# The association of pregnancy with engagement in HIV-care among women with HIV in the UK CHIC Study: a cohort study

Short title: Engagement in HIV-care in pregnant women

Key words: Pregnancy, HIV, engagement in HIV-care, women

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# Abstract

Background: Women with HIV may experience challenges in engaging in HIV-care post-partum.

Methods: We describe changes in engagement in HIV-care pre-, during- and post-pregnancy among women with HIV from the UK Collaborative HIV Cohort (CHIC) Study with a live birth reported to the National Surveillance of HIV in Pregnancy and Childhood (NSHPC) between 2000-2017. To investigate whether changes were specific to HIV, we compared these to changes over equivalent periods among non-pregnant women with HIV in the UK CHIC Study matched on ethnicity, year of conception, age, CD4+ T-cell count, viral suppression, and ART use. Analyses used logistic regression/generalised estimating equations (GEE) with an interaction between case-control status and (pseudo-)pregnancy stage.

Findings: 1,116 matched pairs of pregnant/non-pregnant women were included (median age: 34 [interquartile range: 30-38] years, 80.1% Black African, 12.5% White). In total, 69,330 person-months of follow-up were recorded, 25,412, 18,897 and 25,021 in the pre-, during- and post- (pseudo-) pregnancy stages respectively. Amongst pregnant women, engagement in HIV-care increased during- and post-pregnancy compared to pre-pregnancy (pre: 9979/12707 [78.5%]; during: 8477/9371 [90.5%]; post: 10501/12407 [84.6%]). Amongst non-pregnant control women, engagement in HIV-care remained stable across the three equivalent stages (pre: 9688/12705 [76.3%]; during: 7463/9526 [78.3%]; post: 9892/12614 [78.4%]). The association of engagement in HIV-care with ‘pregnancy’ stage differed significantly by case-control status ($p<0.0001$ for interaction); the odds of engagement in HIV-care was higher during- and post-pregnancy only amongst pregnant women (OR during: 3.32 [2.68-4.12], OR post: 1.49 [1.24-1.79]) and not amongst non-pregnant women.

Interpretation: Women with HIV with a pregnancy resulting in a live birth are more likely to engage in HIV-care post-partum when compared to pre-pregnancy. A detailed

understanding of the reason for this finding may support interventions to maximise engagement in HIV-care for all women with HIV.

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# Research in context

## Evidence before this study

We searched Pubmed for articles relating to [HIV] and [pregnancy] and ([engagement] or [retention]) from 1st January 2000 – 31st January 2021 in high income settings. Previous studies explore only the pregnancy and post-partum period. These studies, largely based on cohorts in the USA, Switzerland and UK, suggest sub-optimal engagement in HIV-care in this period, with only 20-68% of participants remaining engaged in-care. Using data from the National Surveillance of HIV in Pregnancy and Childhood and the Survey of Prevalent HIV Diagnosed (SOPHID) datasets in the UK, Tariq *et al.* previously reported that one in eight HIV-positive women in England, Wales and Northern Ireland do not return for HIV care in the year after pregnancy.

## Added value of this study

Our findings suggest that the antenatal period provides a key opportunity to empower women to engage in HIV-care in the immediate post-partum period through the provision of information, by addressing structural barriers to healthcare access, and by strengthening relationships with clinics and healthcare providers.

## Implications of all the available evidence

The increased engagement in HIV-care in the post-partum period could be viewed as a result of the effectiveness of the multidisciplinary and holistic approach to a pregnancy that is advocated in national guidelines. It is therefore important to understand the drivers of this sustained engagement in HIV-care among pregnant women into the immediate post-partum period, in order to maximise long-term engagement in HIV-care for all women living with HIV.

# Introduction

It has been reported that post-partum women living with HIV may be less engaged in HIV-care (as measured by clinic attendance) and may experience challenges in medication adherence in the post-partum period compared to before pregnancy [1-4]. Using data from the National Surveillance of HIV in Pregnancy and Childhood (NSHPC) and the Survey of Prevalent HIV Diagnosed (SOPHID) in the UK, Tariq *et al.* reported that one in eight HIV-positive women in England, Wales and Northern Ireland did not return for HIV care in the year after pregnancy [1].

