11<sup>th</sup> August, 2012

Health and Community Services Committee
Parliament House
George Street
Brisbane Qld. 4000

Email: hcsc@parliament.qld.gov.au

Dear Health and Community Services Committee,

I hope you will accept this late personal submission from myself as a Senior Clinician to this important Inquiry on behalf of the Senior Clinicians Supportive & Palliative Care Team on the Gold Coast. I feel that I owe the patients and their families on the Gold Coast the right to have this story told, so that this Committee can see for themselves the situation for patients and families facing the last 12 months of life on the Gold Coast.

This submission was unfortunately returned to me after the 6<sup>th</sup> of August deadline, with the request that I put it in as a personal submission instead as the Acting CEO and new GC HHS Board were unclear on how they could meet the deadline of the 6<sup>th</sup> of August to finalise this submission.

Over the last 4 years we have worked extremely hard on the Gold Coast building very close partnerships with the main NGOs (Blue Care, Anglicare& OzCare) and GPGC (now morphed into the Gold Coast Medicare Local. We have a Steering Committee that oversees these close partnerships and now have a regular group of about 15 GPs who have developed a Special Interest in Palliative Care. We, in partnership as a group put in a detailed bid for NPA funds in 2010 to expand our community care (with help from our NGO partners), increase our home-care and home death rate and develop virtual community bed equivalents and public hospice beds with a couple of RACFs on the Gold Coast. However, inspite of this we were unsuccessful and had to make a decision to severely curtail access to our services on the 9<sup>th</sup> of January this year (close 4 beds, no longer admit non-cancer patients, no urgent admissions after-hours over weekends etc.), so that our service did not implode and many of our senior clinicians did not suffer from "burnout" and leave to work in other more appropriately funded services. This submission is the detailed story of this journey as we have had to survive an increase in demand from both hospital and community referrers of >20% per year.

So, I hope you are willing to accept this late submission that tells the Gold Coast Supportive & Palliative Care Service provider and patient & family story.

Yours sincerely,

A/Prof. Rohan Vora

M.B.,B.S. (Uni NSW), FRACGP, FAChPM (on behalf of the Senior Leadership Clinical Team GC HHS)

# A/Prof Rohan Vora submission on Gold Coast Supportive & Palliative Care Service submission to the Qld. Parliamentary Inquiry into palliative care services and home and community care services in Queensland 2012

#### Introduction

#### Overview of GoldCoastHospital& Health Service (GC HHS)

- •Gold Coast HHS will cover an area extending from the New South Wales Border in the southto the Coomera region in Queensland and north to the LoganRiver
- •The HHS will serve a population of over 540,000 people which is forecast to increase to more than 680,000 by2021 (an increase of 26%)
- •Health Services are also provided to the Tweed area of Northern New South Wales
- •Over a quarter of the population within the HHS area (25.4%) were born overseas
- •8.7% of the HHS population speak a language other than English at home
- •Indigenous Australians make up 1.2% of the HHS's population which is 3.8% of Queensland's total IndigenousPopulation
- •The Local Government Areas within the HHS area are the Gold Coast City Council and part of the Scenic-RimRegional Council (Tambourine –Canungra).

#### **Facilities and Services**

- •The GoldCoastHospital and health Service (GCHHS) is a 908-bed service over two campuses in Southport and Robina plus multiple smaller community based facilities. The GCHHS offers services in all major health specialties, including coronary care, renal dialysis, elective surgery, emergency medicine, intensive care, obstetrics, oncology, outpatient services, paediatrics, psychiatry andrehabilitation
- •In 2012, Gold Coast Hospital Southport Campus will be transferred to a new 750 bed tertiary facility to create the Gold Coast University Hospital. The \$1.76 billion health facility will provide complex care, research and teaching opportunities on the Gold Coast and will play a key role in training the clinical leaders of the future

