

BHIVA Standards of care online consultation comments

7 October 2012

Standard 9: Self management

12 September 2012

Matt Williams sent the following message:

Given this includes the phrase "social sequelae" it is perhaps (overall) not in the best or most concise English, and perhaps unintelligible to the lay (eg peer) reader, which is odd because it's about peer support.

There is no acknowledgement of informal peer networks.

There is considerable overlap with eg psychological support standard

2 October 2012

Allan Anderson from Positively UK sent the following message:

Rationale: As the national provider of peer support to people living with HIV, Positively UK strongly endorses the inclusion of peer support as set out in this Standard and the importance of skilled peer workers.

The four major areas of self-management identified on page 2 are not exclusive of one another, and we would welcome the revision of this sentence to 'For people with HIV, self-management priorities fall into at least four interconnected major areas.' We strongly support self-management in all its forms, including the sharing of the BHIVA standards with patients groups. We urge therefore that these be written in as plain English as possible and words such as 'sequelae' be reviewed and replaced e.g. 'psychological and social implications'.

3 October 2012

Roger Pebody from NAM sent the following message:

Please find below a suggested re-wording of the rationale section. I have generally aimed to clarify the language rather than make substantive changes to the meaning.

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Thanks to improvements in antiretroviral therapy and life expectancy, HIV is a long-term chronic condition, but one which requires lifelong adjustments and management by and for people with HIV.

As with other long-term chronic conditions, self-management approaches can help people with HIV to gain confidence, skills and knowledge to manage their own health, with resulting improvements in quality of life and independence.

Self-management involves people with HIV developing an understanding of how HIV affects their lives and of how to cope with the issues and symptoms which it presents. Self management services provide support which encourages people with HIV to make daily decisions that improve health-related behaviours and outcomes.

HIV-associated stigma has many negative effects on the lives of people with HIV, undermining confidence and acting as a barrier to service uptake and utilisation. Appropriate peer support enables people with HIV to develop confidence and gain information and skills from others in an easily identifiable and applicable way, which is critically important for all other aspects of self-management.

For people with HIV, self-management can help with at least four major areas:

- Physical health and well-being, including both HIV-specific and general health matters
- Mental health and well-being
- Economic inclusion and well-being, including access to financial and employment support
- Social inclusion and well-being, including peer support

Self-management as an important part of comprehensive HIV care because:

- People with HIV are frequently best placed to know and understand their own needs.
- It allows people to take greater personal responsibility for their own health and wellbeing.
- Professional resources can be focused where they are most needed.

Services that provide care for people with HIV must be delivered in a way that not only supports but also facilitates self-management. Useful approaches may include making information, techniques and tools available to people, as well as providing skills development and interventions such as coaching which develop people's confidence and competencies. Referral to and interventions from occupational and physiotherapists can optimise functionality which will facilitate many other aspects of self-management.

A variety of modalities can be used to access self-management interventions, including telephone, one to one, group settings and online. The availability of a wide range of interventions with ability to self-refer or access remotely/on line can enable access for people living with HIV, irrespective of where they live.

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Other comments...

The first set of quality of standards should use the same language to describe the areas in which self-management can help as was used in the first set of bullet points in the rationale section.

Auditable outcomes, please add:

HIV services to be able to demonstrate referral mechanisms to peer support programmes.

7 October 2012

Clare Stradling from DHIVA sent the following message:

Thank you for this welcome review of the HIV Standards, and for the time and energy this working group have contributed.

We realise that we are only a small part of the overall HIV journey but as the current evidence indicates that we have an ageing HIV population living with metabolic issues, it is essential that specialist HIV dietetic care is referenced in the standards to ensure future access and delivery of appropriate nutritional care. Optimising diet and lifestyle before the commencement of antiretroviral treatment has been shown to prevent dyslipidaemia (Lazzaretti et al 2012). Therefore we recommend the following amendments.

