

Briefing paper

Extending the role of primary and community care in HIV

1 Introduction

1.1 Aim and scope

This briefing paper sets out principles and points to consider when planning any extension of the role of primary care and community health services in the management of patients with diagnosed HIV infection. It expands on and updates *Standards for HIV Clinical Care*,¹ published in 2007 by the British HIV Association in partnership with the Royal College of Physicians, the British Association of Sexual Health and HIV and the British Infection Society. It provides information to support personalised care planning for people with HIV² and offers guidance to clinicians and commissioners in the light of wider re-configurations of primary, secondary and tertiary NHS services following the *Next Stage Review*³.

1.2 HIV testing and diagnosis

Late diagnosis is the most important factor associated with HIV-related morbidity and mortality in the UK. While outside the scope of this paper which is about care for people with diagnosed HIV, all healthcare providers should take steps to increase uptake of HIV testing in line with the *UK National Guidelines for HIV Testing 2008*⁴. All GPs should routinely offer and recommend diagnostic HIV testing to patients with indicator conditions, and immediately link those testing positive into appropriate treatment and care services. In areas where diagnosed prevalence exceeds 2 per 1000 population, universal HIV testing should be considered for all men and women registering in general practice.

1.3 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:

- 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

¹ <http://bhiva.org/cms1192403.asp>

² Supporting people with long term conditions. Commissioning personalised care planning: A guide for commissioners.
http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_093354

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http://www.dh.gov.uk/en/publicationsandstatistics/publications/publicationspolicyandguidance/DH_085825

⁴ <http://bhiva.org/cms1222621.asp>

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

2 Extending primary and community care engagement

2.1 Principles

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, GPs 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 GPs 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 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.

2.2 Benefits of an extended role for primary and community care

- Patients often find it easier to attend primary care and community clinics than hospitals, especially with the extended opening hours many general practices now offer.
- Primary care has particular strengths in areas which have become important as people with HIV disease live longer, eg cardiovascular disease prevention including smoking cessation, blood pressure and lipid management. Other examples include monitoring of renal function and treatment of mental health problems. Unlike primary care providers, most specialists in HIV medicine have little experience of elderly care, and will be ill-equipped to cope as increasing numbers of people with HIV reach old age and develop a range of co-morbid conditions and social care needs.
- It is increasingly recognised that a minority of people with HIV have poor outcomes because of complex psychosocial issues leading to irregular clinic attendance and treatment refusal or non-adherence. GPs working together with specialists may be particularly well-placed to support this group of patients, in view of their “whole person” approach and good links with community mental health, social care and substance misuse services.
- There may be some avenues for cost-saving. Better primary care links may help hospital-based HIV specialists to avoid unnecessary tertiary referrals for problems which GPs are well-qualified to manage, for example to cardiologists for raised lipids or psychiatrists for simple depression.
- However, in general terms there is no evidence that moving HIV care into the community is cost-effective, and this should not be assumed.

3 Models of general practitioner involvement

Different models can be envisaged, all of which may be appropriate depending on circumstances. In each case there are practical issues to be addressed before care can be provided safely, some of which are highlighted in the boxes.

3.1 Enhanced primary care services

The development of shared care arrangements or enhanced primary care services could involve:

1. GPs taking primary responsibility for the clinical disease areas they traditionally have strengths in and for which patients with HIV are at increased risk. This would include primary cardiovascular disease prevention, treatment of diabetes and hypertension, and management of mental health problems. Other disease areas such as old age frailty may become increasingly important over time. The management protocols for these conditions would generally be no different to those for the general population but would require knowledge and training in the interactions between HIV and chronic non-infectious co-morbidities both in terms of the disease and treatment. Such shared care arrangements are likely to build on the strengths of both GPs and specialists to the benefit of patients and help reduce barriers for primary care involvement. Patients would continue to be seen regularly by their specialist centre for their HIV care.
2. GPs potentially taking responsibility for some aspects of monitoring of HIV infection itself for patients who are stable and doing well, within the context of a clearly defined shared care protocol. This would stipulate what tests and

examinations the GP is expected to perform and when, and what to do if a finding lies outside specified parameters – for example, to refer the patient urgently to the specialist service if HIV viral load becomes detectable in a patient on HAART. As a minimum, all patients should be assessed annually within the specialist HIV service to check on their welfare and maintain the relationship. Clinical governance also requires that specialists have a mechanism for knowing that patients under their care are being monitored appropriately, so protocols must address, for example, what to do if a patient does not attend for follow-up.

Shared care arrangements or enhanced primary care services are already in place in some areas in the UK and experience from these will be invaluable to help inform what is best practice and an effective model.

3.2 GPs working in outpatient HIV clinics

There is scope for GPs to work in conventional outpatient HIV clinic settings, seeing patients who present with primary care problems while liaising closely with specialists to ensure clinical safety and avoid problems such as drug interactions. This is similar to the arrangement by which GPs work in some accident and emergency departments.

