British HIV Association: Prevention and management of loss to follow up in HIV outpatient services: good practice position statement

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It is essential to limit loss to follow up of patients with HIV infection for multiple reasons. Those who completely disengage from follow up are very likely to present eventually with advanced disease, resulting in increased risk of death, ill health and disability, and also of transmission of HIV to others, with considerable associated economic costs. This position statement sets out examples of good practice in preventing and managing loss to follow-up.

1. Characterisation of outpatient cohort

Real-time recording of patients known to have died or transferred out is critical to the process of identifying patients who are disengaging or have disengaged from care.

One approach is to identify all patients seen in the last 12 months from the clinic database, and characterise these as:

- Active (the majority), ie expected to re-attend the clinic for continuing care
- Confirmed transferred out after last visit (based on correspondence with another clinic)
- Presumed transferred out – to be investigated further and confirmation sought
- Seen for a one-off visit (i.e. accessing care elsewhere, and seen for example because they have run out of medication while on holiday)
- Or died since their last outpatient visit.

This process is then extended to patients last seen more than 12 months ago, until ideally the full cohort of all patients ever seen in the service has been characterised. This will initially generate a relatively large number of apparently lost patients, ie active but last seen more than 12 months ago. Subsequently, as more information is obtained, the numbers may fall.

The NHS England HIV quality dashboard includes indicators for the proportion of patients who re-attend during the 12-24 months after HIV diagnosis and after being seen for care. It is valuable to review these as a measure of performance in retaining patients in care, but for individual patient management procedures are needed to recognise and respond to signs of disengagement before the 24 month indicator cut-off is reached.

2. Highlighting patients who are at risk of loss to follow up

Each month the cohort can be searched to identify:

- Active patients (ie expected to re-attend, as in 1 above) seen within the last 12 months, but more than 8 months ago - this takes account of the fact that stable patients are typically seen every 6 months, while allowing some tolerance around this figure.
- Active patients not seen for over 12 months - these are more likely to have truly disengaged from services.

3. Contacting patients who have not been seen for over 8 months

The notes of both groups of patients identified by the monthly search are reviewed to identify and correctly re-characterise any who are known to have died, or transferred out. The NHS Personal Demographics Service can be used to check for possible changes of address.

Those remaining at risk of loss to follow up are then contacted to offer an appointment. This may be by phone, but text, email, post, contact via community HIV services, GP or other medical departments involved in their care may also be used, depending on the patient's wishes, the availability of up to date records, and previous experience of attempts to contact the patient. Ideally this contact should be personal, from a named individual that the patient knows and/or has a rapport with, and not in the form of a proforma/photocopied or standard letter. Peer support, community or social workers may be particularly effective in contacting individuals at risk of disengagement from care. It is acceptable for clinic staff to pass patient details to a peer support worker who has an honorary contract and can thus be considered part of the clinical team.

4. Patients who Do Not Attend an outpatient appointment

All patients who DNA are contacted, within 48 hours and preferably on the day of their missed appointment, by phone or by other methods as outlined in section 3 above. All such individuals are given another appointment, in order to close the feedback loop of follow up (not making an appointment results in an open feedback loop and increases the likelihood of the patient's follow up being overlooked). It is understood that this process may lead to an apparent increase in the proportion of patients who DNA. If initial attempts at contact fail, a letter is sent to the patient and his/her GP (where permission given) within a week, to inform them that the clinic has not been successful in reaching them and that they need to book an appointment immediately. Patients who have not attended within 4 weeks of their original appointment can be reviewed at the next regular multidisciplinary team meeting, with a view to identifying physical or mental health, adherence, social support or similar issues and how these can be addressed.

Patients who cancel an appointment should normally have another appointment made at the same time in order to avoid loss to follow up.

Training administrative staff in simple motivational interviewing may in encouraging patients to attend, and identifying individuals at greater risk of disengagement.

5. Re-engagement of patients who have previously disengaged from follow up

There are many potential reasons for disengagement in care, including

- Practical issues such as childcare or work patterns, inconvenient clinic opening times, difficulty contacting the clinic

- Lack of relationships with HIV healthcare professionals
- HIV not perceived as important
- Personal crisis
- Psychosocial issues
- Stigma
- Alcohol and substance misuse
- Finance and not able to afford to come to hospital
- Personal health beliefs.

At the time of re-engagement, it is essential to try and understand the reasons that led to the individual's disengagement, and where possible to address these. This might mean treatment of mental illness, referral to other agencies for help with drug and alcohol issues, rescheduling appointment times to fit in with travel and childcare etc.

GPs sometimes continue to manage patients who have declined treatment and disengaged from specialist HIV services, hence close liaison with primary care is of value. There may be a role for some sort of link worker. Where a GP is willing, shared care can be offered to patients so they do not have to attend hospital clinics.

