

Standard 6

Organisation name (if you are responding as an individual, please leave blank)			British Infection Association
Name of commentator			Andrew Ustianowski (author) and Anna Goodman (Guidelines secretary and submitting)
Role of commentator			As above
10	6c	76	Would it not be appropriate for those with cognitive functioning symptoms to have <i>screening</i> neuropsychological assessments rather than 'full' assessments unless suggested by the screening tests?

Organisation name (if you are responding as an individual, please leave blank)			Gilead Sciences UK
Name of commentator			Chris Robinson
Role of commentator			HIV Medical Affairs
5	6b	72	Suggest there should be some mention of the fact that some ARVs can have an impact on patient's mental health

Organisation name (if you are responding as an individual, please leave blank)			
Name of commentator			Roy Trelivon
Role of commentator			UK-CAB BHIVA Rep, i-Base staff
8	6	69	This section is excellent. Section 6a. (Emotional well-being) importantly points out that, "Stigma [around HIV] may be in addition to pre-existing stigma based on actual or perceived membership of different social groups (e.g. gender identity, religion, age, class, ethnicity, sexuality etc.)."

Organisation name (if you are responding as an individual, please leave blank)			
Name of commentator			Mel Rattue
Role of commentator			Woman living with HIV
3	6a	70	<p>“can breed stigma persists, both from the general public and within the healthcare system (HIV Stigma Index UK, 2009).”</p> <p>Perhaps here something more can be said about structural abuse against people and specifically women living with HIV (see comment number 1 and 8)</p>
4	6a	70	<p>“Message specific campaigns”</p> <p>I feel these campaigns should be specifically named, i.e. Cant pass it on, U=U</p>
5	6b	71	<p>“skills-based (e.g. mindfulness, benefits support”</p> <p>Mindfulness is more than a skill, Mindfulness Based Cognitive Therapy and Mindfulness Based Stress Reduction are psychological interventions, which have been scientifically proven to be more effective than antidepressants in the treatment of depression, and affective in supporting people living with HIV.</p> <p>http://www.thelancet.com/journals/lancet/article/PIIS0140-6736%2814%2962222-4/abstract</p> <p>https://www.hra.nhs.uk/planning-and-improving-research/application-summaries/research-summaries/positively-mindful/</p> <p>http://www.tandfonline.com/doi/abs/10.1080/09540121.2017.1394434?needAccess=true&journalCode=caic20</p>
6	6b	72	<p>I feel there needs to be a mention here of the high levels of mental health issues experienced specifically by women living with HIV post-diagnosis, and also in relation to receiving a diagnosis during pregnancy.</p>

			How does living with HIV impact on women's mental health? Voices from a global survey JIAS http://onlinelibrary.wiley.com/doi/10.7448/IAS.18.6.20289/abstract
7	6c	75	Cognitive function Latest research, still inconclusive. http://onlinelibrary.wiley.com/doi/10.1111/hiv.12598/abstract?campaign=wolearlyview

Organisation name (if you are responding as an individual, please leave blank)		Scottish Drugs Forum	
Name of commentator		Austin Smith	
Role of commentator		Policy and Practice Officer	
38	6	69	<p>Stepped Care Approach for Psychological Support for Adults Living with HIV</p> <p>It should be noted that staff in drug treatment and support services may not feel able to offer psychological supports due to</p> <ul style="list-style-type: none"> • A lack of understanding of these issues • A lack of awareness of this role • A perceived or real lack of time and/or other resources <p>And that this is a significant barrier to this model of support being made available to people engaged with drug treatment and support services.</p>

39	6a	71	Measurable and auditable outcomes for emotional well-being 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.
40	6b	72	It should be noted that drug use and the medication used in the treatment of substance dependence (e.g. methadone) is used as a screen to exclude people from mental health services. This is a significant issue in addressing the mental health needs of people who have drug problems.
41	6b	74	Measurable and auditable outcomes for mental health 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.
42	6c	75	It should be noted that long term cognitive impairment is a commonly reported (and yet under reported) consequence of substance use and of overdose. This means that there may be higher prevalence of cognitive impairment in people who inject drugs or otherwise use drugs and are living with HIV than among people living with HIV more generally. It is important that services do not waste time and resources in seeking the cause of impairment or in differentiating between people with different causes of impairment to the detriment of the provision of a service to people affected.
43	6c	76	Measurable and auditable outcomes for cognitive function should include separate reporting for people who have been infected through injecting drug use and/or are people who use drugs (not only people who inject drugs) so that issues in this particular group, likely to be overrepresented in terms of cognitive impairment, are not missed in overall statistics.

