

Report: July 2010

# Psychological support for people living with HIV



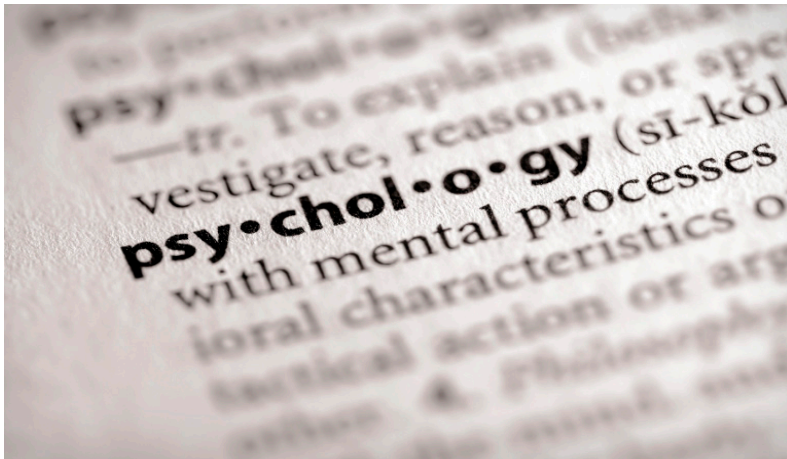
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## Executive Summary

- ▶ There is strong evidence that there is higher prevalence of mental health problems amongst people living with HIV compared with the general population. People with a mental health problem are at greater risk of HIV infection, and people who have been diagnosed with HIV are more likely to develop a mental health problem, for example anxiety or depression.
- ▶ There is also evidence that a range of psychological interventions can make a considerable difference to the long-term health and well-being of someone living with HIV, including how well they manage their condition and adhere to treatment.
- ▶ There are powerful public health arguments for investing in psychological support services for people living with HIV; those receiving appropriate support are less likely to miss medication or engage in unsafe sex – both scenarios in which the risk of onward HIV transmission to other people is increased.
- ▶ There are clearly examples of excellent psychological support services for people living with HIV throughout the UK; some HIV clinics have good dedicated psychological services, and others have effective links with mental health services.
- ▶ Despite evidence of success, there are also problems; these include inconsistency in service provision across areas and clinics, high demand on stretched services and sometimes a lack of joined up working between psychological support services and HIV clinical practice.
- ▶ Consistent, specific standards against which psychological support services for people living with HIV can be commissioned and planned at a local level are missing and are needed.
- ▶ There has been an increased awareness recently within health policy of the value of psychological interventions and the need for extra support for those with long-term conditions - HIV needs to be fully integrated into this strategic approach to long-term conditions.

## Introduction



**In 2009, NAT undertook a project looking into the issue of psychological support<sup>1</sup> for people living with HIV. This topic had been highlighted to NAT as an area of concern by people living with HIV and the organisations which support them, particularly in relation to the extent of psychological need amongst people living with HIV and how it was being met inconsistently, and at times inadequately.**

**In addition, a number of those who were providing psychological services to people living with HIV had contacted NAT to say that they were experiencing cuts to their services, or were concerned that their services were under threat.**

The project began in December 2009, when NAT held three focus groups of people living with HIV, in partnership with Positively Women (now Positively UK), George House Trust and GMFA.

These focus groups provided a snap-shot of some of the psychological needs amongst people living with HIV and experiences of psychological support services. (To read a detailed explanation of the focus groups see page 20.)

The outcomes of these focus groups informed NAT's thinking when planning the next stage of the project.

In February 2010 NAT held an expert seminar, posing the following question: 'What psychological support should people living with HIV receive from locally commissioned health and social care services?'

Sixty people from a range of professions, including clinical psychologists, HIV clinicians, specialist social workers, PCT commissioners and HIV community support workers, attended the seminar to discuss this question.

One participant from each focus group at the beginning of the day provided a summary of what had been discussed at the groups to help ensure that subsequent discussions were user-focused.

The day was then structured around presentations by experts on a range of topics, interspersed with extensive discussion and debate amongst all the attendees. The discussions and outcomes of the seminar form the basis of this policy report.

This policy report is divided into two sections. The first section focuses on the discussions at the expert seminar, highlighting the key issues which arose and areas of debate. The second section draws some conclusions on the basis of these discussions and presents recommendations for action.

1. NAT's definition of 'psychological support' means any form of support which helps people living with HIV with their mental or emotional well-being. This, therefore, covers a range of services which provide this support, from clinical

psychology services to community or peer support services.

## Discussions

**The discussions at the expert seminar fell into two broad categories – psychological needs amongst people living with HIV, and provision of psychological support services for people living with HIV.**

**To reflect this, this section has been divided by theme. Within each strand there was one presentation which provided an essential overview of many of the main issues. Each part therefore begins with a detailed account of this presentation, then describes the discussions during the rest of the day and the key messages which emerged.**

### Psychological needs of people living with HIV

Professor Lorraine Sherr<sup>2</sup> presented the findings from a systematic review of the scientific data on the psychological needs of people living with HIV.<sup>3</sup>

This review, which had been undertaken in collaboration with colleagues,<sup>4</sup> examined all the available studies investigating HIV and mental health, with a particular focus on depression, anxiety, post traumatic stress disorder (PTSD), suicide and coping.

She explained how some areas, for example HIV and depression, have received more attention than other areas, for example HIV and PTSD. This means that the breadth and depth of research findings tends to vary across topics. She also pointed out that research in this area is more frequently carried out in the US, as compared with the UK.

### Mental health problems

Professor Sherr started by reminding attendees that mental health problems are a burden in their own right and they therefore merit attention and care. She explained that psychological problems can be understood to exist at varying levels of severity and chronicity, that they can be acute, reactive, mild, moderate or severe.

An understanding of the differences between various forms of mental health difficulties helps clinicians to decide what form and intensity of support someone should receive. Professor Sherr also outlined studies which show that psychological interventions are able to ameliorate various forms of mental health difficulties.

