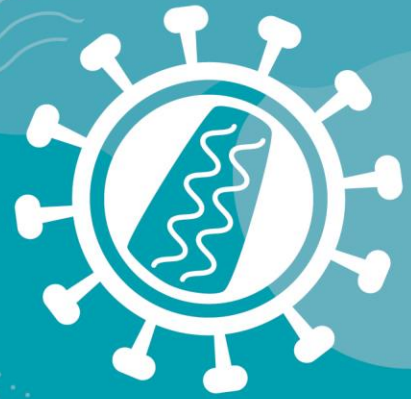


Embedding PROMs in BHIVA standards, what needs to happen

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Embedding PROMs in the BHIVA Standards, what needs to happen?

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Conflict of Interest

I have received speakers fees and an institutional research
grant from Gilead Sciences Ltd

Speakers are required by the Federation of the Royal Colleges of Physicians to disclose conflicts of interest at the beginning of their presentation, with sufficient time for the information to be read by the audience. They should disclose financial relationships with manufacturers of any commercial product and/or providers of commercial services used on or produced for patients relating to the 36 months prior to the event. These include speaker fees, research grants, fees for other educational activities such as training of health professionals and consultation fees. Where a speaker owns shares or stocks directly in a company producing products or services for healthcare this should also be declared.



People living with HIV should be at the centre of their own care

Person-centred care means that services consciously adopt the perspectives of individuals, families and communities to respond to their needs and preferences in humane and holistic ways; the person is a participant, not just a beneficiary of the health system.

2.
Person-
centred
care

Quality Statements (2C & 2D)

Decisions about individual treatment and care

- Services should place the patient at the centre of decision-making and ensure that assessment and delivery of care addresses both clinical and patient-reported outcomes and priorities.
- Issues of well-being continue to be incorporated into clinical and care practices in transparent ways
- A person-centred approach is taken in providing care to ensure that well-being for each person is holistic and meaningful

Measurable & auditable outcomes

- Within HIV care
 - Proportion of people in whom patient-reported outcome measure (PROM) is used to identify symptoms, concerns, priorities and outcomes of care (target: 90% of those with capacity to participate) (BHIVA PROMs in development at time of publication).

PROMs

- Stigma index
- PAM-13
- Medication related PROMs
- Comorbidities - with condition specific PROMS
- GAD7/PHQ9
- DEMQoL
- FRAIL
- **PREMs**

1b. Prevention

2. Person-centred care

2a. Stigma - equitable and non-discriminatory care

2b. Self-management and peer support.....

2c. Participation of people with HIV in their care

2d. Well-being

3. HIV outpatient care and treatment

3a. Access to and retention in care

3b. Outpatient care

3c. Antiretroviral prescribing.....

4. Complex HIV care

4a. Inpatient care

4b. Comorbidities, co-infections and cancers

4c. Supporting people with higher levels of need.....

5. Sexual and reproductive health

5a. Sexual health.....

5b. Reproductive health

6. Psychological care

6a. Emotional well-being.....

6b. Mental health.....

6c. Cognitive function

7. HIV across the life course

7a. Young adults and adolescents living with HIV

7b. Early to middle adulthood.....

7c. Older age

7d. Palliative care

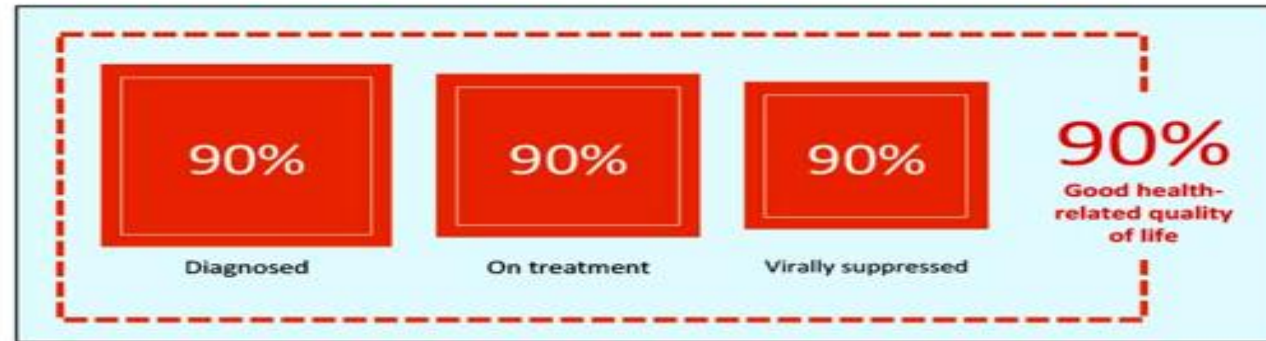
8. Developing and maintaining excellent care

