

BHIVA Standards of care online consultation comments

7 October 2012

General Feedback

13 September 2012

Graeme Calf sent the following message:

One of my concerns is lack of easy communication between patient and HIV clinician. With clinic visits reduced to 6-monthly, there are times inbetween when it would be useful to 'chat', either by telephone or email, to your clinician, but this is often frowned upon, or you are required to make contact via a secretary. In this day and age, is it unreasonable to expect doctors to actually chat with their patients!?

15 September 2012

vincent manning sent the following message:

I have read several of the standards in detail. I think it an omission that matters of a person's faith affiliation or beliefs is not explicitly mentioned anywhere. Is this an oversight or is faith not considered relevant?

16 September 2012

AH sent the following message:

Too many appointments for people who are stable on treatment.

I would also like to remind the panel that under the 1974 sexual health act, to are not obliged to inform your Gp.

I would like the decision of the patient to be respected and not to be pestered every time you visit the clinic to let your Gp know.

18 September 2012

Kevin sent the following message:

I submit, if not already provided for consideration.

Sigma Research, refer "Framework for better living with HIV in England"

<http://www.sigmaresearch.org.uk/files/report2009e.pdf>

NHS SE London "Review of HIV Care and Support Provision" <http://www.selondon.nhs.uk/a/1173>

SLHP "The Bigger Picture 1 and 2" <http://www.slhp.org.uk/The%20Bigger%20Picture.pdf> and

<http://www.slhp.org.uk/files/file1050075.pdf>

Andrew Pearmain "Feast to Famine"

<http://www.nat.org.uk/Media%20library/Files/Policy/2010/Feast%20A5%2097pp.pdf>

HPA "HIV report in the UK 2011"

http://www.hpa.org.uk/webc/HPAwebFile/HPAweb_C/1317131685847

House of Lords report "No Vaccine, No cure"

<http://www.publications.parliament.uk/pa/ld201012/ldselect/lddaids/188/188.pdf> and Dept. of Health response,

http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_130812

NAT report on Social Care and HIV (ASG allowances provided by Central Government)

<http://www.nat.org.uk/media/Files/Policy/2012/HIVSocialCareReport2012forweb.pdf>

Current number of people affected by HIV is around 92,000 with an estimate of 5-7% increase year by year, unless prevention message prevails, I refer also to

<http://socialcarebulletin.dh.gov.uk/2012/07/23/8-million-invested-to-tackle-hiv-and-improve-sexual-health/>

Civitas report on "Commission London's HIV services"

<http://www.civitas.org.uk/pdf/hivcommission2011.pdf> and comments listed at <http://forum-link.net/board/viewforum.php?f=2&sid=4c535bb5fda151bbeaee846f8886903c>

Changes to UK legalization e.g. commission board, Health and Social Care Bill, Independent Living.....

NAT reports such as

<http://www.nat.org.uk/Media%20library/Files/Communications%20and%20Media/Media%20Guidelines/Guidelines%20on%20Reporting%20HIV%20Supplementary%20Information%202009-1.pdf> ,

<http://www.nat.org.uk/Media%20library/Files/Policy/2010/Psychological%20support%20July%202010%20updated.pdf> and <http://www.nat.org.uk/Information-and-Resources/NAT-publications.aspx>

NICE guidance on Testing BEM and gay men (refer to previous submission for links)

I would like also to provide additional information and resource once/if HIV Benefits is back on link for this consultation on standard of care for people living with HIV in 2012.

18 September 2012

Kevin sent the following message:

On the topic of care, social responsibilities, entitlements and support related to that which Parliament passes into Law and which is on the statute books, <http://benefits.tcell.org.uk/forums-keywords/benefits/general-news-information-ie-dwp-government-etc>

To help address these, I further refer to:

<http://benefits.tcell.org.uk/forums-keywords/benefits/benefits-social-care-archive/aids-support-grant-asg>

<http://benefits.tcell.org.uk/forums-keywords/benefits/social-care-rights-responsibilities-entitlements>

Ageing with HIV, <http://benefits.tcell.org.uk/forums/ageing-hiv>

Scotland Standards for Human Immunodeficiency Virus (HIV) Services,
<http://www.healthcareimprovementscotland.org/default.aspx?page=11954>

<http://www.shca.info/PDF%20files/HIV%20Services%20and%20QIPP-report.pdf>

<http://www.rpharms.com/current-campaigns--england/qipp.asp>

<http://www.parliament.uk/documents/lords-committees/hiv aids/HIVAIDSUkev.pdf>

HIV Outpatient services tariff development,
http://webarchive.nationalarchives.gov.uk/+www.dh.gov.uk/en/Managingyourorganisation/NHSFinancialReforms/DH_125788 and
http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_128862

Scottish Government HIV Action Plan, <http://www.shivag.co.uk/BrowseThreads.aspx?ForumID=11>

NICE releases new pain relief guidelines, <http://www.shivag.co.uk/ShowThread.aspx?ID=326>

Other related issues, <http://www.shivag.co.uk/BrowseThreads.aspx?ForumID=9>

<http://forum-link.net/board/>

Address health inequalities, address Equality Act and other UK legalization.

20 September 2012

Musa sent the following message:

i am a Hiv aids patient i kindly need your assistance if possible this is my email
sowemusas@yahoo.com

kindly regards

24 September 2012

Kevin sent the following message:

Additional Good Codes of Practice, I refer to <http://www.hivcode.org/>

24 September 2012

Jane Bruton sent the following message:

Should there be a definition of 'Clinician' for this document

In this instance clinician refers to the health care professional managing the patient which could be doctor or nurse or allied health professional.

Often in other contexts clinician simply means doctor

26 September 2012

Dr A.J.France sent the following message:

These standards fail to address the issue of communication with primary care and thus perpetuate the "precious special status" of HIV, to the detriment of the patients' longterm welfare.

Standard 3 page 4. You have accepted that HIV patients may need to see specialists in other hospital departments, but you think it is OK to keep their GP in the dark. This is wholly impractical. All other hospital departments routinely communicate with GPs. It will be impossible to black out all reference to HIV in their letters. The GMC instructs doctors to write full details in their reports and not to omit relevant information. I think this standard puts you on a collision course with the GMC.

Standard 4 page 3. Safe ARV prescribing, in patients who have already agreed to disclose information to their GP. How can it be acceptable to fail to communicate with the GP in one in five cases ?

I have written to GPs after every consultation with my HIV patients since 1989 and have not had any problems. I use the main hospital case notes. My feeling is that the historical arrangement of separate records with no communication is no longer tenable. Those clinicians who still practice on those lines need to move in to the 21st century.

Standard 5 page 2. The standard writers need to get out a bit more. The proposed 24 hour availability of HIV specialists for inpatient advice and care is not going to happen outside the large cities in the UK. This will not work in Scotland or other parts of the UK with an average population density.

We had a lot of debate about the standards in Scotland over the past few years. My conclusion from that exercise was that a standard should be absolute, i.e. aim for 100% hitting the target. Then do audits to see who is missing the target, and why. If you say 20% failure rate is acceptable, then why did you bother setting standards at all?

When I get in to my car I expect it to start every time I turn the ignition key, not 80% of the time !

27 September 2012

JOHN KIBIRANGO sent the following message:

THIS PROGRAME IS GOOD PROVIDED THEY GIVE US THE INFORMATION IN TIME THANK YOU SO MUCH THIS PROGRAME

28 September 2012

Nick Theobald sent the following message:

No mention of dietitians found.. essential part of our team.

S3 P3 - protein/keratin surely shd be protein/creatinine?

No mention of sexual dysfunction, testosterone deficiency... this is an important issue for PLWHIV and should be included in either 6 or 7 or both.

S8 P3 - hetreosexuals are not the only PLWHIV who choose to plan pregnancies... auditable outcome (1) should not limit by stating 'heterosexual'

1 October 2012

Kaveh Manavi from UHB sent the following message:

This is a well written document that will no doubt help us with the standrads of HIV care. My comments are mainly on measureable outcomes for each standard as below:

Standard One: This is a terribly important outcome for primary care/ non-GU/ non HIV settings. Producing it under standards of care for HIV patients may disown clinicians in those settings from their role in improving this outcome.

1 October 2012

Charity Bhengu from GHT sent the following message:

Social workers, doctors, nurses and all clinical staff need more training in dealing with people living with hiv. Sometimes service user face prejudice, discrimination and judgement by the very professional who should be supporting them.

1 October 2012

Lloyd rycraft from GHT USER sent the following message:

These 12 steps are a good read and also very informative tho I tend to find as someone living with HIV roughly 4/5 years and according to my own consultant and practitioners at GHT it will more or likely quite sometime going off my high CD4 and good viral load.

