



POSITION DESCRIPTION

Position Title: Australian Bronchiectasis Registry (ABR) Manager

Location: Melbourne, Australia

Employment Status: Full time

Reporting to: General Manager Clinical Programs Research & Innovation

Direct Reports: Nil

Date: January 2020

PURPOSE OF POSITION DESCRIPTION

The purpose of this position description is to document the purpose, desired candidate attributes and key responsibilities encompassed within the Australian Bronchiectasis Manager role. The key areas of responsibility and performance indicators are tied to performance review and career development. This document should be reviewed annually as changes in the organisation may result in the need to update the position description.

THE LUNG FOUNDATION MISSION

Lung Foundation Australia's (LFA) vision is to ensure that lung health is a priority for all in Australia and to promote lung health in Australia by:

- Promoting lung health
- Promoting timely diagnosis of lung disease
- Supporting those with lung disease and their carers
- Promoting equitable access to evidence-based care
- Driving quality research and raising funds for medical and scientific research;
- Influencing public policy, through advocacy across all levels of government.

THE LUNG FOUNDATION VALUES

The Lung Foundation operates under the principles and respect for the law and system of government, respect for people, integrity, diligence, and efficiency.

THE LUNG FOUNDATION ENVIRONMENT

The Lung Foundation has three offices with 20 professional / administrative staff based in Brisbane, 4 professional staff based in Sydney (the fundraising and development team), 2 in Melbourne, including the General Manager Clinical Programs Research & Innovation, supported by a team of dedicated volunteers.

POSITION SUMMARY

Working directly with the Australasian Bronchiectasis Consortium (the Steering Committee) and in close consultation with the Chair of the ABR Steering Committee, its sub-committees and members, the ABR Manager is responsible for leading the strategic development, implementation and day-to-day operations of the Registry.

This includes:

- Registry data management and quality reporting
- Maintenance of the Registry Data Dictionary (including ethics)
- Supporting PIs and users through the provision of training
- Advising / assisting ABR site PIs in relation to ethics
- Liaising with international registry partners and stakeholders to ensure a consistent approach / methodology to implementing bronchiectasis registries

SKILLS, QUALIFICATIONS AND KEY ATTRIBUTES REQUIRED (KEY SELECTION CRITERIA)

- Extensive experience in data management and analysis (experience in REDCap is essential, preferably at administrator level)
- Demonstrated experience in program development & implementation within the health sector
- Advanced project management skills, including ability to manage budgets and undertake strategic planning processes
- Highly developed stakeholder engagement and relationship management skills
- Highly developed written and verbal communication skills
- Prior experience / involvement with clinical quality and/or disease registries extremely beneficial
- Demonstrated ability to understand and manage issues of data privacy and ethics requirements and export, analyse and present basic data sets
- Demonstrated ability to work effectively with stakeholders to reach consensus and establish and implement processes
- Demonstrated proficiency in drafting, submitting and presenting scientific abstracts
- Ability to plan, deliver and report on projects and activity aligned to organisational strategy and identified priorities
- Experience overseeing and implementing clinical governance frameworks
- Experience engaging consumers in research related projects
- Integrity, adaptability and flexibility
- Proven leadership skills with ability to provide direction, supervision and support to staff and peers
- Ability to effectively and efficiently manage multiple work plans and competing priorities
- Attention to detail and excellent organisation skills

The following are non-essential but highly desirable:

- Experience of data privacy and ethics applications and approvals in Australia and across jurisdictions
- Knowledge of basic biostatistics
- Experience / relevant qualification in health or health sciences

BACKGROUND

The Lung Foundation launched the Australian Bronchiectasis Registry in 2016 to capture data on patients diagnosed with bronchiectasis, a chronic condition caused by chronic infection of the airways and results in chronic cough, excess sputum production, shortness of breath and coughing up blood. There is currently no cure for bronchiectasis and little information is available on the disease's incidence, diagnosis or mortality rates in Australasia.

Due to the large geographic distances in Australia, collaborative studies in this condition have traditionally been considered impractical. A National Bronchiectasis Registry across Australia provides a platform to study the epidemiology of bronchiectasis and create opportunities for collaborative clinical research within Australia. International agreements, (already in place) mean that the Registry has interoperability with other international registries, thus extending the research potential and translation.

