HIV-positive African women's engagement with HIV care in the UK during and after pregnancy

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Contents

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Appendices

Appendix i: Papers arising from this work

1. Tariq, S. and Woodman, J. Using mixed methods in health research. *JRSM Short Reports*, 2013 June. 4(6) doi:10.1177/2042533313479197.

2. Tariq, S., Pillen, A., Tookey, P.A., Brown, A.E., Elford, J. The impact of African ethnicity and migration on pregnancy in women living with HIV in the UK: design and methods. *BMC Public Health*, 2012 Aug; 12: 596 doi:10.1186/1471-2458-12-596.

3. Tariq, S., Elford, J., Cortina-Borja, M., Tookey, P.A. The association between ethnicity and late presentation to antenatal care among pregnant women living with HIV in the UK and Ireland. *AIDS Care*, 2012 Aug; 24(8): 978-85.

4. Tariq, S., Townsend, C., Cortina-Borja, M., Duong, T., Elford, J., Tookey, P.A. Zidovudine-sparing HAART in pregnant HIV-infected women in Europe: 2000-2009. *J Acquir Immune Defic Syndr*, 2011 Aug: 57(4): 326 -33.

METHODOLOGICAL REVIEW

Using mixed methods in health research

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This work was conceived by both ST and JW who each carried out an independent literature review and collaborated on the structure and content of this report. ST wrote

Summary

Mixed methods research is the use of quantitative and qualitative methods in a single study or series of studies. It is an emergent methodology which is increasingly used by health researchers, especially within health services research. There is a growing literature on the theory, design and critical appraisal of mixed methods research. However, there are few papers that summarize this methodological approach for health practitioners who wish to conduct or critically engage with mixed methods studies. The objective of this paper is to provide an accessible introduction to mixed methods for clinicians and researchers unfamiliar with this approach. We present a synthesis of key methodological literature on mixed methods research, with examples from our own work and that of others, to illustrate the practical applications of this approach within health research. We summarize definitions of mixed methods research, the value of this approach, key aspects of study design and analysis, and discuss the potential challenges of combining quantitative and qualitative methods and data. One of the key challenges within mixed methods research is the successful integration of quantitative and qualitative data during analysis and interpretation. However, the integration of different types of data can generate insights into a research question, resulting in enriched understanding of complex health research problems.

Introduction

Mixed methods research is the use of quantitative and qualitative methods in one study. Research is often dichotomized as quantitative or qualitative. Quantitative research, such as clinical trials or observational studies, generates numerical data. On the other hand qualitative approaches tend to generate non-numerical data, using methods such as semi-structured interviews, focus group discussions and participant observation. Historically, quantitative methods have dominated health research. However, qualitative methods have been increasingly accepted by the health research community in the past two decades, with a rise in publication of qualitative studies.[1] As the value of qualitative approaches has been recognized, there has been a growing interest in combining qualitative and quantitative methods. A recent review of health services research within England has shown an increase in the proportion of studies classified as mixed methods from 17% in the mid-1990s to 30% in the early 2000s.[2] In this paper, we present a synthesis of key literature on mixed methods research, with examples from our own work and that of others to illustrate the practical applications of this approach. This paper is aimed at health researchers and practitioners who are new to the field of mixed methods research and may only have experience of *either* quantitative or qualitative approaches and methodologies. We wish to provide these readers with an accessible introduction to the increasingly popular methodology of mixed methods research. We hope this will help readers to consider whether their research questions might best be answered by a mixed methods study design, and to engage critically with health research that uses this approach.

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Methods

The authors each independently carried out a narrative literature review and met to discuss findings. Literature was identified via searches of PubMed, Google and Google Scholar, and hand-searches of the Journal of Mixed Methods Research, with relevant publications selected after discussion. An important consideration was that papers either had a methodological focus or contained a detailed description of their mixed methods design. For PubMed and Google searches, similar terms were used. For example, the PubMed strategy consisted of title and abstract searches for: ((mixed methods) OR ((mixed OR (qualitative AND quantitative)) AND methods)). We also drew upon recommendations from mixed methods conferences and seminars, and reference lists from key publications.

What is mixed methods research?

The most widely accepted definition of mixed methods research is research that 'focuses on collecting, analysing, and mixing both quantitative and qualitative data in a single study or a series of studies'.[3] Central to the definition is the use of *both* quantitative and qualitative methods in one study (or a series of connected studies). Separate quantitative and qualitative studies addressing the same research question independently would not be considered 'mixed methods' as there would be no integration of approaches at the design, analysis or presentation stage. A recent innovation in mixed methods research is the mixed methods systematic review, which sets out to systematically appraise both quantitative and qualitative literature on a subject area and then synthesize the findings.

Why are mixed methods approaches used?

The underlying assumption of mixed methods research is that it can address some research questions more comprehensively than by using either quantitative or qualitative methods alone.[3] Questions that profit most from a mixed methods design tend to be broad and complex, with multiple facets that may each be best explored by quantitative or qualitative methods. See Boxes 1 and 2 for examples from our own work.

Box 1.
Examples of authors' mixed methods research – JW.

How are general practitioners (GPs) responding to possible child maltreatment in England? A mixed methods study

There is considerable debate about the role that GPs should play in the management of child maltreatment (abuse or neglect). This study aimed to describe and understand the types of responses that GPs were making when faced with a child or family who prompted concerns about child maltreatment. The broad research question about GP responses to child maltreatment prompted several sub-questions; each answered by either a quantitative or qualitative methodology. These sub-questions included:

- How and why do GPs record child maltreatment-related concerns in the electronic health record? (qualitative)[4]
- How frequently do GPs record child maltreatment-related concerns in the electronic health record? (quantitative)?[5]
- Does recording vary over time, by child characteristic and by practice? (quantitative)[5]
- How do primary health care practitioners view the GP's role in responding to child maltreatment? (qualitative)
- What do primary health care practitioners tell us GPs are doing to respond to children who prompt concerns and why? (qualitative)

We analysed quantitative data from the Health Improvement Network (THIN) UK primary care database and conducted qualitative interviews with GPs, Health Visitors and Practice nurses and undertook observations in primary health care settings. In this study, there were two stages of analysis. First, we analysed the data from each study separately and presented findings from each of the data as answers to the sub-questions. Secondly, we integrated the two data and findings to provide a multi-faceted insight into the broader research question about GP responses to maltreatment. A mixed methods design was chosen to facilitate increased breadth and range of study findings; both illuminated different aspects of the same complex issue. In this case, the two methods allowed access to data and insights that each method alone could not provide. Insights from the mixed methods design included differences between the type of maltreatment concerns that are recorded by GPs in the quantitative dataset and the types of concern that were preoccupying and resource-intensive according to the interviews. The interview and observation data also provided an understanding of a wide range of relevant GP responses, from the perspective of the primary care team, whereas the quantitative dataset could only provide data about recording practices.

Usually, quantitative research is associated with a positivist stance and a belief that reality that can be measured and observed objectively. Most commonly, it sets out to test an *a priori* hypothesis and is therefore conventionally described as 'deductive'. Strengths of quantitative research include its procedures to minimize confounding and its potential to generate generalizable findings if based on samples that are both large enough and representative. It remains the dominant paradigm in health research. However, this deductive approach is less suited to generating hypotheses about how or why things are happening, or explaining complex social or cultural phenomena.

Qualitative research most often comes from an interpretive framework and is usually informed by the belief that there are multiple realities shaped by personal viewpoints, context and meaning. In-depth qualitative research aims to provide a rich description of views, beliefs and meaning. It also tends to acknowledge the role of researcher and context in shaping and producing the data. Qualitative approaches are described as 'inductive' as questions are often open-ended with the analysis allowing hypotheses to emerge from data. High-quality qualitative research can generate robust theory that is applicable to contexts outside of the study area in question, helping to guide practitioners and policy-makers.[8] However, for research that aims to directly impact on policy and practice, the findings of qualitative research can be limited by the small sample sizes that are necessary for in-depth exploratory work and the consequent lack of generalizabilty.

Mixed methods research therefore has the potential to harness the strengths and counterbalance the weaknesses of both approaches and can be especially powerful when addressing complex, multifaceted issues such as health services interventions[9] and living with chronic illness.[10]

There are many reasons why researchers choose to combine quantitative and qualitative methods in a study.[11,12] We list some common reasons below, using a hypothetical research question about adolescents' adherence to anticonvulsant medication to illustrate real world applications.

- Complementarity: Using data obtained by one method to illustrate results from another. An example of this would be a survey of

Box 2.
Examples of authors' mixed methods research – ST.

The impact of African ethnicity and migration on pregnancy in women living with HIV in the UK: a mixed methods study
Increasing numbers of HIV-infected women in the UK are becoming pregnant; the majority are Africans. This study aimed to explore outcomes and experiences of pregnancy in migrant African women living with HIV in the UK. This is a complex question encompassing medical and sociocultural factors. Specific objectives included:

- Exploring the association between maternal (i) ethnicity, (ii) African region of birth and (iii) duration of residence in the UK and: timing of antenatal booking,[6] uptake of antiretroviral therapy in pregnancy, virological suppression at delivery, mother-to-child transmission of HIV, and return for HIV follow-up after pregnancy. (quantitative)
- Exploring possible cultural and socioeconomic factors that may contribute to any identified disparities in clinical outcomes. (qualitative)
- Understanding the experiences of pregnancy and health care systems in migrant African women living with HIV in the UK. (qualitative)

We conducted analyses of national surveillance data followed by semi-structured interviews with pregnant African women living with HIV and their health care providers.[7] We supplemented interview data with ethnographic research in a charity supporting people living with HIV and an African Pentecostal church in London. Each type of data was analysed separately with findings from one analysis informing the other. Data were also compared and contrasted at the interpretation stage. Where appropriate and feasible, the quantitative and qualitative data has been presented in an integrated way, rather than as separate studies. The quantitative phase enabled us to identify potentially important disparities in outcomes and health care access. The qualitative phase allowed us to understand what may be driving these disparities, whilst also identifying previously neglected aspects of pregnancy in this group of women such as stigma within health care settings. This mixed methods approach has resulted in a richer understanding of different aspects of HIV and pregnancy, placing marginalized women's voices at the centre of the study.

adolescents with epilepsy demonstrating poor levels of adherence. Semi-structured interviews with a sub-group of those surveyed may allow us to explore barriers to adherence.

- Development: Using results from one method to develop or inform the use of the other method. A focus group conducted with a group of adolescents with epilepsy may identify mobile phone technology as a potentially important tool in adherence support. We could then develop a mobile phone 'app' that reminds patients to take their medication and conduct an intervention study to assess its impact on adherence levels.
- Initiation: Using results from different methods specifically to look for areas of incongruence in order to generate new insights. An illustration of this would be a study exploring the discrepancy between reported adherence in clinic consultations and actual medication adherence. A review of case notes may find adherence levels of over 90% in a clinic population; however, semi-structured interviews with peer researchers may reveal lower levels of adherence and barriers to open discussion with clinicians.
- Expansion: Setting out to examine different aspects of a research question, where each aspect warrants different methods. We may wish to conduct a study that explores adherence more broadly. A large-scale survey of adolescents with epilepsy would provide information on adherence levels and associations whilst interviews and focus groups may allow us to engage with individual experiences of chronic illness and medication in adolescence.
- Triangulation: Using data obtained by both methods to corroborate findings. For example, we could conduct a clinical study measuring drug levels in individuals and documenting self-reported adherence. Qualitative methods such as video diaries may confirm adherence levels.

To this list we would also add political commitment. That is to say, researchers may recognize, and wish to deploy, the strengths of quantitative research in producing generalizable results but may also be committed to representing the voice of participants in their work.

Whatever the reasons for mixing methods, it is important that authors present these explicitly as it allows us to assess if a mixed methods study design is appropriate for answering the research question.[3,13]

How is mixed methods research conducted?

When embarking on a mixed methods research project it is important to consider:

- the methods that will be used;
- the priority of the methods;
- the sequence in which the methods are to be used.

A wide variety of methods exists by which to collect both quantitative and qualitative data. Both the research question and the data required will be the main determinants of the methods used. To a lesser extent, the choice of methods may be influenced by feasibility, the research team's skills and experience and time constraints.

Priority of methods relates to the emphasis placed on each method in the study. For instance, the study may be predominantly a quantitative study with a small qualitative component, or vice versa. Alternatively, both quantitative and qualitative methods and data may have equal weighting. The emphasis given to each component of the study will be driven mainly by the research question, the skills of the research team and feasibility.

Finally, researchers must decide when each method is to be used in the study. For instance a team may choose to start with a quantitative phase followed by a qualitative phase, or vice versa. Some studies use both quantitative and qualitative methods concurrently. Again the choice of when to use each method is largely dependent on the research question.

The priority and sequence of mixing methods have been elaborated in a typology of mixed methods research models. See Table 1 for typology and specific examples.

Table 1.
Examples of studies using mixed methods.

Mixed method design	*Study aim*	*Methods*	*Value of mixed methods design*
Convergent Quantitative and qualitative methods used concurrently and mixed at interpretation stage	To evaluate the Health Foundation's Safer Patients Initiative (SPI) in hospitals in the UK[14]	Quantitative analysis of case note and ward survey data. Qualitative analysis of semi-structured interviews (SSI), focus groups and ward observations.	Both data found little impact of SPI whilst qualitative findings suggested that one explanation may be suboptimal implementation and acceptance from staff. The two types of data corroborate one another (no discernible impact of intervention) and qualitative findings provide one explanation for the unexpected lack of SPI impact on outcomes
Explanatory sequential Qualitative methods used to answer 'why' or 'how' questions generated from preceding quantitative research	To determine what procedures are used in US hospitals to prevent ventilator-associated pneumonia and why[15]	Quantitative analysis of survey data from hospital staff followed by SSI with staff from participating hospitals	The interviews offered one explanation for the quantitative findings that some recommended procedures were used more widely than others (influence of nurses and views about strength of evidence). Both data corroborated the pivotal role of nursing staff and collaborative initiatives
Exploratory sequential Quantitative methods used to answer epidemiological questions generated from preceding quantitative research	To identify and quantify factors contributing to the reduction of alcohol use in hepatitis C positive patients[16]	Qualitative analysis of interviews, illness narratives and threaded discussions from websites followed by quantitative analysis of a survey	The qualitative phase allowed identification of new factors that influence drinking in this group, which could be tested on a larger population using a quantitative survey. Together, the data revealed differences in motivations between abusing and non-abusing drinkers with hepatitis C and facilitated recommendations about more effective ways to improve adherence to medical advice in these groups
Embedded A small qualitative component embedded in a larger quantitative study or vice versa	To assess the efficacy of a vaginal microbicidal gel on vaginal HIV transmission[17]	A randomized controlled trial in with a social science sub-study, comprising in-depth interviews with trial participants and focus groups	The trial found no evidence of an effect of the gel on HIV transmission. Qualitative data demonstrated high levels of acceptability, revealing the gel's use for sexual pleasure, suggesting adherence to future gels could be increased by framing them in terms of sexual pleasure
Mixed methods Systematic Review (SR) An SR combining both data types	To assess the impact of social interventions on teenage pregnancy rates and their appropriateness for the UK[18]	A meta-analysis of quantitative data from controlled trials and systematic review of qualitative studies on teenage pregnancy in England	The meta-analysis of North American data indicated that these interventions were effective. The qualitative review concluded they were likely to be effective and appropriate in a UK setting. Together, the data suggested that there should be a UK policy initiative to invest in these programmes

How is data analysed in a mixed methods project?

The most important, and perhaps most difficult, aspect of mixed methods research is integrating the qualitative and quantitative data. One approach is to analyse the two data types separately and to then undertake a second stage of analysis where the data and findings from both studies are compared, contrasted and combined.[19] The quantitative and qualitative data are kept analytically distinct and are analysed using techniques usually associated with that type of data; for example, statistical techniques could be used to analyse survey data whilst thematic analysis may be used to analyse interview data. In this approach, the integrity of each data is preserved whilst also capitalizing on the potential for enhanced understanding from combining the two data and sets of findings.

Another approach to mixed methods data analysis is the integrative strategy.[20] Rather than keeping the datasets separate, one type of data may be transformed into another type. That is to say that qualitative data may be turned into quantitative data ('quantitizing') or quantitative data may be converted into qualitative data ('qualitizing').[21] The former is probably the most common method of this type of integrated analysis. Quantitative transformation is achieved by the numerical coding of qualitative data to create variables that may relate to themes or constructs, allowing statements such as 'six of 10 participants spoke of the financial barriers to accessing health care'. These data can then be combined with the quantitative dataset and analysed together. Transforming quantitative data into qualitative data is less common. An example of this is the development of narrative psychological 'types' from numerical data obtained by questionnaires.[22]

Potential challenges in conducting mixed methods research

Despite its considerable strengths as an approach, mixed methods research can present researchers with challenges.[23,24]

Firstly, combining methodologies has sometimes been seen as problematic because of the view that quantitative and qualitative belong to separate and incompatible paradigms. In this context, paradigms are the set of practices and beliefs held by an academic community at a given point in time.[25] Researchers subscribing to this view argue that it is neither possible nor desirable to combine quantitative and qualitative methods in a study as they represent essentially different and conflicting ways of viewing the world and how we collect information about it.[8] Other researchers take a more pragmatic view, believing that concerns about the incommensurability of worldviews can be set aside if the combination of quantitative and qualitative methods addresses the research question effectively. This pragmatic view informs much applied mixed methods research in health services or policy.[8]

Secondly, combining two methods in one study can be time consuming and requires experience and skills in both quantitative and qualitative methods. This can mean, in reality, that a mixed methods project requires a team rather than a lone researcher in order to conduct the study rigorously and within the specified time frame. However, it is important that a team comprising members from different disciplines work well together, rather than becoming compartmentalized.[26] We believe that a project leader with experience in both quantitative and qualitative methods can act as an important bridge in a mixed methods team.

Thirdly, achieving true integration of the different types of data can be difficult. We have suggested various analytic strategies above but this can be hard to achieve as it requires innovative thinking to move between different types of data and make meaningful links between them. It is therefore important to reflect on the results of a study and ask if your understanding has been enriched by the combination of different types of data. If this is not the case then integration may not have occurred sufficiently.[23]

Finally, many researchers cite the difficulty in presenting the results of mixed methods study as a barrier to conducting this type of research.[23] Researchers may decide to present their quantitative and qualitative data separately for different audiences. This strategy may involve a decision to publish additional work focusing

on the interpretations and conclusions which come from comparing and contrasting findings from the different data types. See Box 1 for an example of this type of publication strategy. Many journals in the medical sciences have a distinct methodological base and relatively restrictive word limits which may preclude the publication of complex, mixed methods studies. However, as the number of mixed methods studies increases in the health research literature we would expect researchers to feel more confident in the presentation of this type of work.

