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25th Annual Conference of the British HIV Association
Bournemouth 2019

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Declarations

- Dr Ming Lee has no conflicts of interests relevant to this presentation.

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Pilot results from late HIV diagnosis and review process

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- In 2016 around 2,066 patients in England diagnosed late (CD4<350): late diagnoses were preventable in over 1,000 patients
- That year roughly 150 cases of AIDS were preventable and potentially 100-200 deaths were preventable if previous testing opportunities not been missed

BHIVA Standards of Care for People Living with HIV 2018 auditable outcomes for Standard 1

- Proportion of services undertaking a review of all patients diagnosed late (CD4 count <350 cells/mm^3) or very late (CD4 count <200 cells/mm^3 or AIDS), with 'look back' of previous engagement with healthcare services (target: 95%). This critical case review should:
  - Be in line with the forthcoming national standardised process for reviewing late diagnoses (currently in development);
  - Include provision of summary information to commissioners to aid greater understanding of interventions to reduce late diagnosis.

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- Pilot of late diagnosis reviews
  - Multiple sites across England and Wales

- Evaluation of pilot – Online survey to site leads

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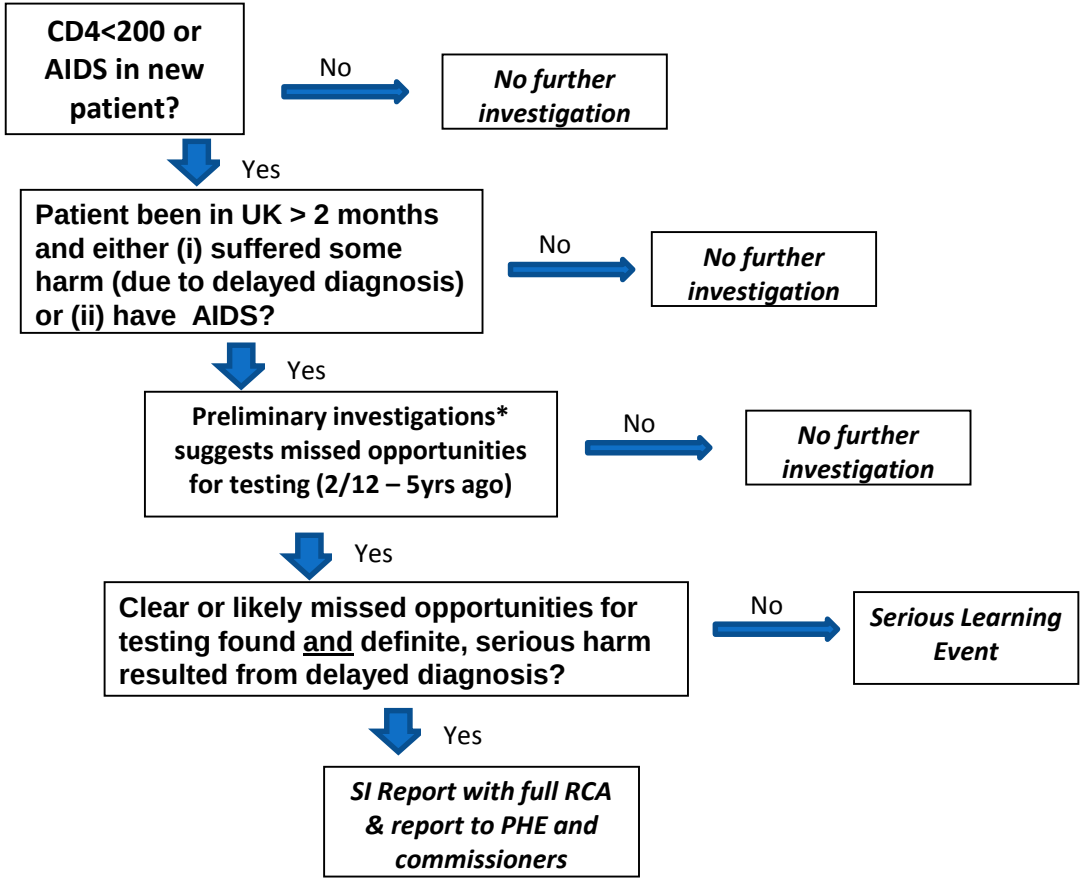
Pilot process for reviewing late HIV diagnoses
(July – December 2018)



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Case-notes review – both inpatient/outpatient episodes

Pathology system: e.g. ICE plus OpenNet function

Summary Care Record (NHS Spine) – GP prescriptions

Other electronic record systems…

Patient recall of accessing healthcare..

