Standard 5a

Organisation name (if you are responding as an individual, please leave blank)			
Name of commentator			Ben Cromarty
Role of commentator			
13	5a	59	This sentence reads badly…People living with HIV who may be at risk of drug use associated with sex, including chemsex, infectious hepatitis, and Sexually Transmitted Enteric Infections (STEI) should be identified and offered support, advice and interventions. …better to have …People living with HIV who may be at risk of drug use associated with sex (including chemsex), infectious hepatitis, and Sexually Transmitted Enteric Infections (STEI) should be identified and offered support, advice and interventions.
14	5a	60	Since the previous Standards, new evidence has emerged regarding transmission of HIV, showing that people living with HIV on antiretroviral therapy with an undetectable viral load in their blood (achieved and sustained for at least 6 months) have a negligible risk of sexual transmission of HIV. …this section would stand out more if it were a separate paragraph.

Organisation name (if you are responding as an individual, please leave blank)			
Name of commentator			Hilary Curtis
Role of commentator			BHIVA Clinical Audit Co-ordinator
7	1b 5a 5b G	19	"Evidence of a patient experience survey to assess satisfaction regarding discussion around HIV transmission and HIV prevention options." etc I'm concerned about outcomes which appear to call for multiple patient experience surveys. Such surveys are potentially wasteful and time-consuming for people to design, collect and analyse data, especially as there are no validated measures for most things. If these outcomes are to be retained at all, I would suggest re-wording them along the lines of "Evidence of inclusion of satisfaction regarding discussion around HIV and HIV prevention options within patient experience surveys" [with cross-ref to section 3b]. That avoids implying there should be separate surveys.
35	5a	62	"hepatitis C screening within 4 weeks of diagnosis" – re-word to be consistent with 4b which says "at diagnosis or 1st clinical appointment" Do we need "Documented evidence of yearly consideration of offer to access to Sexual Health services where HIV services are separate" as well as the first outcome which includes documented offer of SH screen? Suggest add: "Women with HIV aged 25-65 with documented cervical cytology within the past 15 months". It's important because the frequency is different to that for HIV negative women.
36	5a	63	"Documented evidence of risk-reduction discussion within 4 weeks of initial diagnosis, and within 1 week of subsequent risk disclosures. This should include discussion on the use of effective antiretroviral therapy to reduce risks of onward transmission (target: 90% of patients living with HIV)." Wording should be the same as in 1b. "Evidence of a patient experience survey to assess satisfaction regarding discussion around HIV testing of their children."
37	5a	63	

			This isn't really suitable even for inclusion in a patient experience survey, let alone being the topic of a survey in itself. While well-designed qualitative research could be valuable, it can't really be dealt with via a survey because it affects only a subset of people with HIV and in most cases addresses a one-off situation which may be in the distant past.
38	5a	63	In discussion of the 2017 audit, there seems to be reasonable agreement that people may not disclose chemsex when asked about recreational drug use more generally. So I'd suggest re-wording as: "Documented evidence that recreational drug use, including chemsex specifically, and STI risks have been discussed at least annually in MSM and Trans individuals."

Organisation name (if you are responding as an individual, please leave blank)			
Name of commentator			Kaveh Manavi
Role of commentator			Consultant physician in HIV
13	5a	62	'Documented evidence that partners at ongoing risk are informed how to access PrEP/ PEP within 2 weeks of the first PN discussion.'. There is currently no PREP service available on NHS. How can we recommend on ways to access to the service that does not exist?

Organisation name (if you are responding as an individual, please leave blank)			
Name of commentator			Roy Trevelion
Role of commentator			UK-CAB BHIVA Rep, i-Base staff
7	5	59	The split in providers of sexual/reproductive health services, and providers of HIV services, is unhelpful (to say the least). For example, who will provide adequate – integrated – contraception services? Pathways of care need to be developed.

Organisation name (if you are responding as an individual, please leave blank)			
Name of commentator			Mel Rattue
Role of commentator			Woman living with HIV
2	5a	60	"Since the previous Standards, new evidence has emerged regarding transmission of HIV, showing that people living with HIV on antiretroviral therapy with an undetectable viral load in their blood (achieved and sustained for at least 6 months) have a negligible risk of sexual transmission of HIV" The evidence has been available since the Swiss statement in 2008, it has not just emerged, there has been pressure from people living with HIV for the facts to be made known. The science is clear, it is not a "negligible risk", it is Zero risk this statement should not be compromised.

