

### **Executive Summary**

- Services that deliver HIV care across the UK were invited to complete a site survey and patient case note review using a proforma based on auditable outcomes of the Standards for Psychological Support for Adults Living with HIV.
- The response rate was roughly one-third of those invited to participate.
- Regarding the standards of support being met in clinical practice, findings indicated that where psychological needs were identified, management of these needs was generally in keeping with the stepped care model. However, there appeared to be a distinct lack of documentation of mental health history, risk and psychological well-being needs in general. The rate of cognitive screening was also extremely low.
- Regarding service 'set up' and processes, there appeared to be a lack of local policy (for psychological support, risk and treatment adherence), and variation across services in relation to access to relevant professionals. Psychological and cognitive screening tools also varied considerably across sites as did the access to psychological support training. The latter was completely absent for almost half the services.
- Recommendations include the need for a psychological support training package, a call for an increase in local policy development regarding psychological support, risk and treatment adherence, the potential utility of annual review clinics to implement the standards and a requirement for the national standardisation of psychological and cognitive screening tools. Plans for dissemination of findings and future research are also outlined.

# Context: Psychological support needs and implications for nursing

The prevalence of psychological distress among people living with HIV (PLWHIV) is substantially higher than that of the general population (1,2,3), with PLWHIV twice as likely to be diagnosed with depression (4). HIV tends to be concentrated in vulnerable and stigmatised populations, who are already at greater risk of mental health problems than the general population (5). Psychological difficulties can also result from an HIV diagnosis and the challenges of living with the disease (6).

The standards for psychological support launched in 2011 were intended to address this and bring about the creation of services to meet these demands (7). The standards are reinforced by governmental public health policy placing equal emphasis on physical and mental health (8). Furthermore, central government's ambitious mental health strategy, *No health without mental health* (9), acknowledges that mental health is central to our quality of life. The report stresses that it is everyone's business, with good mental health and resilience being fundamental to our physical wellbeing, relationships, attaining potential and achieving goals.

As HIV nurses are often on the frontline and are well placed to play an integral role in the provision of psychological support, it seemed pertinent that the National HIV Nurses Association (NHIVNA) undertook an audit to assess whether the standards for psychological support are being implemented in clinical practice. The intention was also to highlight any gaps in service provision and subsequent training needs.

### Aim

To conduct a National HIV Nurses Association (NHIVNA) audit to investigate the implementation of the Standards for Psychological Support for Adults Living with HIV in order to identify any training and support needs for clinicians.

# **Objectives**

- To identify to what extent the standards of care for psychological support for people living with HIV are being met within clinical practice
- To identify any gaps in current services based on the standards for psychological support in relation to patients' psychological well-being
- To identify strategies to improve the assessment of psychological well-being and provision of support based on the audit findings

# Methods

An audit working group was established, including representatives from The British Psychological Society, National AIDS Trust, UK-CAB, British HIV Association, MEDFASH and Royal College of Nursing (RCN). The working group then developed an audit proforma based on auditable outcomes of the standard for psychological support for adults living with HIV and a matrix was created to cross reference audit questions and the specific standards. All of the eight standards were referenced at least once; however, due to the methodology utilised some standards were more frequently represented than others.

UK services providing HIV care (previously identified by BHIVA audits) were invited to participate in the audit of the standards for psychological support for adults living with HIV. Each service was asked to complete and electronically submit a site survey and a designated number of case note reviews based on service size. Once completed and submitted, the results were compiled in a preliminary report by the project manager.

# **Response rate**

Fifty two sites (roughly one-third of those invited) participated in the audit, submitting data on 1,446 patients in total.

# **Key Findings**

The key findings are presented with reference to relevant standards for psychological support for adults living with HIV (British Psychological Society, BHIVA, MEDFASH, 2011) and auditable outcomes.

To what extent are the standards for psychological support for adults living with HIV being met within clinical practice?



### Documentation of psychological well-being

#### Standard 5 (5.4.1)

Of the 1,446 case notes reviewed, information regarding psychological well-being was documented in 899 (62.2%), meaning there was no recording of psychological well-being in 547 (37.8%) of the cases.