I am not missing the point of what these step are making people aware of but what tends to happen with people like myself they get forgotten about and I think maybe there should be a piece of reading that covers our condition rather than reading you get diagnosed then the meds start etc ... I myself am still not fully understanding what the HIV in my body is doing or its effects am sorry I am on the train at the moment I hope this point is worth sharing and if you you would like me to explain feel free to contact me, but great read on the steps

Lloyd

2 October 2012

Peter I Hill from Service User North Lancashire sent the following message:

Thank you for the opportunity to comment on these 12 Standards of Care - a rare chance for me to give my views on the HIV care I receive/would like to receive.

As a general comment, I would just like to highlight the problems faced by those of us who live some distance from large urban areas.(I live in Lancaster).

Although I am extremely happy with the care I receive from my Consultant who is based in Blackpool and my Nurse Specialist (based in Bradford), both of whom are excellent, I am fearful of the changes

that may occur with the NHS reforms. I attend regular clinics in Lancaster for blood tests, consultations etc. Will this continue?

What can I do to ensure this level of specialist care is maintained.

Though hardly the back of beyond, Lancaster is 65 from Manchester and 40 or so from Blackpool.

STANDARD 5 Should I ever be in need of specialist in-patient care, I presume this would have to be in Manchester or Blackpool (?) since my local hospital, Lancaster Royal Infirmary, does not have appropriately trained consultant led, multi-disciplinary staff in an HIV team. Indeed staff at this hospital are unfamiliar with commonly prescribed HIV anti-retrovirals and seem blatantly unaware of the need for privacy when discussing HIV and medication as a recent in-patient experience confirmed to me (not related to my HIV infection). Ignorance prevails, I am afraid, in the shires.

STANDARD 6 I have never been offered mental, emotional or cognitive well-being support, possibly because none is available in my part of the country and my health authority.

STANDARD 7 There is little/no service user involvement/consultation in this area.

I wonder if the new Clinical Commissioning Groups intend to include Service users in their HIV treatment plans? This would be so useful for all concerned - a huge learning curve is needed for GPs and hospital doctors/nurses in areas such as where I live. Ignorance and attitudes to HIV infection are fixed in the 80s/90s because they see relatively few HIV patients, I assume.

I am more than happy to take part in further surveys/consultation.

3 October 2012

David CHadwick from South Tees Hospitals NHS Foundation Trust sent the following message:

1. In testing section (standard 1) - need clarity on what proportion should be tested. Clearly it may not be appropriate to discuss testing with many elderly patients
 2. statement in standard 3 about getting resistance and HLA B5701 tests within 2 weeks unrealistic - normally takes 3-4 weeks now with Lab21.
 3. In standard 4 - evidence of self-reported adherence in all patients - I don't think this is necessary for all patients: many are clearly adherent for long periods of time...
 4. Standard 5 - by stipulating physicians looking after inpatients must have 2 PAs for inpatient care, you will disqualify many academics and part-time doctors from inpatient care, such as myself, who do 'stints' on the ward. I'd suggest 1PA is sufficient (averaged over a year)
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3 October 2012

Roger Pebody from NAM sent the following message:

This feedback is concerning the supporting text, specifically the discussion of the NHS number.

The quality statements for Standard 12 includes an important point about people with HIV needing to CONSENT to the use of their NHS number. As this is so important to patient trust and confidence, it is vital that this issue is touched upon in the discussion in these pages too.

I suggest the following should be inserted at the very end of the section.

"In view of the particular sensitivities of HIV, it is important to seek explicit consent from patients for the use of the NHS number in data linking."

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In addition, a more minor language suggestion from this section...

Page 2, mention of "one size fits all". There is a risk that some readers will misinterpret this as being about a one size fits all set of standards. Better to specify: one size fits all model of service delivery.

4 October 2012

Guy Baily from Royal London Hospital, Barts Health sent the following message:

As a general comment I think it is important that there is some qualification about the clinical outcome standards (as opposed to standards concerning systems, procedure etc). I appreciate that the evolving NHS management structures are keen that such data should be acquired. I think this means that we should be very careful that such information is accurately described.

Variance in clinical outcome data between treatment centres (VL suppression rates, death rates, lost to follow up rates) will be substantially explained by case-mix; probably this will be a much bigger factor than quality of care although there is no objective means of assessing this. This needs to be stated explicitly in the rationale, probably of standard 3 where there are several of these clinical outcome standards. Otherwise these numbers may be crudely and inappropriately used to infer the comparative quality of services.

Detailed comments:

Standard 3 p4

Nominated consultants. We abandoned this for out-patients some time ago. It does not fit well with the evolving provision of care for stable patients through virtual and nurse-lead services. For all patients not specifically under the direct care of a consultant, we operate a system of joint responsibility by the lead consultants for the clinic. In practice advice is sought from whatever senior opinion is available. We could put a name on each patient's file to comply with this standard but it would not change anything in practice. The standard risks imposing rigidity on the development of

services. Comparison with other chronic disease management services (e.g. diabetes) suggest that greater flexibility is appropriate.

Standard 5 p3

Starting IPs on ART. This presumes greater clarity of evidence and consensus amongst clinical opinion than is the case. 90% at 4 weeks may not be far off much good practice but I do not think it can be a standard There is an implication that failure to start at this time constitutes poor management and that is certainly not necessarily the case. A great many clinical factors can be relevant. The bulk of trial evidence of harm from delay is from longer delays than 4 weeks. I think this should be softened.

Standard 6 p2

Do we have evidence that psychological evaluation fulfils the criteria for introduction as a screening test? Are simple evaluations robust and, most importantly, are we satisfied that we have effective interventions available for the scale and scope of problems that will be identified – if not we should not screen.

5 October 2012

Dr David J Murphy CPsychol from The British Psychological Society sent the following message:

Standard 6 (Psychological Care)

1. We would encourage the inclusion of the 'stepped care model' figure into this section.
2. We understand that a paragraph from the 'competencies' quality statement for this specific standard was removed in this draft, as it was agreed to relocate this paragraph to Standard 11 (Competencies). Our understanding for this move was that this paragraph could be applied to all practitioners. However, we are unable to locate the paragraph within the document and would welcome clarification as to whether this was an intentional or accidental omission.

The Society recommends that this paragraph be included in the quality statement on competencies in Standard 6. The paragraph is as follows:

Required competencies should be defined across the spectrum of four levels of psychological support and practitioners need to demonstrate their competence on an ongoing basis. Services should support the maintenance of such competencies through training, continuous professional development and supervision. In addition to generic competencies required by practitioners for their particular role and professional qualification, all practitioners should be able to demonstrate a minimum set of competencies demonstrating their awareness and understanding of HIV and its impact on those living with the disease. They should possess an awareness of the diversity of needs that PLWHIV may have - especially men who have sex with men, those from minority ethnic communities, women and substance misusers. The required competencies are detailed in Section 6.2.5 (p 54) of the Standards for Providing Psychological Support for Adults Living with HIV.

Standard 7 (Sexual Health & Secondary HIV Prevention)

1. Should this refer to sexual health AND well being?

However promoting 'sexual well being' refers to a wide range of psychosexual counselling interventions for enhancing 'good sex'. How one operationalises and then measures the impact of such interventions is open to discussion. The Society would recommend that this be included as this would ultimately help to promote safer sex.

Standard 8 (Reproductive Health)

1. There are HIV positive gay men, bisexuals and lesbians who may want to become pregnant and have children. Admittedly, there may not be too many of these patients who are interested in doing this. However to restrict these standards to 'heterosexual adults and adolescents' only is discriminatory. The Society would recommend that this is not excluded.

Standard 9 (Self management)

1. In the rationale/introduction, we would recommend reference be made to 'psychological health and/or well being' instead of 'mental health'? The term mental health usually refers to psychiatric symptoms, conditions or diagnoses. The Society understands that 'self management' is for promoting well being and optimising functioning, as opposed to a more restrictive remit of reducing symptoms of depression or anxiety.

2. The Society also believes that the definition of self-management could be clearer. Currently it states 'self-management means developing an understanding of how HIV affects the lives of people and of how to cope with symptoms and issues which it presents'. We think it would be helpful to describe self-management more explicitly.

For example: As with any long-term condition, all people living with HIV make decisions and engage in behaviours that affect their health. People's thoughts and ideas about HIV will have an impact on how they manage their health and influence the success of their relationship with their health-provider.

3. The Society recommends that more examples of self-management are included. For example, making decisions about when to start treatment; considering treatment options; managing side-effects; adjusting to life with a long-term condition; coping with emotional responses; anticipating how to disclose to others.