Professor Sherr highlighted the centrality of mental health when it comes to living successfully with HIV.

She showed how poor mental health can increase the risk of HIV infection, affect someone's ability to manage a chronic illness as well as increase the risk of onward transmission of HIV infection. For example, if a person is depressed or anxious and they are using drugs or alcohol to self-medicate then their chances of being able to practice safer sex may be compromised.

Similarly someone's ability to care for themselves and their health may be affected, as may their ability to protect or disclose their HIV status to their partner.

She therefore explained how mental health is an important factor to consider when thinking about HIV prevention.

2. Head of Health Psychology Unit, Research Department of Infection and Population Health, University College London

3. Supported by Abbott

4. Dr Richard Harding, Dr Jose Catalan, Dr Claudine Clucas, E Sibley, L Ling, N Nagra, G Kulubya

## Discussions

### Psychological problems and HIV

Professor Sherr detailed numerous scientific studies that show that the prevalence of psychological problems amongst people living with HIV is higher than in the general population.

She also highlighted three specific psychological sequelae<sup>5</sup> associated with HIV and its treatment. The first is HIV action in the brain and central nervous system, for example how advanced HIV infection can be associated with dementia; the second is neuropsychiatric effects of HIV medications such as mood or cognitive disturbances associated with certain anti-retrovirals; and the third is the psychological impact of HIV, for example developing anxiety as a consequence of an HIV diagnosis.

Professor Sherr further highlighted the various barriers to identifying psychological problems in people living with HIV.

These include a lack of routine measurement of psychological need within HIV clinical settings, problems associated with managing mental health difficulties in a medical setting, the double effect of clinicians often not enquiring about a patient's mental health and a patient's reluctance to talk about mental health difficulties; and HIV clinicians not being equipped to respond appropriately if there is an identified psychological need.

### Depression, anxiety, suicidal behaviour and PTSD

Professor Sherr highlighted four significant psychological challenges for people living with HIV – depression, anxiety, suicidal behaviour, and PTSD.

She spoke first about depression, which has been identified as the most common psychological challenge for people living with HIV, and which has been most extensively researched.

Professor Sherr highlighted studies which show that people who are depressed are at greater risk of HIV infection in the first place. The available evidence demonstrates that people with depression are less likely to adhere to their HIV treatment; it also shows that depression can (independent of adherence) impact on disease progression, as poor mental health has been shown to increase the rate of immunological decline, so make their condition deteriorate faster than it would otherwise.

She spoke further about effective psychological interventions which can help to ameliorate depression and anxiety (another commonly experienced mood-related disorder that HIV positive people experience), and she highlighted interventions that have been shown to have a high degree of efficacy.

The research on the other two issues which were highlighted – suicidal behaviour, which includes ideation (thoughts), acts (self-harm) and completions; and post-traumatic stress – shows that both of these challenges are prevalent amongst people living with HIV.

Professor Sherr proceeded to add that, in addition to negative mental health, there is a particular dearth of research on the effect of positive mental health on general well-being.

Their recent UK study<sup>6</sup> found that a high proportion of people living with HIV reported a range of symptoms and impacts which resulted from the psychological burden of living with HIV; these included lack of energy, difficulty concentrating, feeling irritable and nervous.

5. 'Residual effects of an illness or injury, particularly effects in the form of impairment' according to Ray Corsini (2002), *The Dictionary of Psychology*, London: Brunner Routledge.

6. Sherr L et al (2007), 'Successive switching of antiretroviral therapy is associated with high psychological and physical burden', *International Journal of STD & AIDS*, Oct; 18(10):700-4

## Coping

A review of coping studies showed that psychological interventions can make a significant impact on how well someone with HIV copes. In fact, psychological support is associated with better coping, treatment adherence, reduced number of hospital admissions and viral suppression.

Professor Sherr made the point that with studies on mental health, there is a strong focus on negative mental health and its implications. There are few systematic studies on positive mental health and its effects, including coping, competence, support seeking and adjustment. She argued that this research could be valuable in making the case for increased psychological support services.

## Other issues

Professor Sherr broadened the area of consideration to examine mental health in relation to post-natal depression. Very few studies monitor this, and those that do show that this is common amongst women living with HIV.

Another under-researched area is around mental health, HIV and children. The HIV-related death of a parent causes psychological distress in children. HIV can also have a detrimental effect on children's cognitive functioning, with outcomes such as special needs or problems at school.

## Psychological interventions

Professor Sherr argued that when it comes to psychological need, it is essential to use interventions which are proven to work. Extensive research has been carried out within the field of mental health on the effectiveness of different types of psychological interventions.

There is a significant amount of evidence around the effectiveness of cognitive behavioural interventions, mixed evidence for counselling, and lots of evidence for using motivational interviewing techniques in the substance misuse field.

### Specific psychological issues which were mentioned during the day included:

- Adjustment
- Alcohol
- Alienation
- Anger
- Anxiety
- Bereavement
- Body image
- Depression
- Diagnosis
- Disclosure
- Drugs
- Fear
- Guilt
- HIV burden
- Illness
- Immigration
- Isolation
- Loss
- Neuropsychology e.g. dementia
- Parenting
- Post-natal depression
- Psychosexual problems
- Rape and sexual trauma
- Relationships
- Self-esteem
- Self-harm
- Sex and sexuality
- Shame
- Side effects
- Social deprivation
- Starting treatment
- Stigma
- Suicide

## Discussions

### Assessment of need

At the end of her presentation, Professor Sherr spoke about the provision of mental health services and how they are able to meet these needs. She said that it is very important to be able to identify whether someone living with HIV has a psychological need. She suggested consistent psychological screening as a way of assessing need.

She also argued that an ideal response model would include both psychiatry and psychology referral pathways once a patient has been identified as having a mental health problem.

Finally, she also highlighted the need for monitoring the support provided and its effectiveness. (See provision of psychological services on page 10.)

### Wider discussions

This presentation provided the scientific foundation for the rest of the discussions around psychological need at the seminar.

