Guidelines: Community reps on BHIVA guideline writing groups

These are guidelines about writing guidelines, which may sound silly but think of them as something to help you do a better job when you are on a guideline writing committee. If they 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 on the guideline writing groups 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 there are many community people with specialist knowledge for a guideline then the lead community rep should collect their views and bring them to the guideline committee. 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 as well. (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 people and life with HIV and not necessarily expertise on medicine.

There are specific sections that community reps should be doing in BHIVA and NHIVNA guidelines. These are the ‘patient involvement’ sections, which usually include a part within the introduction or methodology and a Chapter entitled ‘Patient Involvement in Care’.

You are not expected to be knowledgeable about detailed areas of medical treatment to the point of drafting clinical guidelines on your own. If this is an area of your expertise then of course you can. You are also not expected to comment on everything in the guidelines, it is fine if you agree with something just to say that you agree. Most of the people on guideline groups only comment on some of the guidelines and agree or say nothing about other parts.

You are expected to review as much of the draft guidelines prior to consultation as is possible. When they go out for consultation you should draw attention to the draft guidelines and ask for feedback from people through the UKCAB and other places you think are appropriate. You still have the responsibility to know what is in the guidelines and you can feedback through the formal consultation process as well as through your role on the committee in meetings.

What about training on guidelines?
BHIVA uses the GRADE system in order to come up with recommendations for its guidelines. The GRADE system (Grading of Recommendations Assessment, Development and Evaluation) is a process to ensure recommendations are supported by evidence and say how strong that evidence is. Using this formal system means that BHIVA can have its guidelines accredited by NICE (National institute for Health and Clinical Excellence) which gives them more importance in the NHS. All the members of a guideline writing group have to take part in training about GRADE, not just community reps, the clinicians all have to as well. Some members of a guideline writing group may have done their GRADE training as part of a previous guideline group so it may only be a few members of a committee that do the training or it may be the whole committee.

BHIVA has more information on its website (http://www.bhiva.org/BHIVA-guideline-development.aspx). The resources listed there are also available to community reps but you may have to contact the UKCAB to access them if you are not a member of BHIVA.

How can I discuss the guidelines before they are open for public consultation?
For the majority of guidelines you can put sections on the UKCAB *members-only* part of the forum as soon as they are written and ask others for feedback. You can also talk about them at a UKCAB meeting and ask people for their thoughts. Occasionally a guideline or part of it may be controversial and so the committee may wish it to be discussed only with committee members before the draft is ready for public consultation. If you are in doubt, always ask.

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 comment on the topic you can talk about the guidelines with them. It is usually better to talk about the topic and find out people's views rather than show them draft guidelines.

What do I do if the draft guidelines are not ready before the public consultation?
Do not worry, there is still the formal consultation period. In a perfect world sections would be written and you could then consult through the UKCAB for feedback and feed useful comments into the editing and drafting before a public consultation on guidelines. In reality sections are often written by people at the last minute just before the consultation deadlines. Remember, you can also feedback through the formal consultation process, and ask others to, as well as through your role on the committee.

Do I have to read all of the guidelines?
Yes, you may not need to understand the meaning of every technical detail but you need to know what is in the guidelines. Inputting the views of a person affected by HIV into all parts of the guidelines is the key part of your role. Your views are important for these guidelines and that is why you were chosen. You should also be writing the patient-friendly version so you will need to know all the important things in the guidelines.

What if I need to find out medical information?
For finding information – good sources of information – http://i-base.info/, 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.

How will I know when I need to do things?
BHIVA or Mediscript should provide you with a schedule of the deadlines for when sections in the guidelines must be written, consulted on and then reviewed again. As with all schedules they are dependent on the committee members doing things on time. Remember, like you, all of the committee members are doing this on top of their work – so do not be surprised when things are late or delayed.

What if I need support for my role?
Communicate with other reps – there are a number of other people on guideline writing groups or have previously done it. If you are confused or having problems, do ask the other reps if they have a solution. There is a list of the current UKCAB reps on the website (http://www.ukcab.net/about/community-representatives/) and you can message people through the UKCAB forum if you do not have another 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.

What if I need paper copies of minutes or reports?
Ask the committee secretary or administrator, it is usually someone at Mediscript, for paper copies of the documents to be posted to you in advance of meetings.

What if I realise that I can not carry on in my role as a guideline 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 doing the work 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. Also let the chair of the guideline writing group know if you intend to step down.

What happens when the draft guidelines are finished?
You should inform UKCAB members that the draft is finished and when the public consultation will start. It is helpful to put a link to the BHIVA draft guidelines webpage for people in a post on the UKCAB forum. You may want to put this on the public part of the forum as well because the consultation is to the wider public. Ask people to respond to the consultation and highlight any areas you think are particularly important for people to comment on. This can also be a good time to start the patient friendly version of the guidelines.

What if I fundamentally disagree with something in the guidelines?
Your role is as a representative of the UKCAB and is to make the guidelines better. However, the UKCAB does not have to support the guidelines and if there is something unethical or dangerous it would not. This should be unlikely but if you think something like this is going to happen in the guidelines you are part of writing 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 about the final guidelines. Disputes between people on guideline committees is very common and medics can become angry with each other about a point so it needs to be more than simply a disagreement. If you think something in the guidelines is the wrong way of doing things but are uncertain if it is unethical talk to the other guideline reps and find out what others 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 the UKCAB could withdraw its support and inform the community it did not support the guidelines or a part of them.

What are the 'patient-friendly' guidelines?
UKCAB and BHIVA want to produce an easier to read version of guidelines for patients so that they know what to expect and to ask for if the care they receive does not meet that in the guidelines. It is hoped that as many of the future guidelines as possible will be produced as patient-friendly versions.

What happens when the consultation finishes?
The feedback is reviewed by the committee, or sometimes a sub-group of it, and any changes are discussed and agreed by the committee.

What happens when the final guidelines are published?
You role in the production of these guidelines may be over but you may be asked to help with updates before the next complete revision of the guidelines is written. You should also be working on getting the patient-friendly versions prepared for them to appear on the BHIVA website. You also need to speak to your successor so they are ready for the role.

Do I have to do anything when the patient-friendly version and the final guidelines are completed and available?
Your guideline rep role may have ended but you will have become very knowledgeable about these guidelines and your successor and the UKCAB needs you and your knowledge. You could mentor a future rep or you may want to sit on a different group or committee, or on be a rep on a research trial or you can just come to meetings, comment on the forum, advise and share your knowledge about that topic with the rest of us.

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

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