Jreissati Pancreatic Centre

Epworth

Understanding clinical trials for pancreatic cancer

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Acknowledgements

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The Jreissati Pancreatic Centre at Epworth acknowledges the Traditional Custodians of Country across Australia. We recognise their continuing connection to land, waters, communities and culture.

We pay our respects to Aboriginal and Torres Strait Islander Peoples and to Elders past, present and emerging.

Note to readers

This booklet provides general information about pancreatic cancer. It is not intended to replace advice from your treating team or other qualified professionals. You should always speak with your doctor about decisions that may affect your health. If you require legal, financial or psychological support, we encourage you to seek advice from appropriately trained specialists.

Every effort has been made to ensure the information is accurate at the time of publication. However, evidence and clinical guidance relating to cancer care are continually evolving. The Jreissati Pancreatic Centre at Epworth is not responsible for any loss, injury or damage resulting from reliance on this material.

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VICTORIAN CANCER AGENCY

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About the Jreissati Pancreatic Centre at Epworth

Pancreatic cancer is the eighth most diagnosed cancer in Australia. In 2025, it was estimated that 4,825 people would receive a pancreatic cancer diagnosis. This would account for 2.8% of all cancer diagnoses in the country.[1]

The Jreissati family are all too familiar with the fear and uncertainty that follow a diagnosis of pancreatic cancer, having lived through the experience when Elias was diagnosed at age 54. Knowing the impact the disease has had on their family, Elias, his wife Colleen and the rest of the Jreissati family wanted to change the patient and family experience for others. This led to the establishment of the Jreissati Pancreatic Centre at Epworth in 2021. This Centre provides clinical care and support to patients with a diagnosis of pancreatic cancer, supports early diagnosis and better patient outcomes, advocates for patients and raises awareness and understanding of the disease. 100% of the funding it receives is directed into research, patient support and clinical care.

Our centre comprises three intersecting parts, each of which is integral to improving patient outcomes and experiences

- Comprehensive patient-centred clinical care
- Patient advocacy and support
- Clinical trials and research

We are a specialist centre offering a centralised model of care for pancreatic disease management. This means our patients have access to all healthcare professionals required for their care within a single centre and hospital network. International studies support the view that centralised care improves overall patient outcomes.[2] By managing patients through one main centre, case volume increases, which in turn enhances clinical expertise. This growing expertise drives innovation and leads to advances that will improve patient procedures and treatments in the future.

The **patient experience** is a central focus of our centre. Receiving a diagnosis of pancreatic cancer can be an overwhelming and emotional time, often bringing many questions and uncertainties. Knowing that you are not facing this alone, and understanding where to turn for support, is very important. Once you are referred to the centre, you will meet our pancreatic nurse coordinator, who will be there to guide and support you throughout your care at Epworth. They will be your first point of contact and are always available to answer any questions or concerns you or your family may have.

Understanding clinical trials for pancreatic cancer

Clinical trials play an important role in improving cancer care. They help researchers test new ways to diagnose, treat and manage disease. For people with pancreatic cancer, clinical trials may also offer access to treatment options that are not yet widely available.

This guide is for people who are considering a clinical trial or have been invited to join one. It explains how trials work, what to expect, and where to find further support or information.

This resource does not replace medical advice. Always speak with your healthcare team about decisions that may affect your care.

Watch our video on what to expect during a clinical trial.

What are clinical trials and how do they work?

Clinical trials are research studies that test new ways to prevent, diagnose, treat or manage disease. They are an essential part of improving cancer care and ensuring that treatments are safe and effective.

Trials may explore:

- New medications or combinations of existing treatments
- Changes to how treatment is delivered, such as adjusting the dose or schedule
- Supportive care approaches to manage side effects or improve quality of life
- New tests to detect or monitor cancer

Each trial follows a detailed plan, called a protocol. This sets out who can take part, what the study will involve, and how participants will be monitored. All protocols are reviewed and approved by ethics committees and regulatory bodies before the trial begins.

If you are invited to take part, your doctor or nurse will explain the details and provide written information. You will have time to ask questions. You will only join the study if you choose to give informed consent.