There were representatives present from each of the focus groups which had been held prior to the seminar. They reported back about the range of psychological needs which came up at the focus groups, as well as the participants' experiences of psychological support services (for detailed findings from the focus groups see page 20).

This qualitative feedback showed that there were extensive and varied needs, including many of the mental health challenges which Professor Sherr flagged up. This was confirmed by later conversations, particularly during table discussions.

### Evidence

Many attendees felt that there is not a strong evidence base around need in the UK. Most of the research which Professor Sherr spoke about originated from the United States and elsewhere.

The arguments for the cost-effectiveness of psychological support, which are strong and convincing, could be better supported by a powerful UK evidence base. This means not just encouraging more scientific research, but also encouraging clinical and voluntary services to undertake effective monitoring and evaluation.

For example, if organisations think their peer support services are having a significant impact on the mental and emotional well-being of their clients, they should be gathering evidence to make the case for the continuation of these services.

### HIV clinicians and GPs

Several attendees also called for a change in perspective amongst HIV clinicians. It was highlighted that some clinicians only see HIV in terms of medical need, ignoring the potential psychological needs of people living with HIV. If people are to have their psychological needs met, a more holistic approach needs to be taken within HIV clinics.

This also applies to provision of services in primary care. Some PCTs are insisting that a GP is the first place for someone to go if they need a referral for talking therapy.



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If HIV patients are required to go to their GP before being able to access psychological support, it is essential that GPs are able to respond in a sensitive and appropriate manner to the associated mental health burden that patients living with HIV often carry.

### Spectrum of need

Several attendees, as well as Professor Sherr, argued that there is a spectrum of need amongst people living with HIV from lower level need, such as mild anxiety, to more complex needs, for example HIV and pre-existing psychotic illness.

It was felt that if lower level needs could be met more effectively, it could frequently stop a mild problem from escalating into something which requires an intensive intervention. In addition, it was highlighted that a single event, such as a traumatic incident, can transform lower-level needs into higher-level needs requiring more immediate attention.

### Screening

This ties in with a further issue which was raised frequently during the discussions – that there should be an effective way for HIV clinicians to identify which patients need psychological support, for example having access to HIV specific screening tools, and standards for minimal provision



of psychological assessment and intervention services.

This would help clinicians identify who should be referred for further support, particularly those whose needs are not outwardly obvious or acknowledged. Some attendees suggested that there should be routine psychological screening at particular points in a patient's life, such as straight after an HIV diagnosis, when starting treatment, or when there is a significant family or personal event.

Screening patients for psychological difficulties should not assume a narrow HIV-specific definition. Several people highlighted that many people living with HIV have mental health needs which existed before their HIV diagnosis, and that these problems can be exacerbated by having to adapt to living with HIV. This, of course, can go the other way, and mean that pre-existing mental health needs can worsen the HIV-related needs.

It was also noted that often these issues are inter-related, and it can be very difficult to disentangle what is directly caused by HIV, pre-dates HIV or is exacerbated by HIV infection.

Many attendees felt that there were certain groups which may be particularly in need of psychological support. These included patients who do not attend appointments; those who are obviously distressed; patients with a pre-existing mental health diagnosis; people whose mental or physical health is deteriorating; and those with immigration issues. There was also a question raised about whether, in fact, psychological support should be presumed for certain groups, for example children.

## Discussions

### Stigma

Stigma can be a significant barrier to people asking for the psychological help that they need. HIV and mental health are both stigmatised conditions, so the combination of both can be particularly difficult to manage.

This can have individual implications, for example a patient struggling to disclose that they are struggling to cope to a doctor during a consultation. However, it can also have wider implications in terms of commissioning and needs assessments.

One attendee gave the example of cancer patients going to their local press to demand a better service; and how someone with HIV and a mental health problem is far less likely to do that. When commissioners are commissioning services, they need to remember that stigma may stop people from speaking out about their services and what it is that they need.

### Needs assessments

This is linked with the issue of conducting needs assessments. One attendee said that commissioners need clear indicators and outcomes to assist them throughout the commissioning process, from conducting needs assessments for HIV services to evaluating services.

There needs to be a shared language for describing needs and outcomes, and the continued stigma around HIV and mental health have to be taken into account during the commissioning process.

### Understanding HIV

The question as to whether generic psychiatric and psychological services are able to adequately meet the needs of people living with HIV was also raised during the seminar. Opinions on this differed but during the table discussions the preference appeared to be for specialist services. However, the clear message was that whatever the service, the people working within it had to be able to evaluate psychological difficulties within the context of HIV; this requires practitioners to have a good understanding of HIV and its treatment and the possible side effects of the treatment, including the psychological impact of living with a highly stigmatised chronic illness.

### Provision of psychological support for people living with HIV

Dr Barbara Hedge<sup>7</sup> made a presentation which focused initially on the psychological needs of patients living with HIV before progressing on to discussing gaps in service provision.

#### History of HIV psychological services

Dr Hedge provided a historical perspective of the HIV epidemic focusing on the psychological needs of patients before the advent of effective treatments.

She explained how the psychological challenges which patients faced now are very different from those that they previously had to face, namely how to cope with a very serious physical illness, imminent death and the disclosure of a highly stigmatised disease in the face of very limited treatment outcomes.

She said that currently three of the key psychological stressors are medically related stressors, for example illness and CD4 count; life context stressors such as bereavement and relationship difficulties; and disclosure stressors, for example disclosure of sexuality or disclosure of end of life approaching.

7. Consultant Clinical Psychologist/Head of Psychology Services, St Helen's and Knowsley Teaching Hospitals NHS Trust

## FACT

Before the introduction of effective treatment, people living with HIV would frequently make ‘downward’ comparisons, for example, ‘I’m glad I’m still alive’ or ‘I’m so pleased I survived that opportunistic infection’. Now that effective treatments are available and HIV is a long-term condition, when assessing their quality of life people make ‘upward’ comparisons relating to their perceptions of a ‘normal’ life, for example, ‘I’m not able to form a relationship’ or ‘I find medication side-effects difficult to deal with’.

