

BHIVA Standards of care online consultation comments

7 October 2012

Standard 10: Service user engagement / involvement

12 September 2012

Matt Williams sent the following message:

This is very good, especially the autiables

12 September 2012

AH sent the following message:

Need to stop describing people as HIV + in the 1st sentence of any referral letter even though the presenting complaint might not be HIV related. I have a name and it aint HIV+. The term HIV+ is stigmatising in itself - try saying a person has HIV infection and not in the the 1st line of the letter!!

14 September 2012

Babs Evans sent the following message:

This standard about service user engagement focuses very heavily on engagement in relation to treatment decisions and less about 'care'. It would be good to see some aspiration about involvement in care generally

19 September 2012

John Evans-Jones sent the following message:

1. It is difficult for small services to run a patient / user group - have strong informal with our voluntary sector organisation (their staff attend our clinics) but nothing more formal
 2. Again, as a small service I am not sure it is realistic to expect a separate policy on decision making. We work to BHIVA guidelines, that is enough ?
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2 October 2012

Paul Declé from Forum Link sent the following message:

Quality statements

Individual decisions on care

2nd bullet point

add after "...getting printed information on drugs"... [in an understandable language or media relevant to the cultural, ethnic or age needs of the person about to start treatment].

2 October 2012

Allan Anderson from Positively UK sent the following message:

Rationale: We welcome the greater involvement of people living with HIV in all decisions affecting them and their health. Page one of this standard identifies the need for discussion around 'The person's readiness to take treatment, their knowledge of how the treatment works...' this also needs to include a person's 'knowledge of HIV, viral load and CD4 count'. Positively UK's experience in the field demonstrates that this often a major barrier to people self-managing and adhering to medication, and it cannot be assumed that anyone diagnosed with HIV, or living with HIV for several years, has an understanding of the basics of HIV.

The section 'Additional factors that are related to bot better adherence and treatment outcomes include:', is very comprehensive however we would recommend the inclusion of an additional statement 'Support in reporting side-effects and concerns in taking medications'. Side effects can often be a major barrier to people continuing on medication, yet some patients do not feel confident to report this to their clinician. Greater recognition of this, and support to patients to openly report and discuss side-effects and implications of treatment can only support self-management and adherence.

2 October 2012

Ian Akin, HIV nurse, Surrey Community Health from Surrey HIV network sent the following message:

It is easy for larger centres to have patients forum and representation, but it is difficult for smaller HIV unit which have lesser nnumber of patients to have one.

5 October 2012

David Ogden from HIV Pharmacy Association sent the following message:

Quality statements

“For someone on, or about to start treatment, this involves:

...

- The individual benefit and risks of different treatment options, including potential short- and long-term side effects, using decision support tools.”

“Any service providing care...delivered for people. Effective adherence support services should have shared-decision-making as a core value.”

5 October 2012

Roger Pebody from NAM sent the following message:

I suggest moving the last paragraph of the current rationale section to the beginning of the section.

Please add this to the first set of bullet points: “Social issues and lifestyle factors that could have an impact on adherence and choice of regimen.”

(A similar point is mentioned in the second set of bullet points, but I think this issue needs highlighting as requiring discussion between patient and clinician).

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Suggested quality statements to replace current text:

Individual decisions on care

Patients should be given the opportunity to be involved in making decisions about their treatment, following principles of shared decision making.

People with HIV should be asked which outcomes are most important to them (e.g. balance between virological efficacy and minimal side-effects), be given a range of treatment and care options, have the opportunity to discuss the benefits and risks of different options, and be given sufficient time to make decisions.

Patients should be given the option of routinely receiving copies of all test results.

People with HIV should have access to written information on HIV and its treatment that produced by an organisation that is certified by the Information Strategy, HONCode, or similar accreditation programme.

Planning services

People with HIV should have multiple, varied and widely publicised options to be involved in the planning of HIV service delivery.

Notice for agenda and subsequent non-confidential minutes for meetings related to planning service should be posted in appropriate physical (e.g. public notice board) and virtual (e.g. service provider's web site) locations.

All formally constituted boards should have a structure that includes at least one community representative and a transparent mechanism for community involvement.

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I'm not sure about the last auditable outcome, about evidence of "a policy for shared care in decision-making". I'm not sure if we mean a policy for shared decision-making, or if we mean something else. But most importantly, I'm not quite sure what a policy on this topic would actually look like. Is it a realistic expectation? I think patient involvement is fundamentally about doctors' communication skills and consulting styles, things that are unlikely to be codified in policies.

7 October 2012

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

We particularly welcome the recognition of the impact of wider beliefs on health choices.

In terms of service planning, we agree it is vital as stated that options for involvement be "multiple, varied, and widely publicised". Also essential is that involvement fairly reflects the patient cohort. If only a part of the cohort is represented, inevitably the services will not meet everyone's needs, so clinics must be proactive in recruiting service users into involvement activities. It is never enough to just create an opportunity and see who takes it – in fact this reinforces existing inequalities. Representation should mean exactly that.

Further to this, language in the Standards should be: "at least one community representative" is deeply troubling. Which community? Too often there is taken to be one community of people living with HIV, which does not reflect the diversity of needs and experiences within a diverse patient cohort. One representative is not sufficient, instead the number should be determined by what is needed to be representative of the clinic's patient list.