

## Standard 7a

<b>Organisation name</b> (if you are responding as an individual, please leave blank)			
<b>Name of commentator</b>			Hilary Curtis
<b>Role of commentator</b>			BHIVA Clinical Audit Co-ordinator
40	7a	78	<p>Suggest re-word for clarity as:</p> <p>“Documented evidence of a comprehensive medical and psychosocial summary of paediatric care being provided to the adult service”</p> <p>“Service named leads for transition in both paediatric and adult care”</p>
41	7a	81	“Staff involved in the care of under 18s should be trained in recognition of CSE, how to use Spotting the Signs or a similar tool, and actions to take (100%).”
42	7a	82	<p>“Documented evidence of discussion of alternatives to tenofovir disoproxil fumarate in young adults and adolescents living with HIV”</p> <p>I may be mistaken, but as I understand it, tenofovir alafenamide is one possible alternative.</p>

<b>Organisation name</b> (if you are responding as an individual, please leave blank)			Scottish Drugs Forum
<b>Name of commentator</b>			Austin Smith
<b>Role of commentator</b>			Policy and Practice Officer
44	7a	80	Services working with young adults living with HIV should have an understanding of drug and substance use issues and their relation to HIV status and HIV transmission as well as impact on treatment and engagement with services.

45	7a	81	Young adults living with HIV should be made aware of the issues involved in injecting drug use for themselves and for other people and be aware of alternatives to injecting, route transition.
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<b>Organisation name</b> (if you are responding as an individual, please leave blank)			CHIVA
<b>Name of commentator</b>			Dr Bala Subramaniam
<b>Role of commentator</b>			Executive member, CHIVA
9	7	78	Young adults and adolescents living with HIV. Transition
10	7a	80	Measurable and audit-able outcomes for adolescents and young adults ( 10-24) for sexual history, contraception , prep and pep , and spotting the signs of CSE- there is no age or other criteria for who this auditable standard includes. (Eg not appropriate for 10 and 11 yr olds to have sexual history and contraception status documented).
11	7a	83	Spotting the signs reference - link doesn't work in certain formats.

<b>Organisation name</b> (if you are responding as an individual, please leave blank)			British Psychological Society (BPS)
<b>Name of commentator</b>			Sarah Rutter & Tomás Campbell
<b>Role of commentator</b>			Chair & Treasurer of the BPS Faculty of HIV & Sexual Health
13	7a	80	Rationale section: paragraph 2. Change term “mental ill health” to “mental health difficulties” – for the same reasons stated in comment number 5.

<b>Organisation name</b> (if you are responding as an individual, please leave blank)			Scottish HIV Clinical Leads group
<b>Name of commentator</b>			Dr Nick Kennedy
<b>Role of commentator</b>			Consultant Physician. Former Clinical Advisor on HIV to Healthcare Improvement Scotland (HIS); former Co-chair of HIV Clinical Leads group
26	7a	79	<i>'Clinics should be provided at convenient times, such as after college or work, and in easily accessible locations'</i> . If this statement is going to be retained in the final Standards, it will have to be modified to something like <i>'Clinics should be provided at convenient times, preferably including clinics after college or work, and in easily accessible locations'</i> . Many/most HIV units in Scotland at least do not currently have the resources to provide evening HIV clinics (or for that matter evening clinics in other specialist non-HIV areas) and this is unlikely to change.

## Standard 7b

<b>Organisation name</b> (if you are responding as an individual, please leave blank)			British Infection Association
<b>Name of commentator</b>			Andrew Ustianowski (author) and Anna Goodman (Guidelines secretary and submitting)
<b>Role of commentator</b>			As above
11	7b	87	Please clarify what is meant by 'target as per BHIVA guidance' in the outcomes

<b>Organisation name</b> (if you are responding as an individual, please leave blank)			
<b>Name of commentator</b>			Hilary Curtis
<b>Role of commentator</b>			BHIVA Clinical Audit Co-ordinator
43	7b	87	<p>Other than peer support, the rationale and quality statements don't say that support services should be HIV specialist, and in many areas it wouldn't be viable. Hence suggest:</p> <p>"All HIV services should be linked to relevant community and support services and these pathways should be described and available for service users (target 95%)</p> <p>All HIV services should be linked to HIV-specific peer support and these pathways should be described and available for service users (target 95%)"</p> <p>Not sure that TAsP target really belongs in this section, but if it is to be included it should follow same wording as in 1b.</p>

<b>Organisation name</b> (if you are responding as an individual, please leave blank)			DHIVA Dietitians in HIV Association
<b>Name of commentator</b>			Clare Stradling
<b>Role of commentator</b>			Chair
6	7	86	Recommend inclusion of dietetic services along with smoking cessation, drug and alcohol services. Recommend inclusion of diabetes and hypertension with modifiable risk factor management.

