

## Standard 2a

<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
3	2a	21	BHIVA is the specialist body for the United Kingdom, and though the Equality Act in England is discussed, it would be welcome if relevant/similar legislation in the devolved nations is also mentioned.

<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
8	2a	22	<p>“Recruitment of 10% of patients to complete the NHS national patient experiences survey to assess satisfaction with their care”</p> <p>I don’t think this is possible. There doesn’t appear to be a routine, rolling national survey that people <i>can</i> complete – only one-off or repeated surveys of specific categories of patient, see <a href="http://www.cqc.org.uk/publications/surveys/surveys">http://www.cqc.org.uk/publications/surveys/surveys</a></p>
9	2a	22	<p>“Evidence of a named lead for stigma”</p> <p>Sounds nice, but have any services actually tried this? What was the person’s actual role, and did it work? I’m unconvinced.</p>

10	2a	22	<p>“Evidence that departments provide information to staff in the form of posters or leaflets”</p> <p>The principle is fine, but is “the form of posters or leaflets” too specific? What about electronic forms of info?</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
4	2a	22	'Lead for stigma': I am not sure what role a 'Lead for stigma' would do? What are the roles of the post? How should we measure their success in delivering outcomes?

<b>Organisation name</b> (if you are responding as an individual, please leave blank)			
<b>Name of commentator</b>			Mel Rattue
<b>Role of commentator</b>			Woman living with HIV
1	2a	21	<p>“one in seven (13%) reported hearing negative comments from a healthcare worker about themselves or other people living with HIV.”</p> <p>This is abuse and should be described as such, HIV and women, Invisible no longer research used the definition of abuse in a health setting as including: rude or judgmental service providers; refusing to give you all the information about available services; making you wait until other clients have been seen; denial of care at hospitals etc.</p>

<b>Organisation name</b> (if you are responding as an individual, please leave blank)			LASS
<b>Name of commentator</b>			Service Delivery
<b>Role of commentator</b>			Staff Team
3	2a	21	Consider adding (2010) to Equality Act to read (Equality Act 2010)
4	“	21	Similarly, consider adding year to Stigma Survey UK to read (Stigma Survey 2005)

<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
14	2a	21	<b>We welcome that stigma is explicitly mentioned and ask that the stigma of people who inject drugs is also recognised as an issue affecting engagement with testing and treatment of HIV and the provision of these services.</b>
15	2a	21	<p><b>Stigma</b></p> <p>The recognition that stigma is significant and complicated issue for people from high risk groups including people who inject drugs is welcome.</p> <p>Unfortunately this document reflects stigma experienced by people who inject drugs when engaged with HIV services and the field more generally. Again, they are confined to a single section of a report and again there seems to be little insight as to the specific needs of this group which affects their ability to engage with processes including testing and treatment and, as is occurring in Glasgow during an ongoing outbreak, leading to unnecessary deaths.</p> <p>There needs to be a recognition that staff involved in HIV diagnosis and treatment may well have stigmatising attitudes to people who inject drugs. Scottish Drugs Forum has found stigmatising attitudes towards people with a drug problem exist</p>

			<p>even in the treatment services designed to treat and support them around their substance use and these same prejudices and stigma are potentially even worse in other services including HIV services..</p> <p>Suitable training of HIV testing, diagnosis and treatment staff is part of the solution to this issue and should be prioritised. This training should not be generic drugs training only but expressly designed to challenge preconceptions, prejudice and stigma.</p>
16	2a	22	<p><b>Quality statements</b></p> <p>Staff at all healthcare services, including general practitioners and dentists, <b>and social care workers</b> should receive basic information and training on blood borne viruses and access to resources to supplement their existing knowledge on treating people with HIV.</p>
17	2a	22	<p>Staff at HIV services offering testing, treatment or other should receive basic information and training on injecting drug use that explicitly addresses the stigma and prejudice faced by people who inject drugs and have access to resources to supplement their existing knowledge on treating people with HIV who inject drugs.</p>

<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	
4	2a	22	<p>Stigma- Suggestion: for quality statements- Training of health professionals e.g. students of nursing, medicine etc. should receive basic information and training on BBV during their training.</p>

