

Terms of reference

PHSANZ Registry Committee

1. Oversee the running of the PHSANZ registry.
2. Act as an Advocate for PHSANZ registry for local site and/or state input.
3. Facilitate regular data collection, data updates and data cleaning of local sites.
4. Facilitate production of annual registry reports for PHSANZ, including report for the paediatric population.
5. Facilitate equitable access to registry resources and personnel, including data input and research projects.
6. Plan projects using data collected or linked to PHSANZ registry.
7. Provide final approval of registry use for submitted research proposals.
8. Research committee will have assessed scientific merit and recommended to the registry committee.
9. Maintain register of current projects, with completion dates.
10. Approve abstracts prior to submission, from registry projects.
11. Review process for assessment of non-research based registry data requests, liaising with PHSANZ board (including pharmaceutical industry and government).
12. Attract and provide supervision for potential students/fellows.
13. Participate in quarterly meetings, usually teleconference.
14. Manage and direct Registry personnel (statistician, software manager, project officer etc.).
15. Maintain up to date registry information on PHSANZ website.
16. Liaise with PHSANZ executive board (for finance, annual report, strategic directions).
17. Report to the Executive Board after each formal committee meeting.
18. Facilitate development of registry budget.
19. Aim for long-term sustainable registry.
20. Assist with applications for funding.
21. The committee shall consist of pulmonary hypertension care providers representing multiple medical specialties and shall include minimum 1 nurse.
22. Medical director must be approved by the PHSANZ Executive prior to commencing their two-year tenure.
23. Continuation of director beyond the two-year tenure will need PHSANZ Executive approval on annual basis.
24. PHSANZ sub-committee members may nominate themselves or be invited to participate by the committee.
25. Members may re-nominate themselves every 2 years, but there will be no maximum duration on the committee, in the interests of maintaining continuous engagement with contributing centres.
26. The PHSANZ Executive must approve all nominees.
27. If too many members wish to participate, the PHSANZ Board will vote on the composition of the committee.