She explained that although these stressors may be HIV related they give rise to common emotional reactions including anxiety, depression, guilt and anger. For these, successful, evidence-based interventions are available.

In the early days of HIV disease, with dedicated AIDS funding, psychological or psychiatric provision for people living with HIV was developed within HIV services to help people with these challenges.

Dr Hedge said that this provision resulted in expert multi-disciplinary services which, as time has gone on, have adapted to the changing psychological needs of those with HIV while medical interventions for HIV have advanced.

#### HIV as a long-term condition

Dr Hedge explained how HIV, in the era of effective treatment, has resulted in the illness being viewed as a long-term condition.

As people continue to thrive on treatment, the demand for access to psychological support has grown. The demographic profile of infected people has also changed, and now includes children, older adults, heterosexual people and people who may have migrated to the UK.

Dr Hedge highlighted how psychological challenges facing people living with HIV may have changed, but the need for help with stress and the emotional impact of living with HIV still remains the same.

Dr Hedge described various ways that people cope with adversity. She described primary and secondary appraisal processes which influence how people interpret and respond to difficult life events.

Dr Hedge highlighted the importance of social support in coping with adverse life events. Dr Hedge also spoke about temporal and social comparisons: which are used to appraise quality of life.

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When striving for a ‘normal’ life, a life which includes work, leisure, relationships, sex and self-determination, the quality of life when living with HIV is often assessed as low. She stressed that today’s problems may be different from earlier problems with HIV, but they are just as valid and people still need support with them.

## Discussions

Living with HIV now, therefore, presents different challenges to what it presented before. Individuals now require help with managing a long-term health condition; multiple physical symptoms which can arise from the condition; the side-effects of treatment; adherence to medication regimes and stigma.

She also pointed out that people with HIV have to live with HIV in addition to other issues, many of which they may have been struggling with prior to diagnosis.

### Coping behaviours

Dr Hedge said that the quest for high quality of life and positive mood determines people's coping behaviours, and that these

behaviours will not necessarily be the most advantageous, particularly in relation to adherence or safer sexual practices.

Dr Hedge argued that psychological care, in conjunction with comprehensive clinical care, can have a positive impact on mood, self-esteem and coping strategies.

## Stepped Care

Stepped care is when there are different levels of care, depending on the severity of the case. The NICE guidance for supportive and palliative care for adults with cancer provides the following model of assessment and support:

Level	Group	Assessment	Intervention
1	All health and social care professionals	Recognition of psychological needs	Effective information giving, compassionate communication and general psychological support
2	Health and social care professionals with additional expertise	Screening for psychological distress	Psychological techniques such as problem solving
3	Trained and accredited professionals	Assessed for psychological distress and diagnosis of some psychopathology	Counselling and specific psychological interventions such as anxiety management and solution-focused therapy, delivered according to an explicit theoretical framework
4	Mental health specialists	Diagnosis of psychopathology	Specialist psychological and psychiatric interventions such as psychotherapy, including cognitive behavioural therapy (CBT)

She highlighted the cost-effectiveness of providing psychological support for people living with HIV – as improved mental health helps patients with adherence which not only improves their quality of life, but clearly decreases the need for medical interventions.

### Therapies

Dr Hedge highlighted the need to identify who is in need of psychological care, through psychological assessment or screening.

She also mentioned that there are numerous therapies which are available to help patients manage their psychological difficulties.

Examples included Cognitive Behavioural Therapy, Acceptance and Commitment Therapy, and other mindfulness-based therapies.

Dr Hedge highlighted the importance of choosing the most appropriate therapy through careful assessment and a review of the available clinical evidence.

### Guidance

Dr Hedge explored the range of guidance available on psychological input for people living with HIV.

She argued that, for high quality care, there needs to be a stepped care approach, which matches the appropriate level of care to the identified needs.

There need to be clear clinical pathways, either starting with one low level intervention then moving to higher levels of further support as necessary (see box on page 12), or following a holistic assessment identifying the most suitable level of intervention and stepping up or down from that as necessary.

Service provision will need to be responsive to the local resources and other established care pathways.

Dr Hedge drew attendees' attention to the National Institute of Clinical Excellence (NICE) guidance on reducing the transmission of STIs,<sup>8</sup> including HIV, which encourages sexual health services to identify sexual risk behaviours and employ behaviour change interventions to decrease these risky behaviours.

She also highlighted how HIV specific guidelines, such as the British HIV Association (BHIVA) guidelines for HIV clinical care<sup>9</sup> and the British Association for Sexual Health and HIV (BASHH) and Medical Foundation for AIDS and Sexual Health (MedFASH) guidelines on the management of sexually transmitted infections,<sup>10</sup> only mention psychological support briefly.

She said that there would be value in having a more comprehensive inclusion and focus on psychological issues and needs in these documents.

As illustrations of how the psychological needs of individuals with a physical illness have been acknowledged, Dr Hedge considered two other NICE guidelines.

The first was the NICE guidance on depression in adults with chronic physical health problems<sup>11</sup> which recommends comprehensive assessment and psychological intervention for patients who are depressed or who have sub-threshold depressive symptoms.

8. NICE (2007), *One to one interventions to reduce the transmission of sexually transmitted infections (STIs) including HIV, and to reduce the rate of under 18 conceptions, especially among vulnerable and at risk groups*, [www.nice.org.uk](http://www.nice.org.uk)

9. BHIVA et al (2007), *Standards for HIV Clinical Care*, [www.bhiva.org](http://www.bhiva.org)

10. BASHH and MedFASH (2010), *Standards for the Management of sexually transmitted infections (STIs)*, [www.medfash.org.uk](http://www.medfash.org.uk)

11. NICE (2009), *Depression in Adults with a Chronic Physical Health Problem: treatment and management*, [www.nice.org.uk](http://www.nice.org.uk)

## Discussions

The second guidance was on improving support and palliative care for adults with cancer<sup>12</sup> which says that commissioners and providers of cancer services should ensure systematic psychological assessment at key points, as well as access to appropriate support.

