

# Equity, Equality, Diversity and Inclusion among BHIVA's members and community stakeholders

An independent review



# Acknowledgements

This review was conducted independently by [Purple Pen Research and Evaluation Consulting](#) on behalf of BHIVA. Principal team members included Dr Melvina Woode Owusu, Emma Harvey and Mike O'Driscoll.

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We recognise that engaging in critical reflection on matters concerning equity, equality, diversity and inclusion and/or legally protected characteristics involves introspection on one's own socio-demographic characteristics, social background, privileges or lack of privileges. We appreciate the openness, and willingness to engage with the review process amongst all those that took part in the survey and interview stages of this review and those who responded to interview calls.

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Advisory Group members hold a number of roles within BHIVA including Chair, Vice-Chair, Honorary Secretary, Board member/Trustee, Chair of the External Relations Subcommittee, Chair of the Education and Scientific Subcommittee, Vice-Chair of the Education and Scientific Subcommittee, Vice-Chair of the Conferences Subcommittee, Executive Committee member, Guidelines Subcommittee member, Audit and Standards Subcommittee member and External Relations Subcommittee member.

# Foreword

BHIVA is a UK based association representing professionals in HIV care and came into being in 1995. It is a national advisory body for all aspects of HIV care, and provides a national platform for HIV care issues, as well as delivering and promoting continuing medical education. BHIVA is comprised of sexual health, infectious disease, international, medical, and non-medical members, and despite being small, commands global attention, not least due to its rigorous and much respected guidelines. HIV is a progressive discipline in which to work and BHIVA prides itself on its strong links with the HIV community, aiming to involve individuals living with HIV in all its activities. The diverse nature of the membership and the people living with HIV that BHIVA serves, means that BHIVA must be inclusive. For this and other reasons we proposed the commissioning of this review into equity, equality, diversity and inclusion (EEDI), relating to the BHIVA membership, but also to those who could be BHIVA members but choose not to be. The idea was catalysed by [The Royal College of Physicians independent report into Diversity and Inclusion](#), published in 2020. With this in mind, we proposed a piece of work to examine EEDI within BHIVA, its membership and subcommittees, to examine whether any barriers are perceived to membership or wider participation, and form a set of recommendations to address these, if so. The ambition is to better engage with our members, improve our work to be more inclusive which, hopefully, will benefit members, the community we serve and, ultimately, clinical care for those we treat. We must thank the BHIVA Officers in 2021 for agreeing to commission this work, Medivents Ltd, BHIVA Secretariat, especially Jacqueline English, and Purple Pen Research and Evaluation Consulting, especially Dr Melvina Woode Owusu and Emma Harvey for conducting the research, as well as all those who participated. We look forward to engagement of all BHIVA members in taking forward the suggested actions...

**Dr Tristan Barber and  
Dr Rageshri Dhairawan**



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To learn more about BHIVA, please visit the website: [www.bhiva.org](http://www.bhiva.org)

# Foreword

The BHIVA EEDI Report 2023 is the first ever piece of work of its kind in the 40 years since BHIVA was founded. This is despite the fact that we as a group believe that we are inclusive, we are fair and that we listen. BHIVA is a strong organisation but, as the leading association for professionals and those living with and affected by HIV in the UK, we can only continue to lead and to be the best if we have contributions from and are the voice for ALL our membership.

And so, we asked you what you thought. And you told us. So, thank you. Some of this report might make for uncomfortable reading, however there is also a lot of positivity reflected here too. Both are important.

As Chair, and with the BHIVA Executive and membership, I will work hard to implement the recommendations of this EEDI report.

With your help.

**Prof Yvonne Gilleece**



**Prof Yvonne Gilleece** (she/her)  
Chair of BHIVA

# Executive Summary

The British HIV Association (BHIVA), founded in 1995, is the UK's leading association representing professionals in HIV care. BHIVA provides a national platform for HIV care issues and contributes to international, national and local committees. In addition, BHIVA promotes undergraduate, postgraduate and continuing medical education within HIV care. BHIVA is committed to providing excellent care for people living with and affected by HIV. People living with HIV are members of all subcommittees and treatment guideline writing groups and share their perspectives and experience to help ensure the best possible outcomes for the HIV community.

In 2021, BHIVA commissioned an independent review of Equity, Equality, Diversity and Inclusion (EEDI) among its membership and wider stakeholder community. This review was conducted at a time when many organisations are actively acknowledging inequalities and inequities within and between groups in society and seeking to address the root causes of discrimination and/or disparities in experiences and outcomes. This report provides an insight into how BHIVA is perceived from a broader EEDI perspective, members' experiences of inclusion and belonging within BHIVA and highlights areas where diversity and inclusion can be improved in pursuit of more equitable opportunities and equal outcomes for professionals working in HIV care and the broader HIV community.

In 2022, data collection in support of the review began. 280 survey responses were received to a broad BHIVA stakeholder community survey exploring diversity, engagement, belonging and inclusion. 60% (n=164) of those responding were BHIVA members. 15 (out of 98) subcommittee, working group, panel members responded to an additional survey exploring socio-demographics, including socio-economic background. A further 15 people took part in an individual semi-structured interview. Those who took part in the review represented diverse and intersectional socio-demographic characteristics, and had varying BHIVA membership statuses, lengths, and roles within and outside of BHIVA.

Interviewees included people living with HIV, working in academic research, identifying as being from the HIV community sector and working in clinical medicine and/or nursing. Roles represented were broad, including, consultant, non-consultant, trainee and other healthcare professional communities. Information about organisational rules, subcommittee structures, membership, and related web-based content produced by BHIVA (website and social media content) were also reviewed. All data were analysed using quantitative and qualitative methods.

In general, HIV medicine was considered to be more diverse and liberal than other areas of medicine. Some groups reported feeling represented amongst BHIVA's leadership (demographic data supported this). These were:

- cis women
- gay and bisexual men who have sex with men
- people from Asian ethnic groups
- people living with a recognised disability, including but not exclusively HIV.

Perceptions of broader diversity and feelings of belonging and inclusion were variable. It was noted that while societal inequalities predate and may be bigger and broader than BHIVA, the Association was seen as well-placed to lead others in improving diversity, especially in leadership roles.

## Lack of diversity

The most prominent theme emerging related to a lack of representation of people of non-white ethnicities, clinicians practicing outside of London and England and non-senior clinicians/healthcare professionals in visible BHIVA roles (including Officer, Executive Committee and subcommittee Chair roles). In particular a lack of visible diversity (beyond cis-male and cis-female gender identities) was noted among the BHIVA Executive Committee and Conferences panels/speakers.

This lack of diversity was found to be problematic for BHIVA's stakeholders for four main reasons:

### 1. Blind spots and lack of representation:

Respondents described that the under-representation of population groups at meetings meant that some issues are never or rarely on the agenda for discussion, debate, and prioritisation. The issue of only having a single representative from a population group carried the same risks, as the assumption may be made that a specific perspective had been considered, when importantly a single individual is unable to share the views of an entire group.

BHIVA does go some way to plugging gaps and broadening perspective through the involvement of HIV community members identified and nominated by the UK Community Advisory Board (UK-CAB). However, the following groups are not perceived to be well represented at BHIVA events:

- people who identify as non-binary
- people who identify as trans
- people who practice sex work
- people who are incarcerated
- people who inject drugs.

### 2. Deprioritisation of community-specific issues:

Respondents described the deprioritisation of the needs of **i** - Black communities (e.g., compared with pre-exposure prophylaxis (PrEP) campaigns targeting GBMSM), **ii** - women who identify as gay, lesbian, bisexual and/or who otherwise engage in sex with other women (compared with women who identify as heterosexual) and **iii** - those working outside of London (compared with issues of greater relevance in London e.g., commissioning arrangements).

