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Early life mortality in East London: a feasibility study

Summary report

Fetal and Infant Death in East London

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Key points

Background

City and Hackney and Newham have high rates of infant mortality, while the rate for Tower Hamlets is just above that for England and Wales as a whole. All three areas have high stillbirth rates.

Literature review

Previous research in East London showed that babies born to Pakistani women had the highest infant mortality rates, followed by those born to Africans and West Indians. All these were higher than the rates for babies of white mothers, while babies born to Indian and Bangladeshi mothers had the lowest infant mortality rates.

A review by the National Perinatal Epidemiology Unit concluded that three main factors, the direct effects of poverty, variations in behaviour and differential access to services, combine to cause the persistent and wide inequalities in pregnancy outcomes and in the health of babies.

A scoping study in the Northern Region found that of the interventions which seemed to have the most potential to be effective in improving perinatal and child health in general, many, for example smoking cessation, are good in themselves and may have a beneficial effect on the outcome of pregnancy. Despite this, only a few of these, notably the administration of corticosteroids to mothers in preterm labour will directly reduce infant mortality.

Analyses of routine data about the outcome of births to residents of East London

Analyses of data about births in 1999-2001 from the Regional Interactive Child Health System (RICHHS) showed that overall, 36.7 per cent of mothers were of Asian ethnic origin, 31.7 per cent white, 17.3 per cent African and 7.1 per cent 'West Indian' and that 88 per cent of births took place in the three local maternity units or at home.

The percentage of low birthweight and preterm births was high and in City and Hackney, the percentage of very preterm births was high, compared with England and Wales and England respectively.

West African and Caribbean women had high rates of very preterm birth and high rates of neonatal mortality. Neonatal mortality was low among babies born to Bangladeshi women, despite their high percentage of low weight births

Case note review

There is poor recording of socio-demographic information about mothers and an even greater lack of information about fathers. Not surprisingly, the clinical information was much more complete.

The data supplemented the information gained from the analysis of routinely collected data in suggesting that in the two areas there were different patterns of causation of death which appear likely to be related to differences between the patterns of pathology in the ethnic groups in the local populations.

As the numbers of events were small, ascertainment was incomplete and there were no controls, it was not possible to draw substantive conclusions. Although the case note review gave useful insights, it is not worth undertaking a further case note review unless there are sufficient resources to cover a larger number of years, ensure full ascertainment and include controls.

Areas for future work

Congenital anomalies

The high rate of stillbirth in East London

The high rate of preterm birth, especially in City and Hackney

Geographical variations within East London

Women who apparently did not book for maternity care

Executive summary

This report summarises a feasibility study for further research to increase the understanding of the causes of the high rates of stillbirth and infant mortality in East London in order to inform action aimed at reducing them.

The project consisted of three parts, a review of previous research and published data, analyses of routine data derived from notification of births to women living in City and Hackney, Tower Hamlets and Newham and a review of case notes at the Homerton University Hospital and the Royal London Hospital relating to late fetal losses and terminations, stillbirths and infant deaths. Fuller reports are available separately for the literature review, the case note review and the analyses of routine data for each of the three boroughs.

Background

East London is an area with high levels of deprivation and a very diverse population. In terms of the Index of Multiple Deprivation 2000, all of Hackney's wards and all but one ward from each of Newham and Tower Hamlets are among the most deprived ten per cent in England.

The ethnic composition of the three boroughs of Hackney, Tower Hamlets and Newham varies considerably. The 2001 Census showed that amongst women of childbearing age, black Africans were the largest ethnic minority group in Hackney. After white women, by far the largest group of women of childbearing age in Tower Hamlets, were Bangladeshi. In Newham the proportions of Asian and white women were similar, with black women forming the next biggest group. Data from birth registration show that the proportion of live births to women who were born outside the UK is higher than for London as a whole.

Hackney and Newham have infant mortality rates that are substantially higher than the London average and well above those for England and Wales as a whole. The rates for Tower Hamlets are usually above the England and Wales average but well below those for Hackney and Newham. This situation has persisted for many decades, despite changes in the composition of the local population.

Review of previous research

The literature review covered the epidemiology of low birth weight, gestational age at birth, stillbirths and infant deaths, focussing on research undertaken in East London or relevant to the East London context. This included a considerable body of locally focussed research undertaken during the 1980s and early 1990s in the Department of Epidemiology at the former London Hospital Medical School and two major reviews of the subject.

Previous research in this geographical area showed that, as elsewhere, the overall infant mortality rates were highest for babies born to Pakistani mothers, followed by those born to Africans and West Indians, and then white mothers. Babies of Indian and Bangladeshi mothers had the lowest overall infant mortality rate. Low birthweight and preterm delivery were important factors in infant death.

In terms of interventions aimed at making a difference to infant mortality rates, recent reviews of the literature have emphasised the patchy nature of the available evidence about

interventions commonly assumed to be effective in reducing infant mortality. A scoping study of Perinatal and Infant Health Information in the Northern Region summarised interventions which seemed to have the most potential to be effective in improving perinatal and child health in general. Although many of the identified interventions, for example smoking cessation, are good in themselves and may have a beneficial effect on the outcome of pregnancy, there is very little evidence that all but a few of these interventions will directly reduce infant mortality. A notable exception is the administration of corticosteroids to mothers in preterm labour.

There is even less evidence about the effectiveness of these and other interventions for reducing infant mortality among the most disadvantaged groups of women. With a focus on limiting the impact of poverty and disadvantage on the health and well being of low-income pregnant women, new mothers and their babies (39)The National Perinatal Epidemiology Unit reviewed the evidence from systematic reviews and recent trials. The authors contend that three main factors, the direct effects of poverty, variations in behaviour and differential access to services, combine to cause the persistent and wide inequalities in pregnancy outcomes and in the health of babies. An earlier review by the Unit suggested that poor communication could affect the quality of care.

Analyses of routinely collected birth notification data from the Regional Interactive Child Health System (RICHS)

Data derived from notification of births to residents of the City of London and the boroughs of Hackney, Newham and Tower Hamlets in the years 1999-2001 and of infant deaths among these babies were analysed to provide a descriptive account of the babies and of infant mortality.

The analyses showed that 88 per cent of births took place in one of the three local hospitals or at home. Overall, 36.7 per cent of mothers were of south Asian ethnic origin, 31.7 per cent white, 17.3 per cent African and 7.1 per cent 'West Indian'. The proportion of white mothers was markedly below that for England as a whole and the parity of women giving birth was on average higher.

The percentage of babies with a low birthweight was markedly higher than that for England and Wales. On the other hand, the percentage of births to women under 18 was lower than for England and Wales as a whole. This is surprising given the high rates of teenage pregnancy in some parts of East London, particularly Hackney.

There appear to be particularly high rates of neonatal deaths in babies of African women, who are more likely than others to have very preterm labours and thus very small babies. This pattern is also seen, but to a lesser extent, amongst Afro-Caribbean women. Babies born to Asian mothers are of lower birthweight on average. Their babies are more likely than others to weigh under 2,500g but relatively few are very preterm or weigh under 1,500g. The mortality of babies born to Bangladeshi and Indian mothers is not proportionately higher but babies of Pakistani mothers have high mortality rates.

The analysis also showed that babies of the 4.1 per cent of women who arrived in labour with no record of booking for antenatal care had relatively high rates of stillbirth and infant death.

In Hackney there was a higher percentage of babies who were very low birthweight and very preterm compared with the other boroughs. This is consistent with black Africans being the biggest ethnic minority group and also contributes to the high infant mortality rate. The stillbirth rate in Hackney is also particularly high compared with other boroughs.

Review of case notes

The case note review covered late fetal losses and terminations, stillbirths and infant deaths occurring in the Homerton University and Royal London hospitals to babies born there 2001. In all, 179 deaths were identified and notes were found for 155 of these. This overall total of 179 included 53 where the baby's mother was not resident in City and Hackney, Tower Hamlets or Newham and a further 23 where the mother's area of residence was unknown. These were excluded from the analyses, which covered 103 sets of case notes. The review of case-notes identified gaps in the recorded information in them. While ethnicity is generally recorded there is little recording of measures of social circumstances. By contrast, there is a considerable amount of information about the clinical factors related to the deaths.

Post mortems were carried out in only 36 per cent of cases. The most common causes of death were congenital anomalies, placental problems, infections and unexplained late fetal losses and stillbirths. The case note review suggested that infections might play an important role in neonatal death, particularly amongst the Black African population.

Seven postneonatal deaths were ascertained, but this includes only deaths which occurred in hospital, as most which might have occurred after discharge were not included. The predominant cause amongst hospital deaths was late sequelae of ventilation.

As the numbers of events were small, ascertainment was incomplete and there were no controls, it was not possible to draw substantive conclusions. Although the case note review gave useful insights, it is not worth undertaking a further case note review unless there are sufficient resources to cover a larger number of years, ensure full ascertainment and include controls.

Areas for possible further work

Describing patterns and causes of fetal and infant death amongst local populations is important, but the main aim of the project is to find ways of intervening to reduce stillbirth and infant mortality rates. The lack of clear evidence is disappointing. Further work is required both to explain patterns of fetal and infant mortality and to collect evidence on interventions that are effective in reducing rates.

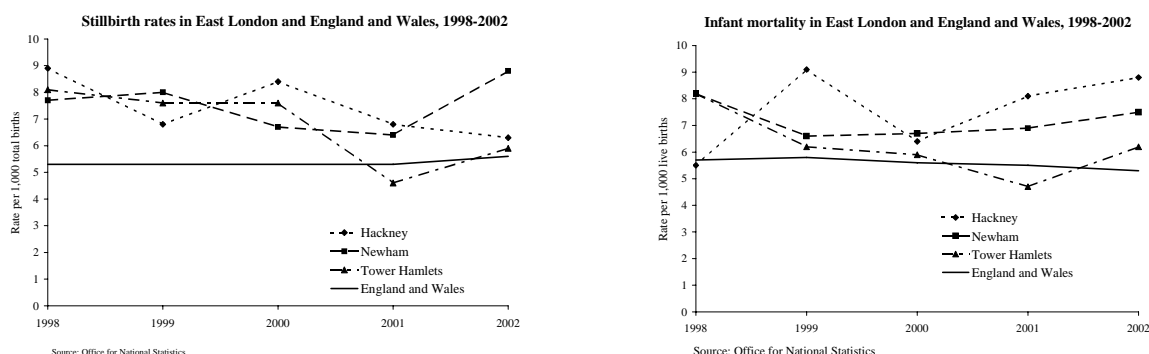
The project identified a number of possible areas for further research. Descriptive research could provide fuller information about the epidemiology of congenital anomalies in the area. Case control studies, possibly in collaboration with other areas, could answer questions about the causes of the high rates of stillbirth and preterm birth. Small area statistics could be used to analyse local geographical variations in the incidence of low birthweight and preterm birth. A focussed study of women who apparently had not booked for antenatal care could elucidate who they were and thus suggest possible approaches to providing the care.