Difficulties in clinical attendance may reflect a change in priorities as women transition to a care-giving role. With increased demands on a woman's time after the birth of her baby, women may experience practical barriers (e.g. lack of childcare facilities) to attending HIV clinic appointments. The continued institutionalised stigma outside of HIV specialised services around conceiving while living with HIV, may create additional obstacles to attendance [5]. However, the apparent reduction in engagement in HIV-care might also reflect a return to a woman's pre-pregnancy level of engagement in HIV-care.

In the UK, pregnant women are expected to continue attending HIV-care concurrently with antenatal care. During this time, women are recommended to initiate antiretroviral treatment (ART), if not already receiving this, and to be monitored every two months until delivery. The UK Collaborative HIV Cohort (CHIC) study has previously reported that post-partum women have a higher risk of viral rebound in the 12 months after delivery compared to matched, non-pregnant controls [2]. If women are at risk of poorer clinic attendance and treatment adherence post-pregnancy, this may have an impact on the long-term health of both themselves and their child [6, 7]. Here, we further explore changes in engagement in HIV-care through clinic attendance pre-, during- and post-pregnancy, compared to matched women living with HIV who have never experienced a pregnancy (control population).

# Methods

## Study design and participants

Women with HIV participating in the UK CHIC Study and with a live birth from 2000-2017 reported in the linked NSHPC dataset were matched 1:1 to non-pregnant women in the UK CHIC study (those with no reported pregnancies in the linked dataset).

## Data sources

The UK CHIC study is an ongoing cohort of individuals with diagnosed HIV (aged >16 years) who have accessed care at one or more of 25 HIV clinics in the UK at any time from 1996 onwards [8]. In brief, electronic healthcare data is collected retrospectively from participating HIV services, including demographic information, ART history, laboratory results, and AIDS diagnoses; the resulting dataset is submitted on an annual basis to the co-ordinating centre.

The NSHPC ran from 1989-2018, conducting comprehensive, population-level surveillance of HIV in pregnancy and childhood in the UK. In 2018 it became part of Public Health England's (PHE) Infectious Diseases in Pregnancy Screening (IDPS) Programme becoming known as the Integrated Screening Outcomes Surveillance Service (ISOSS) [9]. Data on women with HIV accessing antenatal care are reported by all UK maternity units, including information on ethnicity, age, expected delivery date, ART use, CD4+ T-cell counts and HIV viral loads in pregnancy. UK-CHIC has ethics approval (MREC/00/7/47) and ISOSS holds PHE Regulation 3 approval to collect patient data without consent.

Linkage between the two datasets is undertaken annually using an algorithm that utilises demographic and clinical data [10]. The analyses described here are based on UK CHIC data collected up to 31 December 2017.

## Procedures

We consider only one pregnancy per woman, the first live birth reported after HIV diagnosis in the linked UK CHIC-NSHPC dataset. Subsequent pregnancies and those occurring prior to HIV diagnosis were excluded. Women with a pregnancy from 2000-2017 were eligible for analysis if their pregnancy duration was ≥8 months (thus excluding women with pre-term deliveries who are likely to have different clinical outcomes), and if they had been followed for ≥12 months prior to estimated conception date (calculated from estimated delivery date) and ≥12 months after reported date of delivery. The period of follow-up for each woman was separated into three stages: 12 months pre-, during- and 12 months post-pregnancy.

For the matching, eligible pregnant women were initially characterised at estimated conception date using the following criteria: ethnicity (White, Black Caribbean, Black African, Black other, South Asian/Other Asian, Mixed/Other; those with missing ethnicity were excluded), year of conception, age (16-19, 20-24, 25-29, 30-34, 35-49, 40-44, 45-49, >50 years), most recent CD4+ T-cell count if available (<200, 200-350, 351-500, >500 cells per μL), viral suppression (HIV viral load (VL) ≤50 copies per mL, categorised as yes/no or not available), any ever (previous) ART use (yes/no) and time since ART initiation (months).