<b>Organisation name</b> (if you are responding as an individual, please leave blank)			Scottish Drugs Forum
<b>Name of commentator</b>			Austin Smith
<b>Role of commentator</b>			Policy and Practice Officer
46	7b	87	Measurable and auditable outcomes should include separate reporting for people who have been infected through injecting drug use and/or are injecting drug users so that issues in this particular group are not missed in overall statistics.

<b>Organisation name</b> (if you are responding as an individual, please leave blank)			British Psychological Society (BPS)
<b>Name of commentator</b>			Sarah Rutter & Tomás Campbell
<b>Role of commentator</b>			Chair & Treasurer of the BPS Faculty of HIV & Sexual Health
14	7b	84	Rationale section: end of paragraph 3. Where complex care and enhanced care needs are mentioned, it may be helpful to reference section 4c.

<b>Organisation name</b> (if you are responding as an individual, please leave blank)			Positive East
<b>Name of commentator</b>			Mark Santos & Steve Worrall
<b>Role of commentator</b>			Director & Deputy Director
22	7b	86	Replace 'peer mentoring' with 'peer support (which may include peer mentoring)' as mentoring is a specific activity and the offer could be broader.

<b>Organisation name</b> (if you are responding as an individual, please leave blank)			
<b>Name of commentator</b>			Laura Waters
<b>Role of commentator</b>			Consultant Physician
36	7b	G	A lot of this is repeating other sections of the standards and I'm not sure such a wide age band warrants a specific age-related section beyond all the recommendation, quality statement and outcomes listed elsewhere in the document. On a specific note I'm not sure you can make a call for STRs without appropriate evidence and suggest this is left to ART guidelines. 2 steps on form STRs in the quality statements there is a call for vaccination, cervical screening ec etc – this is all covered by other guidelines. I'm rally not sure how this long and disparate list of quality statements is specific to this age group or and do not see what it adds where these are covered elsewhere in (a) the standards (b) evidence based & fully referenced nationasl guidelines

<b>Organisation name</b> (if you are responding as an individual, please leave blank)			NAT
<b>Name of commentator</b>			Yusef Azad

Role of commentator			Director of Strategy
			In the Age-related statistics bullets within the Early to middle adulthood sub-section, the third bullet implicitly refers to the psychosis rate amongst people with HIV, since it is stated as twice the adults' population rate. This raises doubts as to whether the other bullets refer to the general adult population or the population of adults living with HIV. It would be good to clarify.
			There is reference to 'specialist HIV support services' in the outcomes part of this sub-section, the first time this phrase has been used. Would it be clear what this refers to? We presume it is both peer support services and wider specialist advice and advocacy services, often provided by voluntary and community sector organisations.

## Standard 7c

<b>Organisation name</b> (if you are responding as an individual, please leave blank)			
<b>Name of commentator</b>			Ben Cromarty
<b>Role of commentator</b>			
12	4b	52	<p>If you have co-morbidities, it may not be clear who is ‘in charge’ of your care. And due to confidentiality protections and bureaucratic issues, information may not always be shared as much as you’d like between the medical teams who are treating you.</p> <p>These problems are not unique to HIV. They affect large numbers of people with multiple health conditions in the general population, particularly older people.</p> <p>The National Institute for Health and Care Excellence (NICE) has issued guidance on this. NICE says that anyone taking a lot of different medications or who is finding it hard to cope with multiple health problems can ask to have their healthcare reviewed, so that it is better co-ordinated. You could ask any of your doctors to initiate this review.</p> <p>The review should take full account of what is most important to you and include a review of all the medications you are taking. You and your doctor should agree a plan for how future healthcare will be provided. This could include naming a clinician who will co-ordinate your care across different healthcare services and deal with any conflicting advice.</p> <p>NICE doesn’t say who should provide this co-ordinating role, but you could ask your HIV doctor if your clinic can offer any support. There may be a community nurse or clinical nurse specialist who could help co-ordinate your care.</p> <p>Nonetheless, your HIV clinic may suggest that it is done by someone with a broader medical background. This could be your GP or someone else working at the GP practice, such as a community matron or senior nurse. Another option could be a doctor or nurse who specialises in the care of older people (geriatric medicine) – they have particular experience of managing the care of people with multiple health conditions.</p>



