husbands or their friends, in contrast to their mother-in-law:

> Well the first, no, it was only me and my partner, my parents are dead, so I have no family, but on the first one he was here, and he was there, and he did support me, but this one he doesn't live …. He lives in [town], so this has been a lot harder, and I rely on my friends obviously a lot more than … but I can rely on him so …. (FG1WB-P5).
>
> I don't know what I'd done without my other half in this pregnancy he has helped me out so much (FG1WB-P2).

Some mothers described a lack of support from HCP during specific experiences in their pregnancies. Specifically, several participants reported a lack of support at the time of (an earlier) miscarriage. This is shown in the following excerpt:

> You don’t get that support; you don’t get that support either because I had a miscarriage over a weekend. I went on the Friday bleeding … And then they wouldn’t even do a scan because there were no doctors there apparently for the scanning machines or whatever … And they told me to come back on Monday, but by then I have lost the baby to what was the point of that? That was no help at all (FG5B-P1).
>
> Yes when I first moved to [town] … Actually had my second pregnancy in [town] as well, and I don’t think that I have the support that I needed (FG6P-P1).

Conversely, a Bangladeshi mother described a flexible and supportive service in a neighbouring town that she had to access in an emergency at the time of a suspected miscarriage – but when she returned to the local area, she was told she had to wait ten days for an appointment:

> Before I had my daughter I had a miscarriage, but I was in [town], I was staying with my mum and the spotting and stuff started and I had to go to A&E because obviously I had to register there … They said “Actually if you do have any problems you can come in the next few days and if the bleeding gets more and if you are still in [town], then we can do a scan to confirm” … Because I was like five weeks and they can’t do a, they can’t get a heartbeat then, so they said “Come back next week and we will be able to see if there is a heartbeat or not” … And then by then, I had returned to [town], and I called the early something unit. And they said to come in, that they didn’t have an appointment for ten days (FG5B-P2).

Cultural needs of mothers

The Pakistani and Bangladeshi women described their specific cultural needs during their experiences of using maternity services. These included being seen by female staff, modesty and being visited by large numbers of family members while in hospital. The majority of mothers stated a preference for attending female staff (i.e. doctors or midwives); however, some were more affected by being treated by a male than others, especially Pakistani and Bangladeshi participants.

> There was one thing. When you were pregnant, sometimes a male would see you. It affects us religiously (FG9P-P2).
>
> This time, they wanted to check if the uterus was open or not. He [doctor] asked – he was a surgeon. He said it was an emergency C-

> section. He said if I didn’t mind. I was thinking about it, but he said that I had to make the decision straight away (FG9P-P2).

Several mothers explained that while female doctors were preferred, male doctors were acceptable if it was urgent or no other suitable female doctors were available:

> With me there was no other doctor available at that time. So only he could do it (FG9P-P1).
>
> But it is what you are comfortable with … but if it came to worst case scenario, there isn’t available, or you can have a male doctor because … but you just prefer women … (FG5B-P3).

However, one Bangladeshi mother also explained that she found that the hospital did try to accommodate her wish to have a female doctor, but she found most senior doctors were male. Therefore she explained that Muslim women needed to prioritise what was most important.

> I think that when it comes to surgery, and things like that. It is a bit more difficult, erm, which is what I found … but especially if, you want experienced consultants and doctors, are male, to be honest with you, so you have to weigh up what is more important to you (FG5B-P3).

Additionally, another mother explained that she was more comfortable with the male consultant because she had more confidence in him.

> I had two consultants. One was a male, and one was a female … I didn’t have any confidence in the female staff … I spoke with her, she freaked me out (FG5B-P2).

One Pakistani mother described how an emergency medical intervention performed by a male doctor was found to be so embarrassing to both her and her husband, that her husband felt traumatised so much he did not want to accompany his wife to the hospital during the next pregnancy.

> With my first birth it was really difficult because there was only one male doctor there in the whole maternity department that day and my waters had to get broken by a man, while my husband was in the room and that was the most uncomfortable I have ever had to go through with my husband there … because he [husband] was so traumatised he didn’t come with me second time (FG3P-P1).

Within the same FG, another Pakistani mother also shared her embarrassment of having a perineal repair which was performed by a male doctor while her husband was in the room;

however, she believed that male doctors were more experienced than female doctors undertaking medical procedures:

> Well I'm talking about the females and were talking about exactly that you been stitched up by a male, and their husbands have been in the room, and they have cringed, and you know, is usually the male doctors who do those things, don't they? They are much more experienced, they seem to do the hard bits [laughing] (FG3P-P2).

Conversely, other Pakistani mother explained that they did not mind male doctors attending to their care needs.

> Like it [being seen by a male doctor] just didn't bother me like, I never really thought, oh my God he's a male doctor, if they are able to help me then help me by all means (FG3P-P3).

One mother explained that being treated by a male doctor was permitted in Islam;

> Medically and Islamically, as a Muslim, we can have a male doctor there (FG5B-P2).

In the context of parents attending antenatal classes, a minority Pakistani and Bangladeshi mothers explained they would prefer if the class were wholly female since they were not comfortable discussing personal issues in the presence of other men and that perhaps this explained why few Asian women attended antenatal classes:

> To be honest, I would prefer it if it was all just women, as I am discussing my pregnancy then if it is just women then it should be okay, but because it is open to everyone so you can't really say … If you're not really comfortable with other men then you shouldn't go. But the time that the men were there I did not speak up as much. Because I did not want to discuss how I was feeling, with men listening you know … and I didn't want them to have a peep of my belly and [laughs], it's that it's uncomfortable but yeah, if it's about pregnancy and birth I would prefer it just to be women (FG7B-P1).

One Pakistani mother described being embarrassed by an educational video that was screened during her antenatal class, in the presence of men that attended the screening of the video. Furthermore, she explained that she was fasting at the time as it was Ramadan at the time of the classes, and it was too difficult:

> We were shown a video – different people in different experiences of birth, where some said it was really easy and some said it was really difficult and it was all different experiences that you could have. And there was this couple there and that's what I found about …

> Uncomfortable … There was a man there [laughing] … You know and it was Ramadan as well so … I didn't go ... oh, Ramadan is fasting month, and I was fasting that month and I was pregnant so that's why I didn't go because it was just difficult (FG4P-P6).

Some Pakistani and Bangladeshi mothers described their experiences with HCP which highlighted the HCPs' poor understanding of Asian women's need for modesty. One Bangladeshi mother explained how she wanted the curtains closed around her bed, especially when she was breastfeeding, but HCP required the curtains open which compromised the participant's dignity and wish for privacy:

> Well I have had quite a bit of bad experience because after I had my baby I am in the hospital for about three or four days and obviously I cover and obviously the wards are mixed, and there are six people in a cubicle in a room … And everyone's partners are there which is fine, but some of them they will not even let you draw the curtains, so if you're trying to breastfeed you do not want to be uncovered and trying to breastfeed. I am all for … If some people want to breastfeed in public then that is up to them, but I am not going to expose my breasts for the whole world to see, but it is sometimes quite difficult and my husband has had a few ruckuses about it, because it is quite simple, I can't close the curtain because they can't see, but I am feeding and I have had an operation and I can't physically get up and be closing and opening these curtains, but they don't understand … (FG5B-P1).

The same Bangladeshi mother also explained that hospital staff did not appear welcoming to a lot of extended family with children visiting the ward. Moreover, the mother explained this is how she received her emotional support:

> We're not trying to be … We are not trying to isolate ourselves, we are just trying to create a bit of privacy for ourselves because we are people that are used to being covered and we are in a public space which is fair enough, we do not expect a private room, but we do ask that our privacy. Those sorts of things they do not so understand about. The fact that we have a lot of family coming and going and they are not so welcoming about that, and even if you have lots of children they are not so welcoming about that … They can be quite difficult about that, they don't understand that we also have extended family … And you need a lot of support, when you are in hospital the emotional support that you need (FG5B-P1).

6.2 Key findings

There were mostly similarities in the findings between all participants:

- Women have many fears and anxieties during pregnancy.

- Women are poorly informed about pregnancy and often hold idealised views and fatalistic attitudes.
- Going through pregnancy and delivery of an infant is perceived as a life changing event.
- Most women experienced personal intuition regarding their pregnancy health status.
- Women lacked awareness of risk factors for adverse birth outcomes, unless they had experienced this through family or friends.
- Much of the information that women accessed during pregnancy was from previous pregnancy experience or the knowledge of peers. Women felt they had inadequate information, especially about things that might go wrong.
- Few women took folic acid before conception.
- Women co-sleep with their babies in the same bed and sleep their babies on their sides in their cots.
- Experience with maternity staff (and services) was recognised to be dependent on their relationship with the staff, in particular the midwives. Some staff showed understanding while others did not listen to the needs of the women.
- Women did not feel that staff properly listened to their concerns.

Several differences were identified:

- Bangladeshi women use ST.
- Pakistani and Bangladeshi women were aware of the increased risk of congenital anomalies in consanguineous marriages.
- Language proficiency contributed to the confidence of non-English speaking participants when communicating needs with staff.
- There is an increased pressure from the wider community for Pakistani and Bangladeshi women to conceive quickly after marriage, including the preference of a male baby.

- Using cultural therapy was more common in Pakistani and Bangladeshi communities, than WB communities.

6.4 Summary

This chapter has presented the findings from the FG with the lay mothers, which partially addressed objective two[144]: To explore the similarities and differences in maternal health beliefs that influence health behaviours in perinatal mortality in Pakistani, Bangladeshi and WB women, through the maternity care pathway. The findings revealed three main themes: knowledge and information of pregnancy and perinatal mortality, attitudes and perceptions to pregnancy and perinatal mortality and experiences with maternity services. Similarities and differences between the ethnic groups were highlighted (where relevant). Importantly, many of the findings revealed similarities in the participants' knowledge, attitudes, perceptions and experiences of pregnancy.

All the mothers reported fears and anxieties during their pregnancy which included concerns about the wellbeing of the child in addition to themselves. In spite of this, it was apparent through the narrative that the majority of women had limited knowledge regarding their pregnancy. For instance, some women held idealised perceptions, whereas other women normalised the experience. Additionally, women's pregnancy knowledge was influenced significantly by their previous or a peer's experience of pregnancy. Moreover, the majority of women desired more information about their pregnancies, in particular around things that may go wrong. Most women were aware that there was information available, but not everyone understood where to or how to access this information.

Additionally, cultural beliefs played an important part in the majority of Pakistani and Bangladeshi pregnancies, whereas WB participants did not seem to be as involved in cultural beliefs. Many of

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[144] Chapter Seven also presents findings addressing objective two.

the participants demonstrated fatalistic attitudes towards their pregnancy and adverse birth outcomes and Pakistani and Bangladeshi women explained there was a cultural expectation for them to conceive quickly after marriage, which sometimes included gender preference from the wider community for the women to deliver sons. There were differences in the levels of social support that the Pakistani and Bangladeshi participants reported whereby there was more interaction with the extended family compared with WB, who were more reliant on their partners.

The women reported both positive and negative experiences with staff and services. In particular, it was reported that staff showed a poor understanding of Muslim women’s needs, which were not always met. Moreover, limited English language proficiency led to perceived disempowerment. The participants recognised that a caring midwife made a big difference to their perceived experience and that no two pregnancies were alike.

Perinatal mortality in Pakistani, Bangladeshi and White British mothers, in Luton.

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Bedfordshire

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Author's Declaration

"I, Rebecca Louise Garcia declare that this thesis and the work presented in it are my own and has been generated by me as the result of my own original research.

Perinatal mortality in Pakistani, Bangladeshi and White British mothers, in Luton.

I confirm that:

8. This work was done wholly or mainly while in candidature for a research degree at this University;
9. Where any part of this thesis has previously been submitted for a degree or any other qualification at this University or any other institution, this has been clearly stated;
10. Where I have cited the published work of others, this is always clearly attributed;
11. Where I have quoted from the work of others, the source is always given. With the exception of such quotations, this thesis is entirely my own work;
12. I have acknowledged all main sources of help;
13. Where the thesis is based on work done by myself jointly with others, I have made clear exactly what was done by others and what I have contributed myself;
14. Parts of this work have been published as indicated on page v"

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ASR	Adjusted Standard Residuals
ANCOVA	Analysis of Covariance
BAME	Black Asian Minority Ethnic
BMI	Body Mass Index
BiB	Born in Bradford
CMACE	Centre for Maternal and Child Enquiries
CDOP	Child Death Overview Panels
CMiS	Circonia Maternity information System
DOH	Determinants of Health
DM	Diabetes Mellitus
EDD	Expected date of delivery
FG	Focus groups
FASD	Foetal alcohol spectrum disorder
FM	Foetal movements
GDM	Gestational Diabetes Mellitus
GTT	Glucose Tolerance Testing
GAP	Growth Assessment Protocol
HBM	Health Belief Model
HCP	Health Care Professional
HES	Hospital Episode data
HPA	Hypothalamic–Pituitary–Adrenal
IMD	Index of Multiple Deprivation
IMNST	Infant Mortality National Support Team
IMR	Infant Mortality Rate
IUGR	Intrauterine Growth Restriction
LMP	Last menstural period
LBW	Low birthweight
LSOA	Lower-layer super output areas
MLBU	Maternity led birthing unit
MCS	Millennium Cohort Study
MIS	minimum income standard
NHS	National Health Service
NICE	National Institute for Health and Care Excellence
NN4B	NHS Numbers 4 Babies
NS-SEC	National Statistics Socio-economic Classification
NICU	neonatal intensive care unit
NTD	Neural tube defects
ONS	Office for National Statistics
PMR	Perinatal Mortality Rate
PTB	Preterm birth
QOL	Quality of Life
SCT	Sickle Cell and Thalassemia
SGA	Small for Gestational Age
SPSS	Statistical Package for The Social Sciences
SSI	Semi structured interview
ST	Smokeless tobacco
SCM	Social cognition models
SES	Socio-economic status
SB	Stillbirth
TG	Topic guide
TPB	Theory of Planned Behaviour
UK	United Kingdom
WB	White British
WHO	World Health Organisation

Chapter 7: Bereaved mothers' perspectives of poor birth outcomes

7.1 Introduction

This chapter provides the qualitative findings following the face-to-face interviews with the mothers who had suffered a perinatal bereavement in the previous 6–24 months. The semi-structured interviews were developed to partially[145] address objective two: To explore the similarities and differences in maternal health beliefs that influence health behaviours in perinatal mortality in Pakistani, Bangladeshi and WB women, through the maternity care pathway. The face-to-face interviews were conducted by the researcher in English (i.e. no translators were required) and no non-English speaking potential participants expressed an interest to take part (Chapter Four, Section 4.5.3). The interviews were all audio-recorded with consent, and later transcribed verbatim.

The narrative themes are described and participant quotations are provided in Sections 7.1.2–7.1.4. The narrative was analysed for similarities and differences that were evidenced between the participants regarding their health beliefs and health behaviours through the maternity care pathway; and focused on perinatal mortality as experienced by the mothers. To ensure anonymity, identifying information was removed; otherwise the quotations remain verbatim and are coded according to an alphanumerical coding system. The sample structure for each SSI and codes are shown in Table 29.

Table 29: SSI participant codes and ethnicity

Interview	Participant code	Ethnicity
1	BM1WB	WB
2	BM2P	Pakistani
3	BM3P	Pakistani
4	BM4P	Pakistani
5	BM5WB	WB
6	BM6B	Bangladeshi

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[145] The findings from this chapter, combine with the findings in Chapter Six (lay mothers' FG discussions) to fully address objective two. The converged findings are presented in Chapter Nine.

This section presents the main findings of the interviews with the bereaved mothers. It starts with a description of the participant characteristics (7.1.1) and continues with a presentation of the three main themes: knowledge and information of pregnancy and perinatal mortality, attitudes and perceptions of pregnancy and perinatal mortality and experience of maternity services (Section 7.1.2–7.1.4). Figure 27 depicts the themes and sub-themes.

7.1.1 Participant characteristics

Six face-to-face interviews were held in each of the participants' homes, at their request. All the participants had suffered a stillbirth. Five out of the six mothers were born and grew up in the UK, and one Pakistani mother was settled in the UK for the last 15 years. Five out of the six mothers had been educated to GCE A level or BTEC National Diploma (level 3), while the remaining participant was reported to have achieved academic achievement level of GCSE – she was Pakistani but had lived her whole life in the UK. The majority of the participants lived with their husband or partner and their children, and only one Pakistani mother was reported to be residing with her extended family, which consisted of her mother-in-law, father-in-law and her husband. She was also born in the UK. The majority of the mothers had (at least) one other child who was born before the recently deceased infant. Only one mother had successfully conceived after her loss and had delivered a healthy son. All the mothers described reporting their pregnancy to their GP between four and eight weeks of gestation. The participants all reported that they did not smoke or consume alcohol during their pregnancy, however the explicit question of using smokeless tobacco products was not asked.

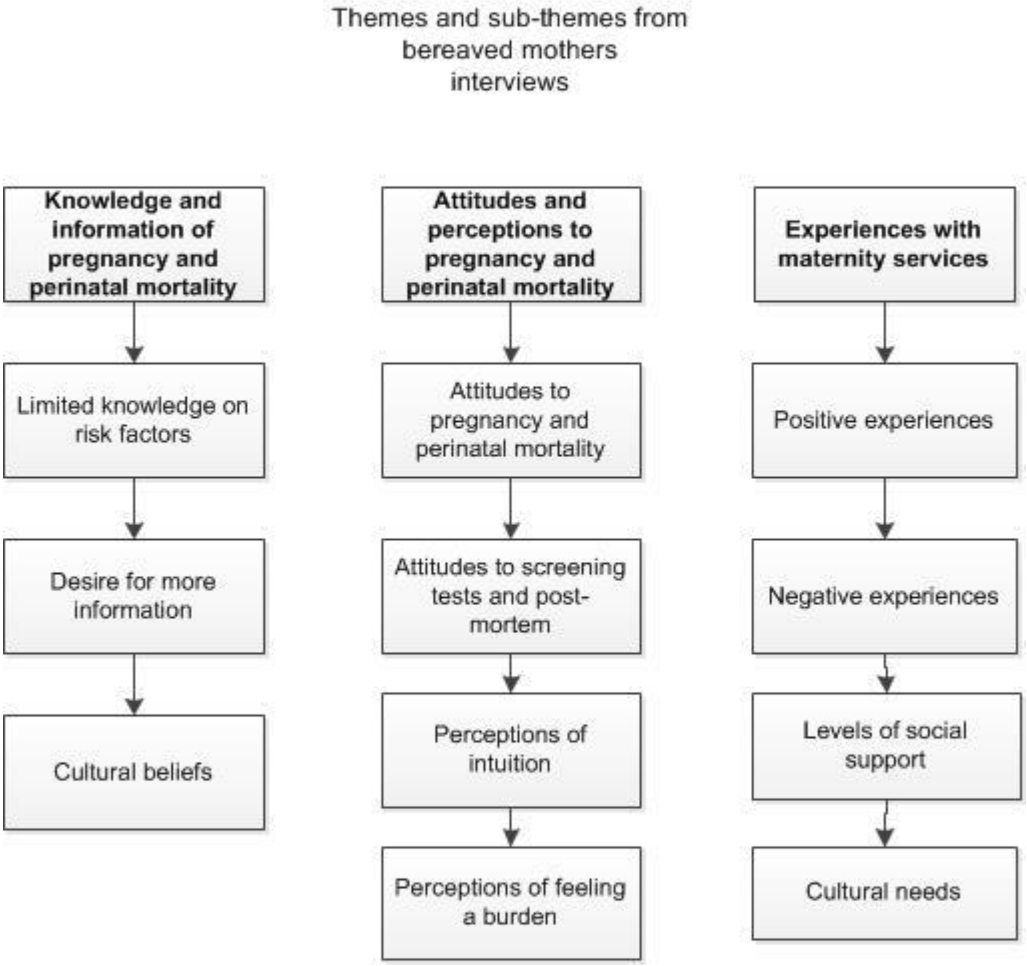

Figure 27: Themes and sub-themes identified from bereaved mothers' interviews

7.1.2 Knowledge and information of pregnancy and perinatal mortality

Three sub-themes emerged within the main theme. These were: limited knowledge on risk factors, the desire for more information and cultural beliefs.

Limited knowledge on risk factors

There was a consensus among the mothers that they believed that there was a paucity of information available in respect of risk factors for adversity during the pregnancy, including stillbirth. This is seen in the following excerpts:

> I don't know these things [stillbirth], I don't know the baby can die in the stomach, or what going to happen. I'm just saying that sometime – sometime after I had my daughter as well and after that every second, every minute, I live (inaudible) I'm checking my baby if he's moving or not (BM3P).

> I'm like the first person that's been through it. I've never – I didn't know about stillbirths till it obviously happened to me and the night before I was reading about it, I even showed my sister-in-law my internet history on my phone in case they think I'm just saying shit (chuckles) (BM4P).

One mother explained that after staff had identified complications, no further information or guidance was provided:

> … it [the placenta] was completely covering the cervix, the worst case one that you can have – not given any information just that that's what I had, and to come back at 32 weeks but they'd make me – no they didn't even say they'd make me an appointment at that time they just said, yeah they just said come back at 32 weeks, no more information (BM1WB).

And she was left unaware of what to do in the event of complications occurring, until a considerable way through her pregnancy:

> It wasn't until I saw the midwife at the routine 28-week appointment that she said to me about the risk of bleeding and that I should have an emergency bag ready in case I needed to go and no need to call an ambulance; no one had ever told me that. So no one had given me any information – that's one thing I'd like to point out (BM1WB).

Another mother explained that she thought there was conflicting advice and information available, whether certain symptoms were ‘normal’ or required the doctor, making it difficult to know what to do. However, she explained that because she had experienced a previous pregnancy, this helped her decide what to do. Consequently, she thought first-time mothers would be particularly unsure of what to do. This is seen in the following narrative:

> I had the shortness of breath, I had the dizziness, I had the being really sick. But some people say that's completely normal there're others say you need to see a doctor. It's kind of like I don't know which way to go, do I just kind of grin and bear it? …But that's only from experience like if [name] was my first one and I was a first time mum with him I might have just left it, I don't know, because it's like contradicting on what you hear, what you read and what you see online (BM5WB).

Another mother explained that she did not fully understand what reduced foetal movement meant, or what she must do in this situation. This is seen in the following:

> I don't know about these things. Then I went to the doctor's on Monday, two days I delayed because I don't know what I need to do – but it's if you go if you don't feel it go straight away (BM3P).

The risk associated with consanguineous marriage was mentioned by two Pakistani mothers, although they did not appear to be fully aware of the implications associated with the cultural practice. This is evident from the following narrative:

> Lots of people saying that to be honest, but we are cousin married as well (BM3P).
>
> Yeah, I think they [cousins] have more genetic problems, don't they? (BM4P).

The majority of the bereaved mothers reported being aware to monitor the baby's movement and 'counting kicks' as an indication of the baby's wellbeing:

> That's all I knew about the kicks, but I didn't know anything else – I did some research and then (inaudible) I do ten – had ten kicks in a morning and in the evening and the movements and everything … (BM6B).

However, one Pakistani mother explained that she did not understand the importance of seeking medical attention promptly, once she had identified changes in the baby's movement patterns. This is depicted in the following excerpt:

> No, I didn't know that [if baby stopped moving I was supposed to go in straight away] … but that time, that day, after two days – I didn't go to doctor's because they're normally telling me appointment after two weeks, three weeks. So that time I didn't go to doctor's because I

> didn't (inaudible) it was like a normal – I didn't know about these things [to go straight away]. So I went Monday, I delayed two days; I didn’t need to do that I needed to go straight away. … and I don't know that one [to go straight away] – and I went on the Monday to doctor and doctor checked me and he sent me straight away to hospital and I went to the hospital and they checked me in … I had a scan and then they said to me “Your baby is not any more” and I feel sad, to be honest (BM3P).

Desire for more information

The participants explained that they thought that most women would be receptive to receiving more information in respect of risk factors in pregnancy, and then, what they ought to do in this situation:

> First, mums, I think there needs to be more information out there. I think if they (want?) it first Mums are more happy and, you know … I do think there needs to be more information for first mums if needed, they need to be there (BM6B).

Following her own experience of SB, one participant described how she thought she had a duty of care to warn other pregnant friends of the risks of perinatal mortality:

> So I think we talk about it from the point of almost like a duty of care (inaudible), like, we've experienced it we don't want you to either. So I don't think we talk about it as a thing of “Oh, let's reminisce on this”, it's more like, “Well this happened to me I don't want it to happen to you”, or anyone else you know. So I think it's more a base for that as a positive thing instead of, yeah just – it's not really dwelling on it, it's just like, I've been there, done that, I don't want you to go through that. So I think it's more of a positive thing that, not on a just sitting here and randomly spark off some conversation about her, at the time parts of it are related to her, sort of thing (BM5WB).

Furthermore, participants described seeking pregnancy-related information from experienced family or friends, who had children of their own. This is seen in the following:

> So after that I used to get (inaudible, accent) to ask family members with – who had (inaudible) kids previously and I go (inaudible) she might be lying down or asleep and other sister she knew it all because she had four kids and I go, “Okay, that's fine” (BM2P).

Cultural beliefs

Cultural beliefs were evident within the narrative from Pakistani and Bangladeshi mothers. It transpired through analysis of the transcripts that cultural beliefs influenced Pakistani and Bangladeshi pregnant women's behaviours. Much of this was centred on food restrictions. For instance, papaya (a fruit) is typically advised to be avoided; believed to induce uterine bleeding or miscarriage:

> Like, they say that fruit, papaya, you shouldn't eat that (inaudible, noisy child) to start when you're pregnant when you find out you shouldn't eat that 'cause you can suffer a miscarriage and, erm, it's like so there's a lot of foods that you have to avoid at that stage so at the start you couldn't eat one lot peanuts, you could eat it towards the middle. So I wanted to, I had peanuts quite a bit towards the middle when I wasn't supposed to when I would only have a little bit but it was just a craving, I had to have it (BM2P).

Another example provided was restricted amounts of protein, such as fish.

> They said to drink plenty of milk and stuff; I was drinking milk and stuff – like my parents would say to me eat fish but just small portions, not allowed to have big portions and stuff like that … (BM4P).

And one mother wondered whether her eating wheat had contributed to her adverse outcome:

> Yeah, 'cause I used to have, like, all kinds of foods, vegetables and everything, but I think in some cultures sometimes – they say that at this stage towards the end you should eat these because it's hot like, you know, and, erm, inside as well so good for you – I think I must have ate some kind of wheat at that time because I was, like, I had I think two months left. And I sometimes think in my view regarding that, erm, not that that's the cause but, that could be one of it, that could be part of it (BM2P).

One Pakistani mother described how she thought older Pakistani people and those 'back home' more readily believed in cultural beliefs; for instance, women who lose a pregnancy (through miscarriage or stillbirth) are considered to be 'a bad omen' and to pass the 'omen' to another pregnant woman, who then risk losing their pregnancies. This was used to offer an explanation for this mother's infant death; however, the participant explained that she perceived these beliefs to be 'rubbish'. This is seen in the following:

> I think it's more the people from ... yeah, back home and like the older generations believe it. With me what my mother-in-law said to me, for example, the lady across that road had a miscarriage and she invited

> me to a party a week before I lost my daughter and they put it down to her giving me, you know, the bad (chuckles) the bad omen and that's why I lost my child. And you know, 'cause you're sort of messed up in the head for a little while you might even believe that, because you want to believe something else, isn't it, you want to hold on to something, but then I think to myself no, that's just nonsense, just rubbish, if it's going to happen it's going to happen regardless, nothing to do with someone losing their kid. But I'm just saying quite a lot of culture comes into play (BM4P).

7.1.3 Attitudes and perceptions of pregnancy and perinatal mortality

Within the main theme, four sub-themes emerged; these are presented next.

Attitude to pregnancy and perinatal mortality

The participants described feeling especially stressed and anxious during their pregnancy:

> I think because of my work it doesn't help at all I was very stressed and very negative, like I wouldn't buy my daughter anything until that same week that everything happened … I just didn't want to buy anything (BM4P).
>
> I was as anxious as hell the whole pregnancy. Fast forward to [name], that's a high risk pregnancy and yes, I was anxious, but I didn't push for anything, I didn't, you know, I just thought, oh well, that's okay (BM1WB).

After their stillbirth experience, the participants described their attitudes towards complications in pregnancy and perinatal mortality, and noted how it was a life-changing experience:

> It [stillbirth] changes your look at everything, there's no like everything is rosy anymore it's just, like, everything could go wrong. It does change your life completely (BM1WB).

The participants discussed the importance that they ascribed to the timing of the death of the baby in respect of how badly they anchored their own experience, in comparison with others who may have experienced an infant death, earlier or later in the pregnancy. This is seen in the following narrative:

> Just because you didn't have your nursery ready yeah, it makes your grieving process harder and things like that, but it's still your baby. The only time I don't (inaudible, garbled) is the early miscarriages like myself because at that point is nothing really. Although it sounds harsh, I know it's a hope and a dream, but it's not a real baby, it

> doesn't have, limbs, it doesn't have, you know, it wouldn't have had a heartbeat at that point. That's the only time I'm kind of like “it's not the same” (BM1WB).

One participant described her perception that the experience of infant mortality was worse than stillbirth; conversely, her friend thought that having a SB was worse as the bereaved mother never had the chance to see the child alive:

> People that go in there, they go in and have their normal labour and then they get their baby at the end of it *…*and that's what keeps me going as well I think *…*you know, but [name] her babies lived months and then they were born and I say to her I can't even begin to imagine what that's like to see their eyes, to have them alive in you and then to have them taken. But then she thinks that mine is worse, 'cause I didn't get that and that's the difference, we've always – it's like my friend that lost her boy at twenty-three weeks she said, “Oh, you've been through far worse, you had the nursery ready…”*.* It's not worse because she was still pregnant, you still have the dreams, the hopes ... (BM1WB).

The majority of bereaved mothers described their specific anxiety surrounding their experience of stillbirth. For example, one participant described her fear of looking at her dead baby as she had no idea what to expect:3

> So [my husband] said, “Would you like to see a photo of him?” And I said, “Yeah, I think I will I want to see what...” 'Cause I was frightened, I didn't know what to expect. I’d never seen a dead person let alone a child; so I said, “Can I see a photo first?” So he showed me a picture, I was, like, big relief, okay, he looks a normal baby (BM1WB).

Attitude to screening tests and post-mortems

The participants believed some screening tests (such as the foetal anomaly scan) had a significant degree of risk of harm to the baby associated with undertaking the test, and this was found to contribute to their decision not to undertake it. This is seen in the following:

> No, I didn't get that [scans] done I was advised not to … Because they said there could be a risk of death or that because they were going to put a needle inside the amniotic fluid ... and that – if there's a small chance that it could harm - I thought, “I'm not going to take the chance”. So that's why I didn't want to do it (BM6B).

Two mothers explained that the process of screening was perceived as too stressful, which impacted on their decision not to take the test. This is seen in the following:

> They advised me everything when I had the scan, they asked me – the midwife said “I'm getting the leaflets”, she explained beforehand as well everything - it was just something I didn't want to get done I think. Maybe I was too nervous going on the tests and everything because of the scans and it was too much and then going for the blood tests and everything and it was just too much (BM2P).

The majority of participants described their attitude towards taking up the offer of a post-mortem following their baby’s death. One participant described how she did not want her baby pulled around:

> I think just because we didn't want people prodding at her and everything because – I don't know but I kind of think she looked kind of peaceful and you don't want people just messing with that let her go peaceful as well … (BM5WB).

The three-month delays associated with having a post-mortem performed on their infant had an impact on the parental decision-making:

> We decided not to have a post-mortem because they said it he'd have to go to [name] in London and it could take three months blah, blah, blah. We said, “No”, we didn't want him cut open anyway; we had agreed to external examinations until they – we'd even signed the consent form thinking it was done there later and it was only because my husband kept pushing for answers that they said, “Oh no, he would be sent off to London” – “Well, right but how long will it take?” – “Oh, we have no idea”. He went on, “Well I want you to find out how long it takes” (BM1WB).

One Pakistani mother explained that the delays in receiving results back was not clear, but they would have taken up the opportunity for an external examination, if it had been offered:

> I didn't know what the ins and outs were, having come across other people it doesn't appear that it does [take long], so I think that it don't take that long for them to actually carry the test out, however it takes that long for them to send the results back and I think that needs to be made clearer, 'cause if we're doing that [having a post-mortem] we wouldn't have the internal, no doubt about it wouldn't have had him sliced around, but we might have had the external scan type thing - that might have shown something (BM2P).

Additionally, one mother had worries that post-mortem procedures may be carried out without consent; as seen in the following excerpt:

> And when they said three months [for the results] - I said, “No, I want to see you rip that up in front of me you're not sending that off.” Then they were so fearful that they'd send it off by accident and the next

> thing they'd know they would have sent (baby) off and we couldn't have done anything about it; so I was, like, “No I want to see that ripped up I don't want to hear of you sending him anywhere”. So we agreed ... (BM1WB).

One Muslim participant explained her religious beliefs behind not having a post-mortem after death:

> Basically – it's obviously that we believe that you shouldn't have it [post-mortem] done because you should go the same way you came. So when she was buried we didn't want to change the way that – we didn't want to put scars on her or anything like that; that's why (BM6B).

Perceptions of intuition

The mothers described perceptions of ‘intuition’ that there was something wrong with their pregnancy. All the participants reported having ‘thoughts’ or ‘feelings’ that something was wrong. This is shown within the following excerpts:

> I dunno, I was having weird thoughts within myself that if I find out that there is something in my culture and my, erm, way of thinking, I get like instincts and stuff like that that ‘something' is coming … I was getting these thoughts, I was getting hints that something is coming our way and I had a feeling, kind of, 'cause I used to, like, I don't know, when I used to go out I used to feel like something telling me to go back, don't go, it was like that … (BM2P).
>
> Just knew there was something wrong and my husband come back from work about half ten at night and I go to him ... 28 weeks – 27 – 27 weeks, yeah – and I go to him, “Look I just don't feel right”; and I'm really upset with myself that I just have gone straight to A&E then but I just didn't want to make a fuss … so she [midwife] sat me down, and she checked me and she goes to me, “I don't want you to get upset, you know, I can't really find a heartbeat but sometimes a baby is back for you towards the stomach, so maybe it's that, don't worry, don't worry, go...”, you know, “…go to the hospital”. But I just knew (BM4P).

Perceptions of feeling a burden

The participants also described their attitude to engaging with services; especially when they had concerns that something was not right with their pregnancy. They explained that the staff appeared so busy; they did not want to be an extra burden:

> But it was the fact that I was made to feel like a burden which is the thought I had before and that it's not important … It was just the

> basics, I mean, all throughout I never wanted to trouble anyone or, you know … they could do without me taking up a bed, taking up their time, you know, again you put yourself at a lower scale than everyone else ... (BM1WB).
>
> But I did feel bad though, I thought, like, “Oh, God, I'm such a burden on these ladies”. But then I got, erm, a listening kit from – I think it's called (name?) Infant Listening Kit and it has like a little pod that you attach to your stomach if you want to hear the heartbeat, so that put my mind at rest as well (BM6B).

A further attitude that was described by the participants was their fear of being negatively judged by the staff – the mothers were worried about asking ‘silly’ questions. This is clear from the following narrative:

> I think that's what a lot of mums feel, they feel judged for asking silly questions or – especially the first five months like going to hospital and stuff you might think, “Oh I'm just being silly - I'm not going to go”, but it could be the difference between saving your baby or any complications or how you help the baby (BM5WB).
>
> I find sometimes GPs can be quite intimidating because they know so much and you can be asking the silliest question or they can ask you a question and you can give them a really silly answer like, oh –“Why are you feeling sick”? “'Cause I just do” – and yeah, I think they can be quite intimidating because you kind of feel like well maybe I'm being silly about it and it's going to be, like, everyone does that ... (BM5WB).

7.1.4 Experiences of maternity services

Four sub-themes emerged: positive experiences, negative experiences, levels of social support and cultural needs; these are presented next.

Positive experiences

All the participants spoke at length about their antenatal and bereavement experience which involved staff and services. At the time of the delivery of their SB baby, the participants described the care that they received at the time from doctors and midwives as being ‘very good’ or ‘good’. This is evident in the following:

> Yeah, I think they were quite good (inaudible) to like what was happening when they are coming in to (inaudible) and that sort of thing and they let my family know everything as well (BM5WB).

> I had two midwives; one was a student, and one was the regular there. The regular lady she was so generally, like, caring and she actually put – like she put a smile on my face when even my mother couldn't put a smile on my face, she was so caring and she (inaudible) when I delivered my son she came to my room, …and she gave me a big hug, and she was, like, "Oh my God he looks just like her". And she was generally just so caring (BM6B).

One mother explained how the midwife was really attentive to her needs and carefully explained everything to the bereaved mother:

> And, yeah, she [midwife] just kind of explained throughout the day what was happening and when the doctor would be round and, yeah, she was really attentive to like what information I needed to know, what I needed to do and everything like that … (BM5WB).

Moreover, the midwives were described as being really personal, supportive and friendly, which extended after the hospital stay:

> I mean, my midwife was really good, she was really personal and she remembered my name every time I went in, I saw her sometimes in Asda she said "Hiya" and we'd talk about everything (BM5WB).

Negative experiences

There were some specific negative experiences, which the mothers reflected on. Two participants described their experience of poor communication between the hospital and community midwifery team and GP, whereby the death of the infant had not been reported to the primary care team, so that on the next face-to-face meeting, mothers were met with health staff expecting to see a live baby. This resulted in undue distress for the mother; as seen in the following excerpts:

> Oh my God it was so horrible I had to – I actually changed my doctor because of how bad it was 'cause basically ... but he was just like, "Oh so it's a 6 weeks baby so how come you didn't bring your baby with you"? And I was, like, "What – what do you mean"? And he was, like, "Where's the baby, I need to check your baby?" And at that point I was ... I didn't know whether to shout at him with anger, or, like, just to cry, and then I (inaudible) "In fact my baby has passed away", and he was, like, "Oh, okay, so tell me what happened". And I had to literally go through every little thing with him, and I was thinking shouldn't it have been reported to him ready? I literally just had a like a breakdown. I thought after six weeks it was getting a bit better because I was getting, like, coming to terms with it (BM6B).

> I was fine, got through everything without crying then the midwife, my community midwife, walks in and that's it, I'm gone. She was, like, “You didn't come to see me today I come up to find out where you were - I thought you might have started bleeding again, I can't believe it” – and she actually had to walk out and said, “I can't deal with this” and walked out. She came to visit me the next day and said, “Oh, I'll come back tomorrow when I've got my head round this, I don't want to cause you more upset, I'll come back tomorrow” … she didn't know; she'd turned up on the Thursday thinking, cause I hadn't made the appointment, she was, “Oh no, she's had bleeding again I'm going to go and find out what's going on” and they said, “Oh yes, she's had a little boy, but he was born sleeping” I was “Oh my God” (BM1WB).

Several participants described difficulty in contacting their midwives outside of their routine appointment time. For example, several mothers had problems contacting their midwife by phone and complained that they never received a call-back after they had left messages.

> My midwife every time I rang her, her phone would be switched off so I would leave her voicemails and I would never really get her to – she would never really call me back, to be honest. So then you would just give up, you know, why would I want to keep ringing someone whose phone is always switched off? 'Cause I think they work unsociable hours, don't they? (BM4P).

One mother complained that prior to delivering the deceased baby, the midwife failed to adequately explain to the mother the macerated condition of the baby, especially since her baby had been dead for a few days:

> They didn't warn me about that [condition of the baby] – I did know the extent of it but she just goes to me, “She might be blue or she might be purple”; she was almost like pickled pears like the only thing she had that was okay was her hands and her feet everything else was – her skin was peeling and then I read on the internet they (inaudible) that's – when they pass away I think it's levels of, you know, like the, erm, what do you call it, I can't remember the word, like slowly the stages of, you know, when they die inside you, so like the skin peeling is I think the second or third stage 'cause it … we found out on Monday so she came out on Friday evening about eight o'clock, she was born (BM4P).

After the doctors had confirmed the death of the baby, the majority of the participants were then given medication to induce labour and given the choice to wait on a ward with other expectant mothers or sent home, which the participants found distressing – either way. The following shows this:

> And, the doctor came in and my mum was saying to the doctor, you know, “What’s going to happen – how is she going to give birth and everything”? … but I think they put a gel inside of me at that point to stimulate the cervix to open. So they said for me to go home for the week and come back on Monday (inaudible) and then they were going to induce me and yeah, that’s how it all started ... I didn’t want to go home, I wanted to stay there and just give birth and just to sit – like the waiting period was hell for me ‘cause I didn’t know what to do. I still had the baby inside of me but I was, like, “What do I do?”, you know, “I’m just waiting to see my baby”.... (BM6B).

> No, either stay on the ward with expectant mothers and new babies, or go home. I would go home all day long, I wouldn’t want to be around that [expectant mothers] – I wouldn’t want to wish anything bad upon anyone or (inaudible) I just don’t think I could have handled it; that’s torture and then, God forbid, what about the women who are in that sort of – who are in that ward for two days, the ones who don’t speak English … maybe they’ve just been messed around in their head for those two days, you don’t know. I’m so glad I didn’t stay there it would have messed me up ... I don’t think you could stay round that; people talking about babies, “Oh how much does your baby weigh”, you know, “Oh what you having, what you having”? (BM4P).

Similarly, the mothers described mixed experiences with being allowed to take their dead baby home. For example, the following extract shows the significance of the empty car seat:

> We were friends through a friend so we kind of met up once and talked about it and everything but yeah, the decision wasn't even hers it was like, “Well you've got to take the baby home”. They had to put the baby in the car seat and (inaudible) in the car and try and (inaudible, TV) with that baby and it was like – I think that, for me, would have been worse than driving home with an empty car seat, which is what we did, we drove home and the car seat (BM5B).

Levels of social support

The bereaved mothers described their experience of the degree of social support that they received, in connection with the death of their baby. The participants described a diverse range of social and emotional support during their bereavement experience. One participant made a comment that no one at the hospital checked the levels of support available to the bereaved mother:

> They just send you home without no support, either here you live with people who are having babies, live in the ward with them, or go home where you've got all these relatives and everyone is just fussing over you and you just want to be left alone, 'cause your whole world has just collapsed (BM4P).

Consequently, many women felt that they needed to be emotionally strong to meet the grieving needs of other family members, over attending to their own grief:

> I'm a lot better, I'm a lot stronger, like even when I had her and gave birth to her and people were coming for to pay respects and condolences and they were all really surprised that I really held myself – like I was very strong. It's not being strong it's just that I've got very ill parents, my dad had a stroke, Mum suffers from depression, my father-in-law suffers from Parkinson's, mother-in-law is ill, so I just didn't want them worrying about me. So you just always have to, like, even put a guard up, I'd rather cry in my room but I won't cry in front of them so, just had to be strong for them, for my family, for my … (BM4P).

> When the birthday [the due date] came that's (inaudible) feel emotional, I just kept it to myself because I don't want my husband to do anything, it's more (damaging?), you know, than any pain, I kept it to myself and I just used to go into town and secretly just buy breast pads and, you know, I didn't want to speak to my husband, you know, kind of – I didn't really want to tell him how I was feeling because I feel like he's already been through a lot as it is and I didn't want to, you know, say to him, “Oh I'm upset because my milk's come and I do not feel like I should have, you know, I should have my baby to breastfeed” (BM6B).

Moreover, a few mothers explained that family support didn’t meet their needs at the time, as they needed their time to process their grief;

> I don't know, it's hard to describe because I didn't feel isolated but I felt like they didn't want me to be alone because if I was alone they thought I was (inaudible) to a breakdown but they didn't understand that I just needed to be alone sometimes. So I don't know if I was isolated but the support was there at the wrong time (giggles), in the wrong way (BM6B).

> Yeah; they [mother-in-law] say to us “Look after yourself” – yeah, they're really helpful as well. When I am doing something they say to me, “Make sure, don't lift heavy things, don't do that, look after yourself, you don't feel it right now but later on you're going to feel it” (BM3P).

Another mother perceived the family problems and lack of family support she experienced before her stillbirth contributed to her feeling of loneliness and increased stress:

> I had such a horrible experience, I had so many family problems because of my in-laws and at one point I was actually walking and still heavily pregnant, I was walking for about a mile, heavily pregnant, carrying shopping as well and it was just horrible and I had no support. So I think in Asian culture where you have no support you have that stress put on you as well. But it's hard going through it alone … and you feel like you're alone and no one understands, no one cares what you're going through either (inaudible) at that point it's just – and then you feel like, you know, you can't tell your husband – because your husband, that's his mum and you don't want to cause him stress as well and you don't want arguments between them (BM6B).

They explained that SB was a very difficult subject to discuss with family and friends, in addition to being unaware of how individuals may react. This is seen in the following narrative:

> Yeah, some do, I have quite a few friends, and they're all at different stages in life. The ones that are closest to me they talk – we talk about (inaudible) quite a lot and like we say that she's having a (big sister?) – and that sort of thing, so we do talk about her as if she was here and that sort of thing. But there are some people I don't talk to about her at all because, I don't know, they weren't – I mean they were there like, we were friends but they weren't there at the time I think they wouldn't be the kind of person at all that could talk about such things 'cause I don't know how they would react to it either (BM5WB).

The majority of participants described how their loss had affected the wider family, including fathers, grandparents and siblings:

> No; it affects the whole family … but you have to remember that she has lost her nephew as well, she's lost something too and it's her first and only nephew – also for grandparents, it's the same for grandparents, not only have they lost a grandchild but they have to watch their children go through the immense pain and they can't ... So for them to have to watch their children go through that must be so painful and then there's grandparents that come on these support groups on facebook and there was one on Saturday, I think it was, saying that that day her granddaughter was going to be born sleeping so what should she do, was there any advice and everyone was take so many pictures. My dad said, you know, he didn't say it to me he said it to my sister it was the worst day of his life, you know, and I've never – I haven't seen my dad cry since (BM1WB).
>
> Hard for, like, my parents, it was their first grand ... they've got grandchildren with – I've got four brothers but I'm the only daughter

> so they would have been, you know, like “Nan” and stuff, so everyone was really excited, so everyone was just really gutted (BM4P).
>
> What am I going to do now, you know, how will I tell my son, you know, I've left him home now – what am I going to tell him? (BM2P).

And all the participants pointed out that talking about miscarriage, pregnancy loss and stillbirth is a sensitive subject and very difficult to discuss with someone. This is seen in the following extracts:

> … some people that, like customers and patients like, if they saw me they were, like they would ask me “Have you had your baby”? And if you tell them (inaudible) they just don't know what to say, they just say they're sorry, like no one wants to talk about it, it's just brushed under the carpet, “So sorry to hear about that” but then they won't ever say that again. Even at home I find my family talks about it but my in-laws they kind of brush it under the carpet, no one really talks about – me and my husband do, I think I talk about her quite a lot (BM4P).
>
> Like I say, I've got several friends that have gone through it at different hospitals, at different stages in pregnancy to the late on, for different reasons, and they don't really speak about – one more so she puts things on Facebook, you know, that I said, she's shared photos so things like that, she was about 41 weeks when she lost him. My other friend, I've never seen a picture of him ... (BM1WB).

However, the participants described both good and bad experiences with specific services. For example, one participant specifically mentioned her experience of local counselling services, which was positive (with SANDS):

> Yeah; SANDS was really helpful, I really appreciated SANDS because they gave that memory book … And that helped me too, the recovery, to be honest, it really helped me just looking at her (inaudible) her little hand-print. We took pictures of the hands as well and, like, she's got her dad's feet (chuckles), it's so funny, but that really helped me with the recovery (BM6B).

And another local counselling provider where her experience was reported to be negative – especially as the consultation was over the telephone and with a male counsellor:

> I did have one session, and I thought I can't tell a stranger what I've been through and then him to think, “Okay, 'bye, talk to you next week” (nervous giggle). Like with you it's okay because I know that, you know, you're looking into it, and you're doing it for us mothers so it's fine, but for me just to talk to a guy – and over the phone as well – so for me to talk to a guy and for him to be, like, “So tell me what happened, yeah” and then, “Okay that's fine”. I thought that was so rude and I thought, no, I'm not doing this (BM6B).

Another mother described her interaction with bereavement counselling services (i.e. CHUMs), suggesting that initial contact was made with her, but was too early in her bereavement journey and that a later contact may have more helpful:

> I wasn't going to have it [bereavement counselling]. They called me two days before the [name] funeral I was not in any fit state to speak to anyone and I was, like, I don't want to speak to anyone blah, blah, blah and that was it, I was struck off the record. Now had they called me a week later possibly, or a couple of months later or six weeks later or something, the outcome could have been different … It's fair enough re ... – some parents will want that help straight away because they feel alone and they need that straight away, some mums, some dads, whatever, but [my partner] will not have counselling whatsoever (BM1WB).

Cultural needs

Several cultural differences in pregnancy between Pakistani, Bangladeshi and WB women were emerged during the interviews. One Bangladeshi mother described her thoughts regarding privacy and concealment surrounding pregnancy. She explained that pregnancy was not openly discussed in Pakistani and Bangladeshi cultures as it is in Western cultures. This is seen in the following excerpts:

> To be honest, like, with the Asian culture I would say when you have a baby – you know with the white culture when you have a baby you feel like everyone's having a baby and everyone's looking forward to it and they were looking forward to it – but it's more of a cover-up thing like, you know, you don't really talk about it much (advice-wise?) 'cause I would say a lot of – my auntie and my cousin they (inaudible, garbled) (myself?) … yeah, and I feel like talking to them and so they – 'cause we don't talk about it [pregnancy] – it's, like it makes it difficult really, the concerns we have are not shared and they're not known as well. And I think that's why it could be a possibility that's why Asian people have, like, more stillbirths 'cause they're not talking about it [pregnancy] as much like, you know, what's your concern? (BM6B).

> I think they just don't understand what you're going through, I think that's what it comes to; they don't understand it that's why they don't want to talk about it, and they don't really want to get that personal with you 'cause, you know, some people think like, you know, you should be reserved about these things (BM6B).

She explained that any conversation or enquiry about the mother's pregnancy was at a superficial level only:

> I don't know, people – if I was completely honest with you the (inaudible) just had a look at it and if you're having a baby, okay, that's great, make sure you're healthy, yeah? That's how they are (chuckles) that's what they do, you know, make sure you're healthy, make sure the baby is healthy, and that's it. Are you having morning sickness? That's all they ask they don't really go too deep into it; I don't think they're really bothered about it you know (BM6B).

She suggested that a possible reason for the reluctance to discuss issues was out of fear of information being misunderstood and miscommunicated to other members of the local community;

> I think they are, like, "Oh I don't want to share my story with another girl and then she could go home, and she could talk about, you know, my issues". And, you know, say like I said to you about my husband and my mother-in-law, that could be portrayed in another way in another household and the Asian community is being portrayed in a different way, it is really private, and it is really hard to talk to another that you don't know, you know, about what you're going through because it can be taken another way and it could come back to you that your mother-in-law (BM6B).

She was the only participant who described the cultural expectations within Pakistani and Bangladeshi communities with respect to extended family living practices (although she did not currently live with her in-laws) and the housekeeping and caring roles that daughters-in-law are expected to perform for the whole family.

> There's a lot of like – especially when you're newly married and if you have a baby early straight after marriage, that's within a year you have a baby but then you still have your duties as a daughter-in-law to do and in an Asian country they (inaudible, garbled) that's very important, if you don't do it then you're just going to have like a bad name about you (BM6B).

Additionally, she explained that grieving is a personal experience, but in Pakistani and Bangladeshi communities, it is looked down upon, and she explained how she felt unsupported.

> I think grieving is something you have to do on your own – with the Asian community it's something to look down on, you know, you don't have to grieve, what are you grieving for, in fact there's something bad to grieve, and it's really stressful, and you feel like you're only – you're going through it yourself no one is supporting you around you (BM6B).

7.2 Key findings

The following similarities were identified:

- Pregnancy was perceived as stressful, with heightened anxiety towards other and future pregnancies, following the loss of their baby.
- The experience of SB induced even more anxiety and fear.
- The mothers perceived the timing of the death (e.g. early – miscarriage, later – stillbirth or neonatal mortality) was associated with a corresponding gradient of grief.
- The mothers all experienced intuition that something was wrong.
- The participants had poor levels of pregnancy information, in particular about possible complications of pregnancy, including perinatal mortality and the correct behavioural actions for women to take.
- The subject of perinatal mortality and pregnancy loss were difficult to talk about, and the experience affected the whole family.
- Participants had limited understanding of the adverse risks associated with having scans, which influenced their uptake behaviour.
- Poor understanding of the post-mortem examination and delays in receiving results contributed to parents' decisions not to have one.
- Participants felt that they were an extra burden to already busy staff.

- Broadly, participants were satisfied with their overall care. However, they reported some difficulties:
  - The timing of bereavement counselling contact was not helpful.
  - There was evidence of poor communication between primary and secondary providers regarding the infant death which resulted in unnecessary distress to the mother.
  - Midwives were poor in answering the phone or returning phone calls.

    - After their bereavement, mothers were sent home or placed in a ward with mothers expecting live infants; both these situations caused distress.
    - Levels of support were assumed (by staff), and participants often had to support the wider family at the time of their baby's death.

The following key differences were found:

- The topic of pregnancy was not openly discussed in Bangladeshi families as it is considered a private matter.
- Cultural beliefs around certain food items, believed to be beneficial or detrimental in pregnancy, guided Pakistani or Bangladeshi mothers' dietary intake.
- There was limited awareness of the risks associated with consanguinity.

7.3 Summary

This chapter has presented the findings from the interviews that took place with the bereaved mothers. In conjunction with Chapter Six, it addressed the second objective 'To explore the similarities and differences in maternal health beliefs that influence health behaviours in perinatal mortality in Pakistani, Bangladeshi and WB women, through the maternity care pathway'.

Three main themes emerged from the narrative: knowledge and information of pregnancy and perinatal mortality, attitudes and perceptions of pregnancy and perinatal mortality and experiences of maternity services. Similarities and differences, where relevant, were highlighted. Importantly, the majority of the findings showed similarities with the participants' health beliefs, knowledge of risks and their descriptions of their experiences of Luton's maternity services.

It was evident that the participants had limited pregnancy-related knowledge and understanding of risk, especially regarding possible complications and the correct health behaviour should they have concerns. This was made worse by their perception that the HCPs were overstretched and this made them reluctant to express their needs. Also, they did not properly understand the PM examination or anomaly scan, and this contributed to their decisions not to undertake them. Consequently, their health behaviour was guided by their previous experience and knowledge or that of family and friends.

The participants found that experience of SB was stressful and reported heightened anxiety towards future (other) pregnancies after the loss of their baby. Moreover, the death was found to affect the whole family and was very difficult to discuss, such that mothers were left supporting other family members. Interestingly, the mothers reported a sense that ‘something was wrong’ before the intrauterine death was confirmed.

Overall, participants were satisfied with their care – especially at the time of delivery of their deceased baby. However, some unsatisfactory experiences were shared, which included poor communication between primary and secondary providers regarding the dead baby, placing the grieving mother in an environment with birthing mothers – which resulted in undue distress for the mother, or failures of midwives in returning mothers’ phone calls when they had concerns. Moreover, the timing of being offered bereavement counselling was also noted to be unhelpful.

Differences which centred on the mothers’ ethnicity and cultural practices were identified. For example, in some Bangladeshi families pregnancy is not openly discussed. Additionally, there was limited awareness of any risks associated with consanguineous marriages. Cultural beliefs surrounding ‘food items’ that were believed to be beneficial or harmful to the mother or baby during pregnancy contributed to dietary health behaviour during pregnancy for Pakistani and Bangladeshi mothers.

Chapter 8: Staff perspectives of the service needs of women

8.1 Introduction

This chapter provides the findings from three FGs and three face-to-face interviews that were designed to address the third objective: Ascertain maternity HCP views on the service[146] needs of Pakistani, Bangladeshi and WB pregnant women. FG discussions and face-to-face interviews were held with HCPs (i.e. midwives [community and hospital based], student midwives, community workers, practice nurse [PN], health visitor [HV] and a General Practitioner [GP]), working with women in the maternity care pathway[147].

As mentioned in Chapter 4, Section 6, the FG and SSI were carried out in English and were audio-recorded (following consent) and transcribed verbatim. The sample structure of the FG and interviews were not designed to be stratified by job role, however, for reasons of practicality, this is what transpired in the field. Detailed characteristics of the participants who took part in the FG and SSI are detailed in Section 8.1.1. The narrative themes are described using participant verbatim quotes to support the descriptions (Sections 8.1.2–8.1.4) and ethnicity is only stated where explicit differences were described by the participants. Any identifying participant information was removed. The coding key for the FG and SSI is found in Table 30. The coding framework for the transcripts is in Appendix 25.

