

Being a Patient Advocate at an Ethics Committee Meeting.

Everybody knows what Ethics Committees do – they are charged with responsibility for ensuring research is conducted according to proper legal guidelines, and ensuring patient safety. Every research project is reviewed by a committee which includes lay representatives (at least one third of those present), and a mix of health care professionals.

Researchers are asked to present their case to such a committee, and answer pertinent questions to clarify their intentions, and scientific approach. Following this, the committee will approve, or make any necessary recommendations for change, or rarely, reject. For this reason, the researcher rightly finds it a bit of an ordeal.

Recently (7 May 2013) I accompanied a researcher who is a professor and leading specialist in her field, to Guildford, to support her research project into what patients really think about the balance of treatment and overall survival (or progression free survival) with resulting toxicities. Toxicities are often dismissed by health care professionals as of little importance, the emphasis being on control of the cancer and survival in one of its forms, rather than quality of life.

Patients very often have a different view, and this researcher's study will attempt to measure this. Exceptionally, working on this particular study there are seven lay representatives who are, or have been, cancer patients at some time in their lives. 'Prof' and we cancer patients felt it to be important to put the patient viewpoint about the value of asking difficult questions albeit in a caring and sensitive manner. Knowing this topic of quality versus quantity is important to cancer patients, I offered my services when the 'Prof' asked for volunteers to accompany her to her application for ethical approval. This is a very novel approach. In my (admittedly short) experience of working on an Ethics Committee, I have never seen a lay advocate in front of me.

The experience was intense, useful, and pointed up several issues which are of interest to all sides of this process.

1 The lay advocate

Leave it to your researcher to explain technical issues about consent, theory, etc.

Prepare well in advance by reading the IRAS submission (this is what the Ethics Committee gets and is the formal application for ethics approval), and all supporting documentation.

Before the meeting, ask your researcher to explain anything you feel needs clarifying.

Applicants introduce themselves to the Committee at the start of the meeting. If there is something very important to you about the project, put it into a few words and say it in your introduction. You are there for a very good reason - let the Committee know what that reason is, how hard you have worked on it, how important it is to patients, and why you are supporting this particular project. Just in case you are not asked later on in the proceedings.

Arrange a signal with your researcher, which will enable you to interject when you have something to add.

Look at the name tags displayed on the table in front of the committee members. Find the lay representatives, and judge their reaction.

While your researcher is speaking to a committee member – perhaps explaining an important point about consent, or theory and thus concentrating on this one topic - try to assess the impact via the expressions of other committee members. They may nod, smile, frown.

Be prepared for what may seem a put-down from some professional members who may think your contribution is not so important, or not understand why you are there. For example, if you mention that you have great confidence in the ability of the researcher's team to interview patients in a sensitive manner, you may find someone has already told the committee that before you get in there. Did they really?

Don't forget that the committee may be slightly uncomfortable with your presence because this is a new initiative by patient advocates. Lay advocates attending with researchers is a novelty as yet. If you are a member of an Ethics Committee, or have worked in this area before, it may be worth a mention.

2 The researcher

Discuss any outstanding issues before the meeting. Talk through and rehearse anything you want to say.

Arrange a signal with your lay advocate should they wish to add something or take part in the discussion.

3 The Committee

Don't ignore the lay advocate. The very fact there is one willing to undergo a fairly stressful experience and support a researcher speaks volumes about that researcher and the study, and the value to patients. It shows the researcher has taken very seriously the requirement to include PPI in the research process, and it shows the lay advocate has confidence in the proposed study.

On a personal note: after the meeting had finished, one of the lay members of the committee made a point of thanking me for coming, and commented on the fact that I had come so far (from Sheffield) to support the research. I hope this is an auspicious sign of approval.

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