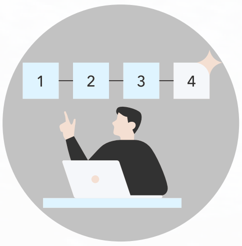
Understanding questionnaires in cancer clinical trials

What are these questionnaires for?

These are questionnaires that ask about how cancer and healthcare affects your wellbeing or your experience of care.

Why do my answers matter?

People's lives can be affected by cancer and healthcare in many ways. Your experience and answers will help health professionals better support other patients in the future and guide treatment options in public healthcare.



What kind of questions will I be asked?

Depending on the questionnaire, you might be asked about any aspect of your experience with cancer and healthcare. Aspects commonly include:

- symptoms, like pain, tiredness and nausea
- physical wellbeing, such as your ability to walk
- emotional wellbeing, such as worry and sadness
- social wellbeing, such as ability to spend time with family and friends
- everyday activities and roles, such as your ability to work and enjoy hobbies

How do I answer the questions?

Questions may look like the below examples:

Please circle the number that best applies to you.
During the past week, did you worry?

1	2	3	4
Not at all	A little	Quite a bit	Very much

Mark an X on the scale to indicate how your health is TODAY.

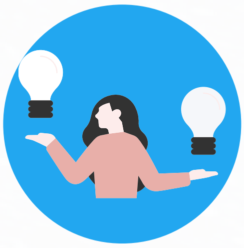
Worst health you can imagine

Best health you can imagine

0 10 20 30 40 50 60 70 80 90 100

You will need to answer the questions on paper, on an electronic device, or in person.

There are no ‘right’ or ‘wrong’ answers - please just answer as honestly and completely as possible.



Can I ask for help with answering questions?

If needed, you can ask someone to help read the questions out to you or record your answers. But your answers should reflect your thoughts and feelings rather than anyone else's.

If you aren't sure what a question means, just guess rather than ask someone else for their opinion. Questionnaires used in research have been designed to accept many types of meanings.

Who will see my answers?

All information you provide must be treated privately and confidentially according to the National Statement on Ethical Conduct in Human Research.

Usually, only the research team will see your answers. Answers are averaged across everyone taking part, rather than just one person. This tells researchers what the most common experiences are.

What if questions aren't relevant to me?

When a question asks about something that is not a problem for you, please actually say this rather than just leave the answer blank.

For example, if you don't have pain, choose 'None', 'Not at all', or '0'.

If you leave the answer blank, researchers will wonder whether you actually had pain but missed the question by mistake.

Will my answers affect my treatment?

In most clinical trials of cancer treatments, your answers won't change your treatment. These trials have other ways to monitor whether someone's treatment should be changed.

However, if you are feeling very unwell, please tell someone on the research or medical teams. Usually, they will be able to manage your problem without needing to change your treatment.

Why am I being asked the same questions repeatedly?

Most clinical trials will ask the same questions on multiple occasions to understand how people are affected by a treatment over time.

This can seem repetitive and unnecessary, especially if nothing has changed for you.

However, it's equally important for researchers to know whether your health has stayed the same or has changed.

For more information about the study you're taking part in, please ask the research staff team.

For more information about cancer clinical trials, please visit https://www.cancer.org.au/cancer-information/treatment/clinical-trials