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[146] ‘Service’ refers to community and hospital based NHS services.
[147] ‘Maternity care pathway’ refers to preconception care, antenatal, intrapartum and postnatal care.

Table 30: Coding key for HCP FG and interviews

FG	Interview	FG code	Participant number	Ethnicity	Coding example
1		FG1	P1-2	all WB	SFG3 P4-WB
2		FG2	P1-10	all WB	
3		FG3	P1-9	P1 –P4 = WB P5 Pakistani, P6 –P9 = WB	
	1	PN1	P1	WB	
	2	HV1	P1	Black African	
	3	GP1	P1	Pakistani	

Section 8.1 begins with descriptions of the characteristics of each FG and SSI (Section 8.1.1) and continues with presenting the main themes and sub-themes which emerged from the transcripts (Sections 8.1.2–8.1.4). Three main themes emerged from the data: staff perceptions of mothers' awareness of risk, maternity services provision in Luton and barriers to service use. Several sub-themes also emerged, and these are described fully. Figure 28 shows the themes and sub-themes.

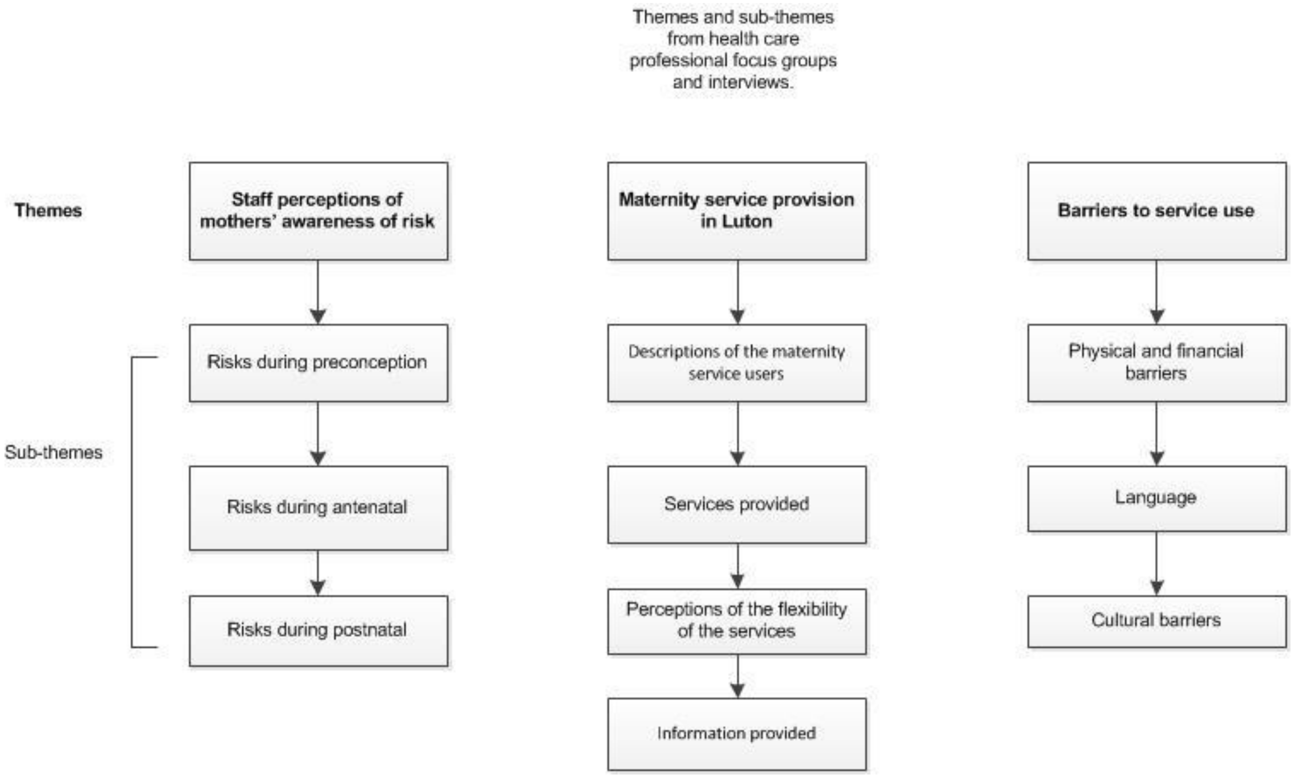

Figure 278: Themes and sub-themes identified following health professionals' FG and interview

8.1.1 Participant characteristics

Staff participants (hereafter referred to as staff) consisted of three health professional FGs, which consisted of predominantly community based midwifery staff. They reported working closely with the women delivering antenatal, intrapartum and postpartum care. In addition to the community midwives, there were three community support staff and student midwives. Moreover, to provide staff perspectives from the wider primary health care team, three interviews took place with a GP, PN, and HV. The FG and interviews took place between October 2015 and January 2016 and were held at the local hospital and GP surgeries located within Luton's wards of Lewsey and Biscot. The ethnic background of the majority of participants was WB, except for one Black African and two Pakistani participants. The number of participants who took part in the staff FG ranged from 2–10 health professionals, while the duration of the discussions lasted between 26 minutes and 117 minutes.

The midwives and community support staff reported working in advisory, supportive, clinical and emotionally supportive roles. The PN advised that she did not care directly for pregnant women unless they were in attendance for other chronic diseases such as asthma management. Pregnancy care was provided by the community midwife, located at the surgery or the GP. The health visitor reported that they initially met with pregnant mothers at 28 to 32 weeks of gestation. However, the midwife remained the primary health professional until after delivery and handover at approximately 7–10 days post-delivery. Therefore the health visitor's role was predominantly postnatal up to five years of age. The GP reported that he would offer medical and clinical support to the care of the pregnant mother throughout the maternity care pathway, including preconception advice.

8.1.2 Staff perceptions of mothers' awareness of risk

Within the main theme, three sub-themes emerged: risks during preconception, antenatal and postnatal period.

Risks during preconception period

The participants discussed their perceptions of mothers' awareness of risk factors during the preconception period for adverse outcomes in pregnancy. The majority of participants believed most women did not have much awareness to undertake preconception care. This is described in the following:

> Well a lot of them [mothers] don't have preconceptual care, they just say "Oh, I will stop the pill today… And we will try for a baby!" They don't access preconception care and they don't necessarily think … They wait until they have already conceived and then done a test but by then they are four weeks, by then (FG2P2-WB).
>
> I don't think there's a lot of information out there for preconception, unless you go through infertility clinics and then of course you get it all … But if you are just getting pregnant spontaneously, you know, there isn't (SFG2-P2).

One participant described the lack of local awareness of risks associated with consanguinity:

> I think if you are looking at preconception one of the things that strikes me from working in [name of district in town] is, where we have a large percentage of BME families, they have no idea about the problems within consanguineous marriages … there is a general lack of knowledge, including family history and that can be a problem (GP1-P).

The midwives showed conflicting opinions whether local mothers consumed folic acid before conception; some participants did not think the mothers did, as seen in the following:

> It's interesting because not lots of them take the folic acid, though …(FG2P3-WB).
>
> Preconceptually – no [folic acid] … (FG2P2-WB).

While other participants believed that the majority of pregnant women did consume folic acid:

> Yes, most people have [taken folic acid] (FG3P2-WB).
>
> I think that they do, [take folic acid] – I mean from the diabetic perspective I am aware that we need to prescribe it because they are

> meant to have a high dose of folic acid … I think that that awareness is there (PN1-WB).

Risks during antenatal period

The participants described the mothers' awareness of risks toward adversity during the antenatal period. The HCP described how the majority of women booked and attended early into maternity services, helping to identify risks earlier:

> The other thing is with women booked much earlier now so, we used to do like 12-week bookings, but now we do much earlier bookings (FG1P1-WB).
>
> We get them at 4, 5, or 6 weeks pregnant, which is really good for us because it means we're getting in much quicker (FG3 P3-WB).

The participants explained that each mother's family history was explored, to identify women with a higher risk of complications.

> Yes there are [families are diverse] now … It's so complicated now we have to ask, but we ask that everybody (FG1P2-WB).
>
> I guess that that is just down to the ethnic makeup of our particular locality, so you know, I think that in a way the women access our service are very varied. In terms of if they've experienced foetal loss there is really … (FG1P2-WB).

The participants discussed how the screening program is not universal, but is offered to women dependent on pre-identified risk factors. The following narratives show how Asian ethnicity, a raised BMI and vitamin D deficiency are identified risk factors:

> …. but being Asian[148] is a risk factor so that they will test those women. Before there was a quite confusing set of criteria that they had to meet before they would get tested [for diabetes], like relating to family history or BMI or things like that, but now actually they found that actually Asian ladies are at more risk so they will test anyone that is Asian … And it might even be that they will retest somebody that is Asian, with a raised BMI, or you know those women have an extra screening in place anyway … So … If their BMI is over 35, they have consultant-led care …(FG1P1-WB).
>
> So they found that a lot of them [Asian mothers] had a vitamin D deficiency is, and the babies weren't well so now they've started

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[148] The term 'Asian' is used in the narrative by the participants to typically refer to Pakistani, Bangladeshi and Indian women.

> doing that, and I think the earlier bookings and things, they are identifying risk factors sooner, I am not sure what else we could do? (F2P1-WB).

The participants described how most women undertook the blood test screening tests offered, as shown in the following:

> But the blood tests, the normal blood tests you very rarely get someone that says no, you know, the HIV and syphilis rubella and all of that … It's really rare … It might be a needle phobic woman … (FG3P4-WB).

However, they explained that the majority of women did not properly understand the benefits of the ultrasound scan(s):

> They don't understand why we are doing it … quite often, quite often they think they are just going to get a picture! (FG1P1-WB).
>
> I think that a lot of people don't realise that the scan is a screening tool so they have a scan expecting to find out the sex and finding out if everything is okay, but we have to counsel them that we might find something abnormal (FG1P2-WB).

Additionally, inadequate knowledge on the risks associated with screening tests:

> I've had one lady in fact, and she has declined all the scans, she's all right with sonicaid, but she won't have any scans, because she says that she has read something online – her husband has said that he has read something online and there is dangers with it …(FG3P3-WB).

Moreover, it was further explained that Pakistani and Bangladeshi mothers mostly decline the more invasive nuchal screening for Down's syndrome, stating it is "whatever God gives them":

> None of mine [Pakistani clients] well, very rarely, the ladies will have the nuchal scan, for the Down syndrome. They all declined that – yes, they say that whatever God gives them, that is what they will get … So … It is obviously their choice whether they have it done or not, it is their choice - informed choice … But very rarely do I have somebody that accepts it (FG3P3-WB).
>
> But the Asian women there is not too many that will have a nuchal test, I think generally they are aware but it's about what they going to do with the information (FG2P1-WB).

Some participants described mothers' misunderstanding of pregnancy-related health information. For instance, several mothers falsely believed they could accurately monitor their unborn babies' heartbeat:

> It is education as well, then my thinking it'll be all right – and maybe thinking it is just having a quiet time, like, I had one lady who thought that she could feel the baby's heartbeat, just by putting her hand on her stomach and it turns out that she did have an IUD[149] at 25 weeks (FG3P1-WB).
>
> Yes, one of my ladies said you can listen to the baby's heartbeat with on your phone, and it's not just her I've had other women say that before (FG3P3-WB).

And the participants shared their experience of the lack of awareness of the risks associated with consanguinity and adverse birth outcomes:

> If you are talking to the ladies they do not see it [consanguinity] as a problem (GP1-P).
>
> People need to be aware of what the problem is [consanguinity] – because they may not be aware, you only need to ask the parents in special care baby unit … Because a lot of our mums go through there … I have a lady who has had three children, and I told her, after the first pregnancy that the baby's deafness was due to the faulty genes … And that there was a chance that she would have other deaf children … [Inaudible] but she thought that because the chance was one in four she had already had her deaf child and didn't realise the risk carried on with each and every pregnancy … And she thought that it was in her husband's, the genes … And she kept going … And now she has three children, and they are all deaf (GP1-P).

One participant expained he thought it was the consequence of inadequate knowledge regarding heritability, which is evident in the following narrative:

> I think that is partly due to lack of knowledge, partly because of their belief system where it is okay to marry… There shouldn't be any problems. I think it is more about, from my experience, they seem to think that it's the genes from the father not from the mother … [inaudible] that's my experience (GP1-P).

Moreover, it was suggested that consanguinity was perceived as a sensitive subject within Pakistani and Bangladeshi communities:

> I know it's a really touchy subject, and people worry about talking about religion especially in the Muslim religion, people just don't talk about it … [inaudible] … So there is nothing that says shouldn't do … [consanguinity], because it's around in the religion, then it is something that you should do, and of course, it causes problems … But they don't see that … But they should be aware of that … (GP1-P).

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[149] IUD – interuterine death, otherwise known as a SB

The participants described their experiences of some women's misunderstanding of the causes of reduced foetal movements:

> … and when it stops moving, this means going to go into labour … (FG3P3-WB).
>
> … And the bigger you get the baby will move less and that's okay because you have less room … [so baby moves less] explanation for decreased movement (FG3 P6-WB).

Delays in mothers seeking help was also described by the participants. For instance, despite constantly being advised to seek midwifery/medical attention if the mothers suspected their baby was not moving, or moving less often, the participants shared their experiences of women delaying seeking help.

> Oh yes! I had one the other week … She said that the baby hadn't moved three weeks! (FG3P4-WB).
>
> I would say, quite often they would phone in the morning and then they won't come in until four o'clock in the afternoon, and we have said you should come in and we will check you over (FG1P1-WB).

The reasons for the delays in seeking help were described by the participants, and involved mothers waiting for their partners to come home before bringing them to hospital:

> Because they had to wait for someone to bring them in, or they had to wait for someone to finish work to bring them in, and get childcare for example and then that delays their access to care, so although they know they got to come in – it may delay it (FG1P1-WB).

Participants described how they did not perceive that any one ethnic group was at higher risk of stillbirth or neonatal mortality than another:

> Years ago used to be specific groups [at risk], but I don't think it is so much now (FG1P1-WB).
>
> No there isn't … [a specific ethnic group suffering perinatal mortality] – you can't really put them into one group specifically (FG1P2-WB).

Risks during postnatal period

The participants described their experience of mothers' awareness of risks associated with the postnatal period. Differences in breastfeeding behaviours between Pakistani, Bangladeshi and WB women were described. For example, they described resistance in Pakistani and Bangladeshi mothers to breastfeed in the early days of pregnancy:

> Breastfeeding as well … There might be differences with breastfeeding, is not so much now but years ago they didn't feel it was right to breastfeed for the first few days. And I don't think so much of a problem now … But it certainly is some people so they still need educating around that (FG1P1-WB).

> Breastfeeding is one of the things that we talk about and especially with ethnic minorities, and because it's diverse, people have different beliefs on breastfeeding (HV1-BA).

In addition the participants described how they perceived the Pakistani and Bangladeshi mothers or mothers-in-law discouraged their daughters/daughters-in-laws' breastfeeding behaviours:

> And they do what their mother did … Or what their mother-in-law did … it's the same as with breastfeeding isn't it? You do what your parents did … Or you do what you're advised to do … (FG P1-WB).

> I would say that British Asian girls would come to us and we'll have a full-on discussion and say yes, yes, yes, this is what I want to do, I am taking my vitamins, I want to breastfeed, I want to do this, this and this and they say all that sort of stuff, but when we see them at home, the baby is with her mother-in-law with the bottle, and the mother will say that she is desperate to breastfeed but the mother-in-law won't let her have it, and things, but they are getting much, much better ... So they say "No I want to breastfeed it's better I want skin to skin" (FG3P6-WB).

The participants also described how women from some ethnic backgrounds co-sleep with their infant and were unaware of the recommended safe sleeping position:

> … safe sleeping with them … but some of them are not actually aware, and if we talk about safe sleeping, the department of health guidelines talk about laying the baby on their back foot to feet, then you come across some people from different ethnicities who say "Oh no, no, no, where I come from, we co-sleep and we lay the baby on their side", but we tell them that no this is the guidelines you need to follow, and sometimes they might challenge you. "Oh, but there isn't many cot deaths" and you can say that how would they know? (HV1-BA).

> We have to look at the sleeping arrangement which is very important, especially if there was a previous death in the family, and child cot death is very rare but it happens so again, if there've been previous deaths in the family, we actually have to work with the mother and actually offer like, practical demonstration to them, give them leaflets for them to have an informed knowledge (HV1-BA.)

8.1.3 Maternity service provision in Luton

Four sub-themes emerged from the main theme of ‘maternity service provision in Luton’.

Descriptions of the maternity service users

The participants reflected on the diversity of their local population. All the participants described the local population in which they worked, as being perceived to be predominantly deprived. However, the participants also explained that while there was much deprivation within the local area, not everyone was actually deprived. This is seen by the following narratives:

> Luton is very needy (laughs) and there’s a lot of … It’s deprived, definitely deprived … so if you went into a family, a house and both parents are unemployed, or you went into a house, and the mother is a single mother with children unemployed and they have no money, and they are actually struggling, there is a food bank that we can actually make arrangement for them to get food, if they have … (HV1-BA).
>
> Half, maybe a bit more, maybe about 60 percent I’m thinking about our caseload [are deprived] (FG3P2-WB).

The ethnic diversity of the town was described as increasing, which has resulted in greater diversity of family origins[150]. Consequently, the participants described the ethnicity of the local population as being ‘varied’:

> Is very varied … Very varied … We cover quite a lot of different communities, so we cover a lot of Polish, Asian community, African community, and Asians (FG1P1-WB).

The participants suggested that deprivation was associated with ethnicity, as seen in the following narrative:

> It [deprivation levels] depends a bit on ethnic background I think, to an extent (FG3P4-WB).
>
> Their [Asian] homes tend to be poorer as well don't they? The Bangladeshis, yeah. The partners do not have such good jobs (FG2P1-WB).

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[150] The Family Origins Questionnaire evaluates the genetic risk of certain heritable disorders.

The participants believed the majority of Pakistani and Bangladeshi women were unemployed, staying at home looking after children:

> They [Asian women] don’t tend to work … they do work within the house … (FG2P3-WB).
>
> I think they [Asian women] just see it as that is what their role is. They don’t see that they should necessarily have a career, or have a job. I think that is why they have so many children, quite often (FG2P2-WB).

Moreover, participants spoke about the educational range of their mothers; some being well-educated, while others were illiterate. Additionally, perceptions that Pakistani and Bangladeshi women had lower levels of educational attainment were described:

> Well, you have people properly from educated backgrounds, to illiterate women single families, mums, dads (FG3P2-WB).
>
> Whereas a lot of the Asian women – I am not sure how many have had a lot of education, probably not a lot of education (FG2P3-WB).

The participants described other differences in Pakistani and Bangladeshi families; for example, extended-family living arrangements:

> I have a lot of that [extended family living] in my case load, where there is several families all live at one address, and quite often you are looking after three sisters at the same time … (FG2P2-WB).

Moreover, the participants explained that Pakistani and Bangladeshi mothers were thought to be younger when they conceived their first pregnancy, compared with other local women:

> Asian women are younger although that can be quite broad … They can be 20 or 21 then it can be having subsequent children when they get older (FG2P2-WB).

The participants thought that a high percentage of Pakistani and Bangladeshi marriages were consanguineous:

> I can’t remember what the rate was … I done a study day … I think it was on the level 3 safeguarding … And there was a lady that came to do the child death review, and she said I think there was something like 60-something percent, and it was to do with the genetics. Because a lot of the women are first cousins, there is a certain percentage, and the deaths were due to genetics due to chromosomes not matching up. I think that is one thing (FG3P3-WB).

Services provided

The participants described some of the local services for women and children, which included the HV services, Children's Centres, GP services, antenatal services (which included screening services and surveillance) and specialist diabetic services for diabetic pregnant women:

> Yes, and we have a specialist diabetic midwife … And we have a diabetic consultant and diabetic obstetrician and the dietician, so it is the combined clinic (FG2P1-WB).

And the services offered by 'Flying Start' to support women at home in a variety of ways, including accessing benefits and assisting women in form-filling:

> But we do ask, don't we? Do you know anyone that can help you fill it out? And this is what … this is what we [Flying Start] do! (FG3P4-WB).
>
> When you think about it – it isn't between nought to five – that's what we are hoping that the Flying Start workers will do. So mum is not sitting at home for five years depressed. We are hoping that we will access them earlier (FG3P4-WB).

The maternity services were described as 'appropriate' to meet the needs of the local community.

> Yeah, services and again I use this word 'appropriate', to meet their needs, so we run some clinics on the weekend, because it's very difficult, it's just so obvious to give a mother an appointment a three o'clock when they have other children, they have to do the school run, so how do they actually attend that service? (HV1-BA).

Perceptions of the flexibility of the service(s)

The NHS as an organisation was thought to be rigid and inflexible, with fixed hospital and or clinic times between 9–5pm, or 8–4pm. This is shown in the following narrative:

> I think in general you could criticise it [the NHS] for being that [service is inflexible] (FG1P1-WB).
>
> We [staff] can be flexible, but the hospital tries, but you know, if it is an afternoon list then it's an afternoon list … (FG1P2-WB).
>
> It's [antenatal clinic] between 8:15 and 3:45 [laughs] (FG3P4-WB).
>
> Well, our midwifery clinics are set days of the week but as far as I am aware, they offer appointments from eight o'clock in the morning right through till four o'clock (PN1-WB).

Contradictory to perceptions that the NHS organisation was rigid, the majority of HCP thought that the local HCP were flexible in meeting the needs of the diverse community it served. For example, midwives described offering drop-in sessions and the HV described weekend availability, which is evident in the following narrative:

> If a woman can't make … we are flexible insofar that if a woman couldn't make an appointment, because we have so many drop-ins now, they have that option, not for all of their maternity care really, but if they couldn't make it on a Wednesday, we have a Saturday and a Sunday one they can go to. Or if they DNA to the clinic in the week, we have the Saturday slot that they can be booked into that … but we don't do evening clinics, though, do we?(FG3P3-WB).
>
> So, morning appointments can be very difficult as well because if they have children, and if they have to take them to school, they can't make it, so we try to make the appointment flexible for them, and we run Saturdays, weekends as well (HV1-BA).

The midwives explained that women could be seen at different times and in alternate venues:

> And they can be seen at different venues; they could be seen at the clinic, or outside at another person's home or something … Anything like that by the midwives … and if they can't come here we can go out to them, so we tend to do that as well … We tend to visit, especially with the Asian communities where they tend to go and stay with family so we can go to the family's house if they are staying there, so we don't always visit their home, we might come visit somebody else's house … (FG1P2-WB).

The flexible working practices accommodating the needs of the mothers are described in the narratives below:

> It is about being flexible, so, when I am booking someone to see a consultant for the first time I will think how many children has she got, I won't book it for nine o'clock in the morning … (FG2P2-WB).
>
> I do try and accommodate them, wherever I can, I try and shift people around and juggle people, and people that want to come in the last appointment or before, we start early and finish late (FG3P4-WB).

Information provided

The participants explained that the majority of the pregnancy and health-related information was provided to the mothers during the 'booking' appointment:

> I think that once they come into hospital they are [provided with information] … but I can say once they come in, and they are booked, and they are seen by the midwives at home, they get given all the information then. They get a huge amount of information (FG1P1-WB).

The information that is provided was perceived to be helpful for the mothers, as seen in the following:

> I think most of the time, the information that we provide them with, they've always found them to be useful, especially with the [name], you'll find that people say "Oh, I didn't know that you could even lay the baby on their back feet to foot, the midwife did not tell me that, so that is really good. I didn't know about the skin to skin, I didn't know about the baby brain development" … so they actually gain some information, things that they don't even know (HV1-BA).
>
> And we signpost them, because the red book[151], when we do the new birth, we tell them all the out-of-hours services, and when we are not available, who they have to contact, it's all in the red book, so they know where to go (HV1-BA).

The participants also described their experiences of sharing pregnancy or baby related health information with local mothers and explained how they thought this was understood to be beneficial; this is seen in the following comments:

> Most of them are receptive to advice because you would find that they didn't know so it's just straight forward, they didn't know, now you have provided them with that information and you have actually given them leaflets to read, you have signposted them to available website to find out more information, and they are receptive to the advice we give them (HV1-BA).

The participants explained that they believed they provided pregnancy-related information to their mothers; however, there was a common belief among mothers that information had not been provided:

> I know that there is a big thing with the midwives, saying the midwives do not give the information out, and this is why it [stillbirth] is happening because we are not giving the information, but the midwives that I have come across I can't see how that is an issue … And we say it to every single woman that comes through the door, the same thing (FG1P4-WB).
>
> On the news, it is all about what care the midwife given it, and the stillbirth rate, and saying that we don't give information, and we don't talk to them about when the baby is moving and things like that … I have never observed that so I find it really bizarre … I hear every

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[151] The 'red book' refers to individual mother-held Child Health Records, issued at birth to all babies.

> single midwife constantly says if the baby isn’t moving, you know who to contact, you have the details, you can tell us 24 hours a day - delivery suite is always open. And that is why I don’t understand, on the news is being said that we are not giving that information, yet I don’t see that (FG3P4-WB).

The participants explained that pregnancy-related information was predominantly provided as paper-based leaflets, available in several languages other than English:

> There are a lot of leaflets in other languages and there are lots of languages out there – but they are all available in our language [English] (FG1P1-WB).

However, they also remarked that a restricted number of leaflets had been translated, into a limited number of languages:

> No, not information leaflets – not in their native languages, no. No – there is not enough [translated leaflets] (FG3P3-WB).

The participants discussed how mothers used various sources to access pregnancy information, including ‘*Dr Google!*’ (FG2P2-WB), but they also reported issues with mothers accessing unreliable information:

> I try and get them to use the NHS sites, but they still go with what they … someone else’s told them (FG3P4-WB).

They explained that the hospital website had lots of information including a virtual tour of the labour ward for mothers:

> There is an online website, there is a lot of information on there, and they can go online, and they can get it from there, and they can contact supervisors and get information from other … So a lot of it is online and in leaflets. There is a video that they can watch as well (FG1P1-WB).
>
> They do an online tour – online virtual tour online (FG3 P2-WB).

And the health visitor team supplied mothers with specific internet sources for information, for literate mothers.

> We also provide them with like, useful websites, department of health, [name], that they can turn to for guidance, and support on things like, if the baby’s not feeding well, not sleeping well, all the way to introducing solids, potty training and behaviour management, so in those groups, we actually signpost them to which site and other areas that they can read, if they can, for them to enhance their knowledge on that … (HV1-BA).

Some participants, however, acknowledged that not every woman might have internet access, and how women without access to the internet obtained the same information was unknown:

> There are quite a few videos on our own – the maternity services website – about services that we offer, but for people who don't have access to the internet, I am not sure …? I don't know? I guess it would be through the GPs (FG1P1-WB).

The participants identified differences in how they perceived WB and Pakistani and Bangladeshi women accessed pregnancy-related health information. For example, they stated that WB women were more informed and pro-active in their information seeking behaviour:

> Yes, my [WB] women have read all the books! They have done all their research (FG2P3-WB).
>
> WB women tend to have either downloaded apps on their phones, or they have read lots of information beforehand so preconception information … And they will have the folic acid and bits were as the Asian women won't … (FG2P2-WB).

The participants discussed how they perceived that South Asian women were more reliant on verbal information provided by family or friends, and in this instance, the HCP has no control over what is advised:

> They [South Asian women] access the basics, they don't necessarily access all the education, they are not very good at accessing that, although they are given the information, and they are all told exactly the same thing … But they do not access it … They rely on their families (FG2P2-WB).
>
> It's all about word of mouth and people knowing, so that is how they [South Asian women] get to know, so one person might know of the services and have the knowledge and they just pass that knowledge on, yeah that's how other people get to know (HV1-BA).

Pregnant or newly-delivered mothers are provided with important contact information/details for contacting maternity services, such as midwives or the health visitors, as seen in the following narrative:

> And we signpost them, because the red book, when we do the new birth, we tell them all the out-of-hours services, and when we are not available, who they have to contact, it's all in the red book, so they know where to go (HV1-BA).

The following narrative explains how once the mother has accessed the maternity services then awareness of other services is provided. Consequently, mothers who are pregnant for the first time may have little awareness of the range of local services:

> The only way they can get to know of the services available is via the Children's Centre, because that's where we actually you know, tell them by word of mouth or give them posters, they access other services like maternity services in Luton or women's centre, the [name] so they get to know of our services via other, you know, other groups or other support services, but again, their own community, their own people actually pass information on as well (HV1-BA).

8.1.4 Barriers to service use

Three sub-themes emerged from the main theme of 'barriers to service use'.

Physical and financial barriers

Several physical barriers in accessing maternity services were described, for some Pakistani and Bangladeshi women, such as having to wait for husbands or partners to provide transport, or permission to attend clinic:

> Dependent on their partners to take them there … Some of them [Asian women] are beholden on their partners to get them there, so if their partners are taxi drivers they won't take them there [hospital] (FG2P2-WB).
>
> … or they may not be allowed, I mean some families have a lot of control over the women in the family, so it may be that (FG1P2-WB).

In addition to women not having financial means to pay for transport:

> Over here it doesn't matter whether they're Asian or whatever they are … They don't have transport and they don't have money, they don't have access to actually get here … (FG1P1-WB).

And lack of childcare was also described as a barrier for women accessing services:

> … and can't get childcare for example, and then that delays their access to care, so although they know they got to come in it may delay it (FG1P2-WB).

Language

Staff identifies not speaking English as a barrier for mothers accessing maternity services, and understanding relevant information. Staff described the challenges of working with women who do not have a good command of English as they explain in that narrative extracts below:

> I think particularly if English is not their first language because we find that when they have had babies, and they bring them into the baby clinic, …They frequently ask things like, where do they go to get the baby weighed? And how do they find out about vitamins for their children? And even though they have the red book, and it has the health visitor name and the contact number at the beginning of the book, many of them do not seem to be aware that this is the person who is their first port of call to go to – so we have to highlight that to them (PN1-WB).
>
> The main one [barrier] is language, and knowledge about what to do in pregnancy … regards access, a lot of the ladies like to use family members … So they will come down to the surgery and ask for emergency appointments. But from a GP point of view, [inaudible], not having time during that appointment slot to maximise the health education and address other issues and also provide translation services (GP1-P).

Additionally, participants described how non-English speaking women may not ask relevant questions:

> The language barrier can also prevent them from actually asking questions. Yes, yes, definitely, the language barrier prevents them … (HV1-BA).
>
> I think if they don't have English as their first language then it can be different … Think that maybe where they get their advice is probably more likely to be family … (FG1P1-WB).

It was explained by the participants that it was not uncommon for family members to accompany non-English speaking women to clinic; however, this was not always considered appropriate, as exemplified in the following narrative:

> Her English was poor to non-existent, so she always used to attend with her teenage daughter to do the translations for her, and although she attended for diabetes one day, she also came to ask me about contraception. And I found it very difficult having to speak to this lady for different choices of contraception through her teenage daughter. I think that her daughter, on that occasion she was asking about whether she could have the contraceptive injection, and I had to try and clarify with her when she had her last period, had she had any unprotected sex since then, and it was a very uncomfortable situation

> to be in having to ask all these questions through the teenage daughter (PN1-WB).

Furthermore, sometimes this might result in the family member conversing with HCP without properly involving the mother, as shown in the following:

> There is an issue, though, when they decline an interpreter, and they say that their husband is going to be there, and then he says yes for her, and you have just to be – can you please tell her what we've just said? (FG3P5-P).

The participants also questioned the accuracy of relaying of important healthcare information when using family members:

> And it's how they are actually telling them … Because I can remember being on delivery suite and explaining that to them how about an epidural. And I have spoken for about five minutes about this epidural, and then they have said it in about, literally ten seconds, so you clearly haven't said all the information (FG3P3-WB).

However, the participants also described concerns that Pakistani and Bangladeshi mothers had in using professional interpreters, in maintaining confidentiality, particularly if the interpreter is perceived to be from the same community. This is evidenced in the following narrative:

> We have an interpreter at the hospital as well, and I refuse to use the interpreter from the hospital because I am so worried that she is from the community as well, and I am so worried that my women won't tell me stuff, so I just use the interpreting service because I am so worried because they are worried about her and the fact that she might say something. Even though, she is bound by the same confidentiality … I've just feel that, just because of that reason. So it is a reality definitely (FG3P4-WB).

Furthermore, the difficulties of building rapport with the mother when using the interpreting service was also described by participants, as the interaction bypasses the staff member and is between the mother and interpreter. This is evident in the following:

> … because it's the third person trying to build that relationship for you (FG3P1-WB).
>
> Yes, it is them building it … You feel that it is the interpreter building the relationship for you (FG3P4-WB).

In addition to the added challenge for staff of using telephone interpreting services and trying to build a relationship with the mother in that situation:

> Using one [interpreting services] over the phone is a nightmare, isn't it? You have to think about everything you want to say … but when you have an interpreter there with you can give much better information (FG3P4-WB).

Furthermore, there were concerns that this might have negative consequences when the staff discusses sensitive issues (e.g. domestic abuse):

> We do ask at booking – if it's appropriate – if there is any domestic abuse, if there is nobody there, but usually, I can't because even if I arrange an interpreter, there is always some family member there … (FG2P3-WB).
>
> I don't think they [non-English speaking mothers] give us the right answers … You can tell by looking at their faces … When you ask them about the domestic abuse, I do not think they tell us the entire truth (FG3P3-WB).

Cultural barriers

Staff shared their understanding and experiences of cultural and religious needs of Pakistani and Bangladeshi women. Several topics were described, issues surrounding modesty, being seen by a male professional, concealment of the pregnancy and confidentiality. The participants discussed the subject of 'modesty', understood that Muslim women are "*shy about exposing their bodies*" (FG2WB-P1), and this also included having male medical/midwifery staff attending to them. This is seen in the following narrative:

> Sometimes its fear, sometimes if you book a woman and she is consultant led care they are very much … Is that a man? But then you try and explain … That then becomes a barrier … Because they don't want to see a man but actually you try and explain that the registrar is female is who you will probably see, or we can book you under a female consultant, but you'll probably see her male registrar (FG2P1-WB).
>
> I had a woman who was having a home delivery because her partner didn't want to go into hospital and be seen by male obstetrician, and I have actually taken our midwives in a Bangladeshi premises, and they kept us waiting, and then they came in and they said we will see her [female midwife] but we won't see him [male midwife], so the midwife said if you won't see both of us then we will go – because we're both exactly the same (FG2P2-WB).

The participants described how cultural norms and expectations shaped the mother's experience and might impact on her health behaviours in pregnancy, irrespective of what the latest research evidence and clinical guidance might suggest. This is seen in the following:

> Like you say, their families often share similar values it is part of their culture sometimes that they will make the decisions that they make, so it isn't anything that is based on evidence, or education or anything like that … It is just because that they normal and that's what people in their communities do (FG1P2-WB).
>
> What is your normal? If it is normal in your community and normal culture, it's what you see, and it's what you will do (FG1P2-WB).

Another example, the term 'pregnancy' was explained to mean 'illness' and being pregnant results in increased attention from her husband and family. This is illustrated in the narratives below:

> I remember speaking to a health care assistant at the hospital and she said that women are taught that it [pregnancy] is more of an illness than a natural thing to be going through, so sometimes I wonder whether they over exaggerate their symptoms (FG3P4-WB).
>
> I think that it [pregnancy and illness] is the attention seeking mechanism. I know that it sounds really sad, but this is just my personal experience. When I went abroad back to Pakistan here are women there … and she says … "This woman is possessed … This woman is hallucinating" … "What do you mean she is hallucinating? What do you mean she's possessed? What's wrong with her?" "Oh, she's got a really high fever, and she's having seizures" … Anyway I've gone in … She's having a seizure … So I couldn't help myself – I had to go and have a look [laughs] .... and basically this woman seems absolutely fine to me yeah? And I am thinking, what are you doing? Why are you doing this? It is really sad, but when you sit and look at them, and you watch, they work really hard but do you get the thanks, or what do they get in return for it? They work … Is the sense that they are not taken out anywhere, you are not treated special, this is your job you do this … (FG3P5-P).

The subject of domestic abuse was also explored by the participants, who felt that in Pakistani and Bangladeshi families it was normal and not widely disclosed, due to fears of bringing shame on the family.

> And there is a lot of domestic abuse within certain cultures as well which is very covered up as well, even not just from the partner, but from the mother-in-law, or the family as well … There is a lot of abuse … Well, I say abuse that is a bit of a generalisation, but there is that element there as well … And it can be quite dangerous for them as well if anyone was to find out that they were pregnant so, it can be quite … They could lose their families and everything … They could

> have no home to go to if they got found out so it's very important to them. They might even come out of their own area (FG1P2-WB).
>
> Yes, it's [domestic abuse] high but in some cultures like the travellers domestic abuse is the norm … It's their normal behaviour, so they don't see it as domestic abuse, they just, it is quite normal. The men in the Asian communities see it as normal behaviour, don't they? (FG2P2-WB).

The participants also discussed their perceptions of the autonomy of Pakistani and Bangladeshi mothers. It was thought that husbands or mothers-in-law impacted important decisions regarding the pregnant women's care needs and this influenced the mother's access, and utilisation of maternity services.

> They [South Asian women] are very influenced by their families … And their families' advice – so, we have no control over that. We try to educate families as well, but it's very difficult because they do listen to their families and in particular to their mother-in-laws. They do exactly what they've been told to do, regardless of what we tell them to do (FG1P1-WB).

The religious needs of privacy and prayer, especially at the time of death of an infant were described by the participants, in addition to the participants' understanding of Muslim women's not being involved in their child's funeral[152]. This is apparent within the following narrative:

> Yes special prayers for the babies … We give them time for that … And they have presented the times that they may need to have some privacy, and they have to be visited by imams, and someone comes to do prayers for the baby we do allow for that … (SFG1P1-WB).
>
> But the whole thing around death is very male dominated; the men go to the mosque, don't they? And the women stay at home … Once the funeral has taken place, the woman has nothing to do with it (FG2P1-WB).

Women's religious attitudes to post-mortems were also described by the participants; whereby certain religions prohibit post-mortems and terminations:

> Post-mortems, in particular, some cultures really wouldn't have a post-mortem and investigations done because of religious beliefs or cultural beliefs,.... The same with screening tests. And terminations, that certainly something that certain cultures would not consider, regardless of what the outcome would be … As a prognosis (FG1P2-WB).

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[152] Culturally women are considered to be of 'faint heart' and therefore discouraged from attending funerals (Sajid, 2003).

A small number of participants described their experiences in dealing with concealed pregnancy, particularly with Pakistani and Bangladeshi mothers. The participants suggested fear and shame might be the reason for this:

> So, I have seen quite a few girls that have got pregnant and they are with their boyfriends, which is not the done Asian thing because she should be married. So they haven't told their family that she is pregnant but the boyfriend knows, and they say that they need help because they are now in danger of honour-based abuse – if the family find out that they are pregnant, we do get that. That is a big safeguarding concern of ours (FG3P5-P).

Many participants also described their experiences of how Pakistani and Bangladeshi mothers had asked the staff to be particularly discreet concerning their antenatal visits, in order that the pregnancy remained private:

> I've only had it with the mother-in-law, she didn't want the mother-in-law to know, and she lived next door, so I had to hide and run in! And I had to phone her for when I was outside, but it was in the early days … It was up until about twenty weeks she wanted to keep it quiet (FG3P4-WB).
>
> I have been asked once to park down the road. She said do you have a marked car? And I said no … [laughs], and then I said to her, is there a problem me coming to your house? … And she said "No, no it is just that all of my neighbours know my mother and my mother doesn't know that I am pregnant (FG2P3-WB).

Moreover, several participants also described how many Pakistani and Bangladeshi mothers did not want other South Asian staff looking after them, for fear of their personal affairs being disclosed to other members of their family or community. This is seen in the following excerpts:

> We have had a couple of ladies that said that they do not want to see an Asian midwife … yes, there was one in the diary the other day, she was an Asian girl herself, but she didn't want to see an Asian midwife post-natally … they don't understand that there is [professional] confidentiality do they? (FG3P4-WB).
>
> I think that comes on trust issues, because it means that the Asian community is tight knit, so she must be related to somebody, somebody, somebody that might know her, who might go home and tell her sister, or her mother, or her husband or somebody about her pregnancy and it will get out (FG3P5-P).

Additionally, the participants spoke of the of the influence of the mother-in-law and other family members in South Asian families, which they thought impacted Pakistani and Bangladeshi women's health behaviours in pregnancy;

> And I always get them say to me, “But my mum said this” … “My mother-in-law said that” … So, yes it is trying to re-educate (FG3P3-WB).
>
> It is no specific although mainly Asian, but this [peer influence] goes for other communities, lots of cultures are very family orientated, much more than the British white family are (FG1P1-WB).

The participants explained the mothers’ inadequate knowledge of pregnancy was also a barrier to mothers accessing services. This was thought to be a consequence of a lack of awareness of the local services, or being unaware of the need to know about pregnancy-related information:

> I think as well that with my Asian women that hardly any of them are primas – so it is not the first time baby, they are on their second or third or fourth or fifth, so they are experienced mothers, so I think that sometimes is like us trying to … What’s that saying … teach your mother to suck eggs … (FG3P3-WB).
>
> And again the thing is they not aware, then they would not be aware to come in and ask! … so it’s a vicious circle … So if they don’t know that a service exists how would they know to come in and ask about it? I suspect therefore that they are very dependent on word of mouth and friends’ experiences and family experiences to glean that information (PN1-WB).

The participants thought that newly arrived migrant mothers would be the most disadvantaged, and reliant on family to guide her through the pregnancy:

> Because I am Asian I think it does depend on the level of education, and if you have just come from abroad and the UK on these are because you are married… and you got pregnant, you will do what your mother-in-law tells you because you do not know any different. So regardless of what the midwife is telling you your mother-in-law will come with you because you don’t know, and she will say yes, yes, yes. But she probably came about twenty-odd years ago over to England as well and didn’t know the stick of English herself at the time. But she does know where the hospital is and where the doctor’s is, so she knows a little bit more than what you do, so therefore she will go with you, and I think that makes a big, big difference as to how much they take in and what they are saying (FG2P5-WB).

Additionally, the participants described their experience of some Pakistani and Bangladeshi women delaying in getting timely support from their families when things go wrong:

> And of course it makes a big difference, whether you live in an extended family and whether you have a few kids to look after, and if you think the baby is not moving, and then you think, I’m going to call him back from work now? To come back and take me? … And then you look at the mother-in-law, and you say the baby is not moving,

> and she says well I am sure it’s going to be fine … And you are thinking that I have to leave the kids with her … And I have to call him back, and when I get there it will be we went last time, and there was nothing wrong, and you’re going again? (FG3P5-P).

8.2 Key findings

The FG and interviews with health professionals revealed several important findings:

- The staff believed that they provide extensive pregnancy related health information, which they assumed was understood and positively impacted on mothers’ health behaviours; for example, mothers seeking prompt medical attention in the event of reduced foetal movements.

- HCP understood that several mothers had lower levels of health literacy, not fully understanding the implications of delayed help, which subsequently impacted negatively on their health behaviour.

- HCP perceived that WB mothers were well informed and were more proactive in seeking information regarding their pregnancy than Pakistani or Bangladeshi women who used verbal information from family and friends.

- HCP provided pregnancy information mainly in leaflet form. However, the internet was widely used as a source of information for many women; however, staff had concerns regarding the accuracy of some internet sources.

- NHS staff explained that maternity services were considered to be ‘appropriate’ for the needs of the local population however it was staff offering flexible services that helped to meet the needs of local women; the NHS as an organisation was rigid.

- Cultural and religious needs of Pakistani and Bangladeshi women were identified, such as the need for prayer time and facilities, and adhering to Islamic instructions for modesty, fears around staff maintaining confidentiality within the community and risks associated with consanguineous marriages.

- Several important barriers were identified for Pakistani and Bangladeshi women accessing services:
    - Not being proficient in English was considered a challenge and the use of translation services was less than ideal as there are problems with rapport building and possible disclosure and discussion of sensitive information.
    - Using family members to help translate during consultations was not thought to be helpful as there are concerns whether the health information is accurately translated. Moreover, some Pakistani and Bangladeshi mothers were not considered autonomous in their decision-making of pregnancy-related health behaviours.
    - Domestic abuse was perceived by the staff to be common and not widely disclosed through fears of the mother bringing shame on the family.

8.3 Summary

This chapter presented the findings following the FGs and SSI with staff working on the maternity care pathway. Three main themes were identified: staff perceptions of mothers’ awareness of risk, maternity service provision in Luton and barriers to service use (shown in figure 28), which have addressed the objective ‘Ascertain maternity health professionals’ views on the service needs of Pakistani, Bangladeshi and WB pregnant women’.

The discussions with HCPs have described the services provided in Luton along the maternity care pathway, and has presented their views on the service needs of women, including Pakistani, Bangladeshi and WB women in Luton. Some contradictory findings were identified. It is evident that there is a mismatch between what pregnancy-related information HCPs perceive they have provided for mothers, and the limited level of mothers’ pregnancy knowledge, which then influences health behaviour and contributes to detrimental effects on birth outcomes, such as delays in help-seeking or not consuming folic acid to prevent congenital disabilities in the early weeks of meiosis.

Chapter 9: Converging the results

9.1 Introduction

This study has taken a converged mixed-method approach (Chapter 4, Section 4.3) (Creswell and Plano-Clark, 2011b). This chapter presents the converged results/findings from Chapter Five (the statistical analysis of the secondary CMiS data), Chapter Six (the findings of the FG with lay mothers), Chapter Seven (the findings of the face-to-face interviews with bereaved mothers) and Chapter Eight (the findings of the FG and face-to-face interviews with HCP). Application of the intersectional approach has provided a useful conceptual framework to understand perinatal mortality and is used here to converge the results/findings, in order to identify simultaneous and aggregated factors that contribute to perinatal mortality. Additionally, by converging the quantitiative results and qualitative findings, the similarities *and* differences between Pakistani, Bangladeshi and WB women becomes clearer; an important factor in the current study (Creswell and Plano-Clark, 2011b).

9.2 Converging the results using an intersectional approach

The intersectional approach was used as the conceptual framework for this study. Chapter Three, Section 3.3 discussed how this is a useful approach to understand similarities and differences between the different participant groups, and understanding how determinants simultaneously intersect to explain the experience of perinatal mortality for Pakistani, Bangladeshi and White women. Figure 29 shows how categories (i.e. heritable, structural factors, health beliefs and health behaviour and SES factors) intersect. It is important to note that while this study reports the converged findings in a linear way (as required by the format of this document), the results and findings intersect simultaneously (i.e. aggregated).

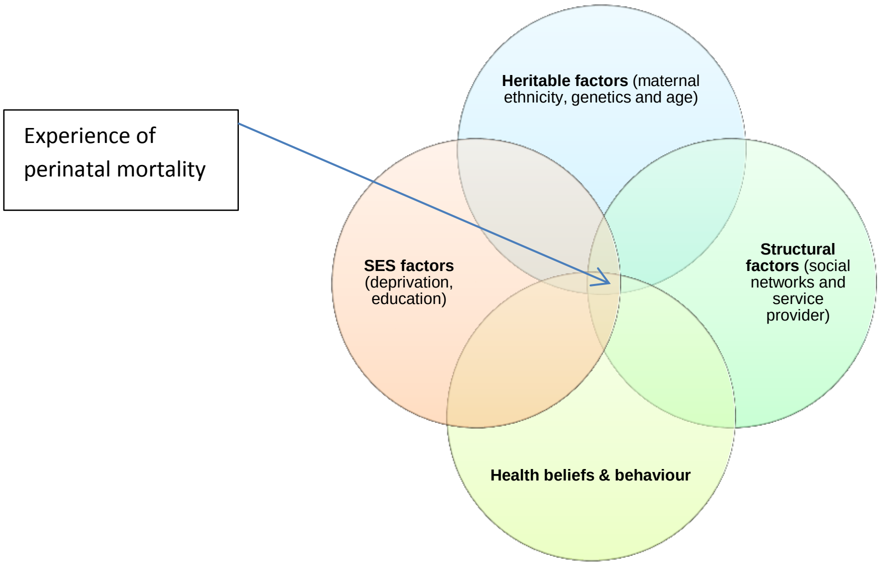

Figure 29: Diagram depicting intersections of the experience of perinatal mortality

The converged results/findings are presented by each intersectional category (Sections 9.2.1–9.2.4), before the intersecting factors are discussed in Section 9.2.5.

9.2.1 Heritable factors

There were some findings and results specific to ethnicity, genetics and maternal age. These are discussed next.

Ethnicity

A number of factors related to ethnicity were identified.

- WB mothers: were over-represented in the cohort by young (<20) and older (>35) maternal age, in addition to parity one and seven and identified as smoking during pregnancy. Additionally, they were over-represented with a high BMI (>30kg/m^2). Furthermore, HCP perceived WB mothers to be more proactive in seeking pregnancy-related information and WB women seldom reported the use of cultural therapy, with the exception of using charms.

- Pakistani mothers: experienced significantly lower birthweight infants (compared with WB women), had a higher rate of pre-existing DM, and GDM, in addition to parity[153] two, three and four. The results also showed that they booked later into maternity services and were over-represented with a lower BMI (<18.5kg/m^2). Pakistani mothers booked later into services compared with WB women. Cultural therapies were common, especially cultural beliefs around eating specific food items which guided the mothers' dietary intake. HCP identified cultural and religious needs for Pakistani mothers (need of prayer time and facilities and modesty).

- Bangladeshi mothers: had the lowest birthweight infants, were over-represented in the GDM group and in the insulin group. Bangladeshi mothers also booked later into services, although slightly more booked before 12 weeks than Pakistani mothers. Pregnancy was not openly discussed, and the use of cultural beliefs around certain food items guided the mothers' dietary intake. Bangladeshi mothers are more likely to use ST, compared with Pakistani or WB women.

A number of findings were relevant to both Pakistani and Bangladeshi mothers:

- Limited English language proficiency contributed to the confidence of non-English speaking participants when communicating their needs with HCP in addition to being a barrier to disclosing sensitive information.

- Some cultural and religious needs of Pakistani women were identified by HCPs – the need of time and privacy for prayer, issues around modesty and confidentiality and HCPs identified risks associated with consanguinity. HCPs also perceived that Pakistani and

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[153] Referring to delivery of infant <24 weeks of gestation

Bangladeshi mothers were seldom employed, were educated to lower standards (than WB women) and were not autonomous in their decision-making, and they believed domestic abuse was common and rarely disclosed. Additionally, they stated Pakistani and Bangladeshi women relied on verbal information from their family and friends.

- There is pressure on all Pakistani and Bangladeshi women from the wider community to conceive quickly after marriage and often this expectation may include preference for a boy, which was upsetting to the participants in this study.

Genetic factors

The findings showed that both Pakistani and Bangladeshi mothers had some awareness of the risks associated with consanguinity, which was not found with WB mothers.

Age

- Specifically the results showed that WB women were over-represented in younger (<20 years) and older (>36 years) age groups. Both these age extremes are associated with higher rates of complications, although for different reasons (Chapter Two, Section 2.5.2) (Fretts, 2005; Draycott, Lewis and Stephens, 2011; Flenady *et al.*, 2011; Leon and Moser, 2012; Kenny *et al.*, 2013; Walker *et al.*, 2016).

9.2.2 Structural factors

The results identified the following structural factors relating to social networks and service providers in Luton.

Maternity services in Luton

- Overall participants were satisfied with their maternity care. Moreover, HCP argued that the services that they provided were ‘appropriate’ to the needs of the community.

- The structure of the maternity services (e.g. appointment times and clinic sessions) were considered rigid and inflexible. It was apparent that some staff would work flexibly to accommodate the needs of their population.

- The mothers described feeling a burden to the staff who they perceived were already extremely busy, and the mothers (regardless of ethnicity) reported that they did not feel that the staff properly listened to their concerns. Consequently, the mothers’ experience was dependent on their relationship with maternity staff, in particular with the midwife.

- As a result of failed communication (of the stillbirth) between the hospital staff and primary care services, the bereaved mothers experienced unexpected visits, questions and avoidable distress.

- The bereaved mothers complained that once the SB had been confirmed they were either sent home or placed on a ward with other women who were due to deliver their live babies at any time – both situations were considered very stressful.

Social networks

The findings revealed that the individuals involved in supporting the pregnant mother at home varied according to ethnicity.

- Pakistani and Bangladeshi mothers had support from their husbands, mother-in-law and sisters-in-law.
- WB mothers had support from their partners, friends or parents.
- Support from individual HCPs to the pregnant or newly delivered mothers varied, and the extent to which their support was considered to be helpful, also varied.
- The women (regardless of ethnicity) reported that the support was considered positive and negative and HCP assumed levels of social support without checking.

9.2.3 Health beliefs and health behaviours

When considering the findings regarding health beliefs and health behaviours there were many similarities and a few differences.

Similarities of women's health beliefs

Several similarities in health beliefs were found, regardless of their ethnicity:

- Pregnancy was perceived as a stressful, life changing event, where women experienced many fears and anxieties, which were exacerbated if they had suffered bereavement.

- Many women experienced personal intuition regarding their pregnancy health status.

- Many mothers had idealised and normalised attitudes toward pregnancy and limited knowledge of pregnancy-related information.

- Many women also had fatalistic attitudes toward their pregnancy.

- There was limited awareness of risk factors for perinatal mortality and what to do when things go wrong.

- Much of the information that women accessed during pregnancy was from previous experience, knowledge of peers, or the internet, but the accuracy of these sources could not be assured.

- The subject of perinatal mortality and pregnancy loss is difficult to talk about, and the experience affected the whole family. There was limited understanding of the post-mortem examination and delays in receiving results, contributing to parents' decisions not to have one.

- Participants felt that they were an extra burden to already busy staff.

Differences in health beliefs

There were a number of differences identified in the mothers' health beliefs.

- Pakistani and Bangladeshi women were more aware of the increased risk of congenital anomalies in consanguineous marriages than WB mothers.

- Pakistani and Bangladeshi women's fatalistic attitudes were associated with 'the will of God/Allah'.

- Pregnancy is a topic which is considered a private matter and not openly discussed in Bangladeshi families.

- English-language proficiency contributed to the confidence of non-English speaking participants when communicating needs with HCP.

Women's health behaviour

There were similarities in women's health behaviour:

- The majority of women co-sleep with their babies in the same bed and position their babies on their sides in their cots, contrary to health advice.
- The majority of women confirmed that they did not take folic acid before conception.

And a few differences were identified:

- Bangladeshi women are more likely to use ST, whereas WB are more likely to smoke tobacco.
- Using cultural therapies was more common in Pakistani and Bangladeshi communities, than WB communities.

9.2.4 SES factors

The specific SES factors[154] were as follows:

- The results of the analysis of the CMiS data[155] for 2014 showed that 81 percent of perinatal deaths were in deprived areas. Additionally, 50 percent of perinatal deaths occurred with WB babies, 46 percent Pakistani infants and 4 percent Bangladeshi infants, showing a clear social gradient in perinatal mortality.

- Mothers who had lower levels of educational attainment had limited health literacy in respect of potential complications during pregnancy and they did not properly understand the correct behavioural actions to take, resulting in delayed help-seeking behaviour.

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[154] Maternal education and IMD.
[155] Birth outcome, sector level postcode and ethnicity.

9.2.5 Intersecting factors between heritable factors, structural factors, health beliefs and health behaviour and SES factors

Several factors intersected simultaneously, with heritable factors, structural factors, SES and health beliefs and behaviours categories. These are reported as follows:

- The mothers' level of educational attainment and knowledge of pregnancy, possible complications and consequences contributed to their decision-making and health behaviours. A lack of understanding resulted in delays in help-seeking.

- Pakistani and Bangladeshi women were more reliant on verbal information (from family and friends), making them less likely to receive accurate pregnancy-related health information.

- Despite popular belief by the HCP, few women took folic acid prior to conception, or during pregnancy, and many women (regardless of ethnicity) contrary to current health advice reported co-sleeping with their babies and would position their infant on their side.

- HCP perceived that WB women were more proactive and informed regarding their pregnancy than Pakistani or Bangladeshi women who relied on verbal information. HCPs made assumptions that all mothers were able to read, understand and act on the leaflets that were provided to deliver the majority of pregnancy-related information, even if provided in another language.

- HCP made assumptions about the level of social support available to mothers, but especially bereaved mothers.

- It was reported that some midwives were poor at answering their phones or returning phone calls which resulted in the mothers delaying help seeking when they had concerns.
- All women described fatalistic attitudes to screening behaviour.
- Pakistani and Bangladeshi households used cultural therapies (typically in dietary form) more commonly than WB.
- Pakistani and Bangladeshi women were aware of increased risks of congenital anomalies as a consequence of consanguineous marriages. HCP were also aware of consanguinity as a risk factor for Pakistani and Bangladeshi mothers.

