



**NSW Health**  
**Hunter New England Local Health District**  
Palliative Care Regional Workshop – Newcastle  
9 June 2017

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# 1. Introduction

**On Friday 9 June 2017, as part of a broader process of developing its strategic directions for palliative care services, NSW Health hosted a workshop in Newcastle with consumers, health sector representatives, and academics to discuss the future of palliative care in the region.**

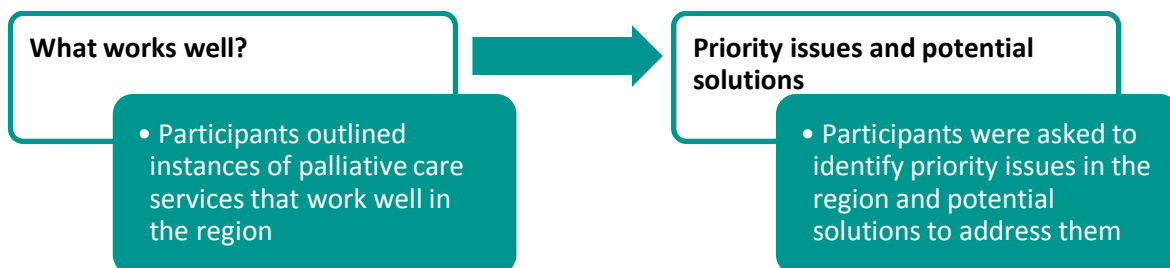
Approximately 50,000 people die each year in NSW and this number is expected to more than double by 2056. With a growing ageing population and an increase in chronic illnesses, the need to provide quality palliative and end of life care will also increase.

High quality palliative care and end of life care is presently provided by a range of health practitioners, both specialist and generalist, working together to ensure the broadest possible access to care. General Practitioners (GPs) and community-based services also have an important role to play. At present, more than half of all deaths in Australia occur in hospitals, though most people indicate that they would prefer to die at home.

The purpose of the Newcastle session, the last of a series of regional roundtables on the subject, was to hear what local stakeholders felt was working best in the region, what their priorities were for palliative care, and what solutions they proposed to the priorities identified.

The workshop was facilitated by Deb Cameron from independent communications and engagement agency, KJA, and commenced with a welcome address from Mr Michael DiRienzo, Chief Executive of Hunter New England Health, and Mr Scot MacDonald MLC, Parliamentary Secretary for Planning, the Central Coast and the Hunter. A number of participants spoke about their personal experience and expertise with palliative care services in the region.

Following this, workshop participants undertook two targeted, small-group discussions:



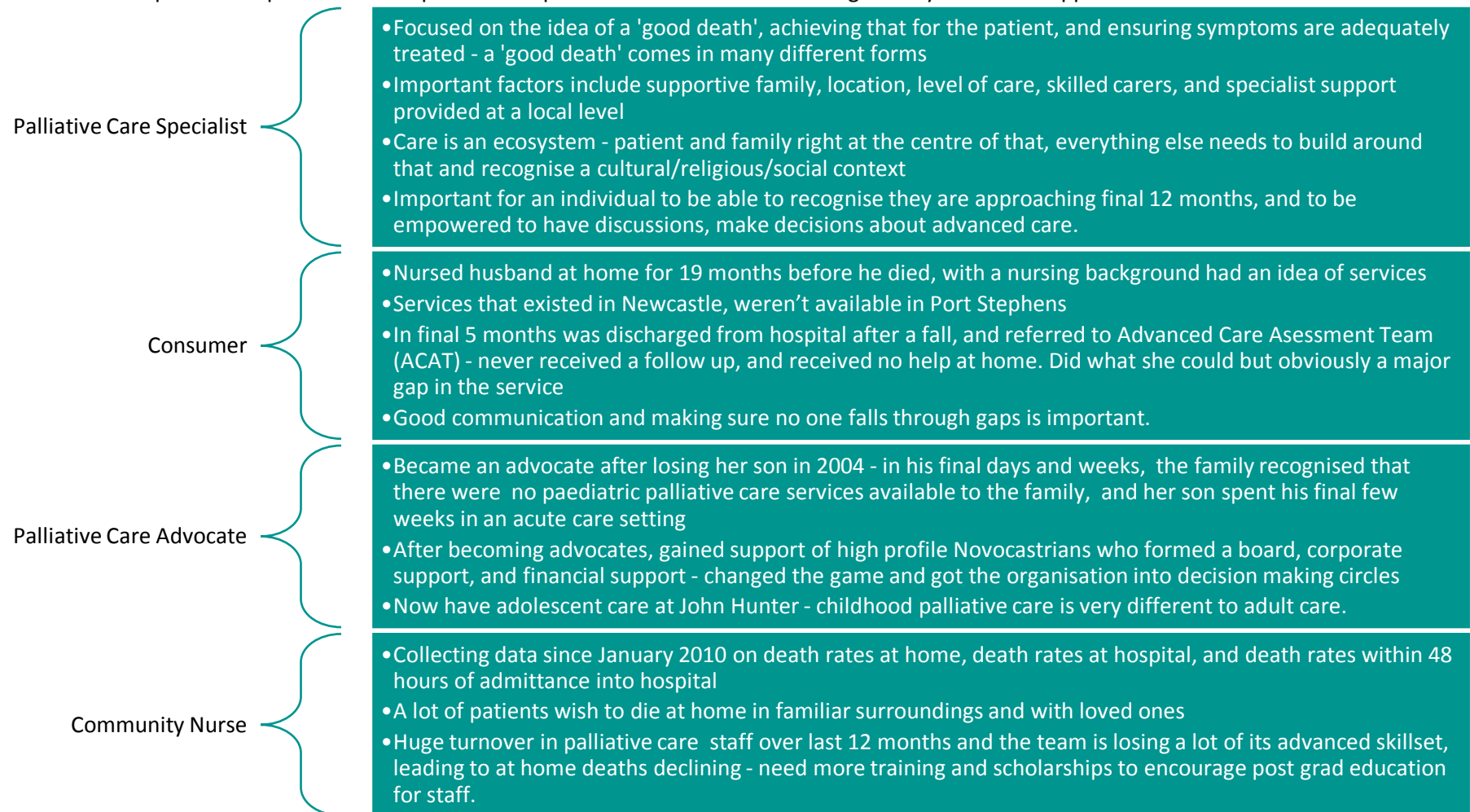
The results of these discussions are summarised in the following sections of this report.

Upon completion of the workshop series, an overarching summary paper will be prepared for NSW Health. This summary paper will inform NSW Health’s development of strategic directions for delivering services to best support people facing a life-threatening illness.

## 2. Workshop Outcomes

### 2.1 Palliative Care Perspectives

Participants spoke about their personal experience and expertise with palliative care services in the region. Key comments appear below.



2.2 **What Works Well?**

**“Where have you seen palliative care services in the region that work well and what did they look like?”**

Note: In addition to sharing palliative care services they felt were working well, participants suggested what was required for palliative care services to work well. This is reflected in the summary table below.