It was, however, noted by some stakeholders that BHIVA has been actively addressing broader geographical representation since it was raised in the 2019 BHIVA members survey.

**3. Social and professional exclusivity:** The observed lack of ethnic and geographic diversity among, and accessibility of BHIVA's leadership contributes to perceptions that BHIVA is socially

and professionally exclusive. The notion of being 'outside of' BHIVA structures was widely shared by people of varying professional working background, clinical seniority, class, ethnicity and geographical area, as well as BHIVA membership status (including those in defined leadership roles).

For some, the perceived exclusiveness of BHIVA reinforced their desire to apply for opportunities and roles e.g., to support their personal or professional development. For others, the exclusive nature of BHIVA felt "impenetrable" and dissuaded them from applying for leadership roles or engaging with activities which interested them and to which they felt able to contribute.

### 4. The self-fulfilling prophecy of representation:

The notion that one cannot be what one cannot see was shared throughout the review. This sentiment transcended ethnic and geographic groups to people with caring responsibilities, those working less than full-time and trainee/more junior healthcare professionals.

Some groups that reported feeling represented (and demographic data supported this) amongst BHIVA's leadership were:

- cis women
- gay and bisexual men who have sex with men
- people from Asian ethnic groups
- people living with a recognised disability, including but not exclusively HIV.

## Societal inequalities reflected within BHIVA

A second key theme emerging was a general concern regarding a lack of diversity within BHIVA's leadership, in part due to societal inequalities which predate and were considered bigger and broader than BHIVA.

BHIVA as a leading organisation in the field of HIV is well-placed to lead others in improving diversity and inclusion, especially in senior roles. Further, a 2022 report from the British Medical Association, Delivering racial equality in medicine and a report published by the Royal College of Physicians stating similar findings suggest that the challenges concerning progression to more senior roles may not be unique to BHIVA.

This review found that BHIVA's professionalism and leadership in the field could facilitate future work with a broader network concerning EEDI and to improve diversity among its leadership.

## Belonging and inclusion

A final theme emerging around belonging and inclusion found that:

- Over half of respondents (57%, n=90) slightly or strongly agreed that they feel respected by BHIVA colleagues.
- Over half of respondents (54%, n=51) slightly or strongly agreed that they felt a sense of belonging among BHIVA colleagues.
- 43% (n=68) slightly or strongly agreed that they would feel confident in voicing a contrary opinion at a BHIVA meeting.
- A third (33%, n=52) slightly or strongly agreed that their unique background and identity are valued by BHIVA.

Inclusion and belonging within BHIVA appear to be challenged by:

**1. an enduring perception of BHIVA as a “professional” and “elitist” organisation** which leads some members to withhold an application or nomination because they do not feel professional or experienced enough and they assume the post will be offered to someone who is more socially connected to the Executive Committee and

**2. the breadth of BHIVA’s reach.** Finding a balance between presenting high-quality, evidence-based (mostly medical) information, in a

trustworthy manner and by recognised experts, while also being accessible to a wide audience (including, medical and community audiences) can be challenging.

A perceived inaccessibility of some roles may be exacerbated by a lack of knowledge concerning eligibility for subcommittee chair roles. A review of BHIVA's rules and processes for eligibility for nomination and election shows, that some BHIVA roles are only accessible to members who, through previous experience, have already demonstrated an understanding of the organisation. BHIVA's need to maintain business continuity and succession planning may be perceived as contributing to a “closed shop”. BHIVA structures and processes may benefit from review to ensure they are clear and accessible by those who potentially could be interested in involvement with the organisation.

**BHIVA members and stakeholders** are encouraged to learn more about BHIVA and its members by taking the following actions:

- visit the BHIVA website.
- follow and engage with BHIVA on Twitter and Facebook.
- reach out to BHIVA Officers, Executive Committee, subcommittee, working group or panel Chairs for more information.
- attend BHIVA events.
- apply for roles when they are advertised.

The following recommendations are intended to provide a pathway for BHIVA to develop a more diverse and inclusive approach, which can:

- foster greater diversity of engagement, membership, and leadership with and within BHIVA
- facilitate more equitable access to opportunities
- address disparities in the experiences of belonging and inclusion and support organisational growth and success.



# Summary Recommendations

Please see pages 27-30 for full recommendations and suggested actions.

- 1. Acknowledge that the review indicates a lack of diversity within BHIVA including of non-white clinicians and non-London based clinicians in leadership and/or visible roles.
- 2. Make and state an organisational commitment to addressing issues and concerns highlighted in this EEDI review, focusing on those who identify with characteristics that have historically received less attention (as above), while maintaining consideration of intersectionality and the inclusion of women and GBMSM and other groups which are now well-represented within BHIVA.
- 3. Ensure that BHIVA's Executive Committee meets with the EEDI Review Advisory Group to discuss the review findings and next steps including the need for and scope of an EEDI Action Group.
- 4. Develop a strategy to reduce the risk of inadvertently widening the gap in accessibility and experience amongst:
  - racially minoritised communities
  - those living/working outside of London
  - HIV community members
  - trainees, non-senior, other professionals and/or those with less flexible working patterns and/or unable to attend events in person.
- 5. Set up an EEDI Action Group that can develop in-depth knowledge of and experience in a range of EEDI issues, enabling them to act as EEDI champions and offer constructive scrutiny and knowledge sharing across the organisation.
- 6. Include process, outcome, and impact measures to support monitoring and evaluation of organisational progress towards EEDI goals.
- 7. Broaden BHIVA's engagement with wider networks to explore EEDI related issues.
- 8. Offer training and support to BHIVA members in leadership positions, including but not limited to Officers, members of the Executive Committee, Subcommittees, Working Groups and Panels on the topics of Equity, Equality, Diversity and Inclusion.
- 9. Provide opportunities for prospective and current BHIVA members to meet with Officers, members of the Executive Committee, Subcommittees, Working Groups and Panels.
- 10. Review and update BHIVA's roles and the way in which they are advertised to increase and broaden accessibility to include new groups, new roles, new mentoring opportunities and updated role descriptions.
- 11. Promote a wider range of benefits of individual membership.
- 12. Review membership fees and the point at which these can be reassessed, to make them equitable for those with changing life/professional circumstances or preferences.

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# 1. Approach to the review

## A note on terminology

This report makes every effort to use positive, inclusive and respectful language. The language used has been selected using guidance from the [World Health Organisation](#) and the [People First Charter](#).

In support of the People First Charter and in recognition of the awareness and the agency of people living with HIV, we use the terms 'people living with HIV', 'people with HIV' and 'people accessing HIV services'.

This report does not use the acronym 'BAME' (Black, Asian and minority ethnic) except where it is presented as part of a verbatim quote provided by interviewees or survey respondents. 'BAME' fails to recognise the importance of the heterogeneity, varying histories, and experiences of different racially minoritised groups. Data and commentary concerning ethnic groups are only grouped to convey race/region of origin-based differences in the data and not in any way to suggest homogeneity or diminish the varying histories and experiences of ethnic groups with the same race/region of origin-based prefix.

In recognition of the differences in men's (cis and trans) sexuality, this report refers to men who identify as gay, bisexual and/or who have sex with men. For brevity only, the abbreviation GBMSM is used.

Wherever possible, the terminology and pattern of speech used by interviewees and in open-ended survey responses has been retained and presented alongside interpretative commentary. The purpose of this is to convey the diversity of thought, language, and expression amongst those who took part in the review. Quotes are presented in speech bubbles and using quotation marks (“”) within the text.