Conclusion

Many of the areas we explore in health are complex and multifaceted. Mixed methods research (combining quantitative and qualitative methods in one study) is an innovative and increasingly popular way of addressing these complexities. Although mixed methods research presents some challenges, in much the same way as every methodology does, this approach provides the research team with a wider range of tools at their disposal in order to answer a question. We believe that the production and integration of different types of data and the combination of skill sets in a team can generate insights into a research question, resulting in enriched understanding.

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The impact of African ethnicity and migration on pregnancy in women living with HIV in the UK: design and methods

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Abstract

Background: The number of reported pregnancies in women with diagnosed HIV in the UK increased from 80 in 1990 to over 1400 in 2010; the majority were among women born in sub-Saharan Africa. There is a paucity of research on how social adversity impacts upon pregnancy in HIV positive women in the UK; furthermore, little is known about important outcomes such as treatment uptake and return for follow-up after pregnancy. The aim of this study was to examine pregnancy in African women living with HIV in the UK.

Methods and design: This was a two phase mixed methods study. The first phase involved analysis of data on approximately 12,000 pregnancies occurring between 2000 and 2010 reported to the UK's National Study of HIV in Pregnancy and Childhood (NSHPC). The second phase was based in London and comprised: (i) semi-structured interviews with 23 pregnant African women living with HIV, 4 health care professionals and 2 voluntary sector workers; (ii) approximately 90 hours of ethnographic fieldwork in an HIV charity; and (iii) approximately 40 hours of ethnographic fieldwork in a Pentecostal church.

Discussion: We have developed an innovative methodology utilising epidemiological and anthropological methods to explore pregnancy in African women living with HIV in the UK. The data collected in this mixed methods study are currently being analysed and will facilitate the development of appropriate services for this group.

Keywords: HIV, Pregnancy, Migrants, Ethnicity, Mixed methods research

Background

HIV infection in the UK

In 2010, an estimated 91,500 people were living with HIV in the United Kingdom (UK) [1]; the number continues to grow, mainly due to increased life expectancy as a result of antiretroviral therapy (ART) [*ibid*]. In the UK, HIV prevalence is elevated both among men who have sex with men (MSM) and African-born heterosexual men and women [1]; for both groups, 5% are estimated to be living with HIV [*ibid*]. Within the UK itself there is substantial geographical variation in diagnosed HIV prevalence: 54 local authorities have a diagnosed HIV prevalence of greater than 2 per 1000 population aged 15–59 years; 29 of these local authorities are in London [1].

HIV in African communities in the UK

There were an estimated 29,200 people born in Africa living with HIV in the UK by the end of 2010, 66% (n = 19,300) of whom were women [1]. The majority of Africans newly diagnosed with HIV in the UK originate from East Africa, although the epidemic has become more diverse over time. The proportion of Africans diagnosed with HIV who are from East Africa has fallen from just under 75% in 2001 to approximately 50% in 2010, whilst in the same time period there was a significant increase in diagnoses in West Africans to a point in 2010 when almost 1 in 3 Africans diagnosed with HIV in the UK were West African (Meaghan Kall, Health Protection Agency, personal communication, 25 June 2012).

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Studies have shown that African patients are more likely to present to medical services at a later stage of HIV infection, with advanced disease and greater immune suppression [1,2]. This is due to a number of factors including lack of perceived risk, fear of stigma and discrimination, lack of HIV testing in general medical settings, and anxieties regarding medical bills for HIV care [3,4]. African heterosexual patients are also more likely to be lost to follow-up from medical care than white MSM [5,6].

Many Africans living with HIV in the UK have a high level of social need [7,8] including financial difficulty [7], social isolation [9] and insecure immigration status [10,11]. These are likely to impact on patients' access to healthcare.

HIV and pregnancy in the UK

There has been a substantial increase in the number of HIV-infected women reported as pregnant to the NSHPC, the UK and Ireland's national surveillance programme for HIV in pregnancy and childhood: a 17-fold increase from 82 in 1990 to over 1400 a year since 2006 [12] , with approximately 80% of pregnancies reported in recent years in women born in Sub-Saharan Africa [13].

The combination of a routine offer of antenatal HIV screening to all pregnant women, use of ART for the prevention of mother-to-child transmission (MTCT), planned mode of delivery and advice to avoid breastfeeding has resulted in a decline in national MTCT rates from approximately 20% in diagnosed women in 1990 [14] to 1.0% in 2000–2006 [15]. The rate is even lower (0.8%) in women who have received at least 14 days of antiretroviral therapy prior to delivery [15].

In the UK, there is a paucity of data on antenatal and postnatal outcomes other than mother-to-child transmission and gestational age at delivery. Rates of virological suppression in pregnancy have been estimated at between 67 to 75% [16-18]. Looking at access to health services, a small study in London demonstrated that up to 65% of mothers living with HIV failed to return for HIV care after delivery [19]. In terms of care prior to delivery, no studies in the UK examining antenatal care access in HIV-infected women have been identified. Furthermore, there is little work specifically focusing on pregnancy in African women living with HIV in the UK, despite this being the largest group.

Qualitative studies have an important role in elucidating reasons for disparity in outcomes and access, and have provided insights into the experiences of pregnant women living with HIV. However, the vast body of qualitative work on pregnancy and HIV has been conducted in North America and Sub-Saharan Africa and may not be applicable in the UK. Few qualitative studies have explored the experience of pregnancy in women living with HIV in the UK, but those which have [20-22] demonstrated high levels of social isolation and stigma in pregnant women living with HIV. These studies highlighted women's pervasive fear of transmitting HIV to their child and their acceptance of interventions to prevent this, but also revealed the difficulties that accompany these interventions. Two of these studies included African participants, although sample sizes were small and they remain unpublished [20,21]. Wilson's Glasgow-based study [22] was larger but the participants were exclusively white British, presenting difficulties in extrapolating results to an ethnically diverse clinic population.

Rationale for this study

Few studies have explored the impact of African ethnicity and migration on pregnancy in women living with HIV [15,20,21,23-26]. This is a complex area of study requiring a range of investigatory approaches. We believe that there is an urgent need for large-scale work, both quantitative and qualitative, exploring the multi-faceted relationship between HIV and pregnancy among African migrant women in the UK.

Study objectives

This study aimed to examine disparities in clinical outcomes and access to services among pregnant African women living with HIV in the UK, and to explore how their experiences of pregnancy may contribute to any identified disparities. For the purposes of this study African was defined as being of black ethnicity and having been born in sub-Saharan Africa. Women of mixed, white or Asian ethnicities who were born in sun-Saharan Africa were not defined as African.

The primary objectives were to:

- explore the association of: (i) ethnicity, (ii) African region of birth, and (iii) duration of residence in the UK with:
  - Time of antenatal booking in women living with HIV
  - Maternal uptake of antiretroviral therapy
  - Detectable maternal HIV viral load at delivery
  - Mother-to-child transmission of HIV
  - Return for HIV care in the calendar year following pregnancy
- investigate possible contextual factors that may contribute to any identified disparities in the outcomes above, using qualitative data
- describe the experience of HIV and pregnancy in individual women's lives

Methods and design

Overall study design

A mixed methods research approach was designed to meet these objectives. The most widely accepted definition of mixed methods research is the "collecting, analysing, and mixing (of) both quantitative and qualitative data in a single study or a series of studies" [27]. The underlying assumption of mixed methods research is that it can address a research question more comprehensively than using either quantitative or qualitative methods alone. Within the field of HIV, a number of recent studies have illustrated the role of mixed methods research in engaging with the complex nature of HIV care [28,29].

Mixed methods model

The present study combines epidemiological and anthropological methods, with each approach given equal weight. We used a sequential explanatory model [27] (Figure 1). The first phase was quantitative, comprising analysis of linked national surveillance data. This was followed by a qualitative phase which sought to explain and contextualise the findings from the first phase whilst highlighting other important aspects of women's experience. This qualitative phase comprised semi-structured interviews and participant observation. The study model was embedded within a framework of feminism. This theoretical lens informed the methods, analysis and interpretation throughout the study. Feminist research has a commitment to non-essentialism, which is an understanding that gender, and other social and cultural groups, are not homogeneous or concrete. By exploring differences among women, and among African women, we have attempted to move away from universal gender and ethnicity categories that dominate most epidemiological literature. Furthermore, we have used qualitative methods in an effort to engage with and document women's experiences, whilst recognising the importance of quantitative research in producing generalisable findings that may inform practice.

Rationale for a mixed methods approach

We chose a mixed methods approach as we were studying a complex biosocial phenomenon and felt that a combination of a variety of methods would enhance our understanding. Furthermore, the quantitative findings would inform our sampling and methods in the qualitative phase and the qualitative data would contextualise the quantitative results. We also felt that this approach would place the voices of women living with HIV at the centre of this study.

Quantitative phase

The quantitative phase comprised secondary analysis of epidemiological data from the National Study of HIV in Pregnancy and Childhood (NSHPC). The analysis of postnatal attendance for HIV care included data from the Survey of Prevalent Infections Diagnosed (SOPHID).

The national study of HIV in pregnancy and childhood (NSHPC)

The NSHPC, coordinated at the University College London (UCL) Institute of Child Health (ICH), is a population-based active surveillance study that aims to include all HIV infected women seeking antenatal care in the UK and Ireland [12]. By the end of 2011 data on approximately 15 000 pregnancies since 1990 were available. Pregnancies in HIV-infected women diagnosed by the time of delivery, and infants born to infected women, are reported through two active parallel schemes managed in collaboration with the Royal College of Obstetricians and Gynaecologists and the British Paediatric

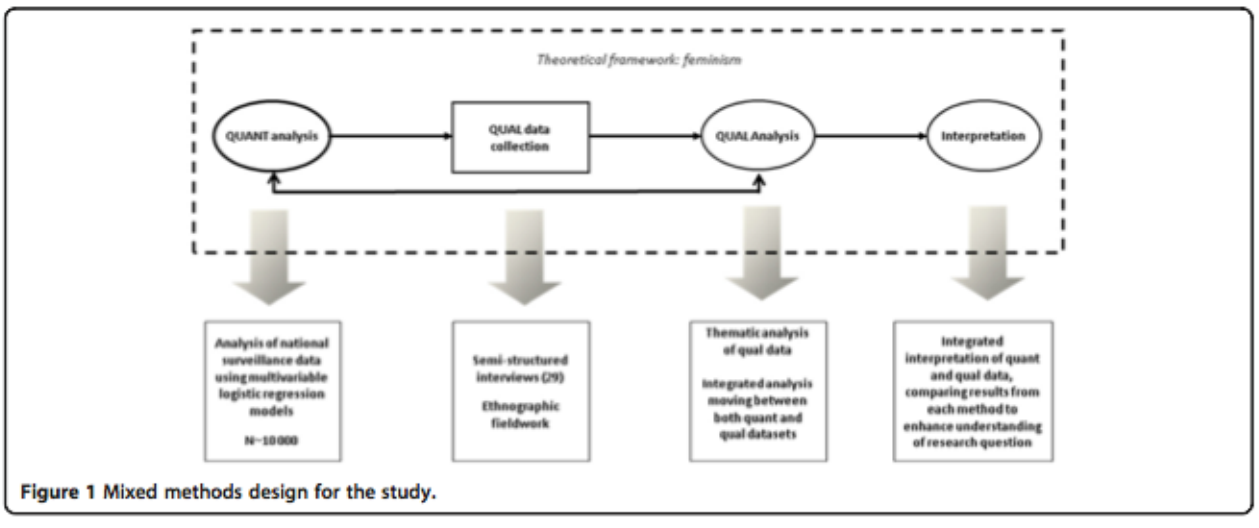

Figure 1 Mixed methods design for the study.

Surveillance Unit [30]; full methods are described elsewhere [13]. Data collected include: maternal demographics, maternal laboratory results, clinical management of pregnancy and delivery, pregnancy outcome, and infant HIV status.

Pregnancies reported to the NSHPC were included in this study if year of delivery or estimated date of delivery (EDD) was between 1990 and 2010. Reports from Ireland were excluded, as this study focused on the UK. Reports were excluded if: the report concerned a twin or triplet who was not the first-born (to avoid duplication of information on the mother), the child was born outside the UK, or if there were no data on maternal ethnicity or country of birth (the key variables of interest).

For analyses of primary outcomes, pregnancies were included if year of delivery or EDD was 2000 or after, corresponding with wider use of ART in pregnancy and more consistency in clinical practice and monitoring than in the previous decade. Pregnancies were also excluded from these analyses if the mother was diagnosed with HIV after delivery. There were further exclusion criteria specific to each analysis and therefore numbers varied depending on the outcome examined.

The survey of prevalent HIV infections diagnosed (SOPHID)

SOPHID is an annual cross-sectional survey of all individuals aged 15 and above with diagnosed HIV infection who attend for National Health Service (NHS) HIV care in the UK within a calendar year [31]. It is coordinated by the Heath Protection Agency and was introduced in 1995. Data collected include: site of care, infection route, ethnicity and date last seen (or date of death) as well as clinical markers.

Record linkage

We created a combined dataset using NSHPC and SOPHID data to explore whether a woman returned for HIV care anywhere in England, Wales and Northern Ireland in the year following pregnancy. Women known by the NSHPC to be pregnant between 1999 and 2009 were matched to the SOPHID dataset by year of pregnancy. A hierarchical matching strategy was implemented using limited identifiers collected in both systems such as: sex; date of birth; residential information; strategic health authority; country of birth; and date of HIV diagnosis. Potential duplicate reports were identified and not included in the analysis. We excluded pregnancies in women reported from Scotland to the NSHPC or reports to SOPHID from Scotland as prior to 2008 Scottish reports to SOPHID were not linked over time, and it was therefore difficult to establish links between records in the same patient prior to 2008. Pregnancies in women known to have moved abroad during their pregnancy were also excluded. There were 9834 eligible NSHPC pregnancies between 1999 and 2009. In 8695 (88.4%) pregnancies we were able to match the mother to a record in SOPHID.

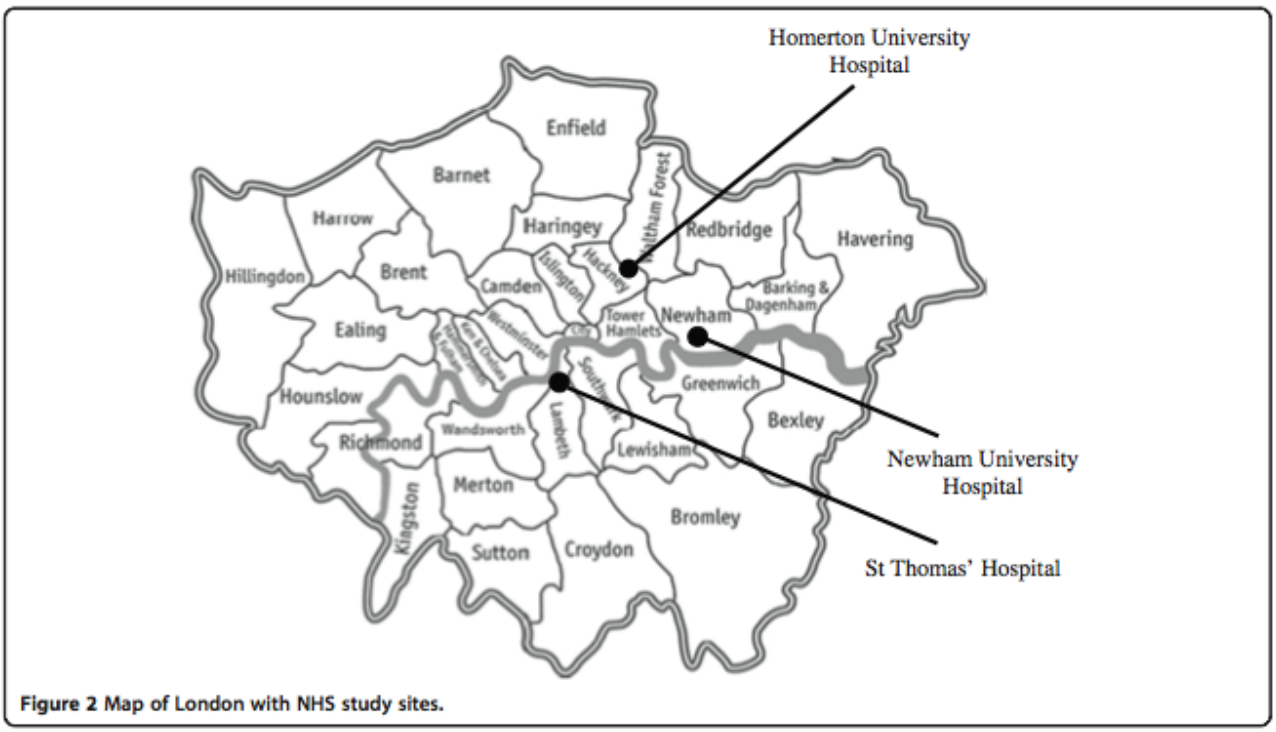

Figure 2 Map of London with NHS study sites.

Qualitative phase

The qualitative phase of the study comprised semi-structured interviews and ethnographic fieldwork.

Semi-structured interviews

The first author conducted semi-structured interviews with pregnant African women living with HIV, healthcare providers, and staff from voluntary sector organisations.

Twenty-three pregnant women were recruited from three specialist NHS HIV antenatal clinics in London between October 2010 and October 2011 (Figure 2). These three sites are among the five hospitals reporting the largest numbers of pregnancies in HIV infected women between 2000 and 2010 (data extracted from most recent NSHPC dataset). Each centre looks after approximately 40 to 50 pregnant women living with HIV each year. They are in boroughs of great ethnic diversity, and also substantial deprivation with all three classified as among the twenty most deprived local authorities in England [32].

Healthcare professionals working at these sites identified and approached women attending for HIV antenatal care who were eligible for the study. Women were eligible if they were of black African ethnicity, were born in sub-Saharan Africa, were diagnosed with HIV and were pregnant (at any gestation). The first author was based on site during HIV antenatal clinics and was able to discuss the study further with women who were interested, providing them with an information sheet. If a woman wished to participate we found a convenient time for her to attend to be interviewed. Written informed consent was obtained prior to each interview. Face-to-face interviews (n = 20) were conducted in a private room in the hospital site with an interpreter present if required (n = 1). Topics covered included experience of pregnancy; attitudes to medical interventions; psychosocial support; experience of healthcare during pregnancy; and stigma and discrimination. A minority of initial interviews (n = 3) were conducted by telephone due to participant preference (Figure 3). Telephone interviewing is increasingly used in health research [33] and is considered effective and especially useful in 'hard to reach' populations such as mothers with young children.

