

# Late HIV diagnosis: identifying missed opportunities for HIV testing in North East England

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#### Background

Public Health England recorded 5164 new HIV diagnoses in 2016 of which **2066 (40%)** were diagnosed late (CD4<350) and **1084 (21%)** very late (CD4<200).

During this period the North East (NE) of England overall had a low prevalence of HIV, <2:1000 of the population are HIV positive. In the NE **47**% of patients were diagnosed late, making it the region in England with the highest rates of late HIV diagnosis.

BHIVA Standards of Care (2013 & 2018) recommend that HIV services should review all patients presenting with CD4<200 or AIDS diagnosis in order to identify potential missed opportunities (MOs) for HIV testing that could have avoided late diagnosis.

### Aims

- Describe numbers and characteristics of patients presenting with late diagnosis
  (CD4<350) in North East England</li>
- 2. Identify and describe missed opportunities for HIV testing
- 3. Review healthcare episodes/sites where missed opportunities most common

#### Method

New HIV diagnoses from Jan 2016 – May 2018 in which patients had **CD4<350 or AIDS at diagnosis** were reviewed by HIV treatment centres within North East England.

Demographic data and details of potential MOs was collected from patient notes, prescribing information from the NHS Spine Summary Care Record and pathology results from OpenNet WebICE system.

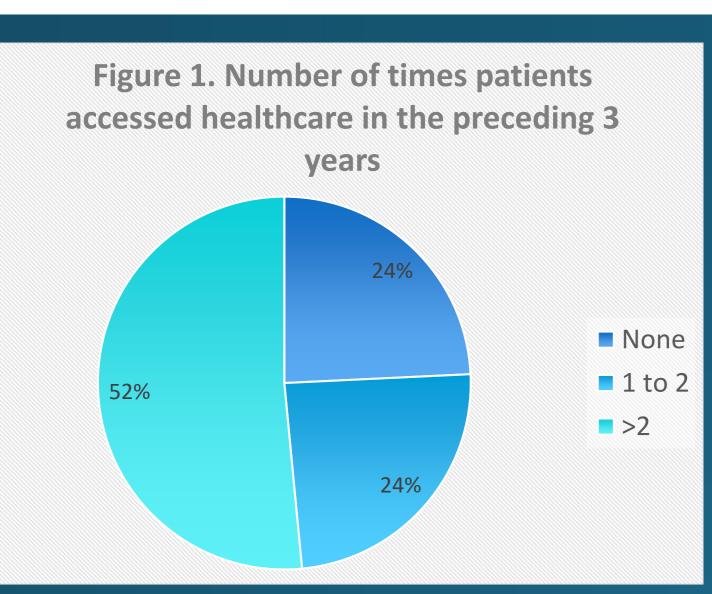
The level of harm suffered by patients presenting late was determined using the National Reporting and Learning System (NRLS) grading system.

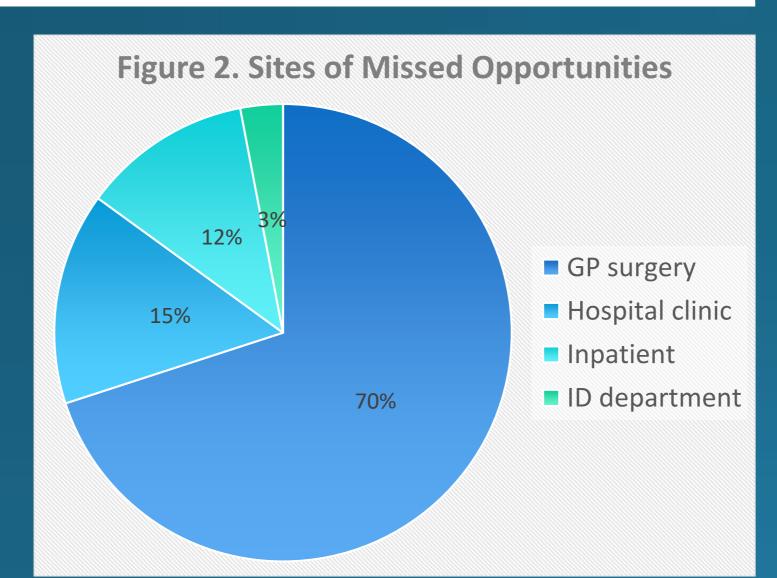
## Results

45 patients across 3 centres were included and general demographics recorded. The patients included had a mean age of 45 years, 76% male, 80% white and 33% MSM.

