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# **Monitoring HIV testing in diverse healthcare settings: results from a sentinel surveillance pilot**

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## **ABSTRACT**

*Objectives:* To assess the feasibility and utility of sentinel laboratory surveillance of HIV testing as a tool for understanding patterns and trends in HIV testing in a range of healthcare services.

*Methods:* Data on all anti-HIV antibody tests carried out by the Leeds Teaching Hospital Trust (LTHT) laboratory over a twelve-month period were collated and analysed by demographic information and place of test. Individuals who tested positive were matched to the national database of HIV diagnoses to identify the proportion newly diagnosed with HIV.

*Results:* 41,013 individuals over one year of age were tested at least once for HIV during the study period, of whom 0.8% (n=312) were positive. The majority of individuals (77%) were tested in a genitourinary medicine (GUM) clinic or as part of antenatal care, whilst routine testing of people undergoing haemodialysis, fertility treatment or occupational health screening accounted for a further 13% of testing. Few individuals (<4%) were tested in general practice. Of the 312 people testing positive, 286 could be matched to the HIV national database and 173 (60%) were identified as newly diagnosed.

*Conclusions:* Little HIV testing is currently performed outside GUM and antenatal settings. Monitoring of HIV testing is essential given new guidelines recommending the expansion of testing in a wide range of settings. Sentinel laboratory surveillance can provide useful demographic data on persons tested for HIV and can assess trends in testing over time. Data on HIV testing could be incorporated into existing hepatitis sentinel surveillance, allowing rapid scale-up of this surveillance scheme with minimal effort.

## INTRODUCTION

An estimated 20,700 of 73,300 adults (28%) living with HIV in the UK are unaware of their infection. Almost one-third of newly-diagnosed individuals are diagnosed late, with a CD4 cell count below 200 cells/mm<sup>3</sup> and at risk of poorer treatment response and increased mortality [1]. Recent research has highlighted missed opportunities to detect HIV infection among patients presenting at a range of non-genitourinary medicine (GUM) health services [2-4]. Scaling-up of voluntary confidential HIV testing is increasingly recognised as a key tool in preventing new infections and reducing morbidity and mortality among infected individuals [5].

In the UK, there is a high uptake of HIV testing at GUM clinics and as part of routine antenatal care [1]. In September 2007, a letter from the Chief Medical Officer (CMO) to healthcare providers encouraged diagnostic testing in non-HIV specialties among people with a recognised risk factor for infection or presenting with a clinical indicator condition such as malaise, weight loss or oral candidiasis [6]. Recent national guidelines have built on this by recommending scaling up the universal offer of an HIV test among people presenting with defined indicator conditions and in specific health care settings such as TB and hepatitis clinics. In addition, the guidelines recommend the expansion of HIV testing to all men and women aged 15 to 59 years registering in general practice or admitted to a general medical ward in areas of high HIV prevalence (defined as an area where the diagnosed prevalence of HIV exceeds 2 per 1000 population) [7]. In the United States, Centres for Disease Control and Prevention guidelines recommend opt-out screening of all patients aged 13 to 64 years in all health-care settings [8].

The Health Protection Agency Centre for Infections (CfI) receives voluntary surveillance reports from clinicians and virology laboratories for all persons newly diagnosed with HIV in the United Kingdom. These are cross-checked with other surveillance systems such as the Survey of Prevalent HIV Diagnosed Individuals (SOPHID) and CD4 surveillance to maximise completeness. In addition, the HPA collects data on the offer and uptake of HIV testing in GUM and antenatal clinics. Little is known about testing practices and yield outside these services. A recent study of HIV testing uptake in general practices found low rates of testing in this setting [9].

The sentinel surveillance of hepatitis testing has been a valuable adjunct to routine hepatitis surveillance systems, providing data on the demographic characteristics of people tested (and testing positive) for viral hepatitis, place of testing, prevalence in the population tested, and long-term trends in testing [10, 11]. Using similar methods we carried out a twelve-month pilot study at one sentinel centre to assess the feasibility and utility of this form of surveillance for monitoring HIV testing.

