



HIV TREATMENT ADVOCATES NETWORK

What is the impact of having UK Community Advisory Board (UK-CAB) representatives on guideline writing committees and academic/clinical research study boards?

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BACKGROUND

Patient involvement is entrenched within the NHS constitution,¹ outlined in the NHS *Five Year Forward View*² and a good practice recommendation in all BHIVA guidelines³. Despite these imperatives, the impact of community involvement (CI) lacks robust evidence.⁴ HIV has traditionally been a leading field for community involvement in research and treatment design.⁵

From inception in 2002, UK Community Advisory Board (UK-CAB) – a network of HIV advocates – has provided community representatives (CRs) to clinical trials, British HIV Association (BHIVA) and National HIV Nurses Association (NHVNA) sub-committees and guideline writing groups, and other research advisory boards. Currently, the UK-CAB has over 40 CRs in various posts. This study describes the impact and challenges of UK-CAB community representation.

METHODS

- 14 semi-structured face-to-face/Skype/telephone interviews were conducted with a mix of clinicians (7M, 7F) from current and previous BHIVA/NHIVNA committees (n=8), HIV trial steering groups (n=4), research advisory board (n=1) and clinical reference group (n=1) all with CRs. Purposive sampling was used to identify suitable England-based professionals.
- Questions primarily centred on current experiences of CR involvement. Interviews were carried out by two trained researchers who are also UK-CAB members.
- Transcript analysis was done using pre-set codes, identified in the findings of the recent MRC research on patient involvement⁶, and emergent themes. The study was limited because only clinicians were interviewed and not community representatives.

“ [T]he study wouldn’t have gone ahead ... without community ensuring the design was reasonable and we were strongly encouraged from the start by the community telling us it’s an important question for them ” EPIDEMIOLOGIST

Table 1: UK-CAB community representatives (at February 2017)

BHIVA sub-committees	
Audit and Standards of Care sub-committee	Ben Cromarty, Rebecca Mbewe
Conferences sub-committee	Paul Clift
Education and Scientific committee	Alastair Hudson
Executive committee	Paul Clift
Fundraising Working Group sub-committee	Terry White
Guidelines sub-committee	Paul Clift
Hepatitis sub-committee	Robert James
BHIVA guidelines	
Hepatitis B co-infection	Paul Bateman
Hepatitis C co-infection	Robert James
HIV-associated malignancies	Simon Collins
Management of HIV infection in pregnant women	Polly Clayden, Beatrice Osoro, Lisa Thorley
Management of SRH of people living with HIV	Polly Clayden, Chris O'Connor, Lisa Thorley
Treatment of TB/HIV co-infection	Esther Dixon-Williams
National guidelines for HIV testing	David Galindo, Jo Josh, Florence Obadeyi, Roy Trevelion
Treatment of HIV-1-positive adults with antiretroviral therapy	Kathleen Charters, Roy Trevelion
Others	
ART-CC cohort	Matthew Williams
BASHH MSM Special Interest Group	Richard Desmond, Michael Harkin
Beyond Undetectable: measuring what matters to people with HIV	Mark Platt, Alice Welbourn
BHIVA working group on recording late HIV diagnoses	Chenal Chintashu
BHIVA Primary Care working group	Garry Brough, Jackie Morton, Angelina Namiba
CHERUB (Collaborative HIV Eradication of viral Reservoirs: UK BRC)	Damien Kelly
DA-D study (Data collection on Adverse events of Anti-HIV Drugs)	Simon Collins
Fanconi study	Ben Cromarty, Paul Clift
Federation of HIV Associations (FHIVA) Steering Committee	Mark Stroud
HAUS study	Memory Sachikonye
HIV Clinical Reference Group	Lizzie Jordan, Jackie Morton
HIV CRG PrEP policy group	Paul Clift, second rep vacant
HIV CRG drugs sub-group	Garry Brough, Simon Collins
HIV respiratory study	Memory Sachikonye
The King's Fund: Future of HIV Services	Robert James, Mel Rattue, Jane Shepherd
London HIV Clinical Advisory Group	Garry Brough, Jake Chambers, Virginia Cucchi, Isaac Samuels
London HIV Prevention Programme Evaluation Advisory Committee	Winnie Sseruma
Low dose efavirenz study	Paul Clift, Michael Harkin
Midlands & East Region Prescribing Guidelines	Tom Haynes, Kwardem Longret, Danu Wheals
MRC CTU Patient and Public Involvement Group	Ben Cromarty
Oxford University vaccine study	Simon Collins
Paediatric Network for Treatment of AIDS (PENTA) Treatment guidelines	Polly Clayden
POPPY study	Memory Sachikonye
Positive Outcomes	Jo Josh, Aicha Kello
PRIME study (Positive Transitions Through the Menopause)	Janine McGregor, Fiona Pettit, Jane Shepherd
PROUD PrEP study	Matthew Williams
NHIVNA executive committee	Longret Kwardem
NHIVNA Psychological Care Audit working group	Kathleen Charters
RIVER (Research in Viral Eradication of HIV Reservoirs)	Damien Kelly
START CAB and scientific steering committee (INSIGHT Research Network)	Simon Collins
UK Collaborative HIV Cohort Study (UK-CHIC)	Roy Trevelion
UK HIV drug resistance database	Simon Collins
The Use, Cost, Outcome of UK Hospital and Community Services for PLHIV	Kathleen Charters, Jason Hale