Early life mortality in East London: a feasibility study Summary report

Introduction

In common with neighbouring East London boroughs, Hackney has had infant mortality rates which were substantially higher than the London average and well above those for England and Wales as a whole. This situation has persisted for many decades, despite changes in the composition of the local population.

Figure 1 Stillbirth and infant mortality rates in East London and England and Wales, 1998-2002



In 2002, City and Hackney Primary Care Trust decided to undertake a feasibility study to inform the design of a larger study to investigate the causes of the high infant mortality in East London. Using funding from the Neighbourhood Renewal Fund and working in collaboration with Newham and Tower Hamlets Primary Care Trusts, local acute trusts and City University, it commissioned a review of relevant past research on the subject, a case note review and analyses of routinely collected data. This summary gives an overview of the information described in fuller detail, in individual reports on each element of the feasibility study.

Hackney, Tower Hamlets and Newham

Across the three boroughs, the proportion of live births to mothers who were born outside the United Kingdom ranges from 47 per cent to 63 per cent compared with 39 per cent in London as a whole, and 14 per cent in England and Wales. Many of these women are from non-English speaking countries. Language diversity has increased further with the entry of new groups of refugees, reflecting the impact of contemporary global conflict (1).

The ethnic diversity of the three boroughs varies considerably. Amongst women of childbearing age, black Africans are the largest ethnic minority group in Hackney, followed by the Turkish, Haredi Jewish, and Vietnamese. By far the largest group of childbearing women in Tower Hamlets after white women is Bangladeshi. In Newham the proportions of Asian and white women are similar, followed by black women.

In terms of social disadvantage, all of Hackney's wards are among the 10 per cent of the most deprived in England as measured by the Index of Multiple Deprivation 2000, as are all but one of Newham's and Tower Hamlets' wards (2).

Literature review

Research in East London

During the 1980s and 90s innovative research into pregnancy and pregnancy outcomes was carried out in the former North East Thames Region by a research group headed by Eva Alberman in the Department of Epidemiology at the London Hospital Medical School. This work focused on updating and validating linkage between routine hospital data, vital statistics and child health records, and on using this information to compare the risks of stillbirth and infant death by ethnic group and, to a lesser extent, by social disadvantage. These developments enabled effective monitoring of fetal and infant mortality for the Region (3).

In 1987 a common hospital maternity database was established for the three East London districts we propose to investigate. This provided a unique opportunity to analyse in excess of 10,000 births a year in areas with sizable ethnic minority communities as well as with marked social deprivation (4). Unfortunately funding came to an end with the abolition of North East Thames Regional Health Authority (NETRHA) in 1996. Data collection systems have not been re-developed or upgraded since then, although new initiatives are being planned to implement the National Programme for Information Technology.

Stillbirths and neonatal deaths by ethnic group in NETHRA in 1983

This report begins with a study of 51,527 births to NETHRA residents, investigating the causes of stillbirths and neonatal deaths by ethnic group and social class (5). The results confirmed previous evidence of regional disparities between populations in NE and NW Thames. NE Thames had more women with high parity, more social class IV and V families, and more births outside marriage. In relation to these risk factors, the perinatal and neonatal death rates for NE Thames were up to 70 per cent higher than for NW Thames.

For NETHRA residents, babies of women born in the UK had the lowest stillbirth and neonatal death rates compared with babies of women born in the Indian sub-continent who had the highest death rates. This applied especially to those born to Pakistani women, whose rate was almost twice that rate of UK born women. Stillbirth and neonatal mortality rates among babies born to fathers of social class V were almost double those of babies born to fathers of social class I. Macerated stillbirths followed by congenital abnormalities contributed disproportionately to mortality, in particular for Irish and Pakistani women. Babies born weighing 4,000g or over to of Pakistani mothers were at greater risk of dying than other groups. Babies weighing 1,500-2,499g were at greatest risk if they were of Irish or Pakistani born mothers, while low birthweight babies were at lowest risk if their mothers were born in the West Indies.

While it does not focus specifically on the residents of Newham, Hackney and Tower Hamlets, or reflect the ethnic profile in those areas, the study is an important starting point for research investigating the contribution of ethnicity to perinatal and infant mortality. The authors point out that defining 'ethnicity' by a mother's country of birth, as they have, would become less valid as more UK born daughters of migrants have babies. It has become apparent in the course of this review that 'ethnic origin', 'country of birth' and 'years living this country' are all relevant to determining the impact of race, ethnicity, migration, and cultural assimilation on mortality.

Infant mortality and Sudden Infant Death Syndrome (SIDS) by ethnic group in East London 1987-1990

Lisa Hilder's work on infant death in East London 1987-1990 is the most comprehensive work on the differential risks for infant death within and between ethnic groups in Hackney, Newham and Tower Hamlets (4).

Overall infant mortality rates were highest for Pakistani mothers, followed by African and West Indians, and then white. Babies of Indian and Bangladeshi mothers had the lowest overall infant mortality rate. Examining mortality in relation to the age at which babies died showed a change in the hierarchy of risk amongst different ethnic groups with African and West Indian babies being at greatest risk of dying in the neonatal period. Babies from all Asian groups had similar neonatal mortality rates to those of white mothers.

A stratified analysis of known risk factors showed that low birthweight and preterm delivery carried the greatest risk of infant death. The proportion with low birthweight, under 2,500g, was highest in West Indian babies, followed by Indians, Pakistanis, Africans, and Bangladeshis. Babies of white mothers had the lowest proportion of low birthweight babies. Further analysis of this data showed that babies of West Indian and African mothers had the greatest risk of very low birth weight, under 1500g, twice that of babies of white mothers (6). This association between black race and very low birthweight persisted in women deemed low risk by age, having social support, and having had antenatal care. Continuing with Lisa Hilder's work (4), babies born between 28 and 36 weeks gestation were from four to seven times more likely to die in the first year than babies born at term. Compared with white mothers, West Indian mothers had twice the rate of preterm birth, before 37 weeks, and three times the rate of extremely preterm birth, before 28 weeks.

Smoking in pregnancy was common only in white and West Indian women, and smoking was associated with a threefold risk of SIDS for babies of white mothers.

The proportion of babies with congenital anomalies was similar in all ethnic groups, but the risk of lethal anomalies amongst Pakistanis was at least twice that of any other group.

Social support varied greatly between ethnic groups, with only one per cent of mothers in Asian groups reporting no support during pregnancy. Seven per cent of white mothers, eight per cent of African mothers and 13 per cent of West Indian mothers reported having no support. The rate of SIDS was twice the average among babies of white and West Indian women reporting lack of support.

Investigation of the different rates of SIDS deaths in babies of Bangladeshi and Anglo-European women, showed low birthweight to be the only risk factor associated with SIDS in both groups (7). The larger effects of preterm birth, high parity, and of maternal age for babies of Anglo-European women suggest that these risks may be ethno-specific to that group. Alternatively the lower rates of SIDS in the Bangladeshi group, despite higher rates of preterm birth, low birthweight and high parity, may result from protective factors specific to that group, for example infant feeding and childrearing practices.

The concept 'ethnic advantage' has been coined to account for variations in infant survival between different ethnic groups. The proposition is that first generation migrants arrive with infant rearing and life style practices that are protective, but that over time, in the next and

subsequent generations, behaviours change in the process of assimilation and any such 'advantage' may be lost (8).

An investigation of the impact of migration on reproductive and maternal behaviour, found that on average birth intervals for Bangladeshi women in Tower Hamlets became shorter after the first five years in this country (9). It was postulated that this was due to the wide availability of formula milk in a community that has traditionally used breastfeeding as a method of contraception and pregnancy spacing.

An audit of obstetric outcomes in Tower Hamlets showed that Bangladeshi women were a low risk population, with fewer interventions than white women, and with a similar perinatal mortality rate (10). The study challenges the view that migrants living in deprived areas necessarily have poor obstetric outcomes and represent a drain on resources. The authors caution that assimilation of Bangladeshis into Western culture, over time, may bring with it some of the poor outcomes of the local white population.

With the exception of Lisa Hilder's study of ethnic differences (4), the studies of perinatal and infant death in East London described above have been descriptive. There were clearly variations in perinatal and infant mortality between ethnic and social groups in East London, and the results demonstrate that risk factors for poor outcomes are not uniform across ethnic groups, suggesting the influence of other socio-biological factors. To reduce inequalities it is necessary to have a more comprehensive understanding about which babies are dying, the immediate causes of their deaths, and about the underlying bio-socio-economic factors and processes that mediate poor outcomes. Improving understanding of the latter should help not only in developing strategies to reduce the disparities, but also in suggesting preventive interventions applicable and potentially beneficial to all social groups (11).

Researching inequalities in stillbirth and infant mortality

Patterns of low birthweight, preterm birth, stillbirth and infant mortality show marked and persistent social class gradients. Ethnic minority populations in the UK share adverse conditions with the most disadvantaged groups in the majority population, and there is considerable evidence that they are worse off in terms of their employment, health and housing (12). Regional variations in infant and perinatal mortality show that the chances of adverse outcomes are greater in less privileged parts of the country. Analyses of mortality data using measures of area and/or individual deprivation have contributed to the evidence of inequalities and show that the associations observed in East London also occur in other parts of England and Wales.

A study of the maternity records of 7,493 women who delivered in the East Midlands between 1986 and 1991 used an area-based deprivation index to assess the association between social deprivation and birthweight (13). Results showed that living in a socially deprived area was a significant factor associated with low birthweight, even after taking into account the associations with smoking and heavy alcohol consumption, both known to be more common in manual social class households.

Another study used birth registration and notification data for England and Wales 1993-2000 to investigate social inequalities in low birth weight (14). Data were analysed to compare individual measures of socio-economic status in terms of couple and sole registered births and manual and non-manual occupational groups. The highest rate of low birthweight, 10.2 per

cent, was among sole registered births and large differentials existed between manual and non-manual groups.

