

# The role of the general practitioner in the community care of people with HIV infection and AIDS: a comparative study of high- and low-prevalence areas in England

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## SUMMARY

**Background.** Policy for the care of people suffering from HIV and AIDS has changed over the past decade. Schemes for shared primary and secondary care have been met with varying success, and patients may be reluctant to become involved. No systematic evaluation comparing the views of primary care providers and users in areas of varying HIV prevalence has been published.

**Aim.** To examine the role of general practice in areas of England with low and high human immunodeficiency virus (HIV) prevalence and to compare barriers to general practice care in each area.

**Method.** We used focus groups, semistructured questionnaires and interviews in north London (high HIV prevalence) and Nottingham (low HIV prevalence).

**Results.** Four focus groups took place in London. A total of 411 general practitioners (GPs) in London and 405 in Nottingham replied to postal questionnaires. Overall, 121 primary care staff in 40 London practices and 26 staff in five Nottingham practices were interviewed. In all, 54 people infected with HIV were interviewed in London and 20 in Nottingham. Providers and users regarded the 24-hour availability and the familiar environment of general practice as its key assets. Lack of expertise and time were its disadvantages. Providers were concerned about inadequate communication with specialist services. Although providers were concerned about confidentiality, whether they had liberal and sympathetic attitudes was more important in deciding whether people with HIV used the service. In the

low-prevalence area, general practice involvement was the result of individual initiatives, and practices were not integrated into specialist care. In the high-prevalence area, HIV care was more usual in general practice, but there was also little integration with HIV services.

**Conclusions.** In high-prevalence districts, a strategy to make HIV care routine for all GPs may be appropriate. In low-prevalence areas, a network of selected, strategically located, relatively high-involvement practices may be more effective in meeting the primary care needs of people with HIV infection and acquired immunodeficiency syndrome (AIDS).

**Keywords:** HIV; AIDS; primary health care team; communication; confidentiality.

## Introduction

POLICY for the care of people with HIV and AIDS has changed over the past decade.<sup>1-7</sup> Schemes for shared primary and secondary care have met with varying success,<sup>8,9</sup> and patients may be reluctant to become involved.<sup>10</sup> Direct access to specialist HIV services and the tradition of confidentiality in genitourinary medicine<sup>11</sup> have reinforced the isolation of general practice. There have been local studies of the views of users or providers,<sup>12,13</sup> but no systematic evaluation comparing the views of primary care providers and users in areas of varying HIV prevalence.

Our aim was to examine the role of general practice in low and high HIV prevalence areas of England and compare barriers to general practice care in each area.

## Method

### Design

In order to evaluate the diversity of views of users and providers, we used focus groups (qualitative) and semistructured questionnaires and interviews (quantitative). The focus groups informed the development of the questionnaires and interviews.

### Settings

**The high-prevalence area.** The former north London family health services authorities Camden and Islington, Ealing, Hammersmith and Hounslow, and Kensington, Chelsea and Westminster (total population 1 332 000) have a high prevalence of HIV infection. By December 1995, there were 12 360 cases of HIV infection, of which 6427 had progressed to AIDS.

**The low-prevalence area.** Nottingham is an urban district health authority in the east Midlands of England with a population of 603 886. Between the start of HIV surveillance in October 1985 and March 1995, 152 cases of HIV infection were notified; of these 61 patients had developed AIDS and 44 had died.

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### Sample

**Focus groups.** We arranged four focus groups, two for providers and two for users. We asked statutory and voluntary organizations to invite patients to contact us. We contacted providers directly.

**Postal survey of general practitioners.** In London, we surveyed all general practitioners (GPs) in the three former family health services authorities (only Ealing and Hammersmith were included in Ealing, Hammersmith and Hounslow). In Nottingham, we surveyed all GPs and all practice managers in the former Nottinghamshire Family Health Services Authority.

**Interviews with general practice staff and users.** In London, we selected practices using random number tables, stratifying by family health services authority, single versus group practice, and by fundholding status. We chose one doctor from each practice randomly for interview. We chose opportunistically for interview the practice manager, practice nurse, and one receptionist in each practice. We sought service users for interview in the same way as for the focus groups. We attempted to contact a diverse group (e.g. ethnicity). In Nottingham, we conducted interviews with GPs and practice staff in five practices that we knew from information in the postal survey had contact with two or more patients infected with HIV.