It advocates a four-level model of care, which includes the delivery of specialist psychological interventions to manage medically related mental health problems, and support for adjustment difficulties.

The Department of Health (DH) report on the psychological management of long-term conditions<sup>13</sup> spoke about how there can be significant cost savings if the NHS manages patients' mental health as well as physical health.

This report said that attention to mental health and well-being through the provision of psychological therapies leads to improvement of people's ability to positively self-manage their long-term physical health conditions.

Thus, Dr Hedge stressed that there is an understanding that appropriate psychological assessment and support should be provided for individuals with a variety of long-term physical conditions. And that these recommendations and documents could be particularly useful for making the case for psychological support for people living with HIV. There should be equivalent provisions for people living with HIV, and these documents could prove a useful lever for advocacy work.

### Recommendations

Dr Hedge went on to present a series of recommendations related to HIV services. The first was that HIV services have to improve their recognition of the need for psychological support, with routine assessment and screening, which echoed Professor Sherr's recommendation.

She argued that initial provision of psychological support would be beneficial – not waiting until there is a problem, but introducing preventive measures such as increasing adaptive coping strategies and social support.

She said that once someone has been identified as being in need of psychological support, there should be provision of this in such a way as to enhance adaptive coping strategies and the management of difficulties.

In terms of the practicality of provision, Dr Hedge said that there needs to be interdisciplinary communication and working between HIV services and psychological or psychiatric services.

She also argued that there has to be appropriate allocation within HIV budgets, within psychology services, and within NHS, private, and voluntary sectors. She said that, clearly, funding has to be available for these services to be provided.

One of Dr Hedge's key concerns was that attention is focused primarily on the medical management of HIV. She said that this is clearly essential but too narrow in focus.

She made it clear that current guidance does not well serve the psychological needs of people living with HIV and that there has to be a role for stakeholders to ensure that this improves.

12. NICE (2004), *Improving Supportive and Palliative Care for Adults with Cancer*, [www.nice.org.uk](http://www.nice.org.uk)

13. DH (2009), *Psychological management of long term conditions, including medically unexplained symptoms*, [www.library.nhs.uk](http://www.library.nhs.uk)

## Wider discussions

Dr Hedge's presentation provided a helpful introduction to how needs are currently being met, particularly within current NHS service provision.

There were also attendees from a range of other settings at the seminar; and to give attendees a flavour of some of these, there were three short talks from representatives of organisations which provide some form of psychological support for people living with HIV.

## Views from outside clinical psychology

Chris Sandford<sup>14</sup> spoke about the patient network and peer support at the Mortimer Market Centre. He focused particularly on the importance of peer support and advice for people living with HIV, and how if someone came into the clinic solely for HIV check-ups and medication, they would be missing half of the picture.

Jo Robinson<sup>15</sup> and Selina Corkery<sup>16</sup> talked about the South London HIV Partnership which is a community-based project jointly commissioned by a group of South London local authorities and PCTs.

They explained how they have health trainers who provide lower level interventions for issues such as living well with HIV, and how these interventions can be very effective.

## Mental health under the New Government

The May 2010 Conservative-Liberal Democrat Coalition Government agreement includes the following commitment:

*“We will ensure greater access to talking therapies to reduce long-term costs for the NHS.”*

However, at the time of writing it was not yet clear as to the future direction of mental health services under the Coalition Government, particularly during a time of cuts in public spending.

Finally, Flick Thorley<sup>17</sup> spoke about the Liaison Psychiatry Service at Chelsea and Westminster Hospital. Her talk was a description of her role as a link between the HIV clinic and psychiatry, and how important it is that patients see someone who has knowledge of, and interest in, HIV.

Dr Mike Youle<sup>18</sup> raised some interesting questions when he spoke from the perspective of an HIV clinician. He said that it was important to identify whose responsibility it is to arrange psychological support, whether it is the HIV clinician or, in fact, a member of staff such as a health advisor.

He spoke about how, unlike patients with other conditions, people living with HIV are able to choose where they go for their care. Therefore, they could choose to go to a clinic where the psychological support services are particularly good if they are unhappy with the support they currently receive.

The representatives from each of the focus groups also spoke about group members' experiences of psychological support services. They spoke about the range of experiences and highlighted some common concerns (for detailed findings from the focus groups see page 20).

This qualitative feedback showed that psychological needs which had been discussed earlier were not being consistently met by services.

14. Patient Representative, Mortimer Market Centre

15. HIV Support Services Manager, Terrence Higgins Trust

16. Editorial Team Manager, NAM

17. Clinical Nurse Specialist HIV and Mental Health, Chelsea and Westminster Hospital

18. Director of HIV Clinical Research, Royal Free Hospital

## Discussions

### Provision of psychological support

There were several key messages relating to the provision of psychological support for people living with HIV, many of which arose during the table and panel discussions.

The main point which arose in relation to NHS psychological services was concern about their capacity to meet the existing level of need.

A couple of attendees said that the number of people needing the support of these specialist services was increasing, but the services are unable to keep pace with this growing demand.

There was also concern about whether services are fully equipped to meet the full range of needs of people who also have co-existing physical health problems.

A participant also asked whether there should be more information on how to match services to patient need.

There were comments on the variable quality of post-test counselling. In addition, several attendees thought that patients need to be better informed about what services are available to them; this included ensuring that services are well described and well sign-posted.

A couple of people also said that patients should be told that there is flexibility in terms of their care and that they can change HIV clinics if they are not satisfied with the service that they are receiving.

There was a significant debate about the role of the voluntary sector as a provider of psychological support. It was highlighted that the voluntary sector is providing services, such as peer support, which are clearly an essential lifeline for many people living with HIV. It was noted that commissioners should recognise the importance of peer support and advice when commissioning services.

Not only are these services important in and of themselves, but they also mean that people living with HIV do not have to approach the NHS for help; in fact, community support organisations are often filling in gaps where NHS provision is patchy or over-subscribed.

However, some attendees expressed strong concern about voluntary sector workers working without the required qualifications or skills. One attendee argued that best practice is when the voluntary sector supports the work of professional NHS healthcare workers, rather than replaces them.

