

# 26th Annual Conference of the British HIV Association 2020



# BHIVA Standards of Care for people living with HIV - Patient Version

**...but we're not calling it that!**

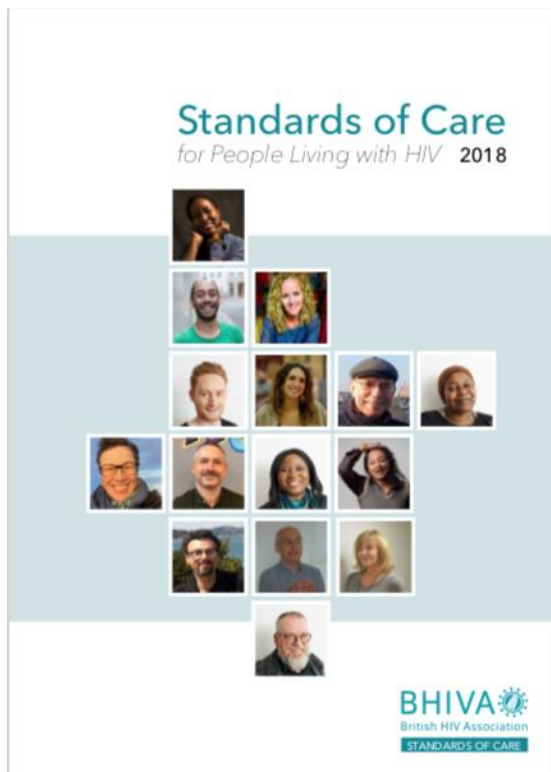
Ben Cromarty  
UK-CAB



# Declaration of Interests relating to this presentation

**No conflict of interest to declare**

# Standards of Care (2018)



For use by:

- Those providing care
- Those commissioning care
- Those receiving care

**A valued and useful document**

# Standards of Care (2018)

But:

- They are long
- They are detailed
- The language used is difficult

**Not ideal for patients!**

# New Steering Group (2019)

## Co-chairs

### Clinician

Ann Sullivan  
Chelsea & Westminster



### Community

Ben Cromarty  
UK-CAB



## Steering Group Members

Fiona Burns - University College London  
David Chadwick - James Cook Hospital  
Paul Clift - UK-CAB  
Cheryl Gower - NAT  
Alison Howarth - University College London  
Rebecca Mbewe - UK-CAB  
Sheila Morris - NHS Lothian  
Angelina Namiba - UK-CAB  
Laura Waters - Central & NW London

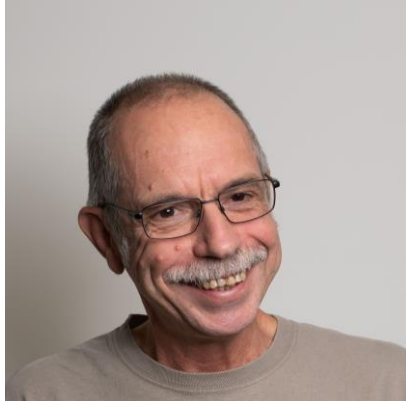
## Project Facilitator

Memory Sachikonye - UK-CAB

## Secretariat

Medivents

# Community Writer Group



Ben Cromarty



Rebecca Mbewe



Roy Trelvelion

**Funding applied for and received**

*Supported by*

**MAC  
AIDS FUND**

**BHIVA**   
British HIV Association

# Guiding Principles

- Purely patient perspective
- Plain English, with readability index Grade 7/8
- Follow the format of the 2018 standards to allow for cross-referencing - but...
- Be brief!
- Key messages in each section highlighted
- Sections need to be fairly stand-alone



# Reviewed and endorsed

Reviewed by:

- original 2018 writing groups
- Steering Committee

Formal approval by:

- Audit and Standards subcommittee
- BHIVA Exec Committee

**Confirmed co-badging with 2018 endorsers**



So what have we got?



