



Report: June 2011

# **The impact of social care support for people living with HIV**

**the results of NAT's snapshot survey of healthcare professionals**



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## Summary of survey findings

This survey strongly illustrates the continuing identified need for social care support for people living with HIV, the positive impact that support has on people's lives and the value placed on it by clinicians.

### ■ Referral to social care

Healthcare professionals frequently refer patients to social care, the majority referring between once a week and once a month. This is a strong indicator of the continuing high level of need for additional support amongst people living with HIV. It is encouraging that healthcare professionals are aware of this need. That healthcare professionals refer so frequently also suggests that they consider local authority funded social care to be a good source of care.

When asked what the main reasons for referral to social care support were, the most frequently cited reasons were those associated with poverty. The high level of poverty-related need was not unexpected as previous research has highlighted poverty as a serious and widespread problem for people with HIV. The need for psychological support was also frequently cited. This is in line with the growing body of research which suggests that people with HIV are more likely to experience psychological need than the general public.

### ■ Access to social care

Almost half of respondents said their patients had trouble accessing social care. Barriers cited included a lack of capacity in local services, high eligibility thresholds and the loss of specialist HIV social care support (with such support being mainstreamed into generic social care services).

Problems accessing specialist support from local authority social services illustrate the heightened importance of the voluntary sector in providing open access, tailored services; a role which was acknowledged by respondents.

### ■ Impact of social care

Healthcare professionals overwhelmingly believe that social care helps their patients. As one respondent put it, social care "helps patients to cope with life!"

The importance of specialist social care support (especially in dealing with poverty-related issues) was highlighted repeatedly throughout the survey responses, as were recent losses of these services and the impact of this on people's care.

In particular social care helps people with HIV by providing physical care, psychological and emotional support, helps people cope with diagnosis, and to adhere to treatment. This supports already existing evidence on the value to wider public health of social care support.

## Introduction

### Aim

NAT carried out a survey to find out what impact healthcare professionals working in HIV feel that social care support has on their patients' ability to manage their HIV and health more broadly.

The aim of the survey was to gather evidence on the value of HIV social care from a medical and public health perspective. Such evidence will be relevant to local decisions on the funding of HIV social care.

### Methodology

The survey was conducted online via Survey Monkey between 7 March and 15 April 2010. It was promoted to members of the British HIV Association (BHIVA), the Children's HIV Association (CHIVA), the National HIV Nurses Association (NHIVNA) and the Society of Sexual Health Advisors via the associations' member lists.

149 healthcare professionals responded to the survey. All questions were optional; therefore not every respondent answered every question. However, all quantitative questions received at least 122 responses.

The survey was anonymous and did not ask respondents for location, so as to ensure that respondents felt able to comment freely. Any identifying information disclosed in comments will be kept confidentially.

The sample was opportunistic and is likely to over-represent those with strong views on social care. Nevertheless, this is a significant number of respondents from amongst busy professionals committed to best practice outcomes. The results offer an important insight into the range of social care need experienced by people with HIV and on the views of healthcare professionals as to how social care benefits their patients.

For the purposes of the survey, social care was explained as services which provide support for people in their daily lives so as to enable them to live independently and play a full part in society. This specifically included services such as counselling, peer support, personal care, respite care, residential care and support for carers. It was also made clear that it included services provided directly by the local authority's

Social Services team, services provided by voluntary sector organisations, and by private providers.

### Interpretation of data

The findings have been grouped by topic into findings concerning referral to social care, the ability of people living with HIV to access social care, and the impact of social care interventions on people with HIV.

The results of quantitative questions are shown graphically and outlined in the text. The responses to qualitative questions have been grouped according to commonly given answers and, where possible, these have been analysed quantitatively. The respondents' responses are also quoted in the report.

Comment is made on the findings in the context of previous research about social care, carried out both by NAT and by other external researchers. The findings are interpreted in the light of this additional research and, where possible, conclusions drawn.

