



Special Commission of Inquiry into Healthcare Funding

Submission Number: 149
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To: The Special Commission of Inquiry into Healthcare Funding

Dear Sir/Madam

I wish to address item B iii of the Terms of Reference:

“how governance structures can support efficient implementation of state-wide reform programs and a balance of system and local level needs and priorities”

In 2008 my infant child was diagnosed with acute myeloid leukaemia and treated at what is now the Cancer Centre for Children in the Children’s Hospital at Westmead (CHW). Since then I have been involved in a wide range of consumer and advocacy activities involving both paediatric/AYA oncology and children’s hospital related issues. This has included current or past membership of the following committees:

- Oncology Parents Advisory Committee (CHW)
- Family Advisory Council (CHW – pre SCHN) (Chair)
- Families and Consumer Council (FACC) – Sydney Children’s Hospital Network (SCHN)
- Quality Safety Committee (consumer member)– Sydney Children’s Hospital Network
- Australia New Zealand Children’s Haematology Oncology Group (ANZCHOG) – National Parent and Carer Advisory Group
- Consumer and Community Advisory Committee – Paediatric Services Building Development – Children’s Hospital at Westmead – Co-chair
- Consumer participant – SCHN paediatric cardiac care crisis Round Table organised by former Health Minister Brad Hazzard (27 July 2019)
- Cancer Australia pdCCRS Grant Review – external reviewer
- Leukaemia Foundation – Members Branch and Stakeholder Committee

My experiences with the above organisations has enabled me to gain useful insight into the issues concerning paediatric and AYA oncology care in NSW and the way in which NSW Health and NSW Cancer Institute prioritise the management of its treatment.

My most notable insight was gained by becoming a full member of ANZCHOG, receiving its specialist consumer training and attending several of its Annual Scientific Meetings held in various state capitals in Australia and New Zealand. This enabled me to visit children’s hospitals in Australia, meet both oncology staff, consumer related staff and other families of children treated in the oncology units of children’s hospitals in Australia.

Most notable has been to compare and contrast the ways in which the states of New South Wales and Victoria manage issues surrounding paediatric and AYA oncology.

However, I must first unequivocally state that the clinical treatment within both states are at the highest levels in Australia and the collegiate relationships between their oncologists, particularly fostered by ANZCHOG, ensures that every child and

young person with cancer gets the opportunity to access the best treatments which are of a world class standard.

Briefly, Victoria has established the following organisations and systems to ensure it has an integrated cancer service for its paediatric and AYA patients regardless of their location in Victoria. This includes:

- The Paediatric Integrated Cancer Service (PICS) which leads network paediatric cancer service across Victoria.
- Victorian AYA Cancer Service (VAYACS) (separate to the Canteen run services)
- The development of an Adolescent and Young Adult Optimal Care Pathway
- Regional Outreach and Shared Care Program (ROSCP)
- The Victorian Paediatric Cancer Consortium (VPCC) consisting of some 9 organisations (children's hospitals, universities, research institutes and a charity)

However, in NSW there is a different approach to the way in which NSW Health and NSW Cancer Institute manage paediatric and AYA oncology:

- Three stand-alone oncology units with the three children's hospitals, two of which are part of the Sydney Children's Hospital Network operate independently of each other with no integrated outreach service across NSW
- NSW Health does not seem to have an integrated strategy for paediatric and AYA oncology services – there is no equivalent to Victoria's PICS or VAYACS. During my involvement with SCHN FACC, I sought to understand the reason for this and met with an SCHN Executive to discuss this issue. The minutes of the 2017 meeting included the following action points (SCHN Trim number available):
 - **ACTION** – (*Name redacted*) to determine who is responsible for a statewide paediatric oncology strategy, and keep Laurence informed.
 - **ACTION** – (*Name redacted*) to contact (*name redacted*) when SCHN Oncology planning process begins, to ensure consumer engagement.

The above action points did not result in me receiving any further information on NSW paediatric oncology strategy and since then I remain none the wiser despite closely following NSW Health and SCHN publicly available information along with information from contacts.

I use the clear differences between the two most populace Australian states to demonstrate that the Inquiry's Terms of Reference must include, where appropriate, the requirement that it also consider whether NSW Health should review, adopt or adapt the methodology of similar services in other states. In my view the Special Commission of Inquiry should not review NSW Health as though it is a remote island's public health service when the Departments of Health in the other Australian States and Territories are delivering the same health care to their respective citizens.

Yours faithfully

Laurence Hibbert