



Why we wrote

“YOUR GUIDE TO”

the 2018 Standards

The BHIVA Standards of Care for People Living with HIV were published in 2018.

They are great, but they’re long, and hard to understand in places. So we’ve written

“Your Guide to...” the Standards

which aims to tell you what you should expect when getting your HIV care.

The Standards are written for three groups of people:

1. People providing care services (such as the NHS and local authorities)
2. Those giving care (such as clinicians, nurses and healthcare professionals)
3. Those receiving care (people living with HIV)

The 2018 Standards cover the full range of care that can help everyone live well with HIV. Starting with HIV diagnosis, they apply right through to end-of-life care. The 2018 Standards are very informative. They explain all aspects of care that people living with HIV can expect to receive. But of course, not everyone will experience every situation described – everyone’s HIV journey is unique. BHIVA’s 2018 Standards are very suited for the first two groups of users (1 and 2 above).

However, there are some issues that make them less suitable for the group that perhaps needs them most – those receiving care.

The issue – The 2018 standards are long!
They’re over 100 pages

The solution...
“Your Guide to...” the 2018 Standards is now much smaller. It’s been reduced to a third of the pages in the BHIVA Standards

The issue – There’s a lot of detail!
This is needed for the NHS and clinicians, but not for most people who are HIV positive.

The solution...
Only essential information for people living with HIV is included in “Your Guide to...”. But there are links to the 2018 Standards for more detail.

The issue – BHIVA use medical language.
This can be hard to understand.

The solution...
“Your Guide to...” the Standards is written by people living with HIV, for people living with HIV. Easy to understand English is used throughout.

The issue – Some key messages could be spelled out more clearly

The solution...
Clear statements on:
U=U
Starting ART and TasP
PrEP

The issue – BHIVA online version is poor
It’s just a PDF file to download

The solution...
“Your Guide to...” has been made into a user-friendly website.
<https://standards.bhiva.org>
There are many links to the 2018 Standards for more information. There are also links to other trusted sites for extra details.

The issue – No option for community feedback on the 2018 Standards

The solution...
A link to two surveys is included. One helps assess how useful “Your Guide to...” is. The second asks questions that might help us see if the Standards are being followed properly.

The issue – It’s not available in printed form

The solution...
“Your Guide to...” is also available in print. It uses the same naming and numbering as the 2018 Standard for ease of reference.

Stigma was originally conceptualised as the creation of a ‘spoiled identity’, which arises from the gap between how a person sees themselves and how they are seen by others. It is seen as a construct based on psychological, social and societal factors. It refers to an extreme disapproval of a person or group based on a characteristic that serves to distinguish them from other members of society. Fear of stigma and discrimination is a leading contributor to poor health outcomes for people living with or affected by HIV.”

Readability Consensus
Grade Level: 14
Reading Level: difficult to read.
Reader’s Age: 21-22 yrs. old (college level)

Your care should be non-judgemental. You should be treated with dignity and respect. You should feel safe from discrimination. You shouldn’t have to worry about being treated unfairly. Staff should support you when you face HIV stigma and discrimination. This support should extend outside the HIV clinics to include all aspects of health and social care.

Readability Consensus
Grade Level: 8
Reading Level: standard / average.
Reader’s Age: 12-14 yrs. old (7th and 8th graders)

Visit <https://standards.bhiva.org>