An investigation into the extent of socio-economic inequalities in low birthweight used post coded infant records in England and Wales for 1986-1992 (15). In addition the research assessed the relative benefits of measuring socio-economic status by social class or by area deprivation, or by both, when using routinely recorded birth and census data to investigate inequalities. The risk of low birthweight had a strong socio-economic gradient, whether measured by social class or area level deprivation. Lone mothers were at greater risk of low birthweight than joint registrants living in similarly deprived areas. Lone mothers had more than double the risk of low birthweight (10 per cent) than the most affluent group of joint registrants in every area deprivation quintile.

Area deprivation performed better than individual social class in describing the extent of inequalities in low birth weight in the population. On the other hand, the authors caution against the use of single indicators when targeting interventions to high risk groups. The majority of births to lone mothers and to joint registrants with fathers in social classes IV and V would have been missed by targeting the most deprived area quintile only. In this case it was necessary to use both individual social class and lone mother status and area deprivation scores, to give a fuller picture of the extent of inequalities.

Factors associated with adverse outcomes

Low birthweight and preterm birth

Infant mortality is strongly correlated with low birthweight. Yet 'low birthweight' is an unsatisfactory outcome for epidemiological studies because birthweight is determined both by fetal growth and by the duration of pregnancy (16). The lack of routinely collected data on gestational age in England and Wales has made it more difficult to estimate the relative mortality due to growth restriction or preterm birth, and to understand the aetiologies and consequences of the two distinct conditions.

There are social class differences in the rates of low birthweight. In relation to disparities in low birthweight by ethnicity, mothers born in 'New Commonwealth' countries have a higher proportion of low birthweight babies than mothers born in the UK (17). Mothers from most of the countries making up the New Commonwealth have higher proportions of low birthweight babies even than UK born sole registrants, the group with the highest proportion of low birthweight in England and Wales (18). Although there is considerable variation within the population, babies born to mothers born in the 'New Commonwealth' have a higher stillbirth and infant mortality rate than babies of UK born mothers, although mortality is highest among babies whose mothers were born in Pakistan (17-19)

Preterm birth is associated with a high proportion of infant deaths. In 2001, 57.7 per cent of neonatal deaths in England and Wales were attributed to immaturity related conditions (20). Scotland is the only country of the United Kingdom to routinely produce official statistics linking socio-demographic factors and gestational age at birth. Between 1990 and 1995 the preterm rate was lowest for singleton births inside marriage where the father's occupation was professional or executive, rising threefold for women with no stated occupation (17). More recent figures for preterm births in Scottish hospitals for 2001 showed that 6.2 per cent of all singleton births were preterm. Analysis by area based deprivation indices showed that 5.1 per

cent of singleton births to women living in the least deprived areas were preterm compared to 7.1 per cent in the most deprived areas (ISD Website).

In the US, and in special studies in the UK, gestation is routinely recorded in birth registration information. It is clear that African-Americans have higher rates of preterm and very preterm delivery than white Americans although the aetiology is poorly understood (21). It is thought that the disparities are cultural rather than racial/genetic because black migrants to the US have lower preterm delivery rates than US born blacks, despite greater poverty (22). In this country there have been few studies investigating preterm delivery by different ethnic group, and they have been done using local systems in which gestational age and ethnicity have not been recorded.

A study in Birmingham between 1979 and 1982 investigated ethnic differences in very low birthweight and neonatal deaths among normally formed babies (23). Very low birthweight was most common in West Indian babies with a rate of 23.2 per 1000 compared with 10.1 per 1000 in babies of Pakistani mothers and 9.1 per 1000 in babies of European mothers. The authors propose that the very low birth weight in West Indians was related to preterm birth rather than growth restriction.

A retrospective study of births in Croydon in the early 90s investigated the incidence of preterm birth and fetal outcome by ethnic origin of the mother (24). The preterm delivery rate for West Indians and Africans was consistently higher than that for Asians and Whites. There was a higher risk of intrauterine death for moderately preterm babies of black mothers. Chorioamnionitis was found in the majority of intrauterine deaths in black mothers. The authors suggest that the vulnerability of black women to preterm labour must be related to a variety of social, behavioural, economic, cultural and environmental factors and that case controlled studies may help to define and to estimate the contribution of these diverse influences.

A recent study in Birmingham investigated whether routinely measured variables explained the increased risk of preterm birth in some UK ethnic groups (25). The main findings were that Afro-Caribbean and African women are at particular risk of preterm delivery. Half of the excess risk in Afro-Caribbeans could be accounted for by deprivation and marital status. The risk in Africans may be partially explained by earlier maturity of the feto-placental unit. A further explanation could be due to the risk due to variations in vaginal flora which vary between ethnic groups (26). The finding that the influence of deprivation may, like other risk factors, be ethno-specific is resonant.

Congenital anomalies

Congenital anomalies are a common cause of infant mortality and accounted for 28 per cent of infant deaths in England and Wales in 2001 (20). Ethnic group and social deprivation are both associated with a higher than average risk of congenital anomalies. A study of infant mortality from congenital anomalies in England and Wales between 1981-5 showed highest mortality was to babies of mothers born in Pakistan (27). Mortality was inversely related to social class in all groups except Afro-Caribbeans.

A number of studies in England and Wales have investigated congenital anomalies by area deprivation indices. In one study, congenital anomalies accounted for over one third of perinatal deaths, and the rate of death attributed to congenital anomaly in the most deprived

areas was almost twice that in the least deprived areas (28). Other studies have shown that while risk of non-chromosomal abnormalities in the most deprived areas is significantly higher than in affluent areas, chromosomal anomalies such as Down's syndrome are negatively correlated with deprivation (29;30). The authors ascribed this to the fact that these anomalies are more common among older women and that women in more privileged groups tend to have their children at older ages.

Sudden Infant Death Syndrome

A high proportion of postneonatal deaths were attributed to the Sudden Infant Death Syndrome, and it has been the subject of a considerable body of research. Death rates attributed to the Sudden Infant Death Syndrome fell sharply between 1988 and 1993. Since then the rate has fallen much more slowly and in 2000 only 17.3 per cent of postneonatal deaths were attributed to this cause (18).

As part of the Confidential Enquiry into Stillbirths and deaths in Infancy (CESDI) a three-year population based case-control study was designed to look at risk factors associated with SIDS following the dramatic fall in its incidence (31). This study showed a strong association between SIDS and many indicators of poverty and social deprivation. A recent analysis by the same researchers investigated the extent to which epidemiological characteristics associated with SIDS were particular to the syndrome or were more general markers of socio-economic deprivation (32). Background epidemiological characteristics of SIDS such as low birthweight, short gestation, high parity, young maternal age, lone parenting, a tendency to bottle-feed, smoke and drink alcohol, are strongly related to social class. This high level of correlation has made it difficult to assess which are the key factors.

In relation to ethnicity and the risk of infant death and SIDS, the results of national studies are consistent with the work undertaken in East London. One of these looked at ethnic differences in postneonatal mortality in a national cohort of babies born between 1982 and 1985 (33). The highest postneonatal mortality rates were observed in babies of Pakistani mothers, and their rates were notably higher than for other Asian groups. The SIDS rate for babies of Bangladeshi mothers was 0.3 per 1000 live births compared to 1.7 in the UK group. The authors found this 'paradoxical', given that perinatal mortality for most causes was higher in migrant groups than in the indigenous population. An investigation into infant care practices in mothers of Bangladeshi and Welsh origin found that the consistently rich sensory environment experienced by the Bangladeshi baby may be a factor, with a physiological basis, that offers protection in relation to SIDS (34).

Another study of children born in Birmingham between 1981 and 1983 confirmed low rates of SIDS amongst Asian groups compared with white mothers, supporting the view that cultural factors may be protective (35). The authors also noted a change from a low rate of SIDS among Afro-Caribbean babies in 1958-61 to a high rate in 1981-1983, suggesting social rather than genetic influences. A similar pattern of first generation advantage disappearing over time has been reported in the US. Among Chinese, Japanese, Vietnamese and Philippino migrant populations in the United States, the incidence of SIDS increased with period of residence (36).

Interventions which might reduce stillbirth and infant mortality

Recent reviews have emphasised the patchy nature of the available evidence about the interventions commonly assumed to be effective in reducing infant mortality. A scoping study of Perinatal and Infant Health Information in the former Northern Region pointed out that the most clear cut evidence came from randomised trials of interventions related to specific conditions while that for other intervention the evidence was far less clear. It summarised interventions which seemed to have the most potential to be effective in improving perinatal and child health in general (37).

It should be stressed that of many of the identified interventions, for example smoking cessation, are ‘good in themselves’ and may have a beneficial effect on the outcome of pregnancy, there is very little evidence that all but a few of these interventions will directly reduce infant mortality. A notable exception is the administration of corticosteroids to mothers in preterm labour (38) Even so, there has been little progress in finding measures which will prevent preterm labour from happening in the first place. Similarly, terminating affected pregnancies is not the same as primary prevention of congenital anomalies.

Summary of interventions which can be effective in improving perinatal and infant health

Intervention	Expected outcomes
Smoking cessation support for pregnant women and parents	Increased birthweight Reduced pregnancy complications (e.g. antepartum haemorrhage) Reduced risk of SIDS and respiratory illness
Promoting immunisation uptake	Reduced mortality and morbidity from vaccine preventable diseases i.e. Meningococcal disease Hib meningitis Whooping cough, diphtheria, tetanus Rubella (congenital rubella syndrome) Measles Mumps
High quality neonatal intensive care services offering known effective interventions	Improved survival and reduced morbidity in preterm infants
High quality obstetric and midwifery services offering effective interventions	Reduced avoidable mortality and morbidity, e.g. due to: Pregnancy induced hypertension Mothers with diabetes Preterm delivery (steroids to promote lung maturity) Intrapartum difficulties Rhesus iso-immunisation
Antenatal screening for HIV and Hepatitis B infection	Reduced mortality and morbidity in infants
Education about folic acid supplementation	Reduced occurrence of neural tube defects
Education about infant sleeping position	Reduced mortality due to SIDS
Promoting breastfeeding <i>[With effective breastfeeding support]</i>	Reduced gastrointestinal infections and atopic conditions in childhood <i>[A protective factor in relation to SIDS]</i>

Source: Perinatal and Infant Health Information, a scoping study. (37)

There is even less evidence about the effectiveness of these and other interventions for reducing infant mortality among the most disadvantaged groups of women. Focussing on limiting the impact of poverty and disadvantage on the health and well being of low-income pregnant women, new mothers and their babies, a project at the National Perinatal Epidemiology Unit reviewed the evidence from systematic reviews and recent trials.(39) It covered smoking cessation and prevention programmes, uptake of breastfeeding, prevention of teenage pregnancy, social support in pregnancy, labour and postnatally, improving the uptake of immunisation, nutrition interventions in pregnancy and interventions on parenting by very young mothers. The authors contend that three main factors, the direct effects of poverty, variations in behaviour and differential access to services combine to cause the persistent and wide inequalities in pregnancy outcomes and in the health of babies.