# Your Guide to...website (1)

[HOME](#)[FOREWORD](#)[STANDARDS](#)[GLOSSARY](#)[ADDITIONAL INFORMATION](#)

**YOUR GUIDE TO**

## Standards of Care *for People Living with HIV 2018*

The BHIVA Standards of Care for People Living with HIV (2018 standards) were published in 2018. They are great - but they are long and hard to understand in some places. So a group of people living with HIV have produced this "Your Guide to..." the 2018 Standards. It aims to tell you about what you should expect when getting your HIV care. There is some useful general information in the Foreword; and there are 8 Standards that cover all aspects of HIV care in the UK throughout your HIV journey...such as testing and diagnosis; starting HIV treatment; sexual health; mental health and emotional wellbeing; and more. We hope you find this Guide helpful and easy to use...there is a quick survey in Additional Information about this, so we can try to improve things for next time



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

[HOME](#)[FOREWORD](#)[STANDARDS](#)[GLOSSARY](#)[ADDITIONAL INFORMATION](#)

Your Guide to...BHIVA Standards of Care for People Living with HIV

Foreword

Acknowledgements

1. Testing, diagnosis and prevention

2. Person-centred care

3. HIV outpatient care and treatment

4. Complex HIV care

5. Sexual and reproductive health

6. Psychological care

7. HIV across the life course

8. Developing and maintaining excellent care

Glossary

Full 2018 BHIVA Standards of Care For People Living with HIV

**YOUR GUIDE TO**

## Standards of Care for People Living with HIV 2018



Foreword



1. Testing, diagnosis and prevention



2. Person-centred care



3. HIV outpatient care and treatment



4. Complex HIV care



5. Sexual and reproductive health



6. Psychological care



7. HIV across the life course



8. Developing and maintaining excellent care

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



- Your Guide to...BHIVA Standards of Care for People Living with HIV
- Foreword
- Acknowledgements
- 1. Testing, diagnosis and prevention
  - 1a. Testing and diagnosis**
  - 1b. Prevention
- 2. Person-centred care
- 3. HIV outpatient care and treatment
- 4. Complex HIV care
- 5. Sexual and reproductive health
- 6. Psychological care
- 7. HIV across the life course
- 8. Developing and maintaining excellent care
- Glossary
- Full 2018 BHIVA Standards of Care For People living with HIV

## **YOUR GUIDE TO** Standards of Care for People Living with HIV 2018

### 1. Testing, diagnosis and prevention

It might seem odd to have a section on testing, diagnosis and prevention. After all, these are Standards for people living with HIV. So, for us, we've already been tested, diagnosed and are probably already being treated for HIV. But as people living with HIV, we might have some particular concerns about prevention. We might also have partners who are not living with HIV, so we need to be aware of, and involved in, prevention strategies.

HIV testing and diagnosis are crucial to stopping the HIV epidemic.



#### 1a. Testing and diagnosis

Routine HIV testing should be offered in a wide range of ways and should be encouraged. It is especially important in communities that have higher rates of HIV. Here, GPs should offer HIV tests. Testing should be offered when you're new to your GP, but also if you haven't had an HIV test in the past year. Routine HIV testing should also be offered in sexual health clinics, other hospital clinics or hospital departments such as A&E. HIV testing should also be offered more widely in the community. This might include home testing or self-sampling. All these testing situations are listed in the 2018 Standards.

If you test HIV positive, you should be given clear information about what to do next, and where to get treatment and support. Information about what to do and where to go must be in easy-to-read language. As for any other infectious disease, testing should also be offered to your sexual partners, and your children, if there is the possibility that they might have been born with HIV.

#### Key messages

- Routine offers of HIV testing should be made in a wide range of healthcare settings.
- Routine testing should also be available in the community, including self-sampling and home-testing.
- In all cases, information about what to do if you test HIV positive should be readily available in a form that is clear and easy to understand.

[Click here to view this page in the 'Full 2018 BHIVA Standards of Care for People Living with HIV' section](#)

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



- Full 2018 BHIVA Standards of Care For People living with HIV
- Foreword
- Acknowledgements
- Introduction and background
- 1. Testing, diagnosis and prevention
- 2. Person-centred care
- 3. HIV outpatient care and treatment
- 4. Complex HIV care
- 5. Sexual and reproductive health
- 6. Psychological care
- 7. HIV across the life course
- 8. Developing and maintaining excellent care
- Appendices
- Glossary
- Your Guide to...BHIVA Standards of Care for People Living with HIV