9.4 Chapter summary

This chapter has presented the converged results and findings from Chapters 5–8. It applied an intersectional approach to identify factors salient to each domain of: heritable factors, structural factors, health beliefs and health behaviours and SES factors before spotlighting the factors that were relevant within the intersection of the four domains, highlighting the experience of perinatal mortality. The intersectional approach has shown similarities and differences between *and* within the experience of Pakistani, Bangladeshi and WB mothers, suggesting that the experience of perinatal mortality is interrelated with several simultaneous and intersecting factors mediating birth outcomes.

Chapter 10: Discussion

10.1 Introduction

Chapters Five to Eight have presented the results and findings and Chapter Nine presented the converged results/findings. This chapter turns its attention to a discussion of the converged findings in the context of the existing evidence on perinatal mortality. Specifically it highlights how the results and findings from this study vary (or not) from the existing evidence base on perinatal mortality. This discussion is presented with respect to each of the study objectives, which were developed to provide an outcome-orientated, practical and substantive answer to the research question (Meissner *et al.*, 2011; Creswell and Plano-Clark, 2011a): How do health beliefs influence health behaviour and contribute to perinatal mortality in babies born to Pakistani, Bangladeshi and WB women living in Luton?

10.2 Discussion of objective one

Objective one aimed ‘to identify the risk factors contributing to perinatal mortality in Pakistani, Bangladeshi and WB women in Luton’. Following a review of the literature for this study, risk factors for perinatal mortality were identified. Secondary CMiS data was then extracted from the hospital, and the variables ethnicity (Pakistani, Bangladeshi, WB), PTB (<24–37 weeks of gestation), LBW (<2500g), diabetes (pre-existing or gestational), BMI (<18kg/m^2, >30kg/m^2), substance misuse (tobacco, alcohol or drugs), parity (first or >3) younger age (<20), older age (>35), late booking (>12 weeks) and deprivation (IMD) were tested against the hypotheses for objective one (Chapter 5, Section 5.3.1-5.3.11).

10.2.1 Ethnic differences in risk factors

Following quantitative analysis of the CMiS data, several statistical differences between Pakistani, Bangladeshi and WB mothers were identified. Each of the statistically significant results will be discussed separately, before the results are discussed as a collective, using the intersectional approach which allows a simultaneous perspective of multiplicative risk factors.

A difference in infant birthweight was found, whereby Bangladeshi mothers had the lightest infants, followed by Pakistani, with WB infants the heaviest, even after controlling for known confounders. This is consistent with previous results which have shown South Asian women deliver infants of lower birthweight than WB women (Dhawan, 1995; Margetts *et al.*, 2002; Harding, Rosato and Cruickshank, 2004; Moser, Stanfield and Leon, 2008; Leon and Moser, 2012). This finding has been pervasive over several generations (Margetts *et al.*, 2002). Specifically, Bangladeshi women have been found to deliver the lightest infants, when compared with Pakistani babies (Moser, Stanfield and Leon, 2008; Leon and Moser, 2012). However, as mentioned in Chapter Two, many studies aggregate the findings for South Asian women, so at present the fact that Bangladeshi women deliver the lightest infants among South Asian women is not yet explicitly stated within the wider literature. Consequently, this result adds to this growing knowledge.

The majority of women who had DM in this cohort were found to be Pakistani, while more Bangladeshi women were found to have GDM and take insulin. Previous research has shown that South Asian women are at a higher risk of developing diabetes during pregnancy (Thorpe *et al.*, 2005; Ferrara, 2007; Makgoba, Savvidou and Steer, 2012; Bryant *et al.*, 2014; Sanchalika and Teresa, 2015). These results contribute further to the sparse evidence base on GDM in British cohorts, which have thus far shown contradictory findings. Makgoba and colleagues (2012) found a higher prevalence in South Asian women, whereas Sheridan and colleagues (2013), identified similar rates of DM between Pakistani and WB women. It is, however, recognised that CMiS categories for diabetes[156] (especially insulin) may be subject to data entry error and may have represented women with GDM or DM. Nevertheless, the results are interesting and warrant further exploration.

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[156] There were 5 CMiS categories: diabetic, gestational, insulin, no diabetes and not specified.

Previous studies have shown that maternal underweight is associated with LBW and PTB (Han *et al.*, 2011), while obesity contributes to perinatal mortality and congenital anomalies (Stothard, Tennant and Bell, 2009; Klebanov, Evans and Brooks-Gunn, 2014; Penn *et al.*, 2014). Using standard BMI thresholds, the results showed that just over one-quarter of Pakistani women were underweight at their booking appointment, while almost half this cohort had BMIs recorded in the overweight category at the time of booking. The prevalence of being overweight is higher in this cohort (WB [44.3 percent], Pakistani [42.8 percent] and Bangladeshi [39.2 percent]) compared with Bryant and colleagues (2014) BiB study, who found that WB (28.4 percent), Pakistani (29.9 percent) and Bangladeshi (29.2 percent) of women had BMI> 25 kg/m2 (Bryant, *et al,.* 2014). The reason for this cohort having a higher prevalence of mothers being overweight is unclear and warrants more investigation.

National figures[157] show Pakistani mothers were more likely to be obese, while Bangladeshi women were more likely to be underweight (National Obesity Observatory, 2011). The results from this study contradict the HSE findings, with a larger proportion of Pakistani mothers being underweight. However, the BMI thresholds applied within this study were consistent with the dominant application of BMI thresholds (National Institute for Health and Care Excellence, 2015). It has been shown that once the WHO-revised BMI thresholds (for Asian people) (Barba *et al.*, 2004) are applied, the prevalence of Pakistani and Bangladeshi mothers classified as underweight or overweight (‘at risk’) changes substantially (Bryant, *et al,.* 2014, Garcia, *et al.,* 2017). Obesity, as discussed in Chapter Two (Section 2.5.3) is associated with poor nutritional status including lower vitamin D and folate consumption and increases the risk of developing diabetes.

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[157] Taken from the Health Survey for England, 2004.

The results also revealed that just over one fifth of WB women smoked during pregnancy. This is higher than national figures that report 10.6 percent of pregnant mothers are smokers (Health and Social Care Information Centre, 2016). Smoking behaviour is three times greater in mothers under twenty years old (Korkodilos *et al.*, 2010), and this cohort found a high prevalence of younger WB mothers. However, some caution is required as the CMiS data represents smoking status at booking, while national figures correspond to smoking status at delivery. Since smoking cessation interventions are targeted at expectant mothers, there will undoubtedly be a difference in smoking behaviour between booking and delivery. Furthermore, smoking behaviour needs to be considered in the context of deprivation (Behrman and Butler, 2007), and Luton has a high IMD rank: 59th out of 326 (Department for Communities and Local Government, 2016). Additionally, no CMiS data captured ST behaviour, which may be present in South Asian women, especially in Bangladeshi pregnant mothers[158]. Therefore, while the prevalence of smoking is shown to be high in WB mothers, the extent of tobacco consumption behaviour (i.e. smoking and chewing) and the associated risk to the unborn foetus is unclear, since at present ST is not recorded in British maternity records.

Parity[159] is a known risk factor for perinatal mortality (Gardosi *et al.*, 2005; Aminu *et al.*, 2014; Penn *et al.*, 2014). Figures have shown a higher percentage of Pakistani mothers deliver three or more infants, compared with Bangladeshi or WB mothers (Office for National Statistics, 2016b). However, in this cohort, the CMiS results found WB mothers were overly represented in parity one and parity seven groups, indicating larger numbers of WB mothers attending maternity services for first or seventh pregnancies, while Pakistani mothers are in attendance for second, third or fourth pregnancies. Together, this suggests that in Luton, parity is a greater risk factor for WB mothers.

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[158] ST was reported to be used as an antiemetic (Núñez-de la Mora, Jesmin and Bentley, 2007).

[159] First and subsequent to four deliveries is an independent risk factor for perinatal mortality (Shah, 2010; Penn *et al.*, 2014).

The CMiS results also found trends in the age data by ethnic group, consistent with identified risks of perinatal mortality. In this Luton cohort, a higher proportion of WB mothers delivered at both extremes of the age range (<20 and <36 years of age), which is associated with increased risk for perinatal mortality, while Pakistani mothers were predominantly aged 21–35 years of age. The North Western Perinatal Survey found similar results, with a larger proportion of WB mothers delivering after 35, while Pakistani mothers were aged under 35 (Kenny *et al.*, 2013). However, this study found that younger WB mothers were over-represented, contradicting previous results (Leon and Moser, 2012). The HCP reported that they believed greater numbers of younger Pakistani and Bangladeshi women delivered, whereas these results show significantly more young WB give birth aged <20 years.

This study hypothesised that there would be differences in perinatal mortality between the ethnicities of the mothers – consistent with trends in national figures (i.e. expected to find higher rates of perinatal mortality in Pakistani and Bangladeshi infants). However, the results were not significant. One explanation for this result may have been the consequence of the small number of deceased cases (n=128) as a percentage of the cohort (0.9 percent); in other words, there was not enough statistical power to reveal significance in these figures (Field, 2013b). Figures have shown that a higher percentage of Pakistani and Bangladeshi infants in England are delivered at earlier gestations, compared with WB infants (Aveyard *et al.*, 2002; Office for National Statistics, 2015a). However, there were no statistical differences found between the ethnic groups in this cohort, of the gestation age at delivery.

In respect of the booking visit, this study found that fewer Pakistani and Bangladeshi mothers had booked into maternity services before 12 weeks, compared with WB mothers. This means that fewer Pakistani or Bangladeshi mothers had received the screening and pregnancy-related health information within the optimum timescale (i.e. <8–10 weeks of gestation) (The National Institute for

Health and Care Excellence, 2008). Additionally, later booking has been associated with increased complications, mortality and morbidity (Centre for Maternal and Child Enquiries, 2011b; Knight *et al.*, 2015). These findings are consistent with previous studies, which identified that WB women booked into services earlier than Pakistani or Bangladeshi women (Kupek *et al.*, 2002; Cresswell *et al.*, 2013).

Perinatal mortality shows a clear social gradient[160] (ONS, 2013). The results of this study found that 81 percent of deaths occurred in Luton's IMD deciles four and five. However, it is recognised that within decile areas, there is a significant variance in the IMD range and that the decile score may not represent the IMD score for the exact postcode. In other words, areas of wealth exist among the deprived areas in Luton and using decile data obscures the exact postcode IMD score (see Chapter 11, Section 11.3 for limitations). Table 31 presents the risk factors that were statistically significant (using inferential statistics), stratified by maternal ethnicity. This demonstrates that the risk factors are slightly different for each group, in addition to highlighting that Pakistani mothers have the greatest number of risk factors. Similarly, ethnic patterning of risk factors has recently been identified in the BiB study (Stacey, *et al.,* 2016), although their study assessed maternal distress with a number of variables, e.g. PTB, SGA, age, parity and BMI. Nevertheless, identifying specific risk factors for women from specific ethnic backgrounds allows for targeted interventions (Garcia, *et al,* 2015).

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[160] Refer to Table 3 in Chapter Two.

Table 291: Details the results salient to each ethnicity

WB	Pakistani	Bangladeshi
Parity 1, 7	Birthweight	Birthweight
Maternal age (16-20, 30+ years)	Diabetes	Gestational diabetes
Smoking	Gestational diabetes	Insulin
BMI $>30kg/m^2$	BMI $< 18.5kg/m^2$	Booking
Deprivation	Parity 2,3,4	Deprivation
	Booking	
	Deprivation	

10.2.2 Applying an intersectional perspective to the risk factors

An intersectional approach (Chapter 3, Section 3.3.3) was applied as the theoretical framework in this study, to reveal the similarities and differences in health beliefs and health behaviours of Pakistani, Bangladeshi and WB mothers in Luton. In utilising an intersectional approach, the intersection of SES, heritable and structural factors with health beliefs and health behaviours can be identified. Similarly, the intersectional approach lends itself to a simultaneous multiplicative perspective – in contrast to the traditional and dominant, additive approach in maternity research.

The results show that the salient risks for perinatal mortality varied according to ethnicity and that health behaviours (such as smoking, BMI and diabetes) were differentiated by ethnicity showing trends (as discussed in the preceding section). Figure 30 shows the factors, and the intersection of simultaneous and aggregated risk factors: deprivation, young or older age, first baby, later booking, smoking, BMI $>30kg/m^2$, pre-existing DM or GDM and maternal ethnicity (Pakistani, Bangladeshi and WB).

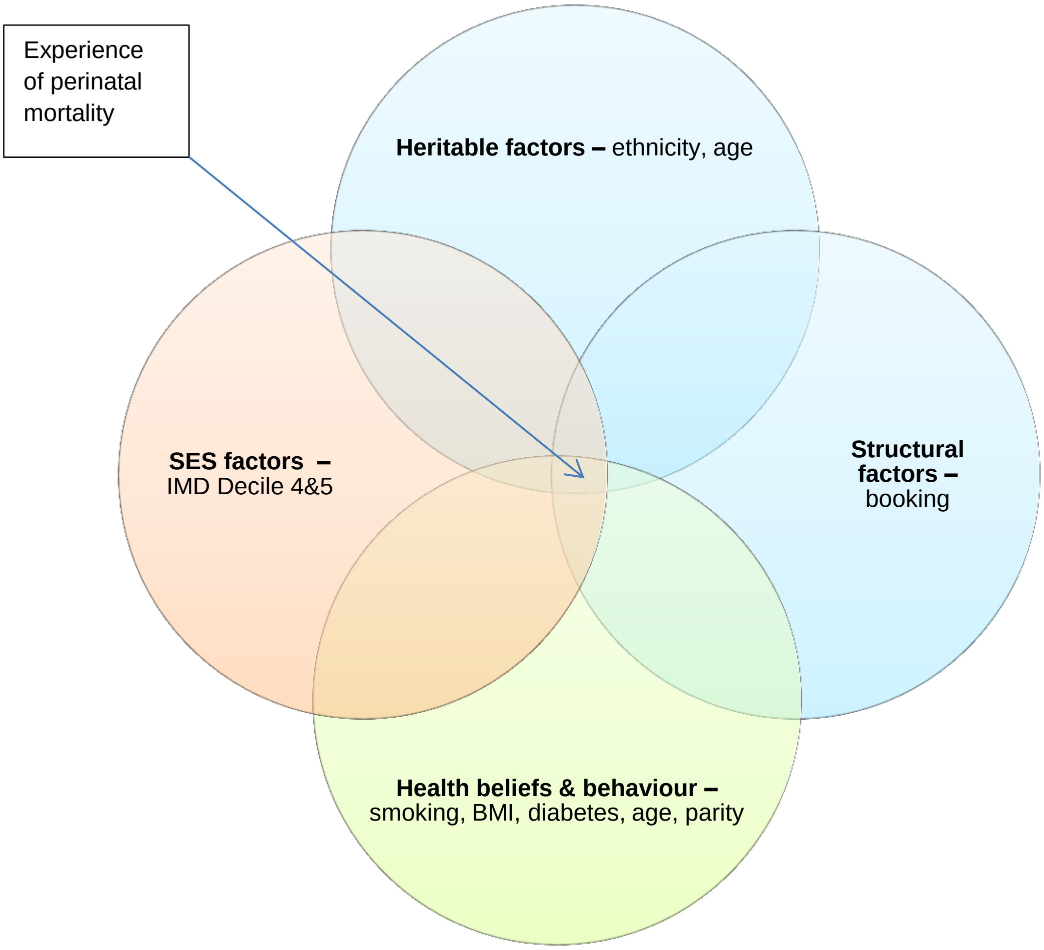

Figure 30: Diagram of insersectional approach highlighting risk factors

Therefore, while much of the existing research has approached analysing risk factors separately, perhaps due to the complexity of the research area and numerous confounds (Kramer, 1987; Kramer *et al.*, 2002), this objective considers a different perspective to the outcomes of the cohort data. While this study has presented the significant results separately, in convention with previous work, it does highlight how risk factors vary by ethnicity. This variance is not explicit in current clinical guidelines[161] – women are treated homogeneously with respect to screening and risk, with the exception of identifying consanguineous marriages, the risk of congenital anomalies, specifically SCT, or being of South Asian decent and at increased risk of developing diabetes

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[161] (National Institute for Health and Care Excellence, 2008; The National Institute for Health and Care Excellence, 2010b; Turner *et al.*, 2010; NICE (National Insitute for Health and Care Excellance), 2014; National Institute for Health and Clinical Excellence (NICE), 2015).

(Dormandy *et al.*, 2010; NHS Screening Programmes SCT, 2014; The National Institute for Health and Care Excellence, 2016). This suggests that distinct risk profile(s) may be clinically relevant to target maternity resources and improve birth outcomes according to maternal ethnicity, which reflects the mothers' health beliefs and subsequent health behaviours (Garcia, *et al.,* 2015).

The intersectional approach posits that the risk factors may simultaneously aggregate. For example, the results of this cohort show that more Pakistani mothers have a lower BMI (<18kg/m^2), which is a risk factor for lower birthweight infants. A lower BMI may imply poorer nutrient intake before and during pregnancy (Roseboom *et al.*, 2001), and is associated with suboptimum levels of folic acid and vitamin D, which contributes to increased risk of NTD or IUGR during pregnancy, with health consequences later in the life-course for the foetus (Roseboom *et al.*, 2001; Tahrani *et al.*, 2010).

IUGR is one of the main contributors to stillbirth (Gardosi *et al.*, 2013), and insufficent vitamin D has been identified as a contributory factor in insulin dysfunction, which may help explain the higher prevalence of diabetes found in South Asians (Pittas *et al.*, 2007; Robinson *et al.*, 2014; Sanchalika and Teresa, 2015). Also, having second and subsequent babies (i.e. Pakistani mothers in this cohort having higher numbers of parity two, three and four) may suggest that the Pakistani mother believes she is knowledgeable about pregnancy and birth, which may explain the later booking into services compared with WB women, who were having more first-born babies. Although this is a tentative explanation, it provides a possible explanation for aggregated risk factors that simultaneously converge.

At present, it is unclear how one risk factor (e.g. maternal age) interacts with another (e.g. diabetes), regarding potentiating a mother's risk for perinatal mortality. For example, does the risk of adversity literally 'double', or do certain combinations of multiple risk factors potentiate the overall risk? And, are some risk factors more potent than others? Unfortunately, the exploratory analysis in this study was not viable, but future work using carefully collected interval variables may be able to assess this.

10.3 Discussion of objective two

Much of the existing research with Pakistani and Bangladeshi women in the maternity setting has excluded the views of WB women (Lucas, *et al*., 2013). Consequently, many of the findings have been attributed to their ethnicity, inadvertently contributing to ‘othering’ and highlighting difference (Hall, 2000; Spelman, 1988). Objective two aimed to ‘explore the similarities and differences in maternal health beliefs that influence health behaviours in perinatal mortality in Pakistani, Bangladeshi and WB women, through the maternity care pathway’. Following analysis, three themes were identified: knowledge and information of pregnancy and perinatal mortality, attitudes and perceptions of pregnancy and perinatal mortality and experience with maternity services.

10.3.1 Similarities and differences in health belief and health behaviour

The majority of the findings identified similarities in mothers’ health beliefs and health behaviours, irrespective of ethnicity. For example, the mothers found pregnancy a life changing and stressful experience, and this was amplified if the mother had suffered an infant bereavement. Furthermore, mothers lacked knowledge regarding risk factors. For example, few women took folic acid before conception to prevent NTD and mothers held idealised, normalised and fatalistic views about pregnancy, with much of their pregnancy knowledge obtained from previous experience or from friends and family. Many women used cultural therapy, although it was more common in Pakistani and Bangladeshi households. The majority of mothers’ experience of maternity care was dependent on their relationship with staff (especially midwives), and many mothers felt that they were not properly listened to when they had concerns.

By contrast, differences were identified as a consequence of ethnicity. For instance, Pakistani and Bangladeshi mothers had awareness of consanguineous marriages increasing their risk of congenital anomalies. Additionally, they perceived pressure from their community and cultural norms to conceive quickly after the wedding (including the preference of a male baby), which the mothers found upsetting. Bangladeshi mothers were found to be more likely to use ST (and be unaware of its dangers) and not openly discuss pregnancy with others. Moreover, limited English-language proficiency contributed to a lack of confidence when interacting with staff.

The majority of the literature focuses on ‘South Asian’, Pakistani or Bangladeshi women’s experiences (Bowes and Domokos, 1996; Ali and Burchett, 2004; Puthussery *et al.*, 2010; Priebe *et al.*, 2011), but has excluded the opinions of WB women (Homans, 1980; Woollett and Dosanjh-Matwala, 1990). This study has intentionally sought the perceptions of WB mothers, to identify similarity (and difference) in health belief and health behaviours during pregnancy, to bring a different perspective to inequalities in perinatal mortality besides ethnicity. As such, ethnicity has been not used as the justification for explaining identified differences (Hall, 1992), and structural SES and heritable factors were also considered (Gunaratnum, 2003).

Since WB women's perceptions were included in this study, it has been possible to identify similarities *and* difference and extend current knowledge. For example, the previous research identified fatalistic attitudes in Pakistani and Bangladeshi women toward their pregnancy and unborn child (Ali and Burchett, 2004; Dartnall, Ganguly and Batterham, 2005; Choudhury *et al.*, 2012; Haddrill *et al.*, 2014). Previously this has been used to explain delayed help-seeking behaviour, later booking (Haddrill *et al.*, 2014) and reduced uptake of screening (Dormandy *et al.*, 2005; Szczepura, 2005; Rowe *et al.*, 2008). However, by including the views of WB women, it became apparent that WB also showed fatalistic attitudes towards their pregnancy, thus challenging earlier explanations why Pakistani and Bangladeshi women delayed engagment with maternity sevices, or refused antenatal screening.

Other similarities in health beliefs revealed that many mothers, regardless of their ethnicity, were unaware of risk factors associated with perinatal mortality, relying on their previous pregnancy experience, the experiences of family or friends to provide information, or the internet. The existing knowledge base also identified that women wanted information (Jayaweera, D'Souza and Garcia, 2005), but has shown that women often don't read the information provided by maternity staff (Dartnall, Ganguly and Batterham, 2005). This suggests the information provided is not accessible or user-friendly and may explain why women source information from the internet, although HCPs had concerns regarding its accuracy (Lagan, Sinclair and Kernohan, 2011).

Furthermore, Pakistani and Bangladeshi women were found to rely on verbal messages, which may be a consequence of historical factors relating to illiteracy levels in migrant women, coupled with the paucity of pregnancy information available to them in their home language (and this then assumes that their language has a written script) (Shaw and Ahmed, 2004) (Chapter 4, Section 4.5.3). Moreover, while Pakistani or Bangladeshi women may speak Urdu or Sylheti, they may not be able to read in that langauge, therefore providing material in their written language assumes literacy and tacit knowledge and understanding, in contrast to being deliberate and explicict in verbal explanations. It is understandable then, that Pakistani and Bangladeshi women access verbal information.

This study identifed that the majority of women had limited knowledge about the risk of adverse outcomes and subsequent health behaviour. Current estimates suggest 25–35 percent of women consume folic acid before conception (Bestwick *et al*., 2014; Tort *et al*., 2013), to reduce the risk of NTD (Lassi *et al.*, 2013) and the estimates are less for South Asian women (Bestwick *et al.*, 2014). Similarly, this study found few mothers consumed folic acid before conceiving, despite many of the pregnancies being planned. This suggests that women are unaware of the benefit of preventative folate consumption and the importance of the timing of meiosis, indicating a need for increased public health awareness (Wellings *et al.*, 2013).

The existing literature documents the role of health literacy (Rowe and Garcia, 2005), maternal education level (Juarez *et al.*, 2014) and English-language proficiency (Redshaw and Heikkilä, 2011) as independent explanations for women's level of understanding of health messages and delayed access to maternity services. It was evident that in this study there was a discrepancy between what the HCPs believe the women comprehended, compared with what the mothers really understood in respect of risk-reducing health behaviour (Section 10.4).

However, the explanations of health literacy, education level and English-language proficiency do not go far enough in explaining why Pakistani and Bangladeshi women experience higher incidences of perinatal mortality. For instance, in this cohort of mothers, Pakistani mothers were the most educated (i.e. 23 percent achieved level 7, and 38 percent achieved level 6), whereas WB had the highest proportion of least educated mothers (60 percent to level 2[162]). Regardless of maternal ethnicity, there was limited knowledge and awareness of risk factors for perinatal mortality throughout the FGs and interviews; consequently, many participants were unclear of risk factors for perinatal mortality.

There was a belief among the English-speaking mothers in this cohort, that non-English speakers would find accessing and understanding pregnancy-related information even more challenging. Additionally, non-English speaking mothers reported they found it hard to express their needs, felt they received less attention and perceived more discrimination from some maternity staff (Atkinson*, et al.,* 2001). This finding further supports the exisiting evidence that limited English is an important barrier to effective antenatal care (Rowe and Garcia, 2003; Small, *et al.*, 2014).

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[162] Level 1 = GCSE, Level 2 = GCSE grades A*-C, Level 3 = A Level, NVQ level 3, Level 6 = Bachelor's degree, Level 7 = Master's degree

10.3.2 Applying an intersectional approach

When the intersectional approach is applied to the findings of objective two, the conjuncture of heritable, structural, SES factors and health beliefs and behaviours become apparent. This highlights how mothers obtained pregnancy related information from other sources (previous experience, peers or the internet), suggestive of two issues; firstly, the notion that information as currently provided is not accessible to mothers and secondly, the quality and accuracy of information accessed from other sources (i.e. family, friends or the internet) is unknown. Both of these issues need more attention, to ensure women receive accessible and reliable information.

Pakistani and Bangladeshi mothers' use of verbal information suggests they are less likely to be in receipt of accurate pregnancy-related information. Furthermore, since pregnancy was not openly discussed in Bangladeshi families, this suggests that in real terms they are reliant on pregnancy information from external sources (i.e. the internet, previous experiences or peers), indicating that Bangladeshi mothers are isolated from reliable health messages and hence more disadvantaged. This may help explain the greater implementation of cultural therapy reported by Bangladeshi and Pakistani women in this study.

Reduced access to reliable messages, paucity of knowledge of risk factors and limited understanding of the pregnancy-related information (even if provided by HCP) may explain the mothers' idealised and fatalistic attitudes to pregnancy. In turn, these may contribute to unhelpful health behaviours, such as delays in help-seeking when foetal movements are reduced or co-sleeping with their baby, as was found in this study. Likewise, limited English language proficiency adds a further barrier to obtaining, exchanging and understanding accurate health information, rendering non-English speakers more vulnerable, as has been identified in earlier reviews (Centre for Maternal and Child Enquiries, 2011; Mumtaz, *et al.,* 2014).

Notwithstanding the points highlighted in this section, some midwives were poor at answering their phones or returning phone calls, which had the consequence of further reinforcing beliefs women had that they were an added burden to busy staff and resulted in mothers delaying help-seeking when they had concerns, or created a further barrier for women seeking clarity over concerns from a reliable source (i.e. midwife).

10.4 Discussion of objective three

Service providers[163] are central to BAME users' satisfaction and engagement (Chapter Two) (Puthussery *et al.,* 2010; El Ansari *et al.,* 2009). Maternity services have been criticised for being homogenous (Witz, 1995), discriminatory (Cross-Sudworth, 2007) with research suggesting the need for increased cultural competence (Ali and Burchett, 2004; Downe *et al.*, 2016). Objective three aimed 'to ascertain maternity health professionals' views on the service needs of Pakistani, Bangladeshi and WB pregnant women'.

10.4.1 Identifying maternity service needs for Pakistani, Bangladeshi and WB mothers

The findings of Chapter Eight showed that HCP considered that they gave all pregnant women wealth of pregnancy-related health information (in leaflet form), and consistent with previous research, it was believed that WB mothers were more proactive and better informed in obtaining information (Woollett *et al.*, 1995), whereas Pakistani or Bangladeshi mothers relied more on verbal information through family or friends, similar to findings by Dartnall and colleagues (2005).

The findings with HCP confirmed mothers had issues of poor health literacy, for instance, the belief that mothers could accurately monitor their unborn baby's heartbeat, as reassurance of the baby's

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[163] at personal (HCP) and provider (services) level

wellbeing (Chapter Eight, Section 8.1.3). Lower levels of health literacy were considered to be influenced by the mother's level of educational attainment, whether the mother was the UK born and their degree of proficiency in English (Rowe *et al.*, 2001; von Wagner *et al.*, 2009; Hauck, Tanabe and Moon, 2011). This is consistent with previous studies that found HCP make assumptions of the reduced ability of migrant women's understanding of health information, but then offer less support to address this (Ali and Burchett, 2004; Dartnall, Ganguly and Batterham, 2005). The findings of this study were analogous, suggesting the same polarity; on the one hand, mothers were considered to be health-illiterate, some with poor English-proficiency and Pakistani and Bangladeshi mothers were believed to be less proactive in information seeking. On the other hand, written information was provided, and assumptions were made regarding women's understanding of the material, given the erroneous supposition that women are motivated and able to read the material provided. This contradiction needs careful attention.

Previous research has highlighted the need for 'clear' health information to be provided to pregnant women, especially migrant, non-English speakers (Rowe *et al.*, 2001; Degni *et al.*, 2012; Jomeen and Redshaw, 2013). Reduced English-language proficiency is a common barrier to accessing and utilising maternity services, cited in the literature (Cross-Sudworth, Williams and Herron-Marx, 2011; Hollowell, Kurinczuk, *et al.*, 2011; Small, *et al.*, 2014). Language was also cited in this study by staff as a barrier, especially for rapport-building and disclosure of sensitive information. Moreover, while staff made efforts to provide women with interpreters for the booking visit, mothers had fears that South Asian interpreters might breach confidentiality within the local Asian community, consequently, family members were utilised. This mirrors previous findings (Atkin and Ahmad, 1996; Katbamna, 2000; Cross-Sudworth, Williams and Herron-Marx, 2011) and suggests an opportunity to reinforce medical professionalism, accountability and confidentiality within the public domain, especially within migrant communities (Section 10.5)

Using family members to translate is problematic; it assumes accurate translations, the understanding of health messages and the ability to make informed decision-making (El Ansari *et al.*, 2009; Psarros, 2014). Moreover, if male partners translate, their explanation of ‘contractions’, ‘labour pain’ and ‘foetal movements’ are based on abstract understanding only and risks being improperly communicated – exacerbated if the couple are health-illiterate (in respect of pregnancy) (Scheppers *et al.*, 2006). Similarly, embarrassment on behalf of the mother may prevent her from disclosing information via a third party (Lowe, Griffiths and Sidhu, 2007). Together, this suggests that poor quality communication is likely when using family members, resulting in suboptimal care.

Research surrounding translation in healthcare settings acknowledges challenges to accurate translations: words or concepts in one language not being present in the other (El Ansari *et al.*, 2009). This combines with cultural nuances in non-verbal behavioural cues, understanding medical terminology and concepts (Communities and Local Government, 2009b), and being familiar with localised slang (Ali, 2003). Moreover, effective communication is central to patient satisfaction and adherence to health regimens (Betancourt *et al.*, 2005; Jomeen and Redshaw, 2013; Nair *et al.*, 2014). Therefore, if staff make assumptions that Pakistani and Bangladeshi women are health illiterate, and simultaneously engage less with non-English speaking mothers, it is perhaps not surprising then, given the complexity of issues around health literacy, communication and language, that Bangladeshi and Pakistani women have been found to report less satisfactory health care experiences (Hirst and Hewison, 2002; Jayaweera, D’Souza and Garcia, 2005; Raleigh *et al.*, 2010). Consequently, more effort should be invested in finding a solution to ensure all women understand pregnancy-related health messages, in addition to addressing any language barriers in healthcare, to meet the needs of the women (e.g. confidentiality, dignity and respect) to facilitate safe and accurate communication between staff and mothers.

Another ambiguity that emerged was the structure of the maternity service in meeting the needs of the local population. On the whole, staff in this study thought that the local maternity services were ‘appropriate’ to meet the needs of the local and diverse population. However, on probing, it transpired that a few staff operated beyond the constraints of rigid appointment systems and worked flexibly to meet women’s needs. These midwives understood that Pakistani and Bangladeshi mothers often had other caring responsibilities and childcare difficulties. Therefore attendance at the antenatal clinic was a lower priority. This cultural awareness and resultant flexibility shows cultural competence, but it was not widely reported within this participant group (Korkodilos *et al.*, 2010; Public Health England, 2015b). Furthermore, due to the paucity of published interventions targeted at BAME pregnant women, it is unclear how many other staff operate similar flexible clinic services, or how successful these are (Garcia *et al.*, 2015).

The HCP showed awareness of cultural differences of Pakistani and Bangladeshi women – such as their religious needs – by means of giving time and privacy for prayer, being visited by the imams, and also understood that religious beliefs contributed to Muslim mothers’ decisions regarding post-mortems and screening tests. In addition, HCP acknowledged Pakistani and Bangladeshi mothers’ need for modesty, which included their preference to be seen by female HCPs. Moreover HCPs understood that Pakistani and Bangladeshi mothers had concerns regarding confidentiality of their circumstances, when working with South Asian HCPs.

HCPs also believed that many Pakistani and Bangladeshi mothers did not make autonomous decisions regarding their pregnancy, but decisions were made in combination with other family members. Moreover, previous studies have highlighted how migrant women fail to have adequate information or understanding to make informed choices (Ali and Burchett, 2004; Dartnall, Ganguly and Batterham, 2005), suggesting that a lack of information contributes to this, rather than a lack of agency (Kitayama, Duffy and Uchida, 2010). Furthermore, with unhelpful staff, especially toward non-English speaking mothers, women then rely on community members for guidance (Dartnall, Ganguly and Batterham, 2005; Jomeen and Redshaw, 2013). Together, this suggests an explanation for why Pakistani and Bangladeshi women may collaboratively seek information from trusted family or friends, rather than HCPs, hence seemingly not making autonomous decisions.

The findings revealed HCPs had an awareness of risks associated with consanguinity, as did Pakistani and Bangladeshi women (Chapter 6, Section 6.1.3, Chapter 7, Section 7.1.3 and Chapter 8, Section 8.2.1). Figures suggest that almost half of Pakistani marriages in England are consanguineous, although the incidence in Luton is unknown (Public Health England, 2016a). The Luton and Dunstable University Hospital NHS Trust uses '*The Family Origins'* questionnaire to identify pregnancies at higher risk which may benefit from additional antenatal screening, although this might have limited utility if mothers book later into maternity services or fail to properly understand the health information. Consanguinity is the common explanation in clinical settings for higher rates of adverse outcomes, including congenital anomalies in Pakistani families (Bittles, Grant and Shami, 1993; Grant and Bittles, 1997; Ali, McLean and Rehman, 2012). However, this ignores the contribution of deprivation, diabetes or obesity in congenital anomalies or perinatal mortality (Ahmad, Atkin and Chamba, 2000).

10.4.2 Applying the intersectional approach

Once the intersectional approach is applied to the findings from objective three, the intersection between heritable, structural, SES factors and health beliefs and behaviours become evident. Importantly, this highlights the assumption by staff that mothers were literate and properly understood the pregnancy-related information provided. The intersectional approach also highlighted the contradiction that on the one hand staff believed women were provided with the relevant knowledge and information to navigate their pregnancy and maternity services; conversely, HCP acknowledged that many women had limited levels of health literacy, providing numerous examples of mothers' aversive health behaviours demonstrating this (Chapter 8, Section 8.1.2).

HCPs believed that WB women were more proactive in seeking pregnancy-related information, while Pakistani and Bangladeshi mothers relied on verbal sources of information from family and friends. Moreover, HCPs were aware that mothers accessed pregnancy-related information from the internet, but had concerns regarding the accuracy of what was being accessed (Sayakhot and Carolan-Olah, 2016). Together this shows that while all women need clearer and more accessible pregnancy-related health information, Pakistani and Bangladeshi mothers are more disadvantaged than WB women insofar that currently, Pakistani and Bangladeshi women source information from family and friends, whereby the accuracy of this information is unknown. The consequences of this are clearly evident in the HCP findings, with Pakistani and Bangladeshi mothers misunderstanding the value of prompt attention and delaying help-seeking when the baby's movements are altered.

Several important barriers were identified for Pakistani, Bangladeshi and WB women accessing services. HCPs believe that the maternity services are 'appropriate' for the needs of the local population. However, the findings suggest that few HCPs meet the needs of the maternity population by operating flexibly within the confines of their rigid clinic structure, ensuring women are seen. This suggests that the current rigid clinic structures fail to meet the needs of the local population.

Having limited proficiency of English was considered challenging by HCPs, and translation services were reported to be unsatisfactory. Moreover, using family members to translate during consultations was also not considered beneficial as HCP had concerns as to whether the health information was accurately translated. Consequently, non-English speaking Pakistani and

Bangladesh mothers are still not being provided with properly translated information to make fully informed choices and have limited understanding of consequences, despite this being highlighted in earlier research (Ali and Burchett, 2004; Korkodilos *et al.*, 2010; Shaw and Ahmed, 2004; Szczepura, 2005).

10.5 Discussion of the intersecting results

Sections 10.2–10.4 discussed the results and findings by each objective. This section now discusses the intersecting factors that have been found to converge across 'heritable', 'SES', 'health beliefs and health behaviour' and 'structural factors' in all three objectives. As before, the intersectional approach was purposefully selected, to be simultaneously multiplicative and to help spotlight previously unseen factors, including power dynamics (Mens-verhulst and Radtke, 2011; Bowleg, 2012).

Deprivation was identified as intersecting across 'ethnicity', 'SES', 'health belief and health behaviour' and 'structural factors' and plays a major role in perinatal mortality. This study found 81 percent of Luton's perinatal mortality in 2014 occurred in areas with an IMD of 4 and 5. Moreover, maternal education levels, as used in this study as a proxy for SES factors, is associated with health beliefs, health literacy and subsequent health behaviour (Section 10.3) (Arntzen *et al.*, 2008; Blumenshine *et al.*, 2010). Understanding risk factors in pregnancy is mediated by education, literacy ability and cognitive skills (Nutbeam, 2006), therefore, in areas of high deprivation, it is likely that mothers will have lower levels of health literacy, and subsequent poorer health behaviour (Taylor, Whittaker and Castle, 2016). Consequently, health messages need to be available in a format that is accessible (e.g. language, reflective of cultural values and a paucity of technical terminology), reinforced by verbal messages and mothers' understanding should be checked, not assumed.

There was a discrepancy between health information that HCPs perceived that mothers had been provided with, and subsequently understood, compared with what mothers knew, especially in respect of risk factors for perinatal mortality. For example, HCPs thought that the majority of mothers took folic acid to prevent NTD, however, very few participants in the FG or interviews took folic acid preconceptually. Approximately one third of women consume folic acid preconception, and the last decade has shown figures in decline (Lassi *et al.*, 2013). More research is needed to determine an accurate consumption rate for Luton, since this finding was obtained through a small number of self-reports. However, anencephaly is fatal, so not taking folic acid to prevent NTD will contribute to mortality statistics on the mortality continuum (Chapter Two, Section 2.3.1).

Nutritional intake relates to folic acid, vitamin D, maintaining a healthy BMI, and the risk of diabetes (Roseboom *et al.*, 2001; Tahrani *et al.*, 2010). This study has found trends according to ethnicity in BMI and diabetes; almost half the women with diabetes were Pakistani, while Bangladeshi mothers were overly represented in the insulin and GD group. Additionally, just over 25 percent of Pakistani mothers were underweight[164], while 19.4 percent of WB women were obese. Being underweight has been associated with PTB, IUGR and LBW (Han *et al.*, 2011). Similarly, obesity is associated with the risk of developing diabetes, and both have been found to contribute to stillbirth and congenital anomalies (Macintosh *et al.*, 2006; Penn *et al.*, 2014; Lindam *et al.*, 2016). Maternal BMI is suggestive of health behaviours (e.g. diet and exercise) and a suboptimal BMI indicates poor nutritional intake i.e. folate and vitamin D, both of which have been implicated in congenital anomalies and diabetes (Berglund *et al.*, 2016; Palacios *et al.*, 2016). It appears that these factors are connected, but it is presently unknown how these risk factors when amalgamated might potentiate the overall risk for perinatal mortality.

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[164] Using standard WHO BMI thresholds (World Health Organsiation, 2016a).

This study found that both HCPs and Pakistani and Bangladeshi mothers were aware of consanguinity as a risk factor for increased genetic anomalies. However, there was a discrepancy between HCPs and mothers; HCPs believed consanguinity was high in the local population and accounted for the poor birth outcomes in Pakistani infants. Conversely, Pakistani and Bangladeshi women were aware of consanguinity as a risk, but unclear specifically how. Reports suggest 49.9 percent of Pakistani marriages are consanguineous, especially in unions from Azad Kashmir (Public Health England, 2016), although large numbers of consanguineous unions were not confirmed in this cohort. These findings contribute to the existing knowledge base in demonstrating that both the local Pakistani and Bangladeshi population need more support to understand the mechanism behind autosomal recessive disorders, in addition to HCPs. HCPs are at risk of minimising other risk factors at the expense of consanguinity, as has been noted previously by Ahmad and colleagues (2000).

There are beliefs among HCPs that Muslim women refuse screening tests and perceptions that they do not undergo terminations (Dormandy *et al.*, 2005; Ahmed *et al.*, 2006; Bryant *et al.*, 2011). Consanguinity coupled with fatalistic attitudes towards the pregnancy are commonly used to account for the high rates of congenital anomalies and perinatal mortality in Pakistani and Bangladeshi babies (Dartnall, Ganguly and Batterham, 2005). Furthermore, previous research shows that Pakistani and Bangladeshi women’s reproductive choices are not just associated with religious beliefs (Ahmad *et al.,* 2000b), consequently HCPs need to fully inform every pregnant mother of the benefits and consequences of screening choices. Furthermore, if screening or post-mortems are not undertaken, fatal defects go undetected; consequently, the true incidence of lethal anomalies remains unclear. Interestingly, a recent study highlighted that South Asian infants in the UK had the highest rates of congenital heart defects; however, the reason for this result is unknown (Knowles *et al.*, 2016). Some scholars have suggested it is associated with deprivation and disadvantage (Vrijheid *et al.*, 2000), in addition to other reasons such as obesity or DM (Macintosh *et al.*, 2006; Yao *et al.*, 2014).

This study found women obtained information from past experiences, the internet and from peers. However, Pakistani and Bangladeshi mothers were more reliant on verbal information; Bangladeshi mothers were less likely to discuss pregnancy with their family. Explanations for the reliance of verbal information found in Pakistani and Bangladeshi mothers, may be the consequence of a paucity of translated materials (Shaw and Ahmed, 2004), poor literacy skills (Rowe *et al.*, 2001) poor English-language proficiency (Jayaweera, D'Souza and Garcia, 2005), culturally insensitive material (Reitmanova and Gustafson, 2008) and unhelpful staff (Jayaweera, D'Souza and Garcia, 2005), or a combination of all these factors. Furthermore, as Bangladeshi mothers were found to be the least likely to discuss pregnancy issues, this renders them the least informed, and as such this might explain their utilisation of cultural therapies in the absence of evidence-based pregnancy information.

Since the source and accuracy of the mothers' self-sourced health information is unknown – information obtained from commercial websites or that which is superficially or inaccurately discussed – this may explain why women have 'idealised' attitudes toward their pregnancy and birth. Furthermore, pregnancy is influenced by women's health beliefs, cultural expectancies, social norms and their ability to access maternity services, hence it becomes a social experience (Woollett *et al.*, 1995; Rezende, 2011) and is mediated by external factors, including disadvantage. Consequently, although pregnancy is a universal and natural life event for most women, it seems that the women in this cohort reflected constricted health beliefs around pregnancy, reflected in their health behaviours as seen in the objective variables in Chapter Five (e.g. BMI and smoking) in addition to their self-reports (Chapters Six and Seven).

10.6 Chapter summary

This chapter has discussed the results and findings for objectives one, two and three. Furthermore, it also discussed the intersecting factors of ‘SES’, ‘heritable’, ‘structural factors’ and ‘health beliefs and health behaviours’, showing that deprivation and inadequate pregnancy knowledge is central to women’s health behaviour. Moreover, by examining similarities and differences, trends became evident in the secondary data (objective one), demonstrating that each ethnic group had a different risk profile, with Pakistani women having the most risk factors. Objective two provided valuable insights, showing mainly similarities in mothers’ health beliefs and health behaviours. Moreover, highlighting important divergence of knowledge between the mothers and HCPs and how reduced knowledge has contributed to health behaviour. Objective three provided support that HCPs assume that women accessing pregnancy-related material (whether this is supplied or sought) makes women knowledgeable in protective health behaviours. Lastly, the intersecting factors (across all three objectives) were provided, suggesting how deprivation influences health literacy and subsequent health behaviour. Moreover, it is evident that several factors are co-joined and offers tentative, but different, explanations to the patterns of risk associated with perinatal mortality in Pakistani, Bangladeshi and WB mothers in Luton.

Chapter 11: Conclusion

11.1 Introduction

This chapter concludes this thesis, presenting my reflections, the study limitations, contribution to the field, the recommendations and suggestions for further research. The conclusion (Section 11.6) shows how this study contributes to the understanding of how health beliefs and health behaviour contribute to perinatal mortality in babies born to Pakistani, Bangladeshi and WB women living in Luton.

11.2 Reflections

This section documents a few reflections as a consequence of my academic journey, where I have gleaned as much about myself as I have about my subject. Among many things, working as a white female researcher working with an etic and emic perspective. On the one hand, I perceived myself as etic to the research process (with the Pakistani, Bangladeshi and Muslim mothers), yet simultaneously being emic (being a mother and a nurse). I found this duality enlightening and was able to understand nuances at the same time as having to ask many clarification questions for concepts and ideas that were new to me. There is disagreement among scholars regarding etic and emic approaches and what might be best for researching migrant communities (Berry, 1990; Headland, Pike and Harris, 1990; Gunaratnum, 2003). However, I believe that this research has benefited from my being WB, while my director of studies being Pakistani has undoubtedly enhanced the overall intersubjective perspective.

Learning to break away from the theme of ‘difference’ which is dominant in Western society and the literature, was an unexpected challenge to my intellectual framework. Scrutiny by my supervisor ensured that I did not essentialise or privilege one ethnic group over another, and this challenged my starting position as a fledgeling PhD student. However, I soon understood by the omission of one group (i.e. the WB in early drafts) I had inadvertently created a difference and introduced bias (Kingdon, 2005). Similarly, by the inclusion of WB women, being careful that they were not to become the comparator group, suggesting WB as the ‘norm’ or gold standard. This perspective allowed me to understand and then see similarity *and* difference, and appreciate diversity among us (all), regardless of socially constructed identities, which are in themselves fluid and context-dependent.

A further theme that has impacted me specifically is ‘language’. It has been essential for the integrity of this research to undertake translation, transliteration and back-translation. As a consequence of reading Headland and colleagues (1990) work on insider/outsider issues, I connected this with language constraints. Understanding that thoughts are language based, and if language fails to convey the meaning and concepts in one language, but does in another, this is a starting point for the failure to properly understand another person’s inner experience. Therefore, I am curious how many ideas may be embedded in women’s health beliefs around pregnancy as a consequence of their language and cultural boundaries that were not shared, because I didn’t ask (being blind to the unknown), or because Pakistani or Bangladeshi women may have found it impossible to describe something which English language (and cultural boundaries) can’t understand.

Lastly, I have been overwhelmed by the support and kindness that I have received from the Pakistani and Bangladeshi community in undertaking this work. To my surprise, I found the access to staff groups more challenging than I imagined – especially as I am a qualified nurse; I wrongly assumed that this would help from an ‘insider’ perspective. However, I was perceived as an ‘outsider’ – a researcher and it was evident that the staff groups felt vulnerable to the scrutiny of research. I am sure that this is not uncommon in health services research, but is a barrier to making real progression.

11.3 Study limitations

There are some important limitations to discuss. Some these became evident as the research progressed, through the challenges experienced during data collection (as discussed in Chapter 4) or difficulties that became apparent in other areas of the research process, after the journey had begun. In reflecting on these limitations, it is hoped that future research will try to mitigate some of these limitations.

- CMiS data: challenges with obtaining the CMiS data were discussed previously (Chapter 4). However further problems existed with the dataset.

- There are both strengths and limitations in using secondary data in research. The advantage with pre-existing data is time saved, and related financial factor(s) that are reduced through accessing secondary data, compared to primary data collection. Also, a large sample size in secondary data set reduces bias and attends to issues of attrition, and therefore the data can be considered more representative of its population (Sarensen *et al*., 1996).

- The limitations of using secondary data also need to be considered. Collection of the data is outside of the control and therefore ‘rigour’ of the research process and may be prone to reduced quality and error (Sarensen *et al.,* 1996). For example, data collection for CMiS is part of a patient’s clinical record, transposed retrospectively from written paper records. Consequently, it may have errors, random and systematic (this is discussed in detail in Chapter 9). In time series data, awareness of differentials in diagnostic accuracy may need to be considered; changes in prevalence rates may be an artefact of altered diagnostic thresholds or improved accuracy in technology (Sarensen *et al.,* 1996). Furthermore, data may have been categorised differently to how the researcher had intended; for example, ethnicity may have been classified broadly as ‘White/Black/Asian’ (Boslaugh, 2007).

- Until the raw data was extracted and assessed it was unclear exactly what kind of data was present, for example ordinal, interval or categorical. It transpired that most of the raw data was categorical, which then needed to be recoded into smaller groups to account for small cell sizes. This presented limitations in conducting the statistical analysis. With hindsight, when designing the research, identifying an individual with the most expertise in the system early on would be more useful, to understand what the raw data output might look like and whether this is helpful in research output terms or considering that another database that may be better.

- Postcode: at the beginning of the research journey it was envisaged that using district level postcode data mapped with IMD data[165] would provide valuable deprivation data on perinatal mortality in Luton. However, only the first three part alphanumerical postcode data was provided due to issues around confidentiality[166]. It was not until the analysis stage that it became evident that district level postcode data did not map onto IMD data, or could not be mapped at ward level. To work around this challenge, the hospital's data governance manager agreed to provide a single year of data[167], using the same inclusion criteria, and provide the variables of ethnicity, birth outcome and sector level postcode. However, in real terms, this had limited value to adding IMD information to the study. Since IMD data is available by full postcode, future research might consider the ethical and methodological challenges in approaching a small number of potentially identifiable cases (as in perinatal mortality) by full postcode data.

- Deprivation data: continuing from the point above (postcode) this study has a significant limitation in being unable to map cases of perinatal mortality by IMD accurately. The results of

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[165] IMD data is available for full postcodes.

[166] The data was considered potentially identifiable as the other variables including ethnicity and perinatal mortality data had been provided.

[167] 2014

this deprivation analysis would have contributed further to our understanding of factors that contribute to perinatal mortality in Luton.

- There is no CMiS data on the timescale between subsequent pregnancies, which would have been useful in narrowing down the parity results further.

- HCP participation in focus groups: contradictory to expectation, recruiting HCPs across some professions in primary and secondary care in Luton proved difficult. On reflection, I was overly optimistic about the interest of HCP involvement in focus groups, and I did not adequately consider the time and workload constraints on NHS staff. Attempting to get a group of HCPs together (albeit from the same profession or mixed occupations) is perhaps unrealistic and face-to-face interviews may successfully recruit for future research with HCPs.

- Conducting exploratory analysis was not possible due to the nature of categorical variables and the small sample size of dead babies in this cohort (n=128). Also, there was not enough statistical power in such as small sample (0.9 percent of cohort size) to determine predictor variables using a Loglinear procedure.

11.4 Contribution to the field

This thesis makes theoretical, methodological and policy related contributions to the field

Theoretically

- This is one of the first studies to explore the similarities and differences between Pakistani Bangladeshi and WB women’s maternal health beliefs and behaviours and how this may impact on perinatal mortality. Therefore, this this thesis makes a valuable contribution to policy, planning and delivery of maternity services in Luton.

- This is one of the first studies to take an intersectional approach to understanding the experience of perinatal mortality and therefore provides a framework to understand the simultaneous intersections/relationships between heritable, SES and structural factors and health beliefs and health behaviour in the experience of perinatal mortality.

- Implementing the intersectional approach extends the use of this theory to a new context and contributes the emerging theoretical and empirical literature that uses the intersectional approach in public health and health services research.

Methodologically

- The mixed-methods approach has provided an arena for integrating and triangulating the views of lay and bereaved mothers, HCP and provides a trustworthy and holistic view of how health beliefs influence health behaviour and contributes to perinatal mortality in infants born to Pakistani, Bangladeshi and WB women, in Luton.

- The study provides some important insights on a white researcher working with different maternal ethnicities and the associated challenges and contingencies, resulting in increased community representation during research.

- A mixed-methods research design has made a theoretical and empirical contribution to the evidence base on the risk factors in Luton, as well as providing in-depth and contextualised information on the role of health beliefs and behaviour to perinatal mortality.

- Working with bereaved mothers and the associated ethical factors provides future researchers working in sensitive areas with strategies and considerations to promote compassionate research, and engaging with bereaved participants.

Policy and planning

- Provides in-depth information on the risk factors (modifiable and otherwise) for Pakistani, Bangladeshi and WB mothers that can then be used to target interventions to improve engagement with services on the maternity care pathway.

- Has identified specific adverse health behaviours (i.e. not taking folic acid, delays in help-seeking when the baby's movements alter and co-sleeping with their infant) which will allow maternity staff resources to be prioritised.

- Has identified a discrepancy between what pregnancy information is provided by maternity services and the knowledge that women have - identifying service improvement.

- This study contributes to the continued development and planning of culturally competent local services.

- Focusing on similarities facilitates a perspective that compliments intervention planning for mainstream service provision, in addition to targeted interventions aimed at specific ethnic groups at risk.

11.5 Policy recommendations and future directions

This study presents evidence based discussion on how health beliefs influence health behaviour and contribute to the experience of perinatal mortality, specifically in Pakistani, Bangladeshi and WB women in Luton. The results and findings provide evidence and allowed for explanations to be made, for inequalities in perinatal mortality in Luton. Whilst the study was specific to Luton some of the findings, when combined with other studies in different geographies, may be generalisable to other areas which have a similar demographic.

- All women in this study wanted more pregnancy-related information, including more information about risk factors for adverse birth outcomes.

  Recommendation: Provide women with pregnancy-related information, specifically on stillbirth, LBW, IUGR, PTB and genetic risks.

- Pakistani and Bangladeshi women were more disadvantaged in accessing pregnancy-related information, which was potentiated if the women did not speak English.

  Recommendation: Developing and evaluating the effectiveness of a verbally-orientated teaching tool (e.g. You-Tube video or mobile App) to determine which might be most suitable to women from diverse ethnicities.

- It was evident that Bangladeshi women are less likely to talk with family members about pregnancy-related matters.

  Recommendation: Develop a targeted intervention for Bangladeshi mothers by asking HCP to actively identify knowledge gaps.

- Health beliefs are impacting on pregnancy related health behaviours.

  Recommendation: Women need more pregnancy-related information before conception. This may include teaching in secondary school, pre-conception counselling and raising public health awareness for women of reproductive age in the population.

- Several factors (e.g. obesity, BMI, maternal age, diet) are suggested to converge, but how the combined mechanisms combine to an overall risk for perinatal mortality is presently unclear.

  Recommendation: Collecting data in a clinical setting to facilitate statistical analysis will assist in understanding the individual contributions of converging factors.

- Fatalistic attitudes were found among the majority of women, regardless of ethnicity. Recommendation: Explore how fatalism contributes specifically to pregnancy related health behaviour in Pakistani, Bangladeshi and WB pregnant women and determine whether formal education levels contribute to this.

- A high proportion of Pakistani and Bangladeshi women were identified to have DM//GDM. Recommendation: To review current GDM screening uptake, review education programs for context of cultural competence in self-management and examine women's knowledge and understanding of the implications of DM/GDM on health outcomes (mother and infant).

- This study identified that staff made assumptions about women's social support. Recommendation: To integrate as part of the clinical assessment procedure, questioning to ascertain women's support structures, especially during times of bereavement; supporting mothers perinatal mental health.

11.6 Conclusion

Perinatal mortality has a clear ethnic dimension, and Luton shows higher than national average figures, with over 50 percent of deaths occurring in Pakistani and Bangladeshi infants (Child Death Overview Panel, 2015). The existing evidence, prior to this study's contribution was mainly descriptive, failing to explore how health beliefs impacts on health behaviour and mediates the pregnancy and childbirth experience, including perinatal mortality. Furthermore, few studies had included WB women's perspective to elucidate the similarities and differences between the ethnic groups. Mixed-methods were used to address the research question: how do health beliefs influence health behaviour, and contribute to perinatal mortality in babies born to Pakistani, Bangladeshi and White British women (WB) living in Luton?

This study aimed to extend current knowledge by exploring how health beliefs influence health behaviour and contribute to perinatal mortality in infants born to Pakistani, Bangladeshi and WB women living in Luton. A convergent mixed-method was used, with an intersectional approach to reveal similarity, difference, multiplicative and obscured factors (Mens-verhulst and Radtke, 2011; Bowleg, 2012). This showed that deprivation intersected across 'SES', 'health beliefs and health behaviours', 'heritable' and 'structural level determinants', with distinct risk profiles between Pakistani and Bangladeshi and WB mothers, and this may help explain inequalities in perinatal mortality.