4. There appear to be an overemphasis on 'support' in the section. Whilst this is obviously important, we believe that it would be beneficial to also discuss how self-management is essential for collaborative care across the patient journey/care pathways.

5. Physiotherapists and occupational therapists are mentioned as examples of how practitioners can promote 'self-management'. Commissioners and service planners may not be aware of how these specific practitioners can do this. The Society urges that some examples are included such as other practitioners, psychologists, pharmacists or nurses.

6. The Society does not believe that any specific model, method or protocol of 'self management' should be promoted in these standards, as the evidence base for using specific protocols in the UK is currently lacking. The Society feels that this needs to be discussed more explicitly.

7. In terms of 'auditable outcomes', The Society does not believe that any one specific professional body should be mentioned or promoted in these Standards. If the British Association for Counselling and Psychotherapy (BACP) are mentioned, then it is only appropriate that other professional bodies such as UKCP, BPS, and BABCP are also mentioned.

8. The Society believes that there are better self-report measures of promoting 'self management' than CORE. CORE is used in the mental health system to measure symptoms of depression, anxiety, psychosis and risk for self harm. The Society understands that 'self management' is broader than reducing psychiatric symptoms. Therefore, 'quality of life' measures might be more appropriate, such as Euro-QoL, MOS-HIV and/or Work & Social Adjustment Scale (WSAS).

General Comments:

1. We are concerned that the 'rationale' or introductory paragraphs for each standard becomes repetitive. We note that in the Psychology Standards, an 'introduction' section usefully weaves all these introductory paragraphs together. In the end, it's a matter of organisation for the whole document, with a focus on making it as brief as possible for the reader who may already know a lot about how HIV management has changed over the past 25 years.

2. We believe that this needs to acknowledge and address how some people living with HIV have concerns about their confidentiality and anonymity. One possibility may be that these standards should encourage clinics and services to set up procedures and policies for patients who want to use pseudonyms and/or refuse to have their NHS numbers recorded.

5 October 2012

Helen Webb from St George's Healthcare Trust, Courtyard Clinic sent the following message:

I have 3 comments regarding the standards:

1. Standard 4, Quality statement 'HIV clinics should provide pharmacist and nurse led interventions that provide educational information and outreach services to support ARV prescribing for difficult to reach patient groups in the local community' I do not fully understand what this statement means. Could we have this clarified, maybe with an example of how this is done in current clinical practice?

2. Standard 8, measurable and auditable outcomes 'Proportion of all heterosexual adults / adolescents with a documented discussion of reproductive choice and contraception....'. Please can we clarify that women beyond child bearing age should be excluded from such an audit.

3. Standard 11, Nursing Team. I do not agree that all nurses working in advanced practice should undertake non-medical prescribing. It will very much depend on their role and the service they work

in as to whether this is necessary or even appropriate. If the writing team feel that this statement should stay in, then I would be grateful if they could define more clearly what 'advanced practice' means.

Otherwise I feel that they are very well structured and will help support clinics in providing excellent care for people living with HIV.

5 October 2012

David Ogden from HIV Pharmacy Association sent the following message:

I am writing on behalf of the HIV Pharmacy Association (HIVPA) in response to the invitation to comment on the 2012 BHIVA Standards of Care for People Living with HIV.

We welcome the profile and recognition given to pharmacy services as part of the MDT throughout the document however we feel in general, that the term "pharmacy" is misleading in that dispensing services are increasingly offered by a range of providers, not all based in hospital settings or with staff that have specialist HIV knowledge, with appropriate training and competency. Most of our comments relate to finer detail on ensuring that the competencies of pharmacy staff are in place to provide the necessary roles in inpatient and outpatient services focussing on patient safety, education and experience. I have listed our suggested amendments against each Standard in turn:

5 October 2012

Christine Wilson from Barnardo's sent the following message:

I'm a social worker within Barnardo's (registered with the Health and Care Professions Council) and having been employed as an HIV Case Manager in South Tyneside for over twenty years, I very much welcomed the opportunity to see the draft "Standards of Care for People living with HIV".

It was good to see that access to "psychosocial assessment" (Page 1 of Standard 2) was identified as a requirement for optimum outcomes in relation to people with newly diagnosed HIV infection and that "socioeconomic factors" (Page 2 of Standard 10) are recognised as being significant in relation to adherence and treatment outcomes. However, it was disappointing to read through the standards and find that the role of social workers wasn't acknowledged.

Since March 2006 a MDT at Newcastle upon Tyne has invited specialist social workers from around the north-east region to consultant-led multi-disciplinary team meetings on a monthly basis. The meetings focus on psychosocial issues and a team of psychologists plus nursing staff also attend. Members of the MDT are keen to facilitate self-management of HIV and social care staff play an important role in ensuring care plans address the self-management priorities referred to on Page 1 of Standard 9. Whilst workers within local communities provide important support in relation to long-term condition management, adherence, advocacy and emotional support the MDT Meetings

predominantly discuss acute needs and a range of complex psychosocial needs, which often go beyond the remit of the hospital-based HIV team.

Some hospital discharges are very complex and funding has to be sourced for care packages, residential care, deep cleansing of people's homes and other essential requirements for a safe return to the community. Although the standards refer to economic inclusion there is no mention of the fact people living with HIV are sometimes destitute, have no recourse to public funds and require intense local support &/or crisis intervention to ensure they can access regional health care services.

Social workers also work with the MDT with regard to sensitive disclosure work and HIV testing (e.g. within families) and can often be best placed to intervene when people are lost to follow-up or they have limited medicine supplies. Safeguarding work is another major area of work and this may involve vulnerable children or young people, domestic abuse, the protection of vulnerable adults and local multiagency risk assessment conferences.

I'm aware the National AIDS Trust are involved in work highlighting the need for social care for people with HIV and it is very much hoped this online consultation will attract a wide range of comments about such needs so that the new Standards of Care can be a realistic tool for local service providers and commissioners to determine the right model of care within their local networks.

5 October 2012

Conrad White from University Hospital of North Durham sent the following message:

Standard3 page 3 - should it be urine protein/creatinine ratio not keratin ratio?

5 October 2012

Iain Reeves from NELNET sent the following message:

NELNET: BHIVA standards comments. Submitted on behalf of the NE London network for HIV and sexual health

General:

Could document benefit from tough edit? It is very wordy in places. Is there scope to reduce the number of standards? Should it be clearer that these are HIV specific – i.e. what is it about HIV that requires these standards? Some of the below, e.g. PPE is generic to all medical services.

Does HIV testing belong in a standards document about HIV treatment and care?

1) HIV testing

-New registration in GP practice – not evidence based with respect to feasibility. May not be best way to get testing done in primary care or to get right people tested – see Time to Test results (diagnoses in West London primary care = 0). RHIVA 2 results suggest this approach works for some practices but not others despite the latter being good testers. Standard needs to be relevant to current care structures.

-Is “offer” in primary care measurable? Testing rate is better measure of outcome.

-Review of very late presenters is a recommendation for practice not an outcome or audit.

2) Access to care

- Access to specialist services should be timed from referral to HIV services not date of receiving result as there may be delay outside control of HIV service.

- What does specialist assessment mean? What are the appropriate qualifications a specialist should have? Does this mean specialist nurse? This is a standard so should be specific – could refer to competencies later on and say which are relevant.

- Document attempts to reconcile previous standards document with HPA quality outcome of CD4 within 1 month. Arguably, it is more of a stretch and more clinically useful to say that patients should have CD4 count within 1 week of receiving diagnosis. Important clinical questions are 1) Is patient unwell? (should be within competence of most qualified nurses/doctor) 2) What is the CD4 count? i.e. how urgently should this person start HAART / be on prophylaxis?

- Arguably, saying that all patients regardless of CD4 count should be seen within 2 weeks is a distortion of clinical priorities.

Retention in care

- Agree. No comments.

3) Outpatient treatment and care

- Perhaps expand on why a dedicated outpatient space is needed in HIV specifically as opposed to other conditions.

- “Evidence that each patient has a nominated consultant for their HIV care”. How does this actually support patient safety? A nominated consultant means nothing if systems are not safe, it’s just someone to blame should things go wrong. In clinics with large numbers of stable patients often the person who knows a patient best will be a nurse specialist or a pharmacist. The key point is that these non-medical staff should have appropriate competencies and access to appropriate supervision and consultant advice when needed. Many clinics operate a system whereby consultant supervision is a shared responsibility within a team of lead consultants.

- spelling error “protein/keratin ratio”, page3

4) Safe ARV prescribing

-“Proportion of patients prescribed first-line therapy that have not developed evidence

of new drug resistance one year later (target: <2 %).”

The meaning of this sentence is tricky; it should say “NOT developed resistance should be >98%.”