## **METHODS**

The Leeds Teaching Hospitals Trust (LTHT) laboratory is part of the Leeds and Bradford Pathology Partnership which performs testing for two teaching hospitals, the primary care services provided by Leeds Primary Care Trust and some primary care services within Bradford and Airedale Teaching Primary Care Trust. It serves an overall population of approximately 1.1 million people. Demographic data for the cities of Leeds and Bradford are described in the latest census report from 2001 [12]; the diagnosed prevalence of HIV per 1000 people aged 15-59 is 1.7 and 1.0 in Leeds and Bradford & Airedale respectively. This site was chosen for the pilot because the computer and communications infrastructure for the hepatitis sentinel surveillance scheme was already well established there.

Laboratory test results and demographic information (such as date of birth and sex) for all samples tested for anti-HIV antibody at this laboratory were extracted electronically from laboratory information systems for the period 1<sup>st</sup> April 2007 to 31<sup>st</sup> March 2008. These data were collated, cleaned and checked for consistency by the sentinel surveillance project co-ordinator, with patient names replaced by pseudonymised soundex codes [13] and individuals identified using a unique unnamed reference number. The dataset was then forwarded to Cfl for analysis.

De-duplication to identify individuals tested more than once under different reference numbers or in different services during the study period was undertaken using date of birth, sex and soundex or GUM clinic number (where available). Age at first test was calculated for each individual, with children aged less than 1 year excluded since positive results in this age group may reflect passively-acquired maternal antibody rather than true infection.

Where an individual had been tested on more than one occasion, the number of tests were recorded, reviewed in chronological order and their HIV status classified using a hierarchical system [10]. If a negative result was followed by a positive result, the individual was classified as positive but flagged as a potential seroconversion: follow-up samples from these cases were then reviewed by the consultant virologist for confirmation.

The origin of the test request was used to define the services in which testing took place, such as general practitioners' (GP) surgeries, GUM clinics, antenatal care and various hospital specialties. These service types were further classified as primary care or secondary care, as shown in Table 1. Each individual was counted only once regardless of the number of tests: if an individual was tested more than once, their test location was classified according to the service type in which they were first tested during the study period. Clinical details accompanying the test request were used to identify women tested as part of antenatal care where the test request did not originate from an antenatal clinic, for example in general practice. 'Individuals tested outside antenatal and GUM settings' were defined as those individuals tested in a service type other than a GUM clinic or antenatal clinic who did not have antenatal screening mentioned in the clinical details field accompanying the test request. All samples referred for confirmatory testing or tested for quality control purposes were excluded.

Individuals who tested HIV positive during the study period were matched to the HPA national database of new HIV diagnoses, using a combination of GUM clinic number, date of birth, sex, soundex, origin of test request and region. A matched individual with a HIV laboratory test date before or up to 21 days after a new diagnosis report (to allow for delays in laboratory processing and data entry) was classified as being newly diagnosed.

Data were managed in MS Access and analysed in MS Excel and STATA (StataCorp, 2003). Differences in the proportion testing positive for anti-HIV were assessed using chi-squared tests. Mean ages were compared using an unpaired t-test.

The HPA has permission from the National Information Governance Board, under Section 251 of the NHS Act 2006, to handle personally identifiable data for the purposes of communicable disease surveillance. Sentinel laboratory surveillance has also been approved by the Northern and Yorkshire Multi-Centre Research Ethics Committee (MREC1/3/76) and the Public Health Laboratory Service Ethics Committee.

## **RESULTS**

During the study period, 41,013 individuals over one year of age were tested at least once for anti-HIV antibody at the LTHT laboratory; 0.8% (n=312) were positive. 48 children aged less than 1 year were also tested, of whom two were positive: these individuals were excluded from all subsequent analyses.

Most HIV testing (77%) took place in GUM clinics and as part of antenatal screening (Table 1). A further 13% could be accounted for by routine screening of people undergoing fertility treatment, occupational health assessment or haemodialysis.

The proportion testing positive was highest among individuals tested in infectious disease services and general medical and surgical departments (Table 1). No individuals tested positive in renal units, occupational health services or Accident and Emergency departments.

