

An integrated Pacific Children's Cancer Registry:

A 5-minute cancer registry to improve clinical care for children in the Pacific

Michael Sullivan^{1,2}, Kirsten Ballantine³, Craig Evans⁴, Laila Saudaudau⁵, and Rigamoto Taito⁶

¹ Royal Children's Hospital, Melbourne, Australia ² University of Otago, Christchurch, New Zealand ³ National Child Cancer Network, Christchurch, New Zealand ⁴ MedSyn Software Limited, Auckland, New Zealand ⁵ Colonial War Memorial Hospital, Suva, Fiji ⁶ Lautoka Hospital, Lautoka, Fiji

Introduction & Background

80% of children and adolescents who are diagnosed with cancer live in low- and middle-income countries.¹ As the health of children in the Pacific improves, childhood cancer is emerging as a significant cause of morbidity and premature death. Historically, cancer care of Pacific children has been under resourced and ad hoc. Since 2006 a New Zealand sponsored program has supported cancer care in the South Pacific region.

The New Zealand Pacific Working Group, under the governance of the National Child Cancer Network, is responsible for supporting service delivery solutions that improve outcomes for children with cancer in Pacific Island countries. Key priorities have been the implementation of adapted treatment protocols in Fiji, Tonga and Samoa and the establishment of a structured twinning programme between clinicians in Fiji and the Children's Haematology Oncology Centre in Christchurch.

National data collection is essential in order to monitor access to child cancer services and to measure improvements in survival and quality of life outcomes. Recognising the need for timely and accurate data on the diagnosis, treatment, survival and outcome of childhood cancer, the Pacific Working Group and World Child Cancer Pacific Chapter have supported the development of a Pacific Children's Cancer Registry (PCCR).

Objective

- 1) To describe the development of the Pacific Children's Cancer Registry, a simple and secure hospital-based registry
- 2) To describe the additional functionality that has been incorporated into the registry in order to support clinical care and encourage sustained data collection in a busy clinical setting

