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Linking hospital and primary care records to enhance hepatitis B, hepatitis C and HIV care

Submission date
29/10/2026

Recruitment status
Not yet recruiting

Registration date
12/11/2026

Overall study status
Ongoing

Last Edited
09/11/2026

Condition category
Infections and Infestations

[X] Prospectively registered
[_] Protocol
[_] Statistical analysis plan
[_] Results
[_] Individual participant data
[X] Record updated in last year

Plain English summary of protocol
Background and study aims
Early detection and treatment of people with blood-borne viruses (BBVs), including HIV, Hepatitis B and Hepatitis C, is important for people's health. But despite improved testing, many people live with undiagnosed BBVs: around 5,000 with HIV, 20,000 with Hepatitis C, and 150,000 with Hepatitis B. Testing is common in sexual health clinics, prisons, intravenous drug services and some Emergency Departments. However, this information is often not included in primary care general practitioner (GP) records and GPs do not normally test people at risk. This means some people are not treated, and it is hard to identify and test their household members (who they live with), and vaccinate those who could be exposed to Hepatitis B.

Better information is needed to develop improved ways of testing, treatment and vaccination in primary care. This cannot be done unless people with, or at risk of, BBV infections can be correctly found in GP records, including their household members. Without this, many people living with undetected or untreated BBVs will have their health damaged, household members will be unprotected, and national plans to end BBV infection will not be met.

Who can participate?
Adults (≥18 years of age) for analysing the prevalence and incidence of BBVs, and adults and children for analysing the HBV and HBV vaccination status of people sharing a household with an adult with incident HBV.

What does the study involve?
Without using people's personal details, the study team will link hospital laboratory data with current GP patient records in North East London to provide new information about BBV levels in the population. These data will also be used to describe the characteristics of people diagnosed with BBVs, including their households, and whether other household members are tested for Hepatitis B and vaccinated. The results will be combined with interviews of clinicians and other health professionals, and representatives of people living with BBVs to identify what works well and what does not in BBV prevention and treatment in primary care.

The study will create a research-ready dataset of Barts Hospital laboratory data and linked primary care records for people currently registered with GPs in the North East London NHS

region.
The study results will be used to estimate the prevalence of BBV (those who have ever had one of the three BBV diagnoses) and incidence of new diagnoses and analyse characteristics of people with BBVs.

Without using people's personal details, the study team will identify household members of people with each BBV, describe household-level characteristics, and vaccination status for Hepatitis B.

The frequency of the most common blood test events at GPs in the five years before diagnosis will be reported to evaluate a strategy to extend the current policy of opt-out testing for BBVs in Emergency Departments to primary care.

These results will be shared with a study community group, and, together with interviews from health professionals, the study team will co-produce a plan for new care routes, with options for future implementation to improve prevention, care and treatment for people living with BBVs and their households, focusing on testing and vaccination.

What are the possible benefits and risks of participating?
This study is being ran to help understand the levels of BBV diagnoses in population and identify the groups most and risk. By providing information about the vaccination status of household members of people with Hepatitis B, it allows us to estimate how well protected household members are.

This study only uses de-identified data, with the patient’s first and last name and date of birth removed and non-meaningful alphanumeric codes for person and address identifiers, which cannot be linked to any other data or converted in a way that would allow researchers to see who the patients are or their address.

Where is the study run from?
The Queen Mary University of London in London, UK.

When is the study starting and how long is it expected to run for?
December 2026 to March 2028.

Who is funding the study?
The National Institute for Health and Care Research School for Primary Care Research (NIHR SPCR), UK.

Who is the main contact?
Dr Marta Wilk, marta.wilk@qmul.ac.uk

Contact information

Type(s)
Principal investigator, Scientific, Public

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Additional identifiers

The National Institute for Health and Care Research School for Primary Care Research (NIHR SPCR) Grant Reference Number
837

Study information

Scientific Title
Enhancing care for people living with hepatitis B, hepatitis C and HIV: observational retrospective mixed methods study of patients and households using linked hospital laboratory and primary care records

Study objectives

Ethics approval required
Ethics approval not required

Ethics approval(s)

Primary study design
Observational

Secondary study design
Epidemiological study

Study type(s)

Health condition(s) or problem(s) studied
Prevalent and incident blood-borne viruses (BBVs), including HIV, hepatitis B and hepatitis C

Interventions

We will estimate the prevalence and 95% confidence intervals (95% CI) for any BBV and – separately - for HIV, HBV and HCV, and describe the characteristics of those infected by major demographic and risk factor variables.

We will estimate the annual incidence of any BBV infection and separately of HIV, HBV and HCV, and describe the characteristics of those with incident infections between 01/01/2021 and 31/12/2025 by major demographic and risk factor variables.

We will derive households from electronic health records and describe the characteristics of households including one or more people living with HBV infection and the HBV vaccination status of household members of people living with HBV.

Intervention Type
Other

Primary outcome(s)
1. Prevalence of at least one positive HIV, or hepatitis B or hepatitis C diagnosis or test result code and no latest code for hepatitis B and hepatitis C resolved, measured using NEL linked primary care and Bart's pathology data electronic health records at 01/02/2016 to 31/12/2025

2. Annual incidence of a positive HIV, or hepatitis B and hepatitis C diagnosis or test result code in the first year of the study or within consecutive 1-year periods with no positive diagnosis ever recorded in any of the previous 1-year periods, measured using patient's electronic health records at 01/02/2016 to 31/12/2025

Key secondary outcome(s)

Completion date
31/03/2028

Eligibility

Key inclusion criteria
1. Adults (≥18 years of age) for analysing the prevalence and incidence of BBVs
2. Adults and children for analysing the HBV and HBV vaccination status of people sharing a household with an adult with incident HBV

Healthy volunteers allowed
No

Age group
All

Lower age limit
0 Years

Upper age limit
100 Years

Sex

All

Total final enrolment
0

Key exclusion criteria
1. All patients recorded with Type 1 opt outs
2. Age >100 years of age at the start of the study
3. People with missing sex and age data

Date of first enrolment
01/12/2026

Date of final enrolment
31/03/2028

Locations

Countries of recruitment
United Kingdom

England

Study participating centre
Barts Health NHS Trust
The Royal London Hospital
80 Newark Street
London
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E1 2ES

Study participating centre
Centre for Primary Care
Wolfson Institute of Population Health
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Sponsor information

Organisation
Queen Mary University of London

ROR
https://ror.org/026zzn846

Funder(s)

Funder type

Funder Name
NIHR School for Primary Care Research

Alternative Name(s)
School for Primary Care Research, NIHR SPCR

Funding Body Type
Private sector organisation

Funding Body Subtype
Universities (academic only)

Location
United Kingdom

Results and Publications

Individual participant data (IPD) sharing plan

IPD sharing plan summary
Not expected to be made available