Where documentation was made, 509 (56.6%) cases were recorded as coping well, with no psychological support required, 176 (19.6%) cases required some information and support for self-management, 167 (18.6%) cases were recorded as having significant levels of distress and/or need for specific psychological support and 47 (5.2%) were recorded as being likely to have a diagnosable psychiatric condition.

#### Management of identified psychological well-being needs

### Standards 2, 4 & 5 (2.4.1; 2.4.2; 4.4.1; 5.4.2)

Of those who were identified as coping well, for some reason (unclear within the scope of this audit) 3 (1%) were still referred to external services and 14 (2%) were supported within clinic with no referral. Where there was some identified need for support/self-management, 62 (35.2%) were referred to an external service and 130 (55%) were supported in clinic with no referral. In cases where significant distress was noted, 118 (71%) were referred to an external service and 100 (27%) were supported in clinic with no referral. When cases were documented as likely to have a diagnosable psychiatric condition, 37 (78.7%) were referred to an external service and 14 (11%) were supported in clinic with no referral. Some cases were both supported in clinic as well as receiving an external referral, and overall 89.4%–97.6% of cases (across all levels of need) received one or both forms of support where some psychological needs were identified. Patterns of referral varied across level of need; 22 (59%) of 37 individuals referred for likely diagnosable psychiatric illness were referred to local secondary care (eg CMHT) services compared with 14 (12%) of 118 of those referred for significant distress and/or need for psychological support (see Table 1).

However, in 21 (5.4%) of the 390 cases audited where some psychological need had been identified (all levels of need based on the step care model) there was no documented management. In 30 (20.1%) of all 1,446 case notes audited the responder was uncertain regarding the management of psychological need; however, in 18 of these cases the initial documentation of psychological well-being was also absent.

#### Documentation of mental health history and risk

#### Standards 2 & 5 (2.4.1; 2.4.2; 5.4.2)

Documentation of mental health history relates to any reference to a person's mental health (e.g. psychological distress, anxiety, depression, psychosis). For the purpose of this audit risk was defined as potential harm to self or others (e.g. suicidal thoughts, self-harm, aggressive threats).

In 339 (23.4%) of the total cases audited there was documentation of a history of mental health issues. In 282 (19.5%) of the total cases audited it was made clear that there was no history of mental health issues for these particular patients. However, in the majority of cases (768; 53.1%) there was no reference to mental health status or history, meaning there was no documentation at all regarding psychological well-being. Additionally, for 57 (3.9%) cases, the respondent marked the 'unsure' option or the item was left unanswered. This suggests that there was also no clear documentation regarding mental health for these clients.

Among the cases where there was a documented history of mental health issues, in 49 (14.5%) there was documentation of risk and in 66 (19.5%) there was documentation that an assessment had found no significant risk. This means a risk assessment was carried out in 115 (34%) cases. However, in 212 (62.5%) cases there was no risk related documentation within the last two years and in 12 (3.5%) cases the respondent was unsure or the item was left unanswered.

2015

Table 1: Types of external service to which individuals were referred, according to level of need	individuals were referred, acc	ording to level of need		
	Likely to have a diagnosable psychiatric illness	Significant level of distress and/or need for specific psychological support	Some need for information and support for self-management	Coping well with no psychological support need
Number (%) referred to external service: totals	37 (100)	118 (100)	62 (100)	3 (100)
Local secondary care (e.g. CMHT)	22 (59)	14 (12)	1 (2)	2 (67)
Local primary care (GP or IAPT)	16 (43)	35 (30)	17 (27)	0) 0
Liaison psychiatry team	6 (16)	13 (11)	3 (5)	1 (33)
Psychological medicine team	5 (14)	11 (9)	3 (5)	0 (0)
Local crisis team	4 (11)	6 (5)	1 (2)	0) 0
Other non-statutory HIV service e.g. peer supprt	3 (8)	11 (9)	10 (16)	2 (67)
HIV specilist psychology service	2 (5)	41 (35)	9 (15)	1 (33)
Non-statutory HIV serivce for counselling	1 (3)	19 (16)	11 (18)	0 (0)
Other non-statutory service (not HIV-specific)	0 (0)	12 (10)	6 (10)	1 (33)
NB: Totals do not add as individuals could be referred to more than one external service	erred to more than one external	service		

2015 =





In some cases risk assessment was documented where there was no history of mental health issues (risk was indicated in 10 cases; assessment found no risk in 47 cases). In this group of 1,107 with no history of mental health issues, there was no documentation of risk assessment in 1,010 (91.2%) cases and 40 (3.6%) cases had 'unsure' responses or the item was unanswered.

