

# Needs and priorities of young people with human immunodeficiency virus

Edward Purssell and colleagues report on a survey to determine how nurses can best respond to care provision for adolescents

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## Abstract

**Aims** To ascertain the views of young people in the UK with human immunodeficiency virus (HIV) about their health care, and to compare these views with the perceptions of nurses involved in this sector and the current social policy response.

**Methods** Young people, aged 16 to 24 years, who have HIV and attend a specialist voluntary organisation and pre- and post-registration nurses attending an HIV care course were selected by convenience sampling. A cross-sectional survey was conducted by questionnaire.

**Results** Hospital-based HIV clinics and services were the favoured source of care. There was consensus among the young people that care providers should be informative and approachable, and that care provision should include help to understand issues, such as pregnancy and contraception.

**Conclusions** Professionals involved in creating future social policy and commissioning services need to respond to young people's priorities and adapt to the patient's developing sexuality and the changing demographics of young people with HIV.

## Keywords

Adolescence, young people, communicable diseases, human immunodeficiency virus

SINCE THE mid-1990s and the introduction of highly active antiretroviral therapy, the human immunodeficiency virus (HIV) has been transformed into a treatable, although still incurable, chronic disease.

A more recent development has been that children who were vertically infected by HIV – that

is, from mother to baby – are becoming young adults. Current treatments allow these young people to lead an essentially normal life, albeit with some restrictions, such as lifelong medication and caution with sexual relationships (Hazra *et al* 2010).

Since the introduction of routine HIV screening in pregnancy in 1989, the number of children infected vertically has fallen dramatically, and more young people are being infected horizontally through, for example, sexual transmission (Health Protection Agency 2011).

Therefore, the epidemiology and experiences of young people with HIV will change over time, reinforcing a needs-led commissioning culture in which healthcare services will be required to adapt to the changing needs and priorities of this group. There are also changes occurring in service provision, most notably an increased focus on quality and cost of care and a move from hospital to community healthcare provision (Miller and Gubb 2011).

## Literature review

Background literature on the subject was obtained through searching local and national policy documents and the broader medical and nursing literature. No time limits were applied to the search criteria, and searches were carried out on Medline and Embase, and the websites of government and major voluntary organisations. The search revealed a lack of data on care provision preferences among this patient population.

This study was undertaken to investigate the views of young people in the UK with HIV about care service provision, and to identify their priorities. By asking respondents directly for their views,

data could be collected that would inform service providers and help shape educational curricula.

The views of nurses attending a specialist HIV care course were obtained to evaluate the extent to which this group of professionals understand, perceive and share these views.

## Aims

This study was aimed at determining the views of young people with HIV about their health care and to compare these views with the perceptions of nurses in this specialty, in light of the current social policy response.

## Methods

Convenience, defined as non-random, patient samples were drawn from two groups: young people aged 16 to 24 years attending Body and Soul, a voluntary organisation providing support for people living with or affected by HIV, and a mixed group of pre- and post-registration nurses undertaking a specialist HIV care course at King's College London. Potential participants were approached opportunistically, either at the adolescent services provided at Body and Soul (young people) or after lectures on the HIV care course (nurses), between November 2011 and February 2012.

Data were collected using a survey that referenced previous questionnaires used by Body and Soul to collect service satisfaction data. The document comprised three sections about provision, information and priorities in health care using a mixture of open, closed, multiple choice and ranking questions and statements.

The resulting questionnaire was distributed to an expert panel for validation and was piloted by five young people with HIV before being distributed to both participant groups. During the validation process subjects were asked to comment on the suitability and wording of each question, as well as the overall content of the questionnaire.

**Ethical considerations** Ethical approval was given by the King's College London Research Ethics Committee, who confirmed that NHS ethical approval was unnecessary. Data analysis and interpretation were undertaken by two researchers, one of whom was a pre-registration nursing student and the other a senior lecturer in charge of the specialist nursing course. This method, however, may have resulted in socially acceptable responses by the nurses.

Confidentiality was maintained as questionnaires were anonymous and did not ask for any personal details, other than data such as age, ethnic origin, gender and HIV status, which were optional.

**Table 1** Demographics of young people (n=31) and nurses (n=43): age and gender

Age (years)	Young people (%)		Nurses (%)	
16-18	8	(25.8)*	0	(0)
19-21	7	(22.6)*	15	(34.9)
22-24	7	(22.6)*	9	(20.9)
25-27	2	(6.5)*	7	(16.3)
28-30	3	(9.7)*	2	(4.7)
31-33	0		2	(4.7)
34	0		1	(2.3)
Did not state age	0		7	(16.2)
<b>Gender</b>				
Male	10	(32.2)†	4	(9.3)†
Female	19	(61.3)†	32	(74.4)†

\* Respondents (n=27)  
† Respondents (n=39) and (n=36) respectively

Neither researcher had links with Body and Soul. Data were analysed by each researcher and agreement was achieved with no major differences identified.