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Definition of missed opportunities

- Adapted from 2008 BHIVA testing guidelines
  - Definite missed opportunities
    - If meets criteria for clinical indicator diseases for HIV infection
  - Possible missed opportunities
    - Examples: Single episode of pneumonia, shingles, weight loss

Table 1: Clinical indicator diseases for adult HIV infection

	AIDS-defining conditions	Other conditions where HIV testing should be offered
Respiratory	Tuberculosis Pneumocystis	Bacterial pneumonia Aspergillosis
Neurology	Cerebral toxoplasmosis Primary cerebral lymphoma Cryptococcal meningitis Progressive multifocal leucoencephalopathy	Aseptic meningitis/encephalitis Cerebral abscess Space occupying lesion of unknown cause Guillain–Barré syndrome Transverse myelitis Peripheral neuropathy Dementia Leucoencephalopathy
Dermatology	Kaposi's sarcoma	Severe or recalcitrant seborrhoeic dermatitis Severe or recalcitrant psoriasis Multidermatomal or recurrent herpes zoster
Gastroenterology	Persistent cryptosporidiosis	Oral candidiasis Oral hairy leukoplakia Chronic diarrhoea of unknown cause Weight loss of unknown cause Salmonella, shigella or campylobacter Hepatitis B infection Hepatitis C infection
Oncology	Non-Hodgkin's lymphoma	Anal cancer or anal intraepithelial dysplasia Lung cancer Seminoma Head and neck cancer Hodgkin's lymphoma Castleman's disease
Gynaecology	Cervical cancer	Vaginal intraepithelial neoplasia Cervical intraepithelial neoplasia Grade 2 or above
Haematology		Any unexplained blood dyscrasia including: • thrombocytopenia • neutropenia • lymphopenia
Ophthalmology	Cytomegalovirus retinitis	Infective retinal diseases including herpesviruses and toxoplasma Any unexplained retinopathy
ENT		Lymphadenopathy of unknown cause Chronic parotitis Lymphoepithelial parotid cysts
Other		Mononucleosis-like syndrome (primary HIV infection) Pyrexia of unknown origin Any lymphadenopathy of unknown cause Any sexually transmitted infection

NPSA/NRLA Harm Grading System

For this process, harm suffered to be put in 1 of 3 categories:

- **Minor (Grade 0/1) – '0' means no harm (asymptomatic)**
- **Intermediate (Grade 2/3)**
- **Major (Grade 4/5)**

	Consequence score (severity levels) and examples of descriptors				
	1	2	3	4	5
Domains	**Negligible**	**Minor**	**Moderate**	**Major**	**Catastrophic**
Impact on the safety of patients, staff or public (physical/ psychological harm)	Minimal injury requiring no/minimal intervention or treatment No time off work required	Minor injury or illness requiring minor intervention Requiring time off work for <3 days Increase in length of hospital stay by 1–3 days	Moderate injury requiring professional intervention Requiring time off work for 4–14 days Increase in length of hospital stay by 4–15 days RIDDOR/agency reportable incident An event which impacts on a small number of patients	Major injury leading to long-term incapacity/ disability Requiring time off work for >14 days Increase in length of hospital stay by >15 days Mismanagement of patient care with long-term effects	Incident leading to death Multiple permanent injuries or irreversible health effects An event which impacts on a large number of patients

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Feedback process for late diagnoses

	No or minimal Harm (0/1) Demonstrated	Some Harm (2/3) Demonstrated ('AE'-equivalent)	Serious Harm (4/5) Demonstrated (SI) ('SAE'-equivalent)
Delayed diagnosis; no clear evidence of missed opportunities for testing			
Delayed diagnosis & possible missed opportunities for testing	*Letter to relevant service*	*Letter to relevant service*	**Serious Learning Event (SLE)**
Delayed diagnosis & definite missed opportunities for testing	*Letter to relevant service*	**Serious Learning Event (SLE)**	**Serious Incident (RCA)**