A follow-up interview after birth was arranged with each woman who had been interviewed during pregnancy (n = 22). Serial interviews can result in the development of increased trust between researcher and participant, facilitating more open discussion [34]. Furthermore, given that the transition between pregnancy and motherhood is a dynamic time, we felt that serial interviews might better capture this changing experience. The follow-up interview occurred at a time convenient for the participant, up to one year after delivery. Topics included experience of delivery; experience of infant feeding; support at home after delivery; and engagement with HIV services after delivery. Some of these interviews (n = 6) were conducted by telephone due to women's difficulty in attending for interview when caring for a newborn infant.

In total 23 women were recruited for the qualitative phase of the study over one year, the majority of them (22) recruited whilst pregnant. One participant had been approached whilst pregnant but chose to defer her interview until after delivery due to poor health. This sample size is typical of much qualitative research and allowed us to reach data saturation. Of the 22 women recruited during pregnancy, 14 (64%) were interviewed postnatally. We were unable to contact the remaining 8 women or they declined to be interviewed again.

Interviews were recorded on a digital voice recorder where possible, unless a participant had objections to this. In these rare cases, extensive contemporaneous written notes were taken.

Initial sampling was purposive as we attempted to recruit women from a range of African regions, with a range of migration histories, and at different stages of diagnosis (Table 1). Sampling was also guided by the initial quantitative results in order to explore emerging findings. As the study progressed the sampling became theoretical as we selected potential cases to test emergent themes and theories.

The first author conducted semi-structured interviews with 4 healthcare providers involved in the care of pregnant women living with HIV. They were recruited from the collaborating NHS sites and were invited to participate by the first author. They included two consultants in HIV medicine, one HIV specialist midwife and one specialist nurse in genitourinary medicine. Interviews were also conducted with two members of staff from voluntary sector organisations with experience of supporting African women living with HIV. These participants were identified through the first author's knowledge of local voluntary sector organisations and were invited to participate by her. The purpose of interviewing health care professionals and voluntary sector workers was to elicit their experience of supporting this group of women and to identify what they saw as barriers to accessing care.

The first author also attended multidisciplinary meetings of healthcare professionals and observed some daily work at the antenatal clinics. These observations were recorded as field notes and were used to deepen and contextualise understanding of the interview data.

Ethnography

Ethnography consists of a combination of participant observation (observing activity whilst engaging directly

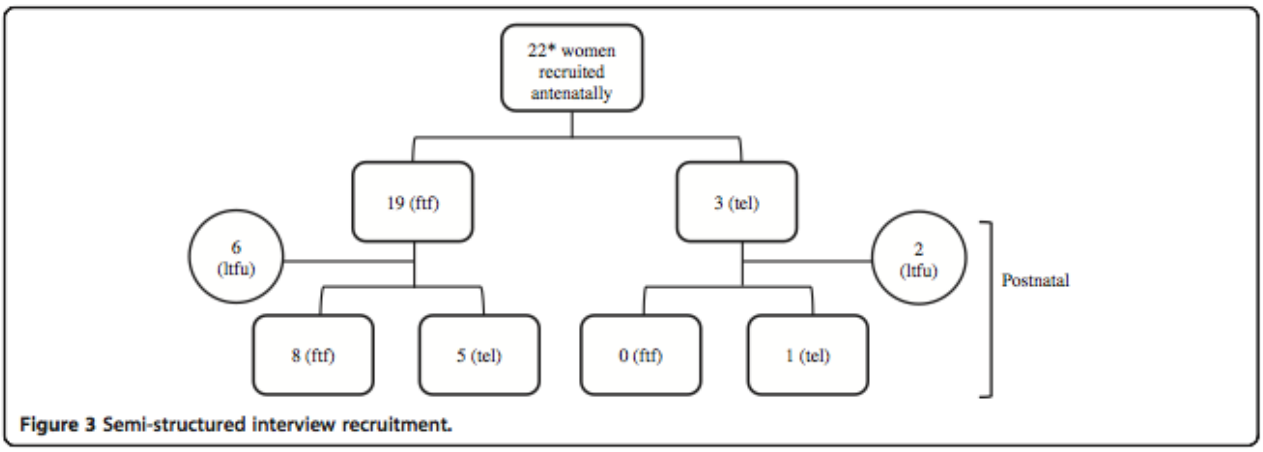

Figure 3 Semi-structured interview recruitment.

with the world being studied), informal conversation, and formal interviews, within a social group. It can contribute to a rich and multidimensional understanding of social phenomena in groups [35]. Two field sites were selected for this study.

The first site was Body & Soul; a London-based charity that has been supporting children and families affected by HIV since 1996. A substantial number of African woman living with HIV who have experience of pregnancy attend Body & Soul. The first author worked at Body & Soul as a volunteer worker between April 2010 and December 2011, completing nearly 90 hours of participant observation. This fieldwork allowed the research team to explore the lived experience of people living with HIV, including some who were pregnant, in a non-clinical setting.

The second site was a Pentecostal church in London which has a largely diasporic Nigerian clergy and congregation. This choice of field site was guided by quantitative findings and initial interview data and this particular church was selected as it had been mentioned by a number of participants. The first author attended church services between July and September 2011, conducting nearly 40 hours of participant observation. This was complemented by watching broadcast footage of services, and conducting in-depth interviews with members of the congregation and people from the local community who are familiar with the church. The focus of this fieldwork was the role of Pentecostal faith in migrant Africans' lives and how this particular church influenced attitudes towards parenthood, health and wellbeing.

Table 1 NHS participant characteristics (semi-Structured Interviews)

Characteristic	Number of participants ($n = 23$)
African region of birth	
East Africa	9
West Africa	11
Southern Africa	0
Middle Africa	3
Duration of residence in UK (years)	
<1	1
1–4	4
5–10	12
>10	6
Immigration status*	
Secure	15
Insecure	8
Diagnosis of HIV	
Prior to current pregnancy	20
During current pregnancy	3

*Secure immigration status is defined as being a UK citizen, a recognised refugee or having exceptional or indefinite leave to remain. Anyone not in these categories is defined as having insecure immigration status.

Ethics

The NSHPC has London Multi-Centre Research Ethics Committee approval (MREC/04/2/009). SOPHID does not require ethical approval as it fulfils a surveillance purpose. The HPA is registered under the Data Protection Act 1998 (registration number Z7749250) to handle data for diagnostic, public health and other purposes. The HPA is also registered under Section 251 of the Health and Social Care Act 2001 and has approval from the Patient Information Advisory Group (PIAG) to handle data for purposes that include surveillance and the control of disease, even where specific patient consent has not been given. Section 251 is renewed annually [36].

The qualitative phase of the study has ethical approval from City University Research Ethics Committee for qualitative research conducted outside NHS sites (ref PhD/09-10/10). It also has approval from the West London Research Ethics Committee for the overall

qualitative phase, including on behalf of the NHS sites (ref 10/10707/49).

Data analysis

This study collected both quantitative and qualitative data. Each dataset has been kept analytically distinct and has been analysed using appropriate techniques. We have moved between the datasets at the analysis stage to use findings from each analysis to generate hypotheses to be explored in the other datasets [37]. Linking will also occur at the interpretation stage, when results from the quantitative and qualitative analyses will be compared, contrasted and combined [38].

Quantitative analysis

Data were analysed using Stata 11.2 (Stata Corporation, College Station, Texas, USA). Data were summarized and examined for improbable values which were then checked against written records and amended accordingly or coded as missing. The dataset was checked for duplicate entries. Records with missing exposure or outcome data were excluded from analysis for the exposure and outcome of interest. Records with missing data on confounding variables were also dropped from final multivariable models. For analyses of trends we used the Bonferroni correction: this accounts for multiple comparisons within a group by adjusting the statistical significance level used for each test, minimising the chance of spurious positive results. For a given outcome, a Chi-square test was performed to compare pregnancies across different ethnicity, regional and migration groups. These groups were then compared for each outcome using univariable and multivariable logistic regression models to estimate odds ratios and adjusted odds ratios, with 95% confidence intervals. A priori confounders were included in final multivariable models. Other variables were included if their inclusion improved model fit. This was assessed using likelihood ratio tests, with a significance level of $p < 0.05$. We used robust standard errors where appropriate to account for potential clustering at a maternal level in sequential pregnancies for some outcomes.

Qualitative analysis

A professional transcription company transcribed all interviews, with quality checks undertaken by the first author. All interview transcripts and notes made during the fieldwork at Body & Soul were entered into NVivo 9. This qualitative data analysis software facilitates the classifying, sorting and linking of qualitative data. We are undertaking a thematic analysis of interview data, using the constant comparative method usually associated with grounded theory [39]. This is an inductive process where each transcript is read several times and sections of the text coded within the database. Coded text are then compared and linked across all the interviews if they capture a similar theme, leading to the development of broader key categories. We will pay particular attention to both the context of coded text, and also to data which does not appear to fit into the emerging thematic framework, in order to deepen our understanding. Some a priori codes will be developed from the quantitative phase, allowing us to interrogate the qualitative data to provide insight into our quantitative findings.

The first author made extensive written field notes during ethnographic fieldwork conducted at both Body & Soul and the Pentecostal church. Ethnographic research at the church also included in-depth interviews with members of the congregation and a local Pentecostal pastor (from a different local church). We also analysed church publications and recordings of television broadcasts of church services. All ethnographic data will be hand coded, using a manual index system to organise the data. We will begin with open coding, a process where codes are identified from the data without restriction, developing broader thematic categories using the constant comparative method.

The coding of transcripts and ethnographic data will be discussed with another member of the research team to improve rigour and reliability of the analysis.

Advisory group

An advisory group was set up to provide guidance and support throughout the study. The group comprised: lay members; clinicians from the collaborating NHS centres; academics with an interest in HIV in African migrant groups; and representatives from Body & Soul and Positively UK.

Discussion

This ongoing mixed-methods study has used epidemiological and anthropological methods to explore outcomes and experiences of pregnancy in African women living with HIV in the UK. Its particular strength is the innovative combination of quantitative and qualitative approaches, which will enable a richer understanding of this complex and multi-faceted area. Although mixed methods are increasingly used in health services research, methods such as secondary analysis of surveillance datasets and ethnography are rarely used in the context of mixed methods research. In a recent review O'Cathain et al. [40] found that the quantitative component in mixed methods health services research largely comprised primary data collection through surveys, other observation studies or intervention studies. Furthermore, semi-structured interviews were the qualitative method of choice in 80% of studies, with participant observation described in less than 1%.

The surveillance dataset used in this study was not designed for our research question and there were therefore no data on key variables such as socioeconomic and immigration status. Furthermore women interviewed in the qualitative phase may not have been included in the surveillance dataset. However, given that almost all pregnant women living with diagnosed HIV are reported to the NSHPC, it is unlikely that findings from the quantitative phase would not apply to women recruited in the qualitative phase and vice versa. The advantage of using surveillance data is the statistical power gained from such large numbers, generalisability, and the efficiency in time. The ethnographic component, although limited in duration as a result of the mixed-methods design, has resulted in a rich understanding of women's lives [35]. The findings may also allow us to inform future HIV surveillance data collection by identifying potential factors that may impact on pregnancy that are currently not collected. We feel that the methodology used in this study could be applied to other settings where complex public health questions arise.

We anticipate that the data obtained from this study will inform the provision of care to pregnant women living with HIV and the development of services that prioritise and address their needs, leading to improvements in maternal and child health.

Abbreviations

HIV: Human immunodeficiency virus; ART: Antiretroviral therapy; MSM: Men who have sex with men; MTCT: Mother-to-child transmission.

Competing interests

The authors declare that they have no competing interests.

Authors' contributions

ST conceived the study. ST designed the study with input from JE, AP and PT. AB and PT supervised the linkage of surveillance datasets. ST was responsible for qualitative data collection, and the data management and analyses of both quantitative and qualitative data. JE, AB, AP and PT provided supervision and guidance on analyses and conduct of the research. ST drafted the manuscript with input from JE, AB and PT. All authors read, revised and approved the final manuscript.

Authors' information

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The association between ethnicity and late presentation to antenatal care among pregnant women living with HIV in the UK and Ireland

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UK and Ireland guidelines state that all pregnant women should have their first antenatal care appointment by 13 weeks of pregnancy (antenatal booking). We present the results of an analysis looking at the association between maternal ethnicity and late antenatal booking in HIV-positive women in the UK and Ireland. We analysed data from the National Study of HIV in Pregnancy and Childhood (NSHPC). We included all pregnancies in women who were diagnosed with HIV before delivery and had an estimated delivery date between 1 January 2008 and 31 December 2009. Late booking was defined as antenatal booking at 13 weeks or later. The baseline reference group for all analyses comprised women of "white" ethnicity. Logistic regression models were fitted to estimate adjusted odds ratios (AOR). There were 2721 eligible reported pregnancies; 63% (1709) had data available on antenatal care booking date. In just over 50% of pregnancies (871/1709), the antenatal booking date was $\geq$13 weeks of pregnancy (i.e., late booking). Women diagnosed with HIV during the current pregnancy were more likely to present for antenatal care late than those previously diagnosed (59.1% vs. 47.5%, $p<0.001$). Where women knew their HIV status prior to becoming pregnant, the risk of late booking was raised for those of African ethnicity (AOR 1.80; 95% confidence interval (CI) 1.14, 2.82; $p=0.011$). In women diagnosed with HIV during pregnancy, the risk of late booking was also higher for women of African ethnicity (AOR 2.98: 95% CI 1.45, 6.11; $p=0.003$) and for women of other black ethnicity (AOR 3.74: 95% CI 1.28, 10.94; $p=0.016$). Overall, women of African or other black ethnicity were more likely to book late for antenatal care compared with white women, regardless of timing of diagnosis. This may have an adverse effect on maternal and infant outcomes, including mother-to-child transmission of HIV.

Keywords: HIV; antenatal care; pregnancy; ethnicity

Introduction

Antenatal care plays an important role in maternal and infant health (Bergsjø & Villar, 1997), providing a woman with information and support to make decisions about her pregnancy (National Institute for Health and Clinical Excellence, 2010). Guidelines from both the United Kingdom and Ireland state that all women should have their first antenatal care appointment, known as "antenatal booking", by 10–13 weeks' gestation (Department of Health, 2009; Health Service Executive, 2011; National Institute for Health and Clinical Excellence, 2010). At this booking appointment, women are given information on pregnancy and enter the antenatal care pathway. They are also offered foetal ultrasound scanning and given the opportunity to have screening for haemaglobinopathies and infectious disease (National Institute for Health and Clinical Excellence, 2010).

Low maternal socio-economic status (Beeckman, Louckx, & Putman, 2010; Brown, 1989; Essex, Counsell, & Geddis, 1992; Melnikow & Alemagno, 1993), young maternal age (Blondel & Marshall, 1998; Delvaux, Buekens, Godin, & Boutsen, 2001; Essex et al., 1992), not having a stable partner (Delvaux et al., 2001) and multiparity (Blondel & Marshall, 1998; Essex et al., 1992) have all been identified as risk factors for late booking in studies from the United States and Europe. Studies from the UK have identified similar risk factors (Florey & Taylor, 1994; Kupek, Petrou, Vause, & Maresh, 2002; Lewis, 1982; Redshaw & Heikkila, 2010; Rowe et al., 2008; Simpson & Walker, 1980).

Maternal non-white ethnicity and migrant status have been shown to play a large role in late presentation to antenatal care. A survey of over 800 women in England found that the odds of late booking in black women were nearly six times that of white women (Rowe et al., 2008). An association between black and minority ethnicity and late booking was also found in another large national survey of maternity care experiences in England (Redshaw & Heikkila, 2010). Furthermore, the authors report

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increased odds of booking beyond 10 weeks in women from black and minority ethnic groups born *outside* of the UK, compared with white women born in the UK. Insecure migration status is a further risk factor with a recent study from Switzerland reporting an 11-fold higher risk of delayed prenatal care in undocumented migrant mothers compared with mothers with legal residency (Wolff et al., 2008). Similar associations between ethnicity or migrant status, and late booking have been reported in numerous other studies from the UK and elsewhere (Alderliesten, Vrijkotte, Van Der Wal, & Bonsel, 2007; Beeckman et al., 2010; Chisholm, 1989; Chote et al., 2011; Delvaux et al., 2001; Essex et al., 1992; Korinek & Smith, 2011; Kupek et al., 2002; Melnikow & Alemagno, 1993; Park, Vincent, & Hastings-Tolsma, 2007; Petitti, Coleman, Binsacca, & Allen, 1990; Simpson & Walker, 1980).

Late initiation of antenatal care is associated with poor maternal and infant outcomes (Florey & Taylor, 1994; Quick, Greenlick, & Roghmann, 1981; Van Hanegem, Miltenburg, Zwart, Bloemenkamp, & Van Roosmalen, 2011). A recent report from the UK's Confidential Enquiry into Maternal and Child Health (CEMACH, 2009) found that antenatal booking beyond 12 weeks gestation was more common in women who had experienced stillbirth or neonatal death. However, it is important not to assume a causal link. Women with socio-demographic risk factors for poor maternal and child health outcomes are also probably more likely to present late for care during pregnancy. Late booking may carry even greater risks in the context of maternal co-morbidity such as HIV infection.

There was an increase in the UK and Ireland in the number of pregnancies among women diagnosed with HIV from under 100 a year in the early 1990s, to over 1400 a year from 2006 onwards (National Study of HIV in Pregnancy and Childhood [NSHPC], 2011). During this time, the rate of mother-to-child transmission (MTCT) of HIV in the UK and Ireland declined from approximately 20% to less than 2% (Duong, Ades, Gibb, Tookey, & Masters, 1999; Townsend, Cortina-Borja, Peckham, de Ruiter et al., 2008). Timely initiation of antenatal care allows for early screening for maternal HIV infection, prompt initiation of antiretroviral therapy (ART), planning of infant delivery and advice regarding avoidance of breastfeeding, all of which contribute to the minimisation of risk of MTCT.

There are few data on the presentation to antenatal care in women living with HIV. A small study from London found that a greater proportion of women living with HIV presented late to antenatal care compared with the local general obstetric population (Parisaei, Anderson, Erskine, & Gann, 2007). Over 80% of women diagnosed with HIV reported as pregnant in the UK and Ireland are of black African ethnicity (Townsend, Cortina-Borja, Peckham, & Tookey, 2008). One of the few studies exploring antenatal care in women living with HIV revealed that African migrants living in France were more likely to initiate antenatal care late than French-born women (Jasseron et al., 2008).

