

Tasmanian Cystic Fibrosis Service, Paediatrics
Submission to Tasmanian Government's Green Paper
Delivering Safe and Sustainable Clinical Services
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Why you should read this green paper submission:

- Highlights the strengths and challenges of working as an informal 'state-wide network'
- Provides evidence for the need of state-wide coordinators for clinical services
- Suggests some systems based solutions to current problems e.g. duplication of guidelines and resources, providing chronic condition care in an acutely focused system

About the Tasmanian Cystic Fibrosis Service, Paediatrics

The Tasmanian Cystic Fibrosis Service (TCFS), Paediatrics, cares for 60 Tasmanian children affected by cystic fibrosis. Apart from the state-wide coordinator of paediatric cystic fibrosis services, the paediatric health care providers at the Royal Hobart Hospital, Launceston General Hospital and North West Regional Hospital are responsible for a relatively small number of patients (i.e. between 11-30 patients). These health professionals provide care to CF as part of a generalist caseload. There is also additional support from the specialised cystic fibrosis team at the Royal Children's Hospital (RCH), in Melbourne, who conduct paediatric outreach services in Hobart, Launceston and Burnie once to twice a year.

By working together as a part of an informal state-wide network for 5 years positive patient outcomes have been achieved in:

- Lung function and nutritional parameters
- Quality of life
- Treatment burden
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Outcomes of the Tasmanian paediatric cystic fibrosis services (combined all regions) are on par with national averages.

Q. How well does the proposed framework (Tasmanian Role Delineation Framework) align with practice in your discipline?

A. Please see formal response to green paper submitted by the Women's and Children's CAG.

Additional point: We believe that the Tasmanian health service should have systems in place to support interdisciplinary care for people with complex chronic conditions such as cystic fibrosis. Interdisciplinary teams expand on the traditional multidisciplinary model, by

integrating discipline specific approaches into an integrated and coherent team based approach. Consequently, each team member has a common understanding and holistic view of all aspects of a patients care. For this approach to be successful one team member needs to act as an overarching coordinator – this can be done from any geographical location and in our experience can be done on a state-wide basis as long as there is local clinician support available to the patient.

Additional point: The TCFS (Paediatrics) has strong ties with the Royal Children's Hospital in Melbourne. In the past the Melbourne cystic fibrosis team provided direct clinical care. Today the Melbourne team provides more of a consultative and educational service (e.g. informal peer review and participating in formal educational events) so that Tasmanian clinicians can build up their clinical skills. This change has enabled Tasmanian clinicians to increase their own confidence in a supported environment. Tasmanian clinicians are also well aware of when they need to refer on for more specialised support.

Q. Where are the areas of service duplication in your discipline?

A. Before we started working as an informal network with state-wide coordination in 2010, there were no state-wide paediatric cystic fibrosis focused policies, procedures or resources (causing inefficiency, inconsistency and potentially suboptimal patient care). All cystic fibrosis resources and guidelines etc. are now created on a state-wide basis in accordance with the Australian Cystic Fibrosis Standards of Care. A cystic fibrosis clinical activity committee was set up across all regions to guide service developments and improvements. The state-wide coordinator role helps facilitate the agreed goals and projects.

Unfortunately (Feb 2015) all guidelines, forms and resources created by the state-wide cystic fibrosis network need to be approved independently by each area health service, with requirements varying significantly across locations.

Q. Where are the gaps?

A. There is no system to approve state-wide clinical guidelines and resources. While the CAG's play an important role, we believe that systems should be put in place to assist clinicians to work together across geographical areas.

Also, some disciplines (e.g. nurses) are currently not able to work across geographical boundaries – award limitations. At times this has limited input into state-wide projects.

Q. Are there any services being inappropriately provided, or planned, at your facility?

A. No

Q. How do we promote and maintain safe primary and community care to consumers such that they seek out these services rather than attend Emergency Departments when their conditions are more advanced?

A. Use of care pathways. Having a state-wide coordinator who is familiar with all patients and has access to their medical records, exacerbation management plans. Doctors including exacerbation management plans on patient-centred treatment plans – and scripts available in pharmacy (coordinator/nurse can direct patients to start antibiotics without contacting a doctor based on set criteria). Up to date treatment plans provided to GP, patient and medical records.

Q. How do we determine which services to focus on to expand the role of primary and community care?

A. See WACS CAG response.

Q. What services do not have sufficient volume or activity in Tasmania to maintain a safe, high quality service?

A. We have highlighted that by paediatric CF clinicians in Hobart, Launceston and Burnie working together that services quality can be improved. This is evidenced by benchmarking data now showing that Tasmanian patients have similar health outcomes to their interstate counterparts.

Q. What additional areas should we be considering for interstate partnerships in order to improve services within Tasmania?

A. In our experience, partnership is the key here. Interstate partnerships should help build up local clinician skills as well as provide additional experience. It is important to remember that evidence based practice = clinician experience (potential for interstate partnership), up to date research knowledge, and consumer experience.

Q. What services, despite comparatively low volumes, should we continue to invest in in Tasmania, and what interstate supports may be required to maintain them?

Paediatric Cystic Fibrosis Services in Tasmania fits into this category. Current arrangements with the Royal Children's Hospital in Melbourne provide good supports.