People living with HIV not in care: time to act!

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People living with HIV who are not in care: Time to Act

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Conflict of Interest

Educational speaker for Gilead Sciences

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HIV in the UK: A success story

- **PLWH**: 100% (101,600)
- **Diagnosed**: 92%
- **On ART**: 98%
- **Suppressed**: 97%

Moving backwards through the treatment cascade

Jose et al 2018 Lancet ID A continuum of HIV care describing mortality and loss to follow-up - a longitudinal cohort study
What I will cover

• What are the consequences of patients not in care?
• What is the size of the problem?
• What are the contributing factors?
• What are the possible solutions?
• What are the actions required?
Terminology

• Lost to follow up vs. Not in care vs. Need to Find

• Laura Waters twitter poll 361 respondents –
  • Not in follow up 13.9%
  • Disengaged from care 20.5%
  • Not engaged in care 47.6%
  • Something else 18%

• Poll at LTFU day – ‘PLWH not in care’

• Need to agree on terminology and definition.
Human cost of not being in care: Cases known to us personally

• 36 year old woman, out of care from 2017 presented with confusion, has PML, 2.5 month hospital admission, discharged to a nursing home, wheelchair bound, PEG fed, not able to verbalise, 9 year old son now being raised by a family member

• 45 yr old man, out of care for several years, presented with headache, CD4 8, cryptococcal meningitis, Went blind despite appropriate treatment, died following a 3 month hospital admission

• 39 yr old woman, out of care from 2004, attended another ED with headache 11/2/20 did not mention HIV, attended Kings ED 13/2/20, died within 12 hours, cryptococcosis.
NHS: Amongst PLWH hospitalised with HIV related illnesses at KCH and GSST, the proportion of those not in care is higher than the proportion of new diagnoses.
At GSST in one year, admissions for OOC patients with HIV infection cost £408,135.

At UHL in one year, maximum cost of a single inpatient stay was £114,000.

**COST OF HOSPITAL ADMISSION FOR PATIENTS NOT ENGAGED IN HIV CARE**
1.8.2018 - 31.8.2019 (n=41)

The total cost for hospital admissions accumulated by PLHIV disengaged from care was £408,135.
‘Lost to Follow up’ (LTFU) work in Lambeth, Southwark and Lewisham (LSL)

• On behalf of Dr Hannah Alexander, Dr Goli Haidari GSTT and Dr Mel Rosenvinge UHL. This project was conducted at Guys, King’s and Lewisham and ran from July 2020-Dec 2021.

• Targeted at people living with HIV who are not in care.

• This project was funded by the Elton John AIDS Foundation (EJAF) and aimed to reengage patients in care.
824 patients were potentially LTFU across 3 sites

2275 patients identified across the three hospitals (total patient cohort = 7092)

UKHSA identified 521 in care leaving 1754

Attempts made to contact all patients identifying 930 in care/abroad/RIP

This leaves 824 patients who are potentially LTFU from these trusts

153/824 patients have been successfully re-engaged (18.5%)
**LTFU Outcome demographics**

<table>
<thead>
<tr>
<th>Category</th>
<th>Re-engaged</th>
<th>CD4 &lt; 200</th>
<th>CD4 &lt; 350</th>
<th>% CD4 &lt; 350</th>
<th>Median CD4</th>
<th>Average CD4</th>
<th>Median Age</th>
<th>Average Age</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>153</td>
<td>48</td>
<td>82</td>
<td>53.6%</td>
<td>305.00</td>
<td>386</td>
<td>46</td>
<td>46</td>
</tr>
</tbody>
</table>

**Outcomes by Gender**
- Female: 87.0% (56.9% of LTFU outcomes)
- Male: 66.0% (43.1% of LTFU outcomes)

- 57% female
- 71% Black African/Caribbean

**Outcomes by Ethnic group**
- Black African & Black Caribbean: 109.0 (71.2% of LTFU outcomes)
- White & Other: 30.0 (19.6% of LTFU outcomes)
- Other: 11.0 (7.2% of LTFU outcomes)
- Asian: 3.0 (2.0% of LTFU outcomes)

**Outcomes by Age group**
- 35-49: 76.0 (49.7% of LTFU outcomes)
- 50-64: 57.0 (37.3% of LTFU outcomes)
- 25-34: 18.0 (11.8% of LTFU outcomes)
- 15-24: 1.0 (0.7% of LTFU outcomes)
- 65 and over: 1.0 (0.7% of LTFU outcomes)

**Outcomes by CD4 range**
- <=350: 820 (53.6% of LTFU outcomes)
- 500+: 40.0 (26.1% of LTFU outcomes)
- 350-500: 31.0 (20.3% of LTFU outcomes)