To our knowledge, there have been no studies in the UK or Ireland specifically investigating antenatal care access in women with HIV. We carried out an analysis of surveillance data from the UK and Ireland to (1) quantify the extent of late antenatal booking in this population and (2) explore its association with maternal ethnicity.

Methods

This analysis was based on data from the NSHPC. The NSHPC, established in 1986, carries out comprehensive population-based surveillance of obstetric and paediatric HIV in the UK and Ireland. Pregnancies in HIV-infected women diagnosed by the time of delivery, and infants born to infected women, are reported through two active parallel schemes managed in collaboration with the Royal College of Obstetricians and Gynaecologists and the British Paediatric Surveillance Unit (Nicoll, Lynn, Rahi, Verity, & Haines, 2000). The full methods are described elsewhere (Townsend, Cortina-Borja, Peckham, & Tookey, 2008). The NSHPC has London Multi-Centre Research Ethics Committee approval (MREC/04/2/009).

Eligibility

We included all pregnancies with an expected date of delivery (if the outcome was not a live or stillbirth) or actual date of delivery between January 2008 (when antenatal booking date started to be routinely collected by the NSHPC) and December 2009. We excluded data on 45 terminations of pregnancy, and 65 pregnancies in women diagnosed with HIV after delivery.

Variables

Antenatal booking was categorised as "early" and "late". "Early" booking was defined as reported antenatal booking before 13 complete weeks' gestation. "Late" booking was defined as booking at 13 or more complete weeks' gestation. Maternal ethnicity was obtained from recorded ethnicity on notification forms. Maternal ethnicity was categorised as "white", "African", "other black" and "other". "African"

ethnicity was defined as being of mixed or black ethnicity and having been born in sub-Saharan Africa. "Other black" ethnicity was defined as being of black African or Caribbean ethnicity and born outside of sub-Saharan Africa. "Other" ethnicity comprised Asian and other ethnicities.

Maternal age at delivery was categorised as <25, 25–34 and ≥ 35 years. Reporting region referred to the geographical region of the unit that reported the pregnancy. The regions were grouped as London; England (not London); Scotland, Wales and Northern Ireland; and Ireland. Injecting drug use referred to probable mode of HIV acquisition in the mother rather than current injecting drug use. ART at conception was categorised as "yes with viral load <50 copies/ml", "yes with viral load ≥ 50 copies/ml" and "no". The first viral load available during the reported pregnancy was used to create this variable.

Statistical methods

Data were analysed using Stata 11.2 (Stata Corporation, College Station, TX, USA). Pregnancy characteristics were compared in early and late booking groups using a Chi-square test. The early booking group was compared with the late booking group using univariable and multivariable logistic regression models to estimate odds ratios and adjusted odds ratios (AORs), with 95% confidence intervals (CIs). Women of white ethnicity were used as the reference group in all analyses. The analysis was stratified by whether a woman had been diagnosed with HIV (1) prior to or (2) during the reported pregnancy. A priori confounders (maternal age at delivery and parity) were included in final multivariable models. Other variables were included if their inclusion improved model fit. This was assessed using likelihood ratio tests, with a significance level of $p<0.05$.

Results

There were 2721 eligible pregnancies with a delivery date or expected delivery date between January 2008 and December 2009. This analysis is based on 1709/2721 (62.8%) pregnancies with data available on antenatal booking date (African ethnicity $n=1303$, other black ethnicity $n=115$, other ethnicity $n=74$ and white ethnicity $n=217$), in 1684 women. Missing antenatal booking date was associated with reporting region, non-live or stillbirth and severe pre-maturity (all $p<0.001$). There was no association between ethnicity and missing booking date ($p>0.1$).

Overall, antenatal booking was late (≥ 13 weeks' gestation) in 51.0% (871/1709; 95% CI: 48.6–51.4%) of pregnancies, including 5.3% (90/1709; 95% CI: 4.2–6.3%) during the third trimester (≥ 28 weeks). Of those booking late, the median gestational week of booking was 16.9 (interquartile range 14.6–32.9 weeks). Time of booking varied with timing of maternal HIV diagnosis. Antenatal booking was late in almost 60% (304/514; 95% CI: 54.9–63.4%) of pregnancies in women diagnosed with HIV during the reported pregnancy compared with 47.5% (567/1195; 95% CI: 44.7–50.2%) of those in women diagnosed before the reported pregnancy ($p<0.001$).

Characteristics of pregnancies

Comparing pregnancies where booking was early with those where booking was late, we found no association between the timing of booking and maternal age or injecting drug use (all $p>0.1$; Table 1) either in women diagnosed before or during the pregnancy. Increasing parity was associated with late booking in those diagnosed prior to the reported pregnancy (χ^2_{trend} test $p<0.001$). Late booking was also associated with increasing parity in those diagnosed during the reported pregnancy, although this was of borderline significance (χ^2_{trend} test $p=0.08$).

We found no association between the timing of antenatal booking and initial CD4 count (Table 1). Among women diagnosed with HIV prior to the reported pregnancy, late booking was associated with not being on ART at conception or having a detectable viral load on treatment ($p<0.001$). We also saw a variation in the timing of antenatal booking across geographical regions, with late booking being more common in pregnancies reported in Ireland in both sub-groups ($p<0.05$; Table 1).

There was an association between maternal ethnicity and timing of antenatal booking (Figure 1). In pregnancies where a woman was diagnosed with HIV prior to the reported pregnancy, 51.0% (470/922) of African women and 38.2% (29/76) of other black women booked late compared with 36.2% (55/152) of white women ($p<0.001$). This association was also seen in the group diagnosed during the reported pregnancy, with over 60% of both African and other black women (238/381 and 26/39, respectively) booking late for antenatal care compared with 43% (28/65) of white women ($p=0.004$).

Multivariable analysis

After adjusting for maternal age, ART at conception, parity and reporting region, maternal African ethnicity was associated with increased odds of late booking in women diagnosed with HIV prior to the reported pregnancy compared with white

Table 1. Comparison of baseline characteristics among pregnancies in women diagnosed with HIV who book early and late for antenatal care ($N = 1709$).

	Diagnosed with HIV prior to reported pregnancy			Diagnosed with HIV during reported pregnancy		
	ANC booking < 13 weeks, n/N (%)	ANC booking ≥ 13 weeks, n/N (%)	p[a]	ANC booking < 13 weeks, n/N (%)	ANC booking ≥ 13 weeks, n/N (%)	p[a]
Maternal age at delivery (years)						
< 25	45/503 (8.9)	42/459 (9.2)	0.973	35/163 (21.5)	44/254 (17.3)	0.260
25–34	304/503 (60.4)	274/459 (59.7)		105/163 (64.4)	160/254 (63.0)	
≥ 35	154/503 (30.6)	143/459 (31.2)		23/163 (14.1)	50/254 (19.7)	
History of injecting drug use						
No	612/628 (97.5)	556/567 (98.1)	0.480	209/210 (99.5)	303/304 (99.7)	0.792
Yes	16/628 (2.5)	11/567 (1.9)		1/210 (0.5)	1/304 (0.3)	
1st CD4 count in pregnancy (cells/mm^3)						
≥ 500	194/577 (33.6)	157/514 (30.5)	0.327	44/190 (23.2)	77/288 (26.7)	0.331
200–499	338/577 (58.6)	306/514 (59.5)		114/190 (60.0)	153/288 (53.1)	
< 200	45/577 (7.8)	51/514 (9.9)		32/190 (16.8)	58/288 (20.1)	
ART at conception						
Yes with earliest viral load < 50 copies/ml	286/573 (49.9)	197/534 (36.9)	< 0.001	N/A	N/A	
Yes with earliest viral load ≥ 50 copies/ml	50/573 (8.7)	57/534 (10.7)		–	–	
No	237/573 (41.4)	280/534 (52.4)		–	–	
Parity						
0	155/579 (26.8)	87/528 (16.5)	< 0.001[b]	111/193 (57.5)	149/284 (52.5)	0.096[b]
1	224/579 (38.7)	217/528 (41.1)		52/193 (26.9)	65/284 (22.9)	
2	132/579 (22.8)	129/528 (24.4)		21/193 (10.9)	54/284 (19.0)	
3	68/579 (11.7)	95/528 (18.0)		9/193 (4.7)	16/284 (5.6)	
Reporting region						
London	281/628 (44.7)	215/567 (37.9)	< 0.001	69/209 (33.0)	141/304 (46.4)	0.001
England (not London)	295/628 (47.0)	252/567 (44.4)		119/209 (56.9)	125/304 (41.1)	
Wales, Scotland, Northern Ireland	15/628 (2.4)	17/567 (3.0)		15/209 (7.2)	18/304 (5.9)	
Ireland	37/628 (5.9)	83/567 (14.6)		6/209 (2.9)	20/304 (6.6)	

ANC, antenatal care; ART, antiretroviral therapy; N/A, not applicable.
[a]p Value obtained by χ^2 test.
[b]p Value obtained by χ^2 test for trend.

women (AOR 1.80; 95% CI: 1.14–2.82; $p = 0.011$; Table 2). In the group diagnosed during the reported pregnancy, the odds of late booking were increased in women of both African ethnicity (AOR 2.98; 95% CI: 1.45–6.11; $p = 0.003$; Table 2) and other black ethnicity (AOR 3.74; 95% CI: 1.28–10.94; $p = 0.016$; Table 2), when adjusted for maternal age, parity and reporting region.

We investigated the effect of excluding pregnancies in women who arrived in the UK or Ireland after conception ($n = 64$). The odds of late booking in women diagnosed with HIV prior to the reported pregnancy remained increased for African women compared to white women (AOR 1.76: 95% CI: 1.12–2.77; $p = 0.014$). In the group diagnosed during the reported pregnancy, the odds of late booking remained increased for both African women (AOR 2.94; 95% CI: 1.38–6.27; $p = 0.005$) and women of other black ethnicity (AOR 4.41; 95% CI: 1.43–13.70; $p = 0.01$).

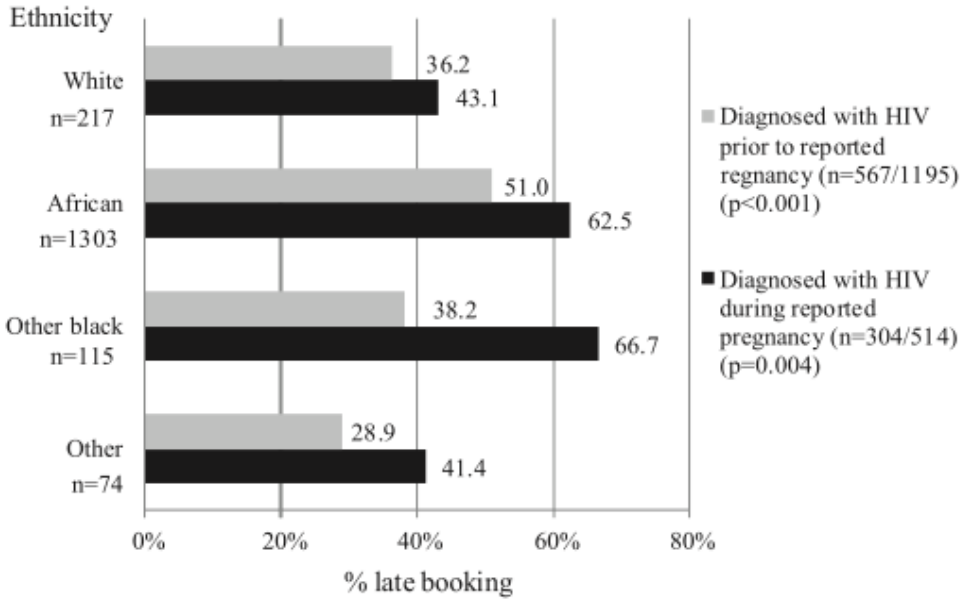

Figure 1. Percentage of pregnancies where women booked for antenatal care ≥ 13 weeks.

Discussion

In this analysis of national surveillance data from the UK and Ireland comprising 1709 pregnancies, we found that in 51% of pregnancies antenatal booking was late, at 13 weeks or beyond. This falls short of current UK and Ireland guidelines (Department of Health, 2009; Health Service Executive, 2011; National Institute for Health and Clinical Excellence, 2010). It is also much higher than national rates of late booking in the general population which have been estimated at approximately 15% (Redshaw & Heikkila, 2010). Our data are probably representative of national experience as it is likely that almost all diagnosed HIV-infected women in the UK and Ireland are reported to the NSHPC (Health Protection Agency, 2008).

Late booking was more common in pregnancies where women were diagnosed during the reported pregnancy than those diagnosed before the reported pregnancy. This is of concern, as these women will have missed the opportunity of earlier screening for HIV. Nearly half of all women who had been diagnosed with HIV prior to their pregnancy booked late for antenatal care. Late booking in the context of maternal HIV infection not only delays the detection of general maternal and foetal complications, but it also precludes timely interventions to prevent MTCT. A retrospective study from the UK has shown that women with moderate to high levels of HIV viral load need to commence ART by 20 weeks' gestation, and possibly earlier, if they are to achieve virological suppression at delivery (Read et al., 2010). Furthermore, late antenatal booking, delayed HIV screening and late initiation of ART have all been identified as contributory factors in cases of MTCT in the UK in recent years (National Study of HIV in Pregnancy and Childhood [NSHPC], Children's HIV Association [CHIVA], & NHS Audit Information Analysis Unit, 2007; Struik et al., 2008).

In this analysis, we found an association between late booking and African or other black ethnicity. In women diagnosed with HIV prior to the reported pregnancy, African women were more likely than white women to book late for antenatal care. In those diagnosed with HIV during the reported pregnancy, African and other black women were more likely to book late than white women. This reflects the well-documented association between ethnicity, migration and late booking seen among pregnant women in the UK in general (Chisholm, 1989; Kupek et al., 2002; Lewis, 1982; Redshaw & Heikkila, 2010; Rowe et al., 2008; Simpson & Walker, 1980). It also fits with findings from a study in France which demonstrated that African migrant women with HIV were more likely than French-born women to book late (Jasseron et al., 2008). Ours is the first study among pregnant women living with HIV in the UK to demonstrate an association between late booking and African or other black ethnicity. It is important not to assume a direct causal effect of ethnicity or migrant status on timing of antenatal booking. They may be markers of other sociocultural factors that contribute to late booking such as poverty, lack of social support, poor understanding of the

Table 2. Crude and adjusted odds ratios for late antenatal booking comparing variables including maternal ethnicity ($N = 1245$)[a]

	Diagnosed with HIV prior to reported pregnancy ($n = 855$)				Diagnosed with HIV during reported pregnancy ($n = 390$)			
	OR (95% CI)	*p*	AOR[b] (95% CI)	*p*	OR (95% CI)	*p*	AOR[b] (95% CI)	*p*
Ethnicity								
White	1.00	–	1.00		1.00		1.00	
African	1.52 (1.00, 2.29)	0.049	1.80 (1.14, 2.82)	0.011	2.81 (1.53, 5.17)	0.001	2.98 (1.45, 6.11)	0.003
Other black	1.06 (0.53, 2.12)	0.868	1.33 (0.64, 2.76)	0.445	3.39 (1.25, 9.19)	0.016	3.74 (1.28, 10.94)	0.016
Other	0.60 (0.26, 1.37)	0.224	0.69 (0.29, 1.64)	0.405	0.86 (0.32, 2.32)	0.762	1.02 (0.35, 2.93)	0.977
Maternal age at delivery (years)								
< 25	1.00		1.00		1.00		1.00	
25 –34	0.96 (0.59, 1.56)	0.874	0.79 (0.47, 1.34)	0.737	1.27 (0.75, 2.14)	0.379	0.95 (0.52, 1.72)	0.868
≥ 35	1.00 (0.60, 1.68)	0.988	0.83 (0.47, 1.46)	0.521	1.84 (0.92, 3.66)	0.082	1.32 (0.59, 2.97)	0.498
ART at conception								
Yes with earliest VL < 50	1.00		1.00		N/A[c]		N/A[c]	
Yes with earliest VL ≥ 50	1.42 (0.89, 2.26)	0.138	1.45 (0.90, 2.35)	0.128	–	–	–	–
No	1.52 (1.14, 2.02)	0.004	1.50 (1.11, 2.03)	0.008	–	–	–	–
Parity								
0	1.00		1.00		1.00		1.00	
1	1.80 (1.25, 2.60)	0.002	1.65 (1.14, 2.40)	0.009	0.85 (0.52, 1.38)	0.504	0.83 (0.49, 1.42)	0.503
2	1.53 (1.02, 2.28)	0.040	1.35 (0.88, 2.05)	0.165	2.38 (1.21, 4.67)	0.012	2.22 (1.06, 4.64)	0.034
3	2.69 (1.69, 4.26)	<0.001	2.32 (1.42, 3.80)	0.001	1.60 (0.59, 4.34)	0.351	1.81 (0.59, 5.51)	0.300
Reporting region								
London	1.00		1.00		1.00		1.00	
England (not London)	1.16 (0.87, 1.54)	0.330	1.20 (0.89, 1.62)	0.195	0.44 (0.28, 0.69)	<0.001	0.49 (0.31, 0.78)	0.003
Scotland, Wales, N Ireland	1.94 (0.82, 4.60)	0.132	2.36 (0.95, 5.88)	0.064	0.35 (0.15, 0.83)	0.017	0.64 (0.25, 1.67)	0.362
Ireland	2.76 (1.63, 4.66)	<0.001	2.53 (1.46, 4.39)	0.001	3.69 (0.82, 16.53)	0.088	4.68 (0.99, 22.18)	0.052

OR, odds ratio; CI, confidence interval; AOR, adjusted odds ratio; ART, antiretroviral therapy; VL, HIV viral load; N/A, not applicable.
[a]Numbers reduced due to missing data.
[b]Adjusted for all other variables in table.
[c]Not included as not applicable.

role of antenatal care (Ndidi & Oseremen, 2010) and cultural constructions of pregnancy (Carolan & Cassar, 2010).

We had no information on potentially important confounders such as when pregnancy was first recognised, legal migrant status, socio-economic status and marital status. There may therefore be some residual confounding in our analyses. This study was limited by the amount of missing data on antenatal booking date. Missing data were associated with reporting region and may reflect variations in reporting practice. It was also associated with severe prematurity, continuing pregnancies and pregnancies in women who had moved abroad, suggesting a lack of opportunity to record booking date. There was no association between ethnicity and missing booking date. Although we cannot exclude the possibility of bias introduced by missing data, we feel that this is unlikely. Finally, we are aware that the ethnicity categories used in this analysis are broad and may obscure differences within heterogeneous groups.