<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
3	2a	22	The Society believes that the quality statements should include the recommendation that staff require training on how to identify the impact and effects of stigma on individuals. Anti-stigma interventions are usually aimed at changing public attitudes towards HIV but often this is not useful for the PLHIV. Anti-stigma training should focus on: what stigma is, where the effects of stigma are manifested in the life of the PLHIV (usually in the domains of feelings of shame, poor self-care, reduced adherence to ART, fear of accidental disclosure of status, fear of interpersonal rejection, fear of violence). (Campbell, Griffiths & Wilkins, 2016). The statements should also focus on how these issues can be addressed practically, how the impact of stigma on the individual can be reduced and how can PLHIV (Campbell, Griffiths & Wilkins, 2016).
4	2b	23	Rationale section: For some long term survivors of HIV, the transition from a wrap-around model of care to a self –management approach may be difficult. It may be important to acknowledge this in the context of person centred care, in terms of the potential detrimental impact on healthcare relationships and engagement, as well as the benefits that the autonomy of self-care can bring.

<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
13	2a	22	'Named lead for stigma': would this be for the NHS Board, working with other patients groups, and not about HIV services? Not very clear. Similarly for staff receiving training on HIV related stigma – presume all NHS staff, not just HIV services?

<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
7	2	22	We would suggest add the following services to the first bullet point in terms of training professionals - mental health, social care, housing and support services trained in HIV

<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
17	2a	22	"Recruitment of 10% of patients to complete the NHS national patient experiences survey to assess satisfaction with their care" – I was not aware of this so suspect some of my colleagues won't be either – how often is it run? Is there a link?
18	2a	22	Is Equality & Diversity training not mandatory in all NHS organisations? If so does this need saying?

<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
			In the 'Measurable and auditable outcomes' section of 2a, it would be useful for greater clarity as to the health settings and staff being referred to. Is it, for example, all staff throughout the NHS and social care services who should receive training in HIV stigma? Should there be a named lead for HIV stigma in every healthcare setting? And what would the role of a named lead for stigma actually involve? There needs to be some further explanatory text earlier on as background to these outcomes.

<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
<b>Role of commentator</b>			Chair, BASHH HIV SIG
6	2a	22	'Lead for stigma': I am not sure what role a 'Lead for stigma' would do? What are the roles of the post? How should we measure their success in delivering outcomes?

## Standard 2b

<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>			
8	2b	23	It says: “Self-management issues around key life phases and moments, for example entry and re-entry into the workforce, establishing relationships, sexual debut, coping with loss, ageing, retirement, transitioning from paediatric to adult services, “ Surely we should start this list of examples with diagnosis! This is often the KEY life-changing event!

<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
11	2b	25	“Proportion of people feeling supported to manage HIV (NHS England Outcome 2.1). (Target 90%)”  Suggest amend target to “Target 90% of those responding” for clarity as to what’s being measured, as well as achievability.
12	2b	25	Suggest amend second, complex outcome to:  “All services to have an agreed pathway from the clinic to peer support and self-management which can be tiered depending upon resources:



			<ul style="list-style-type: none"> <li>▪ Signposting and information given to patients (target 90%)</li> <li>▪ Referral pathways and sharing of data in place between the clinic and agency providing peer support</li> <li>▪ Peer support integrated and delivered within the clinical setting”</li> </ul> <p>This is less ambiguous, and distinguishes the target for services to have a pathway (which I think should reasonably be “all”) from the target for individual patients to be given info (90%).</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
2	2	24	Dietitians are similar to OTs and physios in that they also work collaboratively with people living with HIV to identify goals and develop self-management techniques to promote lifestyle behaviour changes. These include diet, exercise and smoking therefore are not restricted to solely issues around poor nutrition.

<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
2		25	HIV services should maximise the use of peer support as set out in the National Standards for Peer Support in HIV <a href="http://www.hivpeersupport.com">www.hivpeersupport.com</a> , this includes: A range of interventions in place to meet the needs of people living with HIV such as: face-to-face, online, group support, workshops; Services tailored to specific communities e.g. gay and bisexual men, women, <b>African communities</b>

<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
5	2b	23	Changes across life course should include pregnancy and having a baby
6	2b	24	Self-management and peer support: HIV services should maximise use of peer support as set out in the national standards, this includes: add in specific peer support opportunities for adolescents and young people; services tailored to specific communities: adolescents and young adults

<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
4	2b	23	Rationale section: For some long term survivors of HIV, the transition from a wrap-around model of care to a self –management approach may be difficult. It may be important to acknowledge this in the context of person centred care, in terms of the potential detrimental impact on healthcare relationships and engagement, as well as the benefits that the autonomy of self-care can bring.
5	2b	23	Third bullet point - “Mental health and well-being including prevention of mental illness and resilience building” – The Society believes that this needs revising and would recommend that it is changed to, “mental health and well-being, including resilience building and potentially reducing the development and/or exacerbation of emotional distress”

