

4c. Supporting people with higher levels of need

The management of HIV in the era of multiple, highly effective, generally safe and well-tolerated treatment choices can seem quite straightforward. There is however, widespread recognition – as illustrated in these Standards – that a number of factors can act as barriers to successful engagement in care, adherence to treatment and enjoyment of good quality of life. People living with HIV experience high levels of stigma and discrimination because of their diagnosis [ref] but the people affected by HIV are also more likely to be members of communities which are already subject to discrimination and social disadvantage [refs].

There is evidence that people living with HIV are more likely than the general population to have multiple long-term conditions, to have poorer mental health, poorer sexual health and to have problems with alcohol and substance use [ref]. These issues can lead to an individual having a collection of diagnoses which might be seen as a marker of complexity or increased need. This approach does not account for individual variation in the ability to manage these problems and the impact on health overall. The person's individual resources, ability to cope, social connection and support, and the wider socio-cultural context are likely to play a major role in determining the effect of a given health problem.

There is no single, validated framework or tool to identify individuals for whom adhering to HIV treatment and engaging in care requires significant levels of support. While there is considerable awareness of complexity in HIV medicine, at the time of writing there is no validated means for identifying individuals which might allow “risk stratification”, though some work has been done in identifying those more at risk of lower levels of engagement in care (REACH). However, NICE has produced guidance (NG56, Sep 2016) which makes recommendations on tailoring care for people with multi-morbidity, particularly if any of the following apply:

- They find it difficult to manage their treatments or day-to-day activities
- They receive care and support from multiple services and need additional services
- They have both long-term physical and mental health conditions
- They have frailty or falls
- They frequently seek unplanned or emergency care
- They are prescribed multiple regular medications

There is also a paucity of evidence on effective interventions to tackle engagement issues. We recommend that a biopsychosocial approach is used to underpin person-centred care for all people living with HIV. The objective of this approach would be to identify and address factors which are likely to create additional need or vulnerability. It is recognised of course that some factors, such as poverty, are difficult for service providers to influence. Nevertheless, the formulation with the person concerned of what might be called a “personalised care plan” or an “individualised management plan” would allow identification of need, understanding of priorities for that individual and targeting of resources. Ideally such an approach would be shared with all the agencies and services involved with the person with one agency responsible for the co-ordination of care. This whole person approach to care will require contribution from a number of different agencies and

providers across the health and social care spectrum and the third sector, as illustrated in these Standards.

The role of intimate partner violence

Globally, it is estimated that 1 in 4 women experiences violence from an intimate partner in her lifetime (IPV), making this the commonest form of violence against women [USAID Interagency Gender Working Group, 2006; Heise et al. *Soc Sci Med.* 1994;39:1165]. The Crime Survey for England and Wales (CSEW), 2015, estimated that 8.2% of women reported experiencing any type of domestic abuse in the previous year. Dhairyawan et al. (*HIV Med.* 2013;14:303-10) found that over 50% of women attending their inner London HIV clinic reported lifetime experience of intimate partner violence and that this was associated with mental health problems, younger age and other Black (i.e. born outside sub-Saharan Africa) ethnicity. A systematic review and meta-analysis to assess evidence for an association between HIV infection and IPV showed that women living with HIV report higher rates of this than those in the general population (JIAS 2014; 17:18845).

IPV may also occur as a result of a woman's disclosure of her HIV status (Gielen A et al. *Matern Child Health* 2000; 4: 11–20); IPV is also more likely to occur in pregnancy. Screening questionnaires such as the HARK tool (Humiliated, Afraid, Rape, Kick) [Sohal H, et al *BMC Fam Pract* 2007; 8: 49] have been shown to be easy to use and acceptable to women (Dhairyawan et al).

There is very little known about the relationship between IPV and HIV in men.

Services should also have robust referral pathways and support for women and men reporting IPV or the risk of this.

Quality Statements

- At diagnosis, all people with living with HIV should have a comprehensive assessment of their physical and mental health, past medical history, as well as wider determinants of health such as drug and alcohol use, housing, finances, employment, and social support. This should be repeated periodically, for example at the same time as enquiry to screen for symptoms of mental health problems and used to identify those who may have higher levels of need.
- Where increased need is identified a personalised care plan" or an "individualised management plan" should be developed to highlight priorities for that individual and targeting of resources. This should act as a framework for management plans and referrals to other agencies.
- Where social care needs, financial difficulties, housing or other insecurities, are identified, clinics should have as a minimum, signposting to, or information, about sources of advice and support to address these difficulties.
- HIV services should actively prioritise care planning for people with increased needs where there is a clear deleterious interaction with patterns of engagement in care and/or adherence to treatment.
- Enquiry about current or past intimate partner violence should be made at baseline in all newly diagnosed people with HIV and this should be periodically reviewed, for example as part of an annual assessment. HIV services must have robust pathways for

referral to support services for people reporting IPV, be able to conduct risk assessments and to have staff trained in safeguarding issues of children affected.

- Adherence to anti-retroviral therapy is likely to be more challenging for people with higher levels of need and thus the choice of treatment is particularly important. Consideration should be given to drug choice that might facilitate adherence for that individual. For example, homeless people may find storage of large numbers of boxes of medication more difficult, so a lower tablet number may be beneficial.
- Interventions should be planned with the person according to needs as well as clearly agreed priorities and aims. Peer support should be offered to all patients, but in this group, there may be particular benefits to reducing isolation and in providing support in negotiating the health and social care system.
- People with several long-term conditions, who face economic hardship and/or who have alcohol or substance use problems are more likely to have mental health difficulties, which may be more complex. The standards for psychological care are likely to be of particular importance.
- People with multiple needs will often have a number of agencies or services involved in their care, but they may also be the least able to make best use of these services and face challenges in attending the often multiple appointments which are required. A care co-ordinator role has been successfully used in other conditions such as mental health (King's fund report) and is widely advocated for people with complex needs. It is recommended that this role is utilised for people living with HIV with higher levels of need – while not present in all localities, a specialist HIV nurse working in the community may be particularly suitable.
- HIV support services, often provided by the third sector, are of great value in supporting people with higher levels of need. Support provided by clinical and other support services must be as co-ordinated as possible with strong referral and communication links.
- People living with HIV experience significant levels of stigma and discrimination and this can occur in health and social care service which are supposed to help them (Stigma index report). Where support services are provided through generic provision, there must be evidence of knowledge, skill and training in HIV specific issues, particularly around the issues of HIV disclosure, the importance of confidentiality and stigma.
- HIV services should actively identify problems with alcohol and/or drug use in people living with HIV and have robust referral pathways to the relevant support services.
- HIV clinics should have mechanisms to actively identify people living with HIV who have difficulty engaging in routine care or who have problems with adherence to treatment, as evidenced by viraemia that is not explained by other factors. A standard approach to identify and address unmet needs in these people should be adopted.

Measurable and auditable outcomes

- Documented evidence that PLWH who report IPV have been offered referral to appropriate services (target 95%).

- Evidence of existence of formal network arrangements appropriate to a geographical area to ensure that patients with increased needs have equitable access to best-quality advice relating to their rights and access to health and social care and their entitlements to public services and assistance.
- Evidence of an agreed provider assuming the role of care co-ordination for a person with increased needs, within the relevant local area.
- Proportion of people living with HIV screened for alcohol and/or drug use in past year (target 95%).
- Evidence of referral pathways to drug and alcohol support services.
- Documented pathways for persons living with HIV and current mental health problems to have access to HIV care through close coordination between mental health and HIV services.

References

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