Organisation name (if you are responding as an individual, please leave blank)			
Name of commentator			Dr Graham Leslie
Role of commentator			Consultant GUM
1	5a	60	You include this statement "Since the previous Standards, new evidence has emerged regarding transmission of HIV, showing that people living with HIV on antiretroviral therapy with an undetectable viral load in their blood (achieved and sustained for at least 6 months) have a negligible risk of sexual transmission of HIV. Depending on the drugs employed it may take as long as six months for the viral load to become undetectable". This mirrors the U=U statement and suggests that the length of time that a patient has undetectable VL is not relevant, just that they have an undetectable viral load. This is, however, at odds with the 2014 TasP position statement "The person who is HIV positive has a sustained plasma viral load below 50 HIV RNA copies/mL for **more than 6 months** and the viral load is below 50 copies/mL on the most recent test"; and the draft consultation document for SRH for PLWHIV (Sept 2017) "We recommend that heterosexual PLWH with sustained viral suppression (**at least 6 months**) and high adherence to ART can be advised there is no risk of

			onward transmission of HIV to others (1A)". Both of these documents indicate that the person should have an undetectable VL for >6 months. I have already had a patient who has read the U=U position statement and had sex with a partner within 6 months of undetectable VL. I suspect real terms risk very very low but some clarity and internal consistency from BHIVA documents would be helpful.

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
36	5a	62	Measurable outcomes for sexual 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.

Organisation name (if you are responding as an individual, please leave blank)			Salamander Trust
Name of commentator			Alice Welbourn
Role of commentator			Founding Director
1	5	G	**SRH of people living with HIV.** a) Overall it's great to see these. It would be great to start each section with an overall statement on the RIGHTS of people living with HIV in all our diversities to the highest lifelong sexual and repro health and well-being, as a starting point.

2	5	G	Maybe it's also helpful to add that SRH services should be an integral part of HIV care. See also this useful new WHO document on SRH linkages, which it would be useful to reference: http://apps.who.int/iris/bitstream/10665/258738/1/9789241512886-eng.pdf?ua=1
3	5	G	c) It would be really nice if this section could refer to the new WHO Guideline on SRH&R of women living with HIV, since there is a lot of language in there around women's rights and about a women-focused approach that it would be great to flag up and recognise and have acknowledged in the UK also.
4	5	G	d) I am concerned by the complete lack of reference to VAW throughout this section. There are various red flag points throughout this section where VAW could be a huge barrier - eg ART access, partner notification, testing children etc. I think this needs to be fully acknowledged and strategies worked out about how to address it, together with reference to specialist support services. Also it might be helpful to reference: i) Our recent UNWomen et al Global Tx Access Review - which highlights how VAW is a key tx access barrier globally: http://genderandaids.unwomen.org/-/media/files/un%20women/geha/resources/key%20barriers%20to%20womens%20access%20to%20hiv%20treatment%20-%20web.pdf?vs=3556 ii) A paper in the Health and Human Rights Journal which discusses this further, together with recommendations for addressing this: https://cdn2.sph.harvard.edu/wp-content/uploads/sites/125/2017/12/Orza.pdf iii) Our papers in JIAS which address VAW and mental health issues in the context of SRH&R of women living with HIV. VAW paper; Mental Health paper. All these documents have been shaped by women living with HIV globally, including women from the UK, based on our own personal experiences. It would therefore be great if these could be flagged up and their findings woven into this section.
5	5	G	e) See also this useful WHO document, just published, on positive childbirth experiences. It would be great to flag this up at the start of the Reproductive Health section: http://www.who.int/mediacentre/news/releases/2018/positive-childbirth-experience/en/