The results of this study identified that Pakistani women have the greatest number of statistically significant risk factors in this cohort in Luton. Additionally, there are trends in the secondary data according to ethnic group, revealing distinct patterns of risk profiles. Several factors (e.g. obesity, BMI, maternal age, diet) are suggested to converge, but how the combined mechanisms contribute to an overall risk for perinatal mortality is presently unclear. In this study, there were many similarities between women's health beliefs and health behaviour; women idealised pregnancy and were unaware of risks for adverse outcomes and had fatalistic beliefs. Divergence was identified between ethnic groups. Pakistani and Bangladeshi women engaged more with verbal information sources, however, Bangladeshi mothers were the least likely to discuss pregnancy with family. Similarly, while Pakistani and Bangladeshi mothers were more aware of consanguinity than WB mothers, this knowledge was not widespread. Disparity was found between health information that was provided by staff and its subsequent understanding by mothers, identifying an area of development for local services.

This study contributes to the literature on inequalities in perinatal mortality and has implications theoretically, methodologically and for policy makers and providers (Section 11.5) to reconsider the effectiveness of current pregnancy-related health information and to re-evaluate targeting health messages for women's positive health behaviour in pregnancy. For my research practice, I realised that 'hard to reach' communities (i.e. Pakistani and Bangladeshi mothers) were not hard to reach; more resistance was experienced with health professionals who were 'hard to engage'. This is a barrier to identifying areas of improvement and help to reduce inequalities.

References

Abraham, C., Conner, M., Jones, F. and O'Connor, D. (2008) 'Health cognitions and health behaviours', in *Topics in applied psychology: Health psychology*. London: Hodder Education, pp. 135–157.

Abraham, C. and Sheeran, P. (2009) 'The Health Belief Model', in Conner, M. and Norman, P. (eds) *Predicting Health Behaviour*. second. Berkshire: Oxford University Press, pp. 28–80.

Acheson, D. (1998) *The independent inquiry into inequalities in health*. The Stationary Office. doi: 10.1136/bmj.317.7171.1465.

Agresti, A. (2013) *Categorical data analysis*. New Jersey: Wiley.

Ahmad, W. I. U. (2000) *Ethnicity, Disability and Chronic health*. (eds) W. I. U. Ahmad. Buckingham: Open University Press.

Ahmed, A. Atkin, K. Chamba, R. (2000) 'Causing havoc among their children: parental and professional perspectives on consanguitiy and childhood disability.', in Ahmed, W. (ed.) Ethnicity, disability and chronic illness. Buckingham: Open University Press, pp. 28–44.

Ahmed, S., Atkin, K., Hewison, J. and Green, J. (2006) 'The influence of faith and religion and the role of religious and community leaders in prenatal decisions for sickle cell disorders and thalassaemia major.', *Prenatal diagnosis*, 26(9), pp. 801–9. doi: 10.1002/pd.1507.

Ahmed, S., Green, J. M. and Hewison, J. (2006) 'Attitudes towards prenatal diagnosis and termination of pregnancy for thalassaemia in pregnant Pakistani women in the North of England.', *Prenatal diagnosis*, 26(3), pp. 248–57. doi: 10.1002/pd.1391.

Ahmed, S. Saleem, M. Sultana, N. Raashid, Y., Waqar, A., Anwar, M.(2000b). Prenatal diagnosis of beta-thalassaemia in Pakistan: experience in a Muslim country. Prenatal Diagnosis, 20, pp. 378–383. doi:10.1002/(SICI)1097-0223(200005)20:5<378:: AID-PD815>3.0.CO;2-7

Ajaz, M., Ali, N. and Randhawa, G. (2015) 'UK Pakistani views on the adverse health risks associated with consanguineous marriages.', *Journal of community genetics*. doi: 10.1007/s12687-015-0214-8.

Ajzen, I. (1991) 'The Theory of Planned Behavior', *Oranisation behaviour and human decison processes*, 50, pp. 179–211.

Ajzen, I. (2011) 'The theory of planned behaviour: reactions and reflections.', *Psychology & health*, 26(9), pp. 1113–27. doi: 10.1080/08870446.2011.613995.

Ajzen, I. and Fishbein, M. (2005) 'The influence of attitudes on behaviour', in Albarracin, D., Johnson, B. T., and Zanna, M. P. (eds) *Handbook of Attitude and Attitude change: Basic principals*. Mahwah.: Erlbaum, pp. 173–221.

Akhtar, S., Ahmed, A., Randhawa, M. A., Atukorala, S., Arlappa, N., Ismail, T. and Ali, Z. (2013) 'Prevalence of Vitamin A Deficiency in South Asia : Causes , Outcomes , and Possible Remedies', 31(4), pp. 413–423.

Aleksic, D. (2013) 'Provision of Maternity Services for Undocumented Migrants in the United Kingdom and six European Countries', pp. 1–7.

Alexander, G. R., Tompkins, M. E., Petersen, D. J., Hulsey, T. C. and Mor, J. (1995) 'Discordance Between LMP-based and Clinically Estimated Gestational Age : Implications for Research , Programs , and Policy', *Public Health Reports*, 110(4), pp. 395–402. Available at: http://www.jstor.org/stable/4597867?seq=1#page_scan_tab_contents.

Algren, M. H., Bak, C. K., Berg-Beckhoff, G. and Andersen, P. T. (2015) 'Health-risk behaviour in deprived neighbourhoods compared with non-deprived neighbourhoods: A systematic literature review of quantitative observational studies', *PLoS ONE*, 10(10), pp. 1–17. doi: 10.1371/journal.pone.0139297.

Ali, N. (1999) *Community and individual identity of the Kashmiri community: a case study of Luton*. University of Luton. Available at: http://uobrep.openrepository.com/uobrep/handle/10547/241782.

Ali, N. (2003) 'Fluency in the consulting room Screening for domestic violence in general practice : a way forward ?', *British Journal of General Practice*, (July), pp. 514–518. Available at: http://www.ncbi.nlm.nih.gov/pmc/articles/PMC1314639/pdf/14694661.pdf.

Ali, N. (2006) 'Imperial implosions: Postcoloniality and the orbits of Migration', in Ali, N., Kalra, V. S., and Atkin, K. (eds) A postcolonial people: South Asians in Britain. London: Hurst and Co publishers, pp. 158–168.

Ali, N. (2009) 'The making of Kashmiri identity', *South Asian Diaspora*. Routledge , 1(2), pp. 181–192. doi: 10.1080/19438190903109545.

Ali, N. and Burchett, H. (2004) *Experiences of Maternity Services: Muslim Women's Perspectives*. Available at: www.maternityaction.org.uk/.

Ali, N., McLean, C. and Rehman, H. (2012) 'Faulty genes: consanguinity in the Pakistani community', *Ethnicity and Inequalities in Health and Social Care*. Emerald Group Publishing Limited, 5(2), pp. 43–51. doi: 10.1108/17570981211286787.

Ali Hyder, A. and Morrow, R. (2006) 'Culture, Behavior, and Health', in Merson, M., Black, R., and Mills, A. (eds) *International Public Health: diseases programs, systems and policies.* London: Jones and Bartlett Publishers, pp. 41–66.

Alkhawari, F. S., Stimson, G. V. and Warrens, A. N. (2005) 'Attitudes toward transplantation in U.K. Muslim Indo-Asians in West London', American Journal of Transplantation, 5(6), pp. 1326–1331. doi: 10.1111/j.1600-6143.2005.00814.x

Almeida, L. M., Caldas, J., Ayres-de-Campos, D., Salcedo-Barrientos, D. and Dias, S. (2013) 'Maternal healthcare in migrants: a systematic review.', *Maternal and child health journal*, 17(8), pp. 1346–54. doi: 10.1007/s10995-012-1149-x.

Alshawish, E., Marsden, J., Yeowell, G. and Wibberley, C. (2013) 'Investigating access to and use of maternity health-care services in the UK by palestinian women', *British Journal of Midwifery*, 21(8), pp. 571–577. Available at: http://www.scopus.com/inward/record.url?eid=2-s2.0-84882773432&partnerID=tZOtx3y1.

Aminu, M., Unkels, R., Mdegela, M., Utz, B., Adaji, S. and van den Broek, N. (2014) 'Causes of and factors associated with stillbirth in low- and middle-income countries: a systematic literature review', *BJOG : an international journal of obstetrics and gynaecology*, 121, pp. 141–153. doi: 10.1111/1471-0528.12995.

Angelica, M. D. and Fong, Y. (2010) 'Neighborhood deprivation and adverse birth outcomes among diverse ethnic groups', *Ann Epidemiol.*, 20(6), pp. 445–451. doi: 10.1016/j.surg.2006.10.010.Use.

El Ansari, W., Newbigging, K., Roth, C. and Malik, F. (2009) 'The role of advocacy and interpretation services in the delivery of quality healthcare to diverse minority communities in London, United Kingdom.', *Health & social care in the community*, 17(6), pp. 636–46. doi:

10.1111/j.1365-2524.2009.00867.x.

Armitage, C. J. and Conner, M. (2001) ‘Efficacy of the Theory of Planned Behaviour: a meta-analytic review.’, *The British journal of social psychology / the British Psychological Society*, 40(Pt 4), pp. 471–99. Available at: http://www.ncbi.nlm.nih.gov/pubmed/11795063.

Arntzen, A., Mortensen, L., Schnor, O., Cnattingius, S., Gissler, M. and Andersen, A. M. N. (2008) ‘Neonatal and postneonatal mortality by maternal education - A population-based study of trends in the Nordic countries, 1981-2000’, *European Journal of Public Health*, 18(3), pp. 245–251. doi: 10.1093/eurpub/ckm125.

Aspinall, P. J. (1998) ‘Describing the white ethnic group and its composition in medical research’, *Social Science and Medicine*, 47(11), pp. 1797–1808. doi: doi:10.1016/S0277-9536(98)00239-1.

Aston, J., Hooker, H., Page, R. and Willison, R. (2007a) *Pakistani and Bangladeshi women’s attitudes to work and family [research report 48]*. Leeds. Available at: http://dera.ioe.ac.uk/7721/.

Aston, J., Hooker, H., Page, R. and Willison, R. (2007b) *Pakistani and Bangladeshi women ’ s attitudes to work and family. DWP : Research report no 458*. London.

Atkin, K. (2006) ‘Healthcare and BrAsians: making sense of practice and policy’, in Ali, N. Kalra, V. Sayyid, S. (ed.) *A postcolonial people: South Asians in Britain*. Hurst and Co., pp. 224–256.

Atkin, K. (2011) ‘Negotiating ethnic identities and health’, in Graham, H. (ed.) *Understanding health inequalities*. 2nd Edn. Berkshire: Open University Press, pp. 125–141.

Atkin, K. and Ahmad, W. (1996) ‘Family care-giving and chronic illness: how parents cope with a child with a sickle cell disorder or thalassaemia’, *Health and Social Care in the Community*, 8(1), pp. 57–69.

Atkin, K., Ali, N. and Chu, C. (2009) ‘The politics of difference ? Providing a cancer genetics service in a culturally and linguistically diverse society’, *Diversity in Health and Care*, 6, pp. 149–158. Available at: http://diversityhealthcare.imedpub.com/the-politics-of-difference-providing-a-cancer-genetics-service-in-a-culturally-and-linguistically-diverse-society.pdf.

Atkinson, M., Clark, M., Clay, D., Johnson, D. M., Owen, D. D. and Szczepura, A. (2001) *Systematic review of ethnicity and health service access for London. Final report.* Coventry.

Atkinson, R. and Flint, J. (2001) ‘Accessing Hidden and Hard-to-Reach Populations : Snowball Research Strategies’, *Social Research Update*, (33), pp. 1–8.

Auger, N., Delézire, P., Harper, S. and Platt, R. W. (2012) ‘Maternal Education and Stillbirth’, *Epidemiology*, 23(2), pp. 247–254. doi: 10.1097/EDE.0b013e31824587bc.

Aveyard, P., Cheng, K. K., Manaseki, S. and Gardosi, J. (2002) ‘The risk of preterm delivery in women from different ethnic groups’, *International Journal of Obstetrics and Gynaecology*, 109(August), pp. 894–899. Available at: http://onlinelibrary.wiley.com/doi/10.1111/j.1471-0528.2002.01197.x/epdf.

Azmat, G. (2015) *Gender Gaps in the UK Labour Market: jobs , pay and family-friendly policies*. London. Available at: http://cep.lse.ac.uk/pubs/download/ea027.pdf.

Baart, J. L. G. (2003) ‘Sustainable Development and the Maintenance of Pakistan’s Indigenous Languages’, in *Proceedings of the Conference on the State of Social Sciences and Humanities: Current Scenario and Emerging Trends, December 15-17, 2003, Islamabad*. Islamabad, pp. 202–213. Available at: http://fli-online.org/documents/sociolinguistics/development_maintenance_of_pak_lgs.pdf.

Baca-Zinn, M. (2009) 'Field Research in Minority Communities: Ethical , Methodological and Political Observations by an Insider', *Society for the Study of Social Problems*, 27(2), pp. 209–219.

Baguley, T. (2012) 'Online supplement 2: Dealing with missing data', in *Serious Stats. A guide to advance statistics for the behavioural sciences.* London: Palgrave Macmillan, pp. 1–14.

Bahar, Z., Okcay, H., Ozbicakci, S., Beser, A., Ustun, B. and Ozturk, M. (2005) 'The effects of Islam and traditional practices on women's health and reproduction', *Nursing Ethnics*, 12(6), pp. 557–570.

Baker, M. K., Simpson, K., Lloyd, B., Bauman, A. E. and Singh, M. A. F. (2011) 'Behavioral strategies in diabetes prevention programs: A systematic review of randomized controlled trials', *Diabetes Research and Clinical Practice*. Elsevier Ireland Ltd, 91(1), pp. 1–12. doi: 10.1016/j.diabres.2010.06.030.

Balchin, I., Whittaker, J. C., Patel, R. R., Lamont, R. F. and Steer, P. J. (2007) 'Racial variation in the association between gestational age and perinatal mortality: prospective study.', *BMJ (Clinical research ed.)*. British Medical Journal Publishing Group, 334(7598), p. 833. doi: 10.1136/bmj.39132.482025.80.

Baldwin, S. and Griffiths, P. (2009) 'Do specialist community public health nurses assess risk factors for depression, suicide, and self-harm among South Asian mothers living in London?', *Public health nursing (Boston, Mass.)*, 26(3), pp. 277–89. doi: 10.1111/j.1525-1446.2009.00780.x.

Ball, H. L., Moya, E., Fairley, L., Westman, J., Oddie, S. and Wright, J. (2012) 'Bed- and sofa-sharing practices in a UK biethnic population.', *Pediatrics*, 129(3), pp. e673-81. doi: 10.1542/peds.2011-1964.

Ballard, R. (1994) 'The emergence of Desh Pardesh', in Ballard, R. (ed.) *Desh Pardesh: The South Asian Presence in Britain*. London.: C. Hurst & Co, pp. 1–35.

Ballard, R. (2001) 'The Current Demographic Characteristics of the South Asian Presence in Britain : an analysis of the results of the 2001 Census'.

Ballard, R. (2002) 'The South Asian Presence in Britain and its Transnational Connections', in Singh, H. and Vertocvec, S. (eds) *Culture and Economy in the Indian Diaspora*. London: Routledge, pp. 1–30. doi: 10.4324/9780203398296.

Bansal, N., Ayoola, O. O., Gemmell, I., Vyas, A., Koudsi, A., Oldroyd, J., Clayton, P. E. and Cruickshank, J. K. (2008) 'Effects of early growth on blood pressure of infants of British European and South Asian origin at one year of age: the Manchester children growth and vascular health study.', *Journal of hypertension*, 26(3), pp. 412–418. doi: 10.1097/HJH.0b013e3282f3168e.

Bansal, N., Chalmers, J. W. T., Fischbacher, C. M., Steiner, M. F. C. and Bhopal, R. S. (2014) 'Ethnicity and first birth: age, smoking, delivery, gestation, weight and feeding: Scottish health and ethnicity linkage study.', *European journal of public health*, 2008(May 2001), pp. 1–6. doi: 10.1093/eurpub/cku059.

Barba, C., Cavalli-Sforza, T., Cutter, J., Darnton-Hill, I., Deurenberg, P., Deurenberg-Yap, M. and Gill, T. (2004) 'Appropriate body-mass index for Asian populations and its implications for policy and intervention strategies.', *Lancet*. doi: 10.1016/S0140-6736(03)15268-3.

Barnett, A. H., Dixon, A. N., Bellary, S., Hanif, M. W., O'Hare, J. P., Raymond, N. T. and Kumar, S. (2006) 'Type 2 diabetes and cardiovascular risk in the UK south Asian community', *Diabetologia*, 49(10), pp. 2234–2246. doi: 10.1007/s00125-006-0325-1.

Baron, R., Manniën, J., te Velde, S. J., Klomp, T., Hutton, E. K. and Brug, J. (2015) 'Socio-demographic inequalities across a range of health status indicators and health behaviours among pregnant women in prenatal primary care: a cross-sectional study.', *BMC pregnancy and childbirth*. BMC Pregnancy and Childbirth, 15(1), p. 261. doi: 10.1186/s12884-015-0676-z.

Bartley, M. (2008) *Health inequality : an introduction to theories, concepts and methods.* Cambridge: Blackwell Publishers.

Bartley, M., Claderwood, L., Jayaweera, H., Plewis, I. and Ward, K. (2005) 'Childrens origins', in Dex, S. and Joshi, H. (eds) *Children of the 21st Century*. Bristol: The Policy Press, pp. 25–71.

Bedfordshire Clinical Commissioning Group (2013) *Smoking in Pregnancy*.

Beemsterboer, S. N., Homburg, R., Gorter, N. A., Schats, R., Hompes, P. G. A. and Lambalk, C. B. (2006) 'The paradox of declining fertility but increasing twinning rates with advancing maternal age', *Human Reproduction*, 21(6), pp. 1531–1532. doi: 10.1093/humrep/del009.

Behrman, R. E. and Butler, A. S. (2007) *Preterm birth, causes, consequences and prevention*. Edited by R. E. Behrman and A. S. Butler. Washington: National Academies Press. Available at: http://www.nap.edu/catalog/11622.html.

Benzeval, M., Bond, L., Campbell, M., Egan, M., Lorenc, T., Petticrew, M. and Popham, F. (2014) *How does money influence health?* Available at: http://www.jrf.org.uk/sites/files/jrf/income-health-poverty-full.pdf.

Berglund, S., García-Valdés, L., Torres-Espinola, F., Segura, M. T., Martínez-Zaldívar, C., Aguilar, M., Agil, A., Lorente, J. A., Florido, J., Padilla, C., Altmäe, S., Marcos, A., López-Sabater, C. and Campoy, C. (2016) 'Maternal, fetal and perinatal alterations associated with obesity, overweight and gestational diabetes: an observational cohort study (PREOBE)', *BMC public health*. BMC Public Health, in press, pp. 1–12. doi: 10.1186/s12889-016-2809-3.

Berry, J. W. (1990) 'Imposed Etics, Emics, Derived Etics. Their conceptual and operational status in cross-cultural psychology.', in Headland, T., Pike, K., and Harris, M. (eds) *Etics and Emics: The insider outsider debate*. London: Sage Publications, pp. 84–99.

Bestwick, J. P., Huttly, W. J., Morris, J. K. and Wald, N. J. (2014) 'Prevention of neural tube defects: A cross-sectional study of the uptake of folic acid supplementation in nearly half a million women', *PLoS ONE*, 9(2). doi: 10.1371/journal.pone.0089354.

Betancourt, J. R., Green, A. R., Carrillo, J. E. and Ananeh-Firempong, O. (2003) 'Defining cultural competence: a practical framework for addressing racial/ethnic disparities in health and health care.', *Public health reports (Washington, D.C. : 1974)*, 118(4), pp. 293–302. Available at: http://www.pubmedcentral.nih.gov/articlerender.fcgi?artid=1497553&tool=pmcentrez&rendertype=abstract.

Betancourt, J. R., Green, A. R., Emilio Carrillo, J. and Park, E. R. (2005) 'Cultural competence and health care disparities: Key perspectives and trends', *Health Affairs*, 24(2), pp. 499–505. doi: 10.1377/hlthaff.24.2.499.

Bharj, K. K. and Salway, S. M. (2008) *Addressing ethnic inequalities in maternity service experiences and outcomes: responding to women's needs and preferences*, *A Race Equality Foundation Briefing Paper*. Available at: www.raceequalityfoundation.org.uk.

Bhopal, R. (1997) 'Is Research Into Ethnicity and Health Racist, Unsound, or Important Science?', *BMJ*, 314(7096), pp. 1751–1756. doi: 10.1136/bmj.314.7096.1751.

Bhopal, R. (2004) 'Glossary of terms relating to ethnicity and race: for reflection and debate.', Journal of epidemiology and community health, 58(6), pp. 441–445. doi: 10.1136/jech.2003.013466.

Bhopal, R. and Donaldson, L. (1998) ‘White, European, Western, Caucasian, or What ? Inappropriate Labeling in Research on Race, Ethnicity, and Health’, *American Journal of Public Health*, 88(9), pp. 1303–1307. doi: 10.2105/AJPH.88.9.1303.

Bhui, K., Bhughra, D., Goldberg, D., Sauer, J. and Tylee, A. (2004) ‘Assessing the Prevalence of Depression in Punjabi and English Primary Care Attenders: The Role of Culture, Physical Illness and Somatic Symptoms’, *Transcultural Psychiatry*, 41(3), pp. 307–322. doi: 10.1177/1363461504045642.

Bhui, K. and Dinos, S. (2009) ‘Health Beliefs and Culture Essential Considerations for Outcome Measurement’, *Dis Manage Health Outcomes*, 16(6), pp. 411–419. doi: 1173-8790/08/0006-0411.

Bircher, J. and Kuruvilla, S. (2014) ‘Defining health by addressing individual, social, and environmental determinants: new opportunities for health care and public health.’, *Journal of public health policy*. Nature Publishing Group, 35(3), pp. 363–86. doi: 10.1057/jphp.2014.19.

Bishop, F. L. (2015) ‘Using mixed methods research designs in health psychology: An illustrated discussion from a pragmatist perspective’, *British Journal of Health Psychology*, 20(1), pp. 5–20. doi: 10.1111/bjhp.12122.

Bittles, A. (2015) *Global Prevalence of consanguinity*. Available at: http://www.consang.net/images/c/c4/Globalcolourlarge.jpg (Accessed: 4 November 2015).

Bittles, A. . (2013) ‘Consanguineous marriages and congenital anomalies’, *The Lancet*. Elsevier Ltd, 382(9901), pp. 1316–1317. doi: 10.1016/S0140-6736(13)61503-2.

Bittles, A., Grant, J. and Shami, S. (1993) ‘Consanguinity as a determinant of reproductive behaviour and mortality in Pakistan.’, *International journal of epidemiology*, 22(3), pp. 463–7. Available at: http://www.ncbi.nlm.nih.gov/pubmed/8359962.

Blackwell, C. (2015) ‘The Role of Infection and Inflammation in Stillbirths: Parallels with SIDS?’, *Frontiers in Immunology*, 6(June), pp. 1–8. doi: 10.3389/fimmu.2015.00248.

Blane, D. (2006) ‘The life course, the social gradient and heallth’, in Marmot, M. and Wilkinson, R. (eds) *Social Determinants of Health*. 2nd Edn. Oxford: Oxford University Press, pp. 54–78.

Blane, D., Hart, C. L., Smith, G. D., Gillis, C. R., Hole, D. J. and Hawthorne, V. M. (1996) ‘Association of cardiovascular disease risk factors with socioeconomic position during childhood and during adulthood.’, *BMJ*, 313(7070), pp. 1434–8. doi: 10.1136/bmj.313.7070.1434.

Blane, D., Smith, G. D. and Hart, C. (1999) ‘Some social and physical correlates of intergenerational social mobility: Evidence from the west of Scotland collaborative study’, *Sociology*, 33(1), pp. 169–183. doi: 10.1177/S0038038599000097.

Blencowe, H., Cousens, S., Chou, D., Oestergaard, M., Say, L., Moller, A.-B., Kinney, M. and Lawn, J. (2013) ‘Born too soon: the global epidemiology of 15 million preterm births.’, *Reproductive health*, 10 Suppl 1(Suppl 1), p. S2. doi: 10.1186/1742-4755-10-S1-S2.

Blomberg, M., Birch-Tyrberg, R. and Kjølhede, P. (2014) ‘Impact of maternal age on obstetric and neonatal outcome with emphasis on primiparous adolescents and older women: a Swedish Medical Birth Register Study.’, *BMJ open*, 4(11), p. e005840. doi: 10.1136/bmjopen-2014-005840.

Blumenshine, P., Egerter, S., Barclay, C., Cubbin, C. and Braveman, P. (2010) ‘Socioeconomic disparities in adverse birth outcomes: a systematic review.’, *American journal of preventive medicine*. Elsevier, 39(3), pp. 263–72. doi: 10.1016/j.amepre.2010.05.012.

Boerleider, A. W., Wiegers, T. a, Manniën, J., Francke, A. L. and Devillé, W. L. J. M. (2013) ‘Factors affecting the use of prenatal care by non-western women in industrialized western countries: a systematic review.’, *BMC pregnancy and childbirth*, 13, p. 81. doi: 10.1186/1471-2393-13-81.

Bollini, P., Pampallona, S., Wanner, P. and Kupelnick, B. (2009) ‘Pregnancy outcome of migrant women and integration policy: A systematic review of the international literature’, *Social Science and Medicine*. Elsevier Ltd, 68(3), pp. 452–461. doi: 10.1016/j.socscimed.2008.10.018.

Bonellie, S. (2001) ‘Effect of maternal age, smoking and deprivation on birthweight’, *Paediatric and Perinatal Epidemiology*, 15(1), pp. 19–26. doi: 10.1046/j.1365-3016.2001.00324.x.

Boslaugh, S. (2007) *Secondary Data Sources for Public Health: A Practical Guide*. New York, NY: Cambridge University Press.

Bowes, A. M. and Domokos, M. (1996) ‘Pakistani women and maternity care: Raising muted voices.’, *Sociology of Health & Illness*, 18(1), pp. 45–65. doi: 10.1111/1467-9566.ep10934412.

Bowleg, L. (2012) ‘The problem with the phrase women and minorities: Intersectionality-an important theoretical framework for public health’, *American Journal of Public Health*, 102(7), pp. 1267–1273. doi: 10.2105/AJPH.2012.300750.

Bowles, C., Walters, R. and Jacobson, B. (2007) *Born Equal ? Inequalities in Infant Mortality in London . A Technical Report*. Available at: http://www.lho.org.uk/Download/Public/12375/1/Infant_Mortality_FullReport.pdf.

Bowling, A. (2009) *Research Methods in Health*. 3rd editio. Berkshire: McGraw Hill.

Bradby, H. (2003) ‘Describing ethnicity in health research.’, *Ethnicity & health*, 8(1), pp. 5–13. doi: 10.1080/1355785032000109588.

Bradshaw, J., Mayhew, E., Jayaweera, H., Joshi, H. and Ward, K. (2005) ‘Socioeconomic origins of parents and child poverty’, in Dex, S. and Joshi, H. (eds) *Children of the 21st Century*. Bristol, pp. 71–109.

Brah, A. and Phoenix, A. (2004) ‘Ain’t I A Woman? Revisiting Intersectionality’, *Journal of International Women’s Studies*, 5(May), pp. 75–86.

Brooke, O. G., Butters, F. and Wood, C. (1981) ‘Intrauterine vitamin D nutrition and postnatal growth in Asian infants.’, *British medical journal (Clinical research ed.)*, 283(6298), p. 1024. Available at: http://www.pubmedcentral.nih.gov/articlerender.fcgi?artid=1507263&tool=pmcentrez&rendertype=abstract.

Brunner, E. and Marmot, M. (2006) ‘Social organisation, stress and health’, in Marmot, M. and Wilkinson, R. G. (eds) *Social Determinants of Health*. 2nd End. Oxford: Oxford University Press, pp. 6–31.

Bryant, L. D., Ahmed, S., Ahmed, M., Jafri, H. and Raashid, Y. (2011) ‘“All is done by Allah”. Understandings of Down syndrome and prenatal testing in Pakistan’, *Social Science & Medicine*, 72(8), pp. 1393–1399. Available at: http://www.sciencedirect.com/science/article/pii/S0277953611001377 (Accessed: 18 January 2014).

Bryant, M., Santorelli, G., Lawlor, D. A., Farrar, D., Tuffnell, D., Bhopal, R. and Wright, J. (2014) ‘A comparison of South Asian specific and established BMI thresholds for determining obesity prevalence in pregnancy and predicting pregnancy complications: findings from the Born in Bradford cohort’, *International Journal of Obesity*, 38(3), pp. 444–450. doi: 10.1038/ijo.2013.117.

Bryman, A. (2012a) ‘Breaking down the quantitative /qualitative divide.’, in *Social Research*

Methods. 4th edn. Oxford: Oxford University Press, pp. 613–627.

Bryman, A. (2012b) ‘Research Designs’, in *Social Research Methods*. 4th edn. Oxford: Oxford University Press, pp. 44–79.

Bryman, A. (2012c) ‘The Nature of Qualitative Research’, in *Social Research Methods*. 4th edn. Oxford: Oxford University Press, pp. 377–414.

Burton, J., Nandi, A. and Platt, L. (2008) ‘Who are the UK’s minority ethnic groups? Issues of identification and measureent in a longitudinal study’, *Understanding Society Working Paper Series*, (2008–2), p. 52.

Cabieses, B., Waiblinger, D., Santorelli, G. and McEachan, R. R. C. (2014) ‘What factors explain pregnant women’s feeding intentions in Bradford, England: a multi-methods, multi-ethnic study.’, *BMC pregnancy and childbirth*, 14, p. 50. doi: 10.1186/1471-2393-14-50.

Cacciatore, J., Schnebly, S. and Froen, J. F. (2009) ‘The effects of social support on maternal anxiety and depression after stillbirth.’, *Health & social care in the community*, 17(2), pp. 167–176. doi: 10.1111/j.1365-2524.2008.00814.x.

Cantwell, R., Clutton-Brock, T., Cooper, G., Dawson, A., Drife, J., Garrod, D., Harper, A., Hulbert, D., Lucas, S., McClure, J., Millward-Sadler, H., Neilson, J., Nelson-Piercy, C., Norman, J., O’Herlihy, C., Oates, M., Shakespeare, J., de Swiet, M., Williamson, C., Beale, V., Knight, M., Lennox, C., Miller, A., Parmar, D., Rogers, J. and Springett, A. (2011) ‘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 : an international journal of obstetrics and gynaecology*, 118 Suppl, pp. 1–203. doi: 10.1111/j.1471-0528.2010.02847.x.

Cattaccin, S., Antonio, C. and Domenig, D. (2013) ‘Equity Standards for Health Care Organisations: a Theoretical Framework’, *Diversity and Equality in Health and Care ,* 10(4), pp. 249–258.

Central Intelligence Agency (2015) *The World Factbook: Infant Mortality rate*. Available at: https://www.cia.gov/library/publications/the-world-factbook/rankorder/2091rank.html (Accessed: 3 February 2016).

Centre for Maternal and Child Enquiries (2011a) *Perinatal Mortality 2009*. Available at: http://www.hqip.org.uk/assets/NCAPOP-Library/CMACE-Reports/35.-March-2011-Perinatal-Mortality-2009.pdf.

Centre for Maternal and Child Enquiries (2011b) ‘Saving Mothers’ Lives’, *BJOG : An International Journal of Obstetrics and Gynaecology*, 118(March), pp. 1–203. Available at: http://www.hqip.org.uk/assets/NCAPOP-Library/CMACE-Reports/6.-March-2011-Saving-Mothers-Lives-reviewing-maternal-deaths-to-make-motherhood-safer-2006-2008.pdf.

Centre for Workforce Intelligence (2015) *Updated Maternity Care Pathway tool guidance document*. London.

Chaffee, S. and Roser, C. (1986) ‘Involvement and the consistency of knowledge, attitudes and behavior’, *Communication Research*, 13(3), pp. 373–399.

Chakraborty, N. (2003) ‘Determinants of the use of maternal health services in rural Bangladesh’, *Health Promotion International*, 18(4), pp. 327–337. doi: 10.1093/heapro/dag414.

Chambra, R. and Ahmad, W. (2000) ‘Language, communication and information: the needs of parents caring for a severely disabled child’, in Ahmad, W. I. U. (ed.) *Ethnicity, disability and chronic illness*. Buckingham: Oxford University Press, pp. 85–102.

Chang, H. H., Larson, J., Blencowe, H., Spong, C. Y., Howson, C. P., Cairns-Smith, S., Lackritz, E. M., Lee, S. K., Mason, E., Serazin, A. C., Walani, S., Simpson, J. L. and Lawn, J. E. (2013) 'Preventing preterm births: analysis of trends and potential reductions with interventions in 39 countries with very high human development index.', *Lancet*. NIH Public Access, 381(9862), pp. 223–34. doi: 10.1016/S0140-6736(12)61856-X.

Chaturvedi, N. (2001) 'Ethnicity as an epidemiological determinant--crudely racist or crucially important?', *International Journal of Epidemiology*, 30(5), pp. 925–927. doi: 10.1093/ije/30.5.925.

Chebsey, C., Jackson, S., Gleeson, K., Winter, C., Storey, C., Lewis, J., Heazell, A., Fox, R., Draycott, T. and Siassakos, D. (2015) 'Joint perspective, joint decison making: Improving Maternity bereavement care for stillbirth. A Mixed-method multicentre study in the United Kingdom', in *RCOG World Congress 2015*. Brisbane: Royal College of Obstetricians and Gynaecologists, p. 2015. Available at: http://www.rcog2015.com/.

Chen, X.-K., Wen, S. W., Fleming, N., Demissie, K., Rhoads, G. G. and Walker, M. (2007) 'Teenage pregnancy and adverse birth outcomes: a large population based retrospective cohort study.', *International journal of epidemiology*, 36(2), pp. 368–73. doi: 10.1093/ije/dyl284.

Child Death Overview Panel (2013) *Bedford Borough , Central Bedfordshire and Luton Child Death Overview Process Annual Report April 2012-March 2013*. Bedford. Available at: http://www.centralbedfordshirelscb.org.uk/assets/1/cdop_report_2013_to_2014_final.pdf.

Child Death Overview Panel (2015) *Bedford Borough , Central Bedfordshire and Luton Child Death Overview Process Annual Report April 2014-March 2015*. Available at: http://www.centralbedfordshirelscb.org/assets/1/cdop_annual_report_2014-2015.pdf.

CHIMAT (2014) *Luton Child Health Profile*.

Choudhury, N. and Ahmed, S. M. (2011) 'Maternal care practices among the ultra poor households in rural Bangladesh: a qualitative exploratory study.', *BMC pregnancy and childbirth*, 11(1), p. 15. doi: 10.1186/1471-2393-11-15.

Choudhury, N., Moran, A. C., Alam, M. A., Ahsan, K. Z., Rashid, S. F. and Streatfield, P. K. (2012) 'Beliefs and practices during pregnancy and childbirth in urban slums of Dhaka, Bangladesh.', *BMC public health*, 12(1), p. 791. doi: 10.1186/1471-2458-12-791.

Christoffersen-Deb, A. (2012) 'Viability: a cultural calculus of personhood at the beginnings of life.', *Medical anthropology quarterly*, 26(4), pp. 575–94. doi: 10.1111/maq.12008.

Cianfarani, S., Germani, D. and Branca, F. (1999) 'Low birthweight and adult insulin resistance: the "catch-up growth" hypothesis', *Archives of Disease in Childhood - Fetal and Neonatal Edition*, 81(1), pp. F71–F73. doi: 10.1136/fn.81.1.F71.

Clarke, C. (2006) 'Defining ethnicity in a cultural and socio-legal context : the case of scottish gypsy-travellers', *Scottish Affairs*, 54(2006), pp. 39–67. Available at: http://strathprints.strath.ac.uk/836/.

Clarson, C. L., Barker, M. J., Marshall, T. and Wharton, B. a (1982) 'Secular change in birthweight of Asian babies born in Birmingham.', *Archives of disease in childhood*, 57(11), pp. 867–871. doi: 10.1136/adc.57.11.867.

Claydon, J. E., Mitton, C., Sankaran, K. and Lee, S. K. (2007) 'Ethnic differences in risk factors for neonatal mortality and morbidity in the neonatal intensive care unit.', *Journal of perinatology : official journal of the California Perinatal Association*. Nature Publishing Group, 27(7), pp. 448–52. doi: 10.1038/sj.jp.7211766.

Clifford, S., Giddings, S., Southam, M., Williams, M. and Gardosi, J. (2013) 'The Growth

Assessment Protocol : a national programme to improve patient safety in maternity care', pp. 516–523.

CMACE (2010) *Maternal obesity in the UK: findings from a national project*, *CMACE*. doi: 10.1111/j.1399-5448.2009.00616.x.

Cohen, D. (2010) 'Methods in cultural psychology', in Kitayama, S. and Cohen, D. (eds) *Handbook of Cultural Psychology*. New York: The Guildford Press, pp. 196–237.

Cohen, D. and Kitayama, S. (2010) 'Cultural Psychology: This stanza and the next', in Kitayama, S. and Cohen, D. (eds) *Handbook of Cultural Psychology*. New York: The Guildford Press, pp. 847–852.

Cohen, S. and Syme, S. L. (1985) 'Issues in the study and application of social support', in Cohen, S. and Syme, S. L. (eds) *Social Support and Health*. San Francisco: Academic Press, pp. 3–22.

Collins, J. W., Rankin, K. M. and David, R. J. (2011) 'Low birth weight across generations: the effect of economic environment.', *Maternal and child health journal*, 15(4), pp. 438–45. doi: 10.1007/s10995-010-0603-x.

Communities and Local Government (2009a) *The Bangladeshi Muslim Community in England*, *Communities*. London. Available at: http://www.swadhinata.org.uk/document/Bangladeshi_Muslim.pdf.

Communities and Local Government (2009b) *The Pakistani Muslim Community in England Understanding Muslim Ethnic Communities*. Available at: http://www.communities.gov.uk/documents/communities/pdf/1170952.pdf%5Cnpapers3://publication/uuid/309E40AE-E48B-4DD8-8486-939E088E5890.

Conner, M. (2013) 'Health cognitions, affect and health behaviors', *The European Health Psychologist*, 15(2), pp. 33–39.

Conner, M. and Norman, P. (1999) 'The Role of Social Cognition in Health Behaviours', in Conner, M. and Norman, P. (eds) *Predicting Health Behaviour*. Suffolk: Open University Press, pp. 1–23.

Conner, M. and Norman, P. (2005) 'Predicting Health Behaviour: A Social Cognition Approach.', in Conner, M. and Norman, P. (eds) *Predicting health behvaiour.* Second edn. London: Open University Press, pp. 1–373.

Cook, D. (2002) 'Consultation, for a Change? Engaging Users and Communities in the Policy Process', *Social Policy & Administration*, 36(5), pp. 516–531.

Corsini, C. and Viazzo, P. P. (1993) *The decline of Infant Mortality In Europe 1800-1950 - Four National Case Studies*. Florence. Available at: http://www.unicef-irc.org/publications/pdf/hisper_decline_infantmortality.pdf.

Coton, S. J., Nazareth, I. and Petersen, I. (2016) 'A cohort study of trends in the prevalence of pregestational diabetes in pregnancy recorded in UK general practice between 1995 and 2012.', *BMJ open*, 6(1), p. e009494. doi: 10.1136/bmjopen-2015-009494.

Crenshaw, K. (1991) 'Mapping the margins: Intersectionality, identity politics, and violence against women of color', *Stanford Law Review*, 43(6), pp. 1241–1299. doi: 10.2307/1229039.

Cresswell, J. a, Yu, G., Hatherall, B., Morris, J., Jamal, F., Harden, A., Renton, A. and Joannemorrisbartshealthnhsuk, J. M. (2013) 'Predictors of the timing of initiation of antenatal care in an ethnically diverse urban cohort in the UK.', *BMC pregnancy and childbirth*, 13, p. 103. Available at: http://www.pubmedcentral.nih.gov/articlerender.fcgi?artid=3652742&tool=pmcentrez&rendertype=

abstract.

Creswell, J. W. (2013) ‘Philosophical Assumptions and Theoretical Assumptions and’, in *Qualitative Inquiry & Research Design: Choosing among five approaches*. London: Sage Publications, pp. 15–42.

Creswell, J. W., Fetters, M. and Ivankova, I. (2004) ‘Designing a mixed methods study in primary care’, *Annuals of Family Medicine*, 2(1), pp. 7–12. doi: 10.1370/afm.104.INTRODUCTION.

Creswell, J. W. and Plano-Clark, V. L. (2011a) ‘Choosing a Mixed Methods Design’, in *Designing and Conducting Mixed Method Research*. 2nd edn. London: Sage Publications, pp. 53–107.

Creswell, J. W. and Plano-Clark, V. L. (2011b) *Designing and conducting mixed methods research*. 2nd Edn. London: Sage Publications.

Cross-Sudworth, F. (2007) ‘Racism and discrimination in maternity services’, *British Journal of Midwifery*, 15, p. 327–331 ST–Racism and discrimination in materni.

Cross-Sudworth, F., Williams, A. and Herron-Marx, S. (2011) ‘Maternity services in multi-cultural Britain: using Q methodology to explore the views of first- and second-generation women of Pakistani origin.’, *Midwifery*. Elsevier, 27(4), pp. 458–68. doi: 10.1016/j.midw.2010.03.001.

Cross-Sudworth, F., Williams, M. and Gardosi, J. (2015) ‘Perinatal deaths of migrant mothers: Adverse outcomes from unrecognised risks and substandard care factors’, *British Journal of Midwifery*, 23(10), pp. 734–740. doi: 10.12968/bjom.2015.23.10.734.

Crotty, M. (1998) *The Foundations of Social Research*. London: Sage Publishers.

Culhane, J. F. and Goldenberg, R. L. (2011) ‘Racial Disparities in Preterm Birth’, *Seminars in Perinatology*. Elsevier Inc., 35(4), pp. 234–239. doi: 10.1053/j.semperi.2011.02.020.

Culley, L. and Dyson, S. (2010) ‘Race and ethnicity’, in Denny, E. and Earle, S. (eds) *Sociology for nurses*. 2nd Edn. Cambridge, pp. 184–205.

Cutler, D., Deaton, A. and Lleras-Muney, A. (2006) ‘The Determinants of Mortality’, *Journal of Economic Perspectives*, 20(3), pp. 97–120. doi: 10.1257/jep.20.3.97.

D’Souza, L. and Garcia, J. (2004) ‘Improving services for disadvantaged childbearing women.’, *Child: care, health and development*, 30(6), pp. 599–611. doi: 10.1111/j.1365-2214.2004.00471.x.

Dahlgren, G. and Whitehead, M. (1991) *Policies and strategies to promote social equity in health Background document to WHO – Strategy paper*, *Institutet för Framtidsstudier*. Available at: http://s2.medicina.uady.mx/observatorio/docs/eq/li/Eq_2007_Li_Dahlgren.pdf.

Dahlgren, G. and Whitehead, M. (2007) *European strategies for tackling social inequities in health: Levelling up part 2*, *World Health Organization*. World Health Organisation. Available at: http://www.euro.who.int/__data/assets/pdf_file/0018/103824/E89384.pdf.

Dale, A. and Ahmed, S. (2011) ‘Marriage and employment patterns amongst UK-raised Indian, Pakistani, and Bangladeshi women’, *Ethnic and Racial Studies*, 34(6), pp. 902–924. doi: 10.1080/01419870.2011.564058.

Darby-Stewart, A. L., Strickland, C., Jamieson, B. and Warren, J. (2009) ‘Clinical inquiries: do abnormal fetal kick counts predict intrauterine death in average-risk pregnancies?’, *The Journal of family practice*, 58(4), p. 220a–220c.

Darr, A. and Modell, B. (1988) ‘The frequency of consanguineous marriage among British Pakistanis.’, *Journal of Medical Genetics*, 25(3), pp. 186–190. doi: 10.1136/jmg.25.3.186.

Dartnall, L., Ganguly, N. and Batterham, J. (2005) *Access to Maternity Services Research Report*.

Data Protection Act (1998) ‘Data Protection Act 1998’, in. London: TSO, pp. 3–92. Available at: http://www.legislation.gov.uk/ukpga/1998/29/section/7 (Accessed: 6 September 2014).

Datta-Nemdharry, P., Dattani, N. and Macfarlane, A. J. (2012) ‘Birth outcomes for African and Caribbean babies in England and Wales: retrospective analysis of routinely collected data.’, *BMJ open*, 2(3). doi: 10.1136/bmjopen-2012-001088.

Dattani, N., Datta-Nemdharry, P. and Macfarlane, A. (2012) ‘Linking maternity data for England 2007: methods and data quality.’, *Health statistics quarterly / Office for National Statistics*, (53), pp. 4–21. Available at: http://www.ncbi.nlm.nih.gov/pubmed/22410689.

Davey-Smith, G. (1999) ‘Poverty across the life-course and health’, *Inequalities in Health: The Evidence*, pp. 76–86. Available at: http://www.radstats.org.uk/no068/daveysmith.htm.

Davis, A., Hirsch, D. and Padley, M. (2014) ‘A MINIMUM INCOME STANDARD FOR THE UK IN 2014’, (July).

Degni, F., Suominen, S., Essén, B., El Ansari, W. and Vehviläinen-Julkunen, K. (2012) ‘Communication and cultural issues in providing reproductive health care to immigrant women: Health care providers’ experiences in meeting Somali women living in Finland’, *Journal of Immigrant and Minority Health*, 14, pp. 330–343. doi: 10.1007/s10903-011-9465-6.

Department for Communities and Local Government (2015) ‘The English Index of Multiple Deprivation 2015: Guidance’, (Imd), pp. 1–7. Available at: https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/464430/English_Index_of_Multiple_Deprivation_2015_-_Guidance.pdf.

Department for Communities and Local Government (2016) *English indices of deprivation 2015*. Available at: https://www.gov.uk/government/statistics/english-indices-of-deprivation-2015 (Accessed: 10 February 2016).

Department of Health (2008) *Data standards: Ethnic category*. Available at: http://webarchive.nationalarchives.gov.uk/+/http://www.isb.nhs.uk/documents/dscn/dscn2008/dataset/112008.pdf.

Department of Health (2010a) *Healthy Lives , Healthy People: Our strategy for public health in England*. Norwich. Available at: https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/216096/dh_127424.pdf.

Department of Health (2010b) *Our Health and Wellbeing Today*. Available at: https://www.gov.uk/government/publications/our-health-and-well-being-today.

Department of Health (2010c) *Tackling inequalities in infant and maternal health outcomes. Report of the infant mortality support team.* doi: 10.1177/1757913912468651.

Department of Health (2015a) *Abortion Statistics, England and Wales: 2014*, *Sexual Health*. doi: 10.1037//0033-2909.97.3.527.

Department of Health (2015b) ‘The Mandate 2015-2016’, (April 2015-March 2016). Available at: https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/486818/mndate-NHSE-15_16.pdf.

Department of Health (2016) *The Government’s mandate to NHS England for 2016-17*. Available at: http://www.parliament.uk/written-questions-answers-statements/written-statement/Commons/2015-12-17/HCWS440.

Dex, S., Hawkes, D., Joshi, H. and Ward, K. (2005) ‘Parents employment and childcare’, in Dex, S. and Joshi, H. (eds) *Children of the 21st Century*. Bristol: The Policy Press, pp. 207–237.

Dhawan, S. (1995) ‘Birth weights of infants of first generation Asian women in Britain compared with second generation Asian women.’, *BMJ (Clinical research ed.)*, 311(6997), pp. 86–8. Available at: http://www.pubmedcentral.nih.gov/articlerender.fcgi?artid=2550148&tool=pmcentrez&rendertype=abstract.

Dhillon, N. and Macarthur, C. (2010) ‘Antenatal depression and male gender preference in Asian women in the UK.’, *Midwifery*, 26(3), pp. 286–93. doi: 10.1016/j.midw.2008.09.001.

Diabetes UK (2015) *Diabetes facts and stats*. Available at: https://www.mrc.ac.uk/documents/pdf/diabetes-uk-facts-and-stats-june-2015/.

Dormandy, E., Bryan, S., Gulliford, M. C., Roberts, T. E., Ades, a E., Calnan, M., Atkin, K., Karnon, J., Barton, P. M., Logan, J., Kavalier, F., Harris, H. J., Johnston, T. a, Anionwu, E. N., Davis, V., Brown, K., Juarez-Garcia, a, Tsianakas, V. and Marteau, T. M. (2010) ‘Antenatal screening for haemoglobinopathies in primary care: a cohort study and cluster randomised trial to inform a simulation model. The Screening for Haemoglobinopathies in First Trimester (SHIFT) trial.’, *Health technology assessment (Winchester, England)*, 14(20), pp. 1–160. doi: 10.3310/hta14200.

Dormandy, E., Gulliford, M. C., Reid, E. P., Brown, K. and Marteau, T. M. (2008) ‘Delay between pregnancy confirmation and sickle cell thalassaemia screening: A population-based cohort study’, *British Journal of General Practice*, 58(548), pp. 154–159. doi: 10.3399/bjgp08X277267.

Dormandy, E., Michie, S., Hooper, R. and Marteau, T. M. (2005) ‘Low uptake of prenatal screening for Down syndrome in minority ethnic groups and socially deprived groups: a reflection of women’s attitudes or a failure to facilitate informed choices?’, *International journal of epidemiology*, 34(2), pp. 346–52. doi: 10.1093/ije/dyi021.

Downe, S., Finlayson, K., Tunçalp and Metin Gülmezoglu, A. (2016) ‘What matters to women: A systematic scoping review to identify the processes and outcomes of antenatal care provision that are important to healthy pregnant women’, *BJOG: An International Journal of Obstetrics and Gynaecology*, 123(4), pp. 529–539. doi: 10.1111/1471-0528.13819.

Downe, S., Finlayson, K., Walsh, D. and Lavender, T. (2009) ‘“Weighing up and balancing out”: a meta-synthesis of barriers to antenatal care for marginalised women in high-income countries.’, *BJOG : an international journal of obstetrics and gynaecology*, 116(4), pp. 518–29. doi: 10.1111/j.1471-0528.2008.02067.x.

Downes, S. (2015) *Stanford Encyclopedia of Philosophy*, *Stanford Encyclopedia of Philosophy*. Available at: https://plato.stanford.edu/entries/heredity/ (Accessed: 1 January 2016).

Draper, E. S., Kurinczuk, J. J. and Kenyor, S. (2015) *MBRRACE-UK 2015 Perinatal Confidential Enquiry: Term, singleton, normally formed, antepartum stillbirth*, *MBRRACE-UK Perinatal Confidential Enquiry*. Edited by E. S. Draper, J. J. Kurinczuk, and S. Kenyor. Leicester: The Infant Mortality and Morbidity Studies. Available at: https://www.npeu.ox.ac.uk/mbrrace-uk/reports.

Draycott, T., Lewis, G. and Stephens, I. (2011) ‘Confidential Enquiry Executive Summary’, *BJOG*, 118, pp. 12–21. doi: 10.1111/j.1471-0528.2011.02895.x.

Dworkin, S. L. (2006) ‘Who is epidemiologically fathomable in the HIV/AIDS epidemic? Gender, sexuality, and intersectionality in public health.’, *Culture, health & sexuality*, 7(6), pp. 615–623. doi: 10.1080/13691050500100385.

Dyregrov, K. (2004) ‘Bereaved parents’ experience of research participation’, *Social Science and Medicine*, 58, pp. 391–400. doi: 10.1016/S0277-9536(03)00205-3.

Economic and Social Data Service (2012) *Ethnicity : Introductory User Guide*. Available at: http://www.esds.ac.uk/government/docs/ethnicityintro.pdf.

Efkarpidis, S., Alexopoulos, E., Kean, L., Liu, D. and Fay, T. (2004) ‘Case-Control Study of Factors Associated With Intrauterine Fetal Deaths’, *MedGenMed Ob/Gyn & Women’s Health*. Available at: http://0-www.ncbi.nlm.nih.gov.brum.beds.ac.uk/pmc/articles/PMC1395755.

Egerter, S., Marchi, K. S., Metzler, M., Braveman, P. A., Cubbin, C., Egerter, S., Chideya, S., Marchi, K. S., Metzler, M. and Posner, S. (2005) ‘Socioeconomic Status in Health Research’, *JAMA*, 294(22), pp. 2879–2888.

Eggemoen, Å. R., Falk, R. S., Knutsen, K. V., Lagerløv, P., Sletner, L., Birkeland, K. I. and Jenum, A. K. (2016) ‘Vitamin D deficiency and supplementation in pregnancy in a multiethnic population-based cohort’, *BMC Pregnancy and Childbirth*. BMC Pregnancy and Childbirth, 16(1), p. 7. doi: 10.1186/s12884-016-0796-0.

Ellis, N. (2004) ‘Birth experinces of South Asian Muslim women: Marginalised choices within the Maternity Services’, in Kirkham, M. (ed.) *Informed Choices in Maternity Care*. Hampshire: Palgrave Macmillan, pp. 237–244.

Elstad, J. I. (1998) ‘The psycho-social perspective on social inequalities in health’, *Sociology of Health and Illness*, 20(5), pp. 598–618. Available at: http://ije.oxfordjournals.org/content/31/6/1091.full.

ESRC Centre on Dynamics of Ethncity (2013) *Dynamics of Diversity : Does Britain have plural cities?* University of Manchester.

Ethnologue. (2015) *Ethnologue languages of the world: Bangladesh.* Available at: http://www.ethnologue.com/country/BD (Accessed: 16 May 2015).

European Commission (2016) *Eurostat: Your key to European Statistics*. Available at: http://ec.europa.eu/eurostat/data/database (Accessed: 1 October 2016).

Evans, S. L. and Bowlby, S. (2000) ‘Crossing boundaries: Racialised gendering and the labour market experiences of Pakistani migrant women in Britain.’, *Women’s Studies International Forum*, 23(4), pp. 461–474.

Fairbairn, C. (2014) *Registration of stillbirth*, *House of Commons Library*. London. Available at: www.parliament.uk/briefing-papers/SN05595.pdf.

Falah-Hassani, K., Shiri, R., Vigod, S. and Dennis, C.-L. (2015) ‘Prevalence of postpartum depression among immigrant women: A systematic review and meta-analysis.’, *Journal of psychiatric research*. Elsevier Ltd, 70, pp. 67–82. doi: 10.1016/j.jpsychires.2015.08.010.

Fallowfield, L. (2009) ‘What is quality of life ?’, *Health Economics*, (May 2009), pp. 1–8. Available at: http://www.medicine.ox.ac.uk/bandolier/painres/download/whatis/WhatisQOL.pdf.

De Farias Aragão, V. M., Barbieri, M. A., Moura Da Silva, A. A., Bettiol, H. and Ribeiro, V. S. (2005) ‘Risk factors for intrauterine growth restriction: a comparison between two Brazilian cities.’, *Pediatric research*, 57(5 Pt 1), pp. 674–9. doi: 10.1203/01.PDR.0000156504.29809.26.

Farooq, R. (2014) ‘Breaking the silence : Social Disadvantage , Exclusion & Infant Mortality’, in *DCP Annual Conference*. Leeds.

Farrar, D., Fairley, L., Santorelli, G., Tuffnell, D., Sheldon, T., Wright, J., van Overveld, L. and

Lawlor, D. (2015) ‘Association between hyperglycaemia and adverse perinatal outcomes in south Asian and white British women: analysis of data from the Born in Bradford cohort’, *The Lancet Diabetes & Endocrinology*, 8587(15), pp. 1–10. doi: 10.1016/S2213-8587(15)00255-7.

Federenko, I. S. and Wadhwa, P. D. (2004) ‘Women’s Mental Health During Pregnancy Influences Fetal and Infant’, *CNS Spectrums*, 9(3), pp. 198–206.

Feijen-De Jong, E. I., Jansen, D. E., Baarveld, F., Van Der Schans, C. P., Schellevis, F. G. and Reijneveld, S. (2012) ‘Determinants of late and/or inadequate use of prenatal healthcare in high-income countries: A systematic review’, *European Journal of Public Health*, 22(6), pp. 904–913. doi: 10.1093/eurpub/ckr164.

Feilzer, Y. M. (2009) ‘Doing Mixed Methods Research Pragmatically: Implications for the Rediscovery of Pragmatism as a Research Paradigm’, *Journal of Mixed Methods Research*, 4(1), pp. 6–16. doi: 10.1177/1558689809349691.

