

# Supporting retention in care of individuals at risk of disengagement during the COVID-19 pandemic

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## Background

In 2020, there was an estimated 97,204 people living with HIV (PLWH) in the United Kingdom (1). Individuals not engaged in care following initial contact, are described as disengaged or lost to follow up (LTFU). Disengagement from HIV care may lead to adverse health and economic outcomes both individually and at a public health level. Individuals who disengage are at higher risk of significant morbidity, presenting to services with advanced disease, and death (2). There is also increased risk of onwards transmission of HIV from disengaged PLWH who may not be virally suppressed. The British HIV Association (BHIVA) position statement on Prevention and Management of loss to follow up in HIV outpatient services highlights the importance of actively interrogating case notes to determine which individuals have disengaged or are at risk of disengagement (defined as those seen within the last 12 months but more than 8 months ago), exploring individualised reasons for disengagement and having a structured approach to managing individuals at risk of disengagement or LTFU.

The COVID-19 pandemic led to unprecedented national changes to how healthcare was delivered from March 2020, with traditional access to HIV care challenged, and telemedicine becoming more prominent. Our HIV outpatient clinic serves a diverse population with high rates of social deprivation, located in an urban setting. We deliver care to a population in an extremely high HIV prevalence band (>5% per 1,000) (2). Our aim was to create a person-centred, reproducible, robust system for the early detection of patients who were at risk or currently disengaged, to support reengagement in care both during and post the COVID 19 pandemic.

## Methods

A case note review was conducted using Electronic Patient Record (EPR) which identified those at risk of disengagement /disengaged and associated risk factors.

Patients were contacted to identify status of engagement and offer support.

Alerts were placed on EPR for both individuals who had disengaged and those who were at risk of disengagement to ensure rapid access to care should the individual make contact with services.

A systematic 'Did Not Attend' (DNA) recall pathway was implemented, and a database created, enhancing multidisciplinary awareness of individuals at risk.

Third sector organisations, (i.e. George House Trust), drug and alcohol services and clinical psychology services were approached.

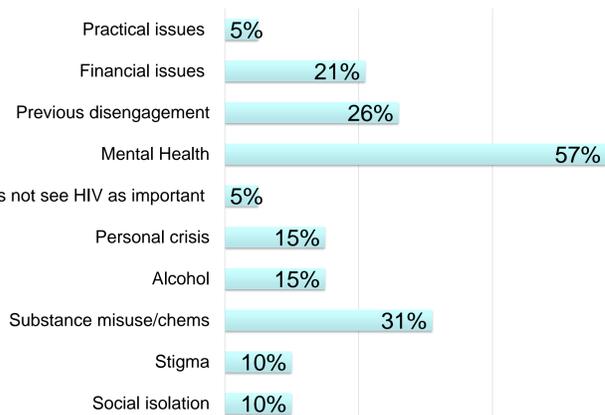
Robust referral pathways were developed to ensure prompt support was offered and delivered.

## Results

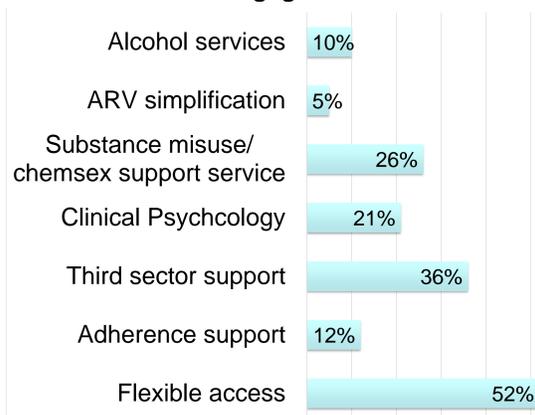
### Individuals identified as at risk of disengagement

Nineteen individuals were identified as being at risk of disengagement either due to extended periods of poor engagement (but less than 12 months) or due to concerns from clinicians given their individual circumstances. Risk factors for disengagement and intervention to support retention of individuals are detailed below.

#### Barriers to engagement with HIV care



#### Intervention used to support re-engagement



Risk factors for disengagement included: Mental health illness (11; 57%) Substance misuse (6; 31%) Alcohol misuse (3; 15%), Previous prolonged disengagement (5; 26%), Financial concerns (4; 21%), Personal Crisis (3; 16%) and Stigma (2; 10%). Interventions to support engagement included: enhanced / flexible access to care (10; 52%), Referral to substance misuse services (REACH) (5; 26%), alcohol support services (2; 10%) and referral to third sector HIV support organisations (7; 36%).

All nineteen individuals identified to be at risk of disengagement remained linked in with HIV care to date, with one individual recommencing antiretroviral medication after a prolonged treatment break.

### Individuals lost to follow up from our service

- Eleven patients were identified to be lost to follow up (LTFU) (last accessed care > 12 months previously):
- Six had re-engaged with HIV care elsewhere.
- Five individuals were untraceable despite multiple attempts to contact via telephone call/ voicemails text messages and/or letters to General Practitioner if patients had given consent for us to do so.

#### Untraceable individuals

- 60% of those untraceable were male.
- The median age was 48 years (range 33- 53 years).
- Four (80%) were of non UK nationality. One individual was an undocumented migrant who had previously spent time in prison.
- Four (80%) were taking antiretrovirals at the time of disengagement and 3 (60%) had undetectable viral loads.
- One individual had not returned for an appointment following the initial diagnosis of HIV.
- 80% last engaged with care > 2 years ago
- Identified risk factors for disengagement were previous poor adherence to antiretroviral treatment, no fixed abode, and non- UK nationality.

A clinical entry was inputted into EPR and pop up alerts on records to highlight importance of rapid clinical review if the individual made contact with the service in the future.

## Conclusions

This project highlights the importance of regularly reviewing individuals who DNA appointments, particularly for more than 8 months. These individuals may be in need of intensive support and therefore early recognition of their status is of paramount importance. The utilisation of EPR ensures a regular and robust recall system for these individuals which is accessible to the multidisciplinary team.

Similarly, this study illustrates that having a structured approach to identifying risk factors for disengagement and an awareness of locally available support services allows prompt delivery of support.

Mental ill health, drugs/chems use and previous disengagement were the commonest barriers to HIV care. All patients with these risk factors regardless of 'DNA' status should be offered meaningful support in a way that is accessible to them during outpatient appointments. It is equally important to screen for these risk factors regularly in patients who have not been previously known to have these difficulties. The Covid-19 pandemic, and social isolation during lockdown lead to an increase in alcohol/ drug misuse, and mental ill health for many individuals (3, 4), which may have led those who have previously managed their care without difficulty, becoming at risk of disengagement.

The most frequently used intervention to facilitate re-engagement was supporting enhanced access to our HIV service. In practice this meant that individuals identified at risk of disengagement who attended HIV services either late or impromptu on days where HIV clinics were not running, were accommodated wherever possible. This demonstrates that being adaptable is paramount to keeping patients engaged in their HIV care. Other frequently used measures was referral to third sector organisations, clinical psychology and drug/alcohol services which was enabled by established links with these organisations.

Our plan is to continue to review all patients on the at risk database at regular intervals and discuss their cases at a multidisciplinary team meeting. Our model for identifying patients who have disengaged /are at risk of disengagement may be reproducible for other HIV centres with individuals at risk of disengagement.

## References

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