This is one of the first large-scale analyses of observational data to specifically explore antenatal booking in women with HIV. Over half of women living with HIV in the UK and Ireland booked late for antenatal care. Late booking was associated with African and other black ethnicity. Further work is required to elucidate the mechanisms that drive these

differences and to develop targeted interventions. In the meantime, healthcare providers should raise awareness of the importance of antenatal care with women living with HIV of reproductive age, encouraging early attendance. This may lead to improvements in maternal and infant health outcomes including further and sustained reduction in rates of MTCT of HIV.

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Use of Zidovudine-Sparing HAART in Pregnant HIV-Infected Women in Europe: 2000–2009

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Background: Increasing numbers of women in resource-rich settings are prescribed zidovudine (ZDV)-sparing highly active antiretroviral therapy (HAART) in pregnancy. We compare ZDV-sparing with ZDV-containing HAART in relation to maternal viral load at delivery, mother-to-child transmission (MTCT) of HIV, and congenital abnormality.

Methods: This is an analysis of data from the National Study of HIV in Pregnancy and Childhood and the European Collaborative Study. Data on 7573 singleton births to diagnosed HIV-infected women between January 2000 and June 2009 were analyzed. Logistic regression models were fitted to estimate adjusted odds ratios (AORs).

Results: Overall, 15.8% (1199 of 7573) of women received ZDV-sparing HAART, with increasing use between 2000 and 2009 ($P < 0.001$). Nearly a fifth (18.4%) of women receiving ZDV-sparing HAART in pregnancy had a detectable viral load at delivery compared with 28.6% of women on ZDV-containing HAART [AOR 0.90; 95% confidence interval (CI): 0.72 to 1.14, $P = 0.4$]. MTCT rates were 0.8% and 0.9% in the ZDV-sparing and ZDV-containing groups, respectively (AOR 1.81; 95% CI: 0.77 to 4.26, $P = 0.2$). The congenital abnormality rate was the same in both groups (2.7%, AOR 0.98; 95% CI: 0.66 to 1.45, $P = 0.9$), with no significant difference between the groups in a subanalysis of pregnancies with first trimester HAART exposure (AOR 0.79; 95% CI: 0.48 to 1.30, $P = 0.4$).

Conclusions: We found no difference in risk of detectable viral load at delivery, MTCT, or congenital abnormality when comparing ZDV-sparing with ZDV-containing HAART. With increasing use of ZDV-sparing HAART, continued monitoring of pregnancy outcomes and long-term consequences of in utero exposure to these drugs is required.

Key Words: antiretroviral agents, highly active antiretroviral therapy, HIV, pregnancy outcome, viral load, congenital abnormalities

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INTRODUCTION

In recent years, there has been a steady increase in the United Kingdom and Ireland in the number of pregnancies among women diagnosed with HIV, from under 100 a year in the early 1990s to approximately 1400 in 2006[1]; a similar pattern has been observed elsewhere in Europe.[2] Appropriate management of delivery, avoidance of breastfeeding, and effective use of antiretroviral therapy have reduced mother-to-child transmission (MTCT) rates in women diagnosed with HIV in the United Kingdom and the rest of Europe from approximately 20% in the early 1990s[3,4] to less than 2% in recent years.[5–7]

Zidovudine (ZDV) is the only antiretroviral drug licensed in pregnancy and has been key in preventing mother-to-child transmission (PMTCT) of HIV.[8,9] In non-pregnant adults in resource-rich settings, use of ZDV is declining due to well-recognized side effects, including hematologic and mitochondrial toxicity. Both tenofovir (TDF) and abacavir (ABC) are currently recommended as first-line treatment for HIV-infected adults in Europe.[10,11] Consequently, an increasing number of women are already taking highly active antiretroviral therapy (HAART) that does

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Summary data from these analyses have previously been presented at the following conference:

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not contain ZDV when they conceive or initiate ZDV-sparing HAART during pregnancy (mainly containing TDF or ABC). Small descriptive studies have shown no evidence of an increased risk of MTCT associated with ZDV-sparing HAART,[12,13] but there is insufficient evidence from large-scale data sets to support its noninferiority compared with ZDV-containing regimens. With respect to safety, the Antiretroviral Pregnancy Registry data do not indicate an increased risk of congenital abnormality with drugs commonly used in ZDV-sparing regimens, except for didanosine.[14] However, data on individual drugs and newer drug combinations remain sparse. Most animal and in vitro studies have not demonstrated any teratogenic effects of either ABC or TDF.[15–17] However, there are case reports of congenital pyelectasis with in utero TDF exposure,[18] and there are concerns about its effect on bone development.[19,20] Analyses of data on ZDV-sparing regimens in pregnancy, although largely reassuring, therefore remain inconclusive.

As a randomized controlled trial comparing ZDV-sparing with ZDV-containing regimens for PMTCT is unfeasible, analysis of observational data is required to provide evidence to guide clinical practice. We carried out an analysis of individual patient data from 2 large European prospective observational studies to explore the use of ZDV-sparing HAART in pregnancy; quantify the extent to which ZDV-sparing HAART in pregnancy is increasing; and compare ZDV-sparing and ZDV-containing HAART with respect to detectable maternal HIV RNA viral load (viral load) at delivery, MTCT, and congenital abnormality. The risk of MTCT and congenital abnormality has previously been explored in these studies, but analyses did not specifically focus on ZDV-sparing regimens.[5,21–23]

METHODS

This analysis was based on data from the National Study of HIV in Pregnancy and Childhood (NSHPC) and the European Collaborative Study (ECS), 2 prospective observational studies managed within the same institution. Comparable data are collected and have previously been combined.[24]

The NSHPC, established in 1986, carries out comprehensive population-based surveillance of obstetric and pediatric HIV in the United Kingdom and Ireland. Pregnancies in HIV-infected women diagnosed by the time of delivery, and infants born to infected women, are reported through 2 active parallel schemes managed in collaboration with the Royal College of Obstetricians and Gynaecologists and the British Paediatric Surveillance Unit[25]; full methods are described elsewhere.[1]

The ECS, established in 1985, is an ongoing observational cohort study in which HIV-infected pregnant women diagnosed by the time of delivery are enrolled, and their infants are followed up according to standard clinical and laboratory protocols.[22] In ECS sites, pregnant women are routinely offered HIV testing and all infected women are invited to participate in the study; there are 29 centers in 10 European countries (Belgium, Denmark, Germany, Italy, the Netherlands, Poland, Spain, Sweden, the United Kingdom, and Ukraine). Pregnancies reported from Ukraine were excluded from this analysis due to the limited use of antenatal HAART.[26] Pregnancies from UK centers were excluded to avoid duplication of cases reported to the NSHPC.

This analysis was reviewed and approved by the research ethics committee of the London School of Hygiene and Tropical Medicine. The NSHPC has London MultiCentre Research Ethics Committee's approval (MREC/04/2/009). The ECS has been approved by the Great Ormond Street Hospital for Children NHS Trust/Institute of Child Health Ethics Committee.

Eligibility

We included all reported live singleton births to women who received HAART for at least 14 days before delivery between January 2000 (by which time HAART was widely available) and June 2009. Seventy-two mother–child pairs lacked information on all 3 outcomes of interest and were therefore excluded.

Variables

HAART was defined as a regimen of 3 or more antiretroviral drugs, including a protease inhibitor (PI) and/or nonnucleoside transcriptase inhibitor (NNRTI), and for simplicity, we use it in this article to include regimens taken solely for PMTCT and those prescribed as treatment for the mother herself. HAART was categorized as ZDV containing if use of ZDV was reported at any stage of pregnancy and as ZDV sparing if not. Only antepartum treatment was considered. Type of HAART was categorized as PI, NNRTI, or PI + NNRTI based and duration of HAART as 2–7, 8–11, 12–23, and ≥24 weeks.

Delivery viral load was defined as the closest reported viral load to delivery measured between 28 days before and 7 days after delivery. Delivery viral load was categorized as undetectable or detectable; "undetectable" was defined as <50 or <400 copies per milliliter, according to the assay detection limits used at the time of report. Baseline viral load was categorized as undetectable (according to the criteria above), 50–999, 1000–9999, and ≥10,000 copies per milliliter. Baseline CD4 count and viral load were defined as the first reported measurement in pregnancy whether before or after treatment initiation.

Injecting drug use (IDU) referred to current or past history of injecting drug use in the ECS and to probable mode of HIV acquisition in the NSHPC. Maternal age at delivery was grouped as <25, 25–29, 30–34, and ≥35 years. Gestational age was grouped as <34, 34–36, and ≥37 completed weeks. Infant infection status was classified as uninfected or infected on the basis of reported polymerase chain reaction or HIV antibody results[5] or indeterminate for infants whose infection status had not yet been reported. Congenital abnormalities (major and minor) were classified according to the World Health Organization's International Classification of Diseases, Tenth Revision,[27] from information provided by clinicians at infant notification or at follow-up. Year refers to year of delivery.

Statistical Methods

Data were analyzed using Stata 10.0 (Stata Corporation, College Station, TX). Secular trends in exposure were assessed

using χ^2 trend tests. The ZDV-sparing HAART group was compared with the ZDV-containing HAART group using univariable and multivariable logistic regression models to estimate odds ratios and adjusted odds ratios (AORs), with 95% confidence intervals (CIs). A priori confounders and variables found to have a confounding effect were included in the final multivariable model. Effect modification by study population (NSHPC or ECS) was assessed to verify the appropriateness of presenting summary odds ratios. Duration of HAART could not be modelled as a continuous variable due to lack of such data in women who conceived on treatment. Two prespecified subgroup analyses were carried out: The analysis of maternal viral load was stratified by whether women had conceived on HAART or started HAART post conception, and the analysis of congenital abnormality was restricted to pregnancies with first trimester HAART exposure. For the analysis of delivery viral load in women starting HAART post conception, we controlled for baseline CD4 and viral load as they potentially reflected pretreatment status; this was not the case in women who conceived on HAART.

RESULTS

Baseline Characteristics of Mother–Child Pairs

This analysis was based on 7573 mother–child pairs reported to the ECS (n = 1263) or NSHPC (n = 6310) with delivery between January 2000 and June 2009. Over three quarters (77.6%) of pregnancies were in women of black ethnicity and less than 5% were in women with a current or previous history of IDU. Median maternal age at delivery was 30.6 years (interquartile range 26.9–34.6 years). Only 15.6% of women had an initial CD4 count of <200 cells per cubic millimeter. About 30% of women were on HAART at conception. HAART was PI based in 56.3%, NNRTI based in 37.0% and PI + NNRTI based in 6.7% of pregnancies. Boosted PIs accounted for nearly two-thirds (3199 of 5204) of PI-based and PI + NNRTI–based HAART regimens. Over half of all deliveries (56.1%) were by elective cesarean section, and 13.9% of infants were preterm (<37-week gestation).

Patterns of ZDV-Sparing HAART Use

Overall, 15.8% of women (1199 of 7573) received ZDV-sparing HAART in pregnancy. Of these, 65% (778 of 1199) took lamivudine during pregnancy. Almost half of women (537 of 1199) received regimes containing TDF, 35% (417 of 1199) ABC, 25% (300 of 1199) didanosine, 18% (216 of 1199) stavudine, and 1% (12 of 1199) other nucleoside reverse transcriptase inhibitors (a substantial minority of women took more than one of these drugs). There were clear baseline differences between women on ZDV-containing and ZDV-sparing HAART particularly with reference to timing of HAART initiation. Women were more likely to be prescribed ZDV-containing HAART than ZDV-sparing HAART if they initiated treatment during pregnancy rather than before [4882 of 5226 (93%) versus 1477 of 2331 (64%); $P < 0.001$) (Table 1). There was also an association between country of report and ZDV-sparing HAART use ($P < 0.001$) with Spain having the highest rate at 25% (46 of 187) compared with 15% (956 of 6310) in the United Kingdom.

Exposure to ZDV-sparing HAART in pregnancy increased over time from 14.7% (48 of 326) in 2000 to 31.6% (68 of 215) in the first half of 2009 (χ^2_{trend} test $P < 0.001$), with most of the increase occurring between 2006 and 2009 (Figure). Among women who started HAART post conception, use of ZDV-sparing HAART in pregnancy increased from 4% in 2006 to 12% in 2009 (χ^2_{trend} test, $P < 0.001$). The proportion of women who were on ZDV-sparing HAART at conception doubled from 15% in 2000 to 31% in 2009 (χ^2_{trend} test, $P < 0.001$).

Detectable Maternal HIV Viral Load at Delivery

Maternal viral load at delivery was reported for 54.4% (4123 of 7573) of pregnancies and was detectable in 26.9% of these (1110 of 4123; 95% CI: 25.6% to 28.3%). In those who had a detectable viral load at delivery, the median viral load was 192 copies per milliliter (interquartile range 90–910 copies/mL). Only a small proportion (8%, 91 of 1110) of detectable viral loads were obtained after delivery. In a univariable analysis, ZDV-sparing HAART was associated with reduced odds of undetectable viral load at delivery (Table 2). After adjusting for duration of HAART and study, we found no difference in risk of detectable viral load at delivery between women receiving ZDV-sparing and ZDV-containing HAART (AOR 0.90; 95% CI: 0.72 to 1.14; Table 2).

Among women who started HAART post conception with available data on confounding variables (n = 2178), there was no evidence of a difference in the risk of detectable viral load at delivery between treatment groups after adjusting for baseline HIV viral load, baseline CD4 count, and study (AOR 1.25 for ZDV-sparing versus ZDV-containing HAART; 95% CI: 0.87 to 1.80; $P = 0.24$). There was also no difference in viral load at delivery among women who conceived on HAART (n = 1196) (AOR 0.79 for ZDV-sparing versus ZDV-containing HAART, adjusting for study; 95% CI: 0.56 to 1.09; $P = 0.17$).

Mother-to-Child Transmission

Infection status was available for 80% of infants (6130 of 7645) by the cutoff date for this analysis; 0.9% of infants were infected (56 of 6130; 95% CI: 0.7% to 1.0%). There was no evidence of a difference in odds of MTCT in women receiving ZDV-sparing HAART compared with those receiving ZDV-containing HAART after adjustment for duration of HAART, study, and mode of delivery (AOR 1.81; 95% CI: 0.77 to 4.26; Table 3).

Congenital Abnormality

Overall, 2.7% (197 of 7404; 95% CI: 2.4% to 3.1%) of infants were reported to have a congenital abnormality. After adjusting for study and maternal age group, the odds of congenital abnormality in pregnancies exposed to ZDV-sparing HAART was similar to the odds in those exposed to ZDV-containing HAART (AOR 0.98; 95% CI: 0.66 to 1.45; Table 4).

In 2554 pregnancies reported to have first trimester exposure to HAART, 42.2% of the regimens were ZDV sparing (1077 of 2554; 95% CI: 40.3 to 44.1). Subgroup analysis of these pregnancies showed no evidence of a difference in the risk of congenital abnormality between ZDV-sparing and ZDV-containing groups (AOR 0.79 for

TABLE 1. Baseline Characteristics of Mother–Child Pairs (n = 7573)

Maternal Characteristic	ZDV-Containing HAART (n = 6374), n (%)	ZDV-Sparing HAART (n = 1199), n (%)	*P*
Ethnicity (n = 7550)			<0.001
Black	4974 (78.3)	882 (73.8)	
White	1086 (17.1)	269 (22.5)	
Asian/others	294 (4.6)	45 (3.8)	
IDU (n = 7360)			<0.01
No	5960 (96.1)	1088 (93.9)	
Yes	241 (3.9)	71 (6.1)	
Maternal age at delivery (n = 7547), y			<0.001
<25	1072 (16.9)	110 (9.2)	
25–29	1979 (31.2)	257 (21.6)	
30–34	2006 (31.6)	738 (61.7)	
≥35	1293 (20.4)	92 (7.7)	
Mode of delivery (n = 7488)			0.12
Elective CS	3564 (56.5)	634 (54.0)	
Emergency CS	1151 (18.2)	243 (20.7)	
Vaginal	1599 (25.3)	297 (25.3)	
Baseline viral load (n = 4963), copies/mL			<0.001
Undetectable	1009 (24.6)	503 (58.5)	
50–999	626 (15.3)	101 (11.7)	
1000–9999	1071 (26.1)	115 (13.4)	
≥10,000	1397 (34.1)	141 (16.4)	
Baseline CD4 count (n = 6993), cells/mm^3			0.14
≥500	1520 (25.9)	316 (28.4)	
200–499	3427 (58.3)	636 (57.2)	
<200	934 (15.9)	160 (14.4)	
Type of HAART (n = 7573)			<0.001
PI	3624 (56.9)	640 (53.4)	
NNRTI	2366 (37.1)	439 (36.7)	
PI + NNRTI	384 (6.0)	120 (10.0)	
Preconception HAART (n = 7557)			<0.001
Yes	1477 (23.2)	854 (71.3)	
No	4882 (76.8)	344 (28.7)	
Duration of HAART (n = 7573), wks			<0.001
≥24	1754 (27.5)	906 (75.6)	
12–23	2823 (44.3)	197 (16.4)	
8–11	1121 (17.6)	59 (4.9)	
2–7	676 (10.6)	37 (3.1)	
Gestational age (n = 7557), wks			0.02
≥37	5504 (86.6)	1002 (83.6)	
34–36	589 (9.3)	131 (10.9)	
<34	266 (4.2)	65 (5.4)	
Year of delivery (n = 7573)			<0.001
2000–2002	1246 (19.6)	205 (17.1)	
2003–2005	2490 (39.1)	290 (24.2)	
2006–2009	2638 (41.4)	704 (58.7)	

CS, cesarean section.

ZDV-sparing versus ZDV-containing HAART; 95% CI: 0.48 to 1.30; $P = 0.35$; adjusted for study and maternal age; data not shown in table).