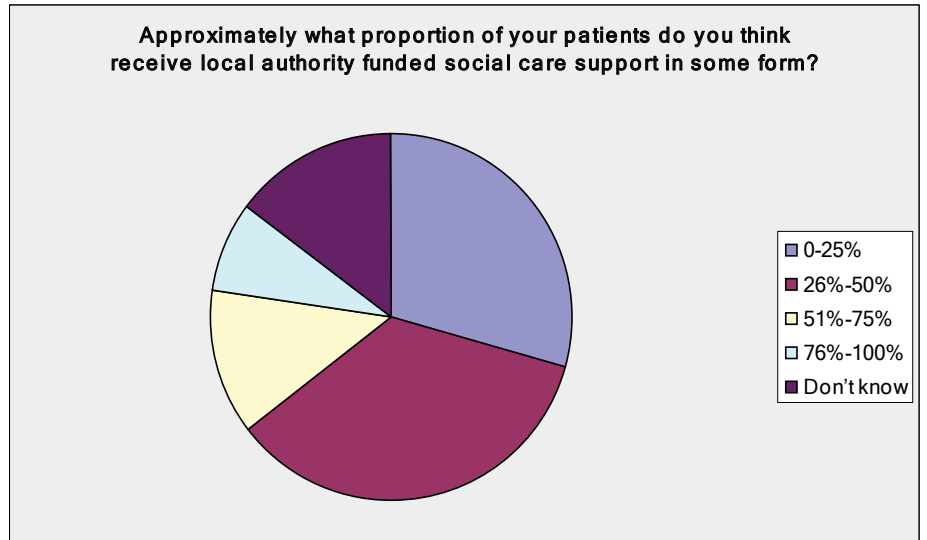
## Findings

### Referral to social care

The survey asked four questions relating to referral of patients to social care services. These looked at the frequency of referral, the percentage in receipt of support, and the reasons for referral.

When asked what proportion of their patients receive local authority funded social care, the majority of respondents thought that up to half of their patients did, which can be broken down into 29.5% who thought up to a quarter did, and 34.9% who thought between a quarter and half did.

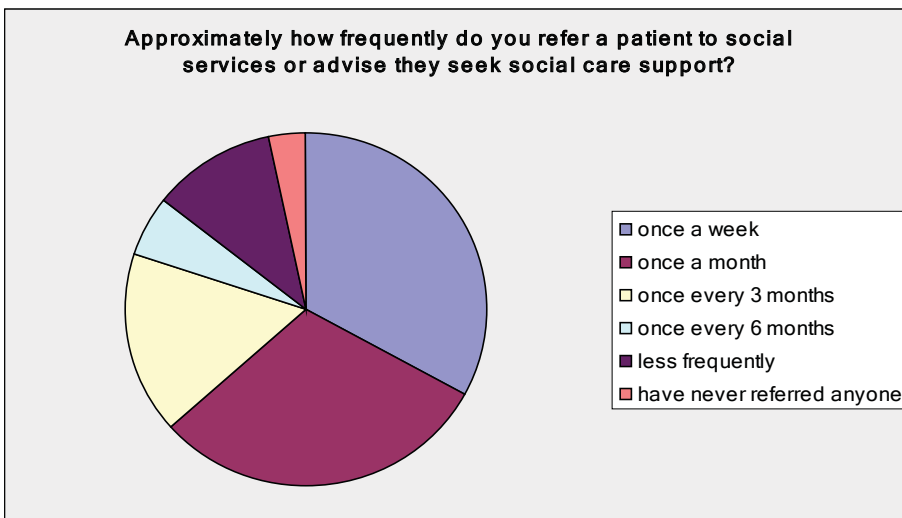
12.8% thought between half and three quarters of their patients received local authority funded social care support, and 8.1% thought over three quarters received this support. 14.8% of respondents were unsure of the number of patients receiving support in this way.



Respondents were then asked how frequently they refer a patient to social services or advise they seek social care support. A third (33.1%) referred patients approximately once a week and almost a third (30.3%) referred patients once a month. 16.6% of respondents referred approximately once every 3 months, 5.5% referred approximately once every 6 months and 11% referred less frequently than once every 6 months.

3.4% were unsure how frequently they referred. However, the majority of respondents (68.5%) found it easy to refer patients to social care services.

The high levels of referral (at least once a month for 65% of respondents) suggest that there is a significant level of need for additional social care support among people with HIV, and that healthcare professionals consider local authority funded social care support to be a good and appropriate source for that care.



Respondents gave a range of reasons for why they refer patients to social services or advise patients to seek social care support. Analysis of the comments made by respondents shows that issues relating to poverty were overwhelmingly the most frequently cited reasons for referral. 64% of respondents cited housing-related issues,

## Findings

35% cited benefits advice, and 31% cited financial problems. Associated issues were also frequently cited; 30% cited asylum/immigration and 20% cited childcare or family issues. Specialist social workers often act as an advocate in regard to poverty-related problems. They undertake a professional to professional liaison role with benefits or housing teams, provide supporting evidence where needed for applications and generally add weight to the case for assistance. This approach can be invaluable in ensuring vulnerable people are able to access the services and entitlements they need. They also provide direct support for people, acting as a key-worker, coordinating their care and generally supporting them. This form of intervention is known as on-going professional social work support. The importance of knowing that there is someone listening to you, who is on your side and helping you can significantly reduce the stress of these situations.

