

# The VCCOR Development Pathway: Advancing Quality in Paediatric Cancer Care: Research, Outcomes, and Service Improvement with VCCOR

Isha Chawla<sup>1</sup>, Cass Williams<sup>1</sup>, Amy Carter<sup>2</sup>, Justine Carder<sup>1</sup>, Belinda Zambello<sup>1</sup>

<sup>1</sup> Victorian Paediatric Integrated Cancer Service (PICS), Melbourne, Australia. <sup>2</sup> National Child Cancer Network, Auckland, New Zealand.



The Victorian Childhood Cancer Outcomes Registry (VCCOR) is a pioneering project that consolidates essential paediatric cancer data to improve survivorship, care, and future treatment breakthroughs. VCCOR will address key research questions and provide valuable insights to shape childhood cancer care. PICS collaborated with the New Zealand National Child Cancer Network (NCCN) to enhance the NZ LEAP (Late Effects Assessment Programme) database design in Victoria, developing the business and functional requirements with extensive stakeholder consultation.

## BACKGROUND

The Victorian Paediatric Integrated Cancer Service's (PICS) Long Term Follow-Up (LTFP) data repository was outdated; providing an opportunity to redevelop the system and enhance longitudinal tracking of health outcomes for all paediatric cancer patients diagnosed and treated in Victoria. Supported by a grant from the Medical Futures Research Fund (MRFF) through the Victorian Paediatric Cancer Consortium, PICS has developed the Victorian Childhood Cancer Outcomes Registry (VCCOR), with a focus on the long-term effects of childhood cancer and cancer treatments.

## DEVELOPMENT PROJECT OBJECTIVE

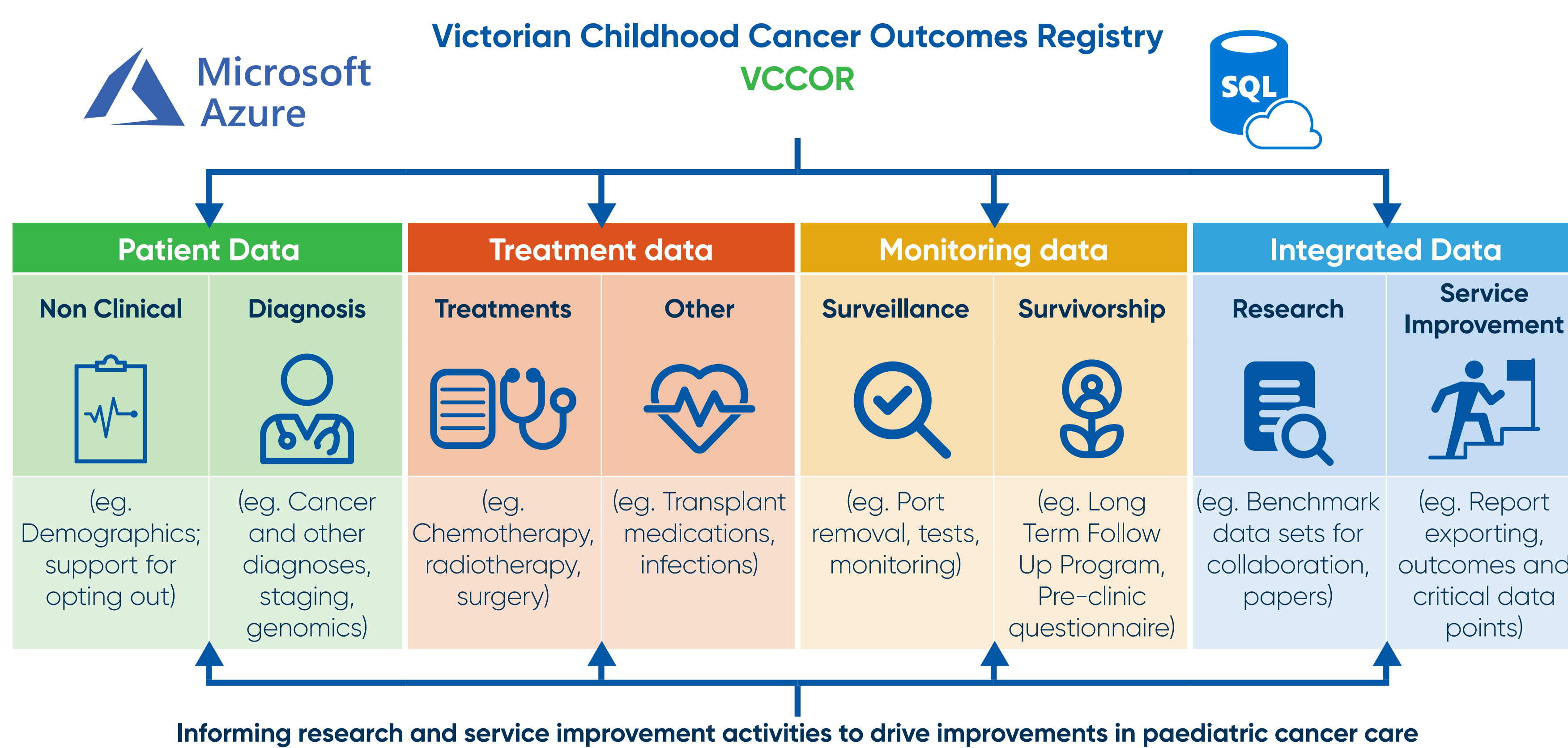
Develop the Victorian Childhood Cancer Outcomes Registry by refining system requirements, progressing system development, and conducting thorough testing. This phase focuses on architecture build, deployment planning, data migration strategy, and integration preparation to ensure a seamless and sustainable system. Key priorities include finalising data agreements, comprehensive documentation, and risk management while maintaining alignment with ethical guidelines and ongoing stakeholder and clinical consultation. The registry will play a crucial role in monitoring outcomes, benchmarking paediatric cancer care, and driving service improvements and critical research.