- 16 (36%) had never previously had a HIV test
- 34 (79%) accessed healthcare in the past 3 years, 23 (58%) more than twice (see figure 1)
- 37 (82%) presented to healthcare with an indicator condition
- 16 (36%) presented with AIDS

31 (69%) patients had one or more MOs and **54 MOs** were recorded in total. The median time between MO to presentation was 21 months (IQR 5-47 months). As demonstrated in **figure 2** MOs were most prevalent in GP surgeries with 28 (70%) of them occurring there, however missed opportunities were found to occur across the board, including one within an infectious diseases department. **75% of patients who presented with AIDS, and 62% of patients with a non-AIDS presentation, had one or more MO.** 





#### Results

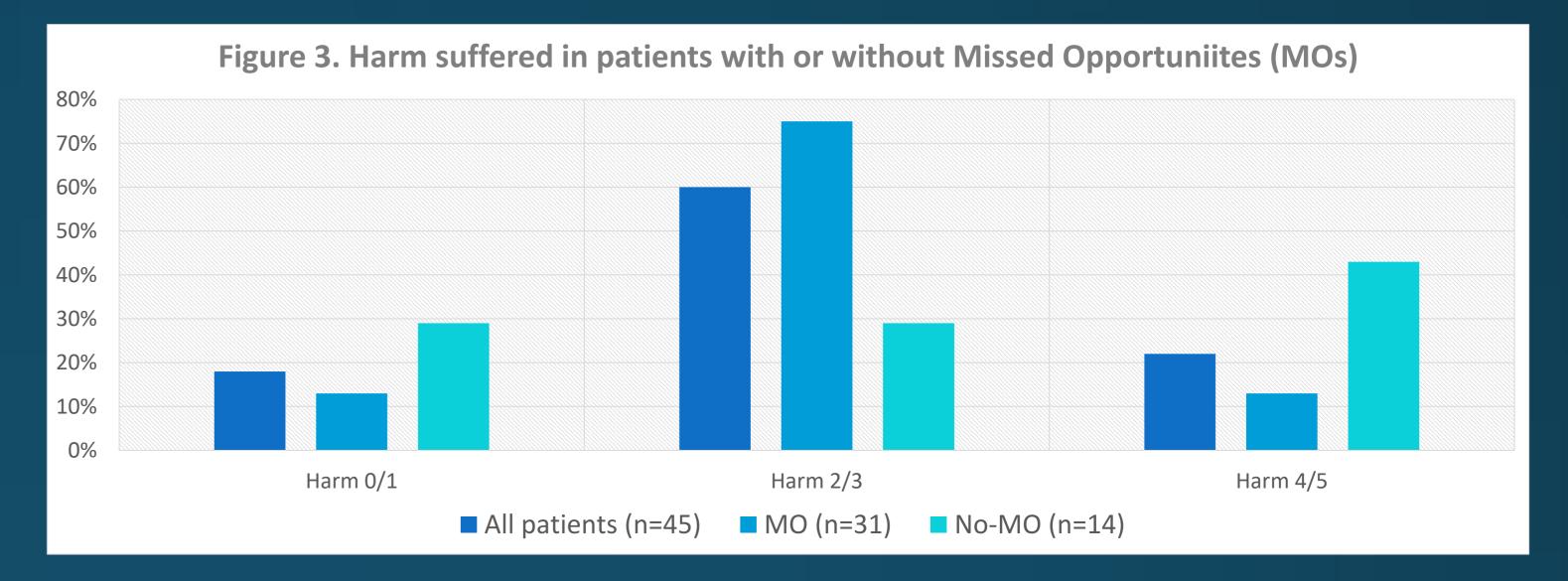
As demonstrated in **figure 3**, 37 patients (82%) suffered moderate or severe harm (NRLS Grade 2-5) due to late diagnosis of HIV. **Of those identified to have MOs 27 (87%) suffered moderate/severe harm** compared to 10 (71%) without MOs, but this difference was not significant.