### Standards

Many attendees echoed Dr Hedge's comments about guidance and strategies for other long-term conditions, such as how systematic psychological interventions are being recommended for other long-term conditions, but not HIV.

Other people mentioned that clinical documents, such as the BHIVA guidelines, only make limited reference to psychological support.

There was a strong consensus amongst attendees that specific standards for HIV psychological support would be valuable, because if well-written and well-used, they would improve the quality of care, as well as the consistency of care across the country.

It was felt that the cost-effectiveness argument, deployed across the long-term conditions guidelines, could be a useful policy hook to make the case for the importance of these standards.

The point was made that standards should not be confused with best practice guidelines, which is an important but separate piece of work which could follow on from a standards document.

## Commissioning

Commissioning was the second area which was debated at length, and this linked in with the discussions around standards as it was felt that standards, models of care, and best practice were needed to inform commissioning.

It was argued that it is important for stakeholders to support commissioners, and that joined-up commissioning between sexual health, mental health and community services is important.

Concern was expressed about PCT boundaries and problems that arise when patients are able to access HIV care anywhere in the country, but if they need a referral, for example to see a psychiatrist or to attend a drug rehabilitation centre, they will be referred back to their local PCT.

## Funding

The question of funding came up more than once, with some attendees suggesting that psychological assessment should be included within the HIV tariff, but with the potential risk of a low figure limiting the amount of psychological support that could be offered.

There was also the suggestion that services could be more astute at using existing funding streams and triggers to obtain funding.

It was also proposed that potentially stakeholders could also adapt existing outcome measures such as Key Performance Indicators (KPIs) as a hook to obtain suitable services.

## Conclusions

- It is clear that there is higher prevalence of psychological need amongst people living with HIV compared with the general population. People with a mental health problem are at greater risk of HIV infection, and people who have been diagnosed with HIV are more likely to develop mental health difficulties. It is also clear that these psychological needs are not being met consistently or being addressed strategically.
- It is essential that those commissioning services are aware of the double stigma that those with HIV and a mental health problem might face. Both of these conditions are highly stigmatised and this can stop those affected from speaking out about their treatment and services. The health service needs to make an extra effort to compensate for the silencing impact of this stigma, particularly when undertaking needs assessments and evaluating services.
- Meeting psychological need is an important objective in and of itself. People living with HIV should not be required to struggle with depression, anxiety, or any other mental or emotional problem alone.
- However, there are also clinical reasons why psychological support is beneficial. Research shows the considerable impact that mental health can have on physical health and on how someone manages their HIV. For example, depression is shown to have an effect on how well someone adheres to their HIV treatment. Clearly, it is cheaper for the NHS to invest in a psychological intervention such as ten sessions with a clinical psychologist, than to pay for immensely costly treatment for someone who has developed resistance to their anti-retroviral therapy.
- Psychological well-being can also influence other aspects of behaviour, including whether people engage in unsafe sex. There are, therefore, strong public health arguments as to why investing in psychological services for people living with HIV is more cost-effective in the long run. Those receiving appropriate support are less likely to miss medication or engage in unsafe sex – both scenarios in which the risk of onward HIV transmission to other people is increased.

## Recommendations

### Standards

- ▶ The Department of Health (DH) should be consistent across long-term conditions and ensure that, just as it has committed to standards of psychological care and support for cancer, it commits to similar provisions for HIV.
- ▶ Relevant professional bodies, in particular the British Psychological Society (BPS) and British HIV Association (BHIVA), should collaborate to draft and publish standards on psychological support services for people living with HIV, involving a broader group of stakeholders.
- ▶ Services should be commissioned on the basis of these standards and should include clarity on how needs are assessed, and outcomes measured.
- ▶ When possible, commissioning should be joined up between mental health, sexual health and community services.
- ▶ The DH should ensure that the HIV Outpatient Tariff, which is currently in development, reflects the standards.
- ▶ Relevant professional bodies such as BHIVA and MedFASH (the Medical Foundation for AIDS and Sexual Health) should include or improve the relevant content on psychological support when updating existing standards for HIV clinical care and management.

### Research

- ▶ The BHIVA and BPS should advocate for more UK research into psychological need amongst people living with HIV and what interventions prove effective in meeting this need.
- ▶ Providers of psychological support services for HIV, including those in the voluntary sector, should develop tools for evaluating their services so they can demonstrate evidence of their effectiveness, including cost-effectiveness.

### Screening

- ▶ The BHIVA audit of care for those with complex psychosocial needs in 2011/12 should include an information gathering exercise to find out what tools and processes are being used in HIV clinics to screen patients living with HIV for psychological need.
- ▶ The BPS and BHIVA should develop tools, or disseminate pre-existing tools, for healthcare professionals in HIV clinics to assist them in assessing whether an HIV patient is in need of some form of psychological support.

### Services

- ▶ All psychological and psychiatric services, whether generic or specialist, should be appropriately HIV literate and be aware of recommended referral pathways.
- ▶ GP services which are very frequently an important component of the psychological care pathway should be HIV literate and understand the implications of an HIV diagnosis on mental health, as well as refer on to specialist services when necessary.
- ▶ HIV and sexual health clinics should offer behaviour change interventions to increase safer sex practices.
- ▶ HIV and sexual health clinics should provide post-test counselling and ensure that this is carried out to a high standard.
- ▶ Increased levels of psychological assessment and treatment should be available for patients at certain points, for example, when starting treatment or changing treatment, or when going through the immigration system.
- ▶ Commissioners of services should acknowledge the importance of peer-led services and ensure continued investment in these.

## Appendix - Report of the Focus Groups

From December 2009 to January 2010 NAT held three focus groups, in partnership with Positively Women [now called Positively UK], George House Trust and GMFA, to find out about psychological needs amongst people living with HIV and their experience of psychological support services.

These focus groups provided a snap-shot of some of the key psychological issues people living with HIV face and informed NAT's thinking when planning the expert seminar.