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Evaluation of Late Diagnosis Pilot (LDP)

- Online structured survey sent to individual site leads

- 4 domains
  - Consent process
  - RCA and SLE analysis
  - Feedback to external services
  - HIV services experience of the LDP

- Statistical analysis done in Minitab, and univariate analysis using student's T test for continuous, and χ^2 test for categorical variables

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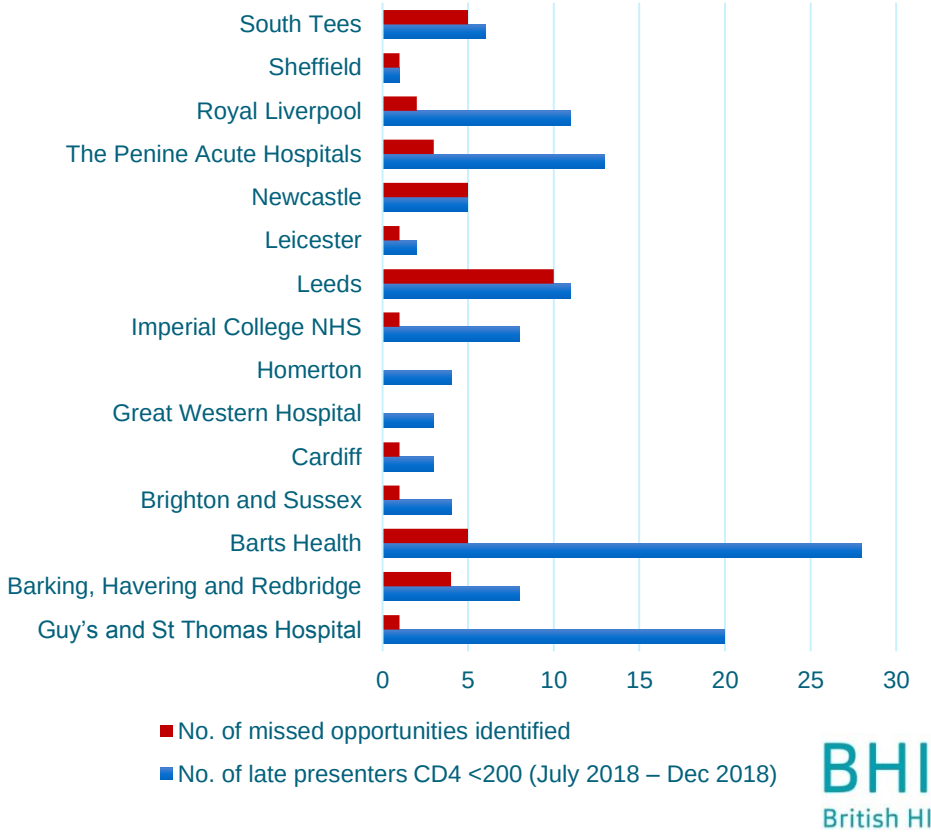
Results

- 15 Trusts participated in the LDP
- Total number of late presenters in pilot period = 127
- Total number of late presenting patients with missed opportunities = 40 (31.5%)
  - 68 missed opportunities in total



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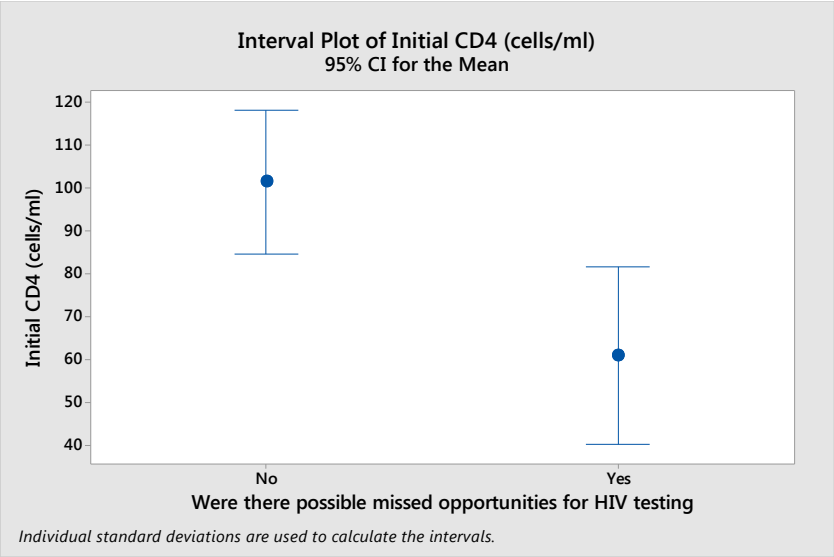
Demographics