The Australian Bronchiectasis Registry research project has the following strategic objectives:

- To provide a comprehensive registry of Australian patients with bronchiectasis
- To study the epidemiology of bronchiectasis patients in Australia (including risk factors for bronchiectasis and disease progression)
- To provide opportunity for patients to be involved in clinical trials for treatment for bronchiectasis
- To provide opportunity for individuals impacted by bronchiectasis to be involved in identifying research priorities and advocating for the needs of patients and families living with the condition
- To increase the awareness of bronchiectasis by physicians, the public, and government bodies
- To ensure patients diagnosed with bronchiectasis have a pathway to access Lung Foundation Australia's information and support service, including the respiratory nurse service as required
- To collaborate with other world centers
- To support and enable research translation, including key processes of care for bronchiectasis diagnosis and management and the development and dissemination of patient-centered educational and self-management resources, including supporting health professionals in their delivery.

REPORTING RELATIONSHIPS

The ABR Manager reports to the General Manager Clinical Programs Research and Innovation for day to day operational and high-level strategic matters. The Chair of the ABR Steering Committee plays a critical role in supporting the ABR Manager in detailed implementation of the ABR strategy and in supporting associated decision making.

EXTERNAL RELATIONSHIPS

The ABR Manager works closely with the Principal Investigators and their sites, ABR Steering Committee and Scientific Sub-committee members and key opinion leaders in non-CF bronchiectasis.

The ABR Manager works closely with representatives at each Registry Site to establish and maintain operations.

The New Zealand, American and Europeans partners are key relationships that the ABR oversees and maintains.

KEY AREAS OF RESPONSIBILITY AND PERFORMANCE INDICATORS

The major areas of work, organised as key areas of responsibility, tasks and performance indicators, are outlined in this section.

Key Areas of Responsibility	Tasks	Key Performance Indicators
Project Management	<ul style="list-style-type: none"> • In conjunction with the General Manger – Clinical Programs, Research and Innovation develop project plans and annual milestones • Executive support – arranging teleconferences, agenda, minutes and organisation of bi-annual meetings and attendance at meetings and conferences • Ethics – Work with the site representative to support ethics application, amendments and progress reporting • Coordinate with Australasian Bronchiectasis Consortium in relation to Registry setup • Help develop and manage standard IP and Registry agreements with each site • Maintain ongoing relationships with sites, monitoring relevant terms of the agreements including data quantity and quality metrics • Work with Steering Committee to agree project milestones and schedule. 	<ul style="list-style-type: none"> • Annual Project Plan developed • One Steering Committee face to face meetings per annum and three teleconferences per annum • Ethics approval for project in each state/territory/centre • Intellectual Property and Registry agreement for all collaborators completed within an agreed period of time from confirmation of participating • Progress against agreed project milestones.
Database Management	<ul style="list-style-type: none"> • Manage REDCap IT platform and perform administrator role for project setup, reporting as well as user and data access groups • Liaise with Principal Investigators to facilitate access to platform to relevant users • Develop operational documents to direct centre activity • Providing a 'help desk' function to users and liaise with IT in Europe and University of Sydney • System testing 	<ul style="list-style-type: none"> • Online ABR database is maintained • Online ABR databased meets Australian Health IT requirements • User access is maintained and within agreed timeframes • Ensure database is maintained within budget • Finalise and obtain ethics approval for new data dictionary; distribute and provide education accordingly • Develop training tools and provide opportunity for education on an annual basis to users
Data analysis and Research	<ul style="list-style-type: none"> • Assist in research projects under the guidance of Chair of the Australasian Bronchiectasis Consortium (steering committee) • Undertake data export cleansing and analysis for reporting 	<ul style="list-style-type: none"> • Accurate and appropriate monitoring of data quantity and completeness to aid successful operation of ABR.