## Review scope

The review was conducted between March 2022 and February 2023, starting with an initial workshop with the Equity, Equality, Diversity, and Inclusion (EEDI) Review Advisory Group to jointly fine tune the scope, processes and key areas of exploration. Eight members attended, representing clinicians, HIV community members<sup>1</sup>, communications, varied sexual orientations, ethnicities, genders, and ages, as well as geographical perspectives. EEDI was recognised as an important, multi-faceted and ongoing consideration for BHIVA's organisational strategy, and it was accepted that the organisation would benefit from collecting baseline demographic data, identifying any areas where improvement should be prioritised and involving members of BHIVA's leadership at key points in the review.

Together with the reviewers, the EEDI Review Advisory Group agreed that the review should aim to:

1. explore socio-demographic characteristics; identities and lived experiences of BHIVA's broad stakeholder community, including members and using the [Equality Act 2010 and the Progress Plus Framework](#)
2. explore the extent to which BHIVA is representative of professionals working in HIV medicine and/or people living with HIV in the UK
3. explore the extent to which the perception of an inclusive culture is shared among BHIVA members, people living with HIV and other BHIVA stakeholders
4. inform BHIVA's organisational development and sustainability plans.

<sup>1</sup> Throughout the review, we refer to HIV community members (people living with HIV) and BHIVA stakeholder community (all those involved with and/or interested in BHIVA as an organisation which includes but is not restricted to people living with HIV).

## Review methodology

The review framework involved data collection via five methods:

- 1. Workshops with the EEDI Review Advisory Group** to define the scope for the review, agree on a methodology and discuss the review findings, consider which aspects of BHIVA's culture, processes and activities are amenable to change and identify specific actions that BHIVA could take to address the review recommendations.
- 2. Anonymous online survey of BHIVA's stakeholder community** to explore identity, lived experiences and characteristics of the broad BHIVA community stakeholders, as well as BHIVA's culture, communications and activities. The survey was designed independently and informed by BHIVA's EEDI Review Advisory Group and diversity monitoring materials, with guidance from the Royal College of Physicians, Equality and Human Rights Commission, Stonewall and the UK census.
- 3. Confidential semi-structured individual interviews**, conducted via Zoom, to explore key themes emerging from the survey, including:
  - perceived culture of BHIVA subcommittees
  - perceived barriers and facilitators to involvement in BHIVA subcommittees and conferences, with specific attention to perspectives under-represented in the survey
  - the extent to which people living with HIV are involved in decision-making within BHIVA.
- 4. Anonymous online survey of BHIVA subcommittee, working group and panel members** to gather additional membership and demographic data. This included the demographic questions in the wider member survey, plus three further questions to inform a measure of socio-economic background.

- 5. Document review** exploring information available about subcommittee structures was reviewed, including logs of membership of subcommittees, terms of reference, and related BHIVA website content and BHIVA Twitter account.

## Recruitment and accessibility

Both surveys were accessible via a link and enabled for completion on a smartphone, tablet, or computer. The first survey invitation and link were shared via email to all BHIVA members and stakeholders (including non-members), BHIVA's Members Matters circulation, BHIVA's EEDI Review Advisory Group, on the BHIVA website, via BHIVA's Twitter page and via the UK-CAB. All those receiving the survey invitation were encouraged to share this amongst their networks to expand the reach of the survey across the broad HIV sector that BHIVA serves. The first survey and interviews were open to everyone in the BHIVA stakeholder community, including:

- BHIVA members;
- people living with HIV;
- all people working in the field of HIV, sexual and reproductive health, and infectious diseases, including clinical medicine, advocacy, and research.

The second survey was sent only to those on a subcommittee, working group or panel (n=98).

## Anonymity and confidentiality

The survey was conducted anonymously via SurveyMonkey and designed and deployed by the reviewers. Care was taken to ensure that individuals could not be identified from any single data item. To avoid the risks of deductive disclosure through reviewing combinations of responses from individuals, all raw data was held securely by the reviewers and only aggregate and summary data shared with BHIVA.

With consent, the reviewers transcribed interviews to support analysis. All transcripts and demographic data captured during the interviews were stored securely by the reviewers.

## Data analysis and interpretation

Quantitative survey data<sup>2</sup> were examined using descriptive inferential and statistical analyses to explore whether there may be indicative associations between findings. Qualitative survey and interview data were analysed using deductive (using the pre-defined review aims as a guide) and then inductive (new themes emerging from the data) methods. The relatively small sample was not randomly selected therefore data presented in this report has been interpreted with care.

Demographic and membership data are presented alongside summary interpretations of survey and interview data and analyses. It is important to note that survey respondents and interviewees took part on a self-selecting and voluntary basis; the sample is not random and therefore biased towards the views of those most willing to share their views online or via Zoom interview. Due to the cascading survey recruitment approach, it is not possible to determine response rates for the first survey. There is a small and unavoidable risk that the survey was completed multiple times by the same individual. Further, due to a high level of interest, it was not possible to interview everyone that expressed an interest; however, care was taken to ensure that a range of characteristics and perspectives were included, with priority given to those from groups that were less represented in the survey, relative to other groups that responded to the survey.

The survey was distributed to BHIVA's broad stakeholder community which includes people living with HIV. The views expressed within the report are from a range of stakeholders including people living with HIV and other BHIVA stakeholders with a professional or personal interest in HIV related topics.

<sup>2</sup> Percentages are rounded up or down to one decimal point so may not always add up to exactly 100%.

# 2. Voices captured

## BHIVA's stakeholder community

280 survey responses were received to a broad BHIVA stakeholder community survey. 60% (n=164) were BHIVA members.

**Age:** 11% (n=30) of respondents were aged under 34. Nearly two-thirds (62%, n=168) were aged 35-54. 27% (n=72) were 55+.

**Gender:** 54% (n=145) of respondents identified as female, 43% (n=116) as male and 2% (n=5) as non-binary and 2% (n=5) preferring to self-describe.

**Sexual orientation:** 60% (n=158) of respondents identified as straight or heterosexual, 26% (n=69) as gay men and 2% (n=6) of respondents identified as gay women/lesbians, 6% (n=16) as bisexual, 5% (n=13) preferred to self-describe and <1% (n=2) were unsure.

**Ethnicity:** 67% (n=179) of respondents were White, 14% (n=37) Asian, 11% (n=29) Black and 6% (n=15) mixed ethnicity. 3% (n=9) reported being of other ethnicities. Less than 1% identified as Black Caribbean, Mixed White and Black African, Latin American or Arabic. No respondents identified as Asian Bangladeshi or Chinese.

**Religion:** 52% (n=135) of respondents reported that they have no religion; 34% (n=89) identified as Christian, 7% (n=17) as Muslim, 4% (n=10) as Hindu and 2% (n=5) as Jewish.

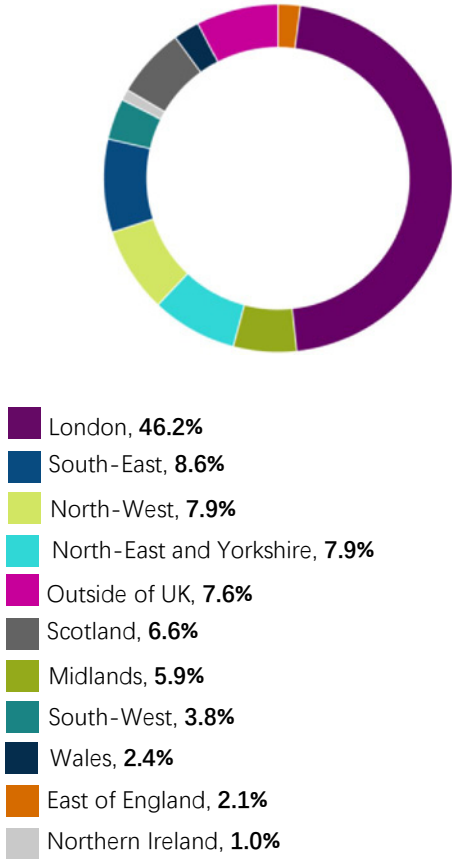
**Disability or long-standing health condition:** 29% (n=78) of respondents reported living with a disability. Of those that described their disability or long-standing health condition (n=75), 77% reported a long-standing illness or health condition, such as HIV. Almost all (92%) of those who reported a long-standing illness or health condition also reported that they are HIV community members/living with HIV.