Key themes	What works well
<p><b>Specialised staff and a well-trained workforce</b></p>	<ul style="list-style-type: none"> <li>• Specialist palliative care services at <b>Calvary Mater Hospital</b> available</li> <li>• Having a <b>24/7 point of contact for carers</b> that they can call, with good access to medical records (e.g. LMNC Palliative care help line)</li> <li>• Responsiveness of <b>palliative care specialists</b> to requests for assistance from GPs is excellent</li> <li>• Experienced skilled staff allowing a focus of care – exceptional pockets of <b>excellence in aged care</b></li> <li>• The quality and level of care of the people in the <b>hospice and aged care sector</b> – have attracted ‘good people with good hearts’ and all about the patient and family and providing a positive experience</li> <li>• <b>Strong leadership</b>, good quality management and an inclusive team approach</li> <li>• <b>Nurse practitioners</b> (either palliative care or end of life practitioners) building a specialist workforce</li> <li>• <b>Lower Mountains Neighbourhood Centre</b> have analysed death rate data to look at how to improve development of palliative care and developed an 8 week volunteer training program</li> <li>• <b>Extra training and qualifications for nurses in palliative care</b> helps to improve quality of care, and succession planning for trained specialists – post grad education and experience</li> <li>• Ongoing <b>nurse education</b>.</li> </ul>
<p><b>Collaboration between services and communication</b></p>	<ul style="list-style-type: none"> <li>• Important no matter who is involved in caring for a patient, they must <b>communicate and plan well</b> together</li> <li>• <b>Good communication with GPs</b> to provide appropriate and timely medications for symptom management, and support from Health Pathways</li> <li>• Important that GPs can have confidence that they can <b>access extra info/assistance as needed</b></li> <li>• Early <b>referrals to palliative care team</b>, collaboration, and Ambulance Authorised Care Plans, and timely conversations about contingencies</li> <li>• <b>Multi-disciplinary team</b> including allied health and NGO’s, working together with a designated specialist clinical lead guiding practice - good communication and trust between health service providers</li> <li>• <b>Communication</b> is key, difficult conversations require skill – between specialists, with GPs, and importantly with patients</li> </ul>

	<ul style="list-style-type: none"> <li>• Health professionals having <b>clear conversations with families and patients</b>, using common language to indicate what stage the person is at, and indicate when palliation begins – this helps the family, carers and patients even though it may not change treatment</li> <li>• These discussions need to be done at the <b>‘right time’ for the patient family/carer</b>. Health professionals need to be able to pick this</li> <li>• <b>Integration of care</b> with good coordination – when an agreement of care is in place it works well</li> <li>• <b>Hunter Alliance</b> – MyNetCare communication platform which allows clinicians and consumers to link up supported by state and federal funded Government organisations.</li> </ul>
<p><b>Localised community care and volunteer assistance</b></p>	<ul style="list-style-type: none"> <li>• Care in community             <ul style="list-style-type: none"> <li>○ <b>Hospice care</b>, care in community – especially in metro areas</li> <li>○ Care in some of the <b>aged care facilities</b> done very well due to the dedication of the staff</li> <li>○ <b>In-home services</b> available in the Hunter area are providing excellent care and support</li> </ul> </li> <li>• Volunteers             <ul style="list-style-type: none"> <li>○ Working well in Maitland with great <b>connection between volunteers, patients and families</b> – respite is very important and care tailored to the families (reliant on dedicated volunteers)</li> <li>○ Motivation to continue as volunteer – personal experience with palliative care and want to give back/help others</li> <li>○ Volunteer <b>transport services</b></li> <li>○ ‘Palliative care volunteers were really helpful when my husband was really ill’.</li> </ul> </li> </ul>
<p><b>Service flexibility/ adaptability and community care</b></p>	<ul style="list-style-type: none"> <li>• <b>Telehealth</b> works well (Scopia) for accessing appropriate professionals – technology needs to be easy and intuitive             <ul style="list-style-type: none"> <li>○ Paediatric providing families with iPads, to be able to communicate via distance and get help when needed</li> <li>○ Connecting not just with specialists or carers, but with families at end of life</li> </ul> </li> <li>• <b>Afterhours care</b> options:             <ul style="list-style-type: none"> <li>○ Access to good advice 24/7</li> <li>○ Access to afterhours ‘rescue pack’ which has appropriate (agreed) medications if needed at health facilities, aged care facilities or pharmacies - if something is wrong and there’s no assistance, default to ED</li> </ul> </li> <li>• Importance of being able to access periods of <b>hands-on care</b> (nursing or allied health) when needed rather than having to go onto a wait list</li> <li>• <b>Visiting Medical Officer (VMO)</b> GP outreach</li> <li>• <b>Port Stephens community nurse</b> led service</li> </ul>