Missing and Unreported Data

Information on viral load at delivery was missing for 45.6% (3450 of 7573) of mother–child pairs. Women with missing viral load at delivery had a lower risk of MTCT than those with viral load reported, but the difference was not statistically significant (0.7% versus 1.1%; 95% CI: 0.4 to 1.2; $P = 0.2$). Women with missing viral loads at delivery were more likely to be white than non-white, have a history of IDU, have an undetectable baseline viral load in pregnancy, have been on treatment for at least 24 weeks (including

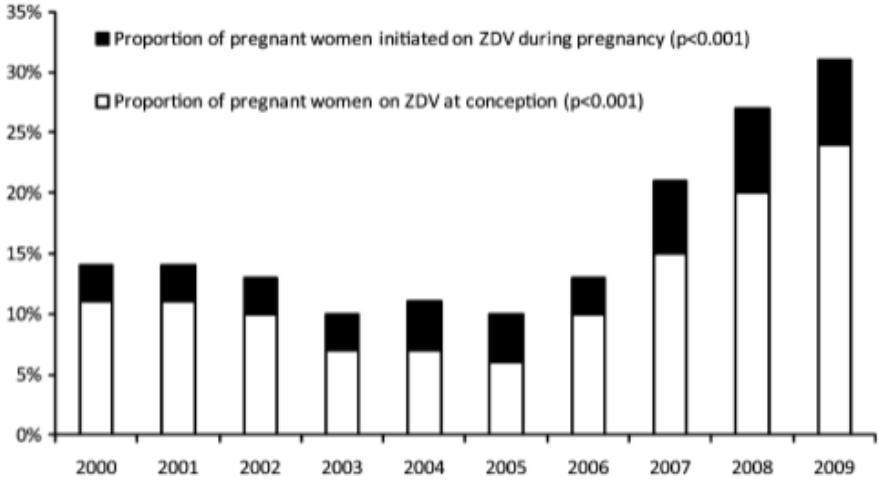

FIGURE. Use of ZDV-sparing HAART over time.

preconception), have delivered earlier in the study period, and have had a vaginal delivery ($P < 0.001$ for all, based on χ^2 test). However, the proportion with missing data on viral load at delivery was similar in ZDV-sparing and ZDV groups (44.1% and 45.8%, respectively, $P = 0.28$).

Infant HIV status was indeterminate in 19.1% (1443 of 7573) of pregnancies at the time of this analysis; these infants were more likely to have been born in later years ($P < 0.001$), with most (61%) born between 2007 and 2009. Their mothers had higher CD4 counts ($P < 0.001$) and had been on HAART for longer ($P < 0.001$), suggesting that these infants would be at low risk of infection. Nearly a quarter of infants (24.7%) exposed to ZDV-sparing HAART in utero had indeterminate status compared with 18.0% exposed to ZDV ($P < 0.001$).

Information on congenital abnormality was missing in 2.2% (169 of 7573) of pregnancies and did not differ in ZDV-sparing and ZDV-containing groups (2.8% and 2.1%, respectively, $P = 0.12$).

DISCUSSION

In this analysis of combined observational data from 2 European studies involving 7573 mother–child pairs exposed to HAART in pregnancy, we found no evidence of a difference in risk of detectable maternal viral load at delivery, MTCT, or congenital abnormality when comparing ZDV-sparing with ZDV-containing HAART. Overall, 16% of women were prescribed ZDV-sparing HAART during pregnancy in this population. The fact that most women initiated ZDV-containing HAART during pregnancy even in 2009 was not surprising in light of the evidence base for use of ZDV in pregnancy; however, we saw an increase in initiation of

TABLE 2. Crude and AORs for Detectable Maternal HIV Viral Load at Delivery Comparing ZDV-Sparing With ZDV-Containing HAART in Pregnancies

	Univariable Model (n = 4123)			Multivariable Model (n = 4123)*		
	n (%)	OR (95% CI)	P	n (%)	AOR (95% CI)	P
ART group			<0.001			0.33
ZDV-containing HAART	3453 (28.6)	1		3524 (28.6)	1	
ZDV-sparing HAART	670 (18.4)	0.56 (0.46 to 0.69)		670 (18.4)	0.90 (0.72 to 1.11)	
Study			<0.001			<0.001
NSHPC	3452 (28.6)	1		3452 (28.6)	1	
ECS	671 (18.2)	0.55 (0.45 to 0.68)		671 (18.2)	0.62 (0.50 to 0.78)	
Duration of HAART (wks)						
≥24	1341 (15.5)	1	—	1341 (15.5)	1	—
12–23	1653 (23.0)	1.70 (1.42 to 2.05)	<0.001	1653 (23.0)	1.59 (1.31 to 1.94)	<0.001
8–11	672 (38.7)	3.44 (2.77 to 4.26)	<0.001	672 (38.7)	3.18 (2.54 to 3.99)	<0.001
2–7	457 (54.3)	6.46 (5.10 to 8.18)	<0.001	457 (54.3)	6.07 (4.74 to 7.77)	<0.001

*Adjusted for study and duration of HAART.
ART, antiretroviral therapy; OR, odds ratio.

TABLE 3. Crude and AORs for Maternal-to-Child Transmission Comparing ZDV-Sparing With ZDV-Containing HAART in Pregnancies

	Univariable Model (Numbers Vary Due to Missing Data)			Multivariable Model (n = 6111)*		
	n (%)	OR (95% CI)	*P*	n (%)	AOR (95% CI)	*P*
ART group			0.64			0.18
ZDV-containing HAART	5227 (0.9)	1		5214 (0.9)	1	
ZDV-sparing HAART	903 (0.8)	0.83 (0.37 to 1.83)		897 (0.8)	1.81 (0.77 to 4.26)	
Study			0.68			0.72
NSHPC	5261 (0.9)	1		5247 (0.9)	1	
ECS	869 (1.0)	1.16 (0.57 to 2.38)		864 (0.9)	1.15 (0.53 to 2.47)	
Mode of delivery						
Elective CS	3515 (0.8)	1	—	3515 (0.8)	1	—
Emergency CS	1095 (1.7)	2.28 (1.26 to 4.12)	<0.01	1095 (1.7)	2.07 (1.13 to 3.76)	0.02
Vaginal	1051 (0.9)	0.78 (0.37 to 1.66)	0.52	1051 (0.9)	0.80 (0.38 to 1.72)	0.58
Duration of HAART (wks)						
≥24	2087 (0.2)	1	—	2078 (0.2)	1	—
12–23	2416 (0.7)	2.95 (1.09 to 8.01)	0.03	2410 (0.7)	3.44 (1.20 to 9.86)	0.02
8–11	1020 (1.0)	4.12 (1.41 to 12.09)	0.01	1017 (1.0)	5.10 (1.65 to 15.77)	0.01
2–7	607 (4.0)	17.14 (6.51 to 45.12)	<0.001	606 (4.0)	20.09 (7.22 to 55.93)	<0.001

*Adjusted for study, mode of delivery, and duration of HAART.
ART, antiretroviral therapy; CS, cesarean section; OR, odds ratio.

ZDV-sparing HAART during pregnancy between 2000 and 2009. In general, use of ZDV-sparing HAART increased over time between 2000 and 2009, particularly among women conceiving on HAART, with approximately 1 in 3 HIV-infected pregnant women receiving ZDV-sparing HAART in 2009.

About 27% of women had a detectable viral load at delivery, similar to rates reported elsewhere,[7,28] and there was no difference whether ZDV was used. The estimated overall rate of MTCT was 0.9%, consistent with other European data,[7] and we found no association with ZDV-sparing HAART. We found no increased risk of congenital abnormality with use of ZDV-sparing HAART. This finding is in line with data from the Antiretroviral Pregnancy Registry, which has not detected an increased risk of congenital abnormality among infants exposed to stavudine, ABC, or TDF.[14] The rate of congenital abnormality reported here was similar to that previously reported in the NSHPC.[21]

This is the first large-scale analysis of observational data sets looking specifically at adverse maternal and infant outcomes after use of ZDV-sparing HAART in pregnancy. Comparison with other sources of population surveillance data for HIV[29] suggests that virtually all diagnosed HIV-infected women in the United Kingdom and Ireland are reported to the NSHPC through its complementary reporting systems.[30] Nonenrolment in the ECS is approximately 5% and is due to migration rather than refusal, with no systematic exclusion.[31]

TABLE 4. Crude and AORs for Congenital Abnormality Comparing ZDV-Sparing With ZDV-Containing HAART in Pregnancies

	Univariable Model (Numbers Vary Due to Missing Data)			Multivariable Model (n = 7383)*		
	n (%)	OR (95% CI)	*P*	n (%)	AOR (95% CI)	*P*
ART group			1.00			0.90
ZDV-containing HAART	6239 (2.7)	1		6220 (2.7)	1	
ZDV-sparing HAART	1165 (2.7)	1.00 (0.68 to 1.48)		1163 (2.7)	0.98 (0.66 to 1.45)	
Study			0.81			0.91
NSHPC	6210 (2.6)	1		6210 (2.6)	1	
ECS	1194 (2.8)	1.05 (0.72 to 1.53)		1173 (2.7)	1.02 (0.70 to 1.50)	
Maternal age group (wks)						
<25	1160 (2.6)	1	—	1160 (2.6)	1	—
25–29	2182 (2.2)	0.87 (0.55 to 1.37)	0.54	2182 (2.2)	0.87 (0.55 to 1.37)	0.54
30–34	2369 (3.0)	1.16 (0.76 to 1.79)	0.49	2369 (3.0)	1.17 (0.76 to 1.80)	0.49
≥35	1672 (2.8)	1.07 (0.67 to 1.70)	0.79	1672 (2.8)	1.07 (0.67 to 1.71)	0.78

*Adjusted for study and maternal age.
ART, antiretroviral therapy; OR, odds ratio.

Although there was a substantial amount of missing data (46%) for delivery viral load, these data were more frequently missing for women on long-term treatment; because virologically suppressed women on long-term treatment probably had less frequent monitoring, and hence less chance of having viral load measured close to delivery, we are likely to have overestimated the proportion of women with detectable viral load at delivery. This is supported by the decreased risk of MTCT in women with missing delivery viral load although this difference was not statistically significant. Given that there was no difference in the proportion of missing data in the ZDV-sparing and ZDV-containing groups, missing data would have resulted in reduced precision but not necessarily biased estimates. In a fifth of cases, infant HIV status had not yet been reported. This was strongly associated with delivery in later years, between 2007 and 2009, and is mainly a result of delay in reporting final laboratory results. Previous sensitivity analyses have shown that this is likely to have a minimal effect on MTCT estimates for the United Kingdom and Irish data.[5]

In this analysis, ZDV-containing HAART was defined as any ZDV exposure in pregnancy and included regimen switches to or from a ZDV-sparing regimen during pregnancy. More detailed information on regimen switches and discontinuation during pregnancy was not available for this analysis. There were no data on other potential confounders such as adherence to antiretroviral therapy, socioeconomic status, smoking, and alcohol use in pregnancy. Data on pregnancy complications and maternal coinfections have only recently been routinely collected in the studies and were not available for this analysis.

We were unable to conduct drug-specific analysis with regard to ZDV-sparing regimens due to small numbers. With increasing use of both TDF and ABC and consequently improved power to detect differences in outcomes, drug-specific analysis is a priority in the future. In this analysis, we were unable to explore long-term consequences of in utero exposure to ZDV-sparing HAART. This is of importance given recent data on TDF and long-term renal and bone toxicity in adults, children, and animal models.[19,20,32,33] Data on children reported to the NSHPC are linked to routinely collected cancer and death registrations in England, but information on other health outcomes is not currently available.[34,35] Although long-term follow-up of uninfected children exposed to ZDV-sparing HAART in utero would be desirable, it is a challenging undertaking.[36] Given the possible adverse effects of in utero exposure to ZDV[37–39] and concerns regarding other drugs, continued pharmacovigilance of all antiretroviral drugs in pregnancy should remain a priority. As clinical trials in pregnancy are not feasible, observational data are needed to provide evidence of the equivalence of newer antiretroviral agents that are not currently licensed for use in pregnancy.

In conclusion, this large-scale analysis of European observational data including more than 7500 mother–child pairs showed that overall outcomes for women on ZDV-sparing HAART in pregnancy are similar to those in women on ZDV-containing regimens. This is reassuring given that a third of women delivering in these studies are now receiving ZDV-sparing HAART in pregnancy, with the trend towards increasing use likely to continue.

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Appendix ii: Presentations arising from this work

Oral

1. Tariq, S., Chau, C., French, C .E., Elford, J., Cortina-Borja, M., Brown, A.E., Delpech, V., Tookey, P.A. *Loss to follow-up after pregnancy among women living with HIV in England, Wales and Northern Ireland: the role of African ethnicity.* 19th Annual Conference of BHIVA, Manchester, UK, 2013.

2. Tariq, S., Pillen, A., Elford, J., Tookey, P.A. *Sameness and difference: results from a mixed methods study exploring pregnancy in migrant African women living with HIV in the UK*. 8th Mixed Methods International Conference, Leeds, UK, 2012.

3. Tariq, S., Elford, J., Cortina-Borja, M., Tookey, P.A. *The association between ethnicity and late presentation to antenatal care among pregnant women living with HIV in the UK and Ireland.* 18th Annual Conference of BHIVA, Birmingham, UK, selected for oral presentation at research poster session, 2012 (highly commended).

4. Tariq, S., Elford, J., Cortina-Borja, M., Tookey, P.A. *The impact of ethnicity on presentation to antenatal care among pregnant women living with HIV in the UK and Ireland.* 19th International AIDS Impact Conference, abstract 90, 2011.

5. Tariq, S., Pillen, A., Tookey, P.A., Elford, J. *Numbers and narratives: a mixed methods study design to explore pregnancy in African migrant women living with HIV in the UK*. 7th Mixed Methods International Conference, Leeds, UK, 2011.

Poster

1. Tariq, S., Tookey, P.A., Elford, J., Pillen, A. *'I just accept it, but in my heart it pains me because as a woman you have to breastfeed your baby.' The impact of infant feeding decisions on African women living with HIV in London.* XIX International AIDS Conference, Washington DC, USA, abstract 6632, 2012.

2. Tariq, S., Chau, C., French, C.E., Elford, J., Cortina-Borja, M., Brown, A.E., Delpech, V., Tookey, P.A. *Loss to follow-up after pregnancy among women living with HIV in England, Wales and Northern Ireland: the role of African ethnicity.* XIX International AIDS Conference, Washington DC, USA, abstract 1370, 2012.

3. Tariq, S., Elford, J., Cortina-Borja, M., French, C.E., Tookey, P.A. *Uptake of antiretroviral therapy in pregnancy is reduced in women from West Africa living in the UK & Ireland*. 6th IAS Conference on HIV pathogenesis, treatment and prevention, Rome, Italy, abstract TUPE283, 2011.

4. Tariq, S,. Cortina-Borja, M., Elford, J., Tookey, P.A. *Among migrant African women, increased duration of stay in the UK or Ireland reduces the risk of detectable maternal HIV viral load at delivery.* 17th Annual Conference of BHIVA, Bournemouth, UK, abstract P160, 2011.

Appendix iii: Literature search strategy

Resources used

- Ebscohost: offers access to various research databases. All my searches were restricted to CINAHL, MEDLINE, PsycInfo and SOC Index.

- International Bibliography of Social Sciences (IBSS): a database produced by the London School of Economics and Political Science with a broad coverage of international material. All my searches were restricted to publications within sociology or anthropology.

- JSTOR: an archive of journals in key fields in the humanities, arts and social sciences. All my searches were restricted to abstracts in English within anthropology, sociology, African studies, health sciences, women's studies and health policy.

- Reference lists of key review articles.

- Conference abstracts: IAS, BHIVA, CROI databases were searched for relevant abstracts on uptake of ART in pregnancy, HIV viral load at delivery, vertical transmission, antenatal care access, postnatal follow-up, stigma in PMTCT services, infant feeding and Pentecostalism (2009-2013).

- Google Reader: Since March 2010 I have used a web-based aggregator to subscribe to RSS feeds from key publications within (i) HIV/AIDS and (ii) Anthropology. I was alerted to new content as it was published and was able to identify papers that were relevant to this thesis. The key clinical publications were: HIV/AIDS: HIV Medicine; STI Online; AIDS; JAIDS; AIDS Care; AIDS Patient Care; AIDS & Behavior; Clinical Infectious Diseases; International Journal of STD & AIDS; African Journal of AIDS Research; The Lancet; The New England Journal of Medicine. The key anthropological publications were: Qualitative Inquiry; Field Methods; Annual Review of Anthropology; Ethnos; Body & Society; American Anthropologist; American Ethnologist; Journal of the Royal Anthropological Institute; Social Science & Medicine; Medical Anthropology Quarterly; Ethnography; Culture, Health & Society; Ethnicity & Health.

- Twitter: Throughout this study I have subscribed to twitter feeds from a number of HIV/AIDS and health organisations including Sigma Research; Sophia Forum; Aidsmap News; National AIDS Trust; AVERT; BASELINE; UNAIDS; WHO; HIV InSite; STI_BMJ; and HIV Insight.

Literature search strategy specific to each chapter (including search terms)

Chapter 1: Introduction

- Epidemiology of HIV and HIV and pregnancy: data obtained from publications (2009-2013) by UNAIDS, WHO, Public Health England (formerly the Health Protection Agency) and the National Study of HIV in Pregnancy and Childhood.

Chapter 2: Literature review

I specifically hand searched publications by the following study groups: National Study of HIV in Pregnancy and Childhood (NSHPC), European Collaborative Study (ECS), Women and Infants Transmission Study (WITS), Swiss Mother and Child HIV Cohort Study (MoCHIV, now part of the Swiss Cohort Study), *French Perinatal Cohort* (*EPF*-ANRS CO1). These are the largest contemporary studies addressing HIV and pregnancy in resource-rich countries.

Uptake of ART:

- Ebscohost (restricted to 2000-2013): SU (HIV OR AIDS) AND TI uptake OR decline OR participa* OR refusal OR adher*) AND AB (pregnan* OR *natal OR matern* OR MTCT OR PMTCT).

Viral load at delivery:

- Ebscohost (restricted to 2000-2013): AB (viral load OR virological suppression OR virological control OR response OR *detectable) AND SU (HIV OR AIDS) AND TI (pregnan* OR matern* or *natal).

Vertical transmission:

- Ebscohost: (TI (HIV OR AIDS)) AND (TI (Mother-to-child transmission OR MTCT OR vertical transmission OR PMTCT)) AND (AB (rates OR risk factors OR predictors)).

Antenatal booking:

- Ebscohost: SU ((HIV OR AIDS)) AND TI (antenatal care OR ante natal care OR prenatal OR maternity service OR maternity care OR booking OR antenatal clinic).

- References on ethnicity and late antenatal booking in general population obtained from a key review paper[1].

Loss to follow-up postnatally:

- Ebscohost: SU (HIV OR AIDS) AND TI (follow-up OR follow up OR care OR return OR access) AND TI (after preg* OR post preg* OR post partum OR mother*).

HIV in African migrants in London:

- Publications by East London Study group, Anderson J and Doyal L, Burns F.

HIV and pregnancy in migrant women:

- Ebscohost: AB (migrant* OR refugee* OR immigrant* OR asylum) AND SU (HIV OR AIDS) AND AB (pregnan* OR matern* or *natal).

Qualitative studies on HIV and pregnancy:

- Ebscohost: TI (HIV OR AIDS) AND TI (matern* OR pregnan* OR antenatal) AND AB (experience OR qualitative OR sociolog* OR anthropolog* OR narrative OR interview* OR ethnograph*).

