

Positively involved

What impact do UK-CAB representatives on guideline writing committees and academic/clinical research study boards make?

Longret Kwardem, Robert James, Jane Shepherd (on behalf of the UK-CAB Steering Group)
UK Community Advisory Board (UK-CAB)

BACKGROUND

- Patient involvement is entrenched within the NHS constitution and a good practice point in British HIV Association (BHIVA) guidelines. Meaningful engagement of patients and communities in decisions affecting them is outlined in the NHS 'Five Year Forward View'.
- However, there is little robust evidence of the impact of community involvement.¹
- HIV has been a leading field for community involvement in research and treatment.²
- Since 2002, the UK Community Advisory Board (UK-CAB) has provided community representatives (CRs) to clinical trials, social science research studies and guideline writing groups, including for BHIVA and the National HIV Nurses Association (NHVNA).
- Currently, UK-CAB has over 40 CRs sitting on various studies and groups (see Table 1).
- We describe the impact and challenges of community involvement from the perspective of UK-CAB CRs – building on the UK-CAB 2017 research conducted with clinicians.³

METHODS

- We conducted 13 semi-structured interviews with a mix of CRs (7M, 6F) from current and previous BHIVA/NHVNA committees (n=11), HIV trial steering groups (n=8), and clinical reference or advisory groups (n=6).⁴ CRs were purposively sampled to provide a diversity of role, experience and demography.
- Interviews were carried out by two trained researchers who are active UK-CAB members. Questions centred on current experiences of CRs.
- Transcript analysis used pre-set codes identified in the Medical Research Council (MRC) review of patient involvement⁵ and in emergent themes.
- The study was limited as it only included CRs (clinicians were interviewed previously).

“It’s important to remember when you are a CR it’s difficult to represent thousands of people. So, you are saying what your views are and it’s fine to say different views of community and I think that’s important for researchers to hear that.”

Definitions

We subscribe to the INVOLVE definition of public/patient involvement in research as research being carried out 'with' or 'by' patients rather than 'to', 'about' or 'for' them.

INVOLVE uses the following terms to distinguish between the different activities:

- **Involvement** – where patients are actively involved in research projects and research organisations
- **Engagement** – where information and knowledge about research is provided and disseminated
- **Participation** – where patients take part in a research study
- **Co-production** – where researchers, practitioners and the public/patients work together, sharing power and responsibility from the start to the end of the project, including the generation of knowledge.

www.invo.org.uk/find-out-more/what-is-public-involvement-in-research-2/

RESULTS

CRs have multiple involvement across organisations, trials and guideline groups and over a number of years ranging from 1.5 years to over 20.

FINDINGS

Impact

- CRs wanted to 'make a difference' and their experience correlated with whether they perceived they had made an impact.
- Commonly cited benefits included: changes in trial design – particularly exclusion and inclusion criteria; inclusion in guidelines of overlooked issues; highlighting concerns of specific groups; bringing community perspectives; IEC resources using community-friendly language; and improvements to clinics.
- Benefits to CRs included: gaining respect and support from HIV professionals; increased learning opportunities; and giving back to their community.
- CRs valued UK-CAB support – training, networking, communicating through the forum – and accountability among activists.

“Some of us come from cultural backgrounds where you think being in a study is being a guinea pig, whereas [when] you understand how research is done, you find your input can be very important in terms of representation of different populations in a study.”

Challenges

- Lack of time was the most commonly cited, with funding second – including to cover CRs expenses.
- Committee chairs' attitudes to CR involvement was highlighted as critical to impact.
- Some felt representation was considered an add-on rather than being integral.
- UK-CAB's sustainability was a concern – not just financially but also in maintaining diversity, and encouraging and retaining new and younger CRs.
- CRs wanted CR-specific training for initial and ongoing development, to support to use the UK-CAB forum.
- CRs saw themselves as both responsible for looking for support and also providing it, even when unsure of the structure for doing so. Knowing another CR to turn to for advice was seen as very helpful.

“I like the fact that UK guidelines are guidelines that talk about 'HIV positive people', not 'infected'. We did a survey of what people think about 'infected' and it was not nice.”

“You have to give up a shift at work and incur other expenses, it all adds up. So for that, getting a bit of money on that one occasion did make a difference.”

“The skills you need to be a community rep are quite often skills you have developed by being active in your own healthcare.”

“I looked at the initial draft that was reviewed and he included peer support in almost every step of the way. My job as a CR was done.”



CONCLUSION

- As with the UK-CAB 2017 research, there was unanimity that people living with HIV must be involved in decision-making on service delivery and clinical care that directly impacts on their lives.
- Specific examples of impacts beneficial to people with HIV were highlighted, along with the value of co-production.
- Concerns about sustainability of community representation remain. “We can do a lot as a network with little funding but can't do anything with no funding”.

“Some ongoing challenges relate to keeping my own knowledge up to date. So much keeps changing.”

RECOMMENDATIONS

- A number of innovative good practice examples of community involvement were identified.
- More support for CRs is needed, including mentoring, specific training and annual meetings for CRs.
- UK-CAB is a valuable resource for providing skilled CRs. Sustainability of this community involvement model needs ongoing attention from researchers, policy-makers, public bodies and funders.

Table 1: UK-CAB community representatives (at March 2018)

| 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 |
| External relations sub-committee | Tom Hayes, Jo Josh |
| Executive committee | Paul Clift |
| Fundraising Working Group sub-committee | Terry White |
| Guidelines sub-committee | Esther Dixon-Williams, Mel Rattue |
| 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 |
| Antiretroviral treatment for HIV-2 positive individuals | Esther Dixon-Williams |
| Others | |
| ART-CC cohort | Matthew Williams |
| BASHM MSM Special Interest Group | Richard Desmond, Michael Harkin |
| 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 |
| D:A: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 |
| HIV CRG drugs sub-group | Garry Brough, Simon Collins |
| HIV respiratory study | Memory Sachikonye |
| London HIV Clinical Advisory Group | Garry Brough, Hussein Hamza, Virginia Cucchi |
| London HIV Prevention Programme Evaluation Advisory Committee | Winnie Sseruma |
| Low dose efavirenz study | Paul Clift, Michael Harkin |
| 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 Kallo |
| PRIME study (Positive Transitions Through the Menopause) | Janine McGregor, Fiona Pettit, Jane Shepherd |
| PROUD PrEP study | Matthew Williams |
| NHVNA executive committee | Longret Kwardem |
| NHVNA 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 |

1. 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.
2. 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
3. Kwardem, L, James R. and Shepherd J. (2017), 'What is the impact of having UK-CAB representatives on guideline writing committees and academic/clinical research study boards?' (Abstract). *HIV Medicine*, 18, Supp 1, p67.
4. Many CRs have served on multiple committees or trials.
5. 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.