Non-pregnant women with ≥12 months of follow-up prior to the pseudo-conception date and ≥12 months follow-up after the pseudo-delivery date (to match the eligibility criteria for pregnant women) were each eligible to be selected as a control for one pregnant woman. To identify the appropriate matched non-pregnant control women, we stratified each non-pregnant woman's period of follow-up into consecutive monthly intervals. The same factors (year, age, CD4+ T-cell count, viral suppression, ever (previous) ART use and time since ART initiation) were determined at the start of each monthly interval. A list of all non-pregnant control women whose criteria were the same as those of each pregnant woman at conception was then created and the control woman with the closest monthly interval date to

each pregnant woman was selected; where multiple control women had the same criteria, one control woman was selected randomly from the list. A control woman's pseudo-conception date was set to the date of the monthly interval where characteristics matched. The pseudo-delivery date was estimated as 266 days later (the average duration of pregnancy).

Engagement in HIV-care was assessed with the Retention and Engagement Across Care services (REACH) algorithm, which uses information on an individual's clinical status to estimate the likely time to the next scheduled follow-up appointment [11]. The shortest expected gap between appointments was 2 months. If the woman had a recent AIDS diagnosis, started ART or changed ART at the initial appointment, the next appointment was expected within 2 months. If the woman was not on ART at the initial appointment, the next appointment was expected within 2–6 months, depending mainly on CD4+ T-cell count. If the woman had started ART, it was expected within 2–6 months, depending on viral load. We used 6 months as the maximum time between visits. If more than one condition applied at the time of the initial care episode, the next care episode was expected within the smaller of the number of months associated with those conditions. Based on this information, each person-month is classified as being 'in-care' or 'out-of-care' according to whether the woman had a return visit within the expected time interval. When clinical information was not available in the dataset to validate the length of the expected gap (ie. 2 or 6 months), the months in question were excluded from the analyses.

Demographic and clinical characteristics not used in the matching algorithm were compared between pregnant and non-pregnant women. In the event where Hepatitis B/C laboratory tests were unavailable, the woman was assumed to be negative on the basis that the underlying rate is extremely low in women with HIV in the UK.

## Statistical analysis

To explore the association between pregnancy/pseudo-pregnancy stage (pre-/during-/post-pregnancy) and the engagement in HIV-care status (‘in’ or ‘out’ of care) of each month of follow-up we used univariable and multivariable logistic regression using generalised estimating equations (GEE) to incorporate the multiple months of follow-up for each woman. Matched pregnant and non-pregnant control women were included in a single model adjusting only for the case-control status of the women and nadir CD4+ T-cell count (not accounted for through the matching criteria). To explore the difference in rates of engagement in HIV-care in this model, we added an interaction term between pregnancy stage and the case-control status of women; for this analysis, the pre-pregnancy stage in non-pregnant women was considered as the reference category. We conducted a sensitivity analysis exploring the effect of Hepatitis B/C co-infection on this association as this was not accounted for as part of the matching process. All analyses were conducted in SAS version 9.4.

## Role of funding source

The funder of the study had no role in study design, data collection, analysis, interpretation, or writing of the report

# Results

A total of 2,643 women from the linked UK CHIC-NSHPC dataset had a recorded live birth from 2000-2017, with the required follow-up both prior to and after pregnancy. Of these, 46 women with no recorded ethnicity were excluded. Of those included (n=2,597), 1,116 women were successfully matched to a non-pregnant control woman (Table 1). At the estimated (/pseudo-) conception date, the women had a median age of 34 [interquartile range (IQR): 30-38] years. The majority were of Black African followed by White and Black Caribbean ethnicity (Table 1). Overall, 65.6% (1,464/2,232) of women had initiated ART prior to the estimated (/pseudo-) conception date; this group had a median of 42 months [IQR: 25-68 months] exposure to ART by that time. Pregnant women who could not be matched to a control were younger, less likely to be of Black African ethnicity and had a lower CD4+ T-cell count at pregnancy (Appendix; page 4).