**Trans identity:** 3% (n=7) of respondents of the wider BHIVA stakeholder survey identified as trans.

Amongst the BHIVA stakeholders, 65% (n=180) of respondents were employed full-time; 22% (n=61) were employed part-time and under 5% (n=13) were retired. At the time of conducting the survey, less than 1% of respondents were on carers or parental leave (n=2); 3% (n=7) were on sick leave and 93% (n=255) of respondents were not on any form of leave.

BHIVA stakeholders shared their main locations of work as:

Main location(s) of work (n=278)



## BHIVA's subcommittees, working groups and panels

In addition, all members of BHIVA's subcommittees, working groups and panels (these are people in positions of leadership and/or with defined roles) were invited to complete an extended demographic survey, which also included validated questions about socio-economic background. Thirty-five people completed this survey.

**Age:** No respondents were under 35 years of age. Nearly half (44%, n=15) were aged 35-44, 27% (n=9) were 45-54 and 29% (n=17) were 55+.

**Gender:** 57% (n=20) of respondents identified as female, 43% (n=15) as male. None identified as non-binary or with any other gender.

**Sexual orientation:** 76% (n=25) reported being straight or heterosexual. 21% (n=7) identified as gay men, and 3% (n=1) as bisexual. No respondents identified as gay women/lesbians, preferred to self-describe or reported that they were unsure.

**Ethnicity:** 82% (n=28) were of a White ethnic group. 9% (n=3) Asian, 3% (n=1) Black, 3% (n=1) mixed ethnicity and 3% (n=1) an other ethnicity.

**Religion:** 42% (n=14) of respondents reported that they have no religion; 52% (n=17) were Christian. A very small proportion were either Muslim (3%, n=1) or Jewish (3%, n=1). No other religions were represented.

**Disability or long-standing health condition:** 26% (n=9) of respondents reporting living with a disability, which included living with HIV.

**Trans identity:** No subcommittee members reported that they identified as trans.

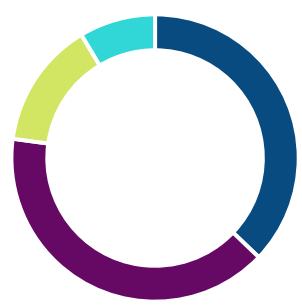
## BHIVA's subcommittees, working groups and panels - socio-economic background

Following the initial survey and interviews with BHIVA broad stakeholder community and interviews, a clear perception emerged that those in BHIVA's leadership roles were predominantly from "middle class" backgrounds and concern was expressed that this may be a contrast to the cohort of people living with HIV and/or negatively impact a sense of belonging amongst those who do not consider themselves to be from "middle class" backgrounds. BHIVA had not previously collected data on socio-economic backgrounds, so this review sought to collect baseline data alongside other demographic characteristics among BHIVA's subcommittee, working group and panel members.

The data presented are from a small number of people (n=35), so it is not possible to draw conclusions. However, it is likely that the socio-economic background of BHIVA's subcommittee, working group and panel members is reflective of wider systemic issues impacting social mobility and diversity amongst those in professional careers such as within academia and medicine.

Asking about parental occupation allowed the reviewers to measure extreme economic and cultural advantage<sup>3</sup> - 6% (n=2) of members of subcommittees, working groups and panels were from lower socio-economic/working class backgrounds.

Schooling



- Selective state-run or state-funded school, 40%
- Non-selective state-run or state-funded school, 37%
- Independent or fee-paying school, 14%
- Attended school outside the UK, 9%

Parental occupation



- Professional backgrounds, 85%
- Intermediate backgrounds, 9%
- Lower socio-economic backgrounds, 6%

<sup>3</sup> 'I don't know,' 'Prefer not to say' and 'Attended school outside the UK' were excluded from this measure.

Another validated measure of extreme economic disadvantage is eligibility for free school meals at any point during one's school years. Amongst this group of respondents (subcommittee, working group and panel members), no one reported being in receipt of school meals.<sup>4</sup>

## Interviewees

15 people took part in an interview, each representing diverse and intersectional socio-demographic characteristics:

**Age:** Ages ranged from <25 to 64 years with the most common age range being 45-54 (n=5).

**Gender:** Female (n=9), Male (n=5), Non-binary (n=1).

**Sexual orientation:** Heterosexual/straight (n=8), Gay (n=5), Bisexual (n=1), Queer (n=1).

**Ethnicity:** White British (n=8); Minority-ethnic groups (n=7).

**Religion:** No religion (n=8), Christian (n=6).

**Disability or long-standing health condition:** 8 reported a disability or longstanding health condition, including 6 with HIV alone and/or HIVplus another condition.

**Trans identity:** No interviewees reported that they identified as trans.

Interviewees had the following roles outside of BHIVA (some had multiple roles):

- people living with HIV
- academic researcher
- HIV community sector member
- consultant
- non-consultant
- trainee
- other healthcare professional.

Interviews were conducted with at least one:

- general member with less than one year's membership
- general member with more than one year's membership
- executive committee member
- officer
- subcommittee member
- subcommittee chair
- prospective BHIVA member.

<sup>4</sup> This question was not applicable for those who finished school before 1980 or who went to school overseas. Twenty-three percent (n=8) of respondents were excluded from this measure as the question was not applicable for them.



# 3. BHIVA as a beacon in HIV

## “If not us, then who?”

In an early session with the EEDI Review Advisory Group, the phrase “if not us, then who?” was shared – the group agreed with the sentiment and set a commitment to and willingness to

- conduct the review in a transparent way
- engage in open reflection on equity, equality, diversity and inclusion
- actively address the barriers to engagement highlighted by the review, by updating and improving its practice moving forwards.

## Successes

Throughout the review, BHIVA, as an organisation, was praised for historical leadership in the HIV sector, with regards to supporting visible representation of GBMSM and cis women in senior roles, people living with HIV, and ongoing HIV community and professional stakeholder involvement. Increasingly, trainees are reported to be gaining visibility too.

“As an employee for a community organisation, I believe BHIVA is very supportive and includes the HIV community in all of its activities.”

“I like that patients and members of community groups are asked to speak at BHIVA conferences for example so that we are not just speaking on people’s behalf.”

“Sometimes feels a bit London centric but I see efforts beginning to be more inclusive of out of London areas.”

Efforts to further increase accessibility in recent years were noted, including a less formal style of the reception events at BHIVA conferences and active and an engaging social media feed.

When asked to describe BHIVA, one interviewee commented:

“I think it’s remarkable how much BHIVA has improved its communication and advocacy in the last few years, especially on social media. It makes it feel more like a living, more human, organisation rather than one that sits on high, and issues guidance and protocols.”

“I would say dynamic, friendly and, also, pioneers. The Global North pays a lot of attention to what BHIVA does and I would say the guidelines are more liberal than many others in Global North. I would also say, listens. I feel that BHIVA listens.”

Other comments which captured widely shared sentiments included:

“I like to believe that BHIVA is a forward thinking, inclusive organisation who speak[s] up for minorities and under-represented groups adversely affected by HIV. I have never seen anything contrary to this from the organisation.”

“Be more public and widely understood about your activities and mission.”

“...I think the lessons learned in lockdown about connecting and working together online could be formalised; though I’m already impressed with what BHIVA has achieved on that front.”