Felce, D. and Perry, J. (1995) ‘Quality of life: its definition and measurement’, *Research in developmental disabilities*, 16(1), pp. 51–74. doi: 10.1016/0891-4222(94)00028-8.

Feldman, P. J., Dunkel-Schetter, C., Sandman, C. A. and Wadwana, P. D. (2000) ‘Maternal Social Support Predicts Birth Weight and Fetal Growth in Human Pregnancy’, *Psychosomatic Medicine*, 725(62), pp. 715–725.

Ferrara, A. (2007) ‘Increasing prevalence of gestational diabetes mellitus: A public health perspective’, *Diabetes Care*, 30(SUPPL. 2). doi: 10.2337/dc07-s206.

Field, A. (2006) ‘Writing Up Research’, *Research Methods in Psychiatry*, pp. 1–20. Available at: http://books.google.com/books?hl=en&lr=&id=YADecaAmD7EC&oi=fnd&pg=PA26&dq=Writing+Up+Research&ots=ZVFUjXS_D7&sig=CjH0wkx9ehJzzDATzMYRuYmbHjI.

Field, A. (2013a) ‘Categorical data’, in *Discoveing statistics using SPSS*. 4th Edn. London: Sage Publications Ltd., pp. 720–760.

Field, A. (2013b) *Discovering statistics using IBM SPSS Statistics*. 4th Edn. London: Sage Publications.

Fikree, F. F., Azam, S. I. and Berendes, H. W. (2002) ‘Time to focus child survival programmes on the newborn: assessment of levels and causes of infant mortality in rural Pakistan.’, *Bulletin of the World Health Organization*, 80(4), pp. 271–6. Available at: http://www.pubmedcentral.nih.gov/articlerender.fcgi?artid=2567769&tool=pmcentrez&rendertype=abstract.

Fisher, P. and Nandi, A. (2015) ‘Poverty Across Ethnic Groups Through Recession and Austerity’, *Joseph Rowntree Foundation Report*, (March), pp. 1–62. Available at: https://www.jrf.org.uk/report/poverty-across-ethnic-groups-through-recession-and-austerity.

Flanagan, S. M. and Hancock, B. (2010) ‘“Reaching the hard to reach”--lessons learned from the VCS (voluntary and community Sector). A qualitative study.’, *BMC health services research*, 10, p. 92. doi: 10.1186/1472-6963-10-92.

Flannelly, K. J., Jankowski, K. R. B. and Flannelly, L. T. (2014) ‘Operational definitions in research on religion and health.’, *Journal of health care chaplaincy*, 20(2), pp. 83–91. doi: 10.1080/08854726.2014.909278.

Flay, B. R. and Petraitis, J. (1994) ‘The theory of triadic influence: A new theory of health behavior with implications for preventative inetrventions’, *Advances in Medical Sociology*, 4, pp. 19–44.

Flay, B., Synder, F. and Petraitis, J. (2009) ‘Triadic Influence’, in DiClemente, R. J. and Kegler, R.

A. (eds) *Emerging theories in health promotion practice and research*. 2nd Edn. New York: Jossey Bass Ltd, pp. 451–510.

Flenady, V., Koopmans, L., Middleton, P., Frøen, J. F., Smith, G. C., Gibbons, K., Coory, M., Gordon, A., Ellwood, D., McIntyre, H. D., Fretts, R. and Ezzati, M. (2011) ‘Major risk factors for stillbirth in high-income countries: a systematic review and meta-analysis.’, *Lancet*. Elsevier Ltd, 377(9774), pp. 1331–40. doi: 10.1016/S0140-6736(10)62233-7.

Freeman, T. (2006) ‘“Best practice” in focus group research: making sense of different views.’, *Journal of advanced nursing*, 56(5), pp. 491–7. doi: 10.1111/j.1365-2648.2006.04043.x.

Freemantle, J., Wood, C., Griffin, C., Gill, P., Calvert, M., Shanker, J., Chambers, J. and MacArther, A. (2009) ‘What factors predict differences in infant and perinatal mortality in primary care trusts in England? A prognostic model.’, *BMJ (Clinical research ed.)*. British Medical Journal Publishing Group, 339, p. b2892. doi: 10.1136/bmj.b2892.

Fretts, R. C. (2005) ‘Etiology and prevention of stillbirth.’, *American journal of obstetrics and gynecology*, 193(6), pp. 1923–35. doi: 10.1016/j.ajog.2005.03.074.

Friedli, L. (2009) *Mental health , resilience and inequalities*, *World Health Organization*. World Health Organisation regional office for Europe. Available at: http://www.mentalhealthpromotion.net/resources/mental-health-resilience-and-inequalities.pdf.

Frisina, P. G., Borod, J. C. and Lepore, S. J. (2004) ‘A Meta-Analysis of the Effects of Written Emotional Disclosure on the Health Outcomes of Clinical Populations’, *The Journal of Nervous and Mental Disease*, 192(9), pp. 629–634. doi: 10.1097/01.nmd.0000138317.30764.63.

Froen, J. F., Heazell, A. E. P., Tveit, J. V. H., Saastad, E., Fretts, R. C. and Flenady, V. (2008) ‘Fetal Movement Assessment’, *Seminars in Perinatology*, 32(4), pp. 243–246. doi: 10.1053/j.semperi.2008.04.004.

Froen, J. F., Tveit, J. V. H., Saastad, E., B??rdahl, P. E., Stray-Pedersen, B., Heazell, A. E. P., Flenady, V. and Fretts, R. C. (2008) ‘Management of Decreased Fetal Movements’, *Seminars in Perinatology*, 32(4), pp. 307–311. doi: 10.1053/j.semperi.2008.04.015.

Fuchs, S. (2001) ‘Introduction’, in *Against Essentialism: A Theory of Culture and Society*. Cam: Harvard University Press., pp. 1–12.

Gagnon, a J., Zimbeck, M., Zeitlin, J., Alexander, S., Blondel, B., Buitendijk, S., Desmeules, M., Di Lallo, D., Gagnon, A., Gissler, M., Glazier, R., Heaman, M., Korfker, D., Macfarlane, A., Ng, E., Roth, C., Small, R., Stewart, D., Stray-Pederson, B., Urquia, M., Vangen, S., Zeitlin, J. and Zimbeck, M. (2009) ‘Migration to western industrialised countries and perinatal health: a systematic review.’, *Social science & medicine (1982)*, 69(6), pp. 934–46. doi: 10.1016/j.socscimed.2009.06.027.

Gale, N. K., Heath, G., Cameron, E., Rashid, S. and Redwood, S. (2013) ‘Using the framework method for the analysis of qualitative data in multi-disciplinary health research.’, *BMC medical research methodology*, 13(1), p. 117. doi: 10.1186/1471-2288-13-117.

Garcés, A., McClure, E. M., Hambidge, M., Krebs, N. F., Mazariegos, M., Wright, L. L., Moore, J. and Carlo, W. a (2012) ‘Training traditional birth attendants on the WHO Essential Newborn Care reduces perinatal mortality.’, *Acta obstetricia et gynecologica Scandinavica*, 91(5), pp. 593–7. doi: 10.1111/j.1600-0412.2012.01374.x.

Garcia, R. L., Ali, N., Papadopoulos, C. and Randhawa, G. (2015) ‘Specific antenatal interventions for Black, Asian and Minority Ethnic (BAME) pregnant women at high risk of poor birth outcomes in the United Kingdom: A scoping review’, BMC Pregnancy and Childbirth. doi: 10.1186/s12884-015-

0657-2.

Garcia, R., Ali, N., Guppy, A., Griffiths, M. and Randhawa, G. (2017) ‘A comparison of antenatal classifications of “overweight” and “obesity” prevalence between white British, Indian, Pakistani and Bangladeshi pregnant women in England. An analysis of retrospective data’, BMC Public Health. BMC Public Health, pp. 1–7. doi: 10.1186/s12889-017-4211-1

Gardosi, J. (2006) ‘New definition of small for gestational age based on fetal growth potential’, *Hormone Research*, 65(SUPPL. 3), pp. 15–18. doi: 10.1159/000091501.

Gardosi, J., Beamish, N., Francis, A., Williams, M., Sahota, M., Tonks, A., Mcgeown, P. and Hart, M. (2005) *Stillbirth and infant mortality, West Midlands 1997-2005: Trends, Factors, Inequalities*.

Gardosi, J., Giddings, S., Clifford, S., Wood, L. and Francis, A. (2013) ‘Association between reduced stillbirth rates in England and regional uptake of accreditation training in customised fetal growth assessment.’, *BMJ open*, 3(12), p. e003942. doi: 10.1136/bmjopen-2013-003942.

Gardosi, J., Kady, S., McGeown, P., Francis, A. and Tonks, A. (2005) ‘Classification of stillbirth by relevant condition at death (ReCoDe): population based cohort study’, *BMJ*, 331(7525), p. 1110. doi: 10.1136/bmj.38629.587639.7C.

Gardosi, J., Madurasinghe, V., Williams, M., Malik, A. and Francis, A. (2013) ‘Maternal and fetal risk factors for stillbirth: population based study.’, *BMJ (Clinical research ed.)*, 346(January), p. f108. doi: 10.1136/bmj.f108.

Gates, B., John, G., Blencowe, H., Cousens, S., Chou, D., Oestergaard, M. Z., Say, L., Moller, A., Kinney, M. and Lawn, J. (2013) ‘15 million preterm births: priorities for action based on national , regional and global estimates’, *Reproductive Health*, 10(S1), pp. 1–14.

Geertz, C. (1963) ‘The integrative revolution: primordial sentiments and politics in the new states’, *Old societies and new states: the quest for modernity in Asia and Africa*, pp. 105–157. doi: The Free Press of Gelncoe.

Geertz, C. (1973) ‘The interpretation of cultures.’, in *Selected Essays*. New York: Basic Books Inc., pp. 1–15.

Geospatial Information Team & Department of Environmental and Regeneration (2014) *Research and Geospatial Information, Luton 2013 population Estimate*. Available at: http://www.luton.gov.uk/Community_and_living/Lists/LutonDocuments/PDF/Lutons Own Population Estimate 2013.pdf.

Gissler, M., Alexander, S., MacFarlane, A., Small, R., Stray-Pedersen, B., Zeitlin, J., Zimbeck, M. and Gagnon, A. (2009) ‘Stillbirths and infant deaths among migrants in industrialized countries.’, *Acta obstetricia et gynecologica Scandinavica*, 88(2), pp. 134–148. doi: 10.1080/00016340802603805.

Glanz, K., Rimer, B. and Viswanath, K. (2008a) *Health behaviour and health education; theory research and practice.* 4th Edn. Edited by K. Glanz, B. Rimer, and K. Viswanath. San Francisco: Jossey Bass Ltd.

Glanz, K., Rimer, B. and Viswanath, K. (2008b) ‘The scope of health behaviour and health education’, in Glanz, K., Rimer, B., and Viswanath, K. (eds) *Health Behaviour and Health Education. Theory, Research, and Practice*. 4th Edn. San Francisco: Jossey Bass Ltd, pp. 3–18.

Glanz, K., Rimer, B. and Viswanath, K. (2008c) ‘Theory research and practice in health behaviour and health education.’, in Glanz, K., Rimer, B., and Viswanath, K. (eds) *Health Behaviour and Health Education. Theory, Research, and Practice*. 4th Edn. San Francisco: Jossey Bass Ltd, pp. 23–38.

Glazier, R. H., Elgar, F. J., Goel, V. and Holzapfel, S. (2004) ‘Stress, social support, and emotional distress in a community sample of pregnant women’, *Journal of Psychosomatic Obstetrics and Gynecology*, 25(3–4), pp. 247–255. doi: 10.1080/01674820400024406.

De Goeij, M. C. M., Van Diepen, M., Jager, K. J., Tripepi, G., Zoccali, C. and Dekker, F. W. (2013) ‘Multiple imputation: Dealing with missing data’, *Nephrology Dialysis Transplantation*, 28(10), pp. 2415–2420. doi: 10.1093/ndt/gft221.

Gogia, S. and Sachdev, H. S. (2010) ‘Home visits by community health workers to prevent neonatal deaths in developing countries: a systematic review.’, *Bulletin of the World Health Organization*, 88(9), p. 658–666B. doi: 10.2471/BLT.09.069369.

Goldenberg, R. L., Culhane, J. F., Iams, J. D. and Romero, R. (2009) ‘Preterm Birth 1: Epidemiology and Causes of Preterm Birth’, *Obstetric Anesthesia Digest*, 29(1), pp. 6–7. doi: 10.1097/01.aoa.0000344666.82463.8d.

Grace, C., Begum, R., Subhani, S., Kopelman, P. and Greenhalgh, T. (2008) ‘Prevention of type 2 diabetes in British Bangladeshis: qualitative study of community, religious, and professional perspectives.’, *BMJ (Clinical research ed.)*, 337(nov04_3), p. a1931. doi: 10.1136/bmj.a1931.

Graham, H. (2011) ‘The challenge of health inequalities’, in Graham, H. (ed.) *Understanding health inequalities*. 2nd edn. Berkshire: Open University Press, pp. 1–25.

Graham, H. and Der, G. (1999) ‘Patterns and predictors of tobacco consumption among women.’, *Health education research*, 14(5), pp. 611–618. doi: 10.1093/her/14.5.611.

Grant, J. and Bittles, A. (1997) ‘The comparative role of consanguinity in infant and childhood mortality in Pakistan’, *Annals of Human Genetics*, 61, pp. 143–149. Available at: http://onlinelibrary.wiley.com/doi/10.1046/j.1469-1809.1997.6120143.x/abstract.

Grant, R. W. and Sugarman, J. (2004) ‘Ethics in human subjects research: do incentives matter?’, *The Journal of medicine and philosophy*, 29(6), pp. 717–38. doi: 10.1080/03605310490883046.

Grant, T., Christopher Graham, J., Ernst, C. C., Michelle Peavy, K. and Brown, N. N. (2014) ‘Improving pregnancy outcomes among high-risk mothers who abuse alcohol and drugs: Factors associated with subsequent exposed births’, *Children and Youth Services Review*. Elsevier Ltd, 46, pp. 11–18. doi: 10.1016/j.childyouth.2014.07.014.

Gray, R., Headley, J., Oakley, L., Kurinczuk, J. J. and Brocklehurst, P. (2010) *Towards an understanding of variations in infant mortality rates between different ethnic groups in England and Wales*. Oxford. Available at: https://www.npeu.ox.ac.uk/.../infant-mortality/Infant-Mortality.

Gray, R., Hollowell, J., Brocklehurst, P., Graham, H. and Kurinczuk, J. J. (2010) ‘Health Inequalities Infant Mortality Target : technical background’, pp. 1–10.

Green, J. M., Hewison, J., Bekker, H. L., Bryant, L. D. and Cuckle, H. S. (2004) ‘Psychosocial aspects of genetic screening of pregnant women and newborns’, *Health Technology Assessment*, 8(33), pp. 1–128.

Grewal, S. K., Bhagat, R. and Balneaves, L. G. (2008) ‘Perinatal beliefs and practices of immigrant Punjabi women living in Canada.’, *Journal of Obstetric, Gynecologic, and Neonatal nursing : JOGNN / NAACOG*, 37(3), pp. 290–300. doi: 10.1111/j.1552-6909.2008.00234.x.

Grote, N., Bridge, J., Gavin, A., Melville, J., Iyengar, S. and Katon, W. (2010) ‘A Meta-analysis of Depression During Pregnancy and the Risk of Preterm Birth, Low Birth Weight, and Intrauterine Growth Restriction’, *Archives of General Psychiatry*, 67(10), pp. 1012–1024. doi: 10.1001/archgenpsychiatry.2010.111; 10.1001/archgenpsychiatry.2010.111.

Guba, E. G. and Lincoln, Y. S. (2001) *Guidelines and Checklist for Constructivist: fourth generation checklist.* Michigan. Available at: http://www.wmich.edu/evalctr/checklists/.

Guba, E. and Lincoln, Y. (1994) ‘Competing Paradigms in Qualitative Research’, in Denzin, N. and Lincoln, Y. (eds) *Handbook of Qualitatitive Research*. Thousand Oaks: Sage Publications, pp. 57–72.

Gunaratnum, Y. (2003) *Researching race and ethnicity, methods, knowledge and power*. London: Sage Publications.

Gunderson, G. and Cochrane, J. (2012) *Religion and the health of the public: Shifting the paradigm.* New York: Palgrave Macmillan.

Gungor, I., Oskay, U. and Beji, N. K. (2011) ‘Biopsychosocial risk factors for preterm birth and postpartum emotional well-being: A case-control study on Turkish women without chronic illnesses’, *Journal of Clinical Nursing*, 20(5–6), pp. 653–665. doi: 10.1111/j.1365-2702.2010.03532.x.

Gupta, P. C., Subramoney, S. and Sreevidya, S. (2004) ‘Smokeless tobacco use, birth weight, and gestational age: population based, prospective cohort study of 1217 women in Mumbai, India.’, *BMJ (Clinical research ed.)*, 328(7455), p. 1538. doi: 10.1136/bmj.38113.687882.EB.

Gupta, P. and Ray, C. (2003) ‘Smokeless tobacco and health in India and South Asia’, *Respirology*, 8(4), pp. 419–431. Available at: http://onlinelibrary.wiley.com/doi/10.1046/j.1440-1843.2003.00507.x/full.

Haddrill, R., Jones, G. L., Mitchell, C. a and Anumba, D. O. (2014) ‘Understanding delayed access to antenatal care: a qualitative interview study.’, *BMC pregnancy and childbirth*, 14(1), p. 207. doi: 10.1186/1471-2393-14-207.

Hale, H. E. (2004) ‘Explaining Ethnicity’, *Comparative Political Studies*, 37(4), pp. 458–485. doi: 10.1177/0010414003262906.

Hall, S. (1992) ‘The West and the Rest: Discourse and power’, in Hall, S. and Gieben, B. (eds) *Formations of Modernity. Understanding modern societies: An introduction*. Cambridge: The Open University Press, pp. 275–333.

Hall, S. (2000) ‘Conclusion: the multicultural question’, in Hesse, B. (ed.) *Unsettled Multiculturalisms*, pp. 209–241.

Halpern, D. and Nazroo, J. (1999) ‘The ethnic denisty effect: results from a national community survey of England and Wales’, *International Journal of Social Psychiatry*, 46(1), pp. 34–46. doi: 10.1177/002076400004600105.

Hamamy, H., *et al,* (2011) ‘Consanguineous marriages , pearls and perils : Geneva International Consanguinity Workshop Report’, *Genet Med*. 13(9). doi: 10.1097/GIM.0b013e318217477f.

Hammersley, M. (2008) ‘Troubles with triangulation’, in Bergman, M. (ed.) *Advances in mixed method research*. London: Sage Publications, pp. 22–36.

Han, Z., Mulla, S., Beyene, J., Liao, G. and McDonald, S. D. (2011) ‘Maternal underweight and the risk of preterm birth and low birth weight : a systematic review and meta-analyses’, *International journal of epidemiology*, 40(1), pp. 65–101. doi: 10.1093/ije/dyq195.

Handisurya, A., Bancher-Todesca, D., Schober, E., Klein, K., Tobler, K., Schneider, B., Pollak, A., Husslein, P., Luger, A. and Kautzky-Willer, A. (2011) ‘Risk factor profile and pregnancy outcome in women with type 1 and type 2 diabetes mellitus.’, *Journal of Women’s Health (15409996)*, 20(2), p.

263–271 9p. doi: 10.1089/jwh.2010.2033.

Hankivsky, O. and Christoffersen, A. (2008) ‘Intersectionality and the determinants of health: a Canadian perspective’, *Critical Public Health*, 18(3), pp. 271–283. doi: 10.1080/09581590802294296.

Hardin, E. E., Robitschek, C., Flores, L. Y., Navarro, R. L. and Ashton, M. W. (2014) ‘The Cultural Lens Approach to Evaluating Cultural Validity of Psychological Theory’, 69(7), pp. 656–668. doi: 10.1037/a0036532.

Harding, S. and Norberg, K. (2005) ‘New Feminist Approaches to Social Science Methodologies: An Introduction’, *Signs: Journal of Women in Culture and Society*, 30(4), pp. 2009–2015. doi: 10.1086/428420.

Harding, S., Rosato, M. G. and Cruickshank, J. K. (2004) ‘Lack of change in birthweights of infants by generational status among Indian, Pakistani, Bangladeshi, Black Caribbean, and Black African mothers in a British cohort study.’, *International journal of epidemiology*, 33(6), pp. 1279–85. doi: 10.1093/ije/dyh186.

Harper, L. M., Chang, J. J. and MacOnes, G. A. (2011) ‘Adolescent pregnancy and gestational weight gain: Do the Institute of Medicine recommendations apply?’, *American Journal of Obstetrics and Gynecology*, 205(2), pp. 1–16. doi: 10.1016/j.ajog.2011.03.053.

Harrison, J., Mullen, P. D. and Green, L. W. (1992) ‘A meta-analysis of studies of the Health Belief Model with adults.’, *Health education research*, 7(1), pp. 107–16. Available at: http://www.ncbi.nlm.nih.gov/pubmed/10148735.

Harrison, V. S. (2006) ‘The pragmatics of defining religion in a multi-cultural world’, *International Journal for Philosophy of Religion*, 59(3), pp. 133–152. doi: 10.1007/s11153-006-6961-z.

Haslam, C. and Lawrence, W. (2004) ‘Health-related behavior and beliefs of pregnant smokers.’, *Health psychology : official journal of the Division of Health Psychology, American Psychological Association*, 23(5), pp. 486–491. doi: 10.1037/0278-6133.23.5.486.

Hatherall, B., Morris, J., Jamal, F., Sweeney, L., Wiggins, M., Kaur, I., Renton, A. and Harden, A. (2016) ‘Timing of the initiation of antenatal care: An exploratory qualitative study of women and service providers in East London’, *Midwifery*. Elsevier, 36, pp. 1–7. doi: 10.1016/j.midw.2016.02.017.

Hauck, F. R., Tanabe, K. O. and Moon, R. Y. (2011) ‘Racial and ethnic disparities in infant mortality.’, *Seminars in perinatology*. Elsevier Inc., 35(4), pp. 209–20. doi: 10.1053/j.semperi.2011.02.018.

Hawkes, S. J., Gomez, G. B. and Broutet, N. (2013) ‘Early antenatal care: does it make a difference to outcomes of pregnancy associated with syphilis? A systematic review and meta-analysis.’, *PloS one*. Edited by M. M. Heimesaat. Public Library of Science, 8(2), p. e56713. doi: 10.1371/journal.pone.0056713.

Hawkins, S. S., Lamb, K., Cole, T. J. and Law, C. (2008) ‘Influence of moving to the UK on maternal health behaviours: prospective cohort study.’, *BMJ (Clinical research ed.)*, 336(7652), pp. 1052–5. doi: 10.1136/bmj.39532.688877.25.

Headland, T., Pike, K. and Harris, M. (1990) *Emics and Etics: The insider/outsider debate*. Edited by T. Headland, K. Pike, and M. Harris. London: Sage Publications.

Headley, A. J. (2004) ‘Generations of loss: contemporary perspectives on black infant mortality.’, *Journal of the National Medical Association*, 96(732), pp. 987–994.

Health and Social Care Act 2012 (2012). Available at: http://www.legislation.gov.uk/ukpga/2012/7/contents/enacted.

Health and Social Care Information Centre (2016). *Statistics on Women's Smoking at Time of Delivery: England*. pp 1-9.

Healthcare for London (2009) *Maternity Care Pathways*.

Henderson, J., Gao, H. and Redshaw, M. (2013) 'Experiencing maternity care: the care received and perceptions of women from different ethnic groups.', *BMC pregnancy and childbirth*. BMC Pregnancy and Childbirth, 13(1), p. 196. doi: 10.1186/1471-2393-13-196.

Van Herk, K. A., Smith, D. and Andrew, C. (2011) 'Examining our privileges and oppressions: Incorporating an intersectionality paradigm into nursing', *Nursing Inquiry*, 18(1), pp. 29–39. doi: 10.1111/j.1440-1800.2011.00539.x.

Herrnstein, R. J. and Murray, C. (1994) 'The Bell Curve', pp. 38–44. Available at: http://academic.sun.ac.za/mathed/174/NatureNurture/Wikipedia.pdf.

Heslehurst, N., Rankin, J., Wilkinson, J. R. and Summerbell, C. D. (2010) 'A nationally representative study of maternal obesity in England, UK: trends in incidence and demographic inequalities in 619 323 births, 1989-2007.', *International journal of obesity (2005)*. Nature Publishing Group, 34(3), pp. 420–8. doi: 10.1038/ijo.2009.250.

Heslehurst, N., Simpson, H., Ells, L. J., Rankin, J., Wilkinson, J., Lang, R., Brown, T. J. and Summerbell, C. D. (2008) 'The impact of maternal BMI status on pregnancy outcomes with immediate short-term obstetric resource implications: A meta-analysis', *Obesity Reviews*, 9(6), pp. 635–683. doi: 10.1111/j.1467-789X.2008.00511.x.

Hinton, P. (2008) *Statistics explained*. 2nd Edn. Sussex: Routledge.

Hirani, S. A. A. and Karmaliani, R. (2013) 'The experiences of urban, professional women when combining breastfeeding with paid employment in Karachi, Pakistan: A qualitative study', *Women and Birth*, 26(2), pp. 147–151. Available at: http://www.sciencedirect.com/science/article/pii/S187151921200090X (Accessed: 14 November 2013).

Hirsch, D. (2011) *A minimum income standard for the UK in 2011*. Available at: https://dspace.lboro.ac.uk/dspace-jspui/bitstream/2134/13295/3/minimum-income-standard-2011-full.pdf.

Hirst, J. and Hewison, J. (2002) 'Hospital postnatal care: obtaining the views of Pakistani and indigenous "white" women', *Clinical Effectiveness in Nursing*, 6(1), pp. 10–18. doi: 10.1054/cein.2002.0250.

HM Government (2015) 'Working Together to Safeguard Children Working Together to Safeguard Children', *Office*, 14(March), p. 393. doi: 10.1080/13561820020003919.

Hochbaum, G., Kegels, S. and Rosenstock, I. (1952) *Health Belief Model.*

Hodgetts, V., Morris, R., Francis, A., Gardosi, J. and Ismail, K. (2015) 'Effectiveness of folic acid supplementation in pregnancy on reducing the risk of small-for-gestational age neonates: a population study, systematic review and meta-analysis.', *BJOG : an international journal of obstetrics and gynaecology*, 122(4), pp. 478–90. doi: 10.1111/1471-0528.13202.

Hofmeyr, G. J. and Novikova, N. (2012) 'Management of reported decreased fetal movements for improving pregnancy outcomes.', *The Cochrane database of systematic reviews*, 4(4), p. CD009148. doi: 10.1002/14651858.CD009148.pub2.

Hofstede, G. (2003) *Culture's Consequences: Comparing Values, Behaviors, Institutions, and Organizations Across Nations*. 3rd Edn. Thousand Oaks: Sage Publications Ltd.

Hogg, M. and Vaughan, G. (2008) 'Persuasion and attitude change', in *Social Psychology.* 5th edn. Essex: Pearson Education, pp. 189–235.

Holick, M. F. (2009) 'Vitamin D Deficiency', *New England Journal of Medicine*, 5(357), pp. 266–281. Available at: http://rfi1.fmrp.usp.br/Grad/Renal/Seminario_paratireoide_LLKE.pdf.

Holloway, I. and Wheeler, S. (1996) *Qualitative Research For Nurses*. Oxford: Blackwell Publishers.

Hollowell, J., Kurinczuk, J. J., Brocklehurst, P. and Gray, R. (2011) 'Social and ethnic inequalities in infant mortality: a perspective from the United kingdom.', *Seminars in perinatology*. Elsevier Inc., 35(4), pp. 240–4. doi: 10.1053/j.semperi.2011.02.021.

Hollowell, J., Oakley, L., Kurinczuk, J. J., Brocklehurst, P. and Gray, R. (2011) 'The effectiveness of antenatal care programmes to reduce infant mortality and preterm birth in socially disadvantaged and vulnerable women in high-income countries: a systematic review.', *BMC pregnancy and childbirth*. BioMed Central Ltd, 11(1), p. 13. doi: 10.1186/1471-2393-11-13.

Hollowell, J., Oakley, L., Vigurs, C., Barnett-page, E., Kavanagh, J. and Oliver, S. (2012) *Increasing the early initiation of antenatal care by Black and Minority Ethnic women in the United Kingdom : a systematic review and mixed methods synthesis of women ' s views and the literature on intervention effectiveness Final Report*.

Homans, H. (1980) *Pregnant in Britain: A sociological approach to Asian and British womens experiences.* University of Warwick.

Home Office (2015) *Statistical News Release : Immigration Statistics Key points 2013*. Available at: https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/406251/immigration-q4-2014snr.pdf.

Horvat, L., Horey, D., Romios, P. and Kis-Rigo, J. (2014) 'Cultural competence education for health professionals.', *The Cochrane database of systematic reviews*, 5(5), p. CD009405. doi: 10.1002/14651858.CD009405.pub2.

Hossain, N., Khanani, R., Hussain-Kanani, F., Shah, T., Arif, S. and Pal, L. (2011) 'High prevalence of vitamin D deficiency in Pakistani mothers and their newborns.', *International journal of gynaecology and obstetrics: the official organ of the International Federation of Gynaecology and Obstetrics*, 112(3), pp. 229–33. doi: 10.1016/j.ijgo.2010.09.017.

House of Commons (2007) *Select Committee on Science and Technology: upper gestational limit*. Available at: http://www.publications.parliament.uk/pa/cm200607/cmselect/cmsctech/1045/104505.htm#a11.

HSCIC (2016) *NHS Digital Indicator Portal*. Available at: https://indicators.hscic.gov.uk/webview/ (Accessed: 18 November 2016).

HSCIS (2016) *Ethnic catagory code*. Available at: http://www.datadictionary.nhs.uk/data_dictionary/attributes/e/end/ethnic_category_code_de.asp?shownav=1 (Accessed: 11 November 2015).

Hudson, N. A. (2008) *Infertility in British South Asian Communities : Negotiating the Community and the Clinic Submitted in partial fulfilment for the award of of*.

Humes, K. R., Jones, N. a. and Ramirez, R. R. (2011) *Overview of race and hispanic origin: 2010, United States Census Bureau*. Available at: http://www.census.gov/population/race/.

Hunt, K. and Batty, D. (2011) ‘gender and socio-economic inequalities in mortality and health behaviours’, in Graham, H. (ed.) *Understanding health inequalities*. 2nd Edn. Berkshire: Open University Press, pp. 141–162.

Husain, N., Cruickshank, J. K., Tomenson, B., Khan, S. and Rahman, A. (2012) ‘Maternal depression and infant growth and development in British Pakistani women: a cohort study.’, *BMJ open*, 2(2), p. e000523. doi: 10.1136/bmjopen-2011-000523.

Hynson, J. L., Aroni, R., Bauld, C. and Sawyer, S. M. (2006) ‘Research with bereaved parents: a question of how not why.’, *Palliative medicine*, 20(8), pp. 805–11. doi: 10.1177/0269216306072349.

Hyppönen, E. and Power, C. (2007) ‘Hypovitaminosis D in British adults at age 45y: nationwide cohort study on dietary and lifestyle predictors.’, *American Journal of Clinical Nutrition*, 85, pp. 860–868. doi: 85/3/860 [pii].

Ibrahim, J. G., Chu, H. and Chen, M.-H. (2012) ‘Missing Data in Clinical Studies: Issues and Methods’, *Journal of Clinical Oncology*, 30(26), pp. 3297–3303. doi: 10.1200/JCO.2011.38.7589.

Inamdar, A., Croucher, R., Chokhandre, M., Mashyakhy, M. and Marinho, V. (2015) ‘Maternal smokeless tobacco use in pregnancy and adverse health outcomes in newborns: A systematic review’, *Nicotine and Tobacco Research*, 17(9), pp. 1058–1066. doi: 10.1093/ntr/ntu255.

Ingram, P (2008) An overview of diversity awareness. The Pennsylvania State University. Available at: http://extension.psu.edu/publications/ui362

Irving, S. M. and Ross, H. (1999) ‘Antenatal and neonatal haemoglobinopathy screening in the UK : review and economic Standing Group on Health Technology Chair ’:, 3(11).

Isajiw, W. W. (1993) ‘Definition and Dimensions of Ethnicity: A Theoretical Framework’, *Challenges of Measuring an Ethnic World: Science, politics and reality: Proceedings of the Joint Canada-United States Conference on the Measurement of Ethnicity April 1-3, 1992*, pp. 407–27. Available at: https://tspace.library.utoronto.ca/handle/1807/68.

Islamic Council for Queensland (2010) *Islamic beliefs affecting health care*. Available at: http://www.health.qld.gov.au/multicultural/support_tools/islamgde2ed-S2.pdf.

Ismail, H., Wright, J., Rhodes, P., Small, N. and Jacoby, A. (2005) ‘South Asians and epilepsy: Exploring health experiences, needs and beliefs of communities in the north of England’, Seizure, 14(7), pp. 497–503. doi: 10.1016/j.seizure.2005.08.006.

Jaber, L., Romano, O., Halpern, G. J., Livne, I., Green, M. and Shohat, T. (2005) ‘Awareness about problems associated with consanguineous marriages: Survey among Israeli Arab adolescents’, *Journal of Adolescent Health*, 36(6), p. 530. doi: 10.1016/j.jaDOHealth.2004.08.003.

Jafri, H., Hewison, J., Sheridan, E. and Ahmed, S. (2015) ‘Acceptability of prenatal testing and termination of pregnancy in Pakistan’, *Journal of Community Genetics*, 6(1), pp. 29–37. doi: 10.1007/s12687-014-0198-9.

Janz, N. K. and Becker, M. H. (1984) ‘The Health Belief Model: a decade later.’, *Health education quarterly*, 11(1), pp. 1–47. Available at: http://www.ncbi.nlm.nih.gov/pubmed/6392204.

Jayaweera, H., D’Souza, L. and Garcia, J. (2005) ‘A local study of childbearing Bangladeshi women in the UK.’, *Midwifery*, 21(1), pp. 84–95. doi: 10.1016/j.midw.2004.09.003.

Jayaweera, H., Joshi, H., MacFarlane, A., Hawkes, D. and Butler, N. (2005) ‘Pregnancy and childbirth’, in Dex, S. and Joshi, H. (eds) *Children of the 21st Century*. Bristol: The Policy Press, pp. 109–133.

Jayaweera, H. and Quigley, M. a. (2010) ‘Health status, health behaviour and healthcare use among migrants in the UK: Evidence from mothers in the Millennium Cohort Study’, *Social Science and Medicine*. Elsevier Ltd, 71(5), pp. 1002–1010. doi: 10.1016/j.socscimed.2010.05.039.

Jessa, F. and Hampshire, A. J. (1999) ‘Use of folic acid by pregnant British Pakistani women: a qualitative pilot study’, *Health Education Journal*, 58(2), pp. 139–145. doi: 10.1177/001789699905800205.

Johnelle Sparks, P. (2009) ‘One size does not fit all: an examination of low birthweight disparities among a diverse set of racial/ethnic groups.’, *Maternal and child health journal*, 13(6), pp. 769–79. doi: 10.1007/s10995-009-0476-z.

Johnson, B., Pressley, M., Bouchard, E. and Stahl, S. (2006) ‘Report of the National Reading Panel : Teaching Children to Read Report of the National Reading Panel : Teaching Children to Read TEACHING CHILDREN TO READ : An Evidence-Based Assessment of the Scientific Research Literature on Reading and Its Implication’, *Secretary*, 2000(0). Available at: http://www.nichd.nih.gov/publications/pubs/nrp/documents/report.pdf.

Johnson, R. B. and Onwuegbuzie, A. J. (2009) ‘Mixed Methods Research : A Research Paradigm Whose Time Has Come’, *Educational Researcher*, 33(7), pp. 14–26. Available at: http://www.jstor.org/stable/3700093.

Johnson, R. B., Onwuegbuzie, a. J. and Turner, L. a. (2007) ‘Toward a Definition of Mixed Methods Research’, *Journal of Mixed Methods Research*, 1(2), pp. 112–133. doi: 10.1177/1558689806298224.

Jomeen, J. and Redshaw, M. (2013) ‘Ethnic minority women’s experience of maternity services in England.’, *Ethnicity & health*, 18(3), pp. 280–96. doi: 10.1080/13557858.2012.730608.

Joshi, K. J., Sochaliya, K. M., Shrivastav, A. V, Gohel, D. M., Purani, S. K., Kartha, G. P. and Joshi, K. J. (2014) ‘A hospital based study on the prevalence of low birth weight in newborn babies and its relation to maternal health factors.’, *Int J Res Med*, 3(1), pp. 4–8.

Juarez, S., Ruvuelta-Eugercios, B., Ramiro-Farinas, D. and Viciana-Fenandez, F. (2014) ‘Maternal education and perinatal outcomes among spanish women residing in Southern Spain (2001-2011)’, *Maternal and child health journal*, 18(8), pp. 1814–1822. doi: 10.1007/s10995-013-1425-4.

Kang, G., Lim, J. Y., Kale, A. S. and Lee, L. Y. (2015) ‘Adverse effects of young maternal age on neonatal outcomes.’, *Singapore medical journal*, 56(3), pp. 157–63. doi: 10.11622/smedj.2014194.

Karlsen, S. and Nazroo, J. Y. (2002) ‘Relation Between Racial Discrimination, Social Class, and Health Among Ethnic Minority Groups’, *American Journal of Public Health*, 92(4), pp. 624–631. doi: 10.2105/AJPH.92.4.624.

Karlsen, S. and Nazroo, J. Y. (2004) ‘Fear of racism and health.’, *Journal of epidemiology and community health*, 58(12), pp. 1017–1018. doi: 10.1136/jech.2004.020479.

Karlsen, S. and Nazroo, J. (2006) ‘Defining and measuring ethnicity and race. Theoretical and conceptual issues for health and social care research.’, in Nazroo, J. (ed.) Health and Social Research in Multi Ethnic Societies. Oxon: Routledge Ltd., pp. 20–39.

Kashima, Y., Yamaguchi, S., Kim, U., Choi, S. C., Gelfand, M. J. and Yuki, M. (1995) ‘Culture, gender, and self: A perspective from individualism-collectivism research’, *Journal of Personality and Social Psychology*, 69(5), pp. 925–937. doi: 10.1037/0022-3514.69.5.925.

Katbamna, S. (2000) *Race and childbirth*. Buckingham: Open University Press.

Katbamna, S., Ahmad, W., Bhakta, P., Baker, R. and Parker, G. (2004) ‘Do they look after their own? Informal support for South Asian carers', *Health and Social Care in the Community*, 12(5), pp. 398–406.

Katbamna, S., Bhukta, P. and Parker, G. (2000) 'South Asian carers experiences of primary health care teams', in Ahmad, W. I. U. (ed.) *Ethnicity, disability and chronic illness*. Buckingham: Oxford University Press, pp. 123–138.

Kazemi, A., Ehsanpour, S., Sadat, N., Zahraei, N. and Hasanzadeh, A. (2011) 'Impact of health belief modification on intention to make smoke free home among pregnant women', *J Re Med Sci*, 16(6), pp. 724–732. Available at: http://www.ncbi.nlm.nih.gov/pmc/articles/PMC3214389/?report=printable.

Kazi, A., Fatmi, Z., Hatcher, J., Niaz, U. and Aziz, A. (2009) 'Development of a stress scale for pregnant women in the South Asian context: the A-Z Stress Scale.', *Eastern Mediterranean health journal = La revue de santé de la Méditerranée orientale = al-Majallah al-ṣiḥḥīyah li-sharq al-mutawassiṭ*, 15(2), pp. 353–61. Available at: http://www.ncbi.nlm.nih.gov/pubmed/19554982.

Kelley, M. C. and Trinidad, S. B. (2012) 'Silent loss and the clinical encounter: Parents' and physicians' experiences of stillbirth-a qualitative analysis.', *BMC pregnancy and childbirth*. BMC Pregnancy and Childbirth, 12(1), p. 137. doi: 10.1186/1471-2393-12-137.

Kelly, Y., Panico, L., Bartley, M., Marmot, M., Nazroo, J. and Sacker, a (2009) 'Why does birthweight vary among ethnic groups in the UK? Findings from the Millennium Cohort Study.', *Journal of public health (Oxford, England)*, 31(1), pp. 131–7. doi: 10.1093/pubmed/fdn057.

Kenny, L. C., Lavender, T., McNamee, R., O'Neill, S. M., Mills, T. and Khashan, A. S. (2013) 'Advanced Maternal Age and Adverse Pregnancy Outcome: Evidence from a Large Contemporary Cohort', *PLoS ONE*, 8(2), pp. 1–9. doi: 10.1371/journal.pone.0056583.

Kent, S. T., McClure, L. a, Zaitchik, B. F. and Gohlke, J. M. (2013) 'Area-level risk factors for adverse birth outcomes: trends in urban and rural settings.', *BMC pregnancy and childbirth*. BMC Pregnancy and Childbirth, 13(1), p. 129. doi: 10.1186/1471-2393-13-129.

Khalil, A., Rezende, J., Akolekar, R., Syngelaki, A. and Nicolaides, K. H. (2013) 'Maternal racial origin and adverse pregnancy outcome: A cohort study', *Ultrasound in obstetrics & gynecology*, 41(3), pp. 278–85. doi: 10.1002/uog.12313.

Khoshnood, B., Loane, M., Walle, H. de, Arriola, L., Addor, M.-C., Barisic, I., Beres, J., Bianchi, F., Dias, C., Draper, E., Garne, E., Gatt, M., Haeusler, M., Klungsoyr, K., Latos-Bielenska, A., Lynch, C., McDonnell, B., Nelen, V., Neville, A. J., O'Mahony, M. T., Queisser-Luft, A., Rankin, J., Rissmann, A., Ritvanen, A., Rounding, C., Sipek, A., Tucker, D., Verellen-Dumoulin, C., Wellesley, D. and Dolk, H. (2015) 'Long term trends in prevalence of neural tube defects in Europe: population based study.', *BMJ (Clinical research ed.)*, 351, p. h5949. doi: 10.1136/bmj.h5949.

Kiernan, K. and Smith, K. (2003) 'Unmarried parenthood: new insights from the Millennium Cohort Study.', *Population trends*, (114), pp. 26–33. Available at: http://www.ncbi.nlm.nih.gov/pubmed/14730813.

Kim, D. and Saada, A. (2013) 'The social determinants of infant mortality and birth outcomes in western developed nations: A cross-country systematic review', *International Journal of Environmental Research and Public Health*, 10(6), pp. 2296–2335. doi: 10.3390/ijerph10062296.

Kingdon, C. (2005) 'Reflexivity: Not just a qualitative metiiodoiogical researcii tool', *British Journal of Medical Midwifery*, 13(10), pp. 622–628.

Kingdon, C., Neilson, J., Singleton, V., Gyte, G., Hart, A., Gabbay, M. and Lavender, T. (2009) 'Choice and birth method: Mixed-method study of caesarean delivery for maternal request', *BJOG:*

An International Journal of Obstetrics and Gynaecology, 116(7), pp. 886–895. doi: 10.1111/j.1471-0528.2009.02119.x.

Kitayama, S. Duffy, S. Uchida, Y. (2010) ‘Self as cultural mode of being’. , in Kitayama, S. and Cohen, D (ed.) Handbook of Cultural Psychology. London. The Guildford Press, pp. 136-175.

Kitzinger, J. (1994) ‘The methodology of Focus Groups: the importance of interaction between research participants.’, *Sociology of Health and Illness*, 16(1), pp. 103–121. doi: 10.1111/1467-9566.ep11347023.

Kitzinger, J. (1995) ‘Introducing focus groups â€™ P’, *BMJ : British Medical Journal*, 311, pp. 299–302.

Klebanov, P. K., Evans, G. W. and Brooks-Gunn, J. (2014) ‘Poverty, ethnicity, and risk of obesity among low birth weight infants’, *Journal of Applied Developmental Psychology*. Elsevier Inc., pp. 1–9. doi: 10.1016/j.appdev.2014.01.003.

Knight, M., Tuffnell, D., Kenyon, S., Shakespeare, J., Gray, R. and Kurinczuk, J. (2015) *MBRRACE-UK: Saving Lives, Improving Mothers’ Care. Surveillance of maternal deaths in the UK Maternal, Newborn and Infant Clinical Outcome Review Programme*. Edited by Marian Knight, D. Tuffnell, S. Kenyon, J. Shakespeare, R. Gray, and J. J. Kurinczuk. Oxford.: National Perinatal Epidemiology Unit. Available at: https://www.npeu.ox.ac.uk/mbrrace-uk/reports.

Knowles, R. L., Ridout, D., Crowe, S., Bull, C., Wray, J., Tregay, J., Franklin, R. C., Barron, D. J., Cunningham, D., Parslow, R. C. and Brown, K. L. (2016) ‘Ethnic and socioeconomic variation in incidence of congenital heart defects’, *Archives of disease in childhood*, pp. 1–7. doi: 10.1136/archdischild-2016-311143.

Koenig, H. G., McCullough, M. E. and Larson, D. B. (2001) *Handbook of Religion and Health*. Edited by Harold G. Koenig. Oxford: Oxford University Press.

Koenig, M. and Al Shohaib, S. (2014) *Health and wellbeing in Islamic societies. background, research and Applications*. New York: Springer New York.

Korkodilos, M., Earwicker, R., Perry, M. and Thorpe, A. (2010) *Tackling inequalities in infant and maternal health outcomes: Report of the Infant Mortality National support team.* doi: 10.1177/1757913912468651.

Kramer, M. S. (1987) ‘Determinants of low birth weight : methodological assessment and meta-analysis’, *Bulletin of the World Health Organization*, 65(5), pp. 663–737. Available at: http://www.ncbi.nlm.nih.gov/pmc/articles/PMC2491072/pdf/bullwho00076-0086.pdf.

Kramer, M. S., Shiliang, L., Zhongcheng, L., Hongbo, Y., Platt, R. and Joseph, K. (2002) ‘Analysis of Perinatal Mortality and Its Components: Time for a Change?’, *Am J Epidemiol*, 156. doi: 10.1093/aje/kwf077.

Krauss, S. E. and Putra, U. (2005) ‘Research Paradigms and Meaning Making : A Primer’, 10(4), pp. 758–770.

Krieger, N. (1994) ‘Epidemiology and the web of causation: Has anyone seen the spider?’, *Social Science and Medicine*, 39(7), pp. 887–903. doi: 10.1016/0277-9536(94)90202-X.

Krieger, N. (2001) ‘Theories for social epidemiology in the 21st century: an ecosocial perspective.’, *International journal of epidemiology*, 30(4), pp. 668–677. doi: 10.1093/ije/30.4.668.

Krueger, R. A. and Casey, M. A. (2009) *Focus Groups. A practical Guide for Applied Research*. 4th

Edn. Los Angeles: Sage Publications Ltd.

Kupek, E., Petrou, S., Vause, S. and Maresh, M. (2002) ‘Clinical, provider and sociodemographic predictors of late initiation of antenatal care in England and Wales’, *BJOG: An International Journal of Obstetrics and Gynaecology*, 109(3), pp. 265–273. doi: 10.1111/j.1471-0528.2002.00524.x.

Kurinczuk, J. J., Hollowell, J., Boyd, P. A., Oakley, L., Brocklehurst, P. and Gray, R. (2010) *The contribution of congenital anomalies to infant mortality*.

Kurinczuk, J. J., Hollowell, J., Brocklehurst, P. and Gray, R. (2009) *Infant mortality: overview and context*. Oxford.

Kurinczuk, J. J. and Rashbass, J. (2015) *Closure of CAROBB and the establishment of a new regional congenital anomaly and rare disease registration service (NCARDRS)*. Available at: https://www.npeu.ox.ac.uk/carobb (Accessed: 19 March 2016).

Kwan, I., Jacklin, P., Cullum, A., Retsa, P., O’Connell, A.-M., Dougherty, M. and Whittle, M. (2007) *Review 7: The effectiveness and cost-effectiveness of interventions to promote an optimal intake of Vitamin D to improve the nutrition of pre-conceptual, pregnant and post-partum women and children, in low income households*. Available at: https://www.nice.org.uk/guidance/ph11/evidence/review-7-vitamin-d-369896509.

Lagan, B. M., Sinclair, M. and Kernohan, W. G. (2011) ‘A web-based survey of midwives’ perceptions of women using the Internet in pregnancy: A global phenomenon’, Midwifery. Elsevier, 27(2), pp. 273–281. doi: 10.1016/j.midw.2009.07.002.

Lakhanpaul, M., Bird, D., Culley, L., Hudson, N., Robertson, N., Johal, N., McFeeters, M., Hamlyn-Williams, C. and Johnson, M. (2014) ‘The use of a collaborative structured methodology for the development of a multifaceted intervention programme for the management of asthma (the MIA project), tailored to the needs of children and families of South Asian origin: a community-based, partici’, *Health Services and Delivery Research*, 2(28), pp. 1–226. doi: 10.3310/hsdr02280.

Lakhanpaul, M., Bird, D., Manikam, L., Culley, L., Perkins, G., Hudson, N., Wilson, J. and Johnson, M. (2014) ‘A systematic review of explanatory factors of barriers and facilitators to improving asthma management in South Asian children.’, *BMC public health*, 14, p. 403. doi: 10.1186/1471-2458-14-403.

Lassi, Z. S., Salam, R. A., Haider, B. A. and Bhutta, Z. A. (2013) *Folic acid supplementation during pregnancy for maternal health and pregnancy outcomes (Review)*. Available at: http://onlinelibrary.wiley.com/doi/10.1002/14651858.CD006896.pub2/abstract.

Lausman, A. and Kingdom, J. (2013) ‘Intrauterine Growth Restriction : Screening , Diagnosis and Management’, *J Obstec Gynaecol Can*, 35(295), pp. 741–748. Available at: http://sogc.org/wp-content/uploads/2013/08/August2013-CPG295-ENG-Revised.pdf.

Lausman, A., Kingdom, J., Gagnon, R., Basso, M., Bos, H., Crane, J., Davies, G., Delisle, M.-F., Hudon, L., Menticoglou, S., Mundle, W., Ouellet, A., Pressey, T., Pylypjuk, C., Roggensack, A. and Sanderson, F. (2013) ‘Intrauterine growth restriction: screening, diagnosis, and management.’, *Journal of obstetrics and gynaecology Canada : JOGC = Journal d’obstétrique et gynécologie du Canada : JOGC*, 35(8), pp. 741–57. Available at: http://www.ncbi.nlm.nih.gov/pubmed/24007710.

Lawn, J. E., Lee, A. C., Kinney, M., Sibley, L., Carlo, W., Paul, V., Pattinson, R. and Darmstadt, G. (2009) ‘Two million intrapartum-related stillbirths and neonatal deaths: where, why, and what can be done?’, *International Journal of Gynaecology and Obstetrics*. International Federation of Gynecology and Obstetrics, 107 Suppl, pp. S5-18, S19. doi: 10.1016/j.ijgo.2009.07.016.

Lawton, R., Ashley, L., Dawson, S., Waiblinger, D., Conner, M. and M, L. R. ; A. L. ; D. S. ; W. D. ;

C. (2012) ‘Employing an extended Theory of Planned Behaviour to predict breastfeeding intention, initiation, and maintenance in White British and South-Asian mothers living in Bradford.’, *British Journal of Health Psychology (BR J HEALTH PSYCHOL)*, pp. 854–871. doi: 10.1111/j.2044-8287.2012.02083.x.

Leon, D. and Moser, K. (2012) ‘Low birth weight persists in South Asian babies born in England and Wales regardless of maternal country of birth. Slow pace of acculturation, physiological constraint or both? Analysis of routine data’, *Journal of Epidemiology and Community Health*, 66(6), pp. 544–551. doi: 10.1136/jech.2010.112516.

Lewis, G. (2012) ‘Saving Mothers’ Lives: The Continuing Benefits for Maternal Health From the United Kingdom (UK) Confidential Enquires Into Maternal Deaths’, *Seminars in Perinatology*, pp. 19–26.

Lilford, R., Chard, J. and Morrison, B. (1999) ‘Commissioning health services research: an iterative method’, *Journal ofHealth Services Research*, 4(3), pp. 164–167. Available at: http://journals.sagepub.com/doi/pdf/10.1177/135581969900400308.

Lincoln, Y., Lynham, S. and Guba, E. (2011) ‘Paradigmatic controversies, contradictions and emerging confluences, revisited.’, in Denzin, N. and Lincoln, Y. (eds) *The SAGE handbook of Qualitative Research*. 4th edn. London: Sage Publications, pp. 97–129.

Lindam, A., Johansson, S., Stephansson, O., Wikström, A. K. and Cnattingius, S. (2016) ‘High maternal body mass index in early pregnancy and risks of stillbirth and infant mortality - A population-based sibling study in Sweden’, *American Journal of Epidemiology*, 184(2), pp. 98–105. doi: 10.1093/aje/kww046.

Linde, A. and Rådestad, I. (2015) ‘Women´s experiences of fetal movements before the confirmation of fetal death — contractions misinterpreted as fetal movement’, *Birth*. Available at: http://urn.kb.se/resolve?urn=urn:nbn:se:shh:diva-1804.

Lindsay, R., Dabelea, D., Roumain, J., Hanson, R., Bennett, P. and Knowler, W. (2000) ‘Type 2 diabete and Low Birth Weight. The role of paternal inheritance in the association of low birth weight and diabetes.’, *Diabetes*, 49, pp. 445–449. Available at: http://diabetes.diabetesjournals.org/content/49/3/445.full.pdf (Accessed: 25 February 2014).

Little, R. J. A. (1988) ‘A Test of Missing Completely at Random for Multivariate Data With Missing Values’, *Journal of American Statisical Association*, 83(404), pp. 1198–1202.

Longman, J. M., Pritchard, C., McNeill, A., Csikar, J. and Croucher, R. E. (2010) ‘Accessibility of chewing tobacco products in England’, *Journal of Public Health*, 32(3), pp. 372–378. doi: 10.1093/pubmed/fdq035.

Loret de Mola, C., Araújo de França, G. V., Quevedo, L. D. A. and Horta, B. L. (2014) ‘Low birth weight, preterm birth and small for gestational age association with adult depression: systematic review and meta-analysis.’, *The British journal of psychiatry : the journal of mental science*, 205(5), pp. 340–347. doi: 10.1192/bjp.bp.113.139014.

Love, A. (2003) *Housing (overcrowding) Bill*. London. Available at: http://www.publications.parliament.uk/pa/cm200203/cmbills/046/2003046.pdf.

Lowe, P., Griffiths, F. and Sidhu, R. (2007) ‘“I got pregnant, I was so like … crying inside …”: experiences of women of Pakistani ancestry seeking contraception in the UK’, *Diversity in Health and Social Care*, 4, pp. 69–76. Available at: http://www.radcliffe-oxford.com/journals/J18_Diversity_in_Health_and_Social_Care/.

Lowry, C. and Scammell, K. (2013) *Smoking cessation in pregnancy : a call to action*. Available at:

http://www.ash.org.uk/files/documents/ASH_893.pdf.

Lucas, A., Murray, E. and Kinra, S. (2013) ‘Heath beliefs of UK South Asians related to lifestyle diseases: a review of qualitative literature.’, *Journal of obesity*, 2013, p. 827674. doi: 10.1155/2013/827674.

Lumley, J. (2003) ‘Defining the problem: The epidemiology of preterm birth’, *BJOG: An International Journal of Obstetrics and Gynaecology*, 110(SUPPL. 20), pp. 3–7. doi: 10.1016/S1470-0328(03)00011-9.

Lurie, N., Fremont, A., Jain, A. K., Taylor, S. L., McLaughlin, R., Peterson, E., Kong, B. W. and Ferguson, T. B. (2005) ‘Racial and ethnic disparities in care: The perspectives of cardiologists’, *Circulation*, 111, pp. 1264–1269. doi: 10.1161/01.CIR.0000157738.12783.71.

Luton Borough Council (2011) *Research and Geospatial Information*. Available at: http://www.luton.gov.uk/Community_and_living/Luton observatory census statistics and mapping/Pages/What are the deprivation levels in Luton_.aspx.

Luton Borough Council (2013) *Maternity and early years – births*. Available at: https://www.luton.gov.uk/Community_and_living/Lists/LutonDocuments/PDF/JSNA/4.2 Maternity and early years.pdf.

Luton Overview and Scrutiny Board (2013) *Review of Infant Mortality Rates in Luton*. Luton.

Macdonald, S. and McGill-Cuerden, J. (2011) *Mayes’ Midwifery: A Textbook for Midwives*. 14th Edn. Balliere Tindall.

Macinnes, T., Tinson, A., Hughes, C., Born, T. B., Aldridge, H. and Joseph Rowntree Foundation (2015) *Monitoring poverty and social exclusion 2015 (summary)*. York. Available at: www.jrf.org.uk.