In total, 69,330 person-months of follow-up were accounted for by the REACH algorithm for both pregnant and matched control women (n=2,232); 25,412, 18,897 and 25,021 person-months in the relevant pre-, during- and post- (pseudo-) pregnancy stages respectively (approximately 5.0% of person-months in this study were excluded due to lack of clinical data to validate engagement in HIV-care). Over three quarters (77.4%) of follow-up time during the pre-pregnancy stage was contributed by those who were engaged in-care. This proportion was higher during-pregnancy with 84.4% of person-time contributed by women who were engaged in-care, but then dropped slightly post-pregnancy (81.5%). After stratification by case-control status, whilst a similar pattern was seen among the pregnant women (pre-: 78.5%; during-: 90.5%; post-: 84.6%; Figure 1), engagement in HIV-care was stable over the three equivalent stages for non-pregnant control women (pre-: 76.3%; during-: 78.3%; post-: 78.4%; Figure 1). The trends over pregnancy in pregnant and control women were similar amongst younger women (aged <35 years) and women who had been diagnosed more recently (diagnosed within 2 years) (Appendix; page 5).

In initial analyses, after adjusting for nadir CD4+ T-cell count and the case/control status of women in the study, the odds of engagement in HIV-care increased by 67% (OR: 1.67 [95% CI: 1.51-1.84]) and 17% (OR: 1.17 [1.06-1.29]) in the during- and post-pregnancy stages, respectively, compared to the pre-pregnancy stage. However, a test of interaction confirmed that the association between 'pregnancy' stage and engagement in HIV-care differed significantly by case-control status ($p<0.0001$). In particular, increased engagement in HIV-care during- and post-pregnancy was only seen among pregnant women (during-pregnancy OR: 3.32 [2.68-4.12]; post-pregnancy OR: 1.49 [1.24-1.79] compared to non-pregnant women pre-pregnancy; Figure 3). In contrast, whilst there was a slight increase in engagement in HIV-care in the 'pseudo during-pregnancy' stage among non-pregnant women (OR: 1.14 (1.02-1.27)) this apparent increase was smaller than that seen among pregnant women during the same stage, with no change in the pseudo post-pregnancy stage (OR: 1.04 (0.92-1.18), Figure 3). Sensitivity analyses exploring the effect of Hepatitis B/C co-infection (not shown) did not differ from the presented analyses.

# Discussion

In this large, representative sample of pregnant women with HIV in the UK, we determined the proportion of time women were engaged in HIV-care pre-, during- and post-pregnancy when attending a UK CHIC clinic. To rule out the possibility that the observed differences could be explained by factors other than pregnancy, we compared pregnant women to closely matched control women from the UK CHIC dataset with no reported pregnancies. We found that pregnant women with HIV were more likely to be engaged in HIV-care during-pregnancy compared to the previous 12 months. Although the proportion of time engaged in HIV-care dropped in the 12 months post-pregnancy it remained significantly higher than that seen in the pre-pregnancy period. This pattern was not seen amongst matched control women, where the rate of engagement in HIV-care remained stable (and at a similar level to that among pregnant women in the pre-pregnancy stage) across the three pseudo-pregnancy stages.

Women were engaged in HIV-care for a total of 80.7% of their follow-up time, similar to that reported previously for both men and women in the UK CHIC cohort [12]. Considering the successes of HIV outcomes reported for women with HIV in the UK [13], we believe this is a good level of engagement in HIV-care. However, for pregnant women, we find engagement in HIV-care is higher during- and post-pregnancy, compared to the proportion of time engaged in HIV-care in the pre-pregnancy stage. Although we found a lower level of engagement in HIV-care in younger women and women who had been diagnosed more recently, as expected based on other published literature [12], the pattern of engagement in HIV-care amongst pregnant vs non-pregnant women remained the same. This higher engagement in HIV-care during-pregnancy may be due to higher motivation of pregnant women to access care, resulting in greater adherence to enhanced monitoring after conception [14].

