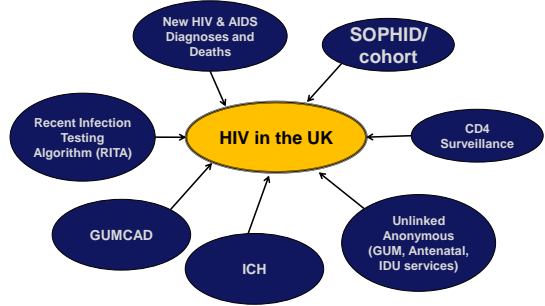


The utility of surveillance: Public health monitoring of the HIV epidemic in the United Kingdom

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Public Health England

HIV National Surveillance Systems, UK



Utility of public health monitoring

- Policy development and development
- Monitoring of public health interventions
- Inform clinical and public health guidelines
- Inform and evaluate primary prevention efforts
- Inform and set standards of care
- Better understand patient experience and satisfaction
- Planning of HIV clinical and social care services
- Commissioning of HIV services and prevention
- Public health research



Why it works

- Partnerships between clinicians, academics and public health experts
- Confidentiality and data security maintained
- Engagement of key stakeholders
- Reviewed and adapted
- Regular outputs and feedback
- Community engagement

The Mail

ON SUNDAY

Sunday 20th November 2011

BRITISH PUBLIC TO PAY £250M FOR GAYS TO SCREW AROUND

British HIV Doctors voted at their recent conference in London to fund the provision of anti-HIV drugs to gay men who are HIV negative so that they can protect themselves against the infection and no longer need to use condoms. This will be at the tax payers expense at a time when waiting times in Accident and Emergency Departments are at an all-time high and the average well-deserving British taxpayer is being denied deserving healthcare interventions such as hip replacements.

Monitoring the HIV epidemic and our response

Routine reporting

- Testing – new diagnoses
- Clinical information – clinics and laboratories
- STI surveillance

Prevalence studies (routine and unlinked anonymous)

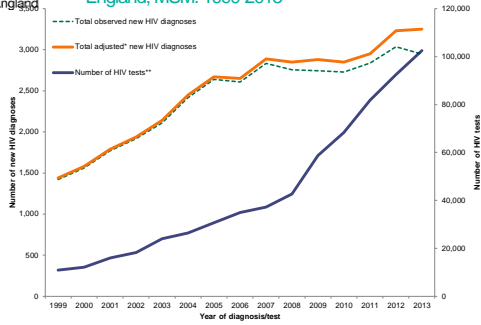
- STI clinics
- Antenatal
- Blood donors
- People who inject drugs

Behavioural surveillance - general population and key populations

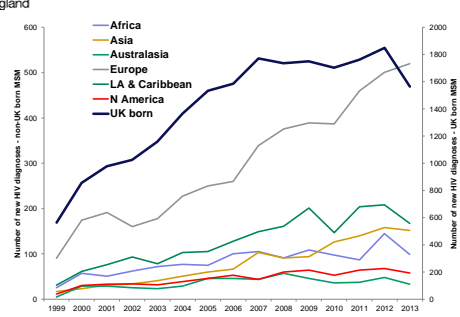
Quality of care indicators



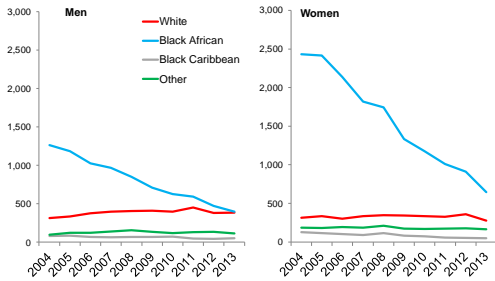
Public Health England
Numbers of new HIV diagnoses and HIV tests England, MSM: 1999-2013



Public Health England
New HIV diagnoses by region of birth, MSM, UK: 1999-2013



New HIV diagnoses among heterosexuals by ethnicity and gender: UK, 2003-2014



Estimates of UK-acquired HIV infection among persons born abroad

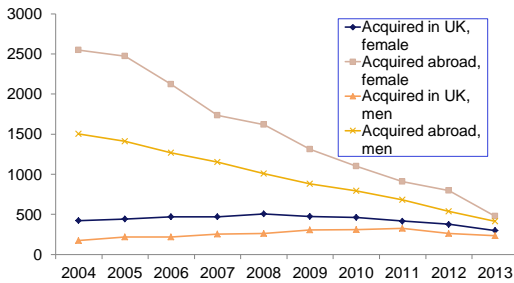
A new method to assign country of HIV infection among heterosexuals born abroad and diagnosed with HIV