**Outcomes by Exposure category**
- Heterosexual contact: 109.0 (71.2% of LTFU outcomes)
- Sex between men: 33.0 (21.6% of LTFU outcomes)
- Injecting drug use: 4.0 (2.6% of LTFU outcomes)
- Mother to child transmission: 4.0 (2.6% of LTFU outcomes)
- MSM and PWID: 2.0 (1.3% of LTFU outcomes)
- Undetermined: 1.0 (0.7% of LTFU outcomes)

**Outcomes by Borough**
- Lewisham: 42.0 (27.5% of LTFU outcomes)
- Lambeth: 33.0 (21.6% of LTFU outcomes)
- Southwark: 32.0 (20.9% of LTFU outcomes)
- Greenwich: 10.0 (6.5% of LTFU outcomes)
- Bromley: 7.0 (4.6% of LTFU outcomes)
- Outside London: 7.0 (4.6% of LTFU outcomes)
- Croydon: 6.0 (3.9% of LTFU outcomes)
- Wandsworth: 3.0 (2.0% of LTFU outcomes)
- Barking & Dagenham: 2.0 (1.3% of LTFU outcomes)
- Harrow: 2.0 (1.3% of LTFU outcomes)
- Others: 9.0 (5.9% of LTFU outcomes)
69 (45%) re-engaged patients came from the 20% most deprived areas in the UK.

In SE London, this issue disproportionately affects women of black ethnicity from areas of social deprivation.

As such it represents a significant health inequality.
How sustainable is Reengagement work? SE London EJAF project Follow up data

• 153 patients were reengaged in care between July 2020 and Dec 2021.
• (117) 76% were still in care 1 year later.
• 1 year after reengagement, 97 had an HIV viral load measured; 63/97 (65%) had a VL of <50cp/ml, 72/97 (74%) had VL <200cp/ml.
Out of care risk factors: validation of REACH study

Evidence base: the REACH study 2017

The REACH study developed an algorithm to assess which individuals are most likely to disengage.

Key features that they identified are:
- Drug + alcohol misuse
- Insufficient money for basic needs and use of public transport to get to clinic (poverty)
- Stigma
- Younger age at diagnosis
- Having children

Our findings: common themes

- Drug + alcohol misuse
- Mental Health
- Poverty
- (Sole) responsibility for children
- Housing and immigration uncertainty
- Stigma/fear of discovery
- Pill/medication fatigue
- Discouraging partners
- Never been unwell
Removing barriers to attendance

- Appointments at venues outside the traditional clinic setting and at flexible times.
- Dedicated smart phone.
- Supermarket and travel vouchers.
- Liaise with support workers – mental health/social work/drug and alcohol support
- Case management approach
- Helping patients transfer to new centres near where they live.
Ms O aged 38
Previous psychosis and psychiatric admission. No recourse to public funds, sole carer for 4 year old son with autism. Unstable housing far from clinic

Ms P aged 41
Previous IDU and on methadone. Daily excess alcohol for over 10 years. Cognitive impairment. Violence from partner who is also alcohol dependent.

Mr K aged 34
MSM, sex work, daily crystal meth use, depression.

- Housing and benefits advice
- Travel vouchers
- Drug and alcohol services
- Peer mentoring
- Food vouchers
- Pragmatic approach
- Mental health support
- Close liaison and communication with key workers
Is this just a SE London problem? How big is the problem?


- Dr Veronique Martin UKHSA data 2022
- The annual cascade of care is a snapshot
- The 2021 data shows patients who attended in 2020 but not 2021 – this group are ‘out of care’.
- But what about patients who defaulted from care in 2016 for example?
- Numbers of patients out of care have been underestimated

Source: UKHSA HARS dataset – 19 Oct 2022
People not retained in HIV care (not seen for 15 months): England, 2021

- Patients seen in 2019 and not in 2020: 4,440
- Patients last seen in 2015 - 2019 and not since: 22,670

Source: UKHSA HARS dataset – 19 Oct 2022
10 years after entering care (2000-2004), 19% of patients living with HIV in the UK are lost to clinical care.

Jose et al 2018, Lancet ID ‘A continuum of HIV care describing mortality and loss to follow-up - a longitudinal cohort study’
Increased reengagement of out-of-care HIV patients using Lost & Found, a clinic-based intervention
AIDS 2022 Linthwaite et al

• ‘Lost & Found’ a clinic-based intervention McGill Chronic viral clinic
• It consists of two core elements: identification and documentation of OOC patients; and systematic contact of OOC patients.
• Over half (56%; 1312 of 2354) of patients were identified as possibly OOC.
• Among these, 44% were followed elsewhere, 19% were still engaged in care, 3% deceased, and 32% OOC.
• Of OOC patients contacted (85%; 359/423), 250 (70%) reengaged.
• Pre-post results indicate people who received Lost & Found were 1.18 (95% CI 1.02–1.36) times more likely to reengage.
Unpacking Linkage and Reengagement in Care: A day in the life of a Positive Charge Care Coordinator 2015

- AIDS United, with support from BMS, launched Positive Charge (PC). Faculty at Johns Hopkins Bloomberg School of Public Health conducted a national evaluation of PC.