Psychological support, including a need for emotional support and counselling, was cited by a quarter of respondents. And physical support, such as home care, personal care, and support with self-care was highlighted by 18% of respondents.

### Access to social care

Almost half of respondents (45.5%) said that their patients had trouble accessing social care support (29.9% said their patients had not had trouble, and 24.6% were unsure).

Specific barriers within the system to accessing services cited by respondents included a lack of capacity in local social care support services either through a lack of funds or a lack of staff, the threshold for qualifying for local authority support being set too high for people with HIV to qualify, and the process once a referral has been made being very slow.

That there is an almost 50% split between respondents whose

***“Often very difficult to obtain services they need from statutory sector”***

***“I would describe the current service provided as poor”***

patients have experienced problems accessing social care support and those who have not suggest that the provision and availability of support is patchy. This was also recognised in the comments which were made. For example, one respondent commented that they had specialist social workers, whereas another stated that “there is no such thing as HIV specific social care support”.

***“We just seem to have run into a brick wall of resistance from the social work hierarchy to the concept of a ‘dedicated’ HIV social worker”***

***“HIV social work post recently deleted by county council”***

***“The loss of designated services means that social care services are not often aware of the particular needs of people with HIV”***

***“The current move to a ‘generic’ approach to social work is very unhelpful for HIV infected patients, who often have complex medical histories and complex needs – requiring someone with some appropriate HIV-related knowledge to address these”***

## Findings

***“It can be difficult to get social care services to appreciate the importance as they set their severity and threshold criteria”***

***“Social care funding is very restricted and not everyone fits the criteria – even though they do need help. In general it is easier to access voluntary sector services”***

***“The threshold for being able to access services, and limited service mean that it is becoming more difficult to access social care support”***

Changes to eligibility thresholds for local authority funded social care were identified by a number of respondents as a barrier to access for patients.

A number of respondents also highlighted unwillingness among patients to access social care support. Suggested reasons for this included an unwillingness to disclose their status for fear of lack of confidentiality and stigma, a belief that social care will interfere with their life, and language barriers.

***“Many of course refuse to be referred due to fear or someone outside of the mainstream health service knowing about their condition and fear of bumping into someone they know”***

***“Patients are often reluctant to accept help for confidentiality reasons or they feel social care is going to interfere with their lives in a negative way”***



## Findings

### Impact of social care

The final questions focused on whether social care support helps patients and which forms of support in particular are beneficial.

The vast majority (77.3%) of respondents thought that the social care support their patients receive helps them. 19.7% were unsure, and only 1 respondent (0.8%) thought social care support did not help their patients. However, the comments made about this question revealed that although respondents thought that generally it helped patients, the level of benefit varied, for a range of reasons including problems accessing services, the loss of HIV-specific social workers, and variations between local authorities.

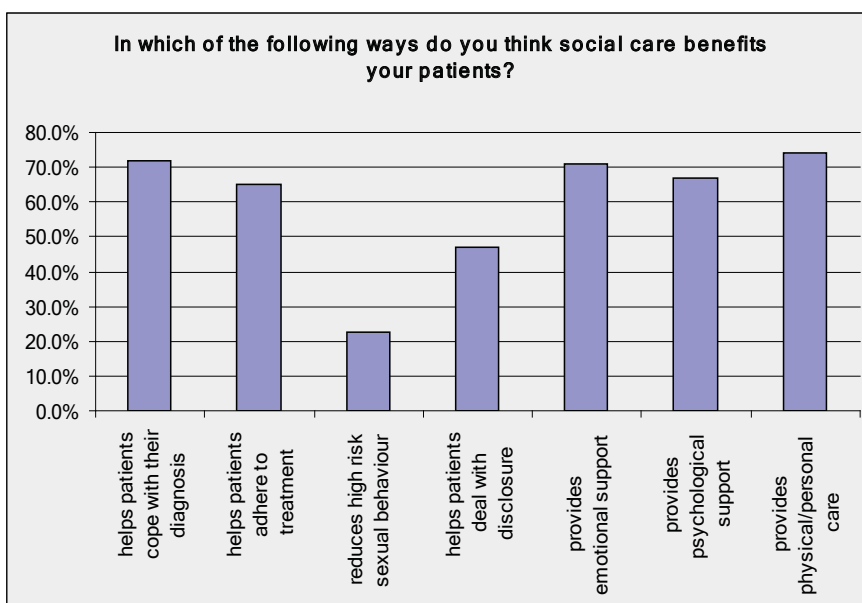
***“Helps patients to cope with life!”***