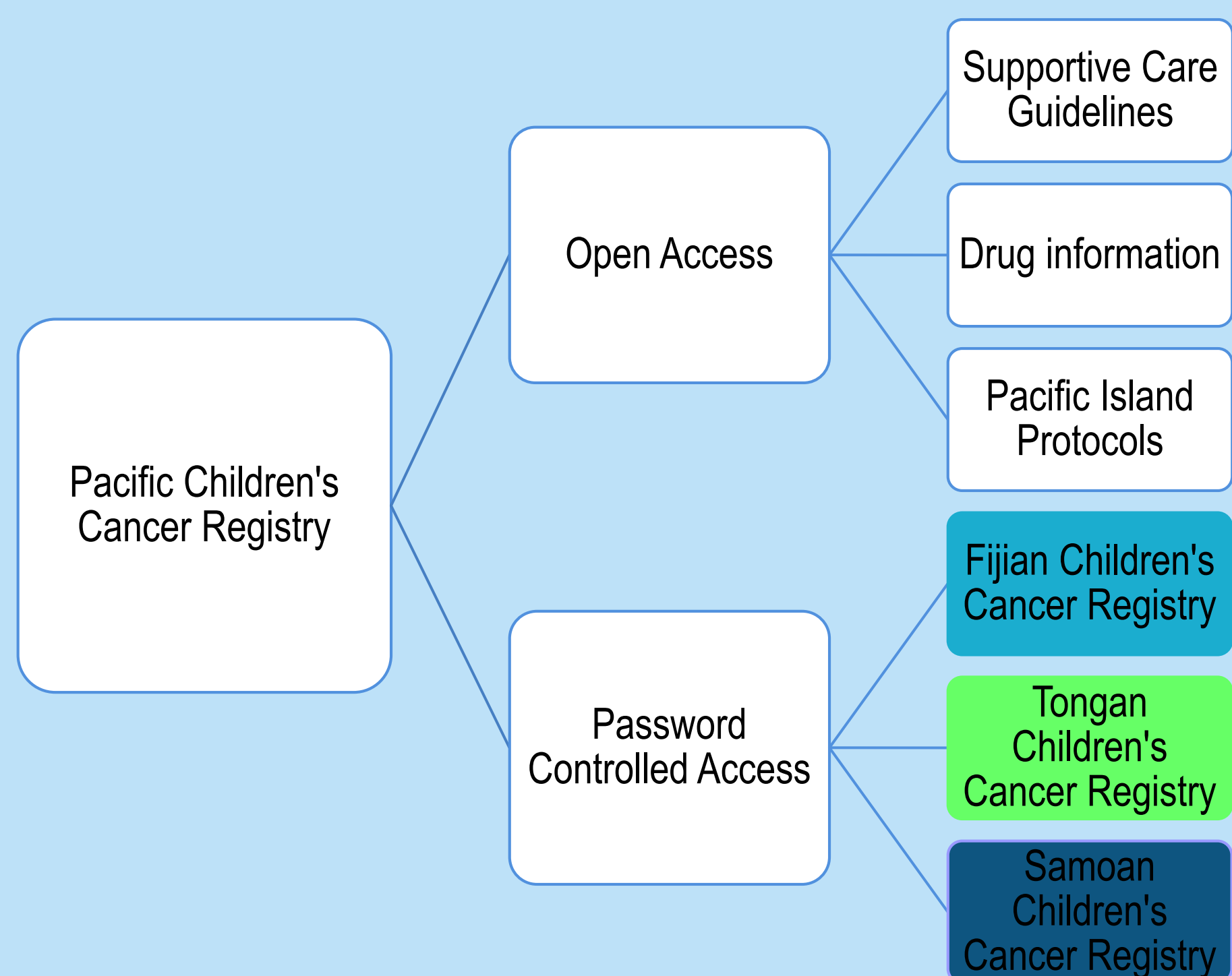
Registry Design & Structure

Registry design;

- Open source database MSQL
- Web based (Microsoft Azure cloud computing platform) with non-web based option
- Desktop, tablet, and smartphone cross-platform
- Configurable – core fields but modifiable for each centre / country

Registry structure:

- General information (e.g. protocols and supportive care guidelines) are freely accessible
- Registry access is password controlled



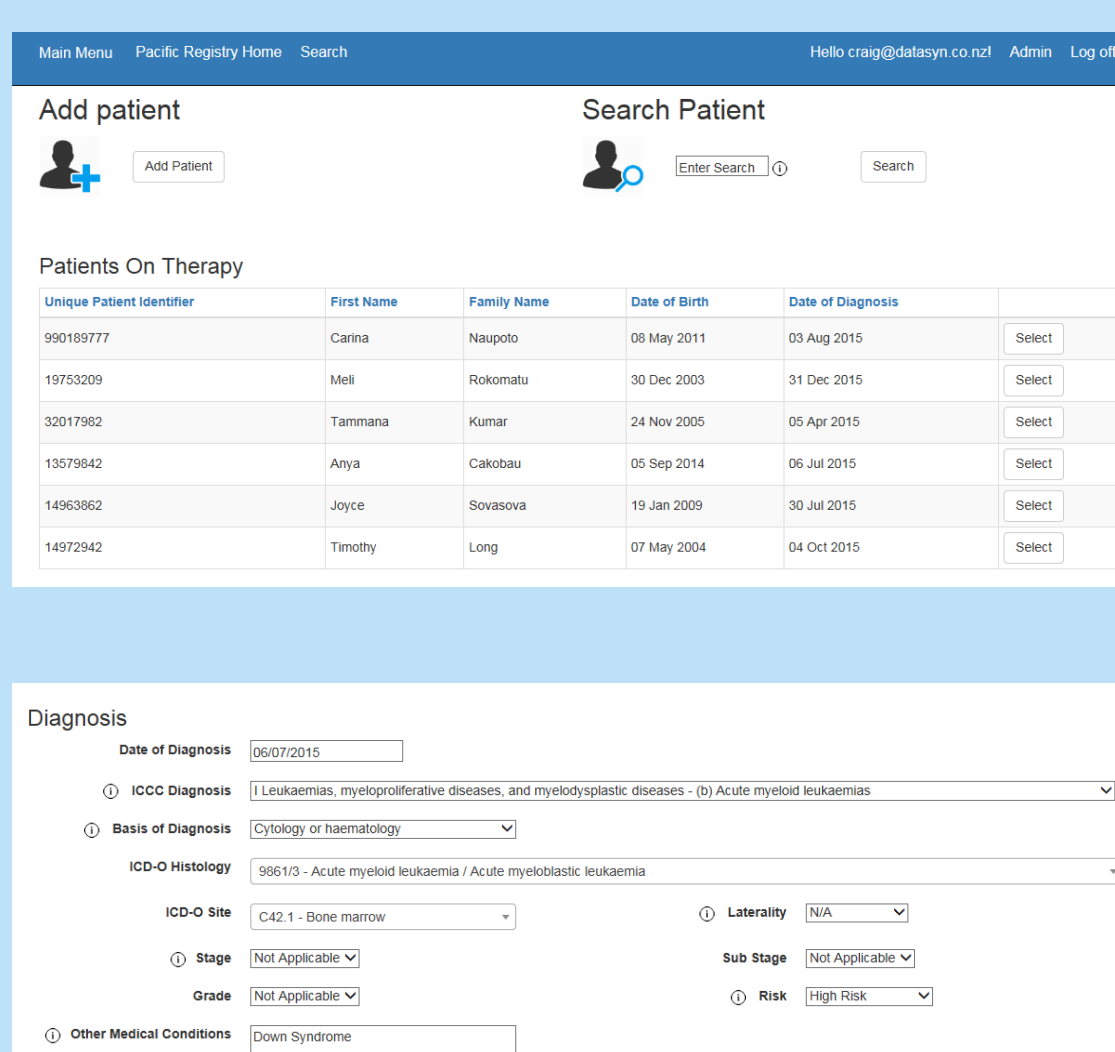
Governance

- A Memorandum of Understanding clearly defines the roles of all parties.
- Each country's registry will operate entirely independently under the direction of a Registry Reference Group and Registry Director.
- The Reference Group is responsible for ensuring that the registry meets all relevant ethical and legal requirements and facilitating the timely, regular and consistent analysis of registry data.
- IACR confidentiality² and registry development guidelines³ have been consulted extensively during the development of the PCCR. All users are authorised by the Registry Director and assigned a level of access appropriate to their role.