There is some evidence that poor communication can contribute to poor perinatal outcome. (40) A review of deaths reported to CESDI identified a number of problems. These were mothers' delays in reporting reduced fetal movements or other changes in pregnancy, professional responses to mothers' concerns, poor record keeping and inter-professional communication and poor communication in the care of women presenting with risks. While there was no evidence that language difficulties contributed to communication failure, the authors point out that the problems identified could only be worse where language is an issue.

English is not the first language for a large proportion of childbearing women in East London. Within East London there have been positive initiatives in health advocacy for ethnic minorities. The results of one study suggested that advocacy involvement in the care of non-English speaking women had a positive effect on a number of outcomes including length of antenatal stay in hospital, induction rates and the mode of delivery. (41)

The above approaches are complementary, one clinical and the other more social. Indeed, in relation to the problem of preterm birth there is increasing awareness of the need for a conceptual framework which links known socio-economic disparities with social stressors, including the impact of racism and poverty, with the developing knowledge about the biological and gene-environment interactions resulting in preterm birth. (42;43) Overall, our review confirms the need for a similarly integrative approach to studying disparities in perinatal and infant death in East London.

Analyses of routinely collected data

As was mentioned earlier, in the late 1980s and early 1990s, a computerised maternity database was established in the former North East Thames Region, including East London. It was used both for providing routine population-based and unit-based maternity data to the NHS and for research. When the regional health authorities were abolished in 1996, funding ceased and the database fell into abeyance. The primary source of data was the Regional Interactive Child Health System (RICHS) with linkages to data from other sources, notably death registration. Records in child health systems are initiated by a notification of birth sent by the person attending the birth, usually a midwife.

To undertake enable the analysis of routine data for this component of the feasibility study, it was necessary to acquire birth notification data from RICHS and other sources to establish a database of births to residents of the City of London and the three boroughs of Hackney, Newham and Tower Hamlets. This required ethics approval and application to Caldicott guardians in each trust to allow us to download the relevant anonymise data from RICHS and analyse them. This process is described in detail in the series of three full reports for each individual primary care trust. Detailed data checking was also required. The checks required were different for each area and are described in the full reports. The considerable work involved has produced an invaluable resource for further research and also for teaching and learning as permission was also obtained to use the data for this purpose. In what follows, the data for births in 1999-2001 to residents of the three areas are summarised and compared.

Place of birth

Although the majority of women delivered in the hospital located in the area covered by their primary care trust, a considerable number did not. The reasons for this are not recorded, but they could include geographical accessibility, individual choice or referral on clinical grounds. Overall, 88 per cent of the births took place in the three hospitals in inner East London, as Table 1 shows.

Characteristics of mothers and their babies

Mother's ages were very fully recorded in all the three areas. As Table 2 shows, the percentages of births to women aged under 18 and other women under 20 were lower than those for England and Wales as a whole. The percentage of births to women in their twenties varied widely between the three areas. Forty six per cent of babies born to residents of Hackney had mothers in their twenties, as in England and Wales as a whole, (18) while the corresponding proportions were 55 per cent in Newham and 60 per cent in Tower Hamlets. City and Hackney had a relatively high proportion of mothers in their forties.

Parity was less fully reported, being missing for 5.3 per cent of births to residents of City and Hackney and 2.3 births to residents of the three areas combined. For those with stated parity, 41 per cent were primiparous compared with 38 per cent in England as a whole in the financial year 2000-01. (44) The percentage with parity 4 or more ranged from 6.8 per cent in Newham to 8.4 per cent in City and Hackney and 8.6 per cent in Tower Hamlets. These were all much higher than the national figure of 6 per cent for England. (44) City and Hackney and, to a lesser extent Tower Hamlets, had particularly high percentages of births at parity 5 or higher.

Table 1 Total live and stillbirths by place of birth and mother's area of residence, 1999-2001

Place of birth	City and Hackney	Newham	Tower Hamlets	Total
Homerton University	10,114	273	499	10,886
Newham General Hospital	33	11,911	57	12,001
Royal London Hospital	157	676	9,524	10,357
All inner East London	10,304	12,860	10,080	33,244
Whittington	902	36	202	1,140
University College Hospital	233	3	6	242
Whipps Cross	34	641	32	707
King George's	3	813	22	838
Other hospitals	696	86	377	1,159
All hospitals	12,172	14,439	10,719	37,330
Home	150	65	128	343
Born before arrival	4	1	0	5
Missing or not known	71	287	56	414
Total births	12,397	14,792	10,903	38,092
<i>Percentage in inner East London hospitals or at home</i>	<i>84.3</i>	<i>87.4</i>	<i>93.6</i>	<i>88.2</i>

Table 2 Total births by mother's age and area of residence, 1999-2001

Age of mother	Numbers				Percentages				England and Wales, 2000
	City and Hackney	Newham	Tower Hamlets	Total	City and Hackney	Newham	Tower Hamlets	Total	
Under 18	230	296	167	693	1.9	2.0	1.5	1.8	2.3
18-19	544	781	570	1,895	4.4	5.3	5.2	5.0	5.2
20-29	5,755	8,132	6,587	20,474	46.4	55.0	60.4	53.7	46.1
30-39	5,298	5,174	3,295	13,767	42.7	35.0	30.2	36.1	43.9
40-49	539	359	266	1,164	4.3	2.4	2.4	3.1	2.5
50 and over	7	17	8	32	0.1	0.1	0.1	0.1	0.0
Missing	24	33	10	67	0.2	0.2	0.1	0.2	
Total	12,397	14,792	10,903	38,092	100.0	100.0	100.0	100.0	100.0

Table 3 Total births by mother's parity and area of residence, 1999-2001

Previous live and stillbirths	Numbers				Percentage of total live and stillbirths			
	City and Hackney	Newham	Tower Hamlets	Total	City and Hackney	Newham	Tower Hamlets	Total
0	4,847	5,856	4,432	15,135	41.3	39.9	41.1	40.7
1	3,157	4,195	2,756	10,108	26.9	28.6	25.6	27.2
2	1,826	2,402	1,703	5,931	15.6	16.4	15.8	15.9
3	868	1,218	947	3,033	7.4	8.3	8.8	8.2
4	402	563	438	1,403	3.4	3.8	4.1	3.8
5 and over	637	447	504	1,588	5.4	3.0	4.7	4.3
All stated	11,737	14,681	10,780	37,198	100.0	100.0	100.0	100.0
Missing	660	111	123	894				
Total	12,397	14,792	10,903	38,092				

Table 4 Total births by mother's ethnic group and area of residence, 1999-2001

Ethnic group	Numbers				Percentage of total live and stillbirths			
	City and Hackney	Newham	Tower Hamlets	Total	City and Hackney	Newham	Tower Hamlets	Total
Bangladeshi	396	217	5,912	6,525	3.6	1.6	58.1	18.9
Indian	716	294	124	1,134	6.5	2.2	1.2	3.3
Pakistani	153	158	93	404	1.4	1.2	0.9	1.2
Asian, not specified*	0	4,560	0	4,560	0.0	34.4	0.0	13.2
All South Asian	1,265	5,229	6,129	12,623	11.5	39.4	60.2	36.7
African	2,315	2,993	643	5,951	21.0	22.6	6.3	17.3
West Indian	1,343	890	207	2,440	12.2	6.7	2.0	7.1
White	4,752	3,342	2,819	10,913	43.2	25.2	27.7	31.7
Turkish	733	41	45	819	6.7	0.3	0.4	2.4
Other	594	769	331	1,694	5.4	5.8	3.3	4.9
All stated	11,002	13,264	10,174	34,440	100.0	100.0	100.0	100.0
Missing	1,395	1,528	729	3,652				
Total	12,397	14,792	10,903	38,092				

* In Newham General Hospital, no distinction was made between categories of south Asian women.

Overall an ethnic group was recorded for all but 9.6 per cent of mothers and it was more fully reported in Tower Hamlets than in the other two areas. As expected, the data in Table 4 showed a picture of ethnic diversity, with nearly three fifths of babies born to residents of Tower Hamlets having mothers of Bangladeshi origin and over a third of those born to residents of Newham had mothers of Asian origin. Over a fifth of babies born to residents of Hackney and nearly a quarter of those born to residents of Newham had mothers of African origin. There were substantial numbers of West Indian mothers in City and Hackney and Newham and of Turkish mothers in City and Hackney. There were some differences in the

ways in which ethnic origin was recorded and these are described in the individual reports for each area. In particular, Newham grouped all South Asians together at this period. The categories used are not strictly comparable to the census categories which should be used on all NHS records.

Table 5 Total births by gestational age at booking and area of residence, 1999-2001

Gestational age at booking	Numbers of live and stillbirths			Percentages of total live and stillbirths				
	City and Hackney	Newham	Tower Hamlets	Total	City and Hackney	Newham	Tower Hamlets	Total
Under 16 weeks	7,959	7,611	7,089	22,659	64.2	51.5	65.0	59.5
16-20 weeks	1,500	3,425	1,659	6,584	12.1	23.2	15.2	17.3
After 20 weeks	1,908	2,653	1,239	5,800	15.4	17.9	11.4	15.2
Not booked	414	725	354	1,493	3.3	4.9	3.2	3.9
Not stated	616	378	562	1,556	5.0	2.6	5.2	4.1
Total	12,397	14,792	10,903	38,092	100.0	100.0	100.0	100.0

Gestational age at booking was relatively completely recorded, with only 4.1 per cent missing. Overall 15.2 per cent of mothers had booked after 20 weeks of pregnancy. This ranged from 11.4 per cent of Tower Hamlets residents to 17.9 per cent of Newham residents. Apparently 3.9 per cent of women never booked and this ranged from 3.2 per cent of Tower Hamlets residents to 4.9 per cent of Newham residents.