Pregnancy can be a period of increased vulnerability for women. However, during this period women with HIV are typically linked into multidisciplinary specialist services designed to maximise and support engagement in HIV-care [15]. Our findings indicate that pregnant women living with HIV adhere to the enhanced level of care that is so often expected during-pregnancy. Whether the increased engagement in HIV-care seen during-pregnancy reflects these measures, a desire by the woman to optimise outcomes for the unborn child, or a combination of both is unknown. It is also important to consider how some barriers to care which may be present when a woman is not pregnant may diminish during this time. For example, women may experience greater employer flexibility around clinic appointments or reduced stigma around attending appointments in a general antenatal clinic rather than an HIV clinic. Consequently, the pregnancy period may provide opportunities for women to optimise their engagement with HIV-care with effects that may persist after pregnancy.

This is the first study to directly compare engagement in HIV-care during the post-pregnancy period to the 12 months pre-pregnancy in women living with diagnosed HIV. In doing so, we demonstrate that pregnancy (or a consequence of it) positively impacts a woman's engagement in HIV-care post-partum. This finding was specific to pregnant women and so is unlikely to reflect a general improvement in engagement with longer follow-up. Neither the UK CHIC nor NSHPC datasets contain detailed data on drivers of engagement in HIV-care. However, based on previous findings, we can speculate that the knowledge gained and resulting benefits from being engaged in multidisciplinary care during-pregnancy may facilitate engagement in HIV-care after pregnancy [5, 15].

This study only explores the immediate 12 months post-pregnancy. Data from the USA and Haiti have reported that engagement in HIV-care can continue to decrease years after pregnancy [16-17]. Women with HIV are increasingly experiencing pregnancy [18], bringing additional challenges when attempting to balance their own HIV-care with the needs of their children. Although our aim was to assess only the impact of pregnancy on engagement in

HIV-care, future studies may consider engagement in HIV-care over the longer, post-pregnancy period.

Previous studies have explored engagement in HIV-care over only the pregnancy and post-partum period for pregnant women with HIV and These studies, largely based on cohorts in the USA, Switzerland and UK, suggest sub-optimal engagement in HIV-care in this period (between 20-68% of participants remained engaged in HIV-care) [1, 3, 5, 19-26]. However, the apparent sub-optimal level of engagement in HIV-care seen in this period may well be better or similar to a woman's own level of engagement in HIV-care (prior to their pregnancy). We highlight that women who have not been pregnant experience a relatively stable rate of engagement in HIV-care. However, we have shown that this stable level of engagement in HIV-care can be improved during-pregnancy. It is therefore important to support all women living with HIV experiencing barriers to accessing HIV-care.

This is one of the largest studies to explore engagement in HIV-care amongst pregnant women matched to non-pregnant women using clinical data from a diverse cohort of women with HIV who are representative of this population in the UK (when compared to recent national estimates). A key strength is the use of the REACH algorithm, a dynamic method of determining engagement in HIV-care. Each person-month of follow-up was determined to be 'in-care' or 'out-of-care' based on the woman's clinical status and follow-up assessments, allowing us to account for changes in the expected engagement in HIV-care over time for each woman. This is important to consider when comparing estimates across studies as previous studies draw upon a binary measure of engagement/retention in HIV-care. Therefore, our estimates of engagement in HIV-care over the pregnancy and post-partum period are not directly comparable. However, it is important to note that the REACH algorithm only considers HIV-related clinical data available in the UK CHIC dataset and does not take into account interactions with healthcare services that do not result in an official 'clinical attendance' record, or support services outside of HIV specialist services. Therefore,

the REACH algorithm may not wholly capture engagement in HIV-care. The algorithm does not incorporate information on comorbidities or socio-economic factors which may also contribute to engagement in HIV-care.