“Maintain online meetings and an online conference presence. The only reason I feel I can ask a question at BHIVA meetings is because I have opportunity to attend online. I cannot afford the time or cost of travel to meetings etc. if no online access.”

Throughout the review, BHIVA's Executive Committee were praised for taking the initiative to commission an independent review of its membership through an EEDI lens. Review participants offered critical reflections on their experience of BHIVA and suggestions for improvement. Several clinicians reported choosing to practice HIV medicine (rather than other medical specialties) because of the sector's perceived diversity and open-mindedness around sexuality.

“[the review] should have happened a long time ago but given that it hasn't, it's really good that it is happening now.”

“Compared to most NHS-related organisations I think BHIVA is doing pretty well, despite mostly having a "White British face" during the past 20 years.”

“It's much, much better with visible diversity in leadership and with [female chair name] and [female chair name] - fantastic leadership.”

BHIVA's stakeholders, for the most part, considered BHIVA to be a leader with respect to the involvement of community-based organisations and representation from people living with HIV. The longstanding (formalised in 2001) relationship with the UK-CAB supports this. BHIVA could extend its efforts for example by encouraging clinic-based members to promote the UK-CAB's new online training course in their settings. This initiative seeks to increase the UK-CAB's membership. BHIVA may also wish to engage other organisations that specifically work with people living with HIV that are less well represented compared with other community groups in BHIVA. Demographic data on BHIVA's leadership suggest that maintaining consistent representation from cis women, men who openly identify as GBMSM and to a lesser extent, people of some Asian ethnicities, has been achieved.

## Room for improvement

BHIVA as a perceived leader in the HIV sector, in the UK and beyond, is well placed to openly prioritise even more meaningful and broader involvement at all levels of the organisation. This can be done by working towards more ambitious goals which maintain compliance on statutory guidance, such as the Equality Act 2010, and create more opportunities for a wider range of HIV community members and professional stakeholders that are more reflective of the population living with HIV. The BHIVA membership can support BHIVA's organisational aims by applying for advertised roles and/or advising BHIVA of any additional or remaining barriers to their participation which BHIVA may be able to address in the future.

# 4. How BHIVA is perceived: Diversity

## Successes

There are signs of representation of the following, sometimes marginalised, groups within leadership positions in BHIVA, including among Officers, the Executive Committee and subcommittee Chairs:

- cis women
- GBMSM
- people from Asian ethnic groups
- people living with a recognised disability, including but not exclusively HIV.

Comments from survey respondents and interviewees suggested that being able to see role models in more senior positions can be encouraging and sends a signal that BHIVA is more diverse than it was previously thought to be.

“ There’s something about representation, seeing someone up there like me. There were no brown women on the [X subcommittee] when I joined, the only women of colour were me and the patient rep[resentative] and I don’t think that is changing at all, like, I feel like representation is not getting better from that point of view.”

“ One thing I would say is that not being the only person from a specific ethnic group helps to feel that the inclusion is meaningful, rather than if you’re the only person from a specific group.”

“ I think it’s hugely improved in recent years when it did feel very London-centric and rather austere.”

“ Thanks to Dr <name> who is visible and brilliant. As a gay Muslim man who is HIV positive, I see her fighting for my rights, and it makes me really grateful. Thank you doctor! ”

## Room for improvement

### Lack of diversity among BHIVA’s leadership

There is, however, room for improvement. In particular a lack of visible diversity (beyond cis-male and cis-female gender identities) was noted among the BHIVA Executive Committee and conferences panels/speakers. One of the recurring themes reported was a perception of limited representation of

- people of non-white ethnicities (with the exception of those of Asian ethnicities)
- clinicians practicing outside of London and England
- non-senior clinicians/healthcare professionals in prominent and visible BHIVA roles.

“ The organisation does not feel inclusive. It lacks diversity in representation of Black and brown people. Often involving the same few people in leadership positions. It is not reflective of our society or our patients and needs to change.”

“ I didn’t think it was for me... I thought everyone [in BHIVA] was much more senior with lots of knowledge and I didn’t feel like one of those people.”

“ [BHIVA needs] more diversity in senior roles to reflect the trainees and the patients who we serve.”

“ It’s [BHIVA] very HIV consultant heavy so it doesn’t always necessarily feel like that’s a place for junior or early career staff there because everything going on in BHIVA is kind of like, it’s been ticking along the way it has for a long, long time. So, coming in as a younger person you don’t want to upset that.”

The challenges presented by a lack of visible diversity among BHIVA's leadership were:

**1. Blind spots:** A common sentiment expressed in the review is that a lack of diversity can lead to "blind spots" where the limited representation of population groups at meetings means that some issues are never or rarely on the agenda for discussion, debate, and prioritisation. The issue of only having a single representative from a population group carried the same risks, as the assumption may be made that a specific perspective had been considered, when importantly a single individual is unable to share the views of an entire group.

One former BHIVA Executive Committee member ('Interviewee X') described an experience of trying to curate a diverse group for a BHIVA event, after which they were contacted with a query/complaint regarding the planning team's neglect to include a trans representative. Interviewee X admitted that their reaction to the query/complaint was initially defensive:

“ So, I thought well, you know, you can't please all the people all the time and I thought...you could think of a lot of people we didn't have because you can't everybody every time. But actually, that didn't address the question...it just really made me think about the whole thing much more, about how hard it is [to engage a diverse group]...”

Interviewee X then went on to describe the organic approach that had been used to identify speakers (based on the immediate meeting group suggesting the names of people they had already seen speak, know already or otherwise believed could deliver at the event or would suit the occasion):

“ We have this person, they'd be really good, I've seen them at this, and you know, before you know it you've got notes on a piece of paper and various people have suggested other people and there were some arguments, they're not available what about if we got this other person in, and you know,

you get yourself sort of enthused about it and you totally don't see the people who are not there. That's the problem, that's the problem that the organisation has.”

Interviewee X reflected:

“You can never quite include everybody, but you can do better than we did then.”

This approach to identifying and referring people for opportunities, is one which makes way for unconscious bias. The criteria for selection are undefined and set by a group that have already been provided opportunities or privilege. This issue is wider than BHIVA and reflected across society, manifesting as, for example, institutional racism. However, in BHIVA's case, the impact of a perceived lack of transparency around how posts and roles are filled is exacerbated by the perceived lack of diverse representation in the leadership roles:

“ The leadership could be more diverse. There is a lack of transparency.”

BHIVA does go some way to plugging gaps and broadening perspective by the involvement of HIV community members identified/nominated by the UK-CAB. It is important to note the bias in involving HIV community members solely identified through organisations, as this may not allow BHIVA to access the views and experiences of people living with HIV who are not engaged with the charitable organisations from which the UK-CAB's membership is drawn. It was also noted that while HIV community involvement is a strong point within BHIVA, people living with HIV, from the following groups, are not well represented at BHIVA events:

- people who identify as non-binary
- people who identify as trans
- people who practice sex work
- people who are incarcerated
- people who inject drugs.

**2. Deprioritisation:** It was suggested by several stakeholders that the observed prioritisation of GBMSM for example, in the delivery of pre-exposure prophylaxis (PrEP), may be due, in part, to GBMSM being well represented within BHIVA's leadership. The survey showed that 26% (n=69) of BHIVA's stakeholders and 21% (n=7) of BHIVA's subcommittee, working group and panel members identified as being a gay man. While the achievements in providing access to PrEP for GBMSM were praised, comparisons were drawn with Black African communities. Although both GBMSM and Black African communities are disproportionately impacted by HIV, many interviewees and survey respondents felt that Black African communities were not given the same attention concerning PrEP. The survey showed that 8.6% (n=23) of BHIVA's stakeholders and 2.9% (n=1) of BHIVA's subcommittee, working group and panel members identified as being of 'Black African' ethnicity.