Characteristics of the pregnancy

Table 6 Total births by numbers of babies born and area of residence, 1999-2001

Number of babies born	Numbers of live and stillbirths			Percentage of total live and stillbirths				
	City and Hackney	Newham	Tower Hamlets	Total	City and Hackney	Newham	Tower Hamlets	Total
1	11,995	14,464	10,632	37,091	96.8	97.8	97.5	97.4
2	366	313	263	942	3.0	2.1	2.4	2.5
3 or more	32	15	6	53	0.3	0.1	0.1	0.1
Missing	4	0	2	6	0.0	0.0	0.0	0.0
Total	12,397	14,792	10,903	38,092	100.0	100.0	100.0	100.0

The data about multiple births shown in Table 6 are in a different form from those which are derived by the Office for National Statistics from birth registration. The latter express multiple birth rates in terms of maternities, defined as pregnancies with one or more registrable live or stillbirths. These show that the multiple maternity rate for England and Wales rose from 14.5 per thousand maternities in 1999 to 14.8 in 2001. Comparison with Table 6 suggests that City and Hackney had a multiple birth rate above that for England and Wales, while multiple birth rates in the other two areas were well below it. This is not surprising because of their lower ages at childbirth and because multiple birth rates are higher in non-manual social groups who are likely to live in more affluent areas. The higher rate in

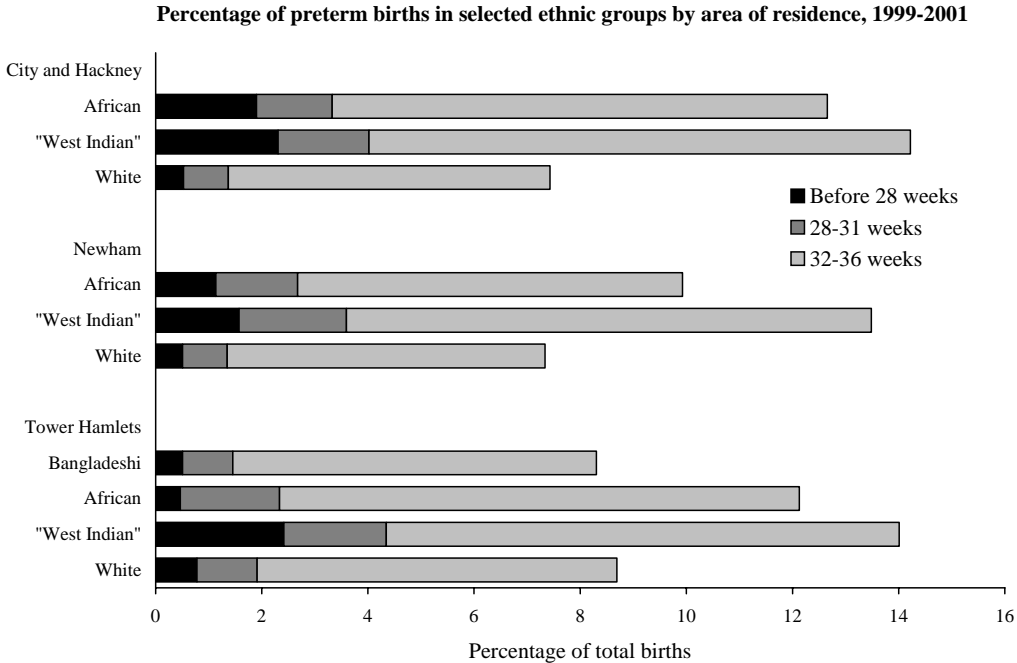
City and Hackney may be a consequence of the higher proportion of older mothers and the presence of women from West Africa, who are known to have relatively high multiple birth rates.

Overall, 9.5 per cent of births were preterm and occurred before 37 weeks, as Table 7 shows. This was considerably higher than the 7 per cent of deliveries which occurred before term in England as a whole in 2000-01. (44) The percentage of births which were preterm ranged from 9.2 in Tower Hamlets to 9.4 in Newham and 9.9 in City and Hackney. The slightly higher percentage in Hackney may reflect the higher rate of multiple births. Hackney also had the highest percentage of births before 28 weeks of gestation.

Table 7 Total births by gestational age at delivery and area of residence, 1999-2001

Gestational age, weeks	Numbers of live and stillbirths				Percentages of live and stillbirths			
	City and Hackney	Newham	Tower Hamlets	Total	City and Hackney	Newham	Tower Hamlets	Total
20-23	23	29	11	63	0.2	0.2	0.1	0.2
24-27	117	88	61	266	0.9	0.6	0.6	0.7
28-31	142	190	125	457	1.1	1.3	1.1	1.2
32-36	942	1,085	806	2,833	7.6	7.3	7.4	7.4
37-41	10,093	12,119	8,606	30,818	81.4	81.9	78.9	80.9
42 and over	1,063	1,234	1,278	3,575	8.6	8.3	11.7	9.4
Missing	17	47	16	80	0.1	0.3	0.1	0.2
Total	12,397	14,792	10,903	38,092	100.0	100.0	100.0	100.0

Figure 2 Preterm birth by ethnic group and area of residence



Post term births, those which occurred at 42 or more weeks of gestation, accounted for 9.4 per cent of births in the area and 11.7 per cent of those in Tower Hamlets. The proportion in each area was well above the five per cent of deliveries which occurred post term in England as a whole in 2000-01.

The preterm birth rate also varied by ethnic group, being highest for West Indians, followed by Africans. Because the African populations of the three areas vary, with West Africans predominating in Hackney and Somalis in Tower Hamlets, Figure 2, shows preterm birth rates for selected ethnic groups by area of residence. It shows clearly that the highest rate of very preterm birth was among West Indians in City and Hackney and Tower Hamlets, followed by Africans in City and Hackney. As the numbers of births to West Indians in Tower Hamlets were small, they did not contribute substantially to the rate of very preterm birth in the borough.

In the area as a whole, 9.9 per cent of total births were low weight, weighing under 2,500g at birth. This is considerably higher than the 7.9 per cent of all births in England and Wales in 2000 which were in this category. (18) The differences between the three areas were not the same as for preterm birth, with 9.7 per cent of babies born to residents of City and Hackney, 9.9 per cent of those born to Tower Hamlets residents and 10.2 per cent of those born to Newham residents weighing under 2500g. The patterns for very low birthweight were different, with 2.2 per cent of babies born to City and Hackney residents, 1.4 per cent of those born to Tower Hamlets residents and 1.8 per cent of those born to Newham residents weighing under 1500g at birth. The overall percentage for the area, at 1.8 per cent is higher than the figure of 1.5 per cent for England and Wales in 2000. (18)

Table 8 Total births by birthweight and area of residence, 1999-2001

Birthweight, g	Numbers of live and stillbirths				Percentages of live and stillbirths			
	City and Hackney	Newham	Tower Hamlets	Total	City and Hackney	Newham	Tower Hamlets	Total
Under 500	21	16	8	45	0.2	0.1	0.1	0.1
500-999	113	105	64	282	0.9	0.7	0.6	0.7
1,000-1,499	141	146	81	368	1.1	1.0	0.7	1.0
Under 1,500	275	267	153	695	2.2	1.8	1.4	1.8
1,500-1,999	231	295	180	706	1.9	2.0	1.7	1.9
2,000-2,499	693	943	748	2,384	5.6	6.4	6.9	6.3
Under 2,500	1,199	1,505	1,081	3,785	9.7	10.2	9.9	9.9
2,500-2,999	2,421	3,353	2,925	8,699	19.5	22.7	26.8	22.8
3,000-3,499	4,539	5,593	4,014	14,146	36.6	37.8	36.8	37.1
3,500-3,999	3,111	3,311	2,136	8,558	25.1	22.4	19.6	22.5
4,000-4,499	894	844	530	2,268	7.2	5.7	4.9	6.0
4,500-4,599	156	113	74	343	1.3	0.8	0.7	0.9
5,000-5,499	19	11	14	44	0.2	0.1	0.1	0.1
5,500-5,999	5	0	0	5	0.0	0.0	0.0	0.0
6,000-6,499	1	0	2	3	0.0	0.0	0.0	0.0
Missing	52	62	127	241	0.4	0.4	1.2	0.6
Total	12,397	14,792	10,903	38,092	100.0	100.0	100.0	100.0

Stillbirth and infant mortality rates

In Table 9, the stillbirth and infant mortality rates among babies born in the three areas in the three years 1999-2001 combined are compared with each other and with the stillbirth and birth cohort infant mortality rates among babies born in England and Wales in the year 2000. (20)

Over the three-year period, City and Hackney had higher rates of antepartum and intrapartum stillbirth as well as higher rates of early neonatal mortality compared with those for the other areas. This could be a consequence of the differences described above but differences in gestational age and birthweight specific mortality could also play a part.

Table 9 Stillbirth and infant mortality rates by area of residence, 1999-2001

	Numbers				Rates per 1,000 births				
	City and Hackney	Newham	Tower Hamlets	Total	City and Hackney	Newham	Tower Hamlets	Total	England and Wales
Stillbirths	99	95	69	263	8.0	6.4	6.3	6.9	5.3
Antepartum	85	87	61	233	6.9	5.9	5.6	6.1	
Intrapartum	13	7	8	28	1.0	0.5	0.7	0.7	
Not known	7	2	1	10	0.6	0.1	0.1	0.3	
Perinatal deaths	154	138	100	392	12.4	9.3	9.2	10.3	8.1
Infant deaths	90	89	56	235	7.3	6.1	5.2	6.2	5.6
Neonatal	63	58	36	157	5.1	3.9	3.3	4.2	3.8
Early	49	42	30	121	4.0	2.9	2.8	3.2	2.8
Late	14	16	6	36	1.1	1.1	0.6	1.0	0.9
Postneonatal	27	31	20	78	2.2	2.1	1.8	2.1	1.8
Total deaths	189	184	125	498					
Total live births	12,298	14,697	10,834	37,829					
Total live and stillbirths	12,397	14,792	10,903	38,092					

Stillbirths are expressed as a rate per 1,000 total live and stillbirths and neonatal, postneonatal and infant mortality rates are expressed as a rate per 1,000 live births

When the stillbirths and infant mortality rates in the area as a whole were compared with the rates for England and Wales, the biggest difference was in stillbirth rates. The rate for the area as a whole and for each of the three areas within it were well above those for England and Wales. Among the stillbirths were eight with gestational ages recorded as 20-23 weeks, which means that they were not registrable. This may be a data recording error. They were therefore removed, resulting in a stillbirth rate of 6.9 per thousand total births. This was well above that for England and Wales. The picture was different for infant mortality, with the rate for Tower

Hamlets being below the England and Wales level, the rate for Newham being above it and the rate for City and Hackney being well above the England and Wales rate.