#### **General comments on Supportive & Palliative Care Service on the Gold Coast**

In a capped funding environment there is no new growth money and the Gold Coast S&PCS acknowledges this. However, we firmly believe that block funding grants in Qld. historically have not been given on a population or activity funding basis and has led to enormous inequities in funding for Palliative Care Services (see Appendix 2), this needs urgent redress if the gap between demand and service provision is not to widen. We also believe that the funds for high quality Supportive and Palliative Care are already being spent inappropriately in the acute care sector via inappropriate A&E presentations, occupied bed days in acute care rather than subacute care beds and in-hospital rather than in the community. However the concentration on A&E waiting times and decreasing elective surgical waiting lists make innovative and cost efficient longer term solutions for End-of-Life Care (last 12 months of life)<sup>1</sup> problematic to focus on. Funding appropriate, evidence based EoL Care & Palliative care in the last 12 months of life will free up acute beds, decrease A&E presentations, and replace inappropriate care with more appropriate Palliative Care in the setting of patient choice. We believe that a significant proportion of this EoL Care (last 12 months of life) could be more appropriately and expertly provided under sub-acute palliative care paradigms and much of it could

<sup>&</sup>lt;sup>1</sup> UK National End-of-Life Care Programme & Strategy plus 6 step Care Pathway: http://www.endoflifecareforadults.nhs.uk/

be provided out-of-hospital or in designated subacute Palliative Care inpatients beds if the Specialist Palliative Care Services had capacity to do so. Acute care delivered in the last several months of life often concentrates on disease modification and trying to achieve increased length of survival. Palliative & QOL outcomes would focus on;

- multidisciplinary symptom management,
- carer support,
- advance care planning,
- coordinating care across settings (at all hours where specialist Palliative Care provider capacity is adequate) as well as disease modification (if the potential benefits outweigh burden and the patient chooses this type of management),
- and finally diagnosing dying and providing expert Terminal Care to both patients and families.

This model of care can be provided in conjunction with public acute care, as well as through NGO and private partnerships, and this is the ideal context for "best practice", safe End-of-Life Care (last 12 months of life - see attached EoL Care diagram Appendix 1) that maximises patient choice.

#### Overview of the Supportive & Palliative Care Service (S&PCS)

The S&PCS is a very busy multidisciplinary service that cares for referred patients and their families in the last 12 months of life. The S&PCS services the whole GC HHS catchment area and works across Inpatients, Consultancy-Liaison (to both hospitals at Southport and Robina and the Health Facility at Carrara) and Community (within the GC HHS service area). We have developed strong collaborative working relationships with our local GPs (via General Practice gold Coast -GP GC), NGO Community nursing services (Blue Care, Anglicare& OzCare), local 8 bed Hopewell Hospice (private and DVA patients only) and our newly formed Medicare Local. We have formed a steering committee that meets regularly throughout the year and enhances our collaborative arrangements and we have weekly multidisciplinary case management sessions with our generalist nursing partners from the NGO services. We have also developed a GP Palliative Care Special Interest group and meet periodically throughout the year for up-skilling sessions, which are also attended by many GP Practice nurses and our NGO community nurses. Our overall budget is set for \$6.4million for 2012-2013.

### Current activity with designated beds (16 open of 20 available) in a specialist palliative care inpatient unit:

1,027 Referrals/yr
444 Hospital Referrals/yr
583 Community Referrals/yr
390 patients on our community register being case managed at any one time
384 deaths managed last 12 months
16% Home Death Rate of patients on our Register
360 Admissions to our Inpatient Unit/yr
5787 OBD/yr (483/month)
10.0 ALOS
90% Occupancy
Budget: \$6.4 million

#### Historical overview 2008-2012

In 2008 the S&PCS had 20 inpatient beds that were generally running at a 70% Occupancy level and there were typically about 200 patients and their families being cared for in the community at any one time. We were seeing about 90% cancer patients and 10% non-cancer patients. Home Death

Rate was ~5% of Palliative Care Registered patients. The annual budget was about \$4.7million. By the beginning of 2011 we were caring for 280 patients and their families in the community at any one time and we were seeing 25% non-cancer patients. The home death rate was ~9%. The budget was \$6.9million. By June 2012 the activity had doubled in comparison with 2008, going up at about 25% per year and we now have 390 patients and their families in the community that we care for at any one time. With a concerted effort and placing more medical time in community we managed to increase our Home Death Rate to 16%. The budget is now \$6.4million.