***“Social care is an integral aspect of someone’s life, it is a piece of the jigsaw that if not there has an impact on the rest of their life – leads to depression, isolation, acopia, lack of motivation etc”***

***“Reduces the challenges and anxieties that some of our cohort face regarding their social care needs, giving the medical team more time to do targeted work relating to the individual’s medical needs”***

***“Social care support is integral to the comprehensive management of HIV-positive patients and their families, especially those belonging to underprivileged communities”***

***“As doctors we are not equipped to provide services around social care support. To the patient these issues are often much more important than the illness itself. I could not cope without the support of social care services”***



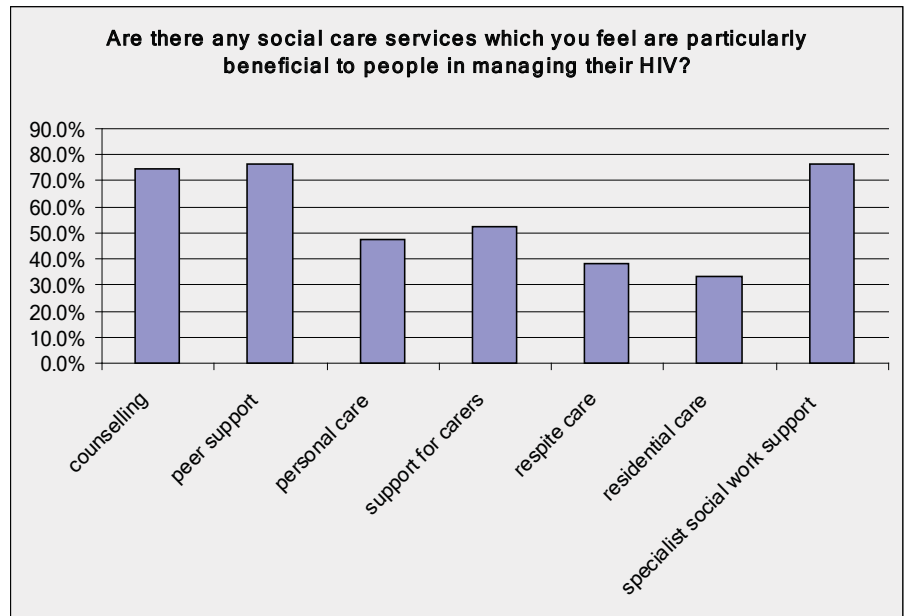
When asked about the ways in which social care support benefits patients, the most frequently cited benefits were ‘provides physical/personal care’ (74.2%), helps patients cope with their diagnosis (71.8%), provides emotional support (71%), provides psychological support (66.9%) and helps patients adhere to treatment (65.3%). These results strongly demonstrate the positive impact social care support can have.



## Findings

A number of specific interventions were highly valued by healthcare professionals. The interventions which were seen to be most beneficial to patients were specialist social work support (76.7%), peer support (76.7%) and counselling (74.4%). However, approximately half of respondents also highlighted support for carers (52.7%) and personal care (47.3%) as being particularly beneficial.

Many respondents specifically highlighted the value of specialist social work support, citing problems of stigma and a lack of understanding about HIV as barriers to people with HIV accessing mainstream social care services.



***“The specialist social care is very important and in my locality this has been completely taken away and the service now provided through the generic social services is woefully inadequate no matter how much individuals try to help they unfortunately don’t have the time and training to provide the service that is needed by our patient group”***

***“My experience has been that specialist services are key for this patient group... there is still an enormous amount of stigma attached to HIV, plus it differs from other chronic conditions in that people often suffer from “episodic disability” ...meaning that they do not always fit the categories imposed by the general services”***

***“Stigma means that people are reluctant to go to generic services with HIV-related issues”***

## Conclusions from the survey

A high proportion of people with HIV have, at some point, social care needs - these include home and personal care support, and emotional/psychological support, but the most frequently cited needs relate to poverty and its associated issues.

HIV clinical staff refer a high proportion of their patients to social care support, do so regularly and value the beneficial impact social care has on their patients' management of their condition.

Social care effectively supports people living with HIV in many aspects of the management of their condition, including coping with diagnosis, adherence to medication, disclosure, safer sex, and in emotional, psychological and physical well-being. Withdrawal of such social care will mean poorer health outcomes for people with HIV, greater risks of onward HIV transmission, and higher costs to public services as

such worse outcomes have then to be addressed.

