



**Advance Research
Directive form**

About This Form

- Before filling out this form, read the document “Learning more about health-related research”. The information in that document will help you complete this form.
- This document is for research related to health and wellbeing. It is not for use in relation to market research by businesses or other organisations.
- **You can review and change your Research Directive** at any time as long as you are well enough to make your own decisions. It is a good idea to review your Research Directive from time to time to make sure it still says what you want.
- The legal status of Advance Research Directives varies across Australian states and territories. As a general principle, if you are not able to make your own decisions in the future, your Research Directive should guide and inform decisions that other people may make about whether or not you take part in research studies.

Advance Research Directive

Part 1: Let's Start to Think about Research

What is research? What does it mean to take part in a research study?

Why do research?

Research helps us learn new things. There are important benefits to doing research. By doing studies, researchers can find out new ways to:

- Prevent and treat diseases
- Provide better care for people who are sick
- Improve quality of life and wellbeing for people with illnesses and disabilities.

Who can take part in research?

Researchers involve a range of people in their studies, including people who are healthy and people who have health problems.

What might I be asked to do?

People can take part in research in many different ways. It could be as simple as answering a short survey. Or it could involve doing activities to test a new medical treatment. The document "Learning more about health-related research" gives examples of different kinds of research studies.

Are there benefits?

If you take part in a study, you might not get any direct benefit. Instead, you might help researchers answer questions that could benefit other people in the future.

Are there risks?

There are sometimes risks in being part of a research study. A risk is the potential for harm, discomfort or inconvenience. For example:

- You might have to take time out of your day to take part in a research activity.
- You might feel uncomfortable about some activities, like researchers asking you personal questions or using a needle to take a small amount of your blood.
- You might feel sick or have side-effects from a new drug or treatment.

Who makes sure a research study is safe and ethical?

Before researchers can ask people to be part of a study, they must get permission from an ethics committee. This is an independent committee that makes sure the research is safe (there are more benefits than risks) and it follows ethical rules. See "Learning more about health-related research" to learn about these ethical rules.

Advance Research Directive – Thinking ahead about taking part in research

Making an Advance Research Directive

People can make an **Advance Research Directive**. A Directive asks you to write down your wishes about taking part in research in the future in case you become too unwell or are unable to choose later.

You make your Advance Research Directive at a time when you are able to think through your options and make choices. You can say whether you agree or disagree to taking part in research activities.

You can also name people you trust who you would like to be involved in decisions about your participation in research.

You can review and change your Directive at any time as long as you are able to make your own decisions.

If you are not able to make decisions in the future, your Directive will tell people your wishes, such as your family, your doctor or a researcher. Your Directive will help them know whether or not you want to be involved in research activities.

This document applies to research that occurs while you are still alive - it does not extend to research after death. Many universities have body donation programs for people who wish to donate their body for medical research. Contact your nearest university, hospital or medical research facility if you would like information about body donor programs in your area.

Part 2: My Wishes about Taking Part in Research

Remember: This Directive is about research into health and wellbeing that has been approved according to ethics rules.

My general wishes about taking part in research about health and wellbeing

In the future, if I lose the ability to make my own decisions (select one box only):

- I am willing to be involved in research.
[Then, please go to the next section to say more about your wishes.]
- I AM NOT willing to be involved in any research.
[Skip to the end to sign the document.]

The next boxes are optional. Please complete them if you would like to say more about your views on taking part in research.

My views about specific research activities

In the future, if I lose the ability to make my own choices, I **would be willing** to be included in a research study that involves:

Please tick each statement below that reflects your wishes	Tick
Asking me questions in a survey or interview (example: asking about my experiences or opinions)	
Observing my behaviour (example: watching how I act if I listen to music)	
Testing my memory or thinking (example: asking me to draw a simple picture or remember specific words)	
Giving me psychological therapy (example: counselling for anxiety or depression)	
Giving me physical therapy or exercises (example: moving my arms or legs, massaging my muscles)	
Giving me certain foods, vitamins or supplements (example: a nutrition drink that might improve my health)	
Giving me experimental medicine (example: an experimental drug that might reverse damage in my brain)	
Taking x-rays or scans of my body (example: to help researchers see how a disease is affecting my brain)	