Another example of this concerned a focus on matters impacting heterosexual women to the neglect of women who identify as gay, lesbian, bisexual and/or who otherwise engage in sex with other women. The perceived limited representation of non-heterosexual women in leadership positions within BHIVA was raised by several cis women, some of whom identified as gay/lesbian. The survey showed that 2% (n=6) of BHIVA's stakeholders identified as a gay/lesbian woman compared with none among BHIVA's subcommittee, working group and panel members.

Similarly, BHIVA conferences were perceived as giving more prominence to topics concerning London rather than other regions. It was, however, noted by some stakeholders that BHIVA has been actively addressing this issue since it was raised in the 2019 members survey.

“ I think it is good to reflect the diversity across the UK and obviously there are some common themes in the UK but there are some different challenges in <...> whether it's around rural populations or the challenges reaching minority ethnic communities in an area like <...>, you know, where

the demographics are quite different as well, or we've got very specific issues around drug use as well, just a very different set up around services so I think it's important to kind of reflect the whole National picture. ”

“ Make membership and conferences cheaper - latter massively expensive. Have noted BHIVA exec pretty much all Caucasian? UK centric which is fine but would add to diversity and interest. Focus on all groups regardless of sexuality and gender and religion and race, and not just LGBTQI as there is a big focus on them which is warranted and understandable but huge issues of stigma in heterosexual community. ”

**3. Exclusivity:** The observed lack of ethnic and geographic diversity among, and accessibility of, BHIVA's leadership contributes to perceptions that BHIVA is socially and professionally exclusive. The notion of being 'outside of' BHIVA structures extended to those that perceive themselves to be 'outside of clinical medicine,' 'outside of the role of a consultant', 'outside of a middle-class background', 'outside of the white ethnic group' and/or 'outside of London'. This view was expressed by non-BHIVA members, BHIVA members without a defined leadership role within BHIVA as well as some BHIVA members with a current and former leadership role, alike.

“ BHIVA is very cliquey; if you are not in the "in" crowd then you are not able to be more involved. I do not put myself forward for anything as I know that it is more of a popularity contest, and I would never be nominated. This is even more the case since I am non-clinical (although an academic with a PhD in HIV). I don't think I am even eligible for the mentoring programme!?! Sadly, I am having to move away from HIV research even though I have worked in this field for more than a decade as I feel I will not be able to progress. ”

“It can however seem like the same people are elected into the committees every year- though not necessarily in the same position. As a result, it can seem, as an outsider, like there is no point applying.”

#### 4. The self-fulfilling prophecy of representation:

The notion that one cannot be what one cannot see was shared throughout the review. This sentiment transcended ethnic and geographic groups to people with caring responsibilities, those working less than full-time and trainee/more junior healthcare professionals, where it was considered that positions of leadership were either not accessible to them or difficult to access without personally knowing a member of the leadership team. Comments suggested that being able to see role models in relatively more senior positions can be encouraging and sends a signal that BHIVA is more diverse than it was previously thought to be.

For some, the perceived exclusiveness of BHIVA reinforced their desire to apply for opportunities and roles, with suggestions that BHIVA could support their personal, professional and career development. For others, the exclusive nature of BHIVA felt like an “impenetrable” organisation, which dissuaded them from taking part in applying for leadership roles and activities which interested them and for which they felt able to contribute.

There were several requests/constructive calls expressing the same sentiments:

“BHIVA needs to commit to representing all aspects of diversity within the organisation, especially at Exec/Officer level. These include geographical representation, whilst remembering most HIV is in London, and abilities for role sharing, especially for those who work less than full time.”

“More diversity in senior roles to reflect the trainees and the patients who we serve.”

“Ongoing representation of Racially Minoritised Communities at executive level and committees/subcommittees.”

# 5. Bigger than BHIVA

“BHIVA reflects the NHS in general. There is apparent inclusivity, and a large proportion of ‘different’ individuals, but firmly in the lower tiers, with perhaps a tokenistic occasional presence of someone different. It’s a bit frustrating when also married with the rhetoric of being so inclusive and politically correct etc. I may re-join when the chair and the proportion of BAME individuals on the committee is similar to the general BHIVA membership.”

“Nothing will ever change for BAME people. Please stop giving us hope.”

A 2022 report from the British Medical Association, [Delivering racial equality in medicine](#), highlighted that ‘there is a significant gap in published and evaluated interventions to address the disparities of ethnic minority doctors’ progression into senior roles’.

In the same year, a [report](#) published by the Royal College of Physicians stated that “While almost half of the RCP’s student membership are from a black, Asian or minority ethnic (BAME) background, fewer than a quarter of those appointed to committee roles and fewer than three in ten fellows are.”

These reports suggests that the challenges concerning progression of BHIVA members to more senior roles within the Association is not unique to BHIVA.

Nonetheless, as per the assertion “if not us, then who?”, BHIVA has stated a commitment to addressing the EEDI issues highlighted through this review and liaising with NHS and medical associations to learn from one another may be helpful.

Worth noting is published data on the [NHS Workforce Race Equality Standard](#), which showed that the number of Black and minority ethnic board members in NHS trusts increased by 128 (38.1%) between 2020 and 2022.

BHIVA's engagement with similar organisations that are working towards or have achieved diverse membership at all levels and an inclusive culture could provide useful case studies and opportunities to exchange knowledge. Engagement with wider networks on matters concerning EEDI could be beneficial for BHIVA as it addresses the Associations' challenges, as described in this report.

# 6. Experiences of BHIVA

## Successes

When asked about a sense of inclusion, belonging and value amongst BHIVA colleagues, BHIVA members, non-members and wider stakeholder community reported the following:

- Over half of respondents (56.6%, n=90) slightly or strongly agreed that **they feel respected by BHIVA colleagues**.<sup>5</sup>
- Over half of respondents (53.5%, n=51) slightly or strongly agreed that **they felt a sense of belonging among BHIVA colleagues**.<sup>6</sup>
- 42.8% (n=68) slightly or strongly agreed that they **would feel confident in voicing a contrary opinion at a BHIVA meeting**.<sup>7</sup>
- A third (32.9%, n=52) slightly or strongly agreed that their **unique background and identity are valued by BHIVA**.<sup>8</sup>

## Room for improvement

### Double-edged sword of exclusivity

Although BHIVA is highly regarded, and considered prestigious and professional, the lack of visible diversity and perceived inaccessibility contributes to what was described as an “elitist” and “cliquey” culture.

However, the “closed shop” perception leads some members to withhold an application or nomination because they assume the post will be offered to someone who is more socially connected to the Executive Committee. This view was commonly expressed, for example, through comments such as:

“ At the moment it feels like inclusion in committees, the board, conferences etc. is based on being part of an ‘in crowd.’ ”

“ The committees feel like a clique - it's hard to break into. ”

“ You think no-one knows who you are and why would they vote for you? It feels like a popularity contest, there isn't much room on the statement to write about yourself... there are advantages for London Consultants as more people know one another... There's perceptions about clique-ness and that does put people off definitely. ”

A perceived inaccessibility of some roles, may be exacerbated by a lack of knowledge concerning eligibility for subcommittee chair roles. By necessity, and as documented within BHIVA's rules and processes for eligibility for nomination and election, some BHIVA subcommittee chair roles are only accessible to those who have already demonstrated a commitment to, and understanding of, the organisation e.g., through holding an active role on a subcommittee. This is to provide continuity across BHIVA's activities, support succession planning and maintain historical knowledge, which are required for the proper functioning of the organisation. Those interested in applying for roles within BHIVA are able to find out more about the current membership, aims and activities of each subcommittee, working group and panel on the [BHIVA website](#).