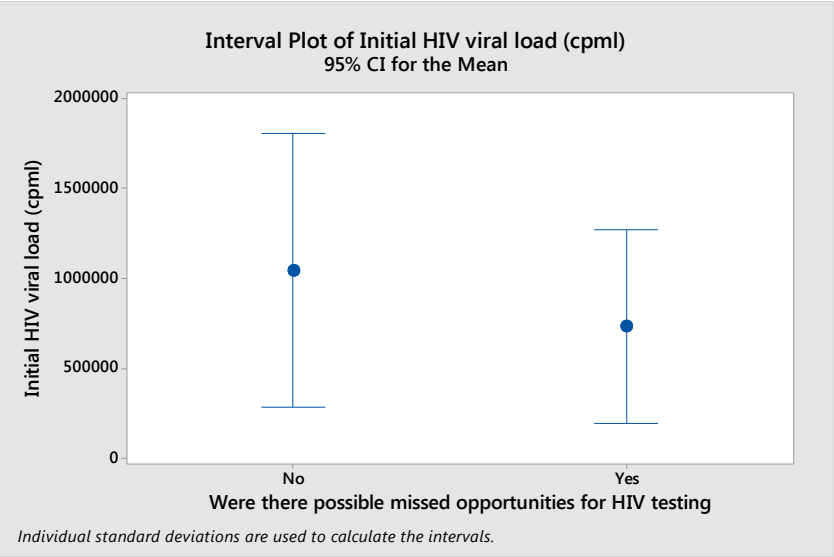
		Late presenters without missed opportunities (N=87)	Late presenters with missed opportunities (N=40)	
Mean Age		44 years (SEM ± 1.3)	47 years (SEM ± 2.0)	p= NS
Gender	Male	60 (69.0%)	31 (77.5%)	p= NS
	Female	26 (29.9%)	9 (22.5%)	
	Transgender	1 (1.1%)	0 (0.0%)	
Likely route of HIV acquisition	Heterosexual	60 (69.0%)	24 (60.0%)	p= NS
	MSM	25 (28.7%)	16 (40.0%)	
	Other	2 (2.3%)	0 (0.0%)	
Ethnicity	Non-White	46 (52.9%)	12 (30.0%)	**p= 0.016**
	White	**41(47.1%)**	**28 (70.0%)**	
Country of birth	Outside UK	61 (70.1%)	17 (42.5%)	**p= 0.003**
	UK born	**26 (29.9%)**	**23 (57.5%)**	

HIV Diagnosis

- Mean CD4 counts were lower at diagnosis in late presenters with missed opportunities for earlier HIV testing