If you decide not to take part, you will still receive standard care. This is based on the best available evidence for your cancer type and stage.

Not all trials lead to new treatments, but every trial contributes to medical knowledge that can improve care in the future.

Types of clinical trials

Clinical trials vary depending on what researchers are aiming to learn. Not all trials involve new medications. Some focus on improving comfort, early detection, or how care is delivered.

Common types include:

- Treatment trials test new drugs, combinations of treatments, or delivery methods (e.g. chemotherapy or immunotherapy)
- Supportive care trials study ways to manage side effects, improve quality of life, or support wellbeing
- Screening or diagnostic trials assess new tests to detect cancer earlier or monitor treatment response
- Prevention trials explore strategies to reduce cancer risk or delay recurrence

Your care team can explain the type of trial being offered and how it fits with your treatment plan.

Why people join trials

People take part in clinical trials for different reasons. Some hope to access new treatments that are not yet available outside a trial. Others want to contribute to research that may help future patients.

Possible reasons include:

- Accessing a treatment that may be more effective or have fewer side effects
- Being monitored closely by a specialist team during the trial
- Exploring options when standard treatments are limited
- Contributing to medical research and the development of future care

Clinical trials are designed to answer research questions. This means outcomes are not guaranteed. Some people may benefit from the trial treatment, while others may not.

Taking part in a trial is voluntary. You can take time to decide and can decline or withdraw at any point.

Phases of clinical trials

Clinical trials are conducted in phases. Each phase has a specific purpose and builds on what was learned in earlier studies.

Phase	Main purpose	What it involves
Phase 1	Tests safety and dosage	Small group of participants. Focuses on finding a safe dose and how the treatment behaves in the body.
Phase 2	Checks if the treatment works	Larger group. Looks at whether the treatment has an effect on a specific type of cancer.
Phase 3	Compares to standard treatment	Large group. Compares the new treatment to existing treatment to measure how well it works.
Phase 4	Long-term monitoring	Happens after approval. Monitors side effects and performance in a wider population over time.

What participation may involve

If you join a clinical trial, your care team will provide detailed information about what to expect. Participation usually involves more monitoring than standard treatment, but the exact requirements will depend on the study.

Below are some common components of a clinical trial:

Stage	What to expect
Screening	Before joining, you will have tests to check whether you meet the eligibility criteria. These may include blood tests, imaging scans, a review of your medical history and a physical examination. Trials have strict inclusion and exclusion criteria to ensure the treatment is suitable and safe. These may relate to your cancer type and stage, previous treatments, age or general health.
Treatment schedule	If you are eligible, the trial team will provide a schedule of treatment visits. This may involve: › Procedures performed in hospital › Chemotherapy or targeted therapy infusions in hospital › Tablets or injections at home or in clinic › Pre-treatment assessments or preparation Your team will explain how often you need to attend and how long each session is expected to take.
Scans and tests	You may have more frequent blood tests, imaging scans (such as CT or MRI), or questionnaires than in standard care. These are used to monitor how the treatment is working, detect side effects early, and ensure your safety during the trial.
Randomisation	In some trials, participants are randomly assigned to one of two or more groups. All groups receive their usual standard treatment such as chemotherapy. Participants are then randomly allocated to receive either the investigational treatment or a placebo in addition to this standard care.

Stage	What to expect
Follow-up	After treatment ends, the trial may continue to monitor your health through follow-up visits. These may include blood tests, scans or check-ins with the research team. Follow-up helps collect longer-term information about the safety and effects of treatment.

You can ask for a written schedule of visits and tests before you decide whether to take part. You can also ask how much time the trial is likely to take and what is expected of you.

Your rights, safety, and how consent works

All clinical trials must meet strict ethical and safety standards. In Australia, every trial is reviewed by a Human Research Ethics Committee to protect the rights, safety and wellbeing of participants.