Rationale section, insert:

Referral to and interventions from dietitians can facilitate lifestyle behaviour changes that will either prevent or reduce the risk of long term co-morbidities associated with over or under nutrition such as cardiovascular disease, diabetes and fatty liver disease.

'Services that provide care for people with HIV must be delivered in a way that not only supports but also facilitates self-management, whilst dealing with the physical, sensory, cognitive, psychological and social sequelae of HIV. Referral to and interventions from occupational and physiotherapists can optimise functionality which will facilitate many other aspects of self-management. Referral to and interventions from dietitians can facilitate lifestyle behaviour changes that will either prevent or reduce the risk of long term co-morbidities associated with over or under nutrition such as cardiovascular disease, diabetes and fatty liver disease.'

Making information and tools available to people, providing skills development and interventions such as coaching in which people are supported to develop their confidence and competencies in given self-management areas are all examples of useful approaches.'

in Quality statements, insert:

by professionals experienced in HIV management, for example HIV specialist dietitians

'People living with HIV should have access to services which promote self-management of HIV including:

- Provision of practical and empowering support, and information on HIV health, treatments and healthy living with HIV, by professionals experienced in HIV management, for example HIV specialist dietitians.
 - Provision of support and information on maximisation of entitlement to health services and support.'
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7 October 2012

Lindsay Short from Calderdale and Huddersfield NHS Foundation Trust sent the following message:

It would be helpful to have something more about sero-discordant couples and pregnancy. In many areas they are assessed by the fertility services by the same criteria as for IVF in spite that it is for prevention of infection rather than infertility. This severely restricts access to individuals to sperm washing as by IVF standards they are ineligible as already having children (either partner) age etc. Many end up either taking a risk, self funding or not at all.

7 October 2012

Will Chegwidden from Rehabilitation in HIV Association sent the following message:

Change “Services that provide care for people with HIV must be delivered in a way that not only supports but also facilitates self-management, whilst dealing with the physical, sensory, cognitive, psychological and social sequelae of HIV. Referral to and interventions from occupational and physiotherapists can optimise functionality which will facilitate many other aspects of self-management.” To “Services that provide care for people with HIV must be delivered in a way that not only supports but also facilitates self-management, whilst dealing with the physical, sensory, cognitive, psychological and social sequelae of HIV. Referral to and interventions from occupational therapists, physiotherapists and speech and language therapists can optimise functionality which will facilitate many other aspects of self-management.

Rationale: Speech and language therapists work alongside OTs and physiotherapists in providing rehabilitation so should be included here. (It’s a common misconception that SLTs only work with disorders of language and swallow, they also work with individuals with cognitive communications disorders which are now known to be prevalent in an HIV population)

7 October 2012

Will Chegwidden from Rehabilitation in HIV Association sent the following message:

Add: Either add the following to the section on “Other professionals”, or preferably have a section entitled “Rehabilitation Team”:

“Physiotherapists, Occupational Therapists and Speech and Language Therapists should be registered with the Health and Care Professionals Council (HCPC) and in addition to the HCPC more specific competencies are outlined in the RHIVA Competencies (2012)(1). Physiotherapists working in any setting should have advanced or senior level skills in neurological, respiratory and musculoskeletal practice, whilst Occupational Therapists and Speech and Language Therapists should have advanced or senior level skills in neurological practice and in particular neurocognitive assessment and treatment. Therapists working in HIV specialist settings should also be able to demonstrate HIV related continuous professional development activity such as completing a RHIVA study day or an online HIV rehabilitation module.”(2)

1. RHIVA Competencies – see below, in publication

2. <http://www.hivandrehab.ca/EN/module.php>

7 October 2012

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

We welcome the inclusion of self-management in the Standards, and especially the broad and inclusive definition used. However, we think more understanding is needed of the role of support organisations: referral arrangements are key but so is recognising that referrals should be accompanied by financial support, through commissioning arrangements. Voluntary and peer services are not free!