Perhaps re-phrase?

5) Inpatient care

-Re “Proportion of all inpatients presenting with an AIDS-defining condition or serious bacterial infection and CD4 count <350 cells/mm³ started on, or maintained on antiretroviral therapy within 4 weeks (target: 90%).”

The above looks like it is based on Zolopa et al 2009. However, the conditions NOT in this study need to be considered as well as the eligibility criterion that patients needed to be well enough to swallow tablets. The evidence is much less conclusive for cryptococcal meningitis, TB and particularly TB meningitis. This outcome is too strong and takes no account of the differing evidence for different AIDS outcomes.

6) Psychological care

-Generally agree. NELNET members concerned that there is not a validated cognitive screening test that can be feasibly introduced in HIV services, thus pragmatism rules. Also concern that ethics of screening for mental health difficulties are complex if there are inadequate services to assess and manage those screening positive.

7) Sexual health

-Agree. These standards should refer to NICE public health guidance with respect to one to one behaviour change.

8) Reproductive health

No mention of PrEP in reducing the risk of transmission in couples wishing to conceive – Partners in PrEP study clearly supports this and it maximises risk reduction along with timed UPSI with treated partner.

9) Self-management

This section makes a number of truth claims which are entirely lacking in supportive evidence, e.g. i) “Professional resources can be more accurately focused where they are most needed.” and ii) “Appropriate peer support enables people with HIV to develop confidence and gain information and skills from others in an easily identifiable and applicable way...” (demonstrated in which studies with respect to HIV?)

Other statements might be worded better e.g. “People with HIV are frequently better placed than anyone else to know and understand many of their needs” – rather, “because of stigma and discrimination people with HIV often need support and advocacy to realise and articulate their needs.” This more clearly articulates the crucial role of the 3rd sector.

Much of this section then goes onto talk about access to and provision of social support and care – this is not self-management though undoubtedly very important.

In Outcome measures for this section:

“Improvement in psychological and emotional well-being, using a recognised measure such as CORE, recommended by British Association of Counselling & Psychotherapy.”

☒ What is this evidence that this is a valid outcome measure in this setting? Isn't this a measure that should be in the psychological care section?

10) Service user engagement/involvement

- This is a generic standard for all health services. Does it need a separate HIV specific standard?
- The following section belongs in outpatient care and ARV management, it's not about involvement in service design and delivery:

“The person's readiness to take treatment, their knowledge of how the treatment works and their personal need for treatment.

- ☒ Cultural or religious beliefs about health, medicine and healing, especially as these relate to HIV treatment.

- ☒ Awareness of any potential unwanted effects.

- ☒ The importance of adherence to the dosing requirements of the drug combination - selected.”

The next bit is about adherence support again and really belongs in outpatient care (see treatment guidelines).

11) Competencies

Generally Agree.

This text belongs in the outpatient care section:

“People who are HIV positive should be registered with a general practitioner unless this is expressly declined by the individual under care. A letter summarising HIV care should be sent from the specialist team to the GP at least once per year and more frequently as necessary to update regarding additional investigations, diagnoses or changes to treatment. The doctor in charge of specialist care should be clearly identified. General practitioners who provide primary care for people with HIV should ensure that clinical information is shared appropriately with the HIV specialist.”

12) Data, Audit and Research

Agree. No comments.

5 October 2012

Yusef Azad from National AIDS Trust sent the following message:

BHIVA Standards of Care for People Living with HIV

NAT submission to consultation

Introduction

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 living with HIV and campaign for change.

NAT congratulates BHIVA and the many individuals and organisations involved in the development of the draft Standards on an excellent job. Our comments below are restricted, for brevity's sake, to questions on the text and suggestions for amendment or addition. But we would emphasise from the outset how comprehensive and well-written the Standards are, how balanced, and how useful we believe they will be in securing better outcomes for people living with HIV. All our criticisms and suggestions need to be read in this context.

NAT welcomes the reference in the first paragraph to the impact of HIV-related stigma and the impact of a range of "biomedical, social, ethical and structural challenges" on the provision of effective HIV care. It is important that the Standards are read in this context. We agree that it is important to consider the needs of people living with HIV who have not yet been diagnosed. We also welcome the commitment to engagement of people living with HIV in service design and delivery.

In particular we welcome the content on HIV Partner Notification, which has to date not received appropriate emphasis in BHIVA documents.

Prisons and Immigration Detention Centres

NAT is pleased to see that the supporting text makes it clear that the Standards apply to all adults living with HIV in the UK, including those in prison and immigration detention. It would be useful for the Supporting Text also to make clear that in order to meet the outcomes of the Standards in terms of health and well-being in such places of detention, it may sometimes be necessary for additional or alternative support, resources and processes to be in place.

Standard 1: Diagnostic Testing for HIV

No comments on substance.

On drafting -

the phrase 'are unaware of the fact' at the end of the second sentence is ambiguous and can refer either to the fact they have HIV or to the fact cited in the first sentence of paragraph on long-term prognosis - needs to be disambiguated.

In the second bullet of the Quality Statements it is unclear what Scottish Standard means - it might be interpreted as only applying in Scotland.

Standard 2: Access to, and retention in, HIV treatment and care

On substance -

The penultimate measurable and auditable outcome on loss to follow up seems strangely calculated. The Quality Dashboard for HIV services being developed has moved to the terminology of retention in care and it might be good to be consistent in language with the Dashboard. Similarly, it is not clear whether denominator and numerator refer to just one and the same clinic or any clinic. It is of course mainly a cause for concern if someone simply disappears from any care at all rather than if they simply move clinic (whether elsewhere in the UK or overseas). We would propose:

Denominator: number of patients who received some aspect of care at the clinic between 24 and 12 months ago.

Numerator: number of patients receiving some aspect of care at a clinic in the UK in the past 12 months and who received some aspect of care in the clinic between 24 and 12 months ago.

Similar amendment should be made on the final measurable and auditable outcome in relation to the newly diagnosed.

Standard 3: Provision of outpatient treatment and care for HIV, and access to care for complex co-morbidity

On substance -

There is helpful content in the rationale on discrimination and the right to be treated with dignity and respect - at the end of the second paragraph three legally 'protected characteristics' are mentioned, race, sex and sexual orientation. There is a case for listing all protected characteristics. In particular, religion or belief should be mentioned given the challenges around some personal beliefs and treatment - it would be useful to remind services of the need always to show respect even in such circumstances. Age and disability could also be usefully mentioned.

In relation to the interface between HIV outpatient and primary care the rationale speaks of 'best practice' in terms of the establishment of clear protocols and pathways. The phrase 'best practice', not commonly used in the Standards, here has the perverse effect of making the recommendation sound weaker than most of the other recommendations in the document. It is in NAT's view essential to care and a pledge under the NHS Constitution [smooth transition between services], and propose amendment to the text to say so.

It is interesting to see Standards where the measurable outcomes have targets attached - should these be in a Standards document and is there a risk for those less than 100% for the document to become dated as performance improves and new targets are needed to 'stretch' services?

In relation to Monitoring NAT has concerns around poor performance in the regular monitoring of patients for hepatitis C and recommend a separate measure which goes beyond screening at

diagnosis and audits also regular screening - either annual for all people living with HIV or more frequent for MSM with HIV.

In relation to the survey of patient experience NAT recommends the outcome measure should be in the last year not the last three years.

On drafting -

In the 'Evidence of protocols' bullet the phrase in brackets '(listed but not confined to the list below)' is unclear.

Standard 4: Safe ARV prescribing: Effective Medicines Management

On substance:

Should not the measurable outcome around development of drug resistance for those on first line therapy be >98%? [NB 'that have not developed evidence ..']

Why is the target for annual documenting of adherence only 70%? That seems too low. NAT recommends a higher target for annual documenting of adherence - 80% at least.

There is a welcome emphasis on 'robust engagement with primary care to minimise drug interactions as an essential element of good practice' and (non-specific) reference to 'Mechanisms [which] should be in place in primary care to check prescriptions issued to people with HIV for drug-drug interactions'. There is not, however, a corresponding measurable and auditable outcome, and NAT recommends that one be added. The outcome around annual communication does not in our view directly address the question of drug-drug interaction and simply repeats, but in a slightly different form, the indicator from the previous Standard. We presume an appropriate indicator would be around no instances of adverse drug-drug interactions for drugs prescribed in primary care for people with HIV and recommend an appropriate measurable and auditable outcome is included.

