

## Shared care in HIV and AIDS: shifting care or shifting costs?

A joint conference on shared care in HIV and AIDS was held by the Royal Colleges of Physicians and General Practitioners, at the Royal College of Physicians of London on 9 October 1997.

With such an uncompromising title conference participants 'pulled few punches' in identifying key areas of concern. The variable success of past shared care schemes made the 'parallel care' model attractive, with its emphasis on specialist management of HIV-specific problems, improved communication with generic services and provision of education and training to deliver high quality primary care, equivalent to that provided for patients with other acute and chronic illnesses. Duplication of roles was inappropriate, inefficient and in nobody's interest; it would be as inappropriate for GPs to take on specialist tasks, such as prescribing or monitoring antiretroviral therapy, as for specialists to encroach upon areas of primary care expertise. The responsibilities of each service will need to be defined. There was a consensus that all parties, including patients, primary care teams, specialists, Trusts and commissioners, should be involved in planning the service, with more leadership from central government to ensure consistency in different parts of the country.

### Background to shared care

**Dr Surinder Singh** (Royal Free Hospital School of Medicine, London) – Early on in the epidemic, GPs expressed unacceptable levels of homophobia and ignorance about HIV in surveys<sup>1</sup>. These shortcomings did not go unrecognised by patients, who turned to the service that had performed their HIV tests to continue with their clinical care, including primary care.

A number of initiatives were set up, primarily driven by specialist centres, to try to 'share care'<sup>2</sup> and redress the balance. In other areas, home support outreach teams from the specialist centres, with varying amounts of generalist involvement, were established<sup>3,4</sup>. More recently primary care facilitators (nurses and doctors) have been appointed to provide information, training and support for GPs and district nurses, and some 'hands on' care liaising with specialist centres.

Encouraging surveys in the early 1990s revealed that most GPs in the highest areas of prevalence in London were seeing patients with HIV<sup>5</sup>. In one study 75% of patients

were registered with a GP who was aware of their diagnosis<sup>6</sup>. The main barriers to GP involvement identified by patients were: concerns about the primary care team's level of knowledge of HIV, discrimination on the basis of lifestyle and a perceived inability to respect confidentiality.

The traditional role of GP as patient advocate and generalist should be part of any model of HIV care<sup>7</sup> together with additional roles in the promotion of sexual health, care during acute and chronic phases of HIV disease, palliative and terminal care, as well as care for the carers and dependants of patients with AIDS. In 1987 the Royal College of General Practitioners set up the HIV and AIDS Working Party to provide support for, and exchange information with, a network of GPs involved in HIV care.

In discussion, concern was expressed that at a joint RCP and RCGP conference, HIV specialists greatly outnumbered general practitioners. In reply it was acknowledged that HIV is still a relatively rare infection for most GP practices, so those present were clearly a self-selected group of highly motivated clinicians with a particular interest in HIV. Their enthusiasm, non-judgemental attitudes and clear knowledge of the issues may not be representative of GPs across the country.

### One example of possible shared care

**Dr Sunil Shaunak** (Royal Postgraduate Medical School, London) – This shared care model was set up before the complexities of combination therapy<sup>8</sup>. Increased communication was its main goal. A locally relevant management guide was constructed and a one-page standardised summary of patient attendances or admissions was faxed to the GP, who also had 24-hour access to an HIV consultant on a mobile phone. The single sheet summary provided information relevant to the primary care of the patient and did not burden doctors with unnecessary details. The project succeeded in reducing the number of outpatient visits, halved the average duration of inpatient admissions, increased GP consultations to an average of three per year per patient and reduced the costs of specialist units. The vital role of a motivated, determined facilitator to encourage GPs, specialist and patients to participate was emphasised. Dr Shaunak's HIV unit was subsequently closed, due in part to the reduction in its activity as a result of the success of the shared care model. This may not serve as a great encouragement for other specialist units to adopt similar strategies. All stakeholders in HIV care need to feel that initiatives in shared care are going to be beneficial, and to view the strategy as non-threatening.