## Results

A total of 74 people responded to the questionnaire, including 31 young people and 43 nurses. Completion rates of the questions answered in the submitted questionnaires were good, although four young people did not complete the demographic questions, which may have been because this question was located on the back of the questionnaire and was missed.

**Demographics** The age and gender of respondents are shown in Table 1. Of the young people, 22 identified themselves as black, compared with four of the nurses; for white ethnicities, the numbers were three and 28, respectively. No data were collected on place of residence or employment of either participating group. With regards to HIV status, 21 (67.7 per cent) and five (16.1 per cent) of the young people answered as positive and negative, respectively. No further medical data, such as CD4 counts or viral load, were collected.

**Table 2** Numbers of young people identifying qualities as important in healthcare practitioners (n=31)

Quality	n=(%)
Advocates for me	25 (81)
Informative and helps me to understand	24 (77)
Supportive and approachable	23 (74)
Non-judgemental	22 (71)
Available and easy to contact	21 (68)
Knowledgeable	18 (58)

**Table 3** Numbers of young people identifying priorities in human immunodeficiency virus care (n=31)

Priority	n= (%)
Promotion of understanding of HIV	25 (81)
Information about sex and sexuality	24 (77)
Provision of condoms/contraception	20 (65)
Pregnancy and HIV	20 (65)
Support with emotional wellbeing	20 (65)
Information about healthy eating	19 (61)
Support with disclosure	19 (61)
Medication and side effects	17 (55)
Opportunities to talk to doctor/nurse about my concerns and feelings	16 (52)

**Source of HIV care** When asked from where they currently received their HIV-related care, 22 young people (76 per cent) reported that it was primarily from hospital-based HIV clinics, four (14 per cent) from their GP and the remaining three (10 per cent) from other hospital service providers. A total of 18 (62 per cent) respondents said they would like to receive their care in hospital-based HIV clinics, five (17 per cent) from their GP, three (10 per cent) from a sexual health clinic and three (10 per cent) from more than one source. Of the 31 young people involved in the survey, two did not respond to the last two questions. Of

those who expressed a preference, 13 (42 per cent) responded that they would like to receive their care from adolescent services, eight (26 per cent) chose adult services and two (6 per cent) chose children's services. Although relatively few young people received their HIV care from their GP, 20 (65 per cent) stated that their GP was aware of their diagnosis, whereas only 12 (27 per cent) of the 43 nurses expected young people to have disclosed their HIV status to their GPs.

Only three (6.9 per cent) nurses correctly thought that young people would prefer to attend an HIV clinic in a traditional hospital setting, although 16 (37.2 per cent) identified that most young people receive their care in HIV clinics in traditional hospital settings. With regards to the age-related context of care, 21 nurses (48.8 per cent) correctly recognised that most young people would prefer specialist adolescent provision, 14 suggested adult services (32.2 per cent) and two (4.7 per cent) more than one setting. One nurse (2.3 per cent) was unsure.

**Disease information** Young people reported that information about HIV was provided from various sources, most notably HIV clinics in 25 cases (81 per cent) and community organisations in 22 cases (71 per cent). However, 15 (48 per cent) named friends and family, 13 (42 per cent) the internet and 13 (42 per cent) their GP as important sources of information, even though relatively few received their HIV care from their GP.

When asked about where they would like to receive information from, 19 (61 per cent) chose HIV clinics, 17 (55 per cent) voluntary organisations and nine (29 per cent) their GP; the internet and family and friends were preferred by six (19 per cent) and online chat rooms by five (16 per cent). Nurses were more likely to think that young people would like to receive information from the internet and chat rooms than was the case, with 27 (63 per cent) and 20 (47 per cent) identifying these preferences, respectively.

**Priorities of care** There were qualities in care provision that were thought to be important, and which tended to be those related to the relationship between young people and their service providers (Table 2). To the question about their priorities for healthcare provision generally (Table 3), 25 (81 per cent) respondents wanted help with understanding HIV, 24 (77 per cent) with aspects of sexuality, 20 (65 per cent) with contraception and 20 (65 per cent) with pregnancy. Twelve nurses (27.9 per cent) thought that understanding HIV and support with disclosure are important care

priorities for young people, but did not ascribe such a high priority to issues that affect all adolescents such as information on healthy eating, which 24 (55.8 per cent) gave as the lowest priority, and pregnancy which 11 (25.6 per cent) gave as the second lowest priority.