Brian D. Rice^{a,b}, Jonathan Elford^b, Zheng Yin^a and Valerie C. Delpech^a

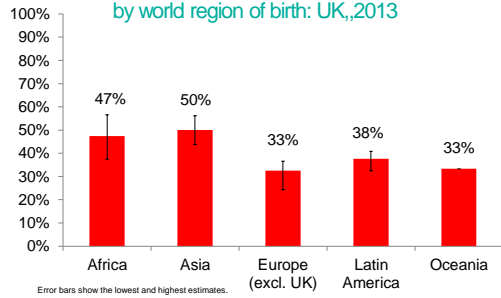
Objective: To apply a new method to ascertain likely place of HIV infection among persons born abroad and diagnosed with HIV in the United Kingdom (UK).
Design: Analysis of heterosexual adults born abroad, diagnosed with HIV in the UK between 2004 and 2010, and reported to the national HIV diagnosis database.
Methods: Year of infection was ascertained by applying an estimated rate of CD4 cell count decline between an individual's CD4 cell count at diagnosis and estimates of CD4-cell count at infection. A person was classified as having probably acquired HIV while living in the UK if estimated year of infection was later than reported year of arrival in the UK.
Results: Of 10612 heterosexual adults born abroad included in the analyses, 85% (9065) were of black-African ethnicity. We estimate that 33% (26–39%) of persons acquired HIV while living in the UK. This percentage increased from 24% (14–39%) in 2004 to 46% (31–50%) in 2010 (P<0.01). The estimate of 33%

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New diagnoses among heterosexual men and women by probable place of acquisition, UK



Proportion of heterosexuals born abroad who probably acquired HIV while living in the UK, by world region of birth: UK, 2013



New HIV diagnoses acquired by UK-born heterosexuals through sex outside the UK

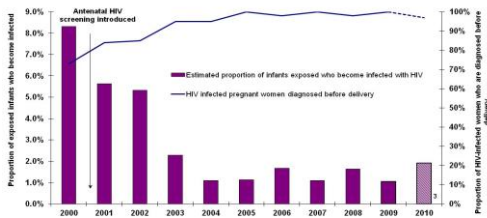


Data from 2002-2010:
15% of UK born adults newly diagnosed with HIV reported acquiring infection abroad
Countries most commonly reported:
 Thailand, South Africa, Nigeria, Spain, Zimbabwe and the USA
Compared to adults who acquired HIV in the UK, more likely to be:

- Heterosexual
- Older
- Contact with sex workers

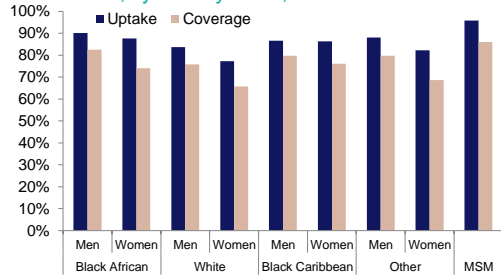
Monitoring of HIV testing

Antenatal screening for HIV



1 Includes previously diagnosed and those diagnosed through antenatal testing
 2 Assumes vertical transmission rate of 26.5% in undiagnosed women and 2.2%, 1.0% and 1.1% in diagnosed women in 1999, 2000-2002 and 2003-2008 respectively.
 3 These data contain reports received by the end of June 2012, data for recent years is subject to reporting delay.

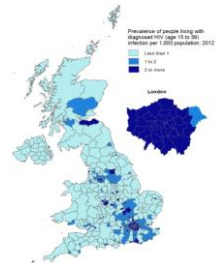
HIV testing coverage and uptake among heterosexuals & MSM attending sexual health clinics, by ethnicity: E&W, 2013



Monitoring of quality of HIV care

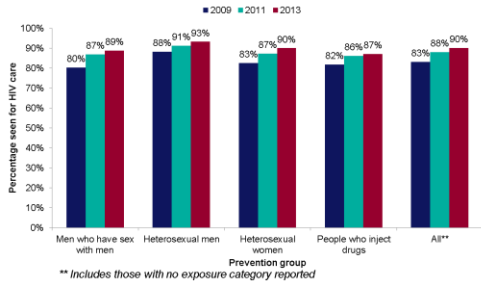
National cohort of Persons seen for HIV care = Prevalence of diagnosed HIV infection

