

# 26th Annual Conference of the British HIV Association 2020



**BHIVA**   
British HIV Association

# Declaration of Interests relating to this presentation

None



# Community Reps on HIV research and guideline groups: 'the bleak and the bright'

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# Who are the reps?

- **Identified through UKCAB – a network of activists and organisations**
- **Vast majority of reps are people living with HIV**
- **Others from the ‘HIV community’ which encompasses partners of people with HIV, parents of children living with HIV and community leaders in those groups at risk (e.g. in relation to PrEP)**
- **In some circumstances it makes more sense for organisational reps to be appointed, e.g. NAT/THT on policy or position statements**

# BHIVA, a leader

- **Patient involvement has a longer history with BHIVA and HIV research than many other professional organisations in clinical care**
- **“I have worked doing HIV research for a long time maybe about 20 years and throughout all the time I have been designing and running trials for people living with HIV, we have always had a CR on trials steering committees”**
- **Involvement of some sort as far back as the Concorde trial**

# So what does everyone think of it?

- **A key part of public policy in the NHS**
- **An important aspect of valuing disabled and people with chronic conditions<sup>1</sup>**
- 1 Cameron, Colin et al., (2019) 'Improving understanding of service-user involvement and identity: collaborative research traversing disability, activism and the academy', *Disability & society*, 34(7-8), pp.1312–1331.



# So what does everyone think of it? The bleak

## Community reps on trial boards

- “CRs are volunteers, which can be an unsustainable model”
- “What is a good research question from an academic perspective? What is good in terms of how I can get a grant? Those questions may have no resemblance to what is important to the community”
- the [CR] said ‘I know what you have written there is the science but you have lost the humanity in it’ and... what came out of it is a very good document”
- “One of the challenges is how do we disseminate information appropriately and in an understandable non-jargon medical way?”

# So what does everyone think of it? The bright

## Community reps on trial boards

- “That was a new angle for [lab scientists] that wouldn’t have had any power if I had said it”
- “I think CAB members are often more educated than some of us.”
- “Some of us come from cultural background where you think being a study is being a guinea pig whereas you understand how research is done and you find your input can be very important in terms of representation of different populations in a study”



# So what does everyone think of it? The bleak

## Community reps in guideline committees

- “You could have a community member you didn’t get on with”
- “you end up with professional community activists so if you look at the people that have been around for years they are almost professional community activist so their views are probably not representative of the people”
- “I think when you are going into a forum and you are the CR and then you get batted down and think that it is because I am a CR, but no it’s because that specialist bats everyone down”
- “there are some settings where it won’t just happen because doctors and patients don’t talk on that same equal level”

# So what does everyone think of it? The bright

## Community reps in guideline committees

- **“UK-CAB has been critical when we applied for accreditation from NICE for guidelines”**
- **“we are often talking about things that are just one element of the HIV pathway ... in terms of getting a holistic view of the HIV pathway the only people that can really do that are the people living with the condition”**
- **“from the consultation, in my experience the most insightful incisive, intelligent comments come from key people from UKCAB. Which is not to say all the comments are brilliant but some people, all their comments were incorporated in the treatment guidelines and you can't say the same about comments we get from many of the clinicians”**



# Conclusions

- **We can help in design/PICA question formation, review, critical analysis and dissemination**
- **Keep on doing it... (sorry not very exciting conclusion)**
  
- **“I think being a community rep is very fulfilling, rewarding and needed for the wider community of PLHIV”**
- **“I wouldn't be on the committee again. I think when the guidelines go out for consultation that this is more effective”**
- **“as a patient and rep future is bleak and bright”**