In the 2022 Executive Committee elections, no nominations were received for the non-London representative, and the existing London representative's nomination was uncontested. This is despite attempts from BHIVA (via Members Matters and video advertisements available on Twitter) to reassure prospective BHIVA leaders of the openness and accessibility of the Executive Committee. This is concerning as 50% of people living with HIV are accessing services outside of London and there is a need to represent these populations, in addition to the clinicians that serve them. This suggests that although the BHIVA Executive Committee at the time openly encouraged applications, there are other barriers to participation and Executive Committee membership which need to be addressed, so that BHIVA's leadership is more representative of the medical profession.

<sup>5</sup> Nearly one third were neutral and only 12% (n=18) slightly or strongly disagreed.

<sup>6</sup> 27% (n=43) were neutral and 19.5% (n=31) slightly or strongly disagreed.

<sup>7</sup> 20.1% (n=) were neutral and 37.1% (n=59) slightly or strongly disagreed.

<sup>8</sup> Half were neutral (50%, n=79) and 17.1% (n=27) slightly or strongly disagreed.



Increasing diversity should be a priority for BHIVA given the Royal College of Physicians “very much supports efforts by medical schools to improve access to a career in medicine for underrepresented groups” and that the organisation is striving to increase the diversity of the future medical workforce to better reflect society.

The challenges of widespread inclusion and BHIVA's commitment to broad stakeholder involvement, including with the HIV community, was widely noted.

The following types of stakeholders completed the BHIVA stakeholder community survey:

Role	n	%
Clinician – consultant	99	36%
Community member/Lived experience of HIV	63	23%
Academic researcher	36	13%
Nurse	22	8%
Pharmacist	16	6%
Sexual health adviser	14	5%
Clinician – STR/SPR	11	4%
Clinician – other	9	3%
Clinician – SAS	8	3%
Retired consultant	3	1%
Student – medical	1	1%
Dietician	2	<1%
Student – non-medical	1	<1%
Clinician – pre-speciality training	0	0%
Other	35	13%
<ul style="list-style-type: none"> <li>• data collection manager in sexual health and BBV/HIV service co-ordinator</li> <li>• student nurse, Clinical Nurse Specialist/ GP/Paramedic</li> <li>• HIV Peer Mentor Coordinator/Navigator, HIV support advocate/Person/partner living with HIV</li> <li>• multiple roles</li> <li>• pharmaceuticals/Industry partners</li> <li>• charity, Voluntary Sector, NGO, Outreach worker</li> <li>• political Group/ Policy and Campaigns Officer</li> <li>• sexual health counsellor, psychosexual therapist, Counsellor, HIV Therapist</li> </ul>		
<b>Total</b>	<b>227</b>	

## Recommendations for BHIVA members and stakeholders

**BHIVA members and stakeholders** are encouraged to learn more about BHIVA and its members by taking the following actions:

- visit the website
- follow and engage with BHIVA on Twitter and Facebook
- reach out for more information
- attend BHIVA events
- apply for roles when they're advertised

### Challenges to meaningful involvement among community members and other professionals

The breadth of BHIVA's reach, results in a challenge. For example, presenting high-quality, evidence-based (mostly medical) information, by experts in the field, in a professional and trustworthy manner may contrast with BHIVA being accessible to a wide audience, including people living with HIV, and those with varying levels of HIV related knowledge in HIV medicine.

**“ Provide sessions open/understandable to nurses/other health professionals. ”**

This conflict was reported as making it challenging for community members, and other professionals, to meaningfully engage with BHIVA's leadership, who appear to community members to be highly knowledgeable. It was also reported that engaging with BHIVA's content and the ability to form and share an opinion without prior experience or training could be challenging for some community members. This was especially true amongst those who speak English as a second language and/or who have a high cultural regard for medics and medical knowledge.

One community member, living with HIV and with over 15 years involvement in the HIV sector commented regarding BHIVA conferences:

“ There’s been some conferences I’ve been to where I question whether I know anything about HIV as the content just goes over my head and I think in those situations if the purpose of the conference or event is to speak to scientific people then that’s fine, there’s not necessarily anything wrong with that, but if the conference is making an effort to engage with different types of people, especially ...community groups, people with lived experience then sometimes it’s important to reflect on how to pitch it, so that nobody feels that they are kind of like, lost in the information sharing. I think of all the different spaces that I’ve been in, it’s sometimes the BHIVA conference space where I’m just like, ‘oh my gosh, do I even know anything about HIV?’ And I know that I do! It’s just the way the information is delivered, it’s like, woah! It’s not about ‘oh, I’m learning something new today,’ it’s like, ‘I don’t even understand what you’re saying’ to be able to digest a little bit of it, to maybe go and do my own research for my own understanding. ”

Another HIV community member stated:

“ People in the community are scared stiff... scared of everybody who is in BHIVA and on the BHIVA Executive. They are scary! Look at how much they know. ”

Regarding matters concerning medical care, there were mixed views about whether HIV community members should be involved in decision-making, whether clinicians’ views should be prioritised over those of people living with HIV and whether medicalised language was overused. For some, offering payment in recognition of community members’ time spent on BHIVA activities was seen as a way to show they are valued.

Reflecting on ways that BHIVA can demonstrate that it values HIV community members, one HIV community member advised:

“ We’ve fought for a place for so long, but people still want to treat us as volunteers... I just think they expect us to give our time and expertise and just be grateful we have a place, but no, that shouldn’t be the case, my time is valuable too...It’s not about paying to your worth, it’s paying for recognition of giving up your time. ”

Importantly, HIV community members also wish to be known for their expertise and/or developing expertise in matters other than their own lived experiences of HIV. This includes medicine, as practicing doctors, academics with research expertise and community-based advocates with expertise in matters of social justice and health promotion, and those with expertise in communications or public relations. It was noted while men who identify as GBMSM are visible on conferences and panels and are involved for their medical expertise, people of Black ethnicity attending are less likely to be visible and presenting on their clinical, academic, or other non-service user merit. So, demographic data from events may mask the extent to which diverse groups are visibly included in senior roles within BHIVA.

### **Challenges to meaningful involvement among medics**

The professionalism and apparent ease of BHIVA leaders was also described by several BHIVA members (also senior, including Executive Committee members) as contributing to a fear of being not being articulate, knowledgeable, and/or ready to join colleagues in a leadership role.

This sentiment has been described elsewhere and by interviewees and survey respondents as “imposter syndrome”:

“...I didn't have any experience; it would have been difficult for me. It's only when you get to do stuff and it gets acknowledged and appreciated and you get to do more stuff that's when you get that confidence. A lot of people forget about getting into the door, people always speak from the position of when they've made it. They talk about, 'oh I've done it, you can do it too' and they forget about a- the struggles, and b- just those bits of luck.”

“...they're [BHIVA Executive Committee] thought of as people who are successful, clever, articulate, knowledgeable, good at speaking and that almost they arrive fully...they were born and, you know, had all these attributes and that, you know, whereas me, I'm not like that so obviously I can't be part of this. I don't know...polished but also relaxed, you know, not nervous. Even when people say they're nervous they don't look it... There's a lot of imposter syndrome in this world, [it] definitely affects people who are not up there, who just think, 'I'm not going to, I'm never going to be a part of this world so I'm not even going to try to become, you know, part of the BHIVA Executive', and I think the loss to the organisation is amazing - calculable.”

An example of including trainees was shared:

“One thing that I think has been really successful was an easy thing to do, was to get trainees to co-chair sessions at the conference, so, you know, you have an experienced chair and a co-chair who's trainee and so that way, you know, they don't have to

prepare at all, they don't have to, you know, rehearse that, do the research but they can get up on the podium and they can, you know, they can chair the session, they've got somebody alongside them who's done it before, they're made to feel welcome and they do it really well and they come out of it feeling good, generally, about themselves and feel like this is an organisation that, you know, that values me and, you know, is demonstrating that I have a place here. So, that was, that I thought was really powerful and very effective.”