			<p>The term ‘mental illness’ can place the problem within the person, rather than acknowledging issues such as historical trauma, social and environmental influences that can contribute to the development of mental health issues. This is particularly important in HIV as it is known that many people living with the condition are experiencing and/or have pre-existing mental health issues (WHO, 2008), and PLWHIV are at risk of being affected by the very real experience of stigma and discrimination (Herek, 2014) that can affect psychological and emotional well-being.</p>
--	--	--	---

<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
8	2b	23	We feel that for that the rational needs to recognise that for self-management to be successful basic needs such as money and housing need to be addressed. Further that people’s ability to self-manage will fall on a spectrum dependent on a variety of factors including language issues, culture and access to support/networks
9	2b	25	How would ‘feeling supported to manage HIV’ metric be measured to ensure consistency

<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
19	2b		Is much of this not duplication of the peer support standards – suggest shortening & signposting

<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
			In 2b, Self-management and peer support, there is a statement that self-management' can help with 'Social inclusion and well-being, including peer support'. Is it not rather that peer support is an element of self-management which can help with social inclusion and well-being – so the text should be redrafted along the lines of 'Social inclusion and well-being (with peer support as a key intervention)'.
			It would be useful in this section on self-management to include content on the fact it can be cost-saving/cost-effective for the NHS, and also some reference to the role of the voluntary and community sector in supporting self-management (not only a reference to peer support).

<b>Organisation name</b> (if you are responding as an individual, please leave blank)			PHE
<b>Name of commentator</b>			Valerie Delpech
<b>Role of commentator</b>			Lead for national surveillance of HIV for the UK
			<p>2b. Self-management and peer support measureable and auditable outcomes</p> <ul style="list-style-type: none"> <li><i>Proportion of people feeling supported to manage HIV (Target 90%) (page 25)</i></li> </ul> <p>PHE's Positive Voices (PV) survey (of persons living with HIV in E&amp;W) could inform this outcome. Individuals are asked to rate the statement: "I feel supported to self-manage my HIV" (Your HIV clinic, D10). Response range: Strongly agree to strongly disagree. The proportion reporting "strongly agree" and "agree" could be used as a measure for this outcome.</p> <p>PV2017 data will be available from 73 clinics who participated</p>

			Future surveys are subject to the availability of future funding
--	--	--	--

## Standard 2c

<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			
13	2c	30	I'm concerned that the targets for 90% of "total people [on treatment]" imply unrealistically high response rates. I'd have no problem with "90% of those responding" which seems more reasonable.

<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			
5	2c	30	'The BHIVA patient-reported outcome measure should be used to identify symptoms concerns, priorities and outcomes of care in 90% of those with sufficient capacity to participate'. Please provide a link to the BHIVA document.

<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			
4	2c	27	The summary at the start of this section is good. It mentions, "... support, training and resources for individuals and groups engaged in this process". And, in the rationale, it mentions, "A range of information resources and support services

			are available to help including promoting treatment literacy. Information can include printed, online information, telephone advice lines, with support services including treatment advocates and one-to-one and group peer-support.” Comment: But this paragraph about support services promoting treatment literacy could be duplicated in the summary upfront.
--	--	--	---

<b>Organisation name</b> (if you are responding as an individual, please leave blank)			LASS
<b>Name of commentator</b>			Service Delivery
<b>Role of commentator</b>			Staff Team
5	2c	29	Consider creating ‘Easy read’ information to increase access to information

<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
18	2c	27	<p>“British HIV Association guidelines recommend that people with HIV be given opportunities to be involved in making decisions about their treatment including ART. Trust and good communication between the person receiving care and the health care practitioner lead to better adherence and outcomes. A range of information resources and support services are available to help including promoting treatment literacy. Information can include printed, online information, telephone advice lines, with support services including treatment advocates and one-to-one and group peer-support.”</p> <p>SDF would suggest that there are complicating factors for people who inject drugs and are at risk of HIV through injecting drugs. One of the issues is that understandings about HIV and HIV treatment are very poorly developed amongst much of the peer group and some of the services that people who inject drugs have and use. This capacity has yet to be built.</p>

			<p>While the gay community or sub-Saharan African communities may offer a model for developing community understanding and knowledge levels, this area will have to be an area of investment in terms of time and resource.</p> <p>The quality standards should include mention of the need for this development.</p>
19	2c	28	<p>‘People with HIV have consistently advocated for participation in decision-making about services they use and for people with HIV to be treated with dignity and respect, to which the design, delivery and performance of clinical services contribute.’</p> <p>This is true for some people with HIV but far less so for people who inject drugs. The demand for empowerment is actually made by people already empowered and articulate and not by the most disempowered and silenced groups. The quality standards should mention this and seek to ensure the empowerment of all patient groups.</p>

<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
6	2c	27	The DoH document “Liberating the NHS: No decision about me without me” should be referenced in the first paragraph under the heading ‘Individual decisions about treatment and care’ on page 23.