So why “Embedding PROMs (PREMs) in the BHIVA Standards what needs to happen?

Currently no mention of PROMs within BHIVA Monitoring Guidelines

1. Not optimising use of PROMs/PREMs?

2.



“self-reported HRQoL should be recognized as a core outcome in the clinical management of individual patients, and in the national and global monitoring of health system responses to HIV”

J Lazarus & K Safreed-Harmon [#4th90](#) and [#BeyondViralSuppression](#)
Lazarus et al (2021) Consensus statement on the role of health systems in advancing the long-term well-being of people living with HIV; <https://www.nature.com/articles/s41467-021-24673-w>

Why do we need a 'BHIVA PROM'

2013 Stds of Care - No validated brief patient reported outcome measure reflecting the diverse needs of people living with HIV designed specifically for use in the clinical setting.

Funding to develop a valid and reliable multidimensional assessment tool that could be integrated into a clinical consultation to support patient assessment and care

Positive Outcomes

- Reflects what matters to people
- Clinically relevant & actionable
- Short - 23 Items – 4 Domains
 - Emotional wellbeing (4)
 - Interpersonal & sexual wellbeing (7)
 - Socioeconomic wellbeing (4)
 - Physical wellbeing (5)
- Psychometrically validated using Rothrock & COSMIN methodology
 - PAM-13; PROQOL-HIV; FRAIL; & virological outcomes

Name: _____ NRN: _____
 O.O.B.: _____ Today's Date: _____

Positive Outcomes: HIV PROM

Please answer the following questions about any problems or worries that you have had over the past 4 weeks. Your answers are privately reported to us. They will help us to improve your HIV care by making sure that we can focus on the things that are most important to you.

1. What have been your **main problems and worries** over the past 4 weeks that you would like to be addressed?

a.
b.
c.

2. In general, how would you rate your **health and wellbeing** over the past 4 weeks? Please think about both physical and emotional wellbeing.

Excellent <input type="checkbox"/> 4	Good <input type="checkbox"/> 3	Average <input type="checkbox"/> 2	Poor <input type="checkbox"/> 1	Very Poor <input type="checkbox"/> 0
---	------------------------------------	---------------------------------------	------------------------------------	---

3. Do you feel you have **enough information** to manage your HIV?

Enough information, the right amount for me <input type="checkbox"/> 4	Information received, but hard to understand <input type="checkbox"/> 3	Information received, but would like more <input type="checkbox"/> 2	Very little information, and would like more <input type="checkbox"/> 1	No information received, and would like information <input type="checkbox"/> 0
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The next few questions ask you more about your **physical** health and wellbeing.

4. Over the past 4 weeks, how much have you been affected by **pain**? This could include headaches, joint pain, neuropathy (which might include pins and needles or burning pain) or any other pain in your body

Not at all <input type="checkbox"/> 0	Slightly <input type="checkbox"/> 1	Moderately <input type="checkbox"/> 2	Severely <input type="checkbox"/> 3	Overwhelmingly <input type="checkbox"/> 4
--	--	--	--	--

5. Over the past 4 weeks, how much have you been affected by **stomach or bowel problems**? This could include sickness, diarrhoea, bloating, feeling sick or other stomach or bowel problems.

