



Submission by the  
Australian College of Children and Young People's Nurses  
To  
Partnering With Consumers Program  
Australian Commission on Safety and Quality in Health Care  
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### **Opening Comments:**

ACCYPN welcomes the opportunity to comment on this important piece of work and commends the Commission on developing a statement focused on paediatrics.

ACCYPN has the vision to promote excellence in health care for children and young people in the context of their family and community. This also relates to excellence in care during and at the end of life. There is a view that the statement should be "care at the end of life" rather than "end of life care" to maintain the focus on the care as opposed to the end of life.

There are four key areas that ACCYPN would recommend should be expanded in the statement. These include:

- **The age - 4 weeks-18 years.**

It is unclear in the statement as to why neonates have been excluded. Infants born with life limiting conditions commence the pathway to end of life care in the neonatal phase. The other reason for inclusion is that the sick neonate is often being cared for in a paediatric facility. Some paediatric palliative care programs work with women and their families when a life limiting condition has been diagnosed in the antenatal period. Many of these children will die prior to 4 weeks of age.

ACCYPN would recommend that the age group be expanded to include neonates.

- **Bereavement Support**

ACCYPN considers that bereavement support needs to be expanded in the document. In the guiding principles an extra principle needs to relate to bereavement support. Bereavement support should be part of the plan of care prior to death and then following the death of the child.

- **Involvement of clinical ethicist**

The document refers to resources in a couple of places if conflict should arise. ACCYPN would recommend that a clinical ethicist and or clinical ethics committee should be considered a resource if available.

- **The Young Person's Rights and the need to advocate on their behalf**

The fact that the young person's management is incorporated into that of the child there are some aspects of caring for a young person that have been omitted. In the caring for young people it is accepted practice that if a young person is "Gillick<sup>i</sup> Competent" then they have the right to make decisions relating to their care.

This document states that the parent has the right to determine what communication occurs with the child. This statement could translate to a young person not being given the right to participate in their care decisions if the parents choose not to communicate the situation with the young person.

ACCYPN recommends that the rights of a competent young person needs to be included within the document. ACCYPN would also recommend that the Commission seek to have a Young Persons Health Advisory Committee review the document.

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<sup>i</sup> Gillick v. West Norfolk & Wisbech Area Health Authority (1985) 3AU ER 402