Table 1. Number of individuals tested, and testing positive, for anti-HIV antibody, by service type.

Service type	Number of individuals tested	% of all testing taking place in this service type	Number of individuals testing positive (% positive)	Number of individuals testing positive who could be matched to national surveillance report	Number of new diagnoses, among those matched to national surveillance (% new diagnoses among individuals tested in this service)
<b>Primary care</b>					
Antenatal screening*	15,795	38.5	37 (0.2)	36	20 (0.1)
Accident and Emergency	34	0.1	0 (0.0)	-	-
General practice	1,568	3.8	22 (1.4)	22	17 (1.1)
GUM clinics	15,764	38.4	173 (1.1)	151	88 (0.6)
Occupational health	1,242	3.0	0 (0.0)	-	-
Prison services	225	0.5	1 (0.4)	1	1 (0.4)
Specialist drug services	422	1.0	2 (0.5)	2	2 (0.5)
<b>Secondary care</b>					
General medical & surgical departments	164	0.4	12 (7.3)	12	9 (5.5)
Infectious disease services	118	0.3	37 (31.4)	36	18 (15.2)
Fertility treatment centres	3,091	7.5	2 (0.1)	2	1 (0.0)
Obstetrics and gynaecology services	38	0.1	0 (0.0)	-	-
Paediatric services	150	0.4	1 (0.7)	0	-
Renal units	1,203	2.9	0 (0.0)	-	-
Other hospital services**	1,191	2.9	25 (2.1)	24	17 (1.4)
Unknown hospital services§	8	0.0	0 (0.0)	-	-
Total, all service types	41,013	100.0	312 (0.8)	286	173 (0.4)

N.B. In this table 'Antenatal screening' refers both to individuals tested in antenatal clinics and those tested as part of antenatal care in other services, as identified by clinical details accompanying the test request.

\*Includes 22 men and 19 individuals of unknown sex tested in antenatal services, none of whom tested positive: this may reflect partner follow-up or errors in data entry at the source laboratory.

\*\*Includes all hospital services not otherwise specified above: these can be broken down further into individual specialties but are grouped here in the interests of brevity.

§ These are hospital services where specific service type could not be identified, and may include any of the secondary care services listed above.



The proportion positive among males tested was more than twice that of females (1.1% v 0.5%), though after excluding antenatal testing the proportion testing positive was similar (1.1% of males v 0.9% of females;  $p=0.174$ ). People aged 15-34 years accounted for 76% ( $n=31,014$ ) of those tested and 50% ( $n=157$ ) of those testing positive. The proportion positive was highest in those aged 35-54 years (2%;  $n=144/8,196$ ).

The number of individuals tested for HIV by this laboratory increased by 5% overall in the six-month period following the Chief Medical Officer letter of September 2007, with a decrease in the number of people testing positive. The largest increase was seen in GUM clinics (17% increase,  $n=7,164$  to  $8,600$ ) and other primary care settings (16% increase,  $n=1,366$  to  $1,624$ ), while testing in renal units and other secondary care services declined.

### **Testing in GUM clinics**

A total of 15,764 individuals were tested at three GUM clinics that send samples to the sentinel laboratory. Around half (51%;  $n=8,029$ ) of individuals tested in GUM clinics were male, while the positivity rate for males and females was 1.2% ( $n=100$ ) and 0.8% ( $n=58$ ) respectively. The majority of those tested (82%;  $n=12,949$ ) and 47% ( $n=82$ ) of those testing positive were aged between 15 and 34 years. The proportion positive (3.5%;  $n=89/2,559$ ) was highest in individuals aged 35-54 years.

### **Antenatal testing**

In total, 15,754 women were tested as part of antenatal care, 37 (0.2%) of whom were positive. Together this accounts for 58% of all females tested (38% of all individuals) and 60% of women aged between 15 and 44 years. The proportion positive among women screened through antenatal care was significantly lower than among those tested in other settings (0.2% v 1.2%;  $p<0.001$ ).

