Ms Rebecca Mbewe
UK CAB Patient Representative
BHIVA Standards Of Care (2018) REVIEW

THE PATIENT REPRESENTATIVE PERSPECTIVE

Presenter: Rebecca Mbewe – UK-CAB
On behalf of the voice of People Living with HIV (PLWHIV)

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UK-CAB is a network for community HIV treatment advocates

The UK-CAB has three main aims

1. To support HIV treatment advocates in the UK.
2. To provide expert training on HIV treatment.
3. To ensure HIV positive people are represented at all levels of our care.

More about the UK-CAB aims.
“NO DECLARATIONS OF INTEREST”
OVERVIEW OF PROCESS

Stage 1

- BHIVA Standards Steering (Working) Group
  - Call out to Patient Reps interested in being part of the process (UKCAB platform)
  - Patient Reps, Clinical Leads & Researchers

- First meeting (May 2017)
  - Attended by patient reps, clinical leads, researchers
  - Consider and discuss the practicalities
  - Selection of 6-7 writing groups of 6-8 diverse members and leads/areas to be covered
  - Timeline agreed
OVERVIEW OF PROCESS

Stage 2

Regular progress meetings
  ▶ Consultation
  ▶ Review
  ▶ Amendments

Stage 3

Continued discussions on format, design
  ▶ Overall decision to use real pictures of PLWHIV
  ▶ Logo selected
WHAT DO BHIVA SoC MEAN FOR PEOPLE LIVING WITH HIV?

Hugely important for:

People Living with HIV: Basis for negotiating better standards of our care
Service Providers: Guide for what basic SoC should look like
Commissioners: To use as a standard on which they should base the minimum value of service provision

Sadly…. Not as many PLWHIV as we would like, know about the BHIVA SoC
We would have loved to see an even greater involvement of Patient Reps

Hopefully… More readable, patient friendly version will mean more accessibility
PATIENT REPRESENTATIVE FEEDBACK

- An eye-opening process – lots of work goes into it and lots to learn
- Great BHIVA initiative but I feel we as PLWHIV need to be more assertive and forthcoming when opportunities such as this arise
- Communicated with throughout the whole process
- Great that PLWHIV were involved all the way through and in each writing group
- Amazing shift of patient centred focus/peer support - extremely gratifying that clinicians seem to be on the same page

But…

- Still lots of clinical references that were hard to understand
- Some patient reps felt that initially there was not much acknowledgement of their presence

OVERALL A GREAT EXPERIENCE
PATIENT REPRESENTATIVE EXPERIENCES OF BEING INVOLVED

“…from what I have seen of the draft SoC and the comments, the revised version will be much appreciated, and needed…to highlight the changes of the past 5 years…”

“The revised new SoC strengthens the role of peer support, which is great. They are also laid out in a way that better reflects someone's HIV "journey."

“…it is a historical document and shows how far we have come. I would not have read it if I wasn’t contributing to this one. No people living with HIV who are not involved/employed in the sector know about it, in my experience.”

“I felt that my thoughts and comments were taken seriously and incorporated into the whole process.”

“The writing team was kept updated right up to submission stage.”

“…being involved in the developing the SoC makes the voice of patients visible. This is all about our lived experiences.”

“I'd like to thank BHIVA for adopting this commendable good practice.”

“As a patient, it is great to see that the Standards of Care cover key areas of our lives and are in place. I truly hope that they can be put into practice and that they become a real working tool for all Health and Social Care providers caring for people living with HIV.”
Acknowledgments

BHIVA for meaningfully involving us People Living with HIV

All the Patient Representatives that were able to make a contribution

In particular

Ben Cromarty
Mel Rattue
Angelina Namiba
Garry Brough
Memory Sachikonye
REFLECTION OF PATIENT INVOLVEMENT IN BHIVA Standards Of Care (2018) REVIEW

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THANK YOU & QUESTIONS

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