- JSTOR (restricted to 2000-2013): (HIV OR AIDS) AND (pregnan* OR mother* OR *MTCT).

- IBSS (restricted to 2000-2013): AB (HIV OR AIDS) AND AB(preg* OR *natal OR *MTCT OR mother*).

Chapter 3: Methods

Mixed methods research: references obtained by hand searching the Journal of Mixed

[1] Rowe, R. E. and Garcia, J. (2003). "Social class, ethnicity and attendance for antenatal care in the United Kingdom: a systematic review." Journal of Public Health 25(2): 113-119.

Methods Research in 2007 -2013, and from expert recommendations at the Mixed Methods International Conference 2010, 2011 and 2012.

Chapter 4: Epidemiological overview of HIV and pregnancy in the UK

Not applicable.

Chapter 5: Using antiretroviral therapy in pregnancy

Not applicable.

Chapter 6: Pentecostalism and divine healing

- Ebscohost (restricted to 1990-2011): (pentecostal*/charismatic) AND (HIV/AIDS).
- IBSS: AB (pentecostal*/charismatic) AND AB (HIV/AIDS).
- JSTOR: (pentecostal*/charismatic) AND (HIV/AIDS) AND (Africa*/UK/Europe).
- City University London, UCL and SOAS Library catalogues: search for Pentecostal OR Pentecostalism OR Charismatic Christianity.
- Key texts on Anthropology of Religion from reading list for Anthropology of Religion Module, UCL Masters Course in Medical Anthropology.

Chapter 7: Engaging with health services during pregnancy

Stigma during labour:

- Ebscohost: SU ((HIV OR AIDS)) AND AB (antenatal care OR ante natal care OR prenatal OR maternity service OR maternity care OR antenatal clinic OR midwives OR labour) AND AB (stigma* OR discrimina* OR attitude*).
- References on maternity services in the UK (including care of women from minority ethnic groups) obtained from a maternity services reading list prepared by the Kings Fund[2].

Chapter 8: Loss to follow-up after pregnancy

[2] The Kings Fund (2011). Reading List: Maternity Services.

Not applicable.

Chapter 9: Infant feeding in the context of HIV

- Ebscohost (restricted to 2000-2013):
    - AB (HIV/AIDS) AND AB (infant fe*/breast fe*/replacement fe*) AND (UK/United Kingdom/England/Scotland/Wales/London).
    - AB (HIV/AIDS) AND AB(infant fe*/breast fe*/replacement fe*) AND (Africa*/Nigeria*/South Africa*/Zimbabw*/Uganda*).
- IBSS:
    - AB (infant fe*/breast fe*/replacement fe*) AND AB (Africa*)..
    - AB (HIV/AIDS) AND AB (infant fe*/breast fe*/replacement fe*).
- JSTOR (restricted to 1990-2013): (HIV/AIDS) AND (breastfe*/infant fe*/replacement fe*/formula fe*).
- City University London, UCL and SOAS Library catalogues: search for breastfeeding OR infant feeding.
- Further key clinical references obtained from presentation by Dr Graham Taylor at the Joint RCOG/BHIVA Multidisciplinary Conference on HIV and Pregnancy (20/01/2012) available at http://www.bhiva.org/documents/Conferences/RCOG-BHIVA/2012Presentations/GrahamTaylor.pdf

Chapter 10: Discussion

Not applicable.

Chapter 11: Final reflections

Not applicable.

Appendix iv: NSHPC notification forms

NSHPC confidential pregnancy notification

MREC approval ref: MREC/04/2/009 *Form date: 01/10* www.nshpc.ucl.ac.uk

CONFIDENTIAL

Woman's date of birth: ___/___/___ Hospital number (or other ref): ..... Soundex .....

Postcode (leave off last letter) ☐☐☐☐ ☐☐■ Previous livebirths ..... stillbirths ..... miscs/terms .....

Ethnic origin ☐ White ☐ Black African ☐ Black Caribbean ☐ Black Other
☐ Asian, Indian Subcontinent ☐ Asian, other / Oriental ☐ Other or mixed, specify .....

Country of birth ..... If not UK/Ireland, date arrived ___/___/____

PROBABLE SOURCE OF MATERNAL INFECTION

Maternal infection probably acquired: ☐ In UK/Ireland ☐ Abroad, specify ..... ☐ NK where

Likely exposure: ☐ Heterosexual - specify partner's likely risk factor, if known .....
☐ Injecting drug use ☐ Vertical transmission ☐ Other, specify .....

TIMING OF DIAGNOSIS

Date of first positive test: ___/___/____ If type 2 only, please tick here ☐

Diagnosed **when**: ☐ During this pregnancy ☐ Before this pregnancy

Diagnosed **where**: ☐ Antenatal ☐ GUM clinic ☐ Other .....

Any evidence of **seroconversion** in this pregnancy? ☐ No ☐ Yes, specify details overleaf ☐ Not known

PREGNANCY

Antenatal booking date: ___/___/___ EDD ___/___/___ (*and/or* LMP ___/___/___)

☐ Continuing to term - if continuing, planned mode of delivery: ☐ Vaginal ☐ CS ☐ Not yet decided

☐ Miscarriage } Date of misc/TOP: ___/___/___ at ..... weeks gestation
☐ Termination } Any congenital abnormality? ☐ No ☐ Yes, please specify.....

DRUG TREATMENT *DURING THIS PREGNANCY*

Was this woman on antiretroviral drugs when she became pregnant? ☐ Yes ☐ No

Did she receive antiretroviral drugs in pregnancy? ☐ Not yet ☐ Yes ☐ No ☐ Declined

Please provide details of antiretrovirals:	Before preg? (please circle)	Date started (or gest week) (if in pregnancy)		Date stopped (or gest week)	
Drug 1	Yes / No	___/___/___	_____	___/___/___	_____
Drug 2	Yes / No	___/___/___	_____	___/___/___	_____
Drug 3	Yes / No	___/___/___	_____	___/___/___	_____
Drug 4	Yes / No	___/___/___	_____	___/___/___	_____

MATERNAL CLINICAL STATUS

CDC Stage C disease ever: ☐ No ☐ Yes* if yes, date of onset: ____/____/____

Symptomatic in this pregnancy: ☐ No ☐ Yes* **Please provide details overleaf*

Concurrent infection(s)? ☐ None ☐ HBV ☐ HCV ☐ Syphilis ☐ Other, specify .....

MATERNAL TEST RESULTS *first test results available this pregnancy*

Viral load ..... copies/ml Date ___/___/___ **CD4** no._____ (_____%) Date ___/___/___

Form completed by: Name _____ Date ___/___/___

Position _____ Telephone _____ Email _____

Thank you for your help. Please return this form to: Dr Pat Tookey, RCOG, 27 Sussex Place, Regent's Park, London NW1 4RG.
Telephone NSHPC on 020 7905 2815 if you have any queries or email nshpc@ich.ucl.ac.uk

NSHPC outcome of notified pregnancy

MREC approval ref: MREC/04/2/009 *form date: 01/11* www.nshpc.ucl.ac.uk

CONFIDENTIAL

Your ref: ..... EDD: Hospital of delivery .....

PREGNANCY OUTCOME ☐ Livebirth *or* ☐ Stillbirth Date ___/___/___ Gestation ..... (wks)

☐ Male ☐ Female Birthweight ..... (kg) Hospital no ..... NHS no .....

Postcode at delivery (leave off last letter) ☐☐☐☐ ☐☐■ Paediatrician .....

Mode of delivery *If twins, please tick here* ☐ *and write details of second twin overleaf*

☐ Elective CS, reason ☐ Prevention of mother-to-child transmission ☐ Other, specify .....

☐ Planned vaginal delivery ☐ Unplanned vaginal delivery, reason .....

☐ Emergency CS, specify reason: .....

What was *planned* mode of delivery? ☐ Vaginal ☐ Elective CS ☐ Not known

Instrumental delivery ☐ No ☐ Yes, details .....

Rupture of membranes ☐ Yes, duration ..... hours ..... minutes *or* ☐ Ruptured only at delivery

Pregnancy complications ☐ No ☐ Pre-eclampsia* ☐ Gest. diabetes ☐ Other* **please give details overleaf*

Congenital abnormalities ☐ No ☐ Yes, specify .....

Other perinatal infections/problems ☐ None ☐ Necrotising enterocolitis ☐ Other, *please give details overleaf*

Did the infant require ventilation ☐ No ☐ Yes, *please give details overleaf*

DRUG TREATMENT DURING PREGNANCY (continue overleaf if necessary)

Ante-partum treatment ☐ No ☐ Yes, reason (if known) ☐ Prevention of mother-to-child transmission ***only***
☐ Maternal health ***and*** prevention of transmission

Antiretrovirals	Date started (or gest week)	Date stopped (or gest week)
Drug 1	___/___/___ _____	___/___/___ _____
Drug 2	___/___/___ _____	___/___/___ _____
Drug 3	___/___/___ _____	___/___/___ _____
Drug 4	___/___/___ _____	___/___/___ _____
Drug 5	___/___/___ _____	___/___/___ _____

Any other significant drugs (eg. PCP prophylaxis, TB treatment, methadone, illicit drugs)

Drug 1 ..... date ___/___/___ Drug 2 ..... date ___/___/___

Intra-partum

☐ None ☐ IV AZT ☐ Single dose nevirapine ☐ Other oral antiretrovirals .....

Post-partum for infant ☐ None ☐ Oral AZT ☐ IV AZT ☐ Other, specify.....

MATERNAL CLINICAL STATUS If woman has died date of death ___/___/___

Symptomatic at delivery: ☐ No ☐ Yes, details.....

MATERNAL TEST RESULTS *NEAR DELIVERY* *just before delivery if possible*

Viral load ..... copies/ml Date ___/___/___ **CD4** no. _____ (_____%) Date ___/___/___

Resistance testing done this pregnancy? ☐ Yes ☐ No ☐ Not known Clade of virus if known .....

Form completed by: Name _____ Date ___/___/___

Position_____ Telephone_____ Email_____

Thank you for your help. Please return this form to: Dr Pat Tookey, RCOG, 27 Sussex Place, Regent's Park, London NW1 4RG.
Telephone NSHPC on 020 7905 2815 if you have any queries, or email nshpc@ich.ucl.ac.uk

NSHPC confidential paediatric notification

LONDON MREC/04/2/009 www.nshpc.ucl.ac.uk

Office use only: *Form date: 01/11*

CSTU	MSTU	SU	PAED	HOSP

Paediatrician

CONFIDENTIAL Please complete this form as far as you can, even if you do not have all details requested

A. CHILD DETAILS

NHS no ..... Hospital no ..... Initials ..... Soundex .....

Date of birth ___/___/___ ☐ Male ☐ Female Home postcode *(leave off last letter)* ☐☐☐☐ ☐☐■

Ethnic origin ☐ White ☐ Black African ☐ Black Caribbean ☐ Black Other

☐ Asian, Indian Subcontinent ☐ Other Asian / Oriental ☐ Other or mixed, specify .....

Born in ☐ UK/Ireland: Hospital of birth ..... Home postcode at birth *(leave off last letter)* ☐☐☐☐ ☐☐■

or ☐ Abroad: Country of birth ..... and date arrived in UK/Ireland ___/___/___

B. HOW WAS THIS CHILD IDENTIFIED AS INFECTED OR AT RISK OF INFECTION?

☐ Mother known to be infected in pregnancy ☐ Child symptomatic

☐ Mother/other family member found to be infected (specify relationship) .....

☐ Other, specify .....

Date of child's first lab investigation ___/___/___

If you are aware of *siblings* reported to us, please give dates of birth or other ref: .....

C. PERINATAL DETAILS

Gestation ..... Birthweight .....

Mode of delivery ☐ Vaginal ☐ Elective CS ☐ Emergency CS ☐ Not known

Congenital abnormalities ☐ No ☐ Yes, specify .....

Other perinatal infections/problems ☐ None ☐ Necrotising enterocolitis ☐ Other, specify .....

Did infant require ventilation ☐ No ☐ Yes, details.....

Antiretrovirals for mother and/or baby to reduce risk of vertical transmission ☐ No ☐ Yes, specify below

Antenatally ☐ None ☐ Yes, specify..... ☐ NK

Intra-partum ☐ None ☐ IV AZT ☐ Single dose nevirapine ☐ Other, specify..... ☐ NK

Post-partum (baby) ☐ None ☐ Oral AZT ☐ IV AZT ☐ Other, specify .....

Was the child breastfed? ☐ No ☐ Yes, breastfed for how long? (wks) ..... ☐ NK if breastfed

D. PROBABLE SOURCE OF INFECTION

1. Exposed to maternal infection? ☐ Yes, please give *mother's* details below ☐ No, go to question 2 below ☐ NK

Mother's date of birth ___/___/___ b) No. of *previous* livebirths..... stillbirths..... miscarriages/terms.....

Mother's country of birth ..... if not UK/Ireland, date arrived ___/___/___

Mother diagnosed ☐ Before this pregnancy ☐ During this pregnancy ☐ At delivery ☐ After the birth of this child

Any evidence of **seroconversion** in this pregnancy? ☐ No ☐ Yes, specify..... ☐ NK

Maternal infection probably acquired ☐ In UK/Ireland ☐ Abroad, specify ..... ☐ NK where

Mother's likely source of infection

☐ Heterosexual exposure, specify partner's likely risk factor(s) if known .....

☐ Injecting drug use ☐ Other, specify..... ☐ No information on mother's exposure

2. Other exposure risk for child? ☐ No ☐ Yes, please give details.....

E. INFECTION STATUS & LABORATORY INVESTIGATIONS

Do you consider this child to be ☐ Infected ☐ Not infected ☐ Indeterminate (definitions on next page)

Please provide supporting test results below:

	pos	neg	sample date	pos	neg	sample date	pos	neg	sample date
Antibody	☐	☐	___/___/___	☐	☐	___/___/___	☐	☐	___/___/___
PCR (DNA or RNA)	☐	☐	___/___/___	☐	☐	___/___/___	☐	☐	___/___/___
	copies/ml			**copies/ml**			**copies/ml**		
If VL detectable:			___/___/___	.....		___/___/___	.....		___/___/___

Any evidence of type 2 infection? ☐ No ☐ Yes

F. THERAPY (tick all that apply and give brief details)

PCP prophylaxis? ☐ No ☐ Yes, specify ..... Date started ___/___/___

Infected children only: Antiretroviral treatment? ☐ Yes, specify drugs below ☐ No ☐ Not known

..... Date treatment started ___/___/___

G. CLINICAL DETAILS

Date of last examination ___/___/___

Has the child had any CDC stage C symptoms? ☐ No ☐ Yes (See back page for definitions)

	Details	**Diagnosis** Presumptive / Definitive	**Date** mm/yy
Opportunistic infections, specify	.....	☐ / ☐	___/___
Severe, symptomatic LIP	.....	☐ / ☐	___/___
Severe recurrent bacterial infection	.....	☐ / ☐	___/___
Severe failure to thrive	.....	☐ / ☐	___/___
Encephalopathy, specify	.....	☐ / ☐	___/___
Neoplasms, specify	.....	☐ / ☐	___/___

Has the child had any other symptoms related to the infection? ☐ No ☐ Yes (See next page for definitions)

Symptoms/signs	**Initial onset** (mm/yy)	**Details**
Mild/asymptomatic LIP	___/___	.....
Severe bacterial infection	___/___	.....
Failure to thrive	___/___	.....
Regression of milestones	___/___	.....
Other related symptoms, specify	___/___	.....

Any other serious infections or conditions? ☐ No ☐ Yes, specify .....

.....

H. FOLLOW UP STATUS

Date of last contact ___/___/___ ☐ Still in follow-up at this unit ☐ Discharged (uninfected)

☐ Follow-up elsewhere, please give details .....

.....

☐ Lost to follow-up ☐ Known to have left UK/Ireland ☐ Dead, date of death ___/___/___

Details of death: Certified cause a) Disease or condition directly leading to death .....

b) Secondary cause(s) .....

Post-mortem? ☐ Not done ☐ Done. Please attach a copy if possible.

Completed by: Name _____ Position_____ Date ___/___/___

Tel no _____ Email_____

Thank you for completing this form. Please return it to: Surveillance Studies Group, MRC Centre of Epidemiology for Child Health, Institute of Child Health, 30 Guilford Street, London WC1N 1BR. Call us with any queries on 020 7905 2815 or email nshpc@ich.ucl.ac.uk

NSHPC follow-up to establish infection status

LONDON MREC04/2/009 www.nshpc.ucl.ac.uk

office use only *Form date: 01.08*

CSTU	MSTU	SU	PAED	HOSP

Paediatrician ..... Hospital .....

CONFIDENTIAL Please complete this form as far as you can, even if you do not have all details requested

Please complete or amend these child details

Date of birth ___/___/___ ☐ Male ☐ Female Initials ..... soundex if available .....

Hospital no ..... NHS no .....

Current home postcode (**leave off last letter**) ☐☐☐☐ ☐☐■

The last report we had on this child related to examination on ___/___/___ when his/her **infection status had not yet been confirmed**. If you have more recent information, please complete all sections of this form.

If you have not seen this child since the last report please tick here ☐, complete the section on **INFECTION STATUS**, provide any test results *not previously reported* and complete the section on **FOLLOW UP STATUS.**

INFECTION STATUS & LABORATORY INVESTIGATIONS

Do you consider this child to be ☐ infected ☐ not infected ☐ indeterminate (definitions overleaf)

Please provide date of sample and ring type of test and result for all diagnostic tests since ___/___/___

	sample date	type of test	result		sample date	type of test	result
1.	___/___/___	antibody / PCR	+ / -	4.	___/___/___	antibody / PCR	+ / -
2.	___/___/___	antibody / PCR	+ / -	5.	___/___/___	antibody / PCR	+ / -
3.	___/___/___	antibody / PCR	+ / -	6.	___/___/___	antibody / PCR	+ / -

THERAPY & CLINICAL DETAILS

PCP prophylaxis? ☐ No ☐ Yes, specify ..... date started ___/___/___

Any other serious infections or conditions? ☐ No ☐ Yes, specify .....

FOLLOW UP STATUS

Date of last contact ___/___/___ ☐ Still in follow-up at this unit ☐ Discharged (uninfected)

☐ Follow-up elsewhere, please give details .....

.....

☐ Lost to follow up ☐ Known to have left UK/Eire ☐ Dead, date of death ___/___/___

Details of death: Certified cause a) disease or condition directly leading to death .....

b) secondary cause(s) .....

