JOB DESCRIPTION TELETHON KIDS INSTITUTE



Why is this Job Description being written?			☐ New Position ☐ Replacement Position ☐ Position re-designed ☐ Position not previously described				
POSITION DETAILS	s:	Position Title:	SENIOR RESEARCH OF	ICER CHILD	DISABILITY RARE DISEASES PROGRAM		
Research Focus Area: Brain and Behavio		ur Team: Child Disability					
Position reports to: (role	:)	Head, Child Disability					
Location: include all possible locations 100 Robert			s Road Subiaco				
POSITION PURPOSE: In one or two sentences briefly summarise the overall purpose of this role, i.e. broadly, what this role does and why							
Oversee the governance, collection and management of and outputs from data relating to two innovative rare disease databases in conjunction with the co-heads of the Child Disability program KEY RESPONSIBILITY AREAS (Please list in order of importance)							
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Key Position Accountabilities What are the main areas for which the position is accountable	% of Total Role	<i>Inputs:</i> What are the key act	tivities or tasks to be carried out?		Outputs: What are the expected end results?	<i>Measures:</i> How it is measured	

Project Management	45%	 Develop an implementation plan for administration of next waves of InterRett and CDKL5 follow-up questionnaires Oversee the completion of the questionnaire instruments and web capture systems Management of the ethics process (applications, reporting and compliance) and approvals Oversee the administration of questionnaires and implementation of follow up strategies 	 Project plan timeline in place Questionnaires prepared for administration in a timely manner Ethics approvals or amendments obtained in timely manner Questionnaires administered and completed within the appropriate timeline 	 Documentation of meetings, agenda and decisions made Timely administration of questionnaires Response fractions
Relationship Management	15%	 Work collaboratively with all members of the Child Disability team Build and maintain consumer involvement in the questionnaire development Assist with the management of collaborations with investigators, consumers and stakeholders 	 Contribution to the working environment of the team Relationships and networks established Consumer involvement 	 Quality relationships achieved to progress project model
Research	25%	 Undertake or supervise the cleaning, coding and management of the data in preparation for analysis Undertake analysis of data in collaboration with other team members. Draft publications in collaboration with Child Disability heads 	 Ensure high quality data management High quality statistical analysis completed and outputs generated Timely output of publications 	 Documentation of data cleaning and decision rules.
Leadership	5%	 Work collaboratively to promote and build the reputation of the research group within the wider community, amongst stakeholders and researchers Participate and contribute to group meetings, strategic planning processes and cross focus area opportunities 	 Active and effective group member 	 Acknowledged as working collaboratively and effectively

Translation	10%	in the writing • Support trans	e preparation of presentations and workshops, and of reports, articles and other documents lating the research findings into practice and policy	High quality, timely oral and written reports	Usefulness of reports for investigators, consumers and community stakeholders		
ESSENTIAL SKILLS, KNOWLEDGE AND EXPERIENCE: Qualifications: what are the minimum educational, technical or professional qualifications required to competently perform role PhD or Masters Degree in health sciences/clinical discipline or equivalent.							
Skills, Knowledge & Experience: DESIRABLE SKILLS, KNOWLEDGE AND EX			 Highly developed interpersonal verbal and written communication skills, including demonstrated ability to work with families of children with a severe disability Demonstrated experience in building relationships and working collaboratively with families and/or clinical/research teams across multiple projects or sites Ability to set goals, manage multiple priorities, take initiative, work independently as well as collaboratively as part of a dynamic group Ability to build community and other stakeholder engagement Strong analytical abilities and practical experience in quantitative data analysis. Experience with data management and statistical analysis. Proven track record as author on peer reviewed publications 				
Qualifications: what a or professional qualification:	re the minim	um educational, technical					
Skills, Knowledge & Experience:			 Flexibility in working with an international study participant group some of whom may not speak English. Speaks languages other than English Experience in the use of Stata 				
SCOPE:							
Financial accountability: Does this role have accountability for a budget? No							
People responsibility: Does this role have any direct reports or indirect reports (through direct reports)? No							

Next level of Program Head supervision Immediate level of Head, Child supervision Disability Other roles reporting Senior Research to immediate Officer supervisor Direct reports (role x no.) ADDITIONAL INFORMATION: is there any additional information that needs to be understood to explain this role?

ORGANISATIONAL CHART: (please complete using position titles or insert diagram below)