Guidance for researchers on writing lay summaries

The NIHR UK Clinical Trials Gateway (UKCTG) website has recently been replaced by Be Part of Research and is currently still being developed. One of the aims is to make the site more user-friendly for people who wish to participate in a clinical trial.

An important part of this is having good lay summaries of clinical trial protocols. Poor lay summaries, which contain lots of highly technical information and language, can leave patients unwilling to join them because it’s difficult to understand what taking part would involve. Having patient and public involvement (PPI) in writing or reviewing these summaries can address this and may prevent a trial failing to recruit to time and target.

If you aren’t working with a patient who can write your lay summary for you, we have put together some tips (below) that we hope will help you to make your lay summary as clear and useful to patients as possible.

We recommend that if your lay summary isn’t written by a patient, you get it reviewed by one, and we can put you in touch with someone to do this. PPI contributors should be paid for their time so you will need to provide a cost code. You can find INVOLVE’s recommended rates of payment here but expect to pay in the region of £10 per lay summary.

If you would like to make use of this service, or need advice on writing a lay summary, please contact the Oxford BRC PPI Manager polly.kerr@phc.ox.ac.uk

Tips for writing a good lay summary

General

- Keep in mind that your audience will vary in education level and may well be going through a time of great stress.
- Avoid long words; use short sentences and bullet point lists.
- Avoid acronyms or use only after you have explained the term in full.
- Use analogies and metaphors e.g. ‘nerves are like cables and are covered in an insulating material called the myelin sheath’.
- Address patients directly as ‘you’, not ‘the patient’.
- Explain medical terms simply: ‘your prostate will be removed (prostatectomy)’.
- Use active speech: ‘you will have radiotherapy’, not ‘radiotherapy will be used’.
Structure

- Make the eligibility clear at the beginning e.g. ‘this trial is recruiting patients aged 18-45 who have diabetes’.
- Continue with a sentence explaining what the trial will do/test.
- Explain how the trial will do this, over how long and with how many clinic visits etc.
- Do not use ‘death’ as an outcome; where possible refer to quality of life.
- Make sure your lay summary has a lay title.

Language

Don’t use jargon; use simple words and cut out unnecessary ones. For example:

- efficacy of X – how well X works
- probability – how likely X is to happen
- participate in – take part
- prior to – before
- discontinue – stop
- in the event of – if
- inform – tell
- scheduled to undergo – due to have
- accordingly / consequently – so
- with reference to / with regard to – about
- if this is the case – if so