- (Almost) all persons attend an NHS clinic
- Annual follow up data (cd4, VL, ART) (SOPHID)
- Linked by soundex to previous years to form national cohort



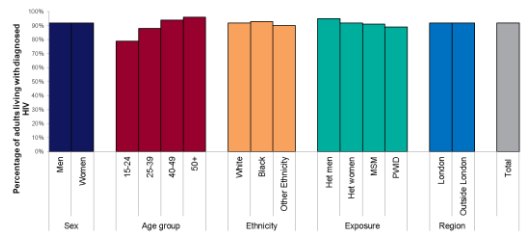
- Data used to inform
- Diagnosed Prev trends
 - Clinical outcomes
 - Testing policies
 - Undiagnosed infection
 - TAsP

Proportion of HIV diagnosed persons with a CD4 <350 cells/mm³ and receiving antiretroviral therapy: United Kingdom, 2009-2013



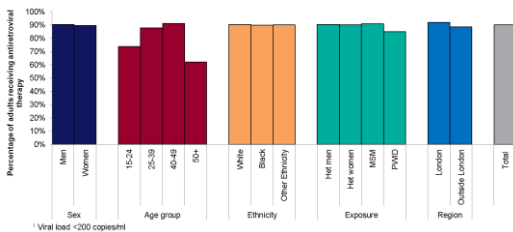
19 New HIV diagnoses and number of persons accessing HIV care in the United Kingdom: 2014

Treatment guidelines: proportion of adults with CD4<350 cells/mm³ receiving antiretroviral therapy: UK, 2013



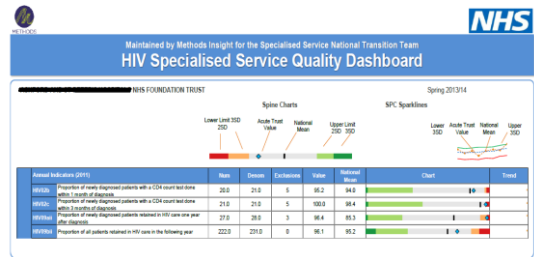
21 HIV in the United Kingdom: 2014

Effectiveness of treatment: proportion of adults achieving viral suppression¹: UK, 2013

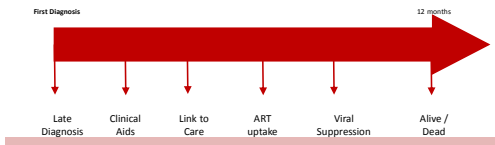


22 HIV in the United Kingdom: 2014

HIV clinical dashboards



Monitoring the first year of HIV care



23 Presentation title - edit in Header and Footer

Monitoring the HIV epidemic and the UK's response

Modelling work – undiagnosed and incidence, projections, scenario setting

Use of CD4 count

- late diagnosis
- Link to care
- Incidence estimates
- Undiagnosed infection estimates
- Probable country of infection



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Estimating undiagnosed infections and its impact on transmission and mortality

Multiparameter synthesis statistical model (MPSS)
CD4 back-calculation

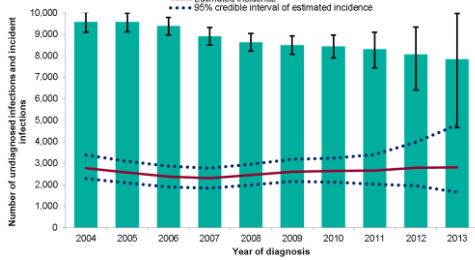
Estimated number of people living with HIV in the UK, 2013

		Diagnosed	Undiagnosed	% unaware
Men	Black African ethnicity	8,400	5,250 (3,400-11,850)	38%
	Non-black African ethnicity	7,500	2,800 (1,600-4,800)	27%
Women	Black African ethnicity	17,200	7,850 (5,300-11,600)	31%
	Non-black African ethnicity	7,950	2,400 (1,500-3,700)	23%
MSM		36,300	7,200 (4,000-11,850)	16%
UK total		81,700	26,100 (20,300-33,800)	24%