<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
10	2c	28	We thought there should be some additional wording that gave a commitment to hearing the diversity of experience from patient groups. This is to ensure that in addition to those who actively engage that there is a commitment to obtaining the views of people that are not as often heard.
11	2c	29	We would suggest that there is a quality statement about access in terms of evening and weekend services
12	2c	31	We were not sure what the first bullet meant under planning services

<b>Organisation name</b> (if you are responding as an individual, please leave blank)			PHE
<b>Name of commentator</b>			Valerie Delpech
<b>Role of commentator</b>			Lead for national surveillance of HIV for the UK
			<ul style="list-style-type: none"> <li><i>Proportion of people who are satisfied with decisions about their care (target: 90% of total people). (pg 30)</i></li> </ul> <p>An overall measure of satisfaction is available from PV, where individuals are asked to rate their HIV clinic (Your HIV clinic, D8). Response range: 0-10. A second measure is also available where individuals are asked to rate the statement: "I am involved in decisions about my HIV treatment and care" (Your HIV clinic, D10). Response range: Strongly agree to strongly disagree. The proportion reporting "strongly agree" and "agree" could be used as a measure for this outcome.</p>
			<ul style="list-style-type: none"> <li><i>Proportions of people who receive written information about their ART, including details for each drug prescribed, or confirm they have been given equivalent oral information if they prefer this option (target: 90% of total people on treatment (pg 30)</i></li> </ul>

			PV survey could provide a proxy measure for this outcome by asking individuals about their experience of “HIV treatment advice” in the last year (HIV related services, E1). 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
			<ul style="list-style-type: none"> <li>• <i>Proportion of people who confirm they have been involved in making decisions about their care (target: 90% of total people) (pg 30)</i></li> </ul> <p>PV survey asks individuals to rate the statement: “I am involved in decisions about my HIV treatment and care” (Your HIV clinic, D10). Response range: Strongly agree to strongly disagree. The proportion reporting “strongly agree” and “agree” could be used as a measure for this outcome.</p>

<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
<b>Role of commentator</b>			Chair, BASHH HIV SIG
7	2c	30	'The BHIVA patient-reported outcome measure should be used to identify symptoms concerns, priorities and outcomes of care in 90% of those with sufficient capacity to participate'. Please provide a link to the BHIVA document.

## Standard 2d

<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>			
9	2d	32	It says: These practices can include: the inclusion of the consideration of social and psychological contexts in the provision of care; the establishment and maintenance of strong professional networks that facilitate continuity of care and efficient referral; productive engagement with community sector organisations to ensure continuing relevance; and public advocacy in partnership with communities to ensure continued best-practice service provision. “ This might read better as a bulleted list...

<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
14	2d	33	The para starting “Optimal well-being is achieved through a combination of factors” should be moved as it doesn’t fit under “Measurable and auditable outcomes”.
15	2d	33	“The proportion of people with a care coordinator (Target 75% of appropriate people)” Suggest deleting this outcome, as it’s not justified by the rationale or quality statements. These don’t even mention “care coordinators” so there’s no indication of what purpose they serve or what they’re supposed to achieve. Plus, even if one accepts the assumption that they can be valuable, the outcome is not measurable because there is no operational, auditable way of defining “appropriate people”.