	<ul style="list-style-type: none"> <li>• <b>Partnerships</b> between Health and the community (equipment funding, beds, etc.)</li> <li>• Recognition of the <b>difference between care for children and adults</b>.</li> </ul>
<p><b>Patient-centred care , family support and choice</b></p>	<ul style="list-style-type: none"> <li>• <b>Patient centred care</b> <ul style="list-style-type: none"> <li>○ Ability to recognise when people are approaching end of life and transition to a palliative approach rather than an acute, curative approach whether in or outside of hospital</li> <li>○ Network vs patient centred care – change the focus to help the health service provide the care to the patient</li> </ul> </li> <li>• <b>Patient choice</b> <ul style="list-style-type: none"> <li>○ Dying in place of choice, or at least <i>having</i> a choice is very important</li> <li>○ There’s no ‘best’ place for end of life, but it is reliant on appropriate support</li> <li>○ Works well when someone is able to get palliative care in their place of choice, following a planned approach and team work</li> <li>○ For the family, control and choice over the situation is important, as is confidence in the people around you</li> </ul> </li> <li>• <b>Cultural Awareness</b> <ul style="list-style-type: none"> <li>○ Aboriginal health workers involved all the way until they are able to return to country – tends to work best when the patient comes from the rural/community settings</li> <li>○ Cultural ‘family room’ facilities to allow for a patient and family/group being accommodated and care provided in that space – preferably opens into garden</li> </ul> </li> <li>• <b>Supporting patients, families and carers</b> <ul style="list-style-type: none"> <li>○ Bereavement care</li> <li>○ Silver Chain self-administration of medication by carers</li> <li>○ Cancer Council – works well when focus is on the patient and family and they are well informed – focus on the emotional needs, practical, and spiritual needs</li> <li>○ Volunteer service to help with washing/cleaning etc</li> <li>○ Skilled bereavement care is a huge bonus for people who have access – Calvary Mater Hospital has a good service.</li> </ul> </li> </ul>
<p><b>Integrated Palliative Care into other services</b></p>	<ul style="list-style-type: none"> <li>• <b>Last Days of Life home care packages</b> to improve care in the home setting</li> <li>• <b>Hospice</b> type environment is great if available in acute facilities</li> <li>• <b>Nurse practitioners and nurse-led models of care</b> integrated with GPs and other community supports</li> <li>• Works well when there is good <b>integration of specialist palliative care services</b> into the general hospital with a multi-disciplinary approach – backed up with access to 24 hour service (focus on priority populations such as mental health (e.g. South Australia</li> </ul>

	<p>model)</p> <ul style="list-style-type: none"> <li>• end of life phase in an <b>acute setting</b> – the principles of palliative care can be used across all sectors</li> <li>• <b>'Home like' settings</b> – private quiet place, kitchen, equipment is hidden (e.g. Nicholas Trust Rooms).</li> </ul>
<p><b>Access to resources, facilities and support</b></p>	<ul style="list-style-type: none"> <li>• Adequate <b>access to equipment</b> in the community to make end of life easier and carer's life easier</li> <li>• <b>Equity of access</b> and timely access to equipment is important – important both health professionals and carers have knowledge on how to access equipment</li> <li>• <b>Primary Care Networks</b> aims to bring all of those external to hospital services together to the families             <ul style="list-style-type: none"> <li>○ Through the home base of primary care clinicians including aboriginal health practitioners to have a key primary relationship with families that are supported by specialist informed Palliative Care team</li> </ul> </li> <li>• <b>End of Life Care Nurse Practitioner Service</b> – Holistic approach, staff empowerment, individualised care, bereavement follow-up.</li> </ul>
<p><b>Recognition of palliative care broader than oncology</b></p>	<ul style="list-style-type: none"> <li>• Recognising palliative care is <b>not all about cancer</b> e.g. heart failure</li> <li>• <b>Renal supportive care service</b>, alignment of multidisciplinary palliative care and nephrology specialist care (and CNC, Dietician, Social work etc)             <ul style="list-style-type: none"> <li>○ Provides choice to patients, patient centred</li> <li>○ Could be scaled for other chronic diseases</li> <li>○ Improved clinicians ability and confidence in communication</li> <li>○ Different way of thinking about treatment options that will provide good care</li> </ul> </li> <li>• Renal care at <b>John Hunter Hospital</b> – the model they have is working really well – really focusing on chronic diseases.</li> </ul>
<p><b>Review and reflection on end of life experience</b></p>	<ul style="list-style-type: none"> <li>• Process to review/analyse <b>end of life information</b> to improve services is important and needs to be tested against people with lived experience</li> <li>• Having the opportunity to <b>look back at a patient's experience</b>, analyse it, assess what happened and what went well or could be improved.</li> </ul>



