



Guidance Document for Researchers designing Patient Information Leaflets

This guidance document has been designed by the MCRN Young Person's Advisory Group, Stand Up, Speak Up!

The group felt it was important for researchers to follow guidance in order to design better Patient Information Leaflets for children and young people involved in clinical studies. It's important for researchers to provide children and young people with enough information to allow them to make a fully informed decision to take part in a study. Well designed Patient Information Leaflets may also help researchers recruit more children and young people into a study and may possibly retain children in that study.

Here are some tips for designing information leaflets for children and young people:

- Five W's to make it simple:

What - what is the study about? What will happen to me in the study?

Why - why is the study being done?

Where - where will the study take place?

When - when will the study begin and possibly finish?

Who - who will lead the study?

- Information broken up into blocks

Top- tip - break the information into smaller chunks, so it's clear for children and young people to read. A long piece of writing puts children and young people off reading it!

- Use different media and formats (e.g DVDs)

Top-tip - think about different ways to communicate with children and young people by using different formats, for example produce a DVD that explains the study, or use websites.

- Presentation - colour, pictures, layout -

Presentation is important because it's the first thing children and young people will notice about a leaflet, the more colourful the better!

Top tip from a young member - put pictures in because it means something, not because you feel you have to! I still won't understand the information by adding a picture to the text.

- Information needs to be planned (not just thrown in!)

Top-tip - information needs to flow, don't repeat sentences, or put words in that don't mean anything.