### **Testing outside GUM clinics and antenatal screening**

9,454 individuals were tested outside GUM clinics and antenatal screening, 102 (1.1%) of whom were positive. 1,568 individuals were tested in general practice, of whom 22 (1.4%) were positive. Figure 1 shows the age and sex distribution of these individuals. Individuals tested outside GUM

clinics and antenatal screening were on average 10.3 years older than those tested in GUM and antenatal settings (unpaired t test; CI=10.0-10.5 years,  $p<0.001$ ); individuals testing positive outside GUM clinics and antenatal screening were on average 2.9 years older than those testing positive in these settings (unpaired t test; CI=0.8-5.0 years,  $p=0.008$ ).

### Repeat testing

Table 2 shows the extent of repeat HIV testing; 3,583 (8.7%) of the 41,013 people tested during the study period were tested more than once. The majority of repeat testing took place in GUM clinics and renal units: 8.5% ( $n=1,335$ ) of individuals tested at a GUM clinic and 57.5% ( $n=692$ ) of individuals tested in renal units were tested more than once over the study period.

Three seroconversions were identified among people tested more than once. All were male GUM clinic attendees, two aged between 35 and 44 years and one aged between 45 and 54 years. On follow-up with requesting clinicians, all were reported to be men who have sex with men (MSM).

Table 2. Number of occasions on which individuals in dataset have been tested for anti-HIV antibody.

Number of tests within twelve-month period	Total number of individuals, all service types	Number of individuals tested in GUM clinics	Number of individuals tested in renal units
1	37,430	14,429	512
2	2,740	1,156	227
3	558	149	241
4	211	25	163
5	56	3	46
6	13	1	12
7	3	1	1
8	1	0	1
9	1	0	1
Total	41,013	15,764	1,204

### **Estimating new diagnoses**

286 (92%) of 312 HIV-positive individuals identified through sentinel surveillance were matched to the national new HIV diagnoses database; of these, 173 (60%) were identified as newly diagnosed during the study period. The proportion of new diagnoses varied between different service types (Table 1).

### **Feasibility**

Establishment of the data collection system for HIV at the LTHT laboratory required a one-off period of three day's work by an IT engineer, since the majority of the necessary hardware, software and data extraction processes were already in place for hepatitis sentinel surveillance (as detailed in [10]). Data extraction by staff at the participating laboratory required approximately one hour's work each month, while data processing and analysis required approximately one day's work per month by an information officer. This pilot involved a set-up cost of approximately £1000 for labour and materials, with projected ongoing costs of approximately £330 per year.

### **DISCUSSION**

This study indicates that the majority of HIV tests are performed in GUM clinics or as part of antenatal care. Furthermore, routine screening in occupational health services, renal units and fertility treatment services – aimed at ruling out infection rather than case detection – accounted for more than half of people tested outside these settings. Less than 4% of individuals were tested in general practice.

There is currently little discussion in the literature of HIV testing surveillance, although one behavioural survey from the US identified differences in self-reported HIV testing rates and locations according to ethnicity [14]. We feel that this paucity of data reflects a gap in current surveillance activities which this study has made an important first step towards addressing.

This pilot study has demonstrated that sentinel laboratory surveillance is a feasible and informative means of monitoring HIV testing in different service types, trends in testing over time

and the demographic characteristics of the population tested. Funding and agreement of existing sentinel laboratories to expand this pilot project has been secured and ethical approval is currently being processed.

One limitation of the study is the possibility of double-counting individuals tested more than once under different hospital or clinic numbers. Although a thorough de-duplication process was undertaken to identify such patients, a small number of duplicates may remain where details such as date of birth or soundex code were unavailable or incorrect. However, completion of patient details used in de-duplication is good in most hospital and primary care settings, and GUM clinic numbers tend to be used consistently within one clinic, so this problem is likely to predominantly affect the relatively small number of individuals moving between GUM and non-GUM services.

In this study, we did not have data on exposure category, ethnicity or country of birth of people tested, since these data are not currently routinely recorded in most laboratory information systems. However, integrated IT systems in some areas do allow access to ethnicity information and the planned upgrade of the NHS Care Records System may improve availability of these data in future.