Not at all <input type="checkbox"/> 0	Slightly <input type="checkbox"/> 1	Moderately <input type="checkbox"/> 2	Severely <input type="checkbox"/> 3	Overwhelmingly <input type="checkbox"/> 4
--	--	--	--	--

6. Over the past 4 weeks, how much have you been affected by problems with your **memory or concentration**?

Not at all <input type="checkbox"/> 0	Slightly <input type="checkbox"/> 1	Moderately <input type="checkbox"/> 2	Severely <input type="checkbox"/> 3	Overwhelmingly <input type="checkbox"/> 4
--	--	--	--	--

7. Over the past 4 weeks, how much have you been affected by problems with your **sleep**?

Not at all <input type="checkbox"/> 0	Slightly <input type="checkbox"/> 1	Moderately <input type="checkbox"/> 2	Severely <input type="checkbox"/> 3	Overwhelmingly <input type="checkbox"/> 4
--	--	--	--	--

8. Over the past 4 weeks, have you been physically able to **carry out your usual activities**? This could include washing, dressing, housework, work, study, leisure activities, socialising, as well as other things

Always <input type="checkbox"/> 0	Most of the time <input type="checkbox"/> 1	Sometimes <input type="checkbox"/> 2	Occasionally <input type="checkbox"/> 3	Not at all <input type="checkbox"/> 4
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Barriers to use

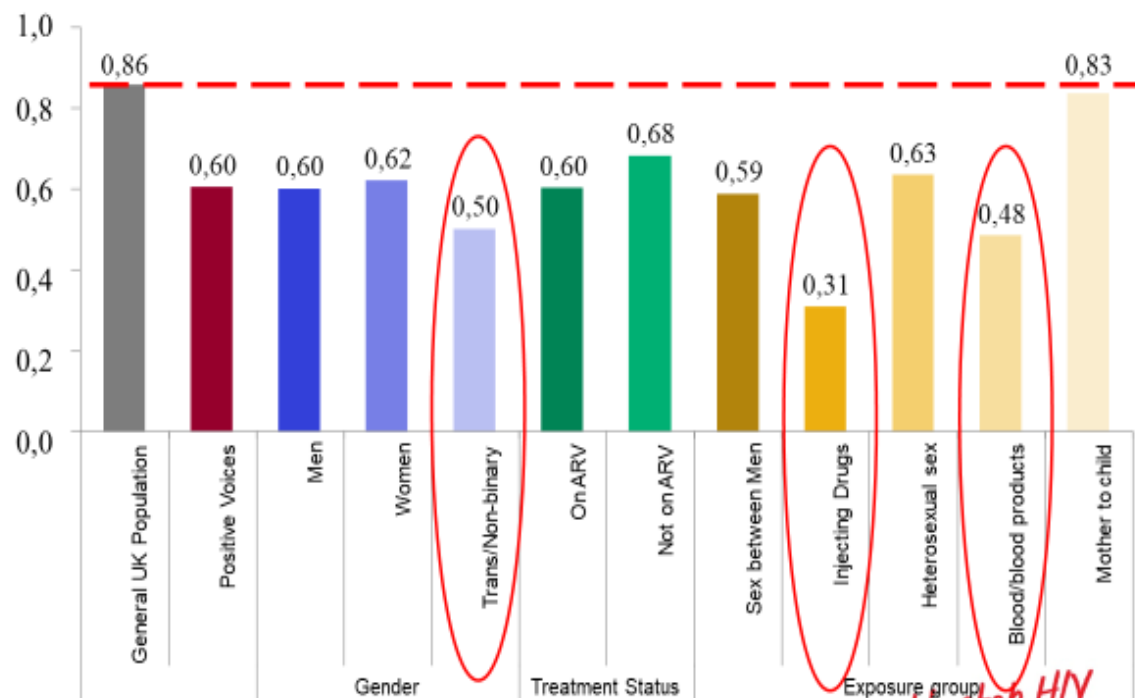


- Which to use
 - Numerous PROMs – Generic, HIV specific or both
 - Validated measures
- Current lack of implementation guidance
 - How to integrate into consultation (delivery & results)
 - Interpretation /support tool
 - Reaching all patients – language / culturally appropriate questions
- Technological constraints – need electronic version
 - EPR & remote consultations
 - Ability to look at data as a series for the individual and at service level
- Resource constraints – time & infrastructure (& money)
- Lack of outcome data to prove that they are beneficial in HIV
 - But plenty in other areas, esp re improving communication & satisfaction
 - Wanted by HIV community