6	5	G	f) While in general, it is good to see positive changes in language use, there are still a few places where it would be great to see different language used. For example, the word infect and it's variations is still used in places where it's either unnecessary, or it could be replaced with acquire/transmit etc – ie more neutral language. Also, for consistency with the pregnancy guidelines it would be good to replace 'mother' with 'woman' wherever possible, so as to acknowledge women in their own full rights, beyond their role as mothers.
7	5	61	Top sexual health bullet. Is routine cervical screening explicit enough here?
8	5	63	Re documentation that children have been tested: This feels very disease-focused, rather than looking at the overall picture. Surely it depends on context - eg whether the children are unwell, whether there is a family history of VAW present, whether there are mental health issues. Surely all these need to be taken into account on a case by case basis. If a child is well and testing her/him could cause VAW and knock-on violence against or other problems for children (eg through marriage breakdown), is this in the best interests of the child? Of course, child protection is key, but if a child appears healthy and is meeting all the normal child development milestones, I am not sure that a narrow focus on the child's HIV testing is the most appropriate action. If violence against the women (and then indirectly against her children) were to result from knowledge that the child needed to be tested, are the health workers supporting the family ready with appropriate support? At a minimum, there might be a risk that the woman might avoid the health service in future and disappear with her children. So surely, the key point here is to build a trusting, respected relationship with the woman, to support her to engage with her partner in a safe way before embarking on testing other children.

Organisation name (if you are responding as an individual, please leave blank)			CHIVA
Name of commentator			Dr Bala Subramaniam
Role of commentator			Executive member, CHIVA
7	5a	60	Sexual health- mentions don't forget the children. Suggest that in the opening section, it states about working in partnership with local Paediatric HIV services to help to facilitate testing of children of adults diagnosed with HIV.

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
21	5a	60	Testing of children is very important, but why is this buried towards the end of a section on Sexual Health? Surely this should be included (possibly with its own little subsection) within Reproductive Health?

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
20	5a	61	Add the end of the first sentence of the 1st bullet add 'who are sexually active'

Organisation name (if you are responding as an individual, please leave blank)			
Name of commentator			Laura Waters
Role of commentator			Consultant Physician
33	5a		Suggest much of this is left to the SRH guidelines – as we are still collating feedback from our consultation process may I suggest we work together to minimise overlap and duplication?

Organisation name (if you are responding as an individual, please leave blank)			ADPH
Name of commentator			Policy Manager - ADPH
Role of commentator			Rachel Cullum
			The reference to HPV vaccine in MSM is out of date

Organisation name (if you are responding as an individual, please leave blank)			PHE
Name of commentator			Valerie Delpech
Role of commentator			Lead for national surveillance of HIV for the UK
			• *Partner notification outcomes should be audited against the BHIVA/BASHH HIV PN standards: (pg 63)* *Standard 1:* ○ *0.6 partners per index case verified tested within 3 months of initiating the PN process;* ○ *0.8 partners per index case reported or verified tested within 3 months of initiating the PN process.* *Standard 2:* ○ *65% of contactable partners verified tested within 3 months of initiating the PN process;* ○ *85% of contactable partners reported or verified tested within 3 months of initiating the PN process;* HARS could be used to inform some of these measures though the HARS indicators do not specify a three month period between PN initiation and testing. Standard 1 0.6 partners per index case can be measured as the proportion of contacts a patient has that were tested. Standard 2 65% of contactable partners tested can be measured as the absolute number of contactable contacts that were tested.

Organisation name (if you are responding as an individual, please leave blank)			BASHH HIV Specialist Interest Group (SIG)
Name of commentator			Tristan Barber
Role of commentator			Chair, BASHH HIV SIG
15	5a	62	'Documented evidence that partners at ongoing risk are informed how to access PrEP/ PEP within 2 weeks of the first PN discussion.'. There is currently no PREP service available on NHS. How can we recommend on ways to access to the service that does not exist?

Standard 5b

Organisation name (if you are responding as an individual, please leave blank)			
Name of commentator			Hilary Curtis
Role of commentator			BHIVA Clinical Audit Co-ordinator
7	1b 5a 5b G	19	"Evidence of a patient experience survey to assess satisfaction regarding discussion around HIV transmission and HIV prevention options." etc I'm concerned about outcomes which appear to call for multiple patient experience surveys. Such surveys are potentially wasteful and time-consuming for people to design, collect and analyse data, especially as there are no validated measures for most things. If these outcomes are to be retained at all, I would suggest re-wording them along the lines of "Evidence of inclusion of satisfaction regarding discussion around HIV and HIV prevention options within patient experience surveys" [with cross-ref to section 3b]. That avoids implying there should be separate surveys.
39	5b	68	The outcome re menopause that the Audit and Standards Sub-Committee proposed for the SRH guidelines is: "Women aged 45-56 with a documented discussion of menopause and enquiry about symptoms (90%)." At the very least, the outcome needs to include an upper age limit. Plus, although the guidelines advise annual enquiry, auditing this is problematic since it's reasonable to stop in individual women who have completed menopause and are symptom-free, which can be well before age 56.