One particular strength of the sentinel laboratory surveillance lies in the ability to match data with the national database of HIV and AIDS diagnoses and deaths to identify the service type in which an individual was first diagnosed. Currently, data on services in which case detection is taking place may be skewed by the fact that people testing positive in non-GUM services may only be reported to national surveillance after referral to GUM clinics for specialist care. The use of multiple identifiers (such as date of birth, sex and soundex/clinic number) in the matching process should allow for identification of such transfers of care.

The 26 individuals (of 312 testing positive in total) who could not be matched may reflect under-reporting to national surveillance: a similar process of matching between sentinel surveillance and routine surveillance data demonstrated considerable under-reporting of hepatitis C diagnoses to national databases [10]. Alternatively, it may result from inadequate data for identifying individuals. 22 of the 26 unmatched individuals were tested in GUM clinics, where

soundex codes are not usually available: although GUM clinic number can usually substitute for soundex in the matching process, it is possible that this identifier was incorrectly entered on the laboratory system or that they had been previously reported under a different clinic number or from a different clinic.

While this pilot study was limited to one laboratory, it offers proof of principle that such surveillance could be rapidly scaled up nationally by incorporation into existing hepatitis sentinel surveillance systems (currently active in 22 laboratories across England). This would enable automated collection of large amounts of data without additional work by the person requesting the test or the need for labour-intensive local audits. It would also provide the opportunity to monitor testing for co-infection with hepatitis B and C in HIV-positive individuals, something which is not currently possible with existing surveillance systems [15]. Such a scheme may also be of value in other countries, particularly those with national health care systems where data collection from a network of representative sentinel laboratories is a feasible proposition.

As this paper has shown, sentinel surveillance can also help identify seroconversions among repeat testers: as data collection continues and longitudinal data accumulate, the potential of this aspect of the study will only increase. Although the roll-out of the serological testing algorithm for recent HIV seroconversion (STARHS) for all newly-diagnosed individuals will facilitate identification of recent infections, ongoing sentinel surveillance of testing provides the opportunity to monitor seroconversions in a range of healthcare settings without the cost and workload associated with additional laboratory testing. A similar system for identification of anti-HCV seroconversions has been successfully integrated into the sentinel surveillance of hepatitis testing study with minimal additional investment of time, providing valuable data on incidence of infection among individuals undergoing repeat testing and routes of transmission of recently-acquired infections.

Recently published UK National Guidelines for HIV Testing [7] have identified levels of testing in primary and secondary care and the number of new HIV diagnoses made in different service types as key auditable standards. The study was conducted before the publication of these guidelines and therefore provides a baseline from which to monitor efforts to expand testing.

Current HIV testing surveillance focuses on GUM clinics and antenatal screening: sentinel laboratory surveillance data provides an opportunity to monitor trends in HIV testing and positivity rates in other health care services, such as general practices and prison clinics. Sentinel surveillance of HIV testing in multiple laboratories would also provide the opportunity to assess local and national trends in testing over time, both overall and in specific service types. Locally, such data may be used to investigate patterns of service use by different demographic groups and to evaluate changes in testing in response to local initiatives, such as awareness campaigns or new guidelines for healthcare professionals.

We conclude that sentinel laboratory surveillance of HIV testing should be prioritised in order to monitor and improve our understanding of patterns of HIV testing in the UK and to inform local and national policy.

#### **KEY MESSAGES**

- Little HIV testing is currently taking place outside GUM and antenatal settings in the UK.
- Sentinel laboratory surveillance is a feasible way of monitoring HIV testing in different service types, trends in testing and demographic characteristics of the population tested.
- Data on HIV testing could be incorporated into existing hepatitis sentinel surveillance, allowing rapid scale-up across England with minimal cost and effort.

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#### **COMPETING INTERESTS**

The authors declare they have no competing interests.

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#### **STATEMENT OF CONTRIBUTORSHIP**

This pilot study was conceived and designed by MH, PK and MR. Data extraction was carried out by AH, MH and ET. Data were analysed by ET and LB. RS matched sentinel surveillance data to the HPA new HIV diagnoses database, under supervision from VD. The paper was written by ET, with comments and contributions from all authors. All authors approved the final version submitted for publication.

