

## **BHIVA Standards of care online consultation comments**

**7 October 2012**

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

**18 September 2012**

**John Evans-Jones sent the following message:**

- 1.<350 mortality indicator - what evidence is there to set standard at 85% survival ?
  - 2.I think that you mean "protein:creatinine ratio" rather than "protein:keratin ratio"
  3. Nominated Consultant - we practice as a team & would question whether this should be indicator of quality
  4. Offer of copies of clinic letters to patients in an NHS quality measure ?
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**24 September 2012**

**Jane Bruton sent the following message:**

RE evidence of a nominated consultant. This may not be able to be measured by documentation of consultant in patient record. The patient may be managed by an advanced nurse practitioner, associate specialist or SpR within a consultant-led team in which the consultant provides an overview support and supervision but would not see the patient for a face to face consultation as it would not be required.

May need to adjust evidence to demonstrate there is robust consultant supervision

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**2 October 2012**

**Paul Declé from Forum Link sent the following message:**

Section 1 Rational;

End of paragraph 2, (add) 'or religious belief'.

Paragraph 3, (include) 'and TDM as required'

Section 2 Quality Statements

Bullet point 2 (include) Reception areas in the list of privacy areas.

Section 3c Patient experience.

Bullet point 1

(include) Reception areas in the list of privacy areas.

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**2 October 2012**

**Hilary Curtis from BHIVA clinical audit coordinator sent the following message:**

The proportion of patients with CD4 <350 on therapy is easily measurable (and I agree should be measured) but is VERY hard to interpret. It involves some perverse effects, eg that very late diagnosis would make the 95% target EASIER to achieve - since someone who starts ART promptly after being diagnosed with a CD4 of 50 will take a long time to immune reconstitute to 350 and will thus contribute greatly to the denominator but only briefly to the numerator, whereas someone who starts equally promptly at a CD4 of 350 will probably contribute equally briefly to the denominator and to the numerator. I am uncomfortable with this outcome because I'm not actually sure whether you want the proportion to go up or down.

The outcome relating to the proportion of patients with a CD4 <350 who are alive is poorly worded - you can't say it should be stratified and then set a target. Perhaps more seriously, the suggested target of 85% indicates that we consider 15% mortality acceptable. This is alarmingly high. Actual mortality within a year of diagnosis among late-diagnosed individuals is only 4%, see [http://www.publicservice.co.uk/feature\\_story.asp?id=19313](http://www.publicservice.co.uk/feature_story.asp?id=19313)

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**3 October 2012**

**Clare Stradling from Heartlands HIV Service sent the following message:**

Quality statement number 5 should include access to dietetic services, e.g.

All services should have appropriate and timely access to emotional, psychosocial and welfare advice and support, dietetic and reproductive health services.

Whilst 'dietetic advice' would fit more cohesively under the 'access to appropriate clinical support services such as pharmacy, adherence advice and counselling' in quality statement 2, I acknowledge that same-day access will not be achievable by all units and is not required as a minimum standard.

Thank you

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**3 October 2012**

**Dr Soe Aung from Faculty of Sexual and Reproductive Healthcare sent the following message:**

Typographical error in Standard 3

Monitoring according to national guidelines 3

It should be Protein/Creatinine ratio instead of Protein/Keratin ratio.

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**5 October 2012**

**David Ogden from HIV Pharmacy Association sent the following message:**

Amendment to quality statement:

“People with HIV should be in receipt of care in a dedicated outpatient department...same-day access to appropriate clinical support services such as dispensing services, specialist HIV pharmacist advice, adherence support and counselling.”

Add one more quality statement:

“A specialist HIV pharmacist should be available to take queries from patients, and GPs regarding antiretrovirals, potential drug interactions, adverse effects, drug administration and appropriate management.”

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**5 October 2012**

**Frances Keane from royal conrwall hospital trust sent the following message:**

co-morbidities could be handled locally where expertise exists. It will be very difficult to provide 24/7 cover for patients in units with < 4 consultants in geographically disparate areas.

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**5 October 2012**

**Roger Pebody from NAM sent the following message:**

Re communication with GPs, the rationale section needs to clearly say that this requires explicit consent from patients.

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**6 October 2012**

**Marc Lipman from Royal Free London NHS Foundation Trust sent the following message:**

the following comments relate in particular to the following standards: 3 - outpt care and access to care for complex comorbidity; 5 - inpatient care; 11 - competencies; and 12 - data, audit and research.

the standards are (perhaps necessarily) very general and in fact are more about what HIV physicians/teams should do re ART etc rather than appearing to discuss links with other specialist teams. I think that this leaves the standards open to the suggestion that HIV physicians can do everything by themselves. Whilst this is often the case, strong links with non-HIV specialist teams are likely to result in increased quality of care as well as educational gain for both sides.