	<ul style="list-style-type: none"> • Assist Steering Committee and Centres in the collection, coordination and analysis of their data • Assist international Committee in the coordination and analysis of the Australian data and reporting 	
Reporting	<ul style="list-style-type: none"> • Prepare reports and data for conferences and site-specific presentations • Develop and produce regular sponsor and stakeholder milestone reports • Develop and produce regular site reports on agreed metrics of data quantity and quality. 	<ul style="list-style-type: none"> • Annual reporting to ABR sites in benchmarking their performance with other comparable centres • Regular (at least bi-annual) reporting to ABC to aid monitoring, review and improvement of processes. • Annual data quality monitoring reporting to sites / Pls to improve data quality. • Monthly reporting on agreed measures / activities to aid LFA business plan reporting
Promotion	<ul style="list-style-type: none"> • Assist in the promotion of the registry to health professionals, including, physicians and general practitioners. • Respond to enquiries from health professionals who may register interest in participating in the ABR • Lead and coordinate a marketing and promotion strategy, including regular ABR newsletters to participating centres and relevant stakeholders • Organise and coordinate state and national education days and meetings to highlight the work and research of the ABR (e.g. TSANZ symposiums) • Support the ABR Steering Committee and participating sites to promote their work at annual meetings, forums and events, including conferences 	<ul style="list-style-type: none"> • A marketing and promotion strategy is designed, endorsed, implemented and reviewed annually thereafter • A calendar of events is developed for the coming year by December each year. • Enquires responded to promptly and professionally • Identify and approach existing forums that may be suitable for promoting Registry work and or research.
Consumer engagement and support	<ul style="list-style-type: none"> • In partnership with the ABC and its subgroups, design and implement a best-practice consumer engagement strategy to identify research priorities and progress the development of patient-centred information and education resources • Consult with the LFA Bronchiectasis Consumer Advisory Committee on the work of the ABR and collaborate where relevant to synchronise strategies and maximise resources • Respond to enquiries from ABR participants (bronchiectasis patients) and their carers; connecting them to LFA consumer communications, engagement opportunities, and 	<ul style="list-style-type: none"> • Consumer Advisory Panel governance policies, procedures and processes embedded into overall ABR governance structure (in alignment with LFA governance framework) • Consumer-centred research priorities are identified and incorporated into the workplan / priorities of the ABR scientific subcommittee and where relevant synchronised with LFA Bronchiectasis Consumer Advisory Committee workplan • Enquires responded to promptly and professionally, referral to Information and support Services as required • Unmet needs (information / tools / resources / services) are

	relevant information & support services as required <ul style="list-style-type: none"> • Work with the LFA Information and Support Service to develop suitable resources to meet the identified needs of the bronchiectasis consumer community. 	identified, scoped and prioritised for potential development in alignment with the LFA consumer engagement strategy and in consultation with the LFA Bronchiectasis Consumer Advisory Committee.
Budget	<ul style="list-style-type: none"> • Work with the General Manager – Clinical Programs, Research and Innovation and the ABR Chair and Steering Committee to identify funding opportunities, raise funds and liaise with sponsors (existing and potential) • Work with the General Manager – Clinical Programs, Research and Innovation and the ABR Chair and Steering Committee to develop and administer annual budgets 	<ul style="list-style-type: none"> • Potential funding opportunities are identified and pursued • Budgets are developed annually in alignment with LFA business planning timelines • Budgets are reviewed and forecasted monthly • Budgetary reporting undertaken quarterly to aid monitoring, evaluation and reporting on ABR projects / contracts and overall performance. • Projects are delivered on time and within budget

PERFORMANCE APPRAISALS

Performance review and career development discussions will take place annually with the General Manager – Clinical Programs, Research and Innovation. A mid-year review will also take place to ensure annual goals / objectives are on track for achievement.

ACCEPTANCE OF POSITION DESCRIPTION

This position description is intended to describe the general nature of the duties performed. It is not intended to be a complete list of all responsibilities, duties and skills required of the ABR Manager position. Other appropriate duties may be assigned that are not listed in the position description.

My signature below indicates that I have reviewed, accepted, and received a copy of this position description.

 Australian Bronchiectasis Registry
 Manager

 Date

 General Manager Clinical Programs, Research
 & Innovation

 Date