Stillbirth and infant mortality rates for the area as a whole are tabulated by birthweight in Table 10. Rates for birthweights under 1,500g and all under 2,500g are compared with those for England and Wales as a whole in Table 11. (20) There it can be seen that birthweight specific stillbirth rates in East London are higher than those for England and Wales as a whole but neonatal mortality rates are actually lower. This may reflect the fact that while East London has high rates of low birthweight and preterm birth, there are two specialist neonatal

Table 10, Stillbirth and infant mortality rates in East London by birthweight, 1999-2001

Birthweight, g	Numbers			Rates				
	Stillbirth	Neonatal	Post-neonatal	Infant	Stillbirth	Neonatal	Post-neonatal	Infant
Under 1000	75	70	16	86	228.7	276.7	63.2	339.9
1000-1499	49	12	5	17	127.6	35.8	14.9	50.7
Under 1500	124	82	21	103	174.2	139.5	35.7	175.2
1500-1999	30	13	6	19	41.0	18.5	8.5	27.1
2000-2499	33	13	11	24	13.8	5.5	4.7	10.2
Under 2500	187	108	38	146	48.8	29.6	10.4	40.0
2500-2999	29	23	11	34	3.3	2.7	1.3	3.9
3000-3499	21	13	18	31	1.5	0.9	1.3	2.2
3500 and over	24	13	10	23	2.1	1.2	0.9	2.1
Missing	2	0	1	1	9.3	0.0	4.7	4.7
Total	263	157	78	235	6.9	4.2	2.1	6.2

Stillbirths are expressed as a rate per 1,000 total live and stillbirths and neonatal, postneonatal and infant mortality rates are expressed as a rate per 1,000 live births

Table 11 Stillbirth and infant mortality rates by birthweight, East London 1999-2001 and England and Wales 2000

Birthweight, g	Stillbirth	Neonatal	Postneonatal	Infant
Under 1,500				
East London	174.2	139.5	35.7	175.2
England and Wales	151.4	182.0	29.9	211.8
Under 2,500				
East London	48.8	29.6	10.4	40.0
England and Wales	42.5	36.7	9.9	46.6

Stillbirths are expressed as a rate per 1,000 total live and stillbirths and neonatal, postneonatal and infant mortality rates are expressed as a rate per 1,000 live births.

Table 12 Stillbirth and infant mortality rates in East London by gestational age, 1999-2001

Gestational age, weeks	Numbers			Rates				
	Stillbirth	Neonatal	Post-neonatal	Infant	Stillbirth	Neonatal	Post-neonatal	Infant
20-23	-	27	4	31	-	428.6	63.5	492.1
24-27	58	39	10	49	218.0	187.5	48.1	235.6
28-31	47	16	4	20	102.8	39.0	9.8	48.8
32-36	75	27	13	40	26.5	9.8	4.7	14.5
37-41	82	42	38	80	2.7	1.4	1.2	2.6
42 and over	1	6	8	14	0.3	1.7	2.2	3.9
Missing	0	0	1	1	0.0	0.0	12.5	12.5
Total	263	157	78	235	6.9	4.2	2.1	6.2

Stillbirths are expressed as a rate per 1,000 total live and stillbirths and neonatal, postneonatal and infant mortality rates are expressed as a rate per 1,000 live births.

Table 13 Stillbirth and infant mortality rates by area of residence and gestational age, 1999-2001

Area	Gestational age, weeks							Total
	20-23	24-27	28-31	32-36	37-41	42+	Missing	
Stillbirths								
<i>Numbers</i>								
City and Hackney		21	22	25	31	0	0	99
Newham		26	13	29	27	0	0	95
Tower Hamlets		11	12	21	24	1	0	69
All		58	47	75	82	1	1	263
<i>Rates</i>								
City and Hackney		179.5	154.9	26.5	3.1	-	-	8.0
Newham		295.5	68.4	26.7	2.2	-	-	6.4
Tower Hamlets		180.3	96.0	26.1	2.8	0.8	-	6.3
All		218.0	102.8	26.5	2.7	0.3	0.0	6.9
Infant deaths								
<i>Numbers</i>								
City and Hackney	16	17	8	13	33	3	0	90
Newham	11	22	6	16	28	5	1	89
Tower Hamlets	4	10	6	11	19	6	0	56
All	31	49	20	40	80	14	1	235
<i>Rates</i>								
City and Hackney	695.7	177.1	66.7	14.2	3.3	2.8	-	7.3
Newham	379.3	354.8	33.9	15.2	2.3	4.1	21.3	6.1
Tower Hamlets	363.6	200.0	53.1	14.0	2.2	4.7	-	5.2
All	492.1	235.6	48.8	14.5	2.6	3.9	12.5	6.2

units in the area. In addition, published data about infant mortality by mother's country of

birth suggest the relationship between birthweight and infant mortality among babies whose mothers were born in Bangladesh is different from that for women whose mothers were born in the United Kingdom. (18,20)

Stillbirth and infant and mortality rates are tabulated by gestational age in Table 12. This shows that preterm births account for over two thirds of stillbirths and infant deaths. There are no national data with which comparisons can be made, as the Office for National Statistics does not receive information about the gestational age at live birth. Stillbirth and infant mortality rates by gestational age for each area separately, shown in Table 13 should be interpreted with care as the numbers involved are small and the table does not include confidence intervals, so further comparative analysis is needed.

When stillbirth and infant mortality rates were tabulated by the mother's ethnic origin in Table 14, it could be seen that stillbirth and infant mortality rates were high among African and West Indian women. For all south Asian women combined, stillbirth rates were above the national average, but infant mortality rates were well below it. It is unfortunate that rates for babies born to Asian women in Newham General Hospital cannot be disaggregated and that the numbers of Indian and Pakistani women in the two other areas are too small to draw inferences about differences in stillbirth and infant mortality rates. The rates for Turkish women are also based on very small numbers and should be interpreted with caution.

Table 14 Stillbirth and infant mortality rates in East London by mother's ethnic origin, 1999-2001

Mother's ethnic origin	Numbers			Rates					
	Stillbirth	Neonatal	Post-neonatal	Infant	Stillbirth	Neonatal	Post-neonatal	Infant	
Bangladeshi	43	15	12	27	6.6	2.3	1.9	4.2	
Indian	11	6	0	6	9.7	5.3	-	5.3	
Pakistani	2	2	0	2	5.0	5.0	-	5.0	
Asian, not specified	32	17	7	24	7.0	3.8	1.5	5.3	
All South Asian	88	40	19	59	7.0	3.2	1.5	4.7	
African	52	34	22	56	8.7	5.8	3.7	9.5	
West Indian	26	17	5	22	10.7	7.0	2.1	9.1	
White	56	33	16	49	5.1	3.0	1.5	4.5	
Turkish	6	1	1	2	7.3	1.2	1.2	2.5	
Other	11	10	3	13	6.5	5.9	1.8	7.7	
All stated	239	135	66	201	6.9	3.9	1.9	5.9	
Missing	24	22	12	34	6.6	6.1	3.3	9.4	
Total	263	157	78	235	6.9	4.2	2.1	6.2	

Stillbirths are expressed as a rate per 1,000 total live and stillbirths and neonatal, postneonatal and infant mortality rates are expressed as a rate per 1,000 live births.

There are no national rates by ethnic origin and, in addition, the categories used in East London vary from the standard categories defined for use in the Census of Population. It is, however, possible to make some limited comparisons with national statistics by mother's

country of birth. Statistics for all births in England and Wales show that stillbirth and infant mortality rates for babies born to women born in Bangladesh are well below the exceptionally high rates for babies whose mothers were born in Pakistan. (18,20) In east London, the rates for women identified as Bangladeshi are lower than those for combined Asian groups, with a stillbirth rate of 6.6 per thousand total births and neonatal, postneonatal and infant mortality rates of 2.3, 1.9 and 4.2 per thousand live births respectively.

Table 15 Stillbirth and infant mortality rates in East London by mother's age

Mother's age	Numbers			Rates				
	Stillbirth	Neonatal	Post-neonatal	Infant	Stillbirth	Neonatal	Post-neonatal	Infant
Under 18	9	2	0	2	13.0	2.9	0.0	2.9
18-19	12	14	3	17	6.3	7.4	1.6	9.0
20-29	122	73	45	118	6.0	3.6	2.2	5.8
30-39	97	65	25	90	7.0	4.8	1.8	6.6
40-49	20	3	5	8	17.2	2.6	4.4	7.0
50-59	1	0	0	0	31.3	0.0	0.0	0.0
Missing	2	0	0	0	29.9	0.0	0.0	0.0
Total	263	157	78	235	6.9	4.2	2.1	6.2

Stillbirth and infant mortality rates by mother's age in Table 15 showed their usual pattern, being highest in births to the youngest and oldest women, but the numbers of infant deaths to mothers under 18 and aged 40 and over was very small. Stillbirth rates were relatively much higher among mothers aged under 18 and those in their forties but accounted for only 3.4 per cent and 7.6 per cent of stillbirths respectively.

Table 16 Stillbirth and infant mortality rates in East London by gestational age at booking, 1999-2001

Gestational age at booking	Numbers			Rates				
	Stillbirth	Neonatal	Post-neonatal	Infant	Stillbirth	Neonatal	Post-neonatal	Infant
Under 16 weeks	138	85	43	128	6.1	3.8	1.9	5.7
16-20 weeks	50	28	11	39	7.6	4.3	1.7	6.0
After 20 weeks	30	20	12	32	5.2	3.5	2.1	5.5
Not booked	28	12	6	18	18.8	8.2	4.1	12.3
Not stated	17	12	6	18	10.9	7.8	3.9	11.7
Total	263	157	78	235	6.9	4.2	2.1	6.2

Stillbirths are expressed as a rate per 1,000 total live and stillbirths and neonatal, postneonatal and infant mortality rates are expressed as a rate per 1,000 live births.

Table 16 shows that stillbirth and infant mortality rates among women who booked after 20 weeks of gestation were no higher than for those who had booked earlier, but rates were high among babies whose mothers had apparently never booked. They were also high among the

group for whom booking information was missing. Together, these two groups accounted for 17 per cent of stillbirths and 15 per cent of infant deaths.

Lessons from the analysis of routinely collected data

It should be stressed that this is a preliminary analysis consisting of simple crosstabulations without the construction of confidence intervals, calculation of relative risks or further analyses to take account of the confounding between factors associated with adverse outcomes. The work required to establish the database, including gaining permission to use the data, obtaining downloads from RICHs, investigating and compensating for anomalies on the coding was considerable. It is a resource for future work and there is much more to be gained from further analysis.