P = 0.003

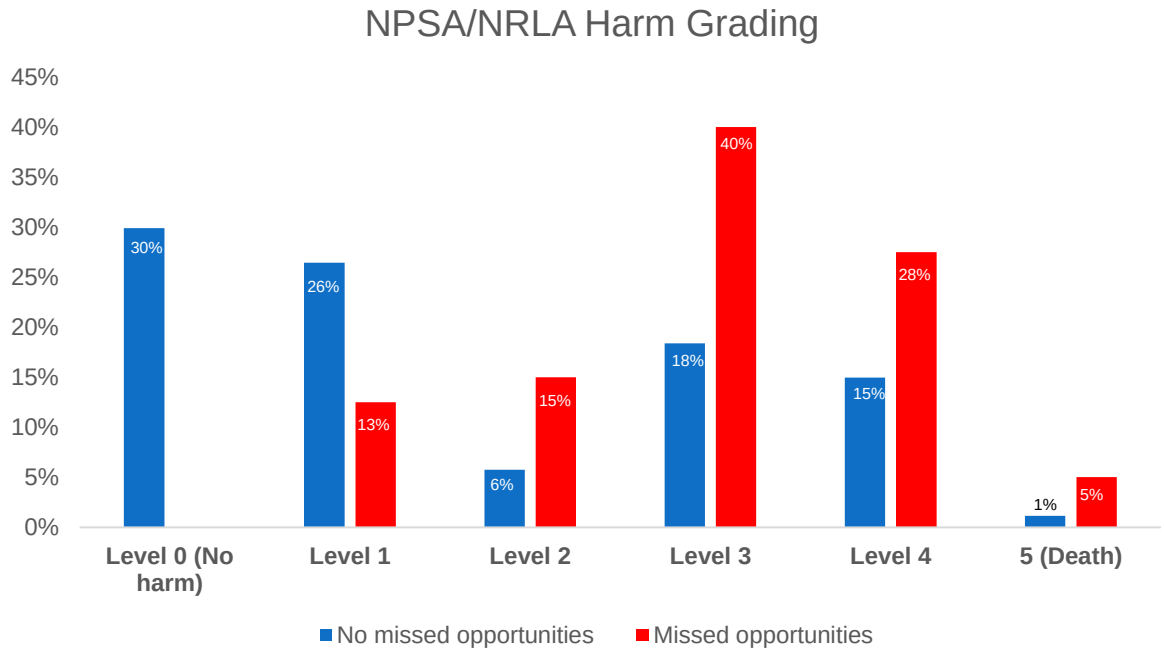


P = 0.616

- AIDS-defining illnesses were also more common (65.0% vs 35.0%, p=0.001)

Harm to patients

- Late presenters with missed opportunities were more likely to experience high levels of harm at diagnosis



P < 0.0001

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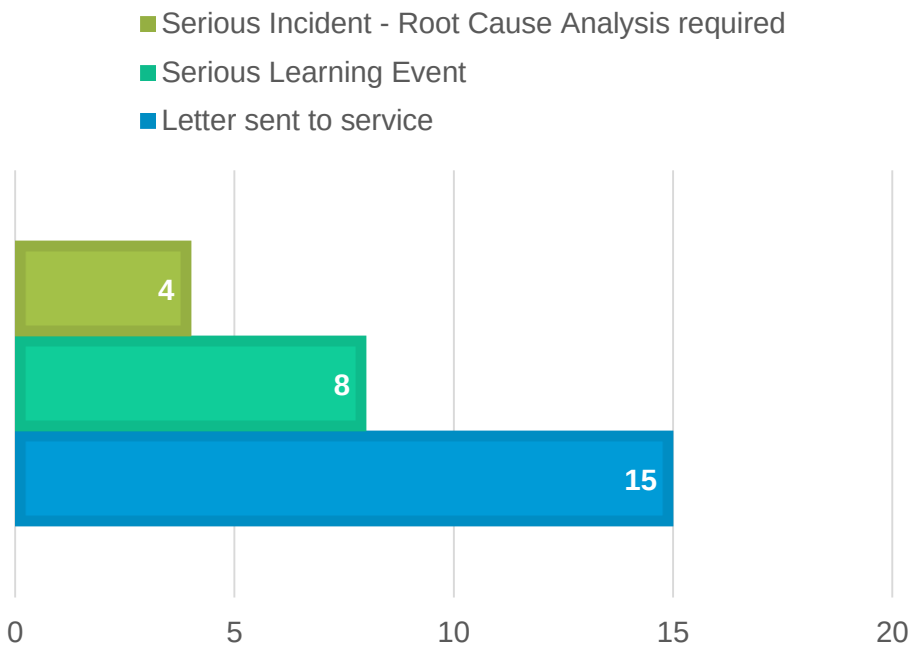
Outcome of LDP review



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Site Example - Manchester

- 3 coroners cases – inquests pending – outside BHIVA pilot period
  1. Coroner's inquest underway: delayed diagnosis with multiple missed opportunities at medical outpatient appointments (oral candidiasis, lung nodules, weight loss)
  2. Coroner's referral made: death from AIDS-defining condition on background treatment with biologics for inflammatory bowel disease, not tested
  3. Coroner's referral made: death from AIDS-defining condition after many appointments with haematology, gastroenterology, breast surgery. Lymphadenopathy and weight loss, no apparent risk factors.
- Through use of governance systems and coroners referrals, proposed task and finish group set up to establish universal testing.