16	2d	33	<p>Suggest re-word next two outcomes as:</p> <p>“The proportion of people screened for mental health needs (target 97%), and of those with identified needs the proportion accessing mental health support services (target 75%)</p> <p>The proportion of people screened for drug or alcohol support needs (target 97%) and of those with identified needs the proportion accessing drug or alcohol support (target 75%)”</p> <p>This avoids undefinable denominators like “appropriate people” which are not auditable.</p>
17	2d	34	<p>“The proportion of people have an assessment for and access to support for intimate partner violence (Target 75% of appropriate people)”</p> <p>The SRH guidelines stress the need to develop local guidelines and pathways <i>before</i> introduction of routine questioning, hence I suggest replacing the above unmeasurable outcome with:</p> <p>“Evidence of a local guideline for enquiry about and pathway for management of intimate partner violence.”</p>
18	2d	34	<p>“The proportion of people have an assessment for and access to support around accessing benefits and financial hardship (Target 75% of appropriate people)”</p> <p>Again, unmeasurable. Suggest instead:</p> <p>“Evidence of a local guideline for assessment for and access to support around accessing benefits and financial hardship.”</p>
19	2d	34	<p>“Evidence of the use of HIV PROMs/PREMs to assess patient experience (Target 95% of all people)”</p>

			Target implies unrealistically high response rate.
20	2d	34	<p>The proportion of people who report accessing wider healthcare services without experiencing stigma and discrimination</p> <p>The proportion of people who report being able to access mental health support in a timely manner”</p> <p>To get the correct denominators, amend to:</p> <p>“Among people accessing wider healthcare services, the proportion who report doing so without experiencing stigma and discrimination</p> <p>Among people with an identified need for mental health support, the proportion able to access this in a timely manner”</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
7	2d	34	' Evidence of the use of HIV PROMs/PREMs to assess patient experience '. Please provide a link to these documents.

<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
20	2d	34	'The proportion of people have an assessment for and access to drug and alcohol misuse support (Target 75% of appropriate people)'

			This is too general. The target for people who have been infected with HIV through injecting drug use should be 100%. The quality of the assessment and the acceptability of the access is, of course, crucial.
--	--	--	---

<b>Organisation name</b> (if you are responding as an individual, please leave blank)			Sophia Forum
<b>Name of commentator</b>			Sophie Strachan
<b>Role of commentator</b>			Co Chair
9	2d	34	We have grave concerns of the likely hood of patients receiving adequate mental health provision in the face of austerity and cuts to sexual health service provision; it is known IAPT are becoming a route of referral but with waiting lists of up to six months or more.

<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
6	2d.	G	There should be further individual discussion and a broadening of the quality statements and measurable and auditable outcomes in relation to integrated care planning, namely in: GPs; specialist services; support services; social care services etc. Models of HIV care that meet the needs of an ageing population need greater involvement and integration with primary care and social care services and we think these aspects needs more detail and greater prominence

<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
14	2b-2d	23-35	Rather too long... Could/ should be condensed.
15	2d	33	'Care coordinator'. Who is this? Do we need a definition of this role?

<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
13	2d	33	We thought that this section should perhaps include a reference to substance/alcohol misuse
14	2d	34	2 <sup>nd</sup> bullet add 'housing'
15	2d	34	8 <sup>th</sup> bullet - We thought there should be a definition around what 'timely' meant and perhaps to be explicit that this should be focused on client need and not institutional resource

<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
20	2d		Again there are some fairly strong statements here – while I am not arguing against them there are no reference for this section at all which I think makes it challenging to argue the validity of some of the measureable and auditable outcomes
21	2d	33	“The proportion of people with a care coordinator (Target 75% of appropriate people)” – I can’t see a definition of a care coordinator nor, more importantly, what constitutes a ‘appropriate person so question the usefulness of this outcome.
22	2d	34	The beyond HIV targets are ambitious and what % should we aim for? “The proportion of people who have the financial and social resources to meet physical and social needs consistent with a reasonable quality of life (for example access to entertainment, opportunities to socialise, travel etc.)” seems a rather complicated measure which, I fear, will mean it is not collected at all – are there similar standards for other long-term conditions? Similarly “the proportion of people who report that their care is planned around them, co-ordinated and integrated” – how do we collect that? Integration is an admirable goal but so far beyond us without a huge restructure to the health and social care funding that it seems too unrealistic for the standards – I am all for aiming high but is specifying an outcome that is (currently) impossible to achieve a useful exercise?

<b>Organisation name</b> (if you are responding as an individual, please leave blank)			
<b>Name of commentator</b>			Shaun watson
<b>Role of commentator</b>			Clinical Nurse Specialist (HIV Community)
		33	General comment – I’d like some clarification about who is the care coordinator as this role is traditionally the remit of a specialist nurse (community or clinic) and rarely a clinician, I’d like this to be made explicit.

<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
			In the Measurable and auditable outcomes for 2d Well-being, how is 'access' defined?