There is no cross-reference in the document between the Standards and we wonder whether this is wise. Of course Standard 4 needs to be read alongside Standard 10 ('Service user engagement/involvement') for the ambitions of Standard 4 (for example around adherence) to be realised. Whilst many if not most readers might read all the Standards together, it is possible they might not - NAT believes there is a value, in addition to stating in the Supporting Text that all Standards need to be read and interpreted in light of each other, also to have reference in each Standard to others which are especially and essentially relevant. So here there should be explicit reference to Standard 10.

Standard 5: Inpatient care for people living with HIV

On substance:

In relation to the Quality statement on confidentiality we would add 'the law' to the first sentence so the relevant phrase reads 'in line with the law, GMC Guidance and national standards'.

In relation to measurable and auditable outcomes is it possible to identify an outcome in relation to provision of support to services without an HIV inpatient unit where the patient is too ill to transfer?

Standard 6: Psychological care

NAT welcomes the emphasis on clinical leads in psychological support services being part of the Multi Disciplinary Team and trusts this will be advocated as the HIV CRG does more work on the components of the MDT for the service specification for HIV outpatient services.

Standard 7: Sexual health and secondary HIV prevention

We welcome in our Introduction to this response the content on HIV Partner notification. A further proposal is an addition to the Quality Statements of a clinic auditing at least annually its HIV partner notification performance. This is recommended in the BASHH Partner Notification Statement.

In relation to the outcome 'Documented PN outcomes or progress update at 12 weeks for 90% of patients', perhaps amend so that it reads '.. or progress update, with further timelines agreed, at 12 weeks for 90% of patients'.

In current BHIVA Guidelines a distinction is made between sexual health screens and the taking of a sexual history. Both of course are important and they may both be implied in the phrase used in the Quality Statement 'Sexual health assessment'. But NAT believes it would be useful to mention explicitly the taking of sexual history in this Standard and in the outcomes (we note also the current consultation on sexual history taking by BASHH). Sexual history not only indicates the possible presence of STIs but also, even in their absence, sexual partners who may have been put at risk of transmission (especially where the patient does not as yet have an undetectable viral load). This is key to ongoing partner notification, and some of the other auditable outcomes in this Standard depend on this taking place. NAT recommend that the six monthly taking of sexual history (2011 BHIVA routine monitoring guidelines) is added as a measurable and auditable outcome.

In the context of the Treatment Guidelines and the content on both use of condoms and discussion of the preventive impact of treatment, we suggest the relevant outcome be amended to read, 'People living with HIV should be provided with appropriate written and verbal information about prevention of HIV transmission, safer sexual practices in the context of antiretroviral therapy, and about mechanisms for partners to access post-exposure prophylaxis'. We suggest 'be provided with' is more appropriate here than 'have access to', and we add a phrase from the Rationale which we think is helpful.

Standard 8: Reproductive Health

The outcome measure around documented discussion of reproductive choice excludes lesbians who are living with HIV and who may wish to conceive and have children - NAT recommends amendment. In particular information around the possibility of having babies who are not HIV positive and how pregnancy can be managed to secure this outcome should also be available for these individuals.

There is mention in the Standard of the provision of ARVs during pregnancy but no mention of provision of infant formula for mothers to avoid breast feeding. NAT recommends that the Standard refer to infant formula, the need to ensure mothers are accessing it and not breastfeeding as recommended clinically, and that local arrangements are in place to provide infant formula to those mothers unable to afford it.

Standard 9: Self management

Although covered in depth at Standard 6, NAT recommends there is brief mention in Standard 9 of the national standards of the psychological support of adults living with HIV (and perhaps also mention of Standard 6) to make sure the document is 'joined up'.

Standard 10: Service user engagement/involvement

The text around this Standard quotes the treatment guidelines on people with HIV having access to in-house, independent and community information providers and peer support resources. This is not then taken further in the Standard or included in the list of outcomes. NAT has heard on a number of occasions from third sector services how important they feel it is for HIV clinics to signpost service users actively to the range of support services available to them in the community, including information-related services.

NAT recommends that there be a further outcome on the Proportion of newly diagnosed people who have received information and signposting to the range of local and national services they can access for further information and support around the management of their condition.

Standard 11: Competencies

This Standard seems at some points to be approaching a definition of the components of an MDT only then to state that its exact composition will depend on the size and location of the service. But if the MDT is defined as the range of clinical professionals to whom people with HIV should have ready access at least within a network arrangement, then surely there can be greater consensus on core components of such an MDT. This does in NAT's view come within the scope of the Standards document and we recommend that the Standards state a minimum set of professional competencies for inclusion in networked arrangements.

Standard 12: Data, Audit and Research

A significant recommendation is the routine request for consent to the use of the patient's NHS number for the linking of data. NAT strongly opposes the inclusion at present of this proposal in the BHIVA Standards. We would also actively oppose the ratification of the BHIVA Standards by the HIV Clinical Reference Group were this provision retained in the Standards. We recommend for the present that this not be included in the final document.

Our reasons are based at this point less on the merits of the case (we are persuadable that it could be a good idea) but rather on the inadequacy of the consultation process. There is no thorough explanation of how the NHS number is used, what it is, what the implications will be in terms of identifiable information - NAT's enquiries about the NHS number from other third sector organisations confirm general ignorance or bafflement as to what the implications are of this proposal. Silence on the proposal is not an indication of consent, in our view, but of inability to come to an opinion. We do not believe that BHIVA have provided adequate explanatory material to inform the consultation process.

We also note active consideration of repeal of the VD regulations is underway - an informed opinion on the NHS Number proposal should be taken in light of any plans around the VD Regulations.

NAT propose a separate and thorough consultation/decision-making process around HIV patient information and the NHS, where data and systems are properly and fully explained and people with HIV (and the organisations which support them) have the time and information to come to a view. It may well be that the outcome of such a process will be confirmation that the NHS number provision is a good idea - but it will be informed agreement which will allay fears, empower patients and encourage consent. A revision of the Standards at a later date could include relevant recommendations if it is thought necessary.

NAT October 2012

7 October 2012

Dr Immy Ahmed-Jushuf from BASHH sent the following message:

DRAFT BASHH RESPONSE TO THE STANDARDS OF CARE FOR PEOPLE LIVING WITH HIV IN 2012

BASHH congratulates BHIVA on the production of these very timely draft revised Standards for HIV Management in view of the of the imminent change in HIV commissioning which will soon be by the NHSCB. The BASHH Board welcome the opportunity to comment on them.

We support the principles outlined in the standards, the inclusion of quality statements, and the objective of ensuring the provision of high quality HIV care for people living with HIV.

We wish to submit the following comments for consideration by the Standards group:-

1. Each standard has a number of quality indicators and auditable outcomes. However, clarification is needed on the suggested use of the auditable outcomes. BASHH submits that in their totality, these are too numerous for any service to be able to routinely measure. We therefore suggest that these are put forward as 'possible' auditable standards' and that each chapter should identify one or two 'key performance indicators' which should always be measured.

2. Standard 3: Provision of outpatient treatment and care for HIV, and access to care for complex comorbidity:

We strongly support the inclusion of

- People with HIV should be in receipt of care in a dedicated outpatient department with privacy in consulting rooms, patient waiting areas, and phlebotomy services together with nearby and same-day access to appropriate clinical support services such as pharmacy, adherence advice and counselling.
- People with HIV should have access to appropriate sexual health screening, treatment and advice.

This is particularly important to maintain stable, streamlined and co-ordinated services.

Standard 4: Safe ARV prescribing: Effective Medicines Management: Page 2, Quality statement: 'Antiretroviral prescribing competencies must be maintained on a continuing basis. It is

recommended that clinicians prescribing ARVs should have at least one HIV clinical PA in their job plan, together with clear evidence of HIV specific CPD'. We endorse the principle that prescribers of ARV should be up to date in their knowledge. However, we question whether it is appropriate to be so prescriptive in National Standards. We are not aware of other National Standards specifying the amount of time that should be allocated to aspects of clinical care. We fully support the principle that an HIV physician's job plan should reflect the workload represented by this element of care, however, the content of a job plan is normally a matter for local negotiation during individual job planning. We recommend that a form of words is used to reflect the need to include an appropriate PA allocation that is specific to and sufficient to cover the HIV workload. This could be 'clinicians prescribing ARVs should have specific HIV clinical PAs allocated according to the workload undertaken; typically this will be 1 PA or more'. We are not aware though that there are clinicians who have less than 1 PA in their job plans.

3. Standard 5: Inpatient care for people living with HIV: Page 3, Measurable and Auditable Outcomes: 'Evidence that consultant physicians who have responsibility for the care of inpatients with HIV infection have up-to-date CPD in both HIV medicine and in general medicine and a job plan with at least two PAs for inpatient care'.