### Analysis

We audiotaped and transcribed the focus group discussions. We identified and compared key themes using a word-processor package.<sup>14</sup> Interview data in London were scored quantitatively and analysed using the Statistical Package for the Social Sciences (version 6.0). We examined differences in means using Student's *t*-test, and differences in proportions using the chi-squared, Mann-Whitney *U*-test and Kruskal-Wallis statistics. We used the Mantel-Haenszel chi-squared test when examining trends. Interviews in Nottingham were audiotaped, transcribed, and analysed by the constant comparative method.<sup>15</sup>

### Results

We collected data between June 1994 and February 1996.

#### Focus groups

**London.** Seven or eight people participated in each focus group. The main themes in the users' groups were establishing a relationship with the GP, knowledge and skills of primary care professionals, attitudes to HIV, confidentiality, access to services, communication, and funding. The main issues in the providers' groups were the role of general practice in prevention, counselling, testing, and medical care, lack of skills and negative attitudes, role of specialist services, confidentiality, communication, support, workload, and costs.

**Nottingham.** The absence of functioning voluntary organizations and the small numbers of users and involved GPs available made focus groups impracticable. Service users were concerned about confidentiality, and few providers considered HIV a current policy issue.

#### Postal surveys

**London.** A total of 642 doctors were eligible to take part, of whom 411 (64%) replied. Almost 75% had discussed HIV prevention with a median of four patients in the preceding four weeks. Most (86%) had cared for at least one HIV-infected patient. Sixty-one per cent of doctors had provided terminal care for AIDS patients. Over half the doctors had had training in HIV and AIDS, but as many again felt they still had training needs.

Doctors were asked about their preparedness to provide ser-

vices on a sliding scale of 1 (always) to 4 (never and would not do so). There were strong associations between training and provision of services. Trained GPs were more prepared to provide free condoms [Mantel-Haenszel (M-H)  $\chi^2 = 2.97$ , *df* = 1, *P* = 0.003], HIV antibody testing (M-H  $\chi^2 = 3.88$ , *df* = 1, *P* = 0.049), pre-HIV test counselling (M-H  $\chi^2 = 8.52$ , *df* = 1, *P* = 0.0035), post-HIV test counselling (M-H  $\chi^2 = 13.67$ , *df* = 1, *P* = 0.0002), monitor HIV-positive patients (M-H  $\chi^2 = 20.86$ , *df* = 1, *P* = 0.0000), prescribe for HIV-related illness (M-H  $\chi^2 = 14.21$ , *df* = 1, *P* = 0.0001), and provide terminal care for patients (M-H  $\chi^2 = 22.45$ , *df* = 1, *P* = 0.0000). Training was not related to preparedness to offer clean injecting equipment to drug users. One quarter did not register known drug users. Only 20% were dissatisfied with HIV services. Less than 40% had a confidentiality statement in the practice, and only 40% sought patients' views when passing information to other practice staff, writing in the notes, or putting information on computers. The doctors regarded lack of time and experience as the main barriers to care.

**Nottingham.** A total of 405 (80%) of the 507 GPs contacted replied. Practice managers from 66 (61%) of 109 practices in the health authority replied. Eighty per cent of doctors had discussed prevention of HIV infection with a median of three patients in the previous 12 months. Twenty-one per cent had been consulted by patients with HIV-related conditions in the previous 12 months. Only 5% reported more than two such patients. Forty-four per cent of inner city GPs reported a consultation, compared with 17% of urban and 11% of rural GPs ( $\chi^2 = 30.835$ , *df* = 2, *P* < 0.001). Inner city GPs who had been consulted reported a mean of 3.4 patients in the previous year, compared with 1.5 for urban and 1.4 for rural doctors (Kruskal-Wallis *H* = 8.20, *P* = 0.017). Ninety-nine per cent of practices had a confidentiality policy, but in only 63% was it written and in only 27% was it available to patients. Thirty-five per cent of practices recorded the patient's diagnosis on the outside of their records. Although in 79% per cent of practices patients could overhear conversations at reception, in 88% of practices receptionists asked patients for clinical information. Eighty-two per cent of practices stated that all doctors in the practice should know of the patient's HIV status, and 20% that receptionists needed to be informed.

#### Interviews

**London.** The overall practice response rate was 66%. We interviewed 121 staff in 40 practices (Table 1). Only 10% of the practices were fundholding. The doctors interviewed did not differ significantly in age or sex from those in the postal questionnaire. We interviewed 54 service users (Table 2), whose mean age was 34 years. Mean time elapsed since their diagnosis of HIV infection was 42 months. Forty-eight (89%) were registered with a GP for a mean of 37 months. In 44 cases (82%), their doctor knew of their diagnosis. In the previous six months, users had visited their doctor a mean of four times and the practice nurse once. Forty-six (85%) used specialist HIV services and had visited a mean of nine times in six months.