Organisation name (if you are responding as an individual, please leave blank)	DHIVA Dietitians in HIV Association
Name of commentator	Clare Stradling

Role of commentator			Chair
5	5	67	Support for mothers who choose to breastfeed, needs to include access and/or referral to a dietitian experienced in infant feeding.

Organisation name (if you are responding as an individual, please leave blank)			
Name of commentator			Roy Trevelion
Role of commentator			UK-CAB BHIVA Rep, i-Base staff
7	5	59	The split in providers of sexual/reproductive health services, and providers of HIV services, is unhelpful (to say the least). For example, who will provide adequate – integrated – contraception services? Pathways of care need to be developed.

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
37	5b	68	Measurable and auditable outcomes for reproductive 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.

Organisation name (if you are responding as an individual, please leave blank)	Sophia Forum

Name of commentator			Sophie Strachan
Role of commentator			Co Chair
15	5b	67	For those requiring fertility support, whilst your standard point 7 states access to local clinics, some serious work needs to be done for HIV positive people to be seen at these settings, lived experience shared of an assessment being stopped due to disclosure of a man's status. Also tests carried out by NHS were not adequate when they were finally able to access another private clinic
16	5b	65	We welcome information on menopause http://www.who.int/reproductivehealth/publications/gender_rights/srhr-women-hiv/en/ as an additional document of support – 2017 edition

Organisation name (if you are responding as an individual, please leave blank)			Salamander Trust
Name of commentator			Alice Welbourn
Role of commentator			Founding Director
1	5	G	**SRH of people living with HIV.** b) Overall it's great to see these. It would be great to start each section with an overall statement on the RIGHTS of people living with HIV in all our diversities to the highest lifelong sexual and repro health and well-being, as a starting point.
2	5	G	Maybe it's also helpful to add that SRH services should be an integral part of HIV care. See also this useful new WHO document on SRH linkages, which it would be useful to reference: http://apps.who.int/iris/bitstream/10665/258738/1/9789241512886-eng.pdf?ua=1

3	5	G	c) It would be really nice if this section could refer to the new WHO Guideline on SRH&R of women living with HIV, since there is a lot of language in there around women's rights and about a women-focused approach that it would be great to flag up and recognise and have acknowledged in the UK also.
4	5	G	d) I am concerned by the complete lack of reference to VAW throughout this section. There are various red flag points throughout this section where VAW could be a huge barrier - eg ART access, partner notification, testing children etc. I think this needs to be fully acknowledged and strategies worked out about how to address it, together with reference to specialist support services. Also it might be helpful to reference: i) Our recent UNWomen et al Global Tx Access Review - which highlights how VAW is a key tx access barrier globally: http://genderandaids.unwomen.org/-/media/files/un%20women/geha/resources/key%20barriers%20to%20womens%20access%20to%20hiv%20treatment%20-%20web.pdf?vs=3556 ii) A paper in the Health and Human Rights Journal which discusses this further, together with recommendations for addressing this: https://cdn2.sph.harvard.edu/wp-content/uploads/sites/125/2017/12/Orza.pdf iii) Our papers in JIAS which address VAW and mental health issues in the context of SRH&R of women living with HIV. VAW paper; Mental Health paper. All these documents have been shaped by women living with HIV globally, including women from the UK, based on our own personal experiences. It would therefore be great if these could be flagged up and their findings woven into this section.
5	5	G	e) See also this useful WHO document, just published, on positive childbirth experiences. It would be great to flag this up at the start of the Reproductive Health section: http://www.who.int/mediacentre/news/releases/2018/positive-childbirth-experience/en/
6	5	G	f) While in general, it is good to see positive changes in language use, there are still a few places where it would be great to see different language used. For example, the word infect and it's variations is still used in places where it's either