6. Partially engaged patients

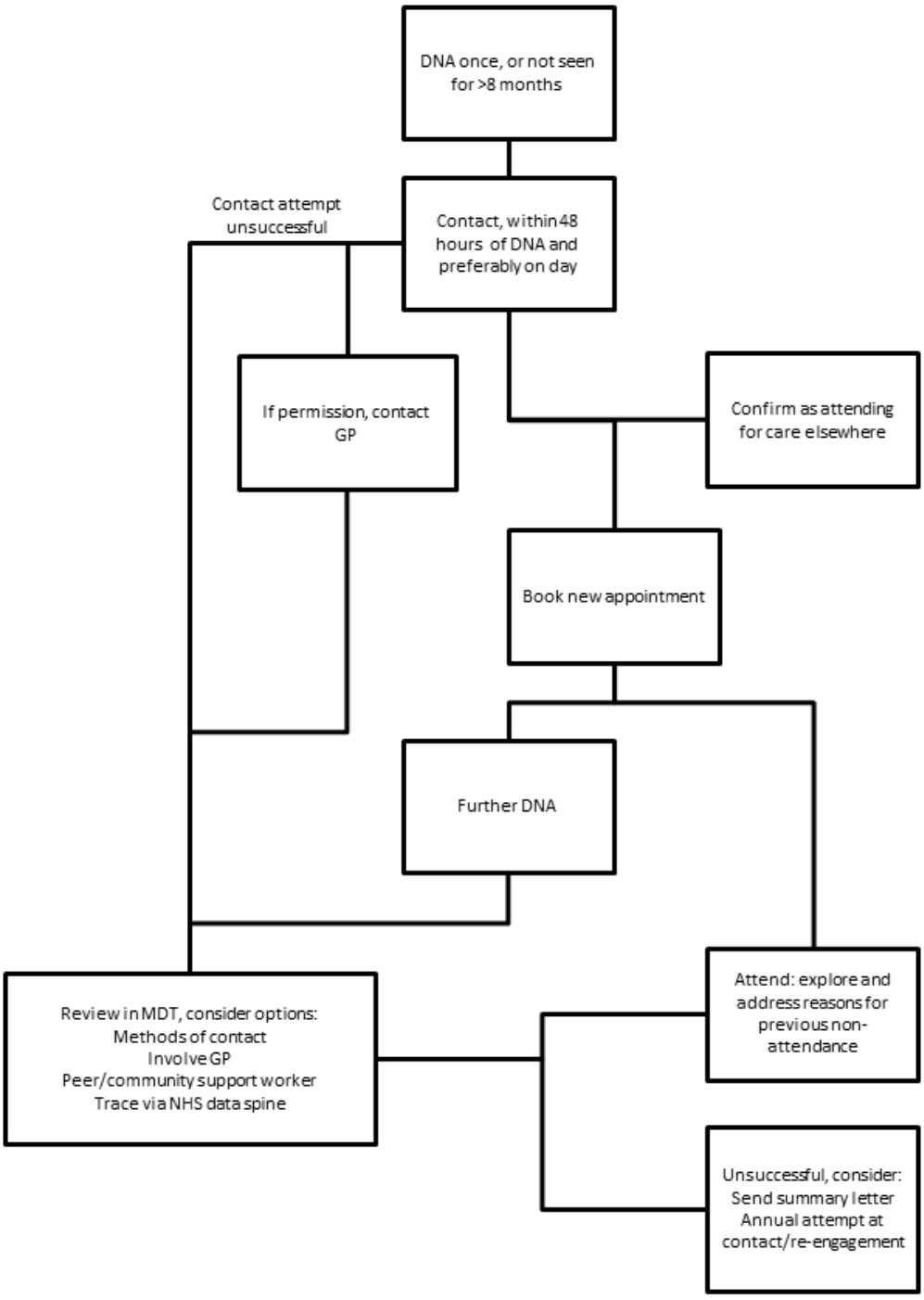
Many patients drift in and out of engagement with services for a variety of reasons. The principles of management for this group are similar to those who disengage a single time, but aims may include development of a strong therapeutic relationship with one or more long-term members of staff (from whichever discipline). Alternative or unconventional means of follow up (e.g. by phone or email, or by contact with community services) may be successful where conventional appointments in the outpatient clinic are not.

7. Failure to re-engage patients

Despite all this, some patients will remain disengaged. In some, this is an active choice. Those in this category who have capacity are likely to be very hard to re-engage. Some clinics advocate sending a summary of care letter to such patients, including blood results, treatment history etc., which will be potentially useful if the patient decides to re-present elsewhere. Periodic (e.g. annual) attempts can be made to contact such patients (by phone) if they have not indicated that they don't want to be phoned.

