



How we wrote

“YOUR GUIDE TO”

the 2018 Standards

The 2018 Standards is the third set of quality standards for the care of people living with HIV in the UK.

It was produced by the British HIV Association (BHIVA), in partnership with care providers, professional associations, commissioners and people living with HIV.

Four Co-chairs headed up a Steering Group of about 30 doctors and researchers. This also included 6 community representatives. Each of the 8 sections had a writing group of about 8 members. There were 1 or 2 community representatives on each writing group.

...but...

...the community reps on the Steering Group pointed out that understanding the 2018 Standards could be difficult. They argued strongly for a “patient accessible” version using easy to read language. But there was no time, and no funding, for this in 2018.

...SO...

...a new, smaller, Steering Group of 10 was set up, with 2 Co-chairs...

It was important to have a simpler version of the Standards. It was great to have the opportunity to work on this!



Ann Sullivan, a clinician from Chelsea and Westminster...



...and Ben Cromarty, a community member from the UK-CAB

A writer group of 3 community members was set up. Some key decisions were made early on about style. “Your Guide to...” is written in a very easy-to-read style. It tries to speak directly to the person receiving care. It is written by people living with HIV for people living with HIV – and who are receiving care.

Its aim is to outline what everyone might expect from HIV care at each stage over a lifetime...from testing and diagnosis to starting ART; from “routine” care to complex care in the case of complications. It covers HIV and sexual and reproductive health, mental health and emotional wellbeing too. HIV and palliative care is also included. We understand that not everyone would need to read every section. So we expect that people would “dip in”. This means they can look at the sections that concern them at any given time.

Importantly, some key points are stressed in the Foreword. These points are about:

- U=U
- Starting ART
- TasP
- PrEP

There is a small amount of repetition between sections. But that’s to ensure clarity. We also had tremendous technical support from many others to help us on this project. Thanks to all those involved... Memory and Jacqueline for keeping us on time and in budget; Steve and Nick for website work; Fiona and Lenita for editing and typesetting... and apologies if we’ve missed anyone!

in partnership with...



... the writer group ...



Roy Trevellion Rebecca Mbewe Ben Cromarty

The headings and the section numbers match the 2018 Standards. This should help you find more detail in the 2018 Standards, if you want.

A user-friendly website has been created. It includes links to further information from trusted websites.

We also produced printed copies. Not everyone has access to computers, and many still prefer a print copy – something that was sadly lacking in the 2018 Standards.

All this has been thoroughly checked by the original writing groups of the 2018 Standards. This ensures accuracy. All comments received and our responses to them have been logged for transparency.

Writing “Your Guide to...” was tough at times. There was such a lot to get through. We often had disagreements that needed to be resolved quickly, and we did! The feedback from others was a great help. The three of us hope it will be useful for all!

Supported by



This project was much more community driven, with half of the Steering Group members from the Community. A funding application was successful and granted by the MAC AIDS Fund.

This allowed the project to get started in mid-2019.

The writer group agreed a set of guiding principles that they tried to follow:

- Tell people about the existence of the Standards, and what (in outline) they contain
- Focus on the perspective of those receiving care, and use sensitive language
- Highlight the key points for those receiving care
- Write in plain English, with a reading age of around 12–13 years.
- Be brief – ideally 2 sides per Standard. But some Standards are long and need more.
- Don’t try to summarise everything! Link to the full 2018 Standards for details.
- Not everyone will read the whole Guide - so make each section as stand-alone as possible

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