Macintosh, M., Fleming, K., Bailey, J., Doyle, P., Modder, J., Acolet, D., Golightly, S. and Miller, A. (2006) ‘Perinatal mortality and congenital anomalies in babies of women with type 1 or type 2 diabetes in England, Wales, and Northern Ireland: population based study.’, *BMJ (Clinical research ed.)*, 333(7560), p. 177. doi: 10.1136/bmj.38856.692986.AE.

Maio, G. R. and Haddock, G. (2010) *The Psychology of Attitudes and Attitude Change*. Los Angeles: Sage Publications.

Makgoba, M., Savvidou, M. and Steer, P. (2012) ‘An analysis of the interrelationship between maternal age, body mass index and racial origin in the development of gestational diabetes mellitus.’, *BJOG : an international journal of obstetrics and gynaecology*, 119(3), pp. 276–82. doi: 10.1111/j.1471-0528.2011.03156.x.

Målqvist, M., Lincetto, O., Du, N. H., Burgess, C. and Hoa, D. T. P. (2013) ‘Maternal health care utilization in Viet Nam: increasing ethnic inequity.’, *Bulletin of the World Health Organization*, 91(4), pp. 254–61. doi: 10.2471/BLT.12.112425.

Manning, F., Wyn Pugh, E. and Boddy, K. (1975) ‘Effect of cigarette smoking on fetal breathing movements in normal pregnancies.’, *British medical journal*, 1(5957), pp. 552–553. Available at: http://ovidsp.ovid.com/ovidweb.cgi?T=JS&PAGE=reference&D=med1&NEWS=N&AN=1139146.

Margetts, B. M., Yusof, S. M., Dallal, Z. Al and Jackson, A. A. (2002) ‘Persistence of lower birth weight in second generation’, *Journal of Epidemiology and Community Health*, 56, pp. 684–687.

Markus, H. R. and Hamedani, M. Y. (2010) ‘Sociocultural psychology: The dynamic interdependence among self systems and social systems’, in Kitayama, S. and Cohen, D. (eds) *Handbook of Cultural Psychology*. New York: The Guildford Press, pp. 3–40.

Marmot, M. (2008) *Closing the gap in a generation: health equity through action on the social determinants of health*, *Health Equity Through Action on the Social Determinants of Health*. Geneve. doi: 10.1080/17441692.2010.514617.

Marmot, M. (2010) *Strategic Review of health inequalities post 2010 Marmot Review*.

Marmot, M. (2012) 'Fair Society , Healthy Lives Michael Marmot RCN and the Public Health Agenda Royal College of Nursing Review of the'.

Marmot, M. (2013) *WHO European Review*. Available at: https://www.instituteofhealthequity.org/projects/who-european-review.

Marmot, M., Allen, J., Bell, R., Bloomer, E. and Goldblatt, P. (2012) 'WHO European review of social determinants of health and the health divide.', *Lancet*, 380(9846), pp. 1011–29. doi: 10.1016/S0140-6736(12)61228-8.

Marmot, M. and Wilkinson, R. (2003) *Determinants of Health. The Solid Facts*. 2nd Edn, *World Health*. 2nd Edn. Edited by R. Wilkinson and M. Marmot. Denmark: World Health Organisation. doi: 10.1016/j.jana.2012.03.001.

Marsella, A. J. and Yamada, A. (2010) 'Culture and psychopathology: Foundations, issues and directions.', in Kitayama, S. and Cohen, D. (eds) *Handbook of Cultural Psychology*. New York: The Guildford Press, pp. 797–821.

Marufu, T. C., Ahankari, A., Coleman, T. and Lewis, S. (2015) 'Maternal smoking and the risk of still birth: systematic review and meta-analysis.', *BMC public health*, 15, p. 239. doi: 10.1186/s12889-015-1552-5.

Maxwell, J. (2011) 'Paradigms or toolkits? Philosophical and methodological positions as heuristics for mixed method research', *Mid Western Educational researcher*, 24(2), pp. 27–30. doi: 10.1016/S2213-1779(13)00434-4.

Maxwell, J. (2013a) 'Conceptual Framework, what do you think is going on?', in *Qualiatative research design: an interactive approach*. London: Sage Publications, pp. 39–72.

Maxwell, J. (2013b) *Qualitative research design, an interactive approach*. 3rd Edn. London: Sage Publications.

Mayhew, L. and Waples, S. (2011) *The growth and changing complexion of Luton's population. A structural analysis and decomposition*.

Mays, N. and Pope, C. (2000) 'Qualitative research in health care. Assessing quality in qualitative research.', *BMJ (Clinical research ed.)*, 320(7226), pp. 50–2. Available at: http://www.pubmedcentral.nih.gov/articlerender.fcgi?artid=1117321&tool=pmcentrez&rendertype=abstract (Accessed: 3 January 2014).

MBRRACE-UK (2015a) *Perinatal Confidential Enquiry, 2015*. Available at: https://www.npeu.ox.ac.uk/publications.

MBRRACE-UK (2015b) *Perinatal Mortality Surveillance Report for births from UK Perinatal Deaths (2013)*. Leicester. Available at: https://www.npeu.ox.ac.uk/mbrrace-uk/reports.

McAlister, A., Perry, C. and Parcel, G. S. (2008) 'How individuals, environments and health behaviours interact: Social cognitive theory', in Glanz, K., Rimer, B., and Viswanath, K. (eds) *Health behaviour and health education, theory research and practice.* fourth edn. San Francisco: Jossey Bass Ltd, pp. 169–189.

Mceachan, R. (2012) *The Born in Bradford (BiB) cohort study : Summary statistics by ethnic* *group*. Available at: http://www.borninbradford.nhs.uk/uploads/downloads/research_and_scientific/cohort_information/Baseline%20Summary%20Factsheet%20BiB.pdf

Mcfadden, A., Renfrew, M. J. and Atkin, K. (2013) 'Does cultural context make a difference to women's experiences of maternity care? A qualitative study comparing the perspectives of breast-feeding women of Bangladeshi origin and health practitioners', *Health Expectations*, 16(4), pp. 124–135. doi: 10.1111/j.1369-7625.2012.00770.x.

McGibbon, E. and McPherson, C. (2010) 'Applying Intersectionality & Complex Theory to Address the Social Determinants of Women's Health', *Women's Health and Urban Life*, 10(1), pp. 59–86.

McLaren, L. and Hawe, P. (2005) 'Ecological perspectives in health research.', *Journal of epidemiology and community health*, 59(1), pp. 6–14. doi: 10.1136/jech.2003.018044.

Meer, N. and Modood, T. (2007) 'Islam and British Multiculturalism', *Global Dialogue*, 9(3). Available at: http://www.worlddialogue.org/content.php?id=416.

Meissner, H., Creswell, J., Klassen, A. C., Plano, V. and Smith, K. C. (2011) *Best Practices for Mixed Methods Research in the Health Sciences*.

Menikoff, J. (2001) 'Just compensation: paying research subjects relative to the risks they bear.', *Issn: 00178012*, Volume: 65, p. Pages: 43-59. Available at: http://www.tandfonline.com/doi/abs/10.1162/152651601300169121?journalCode=uajb20#.VP8ObHysWdk.

Mens-verhulst, J. Van and Radtke, L. (1991) 'Sociocultural equities in the health research: what does the intersectionalities framework offer?', *Intersectional Health Research*, pp. 1–9.

Mens-verhulst, J. Van and Radtke, L. L. (2011) *Intersectionality and health care: support for the diversity turn in research and practice*. Available at: http://www.vanmens.info/verhulst/en/wp-content/Intersectionality and Health Care- january 2006.pdf.

Messer, J. (2011) 'An analysis of the socio-demographic characteristics of sole registered births and infant deaths.', *Health statistics quarterly / Office for National Statistics*, (50), pp. 79–107. doi: 10.1057/hsq.2011.9.

Messina, J., Freeman, C., Rees, A., Goyder, E., Hoy, A., Ellis, S. and Ainsworth, N. (2013) 'A systematic Review of Contexual Factors Relating to Smokeless Tobacco Use among South Asian Users in England', *Nicotine and Tobacco research*, 15(5), pp. 875–882. doi: 10.1093/ntr/nts193.

van de Mheen, H. D., Stronks, K. and Mackenbach, J. P. (1998) 'A lifecourse perspective on socio-economic inequalities in health: the influence of childhood socio-economic conditions and selection processes', *Blackwell*, pp. 193–216. doi: 10.1111/1467-9566.t01-1-00128.

Mikael Häggström (2014) *Medical gallery of Mikael Häggström 2014*. doi: DOI:10.15347/wjm/2014.008.

Miles, M., Huberman, A. and Saldana, J. (2014) 'Fundementals of qualitative analysis', in *Qualitative data analysis*. 3rd Edn. London: Sage Publications Ltd., pp. 69–105.

Mills, T. A., Ricklesford, C., Cooke, A., Heazell, A. E. P., Whitworth, M. and Lavender, T. (2014) 'Parents' experiences and expectations of care in pregnancy after stillbirth or neonatal death: a metasynthesis.', *BJOG : an international journal of obstetrics and gynaecology*, 121(8), pp. 943–50. doi: 10.1111/1471-0528.12656.

Mir, G. (2008) *Research in practice for adults: How can we ensure culturally competent services?* Available at: http://www.etn.leeds.ac.uk/document/resources/RPFA_Outline_14.pdf.

Mir, G. and Spicer, K. (2013) ‘Infant Mortality and Pakistani communities : Social , genetic or what ?’. University of Leeds.

Mir, G. and Tovey, P. (2002) ‘Cultural competency: professional action and South Asian carers.’, Journal of management in medicine, 16(1), pp. 7–19. doi: 10.1108/02689230210428599.

Mir, G. and Tovey, P. (2003) ‘Asian Carers ’ Experiences of Medical and Social Care : The Case of Cerebral Palsy’, *British Journal of Social Work*, 33, pp. 465–479. Available at: http://bjsw.oxfordjournals.org/content/33/4/465.short.

Mirkuzie, A. H., Sisay, M. M., Moland, K. M. and Astrøm, A. N. (2011) ‘Applying the theory of planned behaviour to explain HIV testing in antenatal settings in Addis Ababa - a cohort study.’, *BMC health services research*, 11(1), p. 196. doi: 10.1186/1472-6963-11-196.

Modell, B., Harris, R., Lane, B., Khan, M., Darlison, M., Petrou, M., Old, J., Layton, M. and Varnavides, L. (2000) ‘Informed choice in genetic screening for thalassaemia’, *BMJ*, 320(February), pp. 337–341. doi: 10.1136/bmj.320.7231.337.

Mohangoo, A. D., Blondel, B., Gissler, M., Velebil, P., Macfarlane, A. and Zeitlin, J. (2013) ‘International comparisons of fetal and neonatal mortality rates in high-income countries: should exclusion thresholds be based on birth weight or gestational age?’, *PloS one*. Edited by L. Wright. Public Library of Science, 8(5), p. e64869. doi: 10.1371/journal.pone.0064869.

Moran, A. C., Choudhury, N., Uz Zaman Khan, N., Ahsan Karar, Z., Wahed, T., Faiz Rashid, S. and Alam, M. A. (2009) ‘Newborn care practices among slum dwellers in Dhaka, Bangladesh: a quantitative and qualitative exploratory study.’, *BMC pregnancy and childbirth*, 9(1), p. 54. doi: 10.1186/1471-2393-9-54.

Morell, R. J., Kim, H. J., Hood, L. J., Goforth, L., Friderici, K., Fisher, R., Van Camp, G., Berlin, C., Oddoux, C., Ostrer, H., Keats, B. and Friedman, T. B. (1998) ‘Mutations in the connexin 26 gene (GJB2) among Ashkenazi Jews with nonsyndromic recessive deafness’, *The New England Journal of Medicine*, 339(21), pp. 1500–5. doi: 10.1056/NEJM199811193392103.

Morgan, D. L. (2007) ‘Paradigms Lost and Pragmatism Regained: Methodological Implications of Combining Qualitative and Quantitative Methods’, *Journal of Mixed Methods Research*, 1(1), pp. 48–76. doi: 10.1177/2345678906292462.

Morrison, V. and Bennett, P. (2006) ‘Predicting health behaviour’, in *An introduction to health psychology*. 2nd edn. Essex: Pearson Education, pp. 113–147.

Moser, K., Stanfield, K. and Leon, D. (2008b) ‘Birthweight and gestational age by ethnic group, England and Wales 2005: introducing new data on births.’, *Health statistics quarterly / Office for National Statistics*, (39), pp. 22–31, 34–55. Available at: http://webarchive.nationalarchives.gov.uk/20160105160709/http://www.ons.gov.uk/ons/rel/hsq/health-statistics-quarterly/no--39--autumn-2008/birthweight-and-gestational-age-by-ethnic-group--england-and-wales-2005.pdf.

Mumtaz, Z., O’Brien, B. and Higginbottom, G. (2014) ‘Navigating maternity health care: a survey of the Canadian prairie newcomer experience.’, *BMC pregnancy and childbirth*, 14, p. 4. doi: 10.1186/1471-2393-14-4.

Nagel, J. and Olzak, S. (1982) ‘Ethnic Mobilization in New and Old States: An Extension of the Competition Model’, *Social Problems*, 30(2), pp. 127–143. Available at: http://www.jstor.org/stable/800513.

Naidoo, J. and Wills, J. (2000) ‘Influences on health’, in *Health promotion: Foundations for practice*. 2nd Edn. Edinburgh: Bailliere Tindall, pp. 27–51.

Nair, M., Yoshida, S., Lambrechts, T., Boschi-Pinto, C., Bose, K., Mason, E. M. and Mathai, M. (2014) ‘Facilitators and barriers to quality of care in maternal, newborn and child health: a global situational analysis through metareview.’, *BMJ open*, 4(5), p. e004749. doi: 10.1136/bmjopen-2013-004749.

Nakagawa, S. and Freckleton, R. P. (2008) ‘Missing inaction: the dangers of ignoring missing data’, *Trends in Ecology and Evolution*, 23(11), pp. 592–596. doi: 10.1016/j.tree.2008.06.014.

National Child and Maternal Health Intelligence Network (2014) *Facts and figures on infant mortality and stillbirths*. Available at: http://www.chimat.org.uk/resource/view.aspx?RID=222265.

National Collaborative Centre for Health Public Policy (2015) *Health Inequalities and Intersectionality*. Quebec. Available at: http://www.ncchpp.ca/41/What_s_New_.ccnpps?id_article=1392.

National Institute for Health and Care Excellence (2008) ‘Antenatal care for uncomplicated pregnancies’, *Nice*, (March). doi: 10.1017/CBO9781107415324.004.

National Institute for Health and Care Excellence (2015) *Diabetes in pregnancy : management from preconception to the postnatal period. NG3*. doi: 978-1-4731-0993-3.

National Institute for Health and Clinical Excellence (NICE) (2015) ‘Antenatal And Postnatal Mental Health: Clinical Management and Service Guidance’, *NICE Clinical Guideline*, (4–51), p. Available at: http://www.nice.org.uk/nicemedia/live/11004/30433/30433.pdf%5Cnguidance.nice.org.uk/cg45.

National Maternity Review (2016) *Better births. Improving outcomes of maternity services in England. A 5 year forward view for maternity care.* Available at: https://www.england.nhs.uk/2016/02/maternity-review-2/.

National Obesity Observatory (2011) *Obesity and ethnicity*. Available at: http://www.noo.org.uk/uploads/doc/vid_9851_Obesity_ethnicity.pdf.

Navarro, V. (2009) ‘What we mean by social determinants of health’, *International Journal of Health Services*, 39(3), pp. 423–441. doi: 10.2190/HS.39.3.a.

Nazroo, J. (2009) ‘Socioeconomic status and health: the role of subjective social status’, *Social Science and Medicine*, 67(2), pp. 330–340. doi: 10.1016/j.socscimed.2008.03.038.Socioeconomic.

Nazroo, J. and Karlsen, S. (2001) ‘Ethnic inequalities in health: social class, racism and identity’, *Research Findings*, 10(10). Available at: http://www.lancs.ac.uk/fass/apsocsci/hvp/pdf/fd10.pdf.

Nazroo, J. Y. (2003) ‘The Structuring of Ethnic Inequalities in Health: Economic Position, Racial Discrimination, and Racism’, *American Journal of Public Health*, 93(2), pp. 277–285. doi: 10.2105/AJPH.93.2.277.

Nazroo, J. Y. and Williams, D. R. (2006) ‘The social determination of ethnic / racial inequalities in health’, in Marmot, M. Wilkinson, R. (ed.) *The social determinants of health*. 2nd Edn. Oxford: Oxford University Press, pp. 267–297. doi: 10.1093/acprof:oso/9780198565895.003.04.

Neonatal Mortality Formative Research Group (2008) ‘Developing community-based intervention strategies to save newborn lives: lessons learned from formative research in five countries.’, *Journal of perinatology : official journal of the California Perinatal Association*, 28 Suppl 2(2008), pp. S2-8. doi: 10.1038/jp.2008.166.

NHS Digital (2017) *Maternity Services Data Set*. Available at: http://content.digital.nhs.uk/maternityandchildren/maternity (Accessed: 5 February 2017).

NHS Screening Programmes SCT (2014) *Family Origin Questionnaire Guidance for Health Care*

Professionals. Available at: https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/398766/FOQ_version_3_Feb_2014.pdf.

NICE (National Insitute for Health and Care Excellance) (2014) ‘Diabetes in pregnancy from pre-conception to the postnatal period’, 63(2008), p. 42.

Noble, H. and Smith, J. (2015) ‘Issues of validity and reliability in qualitative research’, *Evidence-Based Nursing*, 18(2), pp. 34–35. doi: 10.1136/eb-2015-102054.

NOMIS (2016) *Labour market statistics : NS-SeC by ethnic group by sex by age*. Available at: https://www.nomisweb.co.uk/census/2011/DC6206EW/view/2092957699?rows=c_ethpuk11&cols=c_nssec# (Accessed: 8 December 2016).

Núñez-de la Mora, A., Jesmin, F. and Bentley, G. R. (2007) ‘Betel nut use among first and second generation Bangladeshi women in London, UK.’, *Journal of immigrant and minority health / Center for Minority Public Health*, 9(4), pp. 299–306. doi: 10.1007/s10903-007-9041-2.

Nutbeam, D. . (2006) ‘Health literacy as a public health goal : a challenge for contemporary health education and communication strategies into the 21st century’, *Health promotion International*, 15(3), pp. 259–268.

Nykjaer, C., Alwan, N. A., Greenwood, D. C., Simpson, N. A. B., Hay, A. W. M., White, K. L. M. and Cade, J. E. (2014) ‘Maternal alcohol intake prior to and during pregnancy and risk of adverse birth outcomes: evidence from a British cohort’, *Journal of Epidemiology & Community Health*, 68(6), pp. 542–549. doi: 10.1136/jech-2013-202934.

O’Connor, D. (2015) *Saving Babies ’ Lives Care Bundle for reducing stillbirth and early neonatal death*. Available at: https://www.perinatal.org.uk/pdfs/NHSE_Care_Bundle_Element_2_Draft_2015.pdf.

O’Reilly, R., Beale, B. and Gillies, D. (2010) ‘Screening and intervention for domestic violence during pregnancy care: a systematic review.’, *Trauma, violence & abuse*, 11(4), pp. 190–201. doi: 10.1177/1524838010378298.

Oakley, A. (1982) ‘The Origins and Development of Antenatal care’, in Enkin, M. and Chalmers, I. (eds) *Effectiveness and Satisfaction in Antenatal Care, Volume 8*. Suffolk: Lavenham Press Ltd., pp. 1–22.

Oakley, L., Maconochie, N. and Doyle, P. (2010) *Multivariate analysis of infant death in England and Wales in 2005 – 06 , with focus on socio-economic status and deprivation*. Available at: www.ons/HSQ42-infant-death_tcm77-141736 (2).pdf.

Office for National Statistics (2011a) *2011 Census: Key Statistics for local authorities in England and Wales KS201EW*, *2011 Key Statistics: For Local Authorities in the United Kingdom*. Available at: http://www.ons.gov.uk/ons/publications/re-reference-tables.html?edition=tcm%3A77-286262.

Office for National Statistics (2011b) ‘Household Questionnaire England: 2011 Census’, pp. 1–32. Available at: https://www.google.de/url?sa=t&rct=j&q=&esrc=s&source=web&cd=1&ved=0ahUKEwjR1PfK7ZDKAhWCOhQKHcRDCYsQFggdMAA&url=http://www.ons.gov.uk/ons/guide-method/census/2011/the-2011-census/2011-census-questionnaire-content/2011-census-questionnaire-for-england.pdf&.

Office for National Statistics (2011c) ‘Luton Borough Profile 2011 Census data’, *Research and Geospatial Team*.

Office for National Statistics (2011d) *Results from the ICD-10 v2010 bridge coding study : stillbirths* *and neonatal deaths*. Available at: www.childhealthbridgecodingstatsbulleti_tcm77-217153 (1).pdf.

Office for National Statistics (2011e) *Statistical Bulletin Gestation-specific infant mortality in England and Wales 2010*. Available at: http://www.ons.gov.uk/ons/dcp171778_282579.pdf.

Office for National Statistics (2012a) *Ethnicity and National Identity in England and Wales (2011)*. Available at: http://www.ons.gov.uk/ons/dcp171776_290558.pdf.

Office for National Statistics (2012b) *Statistical Bulletin Childhood, Infant and Perinatal Mortality in England and Wales, 2012*. Available at: http://www.ons.gov.uk/ons/rel/vsob1/child-mortality-statistics--childhood--infant-and-perinatal/2012/.

Office for National Statistics (2013a) *Characteristics of Birth 1, England and Wales 2012*. London. Available at: http://www.ons.gov.uk/ons/dcp304733_327618.pdf.

Office for National Statistics (2013b) *Child Mortality Statistics Metadata*. Available at: http://www.ons.gov.uk/ons/guide-method/user-guidance/health-and-life-events/index.html.

Office for National Statistics (2013c) *Childhood, Infant and Perinatal Mortality in England and Wales, 2011*. Available at: http://www.ons.gov.uk/.

Office for National Statistics (2013d) *Full story: What does the Census tell us about religion in 2011?* Available at: https://www.ons.gov.uk/peoplepopulationandcommunity/culturalidentity/religion/articles/fullstorywhatdoesthecensustellusaboutreligionin2011/2013-05-16#religion-by-ethnicity.

Office for National Statistics (2013f) *Gestation-specific Infant Mortality in England & Wales, 2011*. Office for National Statistics. Available at: https://www.ons.gov.uk/peoplepopulationandcommunity/healthandsocialcare/causesofdeath/bulletins/pregnancyandethnicfactorsinfluencingbirthsandinfantmortality/2013-10-10

Office for National Statistics (2014a) *Childhood , Infant and Perinatal Mortality in England and Wales, 2012*. London. Available at: http://www.ons.gov.uk/ons/dcp171778_350853.pdf.

Office for National Statistics (2014b) *Gestation specific infant mortality 2012*. London. Available at: http://www.ons.gov.uk/ons/dcp171778_379562.pdf.

Office for National Statistics (2014c) *Indices of deprivation and classification*. Available at: http://www.neighbourhood.statistics.gov.uk/.

Office for National Statistics (2014d) *Mortality Statistics: Deaths Registered in UK by Area of Usual Residence, 2014*. Available at: http://www.ons.gov.uk/ons/search/index.html?newquery=perinatal+mortality+rate+luton.

Office for National Statistics (2014e) *Statistical Bulletin: Gestation specific Infant Moratlity 2012*. Available at: http://www.ons.gov.uk/ons/dcp171778_379562.pdf.

Office for National Statistics (2014f) *Statistical Bulletin Births in England and Wales , 2013*. Available at: http://www.ons.gov.uk/ons/dcp171778_371129.pdf.

Office for National Statistics (2014g) *Statistical Bulletin Births in England and Wales by Parents' Country of Birth: 2013*.

Office for National Statistics (2015a) *Child Mortality Statistics: Metadata*. Available at: http://search.proquest.com/docview/89130757?accountid=12037%5Cnhttp://linksource.ebsco.com/linking.aspx?sid=ProQ:envscijournals&fmt=journal&genre=unknown&issn=14651645&volume=&issue=45&date=2010-04-01&spage=2&title=Health+Statistics+Quarterly&atitle=Child.

Office for National Statistics (2015b) *Gestation-specific Infant Mortality in England and Wales 2013*. Available at: http://www.ons.gov.uk/ons/dcp171778_419800.pdf.

Office for National Statistics (2015c) *Home ownership down and renting up for first time in a century*. Available at: http://visual.ons.gov.uk/housing-census/ (Accessed: 4 November 2015).

Office for National Statistics (2015d) 'Pregnancy and ethnic factors influencing births and infant mortality: 2013', pp. 1–31. Available at: http://www.ons.gov.uk/peoplepopulationandcommunity/healthandsocialcare/causesofdeath/bulletins/pregnancyandethnicfactorsinfluencingbirthsandinfantmortality/2015-10-14.

Office for National Statistics (2016a) *Childhood mortality in England and Wales : 2014*. Available at: http://www.ons.gov.uk/peoplepopulationandcommunity/birthsdeathsandmarriages/deaths/bulletins/childhoodinfantandperinatalmortalityinenglandandwales/2014.

Office for National Statistics (2016b) *Live births by sex, parity and ethnicity, England and Wales*. Available at: https://www.ons.gov.uk/peoplepopulationandcommunity/birthsdeathsandmarriages/livebirths/adhocs/005575livebirthsbyethnicityandparityenglandandwales2008to2014.

Office for National Statistics (2016c) *Neonatal mortality and stillbirths.*, *CCG OIS - Indicator 1.25*. Available at: https://indicators.hscic.gov.uk/webview/ (Accessed: 22 November 2016).

Office for National Statistics (2016d) *Parents' country of birth , England and Wales: 2015*. Available at: https://www.ons.gov.uk/peoplepopulationandcommunity/birthsdeathsandmarriages/livebirths/bulletins/parentscountryofbirthenglandandwales/2015.

Office for National Statistics (2016e) *SOC2010 volume 3: the National Statistics Socio-economic classification (NS-SEC rebased on SOC2010)*. Available at: http://webarchive.nationalarchives.gov.uk/20160105160709/http://www.ons.gov.uk/ons/guide-method/classifications/current-standard-classifications/soc2010/soc2010-volume-3-ns-sec--rebased-on-soc2010--user-manual/index.html (Accessed: 12 March 2016).

Office for National Statistics (2016f) *Super Output Area (SOA)*. Available at: http://webarchive.nationalarchives.gov.uk/20160105160709/http://www.ons.gov.uk/ons/guide-method/geography/beginner-s-guide/census/super-output-areas--soas-/index.html (Accessed: 12 March 2016).

Ogden, J. (2003) 'Some problems with social cognition models: A pragmatic and conceptual analysis.', *Health Psychology*, 22(4), pp. 424–428. doi: 10.1037/0278-6133.22.4.424.

Ogden, J. (2007) 'Womens Health Issues', in *health Psychology: a textbook*. 4th Edn. Maidenhead: Open University Press, pp. 365–392.

Ogden, J. (2012) *Health Psychology*. 5th edn. Berkshire: Open University Press.

Oliver, A. and Mossialos, E. (2004) 'Equity of access to health care: outlining the foundations for action.', *Journal of Epidemiology and Community Health*, 58(8), pp. 655–658. doi: 10.1136/jech.2003.017731.

Oliver, A. and Nutbeam, D. (2003) 'Addressing health inequalities in the United Kingdom: a case study', *Journal of Public Health*. Oxford University Press, 25(4), pp. 281–287. doi: 10.1093/pubmed/fdg091.

Osborne, J. W. (2013) 'Dealing with Missing or Incomplete Data: Debunking the Myth of Emptiness', *Best Practices in Data Cleaning*, pp. 105–138. doi:

http://dx.doi.org/10.4135/9781452269948.

Ota, E., Souza, J. P., Tobe, G. R., Mori, R., Middleton, P., Flenady, V. and Jp, S. (2012) *Interventions during the antenatal period for preventing stillbirth : an overview of Cochrane systematic reviews (Protocol)*, *Cochrane Database of Systematic Reviews*. doi: 10.1002/14651858.CD009599.

Owens, A. and Randhawa, G. (2004) '"It"s different from my culture; they're very different': Providing community-based, "culturally competent" palliative care for South Asian people in the UK', *Health and Social Care in the Community*, 12(5), pp. 414–421. doi: 10.1111/j.1365-2524.2004.00511.x.

Paez, K. A., Allen, J. K., Beach, M. C., Carson, K. A. and Cooper, L. A. (2009) 'Physician cultural competence and patient ratings of the patient-physician relationship', *Journal of General Internal Medicine*, 24(4), pp. 495–498. doi: 10.1007/s11606-009-0919-7.

Palacios, C., De-Regil, L. M., Lombardo, L. K. and Peña-Rosas, J. P. (2016) 'Vitamin D supplementation during pregnancy: Updated meta-analysis on maternal outcomes', *The Journal of Steroid Biochemistry and Molecular Biology*. Elsevier Ltd, (2015). doi: 10.1016/j.jsbmb.2016.02.008.

Pampel, F. C., Krueger, P. and Denney, J. (2010) 'Socioeconomic disparities in health behaviors', *Annual review of sociology*, 36, pp. 349–370. doi: 10.1146/annurev.soc.012809.102529.Socioeconomic.

Parahoo, K. (2006a) *Nursing research, principals, process and issues.* Second edn. Hampshire.: Palgrave Macmillan.

Parahoo, K. (2006b) 'Samples and Sampling', in *Nursing Research, principals, process and issues*. 2nd Edn. New York: Palgrave Macmillan, pp. 256–282.

Parikh, L. I., Reddy, U. M., Männistö, T., Mendola, P., Sjaarda, L., Hinkle, S., Chen, Z., Lu, Z. and Laughon, S. K. (2014) 'Neonatal outcomes in early term birth.', *American journal of obstetrics and gynecology*. Mosby, Inc, 211(3), p. 265.e1-265.e11. doi: 10.1016/j.ajog.2014.03.021.

Patel, R., Steer, P., Doyle, P., Little, M. and Elliott, P. (2003) 'Does gestation vary by ethnic group ? A London-based study over 122,000 pregnancies with spontaneous onset of labour', *International journal of epidemiology*, 33, pp. 107–113. doi: 10.1093/ije/dyg238.

Patel, V., Rahman, A., Jacob, K. S. and Hughes, M. (2004) 'Effect of maternal mental health on infant growth in low income countries : new evidence from South Asia', 328(April), pp. 820–823.

Patterson, O. (2000) 'Taking culture seriously: A framework and a Afro-American illustration', in Harrison, L. E. and Huntington, S. P. (eds) *Culture Matters; how values shape human progress*. New York: Basic Books, pp. 202–218.

Patterson, O. (2004) 'Four modes of ethno-somatic stratification: The experience of Blacks in Europe and the Americas', in Loury, G., Modood, T., and Teles, S. (eds) *Ethnicity, social mobility and public policy: comparing the USA and UK*. Cambridge: Cambridge University Press, pp. 67–121. Available at: http://scholar.harvard.edu/patterson/publications.

Patterson, O. (2014) 'Making Sense of Culture', *Annual Review of Sociology*, 40(1), pp. 1–30. doi: 10.1146/annurev-soc-071913-043123.

Penn, N., Oteng-Ntim, E., Oakley, L. L. and Doyle, P. (2014) 'Ethnic variation in stillbirth risk and the role of maternal obesity: analysis of routine data from a London maternity unit.', *BMC pregnancy and childbirth*, 14(404). doi: 10.1186/s12884-014-0404-0.

Pennebaker, J. W. (2013) ‘Writing about emotional experiences as a theraputic processes’, *Psychological Science*, 8(3), pp. 162–166.

Perinatal Institute for Maternal and Child Health (2011) *Intrauterine growth restriction, stillbirths and prevention. Prevalence of IUGR.* Available at: http://www.pi.nhs.uk/pnm/clinicaloutcomereviews/index.htm.

Petherick, E. S., Fairley, L., Parslow, R. C., McEachan, R., Tuffnell, D., Pickett, K. E., Leon, D., Lawlor, D. A. and Wright, J. (2016) ‘Ethnic differences in the clustering and outcomes of health behaviours during pregnancy: results from the Born in Bradford cohort’, *Journal of Public Health*, pp. 1–9. doi: 10.1093/pubmed/fdw098.

Phillimore, J. (2014) ‘Delivering maternity services in an era of superdiversity: the challenges of novelty and newness’, *Ethnic and Racial Studies*, (December 2014), pp. 1–15. doi: 10.1080/01419870.2015.980288.

Phillimore, J. (2015) ‘Ethnic and Racial Studies Delivering maternity services in an era of superdiversity : the challenges of novelty and newness’, (December 2014), pp. 37–41. doi: 10.1080/01419870.2015.980288.

Phillimore, J. (2016) ‘Migrant maternity in an era of superdiversity: New migrants’ access to, and experience of, antenatal care in the West Midlands, UK’, *Social Science and Medicine*. Elsevier Ltd, 148, pp. 152–159. doi: 10.1016/j.socscimed.2015.11.030.

Pintaudi, B., Lucisano, G., Pellegrini, F., D’Ettorre, A., Lepore, V., De Berardis, G., Scardapane, M., Di Vieste, G., Rossi, M. C., Sacco, M., Tognoni, G. and Nicolucci, A. (2015) ‘The long-term effects of stillbirth on women with and without gestational diabetes: a population-based cohort study.’, *Diabetologia*, 58(1), pp. 67–74. doi: 10.1007/s00125-014-3403-9.

Pittas, A. G., Lau, J., Hu, F. B. and Dawson-hughes, B. (2007) ‘The Role of Vitamin D and Calcium in Type 2 Diabetes . A Systematic Review and Meta-Analysis’, *The Journal of clinical endocrinology and metabolism*, 92(6), pp. 2017–2029. doi: 10.1210/jc.2007-0298.

Platt, M. J. (2014) ‘Outcomes in preterm infants.’, *Public health*. The Royal Society for Public Health, 128(5), pp. 399–403. doi: 10.1016/j.puhe.2014.03.010.

Platts, J., Mitchell, E. A., Stacey, T., Martin, B. L., Roberts, D., McCowan, L. and Heazell, A. E. P. (2014) ‘The Midland and North of England Stillbirth Study (MiNESS).’, *BMC pregnancy and childbirth*, 14, p. 171. doi: 10.1186/1471-2393-14-171.

Pociot, F. and Lernmark, Å. (2016) ‘Genetic risk factors for type 1 diabetes’, *The Lancet*. Elsevier Ltd, 387(10035), pp. 2331–2339. doi: 10.1016/S0140-6736(16)30582-7.

Price, S. (2007) ‘Domestic Abuse in pregnancy: A public health perspective.’, in Edwards, G. and Byrom, S. (eds) *Essentail Midwifery Practice, Public Health*. West Sussex: Blackwell Publishers, pp. 135–153.

Priebe, S., Sandhu, S., Dias, S., Gaddini, A., Greacen, T., Ioannidis, E., Kluge, U., Krasnik, A., Lamkaddem, M., Lorant, V., Riera, R. P., Sarvary, A., Soares, J. J. F., Stankunas, M., Strassmayr, C., Wahlbeck, K., Welbel, M. and Bogic, M. (2011) ‘Good practice in health care for migrants: views and experiences of care professionals in 16 European countries.’, *BMC public health*. BioMed Central Ltd, 11(1), p. 187. doi: 10.1186/1471-2458-11-187.

Psarros, A. (2014) *Women’s voices on health: addresing barriers to accessing primary care*. Womens Health and Equality Consortium & Maternity Action. Available at: http://www.maternityaction.org.uk/wp/wp-content/uploads/2014/05/Access-to-Primary-Care-report-FINAL.pdf.

Public Health England (2015a) *Luton Health Profile 2015*. Available at: http://www.apho.org.uk/resource/item.aspx?RID=171770.

Public Health England (2015b) *Reducing infant mortality in London: An evidence-based resource*. Available at: https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/431516/Reducing_infant_mortality_in_London_2015.pdf.

Public Health England (2016a) *Infant and Perinatal Mortality in the West Midlands*. Available at: https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/515800/InfantMortalityInTheWestMidlandsFinal.pdf.

Public Health England (2016b) *The National Congenital Anomaly and Rare Disease Registration Service (NCARDRS)*. Available at: https://www.gov.uk/guidance/the-national-congenital-anomaly-and-rare-disease-registration-service-ncardrs (Accessed: 19 March 2016).

Puthussery, S., Twamley, K., Macfarlane, A., Harding, S. and Baron, M. (2010) '"You need that loving tender care": maternity care experiences and expectations of ethnic minority women born in the United Kingdom.', *Journal of health services research & policy*, 15(3), pp. 156–62. doi: 10.1258/jhsrp.2009.009067.

Puthussery, S., Twamley, K., Mirsky, J., Macfarlane, A., Harding, S., Baron, M., Mirsky, J., Baron, M. and Macfarlane, A. (2008) '"They"re more like ordinary stroppy British women': attitudes and expectations of maternity care professionals to UK-born ethnic minority women.', *Journal of health services research & policy*. Radcliffe Publishing, 13(4), pp. 195–201. doi: 10.1258/jhsrp.2008.007153.

Quispel, C., Bangma, M., Kazemier, B. M., Steegers, E., Hoogendijk, W. J. G., Papatsonis, D. N. M., Paarlberg, K. M., Lambregtse-Van Den Berg, M. P. and Bonsel, G. J. (2014) 'The role of depressive symptoms in the pathway of demographic and psychosocial risks to preterm birth and small for gestational age.', *Midwifery*. Elsevier, 30(8), pp. 919–25. doi: 10.1016/j.midw.2014.03.008.

Raatikainen, K., Heiskanen, N. and Heinonen, S. (2007) 'Under-attending free antenatal care is associated with adverse pregnancy outcomes.', *BMC public health*, 7, p. 268. doi: 10.1186/1471-2458-7-268.

Rabe, M. (2003) 'Revisiting insiders and outsiders as social researchers', *African Sociological Review*, 7(2), pp. 149–161.

Raleigh, V. S., Hussey, D., Seccombe, I. and Hallt, K. (2010) 'Ethnic and social inequalities in women's experience of maternity care in England: results of a national survey.', *Journal of the Royal Society of Medicine*, 103(5), pp. 188–98. doi: 10.1258/jrsm.2010.090460.

Raman, S., Nicholls, R., Ritchie, J., Razee, H. and Shafiee, S. (2016) 'How natural is the supernatural? Synthesis of the qualitative literature from low and middle income countries on cultural practices and traditional beliefs influencing the perinatal period', *Midwifery*, 39, pp. 87–97. doi: 10.1016/j.midw.2016.05.005.

Rashid, S. F. (2007) 'Kal Dristi , Stolen Babies and "Blocked Uteruses": Poverty and Infertility Anxieties among Married Adolescent Women Living in a Slum in Dhaka, Bangladesh', *Anthropology & Medicine*. Routledge, 14(2), pp. 153–166. doi: 10.1080/13648470701381465.

Raskin, J. D. (2002) 'Constructivism in Psychology : Personal Construct Psychology , Radical Constructivism , and Social Constructionism', 5(3).

Ravelli, A. C. J., van der Meulen, J. H. P., Michels, R. P. J., Osmond, C., Barker, D. J. P., Hales, C.

N. and Bleker, O. P. (1998) ‘Glucose Tolerance in Adults after Prenatal Exposure to Famine.’, *The Lancet*, 351(9097), pp. 173–177. Available at: http://www.sciencedirect.com/science/article/pii/S0140673697072449.

Ravelli, A. C. J., Tromp, M., Eskes, M., Droog, J. C., van der Post, J. A. M., Jager, K. J., Mol, B. W. and Reitsma, J. B. (2011) ‘Ethnic differences in stillbirth and early neonatal mortality in The Netherlands.’, *Journal of epidemiology and community health*. BMJ Publishing Group Ltd, 65(8), pp. 696–701. doi: 10.1136/jech.2009.095406.

Ravitch, R. and Riggan, M. (2012) *Reason & Rigor: How conceptual frameworks guide research*. Thousand Oaks: Sage Publications.

Redshaw, M. and Heikkilä, K. (2011) ‘Ethnic differences in women’s worries about labour and birth.’, *Ethnicity & health*, 16(3), pp. 213–23. doi: 10.1080/13557858.2011.561302.

Redshaw, M. and Henderson, J. (2014) *Safely delivered: A national survey of womens experiences of maternity care 2014*. Available at: https://www.npeu.ox.ac.uk/downloads/files/reports/Safely delivered NMS 2014.pdf.

Redshaw, M., Rowe, R. and Henderson, J. (2014) *Listening to parents after stillbirth or the death of their baby after birth*. Oxford. Available at: https://www.npeu.ox.ac.uk/listeningtoparents.

Rees, G. A., Doyle, W., Srivastava, A., Brooke, Z. M., Crawford, M. A. and Costeloe, K. L. (2005) ‘The nutrient intakes of mothers of low birth weight babies - a comparison of ethnic groups in East London, UK.’, *Maternal & child nutrition*, 1(2), pp. 91–9. doi: 10.1111/j.1740-8709.2005.00012.x.

Regmi, K., Naidoo, J. and Pilkington, P. (2010) ‘Understanding the Processes of Translation and Transliteration in Qualitative Research’, *International Journal of Qualitative Methods*, 9(1), pp. 16–26.

Reid, C. and Herbert, C. (2014) ‘“Welfare moms and welfare bums”: Revisiting poverty as a social determinant of health’, *Health Sociology Review*. Routledge, 14(2), pp. 161–173. doi: 10.5172/hesr.14.2.161.

Reidpath, D. D. and Allotey, P. (2003) ‘Infant mortality rate as an indicator of population health’, *J Epidemiol Community Health*, 29(57), pp. 344–346. Available at: http://jech.bmj.com/content/57/5/344.full.pdf+html.

Reifsnider, E., Gallagher, M. and Forgione, B. (2005) ‘Using ecological models in research on health disparities’, *Journal of Professional Nursing*, 21(4), pp. 216–222. doi: 10.1016/j.profnurs.2005.05.006.

Reitmanova, S. and Gustafson, D. L. (2008) ‘“They can’t understand it”: Maternity health and care needs of immigrant Muslim women in St. John’s, Newfoundland’, *Maternal and Child Health Journal*, 12(1), pp. 101–111. doi: 10.1007/s10995-007-0213-4.

Research and Geospatial information (2015) *2015 Indices of multiple deprivation: Luton*. Available at: https://www.luton.gov.uk/Environment/Lists/LutonDocuments/PDF/Planning/Observatory/2015 Indices of deprivation in Luton.pdf.

Rezende, C. B. (2011) ‘The experience of pregnancy: subjectivity and social relations’, *Vibrant: Virtual Brazilian Anthropology*, 8, pp. 529–549. doi: 10.1590/S1809-43412011000200026.

Richard, L., Gauvin, L. and Raine, K. (2011) ‘Ecological models revisited: their uses and evolution in health promotion over two decades.’, *Annual review of public health*, 32, pp. 307–326. doi: 10.1146/annurev-publhealth-031210-101141.

Richardson, R. and Wood, A. (2009) ‘Pakistani identities and communities in Britain’, in *The* *achievment of British Pakistani learners*. Staffordshire: Trentham Books, pp. 1–9.

Richie, J. and Spencer, L. (1995) ‘Qualitative data analysis for applied policy research’, in Bryman, A. and Burgess, R. (eds) *Analyzing Qualitaive Data*. London: Routledge, pp. 173–195.

Richies, G. and Dawson, P. (1996) ‘Making Stories and taking stories: Methodological reflections on researching grief and marital tension following the death of a child.’, *British Journal of Guidance Counselling*, 24(3), pp. 1–6. Available at: http://0-search.ebscohost.com.brum.beds.ac.uk/login.aspx?direct=true&db=afh&AN=9612122155&site=eds-live&scope=site.

Rimer, B. and Glanz, K. (2005) *Theory at a glance. A guide for health promotion practice*. 2nd edn. U.S. National Cancer Institute.

Rindskopf, D. (2004) ‘Trends in catgorical data analysis: new, semi new and recycled ideas.’, in Kaplan, D. (ed.) *The SAGE Handbook of Quantitative Methodology for the Social Sciences*. California: Sage Publications Inc., pp. 137–151.

Robertson, S. S. and Dierker, L. J. (2003) ‘Fetal cyclic motor activity in diabetic pregnancies: Sensitivity to maternal blood glucose’, *Developmental Psychobiology*, 42(1), pp. 9–16. doi: 10.1002/dev.10045.

Robinson, S., Nelson-Piercy, C., MA, H., Selby, P. and Warner, J. (2014) ‘Vitamin D in pregnancy’, *Royal College os Obstetricians & Gynaecologists*, Scientific(43), p. 11. doi: 10.1097/GCO.0b013e3283505ab3.

Roe, K. M., Minkler, M. and Barnwell, R.-S. (1994) ‘The Assumption of Caregiving: Grandmothers Raising the Children of the Crack Cocaine Epidemic’, *Qualitative Health Research*, 4(3), pp. 281–303. doi: 10.1177/104973239400400303.

Rose, D. and Pevalin, D. J. (2005) *The National Statistics Socio-economic Classification: Origins, Development and Use*. Essex: Palgrave Macmillan.

Roseboom, T. J., van der Meulen, J. H. P., Ravelli, A. C. J., Osmond, C., Barker, D. J. P. and Bleker, O. P. (2001) ‘Effects of prenatal exposure to the Dutch famine on adult disease in later life: an overview’, *Molecular and Cellular Endocrinology*, 185(1–2), pp. 93–98. doi: 10.1016/S0303-7207(01)00721-3.

Ross, M. G. and Beall, M. H. (2009) ‘Adult Sequalae of Interuterine Growth Restriction’, *Seminars in Perinatology*, 32(3), pp. 213–218. doi: 10.1053/j.semperi.2007.11.005.Adult.

Rowe, R. E. and Garcia, J. (2003) ‘Social class, ethnicity and attendance for antenatal care in the United Kingdom: a systematic review’, *Journal of Public Health*, 25(2), pp. 113–119. doi: 10.1093/pubmed/fdg025.

Rowe, R. E., Garcia, J. and Davidson, L. L. (2004) ‘Social and ethnic inequalities in the offer and uptake of prenatal screening and diagnosis in the UK: A systematic review’, *Public Health*, 118(3), pp. 177–189. doi: 10.1016/j.puhe.2003.08.004.

Rowe, R. E., Garcia, J., Macfarlane, A. J. and Davidson, L. L. (2001) ‘Does poor communication contribute to stillbirths and infant deaths? A review.’, *Journal of public health medicine*, 23(1), pp. 23–34. Available at: http://www.ncbi.nlm.nih.gov/pubmed/11315689.

Rowe, R. and Garcia, J. (2005) ‘Ethnic minorities access to antenatal screening’, *British Journal of Midwifery*, 1(2), pp. 101–105.

Rowe, R., Magee, H., Quigley, M., Heron, P., Askham, J. and Brocklehurst, P. (2008) ‘Social and ethnic differences in attendance for antenatal care in England.’, *Public health*. Elsevier Ltd, 122(12), pp. 1363–72. doi: 10.1016/j.puhe.2008.05.011.

Rowe, R., Puddicombe, D., Hockley, C. and Redshaw, M. (2008) ‘Offer and uptake of prenatal screening for Down syndrome in women from different social and ethnic backgrounds’, *Prenatal Diagnosis*, 28(November), pp. 1245–1250. doi: 10.1002/pd.

Roy, L. C., Torrez, D. and Dale, J. C. (2004) ‘Ethnicity, traditional health beliefs, and health-seeking behavior: Guardians’ attitudes regarding their children’s medical treatment’, *Journal of Pediatric Health Care*, 18(1), pp. 22–29. doi: 10.1016/S0891-5245(03)00112-3.

Royal College of Nursing (2009) *Research ethics*. London. Available at: http://www.rcn.org.uk/__data/assets/pdf_file/0007/388591/003138.pdf.

Royal College of Obstetricians and Gynaecologists. (2015) *Alcohol and pregnancy About*. Available at: https://www.rcog.org.uk/globalassets/documents/patients/patient-information-leaflets/pregnancy/pi-alcohol-and-pregnancy.pdf.

Royal College of Obstetricians and Gynaecologists (2003) *Periconceptional Folic Acid and Food Fortification in the Prevention*. Available at: https://www.rcog.org.uk/globalassets/documents/guidelines/scientific-impact-papers/sip_4.pdf.

Royal College of Obstetrics and Gynaecologist (2008) *Standards of maternity care : report of a working party*, *Kätilölehti*. Available at: http://www.ncbi.nlm.nih.gov/pubmed/21555084.

Rubinelli, S., Kreps, G. L. and Amann, J. (2014) ‘Revisiting the concept of health literacy . The patient as information seeker and provider’, *The European Health Psychologist*, 17(6), pp. 286–290.

Sachdev, H. P. S. (2001) ‘Low birth weight in South Asia’, *International Journal of Diabetes in Developing Countries*, 21(1), pp. 13–31.

Saffron, K. and Nazroo, J. Y. (2002) ‘Agency and structure : the impact of ethnic identity and racism on the health of ethnic minority people’, 24(1), pp. 1–20.

Saigal, S., Stoskopf, B., Streiner, D., Paneth, N., Pinelli, J. and Boyle, M. (2006) ‘Growth trajectories of extremely low birth weight infants from birth to young adulthood: A longitudinal, population-based study’, *Pediatric Research*, 60(6), pp. 751–758. doi: 10.1203/01.pdr.0000246201.93662.8e.

Sajid, A. (2003) *Death and Bereavement in Islam*. Brighton.

Sallis, J., Owen, N. and Fisher, E. (2010) ‘Ecological models of health behaviour’, in Glanz, K., Rimer, B., and Viswanath, K. (eds) *Health behaviour and health education, theory research and practice.* 4th Edn. San Francisco: Jossey Bass Ltd, pp. 465–484.

Salway, S. Ali, P. Ratcliffe, G. and Bibi, S. (2012) Understandings related to consanguineous marriage and genetic risk: Findings from a community level consultation exercise in Sheffield and Rotherham. Available at: https://www.researchgate.net/publication/299507582_Understandings_related_to_consanguineous_marriage_and_genetic_risk_Findings_from_a_community_level_consultation_exercise_in_Sheffield_and_Rotherham

Salway, S., Allmark, P., Barley, R., Higginbottom, G., Gerrish, K. and Ellison, G. (2009) Update Researching ethnic inequalities. Available at: http://sru.soc.surrey.ac.uk.

Salway, S., Mir, G., Turner, D., Ellison, G. T. H., Carter, L. and Gerrish, K. (2016) ‘Social Science & Medicine Obstacles to “ race equality ” in the English National Health Service : Insights from the healthcare commissioning arena’, *Social Science & Medicine*. Elsevier Ltd, 152, pp. 102–110. doi:

10.1016/j.socscimed.2016.01.031.

Salway, S., Nazroo, J., Mir, G., Craig, G., Johnson, M., Gerrish, K., Sarah, S., James, N., Mir, G., Gary, C., Johnson, M. and Gerrish, K. (2010) ‘Fair Society, Healthy Lives: A missed opportunity to address ethnic inequalities in health. Rapid response, 12 April 2010.’, *British Medical Journal*, 340(APRIL). Available at: http://www.bmj.com/rapid-response/2011/11/02/fair-society-healthy-lives-missed-opportunity-address-ethnic-inequalities-.

Sanchalika, A. and Teresa, J. (2015) ‘Risk of Gestational Diabetes Among South Asian Immigrants Living in New Jersey-a Retrospective Data Review.’, *Journal of racial and ethnic health disparities*, 2(4), pp. 510–6. doi: 10.1007/s40615-015-0099-6.

Sanchez, N. A. (2001) ‘Mothers perceptions of benefits of perinatal loss support offered at a major university hospital’, *Journal of Perinatal Education*, 10(2), pp. 23–30. Available at: http://www.ncbi.nlm.nih.gov/pmc/articles/PMC1595068/.

Sarensen, H. T., Sabroe, S. and Olsen, J. (1996) ‘A Framework for Evaluation of Secondary Data Sources for Epidemiological Research’, *International Journal of Epidemiology O International Epidemiological Association International Journal of Epidemiology*, 25(25), pp. 435–442. doi: 10.1093/ije/25.2.435.

Sayakhot, P. and Carolan-Olah, M. (2016) ‘Internet use by pregnant women seeking pregnancy-related information: a systematic review’, *BMC Pregnancy and Childbirth*. BMC Pregnancy and Childbirth, 16(1), p. 65. doi: 10.1186/s12884-016-0856-5.

Schaaf, J. M., Mol, B.-W. J., Abu-Hanna, A. and Ravelli, A. C. J. (2012) ‘Ethnic disparities in the risk of adverse neonatal outcome after spontaneous preterm birth.’, *Acta obstetricia et gynecologica Scandinavica*, 91(12), pp. 1402–8. doi: 10.1111/aogs.12013.

Schachter, A., Kimbro, R. T. and Gorman, B. K. (2012) ‘Language Proficiency and Health Status: Are Bilingual Immigrants Healthier?’, *Journal of Health and Social Behavior*, 53, pp. 124–145. doi: 10.1177/0022146511420570.

Schafer, J. L. and Graham, J. W. (2002) ‘Missing data: Our view of the state of the art.’, *Psychological Methods*, 7(2), pp. 147–177. doi: 10.1037/1082-989X.7.2.147.

Scheppers, E., van Dongen, E., Dekker, J., Geertzen, J. and Dekker, J. (2006) ‘Potential barriers to the use of health services among ethnic minorities: a review.’, *Family practice*, 23(February), pp. 325–348. doi: 10.1093/fampra/cmi113.

Schwant, T. (2000) ‘Three Epistemological Stances for Qualitative Inquiry. Interpretivism, Hermeneutics, Constructionism.’, in Denzin, N. and Lincoln, Y. (eds) *Handbook of Qualitatitive Research*. 2nd edn. London: Sage Publishers, pp. 189–913.

Sebire, N., Jolly, M., Harris, J., Wadsworth, J., Joffe, M., Beard, R., Regan, L. and Robinson, S. (2001) ‘Maternal Obesity and Pregnancy Outcome: A study of 287,213 pregnancies in London’, *International Journal of Obesity*, 25, pp. 1175–1182. doi: 10.1038/sj.ijo.0801670.

Senior, P. A. and Bhopal, R. (1994) ‘Ethnicity as a variable in epidemiological research.’, *BMJ (Clinical research ed.)*, 309(6950), pp. 327–330. doi: 10.1136/bmj.309.6950.327.

Seri, I. and Evans, J. (2008) ‘Limits of viability: definition of the gray zone.’, *Journal of Perinatology : Official Journal of the California Perinatal Association*, 28 Suppl 1, pp. S4-8. doi: 10.1038/jp.2008.42.

Sewell, W. H. (2005) ‘The concept(s) of Culture’, in Spiegel, G. M. (ed.) *Practicing history: New directions in historical writing after the linguistic turn*. New York: Routledge, pp. 35–71.

Shah, P. S. (2010) ‘Parity and low birth weight and preterm birth: a systematic review and meta-analyses.’, *Acta obstetricia et gynecologica Scandinavica*, 89(7), pp. 862–75. doi: 10.3109/00016349.2010.486827.

Shai, I., Jiang, R., Manson, J. E., Stampfer, M. J., Willett, W. C., Colditz, G. A. and Hu, F. B. (2006) ‘Ethnicity, Obesity, and Risk of Type 2 Diabetes in Women: A 20-year follow-up study’, *Diabetes Care*, 29(7), pp. 1585–1590. doi: 10.2337/dc06-0057.

Sharifian, F. (2017) ‘Cultural Linguistics and linguistic relativity’, *Language Sciences*, 59(2017), pp. 83–92. doi: 10.1016/j.langsci.2016.06.002.

Sharp, K. (2010) ‘Nursing and the sociology of healthcare’, in Denny, E. and Earle, S. (eds) *Sociology for nurses*. 2nd Edn. Cambridge: Policy Press, pp. 7–28.

Shaw, A. (2000) ‘Biradari Solidarity and Cousin Marriage’, in *Kinship and Continuity*. Australia: Harwood Academic Publishers, pp. 137–161.

Shaw, A. (2011) ‘Risk and reproductive decisions: British Pakistani couples’ responses to genetic counselling.’, *Social science & medicine (1982)*. Elsevier Ltd, 73(1), pp. 111–20. doi: 10.1016/j.socscimed.2011.04.011.

Shaw, A. (2012) ‘“They say Islam has a solution for everything, so why are there no guidelines for this?” Ethical dilemmas associated with the births and deaths of infants with fatal abnormalities from a small sample of Pakistani Muslim couples in Britain.’, *Bioethics*, 26(9), pp. 485–92. doi: 10.1111/j.1467-8519.2011.01883.x.

Shaw, A. (2014) ‘Rituals of infant death: Defining life and islamic personhood’, *Bioethics*, 28(2), pp. 84–95. doi: 10.1111/bioe.12047.

