Starting a Conversation About Clinical Trials With Your Doctor

Thank you for caring enough to consider talking to your doctor about clinical trials.

You are one of the 47% of Australians that wants to hear about clinical trials from their GPs as found by the 2012 government-funded National Survey on Attitudes Towards Clinical Trials.

If you're not used to asking your doctor questions, you might be feeling unsure how to bring up research or clinical trials. We hope this short guide will help you start that general conversation. This is not however meant to be a list of questions you should ask if you find or are approached about a specific trial – there are other questions you should ask if that happens.

By being proactive and talking to your doctor about clinical trials before you think you might need one, you'll know what help you can expect from your doctor if you want to get involved in research. Or you may uncover a care option you hadn't considered before.

Starting the conversation with your doctor.

The following ideas and questions are meant to help prompt the discussion. They are not meant to be trick questions, but rather to help you figure out if, and how, you and your doctor might work together if research is a care option you'd like to consider.

Potential ways you could bring up clinical trials

- "Dr, We've not spoken about this before, but it is something I am/have become interested in. So I want to talk to you to see what you think. Would you have a few minutes to answer some questions about clinical trials?"
- "Dr, I'm interested in finding out more about clinical trials, and I wondered if I could ask you about them?"
- "Dr, you've just suggested I should do/use XXX. Do you know if there might be any research studies also looking at how to deal with/treat my health problem?"

Potential questions you could ask if your doctor has time and is willing to talk...

- What do you know or think about clinical trials?
- Do you think trials are something I should consider doing?
- Have you ever thought about clinical trials as a care option for me?
- Would you support the idea if I wanted to be in a clinical trial?
- Do you think I should consider a clinical trial for helping with my XXX?
- Would you know where I could look for a clinical trial?
- Would you help me look for a clinical trial?
- If I find a clinical trial myself, are you happy to help me get in touch with the trial doctor or help me work out if the trial is right for me?
- Are you involved in clinical research yourself?

If your doctor answers a question negatively, or you are surprised by an answer, consider asking 'Why?' so you can further understand the context for their answer.

Helping your Doctor

If you get the sense that your doctor may not really know how to help or support you around clinical trials, and is willing to learn more, you could suggest that they visit:

- Research4Me <u>Publications</u> Website to download our Resource for Australian clinicians, or send an email to <u>MoreInfo@Research4.Me</u> to ask for a copy.
 - Australian Clinical Trials to learn about or search for trials.

The top 3 things you should know before talking to your doctor about clinical trials.

1. Not all doctors know about clinical trials

Just as there are doctors with specialist knowledge about different health issues, there are doctors that have more knowledge of clinical trials. No one doctor knows about the 1000+ clinical trials that start in Australia each year, not even the specialists, and not every doctor understands how trials work, or the risks and benefits of trials. Talking to your doctor will help you understand their interest and capacity to help you if you are interested in clinical trials.

If you decide to take part in a trial, it is a good idea to tell your doctor so they don't accidentally do something that might affect your participation or safety while in the trial.

2. Not every trial will be right for you, and you don't have to say YES to taking part

Clinical trials have very strict eligibility criteria that aim to make sure it is safe for the individual to take part, and that the group being researched are clearly defined. As such, you may not be eligible for every trial you find. The research team will discuss this with you.

Equally, not every trial you find will be right for you. You will need to consider the benefits, risks and commitments of the research, and how that fits with your life. Take the time to think about it and talk to your doctor or others that might be able to help you evaluate what's right for you. It is perfectly OK to say no to a trial – your future care will not be affected.

3. Not everyone may agree with your choice to consider, or say yes or no to, a trial

Only you know what is right for you in terms of your health care. As with all things, the people in your life (family, friends, work colleagues, your doctor), may have different opinions about what you should do, shaped by their own perceptions, experiences, knowledge, risk profile or understanding of how your condition affects you. You ultimately need to decide what is right for you, including whether or not you decide to take part in a clinical trial.

Learning More About Clinical Trials

To learn more about clinical trials in Australia, the government-funded website is <u>Australian Clinical Trials</u>. This website provides trial search and alerts functions, stories and useful information for the public (consumers), healthcare professionals and researchers. The Consumer Health Forum of Australia's <u>Consumer Guide to Clinical Trials</u> also provides a brief overview of the basics of trials. And if you still have questions, tap into the resources on our <u>Website</u> or social media to ask questions, share experiences and learn from others about participating or being more involved in research, and subscribe to our <u>Newsletter</u> for monthly updates on trials starting in ANZ.

Other health consumer organisations and patient groups may also be able to support you.

If you found this Conversation Starter helpful, or have suggestions for how we can improve it, please email MoreInfo@Research4.Me