**Role of general practice.** There was broad agreement between all staff that general medical care, psychological support, and referral are important in general practice management of HIV infection. No doctor and only 3% of practice nurses mentioned terminal care as an important role. General practitioners emphasized that they provided one-to-one care, local knowledge, 24-hour availability, and a more 'normal' environment than the hospital. Only 6%, however, suggested that the support of partners and carers was important. Twenty-two per cent of users were uncertain about the role of general practice. The remainder emphasized general medical care, psychological support, and availability.

**Table 1.** Practice staff interviewed.

	London	Nottingham
Practices	40	5
General practitioners	31	11
Practice nurses	33	5
Administrative staff	57	6
District nurses	0	4

**Table 2.** Details of patients interviewed.

	London	Nottingham
Men	41	18
Women	13	2
White	43	20
Black African	10	–
Other ethnic	1	–
AIDS	11	2
HIV seropositive	43	18

*Role of specialist services.* General practitioners believed specialist centres best provided specialist medical care, counselling, the latest information on drug trials, and training. Practice nurses thought specialists could help make contact with services such as HIV specialist dentists and social services. Users valued the specialist knowledge, open access, and non-judgemental approach of specialist services. They regarded accepting attitudes of staff as paramount.

*Involvement of general practice.* Seventy-nine per cent of the GPs had cared for HIV-infected patients, a figure similar to 86% in the postal survey. Only 35% of practice nurses had cared for HIV-infected patients. Terminal care was as common as other interventions for the doctors, but was very uncommon for the nurses. Half of the doctors and practice nurses did not feel clinically or emotionally supported in their work with people with HIV. Practice nurses were most often regarded as staff who should know of a patient's HIV status. Up to one quarter of all staff (clinical and non-clinical) thought all staff in the practice should know. This was in order to protect themselves from risk, provide effective care, and respond to patients' needs.

*General practice barriers to care.* Commonest suggestions from the doctors were lack of knowledge, experience, and time, and ignorance and fear on the part of staff. Eighteen per cent of doctors admitted that doctors may discriminate against patients. Twenty-two per cent of doctors and 29% of nurses regarded the structure of general practice (e.g. appointment times and dealing with receptionists) as a problem. They did not regard the costs of HIV care as an important barrier. Thirty-three per cent of doctors, 38% of practice nurses, and 40% of non-clinical practice staff regarded fear about confidentiality as the greatest barrier to the use of their services. Users did not often cite lack of confidentiality as a barrier. They were more concerned with lack of specialist knowledge and negative attitudes of staff. Only users mentioned negative attitudes to homosexuality as a barrier to primary medical care.

*Specialist barriers to primary care.* The practice staff regarded specialist barriers as poor communication and liaison, usurping general practice's holistic role, and discouraging patients from using general practice. Only 24% of users thought that barriers stemmed from specialist services. They were twice as likely to consider that barriers to general practice care came from within general practice itself.

*Nottingham.* All 11 doctors (Table 1) reported limited experience

of the management of people with HIV disease. None had had ongoing contact with asymptomatic patients. None of the practice nurses, but all the district nurses, had had contact with HIV-infected patients. The district nurses liaised more closely with genitourinary medicine than general practice. The typical pattern of contact for the doctors was an initial consultation, followed by a period of non-contact while the patient was (presumed to be) asymptomatic. This was followed (in some cases) by a period in which the GP provided psychological support to complement the clinical care delivered by genitourinary medicine. Terminal care was likely to be delivered by a district nurse, with the GP only slightly involved. The doctors identified specialist disease management, clinical care, and HIV-related prescribing as the responsibility of genitourinary medicine. Their role was to provide general support. They were content with their secondary role in service provision, although most (8 doctors out of eleven) found communicating with specialists difficult.

Twenty service users agreed to be interviewed (Table 2), 19 of whom identified hospital departments as their main source of care. Fourteen reported that their GP knew of their HIV status. In two cases, the doctor was involved in the patient's care without knowing the HIV diagnosis. All patients valued the familiar, confidential, and unconditional nature of genitourinary medicine. They used GPs only with reluctance. Patients were apprehensive that their GPs would perceive the costs of HIV care as an unwelcome drain on resources. Concerns about discrimination and confidentiality were universal and not specific to general practice. However, concerns were expressed about the release of medical information by GPs to insurance companies, information sharing within the primary care team, and the risk of accidental disclosure through a chance encounter with a relative or neighbour in the practice. Users associated transfer from outpatient specialist care to general practice with the transition from living with HIV to dying from AIDS. It entailed admitting that deterioration was under way.