If permitted, contacting the patient's GP may help to re-establish HIV follow up, and may also help to ensure that opportunistic infections and other problems associated with untreated HIV infection are managed promptly.

Patients with an NHS number may sometimes be tracked if they have used NHS services elsewhere or registered with a GP, and this may be a way of establishing that they have moved out of area, and also of attempting to re-engage them in follow up.



Flow-chart: managing DNA and re-engaging patients

Strategies for keeping people engaged and retained in care

- Proactive approach to managing non-attendance in real time
- Systems in place to manage cancelled appointments
- Check and verify contact details at each visit including address, telephone number, e-mail address and GP
- Check and verify consent to be contacted by various means at each visit, including contact via GP or community/peer support services
- Identify DNA pathway for all clinic services including new patients, people starting therapy, blood appointments and virtual clinics
- Mechanisms in place to monitor when ARV prescriptions are due for renewal
- Develop a consistent approach to managing individuals and building relationships with clinic staff
- Identify individuals within the caseload who have a history of poor attendance or are at risk of non-attendance
- Offer a drop-in service or open access for those with a history of poor attendance
- Work with individual patients to identify reasons for non-attendance and agree a plan of care
- Assess support needs in relation to repeated non-attendance and refer for counselling, psychology and community support where required
- Involve GP, community nurses or key workers in contacting people at risk of lost to follow-up
- Individualise letters to patients who have not attended and include a named person for them to contact as opposed to standard letters
- Enable easy access by telephone to clinical staff,

Strategies for managing non-attendance (DNAs)

1. Dialogue with patients to understand and address reasons for non-attendance
2. Maintain a closed loop approach to managing non-attendance by arranging another appointment for the patient
3. Offer a telephone consultation for patients who do not attend routine clinic appointments and rearrange another appointment by phone, text or letter
4. Where patients consistently do not attend appointments, follow the strategies for lost to follow-up after two episodes of non-attendance
5. Identify follow-up plans at the end of each appointment, particularly for patients who are monitored less frequently
6. Systems in place to enable patients to make their next follow-up appointment on the day they attend the clinic
7. Individualise appointments for patients who have difficulty attending, eg early morning appointments or identify specific days that are more suitable.
8. Consider outreach services for those who don't like coming to the clinic
9. There is evidence to suggest that displaying DNA figures in public waiting areas does not improve DNA rates and is more likely to encourage non-attendance (Martin et al)

Strategies for managing lost to follow-up

1. Ensure data systems in place to identify lost to follow-up at 8 and 12 months
2. Focus on addressing non-attendance in real time
3. Target lost to follow-up at 8 months to prevent them becoming lost to follow at 12 months
4. Check against RIP lists and transfer records
5. Include GP in correspondence about non-attendance where permission has been given
6. When unable to contact patients, check contact details with GP (anonymously if required)
7. Use all forms of contact that patient has consented to
8. Utilise community services to assist in contacting the patient
9. If unable to contact patient through above mechanisms, send a recorded letter on hospital headed notepaper
10. Utilise Personal Demographics Service if no response to identify if patient has moved away from the area
11. When patient returns to care undertake a thorough physical and psychological assessment.

8. Further reading

Chi BH, Yiannoutsos CT, Westfall AO et al. Universal definition of loss to follow up in HIV treatment programs: a statistical analysis of 111 facilities in Africa, Asia and Latin America. *PLOS Medicine* 2011 DOI: 10.1371/journal.pmed.1001111

Martin SJ, Bassi S, Dunbar-Rees R. Commitments, norms and custard creams – a social influence approach to reducing did not attends (DNAs). J R Soc Med 2012: 105: 101-4. DOI 10.1258/jrsm.2011.110250

Annex: Sample letter for patients who do not attend, if immediate attempt at phone contact has not succeeded

TRUST/NHS LOGO

Dr Jane Smith
Dr David Jones
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Clinic name and address

Clinic phone numbers
Clinic website address

Our ref: JS/HM000.00

Date: 26/05/2016

Private & Confidential
Joe Bloggs
7 Elmer Cottages
Lower Nutscombe
PZ7 3GT

Dear Joe

I'm sorry you were not able to make your doctor's appointment with me today. I hope everything's okay with you. I have arranged another appointment for you to see me on 9th June at 3.20. We can do any blood tests on that day if that's easier for you.

Please let us know if you need any further medication before that date or if you have any problems attending that appointment on 9th June, otherwise we look forward to seeing you then.

Yours sincerely

Electronically checked and signed

Jane Smith
Consultant in HIV/GU Medicine