- Implemented in five locations across the United States, each of the five PC programs was designed locally.

- Each PC program employed the intervention strategies most appropriate given the location, identified needs, target population, and local context.

![FIGURE 1. Framework for Engagement in HIV Care](image)
Themes for key elements of reengagement work

- Rapport
- Relationships – between organisations
- Persistence
- Case management
- Address and prioritise the patients’ needs
- Individualised approach
UKHSA need help from clinics! To identify who is truly out of care and who is not

- UKHSA send every clinic their HIV dashboard every year.
- New from 2022 they sent us all a list of patients last seen at our clinics but not seen for > 1 year
- They have done the cross referencing so patients on this list have not been seen at another UK clinics
Patient follow up sheet – please locate and complete!
What further action is required?
Practical Actions

<table>
<thead>
<tr>
<th>Contributing factors</th>
<th>Possible solutions?</th>
</tr>
</thead>
<tbody>
<tr>
<td>• For patients out of care/area, it is difficult to navigate the system</td>
<td>• Dedicated navigation phone line/website/email</td>
</tr>
<tr>
<td>• Didn’t think would get ill, not sure of need for treatment</td>
<td>• Public health campaign</td>
</tr>
<tr>
<td>• Lack of communication between GP and hospital – often due to lack of patient consent</td>
<td>• Embedded peer mentorship/more information</td>
</tr>
<tr>
<td>• ART cannot be DOTed with OST</td>
<td>• Less secrecy/more consensus re info sharing</td>
</tr>
<tr>
<td></td>
<td>• Script with methadone prescribing</td>
</tr>
</tbody>
</table>
Minimum aim

- All clinics to have a LTFU contact
- All clinics to look at the UKHSA data and revert back
  - Flexible and understanding attitude
- Better communication between clinics and community organisations

Nice to have

- Better/formal links with housing/drug and alcohol
  - Funded teams of workers who will outreach into community to find patients and help them navigate the system
- Better links between primary and secondary care

Ambitious

- Public Health campaign ‘Our door is open’
- Functional networks of clinical and third sector organisations
- Outreach into the non-HIV community to try and address stigma
Action taken so far

• ED testing!
• Funding – reengagement work has been funded by the ICS in SE London since Jan 2022
• Data – UKHSA are sending everyone a list of all pts not seen in > 1 year from their service, lack of awareness of this amongst clinicians.
• ‘LTFU’ day in SE London, attended by 100 attendees from clinics, policy makers, third sector
• HIV-AP ISG have set up a task and finish group on PLWH not in care.
• BHIVA audit is on patients admitted with HIV related illnesses and whether they are in care or not.
• Research – SHIELD study Dr Rageshri Dhairyawan
‘Not in Care’ take home messages 1

• Patients can go backwards on the cascade of care and fall out of care.
• In SE London, this is driving considerable morbidity and mortality.
• It is expensive for the NHS and society, threatens HIV elimination, achieving UNAIDS targets and may drive transmission.
• This issue disproportionately affects women of black ethnicity from areas of social deprivation. As such it represents a significant health inequality.
• Thanks to the funding from EJAF we were able to link 153 patients back into care and give them the opportunity to restore their health.
• The majority of patients who were re-engaged through the SE London EJAF sponsored project remain in care and the majority have a VL <200 at 1 year.
‘Not in Care’ key messages

• The number of PLWH not in care probably outweighs the number who are undiagnosed.
• UKHSA have given every clinic a list of patients potentially out of care
• Actions are required to make HIV care easier to access and to create more reengagement projects.
• Reengagement work is resource intensive and needs funding.
• The issue of patients not in care should be a top priority for us as an HIV care community.
What do patients say?

‘Didn't want to come to Caldecot or anywhere in hospital as is a beautician and knows lots of Kings staff, esp nurses. Doesn't care if people know about her status but doesn't want her teenage son 'tarred’.’

‘Around us, everyone thinks that HIV is a different sickness to diabetes, bloods pressure, even COVID. People in the community will push you to the side. I was running from the clinic. They were calling, calling me.’

‘He says he still feels guilty about the HIV and tries not to think about it. He doesn't like to make close friends as he doesn't want to have to lie about it.’

Has been LTFU, emotional issues and low self-worth mental withdrew form getting HIV treatment, belief not deserving of treatments
Feels very lonely, lives in room in shared house but not social, can see is viscous circle, pushes people away when really wants intimacy and emotional connection, increased anxiety, describes panic attacks at times.
Thank you for listening