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Evaluation of LDP – Survey results

- Responses from 12 sites
- LDP was carried out either with presumed consent (50%) or verbal consent sought (50%)
- Reasons for not being able to carry out LDP

Access to SCR/Spine was not available during audit period
Patient died before consent could be obtained
We were unable to contact one patient during the study period to obtain consent
1 patient was not approached as it was felt that this would be distressing due to their severe mental health problems

- All other patients contacted gave consent for LDP

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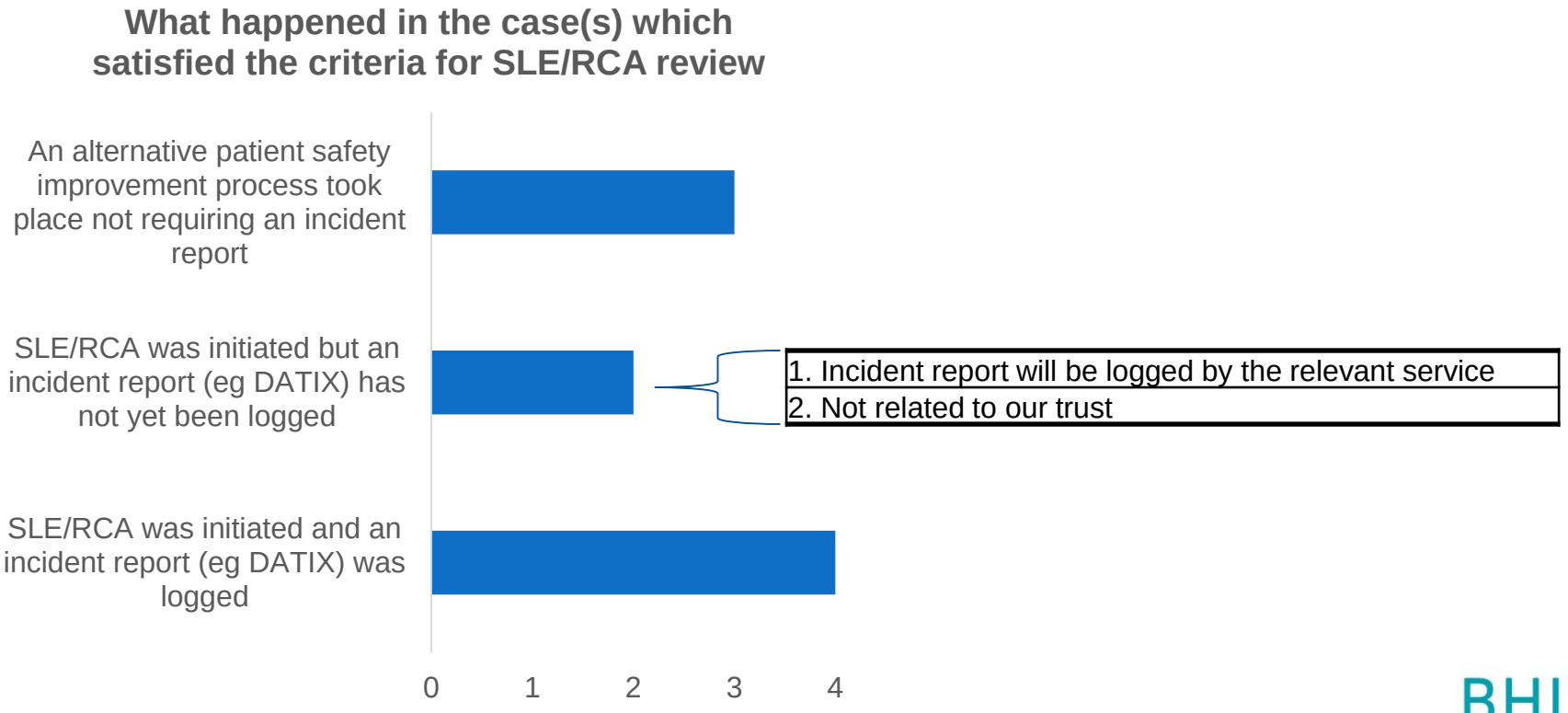
RCA and SLE analysis