If you take part in a clinical trial, you have the right to:

- Receive clear written and verbal information about the trial
- Ask questions at any time
- Take time to consider your decision before joining
- Decline to participate without affecting your care
- Withdraw from the trial at any time, for any reason
- Be informed if new information arises that may influence your decision

Before starting, you will be asked to sign a consent form. This confirms that:

- You understand what the trial involves
- You have had the opportunity to ask questions
- You agree to participate voluntarily

This process is known as informed consent. It does not obligate you to continue. You may change your mind at any point, and your care team will discuss alternative options with you.

Your health and safety will be closely monitored throughout the study. If serious side effects occur, your doctor may recommend stopping the trial treatment to protect your wellbeing.

Common misconceptions

It's normal to feel unsure about clinical trials, especially if you haven't been part of one before. Below are some common misconceptions, and the facts behind them:

Misconception	Fact
'I'll be treated like a guinea pig.'	Clinical trials follow strict ethical standards. Your safety, rights and informed consent are prioritised at every stage.
'If I join a trial, I might get no treatment at all.'	If a proven treatment exists, you will continue to receive standard care. Most cancer trials test a new treatment alongside, or compared with, existing care.
'If I say no, I won't get good care.'	Declining a trial will not affect the quality of your care. Your team will continue to offer the most appropriate treatment based on current evidence.
'Trials are only for people who have no options left.'	Some trials are offered when standard treatments are limited, but others are available earlier in the treatment pathway, including at diagnosis.
'Once I join, I can't leave.'	You can withdraw from a trial at any time. This decision will not affect your care or access to future treatment.

If you have concerns or are unsure, speak with your care team. They can explain how the trial works and help you make an informed decision.

Questions to ask before joining a clinical trial

Before deciding whether to join a clinical trial, it can help to ask questions and take notes. You may want to bring a family member or friend to the discussion for support.

Here are some useful questions to consider:

- What is this trial testing? Why is it being done?
- Why am I being invited to take part? Are there other treatments I can consider?
- What treatment will I receive? How is it different from standard care? Will I know what treatment I'm getting?
- How often will I need to attend appointments? Where will the trial take place? Will I need to travel or stay overnight?
- What are the possible risks or side effects? How will these be managed?
- Can I keep seeing my current doctor? What happens if the trial treatment stops working?
- Will it cost me anything to participate?

It's okay to ask for written answers, or to come back with more questions later. You don't have to decide on the spot.

If a family member or carer is helping you make decisions, they are welcome to ask questions or attend appointments with you. Support is available for carers too, including practical advice, emotional support and resources to help them understand the trial process.

What happens if you leave a trial or the trial ends

You have the right to leave a clinical trial at any time. This will not affect your care or your relationship with your treating team. You do not need to give a reason, although the research team may ask for feedback to improve future studies.

If you withdraw, your care team will talk with you about the next steps. These may include returning to standard treatment, continuing parts of the trial (if appropriate), or considering other available options.

When a trial ends, for an individual or for all participants, the research team will review the outcomes. In some cases, trial treatments may become available outside the study, through special access programs, new trials or regulatory approval. Access is not guaranteed, but your team will explain what options are available at the time.

You can also ask:

- Whether you will receive a summary of the trial results
- Whether long-term follow-up is planned after the study ends
- How your data will be stored

Your care team will support you through this process and ensure that decisions are based on what is known at the time.

Key takeaways

Choosing whether to take part in a clinical trial is a personal decision. Some people see a trial as a way to access a potential new treatment. Others value the opportunity to contribute to research that may benefit future patients.

This booklet has explained what clinical trials involve, what participation may require, and where to find further support.

If a trial is offered to you:

- Take time to consider your options
- Ask questions and discuss them with your care team
- Request written information, including the consent form and schedule of visits
- Consider whether you would like to involve a family member or carer in your decision

Clinical trials are voluntary. You can say no, change your mind, or leave at any time. These decisions will not affect the care you receive.

Contact us

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pancreaticcentre.org.au

Glossary

Chemotherapy: A type of cancer treatment that uses drugs to destroy or slow the growth of cancer cells.

Clinical trial: A research study that tests new ways to prevent, diagnose, treat or manage disease. Clinical trials are designed to improve care and ensure treatments are safe and effective.

Consent (informed consent): The process of agreeing to take part in a trial after receiving clear information about what is involved. You will be asked to sign a consent form before joining. Consent is voluntary and can be withdrawn at any time.

