People living with HIV not in care: how can the data help?

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Conflict of Interest

- I declare that I have no conflict of interest
Continuum of HIV care: England, 2021

- 95% People diagnosed
- 99% People on treatment
- 98% People virally suppressed

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

Example: 2021 not seen in care for at least 15 months since last HIV care appointment between October 2019 and September 2020

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

P088 - UKHSA engagement data: a useful tool for HIV centres to identify patients not in care

Source: UKHSA HARS dataset – 19 Oct 2022
Estimated number of people with transmissible levels of HIV: England, 2021


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Retention in care – Variability by clinics and by trust in absolute numbers and proportion

Source: UKHSA HARS dataset – 19 Oct 2022
Retention in care – Higher proportion of people not retained in care in London compared with other regions

Source: UKHSA HARS dataset – 19 Oct 2022
HIV surveillance

Patient attends HIV clinic → Consultation is recorded on local IT system → At the end of each quarter extract of all consultations is submitted to UKHSA → Data are processed, cleaned, merged with other data sources and deduplicated to identify patients seen at more than one clinic → Database generated covering:

- All new HIV diagnoses, AIDS diagnoses and deaths
- All consultations for people seen for HIV care

Surveillance, quality of care and commissioning outputs generated

Able to monitor a patient through all consultations, including change of clinic, till death
Limitations

Matching
- Limited patient identifiers
- Patients turning up to new clinic with different identifiers
- Review and improve matching algorithm
- Enhanced follow-up

Reporting issues
- Incomplete HARS returns
- Virtual consultations
- Patients leaving the country
- Send data summary reports
- Ensure reporting is complete
- Review and update HIV Dashboard

Deaths
- Not always known when a patient dies
- Reporting deaths is difficult
- Linkage to ONS deaths is not perfect
- Report known deaths to the National HIV Mortality Review
- Update in HIV Dashboard

People living with HIV not in care: how can the data help?
HIV Dashboard

- Specialised Services Quality Dashboards (SSQD)
- Designed to provide assurance on the quality of care to NHS England
- Generated by UKHSA using HARS data
- Preliminary HIV Dashboard results sent to clinics for review – feedback used to update database
Accessing the preliminary HIV Dashboard

- Email from hiv.dashboard@ukhsha.gov.uk / donotreply@ukhsha.gov.uk

1. Log into the HIV & STI Web Portal

2. Download the Dashboard file

3. Review the results

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HIV Dashboard - Patient follow-up

- All patients requiring review listed in one worksheet
- HIV Dashboard HIV09aii and HIV09bii look at all patients seen in previous year and not in current
- Patients not seen in the past 5 years also highlighted
- Clinics can provide updates to these if not reported correctly

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<th>Patient identifier</th>
<th>HIV09aii / HIV09bii - engagement in care</th>
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Impact of follow-up data from clinics to UKHSA

- CD4 at diagnosis – 261 added (116 (44%) <350)
- Viral load – 5,287 added (4,269 (80%) undetectable)
- Patients not lost to follow-up in 2021 – 721

- 63% of sites responded to Dashboard follow-up
# How we can improve data on engagement in care?

## How can clinics help UKHSA?

- Ensure HARS data is submitted on time and as accurately as possible
- Review data completeness and summary reports
- Review the preliminary Dashboard results and provide feedback
- Keep us up to date with changes to key staff

## How can UKHSA help clinics?

- Send lists of patients not seen for care in a 6 monthly basis
- Review patients lost to follow-up list
- Feedback on data quality
- Improve guidance or conduct workshops
Take home message

- Total number of people not retained in care is higher than previously reported

- Improvements in data quality will provide more accurate numbers of patients not retained in care – Please review your clinic Dashboard results