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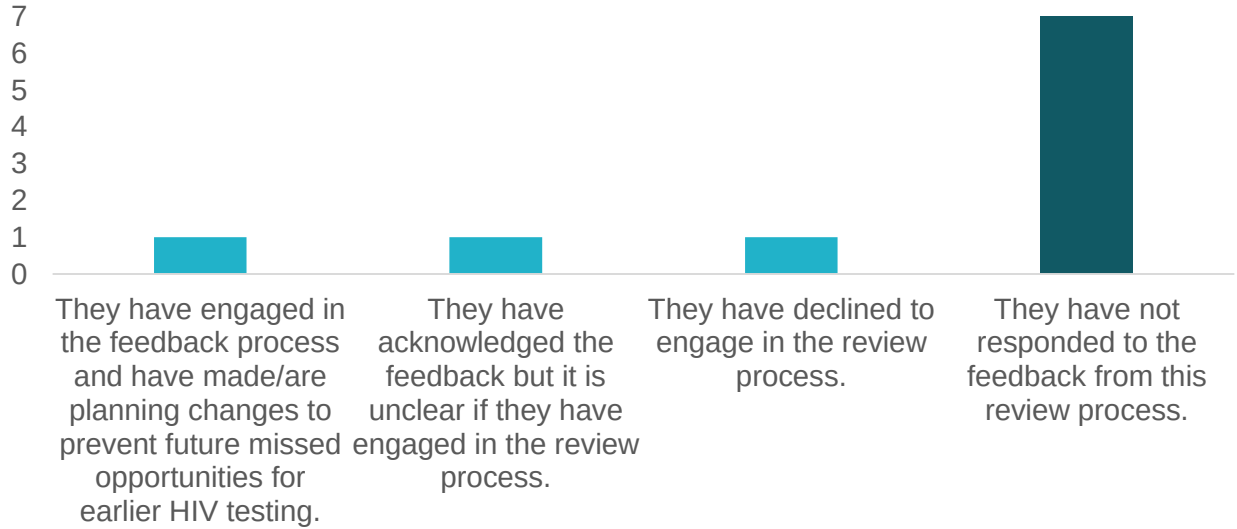
Feedback to services

- 10 sites contacted the relevant services where missed opportunities for earlier HIV testing were identified
  - Statements best describing response(s) from contacted services



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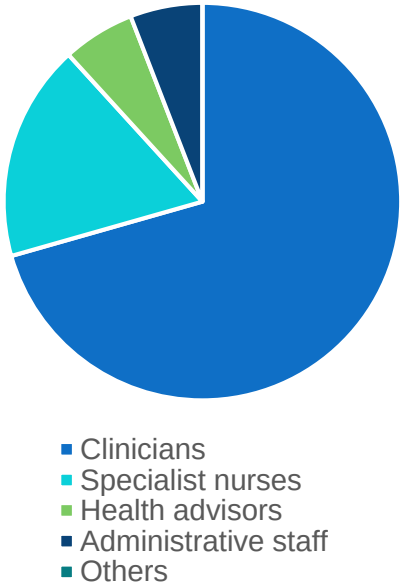
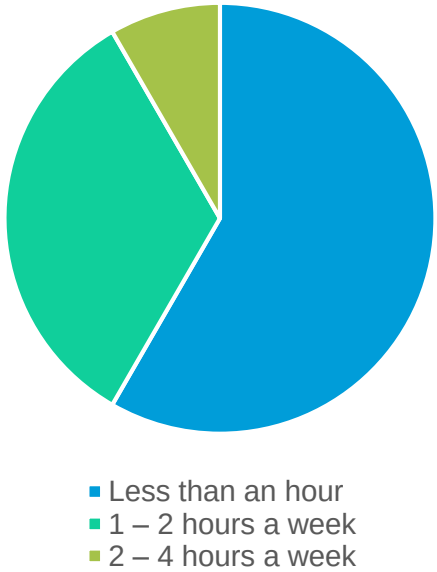
Individual HIV services' experience of LDP

