

Lost to follow up among an Edinburgh cohort of patients in HIV care



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Background; Long term follow up for HIV patients is key for good management of the condition. Many patients fail to attend for specialist follow up to the detriment of their health. We sought to find patients who were Lost to Follow Up (LFU) in Edinburgh, identify their current status and invite them back to the clinic.

Methods; We identified patients who had been followed up at the Regional Infectious Disease Unit but who had not attended in the previous 9 months (from 1989 to 2011). HPS/HPA were contact to ascertain if the patients had a recent viral load/CD4 count and where: Edinburgh or not in Edinburgh; we did not have the exact location from HPS/HPA. We used the knowledge of RIDU staff to assign locations to patients. GPs were contact to find if patients were still registered with the practice or not. If not, we sent their details to health records for tracing. We calculated the time spent in the clinic (from date of first visit to the date of the last) and used their last known address to assign a postcode deprivation score. For those identified as having not sought care out-with Edinburgh, we contacted their GPs/health records enquiring if they were still registered with the practice or had moved on. We used the personal knowledge of staff in the RIDU to identify the status of those remaining. We then sent out letters to patients/GPs inviting them back to the clinic.

Fig 2 - Results of Contact with Patients/GPs

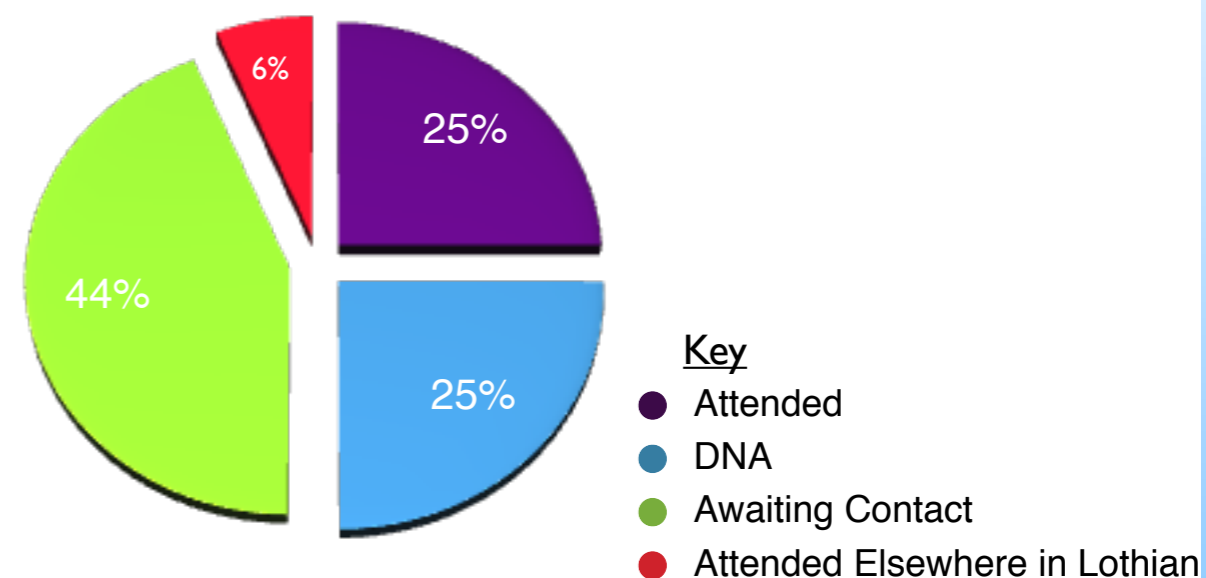
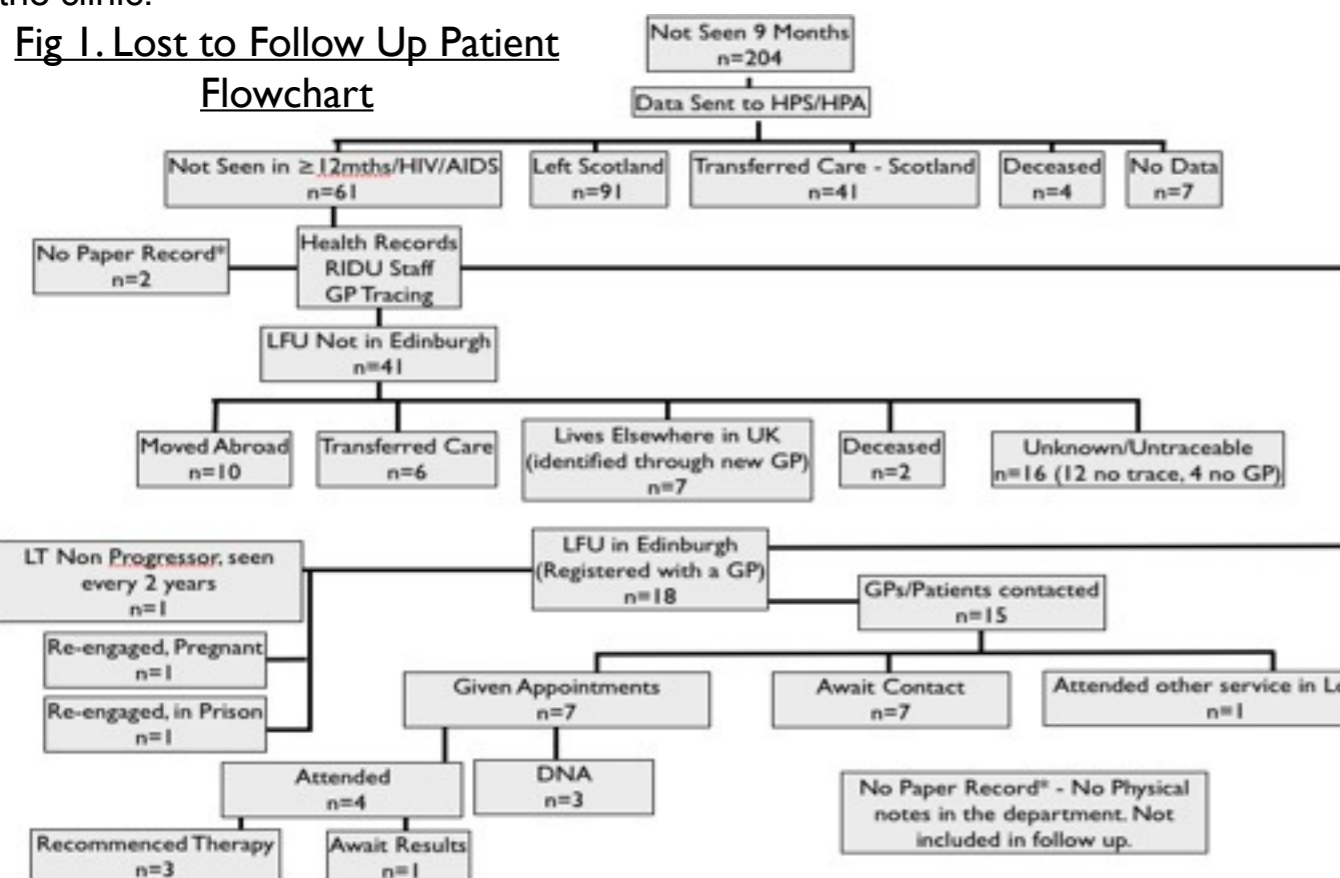


Fig 1. Lost to Follow Up Patient

Flowchart



Results; 204 (19%) patients being followed up were identified as being LFU. Of these; 6 (3%) had died, 155 (76%) had moved elsewhere, 25 (12%) could not be traced and 18 (8%) were still in Edinburgh. Of these, 1/18 re-engaged when she became pregnant, 1/18 reengaged automatically through the prison service, 1/18 was a LT non progressor and attends every 2 years and 15/18 had letters sent to their GP. Of these, 8 were written to personally. We await contact from 7/15. 1/15 attends another HIV service in Edinburgh. 7/15 were given appointments. Of these 4 attended and restarted therapy, we await the results of 1. 3 DNAs were sent further appointments. Mean FU time was longer for the LFU vs. whole group (1832 days vs.1408 days). Mean deprivation quintile was 9.78 suggesting these patients did not live in overly deprived areas [median score -10].

Conclusion; The results show, reassuringly, most patients deemed LFU were receiving care elsewhere. The study shows the assistance national databases can offer in assessing and tackling LFU. Updating records with national databases should be done yearly. Unfortunately a significant number of patients could not be traced and this remains a problem. Further research is needed to identify the best strategies to retain patients in clinical care.