### 2.3 Priority Issues and Potential Solutions

“What are the priority issues that we need to address to continue to improve palliative care services in the region? What could be the solutions to address these issues?”

Small group responses to these questions are collated and summarised in the table below.

Ensure sufficient local resources are available	
Priorities	Possible Solutions
<p><b>Build the capacity of the palliative care system</b></p>	<ul style="list-style-type: none"> <li>• Make <b>recommendations to the Commonwealth</b> through the appropriate channels around amending accreditation to incorporate requirements around the care of palliative patients</li> <li>• <b>Case conferencing</b> similar model to Diabetes Alliance - case conferencing at the GP practice to benefit the individual patient and to up-skill GPs for the benefit of future patients</li> <li>• Better <b>access to medical records</b> across the various information platforms being used, eg: ‘MyNetCare’</li> <li>• Recruit the <b>right staff with the right attributes</b> to work with palliative patients and offer external clinical supervision for all staff working in palliative care</li> <li>• Designated and <b>appropriate room spaces</b>/facilities for patients and families</li> <li>• Palliative care staff do good work, but they are understaffed – <b>need more specialists</b></li> <li>• Emergency Department and <b>Intensive Care Unit (ICU)</b> presentations are becoming increasingly part of the process for people facing end of life</li> <li>• More <b>domestic support</b> e.g. shower, housework, social work and OT services</li> <li>• A <b>telehealth</b>-enabled hub</li> <li>• <b>Continuity of care</b> within teams.</li> </ul>
<p><b>Nurses and Nurse Practitioners</b></p>	<ul style="list-style-type: none"> <li>• Need more <b>specialist palliative care nurses</b></li> <li>• Provide <b>training for nurses/nurse practitioners</b> so that the system can be less ‘doctor dependent’ - access to scholarships</li> <li>• <b>Training for general nurses in palliative care</b> (what to expect, symptom, management equip)</li> <li>• Build up <b>palliative care skills for nurses</b> who are working in areas where there are no specialised palliative care services, with access to specialist advice when needed</li> </ul>

	<ul style="list-style-type: none"> <li>• Increased <b>support for nurse practitioners</b> for aged care, chronic disease and dementia</li> <li>• Equal emphasis on <b>non-clinical</b>, e.g. volunteers, spiritual, and bereavement to support consumers.</li> </ul>
<b>Aged Care/Palliative Care</b>	<ul style="list-style-type: none"> <li>• Expand the scope of the <b>aged care emergency service</b> and defining the responsibilities of both Residential Aged Care Facilities (RACFs) and ACE in the care of the dying patient</li> <li>• <b>24/7 registered nurse coverage</b></li> <li>• <b>Aged care facilities</b> need access to specialist advice and medication (availability of after-hours end of life medication kit that can be used by staff after hours on doctor's advice)</li> <li>• Augmented <b>Advanced Care Directives</b> – not just avoiding hospital, but also ways to get advice e.g. telehealth</li> <li>• <b>High skill set needed</b> in end of life care e.g. end of life champions, nurse practitioners to facilitate effective advanced care planning</li> <li>• Enabling <b>aged care services</b> to better provide EOL services to prevent admissions to hospital.</li> </ul>
<b>General Practitioners</b>	<ul style="list-style-type: none"> <li>• Better definition of <b>role of GPs</b> needed and access to GP when needed</li> <li>• Practicalities of being able to go to the <b>GPs</b> as the patient's condition worsens – so often nurses play major role</li> <li>• Problem of lack of <b>experience</b> with management of palliative care patients.</li> </ul>