Post-mortem? ☐ Not done ☐ Done (please attach a copy if possible)

Completed by: Name _____ Position_____ Date ___/___/___

Tel no _____ Email_____

Thank you for completing this form. Please return it to: Surveillance Studies Group, MRC Centre of Epidemiology for Child Health, Institute of Child Health, 30 Guilford Street, London WC1N 1BR. Call us with any queries on 020 7905 2815 or email nshpc@ich.ucl.ac.uk

Appendix v: Participant characteristics (semi-structured interviews)

Name	Age	Country of Birth	Time in UK	Immigration status	Education	Employed	Religion	Marital status
Mary	33	Zambia	20	Secure	Higher	No	Catholic	Single
Ede	34	Nigeria	6	Secure	Higher	Yes	Pentecostal	Married
Patricia	37	Nigeria	7	Insecure	Secondary	No	Catholic	Relationship
Grace	39	Ghana	14	Insecure	Secondary	No	Pentecostal	Married
Mehret	31	Ethiopia	7	Secure	Secondary	No	Christian (orthodox)	Single
Fatima	28	Ivory Coast	5	Secure	Secondary	Yes	Muslim	Married
Audrey	34	Zimbabwe	9	Secure	Secondary	Yes	Christian (unknown)	Relationship
Sandrine	31	Cameroon	8	Secure	Higher	No	Catholic	Relationship
Patience	39	Uganda	8	Secure	Higher	Yes	Pentecostal	Single
Bolade	37	Nigeria	4	Insecure	Higher	Yes	Pentecostal	Relationship
Femi	34	Nigeria	3	Insecure	Higher	Yes	Protestant	Single
Marie	28	Cameroon*	6	Insecure	Higher	Yes	Pentecostal	Married
Nancy	35	Congo	8	Secure	Higher	Yes	Catholic	Relationship
Stella	36	Nigeria	6	Secure	Higher	Yes	None	Single
Mariama	28	Guinea	2	Insecure	Primary	No	Muslim	Single
Thandiwe	41	Zambia	16	Secure	Higher	No	Pentecostal	Single
Effia	32	Ghana	0	Insecure	Higher	Yes	Pentecostal	Married
Semret	33	Eritrea	11	Secure	Higher	Yes	None	Relationship
Hope	41	Uganda	7	Insecure	Higher	Yes	Catholic	Married
Rachel	38	Kenya	2	Secure	Secondary	No	Pentecostal	Single
Ruth	26	Uganda	9	Insecure	Secondary	Yes	Pentecostal	Relationship
Faith	29	Kenya	11	Secure	Secondary	Yes	Catholic	Married
Esther	35	Ghana	11	Secure	Secondary	No	Pentecostal	Married
Charity	29	Zimbabwe	11	Insecure	Higher	No	Christian (Adventist)	Single

*****Brought up in Nigeria since infancy. **Definitions:** Secure immigration status was defined as being a UK citizen, a recognised refugee or having exceptional or indefinite leave to remain. Anyone not in these categories was defined as having insecure immigration status. Secondary education is defined as up to secondary school. Higher education was defined as college or university education (including higher professional qualifications). Married included cohabiting relationships.

Appendix vi: Interview guide

Interviews during pregnancy

Can you tell me about this pregnancy so far?

Can you tell me about your health? What has life been like since being diagnosed with HIV?

What is life like at the moment? What makes life easier, what makes life harder?

How do you feel about the future?

Given your experiences what do you think might make pregnancy difficult if you have HIV?

Why do you think some women might miss hospital appointments?

What do you think would make the experience easier?

Is there anything you would like me to feed back to the managers or doctors here?

Post-natal interviews

Can you tell me how have things been since we last chatted?

How was the delivery?

What happened after hospital? How did you manage at home?

How's it going with the baby's feeding?

How does it feel being a mum?

How was it coming back to clinic?

OR

Will you be coming back to clinic?

How have you found the experience of this pregnancy from beginning to now when you look back?

How have you found the experience of being in this study?

Is there anything important that you think we haven't talked about?

Appendix vii: Sample participant information sheet (NHS)

Homerton University Hospital NHS
NHS Foundation Trust

Experience of HIV and Pregnancy: how can we improve care to women and children?

My name is Shema Tariq and I am a researcher based at City University London. I would like to invite you to be part of a research project. Before you decide, it is important for you to understand why the project is taking place and what it will involve. Please take time to read the following information carefully and discuss it with others if you wish. Ask me if anything is not clear or if you would like more information.

What is the purpose of the project?
HIV affects about 1000 pregnant women a year in the UK; most of them from Africa. There has been very little research on what it is like to be an African woman living with HIV and be pregnant or be a mother. I want to understand what this might be like so we can improve the care given to women and children in hospitals and to be able to support families affected by this.

Why have I been asked to take part?
I will be talking to a variety of people (including doctors, patients, midwives and community workers) to find out their views on issues such as health, pregnancy, religion and discrimination. We are asking all women who were born in Africa and come to this clinic if they want to take part. I am interested in your experiences and opinions on how we can make things better.

Do I have to take part?
No, **taking part is voluntary**. If you don't want to take part, you don't have to give a reason and no pressure will be put on you to try and change your mind. Not taking part will not affect your medical care in any way. You can stop the discussion at any time and ask for the interview to be destroyed after taking part if you change your mind. If you change your mind about being part of the project after the interview you can contact me and I will destroy all information related to you immediately.

What will I have to do if I take part?
If you wish to be part of this project you can contact me on the number/email at the end of this leaflet. We can arrange a time that is convenient for you to come back and meet me in the hospital. I can answer any further questions you might have. If you agree I will ask you a number of questions on the issues already mentioned. There aren't any right or wrong answers – you are the expert here. You **do not** have to answer any questions that make you feel uncomfortable. This conversation will last between 1 -2 hours. You will have a choice between me recording the interview on tape or taking written notes. If you agree, we will meet or have a telephone conversation after you have had your baby to discuss some points further.

If I agree to take part what happens to what I say?
All the information you give me **will be confidential** and used for this research only. All information I get during the study will have names removed so nobody will be able to identify you from the information you supply. Your name will be replaced by a study number and a made-up name. No one apart from me will know who you are. No one except me will know you have taken part in the project unless you choose to tell other people such as your midwife. The tape recorder I use is protected by fingerprint technology and a password. This means that I am the only person who has access to recordings. The only people who will listen/read the interview will be me, my university supervisors and the secretaries who type the interviews up. They are not allowed to discuss the contents of the interview with anyone. All material related to the

research is kept in locked cabinets or a password protected computer. The information will be used to write my PhD, articles for doctors, leaflets for patients and presentations at medical conferences and hospitals. If you wish to receive a copy of the findings I will send you this when the project is finished.

What are the benefits to me of taking part?
I hope you will find the discussion interesting and enjoyable as it is a chance to get your opinions on these issues heard. This study will be shown to people working in the NHS and support groups so that services are improved. Many people enjoy having been part of something that improves the health of people in their community.

What if I am not happy with the project?
If you have any concerns about the project I hope you will be able to raise them with me or your medical team. If this is not possible or you are unhappy with something I have done or said, you may make a complaint via the Patient Advisory Liaison Service at the hospital on:

PALS
Homerton University Hospital NHS Foundation Trust
Homerton Row
London E9 6SR

Telephone: 020 8510 7315

You can also contact my university. You need to phone **020 7040 3040**. You can then ask to speak to the Secretary of the Ethics Committee and inform them that the name of the project is: Experience and outcome of pregnancy among women living with HIV in the UK - impact of ethnicity and African region of origin. You can also email the secretary on anna.ramberg.1@city.ac.uk

If you are upset by any of the issues we talk about please let either myself or your medical team know. We can find you further support.

What do I do now?
If you are interested in taking part please contact me by telephone/email/post or approach me in person. I will arrange a time that is convenient for you to meet me in the hospital. I will ask you to sign a form to confirm that you agree to take part. I will reimburse you for your expenses. Any further interviews may be conducted by telephone if you wish.

Who is organising and funding the project?
This project is based at City University London. It is funded by the UK Medical Research Council, a national organisation devoted to health and medical research. It has been reviewed by the NHS and the university to ensure it is being carried out correctly.

Contact details:

Shema Tariq
Tel: 07952133279
Email: shema.tariq.2@city.ac.uk
Address:
Department of Public Health,
City University London,
20 Bartholomew Close,
London EC1A 7QN

Thank you very much for reading this and considering taking part.

This project has ethical approval from West London Research Ethics Committee (Ref 10/H0707/49)

Appendix viii: Sample consent forms

Homerton University Hospital NHS
NHS Foundation Trust

Consent Form: NHS patients

Attitudes towards HIV and Pregnancy in the African community in the UK: how can we improve care to women and children?

Thank you for agreeing to participate in this project. Please read/listen to the following, initial the boxes and then sign the form:

1. I have read and understood the attached information sheet and have had the opportunity to ask questions: ☐

OR:

I have had the attached information sheet explained to me and have had the opportunity to ask questions: ☐

2. I understand that I can withdraw from the study at any time without having to give any reasons: ☐

3. I understand that withdrawing from the study will not affect me in any way : ☐

4. I am aware of, and consent to the tape recording of my discussion with the researcher : ☐

OR:

I am aware of, and consent to the researcher taking written notes during the course of the discussion: ☐

5. I agree for the researcher to contact me by telephone after I give birth to arrange an interview ☐

6. I agree with the publication of the results of this study in research journals and articles for community organisations, and for presentation at conferences and at hospitals. I understand that I will not be identified in these publications or presentation: ☐

7. I would like to be involved in this research project: ☐

8. Please provide contact details **if you wish to receive results of the study** by email/post

Name of participant:.....

Signature/Print of Participant:.....

Date: .....

Name of researcher:.....

Signature of Researcher: .....

Date: .....

Appendix ix: Ethical approcal (City University Research Ethics Committee)

CITY UNIVERSITY LONDON

School of Community and Health Sciences

Research Office
20 Bartholomew Close
London EC1A 7QN

Tel: +44 (0) 20 7040 5763
Fax: +44 (0) 20 7040 5409

www.city.ac.uk

Ref: PhD/09-10/10

18 May 2010

Dear Shema

Re: Experience/Outcome of pregnancy in African women living with HIV in the UK

Thank you for forwarding amendments and clarifications regarding your project. These have now been reviewed **and approved** by the Chair of the School Research Ethics Committee, with the proviso that you forward a final copy of all documentation for the files, as requested by the Chair of the Committee, Nick Drey.

Please find attached, details of the full indemnity cover for your study.

Under the School Research Governance guidelines you are requested to contact myself once the project has been completed, and may be asked to complete a brief progress report six months after registering the project with the School.

If you have any queries please do not hesitate to contact me as below.

Yours sincerely

Carol Dossett

Carol Dossett
Research Administrator

c.dossett@city.ac.uk

0207 040 5763

Appendix x: Ethical approval (West London Research Ethics Committee on behalf of NHS centres)

National Research Ethics Service
West London REC 1
Room 4W/12, 4th Floor
Charing Cross Hospital
Fulham Palace Road
London
W6 8RF
Telephone: 020 3311 7258
Facsimile: 020 3311 7280

Dr Shema Tariq
MRC Research Fellow in Health Services and Health of the Public
City University London
Department of Public Health
20 Bartholomew Close,
London EC1A 7QN

30 June 2010

Dear Dr Tariq

Study Title: **Experience and outcome of pregnancy among women living with HIV in the UK: impact of ethnicity and African region of origin**
REC reference number: **10/H0707/49**
Protocol number:

The Research Ethics Committee reviewed the above application at the meeting held on 23 June 2010. Thank you for attending to discuss the study.

Ethical opinion

The members of the Committee present gave a **favourable ethical opinion** of the above research on the basis described in the application form, protocol and supporting documentation, subject to the conditions specified below.

Ethical review of research sites

The favourable opinion applies to all NHS sites taking part in the study, subject to management permission being obtained from the NHS/HSC R&D office prior to the start of the study (see "Conditions of the favourable opinion" below).

Conditions of the favourable opinion

The favourable opinion is subject to the following conditions being met prior to the start of the study.

Management permission or approval must be obtained from each host organisation prior to the start of the study at the site concerned.

For NHS research sites only, management permission for research ("R&D approval") should be obtained from the relevant care organisation(s) in accordance with NHS research governance arrangements. Guidance on applying for NHS permission for research is available in the Integrated Research Application System or at http://www.rdforum.nhs.uk. Where the only involvement of the NHS organisation is as a Participant Identification Centre, management permission for research is not required but the R&D office should be notified of the study. Guidance should be sought from the R&D office where necessary.

Sponsors are not required to notify the Committee of approvals from host organisations.

It is responsibility of the sponsor to ensure that all the conditions are complied with before the start of the study or its initiation at a particular site (as applicable).

Approved documents

The documents reviewed and approved at the meeting were:

Document	*Version*	*Date*
Investigator CV	Shema Tariq	
Protocol	1	01 May 2010
Interview schedule: CM1	1	
REC application		30 April 2010
Interview Schedules/Topic Guides	1	
Interview Schedules/Topic Guides	v1.0 - IS: NHS	01 May 2010
Participant Information Sheet: Community members	1	01 May 2010
Participant Information Sheet: Focus group (community)	1	01 May 2010
Participant Consent Form: HCP	1	01 May 2010
Participant Consent Form: HO	1	01 May 2010
Participant Information Sheet: community workers	1	01 May 2010
Participant Information Sheet: NHS patient	1	01 May 2010
Participant Information Sheet: Host organisation (community)	1	01 May 2010
Participant Information Sheet: Healthcare provider	1	01 May 2010
Participant Consent Form: CM	1	01 May 2010
Participant Consent Form: CW	1	01 May 2010
Participant Consent Form: FGD	1	01 May 2010
Participant Consent Form: NHS	1	01 May 2010
Interview schedule: CM2	1	
Interview schedule: FGD CW	1	
Interview schedule: HCP	1	
Funders letter	1	30 April 2010
CV	Jonathan Elford	
Interview schedule: FGD CM	1	

Membership of the Committee

The members of the Ethics Committee who were present at the meeting are listed on the attached sheet.

Statement of compliance

The Committee is constituted in accordance with the Governance Arrangements for Research Ethics Committees (July 2001) and complies fully with the Standard Operating Procedures for Research Ethics Committees in the UK.

NHS
National Research Ethics Service

After ethical review

Now that you have completed the application process please visit the National Research Ethics Service website > After Review

You are invited to give your view of the service that you have received from the National Research Ethics Service and the application procedure. If you wish to make your views known please use the feedback form available on the website.

The attached document "After ethical review – guidance for researchers" gives detailed guidance on reporting requirements for studies with a favourable opinion, including:

- Notifying substantial amendments
- Adding new sites and investigators
- Progress and safety reports
- Notifying the end of the study

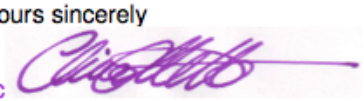
The NRES website also provides guidance on these topics, which is updated in the light of changes in reporting requirements or procedures.

We would also like to inform you that we consult regularly with stakeholders to improve our service. If you would like to join our Reference Group please email referencegroup@nres.npsa.nhs.uk.

10/H0707/49	**Please quote this number on all correspondence**

With the Committee's best wishes for the success of this project

Yours sincerely



cc

Dr Catherine Urch
Chair

Email: clive.collett@imperial.nhs.uk

Enclosures: *List of names and professions of members who were present at the meeting and those who submitted written comments*
"After ethical review – guidance for researchers"

Copy to: *Dr Shema Tariq*

Appendix xi: Sample participant information sheet (church)

CITY UNIVERSITY LONDON

Health, Hope and Parenthood: The role of the church

My name is Shema Tariq and I work at City University London. I would like to invite you to be part of a project looking at health and religion. Before you decide, it is important for you to understand why the project is taking place and what it will involve. Please take time to read the following information carefully and discuss it with others if you wish. Please ask me if anything is not clear or if you would like more information.

What is the purpose of the project?
I am a looking at how we can improve the health of African pregnant women, especially those who suffer from illness during their pregnancy.

I would like to learn how people from African communities manage their health and cope with illness. The work I have done so far with African women across London has shown me that going to church is a very important aspect of people's lives. Very little work has been done on how church can affect people's experience of pregnancy and illness. I would like to find out and learn more.

Why have I been asked to take part?
You have been approached as you are a member of a large church where people of African background might attend.

Do I have to take part?
No, **taking part is voluntary.** If you choose to allow me to come to your church I will attend church regularly. I will always be open about the fact I am doing this project. If a person does not wish to talk to me after finding out about my project, I won't approach them again. I will make it my priority not to get in the way of any normal activities. You are always free to ask me to leave at any point if you feel that my presence is not appropriate.

What will I have to do if I take part?
I will spend time attending services and chatting to members of the congregation. I will be observing and listening to what happens in services and how people feel about coming to church. I may have more in depth conversations with people who wish to chat more about how the church affects health, feelings of hope and parenthood. I would also like to talk to church elders to gain a deeper understanding of your church.

If I agree to take part what happens to what I say?
All the information **will be confidential** and used for this project only. I will not use the church's name in any writing. This is typical of research projects. All information I get during the study will have names removed so nobody will be able to be identified. Names will be replaced by a made-up name. No one apart from me will know who you are. All material related to the project is kept in locked cabinets or a password protected computer at the university. The information will be used to write my PhD, articles for doctors, leaflets for patients and presentations. I would be really happy to come back after I finish the project and speak about what I have learned.

What are the benefits to me of taking part?
I hope you and your congregation will find our conversations interesting and enjoyable. It is a chance to get your opinions heard. This study will be shown to people working in the NHS and support groups so that people learn about how religion affects people's lives. I hope it will lead to an improvement in the health of pregnant women from African communities and their babies. I find that many people enjoy having been part of

something that improves the overall health of people in their community.

What if I am not happy with the project?
If you have any concerns about the project I hope you will be able to raise them with me.

You can also contact my university. You need to phone **020 7040 3040**. You can then ask to speak to the Secretary of the Ethics Committee and inform them that the name of the project is: **Health, Hope and Parenthood: The role of the church.**

You can also email the secretary on anna.ramberg.1@city.ac.uk

If any problems arise during the project I will make sure I come to you and discuss it.

What do I do now?
If you are willing to let me come and learn from you I would like to ask you to sign a form to confirm that you agree to take part.

Who is organising and funding the project?
This project is based at City University London. It is funded by the UK Medical Research Council, a national organisation devoted to health and medical research.

It has been reviewed by the university to ensure it is being carried out correctly.

I sincerely thank you for taking the time to read this and consider taking part.

Contact details:

Shema Tariq
Tel: 07952133279
Email: shema.tariq.2@city.ac.uk
Address:
Department of Public Health,
City University London,
20 Bartholomew Close,
London EC1A 7QN

This project has ethical approval from West London Research Ethics Committee (Ref 10/H0707/49) and City University London