Each of the three partner organisations recruited for the focus groups. Positively Women recruited female service-users living with HIV, George House Trust recruited black African male and female service-users living with HIV, and GMFA recruited gay men living with HIV who are members of their volunteer network.

The focus groups, therefore, had a range of people of different ethnicity, sexuality, age, gender, and experience. In total, 32 people took part in the focus groups.

NAT facilitated each of the focus groups and asked a range of open questions to generate discussions. The definition of psychological support was explained as 'forms of support which help people living with HIV with their mental or emotional well-being'. This was to ensure that the discussions could be as broad as possible and would include informal as well as formal forms of support.



**I remember when I was first diagnosed... I wanted somebody to talk to who had been diagnosed a long time who had gone through a few treatments, so I could say 'what the hell is all this about? I've got one hundred and five leaflets and I don't know which one of them I should read'.**

Each focus group had different atmospheres and emphases. At Positively Women much of the session focused on peer support and how it helps meet psychological need, at George House Trust the group emphasised experiences of the immigration system and the impact that these have on mental and emotional well-being, and in the GMFA session the discussions were much more orientated around psychological support services, particularly within the NHS.

### What are the psychological needs?

There were a range of issues that focus group participants felt they needed psychological support with. These can be divided into four categories: managing HIV, psychological implications of an HIV diagnosis, relationships and other issues.

#### Managing HIV

Two issues relating to managing HIV came up at every focus group. The first was receiving an HIV diagnosis and how psychological support at this time would be helpful.

There were discussions about the shock of initial diagnosis, fears for the future and how overwhelming the experience was.

One GMFA participant said that when he was first diagnosed he was overloaded with information and wished there had been someone he could talk to who understood what he was going through.

The second topic was disclosure; many participants were fearful of the potential consequences of disclosure, for themselves and for others, especially loved ones.

Disclosure was mainly spoken about in the context of family, friends and acquaintances, but also arose in relation to the workplace in the GMFA focus group.

In the Positively Women focus group, disclosure was linked with the issue of starting treatment, and how taking medication can disclose HIV status.

One woman had felt compelled to tell her children about her HIV because they had seen her pills. It was felt in this group, and in the GMFA one, that starting treatment was another time when psychological support could be helpful.

**“ You know, and the depression is horrendous. You know, this, it’s not ordinary depression, you can’t even lift your head. I mean, in my case, I can’t even sleep at night...”**

The physical effects of HIV were also highlighted in these two groups. Support with pain management, particularly the mental and emotional implications of chronic pain, was mentioned by a couple of people, as was having help with the side-effects of treatment and coping with illness.

### Psychological implications of HIV diagnosis

The topic of anxiety arose in all of the focus groups, particularly in relation to concern about the future and worries about the consequences of HIV for loved ones.

One GMFA participant had experienced such severe anxiety at one point in the past that he was unable to function normally or hold a coherent conversation.

The issue of depression was another significant topic spoken about in all of the groups. There were concerns about anti-depressants – that they might interact with HIV drugs, or be ineffective – as well as discussions about the severe impact that depression can have on someone’s quality of life.

Both of these were psychological conditions which some participants felt they needed support with.

Of equal importance during discussions were two inter-linked areas which came up in all three focus groups.

The first was stigma and its many effects, including loss of confidence, and feeling fearful of disclosing HIV status. This was very tied into discussions around self-esteem and the way that stigma is often a significant factor in low self-esteem.

The George House Trust focus group spent a significant part of the time talking about low self-esteem, and the impact that immigration status also has on this (see ‘Other’ on page 22). This was an area in which people felt some form of support would be helpful.

In the Positively Women and the George House Trust focus groups, several people spoke of contemplating, and in one case, attempting suicide. This was spoken about as a perceived escape from life’s difficulties, during a time of great distress.

One Positively Women participant said that after being diagnosed with HIV she thought that it would be easier to kill herself than confront an uncertain future.

The issue of escape also came up in relation to alcoholism. In the George House Trust focus group, participants discussed how some people turn to alcohol as a way to avoid confronting their problems.

## Appendix - Report of the Focus Groups

### Relationships

Many participants in all of the groups talked about needing some form of support with managing relationships with partners, family, friends and community, whether it be support with disclosure, help at times of crisis such as relationship breakdown, or support with forming relationships.

Someone at the George House Trust group said that having HIV had affected his confidence when it came to starting relationships and was concerned about disclosing his status later on.

**“ ...it’s just me alone looking at the four walls. Maybe just listening to the radio... Isolation. You’re isolated. Yeah, like you’ve gone in a jail. You’re alone there.**

Tied in with this was concern about isolation in the Positively Women and George House Trust focus groups.

Additional issues which came up in both of these groups included bereavement and how to deal with the loss of a loved one, and difficulties around negotiating safer sex, particularly in the context of lack of confidence and being in a dependent relationship.

One person at George House Trust asked how a woman could be expected to request that her partner use a condom if she was fully dependent on him to provide for her.

### Other

One of the most significant topics to emerge, particularly from the George House Trust focus group, but also from the Positively Women one, was the needs of migrants, especially asylum seekers.

Many participants discussed the impact of unsure immigration status on self-esteem, particularly the effects of being unable to work and being dependent on vouchers to survive.

A range of problems were highlighted as resulting from unsure immigration status, from drinking too much as a result of not being able to fulfil community expectations, to suicidal thoughts because of fear of deportation.

**“ I know that anytime I can be taken and moved back. And sometimes you think of taking medication. What’s the point? I’d rather leave it because I take this medication and the second time, the next time I’ll be sent back to my country where I won’t get this medication. You just feel like just surrendering your life.**

One person in the George House Trust session said that she was hoping to become unwell because she thought it would increase her chances of being allowed to stay in the country.

Participants in both the Positively Women and George House Trust focus groups raised the impact of mental health on physical health and how good mental and emotional well-being can have a considerable effect on how well someone manages their HIV.

In the GMFA focus group, one issue which came up was the sense of feeling pressure to be fine and to carry on as normal, because a lot of the messages about HIV now stress that people with HIV can live normal lives.