			unnecessary, or it could be replaced with acquire/transmit etc – ie more neutral language. Also, for consistency with the pregnancy guidelines it would be good to replace 'mother' with 'woman' wherever possible, so as to acknowledge women in their own full rights, beyond their role as mothers.
9	5	65	In addition to what you have here, what about male reproductive health - eg prostrate and testicular cancers? Fertility issues for men etc. This section seems to be just women-focused? And what about trans people's health issues? Also, what about young women pre-childbirth seeking contraceptive and other support? Has this been covered well in the section on young people? It would be good to cross reference, if so...
10	5	66	Thank you for flagging up osteoporosis. I suggest it is also important to think about what ARTs women are being given during child-bearing years or earlier, especially those which affect bone density, to avert inadvertent exacerbation of future problems.
11	5	66	Bottom line – termination – suggest adding in where DESIRED BY THE WOMAN AND available, to make it clear, this is ONLY when women want this.
12	5	67	Re management of pregnancy – please add in STI barrier methods during and after pregnancy (again a VAW issue)
13	5	67	Re MDTs – please consider adding in a peer support worker – eg 'Mentor Mother' here, to be consistent with the pregnancy guidelines.
14	5	68	"annual review includes men" – please refer again to the potential VAW red flag issues highlighted earlier.

Organisation name (if you are responding as an individual, please leave blank)			CHIVA
Name of commentator			Dr Bala Subramaniam
Role of commentator			Executive member, CHIVA
8	5b	67	Reproductive health- quality statements about free infant formula- agree - But difficult to implement. Is this meant for commissioners, adult or paediatric services?

Organisation name (if you are responding as an individual, please leave blank)			British Psychological Society (BPS)
Name of commentator			Sarah Rutter & Tomás Campbell
Role of commentator			Chair & Treasurer of the BPS Faculty of HIV & Sexual Health
11	5b	65	The Society believes that it is important to have a section on antenatal, perinatal and post-natal depression in the section of reproductive health. This need not be extensive, perhaps just drawing attention to this potential issue and referencing other documents that may be useful for guidance (e.g. BHIVA guidelines on sexual and reproductive health of people living with HIV) It could read as the following: Given that pregnant women living with HIV are particularly vulnerable to psychological and emotional distress (Brandt et al, 2009; Bernatsky, Souza & John 2007) and are likely to be at considerable risk of postpartum depression (Stringer et al, 2014; Yator et al, 2016) pathways to assess and respond to mental health issues throughout the period of pregnancy should be in place.

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
22	5b	62	Frequency of HCV screening. Is annual HCV screening required for all individuals attending HIV services, or could/ should this be less frequent if no ongoing risks identified?

23	5b	67	We suggest that a quality statement regarding immediate HIV testing in untested women presenting in labour should be added. We appreciate this is in BHIVA guidelines, but if discussing labour and timescales in the standards we feel this has to be added

Organisation name (if you are responding as an individual, please leave blank)			
Name of commentator			Laura Waters
Role of commentator			Consultant Physician
34	5b		As above - and the reference here are very broad! So you meant menopause refs from the SRH guidelines? In which case signpost these??

Organisation name (if you are responding as an individual, please leave blank)			NAT
Name of commentator			Yusef Azad
Role of commentator			Director of Strategy
			In relation to the sub-section on Reproductive health, and the content on formula milk, we welcome the reference in the Quality statements to 'free formula milk for those who are unable to afford it'.
			We believe this should also be reflected in the 'Measurable and auditable outcomes' section – perhaps with an expectation that a system is in place in each clinic to identify women in this situation and an agreed process to alert relevant bodies to this need so as to secure free formula milk provision.

Organisation name (if you are responding as an individual, please leave blank)			PHE
Name of commentator			Valerie Delpech
Role of commentator			Lead for national surveillance of HIV for the UK
			• *Proportion of women living with HIV with documented discussion of current reproductive choice and current contraception during a defined period (numerator: number of women of reproductive age with documented discussion during defined period; denominator: total number of women of reproductive age attending HIV service during defined period; target 90%). (pg 68)* PV survey could provide a measure for this outcome as it asks individuals about their experience of "Family planning or advice on getting pregnant" in the last year (Health services, E2). Possible responses are: I have received this, I needed this, but could not get it, I needed this, but did not try to get it and I did not need this.