



HIV TREATMENT
ADVOCATES NETWORK

Guidelines: Community reps on BHIVA and NHIVNA committees and clinical/research study boards

These are guidelines about your role as a community rep, the expectations, requirements and support you can get from the UKCAB. If these guidelines are not helpful tell us why and how we could make them better. If you have some good or better ideas about what works for community reps please let us know. And remember these are guidelines, that means you do not have to follow them exactly as they are written and if you have a good reason for going against these guidelines then you should do so. – *The UKCAB Steering Group*

Why does the UKCAB have reps on these committees?

A number of organisations including BHIVA and NHIVNA have a policy of having people with HIV or from the HIV community on decision making and guideline writing committees. This is their way of trying to ensure committees and guidelines have genuine involvement from people living with, affected by or highly knowledgeable about life with HIV (this usually means people working for community organisations in the field of HIV). BHIVA, NHIVNA and the Medical Research Council formally ask the UKCAB to provide one or more people to take up these roles in their committees. The UKCAB Steering Group decides if the position is suitable for election, generally for governance and policy making committees, or selection, generally for roles that have specific knowledge or skills requirements, such as trial methodology for a clinical trial steering group.

Who do I represent?

Your role is as a representative for the UKCAB and this is the group you are expected to report back to and consult with. The members-only UKCAB forum board is the best way to report back your work and ask for feedback from other members. The public forum board may be the best place to post about public consultations and ask for feedback for those consultations. UKCAB membership is open to individuals and organisations and is predominantly made up of people living with HIV. All of the major community organisations in HIV are also members of UKCAB.

As a UKCAB rep on these committees you do not represent everyone with HIV because this is impossible and because you are equal to the other people on the committee and they do not represent every doctor, nurse or pharmacist in HIV. They are there to provide their own opinion and expertise and so are you. If you have collected the views of other people with HIV, especially if done through the UKCAB forum, then you are expected to pass on those views. (Bear in mind it is fine to say that people have different views about something, we are not united in our views about everything).

What should I be doing on the committee?

You are a community rep and your expertise is about life with HIV, which is why you were chosen for the role. UKCAB research found that the most important thing that community reps brought to committees was their life experience and the ability to see how decisions being made in one small area of care fitted into the whole life experience of living with HIV.¹ Professionals wanted and needed this knowledge because they often did not have it. You are not expected to be knowledgeable about detailed areas of medicine or nursing as a community rep although if you do then that is great. You are expected to be involved in the decision making of the committee you are

¹ 'What is the impact of having UK-CAB representatives on guideline writing committees and academic/clinical research study boards', Kwardem et al. 2017

on. That does not mean you are expected to say something about every point that is discussed but you are expected to contribute just as the other members do. You should also ask for thoughts or feedback from people through the UKCAB and other places you think are appropriate to ensure you can bring a wider view to the committee.

Some of the things discussed at the committee may be sensitive or confidential and you should not pass on this type of information. It is important to always ask at the start of your role what information can be shared outside of the committee and keep checking throughout.

Can I ask for the views of people who are not part of the UKCAB?

Yes, in general as long as you think they are suitable people to give you information that will help in your role. You are expected to bring the views of people with HIV to the committee, so generally, the more people with HIV, their carers, and advocates the better.

What if I need to find out medical information?

For finding information – good sources of information – <http://i-base.info/> and <https://www.aidsmap.com/> are community organisations that provide information about HIV treatment. <http://www.ncbi.nlm.nih.gov/pubmed> is a website that will search large numbers of medical journals for articles. You can usually read the summaries or abstracts of published articles and some UKCAB members may be able to access whole articles if you really need to read them. UKCAB is negotiating for the community rep on the BHIVA Executive committee to be able to access medical journals in order to provide for community reps on guideline committees. You can also ask other UKCAB members or a clinician on the committee. They should not be expecting you to know detailed medical information and most are very happy to explain things or send articles to you.

How will I know when I need to do things?

The committee itself may well decide when they will have their meetings. They may have a list many months in advance, but they may also simply pick the date for their next meeting at the end of the last one. Remember, like you, all of the committee members for NHIVNA and BHIVA are doing this on top of their jobs – so do not be surprised if things like minutes or papers are late or only available at the last minute.

What if I need support for my role?

Communicate with other reps – there are a number of other people who are reps or have previously done it. If you are confused or having problems, do ask the other reps if they have a solution. A list of the current UKCAB reps is on the website (<http://www.ukcab.net/about/community-representatives/>) and you can message people through the UKCAB forum if you do not have a way of contacting them.

UKCAB also holds treatment advocacy training once a year and quarterly meetings on specific issues. You are strongly recommended to attend at least one of these meetings a year – and it is good way to feedback and get support from other community reps. The UKCAB Steering Group is always available for ongoing support and can arrange mentoring and shadowing by more experienced reps.

Will I be reimbursed for expenses?

Travel expenses are normally reimbursed by the committee where you provide representation.

What if I need paper copies of minutes or reports?

Ask the committee secretary or administrator, for BHIVA committees it is usually someone at Mediscript, for paper copies of the documents to be posted to you in advance of meetings.

What if I fundamentally disagree with something the committee decides or wants to do?

Working on a committee involves compromise and joint decision making so it is inevitable that you will not agree with every decision they make. Your role is as a representative of the UKCAB and is to

ensure the decisions made by the committee are good ones for people with HIV. However, the UKCAB does not have to support the decisions of any other organisation. Sometimes committees have to make very difficult decisions, such as about resources, and all the choices are uncomfortable and the views of the community rep can be very important in this situation. If the decision that is made or the thing the group wants to do is fundamentally unethical or dangerous then the UKCAB would not support it.

This should be unlikely but if you think something like this is going to happen then you must contact the UKCAB Steering Group and let them know your concerns. They will be the group that will decide if the UKCAB remains part of the group. You are a volunteer and can resign if you are personally uncomfortable with the committee or group and the UKCAB can select another rep if it wishes to continue working with the group. Disputes between people on committees are not unusual and professionals can sometimes become angry with each other so it needs to be more than simply a disagreement. If you think a decision being made is wrong but are uncertain if it is unethical, talk to the other community reps and the UKCAB Steering Group to find out what they think.

The very first set of BHIVA treatment guidelines was criticised by the community as dangerous, bad science and wholly unethical. People with HIV were advised to ignore the guidelines and see a doctor who ignored those guidelines. BHIVA and its guideline writing system has changed significantly since then and we have never had that situation again. However, if something similar were to happen in the future with any group that the UKCAB works with, the UKCAB could withdraw its support and inform the community it did not support the decision made by that group.

What if I realise that I can not carry on in my role as a rep?

Sometimes life gets in the way or the role feels too demanding or not what you thought it would be. But disengaging by not answering emails or not turning up for meetings damages the credibility of the UKCAB and community representation. It is really important you communicate any issues you have with your role as soon they become apparent. Contact the UKCAB administrator or Steering Group first and foremost, especially if you intend to step down so that they can get you more support or recruit a replacement. Let the chair of the committee know if you need to step down and always let them know in advance if you can not attend a meeting.

Do I have to do anything when my time as a rep is completed?

Your community rep role may have ended but you will have become very knowledgeable about this role and your successor and the UKCAB needs you and your knowledge. You need to speak to your successor so they are ready for the role. You could also mentor a future rep or sit on a different group or committee, or be a rep on a research trial or you can just come to meetings, comment on the forum, advise and share your knowledge about the topic with the rest of us.

Contact

UKCAB administrator: Memory Sachikonye, memory.sachikonye@ukcab.net
<http://www.ukcab.net/>

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