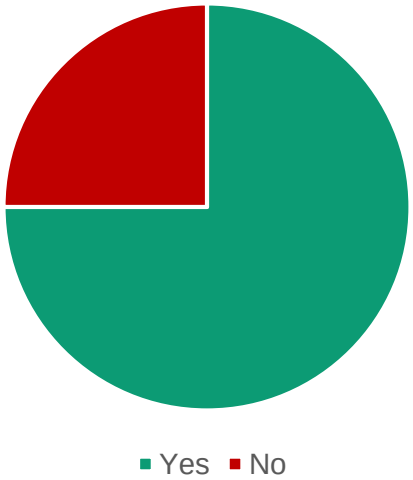
Which member(s) of the multidisciplinary team were involved in the process of identifying missed opportunities for earlier testing in late diagnosis



How many hours a week on average has this review required in your department for the staff member(s) involved in this review process



Is this a sustainable process in your department



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Individual sites' experience of LDP

Very much in favour of the process, although in the single case we identified in the pilot, it was uncertain whether there were clearcut missed opportunities in the GP setting.

Our service has undertaken a HIV late diagnosis review which is discussed alongside our Mortality meeting every year .At our last review, feedback was sought from GPS regarding the type of feedback they would find most helpful . Feedback options include:

1.A general 'lessons learned' letter to all GP surgeries (Leeds, Wakefield and Dewsbury) including the results of our audit and describing HIV clinical indicator scenarios with potential opportunities for early HIV testing
2. A letter regarding the specific patient from your practice with further information
3.Training sessions on HIV testing and clinical indicator conditions
4.All of the above

Hard to do this prospectively patients were bought to HIV MDT

Datix and initiating RCA's is less time consuming than chasing external organisations for patient care reviews. We can't do the latter with current time available. We sent 2 requests for RCA's external but they haven't as far as we are aware done them as they did not recognise missed opportunities.

Useful if we could have had access to GP systems

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Summary

- Patients with lower CD4 count, AIDS-defining illness and increased harm at diagnosis, including death are still more likely to have missed opportunities for earlier HIV testing.

- Caucasian ethnicities and those born in the UK more likely to have missed opportunities for earlier testing.

- Some Trusts' Patient Safety Teams were cautious about or reluctant to use SI/SLE processes

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Summary

- Process of obtaining consent for accessing records varied during the pilot, and should consider undertaking review of late diagnoses in the interest of patient safety, informing patients where possible.
- The LDP was a sustainable process with current resources in most centres
- Adopting late diagnoses review can lead to improvements in patient safety and preventing further missed opportunities e.g. Manchester example
- Next steps – UK-wide process

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Acknowledgements

Pilot Site Leads

- Nick Larbalestier, GSTT
- Daniella Chilton, GSTT
- Emily Clarke, RLBUHT
- Emma Rutland, WSH
- Yvonne Gileece, BSUH
- Athavan Umaipalan, BHR
- Clare van Halsema, PAT
- Joanne Bassett, Sheffield
- Karen Rogstad, Sheffield
- Amy Mammen-Tobin, Leeds
- Sarah Schoeman, Leeds
- Iain Stephenson, Leicester
- Adrian Palfreeman, Leicester
- Ashley Price, NUTH
- Laurence Dufour, Barts Health
- Chloe Orkins, Barts Health
- Andrew Freedman, Cardiff
- Lucy Garvey, Imperial NHS
- Iain Reeves, Homerton
- Nikhil Premchand, Northumbria
- Luciana Rubinstein, NWUHT
- Megan Jenkins, NBT
- Francesca Knapper, NBT
- Mark Gompels, NBT

Other Support

- Hilary Curtis, BHIVA
- Mas Chaponda, HIV CRG
- Philippa Matthews, RCGP
- Valerie Delpeche, PHE

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