This level of service demand has been impossible to manage, even with the close partnerships we have developed with generalist community care providers (NGOs, GPs and Medicare Local) on our current budget and we have had to create various types of service access blocks as a demand management strategy. On 9th of January 2012 to prevent "staff burnout" and a complete collapse of the service we had to:

- 1. Decrease our Inpatient Unit from 20 to 16 beds
- 2. We **stopped taking on any non-cancer patients** (except Motor Neurone and Community Paediatric patients)
- 3. We **stopped admitting any acutely unwell patients after midday Friday** (as we did not have capacity for sustainable Consultant weekend ward rounding)

The result of these cuts have been to increase bed-block, with more Palliative Care Registered patients occupying acute ward beds (on average there are 10-12 Palliative Registered patients occupying acute ward beds at any one time) and attending A&E after hours. The demands for our service continue to rise and we may need to create even further access blocks, for our service to survive into the future.

Current Major service gaps for Palliative Care patients and their families on the Gold Coast are:

- No access for non-cancer patients (should make up ~50% of our workload) these are
  typically end stage chronic disease patients with cardiac, respiratory, neurological and renal
  pathology
- No access to Specialist Palliative Care for **RACF patients**
- No access to Specialist Palliative Care for Private Hospital Inpatients (we have no capacity to manage a Private Hospital Outreach Service), unless they are admitted to our public beds (this increases our bed-block even further, with ~25% of our beds occupied by Private patients at any one time).
- No capacity for outreach to our only Community Hospice Hopewell Hospice (only takes
  private patients and DVA patients of low complexity due to lack of any Specialist Outreach or
  up-skilling service)
- No public hospice beds
- No overnight respite or specialist nurse on-call overnight so home death rates are unlikely to go beyond the current 16%
- Minimal indigenous access to Palliative Care services due to lack of ability to provide adequate home-based palliative care

#### **Current Service Clinical Staffing Profile:**

Senior Medical: 2.5FTE Staff Specialists (+0.5FTE Medical Director) – supported by 2 registrar and 2 intern positions

Senior Nursing: IPU - 1.0FTE CNC (+ 1.0FTE Nurse Unit Manager) & currently 6.5 NHPPD<sup>2</sup>
Consultancy-Liaison - 1.0FTE CNC (unrelieved position)
Community 2.0FTE CNCs (one is a shared partnership position with NGOs)

<sup>&</sup>lt;sup>2</sup> Nursing Hours Per Patient Per Day - national standard is 6.5NHPPD, modelling based on PCOC data from Townsville Specialist Palliative Care Unit suggests that 7.5NHPPD should be the goal due to complexity of needs of referred Palliative Care patients and their families/carers.

Allied Health: Social Work 2.8FTE

OT 1.4FTE

Pharmacist 0.5FTE

Allied Health Assistant 0.8FTE

Modelling from various sources including Qld Health Palliative Care Service Planning Benchmarks suggests that we are very under-resourced:

#### Expected Public Beds for a population of 540,000 and based on current activity levels:

22 using Qld Health modelling and 29 using PCA modelling (assuming 20% should be private)<sup>3</sup>

**Gap: 6-13 designated beds** 

**Expected Specialist Doctors:** 

**5.4FTE** using ANZSPM Workforce modelling <sup>4</sup> & **8.1FTE** using PCA modelling <sup>5</sup>

**Gap: 2.5-5.0FTEs** 

**Expected Community Nurses**(PCA Service Planning Guide):

**3.4-4.5FTE** CNCs

Gap: 1.5-2.5FTE

**Expected Consultancy-Liaison Nurses** (PCA Service Planning Guide):

**2.0-3.5FTE** CNCs **Gap: 1.0-1.5** 

Allied Health Staff (PCA Service Planning Guide):

Gaps:

Physiotherapy = 2-3FTE Social Work = 1-2FTE

Occupational Therapy = 1-2

Pharmacist = 1-2

#### **Specifically addressing the Terms of Reference of this Inquiry:**

#### **Settings for Palliative Care Service Provision on the Gold Coast**

Supportive and Palliative care needs to be provided seamlessly across all settings (community home, RACF or hospice, consultancy-liaison in a non-designated hospital bed or inpatient in a designated palliative care hospital bed). Much palliative care is provided by GPs and Community nurses in community settings and non-palliative Medicine specialists in hospitals. There is also an 8 bed facility(CSCF Level 2-3 service) for low complexity Private and DVA patients at Hopewell Hospice on the Gold Coast. Patients and families would prefer for the End-of-Life care (last 12 months of life) to occur at home, including often even terminal care or "dying" at home if adequately supported. We have introduced a **Registration** and **Tracking** system so that we can catch up in a timely fashion with any of our **Registered Patients** who have been admitted overnight to acute care beds. Our Consultancy-Liaison Team attempts to assess and rapidly transfer our **Registered Patients** to subacute care beds or discharge them home, connecting them with Community nursing staff and GPs for ongoing care. Most patients and families (60%-90%) would prefer to be managed at home

http://www.anzspm.org.au/c/anzspm?a=sendfile&ft=p&fid=1310671368&sid=

<sup>&</sup>lt;sup>3</sup> Qld. Health Planning Branch - Adult Palliative Care Service Planning Benchmarks

<sup>&</sup>lt;sup>4</sup> ANZSPM Workforce strategy 2011-2015 and beyond

<sup>&</sup>lt;sup>5</sup> PCA: Palliative Care in Australia a Service Planning Guide 2003

rather than in hospital<sup>6</sup>, however they are not being given this choice. Home death rates in Qld. for even Palliative Care Registered patients are low (16%) where community care is not readily available<sup>7</sup>. However, where specialist Palliative Care access is provided round-the-clock the Home Death Rate for Palliative Care Registered patients is 50-60%<sup>8</sup>, <sup>9</sup>. We have been able to increase our **Home Death Rate** from **5% to 16%** and could go up to **50-60%<sup>10</sup>** if we had capacity to better support patients and families and support "virtual beds" or "bed equivalents" for many more of our patients to be able to spend more of their last several months at home and for more to be able to die at home if that was their choice. Without access to public hospice beds and no capacity for a Specialist Outreach service to any community hospice beds many of our patients end up having to spend the last few weeks of life in our inpatient unit beds, where they are well cared for. However, with adequate resourcing of community hospice beds (e.g. at some local RACFs, with increased & upskilled nursing staff numbers) some of the terminal care could occur out of our necessarily shorter stay "acute symptom management inpatient unit" (our ALOS 10 days - national average is 14 days).

As we have no capacity for Specialist outreach to the 89 RACFs on the Gold Coast, any RACF patients with complex palliative care symptom needs must be admitted via A&E to acute care beds to be referred to our service. These patients are stabilised and sent back to the RACFs, without any access to further Specialist Palliative Care oversight and may eventually die in an acute hospital bed, as most RACFS have limited capacity to deal with escalating symptoms and needs..

There is an emerging outcomes based and health economic literature that shows that early referral (prognosis of 6-12 months rather than just 1-3 months) to Specialist Palliative Care leads to higher patient and family/carer satisfaction, more appropriate care in the setting of choice rather than inappropriate or "futile" care in hospital, better quality of life for patients & families and cost efficiencies for the health system. Taking all this into account our S&PCS has been up-skilling GPs, GP Practice nurses and NGO community nurses in EoL care (last 12 months of life), providing a specialist on-call phone advice access service to all GPs and NGO community nurses round-the-clock Hence, we have been receiving earlier referrals already than many other Qld. Specialist Palliative Care Services, where the average time from referral to death is 45 days (PCQ submission to Senate Inquiry 2012). Our S&PCS has an average time from referral to death of 97 days and we are hoping that this will eventually reach about 6 months (N.B. the US Home Hospice Programme allowed length of stay is 6 months, based on health economic data showing that this maximises the decrease in use of expensive inappropriate largely hospital-based care and has higher patient and family satisfaction rates).