Shaw, A. and Ahmed, M. (2004) ‘Translating Genetics Leaflets into Languages Other Than English: Lessons from an Assessment of Urdu Materials’, *Journal of Genetic Counseling*, 13(4), pp. 321–342. doi: 10.1023/B:JOGC.0000035525.68249.52.

Shaw, M., Dorling, D. and Smith, G. (2006) ‘Poverty, social exclusion, and minorities.’, in Marmot, M. and Wilkinson, R. (eds) *Social Determinants of Health*. 2nd edn. Oxford: Oxford University Press, pp. 196–224.

Shenton, A. K. (2004) ‘Strategies for ensuring trustworthiness in qualitative research projects’, *Education for Information*, 22, pp. 63–75.

Sheridan, E., Wright, J., Small, N., Corry, P. C., Oddie, S., Whibley, C., Petherick, E. S., Malik, T., Pawson, N., McKinney, P. A. and Parslow, R. C. (2013) ‘Risk factors for congenital anomaly in a multiethnic birth cohort: an analysis of the Born in Bradford study’, *The Lancet*. Elsevier Ltd, 382(9901), pp. 1350–1359. doi: 10.1016/S0140-6736(13)61132-0.

Shevell, T., Malone, F. D., Vidaver, J., Porter, T. F., Luthy, D., Comstock, C. H., Hankins, G. D., Eddleman, K., Dolan, S., Dugoff, L., Craigo, S., Timor, I. E., Carr, S. R., Wolfe, H. M., Bianchi, D. W. and D’Alton, M. E. (2005) ‘Assisted reproductive technology and pregnancy outcome.’, *Obstetrics and gynecology*, 106(5 Pt 1), pp. 1039–45. doi: 10.1097/01.AOG.0000183593.24583.7c.

Sibai, B., Dekker, G. and Kupferminc, M. (2005) ‘Pre-eclampsia’, *Lancet*, 365(9461), pp. 785–799. doi: 10.1016/s0140-6736(05)17987-2.

Silverwood, R. J., Pierce, M., Hardy, R., Sattar, N., Whincup, P., Ferro, C., Savage, C., Kuh, D. and Nitsch, D. (2013) ‘Low birth weight, later renal function, and the roles of adulthood blood pressure, diabetes, and obesity in a British birth cohort.’, *Kidney international*, 84(6), pp. 1262–70. doi: 10.1038/ki.2013.223.

Singh-Bhopal, R. (1986) ‘The inter-relationship of Folk, Traditional and Western Medicine within an Asian Community in Britain.’, *Social Science and Medicine*, pp. 99–105.

Small, N. (2012) ‘Infant Mortality and Migrant Health in Babies of Pakistani Origin Born in Bradford, UK’, *Journal of Intercultural Studies*. Routledge, 33(5), pp. 549–564. doi: 10.1080/07256868.2012.701610.

Small, R., Roth, C., Raval, M., Shafiei, T., Korfker, D., Heaman, M., McCourt, C. and Gagnon, A. (2014) ‘Immigrant and non-immigrant women’s experiences of maternity care: a systematic and comparative review of studies in five countries.’, *BMC pregnancy and childbirth*, 14(1), p. 152. doi: 10.1186/1471-2393-14-152.

Small, R, *et al.* (2014) ‘Immigrant and non-immigrant women’s experiences of maternity care: a systematic and comparative review of studies in five countries’, *BMC Pregnancy and Childbirth*, 14(1), p. 152. doi: 10.1186/1471-2393-14-152.

Søgaard, M. and Vedsted-Jakobsen, A. (2003) ‘Consanguinity and congenital abnormalities.’, *Ugeskrift for laeger*, 165(18), pp. 1851–5. Available at: http://www.ncbi.nlm.nih.gov/pubmed/12772391 (Accessed: 26 October 2015).

Spector, R. (2004a) *Cultural Diversity in Health and Illness*. New Jersey: Pearson Education.

Spector, R. (2004b) ‘Healing Traditions’, in *Cultural Diversity in Health and Illness*. New Jersey: Pearson Education, pp. 101–118.

Spector, R. (2004c) ‘Health and Illness in the Asian Population’, in *Cultural Diversity in Health and Illness*. New Jersey: Pearson Education, pp. 209–223.

Spelman, E. V. (1990) *Inessential woman problems of exclusion in feminist thought*. London: The Womens Press Ltd.

Spencer, L., Richie, J. and O’Conner, W. (2003) ‘Analysis: Practices, prinicipals and process’, in Richie, J. and Lewis, J. (eds) *Qualitative Research Practice: A Guide for Social Science Students and Researchers*. London: Sage Publications, pp. 199–218.

Spicer, J. (2005) *Making sense of Multivariate Data Analysis*. California: Sage Publications Ltd.

Spong, C. Y., Reddy, U. M. and Willinger, M. (2011) ‘Addressing the complexity of disparities in stillbirths’, *The Lancet*. Elsevier Ltd, 377(9778), pp. 1635–1636. doi: 10.1016/S0140-6736(11)60025-1.

Sque, M., Walker, W. and Long-Sutehall, T. (2014) ‘Research with bereaved families : A framework for ethical decision-making’, *Nursing Ethics*, 21(8), pp. 946–955. Available at: http://0-eds.a.ebscohost.com.brum.beds.ac.uk/eds/pdfviewer/pdfviewer?vid=12&sid=56faca6a-d6a3-4cfd-b520-10522468f762@sessionmgr4003&hid=4113.

Srivastava, A. and Thompson, S. B. (2009) ‘Framework Analysis: A Qualitative Methodology for Applied Policy Research’, *JOAAG*, 4(2), pp. 72–79. Available at: http://www.joaag.com/.

Srivastava, U. R., Singh, M. and Jain, M. (2007) ‘Role of Psycho-Social Factors in Preterm Delivery and Low Birth Weight: A critical review’, *JiHP*, 2(1).

Stainton-Rogers, W. (2006) ‘Logics of Enquiry’, in Potter, S. (ed.) *Doing Post Graduate Research*. Second. Milton Keynes: Open University Press, pp. 73–92.

Stanfield, K. M., Wells, J. C., Fewtrell, M. S., Frost, C. and Leon, D. A. (2012) ‘Differences in body composition between infants of South Asian and European ancestry: the London Mother and Baby Study.’, *International journal of epidemiology*. Oxford University Press, 41(5), pp. 1409–18. doi:

10.1093/ije/dys139.

Stanley, L. and Wise, S. (2002) *Breaking out again; feminist onotology and epistomology*. 2nd edn. London: Routledge.

Stansfield, S. (2006) ‘Social support and social cohesion’, in Marmot, M. and Wilkinson, R. (eds) *Determinants of health*. 2nd edn. Oxford: Oxford University Press, pp. 148–172.

Statham, H., Solomou, W. and Green, J. (2001) *When a baby has an abnormality: a study of parents experiences*. University of Cambridge.

Steckler, A., McLeroy, K., Goodman, R., Bird, S. and McCormick, L. (1992) ‘Toward Integrating Qualitative and Quantitaive Methods: An Introduction.’, *Health Education Quarterly*, 19(1), pp. 1–8.

Steer, P. (2005) ‘The epidemiology of preterm labour’, *BJOG : an International Journal of Obstetrics and Gynaecology*, 112(March), pp. 1–3.

Still-Birth Act (1992) *Still-Birth (definition) Act 1992 : Elizabeth II*. London, England: The Stationary Office. Available at: http://www.legislation.gov.uk/ukpga/1992/29/pdfs/ukpga_19920029_en.pdf.

Stothard, K. J., Tennant, P. W. G. and Bell, R. (2009) ‘Maternal Overweight and Obesity and the Risk of Congenital Anomalies’, 301(6).

Stow, C. (2004) ‘Carol Stow Specialist Speech and Language Therapist (Bilingualism) Rochdale PCT September 2004 Identifying speech disorders in Pakistani heritage children The Pakistani heritage community in the UK The Pakistani heritage community in RCSLT SIG Bilingual’, (September).

Strauss, A. and Corbin, J. (1994) ‘Grounded theory methodology, an overview.’, in Denzin, N. and Lincoln, Y. (eds) *Handbook of Qualitative Research*. London: Sage Publications, pp. 273–285.

Stroebe, M., Stroebe, W. and Schut, H. (2003) ‘Bereavement research: methodological issues and ethical concerns.’, *Palliative medicine*, 17, pp. 235–240. doi: 10.1191/0269216303pm768rr.

Surkan, P. J., Rådestad, I., Cnattingius, S., Steineck, G. and Dickman, P. W. (1999) ‘Social support after stillbirth for prevention of maternal depression’, *Acta Obstetricia et Gynecologica Scandinavica*, 88(12), pp. 1358–1364. doi: 10.3109/00016340903317974.

Sutan, R. and Miskam, H. M. (2012) ‘Psychosocial impact of perinatal loss among Muslim women.’, *BMC women’s health*, 12, p. 15. doi: 10.1186/1472-6874-12-15.

Sutton, S. (2004) ‘Determinants of health-related behaviours: Theoretical and methodological issues’, *The Sage handbook of health psychology*, pp. 94–126. doi: 10.4135/9781848608153.n4.

Swamy, G. K., Ostbye, T. and Skjaerven, R. (2008) ‘Association of Preterm Birth with Long-Term Survival, Reproduction and Next-Generation Preterm Birth.’, *JAMA : the journal of the American Medical Association*, 299(12), pp. 1429–1436. Available at: http://www.mednet.co.il/upload/infocenter/info_images/JAMA - March 2008 - long-term survival and reproduction.pdf.

Swanson, V. and Power, K. (2000) ‘A theoretically based, cross-cultural study of infant feeding in new mothers and their partners’, in Watson, J. and Platt, S. (eds) *Researching Health Promotion*. London: Routledge, pp. 183–206.

Swanson, V. and Power, K. G. (2005) ‘Initiation and continuation of breastfeeding: Theory of planned behaviour’, *Journal of Advanced Nursing*, 50(3), pp. 272–282. doi: 10.1111/j.1365-2648.2005.03390.x.

Szczepura, A. (2005) ‘Access to health care for ethnic minority populations.’, *Postgraduate Medical Journal*, 81(953), pp. 141–7. doi: 10.1136/pgmj.2004.026237.

Tabachnick, B. and Fidell, L. (2014) ‘Multiway frequency analysis’, in *Using multivariate statistics*. Internatio. Harlow: Pearson Education Limited., pp. 915–971.

Tahrani, A. A., Ball, A, Shepherd, L., Rahim, A, Jones, A. F. and Bates, A (2010) ‘The prevalence of vitamin D abnormalities in South Asians with type 2 diabetes mellitus in the UK’, *International Journal of Clinical Practice*, 64(3), pp. 351–355. doi: 10.1111/j.1742-1241.2009.02221.x.

Tarafder, T., Sultan, P. and Rashid, T. (2013a) ‘Reproductive health beliefs and perceptions among slum women in Bangladesh’, in Dalziel, P. (ed.) *37th Annual Conference of the Austrailian and New Zealand regional science assosciation international*. Queensland: Lincoln University, New Zealand., pp. 124–136.

Taylor, D., Bury, M., Campling, N., Carter, S., Grenfied, S., Newbold, J., Rennie, T., Garfied, S. and Newbould, J. (2006) *A Review of the use of the Health Belief Model (HBM), the Theory of Reasoned Action (TRA), the Theory of Planned Behaviour (TPB) and the Trans-Theoretical Model (TTM) to study and predict health related behaviour change*, *National Instsitute of Clinical Excellence*. London. Available at: http://publications.nice.org.uk/behaviour-change-the-principles-for-effective-interventions-ph6.

Taylor, L., Whittaker, L. and Castle, D. (2016) *Inquiry Report into NHS England’s Five Year Forward View: Behaviour Change, Information and Signposting*.

Teddlie, C. and Tashakkori, A. (2011) ‘Mixed method Research: Contempory issues in an emerging field.’, in Denzin, N. and Lincoln, Y. (eds) *The SAGE handbook of Qualitative Research*. 4th edn. London: Sage Publications, pp. 269–285.

Teddlie, C. and Yu, F. (2007) ‘Mixed Methods Sampling: A Typology With Examples’, *Journal of Mixed Methods Research*, 1(1), pp. 77–100. doi: 10.1177/2345678906292430.

Temple, B. and Edwards, R. (2002) ‘Interpreters / Translators and Cross-Language Research : Reflexivity and Border Crossings’, *International Journal of Qualitative methods*, 1(2), pp. 1–12.

Temple, B. and Young, A. (2004) ‘Qualitative Research and Translation Dilemmas’, *Qualitative Research*, 4(2), pp. 161–178. doi: 10.1177/1468794104044430.

The National Institute for Health and Care Excellence (2008) *Antenatal care CG62*. Available at: http://guidance.nice.org.uk/CG62.

The National Institute for Health and Care Excellence (2010a) *Antenatal Care*. Available at: http://www.nice.org.uk/guidance/cg62/chapter/guidance.

The National Institute for Health and Care Excellence (2010b) *Maternal and Child Nutrition*, *NICE Public Health Guidance 11*. Available at: http://www.nice.org.uk/guidance/ph11/resources/guidance-maternal-and-child-nutrition-pdf.

The National Institute for Health and Care Excellence (2010c) *Pregnancy and complex social factors CG110*. Manchester. Available at: http://guidance.nice.org.uk/CG110.

The National Institute for Health and Care Excellence (2012) *Smokeless tobacco: South Asian communities. PH39*. Available at: https://www.nice.org.uk/guidance/ph39/resources/smokeless-tobacco-south-asian-communities-1996305871813.

The National Institute for Health and Care Excellence (2013) *BMI : preventing ill health and premature death in black , Asian and other minority ethnic groups in the UK (PH46)*. Available at: www.nice.org.uk/guidance/ph46.

The National Institute for Health and Care Excellence (2016) *Diabetes in pregnancy. management of diabetes and it's complications from preconception to th epostnatal period*, *National Institute for Health and Care Excellence*. Available at: https://www.nice.org.uk/guidance/ng3/evidence/full-guideline-3784285.

Thorpe, L. E., Berger, D., Ellis, J. A., Bettegowda, V. R., Brown, G., Matte, T., Bassett, M. and Frieden, T. R. (2005) 'Trends and racial/ethnic disparities in gestational diabetes among pregnant women in New York City, 1990-2001', *Am J Public Health*, 95(9), pp. 1536–1539. doi: AJPH.2005.066100 [pii]\r10.2105/AJPH.2005.066100.

Tinson, B. A., Ayrton, C., Barker, K., Born, T. B., Aldridge, H. and Kenway, P. (2016) Monitoring poverty and social exclusion 2016. Joseph Rowntree Foundation.

Toher, C., Lindsay, K., Mckenna, M., Kilbane, M., Curran, S., Harrington, L., Uduma, O. and Mcauliffe, F. M. (2014) 'Relationship between vitamin D knowledge and 25-hydroxyvitamin D levels amongst pregnant women', *Journal of Human Nutrition and Dietetics*, 27(3), pp. 261–269. doi: 10.1111/jhn.12150.

Tonks, A., Fowler, T. and Williams, D. (2014) 'Stillbirth and infant mortality from congenital anomalies and autosomal recessive (AR) conditions in Birmingham ethnic groups', *Arch Dis Child Fetal Neonatal Ed*, 99(153–154). Available at: http://fn.bmj.com/content/99/Suppl_1/A153.4.

Tort, J., Lelong, N., Prunet, C., Khoshnood, B. and Blondel, B. (2013) 'Maternal and health care determinants of preconceptional use of folic acid supplementation in France: Results from the 2010 National Perinatal Survey', *BJOG: An International Journal of Obstetrics and Gynaecology*, 120(13), pp. 1661–1667. doi: 10.1111/1471-0528.12414.

Tov, W. and Diener, E. (2010) 'Culture and subjective wellbeing', in Kitayama, S. and Cohen, D. (eds) *Handbook of Cultural Psychology*. New York: The Guildford Press, pp. 691–714.

Townsend, P. (1979) *Poverty in the United Kingdom: A Survey of household resources and standards of living*. California: University of California Press. Available at: http://www.jrf.org.uk/sites/files/jrf/uk_without_poverty_summary.pdf.

Traviss, G. D., Meer, S., West, R. M. and House, A. O. (2013) 'Life events and difficulties and their association with antenatal distress in White and South Asian women in the UK', *Social Psychiatry and Psychiatric Epidemiology*, 48(5), pp. 725–734. doi: 10.1007/s00127-012-0584-8.

Traviss, G., West, R. and House, A. (2012) 'Maternal mental health and its association with infant growth at 6 months in ethnic groups: results from the Born-in-Bradford birth cohort study.', *PloS one*. Edited by L. Myer. Public Library of Science, 7(2), p. e30707. doi: 10.1371/journal.pone.0030707.

Triandis, H. C. (1989) 'The self and social behavior in differing cultural contexts.', *Psychological Review*, 96(3), pp. 506–520. doi: 10.1037/0033-295X.96.3.506.

Triandis, H. C. (2010) 'Culture and psychology: A history of the study of their relationship', in Kitayama, S. and Cohen, J. (eds) *Handbook of Cultural Psychology*. New York: The Guildford Press, pp. 59–77.

Tucker, A., Ogutu, D., Yoong, W., Nauta, M. and Fakokunde, A. (2010) 'The unbooked mother: A cohort study of maternal and foetal outcomes in a North London hospital', *Archives of Gynecology and Obstetrics*, 281(4), pp. 613–616. doi: 10.1007/s00404-009-1152-7.

Turner, J. A., Lowe, S. A., Brown, M. A., Dekker, G. A., Gatt, S., McLintock, C. K., McMahon, L. P., Mangos, G., Moore, M. P., Muller, P., Paech, M., Walters, B., Lindheimer, M. D., de Swiet, M., Van Assche, A. and Moutquin, J. M. (2010) *Hypertension in pregnancy: diagnosis and management*.

doi: 10.1111/j.1479-828X.2009.01003.x.

Twamley, K., Puthussery, S., Harding, S., Baron, M. and Macfarlane, A. (2011) ‘UK-born ethnic minority women and their experiences of feeding their newborn infant.’, *Midwifery*. Elsevier, 27(5), pp. 595–602. doi: 10.1016/j.midw.2010.06.016.

Twamley, K., Puthussery, S., Macfarlane, A. and Harding, S. (2009) ‘Recruiting UK-born ethnic minority women for qualitative health research – lessons learned from a study of maternity care’, 27(1), pp. 25–38.

UCL Institute of Health Equity (2013) *Review of social determinants and the health divide in the WHO European Region: executive summary*.

UNICEF (2015) *Statistics Pakistan*. Available at: http://www.unicef.org/infobycountry/pakistan_pakistan_statistics.html (Accessed: 16 May 2015).

Universities UK & Higher Education Statistics Agency (2014) *Patterns and trends in UK higher education 2014*. Available at: http://www.universitiesuk.ac.uk/highereducation/Documents/2014/PatternsAndTrendsInUKHigherEducation2014.pdf.

Unterscheider, J., Horgan, R., O’Donoghue, K. and Greene, R. (2009) ‘Reduced fetal movements’, *The Obstetrician & Gynaecologist*, 11(4), pp. 245–251. doi: 10.1576/toag.11.4.245.27527.

Unwin, J. (2014) *A UK without poverty*. Available at: http://www.jrf.org.uk/sites/files/jrf/uk_without_poverty_summary.pdf.

Van Herk, K. a., Smith, D. and Andrew, C. (2011) ‘Examining our privileges and oppressions: Incorporating an intersectionality paradigm into nursing’, *Nursing Inquiry*, 18(1), pp. 29–39. doi: 10.1111/j.1440-1800.2011.00539.x.

Vaughn, L., Jacquez, F. and Baker, R. (2009) ‘Cultural health attributions, beliefs, and practices: Effects on healthcare and medical education’, *Open Medical Education journal*, 2, pp. 64–74. Available at: http://www.benthamsciencepublisher.com/open/tomededuj/articles/V002/SI0016TOMEDEDUJ/64TOMEDEDUJ.pdf.

Vrijheid, M., Dolk, H., Stone, D., Abramsky, L., Alberman, E. and Scott, J. E. S. (2000) ‘Socioeconomic inequalities in risk of congenital anomaly’, *Arch Dis Child*, 82, pp. 349–352. Available at: http://adc.bmj.com/content/82/5/349.full.pdf+html.

Wadhwa, P. D., Culhane, J. F., Rauh, V. and Barve, S. S. (2001) ‘Stress and preterm birth: neuroendocrine, immune/inflammatory, and vascular mechanisms.’, *Maternal and child health journal*, 5(2), pp. 119–125. doi: 10.1023/A:1011353216619.

Wadsworth, M. E. and Kuh, D. J. (1997) ‘Childhood influences on adult health: a review of recent work from the British 1946 national birth cohort study, the MRC National Survey of Health and Development.’, *Paediatric and perinatal epidemiology*, 11(1), pp. 2–20. doi: 10.1046/j.1365-3016.1997.d01-7.x.

von Wagner, C., Steptoe, A., Wolf, M. S. and Wardle, J. (2009) ‘Health literacy and health actions: a review and a framework from health psychology.’, *Health education & behavior : the official publication of the Society for Public Health Education*, 36(5), pp. 860–77. doi: 10.1177/1090198108322819.

Walker, K. F., Bradshaw, L., Bugg, G. J. and Thornton, J. G. (2016) ‘Causes of antepartum stillbirth in women of advanced maternal age’, *European Journal of Obstetrics & Gynecology and Reproductive Biology*. Elsevier Ireland Ltd, 197, pp. 86–90. doi: 10.1016/j.ejogrb.2015.11.032.

Walsh, D. and Evans, K. (2014) ‘Critical realism: an important theoretical perspective for midwifery research.’, *Midwifery*. Elsevier, 30(1), pp. e1-6. doi: 10.1016/j.midw.2013.09.002.

Ware, J. H., Harrington, D., Hunter, D. J. and D’Agostino, R. B. (2012) ‘Missing Data’, *New England Journal of Medicine*, 367(14), pp. 1353–1354. doi: 10.1056/NEJMsm1210043.

Warland, J., O’Brien, L. M., Heazell, A. E. P. and Mitchell, E. a. (2015) ‘An international internet survey of the experiences of 1,714 mothers with a late stillbirth: the STARS cohort study’, *BMC Pregnancy & Childbirth*. BMC Pregnancy & Childbirth, 15(1), p. 172. doi: 10.1186/s12884-015-

0602-4.

Warland, J., O’Leary, J., McCutcheon, H. and Williamson, V. (2011) ‘Parenting paradox: parenting after infant loss.’, *Midwifery*. Elsevier, 27(5), pp. e163-9. doi: 10.1016/j.midw.2010.02.004.

Weinstein, N. D. (1993) ‘Testing four competing theories of health-protective behavior.’, *Health psychology : official journal of the Division of Health Psychology, American Psychological Association*, 12(4), pp. 324–33. Available at: http://www.ncbi.nlm.nih.gov/pubmed/8404807.

Wellings, K., Jones, K. G., Mercer, C. H., Tanton, C., Clifton, S., Datta, J., Copas, A. J., Erens, B., Gibson, L. J., Macdowall, W., Sonnenberg, P., Phelps, A. and Johnson, A. M. (2013) ‘The prevalence of unplanned pregnancy and associated factors in Britain: Findings from the third National Survey of Sexual Attitudes and Lifestyles (Natsal-3)’, *The Lancet*, 382(9907), pp. 1807–1816. doi: 10.1016/S0140-6736(13)62071-1.

Wells, J. C. K., Sharp, G., Steer, P. J. and Leon, D. a (2013) ‘Paternal and Maternal Influences on Differences in Birth Weight between Europeans and Indians Born in the UK.’, *PloS one*, 8(5), p. e61116. doi: 10.1371/journal.pone.0061116.

West, J., Lawlor, D. A., Fairley, L., Wright, J., (2014) ‘Differences in socioeconomic position, lifestyle and health-related pregnancy characteristics between Pakistani and White British women in the Born in Bradford prospective cohort study: the influence of the woman’s, her partner’s and their parents’ place ’, *BMJ open*, 4(6), p. e004805. doi: 10.1136/bmjopen-2014-004805.

West, J., Lawlor, D., Fairley, L., Bhopal, R., Cameron, N., McKinney, P., Sattar, N. and Wright, J. (2013) ‘UK-born Pakistani-origin infants are relatively more adipose than white British infants: findings from 8704 mother-offspring pairs in the Born-in-Bradford prospective birth cohort’, *Journal of Epidemiology & Community Health*, 67(7), pp. 544–551. doi: 10.1136/jech-2012-201891.

Whincup, P. H., Nightingale, C. M., Owen, C. G., Rudnicka, A. R., Gibb, I., Mckay, C. M., Donin, A. S., Sattar, N., Alberti, K. G. M. M. and Cook, D. G. (2010) ‘Early emergence of ethnic differences in type 2 diabetes precursors in the UK: The child heart and health study in England (CHASE study)’, *PLoS Medicine*, 7(4), pp. 1–10. doi: 10.1371/journal.pmed.1000263.

White, M., Bush, J., Kai, J., Bhopal, R. and Rankin, J. (2006) ‘Quitting smoking and experience of smoking cessation interventions among UK Bangladeshi and Pakistani adults: the views of community members and health professionals.’, *Journal of epidemiology and community health*, 60(5), pp. 405–411. doi: 10.1136/jech.2005.040345.

Whitehead, M. and Dahlgren, G. (2007) ‘Concepts and principles for tackling social inequities in health : Levelling up Part 1’, *World Health Organization*, (2), pp. 1–45. Available at: http://www.euro.who.int/__data/assets/pdf_file/0010/74737/E89383.pdf.

Wilcox, A. J. (2002) *The Analysis of Birth Weight and Infant Mortality : An Alternative Hypothesis*. Available at: http://www.uwlax.edu/faculty/giddings/ECO108/Week 12/BirthWeight.pdf.

Wilcox, A. J. (2001) ‘On the importance--and the unimportance-- of birthweight’, *International Journal of Epidemiology*, 30(6), pp. 1233–1241. doi: 10.1093/ije/30.6.1233.

de Wilde, J. a, van Buuren, S. and Middelkoop, B. J. (2013) ‘Trends in birth weight and the prevalence of low birth weight and small-for-gestational-age in Surinamese South Asian babies since 1974: cross-sectional study of three birth cohorts.’, *BMC public health*. BMC Public Health, 13(1), p. 931. doi: 10.1186/1471-2458-13-931.

Wilkins, R., Sherman, G. J. and Best, P. A. (1991) ‘Birth outcomes and infant mortality by income in urban Canada, 1986.’, *Health reports / Statistics Canada,* 3(1), pp. 7–31.

Williams, D. R. (2002) ‘Racial / Ethnic Variations in Women ’ s Health : The Social Embeddedness of Health’, *American Journal of Public Health*, 92(4), pp. 588–597. doi: 10.2105/AJPH.92.4.588.

Winje, B., Wojcieszek, A., Gonzalez-Angulo, L., Teoh, Z., Norman, J., Frøen, J. and Flenady, V. (2015) ‘Interventions to enhance maternal awareness of decreased fetal movement: a systematic review’, *BJOG: An International Journal of Obstetrics & Gynaecology*, (DECEMBER), p. n/a-n/a. doi: 10.1111/1471-0528.13802.

Wise, P. H. (2003) ‘The anatomy of a disparity in infant mortality’, *Annu Rev Public Health*. Annual Reviews 24, pp. 341–362. doi: 10.1146/annurev.publhealth.24.100901.140816\r100901.140816 [pii].

Witz, A. (1995) ‘Medical men and midwives’, in *Professions and patriarchy*. London.: Routledge, pp. 104–128.

Wolff, P. and Holmes, K. J. (2011) ‘Linguistic relativity’, *Wiley Interdisciplinary Reviews: Cognitive Science*. John Wiley & Sons, Inc., 2(3), pp. 253–265. doi: 10.1002/wcs.104.

Woollett, A. and Dosanjh-Matwala, N. (1990) ‘Pregnancy and antenatal care: the attitudes and experiences of Asian women.’, *Child: care, health and development*, 16(1), pp. 63–78.

Woollett, A., Dosanjh, N., Nicholson, P., Marshall, H., Djhanbakhch, H. and Hadlow, J. (1995) ‘The ideas and experiences of pregnancy and childbirth of Asian and non-Asian women in East London’, *British Journal of Medical Psychology*, 68, pp. 65–85.

World Bank (2016) *People : World Development Indicators: Mortality*. Available at: http://wdi.worldbank.org/table/2.21 (Accessed: 8 December 2016).

World Health Organisation (2005) *WHO: Social determinants of health*, *Commission on social determinants of health*. World Health Organization. Available at: http://www.who.int/social_determinants/thecommission/finalreport/key_concepts/en/ (Accessed: 6 December 2013).

World Health Organisation (2006a) *Neonatal and Perinatal Mortality*. France.

World Health Organisation (2006b) *Promoting Optimal Fetal Development: Report of a Technical Consultation*. Geneva. Available at: http://www.who.int/nutrition/publications/fetal_dev_report_EN.pdf.

World Health Organisation (2011) *Optimal feeding of low birth- weight infants in low-and middle-income countries 2011*. World Health Organisation.

World Health Organisation (2012) *Pakistan: Maternal and Perinatal Health Profile*. Available at: http://www.who.int/maternal_child_adolescent/epidemiology/profiles/neonatal_child/pak.pdf.

World Health Organisation (2013) *Preterm birth*. World Health Organization. Available at: http://www.who.int/mediacentre/factsheets/fs363/en/ (Accessed: 1 May 2014).

World Health Organisation (2014) *Track 2: Health literacy and health behaviour*. World Health Organization. Available at: http://www.who.int/healthpromotion/conferences/7gchp/track2/en/#

(Accessed: 25 March 2014).

World Health Organization (1996) ‘Care in Normal Birth: a practical guide’, *Journal of Chemical Information and Modeling*, 53(9), pp. 1689–1699. doi: 10.1017/CBO9781107415324.004.

World Health Organsiation (2016a) *Body Mass Index - BMI*. Available at: http://www.euro.who.int/en/health-topics/disease-prevention/nutrition/a-healthy-lifestyle/body-mass-index-bmi (Accessed: 16 January 2016).

World Health Organsiation (2016b) *Congenital anomalies*, *Fact Sheet 370*. Available at: http://www.who.int/mediacentre/factsheets/fs370/en/ (Accessed: 24 November 2015).

Wright, J., Small, N., Raynor, P., Tuffnell, D., Bhopal, R., Cameron, N., Fairley, L., Lawlor, D. A., Parslow, R., Petherick, E. S., Pickett, K. E., Waiblinger, D. and West, J. (2013) ‘Cohort Profile: The Born in Bradford multi-ethnic family cohort study.’, *International journal of epidemiology*. Oxford University Press, 42(4), pp. 978–91. doi: 10.1093/ije/dys112.

Yadav, H. and Lee, N. (2013) ‘Maternal factors in predicting low birth weight babies’, *Medical Journal Malaysia*, 68(1), pp. 44–47.

Yakoob, M. Y., Menezes, E. V, Soomro, T., Haws, R. A., Darmstadt, G. L. and Bhutta, Z. A. (2009) ‘Reducing stillbirths: behavioural and nutritional interventions before and during pregnancy.’, *BMC pregnancy and childbirth*, 9 Suppl 1(Suppl 1), p. S3. doi: 10.1186/1471-2393-9-S1-S3.

Yali, A. M. and Lobel, M. (2002) ‘Stress-resistance resources and coping in pregnancy’, *Argumentation and Advocacy*, 15(3), pp. 289–309. doi: 10.1558/jsrnc.v7i2.154.

Yao, R., Ananth, C. V., Park, B. Y., Pereira, L. and Plante, L. A. (2014) ‘Obesity and the risk of stillbirth: A population-based cohort study’, American Journal of Obstetrics and Gynecology. Elsevier Inc, 210(5), p. 457.e1-457.e9. doi: 10.1016/j.ajog.2014.01.044.

Yardley, L. and Marks, D. (2004) ‘Introduction to Research Methods in Clinical and Health Psychology’, in Marks, D. and Yardley, L. (eds) *Research Methods for Clinical and Health Psychology*. London: Sage Publishers, pp. 1–240.

Yeasmin, S. F. and Regmi, K. (2013) ‘A qualitative study on the food habits and related beliefs of pregnant British Bangladeshis.’, *Health care for women international*, 34(5), pp. 395–415. doi: 10.1080/07399332.2012.740111.

Yu, J. (2012) ‘A systematic review of issues around antenatal screening and prenatal diagnostic testing for genetic disorders: women of Asian origin in western countries.’, *Health & social care in the community*, 20(4), pp. 329–46. doi: 10.1111/j.1365-2524.2011.01036.x.

Yuval-Davis, N. (2006) ‘Intersectionality and Feminist Politics’, *European Journal of Women’s Studies*, 13(3), pp. 193–209. doi: 10.1177/1350506806065752.

Zanchetta, M. and Poureslami, I. M. (2006) ‘Health literacy within the reality of immigrants culture and langauge’, *Canadian Journal of Public Health*, 97(2), pp. S26–S30.

Zeh, P., Sandhu, P., Cannaby, A. M. and Sturt, J. (2012) ‘A systematic review of cultural barriers impeding ethnic minority groups from accessing effective diabetes care services’, *Diabetic Medicine*, Conference, p. Diabetes UK Professional Conference 2012 Glasgow U. doi: http://dx.doi.org/10.1111/j.1464-5491.2011.03555_2.x.

Zeitlin, J., Mortensen, L., Prunet, C., Macfarlane, A., Hindori-Mohangoo, A. D., Gissler, M., Szamotulska, K., van der Pal, K., Bolumar, F., Andersen, A.-M. N., Olafsdottir, H. S., Zhang, W.-H., Blondel, B. and Alexander, S. (2016) ‘Socioeconomic inequalities in stillbirth rates in Europe: measuring the gap using routine data from the Euro-Peristat Project’, *Bmc Pregnancy and*

Childbirth. BMC Pregnancy and Childbirth, 16, pp. 15–15. doi: 10.1186/s12884-016-0804-4.

Zhang, W. and Creswell, J. (2013) ‘The use of “mixing” procedures of mixed methods in health services research’, *Medical Care*, 51(8), pp. e51–e57. Available at: http://journals.lww.com/lww-medicalcare/Abstract/2013/08000/The_Use_of__Mixing__Procedure_of_Mixed_Methods_in.17.aspx.

Appendices

Appendix 1: Topic guide, lay mothers

University of Bedfordshire

Identifying factors that contribute to low birth weight, stillbirth and infant mortality in Pakistani and Bangladeshi women living in Luton

Topic Guide – Lay Mothers

1. Introduction

- Thanks.
- Introduce self, supervisors and University of Bedfordshire.
- Give background & purpose to study: we want to identify factors that may contribute to poor birth outcomes in babies of Pakistani and Bangladeshi women in Luton. This will help identify areas to improve maternity services in the future.
- Explain the idea of maternal health beliefs, how these are different in different cultures and how this as yet has not been properly explored in Pakistani or Bangladeshi women living in UK.
- Refer participants to information sheet – check that they have read and understood the information sheet, confidentiality information and check understanding.
- Explain the consent procedure, right to withdraw, confidentiality and audio recording of the discussion. Break at any time if required. Interview discussion to last 60–90 minutes.
- Explain how the discussion that is going to take place will be used in the research.
- Findings form part of PhD thesis and will be published in academic journals and findings feedback – local presentation to local service providers and interested community members.
- Respectful listening.
- Allow for questions.
- Complete consent forms, bio questionnaire and conduct icebreaker.

2. Perceptions of pregnancy

I would like to ask you your views on pregnancy, before during and after birth.

What have/had you heard about pregnancy before having your children?

- *Probe: perceptions of pregnancy-difficult/easy, risk factors associated with pregnancy (low birthweight, stillbirths, infant deaths, congenital abnormalities/disabilities), number of pregnancies.*
- *Probe: views on when to see a doctor (secrecy, concealment, shame, confirmation of pregnancy), pregnancy - natural event (so medical confirmation not required) awareness of screening, awareness of the benefits of antenatal clinic.*

In your view/experience what are the symptoms of a healthy pregnancy and one where something may not be right with the pregnancy?

- *Probe: for what is considered a healthy pregnancy e.g. missed period, morning nausea and/or sickness, tiredness, sore breasts, breast changes (larger), changes in skin colour (e.g. darker nipples), changes to sense of smell or taste (food likes/dislikes), some weight gain.*
- *Probe: for pregnancy where something may not be right e.g. decreased foetal movements, vaginal bleeding/discharge, stomach cramps, swollen ankles.*

Where is this information from?

- *Probe: family, friends,internet, television, radio (which stations), GPs, midwives, health visitors, others (identify).*

Can you explain to me what being pregnant and giving birth to a healthy child means to you?

- *Probe: impact on status – own family, in-laws, extended family, community.*
- *Probe: impact on the role in own family and in-laws.*
- *Probe: cultural expectation to have children, a natural event, a natural life progression, special event.*
- *Probe: impact on perceptions of attractiveness, religiosity (being closer to God during pregnancy and birth).*

What roles do/did people you know play during your pregnancy?

- *Probe: husband, family, in-laws, friends, extended family, community.*
- *Probe: healthcare staff (GP, midwives, health visitors, hospital consultants).*

How do people you have mentioned influence decisions about your pregnancy and birth?

- *Probe: what decisions they influence e.g. getting pregnant, pregnancy choices (screening, delivery, diet and lifestyle choices) during pregnancy and birth.*
- *Probe: support (explore what type of support) and the role of support on autonomy, privacy and confidentiality.*
- *Probe: modern medicine verses allopathic or traditional medicine.*

3. Knowledge & information

I'd like to discuss where you got your pregnancy advice and information from before, during and after pregnancy.

What does the Luton maternity service offer to local women?

- *Probe: for awareness of available services at preconception (preconception advice from GP), antenatal (booking, screening tests, surveillance, antenatal class, birth preparation), postnatal (midwifery checks, mother and baby monitoring, baby clinics with health visitor, six-week check up with GP, family planning advice).*
- *Probe: who provided this information friends, family, internet, television, radio (which stations) GP, midwives, health visitors, others (identify).*
- *Probe: if information provided was enough to prepare you for the birth, if not why not?*

Was the information provided accessible and acceptable?

- *Probe: what form was the information provided in(oral, written).*
- *Probe: was the information understandable, any communication issues like language/literacy, if interpreters were available to ease communication, where they were used.*
- *Probe: if any part of the service impacted on patients' cultural and religious values e.g. availability of female staff, screening advice termination of pregnancies, informed choice.*

4. Views on low birthweight, stillbirths and infant mortality

I would like to talk about your views on low birthweight, stillbirths and infant mortality.

What do you understand is low birthweight?

- *Probe: birthweight less than 2500g or 5.5lb, small babies=healthy/unhealthy*

What are the risk factors for low birthweight?

- *Probe: biological factors – perceptions about the causes of poor birth outcomes: diet and nutrition, late booking, comorbidities, consanguinity, age, previous complications, ethnicity, known risk factors, preterm birth (before 37 weeks), God's will.*
- *Probe: cultural/religious perceptions: black magic (wind, curses), fatalistic explanations/God's will*

How can low birth weight be prevented, if at all?

- *Probe: adequate nutrition (vitamin D, folic acid, iron, hot/cold foods, avoiding shellfish and high infection risk foods), regular antenatal monitoring, antenatal classes (education) termination of abnormal foetus (detected through screening), screening uptake.*
- *Probe: cultural/religious perceptions – consanguineous marriages, not smoking (including smokeless tobacco and betal nut), supernatural beliefs (avoiding the evening wind, curses, evil eye, avoiding solar/lunar eclipses, amulets, enchanted water, prayer).*

What are the risk factors for stillbirth?

- *Probe: biological factors – perceptions about the causes of poor birth outcomes: diet and nutrition, late booking, comorbidities, consanguinity, age, previous complications, ethnicity, known risk factors, God's will.*
- *Probe: cultural/religious perceptions: black magic, fatalistic explanations/God's will*

How can stillbirth be prevented, if at all?

- *Probe: adequate nutrition (vitamin D, hot/cold foods, avoiding shellfish and high infection risk foods, folic acid, iron), regular antenatal monitoring, antenatal classes (education) termination of abnormal foetus (detected through screening), screening uptake.*
- *Probe: cultural/religious perceptions - consanguineous marriages, not smoking (including smokeless tobacco and betal nut), supernatural beliefs (avoiding the evening wind, curses, evil eye, avoiding solar/lunar eclipses, amulets, enchanted water, prayer).*

What are the risk factors for infant death?

- *Probe: biological factors – perceptions about the causes of poor birth outcomes: diet and nutrition, late booking, comorbidities, consanguinity, age, previous complications, ethnicity, known risk factors, God's will.*
- *Probe: cultural/religious perceptions: black magic, fatalistic explanations/God's will*

How can infant death be prevented, if at all?

- *Probe: adequate nutrition (vitamin D, hot/cold foods, avoiding shellfish and high infection risk foods, folic acid, iron), regular antenatal monitoring, antenatal classes (education) termination of abnormal foetus (detected through screening), screening uptake.*
- *Probe: cultural/religious perceptions - consanguineous marriages, not smoking (including smokeless tobacco and betal nut), supernatural beliefs (avoiding the evening wind, curses, evil eye, avoiding solar/lunar eclipses, amulets, enchanted water, prayer).*
- *Probe: breastfeeding (discarding colostrum), safe sleeping practices.*

5. Your experiences of current services and maternity healthcare professionals

I'd like to ask about the issues related to current maternity services and maternity healthcare professionals in Luton.

How were you referred to maternity services in Luton?

- *Probe: for referral route and experience, late booking (after 12 weeks of pregnancy*)

What maternity services have you or did you access?

- Probe: *maternity services–- preconception (preconception advice from GP), antenatal (booking, screening tests, surveillance, antenatal class, birth preparation), postnatal (midwifery checks, mother and baby monitoring, baby clinics with health visitor, six-week check up with GP, family planning advice).*

Where you offered screening services?

- *Probe: awareness of screening services/conditions.*
- *Probe: for information provided, understanding of opting in or out and concept of informed choice, impact of information on future pregnancies.*

Are you aware of any reasons why women in Luton wouldn't use the local maternity services?

- *Probe: favouring alternative healthcare (herbalists, traditional healers), pregnancy being a natural event – not needing medical intervention, concealment/secrecy of pregnancy, lack of information of available services, unaware of benefits of services, fear of advice (termination of pregnancy), transportation problems, lack of trust in the service providers, language and communication problems, lack of female staff/separate facilities for women, cultural and religious beliefs.*

How could maternity services in Luton be more suited to your needs?

- *Probe: advocates, female staff, female only antenatal classes, separate facilities for women, culturally competent staff, community-based support.*

6. Closing. Any other comments, suggestions or questions

Any further thoughts and reflections?

Summarise key points of discussion

Appendix 2: Framework of ethical considerations in research with bereaved participants

Ethical considerations		**Strategies.**
Participant recruitment	Access, confidentiality	Use key person to identify potential participants and to distribute pre-prepared recruitment letters on behalf of research team
	Regard	Recruit potential participants sending out a maximum of five letters to ensure participants are not left waiting for an interview
	Respect, relevance	Consider the timescale as in similar research, 6 to 24 months post bereavement
	Compassion	Use our personalised covering letter introducing study
	Informed choice	The provision of clearly written research information, with an invitation for the participant to contact the researcher. Researcher to demonstrate a timely response.
	Non-coercion	Provide at least 10 days for participants to consider taking part
The interview	Respect, choice	Choose a mutually convenient date time and venue, avoiding significant dates such as birthdays
	Safety	Ensure supervisor is aware of planned interviews, venue address and researcher to confirm safe exit once interview is over
	Support	Researcher to be competent in dealing with distress. Provide contact details for support services at the beginning of the interview process and again at the end.
	Informed consent	Read our study information sheet. Allow participants to ask questions. Explain the procedure. Obtain written consent.
	Confidentiality and anonymity	Digital audio recording and transcripts to be secured on a password protected University computer and encrypted USB. De-identified data at the point of transcript, use codes.
Post interview follow-up	Support	Arrange for follow-up telephone call to ensure participant is properly supported and answer any questions, 24-48 hours post interview
	Support	Provide information regarding support services
	Involvement	Provide participants the opportunity to review the transcript, and to attend the findings feedback presentation
	Support	Establish regular feedback with supervisory team and use reflective diary to support researcher

Adapted from Sque *et al.*, 2014

Appendix 3: Topic Guide, bereaved mothers

LUTON & DUNSTABLE UNIVERSITY HOSPITAL
CLINICAL EXCELLENCE, QUALITY & SAFETY

Explaining factors that contribute to low birth weight, stillbirth and infant mortality in Pakistani and Bangladeshi women living in Luton

University of Bedfordshire

Topic Guide – Bereaved Mothers

1. Introduction

- Thank you for agreeing to take part.
- Give background & purpose to study: we want to identify factors that may contribute to low birth weight, stillbirth and infant mortality in babies of Pakistani and Bangladeshi women in Luton. This will help identify areas to improve maternity services in the future.
- Acknowledge the loss of their baby.
- Acknowledge that the topic is upsetting/sensitive. If they want to have a break at any time (and stop the recording) that is absolutely fine.
- Check what support is in place for after the interview/later that day (i.e. who), signpost to counselling services (give contact numbers).
- Explain the consent procedure, right to withdraw, confidentiality and audio recording of the discussion. Break at any time if required. Interview discussion to last 60–90 minutes. Check that they have understood the information sheet, confidentiality information and check understanding.
- Explain how the discussion that is going to take place will be used in the research.
- Findings form part of PhD thesis and will be published in academic journals and findings feedback – local presentation to local service providers and interested community members.
- Complete consent forms, bio questionnaire.

Rapport building *[build on answers to establish rapport]*

How do you self-define you ethnic group?

Probe: Pakistani, Kashmiri, Bangladeshi, Asian, Asian British, Muslim, English.

Have you lived in the UK long?

Probe: since birth or migrated when?

Where did you go to school?

Probe: location (UK or abroad), level of education attained.

Tell me about who lives at home with you?

Probe: for husband/partner/children/parents/parents-in-law.

Do you work?

Probe: for home-maker, housewife, carer, employed work, if employed what work.

For the purposes of completeness, can I ask whether you smoked or drank alcohol during your pregnancy?

Probe: how much/how often.

1. The mother’s story and context

I would really like to start by hearing about you and your and experience. Is that okay?

When did you first realise that something may not be right with your pregnancy?

- *Probe: for thoughts on your pregnancy, what signs suggested something was not right, e.g. decreased foetal movements, vaginal bleeding/discharge, stomach cramps, swollen ankles, "feelings something was wrong".*
- *Probe: for views on when in the pregnancy did something go wrong? (first pregnancy, second pregnancy etc.).*
- *Probe: what actions you took when you realised something was wrong e.g. friends, family, GP, A&E, midwife, obstetric ward, NHS Direct/111*
- *Probe: for views on what actions others took? Partner, family, GP, hospital staff.*
- *Probe for: any actions taken or not taken that are important to you in respect of your culture? What support did you receive?*
- *Probe: for what happened next e.g. the delivery, what follow up received?*
- *Probe: what aftercare and/or counselling support did you access/receive (if not, why not, views on counselling support if received.*

I would like to hear your views on what you think went wrong.

- *Probe: for thoughts on why things went wrong in the pregnancy (personal health behaviours, access to care, help-seeking behaviours, comorbid factors, God's will, genetic/hereditary factors or family history.*
- *Probe: for thoughts on the reasons behind decisions made (e.g. screening), autonomous or collaborative decision making e.g. husband, family decision, doctor's advice and why?*
- *Probe: for services accessed, post-mortem, MRI (if not why not).*

2. Your experiences of maternity services and maternity healthcare professionals

I'd like to ask about the issues related to your experience of maternity services and maternity healthcare professionals in Luton.

How were you referred to maternity services in Luton at the beginning of the pregnancy?

- *Probe: for referral route, how referred.*
- *Probe: for how many weeks gestation at referral and factors influencing decision.*

What maternity services did you access?

- *Probe: for views on maternity services – lifestyle changes; preconception (preconception advice from GP), antenatal (booking, screening tests, specialist screening services, surveillance, antenatal class, birth preparation), specialist clinics (diabetes or hypertension), bereavement follow up (consultant or GP), bereavement midwife.*

I would like to ask you your views and experience of antenatal tests and checks (i.e. screening) services?

- *Probe: for experience of when in pregnancy, by whom, and if known why e.g. cousin marriage, hereditary risk.*
- *Probe: for experience and awareness of screening services/conditions (Down's syndrome, thalassemia, normal growth/development and infectious diseases).*

- *Probe: for what information was provided, understanding of opting in or out of screening services, sufficient information to make confident decisions regarding pregnancy and risks/benefits of these decisions and impact of information on future pregnancies.*
- *Probe: for views on decisions made e.g. screening vs. no screening, reasons for decision?*
- *Probe: for your views of religious reasons (perceptions of Fatwa), God's will.*

In your view are there any reasons why you (or other Pakistani/Bangladeshi/White –*delete as appropriate* women in Luton) wouldn't use the local maternity services?

- *Probe: for views on favouring alternative healthcare (herbalists, traditional healers), pregnancy being a natural event and therefore not needing medical intervention, concealment/secrecy of pregnancy, lack of information of available services, unaware of benefits of services, fear of advice (termination of pregnancy), conflicts with cultural and religious beliefs, transportation problems, lack of confidence and trust in the service providers e.g. receiving misinformation/inadequate, biased or stereotyped information, previous experience of self or others' poor outcomes, language and communication problems, lack of female staff/separate facilities for women, lack of understanding toward cultural and religious choices.*

3. Knowledge & information

I'd like to discuss with you what you know about the services that are offered in Luton for pregnant women and where you got your information and advice about your pregnancy from.

What does the Luton maternity service offer to local women?

- *Probe: for views on awareness of available services at preconception (preconception advice from GP, folic acid, healthy eating), antenatal (booking, screening tests, surveillance, antenatal class, birth preparation), follow-up afterwards (consultant, GP).*
- *Probe: for views on who provided this information – friends, family, internet, television, radio (which stations) GP, midwives, health visitors, others (identify).*
- *Probe: for your ideas and perceptions of caring for yourself during pregnancy – what to do and what not to do. Medication during pregnancy verses allopathic or traditional medicine. Nutrition (eating down, vitamins). Work, rest.*
- *Probe: for views on whether information provided was enough to prepare you for the pregnancy and if not why not, cultural perceptions of the services.*

Was the information provided accessible and acceptable?

- *Probe: for views on what form the information was provided in (oral, written).*
- *Probe: for views on whether the information was understandable, any communication issues like language/literacy, if interpreters were available to ease communication, where they were used.*
- *Probe: views on whether any part of the service impacted on patient's cultural and religious values e.g. availability of female staff, screening advice, termination of pregnancies, informed choice.*
- *Probe: for information on autonomous/collaborative/guided decision making and what was important during this process.*
- *Probe: preparations for burial, washing, dressing, prayers materials.*

4. Views on low birthweight, stillbirths and infant mortality

I would like to talk about your views on … [select appropriate: low birthweight or stillbirth or infant mortality].

**Use only the appropriate section(s) below to reflect the mother's bereavement story:*

Low birth weight (preterm deliveries or small for gestational age)

What do you understand as low birthweight?

- *Probe: views on reasons birthweight less than 2500g or 5.5lb, small babies=healthy/unhealthy, growth restricted.*

What are the risk factors for low birthweight?

- *Probe: views on biological factors – perceptions about the causes of poor birth outcomes: diet and nutrition, late booking, comorbidities, family genetic/hereditary history, cousin marriage, age, previous complications, ethnicity, known risk factors, preterm birth (before 37 weeks) God's will.*
- *Probe: views on cultural/religious perceptions: black magic (wind, curses), fatalistic explanations/God's will.*

How can low birth weight be prevented, if at all?

- *Probe: views on adequate nutrition (vitamin D, folic acid, iron, hot/cold foods, avoiding shellfish and high infection risk foods), regular antenatal monitoring, antenatal classes (education) termination of abnormal foetus (detected through screening), screening uptake, screening for family genetic/hereditary history, cousin marriage.*
- *Probe: views on cultural/religious perceptions avoiding cousin marriage, not smoking (including smokeless tobacco and betal nut), supernatural beliefs (avoiding the evening wind, curses, avoiding solar/lunar eclipses, amulets, enchanted water, prayer).*

Stillbirth

What are the risk factors for stillbirth?

- *Probe: views on reasons – biological factors – perceptions about the causes of poor birth outcomes: diet and nutrition, late booking, comorbidities, avoidance of cousin marriage, age, previous complications, ethnicity, known risk factors, God's will.*
- *Probe: views on cultural/religious perceptions: black magic, fatalistic explanations/God's will*

How can stillbirth be prevented, if at all?

- *Probe: views on adequate nutrition (vitamin D, hot/cold foods, avoiding shellfish and high infection risk foods, folic acid, iron), regular antenatal monitoring, antenatal classes (education) termination of abnormal foetus (detected through screening), screening uptake.*
- *Probe: views on cultural/religious perceptions – avoidance of cousin marriage, not smoking (including smokeless tobacco and betal nut), supernatural beliefs (avoiding the evening wind, curses, avoiding solar/lunar eclipses, amulets, enchanted water, prayer).*

Infant death

What are the risk factors for infant death?

- *Probe: views on reasons – biological factors – perceptions about the causes of poor birth outcomes: diet and nutrition, late booking, comorbidities, avoidance of cousin marriage, age, previous complications, ethnicity, known risk factors, God's will.*

- *Probe: views on cultural/religious perceptions: black magic, fatalistic explanations/God's will*

How can infant death be prevented, if at all?

- *Probe: views on adequate nutrition (vitamin D, hot/cold foods, avoiding shellfish and high infection risk foods, folic acid, iron), regular antenatal monitoring, antenatal classes (education) termination of abnormal foetus (detected through screening), screening uptake.*
- *Probe: views on cultural/religious perceptions – avoidance of cousin marriage, not smoking (including smokeless tobacco and betal nut), supernatural beliefs (avoiding the evening wind, curses, avoiding solar/lunar eclipses, amulets, enchanted water, prayer).*
- *Probe: views on breastfeeding (discarding colostrum), safe sleeping practices.*

5. Service improvements

I would like to ask you your views on how services might be changed.

Based on your experience, what are your views on how professional maternity staff in Luton might better meet your individual needs?

- *Probe: for advocates (or patient representative), female staff, female only antenatal classes, separate facilities for women.*
- *Probe: for culturally competent staff e.g. staff that have awareness of diverse religious, cultural beliefs, and different social needs (connectedness with others, friends, community , maternity services that empower and meet diverse needs, non-judgmental, and encourage inclusion and trust.*
- *Probe: for culturally appropriate services, i.e. how can things be done more culturally or religiously sensitively?*

What else could have been done to help you through your difficult time?

- *Probe: institutional support: for views on counselling and support services offered.*
- *Probe: professional support (staff) i.e. rapport, respect, empathy, listening.*
- *Probe: social support (partner, family, friends) i.e. respect, empathy, listening, acknowledgement.*

If there was one recommendation you could make what would it be?

- *Probe: views on how services could be improved to support bereaved mothers*.

6. Closing. Any other comments, suggestions or questions

I would like to ask you for your final thoughts/ reflections as we come to the end of our discussion.

You have been through a difficult experience and I am grateful that you have shared it. Your views are very valuable to us and we hope that you have not found it too distressing to share your experience. Your views will help develop future maternity services, as together with other women's experiences, we will be able to highlight areas for change to make improvements for mothers and their families.

Ask if they would like summary of the findings of the research?

Summarise key points of discussion

[signpost support services]

Appendix 4: Consultant cover letter

[

LUTON &
DUNSTABLE
UNIVERSITY
HOSPITAL

CLINICAL EXCELLENCE, QUALITY & SAFETY

[date]

Dear [mothers name],

I know that you have suffered a baby death and that we are writing to you at this sensitive time. Our reason for writing to you is to ask you if you are willing to participate in a study that is exploring the factors that contribute to low birth weight, stillbirth and baby deaths in Luton. This study is considering the views of bereaved mothers and local health professionals with the aim to improve maternity services that are provided locally.

This study is being carried out by Rebecca Garcia from the University of Bedfordshire as part of her PhD programme. There is a letter enclosed which explains the study further and what is involved if you decide to take part. I would like to reassure you that Rebecca (or the University of Bedfordshire) have not been given your name, address or any other details about you. The care you receive in hospital will not be affected by whether you take part in the study or not. Taking part in the study is entirely up to you, and what you share with Rebecca will be in the strictest confidence.

Please use the reply slip to indicate whether you are willing for Rebecca to contact you to discuss the study further. If you decide you do not want to take part, this will be noted and you will not receive any more communication regarding this study. This is an important study and your views are essential to us. I hope that you will be able to share your views with Rebecca.