### Is shared care always the best approach?

**Dr Judy Bury** (The Spittal Street Centre, Edinburgh) – Initial models of shared HIV care often involved the GP in monitoring CD4 lymphocyte counts and other specialist work. Transferring specialist work to the GP may compromise the complementary role and expertise of the primary care team.

Rapporteurs: **JONATHAN D CARTLEDGE** MRCP, Department of Genitourinary Medicine, Camden and Islington Community Health Services, and **IAN V D WELLER** MD FRCP, Professor, Department of Sexually Transmitted Diseases, University College London Medical School, London



Since most GPs will see HIV patients rarely, attempting to encourage a specialist interest in this area is, in most cases, inappropriate. Even in central London, protocol-led strategies of shared CD4 cell count monitoring failed because of lack of patient willingness to participate<sup>9</sup>. However, 75% of patients had seen their GP in the previous year and most were happy for their GP to be kept informed of their health status. Specialist teams can show an intense interest in all aspects of the patient's life, sharing information across disciplines. This 'totalising gaze'<sup>10</sup> was considered disempowering and intimidating for patients. To escape from 'big brother' to a GP, who can advise and care on a one-to-one basis, without such all-encompassing knowledge, was a relief for some patients<sup>11</sup>.

In a study of HIV-positive women (S Madge, personal communication), most GP consultations were for non-HIV-related matters, clearly a very appropriate use of primary care. However, GPs need to be well informed about their patients' current HIV disease status and changes in treatment if they are to manage other conditions in parallel.

Pregnancy is an issue that requires increased education, since some GPs still consider termination to be the only real option for an HIV-positive woman.

The strategy of parallel care has the potential to strike the correct balance, with specialists dealing with HIV-specific issues and providing GPs with sufficient information to allow them to offer comprehensive primary care of a nature similar to that available to other patients with chronic conditions.

### Drug therapy: why, who, where?

**Dr Ian Williams** (University College London Medical School) – There is now overwhelming evidence that combination antiretroviral therapy delays clinical progression of disease and increases survival. The CD4 lymphocyte count and serum viral load are being used to predict prognosis, monitor therapeutic response and influence changes in treatment. More recent work has shown a greater short-term antiviral effect and clinical benefit with triple than with double antiretroviral combinations<sup>12</sup> and yet some NHS commissioners have been slow to countenance their use. When, in the natural course of HIV infection, treatment should be started is largely unanswered. National guidelines exist<sup>13,14</sup> but these are as much based on biological rationale and 'expert opinion' as on data from controlled trials. The British guidelines differ from those in the United States and all will need regular updating. Even within the UK, specialists have different opinions.

To provide antiretroviral therapy with an acceptable standard of care, requires regular access to CD4 cell and viral load measurements, and knowledge in depth of the current drugs available. A few GPs in high prevalence areas may be happy to take on HIV as their area of specialist interest, but the majority will not. However, the GP may have an important role to play as patient advocate and in enhancing compliance with treatment.

### New challenges for primary care

**Dr Chris Ford** (general practitioner, London) – The pattern of HIV disease is changing. Combination therapy has shifted the emphasis of care to the outpatient setting and increased the potential for input from the generalist. However, the quality of care provided by GPs is variable. There has only been a gradual improvement in the management of chronic diseases, preventative work remains limited despite considerable efforts and there have been moves away from GPs providing an acute 24-hour service. Much of GP education is still dependent on support from the pharmaceutical industry.

In Dr Ford's own practice in central London, which has 54 known HIV-positive clients (14 being drug users), 13% used only GP services and never attended a specialist centre and a further 20% only used secondary services when referred by their GP. Similarly, a review of over 700 HIV-positive clients in Lothian, mainly drug users, found that 14% never used specialist services and that 20% saw neither a GP nor a specialist. In other studies 77–90% of positive patients have been registered with GPs<sup>15</sup>. Both GPs and specialists need to look at engaging HIV-positive people who currently do not seek any medical care. A recent GP questionnaire survey (M King, personal communication) highlights GPs' greatest concerns as a lack of knowledge and experience and keeping abreast of such a rapidly changing field.