### Rate of cognitive screening

### Standard 5 (5.4.1)

Over all of the case notes, only 22 (1.5%) documented that cognitive screening questions (three questions relating to cognitive and executive function) were asked in clinic, 41 (2.8%) had received a brief cognitive screen using a standardised tool (e.g. Montreal Cognitive Assessment, Mini Mental State Examination), and 28 (1.9%) had participated in a full neuropsychological assessment by a psychologist or other similarly qualified professional.

How are services set up to meet the standards of psychological support in relation to patients' well-being?

### Departmental policies and teams

### Standard 7 (7.4.1)

Of the 52 services that responded, 13 (25%) have a psychological support policy, 9 (17.3%) have a risk policy and 18 (34.6%) have a treatment adherence policy. The composition of HIV specialist teams was as shown in Table 2 below. There was no mental health professional member (psychologist, mental health nurse, liaison psychiatrist or social worker) in 21 (40%) teams.

### Psychological screening tools

#### Standard 5 & 8 (5.4.1; 8.4.2)

Twenty-two (42.3%) sites stated that they used psychological screening tools in practice, whereas 28 (53.8%) sites stated they did not use a specified screening tool. The screening tools identified by those services which utilised them were of a very broad range, the most frequently used being the Hospital Anxiety and Depression Scale (HADS), the Patient Health Questionnaire (PHQ) and the Generalised Anxiety Scale (GAD).

### Cognitive screening tools

#### Standards 5 & 8 (5.4.1; 8.4.2)

Twenty-eight (53.8%) sites stated that they used a cognitive screening tool in practice, and 18 (34.6%) sites stated that they did not use any standardised screening method. Again, the cognitive screening tools identified by the services that used them varied widely. However, the instrument used most frequently by far was the Mini Mental State Examination (MMSE).

### Staff training for psychological support

### Standard 6 (6.4.1)

Almost half of the sites (48%) reported not having access to training regarding the delivery of psychological support. For the sites that did report accessible training, there appeared to be a general pattern somewhat related to site size, in that services with larger patient numbers tended to report higher training availability.

L	(	)
٦		_
(	_	)
ſ		Л

www.nhivna.org		
www.minvna.org		

Table 2: Specialist staff across HIV services	across HIV services		
	Number (%) of sites where professional is part of a specialist HIV team	Number (%) of sites where professional is specialist in HIV or HIV with sexual health and/ or blood-borne viruses	Number (%) of sites where professional is generic but working partly in HIV
Specialist HIV physician	52 (100)	52 (100)	NA
HIV specialist nurse	37 (71)	37 (71)	NA
Psychologist	24 (46)	14 (27)	10 (19)
Mental health nurse	5 (10)	3 (6)	2 (4)
Liaison psychiatrist	8 (15)	2 (4)	6 (12)
Social worker	12 (23)	7 (13)	5 (10)
Counsellor	7 (13)	5 (10)	2 (4)
Health advisor	27 (52)	11 (21)	16 (31)
HIV specialist pharmacist	37 (71)	37 (71)	NA
HIV peer support/voluntary worker	y worker 22 (42)	22 (42)	NA



### Patient information and feedback

### Standard 1 (1.4.1; 1.4.2)

Over half (65.4%) of the sites reported that they display health promotion leaflets. Similarly, over half (63.5%) of the sites had conducted a survey of patient satisfaction within the last two years.