We endorse the statement in respect of CPD and the importance of ensuring that inpatient care is appropriately reflected in the job plan. However, as in Standard 4, we believe that the statement as it stands is too prescriptive and question whether it is appropriate to be included in National Standards. We agree that the time allowed within the job plan for in-patient care should reflect the inpatient workload within the service, as well as the size of the team of HIV clinicians who share this work load. This is a matter for the local Trust and individual job plan negotiations. There are different models of inpatient care throughout the country and for many outside London the HIV inpatient workload may not justify 2 PAs for each of the HIV specialists on the rota providing 24 hours inpatient consultant advice and expertise. As an alternative, there will be consultant general physicians available to provide 24 hour advice whose job plans do contain at least 2 PAs for inpatient care but they will not be trained or have up-to-date CPD in HIV medicine. In our view, Trusts will either not respect this standard or, more worryingly, apportion this in-patient responsibility to general physicians, which would be a retrograde step. In the rationale it states "HIV-positive people presenting with complications of HIV are often critically ill with life threatening conditions and require complex care provided by an HIV specialist consultant-led multidisciplinary team, frequently in collaboration with other medical specialties." We believe the key is to consultants having up-to-date CPD, but being able to recognise their own limitations and knowing when to call in the help of other medical specialties. So for those whose inpatient workload is relatively low there will be a lower threshold to call upon the expertise of other specialties. This "shared-care" is an established and acceptable model of care, for instance even the most experienced HIV team need to transfer sick patients to ITU but it is not expected that the anaesthetists need to have expertise in HIV. The HIV team provide that aspect of care and rely on the anaesthetists to provide the intensive life-support that the patient needs. We would therefore recommend the following: 'Evidence that consultant physicians who have responsibility for the care of inpatients with HIV infection have up-to-date CPD in both HIV medicine and general medicine, and a job plan which appropriately reflects the work load'.

4. Standard 6: Psychological care: We strongly support the inclusion of this Standard as psychological support has been cut from some services. Page 2, Quality statement: 'Such psychological support services should be effectively coordinated within a managed framework.' We suggest that this should be changed to 'a managed clinical framework'.

5. Standard 11: Competencies: Page 2, Quality statement: 'Specialist knowledge of these areas is required for the management of HIV, and therefore consultant physicians overseeing care should be competent in these areas. The Diploma of HIV Medicine (Dip HIV Med) is compulsory for specialist trainees in genitourinary medicine enrolled on the 2010 curriculum (or later). The syllabus for the exam is updated regularly. Although not compulsory for ID trainees it is encouraged'. This is an interesting difference. The purpose of the Dip HIV Med is to ensure that all prospective GUM Consultants have been independently assessed and deemed competent to delivery HIV care. How is this assessed in prospective ID consultants?

We appreciate the opportunity to contribute to the Standards and trust that the above feedback is given due consideration. BASHH is keen to work in partnership with BHIVA and support this essential piece of work.

Dr Janet D Wilson Dr Immy Ahmed-Jushuf

President Chair, Clinical Standards Unit

7 October 2012

adrian palfreeman from south trent GU/HIV physicians sent the following message:

We congratulate BHIVA on its timely production of these excellent and well thought out standards.

We have some suggestions on a slight change in wording in sections 3 and 4 regarding the number of PAs allocated to both prescribing and in-patient care.

We believe that obliging trusts to include specific items in job plans does not reflect the realities of clinical practice, especially outside London where patent care is shared between consultants and departments in order to provide an integrated service. This has been successful as evidenced by the excellent clinical outcomes in the UK of which we should be rightly proud. We believe that the form of words suggested in the BASHH response "clinicians prescribing ARVs should have specific HIV clinical PAs allocated according to the workload undertaken; typically this will be 1 PA or more" would be more appropriate.

For inpatient care where shared care between ID and GU is the norm in South Trent mandating 2 PAs for inpatient care is also unhelpful and may disrupt existing effective arrangements. Again we would support the BASHH suggested form of words" Evidence that consultant physicians who have responsibility for the care of inpatients with HIV infection have up-to-date CPD in both HIV medicine and general medicine, and a job plan which appropriately reflects the work load" would be more appropriate.

We hope these comments are helpful and we would like to thank all those who worked on these standards for producing this vital document in time for the new commissioning process

Adrian Palfreeman

Jyoti Dhar

Immy Ahmed

on behalf of South Trent GU/HIV Physicians

7 October 2012

Philippa James from Sex, Drug and HIV Group of RCGP sent the following message:

We welcome the recognition of the importance of primary care in the diagnosis and management of people living with HIV.

7 October 2012

Dr Ian Cormack from SWAGNET sent the following message:

We welcome these new standards at such a critical time with possible commissioning changes to the way we deliver HIV care. We share the same concerns as BHIVA that the highest standards of care are maintained and that improving testing and care should be supported by a dedicated HIV clinical champion in public office provided there is no conflict of interest with any political agendas.

We would like to see any relevant sections (or an executive summary) distributed to our colleagues in relevant medical specialities. We are pleased that the guidelines recognise the importance and value of clinical networks in delivering and co-ordinating HIV care.

Standard 1 : diagnostic testing for HIV

Please could the salient points be distributed to GPs, General medical teams and any allied specialties as a reminder of the BHIVA testing guidelines.

We welcome and support the suggestion that the offer and uptake rate of HIV tests should be audited in hospitals and GP surgeries in high prevalence areas. Perhaps there could be a standard set for % offer rate for HIV tests in these settings. Maybe even a CQUIN?

Standard 2 : access to and retention in HIV treatment and care

Lost to follow-up patients are dealt with in different ways across clinics and some standardisation/guidance would be helpful. We are currently looking at this issue in SW London and would be happy to contribute to any future developments in this area.

We welcome the guidance regarding transfer of care letters/clinical summaries but would like to see “full clinical summary” expanded upon. Perhaps there should be a minimum dataset to be given on a transfer of care letter where the information is available or known. Eg Date of diagnosis, baseline CD4/VL, Baseline resistance test, accurate HAART history with details of drug adverse events/intolerances. Formalisation and standardisation of this would help improve patient experience and clinic efficiency. This could be done as a BHIVA audit.

Standard 4 Safe ARV prescribing

“Outreach services to support anti-retroviral therapy prescribing for difficult to reach patient groups in the local community”. I would like to see greater support for this important aspect of care and more involvement from community mental health teams. It can be difficult to get psychiatric support and this “outreach work” is often done by overstretched community nurses dealing with other issues. There is some concern over the dilution to specialised posts to generic post. Robust training and support is required in addition to strong links with specialised centres which are essential in order to optimise specialist care from a generic service.

Standard 5 : Inpatient care

These are very helpful. It would be nice to see some further description of type of HIV inpatient care provided by different centres eg previously undiagnosed HIV v diagnosed in care v HIV defaulters.

The number of admissions per se does not accurately reflect the amount of work done by inpatient teams.

Eg 35% of our inpatients were previously undiagnosed and represented >50% of the inpatient work at our hospital in terms of patient days and were more labour intensive.

I would like to see mortality rate, Post mortem rate in HIV related deaths, time to HIV test after admission, survival from different OIs esp PCP and ITU survival as measurable outcomes.

These guidelines are very helpful and provide a great deal of measurable outcomes that can be used to improve practice and the care of HIV patients.

Regards

Ian Cormack

Consultant Physician

Croydon University Hospital

Clinical Lead for SWAGNET

7 October 2012

Will Chegwiddden from Rehabilitation in HIV Association sent the following message:

Comments on the Standards of care for people living with HIV in 2012

RHIVA: The Rehabilitation in HIV Association, representing Occupational Therapists, Physiotherapists and Speech and Language Therapists working with people living with HIV

We would like to firstly thank BHIVA and the individuals and organisations involved with this important rewrite of the Standards of care for people living with HIV for inviting RHIVA to be part of the review process. In particular we welcome the recognition that HIV is now seen as much more than just a medically managed condition, where, as described in the supporting text “chronic long term condition management is becoming increasingly relevant”. We note the supporting text also describes the “above-average risk for cardiovascular, metabolic, bone and neurological problems” and recognises the importance of “psychological, emotional and social well-being”.

Our comments, listed below, mainly hinge around ensuring that these standards reference the important role that rehabilitation plays in the management of long term conditions. We have also taken the opportunity to reference our newly developed competencies for rehabilitation professionals, for both those rehabilitation professionals working in HIV specialist settings with the most vulnerable individuals living with HIV, as well as the significant number of rehabilitation professionals working in non HIV specialist health and social care settings. This should include not only the active rehabilitation that individuals require as part of inpatient care and in the community which is usually provided by health services, but also recognise the importance of the care and support of ongoing disability provided by social care providers.