Please tick each statement below that reflects your wishes	Tick
<p>Taking measurements about my body (example: my blood pressure)</p>	
<p>Putting something on my body, like a bracelet, that keeps track of information (example: how much time I spend in bed)</p>	
<p>Taking a sample of my blood or other body fluid for <i>genetic</i> research (example: to find out if I and my relatives have a gene that increases the risk of getting diseases) Note: <i>Genetic</i> research looks at diseases that can run in families. You inherit genes from your parents and you pass your genes on to your children.</p>	
<p>Taking a sample of my blood or other body fluid for <i>non-genetic</i> research (example: to find out if my blood shows I had an infection in the past that increases my risk of getting diseases)</p>	
<p>Looking at my personal records, such as medical records or test results stored at my doctor's office, hospital or other care facility (example: to study how a past illness might be related to my current health problem)</p>	
<p>Accessing stored samples of my blood, body fluids or other tissues (example: If I had blood taken in the past for another reason, researchers might ask the hospital for access to that blood for study)</p>	

Wishes or worries about research

Please note any specific wishes about types of research projects or activities you **would want** to take part in (example: interest in being part of studies into particular diseases or health problems)

Please note any specific wishes about types of research projects or activities you **would NOT want** to take part in (example: any worries or concerns about being in a research study)

Using your Directive in the future

Even if you lose the ability to make your own decisions, you might still be able to express your feelings about being involved in a research activity.

A person doing research must check whether you are okay to go ahead. If you are **not happy** to do the activity, this should be respected, even if your Directive says you agree to that activity.

For people who are unwell, it is sometimes hard for them to express whether they are happy or unhappy with doing a research activity. If this happens to you, do you prefer that:

Your wishes in this Directive are followed as much as possible.

OR

Your feelings – as you are able to express them in the future – are followed as much as possible.

Part 3: Choosing a Supporter and Decision-Maker

You can choose people you trust to be involved in decisions about your participation in research studies.

These people can:

- Support you to make your own decisions as long as you are able. For example, they could help you talk to your doctor about being part of a study. They could help you read and understand information about a research study.
- Use your Advance Research Directive to discuss your wishes with researchers if you are not able to make your own choices.

There is space to name up to two people who you think are best suited to be involved in decisions and to support you to take part in research studies.

It is important to discuss your Research Directive with the person(s) you name below. This will help them know and understand your wishes. If you might like them to involve other people in future decisions, such as other family members, you can discuss that with them.

Note: Have you already made a legal document to appoint a Health Care Decision-Maker? If yes, it is a good idea to name the same person(s) here.


My supporters / decision-makers

Person 1 - Name

Address

Email

Phone

Signature of Person 1: 


I understand the wishes set out in this form and my role (as described above).

Person 2 - Name

Address

Email

Phone

Signature of Person 2: 

I understand the wishes set out in this form and my role (as described above).

Part 4: Signatures

By signing below, I confirm that:

- I understand the information and choices set out in this Directive
- I understand that if I am not able to make decisions in the future, this Directive will tell people my views about taking part in research studies
- I made this Directive of my own free will
- I am aware I can review and change this Directive at any time as long as I am able to make my own decisions
- I understand this Directive replaces any version of the form I completed in the past.

Signature 

Name (please print)

Date

Address

Email

Phone

After you complete this form:

- Make sure other people know your wishes. Share copies of your Research Directive with anyone you named as a supporter/decision-maker, family members or other people who you think should know your wishes.
- Keep a copy of your original Research Directive form with your other 'planning ahead' documents, such as your Enduring Power of Attorney document, Advance Care Directive and similar documents.

Witness (if applicable)

I confirm that _____ signed this Directive on ____ / ____ / ____

Signature 

Name (please print)

Date

Address

Email

Phone

Person who provided assistance in the preparation of this Directive (if applicable)

I provided assistance to _____ in preparing this Directive (example, by helping to read and understand the document).

I confirm that I had no reason to doubt their ability to complete the Directive.

My relationship to the person or my role is: _____ (example, health professional, solicitor, researcher).

Signature 

Name (please print)

Date

Address

Email

Phone



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