# Strengths

- Nursing staff engaged well with the audit, resulting in a good response rate, meaning that a substantial amount of data was provided.
- The audit was the first attempt to gain a snapshot of the assessment and documentation of psychological and emotional well-being in HIV medical clinics across the country. This information can be utilised to build upon existing services' strengths and address service gaps, with a view to improving holistic health care. It also helps to bring the importance of emotional well-being into focus within physical healthcare delivery.
- There appears to be some evidence that, where psychological needs are identified, appropriate support is being provided and the stepped care model outlined in the standards is being implemented to some degree. This is reflected by the percentage of referrals to external mental health agencies increasing as the level of psychological distress intensifies.

# Audit Limitations

Although the response rate was commendable, it was lower in comparison to previous BHIVA audits. Participation may have been affected by a very limited timescale in which clinicians had to gather a broad scope of information. Additionally, data may have been biased, as there was perhaps some room for interpretation in responses to certain items, due to the nature of the subject matter.

There was some lack of equity regarding the extent to which each of the eight standards were covered, due to the methodology lending itself better to some auditable outcomes than others. Also, only key findings are presented as there was a vast amount of data that could not be represented within the scope of this audit report.

# Recommendations

As almost half of the services did not have access to training to help equip staff with the skills and confidence to provide psychological support to PLWHIV, training of this nature is needed. Using a blended learning approach there is a plan for NHIVNA and the BPS to develop a package of training to help nurses, and other relevant healthcare professionals, including those working in the voluntary sector, provide psychological support as part of a holistic healthcare approach. It is anticipated that this training package will be rolled out across the UK, potentially utilising a range of methods that might include stand-alone study days, conference lectures and e-learning modules.

Standard 6 (6.4.1)



A considerable number of services did not have policies referring to psychological support, risk and treatment adherence. It is therefore recommended that there be development of local policies that focus on these issues in order to guide HIV healthcare, by ensuring that the standards for psychological support are being advocated and met.

### Standard 7 (7.1.1)

As there was a lack of documentation of cognitive screening, psychological well-being, mental health history and risk in many cases, it is recommended that a structure be put in place to ensure these assessments are carried out. This could take the form of services offering annual health review clinics that incorporate assessment of these issues. This could be a useful way to ensure that services are meeting the standards for psychological support, in terms of identifying needs.

### Standard 5 (5.4.1)

It appears that the tools currently being used for psychological/emotional and cognitive screening vary considerably across services. Regarding cognitive assessment, the most common tool utilised was the MMSE, which has been found to have poor sensitivity for HIV-associated neurocognitive disorder (10). The national standardisation of screening methods in HIV services is recommended. This is likely to aid cross service communication/comparison both for clinical practice and research purposes.

Standard 8 (8.4.2)

# **Other Activities**

### Audit publications

Publication and feedback is an essential part of the audit cycle, to enable healthcare professionals to reflect on findings and change practice if necessary. With this in mind, the audit steering committee sends each clinical service a confidential summary of its own results with aggregated data for comparison, as well as presenting the findings at study days and conferences. The findings will also be available on the NHIVNA website **www.nhivna.org**. As this is the first national audit that NHIVNA has developed it is hoped that the findings will be written up for publication in an appropriate peer review journal.

### National collaborative study day

NHIVNA and the British Psychological Society are working in collaboration to produce a study day in October 2015 which will focus on the emotional well-being of PLWHIV and psychological support in clinical practice. It is anticipated that the study day will provide an opportunity to share knowledge and experiences, with a view to developing a psychological support training package as referred to in the recommendations relating to Standard 6.

### **Exploratory research**

An online survey has been developed to help identify nurses' knowledge, skills and confidence regarding the provision of psychological support for patients in clinical practice. The online survey will also establish future training needs for nurses within this area of patient care.



### **Future audits**

It was agreed within the steering committee that a repeat of this audit would not be beneficial at this time, as changes relating to the recommendations will take time to implement. However, there was a suggestion that, at a local level, centres should be encouraged to re-audit their services annually using the patient case notes audit provided or a version adapted to fit service specifics.