Organisation name (if you are responding as an individual, please leave blank)	Sophia Forum
Name of commentator	Sophie Strachan
Role of commentator	Co Chair

17	6	70	<p>Level 3 support, is few and far between with ever diminishing services, IAPt are becoming a referral source with under qualified people offering nothing more than CBT – so if that is the way forward it is very worrying but also need to determine level of knowledge re HIV and all that comes with it – waiting times can be over 6 months</p> <p>Need will vary for each person dependant on gender identity, ethnicity and orientation and adjustment</p>
18	6b	72	<p>Welcoming quality standards, but how realistic in current austerity and mental health services at bursting point. Actual referral to anything other than a GP despite supporting letters is failing patients (speaking from current experience) despite PTSD, moderate depression and bereavement</p>

Organisation name (if you are responding as an individual, please leave blank)	Salamander Trust
Name of commentator	Alice Welbourn
Role of commentator	Founding Director

15	6	G	<p>Psycho-social care: Could the writers please remove “infection” or, if necessary change it to "acquisition” or “transmission” as in the UNAIDS Terminology Guidelines 2015 .See also eg Dilmitis et al JIAS 2012.</p>
16	6	G	<p>High levels of mental health issues were experienced by women living with HIV post-diagnosis, found in our global values and preferences survey (Orza et al 2015 JIAS). These were even higher for women living with HIV with other socially marginalised identities.</p>
17	6	G	<p>Mental health issues can also be exacerbated by violence against women living with HIV. It is good to see this huge issue flagged up in this section. Here is an article we wrote about this also in JIAS. The preferred term is now “violence against women” rather than ‘gender-based violence’, to be more specific and focused about how it is experienced by women. It is important to note here that violence in healthcare settings shoots up post-diagnosis. I feel it is also important to flag up in section 6 the additional gender dimensions for women in relation to mental health. Many women experience VAW, yet find it extremely hard to discuss it with others, which can cause additional stress. These also include pregnancy and a woman’s natural fears for the safety of her unborn child, as well as the intimate partner violence which can commonly</p>

			start or increase during pregnancy, whether or not a woman has HIV. [Both these cited papers are based on a global survey of women living with HIV, with ca. 50 women from the UK taking part. Results from the UK reflected the global results closely.]
18	6	G	Re message campaigns such as U=U, some people, myself included, feel uncomfortable with this message, because they/I still feel that it is putting the implicit responsibility on us as people with HIV to be undetectable, rather than promoting <i>joint</i> responsibility for <i>all</i> sexual activity, whether HIV is present or not, between consenting adults. So such campaigns need to be clear about this – otherwise there is risk of this assumption of individual responsibility being reinforced.
19	6	G	Re the 4 th 90 – this can also be viewed as the oxygen which breathes life into the other 3 90s – ie without Quality of Life throughout the other 3, none of them can be achieved.
20	6	73	Rather than ‘substance abuse’, the preferred term in harm reduction work is “substance use”.

Organisation name (if you are responding as an individual, please leave blank)			Scottish HIV Clinical Leads group
Name of commentator			Dr Nick Kennedy
Role of commentator			Consultant Physician. Former Clinical Advisor on HIV to Healthcare Improvement Scotland (HIS); former Co-chair of HIV Clinical Leads group
24	6a	70	Stigma: There is an overlap here with section 2a – is this intentional? Also, one Clinical Lead considered that discussing and documenting HIV related stigma for all new patients seems somewhat negative – ‘its almost saying that “its very common and look out for it”, which may not necessarily be a positive approach for a worried patient with a new HIV diagnosis’

Organisation name (if you are responding as an individual, please leave blank)				Positive East
Name of commentator				Mark Santos & Steve Worrall
Role of commentator				Director & Deputy Director
21	6	71	measurable 3 rd bullet add 'and emotional support' after the word 'peer'	

Organisation name (if you are responding as an individual, please leave blank)				
Name of commentator				Laura Waters
Role of commentator				Consultant Physician
35	6	G	I apologise I have not had time to cross-reference thi section with the psychological standards but, apologies for being repetitive, suggest this could benefit from some pruning and signposting	

Organisation name (if you are responding as an individual, please leave blank)				
Name of commentator				Sophie Strachan
Role of commentator				
			I wanted to bring to your attention the recently publicised NICE quality standards regarding the mental health of adults in contact with the criminal justice system, all four standards equally important but especially 3 & 4 in the context of care pathway	

Organisation name (if you are responding as an individual, please leave blank)			NAT
Name of commentator			Yusef Azad
Role of commentator			Director of Strategy
			The reference to stigma in the general public is best referenced by NAT's report of its Ipsos MORI survey on public attitudes to HIV, 'HIV: Public Knowledge and Attitudes 2014' https://www.nat.org.uk/sites/default/files/publications/Mori_2014_report_FINAL_0.pdf . This document could be included also in the References at the end along with NAT's report 'Tackling HIV Stigma: What Works?' NAT July 2016.
			How, in the Quality statements, can 'The potential burden of living with and managing a chronic illness' be routinely monitored? Similarly, in the Measurable and auditable outcomes, the phrase in the first bullet point 'discussion of potential HIV related stigma' is a bit unclear. Does this mean discussion of any fears or experience of stigma, whether external or internal?
			In sub-section 6b first paragraph, it would be useful to include the general population comparator for the 2014 study cited re elevated depression and anxiety among people living with HIV.
			In relation to the content on 'timely assessment and management' in Quality statements and outcomes, can we be more specific as to what 'timely' means? Are there wider mental health standards/outcomes to which we can refer?