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Back-calculation estimate of HIV incidence and prevalence of undiagnosed infection among MSM: UK, 2004-2013



5 HIV in the United Kingdom: 2014



Monitoring the HIV epidemic and the UK's response

Linking with other databases (using limited identifiers)

- STI clinic data
- Testing data
- HIV resistance database including phylogenetics projects
- Office of national statistics – deaths ? Cancer
- TB diagnoses
- Invasive pneumococcal disease
- ?hospitalisation data

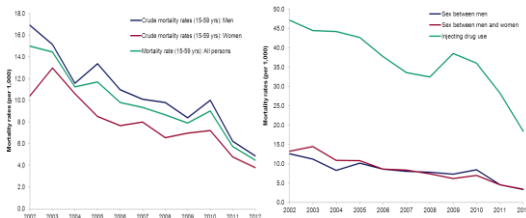


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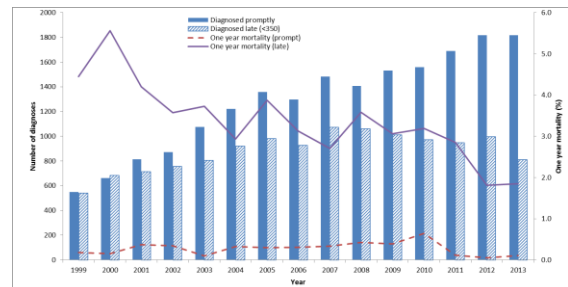
Monitoring of deaths among PLHIV

- 'Persons diagnosed early can expect a near normal life span'
- In 2012, death rates among persons with HIV were 3 X that of general population



29 HIV in the United Kingdom: 2013

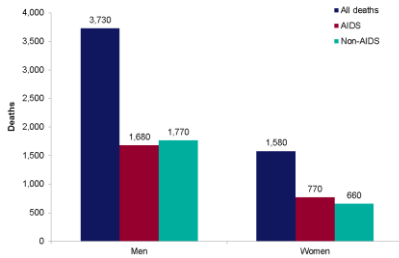
MSM with diagnosed HIV, United Kingdom



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Deaths among people diagnosed with HIV in the era of ART: England and Wales, 1997-2012



Engagement of people living with HIV

Developing patient experience measures

“Positive Voices” – Concept

1. Use SOPHID as a national sampling frame to pre-select a random sample of HIV-positive patients to receive a survey invitation
2. Recruitment when patients attend the HIV clinic for routine care
3. Responses linked to clinical data (VL, CD4, ART, resistance) in SOPHID
4. Repeated at regular intervals

Questionnaire Domains

1. **HIV diagnosis and treatment**
 - Testing history
 - Adherence
 - Attitudes toward ART
2. **Comorbidities**
 - Non-HIV related conditions
 - Medications
3. **Quality of Life**
 - EQ-5D
 - Functional assessment of HIV
 - Mental Health
4. **Stigma and Discrimination**
 - Disclosure
 - Experiences with discrimination
5. **Sex & Relationships**
 - Condom use
 - Number and type of partners
 - STI testing history
6. **Health & Lifestyle**
 - Tobacco, alcohol, and drug use
 - Body Mass Index (BMI)
7. **Service Use and Satisfaction**
 - Health service usage
 - Support organisation access
 - Patient experience and satisfaction
8. **Sociodemographic**
 - Employment
 - Education
 - Religion

Questionnaire Development

- Literature review
 - Health-related quality of life
 - HIV stigma
 - Adherence
- Use of validated tools
 - Health Survey for England (HSE)
 - UK Household Longitudinal Survey (UKHLS)
 - British Household Panel Survey (BHPS)
 - National Survey of Sexual Attitudes and Lifestyles (NATSAL)
 - Medical Monitoring Project (MMP)

Instrument	Description
EQ-5D	Generic health-related quality of life (5-items)
FAHI-HIV	HIV specific health-related quality of life (40-items)
AUDIT-C	Alcohol misuse
QRisk	CVD risk
ACTG Adherence	Tablet adherence
Berger HIV Stigma Scale (brief)	Internalized, perceived, and enacted stigma