Good primary care for HIV-positive patients should focus on its strengths, ie continuity, family and carer support, the management of non-HIV-related diseases, DHSS benefits, contraception, pregnancy advice, psychological support, travel medicine and terminal care. The GP is ideally placed to play an important role in HIV prevention and condom provision. A recent GP practice intervention with a safe sex leaflet significantly increased condom use (T Oliver, C Ford, personal communication).

Should GPs view HIV testing as part of their role? In London, less than 5% of HIV tests are carried out in general practice<sup>16</sup>. One concern has been insurance application forms. BMA guidelines<sup>17</sup> argue that it is essential that a doctor does not speculate about the patient's lifestyle or risk for HIV infection when completing such forms. There is clearly a need for all services to recognise these guidelines and to adhere to them for all patients.

Uptake of antenatal HIV testing by pregnant women is as low as 5% in some London units<sup>18</sup>. The GP may be well placed to offer testing in this context. HIV-positive patients perceive confidentiality and discrimination to be barriers to involving the primary care team. Waiting room posters and practice leaflets guaranteeing confidentiality and non-discrimination to all comers may help overcome these problems, but only if there is a real commitment by staff to the underlying principles.

### Where to die?

**Caroline Stirling** (Whipps Cross Hospital, London) – Amidst the current optimism resulting from the success of combi-



nation therapy, it remains important not to lose sight of the grim reality that HIV is an incurable disease, and that the need to consider care at the end of life remains. A recent survey of patients from the Royal Free Hospital revealed little change in the proportion dying in hospital (~60%) since the late 1980s. However, in a Canadian study, less than 10% of those expressing a preference wished to die in hospital<sup>19</sup>. The realities of terminal care at home, in hospital and in a palliative care unit must be considered (Table 1). Where appropriate and possible, preparation and discussion with the patient, his/her carers and professionals involved, both in the community and in the acute centre, facilitate optimal care at the end of life.

**Debate: provision and commissioning of HIV care: who leads?**

Those who expected a lively debate on the issue of who leads in provision and commissioning may have been pleasantly surprised by the degree of healthy agreement. There was unanimous agreement that the divisive culture of the purchaser-provider split should be replaced by one of more open consultation of all stakeholders so that planning benefits from the expert knowledge of all those involved. There was agreement that no one stakeholder should take the lead in commissioning but there should be a partnership allowing each partner to contribute his or her expert knowledge and do what each does best.

**Jane Carrier** (Centre for Research on Drugs and Health Behaviour, London) succinctly summarised the need to consider quality, access, cost-effectiveness and evidence based practice. Optimising our service in each of these areas is timely, with the move towards residence based funding and the Inner London Commissioning Group's evaluation of the relationships between large specialist centres and local providers.

**Professor Anthony Pinching** (St Bartholomew's and The Royal London School of Medicine and Dentistry) summarised the six 'Rs' that need to be addressed: role defining, responsibilities, reading and writing (communication), respect, rational planning and resources. Patients' needs should 'lead' provision and commissioning of care, but he expressed concern that in an era of evidence based practice, some commissioners were introducing strategies that had not been 'reality tested'.

**Dr Greg Battle** (general practitioner, London) welcomed a move away from the culture of suspicion and fears over territory and access to resources towards more transparency and honesty. He felt that informing GPs should be an opt-out rather than opt-in decision for patients.

**Douglas Slater** (UK Coalition for People Living with HIV and AIDS, London) felt that patients should not lead the decision-making around provision and commissioning, since the majority are unaware of the structure of the NHS, and the core provision options. The limited ability of patient participants in the debate to be true representatives of all those affected by the virus needs to be acknowledged. As

