



# Position Description

<b>JOB TITLE:</b>	<b>Data Manager</b>
<b>DEPARTMENT:</b>	<b>Zero Childhood Cancer</b>
<b>THEME:</b>	<b>Personalised Medicine</b>
<b>REPORTS TO:</b>	<b>Zero Childhood Cancer Program Leader</b>
<b>LAST DATE REVIEWED:</b>	<b>1 December, 2020</b>

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## JOB SUMMARY

The ZERO Childhood Cancer National Personalised Medicine Program (ZERO) is Australia's first and most comprehensive personalised medicine program for children and young people. A unique, multidisciplinary program bringing together cutting-edge science, the latest technology, and the brightest minds in research and clinical care, it is on a path to change the model of care for children with cancer today. Having already demonstrated significant impact in improving the lives of children faced with the most challenging prognosis, the program is now in preparation to expand and grow to include all Australian children and young people with cancer by 2023.

ZERO is a joint initiative led by the Children's Cancer Institute (CCI) and Kids Cancer Centre, Sydney Children's Hospital, Randwick, and involves several national and international program partners which include eight of Australia's major children's hospitals and 23 research institutions.

This newly created position will report to the ZERO Program Leader, and work closely with other key relevant CCI teams, including Risk and Strategy Implementation, Technology Services Group (TSG) and Computational Biology (CB). The ZERO Data Manager will be responsible for overseeing the effective management of the increasingly large and complex datasets generated by the ZERO program. This role will involve managing, coordinating and implementing any necessary processes to ensure compliance and alignment with the organizational data management and governance frameworks.

The ideal candidate will have experience in managing numerous large and complex datasets, with a strong understanding of databases, genomic data, hospital data including protected health information (PHI) data, and data privacy and protection issues. This role will also be responsible for streamlining data migration and data tracking activities for these large, disparate data sets, from multiple sources such as the cloud and HPC environments, towards enabling the integrative analysis of this data by biostatisticians and other researchers.

This is a full-time role for three years. Remuneration includes access to generous salary packaging. The role will be predominantly based at Randwick, Sydney, with flexible working arrangements to work remotely.

## PRIMARY TASKS / RESPONSIBILITIES

- Working in collaboration with the CCI Chief Information Officer and Data Governance Committee in delivering and managing the data governance strategy and framework across the personalised medicine theme at CCI.



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- Establishing and implementing program procedures for the storage and retention of research data and records within the personalised medicine theme.
- Maintain data frameworks, business rules, data dictionaries, policies and procedures in alignment with CCI's data governance framework for the capture, management, dissemination and manipulation of the organisation's data, driving their adoption
- Ensure that business processes and procedures are aligned with the Data Governance Policy and Research Data Management Function Policies
- Maintaining a register of the establishment and ownership of databases and data repositories containing confidential information within the personalised medicine theme.
- Ensuring effective local protocols are in place to guide the appropriate use of data and materials
- Responsible for ensuring that all legal, regulatory, and policy requirements are met in relation to the specific data and that the data and materials conform to legal, regulatory, exchange, and operational standards
- Ensuring that the process for the administration of data and material is in accordance with the Research Data Management Lifecycle
- Responsible for the quality, integrity, implementation, and enforcement of data management within the personalised medicine theme.
- Develop a Data Register outlining data storage and access plans for the management of any data generated within the ZERO program.
- Ensuring that all Research Data is classified appropriately and registered in the Program Data Register
- Establish the necessary protocols and processes for the secure and efficient migration, tracking and onsite storage of data extracted from the cloud, HPC, or other partner sites.
- Collaborating with ZERO research partners to influence the data governance agenda and create a strong Data Governance culture across the organisation and ZERO partners network.
- Keeping abreast of changes to legislation and developing measures to adopt and implement those changes in harmonisation with the wider organization and incorporate the changes into current and future data policies and standards.
- Establishing a rapport with Research teams comprising of data users, stewards and custodians to work towards aligning with the FAIR data principles as well as national and global data sharing efforts; and incorporating Global Alliance for Genomics and Health (GA4GH), and other emerging bodies, guidelines/policies as they evolve coordinate data governance projects across multiple areas including data Framework, data Quality, data Risk, data Security and data generation and storage.

## MINIMUM REQUIREMENTS

### Qualifications

- Relevant tertiary qualifications in a data related discipline (e.g. computer science, bioinformatics, information systems, eHealth, statistics, mathematics, health sciences or other relevant discipline)
- Relevant post graduate qualifications and/or extensive relevant experience in Data or Information Security Governance and Compliance.

### Experience and requirements



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- Formulating management techniques for quality data collection to ensure timeliness, adequacy, accuracy and legitimacy of data
- Demonstrated experience in policy and guidelines development
- The application of privacy protection principles, with regard to sensitive personal information
- Understanding of linked administrative data systems, with knowledge of clinical health data being desirable
- Implementing and enacting policies for effective data management
- Providing expertise on data collection, analysis and reporting
- Excellent stakeholder management skills and interpersonal skills
- Strong professional written and oral communication skills
- Previous experience in health or medical research is highly desirable

## KEY SKILLS

- Confidentiality, sound judgement, initiative
- Ability to think pro-actively and creatively at strategic and tactical levels
- A team player with energy and enthusiasm
- Exceptional organisational capability with strong time management and the ability to work on multiple initiatives concurrently
- Strong solutions focussed analytical and problem solving skills with attention to detail
- Excellent interpersonal, verbal, and written communication skills, with proven ability to communicate effectively with stakeholders with varied skill sets and knowledge bases
- Ability to work independently, meet strict deadlines, demonstrate initiative, and respond and adapt rapidly to changes in priorities and the environment

## Children's Cancer Institute policies applicable

- Code of Conduct/Ethics
- Whistle-blowing
- Use of Electronic Resources
- Workplace Health & Safety
- Appropriate Workplace Behaviour
- Privacy

## SERVICE STANDARDS

- Respond to phone calls and emails within 48 hours



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## COMPLIANCE AND CODE OF ETHICS AND CONDUCT

Staff members are responsible for ensuring that they are familiar with and comply with their conditions of employment as stated in their individual contract, all Children's Cancer Institute Policies and Procedures and relevant ethical and regulatory guidelines. Staff must be aware that breaches by individuals will not be tolerated or condoned and may be subject to the Disciplinary Action Policy.

Your knowledge and awareness of Children's Cancer Institute Policies and Procedures (including the Code of Ethics and Conduct), will be monitored from time to time to ensure that our compliance program is effective.

Part of compliance adherence involves the use of standardised forms, checklists, and other aids (as appropriate) to ensure that important compliance issues are not overlooked. All forms must be used in accordance with instructions and the procedures as outlined in the relevant policies and procedures to ensure that compliance to the laws and regulations occurs.

## W H & S

- Must adhere to all WHS policies and procedures including reporting incidents within 24 hours
- Take reasonable care for their own health and safety and the health and safety of other people who may be affected by their conduct in the workplace
- Actively participating in health and safety meeting, training and induction programs
- Complying with all safe work procedures and instructions
- Use equipment in compliance with relevant procedures, without wilful interference or misuse
- Ensure that any hazardous conditions, near misses and injuries are reported immediately to the supervisor
- Must not wilfully or recklessly interfere with or misuse anything provided in the interest of environment health and safety or welfare

## REPORTING STRUCTURE

Position reports direct to: Personalised Medicine Program Manager

Departmental Structure: See Organisation Chart

**Note:** *Reporting structure may change subject to management decisions and business requirements.*