BHIVA Position Statement

The future role of primary and community care in HIV

Introduction

This paper sets out the British HIV Association's position as to principles which should underpin future models of care for patients with diagnosed HIV infection. It is intended as a basis for discussion with stakeholders with a view to developing standards specifically for the role of primary and community care services, to expand upon the *Standards for HIV Clinical Care*[1] which BHIVA published in 2007 in partnership with the Royal College of Physicians, British Association for Sexual Health and HIV, and British Infection Society.

Key features of HIV as a long term condition

As described in *Standards for HIV Clinical Care*, HIV infection has become a complex, chronic medical condition, but retains exceptional features which mean it differs fundamentally from conditions widely managed in primary care, eg diabetes. Particularly relevant points include that:

- Late diagnosis is the most important factor associated with HIV-related morbidity and mortality in the UK. A prime objective must be to promote earlier diagnosis through more widespread testing in line with the *UK National Guidelines for HIV Testing*[2].
- The long term outcome of treated HIV infection is unknown. The introduction of highly active antiretroviral therapy (HAART) in the late 1990s brought dramatic improvements in survival and the hope that people with HIV may enjoy near-normal life expectancy. However, since then the spectrum of HIV disease has widened as more problems are recognised as being associated with the virus and/or its treatment, for example increased risks of cardiovascular disease, liver disease, various cancers, kidney disease, osteoporosis and neurocognitive disorders. It remains to be seen what new issues may emerge as people with HIV grow older, and vigilance is essential.
- Stigma is still important. "Normalising" HIV through greater involvement of generic services can help to address this, but patient choice must be respected. Some HIV patients may want to be seen in an ordinary primary care environment which they perceive as less stigmatising than a specialist outpatient or GUM clinic. Others retain genuine fears about being seen to attend general practice by receptionists or neighbours within their local community, and welcome the relative anonymity of a larger clinic.
- A proportion of people with HIV have complex needs due to advanced disease, drug resistance, co-infection or co-morbidity, requiring management by a team of HIV specialists at a larger centre. All HIV services need clear referral pathways for such

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[1] British HIV Association in partnership with the Royal College of Physicians, British Association for Sexual Health and HIV and British Infection Society. Standards for HIV Clinical Care, 2007. See: http://bhiva.org/HIVClinicalCare.aspx

[2] British HIV Association, British Association for Sexual Health and HIV, British Infection Society. UK National Guidelines for HIV Testing, 2008. See: http://bhiva.org/HIVTesting2008.aspx

patients with links to related specialties such as hepatology, oncology and neurology/neurosurgery.

Principles for extending primary and community care engagement

Standards for HIV Clinical Care recommends that HIV services should strongly advise patients to register with a GP and, unless patients refuse consent, should keep GPs updated regarding their clinical status and medication. However, primary and community services have traditionally not played a major role in the care of people with HIV in the UK, and patients often attend their HIV clinic for minor problems not associated directly with HIV infection which could be managed in primary care. Thus if HIV patients are to benefit from an extended primary care role, this needs to be within the context of clear guidelines and protocols giving clinicians the confidence to provide care safely without feeling pressurised to take on work which would more appropriately be done by specialists. The following principles should apply:

- To avoid fragmentation of care, all providers of HIV-related care should be networked or linked to hospital-based specialist services, with defined protocols and referral pathways, including for urgent referrals.
- Good two-way communication between primary or community care providers and specialists is essential for optimal care.
- Every patient with HIV infection must remain under the care of a suitable specialist service.
- Every patient with HIV infection must be strongly encouraged to register with a GP and involve him or her in their care.
- Patients should have a choice as to whether to receive treatment and care for their HIV infection in specialist settings only or whether to take part in shared care arrangements.
- Outcomes and adherence to standards and guidelines need monitoring and audit irrespective of how care is organised.
- Clear lines of accountability are needed as regards both clinical governance and funding for each aspect of care.

Next steps

BHIVA will seek to engage with stakeholders to consider how greater primary and community care involvement can benefit people living with HIV. While models of care should reflect local circumstances, BHIVA hopes to develop consensus standards which should underpin such models, based on the principles set out above.