			(...this is from AIDSmap Factsheet...) This document needs to say something along these lines...
15	7c	89	...see my comment 12...it is worth repeating here in this section as well

<b>Organisation name</b> (if you are responding as an individual, please leave blank)			DHIVA Dietitians in HIV Association
<b>Name of commentator</b>			Clare Stradling
<b>Role of commentator</b>			Chair
7	7	88	include diabetes here at bottom of page

<b>Organisation name</b> (if you are responding as an individual, please leave blank)			Terrence Higgins Trust
<b>Name of commentator</b>			Alex Sparrowhawk
<b>Role of commentator</b>			Membership and Involvement Officer
9	7c.	G	Why are there no quality statements or measurable and auditable outcomes? We think this section needs further work and much more details as it includes some of the most vulnerable people living with HIV in the UK at this time. The concerns and needs of the first generation of people ageing with HIV are well documented in THT's <i>Uncharted Territory</i> report and we would advise that the report is used as a point of reference to strengthen this section of the standards.

			<p>Issues and concerns relating to social care, finances and social isolation were all prominent in the research and should be addressed here.</p> <p>The report can be accessed here: <a href="http://www.tht.org.uk/unchartedterritory">http://www.tht.org.uk/unchartedterritory</a></p>
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<b>Organisation name</b> (if you are responding as an individual, please leave blank)			British Psychological Society (BPS)
<b>Name of commentator</b>			Sarah Rutter & Tomás Campbell
<b>Role of commentator</b>			Chair & Treasurer of the BPS Faculty of HIV & Sexual Health
12	7c	88	As people with HIV grow older with the condition, an increasing number will develop dementia (High et al, 2006; Valcour et al, 2004; <a href="https://www.nhivna.org/file/ouOzNrhVtHpkJ">https://www.nhivna.org/file/ouOzNrhVtHpkJ</a> ). Some will require increased support within their own homes and /or residential care. Support staff may require additional training about the needs of PLHIV.

<b>Organisation name</b> (if you are responding as an individual, please leave blank)			Scottish HIV Clinical Leads group
<b>Name of commentator</b>			Dr Nick Kennedy
<b>Role of commentator</b>			Consultant Physician. Former Clinical Advisor on HIV to Healthcare Improvement Scotland (HIS); former Co-chair of HIV Clinical Leads group
27	7c	88-90	Section 7c older people- this section has no Quality Statements or suggested Auditable Outcomes which we feel is a major missed opportunity. It is imperative that further thought is given to this area and that the relevant Qs and AOs are developed.

<b>Organisation name</b> (if you are responding as an individual, please leave blank)			Positive East
<b>Name of commentator</b>			Mark Santos & Steve Worrall
<b>Role of commentator</b>			Director & Deputy Director
23	7c	88	What is the age range for 'older age' is it >50
24	7c	88	Person Centred Care – references to THT seem very specific and needs to be more general

<b>Organisation name</b> (if you are responding as an individual, please leave blank)			NAT
<b>Name of commentator</b>			Yusef Azad
<b>Role of commentator</b>			Director of Strategy
			The version of the consultation document we have looked at does not as yet have Quality statements or Measurable and auditable outcomes for the 'Older age' sub-section. It will be important to have content on social services. In that context, we would mention NAT's 'HIV training for care providers' (Dec 2016) and NAT's 'HIV: A Guide for Care Providers' (July 2015).