Yours sincerely,

[consultant name]

Appendix 5: Bereaved mother cover letter from researcher

Dear Parents,

This letter has been forwarded to you by The Luton and Dunstable University Hospital Maternity Department (L&D). Your details have been identified by maternity clinicians on my behalf and I am writing to ask if you would be willing to take part in a research study looking at the factors that contribute to baby deaths. I am conducting this study as part of my PhD (under the supervision of Dr Nasreen Ali and Professor Gurch Randhawa) at the University of Bedfordshire.

The purpose of this research study is to understand factors that may contribute to baby deaths in Luton. We want to speak with mothers who have experienced this tragedy to understand their experiences so that we can make service improvements and reduce the number of baby deaths.

If you agree to take part you will be invited to talk to a researcher about your experiences in a face-to-face interview lasting approximately 1-2 hours at a time and place of your choosing. Your stories are very valuable to us.

At this time, I do not know any of your personal details or the information held in your maternity records. **Please return the enclosed** slip in the pre-paid envelope provided giving me permission to contact you by telephone (**or to ensure we do not contact you again**) and discuss with you about your potential participation in this research study and answer any questions you may have. You can also contact me directly on 07598330636.

I know that this may be a difficult time for you and that receiving this letter may cause you some additional distress and recall of difficult memories. If this is the case, we apologise sincerely, but we hope that you will understand our reasons for contacting you. I look forward to hearing from you.

Yours sincerely

Rebecca Garcia RGN. MSc. MBPsS.
PhD Researcher
Institute for Health Research
http://www.beds.ac.uk/research/ihr
University of Bedfordshire
Tel 01582 743744 or 07598330636

Appendix 6: Bereaved mother information sheet

Participant information sheet

Views on baby death study

I (Rebecca Garcia) would like to invite you to take part in my research study. But before you decide I would like you to understand why the research is being done and how it involves you. This information sheet has been produced to help you decide whether to take part.

Part 1 of this sheet tells you the purpose of this study and what will happen to you if you take part. Part 2 gives you more detailed information about the study. If you are considering taking part, I will discuss the research study and what this means for you in more detail before you decide and this will take about 10 minutes over the telephone.

The purpose of this study is to identity areas for improving maternity services and will meet the requirements for a PhD qualification, supervised by Dr Nasreen Ali and Professor Gurch Randhawa at the University of Bedfordshire.

If you have any questions, please contact me by phone (07598330636) or email Rebecca.Garcia@beds.ac.uk

Part 1: An overview about your participation

Babies that are born too early (before 37 weeks of a 40 week pregnancy) or too small (less than 2.5kg at birth) are more likely to be poorly or die. Figures show that Pakistani mothers have more babies that are born early and Bangladeshi mothers have more babies born that are considered very small and Pakistani and Bangladeshi mothers living in Luton experience high rates of baby death. This study aims to explore the factors that might contribute to these poor outcomes, so that the local services can make improvements to the care of these mothers during pregnancy and childbirth to reduce the higher numbers of baby deaths.

Why have I contacted you? The reason you have been asked to take part is because hospital records show that you have suffered the loss of your baby in the last 2 years. Your views are really valuable to us and we would like to discuss your experience of losing a baby with you.

Do I have to take part? Taking part is completely up to you. If you decide to take part, you will be asked to sign a consent form. A courtesy letter will be sent to your GP informing him that you have agreed to take part. You may change your mind at any time, including during the interview. This will not affect the care you receive in any way. Taking part in this research study will not impact on the care that you are receiving at the hospital or with your GP.

What will happen if I take part? If you are considering taking part, I (or a translator from the University) will telephone you to discuss taking part and answer any questions you may have. If you decide to take part, a time, date and place of your choice will be agreed to carry out a face-to-face interview, (but no sooner than 14 days, giving you time to think carefully about taking part). At the beginning of the interview, you will be asked to sign a consent form that shows that you agree to take part. The interview will be audio recorded so that I do not miss any valuable information that you share. The interview gives you a chance to talk about your recent experience. After the interview it is normal that you may like to talk a bit more to me, more informally. The whole process will take about 90 minutes. **If you decide not to take part, please return the opt in/out sheet using the envelope provided, making it clear you do not want to take part and you**

will receive no more contact. After the interview, the audio recording is typed up and any identifying information is removed (for example name, place or date becomes written as [name][place][date]).

As a thank you I am offering you a £20 High Street voucher (which will be paid if you take part in the interview for 30 minutes or more). A few weeks after the interview, you may be asked to review a copy of the interview transcript. This is to make sure the record is an accurate account of our discussion. I will discuss the exact process for this with you on the day of the interview.

What are the advantages and disadvantages of taking part? Some women find talking about their pregnancy and loss of their baby helpful. I understand that discussing your bereavement experience will be upsetting and bring back difficult memories. I will be sensitive to this and make sure you are supported after the interview. If you experience distress, I will help you contact your GP and baby bereavement support charities who can help you. While I can't promise you will find it helpful having taken part, it is hoped that as a result of this research we will better understand factors that may contribute to babies dying.

What if there is a problem? Should you have any concerns or complaints during taking part in the study; part 2 details how this will be addressed.

Will my taking part in the study be kept confidential? Any information you share with me and the research team (Dr Ali, Professor Randhawa and a University translator) will be treated in the strictest confidence. This means that anything you tell us will not be shared with the hospital staff or affect your care in any way, including post-mortem counselling. All information will be de-identified so that no identifying features to the story that you share will identify you or be published or shared outside the research team.

The research is expected to take 18 months until the results are published.

If you are still interested take part, please read part 2 carefully before you decide.

Part 2: More detail

What happens if I change my mind? You can decide to withdraw at any time, even during the interview process. If this happens, I will discuss with you and ask your permission to keep any audio recordings made so far. If you decide you do not want your recording kept by the research team, then the audio recording will be destroyed.

What do I do if there is a problem?

Complaints: If you have any concerns please contact me (researcher) rebecca.garcia@beds.ac.uk or mobile 07598330636. If you remain unhappy and wish to discuss the matter more formally please contact Dr Nasreen Ali (Director of Studies) nasreen.ali@beds.ac.uk or mobile 07969062428.

Harm: No harm is intended by taking part in this research. The University of Bedfordshire operates indemnity insurance for students undertaking research. Please contact the University of Bedfordshire for more details.

Will my taking part in this study be confidential? Your details and information will be kept confidential. This means that I and the "research team" (meaning supervisors Dr Ali, Professor Randhawa and a University approved translator) will only have access to your personal information such as name and phone number (and this is only if you provide it). All data (i.e. recordings, transcripts and analysis) will be de-identified to protect your privacy and identity. Special care will be taken to make sure that no identifying features of your unique experience are published.

Personal information (names, addresses and phone numbers) will be kept in a locked filing system in a locked and alarmed building at the University of Bedfordshire, Putteridge Bury Campus. Personal information is only used for the purpose of contacting you for the current study and to ensure Dr Ali is aware of my whereabouts while I am conducting your interview. Paper consent forms and bio-questionnaire information will be kept separate, but also in a locked filing system, in a locked and alarmed facility at the University. All audio recordings, transcripts and analysis will be kept on an encrypted USB and University password protected computer. Data will be kept for a maximum of 5 years (as per current guidelines) and only used in association with the current research study. The safe destruction of digital and paper material will follow University procedures at that time, following data protection legislation.

Also, I am required to report any concerns regarding any risks of harm to Dr Ali, to ensure the correct safeguarding procedures are followed.

Will my GP be informed? You will be asked for your consent, so that I can inform your GP of your participation in this study. This will be done by a simple courtesy letter informing him/her of your participation (you may see this if you wish). The reason for this letter is to ensure your ongoing emotional wellbeing as the interview may be upsetting and you might need further counselling support from your GP and or other counselling services in the weeks following the interview.

What happens to the results of the study? At the end of the study the results will be published in an academic thesis, international academic journals and a local “Findings feedback” presentation which will be given to the local population and interested people. Care will be taken so that you or your experience(s) are not identifiable in any way in these publications or presentations.

Who is organising and funding the study? This study is being funded by the Steel Charitable Trust in the form of a stipend for a PhD. The PhD is being conducted at the University of Bedfordshire, under the supervision of Dr Nasreen Ali and Professor Gurch Randhawa.

Who has reviewed this study? Research conducted in the NHS is considered by an independent group of people (known as the Research Ethics Committee) to protect your interests. This study was reviewed and given a favourable opinion by Essex Research Ethics Committee, on 18th June 2015.

Can I get more information about taking part in research?

General information about taking part in research can be found from the NHS Choices website:
http://www.nhs.uk/Conditions/Clinicaltrials/Pages/Gettinginvolvedinresearch.aspx

Further information about this research study is available from myself (researcher) rebecca.garcia@beds.ac.uk or mobile 07598330636.

If you want to discuss taking part with a neutral person, please contact The Child Bereavement Charity on 0800 0288840. If you have concerns or are unhappy, please contact Dr Nasreen Ali (Director of Studies) nasreen.ali@beds.ac.uk or mobile 07969062428.

For more information, please contact:

Rebecca Garcia
Research Student
Institute of Health Research
University of Bedfordshire
Putteridge Bury
Hitchin Road
Luton
LU2 8LE
Telephone 01582 743744
Mobile 07598330636
Email Rebecca.Garcia@beds.ac.uk

Appendix 7: Bereaved mother opt-in / opt-out sheet

****PLEASE RETURN IN PRE-PAID ENVELOPE PROVIDED****

Study exploring baby death in Luton.

Please initial

I agree for Rebecca (or an approved translator) to contact me to discuss this research further……………………………………………………………………………….[ ]

I do not want any more contact from Rebecca ………………….………….... [ ]

Only provide your name and telephone number if you wish to discuss this further.

Name: ____

Telephone number____

Best time for Rebecca to call? ____________________________________

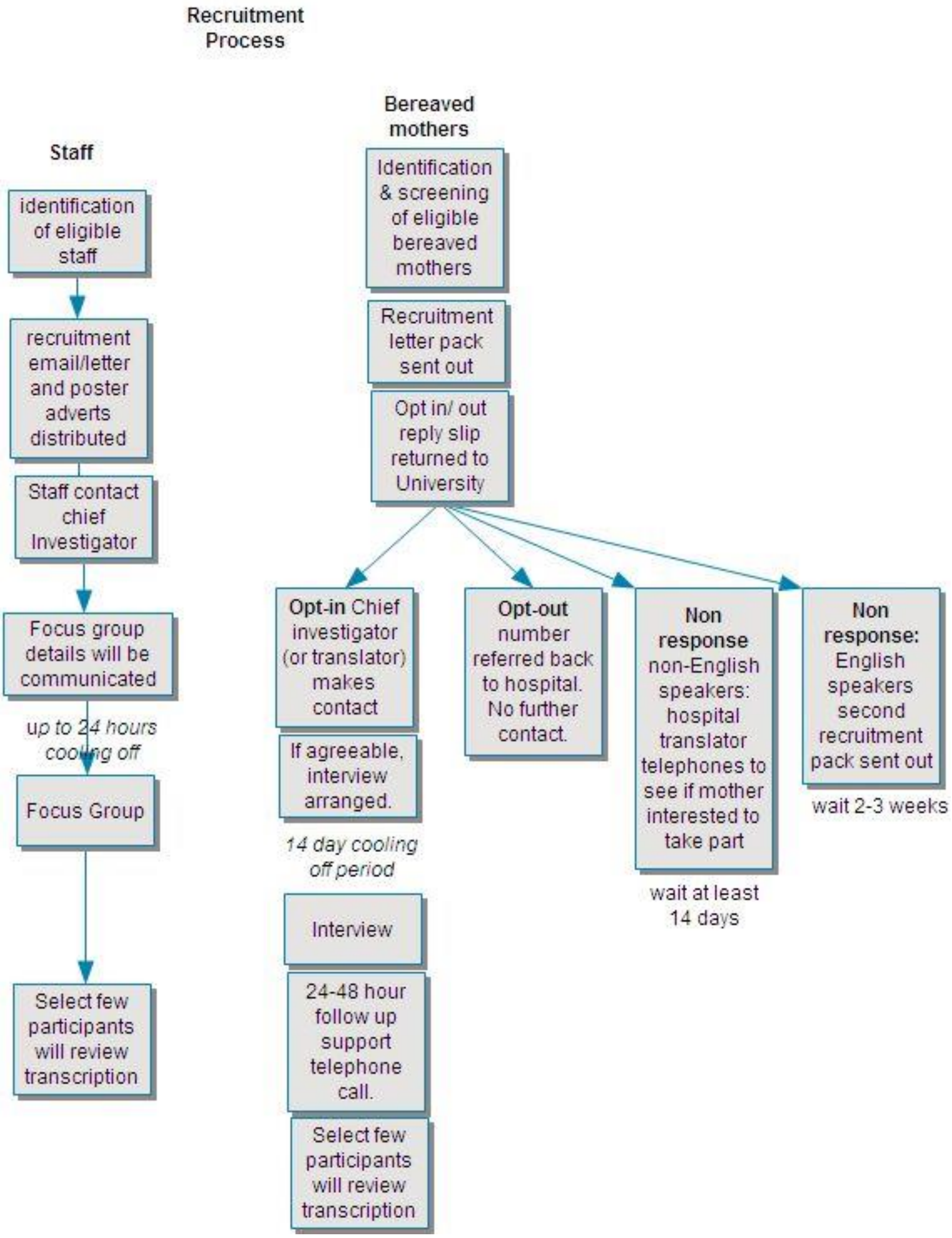
I would like to speak with someone in [state language] _______________________

Please return this form to

Rebecca Garcia
(c/o Dr N Ali)
Institute of Health Research
University of Bedfordshire
Putteridge Bury
Hitchin Road
Luton
LU2 8LE

[For hospital use only…participant code: ________] This code ensures your personal details are not shared with the researcher unless you agree and provide contact details.

Appendix 8: Bereaved mother recruitment process chart



Appendix 9: Consent form – mothers

Consent Form (mothers)

LUTON & DUNSTABLE UNIVERSITY HOSPITAL
CLINICAL EXCELLENCE, QUALITY & SAFETY

University of Bedfordshire

Title of Project: **Explaining factors that contribute to low birth weight, stillbirth and infant mortality in Pakistani Bangladeshi women living in Luton.**

Name of Researcher: Rebecca Garcia (Supervisor: Dr Nasreen Ali)

Please initial the box

I confirm that I have read and understood the information sheet given to me by the researcher. I confirm that I have had the chance to ask questions. ☐

I understand that taking part is voluntary and that I may stop and withdraw my data at any time. ☐

I understand that I may become upset. ☐

I give my consent to take part in the above study. ☐

I give my consent for the interview / focus group to be audio recorded and transcribed (written out). ☐

I consent to the researcher sending my GP a courtesy letter, informing them of my taking part in this study (mothers only). ☐

Name of Participant (print) ________________ Signature ________________ Date ________________

Researcher (print) ________________ Signature ________________ Date ________________

To be completed by researcher only Research Site______________________________
Participant Identification Number____

Appendix 10: GP letter (bereaved mothers participation)

Institute of Health Research
University of Bedfordshire
Putteridge Bury
Hitchin Road
Luton
LU2 8LE

Dear [name of GP]

Re: [insert patients name and date of birth]

I am writing to inform you that the above named patient has agreed to take part in a local research study which is being carried out for a PhD looking at *factors that contribute to low birth weight, stillbirth and infant mortality in babies born to Pakistani Bangladeshi and white British women in Luton*.

Participation in this research study involves a face-to-face interview discussing [name of patient] bereavement experience lasting approximately 1½ hours. Most parents who take part in bereavement research have found it cathartic; however, in the event that [name of patient] should become distressed the researcher will stop the interview. If [name of patient] should require further support she will be directed towards your care. In addition [name of patient] will be signposted to a number of specific bereavement charities:

Babies born too small, too soon, too sick (BLISS) - **0500 618140**

http://www.bliss.org.uk/

Child Bereavement UK – **0800 0288840**

http://www.childbereavementuk.org/

Muslim Bereavement Support Service - **020 3468 7333**

http://mbss.org.uk/services/default.html

Sakoon (Islamic) Counselling Services - **07943561561 or 07960735611**

http://www.sakoon.co.uk/

This study has received ethical approval from Essex Research Ethics Committee on (insert date). I enclose the participant information sheet for your information, however if you have any questions, please contact me on 07598330636 or rebecca.garcia@beds.ac.uk

Yours sincerely,

Rebecca Garcia RGN. MSc. MBPsS.
PhD student
Institute for Health Research
University of Bedfordshire

Appendix 11: Bereaved mothers debrief sheet

Research Site____

Participant Identification Number__________________________

Exploring Baby Deaths Debrief Form

My study is being done to identify some of things that may add to the risk of low birth weight, stillbirth and infant death in babies of Pakistani and Bangladeshi women, living in Luton.

A large number of risk factors have already been identified and it is still unclear why low birth weight or stillbirth continues in Pakistani and Bangladeshi families living in the UK. Low birth weight occurs more commonly in babies of Bangladeshi or Pakistani families. Numbers show that infant deaths are particularly high in Pakistani families but the reasons are not clear. This study is aiming to understand this better, in the context of women living in Luton. It is hoped that the results from this study will provide some insight and understanding to the problem and in turn, will help develop culturally appropriate maternity services in the future.

Thank you for your help.

If you have experienced distress and would like to talk to someone, please contact:

Babies born too small, too soon, too sick (BLISS) - **0500 618140**

http://www.bliss.org.uk/

Muslim Bereavement Support Service - **020 3468 7333**

http://mbss.org.uk/services/default.html

Sakoon (Islamic) Counselling Services - **07943561561 or 07960735611**

http://www.sakoon.co.uk/

Stillbirth and Neonatal Death Charity **– 0207 436 5881**

http://www.uk-sands.org/

If you wish to receive an invitation to the ‘findings feedback’ presentation once the study is finished, please contact me Rebecca.Garcia@study.beds.ac.uk

Appendix 12: Staff recruitment poster

University of Bedfordshire

LUTON & DUNSTABLE UNIVERSITY HOSPITAL

CLINICAL EXCELLENCE, QUALITY & SAFETY

A local study identifying and exploring causes for infant deaths

Your help is needed!

A researcher from the University of Bedfordshire is conducting a study identifying and exploring the causes of stillbirth, low birthweight and infant mortality in Pakistani and Bangladeshi women living in Luton. The researcher is looking for the views and opinions of healthcare staff working in the maternity care pathway in Luton, in order to help understand the possible causes of infant death in this population locally. It is intended to run a series of small discussion groups in order to discuss the issues collectively with other healthcare workers.

All information shared in the study will be treated in confidence and no participants will be identified.

Please contact **REBECCA GARCIA** for more information:

Telephone: 01582 743744 / 07598330636

Or email Rebecca.Garcia@study.beds.ac.uk

Appendix 13: Primary care staff recruitment letter

University of Bedfordshire

LUTON & DUNSTABLE UNIVERSITY HOSPITAL
CLINICAL EXCELLENCE, QUALITY & SAFETY

Dear Colleague,

A local study identifying and exploring causes of infant deaths.

I am writing to invite you to participate in the above study.

As you are aware, adverse birth outcomes (low birth weight or infant mortality) is problematic for Pakistani and Bangladeshi women. Luton has a large Pakistani and Bangladeshi community and therefore this research within the local population is salient. The Department of Health and Public Health Luton have also made reducing infant mortality and maternal inequalities key priorities.

It is hoped that this local research will add to the existing body of research by identifying risk factors locally for pregnant women, identification of similarities and differences of cultural maternal health beliefs and include an understanding of health care professional views on the needs of Pakistani and Bangladeshi women, which together will help forward current policy and maternity interventions in this disadvantaged and high risk group of mothers.

Please contact Rebecca Garcia directly, where arrangements will be made to participate in focus group discussions (small group discussions of 6–8 clinicians, lasting approximately 60 minutes). Please refer to the attached information sheet for further information.

Many thanks in advance of your time in contributing to this valuable research.

Yours sincerely,

Rebecca Garcia RGN. MSc. MBPsS.
PhD student
Institute for Health Research
http://www.beds.ac.uk/research/ihr
University of Bedfordshire
Tel 01582 743744 or 07598330636

Appendix 14: Staff information sheet

LUTON & DUNSTABLE UNIVERSITY HOSPITAL
CLINICAL EXCELLENCE, QUALITY & SAFETY

Participant information sheet

University of Bedfordshire

A local study identifying and exploring causes of infant death.

I (Rebecca Garcia) would like to invite you to take part in my research study. But before you decide I would like you to understand why the research is being done and how it involves you. This information sheet has been produced to help you decide whether to take part.

Part 1 of this sheet tells you the purpose of this study and what will happen to you if you take part. Part 2 gives you more detailed information about the study. If you are considering taking part, I will discuss the study and what this means for you in more detail before the focus group and this will take about 5–10 minutes over the telephone.

The purpose of this study is to identify areas for improving maternity services and will meet the requirements for a PhD qualification, supervised by Dr Nasreen Ali and Professor Gurch Randhawa at the University of Bedfordshire.

If you have any questions, please contact me by phone (07598330636) or email Rebecca.Garcia@beds.ac.uk

Part 1: An overview

Pakistani and Bangladeshi mothers living in Luton experience higher rates of infant mortality than white British mothers. Figures have shown that Pakistani mothers have higher rates of babies that are born preterm and Bangladeshi mothers have higher rates of infants born considered small for gestational age (< 2.5kg at birth). Babies that are born preterm or small for gestational age have higher rates of morbidity and mortality. This study aims to explore the factors that might contribute to this poor outcome so that the local services can make improvements to the care of these mothers during pregnancy and childbirth to reduce the high numbers of infant deaths in this population.

Why have we contacted you? The reason you have been asked to take part is because you are part of the multi-disciplinary staff team providing front line care for pregnant mothers in Luton. Consequently, I am interested in your knowledge, experience and views on the maternity care needs of local women accessing the maternity care.

Do I have to take part? Taking part is completely up to you. If you decide to take part, you will be asked to sign a consent form. You may change your mind at any time, including during the focus group (group discussion), without providing a reason.

What will happen if I take part? If you are considering taking part, Rebecca will telephone/email you to discuss taking part and answer any questions you may have. If you agree to take part, a focus group will be arranged (no sooner than 24 hours), consisting of 6–8 other staff members. At the beginning of the focus group, Rebecca will go through the information sheet and answer any questions. You will then be asked to sign a consent form that shows that you agree to take part. The focus group will be audio recorded so that we do not miss any valuable information that you share. The group will discuss care needs of pregnant women in Luton. This will take up to 90 minutes. After the focus group, the audio is transcribed. At the point of transcribing, all personal details and information becomes de-identified.

What are the advantages and disadvantages of taking part? The topic of babies being unwell or dying is upsetting, however Rebecca will be sensitive to this. The discussion group will focus on your thoughts and ideas around maternity care needs for expectant women using maternity services in Luton. This will help inform policy and future service development.

What if there is a problem? Should you have any concerns or complaints during taking part in the study, part 2 details how this will be addressed.

Will my taking part in the study be kept confidential? Any information you share with the research team will be treated in the strictest confidence. However, confidentiality from other focus group members cannot be fully assured (see part 2 for a fuller explanation). The audio recording is transcribed and identifying information will be de-identified so that names, dates and places become; [name] [date] [place].

The research is expected to take 18 months until publication.

If you are still interested take part, please read part 2 carefully before you decide.

Part 2: More detail

What happens if I change my mind? You can decide to withdraw at any time, even during the focus group discussion. You do not have to give a reason. It will be explained before commencing any focus group sessions that Rebecca will keep any audio recordings made up to the point at which you decide to withdraw, due to the complexity of extracting conversational data from the audio recording.

What do I do if there is a problem?

Complaints: If you have any concerns please contact Rebecca Garcia (researcher) rebecca.garcia@beds.ac.uk or mobile 07598330636. If you remain unhappy and wish to discuss the matter more formally please contact Dr Nasreen Ali (Director of Studies) nasreen.ali@beds.ac.uk or mobile 07969062428.

Harm: No harm is intended by taking part in this research. The University of Bedfordshire operates indemnity insurance for students undertaking research. Please contact the University of Bedfordshire for more details.

Will my taking part in this study be confidential? Your details and information will be kept confidential. This means that Rebecca and the “research team” (meaning supervisors Dr Ali, Prof Randhawa and a University approved translator) will only have access to your personal information. Data (i.e. recordings, transcripts and analysis) will be de-identified to protect your privacy and identity.

Personal information (names, email addresses and phone numbers) will be kept in a locked filing system in a locked and alarmed building at the University of Bedfordshire, Putteridge Bury Campus. This information is used only for the purposes of communicating with you for the current study. Paper consent forms and bio-questionnaire information will be kept separate, but also in a locked filing system, in a locked and alarmed facility at the University. All audio recordings, transcripts and analysis will be kept on an encrypted USB and University password protected computer. All research data will only be shared with the research team and a University approved translator (if required). Data will be kept for a maximum of 5 years (as per current guidelines) and only used in association with the current research study. The safe destruction of digital and paper material will follow University procedures at that time, following data protection legislation.

Confidentiality from other focus group members cannot be fully assured. At the beginning of each focus group, Rebecca will request that the focus group conversation is kept confidential between members and not discussed beyond the session. Also, Rebecca is required to report any concerns regarding any risks of harm to Dr Ali, to ensure the correct safeguarding procedures are followed.

What happens to the results of the study? At the end of the study the results will be published in an academic thesis, international academic journals and a local “Findings feedback” presentation which will be carried out to the local population and interested people.

Who is organising and funding the study? This study is being funded by the Steel Charitable Trust in the form of a stipend for a PhD. The PhD is being conducted at the University of Bedfordshire, under the supervision of Dr Nasreen Ali and Professor Gurch Randhawa.

Who has reviewed this study? Research conducted in the NHS is considered by an independent group of people (known as the Research Ethics Committee) to protect your interests. This study was reviewed and given a favourable opinion by Essex Research Ethics Committee (insert date)

Can I get more information about taking part in research?

General information about taking part in research can be found from the NHS Choices web site:
http://www.nhs.uk/Conditions/Clinicaltrials/Pages/Gettinginvolvedinresearch.aspx

Further information about this research study is available from Rebecca Garcia (researcher) rebecca.garcia@beds.ac.uk or mobile 07598330636. If you want to discuss taking part with a neutral person, please contact The Child Bereavement Charity on 0800 0288840. If you have concerns or are unhappy, please contact Dr Nasreen Ali (Director of Studies) nasreen.ali@beds.ac.uk or mobile 07969062428.

For more information, please contact:

Rebecca Garcia
Research Student
Institute of Health Research
University of Bedfordshire
Putteridge Bury
Hitchin Road
Luton
LU2 8LE
Telephone 01582 743744
Mobile 07598330636
Email Rebecca.Garcia@beds.ac.uk

Appendix 15: Staff consent form

LUTON &
DUNSTABLE
UNIVERSITY
HOSPITAL
CLINICAL EXCELLENCE, QUALITY & SAFETY

Consent Form (staff)

University of
Bedfordshire

Title of Project:

Explaining factors that contribute to low birth weight, stillbirth and infant mortality in Pakistani and Bangladeshi women living in Luton.

Name of Researcher: Rebecca Garcia (Supervisor: Dr Nasreen Ali)

Please initial the box

I confirm that I have read and understood the information sheet given to me by the researcher. I confirm that I have had the chance to ask questions. ☐

I understand that taking part is voluntary and that I may stop and withdraw my data at any time. ☐

I understand that I may become upset. ☐

I give my consent to take part in the above study. ☐

I give my consent for the interview / focus group to be audio recorded and transcribed (written out). ☐

Name of Participant (print) Signature Date

______________________ ____

Researcher(print) Signature Date

______________________ ____

To be completed by researcher only Research Site______________________________
Participant Identification Number____

Appendix 16: Staff bio-questionnaire

LUTON & DUNSTABLE UNIVERSITY HOSPITAL
CLINICAL EXCELLENCE, QUALITY & SAFETY

University of Bedfordshire

Study looking at identifying and exploring infant deaths

Bio-Questionnaire (staff)

Question	Response
Age?	
Ethnicity?	
How long have you lived in UK?	
Highest level of education? (GCSE, NVQ, None…..etc.)	
Current job role?	
Length of time in current job?	

Appendix 17: Staff topic guide

LUTON & DUNSTABLE UNIVERSITY HOSPITAL
CLINICAL EXCELLENCE, QUALITY & SAFETY

University of Bedfordshire

Maternity health professional's views on the service needs of Pakistani, Bangladeshi and white British pregnant women

Topic Guide

1. Introduction

- Thanks.
- Introduce self, supervisors and University of Bedfordshire.
- Give background and purpose of the study: we want to identify factors that may contribute to poor birth outcomes in babies of Pakistani and Bangladeshi women in Luton. This will help identify areas to improve maternity services in the future.
- Explain how current literature shows that Pakistani and Bangladeshi mothers have worse birth outcomes when compared to white British women and therefore shows inequalities. Evidence also shows that mothers' level of satisfaction is influenced by their experience, with the staff (personally) and services (institutionally).
- Refer participants to information sheet – check that they have read and understood the information sheet, confidentiality information and check understanding.
- Explain the consent procedure, right to withdraw, confidentiality and audio recording of the discussion. Break at any time if required. Interview discussion to last 60-90 minutes.
- Explain how the discussion that is going to take place will be used in the research.
- Explain that the findings form part of PhD thesis and will be published in academic journals and findings feedback – local presentation to local service providers and interested community members.
- Respectful listening.
- Allow for questions.
- Complete consent forms, bio questionnaire and conduct icebreaker.

2. Information about maternity services

I'd like to start by talking about what maternity services are offered in Luton and your roles in that service.

What are your role(s) within the maternity services pathway?

- *Probe: for role (title) and place in maternity care pathway e.g. preconception/ antenatal/ post-natal.*
- *Probe: for views on job role e.g. clinical or care led decision maker, supportive, advocate, educational, surveillance*.

Would you describe the client group that accesses your services?

- *Probe: for diversity of clients e.g. which ethnic groups (which ethnic groups do you see most often),SES, employed / unemployed, health literate / health illiterate*
- *Probe: younger/ older women, comorbidities -which are most common and similarities/differences among different ethnic groups, high-risk pregnancies e.g. examples, views on causes.*

- *Probe: for views on how this has changed over time/during your work career e.g. changes in ethnic groups accessing services, comorbidities, education.*
- *Probe: for speed of observed changes in client group(s) (if any).*
- *Probe: what is the general catchment area to your service i.e. Luton only or further afield.*

What would you expect pregnant mothers to know about local maternity services?

- *Probe: for mothers' knowledge of maternity care pathway, awareness of preconception care, types of antenatal care (hospital/community/home), benefits of early-screening, monitoring and surveillance scans, specialist genetic screening services, labour ward visits, role of health visitors and Children's Centres advice and baby developmental checks.*
- *Probe: for where mothers would be able to get information about available local services from e.g. midwife, GP, leaflets, Children's Centre, TV, internet, family, friends, and previous experience*.
- *Probe: for views on* ***differences*** *in knowledge among different ethnic groups e.g. Pakistani/Bangladeshi women compared to women from white and other ethnic groups in relation to knowledge of pre-conception advice, folic acid, healthy diet during pregnancy, antenatal care (surveillance), early-screening (risk detection), scans, labour ward visits, health visitors, Children's Centres, post-natal checks, baby checks, genetic screening, breast feeding clinics.*
- *Probe: for views on* ***similarities*** *in knowledge among different ethnic groups e.g. Pakistani/Bangladeshi women compared to white women and other ethnic groups in relation to knowledge of pre-conception advice, folic acid, healthy diet during pregnancy, antenatal care (surveillance), early-screening (risk detection), scans, labour ward visits, health visitors, Children's Centres, post-natal checks, baby checks, genetic screening, breast feeding clinics.*
- *Probe: for views on the reasons for differences and similarities in knowledge of services by Pakistani, Bangladeshi and other ethnic groups e.g. language and communication, length of stay in UK, born in UK, education (British Education/no education), cultural and/or religious influences (God's will, collaborative influence on decision making / autonomous decision making), differences in health literacy.*

3. Using maternity services

I would like to discuss your opinions on how Pakistani and Bangladeshi women use maternity services.

Are there any differences in the way that Pakistani/Bangladeshi mothers use maternity services when compared to white and other ethnic groups?

- *Probe: for views on women favouring alternative healthcare (herbalists, traditional healers), perceptions of pregnancy being a natural event and not needing medical intervention, antenatal or post natal depression.*
- *Probe: for views of women's poor knowledge or information of available services, unaware of benefits of services, entitlement to services, low trust and confidence in service providers, delayed access, high/low expectations of service, high/low perceived satisfaction.*
- *Probe: for communication barriers, language barriers, poor understanding (and application) of positive health issues related to maternal health i.e. health literacy (e.g. taking of folic acid).*
- *Probe: for views on physical barriers, e.g. transport problems, lack of money for taxi.*
- *Probe: for views of cultural factors e.g. concealment/secrecy of pregnancy, lack of trust in the service providers, cousin marriage, language and communication problems (e.g. husband speaking English, embarrassment of disclosure of sensitive issues), needing permission to attend appointments (passivity), levels of social support.*
- *Probe: for views around religion, e.g. fear of advice – termination of pregnancy (fatalistic views), lack of female staff/separate facilities for women (purdah), God's will.*

- *Probe: for views on delayed booking (and reasons why), non-concordance with appointments / services, breast feeding behaviour +/-.*

4. Providing services to diverse ethnic groups

I would like to discuss some of the barriers you experience when delivering maternity services to Pakistani/Bangladeshi women, white and other ethnic groups and how you address these (enablers).

In your views what are the barriers you experience when delivering maternity services to Pakistani and Bangladeshi women and how (if at all) these are different from white women/women from other ethnic groups?

- *Probe: for views on cultural barriers e.g. knowledge of cultural behaviours, limited cultural awareness, symptom expression (cultural differences), differences in autonomous or collaborative decision making, low trust, poor understanding on cultural conceptions of pregnancy and institutional care (e.g. 40 day confinemen)t, pregnancy as a natural event, shame, (embarrassment) patients' fears that hospital increases risk of interventions and poor outcomes.*
- *Probe: for religious barriers e.g. halal diet, staff understanding of religious requirements, requirement of female staff, staff understanding of religious needs pre/post-delivery (including death and burial rituals).*
- *Probe: for views on effective communication, language and communication barriers language proficiency, access and availability of medically trained interpreters, interpreters as advocates, information provided in other languages poor or reduced level of information provided in alternate language, poor health and language literacy (even if information provided in Urdu or Bengali), poor informed decision making by patient.*
- *Probe: for service organisation barriers e.g. rigid appointments, structural organisation of services that leads to shame//embarrassment, poor cultural competence, lack of cultural competence training, poor awareness of when/where/how to access help outside routine appointments.*
- *Probe: for experience of staffing issues e.g. under staffing,numbers of midwives and skill mix, ethnic/religious diversity of staff.*

In your opinion, what personal (staff) and structural (NHS) enablers might help overcome the barriers you mentioned?

- *Probe: for views on cultural enablers e.g. knowledge of cultural behaviours, good cultural awareness, symptom expression (cultural differences), differences in autonomous or collaborative decision making, awareness of cultural issues – shame, (embarrassment) patients fears that hospital increases risk of interventions and poor outcomes and sensitive staff (institutional responses).*
- *Probe: for views on religious enablers e.g. providing halal diet, staff understanding (respect) of religious requirements, requirement of female staff, staff understanding of religious needs pre/post-delivery (including death and burial rituals).*
- *Probe: for views on effective communication, effective strategies to overcome language difficulties, access and availability of medically trained interpreters, interpreters as advocates, information provided in other languages, poor or reduced level of information provided in alternate languages and mediums (TV, podcast), strategies to overcome poor health and language literacy (even if information provided in Urdu or Bengali), improved decision making by patient.*
- *Probe: for views on service organisation enablers e.g. flexible appointments, structural organisation of services that decreases risks of shame/embarrassment, access to transport.*
- *Probe: for views on staffing issues e.g. appropriate staff skill mix,numbers of midwives and skill mix, ethnic/religious diversity of staff, empathetic staff.*

In your experience/view how does your ethnicity/ethnic group identity impact on the relationship between you (care giver) and a Pakistani or Bengali mother?

- *Probe: for views on the staff understanding of "ethnicity" (race concept/biological or umbrella term for self-identity including cultural/religious factors), explanations of diversity and difference.*
- *Probe: for the views of staff definition of SES status (education, income, occupation) SES status: perception of poverty, perceptions of poor education, perception of poorer paid employment.*
- *Probe: for views on whether SES impacts on staff relationship (caregiver – mother) and how?*
- *Probe: for understanding of cultural differences between groups and within group diversity: i.e. women as homemakers or employed, numbers of children, extended or nuclear family living, increased/decreased social support, autonomous/collaborative decision making, higher/lower perceived control, within-group diversity and between group diversity.*
- *Probe: for views on whether cultural differences impact on staff relationship (caregiver – mother) and how?*
- *Probe: views on religious differences e.g. perception that Qur'an dictates no terminations, fatalistic views, benefit of prayer.*
- *Probe: for view on whether religion impacts on staff relationship (caregiver – mother) and how?*

Discuss if these are similar or different to barriers experienced when delivering maternity services to other ethnic groups

5. Views of high-risk pregnancies.

I would like to ask your views on high risk pregnancies and adverse birth outcomes (low birth weight, stillbirth and infant mortality) in Pakistani and Bangladeshi women.

Summary of statistics in Luton

Low birth weight and infant mortality is higher in Luton than the national average: LBW is 9.5% versus 6.5% nationally; and infant mortality rate is 6.5/1000 live births versus 4.0/1000 live births nationally. In Luton, the number of stillbirths reported in 2012 was 38 and this was the highest number recorded in the East of England[168]. Moreover, Dallow ward reports the highest infant mortality rate in Luton and has the highest proportion of Pakistani residents[169]. In the United Kingdom (UK), Pakistani mothers demonstrate the highest perinatal death rate (53.1/1000 live births) compared to white British mothers (23.3/1000 live births)[170]

In your experience/view how does being a Pakistani or Bangladeshi mother in Luton impact on the risk of a low birth weight, stillbirth or perinatal death, compared to other mothers of different ethnic groups?

- *Probe: for views on poor communication, language and communication barriers, language proficiency, access and availability of medically trained interpreters, interpreters as advocates, information provided in other languages, poor or reduced level of information provided in alternate*

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[168] (Luton Clinical Commissioning Group, 2014; Clinical Indicators Team, 2014; Office for National Statistics, 2013b)

[169] (Child Death Overview Panel, 2013a)

[170] (Office of National Statistics, 2011b)

language, poor health and language literacy (even if information provided in Urdu or Bengali), poor informed decision making by patient, traditional or alternative medicine used, reduced understanding of risks.

- *Religious: fear of advice – termination of pregnancy (fatalistic views), lack of female staff/separate facilities for women (purdah) embarrassment, God's will, perception that Qur'an dictates no terminations, benefit of prayer.*
- *Probe: for views on cultural barriers e.g. knowledge of cultural behaviours, poor cultural awareness, symptom expression (cultural differences), differences in lifestyle choices (e.g. bedrest v activity), understanding of healthy eating in pregnancy (vegetarian and halal diets), differences in autonomous or collaborative decision making, low trust of staff, poor understanding of cultural conceptions of pregnancy and institutional care (e.g. 40 day confinement), pregnancy as a natural event, shame, (embarrassment) patients fears that hospital increases risk of interventions and poor outcomes, therefore delays interactions. Belief that pregnancy is "natural" and therefore not to be interfered with.*

In your view, what are the causes of low birth weight, stillbirth and infant mortality among Pakistani and Bangladeshi women?

- *Probe: biological factors: genetics/hereditary, cousin marriage, early programming hypothesis (development in the womb influences later life events including health outcomes and pre-determined stress responses), preterm birth, growth retardation, congenital abnormalities, comorbid diseases (e.g. obesity and diabetes), maternal age, number and frequency of pregnancies, Asian women delivering smaller babies.*
- *Probe: views on psychological factors (antenatal/postnatal depression, stress, perceived control, autonomy).*
- *Probe: views on social factors (cousin marriage, collaborative decision making), cultural factors(e.g. ethnicity, poverty, communication issues, health literacy, normalising pregnancy).*
- *Probe: your views on whether risk factors as consequence of other issues, i.e. health inequalities, SES factors, poverty, poor health literacy.*

Discuss if these are similar or different to barriers experienced when delivering maternity services to other ethnic groups.

6. Service improvements

I would like to understand what changes/improvements to maternity services you think are needed to reflect the diversity of clients and specifically the needs of Pakistani and Bangladeshi women.

Are there any changes we can make to services locally that may improve adverse birth outcomes in Pakistani or Bangladeshi mothers?

- *Probe: for views on advocates (i.e. person working on behalf of mothers), female staff, female only antenatal classes, separate facilities for women, culturally competent staff (e.g. staff that have awareness of diverse religious, cultural beliefs, and different social needs, connectedness with others, friends, community), maternity services that empower and meet diverse needs, non-judgmental, and encourage inclusion and trust. Community-based support, more information in variety of languages and mediums (TV, computer, apps), proactively information-giving services.*
- *Probe: for ideas on staff training /information on cultural and religious behaviours influencing Pakistani and Bangladeshi women's maternity choices, what type of training/information specifically, who should deliver this and when, organisation support to undergo training e.g. resources/time.*

6. Closing. Any other comments, suggestions or questions

Any further thoughts and reflections?

Summarise key points of discussion

Appendix 18: Institute for Health Research Ethic approval

University of
Bedfordshire

Institute for Health Research
Putteridge Bury
Hitchin Road
Luton
Beds LU2 8LE

26 November 2014

Rebecca Garcia
Student number: 0913079

Dear Rebecca Garcia

Re: IHREC Application No: IHREC442
Project Title: Explaining factors that contribute to low birth weight, stillbirth and infant mortality in Pakistani and Bangladeshi women living in Luton.

The Ethics Committee of the Institute for Health Research has considered your revised application and has decided that the proposed research project should be approved with no further amendments.

Please note that if it becomes necessary to make any substantive change to the research design, the sampling approach or the data collection methods a further application will be required.

Yours sincerely

Dr Yannis Pappas

Head of PhD School, Institute for Health Research
Chair of Institute for Health Research Ethics Committee

Appendix 19: NHS Ethic approval

NRES Committee East of England - Essex
The Old Chapel
Royal Standard Place
Nottingham
NG1 6FS
Telephone: 0115 883 9695

NHS
Health Research Authority

18 June 2015
Mrs Rebecca Garcia
University for Bedfordshire
Putteridge Bury
Luton
LU2 8LE
Dear Mrs Garcia

Study title:	**Explaining factors that contribute to low birth weight, stillbirth and infant mortality in Pakistani and Bangladeshi women living in Luton.**
REC reference:	**15/EE/0181**
Protocol number:	**n/a**
IRAS project ID:	**157751**

Thank you for your submission of 02 June 2015, responding to the Committee’s request for further information on the above research and submitting revised documentation. The further information has been considered on behalf of the Committee by the Chair and another Committee member.
We plan to publish your research summary wording for the above study on the HRA website, together with your contact details.
Publication will be no earlier than three months from the date of this favourable opinion letter. The expectation is that this information will be published for all studies that receive an ethical opinion but should you wish to provide a substitute contact point, wish to make a request to defer, or require further information, please contact the REC Manager, Mrs Helen Poole, NRES Committee.EastofEngland-Essex@nhs.net.
Under very limited circumstances (e.g. for student research which has received an unfavourable opinion), it may be possible to grant an exemption to the publication of the study.

Confirmation of ethical opinion
On behalf of the Committee, I am pleased to confirm a favourable ethical opinion for the above research on the basis described in the application form, protocol and supporting documentation as revised, subject to the conditions specified below. Conditions of the favourable opinion
Management permission or approval must be obtained from each host organisation prior to the start of the study at the site concerned.

Conditions of the approval
Management permission ("R&D approval") should be sought from all NHS organisations involved in the study in accordance with NHS research governance arrangements.
Guidance on applying for NHS permission for research is available in the Integrated Research Application System or at http://www.rdforum.nhs.uk. Where a NHS organisation’s role in the study is limited to identifying and referring potential participants to research sites ("participant identification centre"), guidance should be sought from the R&D office on the information it requires to give permission for this activity.
For non-NHS sites, site management permission should be obtained in accordance with the procedures of the relevant host organisation.

Sponsors are not required to notify the Committee of approvals from host organisations
Registration of Clinical Trials All clinical trials (defined as the first four categories on the IRAS filter page) must be registered on a publically accessible database. This should be before the first participant is recruited but no later than 6 weeks after recruitment of the first participant. There is no requirement to separately

notify the REC but you should do so at the earliest opportunity e.g. when submitting an amendment. We will audit the registration details as part of the annual progress reporting process.

To ensure transparency in research, we strongly recommend that all research is registered but for non-clinical trials this is not currently mandatory. If a sponsor wishes to request a deferral for study registration within the required timeframe, they should contact hra.studyregistration@nhs.net. The expectation is that all clinical trials will be registered, however, in exceptional circumstances non registration may be permissible with prior agreement from NRES. Guidance on where to register is provided on the HRA website.
It is the responsibility of the sponsor to ensure that all the conditions are complied with before the start of the study or its initiation at a particular site (as applicable).

Document	*Version*	*Date*
Copies of advertisement materials for research participants [staff recruitment flyer]	v1	17 March 2015
Evidence of Sponsor insurance or indemnity (non NHS Sponsors only) [Insurance 1]	v1	14 April 2015
GP/consultant information sheets or letters [consultant cover letter]	v1	01 April 2015
Interview schedules or topic guides for participants [Staff TG v1]	v1	14 April 2015
Interview schedules or topic guides for participants [Bereaved mothers TG v1]	v2	02 June 2015
Letters of invitation to participant [recruitment pack]	v1	14 April 2015
Letters of invitation to participant [staff invite letter]	v1	17 March 2015
Non-validated questionnaire [staff Bio Q]	v1	17 March 2015
Non-validated questionnaire [mother bioQ]	v1	17 March 2015
Other [Debrief and help]	v1	14 April 2015
Other [GP letter from researcher]	v1	02 June 2015
Other [GCP certificate]	v1	02 June 2015
Other [Reviewer response table]	v1	02 June 2015
Participant consent form [consent form]	v2	02 June 2015
Participant consent form [mothers consent form]	v2	02 June 2015
Participant information sheet (PIS) [mothers info sheet]	v2	02 June 2015
Participant information sheet (PIS) [staff info sheet]	v2	02 June 2015
Research protocol or project proposal [Protocol Infant mortality]	v2	02 June 2015
Summary CV for Chief Investigator (CI) [CV Rebecca Garcia]	v1	14 April 2015
Summary CV for supervisor (student research) [CV Nasreen Ali]	v1	22 April 2015
Summary, synopsis or diagram (flowchart) of protocol in non technical language [Recruitment process]	v2	02 June 2015

Statement of compliance

The Committee is constituted in accordance with the Governance Arrangements for Research Ethics Committees and complies fully with the Standard Operating Procedures for Research Ethics Committees in the UK.

After ethical review

Reporting requirements

The attached document “After ethical review – guidance for researchers” gives detailed guidance on reporting requirements for studies with a favourable opinion, including:

- Notifying substantial amendments
- Adding new sites and investigators
- Notification of serious breaches of the protocol
- Progress and safety reports
- Notifying the end of the study

The HRA website also provides guidance on these to

User Feedback

The Health Research Authority is continually striving to provide a high quality service to all applicants and sponsors. You are invited to give your view of the service you have received and the application procedure. If you wish to make your views known please use the feedback form available on the HRA website: http://www.hra.nhs.uk/about-the-hra/governance/quality-assurance/

HRA Training

We are pleased to welcome researchers and R&D staff at our training days – see details at http://www.hra.nhs.uk/hra-training/

15/EE/0181 Please quote this number on all correspondence

With the Committee’s best wishes for the success of this project.

Yours sincerely
PP

Dr Alan Lamont
Chair

Email: NRESCommittee.EastofEngland-Essex@nhs.net

Enclosures: “After ethical review – guidance for researchers”

Copy to:

Dr Nasreen Ali
Ms Diana Hardy, Luton and Dunstable University Hospital

Appendix 20: Confidentiality agreement

Confidentiality Agreement

It is understood and agreed to that the below identified discloser of confidential information may provide certain information that is and must be kept confidential. To ensure the protection of such information, and to preserve any confidentiality necessary under patent and/or trade secret laws, it is agreed that

1. The **Confidential Information** to be disclosed can be described as and may include:

   Research and development, Personal experiences and opinions, invention description(s), technical and business information relating to proprietary ideas and inventions, ideas, patentable ideas, trade secrets, interview transcriptions, existing and/or contemplated products and services, finances and financial projections, customers, clients, marketing, and current or future business plans and models, regardless of whether such information is designated as ‘Confidential Information’ at the time of its disclosure.

2. The ***Recipient*** agrees not to disclose the confidential information obtained from the ***discloser*** to anyone unless required to do so by law.

3. This Agreement states the entire agreement between the parties concerning the disclosure of Confidential Information. Any addition or modification to this Agreement must be made in writing and signed by the parties.

4. If any of the provisions of this Agreement are found to be unenforceable, the remainder shall be enforced as fully as possible and the unenforceable provision(s) shall be deemed modified to the limited extent required to permit enforcement of the Agreement as a whole.

WHEREFORE, the parties acknowledge that they have read and understand this Agreement and voluntarily accept the duties and obligations set forth herein.

Recipient of Confidential Information:

Name (Print or Type):

Signature:

Date:

Discloser of Confidential Information:

Name (Print or Type): Rebecca Garcia (University of Bedfordshire)

Signature:

Date: 28-01-2016

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Appendix 21: Lay mothers FG characteristics

Table A1 focus groups characteristics

Focus group	**Ethnicity**	**FG Language**	**N**	**Duration (minutes)**
1	WB	English	5	70
2	WB	English	5	69
3	Pakistani	English	4	84
4	Pakistani	English	6	134
5	Bangladeshi	English	4	73
6	Pakistani	English	3	88
7	Bangladeshi	Sylheti	4	81
8	Bangladeshi	Sylheti	8	64
9	Pakistani	Urdu	7	62
Total			46	

Tables A.3 – A.11 Participant characteristics of each focus group

Table A.3

Focus group 1							
White British	**Participant**	**Age**	**Time in UK?**	**Highest education level**	**Domestic Family members**	**Number of existing children**	**Gestation (weeks) on first GP appointment**
	1	23	23	GCSE	partner	2	9
	2	24	24	Level 2 NVQ	partner + 2 children	2	10
	3	23	23	GCSE	daughter	1	14
	4	42	42	GCSE	daughter	6	6
	5	23	23	GCSE	partner	2	17

Table A.4

Focus group 2							
WB	**Participant**	**Age**	**Time in UK?**	**Highest education level**	**Domestic living arrangements**	**Number of existing children**	**Gestation (weeks) on first GP appointment**
	1	27	27	NVQ 3	parents	1	6
	2	25	25	NVQ 3	mum, stepdad	1	7
	3	25	25	GCSE	son	1	6
	4	40	40	NVQ 3	husband 2 sons	2	4
	5	32	32	A level	husband, 3 children	3	5

Table A.5

Focus group 3							
Pakistani	**Participant**	**Age**	**Time in UK?**	**Highest education level**	**Domestic living arrangements**	**Number of existing children**	**Gestation (weeks) on first GP appointment**
	1	32	14	NVQ 2	husband, 2 children	2 (+1)	6
	2	38	38	MA	husband 6 children	6	6
	3	28	28	Cert Ed	husband, son, sister, brother-in-law	1	1
	4	24	24	BA (hons)	husband, children	2	6

Table A.6

Focus group 4							
Pakistani	**Participant**	**Age**	**Time in UK?**	**Highest education level**	**Domestic living arrangements**	**Number of existing children**	**Gestation (weeks) on first GP appointment**
	1	34	8		husband, child	1	4
	2	30	30	PG degree	parents-in-law, husband, sister in law	2	5
	3	40	31	degree	husband children	6	4
	4	27	5	MBA	husband, daughter	1	6
	5	31	31	BSc	husband, children	2	8
	6	34	34	BSc	husband, child	1	6

Table A.7

Focus group 4							
Bangladeshi	**Participant**	**Age**	**Time in UK?**	**Highest education level**	**Domestic living arrangements**	**Number of existing children**	**Gestation (weeks) on first GP appointment**
	1	33	33	BA (hons)	husband, 5 children	5	8
	2	28	25	NVQ	husband, in-laws	1	6
	3	28	28	GCSE	mum	2	4
	4	27	27	A level	husband, children	2	5

Table A.8

Focus group 6							
Pakistani	**Participant**	**Age**	**Time in UK?**	**Highest education level**	**Domestic living arrangements**	**Number of existing children**	**Gestation (weeks) on first GP appointment**
	1	39	39	MSc	husband, daughter	1	3
	2	41	41	A level	husband, children	3	5
	3	32	32	BSc	husband, child	1	15

Table A.9

Focus group 7							
Bangladeshi (Sylheti)	**Participant**	**Age**	**Time in UK?**	**Highest education level**	**Domestic living arrangements**	**Number of existing children**	**Gestation (weeks) on first GP appointment**
	1	30	30	BSc	husband, daughter	1	5
	2	31	31	BSc	husband, 4 children, in-laws	4	5
	3	26	5	GCSE equal	husband, daughter	3	10
	4	32	8	GCSE	husband, child	1	6

Table A.10

Focus group 8							
Bangladeshi	**Participant**	**Age**	**Time in UK?**	**Highest education level**	**Domestic living arrangements**	**Number of existing children**	**Gestation (weeks) on first GP appointment**

(Sylheti)	1	31	11	Level 2 NVQ	husband 2x children	2	6
	2	33	30	GCSE	husband 3x children	3	6
	3	34	32	Level 3	husband, mother-in-law, 3 children	3	7
	4	26	8	GCSE equiv	mother-in-law, husband, 4 children	4	4
	5	31	31	NVQ	husband, 2 children	2	12
	6	42	21	GCSE equiv	husband and child	4	6
	7	33	2	BA (hons)	husband, 4x children	4	8
	8	29	9	A level equi	Husband, 3x children	3	6

Table A.11

Focus group 9							
Pakistani (Urdu)	**Participant**	**Age**	**Time in UK?**	**Highest education level**	**Domestic living arrangements**	**Number of existing children**	**Gestation (weeks) on first GP appointment**
	1	23	2	BA (hons)	husband, mother-in-law, father-in-law, son, husband's brother	1	3
	2	25	4	Matric (GCSE)	Mother-in-law, father-in-law, husband and daughter	1	5
	3	30	6	MPA	husband and children	2	3
	4	33	8	ITQ ESOL 2	mother and father-in-law	2	12
	5	33	16	year 8	husband and 4 children	4	2
	6	38	38	GCSE	2 daughters	2	7
	7	49	39	matrick (GCSE)	husband 5 children	5	12

Appendix 22: Lay mothers coding framework

Main theme	Sub-theme	Sub-sub theme
Knowledge and information of pregnancy and perinatal mortality	Limited knowledge of risk factors	
	Desire for more information	
	Cultural beliefs	
Attitudes and perceptions to pregnancy and perinatal mortality	Attitudes about pregnancy and perinatal mortality	
	Perceptions of intuition	
	Culture and religion in perceptions of pregnancy	Genetic factors
		Fatalistic attitudes
Experiences with maternity services	Positive experiences	
	Negative experiences	
	Levels of social support	
	Cultural needs	

Appendix 23: Bereaved mothers coding framework

Main theme	**Sub-theme**
Knowledge and information of pregnancy and perinatal mortality	Limited knowledge of risk factors
	Desire for more information
	Cultural beliefs
Attitudes and perceptions to pregnancy and perinatal mortality	Attitudes about pregnancy and perinatal mortality
	Attitudes to screening tests and post-mortems
	Perceptions of intuition
	Perceptions of feeling a burden
Experiences with maternity services	Positive experiences
	Negative experiences
	Levels of social support
	Cultural needs

Appendix 24: Bereaved mothers characteristics

	Ethnicity	Highest qualification?	Resides with	Employed	Smoker?
1	WB	B-Tec	husband and child	p/t	stopped when preg
2	Pakistani/Muslim	A levels	husband and child	no	no
3	Pakistani	GCSE	husband and children	no	no
4	Pakistani	A levels	husband, mother-in-law, father-in-law	f/t	no
5	WB	A levels	partner & son	no	no
6	Bangladeshi	B-Tec	partner & son	no	no

Appendix 25: Staff coding framework

Main theme	**Sub-theme**
Staff perceptions of mothers' awareness of risk	Risks during preconception
	Risks during antenatal period
	Risks during postnatal period
Maternity service provision in Luton	Descriptors of service users
	Services provided
	Perceptions of the flexibility of services
	Information provided
Barriers to service use	Physical and financial barriers
	Language
	Cultural barriers