Key registry fields

The PCCR has an uncomplicated, user-friendly interface. Initial registration to capture all standard cancer registry data fields has been simplified to a 5-minute "on the ward" clinical task.

The PCCR collects all minimum demographic, diagnostic and status information according to IACR guidelines.² All cancers are classified according to the International Classification of Childhood Cancers.



The main screen lists all patients who are currently receiving treatment at each hospital.

All other patient registrations can be searched by unique identifier, (partial) name, date of diagnosis or date of birth.

Tool tips provide additional assistance for data entry when required

Drop down options are used wherever possible. Site and histology can be searched by code or partial word.

Additional Functionality

We have demonstrated with the New Zealand Children's Cancer Registry that it is possible to obtain highly accurate and comprehensive data when we establish a clear clinical benefit for patient registration. Following consultation with Fijian and New Zealand clinicians involved in the twinning programme, we have introduced a number of additional data fields and features to the registry;

Patient status: includes additional data fields such as reasons why a patient did not complete treatment in order to identify and address treatment barriers

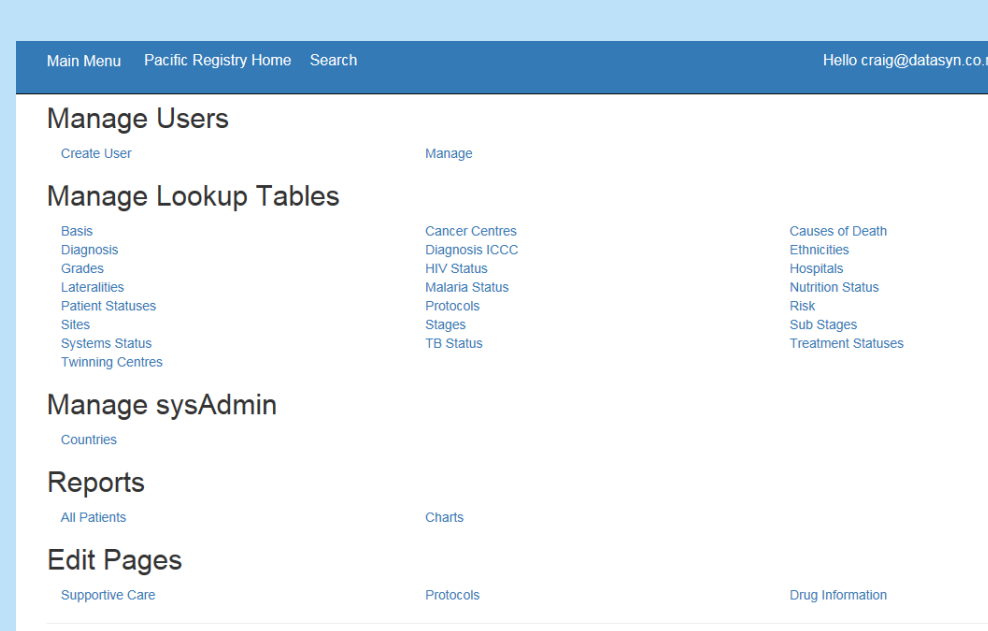
Medical history: provides a clear structure for recording the patient's relevant medical history

Treatment summary: includes start and end of treatment date and surgical, chemotherapy and radiation treatment information

Images and data: allows for secure data transfer for expert review

Case conference: for recording discussions during twinning meetings and MDM

Patient report: provides a printer-friendly patient summary for placement in the patient's medical notes



Manage Lookup Tables: allows changes to be easily made by the Registry Director as required

Reports: provides a panel of self-generating analyses and automated reports and allows full data download capability for data verification, research, and service delivery planning purposes

Conclusion

Currently in its development phase, the PCCR is intended to be a simple and secure web-based registry which will provide each Pacific country with their own country-specific children's registry.

In addition, the PCCR will include unique functionality to support clinical care, including an open-access repository of treatment protocols and supportive care guidelines.

References

- ¹ Rodriguez-Galindo, C. et al (2015). Toward the cure of all children with cancer through collaborative efforts: Pediatric oncology as a global challenge. *Journal of Clinical Oncology*, 33(27)
- ² International Agency for Research on Cancer (2004). *Guidelines on confidentiality for population-based cancer registration*. Internal Report No. 2004/03. IARC, Lyon
- ³ Bray, F., Znaor, A., and Cueva, P et al (2014). *Planning and developing population-based cancer registration in low- and middle-income settings*. IARC Technical Publications, 43. WHO Press, Switzerland

Acknowledgements

We thank the National Child Cancer Network and World Child Cancer Charitable Trust for their financial support of the development of the registry. Feedback from Fijian and Christchurch clinicians involved in the twinning programme has been invaluable.