Re-engaging and identifying reasons for HIV patients lost to follow-up

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Background

- A significant number of HIV patients become lost to follow-up (LFU). HIV patients lost to follow-up (PLFU) are at increased risk of morbidity, mortality and onward transmission.
- The human impact, resource and economic implications of PLFU are unknown.
- 5% of HIV positive patients are LFU annually (from 2000-2007).[1]
- There are currently no national protocols for re-engaging patients.
- *"Factors associated with loss to follow-up include being female, younger age (<35 years), black African, not receiving antiretroviral therapy, recently diagnosed, and infected outside the UK. Further studies are needed to understand the reasons why some patients are not retained in HIV care."* [1]
- *"Future studies should focus on understanding patients' perspectives on discontinuing care, examine clinic/health factors influencing the risk of being LTFU, and develop interventions to prevent LTFU."* [2]
- We aimed to identify and contact our PLFU, to re-engage them with care, document reasons for LFU and their outcomes, from the HIV department at the North Middlesex University Hospital.

Methods

- PLFU, defined as non attendance for more than one year, (excluding patients that subsequently re-attended) were identified from our electronic patients record, CLIMATE™ database from 1995 to November 2011.
- Patient demographics and clinical characteristics were collated.
- PLFU were contacted according to the department protocol: contacting patients by all means permissible - telephone contact, letters, GP contact (telephone contact and letters). Where contact was possible but not achieved by telephone, patients were re-contacted 2 weeks later. Contact was made by doctor and a specialist nurse. Contact was only made by methods recorded as acceptable for patients as recorded in their records.
- Reasons for non attendance were explored and PLFU invited to attend.

Objectives

- To identify patients who were truly LFU
- To re-engage patients LFU, back into HIV services
- To identify patients reasons for being LFU
- To identify trends in patients LFU
- To identify ways to prevent LFU

Results

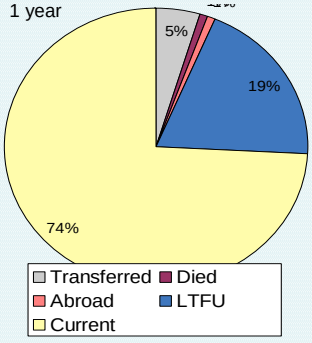
Patient demographics

- 1088 patients were registered from 1995 to November 2011.
- 26% (280/1088) had not attended for more than one year: 0.8% (9/1088) died, 0.9% (10/1088) left the UK, 4.7% (52/1088) transferred care and 19% (209/1088) were defined as LFU (see illustration 1).
- Patient characteristics reflected our cohort demographics (see table 1).

Table 1: Patient Characteristics

Parameter	Result
Gender - female	53.8%
Median age in years (range)	42% (30-86)
Ethnicity — Black African	80%
Black other	9%
White	9%
Asian	1.5%
Other/Unknown	0.5%
On HAART	35%
Last attendance	40% in 2010
Last CD4 count (cells/mm^3)	mean 455 (30-1040)
Last viral load (copies/ml)	mean 40,694 (20-70,4517)
Minimum CD4 count (cells/mm^3)	mean 327 (5-920)
Highest viral load (copies/ml)	mean 70,087 (50-70,4517)

Illustration 1: Outcome of patients with no attendance for 1 year



Patient contact: Telephone, letters, GP

1) Telephone contact: Of 6% PFLU (15/209) who were successfully contacted, ten made an appointment. 30% of PLFU had potential contact (voicemail or phone unanswered). 31% gave permission for telephone contact, 16% did not and 53% did not have permission documented.

2) Letters: 21% (43/209) had given permission to send letters: one patient made an appointment, and two letters were returned. 4% did not, 2% did not have an address registered and 73% did not have permission documented.