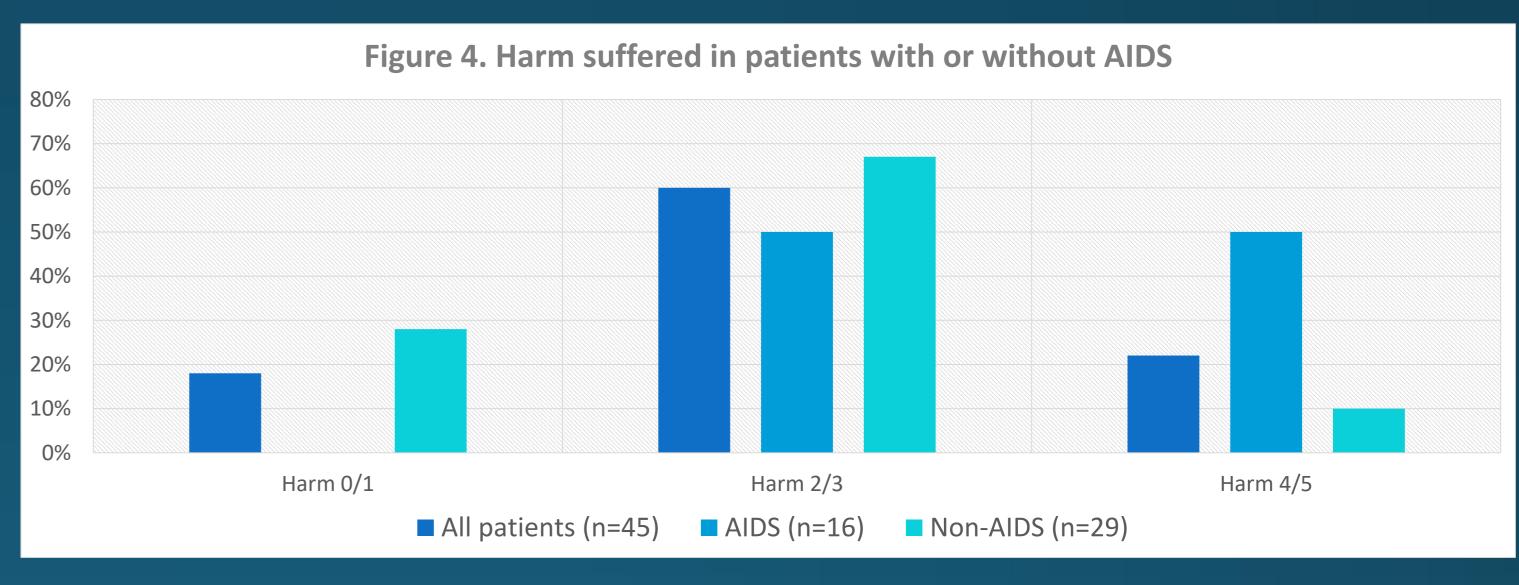
Of the 16 (36%) of patients who presented with AIDS, all 100% suffered moderate/severe harm which was significantly more (p<0.001) than the 72% of non-AIDS presenters suffering moderate/severe harm (**figure 4**).

Of the 45 patients 27 (60%) suffered moderate harm with 85% of these cases having MOs identified, suggesting harm could have been prevented.

10 (22%) suffered severe harm including 3 patients who died. Cause of death for the 3 individuals was recorded as Burkitt's lymphoma, Pneumocystis Jirovecii Pneumonia and pneumonia. Of these deaths 2/3 had MOs identified. Of the other 7 patients who suffered severe harm 2 had MOs identified. This demonstrates that of the 22% of patients who suffered severe harm 40% had MOs and therefore could have been preventable.

Overall, 27 (87%) of patients with an identified MO suffered moderate or severe harm due to the late HIV diagnosis, including 13 (76%) patients presenting with AIDS and 2 (67%) patients that died.





# Conclusions

This study indicates that MOs for HIV testing can be identified in a high proportion of patients with late HIV diagnoses, through using a comprehensive review of hospital records, primary care prescriptions and pathology tests.

The majority of these late HIV presenters suffered moderate/severe harm; this harm was probably preventable in most patients with identified MOs for testing.

The review mechanism used here could be used to aid the systematic review of late HIV diagnoses and identify interventions to reduce MOs for testing.

## References

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- B. British HIV Association. Standards of care for people living with HIV. London: Mediscript Ltd; November 2012.