**Table 1. Where to die with HIV.**

Site of terminal care	Advantages	Disadvantages
<b>Hospital</b>	<ul style="list-style-type: none"> <li>● Instant access to care</li> <li>● Security</li> <li>● Anonymity</li> <li>● Continued relationship with professionals</li> </ul>	<ul style="list-style-type: none"> <li>● Loss of autonomy</li> <li>● Loss of control</li> <li>● Lack of privacy</li> <li>● Culture of acute treatment rather than symptom control</li> </ul>
<b>Palliative care unit</b>	<ul style="list-style-type: none"> <li>● Care and comfort</li> <li>● Privacy</li> <li>● Autonomy</li> <li>● Focus on symptom control</li> <li>● Preparation for all aspects of dying</li> </ul>	<ul style="list-style-type: none"> <li>● Lack of anonymity</li> <li>● Prejudices</li> <li>● Lack of facilities for acute treatment</li> </ul>
<b>Home</b>	<ul style="list-style-type: none"> <li>● Freedom of expression</li> <li>● Greater control</li> </ul>	<ul style="list-style-type: none"> <li>● Insecurity without full-time professional care</li> <li>● Symptom control less easy to ensure</li> <li>● Intrusion of multiple professionals into home</li> <li>● Carer exhaustion</li> </ul>

well as rights, patients should accept responsibilities, such as staying aware of the issues facing the NHS, treatment issues, adopting a professional relationship with their professional carers but not trying to second guess their doctors. Clearly the ability of different individuals to accept and adopt such responsibilities would vary. The 'one stop shop' delivery of care by specialist centres was attractive to patients, and should be considered in plans to separate out primary care aspects.

In discussion, the voluntary sector's contribution to care was highlighted. It was felt to be vital and cost-effective. To see it as the 'soft optional extra' which can be sacrificed to finance combination therapy was shortsighted, in view of the uncertainty with respect to the duration of treatment benefit. The provocative suggestion that HIV might be integrated into general medicine rather than a specialty was rejected by Professor Pinching. It remains too rare a condition for the average general physician to gain sufficient expertise in the rapidly changing complexities of management, and as with other diseases, patient survival is related to physician experience.

**Elective sessions**

Rapporteurs from each group reported back to the main group with sound bites and bullet points from the session discussions (Table 2). There was insufficient time for participants to discuss them comprehensively but a number had already come out from the presentations and discussion earlier in the day.



On leaving the conference, optimism about the proposed parallel care model, with its emphasis on communication and cooperation and each party taking on what they do best, was tempered by a concern that the views expressed by the enthusiastic and interested but self-selected delegates might not be truly representative. Unless individual general practitioners really want greater involvement in the care of HIV-positive patients, and unless specialist units can 'let go' without fear of being closed and patients are comfortable with these arrangements, these potentially important initiatives for improvement in patient care will be constrained.