HIV specialist social care workers are greatly appreciated. There are, however, a declining number of such specialist workers as financial pressures move many local authorities to mainstream social care for people with HIV within generic services. NAT's survey found worries amongst some people with HIV around confidentiality and stigma within social services departments which can act as a barrier to accessing social care. These findings suggest that HIV specialist social care support should wherever possible, be maintained (particularly in high prevalence areas). Innovative solutions should be considered such as a number of local authorities sharing some HIV specialist social care staff to whom complex cases can be referred and who can also act as trainers for generic social care providers. More generally it is increasingly important that all

social care staff are well trained on all aspects of HIV - physical, psychological, clinical and social.

Increasingly high eligibility thresholds are being applied to those applying for individual social care support. The Government has, however, made clear the importance of social care's preventive function in ensuring lower level need does not become acute (and thus more difficult and costly to address).<sup>1</sup> Furthermore, there is a distinct budget line within the local authority Formula Grant for 'HIV/AIDS Support', calculated on the basis of local HIV prevalence, and clearly aimed at meeting such broader need. Local authorities should put arrangements in place to ensure these funds are spent as intended, whether through greater flexibility on eligibility thresholds, greater provision of lower level one-to-one social care support, or greater support for voluntary sector open-access tailored services.

<sup>1</sup> Department of Health, *A Vision for Adult Social Care: Capable Communities and Active Citizens*, (2010)

## Appendix: Survey questions

### HIV clinics survey

#### The role and impact of social care support for people living with HIV

##### Aims of the survey

- To find out what impact HIV clinics feel that social care support has on their patients' ability to manage their HIV and health more broadly
- To gather evidence as to the value of HIV social care from a medical and public health perspective that can be used to argue the case for funding for HIV social care at a local level

##### Introduction - What is social care?

Social care refers to services which provide support for people in their daily lives so as to enable them to live independently and play a full part in society. In terms of HIV specific social care, this may refer to services such as counselling, peer support, personal care, respite care, residential care and support for carers. It also covers other services provided by local authorities to people with HIV.

It can also include assistance to help people overcome barriers to inclusion, for example, supported entry into work.

Social care includes both the services provided directly by the local authority's Social Services team, but also the services provided by voluntary sector organisations, and sometimes private providers. Services are sometimes referral only, but many may be more open access.

This survey is being carried out by NAT. For more information about NAT please visit our website: [www.nat.org.uk](http://www.nat.org.uk)

**Question 1.** Approximately what proportion of your patients do you think receive local authority funded social care support in some form, i.e. either via the local authority social services team, or via a voluntary sector organisation?

0-25%

26%-50%

51%-75%

76%-100%

Don't know

**Question 2.** Approximately how frequently do you refer a patient to social services or advise they seek social care support?

once a week

once a month

once every 3 months

once every 6 months

less frequently

have never referred anyone

## Appendix: Survey questions

**Question 3.** What are the reasons you refer patients to social services or advise patients to seek social care support?

**Question 4.** Generally do you find it easy to refer patients to social care support services?

Yes

No?

Any other comments

**Question 5.** Have any of your patients had trouble accessing HIV social care support?

Yes

No

Don't know

Any other comments?

**Question 6.** Generally do you feel the social care support your patients receive helps them?

Yes

No

Unsure

My patients do not receive social care support

Any further comments?

**Question 7.** In which of the following ways do you think social care support benefits your patients? (select as many answers as are appropriate)

helps patients cope with their diagnosis

helps patients adhere to treatment

reduces high risk sexual behaviour

helps patients deal with disclosure

provides emotional support

provides psychological support

provides physical/personal care

other (please provide details)

## Appendix: Survey questions

**Question 8.** Are there any social care services which you feel are particularly beneficial to people in managing their HIV? (select as many answers as are appropriate)

counselling

peer support

personal care

support for carers

respite care

residential care

specialist social work support

other (please provide details)

**Question 9.** Do you have any other comments you would like to make about social care support for people living with HIV?

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NAT would like to thank BHIVA, CHIVA, NHIVNA and the Society of Sexual Health Advisors for distributing this survey to their members, and all the healthcare professionals who took the time to respond.



[www.nat.org.uk](http://www.nat.org.uk)

## About NAT

NAT is the UK's leading charity dedicated to transforming society's response to HIV. We provide fresh thinking, expertise and practical resources. We champion the rights of people with HIV and we campaign for change.

**SHAPING ATTITUDES.  
CHALLENGING INJUSTICE.  
CHANGING LIVES.**

All NAT's work is focused on achieving four strategic goals:

- Effective HIV prevention in order to halt the spread of HIV
- Early diagnosis of HIV through ethical, accessible and appropriate testing
- Equitable access to treatment, care and support for people living with HIV
- Eradication of HIV-related stigma and discrimination.

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