“ We are often talking about things that are just one element of the HIV pathway ... and, actually, 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. ” CONSULTANT

FINDINGS

Impact of community representation

The most common benefits cited were that CRs bring lived experience and a whole pathway perspective to a project. Community representatives also:

- bring issues directly from the community
- ensure research is responsive and focused on community priorities rather than that of funders, professionals or academics
- ensure research is more robust – face-to-face community perspectives inform study design and methods
- support all stages of research – from design, recruitment and analysis to production of easy to understand patient information and co-publishing/presenting at conferences
- bring advocacy skills, patient-centred and non-clinical approaches, empathy and mentoring. For example: “That [domain in the HIV Quality Dashboard] did not come from the clinician group, that came from the community.” (Consultant); and “They [CRs] give context to the decision we are making.” (Consultant)

“ Our clinic rep is very influential, when we were given wards he went and looked around and it dictated our strategy. ” CONSULTANT

Specific benefits: Some clinicians experienced unexpected benefits: “One thing I have learned is about language and HIV ... I don’t think I really understood the power of language [before]”. (Consultant). Another recognised, “the historical perspective ... about how things have been managed, lessons that have been learned, mistakes that have been made”. (Consultant)

Wider benefits outside of committees/steering groups were mentioned, for example; in clinics, research direction, trial design, information dissemination and guideline writing.

Challenges

Funding was the main reported challenge. CRs are volunteers, which can be an unsustainable model. Observation was that researchers/funders with no experience or awareness of CI may not understand its place and value, and competing priorities may exist.

Differing knowledge levels of CRs was considered an asset; “I think CAB members are often more educated than some of us.” (Consultant). However, it was felt that CRs needed regular support and training: “Some of the challenges come with terminology.” (Consultant). There were also concerns that the more experienced community members are phasing out with little or no replacement.

Representation: Some were impressed at CRs ability to bring a range of views from the HIV community. Others were uncertain about existing feedback systems and concerned that viewpoints of some groups went unheard. Observation was also that the newly diagnosed may have different needs from those with a long-term diagnosis.

“ ... We always ask the community rep; have you spoken to the wider audience and what have they said, so that person knows they are representing [others]. ” (Consultant)

“ 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. ” (Consultant)

1. See <https://www.gov.uk/government/publications/the-nhs-constitution-for-england/the-nhs-constitution-for-england>
 2. NHS (2014). *Five Year Forward View*, p13. Available at: <https://www.england.nhs.uk/wp-content/uploads/2014/10/5yfv-web.pdf>
 3. For example, see <http://www.bhiva.org/documents/Guidelines/Treatment/2016/treatment-guidelines-2016-interim-update.pdf>
 4. Brett et al (2010). A systematic review of the conceptualisation, measurement, impact and outcomes of patients and public involvement in health and social care research. London: The PIRICOM Study.
 5. Rhodes et al (2010). Community-based participatory research (CBPR): A new and not-so-new approach to HIV/AIDS prevention, care, and treatment. *AIDS Educ Prev*. 2010 Jun; 22(3): 173–183.doi: 10.1521/aeap.2010.22.3.173.
 6. South et al (2016). Models and impact of patient and public involvement in studies carried out by the MRC CTU at UCL. *Trials*. 17:376 DOI 10.1186/s13063-016-1488-9.

CONCLUSION

- All professionals in this study identified CRs’ unique impact and rated CRs’ contribution as highly effective and beneficial.
- The learning opportunity for individual clinicians, as well as the difference CRs make to decision-making, was particularly highlighted.

“ I wouldn’t have achieved that on my own it was really down to the hard work and experience of the peer researchers/community. ” CONSULTANT

- Results were similar to findings from South et al (2016), with a number of innovative, good practice examples of CI identified.
- The UK-CAB was seen as a valuable resource for providing skilled CRs, and that effective representation and sustainability of the CR model need ongoing attention.
- There was unanimity that people living with HIV must be directly involved in decision-making on service delivery and clinical care that will have a direct impact on their lives.

“ We all get very focused on what we are doing, so even though we may work in a multi-professional group, we can be quite focused. So having a CR it’s like a breath of fresh air. You get another perspective and I think it keeps us on our toes. ” CONSULTANT

RECOMMENDATIONS

- Include funding for CI as a good practice standard in all research applications.
- Research bodies/organisations that benefit from community input should support the contribution of new CRs by facilitating observer roles, inductions, shadowing, mentorship and debriefing.
- All stakeholders must work in partnership to increase CRs knowledge and skills; for example, short courses on clinical trial design, research methodologies and peer research.
- UK-CAB to better promote and profile its work around community representation, and develop tailored guidelines on CR expectations, role description and representation.
- UK-CAB to identify general resources in the patient involvement field, for example the INVOLVE library, and ensure that good practice examples of HIV CI are included in them, and this resource is subsequently promoted throughout the HIV sector.
- Build on this research study with a community representatives’ arm.
- All stakeholders build stronger relationships and collaborations between NHS, third sector and patient/advocacy groups/networks, developing regional networks to better influence local and national decisions and connect people living with HIV, in all their diversity, with patient involvement opportunities.

“ ... 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. ” CONSULTANT