The analyses done so far show clear differences between the births in the areas of inner East London covered by City and Hackney, Newham and Tower Hamlets primary care trusts. Firstly they show where the resident population receive delivery care and differences in the extent to which they give birth outside inner East London. While 94 per cent of births to Tower Hamlets residents take place in inner East London, this is the case for 84 per cent of births to residents of City and Hackney and 87 per cent of residents of Newham.

The area has a relatively low percentage of births to women under the age of 18 and others under 20. Newham and Tower Hamlets had high percentages of women in their twenties while City and Hackney had a relatively high proportion of births to older mothers. Along with Tower Hamlets, it had a relatively high proportion of births of parity 5 and higher.

Despite anomalies in the recording of ethnic origin, it could be established that just over a third of births to Newham residents and nearly three fifths of births to Tower Hamlets residents had south Asian mothers. A fifth of mothers in City and Hackney and Newham described themselves as African. Multiple birth rates were below the national average for England and Wales, except in City and Hackney, whose mothers were older and whose population includes West African women, a group which is known to have a high rate of spontaneous multiple birth.

All the three areas had high rates of low birthweight and preterm birth, although these were not directly correlated with each other except that City and Hackney had high rates of both very preterm birth and very low birthweight.

All the three areas had stillbirth rates which were well above the rates for England and Wales, with City and Hackney's being particularly high. For the area as a whole, birthweight specific stillbirth rates at weights under 1500g and under 2500g were above those for England and Wales. Stillbirth rates were particularly high among African and West Indian women. The rate also appeared high among Turkish women, but was based on only seven stillbirths. Stillbirth rates were also high among women who apparently had not booked for maternity care and among those for whom there was no booking information.

Infant mortality rates showed a rather different pattern. The rate for Tower Hamlets was below that for England and Wales, while the rate for Newham was above it and the rate for City and Hackney was considerably higher. In the area as a whole, birthweight specific neonatal and infant mortality rates for low birthweight and very low birthweight babies were

actually below those for England and Wales, while postneonatal mortality rates were marginally higher. Factors which could have contributed to this include the presence of two tertiary neonatal units and the more favourable association between birthweight and mortality in babies born to Bangladeshi and Indian mothers. Infant mortality rates for babies born to Asian mothers were similar to those for the white population, while those for babies born to African and 'West Indian' mothers were considerably higher. As with stillbirths, infant mortality rates were highest among babies born to women who had not apparently booked or for whom there was no information about booking.

Case note review

The initial aim of this part of the project was to undertake a review of case notes of stillbirths and infant deaths, including both:

- a) Stillbirths and deaths occurring in City and Hackney, Tower Hamlets and Newham to babies born there during 2000 and 2001, including infant deaths elsewhere of babies born in these areas in 2000 or 2001.
- b) Stillbirths and deaths of babies born outside the area to residents of the area. This is needed to obtain information about all events occurring to the resident population, as it was the infant mortality among the population rather than questions about clinical care which raised concern and led to the project.

As work got under way, identifying the case notes was found to be more time consuming than originally envisaged so with the agreement of the Steering Group, the time period was restricted to 2001 and part b) was dropped from the feasibility study, although these stillbirths and deaths of babies born outside the area are important and will be included in the proposal for further research. Because of time constraints, this review was restricted to deaths of babies born at the Homerton University Hospital and the Royal London Hospital as they were thought to serve the most contrasting populations and that the numbers would be adequate for the purpose of the feasibility study. Equally importantly, clinical staff in these two hospitals were already actively involved in the study. Newham is well recognised to have a very high risk obstetric population and it intended that it will be included in plans for any future study.

An Access database was developed to hold the data extracted from the case notes and record information about the following subjects:

- Booking status
- Characteristics of the mother and father
- Birth details
- Health and pregnancy details
- Social factors
- Characteristics of stillbirths and late fetal losses
- Characteristics of neonatal and infant deaths
- Categorisation of and analysis of causes of death

As well as registrable stillbirths and infant deaths, information was recorded about late fetal deaths at 20-23 weeks of gestation and about terminations of pregnancy at 20 or more weeks of gestation. These were subdivided into the seven categories shown in Table 17. Crosschecks were made with data recorded on the RICH system to help identify the mother's area of residence.

In all, 179 deaths were identified and notes were found for 155 of these. This overall total included a 53 where the baby's mother was not resident in City and Hackney, Tower Hamlets or Newham and a further 23 where the mother's area of residence could not be assigned, as Table 18 shows. Some may have initially booked at the Homerton or the Royal London, but in the majority of cases, the mother had been transferred to one of these two hospitals for

delivery or the babies had been transferred for neonatal care. This is not surprising, given that both hospitals are tertiary referral centres.

Table 17 Categories of death

Category	Explanation
1 Late fetal loss	Fetal death at 20-24 completed weeks of gestation
2 Termination of pregnancy	Termination of pregnancy at any gestation
3 Stillbirth	Fetal death after 24 completed weeks of gestation
4 Neonatal death on labour ward	Neonatal death on labour ward
5 Early neonatal death on neonatal unit	Death in neonatal unit at 0-6 days after live birth
6 Late neonatal death on neonatal unit	Death in neonatal unit at 7-27 days after live birth.
7 Postneonatal death	Death at 28-364 days after live birth.

Table 18 Notes found at Homerton and Royal London Hospital by area of residence

Category of death	Area of residence														
	City and Hackney			Tower Hamlets			Elsewhere			Not ascertained			All		
	All	Not in RICHs	In RICHs	All	Not in RICHs	In RICHs	All	Not in RICHs	In RICHs	All	Not in RICHs	In RICHs	All	Not in RICHs	In RICHs
Non-registrable deaths	19	18	1	9	8	1	15	13	2	11	11	0	54	50	4
Late fetal losses	15	15	0	7	6	1	13	12	1	8	8	0	43	41	2
Terminations of pregnancy	4	3	1	2	2	0	2	1	1	3	3	0	11	9	2
Registrable deaths	52	0	52	23	0	23	38	8	30	12	12	0	125	20	105
Stillbirths	26	0	26	12	0	12	11	0	11	1	1	0	50	1	49
Early neonatal	10	0	10	4	0	4	9	2	7	2	2	0	25	4	21
Late neonatal	11	0	11	5	0	5	13	5	8	8	8	0	37	13	24
Postneonatal	5	0	5	2	0	2	5	1	4	1	1	0	13	2	11
All categories of deaths	71	18	53	32	8	24	53	21	32	23	23	0	179	70	109

The focus of this report is the 103 deaths where the mother was resident in one of the two areas included in the study and the case notes were available. Table 19 shows the numbers in each of the categories defined above. In addition to the babies excluded from analyses because their case notes were missing, analyses may also exclude a few babies who died after discharge from hospital. Their deaths may not have been known to the hospital, particularly if they occurred in the postneonatal period.

Table 19 Numbers of deaths by category

Category	City and Hackney	Tower Hamlets	Total	Percentage
1 Late fetal loss	15	7	22	21
2 Termination of pregnancy	4	2	6	6
3 Stillbirth	26	12	38	37
4 Neonatal death on labour ward	4	0	4	4
5 Early neonatal death on neonatal unit	6	4	10	10
6 Late neonatal death on neonatal unit	11	5	16	16
7 Postneonatal death	5	2	7	7
Total	71	32	103	100

Over a fifth of the deaths were non-registrable late fetal losses and a further six per cent were terminations of pregnancy. Just over a third were registrable stillbirths and a similar proportion were infant deaths.

Completeness of data items

Appendix 1 in the full report of this case note review lists all the data items recorded and the extent to which each item was present or missing. This shows that hospital code, baby's and mother's number, mother's age, date of birth and post-code, both parents' ethnic origin, country of birth, first language and religion, all booking details, baby's details such as birthweight, gestation, date of birth and death, place of birth and death, previous pregnancy history, clinical details about neonatal care and the death were relatively complete and present on from three quarters to all records. In contrast, social factors such as housing, smoking, alcohol intake, and drug usage were around 50 per cent complete. The most poorly documented items were fathers' details including age, occupation, country of origin, religion, and years living in the UK. These were less than 25 per cent complete.

Thus, as would be expected, clinical and demographic information was much more complete than information about the woman and her partner's social circumstances. This summary focuses on the clinical information about the cause of death. A fuller range of variables is summarised in the full report of this case note review.

Clinical causes of death

Identifying and classifying primary causes of death

A classification was drawn up by two neonatologists. They then used data on the database to assign the primary cause of death by assessing each case individually. This was necessary as many cases had numerous risk factors or documented causes and so the main cause of death was often not obvious. In addition, in many cases, a post-mortem was not undertaken and so it was not possible to confirm the cause of death that way. Post-mortems were carried out in

only 37, or 36 per cent, of cases, as Table 20 shows. Those not done were either declined by parents, or were carried out elsewhere, or were not requested or information about what happened was not known.

Table 20 Post mortems

	City and Hackney	Tower Hamlets	Total	Percentage
Requested and done	29	8	37	36
Declined by parents	23	12	35	34
Died elsewhere	1	1	2	2
Limited post-mortem	0	2	2	2
Not requested	6	6	12	12
Requested and not done	2	0	2	2
Not known	10	3	13	13
All	71	32	103	100

Details of the classification of causes of death can be found in the full report. Because of the relatively small numbers involved, there were no deaths attributed to some of the causes listed and some categories shown there have been combined in Tables 21 and 22.

Table 21 shows the causes of late fetal loss and of late termination of pregnancy. Many of the late fetal losses were unexplained, although infection played an important part. All the terminations were because of congenital anomalies.

Table 21 Causes of late fetal loss and grounds for termination of pregnancy

Cause	Late fetal loss	Termination
Infection	5	0
Ante-partum haemorrhage	1	0
Cord prolapse	1	0
Cervical incompetence	1	0
Congenital anomalies	1	6
PET	1	0
Placental insufficiency	1	0
Unexplained	9	0
Other	0	0
Unknown	2	0
All	22	6

Stillbirths and infant deaths are tabulated by cause in Table 22. For a third of the stillbirths and eight per cent of infant deaths, which include all the categories of neonatal and postneonatal death, the cause was unexplained. The in-utero conditions, including congenital anomaly were a major cause of stillbirth and infant death. Placental problems and infections also made a substantial contribution in City and Hackney, while asphyxial conditions made a larger contribution to the numbers of deaths in Tower Hamlets.