## Standards of Care for People Living with HIV 2018

### 1. Testing, diagnosis and prevention

#### 1a. Testing and diagnosis

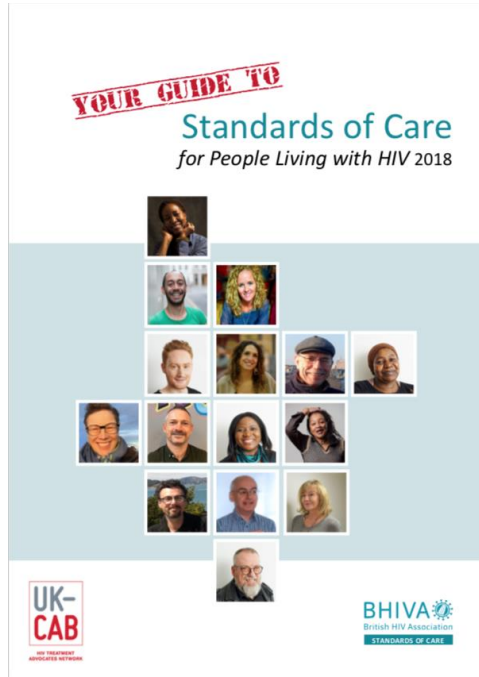
People attending healthcare services (primary, secondary and tertiary care) should be offered diagnostic tests for HIV in accordance with current national guidance.



- Rationale
- Quality statements
- Measurable and auditable outcomes
- References

[Click here to view this page in the 'Your Guide to...BHIVA Standards of Care for People Living with HIV' section](#)

# Your Guide to...A5 printed brochure



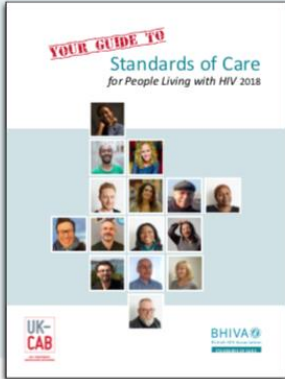
**Preference to use website**

Not everyone has internet access  
- often the most vulnerable groups

Not everyone is comfortable using the internet  
- shared accommodation  
- older population?

# Advertising material

## A3/A4 posters



**YOUR GUIDE TO**  
Standards of Care  
for People Living with HIV 2018


The BHIVA Standards of Care for People Living with HIV were published in 2018. They are great - but long and hard to understand in places.

So we have written  
**"YOUR GUIDE TO"**  
which aims to tell you what you should expect when getting your HIV care.

Visit <https://standards.bhiva.org>  
If you do not have internet access, please ask your HIV clinic or HIV support group for help. They may have a limited supply of print copies available.

UK-CAB  
BHIVA

## A6 postcards



**YOUR GUIDE TO**  
Standards of Care  
for People Living with HIV 2018

Hello!

The BHIVA Standards of Care for people living with HIV were published in 2018. They are great - but they are long and hard to understand in places.

So they are not great for us - people living with or affected by HIV. A group of us have written "Your Guide to" which aims to tell you what you should expect when getting your HIV care.

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

If you do not have internet access, please ask your HIV clinic or HIV support group for help. They may have a limited supply of print copies available.

I hope you find it useful!

B, R & R

**BHIVA**  
British HIV Association  
STANDARDS OF CARE

Anyone Affected by HIV  
Everytown,  
NE Where  
The Street Where I Live  
United Kingdom

UK-CAB

British HIV Association



# We need your help!

Ideally, steer people to the website - **available now**

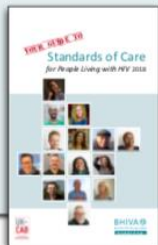
But print copy for those who most need it

Distribution best done locally by HIV clinics and support groups

- initial email to all, asking for number needed (Dec 2020)
  - with pdf of all print material
- one-off mailing of brochures, ads, and postcards (Feb 2021)

**Hopefully, more face-to-face meeting by then**

# More information in Exhibition Area



## 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”

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

The Standards are written for three groups of people:

1. People who provide care services (such as the NHS and Local Authorities)
2. Those giving care (such as clinicians, nurses and healthcare staff)
3. Those who receive 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 2018 Standards are very useful 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.



## 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...

in partnership with...



# Thank you...

...to everyone who made this possible!

**Funding from M.A.C. AIDS Fund**  
**SoC Steering Group**  
**Writer Group**  
**2018 reviewers**  
**BHIVA and UK-CAB reviewers**  
**Co-badging from other organisations**  
**Secretariat support from Medivents**  
**Web support**  
**“behind the scenes” support**