This arrangement may be popular with those patients who are used to receiving all their care from the HIV clinic, but has some drawbacks. A clinic-based GP who is not local to the patient's home may not be ideally placed to liaise with community mental health and social care services and would not be able to offer the whole range of primary care services that GPs currently provide. On the other hand, the experience of seeing a clinic-based GP may reassure some patients and encourage them to register with their own GP and involve him or her in their care, which the clinic GP may also help to facilitate.

3.3 Outreach from specialist services to community settings

Specialist nurses or physicians from a specialist HIV service may undertake clinic sessions, including virtual clinics, alongside GPs in community health centres or polyclinics. This arrangement would be suitable for routine follow-up and monitoring of stable patients with HIV, and potentially offers convenience as well as close liaison between primary and secondary care.

[PRACTICAL ISSUES TO GO IN BOXES]

Practical issue: drug interactions

HAART drugs have a wide range of interactions with other drugs from many different classes⁵. This creates potential safety issues even for routine primary care for patients on HAART, necessitating not only close communication with specialists but also modification of prescribing guidance. For example, many PCT policies stipulate the choice of simvastatin as the only generically available and cheapest drug in the statin class. But simvastatin has major interactions with HAART, whereas some other statins are safe to use. Protocols must therefore specify that patients on HAART should not be prescribed simvastatin and must be excepted from this aspect of PCT policies and guidelines.

⁵ <http://www.hiv-druginteractions.org>

Practical issue: sexual health

Guidelines recommend six-monthly sexual health assessment for people living with HIV, with prompt diagnosis and treatment of STIs whenever necessary together with appropriate partner notification, and the annual offer of a full sexual health screen⁶. Strategies to prevent onward transmission of HIV are an important part of HIV treatment and care services and include not only screening and treatment of STIs but also provision of psychology and counselling services to help effect behaviour change. GPs increasingly provide basic sexual health screening but this may need to be adapted for HIV patients, as the risk of syphilis, LGV, and other STIs may be higher in certain HIV populations and the clinical presentation atypical.

Practical issue: viral hepatitis co-infection

Some people with HIV are at increased risk of acquiring hepatitis C co-infection. Early diagnosis is important because the chance of successful treatment is much higher for acute than chronic hepatitis C. Shared care protocols should therefore specify circumstances in which GPs should arrange hepatitis C and liver function testing.

Practical issue: information governance

Efficient shared care depends on shared information so that, for example, the results of relevant tests done in general practice are available in specialist settings and vice versa. Otherwise, at best tests may be repeated wastefully and at worst vital information may be missing when needed in an emergency. But appropriate information sharing does not mean full integration of records, which neither patients nor clinicians would necessarily want. Protocols need to determine what information should be shared, and how in practice this can be achieved. This might include patient-held summaries, as for shared care for some other conditions, although this has not been tested for HIV where concerns about stigma may affect acceptability.

Practical issue: HAART prescribing and dispensing

HAART is highly effective in suppressing HIV viral activity and preventing disease progression, but requires long term use of combinations of complex high cost drugs. All have significant adverse effects, some of which may be as yet unrecognised, and several interact extensively with other medications. Legal responsibility for prescribing lies with the doctor who signs the prescription⁷ and it is unlikely that GPs can or would wish to maintain sufficient expertise in HIV to prescribe HAART safely in the community, nor would there be routine access to specialist pharmacists in the community. Review of prescriptions by an HIV-experienced pharmacist provides an important additional safety check; patients starting or changing their treatment should go through the prescription with the pharmacist to make sure they understand how to take their drugs.

There are further issues. Some PCT policies restrict prescriptions to a maximum of one month's supply, which would be inconvenient for people needing long term HAART. Community pharmacists may be reluctant to assume the financial risk of stocking expensive HAART drugs, quite apart from the governance risk associated with dispensing complex unfamiliar medication. Patient groups may also be concerned about the impact of prescription charges.

⁶ Fakoya A, Lamba H, Mackie N, et al. British HIV Association, BASHH and FSRH guidelines for the management of the sexual and reproductive health of people living with HIV infection 2008. *HIV Medicine* (2008), 9, 681–720. DOI: 10.1111/j.1468-1293.2008.00634.x

⁷ Department of Health circular EL (91) 127 cited in British National Formulary BNF 56.

Practical issue: laboratory services

CD4 T-lymphocyte cell counting is routinely used to monitor immune function in HIV patients, whether on or off HAART. Blood samples for CD4 count testing need to be transported to specialist laboratories quickly, otherwise the sample deteriorates and is no longer suitable for processing. If CD4 counting is to be provided in community or primary care settings, special laboratory and sample transport arrangements may be needed with additional costs.