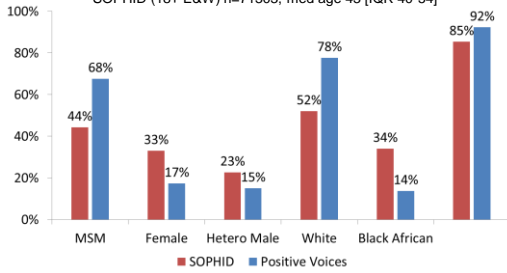
Positive Voices - pilot

- May – November 2014
- RCT design to assess best recruitment methods
- 30 HIV clinics - inside/outside London, large/small clinics. 1/3 of pop accessing HIV care.
- Sample size =4,350 participants to invite, 27% recruited



Results - Main Demographics

Positive Voices n=782, med age 47 [IQR 40-54]
SOPHID (18+ E&W) n=71303, med age 43 [IQR 40-54]

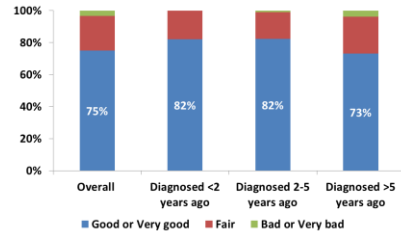


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Results: Overall health

"In general, would you say your health is?"

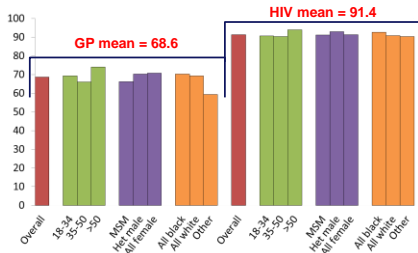
• No noticeable differences by age or gender and sexual risk



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Satisfaction with Care – HIV specialist and GP

"Overall, how would you rate your GP/HIV specialist services?"



*96.5% of respondents reported having a GP

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Disclosure

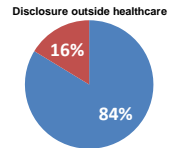
"Does your GP know your HIV status?"

• No noticeable differences by age or gender and sexual risk



"Apart from health care staff, have you told anyone that you have HIV?"

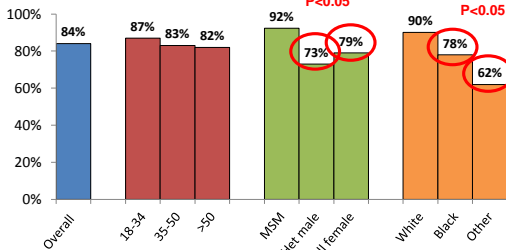
• Differences by ethnicity and gender and sexual risk exist



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Disclosure

"Apart from health care staff, have you told anyone that you have HIV?"



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Patient experience

"If you wish, please use the space below to tell us about when you have experienced discrimination because of your HIV status."

"I had a nurse recommend to another nurse to double-glove because of my status in front of me..."
- Man, 24, diagnosed 2013

"When I registered with a GP the doctors said 'Oh great another POS person', I left and complained to the practice manager still not had a response."
- Man, 33, diagnosed 2008

"[At the] dental clinic, I was put last on list to be attended to that day."
- Woman, 52, diagnosed 2007

"I have had issues with GPs - they often have little or no experience with HIV+ patients and don't have a clue about how to approach you. Its not discrimination, but a lack of experience..."
- Man, 42, diagnosed 2012

"My dentist left me in agony for over a year as she didn't want to do the extractions because of the blood."
- Man, 46, diagnosed 2010

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Positive Voices next steps

- Dissemination of findings
- Piloting of iPads in clinics
- PLHIV engagement events
- Use of Positive Voices
 - Part of routine Public health monitoring
 - Patient engagement and satisfaction – included on dashboards
 - Selected population and focused surveys (eg BME, women, older age)
 - Matching to HARS – rich source of clinical and self reported information

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Conclusions

- *good and timely public health monitoring drives & monitors policy and prevention and interventions at all levels*
- First year of HIV diagnosis is crucial
- Monitoring of Clinical outcomes can be achieved with minimal data
- Good data collection requires a skilled public health workforce with epidemiological expertise – trust and robust confidential data systems
- Sensitive methods of collecting accurate risk information
- Work closely with modellers and statisticians to estimate undiagnosed & incidence infections
- Engagement of people most affected at all levels

Help
improve
the
lives



We gratefully acknowledge

persons living with HIV,

*clinicians, health advisors, nurses, microbiologists,
public health practitioners, data managers and other
colleagues who contribute to*

the surveillance of HIV and STIs in the United Kingdom