Some limitations of our study must be highlighted. Firstly, women are matched between the two datasets using a deterministic matching algorithm. Although this uses demographic and clinical data, the accuracy of linkage lies in the data provided, which may result in undermatching. However, all biomedical data (e.g. CD4+ T-cell counts, viral loads, etc.) collected in UK CHIC are automatically uploaded from the laboratory to participating HIV clinics. Therefore, we expect the data to be complete, reducing the likelihood of inaccuracies. As our dataset only provides information after HIV diagnosis, our analyses exclude women who were diagnosed with HIV during their pregnancy, a group that may face additional challenges and require specific support during pregnancy; we cannot rule out the possibility that a small number of women may have had an unrecorded pregnancy prior to their HIV diagnosis. In addition, we have considered only a woman's first pregnancy resulting in a live birth that is recorded in the linked dataset. Analyses therefore do not consider women who have experienced adverse pregnancy outcomes; and women with larger families who may have greater difficulties in engaging in-care. Our analysis only included women who accessed care at one of the 25 clinics that participate in UK CHIC for $\geq$12 months before and after their pregnancy. As information is not captured on movements to non-participating clinics, we excluded a small number of women who were permanently lost to follow-up during the post-partum period in order not to inaccurately classify these women as disengaged from care. Finally, only approximately 40% of women could be successfully matched to a non-pregnant control. However, we found a similar pattern of engagement in HIV-care across the pregnancy stages when we included all eligible pregnant women, suggesting that this has not introduced selection bias.

In summary, drawing on population-level pregnancy surveillance data on HIV in pregnancy in the UK, we find women with HIV who have had a pregnancy resulting in a live birth and were under follow-up at a centre reporting to UK CHIC for the length of their pregnancy and 12 months after are more likely to engage in-care post-partum compared to their own level of engagement in HIV-care pre-pregnancy. The high levels of engagement in HIV-care achieved by women living with HIV during-pregnancy is testament to their commitment to their health and wellbeing in this vulnerable period. These findings suggest that the antenatal period provides a key opportunity to empower women to engage in-care in the immediate 12 months after pregnancy through the provision of information, by addressing structural barriers to healthcare access, and by strengthening relationships with clinics and healthcare providers. Much of this is a result of the effectiveness of the multidisciplinary and holistic approach advocated in national guidelines [27]. Non-pregnant control women do not have this benefit, and it is therefore important to understand the drivers of this sustained engagement in HIV-care among pregnant women into the post-partum period in order to maximise engagement in HIV-care for all women living with HIV regardless of reproductive status.

## Contributors

HO: conceptualisation, formal analysis, investigation, methodology, visualisation, writing – original draft, and writing – review & editing. ST, FB, YG, RD, HP, and CT: validation, and writing – review & editing. TH: data curation, and writing – review & editing. CS: conceptualisation, funding acquisition, supervision, methodology, validation, and writing – review & editing.

HO & CS had full access to all the data in the study. All authors had final responsibility for the decision to submit for publication

## Disclosure of interest

ST has received funding from Gilead for participation in educational events and Sophia Forum for consulting the development of a programme of support for women with HIV. FB has received funding for development and presentation of educational material from Gilead Sciences. CT has received funding from ViiV Healthcare for participation in educational events. CAS and YG have received funding for membership of Data Safety and Monitoring Boards, Advisory Boards and for preparation of educational materials from Gilead Sciences, ViiV Healthcare and Janssen Cilag. The other authors declare no conflicts of interest.

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# Data sharing policy

The UK CHIC study welcomes proposals for research from existing and potential new collaborators at any time. Any bona fide researcher may submit a proposal: either for novel scientific research using UK CHIC data, or for verification and replication of published analyses of UK CHIC data. All research proposals are subject to review by the UK CHIC Steering Committee for evaluation of the scientific value, relevance to the study, design and feasibility, statistical power and overlap with existing projects. If the proposal is for verification/replication of a published analysis, data will then be made available. A decision on whether a proposal has been approved is normally made within one month of its submission. Support for statistical analyses may be available from the study team.

For further information please contact the UK CHIC study principal investigator Prof Caroline A Sabin at c.sabin@ucl.ac.uk.