## Discussion

Our method was constrained by the cultural and service differences between the two centres. In the low-prevalence area, users were more concerned about the confidentiality of the research, and providers were less interested than in the high-prevalence area. Our variable response rates, non-random selection of focus group participants, and small numbers (e.g. service users in Nottingham) may have produced a degree of selection bias. Nevertheless, important findings emerged. General practitioners in both areas felt that they lacked time and expertise. Providers and users regarded the 24-hour availability of support and the familiar environment of general practice as its key assets. Lack of expertise and time were its disadvantages. Providers were particularly concerned about inadequate communication with specialist services. Although providers were concerned about maintaining confidentiality, users believed that liberal and sympathetic attitudes were more important in guiding whether or not they consulted their GP.

In the low-prevalence area, primary care involvement was limited and occurred mainly as a result of individual initiatives. Practices that became involved were not effectively integrated into the existing pattern of provision. In high-prevalence districts, where most GPs have had at least some experience, HIV care may reasonably be regarded as a more routine component of service. However, even here GPs and nurses lacked emotional support and were poorly integrated into overall HIV services.

Primary care provision should be part of overall care that is appropriate to the changing needs of patients, even if the mecha-

nisms for delivering this may vary according to local circumstances. In high-prevalence districts, a strategy to make HIV care routine for all GPs may be appropriate. In low-prevalence areas, a network of selected, strategically located, relatively high-involvement practices may be more effective in meeting the primary care needs of people with HIV infection and AIDS. If necessary, this provision could be supplemented by a GP with HIV expertise working alongside the secondary specialists.<sup>16</sup> This model has also been used in HIV/AIDS care in low-prevalence areas of the country (G Cooke, Leicester, personal communication).

With rapid developments in the understanding of the pathogenesis of HIV infection and in multiple antiretroviral treatments, some are arguing that HIV infection is a disease that is best managed by physicians who are well trained in the field, be they specialist consultants or GPs.<sup>17</sup> There is evidence that generalists may be less adept at detecting particular physical findings in HIV infection.<sup>18</sup> The idea that asymptomatic people are candidates for health monitoring in primary care rather than medical intervention has been challenged as outdated.<sup>17</sup> General practitioners, however, have a role that transcends the medical treatment of an infection. Our data would indicate that they can perform an important public health role in prevention, as well as providing long-term, 24-hour care and support for HIV-infected patients and their relatives.

Although most HIV-infected people in both areas claimed that they involved GPs in their care, they used them reluctantly as a substitute for specialist care when that was unavailable. Their desire to maintain confidentiality and avoid stigma strongly influenced the way they perceived and used their GPs.<sup>19</sup> A clear demonstration of confidentiality and anti-discrimination policies is important in comprehensive HIV care. However, the importance of confidentiality may vary. When few people are affected in a small community, confidentiality may be more critical than in the impersonal environment, typical of metropolitan, high-prevalence areas. In addition, clear policies will only work when the attitudes of staff encourage patients to use the service.

There is a need to resolve problems that occur at the primary-secondary interface in both high- and low-prevalence areas.<sup>20</sup> Almost 15 years after the identification of the first cases, HIV care is still not always regarded as a legitimate part of general practice. Our work has led to the development of guidance for professionals and users that is soon to be released.<sup>21</sup> Core recommendations in this guidance are:

1. Formalized channels are needed for the exchange of information between specialist and GP. It must be agreed with patients when communication should begin and how often it should be made.
2. Patients should be advised of the advantages of informing their GP or assisted in finding one with whom they feel comfortable.
3. Users' groups should encourage patients to enter a dialogue with their GP about the exchange of information and anti-discrimination statements in the practice.
4. Clear, local policies should be established for the management of patients who wish to die at home. The role of the GP needs to be clarified.
5. Explicit statements should be displayed in general practices on confidentiality and non-discrimination based on gender, sexuality, ethnicity, HIV status, and drug use.
6. Education about the transmission of HIV and training in universal precautions will increase the confidence of practice staff and reduce their need to know of a patient's serostatus.

7. Training of practice staff should address attitudes to HIV, homosexuality, and drug use.

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