

HIV pilot – Establishing lost to follow up services to re-engage people in care

The REACH Study, which focused on a large London cohort found that:

- Over half did not always have money for basic needs and 20% reported moderate or severe hunger.
- 2 in 5 people reported self stigma
- 1 in 3 people (32%) had depression

Disengagement in care results in high morbidity, premature mortality, the development of complications that drive avoidable hospital admissions and increases the risk of onward transmission. **The majority of HIV transmissions (42.2%) arise from people aware of their HIV status and not on effective treatment.**

All Trust HIV services have some form of LTFU monitoring but this ranges from dedicated CNS to automated computer messages and discussions between clinicians.

The LTFU service across GSTT and KCH re-engaged 11.4% of their total LTFU population (705) in 14 months, and 51% of those people are now virologically suppressed.

8. Many people living with HIV are vulnerable people with psycho-social needs. They are individuals who are disenfranchised with difficult lives, competing needs and high levels of stigma.



10. Re-engagement of people living with HIV who know their status but are not currently on treatment is essential to reaching zero transmissions by 2030.



12. The cost to find or re-engage one person with HIV is less than £10,000, whilst each person living with HIV newly linked to care could avoid NHS costs of over £200,000 whilst reducing the risk of onward transmission.



Engagement in care



9. Some people disengage with their care, stop their treatment and become lost to follow up (LTFU). One study (REACH) found 28.1% of people who entered HIV care were lost to care within 10 years. This disproportionality affects more marginalised and stigmatised populations.

Factors associated with non-attendance include younger age, longer duration of HIV infection, having children, not being registered with a GP, not being a homeowner and drug/alcohol dependency.

11. Re-engagement involves information gathering at a patient level and cross working with GPs, other hospitals and specialties and pan-sector working. The service also focuses on removing barriers to attendance.



13. Lost to follow up services have been sponsored at LGT, KCH and GSTT by the Elton John Aids Foundation (EJAF), however this funding ended in December 2021. This pilot aims to provide sustainable funding for this important service.

Feedback from people lost to follow up:

- "I got busy and forgot my own health. I have a child with autism who isn't communicating and had lots going on at home".
- "I have emotional issues and low self-worth. I mentally withdrew from getting HIV treatment because I believed I wasn't deserving of treatment"
- "I know I haven't been for a long time and I'm worried for myself and scared and shamed to come to hospitals to see doctors. Yes, I'd be grateful if you could arrange an appointment for me to see you".
- "I stopped coming after my doctor moved from STH to Guy's. Also, my ex-partner was very negative about HIV and taking medication. I have been thinking about coming back to clinic and needed to find the courage".