

Position Description


Health Data Lead: Patient-Partnered Research Development



Position Title:	Health Data Lead		
Reports To:	Direct	Dr Justine Ellis, Associate Head Research	
	Indirect	Head of Research	
Direct Reports:	N/A		
Position Type:	Part time, 15.2 to 19 hrs p/w (FTE 0.4 - 0.5) 6-month Maximum Term	Location:	305 Grattan Street, Melbourne (working from home as required during the COVID-19 pandemic)
Key Relationships:	Internal	<ul style="list-style-type: none"> • Patient-Partnered Research Development Team including: <ul style="list-style-type: none"> ○ Genomics Lead ○ Consumer Partnerships Lead ○ Digital Communications Lead • Patient-Partnered Research Project Governing Bodies • VCCC Research Team • Other VCCC Teams • Cancer Research Advisory Committee (CRAC) • Cancer Consumer Advisory Committee (CCAC) 	
	External	<ul style="list-style-type: none"> • Project Funder • International Research Collaborators • Cancer Centres across Australia and New Zealand • Hospital Medical Records Departments across Australia and New Zealand • Cancer Patients, Support and Advocacy Groups, Australia and New Zealand • Research Ethics & Governance Teams • Other key stakeholders as required 	

POSITION CONTEXT

The Victorian Comprehensive Cancer Centre (VCCC) has an opportunity to develop a patient-partnered cancer research project across Australia and New Zealand (ANZ). The project will be modelled on, and strongly aligned with, an existing international patient-partnered cancer research project. Working with consumers, the plan will be to adapt the project for the ANZ environment, bringing together existing clinical data and tumour specimens, collecting patient-reported data and additional biospecimens, and generating genomic data from both adult and paediatric research participants. Data would be de-identified, pooled internationally, and made freely available to the international cancer research community for discovery research.



In the first instance, the Funder has requested that VCCC alliance develop a proposal, setting out how the patient-partnered research project would be conducted across ANZ and the resources required to implement the project.

POSITION PURPOSE

The Health Data Lead will be responsible for developing the Health Informatics aspects of the Proposal.

The role will also be responsible for developing relevant sections of a Human Research Ethics Committee (HREC) application, which would be submitted following acceptance of the proposal by the Funder.

The Health Data Lead will work closely with the broader Patient-Partnered Research Development Team, including the VCCC Associate Head Research, and the Genomics, Consumer Partnerships, and Digital Communications Leads, to ensure timely and integrated development of the overall proposal. The Patient-Partnered Research Development Team will work with the international study team to map, apply and adapt processes and solutions for the ANZ environment. Effective engagement with a variety of stakeholders and service providers across Australia and New Zealand will be required in developing these solutions.

As a small and dynamic team, VCCC alliance staff, managers and program managers are expected to be comfortable and willing to manage their own administration, with limited amount of centralised support.

ORGANISATIONAL CONTEXT

Vision

The vision for the Victorian Comprehensive Cancer Centre (VCCC) alliance is to save lives through the integration of consumer-engaged cancer research, education and patient care.

Founded in the holistic principles of the internationally-recognised Comprehensive Cancer Centre model, the VCCC alliance brings together 10 of Victoria's leading research, academic, and clinical institutions to achieve what can only be done through state-wide collaboration. Together we will improve outcomes in cancer in metropolitan, regional and rural Victoria, and forge new approaches to cancer research, education, and patient care for all.

Operating Environment


The VCCC's multi-site, multidisciplinary model brings together the complementary strengths of Peter MacCallum Cancer Centre, Melbourne Health (including The Royal Melbourne Hospital), the University of Melbourne, Walter and Eliza Hall Institute of Medical Research, The Royal Women's Hospital, The Royal Children's Hospital, Western Health, St Vincent's Hospital Melbourne (including St Vincent's Institute), Austin Health (including the Olivia Newton-John Cancer Research Institute and Austin Lifesciences) and Murdoch Children's Research Institute.

The VCCC has a 3.5-year agreement to June 2024 with the Department of Health and Human Services to develop and implement new and innovative cancer research and treatment programs under an agreed Strategic Program Plan.

Our Team

VCCC is made up of a tight-knit team of staff who form the backbone working to facilitate the power of collective impact across the VCCC alliance and beyond.

Collective impact underpins 'how' we work and how we enable not only the work of the alliance, but how we positively influence the culture of our shared working experience. Collective impact starts by defining a shared problem and working together with our members, consumers and partners to codesign a shared vision to solve it. We agree on how to regularly measure progress, to not only communicate headway but to also allow for continuous learning and improvement.



The VCCC team foster and coordinate the expertise of the alliance and other partners to encourage and enable collective effort to achieve more than any single entity can achieve on its own. At the VCCC, our team, along with our distributed leaders, are our backbone. We are dedicated to facilitating the expertise of the alliance in the ambitious task of implementing sustainable systemic change to continuously improve equitable care and outcomes for cancer patients.