We have also previously extensively documented our members’ concerns that the overall structure these standards has some flaws and in particular we would like to highlight one final time the following issues:

- we feel that including the assessment and treatment of neurocognitive impairment with psychological health does not appropriately reflect the importance of this issue, and that neurocognitive functioning, whilst related to psychological health, is not a sub-category of psychological health; and
- the standard for self management appears to contradict the otherwise consistent approach of these standards in being based around what standard of care an individual can expect rather than focussing on a model of service delivery.

We recognise there are identified reasons for the current proposed structure of the standards. Firstly, we recognise the existence of existing BHIVA standards on psychological care which include assessment and treatment of neurocognitive functioning and as such it makes sense that these standards make close reference of the psychological care standards. We hope that in future revisions of the range of BHIVA standards that the assessment and treatment of neurocognitive functioning will be treated as an issue in its own right and acknowledged as an important issue of everyday functioning that affect many people living with HIV and their ability to manage their HIV health. Secondly, we recognise BHIVA’s ambition in highlighting the importance of self management by having a standard that highlights this important approach. From a rehabilitation perspective it does present us with an incongruous position where we have a standard on the treatment of

psychological and cognitive function but then not on physical functioning. We also question why there would be a standard highlighting one particular model of service delivery and not others.

At this stage are aware that the overall structure is unlikely to change however we did want to raise this issues as part of our official response. We do however note that some of our previous feedback has been incorporated in to the standard on self management which we do appreciate.

Finally we welcome the UNAIDS approach to language in these standards. We would recommend that terminology around long term condition management uses the language adopted in the World Health Organisation's International Classification of Functioning, Disability and Health. As such you will see our language refers to impairments (of body structures and body functions) and disabilities (i.e. how these impairments cause activity limitations and participation restrictions). These terms are those widely used in rehabilitation settings and literature in the UK and in many international settings.¹

Where we feel there is a small or simple change we have reproduced the original text, once without change, and once with our suggested change in bold, for clarity, as well as giving a short rationale for our recommendation for change. We have also submitted the individual feedback below to each standard as part of the online feedback process.

Comments:

Standard 3: Provision of outpatient treatment and care for HIV, and access to care for complex co morbidity

Change "All services should have appropriate and timely access to emotional, psychosocial and welfare advice and support, and reproductive health services." to "All services should have appropriate and timely access to emotional, psychosocial and welfare advice and support, physical and cognitive rehabilitation services, community disability management services, and reproductive health services."

Rationale: This standard does not currently reference management of physical and cognitive impairments and disabilities. Adding in this phrase ensures that service design considers access to assessment for, and provision of rehabilitation (be that provided locally or via an external pathway) as well as ongoing community disability management and social care.

Standard 5: Inpatient care for people living with HIV

Change "People who are HIV positive who require admission to hospital should experience effective discharge planning to ensure timely length of stay, appropriate arrangements for ongoing care and safe discharge." to "People who are HIV positive who require admission to hospital should experience effective discharge planning to ensure timely length of stay, appropriate arrangements for ongoing rehabilitation, care and safe discharge."

Rationale: The term "care" does not generally indicate rehabilitation and current DH approaches to early supported discharge highlight rehabilitation as central to effective discharge processes; social care has also evolved so that care is no longer considered just a "package of care" but usually

“reablement” which is a rehabilitation and care hybrid. Adding the term “rehabilitation” to this statement relating to discharge will reflect current good practice.

Change:

Arrangements for care in specialist HIV inpatient services must ensure there is:

- o appropriate and timely escalation of care to HDU and ITU when indicated
- o 24-hour availability of pharmacy services and advice
- o An HIV specialist consultant physician-led multidisciplinary team
- o 24-hour availability of HIV specialist inpatient consultant advice and expertise
- o timely access to diagnostic investigations
- o timely access to other medical and surgical specialists when required
- o timely access to psychosocial and welfare advice and support
- o timely access to peer support

To:

Arrangements for care in specialist HIV inpatient services must ensure there is:

- o appropriate and timely escalation of care to HDU and ITU when indicated
- o 24-hour availability of pharmacy services and advice
- o An HIV specialist consultant physician-led multidisciplinary team
- o 24-hour availability of HIV specialist inpatient consultant advice and expertise
- o timely access to diagnostic investigations
- o timely access to other medical and surgical specialists when required
- o timely access to assessment and provision of inpatient rehabilitation
- o timely access to psychosocial and welfare advice and support
- o timely access to peer support

Rationale: Early access to rehabilitation has been shown to improve clinical outcomes and reduce length of stay and is considered good practice in modern healthcare. Certain aspects of rehabilitation (such as physiotherapy input in to respiratory management, speech and language assessment of safe swallow, and occupational therapy/physiotherapy management of soft tissue shortening/contracture and pressure areas) are essential in avoiding potential life threatening or severely disabling conditions. Timely access to these services needs mention here.

Standard 6: Psychological care

We feel that more is required in this standard to specifically highlight the importance of screening, assessment and treatment of neurocognitive disorders. We would make the following suggestions:

That a specific paragraph is inserted in to the first section of this standard that highlights neurocognitive disorders:

“Screening for cognitive impairment should be carried out regularly as described in the Standards for Providing Psychological Support for Adults Living with HIV. Where concerns are raised, individuals living with HIV should have access to further assessment and rehabilitation provided by suitably competent professionals. This may include locally embedded services or require referrals to community rehabilitation services including occupational therapy, neuro-psychology, speech and language therapy and neuro-psychiatry and social care. Individuals living with cognitive impairment may also require access to ongoing social care.”

We would also suggest adding a specific statement in the quality standards:

“People living with HIV should have access to a range of cognitive rehabilitation and support services appropriate to their needs.”

Rationale : It is documented that for patients with HIV related cognitive impairment specialist rehabilitation can result in improvements in cognitive function. In addition the psychological impact of an HIV diagnosis can be reflected in reported cognitive impairment. Introduction of strategies can enable individual to cope better and reduce symptoms of anxiety and depression that could be exacerbating cognitive functioning. People living with long term conditions who develop strategies to manage their condition are better at drug adherence, hospital attendance and are less likely to be admitted to hospital.

We also feel that these standards should specifically reference referral to lifestyle management and functional rehabilitation aspects of psychological care. We would recommend the following change:

“Clear pathways should be developed and adopted between services providing HIV clinical treatment and those offering psychological support. Psychological support should be delivered through a network of providers with different levels and types of expertise in

psychological issues for people living with HIV. Psychological support should include access, when necessary, to local mental health services, including psychiatric and community support, as well as to social and legal services and services managing the functional impact of psychological difficulties. Services should be planned to provide seamless integration across levels of psychological support, including transitions between services for people of all ages living with HIV. For more information about the stepped-care model, please refer to...”

Standard 9: Self management

Change “Services that provide care for people with HIV must be delivered in a way that not only supports but also facilitates self-management, whilst dealing with the physical, sensory, cognitive, psychological and social sequelae of HIV. Referral to and interventions from occupational and physiotherapists can optimise functionality which will facilitate many other aspects of self-management.” To “Services that provide care for people with HIV must be delivered in a way that

not only supports but also facilitates self-management, whilst dealing with the physical, sensory, cognitive, psychological and social sequelae of HIV. Referral to and interventions from occupational therapists, physiotherapists and speech and language therapists can optimise functionality which will facilitate many other aspects of self-management.

Rationale: Speech and language therapists work alongside OTs and physiotherapists in providing rehabilitation so should be included here. (It's a common misconception that SLTs only work with disorders of language and swallow, they also work with individuals with cognitive communications disorders which are now known to be prevalent in an HIV population)

Standard 11: Competencies

Add: Either add the following to the section on "Other professionals", or preferably have a section entitled "Rehabilitation Team":

"Physiotherapists, Occupational Therapists and Speech and Language Therapists should be registered with the Health and Care Professionals Council (HCPC) and in addition to the HCPC more specific competencies are outlined in the RHIVA Competencies (2012)². Physiotherapists working in any setting should have advanced or senior level skills in neurological, respiratory and musculoskeletal practice, whilst Occupational Therapists and Speech and Language Therapists should have advanced or senior level skills in neurological practice and in particular neurocognitive assessment and treatment. Therapists working in HIV specialist settings should also be able to demonstrate HIV related continuous professional development activity such as completing a RHIVA study day or an online HIV rehabilitation module."³

1. <http://www.who.int/classifications/icf/en/>
2. RHIVA Competencies – see below, in publication
3. <http://www.hivandrehab.ca/EN/module.php>

7 October 2012

Jacqueline Stevenson from African Health Policy Network (Ffena) sent the following message:

AHPN welcomes these Standards and the work which has clearly gone in to creating them. We also welcome the opportunity, as AHPN and with Ffena, to comment on the Standards. We would though in future consultations like to see consultations being open over a longer period, with more forewarning to organisations like ours to allow us to plan consultation activities with our members. Ffena, the only national network of Africans living with and affected by HIV, would welcome the opportunity to play a more active role in both participating in and facilitating BHIVA consultations. We would like to see future consultations made available in more accessible formats, including offline materials, simplified online processes, shorter questionnaires, and through pro-active engagement with existing groups through Focus Groups and other 'real-life' consultation. Meaningful consultation is vital to ensure relevance and utility for all patient groups. We would encourage BHIVA to consider producing consultation materials such as topic guides, to support

organisations, community groups and networks to facilitate consultation discussions with communities who may not be reached by online processes.