Public Health
England

EQ-5D-5L utility values in general population vs HIV populations



SECTION E:

E2 HEALTH SERVICES

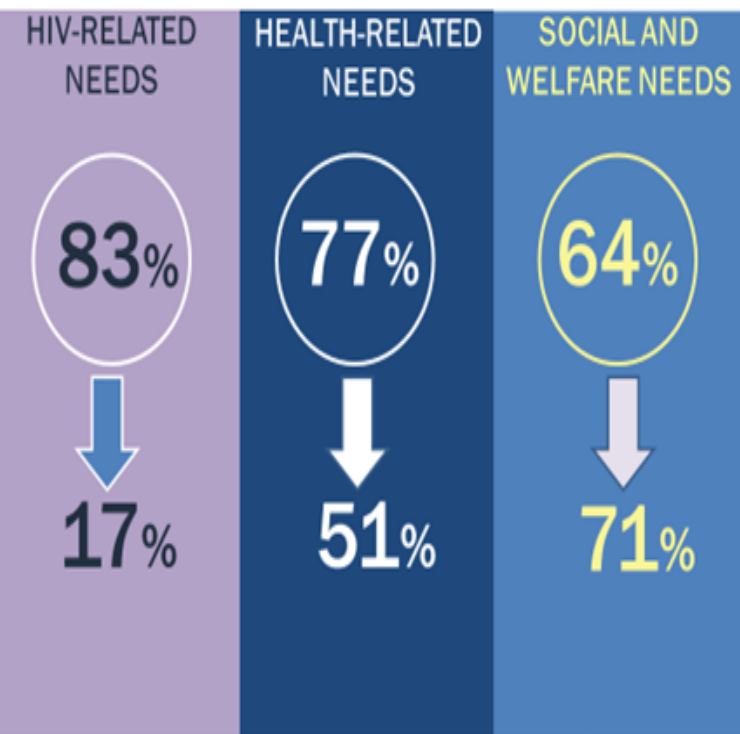
Below
last Yl

E3 SOCIAL AND WELFARE SERVICES

Below a list of services or help that you may have needed and/or received, **in the last YEAR**. For each of these, please tick the box that is closest to your experience.

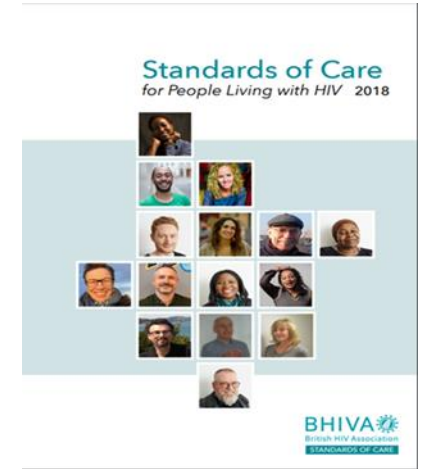
In the last YEAR...	I have received this.	I needed this, but could not get it.	I needed this, but did not try to get it.	I did not need this.
Housing support	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Meal or food services	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Childcare services	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Relationship advice	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Help dealing with isolation	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Employment advice	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Career skills and training	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Help claiming benefits	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Financial advice	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Legal advice	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Immigration support	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Domestic violence support	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

Identified unmet need



In Summary

- Need consensus on:
 - What we are measuring & why
 - How we are measuring it
- Have the mechanisms, training & support to implement
- Have interventions and services in place to address unmet need
- Commitment to review - data and measure
- Standards vs Guidelines?



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Thank you

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