Another topic raised was the needs of older people with HIV and what form of provision, such as dementia care, there will be later in life for them.

## What forms of support are meeting these needs?

There were several different forms of support which were identified during the focus groups as meeting, or not meeting, this need.

These can be divided into categories: HIV support organisations, HIV clinicians, NHS psychological services, counsellors (within the NHS and within the voluntary sector), informal forms of support and other.

### HIV support organisations

At Positively Women, the importance of peer support was discussed extensively. It was deemed to be effective because it is 'very human'.

It was felt by members of the group that people going through the same experience would have more understanding of what their peers are feeling than those not in the same situation.

Some participants also highlighted the benefit of being supported by peers with knowledge, as well as experience, of HIV.

At George House Trust, the advantages of attending an organisation where other people are in a similar situation were also raised. The discussion focused significantly on the difference between 'formal' support, such as George House Trust, and 'informal' support, for example, family, friends and community.



**...it's like sometimes they send you to the doctor, they send you to the psychologist, they send you to the social worker. You know, everybody is like a professional. And instead what I got from peer support was something very human. It was somebody who knew what I was going through because they were going through it themselves.**

It was felt by many in the group that formal support was more consistent, more confidential, and less judgemental than informal support (see 'Informal forms of support' on page 25).

There was little experience of support groups amongst participants in the GMFA focus group. One participant said he was unaware of any groups except for one high profile service provider, whereas another said that he did not know of any good support groups.

### HIV clinicians

One issue that came up at every focus group was how some clinicians do not ask wider questions relating to mental or emotional well-being.

In the Positively Women focus group, one participant said that because she was white and middle-class she was not offered any additional support by her doctor, because they assumed she would cope.

One GMFA participant said that if a patient looked fine, their clinician would probably assume they were, and not bother to ask about wider well-being. However, another person in the group felt that their doctor was interested in non-medical matters and did ask broader questions.

## Appendix - Report of the Focus Groups

### NHS psychological services

The GMFA focus group spent the most time discussing NHS services. Much of the discussion was negative, highlighting the lack of funding and the cutting of services in some places, as well as how provision across the country is inconsistent and something of a 'postcode lottery'.

There was particular concern in the group about how someone living with HIV would access support if they did not live in London, particularly if they live in a rural area.

There were also frustrations amongst the group with actual services, particularly long waiting times and time limitations (for example, each patient being allowed a maximum of ten sessions with a psychologist).

Some participants felt that the process of being referred for psychological support could be unnecessarily complicated, and raised the question of how 'bad' someone would need to be before they could actually access a psychological service.

It was also highlighted by a couple of participants that many services are strict about ensuring that the psychological problem is HIV-related before help will be offered; they felt that, in reality, it is too simplistic to try to disentangle the issues into 'HIV-related' and 'not HIV-related'.

There were people in the GMFA group who also had positive things to say about NHS services, including a few participants who had had good experiences.

For example, one man had had some effective sessions with a psychiatrist for anxiety, and another person felt that the NHS was more reliable than voluntary services.



**I think it's a bit of a post code lottery, really. Depends what clinic you go to and what services they have. My experience has been really good in terms of the support I've had. And I hear from other people that it's not been good. So I think it just depends...**

The other two focus groups focused on services a lot less. However, at Positively Women one woman had found her NHS psychologist very helpful, particularly for encouraging her to attend a support organisation.

Another person was unable to see a psychologist despite wanting the help of a professional, because she was deemed not to meet the high threshold of eligibility; she said that she was considering moving because of the dearth of useful services in her area.

Some participants at George House Trust echoed the frustrations of the GMFA group around long waiting times and insistence that psychological problems have to be HIV-related.

### Counsellors (within the NHS and the voluntary sector)

At least one person in every focus group had negative comments about counselling. Criticisms ranged from a participant at the Positively Women group who felt that it did not help, to someone at GMFA whose counsellor behaved inappropriately.

The issue of waiting times to see a counsellor also came up on more than one occasion. One woman at George House Trust said that she had been unable to afford to get transport to a counsellor who she had been referred to, and had been waiting for over a year to see one closer to where she lived.

However, others had positive things to say about counselling, including someone at George House Trust who said that counselling had really helped her come to terms with her HIV diagnosis, and another who said that it had helped improve his self-esteem.

### Informal forms of support

All of the focus groups discussed how often mental and emotional support are provided informally by partners, friends, family and the community.

Many participants in the GMFA focus group made it clear that these forms of support were the norm and that they would only use services either when a problem became quite serious, or they felt they needed to speak to someone who is not emotionally involved.

The emphasis in the Positively Women and George House Trust focus groups was different. The discussions focused far more on concerns about relying on informal support. This was for a range of reasons, including not trusting other people to react appropriately, to a reluctance to rely on others because of the potential burden it might place on them.

However, there were some in the groups who highlighted how helpful family members and friends had been in providing support.

In the George House Trust and GMFA focus groups the topic of getting support from the internet was also raised, particularly forums and online support networks.

One participant in the George House Trust Group explained that she had found a network of women living with HIV, which is partly web-based, and really appreciated being able to email them about certain issues.

Someone in the GMFA focus group had found an online group of men who had been diagnosed for a long time and he said that it was one of the best forms of support that he had accessed, and when he was newly diagnosed, they were the people he wanted to talk to the most.

### Other

At the GMFA focus group, several participants made it clear that they felt that Social Services were not a viable means of support for someone living with HIV, unless they were 'at death's door'.

A couple of people said that they did not think people living with HIV were a priority for social services, and that they just focused on children and the elderly.

At the George House Trust focus group, the church was flagged up as a potential form of support. However, feelings about this were mixed.

Some participants felt that the church often had negative attitudes towards HIV and that pastors could be judgemental, while some felt that the church could be a helpful form of support and that it very much depended on which church it was.

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## About NAT

NAT is the UK's leading charity dedicated to transforming society's response to HIV. We provide fresh thinking, expert advice and practical resources. 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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