There doesn't really seem to be anything re specific conditions. I would have thought that ensuring eg TB and HIV services are integrated is important and could be used as an example of good practice.

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**7 October 2012**

**Dr Olufunso Olarinde from South Yorkshire HIV Network sent the following message:**

Standard 3

The management of everyone who has HIV with >2-class resistance/drug intolerance or a comorbidity that significantly impacts on antiretroviral choice should be

discussed with specialist colleagues as part of a real or virtual clinic.

Monitoring according to national guidelines

- Patients with urinalysis and/or urine protein/creatinine ratio performed in the last year

(target 80%)

Comments:

- We assume email correspondence counts as 'virtual clinic' as this standard may otherwise be difficult for smaller units to achieve
  - Should it be Protein:Creatinine ratio?
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**7 October 2012**

**Clare Stradling from DHIVA sent the following message:**

Thank you for this welcome review of the HIV Standards, and for the time and energy you have contributed.

As acknowledged in the supporting text for the Standards, 'Increased life expectancy results in an ageing HIV-positive population with above average risk for cardiovascular, metabolic, bone and neurological problems, all of which are layered on top of an already complex medical condition', it is therefore crucial that HIV specialist dietitians form part of the chronic long-term condition management. We therefore recommend the following amendments.

in quality statement, insert:

dietetic

'All services should have appropriate and timely access to emotional, psychosocial and welfare advice and support, dietetic and reproductive health services.'

in quality statement, insert:

an AHP-led annual screening review and

'Everyone who is HIV positive should have access to an AHP-led annual screening review and services to manage the identified comorbidities safely, in collaboration with the appropriate non-HIV specialist team. The management of common comorbidities may be provided within the specialist HIV unit; otherwise clear pathways must be developed with regional services for people with complex and/or less common comorbidities.'

in auditable outcomes, patient experience, insert:

dietitian

'Ready access to defined support services within or close to out-patient (sexual health advisor, counsellor, adherence specialist, pharmacy, dietitian, phlebotomy) (target:100%)."

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## **7 October 2012**

**Jeromy Sachs from private individual sent the following message:**

"proportion of patients who are still alive after 1 year....."

This type of phrase is pretty scary for newly diagnosed HIV+ people to read, although I dont have any alternative suggestion, I advise caution.

Will this Standard be used only by health professionals or also by the patients?

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**7 October 2012**

**Philippa James from SDHIV Group of RCGP sent the following message:**

We agree about the importance of good GP/Specialist communications. We wondered whether it would be useful to reference the letter template which was drawn up between the BHIVA/SDHIVRCGP joint working group last year?

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**7 October 2012**

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

RHIVA is the Rehabilitation in HIV Association and is the BHIVA affiliated organisation representing Occupational Therapists, Physiotherapists and Speech and Language Therapists working with people living with HIV. This includes representing the therapists working in specialist HIV inpatient settings and specialist HIV outpatient settings, as well as leading on policy, education and quality issues for therapists working with people living with HIV in non-specialist settings including but not limited to inpatient wards, community rehabilitation services, social services and outpatient clinics. As well as BHIVA affiliation, we maintain links to our relevant professional bodies and have been involved in the overall development of these standards and the comments on this specific section are in addition to the general submission we have also made, where we also represent the specific comments below. 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, for clarity, as well as giving a short rationale for our recommendation for change.

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.

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**7 October 2012**

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

“Monitoring and treatment for people with HIV infection needs to be in accordance with current national guidelines to maximise health and life expectancy and minimise morbidity and mortality.” –

and also to minimise health inequalities between areas and communities, reflecting in particular the focus of the Public Health Outcomes Framework.

While we welcome the recognition that individuals should be “treated with dignity and respect regardless of race, sex or sexual orientation.” – for completeness this should also include ethnicity, disability, and immigration status.

Increased integration with primary care is essential, but so is recognition that some individuals and groups find accessing primary care difficult, and should not experience lower standards of care as a result.

We welcome the call for access to reproductive health services – identified as lacking at our recent Ffena Women’s Conference. Women and men living with HIV need better information, support and access to these services. We would be happy to share the relevant findings from our conference to assist with development of this.

We believe that patient experience surveys should be disaggregated to reflect patients’ gender, ethnicity and sexual orientation and other protected characteristics, to ensure that all patients are having their needs met.