Table 22 Stillbirths and infant deaths by cause

<i>Cause of death</i>	Numbers of deaths			Percentages of deaths		
	City and Tower Hackney Hamlets	Total	City and Tower Hackney Hamlets	Total	City and Tower Hackney Hamlets	Total
Stillbirths						
In-utero genetic/ metabolic/ developmental insults	5	2	7	19	17	18
Infection	0	1	1	0	8	3
Placental dysfunction	12	2	14	46	17	37
Asphyxia	0	2	2	0	17	5
Other	0	1	1	0	8	3
Unexplained	9	4	13	35	33	34
Total	26	12	38	100	100	100

Infant deaths						
In-utero genetic/ metabolic/ developmental insults	9	2	11	35	18	30
Infection	3	1	4	12	9	11
Placental dysfunction	2	0	2	8	0	5
Asphyxia	1	4	5	4	36	14
Consequences of preterm birth	8	3	11	31	27	30
Other	0	1	1	0	9	3
Unexplained	3	0	3	12	0	8
Total	26	11	37	100	100	100

Table 23 Stillbirths and infant deaths classified according to the Aberdeen Obstetric Classification

<i>Cause of death</i>	Numbers of deaths			Percentages of deaths		
	City and Tower Hackney Hamlets	Total	City and Tower Hackney Hamlets	Total	City and Tower Hackney Hamlets	Total
Stillbirths						
Congenital anomaly	4	2	6	15	17	16
Isoimmunisation	0	1	1	0	8	3
Pre-eclampsia	1	2	3	4	17	8
Antepartum haemorrhage	4	0	4	15	0	11
Maternal disorder	3	4	7	12	33	18
Unexplained	14	3	17	54	25	45
Total	26	12	38	100	100	100
Infant deaths						
Congenital anomaly	7	2	9	27	18	24
Pre-eclampsia	2	0	2	8	0	5
Antepartum haemorrhage	2	1	3	8	9	8
Maternal disorder	4	3	7	15	27	19
Miscellaneous	5	1	6	19	9	16
Unexplained	6	3	9	23	27	24
Not known	0	1	1	0	9	3
Total	26	11	37	100	100	100

The causes of stillbirth and infant death were also recoded using the Aberdeen obstetric classification and the Fetal and Neonatal Factor classification used in the Confidential Enquiry into Stillbirths and Deaths in Infancy.(45) As Tables 23 and 24 show, using these classifications raised further questions about differences between City and Hackney and Tower Hamlets residents, although the numbers of events were too small to draw definitive conclusions or make comparisons with national data from CESDI.

Table 24 Causes of stillbirth and infant death classified according to the Fetal and Neonatal Factor Classification

<i>Cause of death</i>	Numbers of deaths			Percentages of deaths		
	City and Tower Hackney	Tower Hamlets	Total	City and Tower Hackney	Tower Hamlets	Total
Stillbirths						
Congenital anomaly	4	3	7	15	25	18
Asphyxia before birth	20	9	29	77	75	76
Infection	1	0	1	4	0	3
Unclassifiable or unknown	1	0	1	4	0	3
Total	26	12	38	100	100	100
Infant deaths						
Congenital anomaly	10	2	12	38	18	32
Asphyxia before birth	3	3	6	12	27	16
Hyaline membrane disease	3	2	5	12	18	14
Infection	7	4	11	27	36	30
Unclassifiable or unknown	3	0	3	12	0	8
Total	26	11	37	100	100	100

Lessons from the case note review

Although only tentative conclusions can be drawn from these hospital-based data, the information about clinical causes of death gives valuable insights. They indicate that infections may play an important role in neonatal death, particularly in the Black African population in City and Hackney. They also point to the role of congenital anomalies, not only among registrable stillbirths and neonatal deaths and among terminations of pregnancy on medical grounds, but also among late fetal losses. The latter two categories are not included in the statistics which attract the attention of organisations concerned with regulation and performance management, but they still cause considerable distress to the people concerned.

Undertaking the case note review has also involved essential groundwork for future research. It has led to an understanding of the problems involved in locating case notes and extracting data from them. It has clarified that although spaces are provided in notes for collecting information about patients social circumstances, most of these items are missing and will therefore need to be collected by other means in any future research on infant mortality in East London.

As the numbers of events were small, ascertainment was incomplete and there were no controls, it was not possible to draw substantive conclusions. Although the case note review

gave useful insights, it is not worth undertaking a further similar case review unless there are sufficient resources to cover a larger number of years, ensure full ascertainment and include controls.

Outstanding items from the feasibility study

A number of items were either dropped from the feasibility study because of lack of time, or delayed until the data were available.

Cause of death

We were unable to review the case notes for all deaths of babies born in 2001. As well as deaths at Newham, deaths at other hospitals were omitted. This means that we do not have a comprehensive overview of causes of death among babies born in East London. Completing the case note review would be very time consuming, but we could get a more complete picture than we have at present from Confidential Enquiry into Maternal and Child Health (CEMACH), formerly CESDI, records and death registration records.

Death certificates have already been requested from ONS. There are conditions of confidentiality, but arrangements were made by Lisa Hilder to undertake analyses within the CESDI London office and these need to be reviewed now that responsibility has passed to CEMACH.

Further analyses of data from RICHs

The analyses undertaken so far have been limited to crosstabulations. Fuller univariate analyses with relative risks and confidence intervals and then multivariate analyses, which would take account of intercorrelations, would enable us to learn considerably more from these data.

Areas for future investigation

Despite their incompleteness and preliminary nature, findings of the case note review and the analyses of routine data suggest that, many of the factors identified in earlier research in East London and elsewhere are still present. The major exception to this is the fall in the rate of sudden infant death in East London and elsewhere.

Congenital anomalies

Congenital anomalies are still an important cause of fetal loss and infant death. Irrespective of how the pregnancy is terminated, they are a loss for the parents. Little is known about the epidemiology of congenital anomalies in East London, as it has no congenital anomalies register, but fuller information could be found using details of anomalies reported in the birth notification to RICHs and thence to the National Congenital Anomalies System, plus local special needs registers, stillbirth and death certificates and a more comprehensive case note review.

In the longer term, our knowledge of the epidemiology of congenital anomalies could be improved by establishing a congenital anomalies register. Economies of scale would suggest that it should not be restricted to the three inner East London areas covered by this feasibility study.

The high rate of stillbirth in East London

All three areas had a high rate of stillbirth. More detailed information is needed about the causes of this in order to focus further investigations. This could be obtained from a fuller case note review, from death certification, from the CEMACH/CESDI rapid report forms and from postmortem reports.

It would appear from the case note review that both congenital anomalies and unexplained antepartum stillbirths make a major contribution to the high stillbirth rate, but the data from the case note review are not sufficiently robust to make inferences about this. Data for England and Wales show wide social class differences in rates of stillbirths attributed to antepartum asphyxia, anoxia or trauma and in remaining antepartum deaths, most of which are unexplained. Although there are minimal social class differences in rates of stillbirth attributed to congenital anomalies, social class differences do exist for infant deaths.

The numbers of unexplained antepartum stillbirths in East London are also likely to be insufficient for investigating by means of a case control study and a wider collaborative approach would be needed, involving CEMACH and collaborators in other areas with high rates of antepartum stillbirths.

The high rate of preterm birth in East London, particularly in City and Hackney

The analysis of routine data identified high rates of preterm birth especially in City and Hackney, but not of birthweight specific mortality. Factors which may lie behind this include social and environmental factors and data about these are not collected routinely. It would therefore be worth considering a case control study of preterm birth among babies without congenital anomalies. Again the numbers involved may be too small to give sufficient statistical power and a wider approach involving collaborators in other areas may be needed.

Meanwhile, more information could be derived from the available routine data. The higher proportions of older women, and women of high parity may contribute to the high rates of preterm birth and low birthweight. The substantial population of Orthodox Jewish women resident in the area may account for some of this. Given more time, it would be possible to separate this group from other white women but this could not be completed due to time constraints. Babies born to African women and West Indian women appear to have a substantially higher risk of death overall. The clustering of antenatal infection and congenital anomalies amongst babies of African mothers may underly this. Both these factors are associated with preterm birth. In the short term there is the need for some further analysis to investigate more fully the associations observed. In addition, an opportunity to validate at least some of the data with discrepancies by comparing RICHs data with the original notes would strengthen the findings.

The majority Bangladeshi community in Tower Hamlets has a low rate of infant mortality. With the decline in deaths attributed to SIDS the rate is no longer exceptionally low in the postneonatal period, but neonatal mortality rates are below those of the white population. Bangladeshi mothers are increasingly second generation women who are settled and largely bilingual. Rates of infant mortality amongst the white residents of Tower Hamlets are lower than for white residents of the other East London boroughs. This may reflect changes in the population following the influx of middle class people into the luxury Docklands developments.

Geographical variation within the boroughs

Although the numbers of stillbirths and infant deaths are too low to plot by ward or other small area, it should be possible to do this for preterm birth and low birthweight. Analysing these routine data in relation to indices of deprivation and other data available at a similar level of disaggregation should enable us identify areas where there may be particularly strong associations with social and environmental factors

Women who apparently did not book for care

High rates of mortality are recorded among babies for whom there is no record of booking. These may be particularly marginalised women. A pilot postal survey of 33 maternity units in the London Region was conducted by Carolyn Roth of City University in 2001. Of the 23 units responding to her questionnaire, only 9 were able to calculate the numbers of women cared for in labour without prior antenatal care, during some or all the years from 1998 to 2001. Rates of unbooked births, where reported, were between one and two per cent although two units reported rates between two to 5.6 per cent, representing 10 or more women each month. It was suggested by respondents that women who are refugees or asylum seekers are disproportionately represented within unbooked births.

While any conclusions that can be drawn from this preliminary survey of London maternity units are limited, it demonstrates an absence of routine monitoring of the incidence and trends in unbooked labours. It also suggests that there are some maternity units in which the rates of unbooked births are very much higher than others, a phenomenon which requires further investigation. Further investigation of rates and characteristics of unbooked births and late booking is desirable to illuminate the factors which might account for women not receiving antenatal care or receiving it at a stage in pregnancy too late to enjoy maximum advantage.

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Fetal and Infant Death in East London

This report summarises a feasibility study for further research to increase the understanding of the causes of the high rates of stillbirth and infant mortality in East London in order to inform action aimed at reducing them.

The project consisted of three parts, a review of previous research and published data, analyses of routine data derived from notification of births to women living in City and Hackney, Tower Hamlets and Newham and a review of case notes at the Homerton University Hospital and the Royal London Hospital relating to late fetal losses and terminations, stillbirths and infant deaths.

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