Eligibility criteria: The rules that determine who can take part in a clinical trial. These are based on medical factors such as cancer type, stage, age or previous treatment.

Ethics committee: A group that reviews and approves research studies to ensure the rights, safety and wellbeing of participants are protected.

Immunotherapy: A type of treatment that uses the body's own immune system to help fight cancer.

Monitoring: The regular checks and assessments that happen during a trial to make sure the treatment is safe and working as intended.

Phase 1 / 2 / 3 / 4 trials: The stages of a clinical trial. Each phase answers different questions about safety, effectiveness and long-term outcomes.

Placebo: A substance or treatment that looks like the real treatment but has no active ingredients. Used in some trials to compare effects. Placebos are not used in cancer trials when effective treatment already exists.

Protocol: The formal plan for how a trial will be run. It outlines the purpose of the trial, who can join, what treatment will be given, and how safety will be monitored.

Randomisation: A process used in some trials to assign participants to different treatment groups by chance. This helps ensure the results are fair and unbiased.

Side effects: Unwanted effects of a treatment. Side effects may be mild or serious and are closely monitored during clinical trials.

Standard care: The usual treatment for your cancer based on current medical guidelines. You will continue to receive standard care even if you choose not to join a trial.

Supportive care trial: A type of trial that focuses on improving comfort, managing side effects or supporting emotional and physical wellbeing during treatment.

Targeted therapy: A cancer treatment that works by targeting specific features or changes in cancer cells.

Trial coordinator / research nurse: A member of the trial team who helps organise appointments, monitors progress and supports participants throughout the study.

Additional resources

General

Australian Clinical Trials (Australian Government)

This is the Australian Government's official website for clinical trial information. It explains what clinical trials are, what participation may involve, and how to make an informed decision. It also includes patient checklists and tools to help guide conversations with your doctor.

australianclinicaltrials.gov.au

Australian New Zealand Clinical Trials Registry (ANZCTR)

ANZCTR is a national register of clinical trials approved in Australia and New Zealand. You can search for trials by condition, location or treatment type. Trial listings include eligibility criteria and contact details. The site is mainly designed for health professionals but may be helpful if you are exploring options with your care team.

anzctr.org.au

ClinicalTrials.gov

ClinicalTrials.gov is an international registry of research studies maintained by the U.S. National Library of Medicine. It includes listings for trials taking place around the world, including some not yet listed in Australian registries. The site is designed for health professionals and researchers, so some information may be technical. It may be useful if you are working with your care team to explore international options.

clinicaltrials.gov

Pankind Trial Finder

A search engine which allows you to search for pancreatic cancer clinical trials being conducted across Australia, providing information about study aims, eligibility criteria, locations and contact details. It is designed to help patients and their care team identify potentially suitable clinical trial opportunities.

https://trialfinder.pankind.org.au/home

Financial and legal advice

Cancer Council's Financial Assistance Program

Provides advice and support on a variety of topics including legal issues, financial planning, small business accounting, workplace (HR or recruitment) advice.

13 11 20

cancer.org.au/support-and-services/practical-and-financial-assistance

Community Legal Centres Australia

Provides links to local community legal centres across Australia.

clcs.org.au/legal-help

Cancer Council's Dealing with Debt factsheet

Information for people who are having trouble paying their debts.

cancer.org.au/assets/pdf/dealing-with-debts

Services Australia's Financial Information Service

Information on employment, disability, sickness and carer payments.

132 850

servicesaustralia.gov.au

Type 'Financial Information Service' in the search box

Cancer Council's Help with Bills factsheet

Explains options to help you pay your utility bills, including rebates, discounts, and concessions

cancer.org.au/assets/pdf/help-with-bills-factsheet

Money Smart

Financial tips from the Australian Securities and Investments Commission (ASIC). Includes the Financial Advisers Register.