In addition, clinicians reported mixed experiences of being able to allocate time to BHIVA activities, expressing the sentiment of:

“An additional issue around equity and inclusion in BHIVA is that none of us get paid to do the work. You either have to be really dedicated or work for a Trust that is flexible enough to allow you the time.”

There were also several requests/constructive calls expressing the same sentiments:

“More explanation about the various roles and what they require, how to apply for them and why it might be a good idea to do them other than out of some sort of personal ambition (being important etc.)”

“The move to virtual has facilitated attendance at certain meetings and events.”

“Encourage the non-doctor voice to be a bit louder.”

# 7. Recommendations

- **1. Acknowledge that the review indicates a lack of diversity within BHIVA including of non-white clinicians and non-London based clinicians in leadership and/or visible roles.**

*Example action:*

Publish report of the key review findings

- **2. Make and state an organisational commitment to addressing issues and concerns highlighted in the review, focusing on those who identify with characteristics that have historically received less attention (as above), while maintaining consideration of intersectionality and the inclusion of women and GBMSM and other groups which are now well-represented within BHIVA.**

*Example actions:*

- a. Introduce positive action statements advising BHIVA stakeholders of intentions for organisational change.
- b. Publish EEDI Strategy advising BHIVA's broad stakeholder community of its goal and approach to embedding them
- c. Invite expressions of interest to join an EEDI Action Group, including chair and deputy chair roles.

- **3. Ensure that its Executive Committee meets with the EEDI Review Advisory Group to discuss the review findings, next steps including the need for and scope of an EEDI Action Group.**

*Example actions:*

- a. Develop an EEDI code of practice and pledge (to accompany membership renewals) to support sustained attention to the issues of diversity and inclusion, starting with BHIVA's most senior leadership roles (Officers, Executive Committee, Subcommittee, Working Group and Panel Chairs).

- b. Broaden BHIVA's Objects and Powers of the Association to align with the extended remit of the organisation's strategies to reduce the risk of inadvertent disadvantage.
- c. Add the relevant recommendations to Executive Committee and subcommittee meeting agendas and to the Annual General Meeting.

- **4. Develop a strategy to reduce the risk of inadvertently widening the gap in accessibility and experience amongst:**
  - racially minoritised communities
  - those living/working outside of London
  - HIV community members
  - trainees, non-senior, other professionals and/or those with less flexible working patterns and/or unable to attend events in person.

**Members of these groups who took part in the review suggested the following recommendations to address their needs:**

➤ **Members of racially minoritised communities**

- a. share mental health guidance to support BHIVA stakeholder community, for example those affected by Covid-19 and Black Lives Matters Movement, noting that these have fallen heavily on racially minoritised, including black communities;
- b. actively encourage and support professionals from racially minoritised communities to engage in mentoring (as both mentors and mentees);
- c. create and/or support access to safe fora for discussion of challenges in BHIVA and HIV care roles that are specific to issues of EEDI;
- d. wherever possible, ensure more than one person from a racially minoritised community is involved in any given group; and/or
- e. wherever possible, ensure that people from Black ethnic groups are invited to BHIVA events, committees, working groups and panel members on a wide range of topics and not exclusively regarding their experience of living with HIV, race, stigma, and inclusion.

➤ **Those living/working outside of London**

- a. protect sessions within event programmes to explore regional case studies, presented by invited regional speakers; and/or
- b. set up regional meetings and events (conference highlights and discussion - "BHIVA on the road").

➤ **HIV community members (those people living with HIV)**

- a. use more inclusive language throughout all BHIVA communications;
- b. discuss more universally accessible topics, in addition to medical/clinical topics; and/or
- c. explore the feasibility of offering more free educational events.

➤ **Trainees, non-senior, other professionals and/or those with less flexible working patterns and/or unable to attend events in person**

- a. offer social events at various times of day;
- b. offer events specifically to facilitate networking within and between:
  - Trainees/fewer senior colleagues
  - Non-medics
  - HIV community members;
- c. maintain options to attend a range of online and in-person events and where possible, hybrid events;
- d. offer flexible conference registration options;
- e. consider making 'BHIVA Conference highlights' available more widely – such as 'Best of CROI'; and/or
- f. offer catch-up options for those with less flexible schedules.

➤ **6. Include process, outcome, and impact measures to support monitoring and evaluation of organisational progress towards EEDI goals.**

*Example actions:*

- a. Collect anonymous data on socio-demographic characteristics of BHIVA members, and event attendees, to support more sophisticated and longer-term monitoring and evaluation of EEDI and to determine the extent to which initiatives are accessible to people with different experiences and backgrounds. Ensure the data collection fields are harmonious across working groups, panels, and subcommittees (build on the baseline questions used in this review).
- b. Share anonymised socio-demographic data, incl. on socio-economic background, and use this to openly review composition of subcommittees, working groups and panels.
- c. Set diversity targets for membership of the Executive Committee and Officers. This should form part of an organisational strategy, to better reflect the diversity of BHIVA's wider membership and the broad stakeholder community that BHIVA serves, including people living with HIV.

➤ **7. Broaden its engagement with wider networks to explore EEDI related issues.**

➤ **8. Offer training and support to BHIVA members in leadership positions, including but not limited to Officers, members of the Executive Committee, subcommittees, Working Groups and Panels on the topics of EEDI.**

*Example action:*

Offer or signpost to the following training and support for EEDI: unconscious bias; valuing difference; and/or handling difficult conversations.

➤ **9. Provide opportunities for prospective and current BHIVA members to meet with Officers, members of the Executive Committee, subcommittees, working groups and panels.**

➤ **10. Review and update BHIVA's roles and the way in which they are advertised to increase and broaden accessibility to include new groups, new roles, new mentoring opportunities and updated role descriptions.**

*Example actions:*

- a. Identify roles which can be shared effectively between two people (including Chairs, Officers, Executive Committee roles) and update role description/advertised requirements accordingly.
- b. Expand opportunities to experience BHIVA operations, shadowing, and mentoring, for example:
  - data collection;
  - monitoring and career tracking; and/or –
  - offer training in preparation for a role.
- c. Consider multiple national, regional or local BHIVA leadership roles, such as for the devolved nations or NHS regions.

Interviewees suggested that the following may support some individuals to play an active role in BHIVA.

- a. emphasise the value of diversity of thinking in reducing the risk of blind spots and addressing the broad needs of people living with HIV;
- b. be clear in adverts with regards to the expectations of the roles and time commitment involved;
- c. make stakeholders aware of support that is available e.g., mentorship by existing BHIVA members from a varied range of social and professional backgrounds.

## ➤ **11. Promote a wider range of benefits of individual membership.**

Interviewees suggested that stating that BHIVA offers the following opportunities may motivate some individuals to play a more active/defined role in BHIVA:

- a. Develop career enhancing skills such as research, leadership, communications
- b. Make a difference nationally which may not be possible in local settings
- c. Learn about matters of national and international importance
- d. Contribute to social justice and advocacy among those communities living with HIV
- e. Exchange experiences of challenges and good practice with others.

## ➤ **12. Review membership fees and the point at which these can be reassessed, to make them equitable for those with changing life circumstances or preferences.**

It is advised that the recommendations offered in this document are considered in the context of the impact on BHIVA's longer term organisational strategies, governance structures and processes.

# Equity, Equality, Diversity & Inclusion Review

An independent report by Purple Pen Research and Evaluation Consulting  
[www.purplepen.co.uk](http://www.purplepen.co.uk)

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