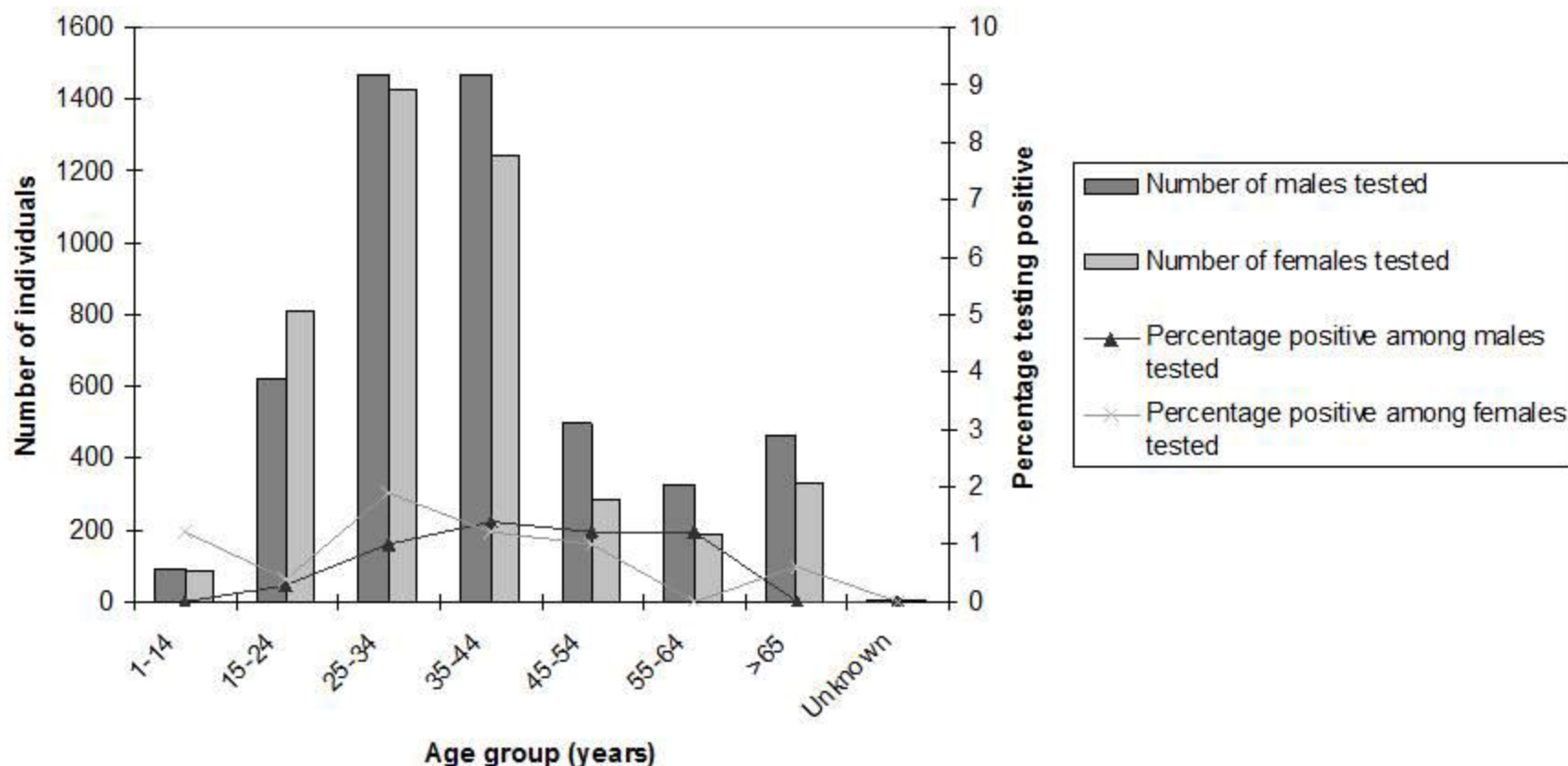
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Figure 1. Number of individuals tested, and percentage testing positive, for HIV outside GUM clinics and antenatal screening, by age and sex (n=9,454).



N.B. Does not include individuals of unknown sex (n=123; proportion positive=3.3%).