1300 300 630

moneysmart.gov.au

State Trustees

Public Trustees who can help you prepare a will and manage your finances. Contains links to public trustees by state and territory.

willshub.com.au/succession-law-resources/public-trustees/

Cancer Council's Superannuation and Cancer factsheet

Advice on finding and accessing super, tax implications of accessing super, and super-related insurance.

cancercouncil.com.au/wp-content/uploads/2022/09/Superannuation-and-Cancer.pdf

Counselling and mentoring services

Canteen

Free counselling and emotional support to young people and their families who are impacted by cancer.

1800 226 833

canteen.org.au

Care Search

Australian Government website that provides palliative care information and links to services for people affected by cancer.

caresearch.com.au

Kids Helpline

Telephone and online counselling service and crisis support for young people aged 5–25.

1800 55 1800

kidshelpline.com.au

Pancare support groups

Online and face-to-face support groups for patients and carers.

1300 881 698

pancare.org.au/living-well/support-groups/upper-gastrointestinal-cancer-support-groups

Pankind Support Navigator

(02) 7207 6970

support@pankind.org.au

Telephone support groups

The below telephone support groups are free, professionally facilitated support groups. They are open groups and you can join in whenever you feel well enough, on an ongoing basis,

from anywhere in Australia.

Members are telephoned by Cancer Council so there are no costs to participate. You can be called on a landline or a mobile.

The Pancreatic Telephone Support Group meets the first and third Wednesdays of the month from 1.30pm–2.30pm (EST) and accepts new members at any time.

The Advanced Cancer Telephone Support Group meets the first and third Tuesday of the month from 1.30pm–2.30pm (EST) and is for people with a variety of cancers, including pancreatic cancer.

The Carers' Telephone Support Group meets the second and fourth Wednesdays of the month from 1.30pm–2.30pm (EST) and is for people caring for someone with any cancer, including pancreatic cancer.

To find out more about any of these telephone support groups, 1300 755 632 or email tsg@nswcc.org.au.

Medicare Safety Nets thresholds

Medicare Safety Nets have thresholds. When you spend certain amounts in gap and out of pocket costs, you may reach these thresholds. Once you've reached the thresholds, you'll begin to receive higher Medicare benefits. This means you'll receive more money back for certain Medicare-funded services.

servicesaustralia.gov.au/what-are-medicare-safety-nets-thresholds

Please make sure you register so that your payments are counted towards the threshold.

Information for carers

Carer Gateway

Links carers to local support services such as emergency respite care, counselling and peer support groups. Offers practical information, resources and support packages for carers.

1800 422 737

carergateway.gov.au

Carers Australia

National body working with state and territory Carers Associations to provide information and counselling for carers.

1800 242 636

carersaustralia.com.au

Advance care planning

Advance Care Planning Australia

Information about planning for your future healthcare, including advance care directives.

1300 208 582

advancecareplanning.org.au

My Values

A set of specially constructed statements designed to help you identify, consider and communicate your wishes about the medical treatment you would want in the later stages of life.

myvalues.org.au

Helpful guides and factsheets

Cancer Council's Employment and Cancer factsheet

This fact sheet answers some common questions people have about their rights. It explains federal employment laws and protections under anti-discrimination laws.

cancer.org.au/assets/pdf/employment-and-cancer

Cancer Council's Getting your Affairs in Order factsheet

Instructions on making a will, preparing documents that will help others to make decisions for you if you're not able to make them yourself, nominating a beneficiary for your superannuation and insurance, and sorting out legal and financial paperwork.

cancer.org.au/assets/pdf/getting-your-affairs-in-order-factsheet

My Aged Care

Established by the Australian Government to help you find and access the right government-funded aged care services.

You can call the My Aged Care Contact Centre on 1800 200 422.

Monday to Friday 8am to 8pm and Saturdays 10am to 2pm

myagedcare.gov.au

Notes

References

1. Cancer Australia, *Pancreatic cancer in Australia statistics*, Cancer Australia, 2025, accessed 1 December 2025.
2. OO Faluyi, JL Connor, M Chatterjee, C Ikin, H Wong and DH Palmer, 'Advanced pancreatic adenocarcinoma outcomes with transition from devolved to centralised care in a regional Cancer Centre', British Journal of Cancer, 2017, 116:424-431.

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epworth.org.au/giving

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