



PURPLE TRANSLATIONAL PLATFORM

PANCREATIC CANCER: **U**NDERSTANDING
ROUTINE **P**RACTICE & **L**IFTING **E**ND RESULTS

The PURPLE Registry - Information for Patients

PURPLE: Pancreatic cancer: Understanding Routine Practice and Lifting End results

What is the PURPLE Registry?

The PURPLE Registry has been set up to create an ongoing record of the treatment and outcomes of patients diagnosed with pancreatic cancer. The PURPLE registry is a 'non-interventional' registry as it collects medical information about patients with pancreatic cancer, as they undergo their routine, day to day treatment and care. Currently, the PURPLE registry receives this data from medical staff at over 45 participating hospitals in Australia, New Zealand and Singapore.

Established by clinicians and scientists at The Walter and Eliza Hall Institute of Medical Research (WEHI) in October 2016, the PURPLE registry has been designed to support and encourage much needed research into pancreatic cancer.

What are the aims of the PURPLE Registry?

The aim of the PURPLE Registry is to improve knowledge sharing and the ability for research laboratories and cancer centres to work together to improve outcomes for pancreatic cancer patients. The goal of the registry is to create a broad information system that brings together cancer data from patients diagnosed with pancreatic cancer and current research knowledge into a single unique platform that is efficient and has the future ability to expand as needed.

Who is the PURPLE registry for?

You may be eligible to join the registry if you are aged 18 years or above and have been newly diagnosed with pancreatic cancer (with or without spread or metastatic disease), in any state of health and are yet to receive treatment.

What information does the PURPLE Registry collect?

The registry collects data on the way patients present or come forward for care for pancreatic cancer and the course their disease takes including the details of any surgery, medication and any information about the management and outcomes of their disease during routine or day to day care.

How does the PURPLE Registry collect data?

This registry collects patient's medical data using existing data collection and analysis resources built up over the last 15 years at the WEHI. The medical information or data included in the registry is collected by medical staff at hospitals and treatment centres where patients receive care for their cancer.

What is the data used for?

Knowledge learned through the data collected in the registry is being used by clinicians and researchers to improve our understanding of the presentation, clinical course and management of pancreatic cancer in Australia and other participating countries. The registry originally set out to enrol at least 800 eligible patients over 10 years. The registry currently holds the data of over 4000 patients and is continually expanding. Any requests from clinicians or researchers to use the data goes through a strict multi step approval process to ensure each request is medically, ethically and scientifically sound.

If you would like any further information about the PURPLE registry, including finding out how to have your medical data included please contact us either by email or using the 'Contact Us' form on our website.

Email: purplepancreas@wehi.edu.au

Website: purplepancreas.org.au