Equity of access	
Priorities	Possible Solutions
<b>Access to medications and equipment</b>	<ul style="list-style-type: none"> <li>• General community availability of <b>after-hours rescue packs</b> and robust processes around this (defined number of medications in a recognised place)</li> <li>• Access to <b>occupational therapists</b> specifically for equipment prescription</li> <li>• State based funding for <b>home equipment</b></li> <li>• Access to <b>equipment and services</b> in a timely manner.</li> </ul>
<b>Equity of access to services</b>	<ul style="list-style-type: none"> <li>• <b>Geography</b> – further away from major centre available services differ</li> <li>• <b>Ability to navigate the system</b> – frustrations when one doesn't know where to start - need assistance to navigate</li> <li>• <b>Support for GPs</b> and practice nurses to increase their knowledge of what services are available e.g. PHN</li> </ul>

	<ul style="list-style-type: none"> <li>• <b>Rural and regional</b> support</li> <li>• <b>Nurse practitioner</b> models.</li> </ul>
<b>Chronic disease and access to support/palliative care</b>	<ul style="list-style-type: none"> <li>• Implement the <b>renal supportive care</b> model for all chronic diseases</li> <li>• <b>Timing</b> for this e.g. Motor Neurone Disease, oxygen clinic, heart failure, end stage liver disease</li> <li>• <b>Multi-disciplinary team</b> involvement</li> <li>• Support and <b>reassurance for carers</b></li> <li>• <b>Coordinated care</b> and earlier conversations around trajectory</li> <li>• Allows for <b>symptom management</b> in a more coordinated approach.</li> </ul>

Models and approach to Palliative Care	
Priorities	Possible Solutions
<b>Early engagement with Palliative Care and Planning</b>	<ul style="list-style-type: none"> <li>• <b>Ambulance authorised</b> palliative care plans</li> <li>• Use of the '<b>end of life toolkit</b>'</li> <li>• <b>Community awareness</b> and profile not understood or valued.</li> </ul>
<b>Funding models &amp; new models of care</b>	<ul style="list-style-type: none"> <li>• Expand <b>renal supportive approach</b></li> <li>• Review <b>incentives</b> e.g. Medicare</li> <li>• Palliative care <b>billing code</b> for consultation for non-specialists</li> <li>• Recognise that <b>euthanasia legislation</b> will be a significant challenge to palliative and end of life care.</li> </ul>
<b>Culturally competent and sensitive care</b>	<ul style="list-style-type: none"> <li>• <b>Culturally and Linguistically Diverse (CALD)</b> clients need better understanding of what palliative care can do and better access to services</li> <li>• After consultation with communities – increase in palliative care skill for <b>local health care workers</b></li> <li>• Employing more <b>Aboriginal staff</b> in all sectors and department – cultural support; connection with aboriginal community.</li> <li>• Dedicated <b>family rooms</b> – with view and access to outside – family and group support – areas for ceremonies.</li> </ul>
<b>Compassionate, planned approach</b>	<ul style="list-style-type: none"> <li>• Change in approach to <b>performance indicators</b> for end of life</li> </ul>

	<ul style="list-style-type: none"> <li>• A change of focus on <b>performance indicators</b> for people in the last 12 months of life</li> <li>• Improving or strengthening end of life ‘networks’ to empower and improve the care of individuals within that community – a <b>new ‘healthcare philosophy’</b>.</li> </ul>
<p><b>Better integration of services, especially in rural settings</b></p>	<ul style="list-style-type: none"> <li>• Need to find a way that all <b>the funding bodies can be best utilised</b> i.e. funds in one bucket– and driven by families and patients</li> <li>• <b>Hunter Alliance/ MyNetCare communication platform</b> which allows clinicians, consumers to link up supported by state and federal funded Government organisations.</li> </ul>



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