As an additional point, AHPN believes that across all the standards, data collection against the auditable outcomes must be gathered and disaggregated based on patient characteristics, including ethnicity. We want to see equalities information gathered and results disaggregated accordingly in order to facilitate improved knowledge on whether all groups affected by HIV are receiving the same standards of care.

We also have concerns around some of the language used in the Standards e.g. “the virus and the host” – which we believe is unhelpful and even offensive, and likely to make people living with HIV feel disengaged with the standards and the process.

One aspect missing from the Standards is the essential role and value of carers, which should be better acknowledged, in particular how clinicians should work with patients to identify their sources of care and support.

Finally, more information and thinking is needed on how the standards will be upheld, how they can be applied equally in different geographic areas and what contribution they will make to reducing health inequalities.

7 October 2012

Catherine Murphy from Terrence Higgins Trust sent the following message:

Terrence Higgins Trust would like to offer the following comments on the BHIVA Standards for the care of people living with HIV, 2012.

Misc

We welcome the particular recognition that the Standards give the psychological, emotional and social wellbeing of people living with HIV and the role of services in providing appropriate care to optimise wellbeing.

We would like to see the phrase ‘HIV positive people’ substituted with the phrase ‘people living with HIV’ wherever it, or similar, appears in the document.

Throughout the document numerous references are made to ‘timely’ or ‘ready’ access. We would suggest that timeframes should be clearly stated where possible.

Supporting text for Standards

Numbers and context: the statistics quoted are very heavily focussed on data from 2010. This will quickly become outdated so it may be useful to use data which relates to trends over the last five/ten years rather than focussing on 2010 only.

We would welcome the inclusion of a few lines in this introductory text that relates to the range of psycho-social influences on outcomes for people living with HIV in particular mental health issues and financial and social exclusion.

We would suggest consideration of whether the introductory text should include some reference to the National Commissioning Board and the role of national commissioning of HIV services in coming years.

Standard 1. Diagnostic Testing for HIV

We would welcome a slight revision to the following Quality Statement:

‘All those who present to medical services with identifiable risk factors (behavioural and geographical) should be offered an HIV test.’

We do not disagree with the aim of this statement, but we do think it could be misconstrued to mean for example that a gay man or African person should always be offered an HIV test when attending, primary care services, when a regular offer of a test is enough/ more appropriate.

We would suggest that the third measurable and auditable outcome in this section should be divided into two outcomes.

We would welcome clarity as to whether there should be individual outcomes pertaining to all the clinical settings where HIV testing should be required. For example, is it outwith the scope of these standards to quote outcomes in relation to testing in antenatal care? Would it be helpful to have a complete list for clarity, so as not to send any unintended message that other settings are of lesser importance?

Standard 2. Access to, and retention in HIV treatment and care

We would welcome the inclusion of the following in the third paragraph of the rationale:

‘Access to HIV appropriate emotional, psychological and peer support and specialist advice is particularly important..’

We would suggest that the first paragraph on page 13 needs to be revised. We do not support the the statement:

‘services should seek to maximise opportunities for people living with HIV to attend.’

Services must be as accessible as possible and barriers to access anticipated and removed. However, self management should also be encouraged in those people who can benefit and the statement above can be interpreted and as encouraging an unnecessary level of dependency on clinic services.

The rationale of standard 2 correctly identifies the impact that financial and social crisis can have on a person’s retention in care. However, the quality statements and measurable and auditable outcomes contain nothing relating to these factors. We would recommend inclusion of requirements on services to have clear referral pathways for patient’s encountering financial or social crisis, such as homelessness or loss of welfare benefits. These referral pathways are outlined in Standard 5, but

should equally apply to outpatient care. We would recommend that these referral pathways should provide timely access to:

‘HIV appropriate emotional, psychological and peer support and specialist advice’

These links are crucial in retaining and returning people in crisis to care. The standards need to be bold in setting these requirements out, otherwise they will continue to be ad hoc across the country and their absence will continue to undermine patient outcomes.

Standard 4. Safe ARV prescribing: Effective Medicines Management

We would query the statement on paragraph 7 of the rationale which states that HIV medication accounts for 20% of the entire NHS drugs budget.

Standard 5. Inpatient care for people living with HIV

Care arrangements: We would suggest that the final bullet point in the section should be changed from:

‘Timely access to psychological and welfare advice and support’

To:

‘Timely access to HIV appropriate emotional, psychological and peer support and specialist advice’

This statement could be used to provide consistency throughout the document.

Standard 6. Psychological care

We would suggest that the rationale to standard 6 should be shorter. It should provide a brief overview and direct to BHIVA psychological standards. As it currently reads it includes some examples, such as those outlining possible times of crisis. We believe that it is better to keep such descriptions brief and to direct to a fuller explanation in the dedicated standards, rather than to risk unintentionally prioritising some factors over others .

The last paragraph of the rationale contains the statement:

‘They should possess an awareness of the diversity of needs that people living with HIV may have - especially men who have sex with men... etc.’

We do not think the list of at risk groups listed adds to the statement and runs the risk of excluding some affected groups.

Standard 7: Sexual health and secondary HIV prevention

We would suggest that the following should be removed from the third paragraph of the rationale:

‘...although patients and healthcare workers need to be aware that medical notes can be obtained by a court order during police investigations’.

This statement emphasises the issue of medical records over the importance of patients having a rounded understanding of their legal rights and the law on STI transmission.

We would suggest removal of the following sentence from paragraph four of the rationale:

‘ensuring sexual partners are aware of the presence of HIV within the relationship’. We think this statement is unhelpful and portrays HIV as a third party or unwanted presence in a relationship.

Sexual health: we would welcome consideration of whether HCV should be included in routine tests in the same way as syphilis?

Measurable and Auditable Outcomes: we would suggest including the following:

‘Documented evidence that patients and staff have access to up to date information and/or training on the current law on STI transmission in the UK.’

Standard 8: Reproductive Health

We would welcome reference in the first paragraph of the rationale to the new NICE Fertility Guidelines and the implication for access to services for people living with HIV. The regulation that the first paragraph refers to is historical and the NICE guideline should ensure that this does not happen in future.

The third measurable and auditable outcome needs to be reworded. In particular the first sentence which reads:

‘...pregnant by a multidisciplinary team’

Standard 9. Self management

We would like to add a quality statement in the revised version which relates to access to financial advice.

We would also welcome the opportunity to add auditable outcomes that include clearly required referral pathways to an identified range of sources of support.

Standard 10: Service user engagement/involvement

We would suggest that some rewording of the rationale may be needed. In particular, we are not sure that the wording on treatment adherence is necessary as the audience will be familiar with these facts. We also don’t think the reference to financial limitations on second and third line treatment combinations is helpful. The meaning of the final sentence in the first paragraph is also unclear.

We would welcome removal of the phrase ‘HIV positive people’ from this section.

Quality statement: we would welcome clarification of what is meant by ‘options’ in the second bullet point of this section. What is meant by the phrase ‘things in the bullet points’ is also unclear.

Measurable and auditable outcomes: We would suggest that a recommendation should be made in this section to accessible resources, including provision in appropriate languages.

We would also welcome a outcome which requires auditing of patient involvement from an equalities perspective to ensure that there are no specific barriers for particular demographic groups.

Standard 11. Competencies

If the GP letter requirement is to be retained in this section it is important to be clear that patients must consent to their GP being contacted.

8 October 2012

Anna Bamford from Sussex Community NHS Trust sent the following message:

Clear and informative document

Although there is no mention of HIV Nurse Specialists who are not in GUM/HIV clinics but community based who see people in their own homes working with a LTC model. Is this because there is an expectation for in the future that all will be under acute hospitals?

The use of NHS numbers is a concern for patients from their feedback with us around confidentiality.

Around discharge planning (page 2) and sending a summary within 24 hours of discharge - this maybe by email, but many people do not have secure links between different organisations - may need guidance around this. Will patients also receive a copy?

No definition of out reach services - can you give some examples.

many thanks,

Anna