**References**

- 1 Boyton R, Scambler G. Survey of GPs' attitudes to AIDS in the North Thames and East Anglian Regions. *Br Med J* 1988;**296**:538-40.
- 2 Pinching AJ. Models of clinical care. *AIDS* 1989;**3**(Suppl 1):209-13.
- 3 Smits A, Mansfield AJ, Singh S. Facilitating care of patients with HIV infection by hospital and primary care teams. *Br Med J* 1990;**300**:24-43.
- 4 Bury J, Simmonte M, Jacquet C. Training primary care staff about HIV prevention. Oral presentation, 3rd International Conference on home and community care for persons living with HIV/AIDS. Amsterdam, May 1997.
- 5 Hoolaghan T, Blache G. Health promotion in general practice project. Summary report 1991-92. London: Royal Free Hospital Health Promotion Unit. 1992.
- 6 Shaw M, Tomlinson D, Higginson I. Survey of HIV patients' views on confidentiality and non-discrimination policies in general practice. *Br Med J* 1996;**312**:1463-4.
- 7 Mansfield SJ, Singh S. Who should fill the care gap in HIV disease? *Lancet* 1993;**342**:726-8.
- 8 Smith S, Robinson J, Hollyer J, Bhatt R, *et al.* Combining specialist and primary health care teams for HIV positive patients: retrospective and prospective studies. *Br Med J* 1996;**312**:416-420.
- 9 Grun L, Murray L. Acceptability of shared care for asymptomatic HIV positive patients. *Fam Pract* 1995;**12**:299-302.
- 10 Foucault M. *The birth of the clinic*. London: Routledge, 1973.
- 11 Huby G, Porter M, Bury J. Quality of care for people with HIV and AIDS in Lothian. Department of General Practice, University of Edinburgh, 1995.
- 12 Hammer SM, Squires KE, Hughes MD, Grimes JM, *et al.* A controlled trial of two nucleoside analogues plus indinavir in persons with human immunodeficiency virus infection and CD4 cell counts of 200 per cubic millimeter or less. AIDS Clinical Trials Group 320 Study Team. *N Engl J Med* 1997;**337**:725-33.
- 13 British HIV Association. Guidelines for antiretroviral treatment of HIV seropositive individuals. *Lancet* 1997;**349**:1086-92.
- 14 Antiretroviral therapy for HIV infection in 1997. Updated recommendations of the International AIDS Society - USA panel. *JAMA* 1997;**277**:1962-9.
- 15 Bury JK, Ross A, van Teijlingen E, Porter AM, Bath G. Lothian general practitioners, HIV infection and drug misuse: epidemiology experience and confidence 1988-1993. *Health Bull (Edinb)* May 1996;**54**(3):258-69.
- 16 Birthistle K, Macquire H, Atkinson P, Carrington D. Who's having HIV tests? An audit of HIV test requests in a large London teaching hospital. *Health Trends* 1996;**28**(2): 60-3.
- 17 BMA Professional Division Guidance. *Guidance on performing HIV tests for life insurance companies*. London: BMA, 1989.
- 18 MacDonagh SE, Masters J, Helps BA, Tookey PA, Gibb DM. Why are antenatal policies in London failing? *Br J Midwifery* 1996;**4**:466-70.
- 19 Goldstone I, Kuhl D, Johnson A, Le R, McLeod A. Patterns of care in advanced HIV disease in a tertiary treatment centre. *AIDS Care* 1995;**7**(Suppl 1):S47-S56.

**Table 2. Bullet points from the elective sessions.**

Elective session	Bullet points
<b>HIV commissioning</b>	<ul style="list-style-type: none"> <li>● Re-evaluation of services to match needs</li> <li>● Improved communication within and between health authorities to redress the inequalities of service provision in different areas of the country (eg protease inhibitor prescribing) and to avoid each area re-inventing the wheel</li> </ul>
<b>Primary care led health planning and commissioning</b>	<ul style="list-style-type: none"> <li>● Reject primary care leadership of commissioning</li> <li>● Primary care involvement in partnership with other stakeholders</li> </ul>
<b>Defining roles</b>	<ul style="list-style-type: none"> <li>● Walk-in clinics in HIV specialist centres duplicate the role of primary care services</li> <li>● As such they undermine 'parallel care' but may be                             <ul style="list-style-type: none"> <li>- popular with patients looking for a one stop shop</li> <li>- popular with specialists keen to provide holistic care</li> <li>- popular with busy GPs without specialist HIV knowledge</li> </ul> </li> <li>● Confidentiality and same day access need to be addressed by primary care to enable provision of a service as attractive to patients as walk-in clinics</li> </ul>
<b>Increasing GP involvement</b>	<ul style="list-style-type: none"> <li>● Confidentiality concerns remain a major barrier for patients</li> <li>● GP-led antenatal testing needs to be explored</li> </ul>
<b>Palliative care</b>	<ul style="list-style-type: none"> <li>● Involve palliative care colleagues early for symptom control before terminal illness</li> <li>● HIV specialists have a role in promoting palliative care services</li> </ul>
<b>Family issues</b>	<ul style="list-style-type: none"> <li>● Most families living with HIV are African and sensitivity towards cultural issues is needed</li> <li>● The needs of the child must be addressed - in terms of informing, caring and support</li> </ul>
<b>Shared care for drug users</b>	<ul style="list-style-type: none"> <li>● Contract and boundary setting is essential and all providers must be involved and committed to such strategies</li> <li>● GPs need ongoing education and support in their care of drug users</li> </ul>
<b>Monitoring combination therapy</b>	<ul style="list-style-type: none"> <li>● GPs have a role in monitoring compliance and side effects</li> <li>● Efficacy monitoring (CD4 count and viral load measures) is generally inappropriate in the primary care setting</li> </ul>