



INCREASE YOUR **SKILLS** AND
BECOME A STRONGER **PATIENT ADVOCATE**



Open Academy Meetup - April 2023

Importance of a scientific and medical committee or council in a patient organisation and how to set it up

Medical and scientific advisory committees can be used for:

Scientific advice, clinical advice, research governance guidance, developing medical guidelines, addressing challenges of the patient organisation, helping with the advocacy efforts of the patient organisation, to provide education whether it's to the organisation's members or wider stakeholder groups, among other things.

Your first step is to decide on the primary function of the committee (what you want the committee to do for your organisation) before starting to recruit experts.

Why the experts would want to be part of your committee:

There are three main reasons why scientists and clinicians might get involved in these kinds of committees.

- 1) The first is because it is a noble and worthy cause and they might want to make a contribution to your organisation and the work that it does.
- 2) The next is that they might want to use their participation to further their career clinically and scientifically.
- 3) The third is that they may also want the recognition associated with being part of your committee.

Talking to potential clinicians or scientists:

You need to find out why they might want to be involved. Be clear about what you want the committee to do and allow them to be open and transparent about what they want to get out of it. The more open and honest and transparent all parties are, the better synergies you get and the more effective your Committee will be.

How to find experts:

As patient advocates, you work or know small communities of scientists and clinicians who have an interest in your field. The way you find and engage with them is by reaching out to them, engaging them at conferences, inviting them to speak at your meetings/events, by asking your members about the clinicians and scientists that they've come across. It's these conversations that will lead you to generate and create an effective clinical and scientific committee.

Tip!

Use PubMed to find scientists and clinicians that know your disease.

An example from the rare diseases community - With the goal of connecting the global community of physicians, researchers, patients and loved ones to accelerate Castleman Disease research, treatment, and patient care, the CDCN started by contacting all of the authors from the 2,000+ papers on PubMed associated with Castleman disease.

Challenges and barriers when creating your committee:

The main challenge is the **limited availability of the experts.**

Most of the people who you want to get involved are incredibly busy (time-poor). In fact, the more time-poor they are, the more likely you are to want them in your group because those are the people who are active and effective within the field you are interested in. That's why you've got to make life easy for them to contribute and be involved.

How can you address that?

- Know what contribution they want to make and what you want them to do. Because their time will be limited, they may need a considerable amount of shepherding.
- Make sure the committee meets with a defined regularity. For example, the first Tuesday of the month. Having a predictable pattern to when the committee will meet, will make it much easier for the experts to slice out time in their schedules to get involved.
- Be clear about the topics on the agenda.
- Keep track of the time and don't let the conversation derail.
- Refresh and remind the members of the committee what was discussed in the previous meeting, and what each of them said about each topic.
- Find out who is the assistant or secretary of the members of the committee.

- Identify someone in your organisation whose role will be to organise and administer the committee. Someone who can reach out and liaise with the secretaries/assistants of the members of the committee.

How to keep the members of your committee engaged:

- Don't be afraid to have conversations with the members of the committee about what's working well and what's not working. That kind of honesty is really important.
- The meetings have to be valuable not just for you as an organisation but for the members of the committee. Keeping the meetings fresh, alive, interesting and relevant to your organisation and the experts is a joint piece of work.
- The members within your organisation will often be really helpful in generating the energy, enthusiasm and direction to deliver the things that you're after as an organisation.
- A certain level of soft skills is required to manage and engage with the group.

"I feel we're competing with other rare disease patient organisations for the same experts."

You may feel you are in competition with other similar rare diseases as you are approaching similar experts but that is not the case as each organisation and purpose of a scientific advisory board is unique. Rather try to encourage new blood into the committee, perhaps targetting younger scientists or PhD students who are enthusiastic about the work that your organisation does and goals you wish to achieve. You can also ask the experts to contribute without committing to something longer term as you start to organise those working relationships. For example, ask them to help draft a best practice guideline or an evidence-based review. This would give them a reason to get involved without a long-term commitment.

Tip!

Ask the experienced specialist you want to invite to your committee whether they have somebody in their team, who is motivated and interested, that could join on their behalf.

It's a good practice to find those early career scientists and physicians who don't yet have their expertise locked down but are within the bounds of the field, find their career aspirations and transform them into experts.

If the experts you've approached don't care about your disease, they're not the experts you want or need and they're not an expert in your disease!

Finally, never lose sight of the worth of the patient! You are the resource and lived experience!

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