# References

- 1. Bing EG, Burnham AM, Longshore D *et al* (2001) Psychiatric disorders and drug use among human immunodeficiency virus-infected adults in the United States. *Arch Gen Psychiatry*, **58**, 721–28
- 2. Harding R, Lampe FC, Norwood S (2010) Symptoms are highly prevalent among HIV outpatients and associatied with poor adherence and unprotected sexual intercourse. *Sex Transm Infect*, **86**, 520–24
- 3. World Health Organization (2008) *HIV/AIDS and Mental Health*. EB124/6 November 2008. http://apps.who.int/gb/ebwha/pdf\_files/EB124/B124\_6-en.pdf
- 4. Ciesla J, Roberts JE (2001) Meta-analysis of the relationship between HIV infection and risk of depressive disorders. *Am J Psychiatry*, **158**, 725–30
- 5. Petrak J, Miller D (2002) Psychological management in HIV infection. In: Miller D, Green J, eds. *The Psychology of Sexual Health*. Blackwell Science, Oxford
- 6. Power R, Tate HL, McGill SM (2003) A qualitative study of the psychosocial implications of lipodystrophy syndrome on HIV positive individuals. *Sex Transm Infect*, **79**, 137–41
- British Psychological Society (BPS), BHIVA, MEDFASH (2011) Standards for psychological support for adults living with HIV. MEDFASH, London. Available: www.bhiva.org/ StandardsForPsychologicalSupport.aspx. Accessed 7 February 2014
- Department of Health (DH) (2011) Healthy Lives, Healthy People: our strategy for public health in England. The Stationery Office (TSO), London. Available: www.gov.uk/government/publications/healthy-lives-healthy-people-ourstrategy-for-public-health-in-england. Accessed 7 February 2014
- Department of Health (DH) (2011) No health without mental health: a cross-government mental health outcomes strategy for people of all ages. The Stationery Office (TSO), London. Available: www.gov.uk/government/publications/the-mental-health-strategy-for-england. Accessed 7 February 2014
- 10. Skinner S, Adewale AJ, Deblock L, Gill MJ, Power C (2009). Neurocognitive screening tools in HIV/AIDS: comparative performance amoung patients exposed to anti-retroviral therapy. *HIV Medicine*, **10**, 246–52.



### Acknowledgements

### **NHIVNA Psychological Audit Working Group**

#### Michelle Croston (Chair)

Senior Lecturer/Specialist Nurse, Manchester Metropolitan University and North Manchester General Hospital

#### Yusef Azad

Director of Policy and Campaigns, National AIDS Trust

#### Kathleen Charters

Community Representative, UK Community Advisory Board

#### Hilary Curtis

NHIVNA Audit Co-ordinator, Regordane Editorial and Design Services

#### Helen Donovan

Public Health Advisor, RCN/Executive Nurse Member for Barnet CCG Board, Barnet Clinical Commissioning Group

#### Stuart Gibson

Clinical Psychologist, Barts Health NHS Trust, London

#### **Ruth Lowbury**

Chief Executive, MEDFASH (Medical Foundation for HIV & Sexual Health)

#### **Alexander Margetts**

Clinical Psychologist, Central and North West London NHS Foundation Trust (for British Psychological Society)

#### John McLuskey

Associate Professor, University of Nottingham

#### Sarah Rutter

Clinical Psychologist, HIV Support Team, North Manchester General Hospital

#### Jason Warriner

Public Health Forum Chair, RCN/UK Director of Quality and Clinical Services and Marie Stopes International

We would also like to thank all the clinical centres who participated in the audit.



NHIVNA aims to provide an academic and educational forum for the dissemination of original nursing research in the field of HIV/AIDS. We aim to address the communication and support-needs of nurses working in this area.

We hope that these activities will assist in the promotion of good practice in the care of people with HIV.

Published by: © Mediscript Ltd October 2015

NHIVNA Secretariat

1 Mountview Court · 310 Friern Barnet Lane · London N20 0LD Tel: +44 (0)20 8446 8898 · Fax: +44 (0)20 8446 9194 · Email: nhivna@nhivna.org · Web: www.nhivna.org Registered Charity No: 1099074 <sup>9</sup>ublication Date: October 2015