



Guidance Document for Researchers designing Patient Information Leaflets for Children and Young People

This guidance document was designed by the National Institute for Health Research (NIHR) GenerationR Young Person's Advisory Group www.generationr.org.uk

The guidance is aimed at researchers to help design better Patient Information Leaflets for children and young people invited to participate in health research.

It is important for researchers to provide children and young people with enough comprehensible 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 and retain more children and young people into studies.

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

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Tip 1 Separate the information sheet into part 1 and part 2:

Part 1 - summary of the study, which invites the child or young person to read part 2 if they are interested in the study

Part 2 - further information about the study which incorporates the five W's to make it simple:

What - what is the study about? What will happen to me in the study? What are the possible benefits and risks?

Why - why is the study being done?

Where - where will the study take place, will I need to take time off school, and if so how much time? Would it affect my social life?

When - when will the study begin and possibly finish?

Who - who will lead the study?

Tip 2 Have a separate leaflet available to children and young people explaining what research is. Try to avoid explaining everything in one leaflet. If possible you could try using different media and formats (e.g. videos, games, websites e.tc.)

Tip 3 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! Using a good font also helps.

Tip 4 Presentation is important because it's the first thing children and young people will notice about a leaflet, the more colour the better!

Tip 5 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".

Younger children relate to illustrations and cartoons

Young people relate more to photographs of real situations relating to clinical trials, maybe photographs of young people actually involved in trials.

Tip 6 Information needs to be planned (not just thrown in!)

Information needs to flow, don't repeat sentences, or put words in that don't mean anything.

Tip 7 Keep it simple and easy to understand, don't put too many scientific words in.

Tip 8 Seek advice from children and young people before going to an ethics committee



National Institute for
Health Research

For further information about the work of the NIHR
GenerationR Young Person's Advisory Group please visit the
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