

Glasgow 2013 – How to write a lay summary.
By Helen Bulbeck of Brainstrust.

Jim Elliott and Helen Bulbeck of Brainstrust looked at how to write a lay summary, and Patient and Public Involvement (PPI) in research.

Lay summaries – Helen Bulbeck.

This presentation was given at the request of NIHR at conference, 2012.

Lay summaries are important because they express the thoughts of the researcher in terms that patients looking at entering clinical trials can easily understand. A readily comprehensible summary in the patient information sheet is a 'must', so patients will join a clinical trial understanding the concept behind the research and how it might benefit them. A well written summary is also useful for lay reviewers who are members of funding and ethics committees.

Many lay summaries are merely shortened cut-and-paste copies of whatever has been written in the trial protocol. Jim and Helen showed that this can be much improved upon, and with researchers, developed guidelines for the creation of a good lay summary.

Helen first defined a lay summary and its purpose, then covered general principles. A poor example was compared and contrasted with one which was well written.

Remember that the audience for this lay summary is very heterogeneous, and ranges from lay people of differing educational attainment to.

Patients in consultations or clinic are under stress, so use plain English. This means no long words such as concomitant, use of short sentences with a maximum of 15 to 20 words, and use acronyms only after the full term has been used and explained. For example, Health Research Authority (HRA).

Do not use compound sentences with many clauses and sub-clauses.

Analogies and metaphors are good, to aid understanding. For example, 'nerves are like cables and are covered in an insulating material called the myelin sheath'.

Use second person words, such as 'you', not 'the patient'. Use scientific terms after it has been put into plain English. Eg 'your prostate will be removed (prostatectomy)'.

Speak in the active sense, eg 'you will have radiotherapy', not 'radiotherapy will be given to you'.

Use connective words to develop links between ideas, such as 'although', or 'however'.

The lay summary should be right at the front of any document, and always remember it is being written for the patient, not the researcher.

Consider that the patient may have a poor prognosis, but this should not be anywhere in the summary. Neither should the word 'death' be given as an outcome – it will render the study very unattractive to patients. Always reference quality of life, as this is of prime importance to the patient.

Include a glossary of key words and acronyms.

The result of all this? Engaged patients who enter trials.

See the Brainstrust principles for a good lay summary. (Link to Brainstrust document here.)

Brainstrust can be found here: <http://www.brainstrust.org.uk/index.php>.

Thank you to Helen Bulbeck of Brainstrust for permission to circulate the summary template.

PPI in research – Jim Elliot.

Jim Elliot listed basic principles of good practice.

Research projects and studies should have a lay person as co-applicant, who is of equal status.

Find tasks the lay person can do. Examples may be design of questionnaires and forms, and writing the lay summary. Do they have the skills or is training required, in which case it should be provided. How can the lay person add value for the researcher.

PPI should always be properly financed and budgeted for. Reimburse for travel and expenses. Pay for time used in meetings and conference, and working, at the approved INVOLVE rate. (Currently £10 per hour at May 2013)

The study is about the patient, not the researcher. There is no point in doing the study if it does not make a difference to the patient in terms of quality of life, or improved survival.

Lay/patient advocates can increase recruitment using social media such as Twitter, Facebook, and podcasts.

Lay/patient involvement in funding panels can influence decisions in favour of what matters to patients and prioritise topics. Vacancies for such panels are advertised.

The delegates were then divided into three groups to study practical effects of PPI on trial design. A few examples are as follows:

Contribution to QoL aspect of studies, asking questions of patients and carers separately, to account for different views. PPI can improve QoL studies.

Change questionnaires to ensure questions are meaningful and relevant to the patient.

Lay advocates can say things academics cannot or will not.

Ethical issues can be discussed and addressed prior to going to Ethics Committee.