Illustration 2: Outcome of telephone contact

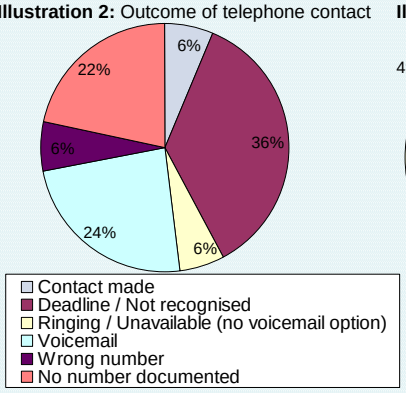
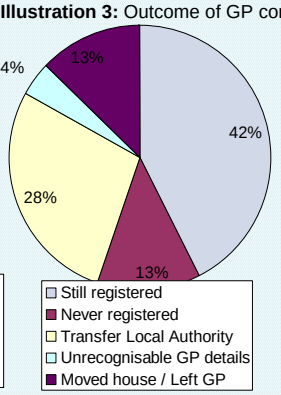


Illustration 3: Outcome of GP contact



3) GP contact: 23% (47/209) had given permission to contact their GP: Of these 43% were still registered, 41% had transferred care, 13% had never registered at the practice given and 4% gave details of non-existent practices. 5% did not give permission to contact their GP, 38% were not registered with a GP and 34% did not have permission documented. 4% (2/47) GPs required written permission for information about patients. 10% (2/20) GPs stated they would contact patient of those still registered (verbal). No appointments were made as a result of these efforts.

Outcomes of patients lost to follow-up

- Patients deemed LFU: 19% (209/1088) of our total patient cohort are lost to follow-up. This included patients were there was no permission to contact (via telephone, letter or GP), no contact details registered and no response to contact if permission was ascertained.

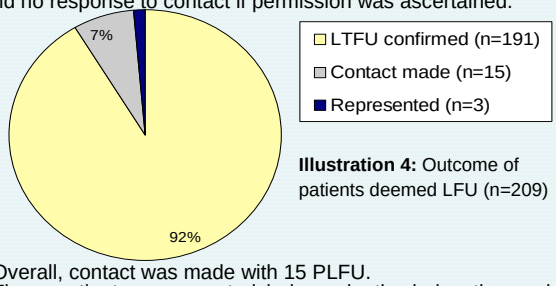


Illustration 4: Outcome of patients deemed LFU (n=209)

- Overall, contact was made with 15 PLFU.
- Three patients re-presented independently during the evaluation period, all with serious medical complications of HIV:
- 1) Toxoplasmosis
- 2) Klebsiella sepsis
- 3) Possible stroke.
- Five patients successfully re-engaged.
- Of the remaining ten patients: two openly said they did not want to re-engage in services because they were too busy, the other eight either asked to be contacted again or stated they would make an appointment when ready.
- Reasons for non-attendance are summarised in table 2.
- It was not possible to ascertain reasons for the remaining patients.

Table 2: Reasons identified for LFU

Studying
Imprisoned abroad
Family problems
Busy
Using prayers
Denial
Too far to clinic
Pill burden
Forgetfulness
Angry with non-HIV department

Conclusions

- 17% (191/1088) of our total HIV cohort remain LFU. Five patients re-engaged in services, and just under half remain potentially traceable. Confidentiality and ethical issues are a barrier to contacting these patients and each case must be assessed individually. Work to trace our PLFU continues.
- We are using this data to improve our LFU procedures, including regular review of our database to pick up PLFU as early as possible. We are also working to ensure permission for all means of contact is documented for all patients.
- Re-engaging PLFU back into HIV services is an increasingly important priority, as treatment and long term prognosis has improved, to reduce morbidity and mortality, onward transmission. Barriers to retention in care, including stigma, disclosure, psychological and religious issues need to be addressed. PLFU represent potential lost revenue for HIV services and the economic implications at a national and local level should also be explored further.
- HIV has unique ethical implications regarding confidentiality and potential disclosure to GPs when permission has not been clearly given by PLFU. National guidelines would be of value in helping to guide this process.

References:
1. Health Protection Agency. HIV in the United Kingdom: 2011 Report. London: Health Protection Services, Colindale. November 2011. 2. Fleishman JA. *Establishment, retention, and loss to follow-up in outpatient HIV care.* J Acquir Immune Defic Syndr, online edition. DOI: 10.1097/QAI.0b013e318258c696, 2012