## Discussion

When asked from where they currently receive their HIV care, most young people responded that it was from an HIV clinic in hospital, and nearly two thirds indicated that they would prefer to remain in this setting. This preference may conflict with the current changes in the NHS, with moves towards care pathways that stem from primary care and general practice (Miller and Gubb 2011). The young people's choice may reflect the current pattern of service provision, but it may also indicate a fear of stigma in the community should diagnosis be inadvertently disclosed (Anderson *et al* 2008). Neither, were directly investigated in this study. Nearly two thirds of the young people had disclosed their HIV status to their GP, unbeknown to most nurses. Thus an unfounded fear of breaching confidentiality could be limiting interprofessional communication.

In response to a question about the age-related care setting in which they would prefer to receive their care, the most popular choice was that of dedicated services for young people. There is a growing cohort of young people transitioning from children's to adults' HIV services and this will increase as survival rates associated with HIV improve (Foster *et al* 2009). There are a number of transitions that occur during this period, including social, educational and employment changes, many of which are affected by, and may add to, the challenges associated with being a young person with HIV. For example, lifelong reception of medication is desirable for services to be provided in a developmentally appropriate fashion (Gleeson and Turner 2012). But, there are organisational and cost implications to this approach that point to the importance of collaboration and joint working between children's and adults' services.

When asked from where they would like to receive health information, most young people preferred HIV clinics and voluntary organisations. Only a few respondents opted for online services such as chat rooms, perhaps reflecting difficulties in accessing reliable or appropriate information from this unregulated source. The increasing use of online and mobile technologies by individuals and health services may change this view over time. The importance of recognising the limitations



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of the internet as a source of information is shown by research from UK telecommunications regulator, Ofcom. When asked, 27 per cent of 16-24 year olds agreed with the statement: 'I think that if they have been listed by the search engine, [these] websites will have accurate and unbiased information', and 13 per cent reported not worrying about accuracy or bias (Ofcom 2012).

The popularity of community organisations as sources of information may reflect the attendance of young people at such organisations, and supports the move towards joint working arrangements with the voluntary sector (Madge *et al* 2011) and wider user involvement (Hamblin 2011).

When young people were asked what they wanted from HIV services, the top requirement was that service providers should include opportunities for them to gain a greater understanding of HIV. The high priority also afforded to information about sex and sexuality emphasises the need for sexual health education, particularly as a significant number of young people with HIV are sexually active (Koenig *et al* 2011). Suboptimal use of condoms puts young people at risk of sexually transmitted infections, transmission of HIV to others, and unplanned pregnancy (Moses and Dhar 2012). An individual knowingly living with the infection and aware of

Triple-combination antiretroviral drugs have made the human immunodeficiency virus a treatable disease

*Most respondents wanted to be perceived and treated as normal adolescents with their more general needs being paramount*



how HIV is transmitted, who has sex with someone who is HIV-negative without a condom and subsequently transmits it to that person, may be found guilty of reckless or intentional transmission (National AIDS Trust 2010).

Multiple answers were given to the question about which qualities are important in care providers. The three favoured qualities were:

- Advocacy.
- Being informative and understandable.
- Being supportive and approachable.

Most respondents wanted to be perceived and treated as normal adolescents (Hamblin 2011) with their more general needs being paramount – this population has traditionally been expected to adapt to health service providers (Gleeson and Turner 2012).

**Limitations** This study has limitations; in particular, it was based on a convenience sample of young people attending one voluntary organisation, and a group of pre- and post-registration nurses attending a specialist HIV course at a single university.

## Conclusion

The data presented here offer an insight into the needs and priorities of young people with HIV, and

provides those offering care and education evidence on which to base their provision, as well as influence future social policy decisions.

From a clinical perspective, it is important to respond to the needs of this group and that decision makers understand and share their vision of care.

Some themes emerged which might help inform practice. In particular, young people valued the ‘human’ side of care provision, emphasised the importance of their sexuality and are more traditional users of healthcare services than some providers assume.

## Implications for practice

- Specialist HIV clinics and adolescent services are the favoured source of care and information.
- Priorities include understanding HIV issues and treatment, sexuality, pregnancy and contraception.
- Healthcare professionals should be informative, approachable and prepared to advocate.
- Commissioners and care providers should adapt to the patient’s developing sexuality, the changing demographics of young people with HIV and the changing patterns of healthcare provision.

## Online archive

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**Conflict of interest**  
None declared

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