

# Registry-Based Patient-Reported Outcome Measures (PROMs) & Experience Measures (PREMs) for Pancreatic Cancer: A Pilot Study



Epworth  
Research

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## Introduction

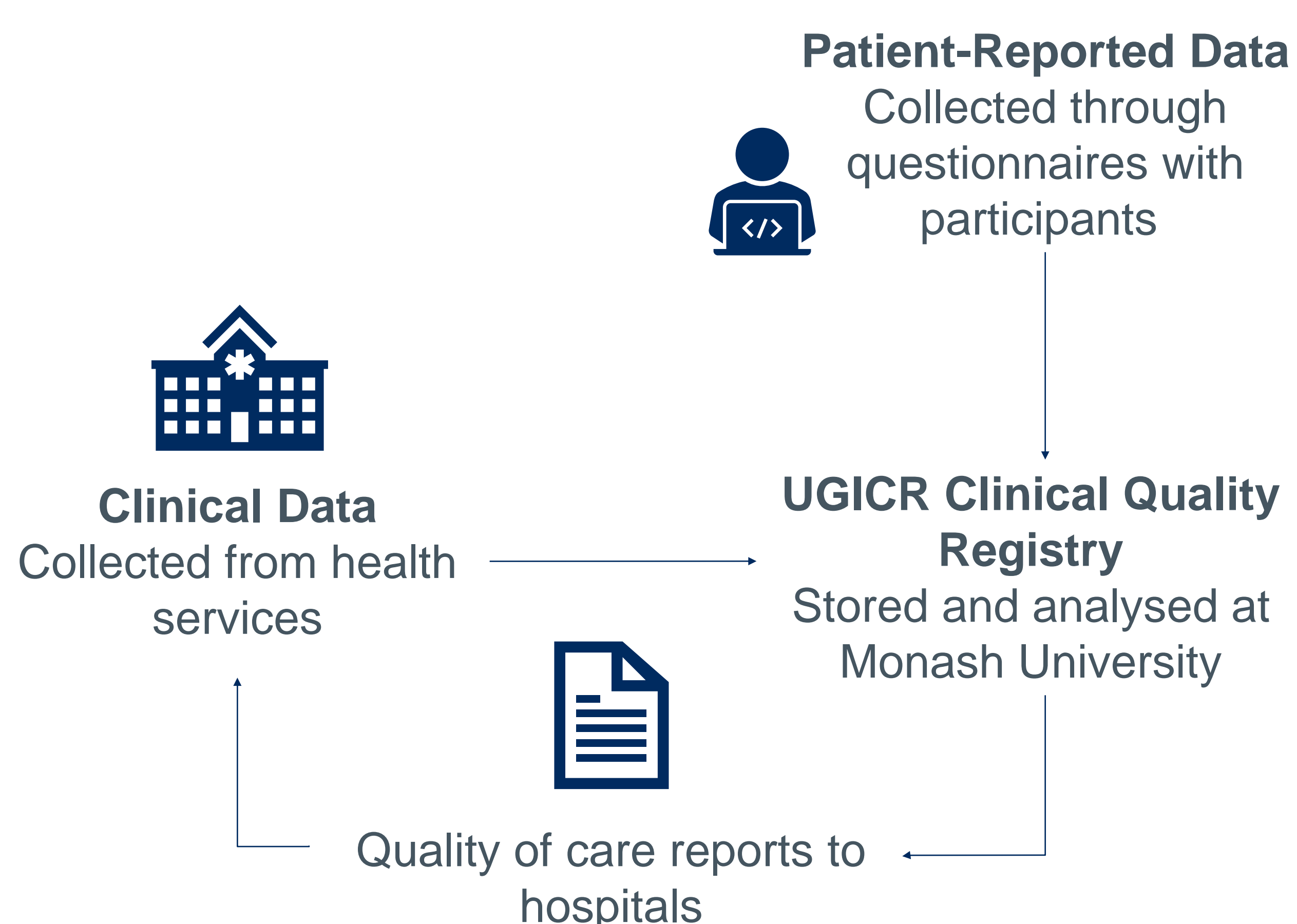
The Upper Gastrointestinal Cancer Registry (UGICR) is a clinical quality registry based at Monash University. The registry collects clinical data from hospital medical records to improve the outcomes and quality of care for individuals diagnosed with pancreatic, oesophagogastric (OG), biliary and primary liver (hepatocellular carcinoma) cancers.

Collecting PROM and PREM data through the registry provides subjective insight into the patient's outcomes and experiences, which when integrated into clinical practice may improve quality of care.

## Aims

1. To develop the systems, processes, and materials to electronically collect registry-based PROMs and PREMs for the UGICR.
2. To pilot PROMs and PREMs data collection for UGICR participants with pancreatic cancer from 10 health services in Victoria, including Alfred Health, Monash Health, Eastern Health, Austin Health, Western Health, Ballarat Health Services, St Vincent's Hospital Melbourne, Epworth HealthCare and Northern Health.
3. To evaluate the acceptability and feasibility of the electronic collection of PROMs and PREMs with clinicians and consumers.

## Fig 1. Patient-reported data in the UGICR



## Methodology

### Clinician & Consumer Engagement

*June to December 2019 - Completed*

- Selection of tools: EORTC QLQ-C30 & PAN-26
- Develop database to facilitate electronic data collection through SMS and email
- One focus group with clinicians, and three consumer engagement interviews

### PROMs & PREMs Data Collection

*January 2020 to October 2021 - In progress*

- Recruitment of participants through the UGICR
- 93 participants contacted
- 38 participants have completed the questionnaire (response rate: 41%)

### Evaluation

*November to December 2021*

- Feedback from consumers
- Feedback from clinicians
- Analysis of data and reporting

## Expected Outcomes

- Findings will determine the processes of collecting and reporting PROMs and PREMs, and how patient-reported data collection can be expanded to all UGICR participating sites for all modules of the registry.
- PROMs and PREMs data will contribute to UGICR quality of care reports provided to hospitals.

## Key Points

- The UGICR is piloting the collection of registry-based electronic PROMs and PREMs for people with pancreatic cancer.
- The processes for collecting PROMs and PREMs has been guided from input by clinicians and consumers.
- Pilot evaluation findings will advise the expansion of PROMs and PREMs into the wider registry.



Twitter: @UGICR\_Aus Website: [ugicr.org.au](http://ugicr.org.au)

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