<b>Organisation name</b> (if you are responding as an individual, please leave blank)			PHE
<b>Name of commentator</b>			Valerie Delpech
<b>Role of commentator</b>			Lead for national surveillance of HIV for the UK
			<ul style="list-style-type: none"> <li><i>The proportion of people who have an assessment for and access to mental health support services (Target 75% of appropriate people) (pg 33)</i></li> </ul> <p>PV survey could provide a proxy measure for this outcome by asking individuals about their experience of "Psychologist or counsellor" and "Help to manage stress" 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</p>
			<ul style="list-style-type: none"> <li><i>The proportion of people have an assessment for and access to drug and alcohol misuse support (Target 75% of appropriate people) (pg 33)</i></li> </ul> <p>PV survey asks about experiences of "Alcohol counselling or treatment", "Drug counselling", "Chemsex support" and "Drug detox or maintenance treatment" in the last year (Health services, E2). Possible responses as above</p>
			<i>The proportion of people have an assessment for and access to support for intimate partner violence (Target 75% of appropriate people) (pg 34)</i>

			<p>PV survey asks about experiences of “Domestic violence services” in the last year (Social and welfare services, E3). Possible responses as above</p>
			<ul style="list-style-type: none"> <li>• <i>The proportion of people have an assessment for and access to support around accessing benefits and financial hardship (Target 75% of appropriate people) (pg 34)</i></li> </ul> <p>PV survey asks about experiences of “Help claiming benefits” and “Financial advice” in the last year (Social and welfare services, E3). Possible responses as above</p>
			<ul style="list-style-type: none"> <li>• <i>Evidence of the use of HIV PROMs/PREMs to assess patient experience (Target 95% of all people) (pg 34)</i></li> </ul> <p>Participation of clinics in the PV survey could be used as evidence of the usage of HIV PROMS/PREMS to assess patient experience</p>
			<ul style="list-style-type: none"> <li>• <i>The proportion of people who report good quality of life (pg 34)</i></li> </ul> <p>PV survey asks five questions from the EQ-5D on quality of life that would measure this outcome. These questions relate to mobility, self-care, usual activities, pain and discomfort and anxiety and depression (Health and Wellbeing. F3-F7).</p>
			<ul style="list-style-type: none"> <li>• <i>The proportion of people who report accessing wider healthcare services without experiencing stigma and discrimination (pg 34)</i></li> </ul> <p>PV survey asks if individuals because of their HIV status have experienced any of the following in a healthcare setting: “Been worried that you would be treated differently to other patients”, “Avoided seeking healthcare when you needed it”, “Been treated differently to other patients” and “felt that you were refused healthcare or delayed a treatment or medical procedure”. Response range: Yes in the past year, Yes more than a year ago, no. The first two responses can be used as a measure of stigma and discrimination.</p>
			<p><i>The proportion of people who have the financial and social resources to meet basic needs (pg 34)</i></p>

			PV survey asks “Do you have enough money to meet your basic needs? (Social and demographic information, I9)
			<ul style="list-style-type: none"> <li><i>The proportion of people who have the financial and social resources to meet physical and social needs consistent with a reasonable quality of life (for example access to entertainment, opportunities to socialise, travel etc.) (pg34)</i></li> </ul> <p>The PV survey question on “in the last year, what was your total household income before tax? (Social and demographic information, I10) and “in the last year, indicate all of your sources of income” (Social and demographic information, I7) could be used to infer whether individuals have the finances for a reasonable quality of life. The latter question includes different forms of state benefit.</p>
			<ul style="list-style-type: none"> <li><i>The proportion of people who report that their care is planned around them, coordinated and integrated (pg 34)</i></li> </ul> <p>This outcome could be partly met with PV, which asks individuals about GP care and its coordination with a statement that is rated with responses such as strongly agree: “As far as I am aware, my HIV specialist and my GP communicate well regarding my health” (Health service use and satisfaction, D6). A further question satisfaction on being involved in decisions in HIV clinics could also be used as a measure: “I am involved in decisions about my HIV treatment and care” (Your HIV clinic, D10). Response range: Strongly agree to strongly disagree.</p>

<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
<b>Role of commentator</b>			Chair, BASHH HIV SIG
8	2d	33	'The proportion of people with a care coordinator (Target 75% of appropriate people). ' what are the definitions for ' appropriate people'?
9	2d	34	'Evidence of the use of HIV PROMs/PREMs to assess patient experience '. Please provide a link to these documents.

<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
6	2d	33	'The proportion of people with a care coordinator (Target 75% of appropriate people). ' what are the definitions for ' appropriate people'?