## Standard 7d

<b>Organisation name</b> (if you are responding as an individual, please leave blank)			
<b>Name of commentator</b>			Hilary Curtis
<b>Role of commentator</b>			BHIVA Clinical Audit Co-ordinator
44	7d	93	<p>Suggest omit or move “(as recommended by the Committee of Ministers of the Council of Europe (Rec 23 2004) as a tool for strengthening palliative care across Europe) “ – this might go in rationale but is better left out of the outcome.</p> <p>Do we also need a target about recognising when people have life limiting illness? Eg, “Among people dying, proportion previously recognised and managed as having life-limiting illness”.</p>

<b>Organisation name</b> (if you are responding as an individual, please leave blank)			
<b>Name of commentator</b>			Kaveh Manavi
<b>Role of commentator</b>			Consultant physician in HIV
15	7d		<p>This is a strange section for a HIV centre to follow in 2018. It would have been appropriate in 1990s and pre-HAART era. The end of life planning for HIV patients at present is very rarely related to HIV infection. The document earlier acknowledges the remarkable success in HIV care that has made the infection a chronic condition. The majority of PLWH now die of causes similar to those in general population. I struggle to understand how should PLWH's palliative care differ from those not with HIV infection. In practice, how should HIV centres following up patients once every six months, lead on their end of life process when GPs and Palliative Care Physicians have been delivering this more competently? I also find it strange that we are advised to follow a european website and document written in 2004 when UK guidelines on palliative care would be more up-to-date. I regret that in my view this section is not relevant.</p>

<b>Organisation name</b> (if you are responding as an individual, please leave blank)			
<b>Name of commentator</b>			Roy Trevelion
<b>Role of commentator</b>			UK-CAB BHIVA Rep, i-Base staff
10	7d	91	Important to include palliative care at this moment in time. As Richard Harding said in his presentation at BHIVA, we are, "Moving the conversation from <b>why</b> people die to <b>how</b> people die."

<b>Organisation name</b> (if you are responding as an individual, please leave blank)			Scottish Drugs Forum
<b>Name of commentator</b>			Austin Smith
<b>Role of commentator</b>			Policy and Practice Officer
47	7d	91	The last paragraph is a good example of the coverage of this document that largely does not identify particular groups but when it does these are men who have sex with men and sub-Saharan Africans exclusively. This needs more thought and to be a truly inclusive document.

<b>Organisation name</b> (if you are responding as an individual, please leave blank)			African Health Policy Network
<b>Name of commentator</b>			Deryck Browne
<b>Role of commentator</b>			Chief Exec
4		91	For patients of <b>African heritage</b> , cultural differences in the acceptance and the patient's interpretation of pain[28-30] should be taken into account to avoid under-treatment.

<b>Organisation name</b> (if you are responding as an individual, please leave blank)			Scottish HIV Clinical Leads group
<b>Name of commentator</b>			Dr Nick Kennedy
<b>Role of commentator</b>			Consultant Physician. Former Clinical Advisor on HIV to Healthcare Improvement Scotland (HIS); former Co-chair of HIV Clinical Leads group
29	7d	93	<i>'Clarity is needed on who should be involved in care planning and provision in the case of reduced capacity. The Mental Capacity Act 2005 allows people to express their preferences for care and treatment, and to appoint a trusted person to make a decision on their behalf should they lack capacity in the future (see references for further information in capacity and the Mental Capacity).'</i> The above statement applies to England. There is a need to describe the legislation in Scotland such as Adults with Incapacity and Mental Health Act Scotland, or at least make reference to this. Also need to ensure the different legislation in N Ireland and Wales are reflected.

<b>Organisation name</b> (if you are responding as an individual, please leave blank)			
<b>Name of commentator</b>			Mary Dicks
<b>Role of commentator</b>			Clinical Psychologist
			Disclosure of underlying cause of death on death certificate may be contrary to advance directive of deceased – could some guidance be given?

<b>Organisation name</b> (if you are responding as an individual, please leave blank)			BASHH HIV Specialist Interest Group (SIG)
<b>Name of commentator</b>			Tristan Barber

Role of commentator		Chair, BASHH HIV SIG	
17	7d		<p>This is a strange section for a HIV centre to follow in 2018. It would have been appropriate in 1990s and pre-HAART era. The end of life planning for HIV patients at present is very rarely related to HIV infection. The document earlier acknowledges the remarkable success in HIV care that has made the infection a chronic condition. The majority of PLWH now die of causes similar to those in general population. I struggle to understand how should PLWH's palliative care differ from those not with HIV infection. In practice, how should HIV centres following up patients once every six months, lead on their end of life process when GPs and Palliative Care Physicians have been delivering this more competently? I also find it strange that we are advised to follow a European website and document written in 2004 when UK guidelines on palliative care would be more up-to-date. I regret that in my view this section is not relevant.</p>