Team Purpose

Be known for enabling the best research-led cancer care for all

Team Values

Better Together *we connect and support to empower sustainable change*

Integrity *we are respectful of the cancer community and accountable for our contribution*

Bold *we cultivate ideas and dare to innovate*


Patient-Centred *we place patients with cancer at the centre of all we do*

For All *we champion equity of cancer care for every Victorian*

Main Responsibilities

- Working with international study staff to facilitate knowledge transfer, create a detailed map of international study processes related to:
 - Patient consent for access to medical records
 - Medical Record release requests to healthcare organisations
 - Development of a data dictionary and abstraction of relevant data from medical records
 - Collection of patient-reported data
 - De-identification and secure storage of medical and patient reported data
 - Linking of datasets, including genomics data
 - Other processes relevant to the capturing of medical and patient reported data for use in the study
- Identify aspects of these international study processes that can transfer directly to the ANZ environments and those that require adaptation
- Working closely with consumers through the Patient Partnerships Lead, recommend solutions that would enable the study to function in every state and territory in Australia and in New Zealand, and that represent optimal benefit and value for money
- Engage and build relationships with key stakeholders across ANZ, including healthcare organisations, medical record departments, patients, clinicians, study investigators and study teams, members of governing bodies such as project advisory committee(s), content experts and service providers
- Develop sections of the proposal relevant to the above domains, including detailed resourcing and budgeting and risk assessment, working closely with other Leads to ensure integration into the overall project proposal
- Develop relevant sections of a Human Research Ethics and Governance application, including participant information and consent forms
- Contribute to VCCC internal meetings, leading by example, sharing updates, knowledge and expertise and looking to improve and innovate at every opportunity

General

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- Share information and work collaboratively and collegiately with all VCCC staff, stakeholders and committees
 - Work in accordance with VCCC policies and procedures, following reasonable directions
 - Assist with or take on other relevant duties to support the VCCC team as reasonably required.

Special Requirements

- VCCC and the hospital building we work within is a smoke-free environment. All employees are expected to respect this policy to the fullest degree and with a very mindful approach
- Maintain a valid Right to Work in Australia
- Satisfactory completion of National Police Check. In some cases, a Qualifications Check may be required and will be advised prior to appointment

Key Selection Criteria:

Experience

- Experience accessing health data (especially hospital medical records) for research, including secure data storage and an understanding of applicable ethics and governance requirements
- Experience effectively managing the requirements of multiple stakeholders including senior academics, clinicians and researchers and senior stakeholders in industry and philanthropy
- Experience developing and writing research protocols and/or funding applications
- Solid experience in research budgeting and resourcing

Expertise

- Excellent understanding of and experience using project management frameworks and methodologies with enough experience and skill to adjust processes and problem solve to remove unnecessary complexity
- Proven time management and prioritisation skills
- Excellent written and oral communication skills, particularly writing with a targeted purpose and audience
- Well-developed analytical skills and the ability to synthesise information to resolve complex problems
- Solid understanding of Australian health information privacy laws
- Proficient in the use of Microsoft Office suite

Desirable

- Project Management, Process or Business Analyst experience
- Experience working with confidential and private medical records
- Experience and expertise in writing research ethics and governance applications
- Experience working with international research collaborators
- Experience working with online collaboration platforms

Qualifications

- Tertiary degree (or postgraduate qualification) in a relevant discipline such as public health, science, research



The Person

- Team oriented and skilled in building strong and sustainable relationships to build consensus and achieve stronger results together
- Shares ideas and welcomes alternatives from diverse stakeholders to drive solutions and overcome barriers
- Thinks laterally and pursues opportunities for innovation
- Consciously considers equitable approaches to cancer care to include and address the needs of vulnerable groups
- Comfortable in taking the initiative and exercising judgement with diplomacy and sensitivity in resolving matters as they arise
- Persuasive, with the ability to positively influence others and build consensus
- Innovative and adaptable in the face of changing organisational priorities and ambiguous
- Calm in dealing with time demands, incomplete information or unexpected events

Equity and Inclusion:

The Victorian Comprehensive Cancer Centre (VCCC) is an equal opportunity employer and is committed to providing a workplace free from all forms of unlawful discrimination, harassment, bullying, vilification and victimisation.

The VCCC makes decisions on employment, engagement, promotion and reward on the basis of merit. We are committed to all aspects of equal opportunity, diversity and inclusion in the workplace and to providing all staff, contractors, appointees, secondees, volunteers and partners with a safe, respectful and rewarding environment. This commitment is set out in more detail in the VCCC Equal Opportunity Policy and Bullying Prevention Policy.

Term:

The tenure of this 6-month role is linked to funding of the project Agreement. Potential opportunities for appointment beyond the term will be dependent upon further funding and operational requirements.