## FUTURE MILESTONES

Over the coming year, the focus will shift to seamless data integration, maintaining high data quality, and expanding the registry's functionality to enhance clinical decision-making and further drive service improvements and research into paediatric cancer care. PICS' long term aim for VCCOR is to deliver a configurable, sustainable outcomes registry, tracking paediatric cancer patients in Victoria from diagnosis to survivorship.

## THE VICTORIAN CHILDHOOD CANCER OUTCOMES REGISTRY

A complete service improvement, quality monitoring, and research data platform encompassing **all Victorian survivors of childhood cancer**.



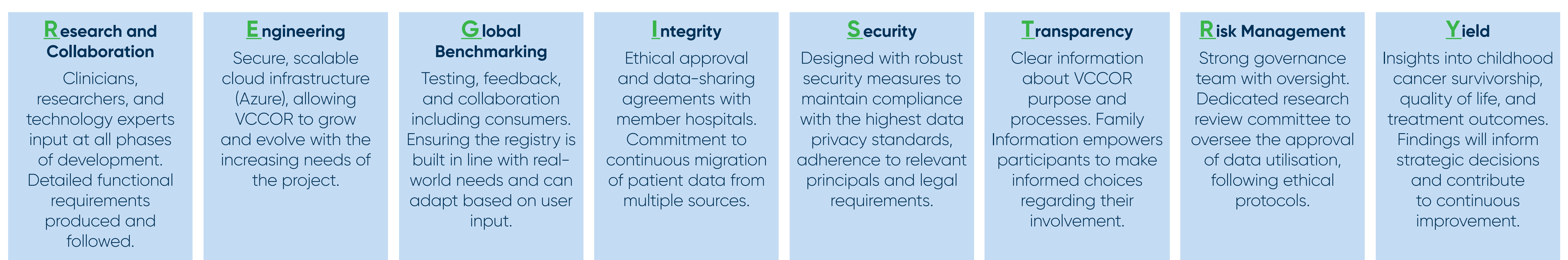
## KEY RESEARCH THEMES

Key paediatric cancer clinicians and researchers contributed their insights during the grant process and through surveys, identifying the critical questions that must be addressed to advance knowledge in cancer survivorship.



## PICS VCCOR R.E.G.I.S.T.R.Y. development framework

The development of this registry is built around our **R.E.G.I.S.T.R.Y. Framework**, a dynamic, interconnected structure consisting of eight key pillars. These pillars represent the essential components that drive the project's success, ensuring that all key aspects are addressed and integrated into a cohesive system.



## FAMILY INFORMATION SHEET

The family information sheet was developed in consultation with consumer representatives with lived experience, is designed to be clear, accessible, and not overwhelming. It includes information on purpose, privacy, confidentiality, security, access, and data management, ensuring consumers fully understand their rights and how their information is handled and protected.



## POTENTIAL FUTURE OUTCOMES

The VCCOR registry aims to improve paediatric cancer care by enabling research into potential late effects, and as a result, driving service improvement and updating standards of care.

- VCCOR will link with other data sources, to drive advancements in understanding and management of late effects and will enable service improvement by providing evidence to support new standards of care.
- VCCOR will enable better patient outcomes by supporting clinicians to identify and prioritise patients based on their risk for significant late effects for timely screenings, interventions and management of late effects.

Learn more about the VCCOR project



The Paediatric Integrated Cancer Service is supported by the Victorian Government