Organisation name (if you are responding as an individual, please leave blank)			UK-CAB
Name of commentator			Mel Rattue
Role of commentator			
			Emotional well-being

		<p>This new section now includes peer support as a quality statement, which should be sign posted, discussed and documented.</p> <p>It also recognises the importance of:</p> <p>Holistic care, being more than a Viral load.</p> <p>Social and recreational gatherings, hosted by organisations and the NHS.</p> <p>How movement to primary care and self management can be stressful.</p>
		<p>The 1st and 2nd drafts written mention stigma:</p> <p>“The UNAIDS campaigns for ‘zero discrimination’ and initiatives such “U=U” educating people about the role of undetectable viral load upon infection rate could help address this stigma, and these messages should be promoted by HIV services to both PLWH and the wider public.”</p> <p>In the latest version U=U has been changed to "Message specific campaigns"</p> <p>I have suggested that U=U is returned to the final draft,</p> <p>U=U, sparked discussion on other forums as some people living with HIV feel uncomfy with this message, because they feel that it is putting the implicit responsibility on us as people with HIV to be undetectable, rather than promoting <i>joint</i> responsibility for <i>all</i> sexual activity, whether HIV is present or not, between consenting adults.</p> <p>Perhaps this is why it was changed to “messaging campaigns such as U=U” rather than about “U=U” specifically?</p> <p>Another thought was U=U places the responsibility for HIV transmission firmly where it belongs: on the global healthcare system. It takes that responsibility away from the individual.</p> <p>Ever since the START and PARTNER study results, the scientific debate on whether it is better for the individual to take ART or not is over.</p> <p>It is overwhelmingly clear that if someone takes ART and achieves an undetectable viral load, they cannot transmit HIV. Clearly this is of benefit to society, but it is NOT a social obligation on the individual's part. On the contrary, as a number of opinion surveys have found, it is an objective earnestly *desired* by people with HIV themselves: no longer being infectious is consistently ranked within the top three benefits of taking ART by people with HIV in surveys. Given that anxiety about transmitting to partners, fear of disclosure, shame about status and concern about possible criminalisation are all matters that may contribute to isolation and depression, and therefore to poor coping and illness, it is at least</p>

		<p>arguable that the prevention benefits of viral suppression are of as much direct *clinical* benefit to individuals as they are of social benefit.</p> <p>On an abstract and ideal level we all have joint responsibility for keeping ourselves safe sexually. In the real world, however, viral undetectability actually relieves the HIV+ person from what may be an intolerably onerous burden of disclosure, of insisting on condom use, of being courageous enough to risk rejection and violence, and of many other things. Stigma is the result of fear and if people with HIV become less fearful to their partners, the stigma against them may start to ebb away.</p>
		<p>There was also discussion about womens mental health and how this needs to be included, perhaps even another subsection?</p> <p>It is felt there is further research needed for women especially the impact of being diagnosed when pregnant, and gender based violence. I attended a mentor mother group where many positive women shared their experience of healthcare abuse here in the UK, so I feel it is important to mention, it is also a global issue.</p> <p>http://www.who.int/reproductivehealth/publications/gender_rights/Ex-Summ-srhr-women-hiv/en/</p> <p>How does living with HIV impact on women’s mental health? Voices from a global survey, and the Invisible no more research, have definitions of GBV and abuse which I believe should be mentioned somewhere. “violence against positive women is any act, structure or process in which power is exerted in such a way as to cause physical, sexual, psychological, financial or legal harm to women living with HIV”</p> <p>Orza L et al. Journal of the International AIDS Society 2015,18(Suppl5):20285 http://www.jiasociety.org/index.php/jias/article/view/20285 http://dx.doi.org/10.7448/IAS.18.6.20285</p>
		<p>Cognitive Function, had less comments, I personally felt it was fair how, it is described as perhaps we will never know how much cognitive decline correlates with HIV.. there is new research but still inconclusive.</p> <p>http://onlinelibrary.wiley.com/doi/10.1111/hiv.12598/abstract?campaign=wolearlyview</p>

			<p>Did you receive any more information on different screening tools? I was also sent the NHIVNA psychological support skills work book, which I feel is a really useful tool worth mentioning I have attached this for your information.</p>