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<sup>&</sup>lt;sup>6</sup> Palliative Care Australia submission to the Senate Inquiry into Palliative Care 2012 (submission 98): http://www.aph.gov.au/Parliamentary\_Business/Committees/Senate\_Committees?url=clac\_ctte/palliative\_care/submissions.htm

<sup>&</sup>lt;sup>7</sup> PCQ Submission to the Senate Inquiry into Palliative Care (submission 130)

<sup>&</sup>lt;sup>8</sup> Silver Chain W.A. submission to Health & Hospitals Reform Commission 2009

<sup>&</sup>lt;sup>9</sup> St. Vincent's Brisbane: conversation about current data from Home Care Team 2012

<sup>&</sup>lt;sup>10</sup> Silver Chain submission to Health Reform Commission Inquiry 2009 & St. Vincent's Brisbane verbal report on recent data submission by their Specialist Home Care Team

<sup>&</sup>lt;sup>11</sup> PCA Submission to Senate Inquiry into Palliative Care: The benefits of palliative care (pp132-134)

#### **Home & Community Care Services integration with Palliative Care**

HACC services are commonly not provided for Palliative Care patients around Qld., even though many of their care needs are generalist in nature and only some needs are more specialist. On the Gold Coast we have managed to negotiate with our GCHHS HACC service provider to acknowledge this. However, there is no guarantee that this will continue. If these generalist needs are not funded they become a major drain on scarce Specialist Palliative Care community funds and will lead to even more frequent hospital admissions or inappropriate admission to RACFs. This problem needs urgent redress.

There needs to be better linkage rather than exclusivity between HACC, CAPS, EACH and EACH-D service providers. This is very confusing for care providers let alone patients and families. We spend a lot of time helping families negotiate the different funding silos.

MASCC is yet another complex are that can cost Palliative Care services a lot of time and money to negotiate or fund equipment themselves.

The move to make all patients under 65 come under state funding arrangements may further segment care and lead to further waste of time as the system is made even more complex and inequitable. Hopefully, this will not be the case and this welcome inquiry will decrease the barriers and funding silos to make care readily available based on need. Flexible funding packages can be one efficient solution to these problems.

Respite care is an essential part of Community Palliative Care and family/carer support and can potentially avoid unnecessary hospital admissions. This care needs to also include overnight respite care if we are to adequately support families who are caring for patients dying at home. We have utilised some one off funds to provide such a service in a limited way, so we are well aware of how to make this approach work.

#### Collaboration with Chronic Disease, disability, aged care and community services

The more EoL Care can be shared and the skills and capacity of existing community care providers enhanced the better for patients. This needs enhanced capacity of the currently inadequate Specialist Palliative Care workforce to be involved in training and supervising the generalist or non-Palliative Care Specialist workforce to provide high quality EoL Care.

Building collaborative and formal partnerships with other Community care Providers is vital for efficient and seamless community care round-the-clock. However, if patient and family safety and care quality are to be maintained then this requires a significant amount of training and supervisory plus on-call availability of the Specialist Palliative Care Service providers.

Currently people under the age of 65 who are unable to go home because of their complex care needs spend a very long time in hospital (3-5 months or more) whilst they are awaiting assessment by Disability Support Qld. for eligibility of further community care & support. For palliative care patients 99% of the time the answer is "no" and then ACAT can be consulted, a process that is a lot shorter (1-3 weeks) and the patient is then eventually placed in an RACF. This process is in urgent

need of streamlining for Palliative Care patients and families. It is traumatic for all concerned when patients deteriorate and die whilst awaiting the completion of the process.

Capacity of the Gold Coast S&PCS need to be greatly enhanced before the large service gap in not providing Palliative Care for non-cancer patients can be overcome. These patients would be expected to eventually make up 50% of our referrals (they were making up 25% of our referrals in 2011). There needs to be an urgent re-establishment of the links that we were developing before the essential 9th January service cuts with chronic disease service providers in the hospital and community settings: Heart Failure, COPD, Renal Failure and Aged Care services. However, a 50% increase in our referrals would be impossible to manage under current funding arrangements. A principle needs to be endorsed and adequately funded via any new Purchasing Agreements that all advanced disease MDT case conference and OPD clinics should have a Palliative Medicine Specialist and Specialist Palliative Care Nurse Practitioner/Specialist Palliative Care CNC present, if early Palliative Care referral is to become a reality and inappropriate or futile in-hospital care is to significantly decrease. Much of this work is consultative in nature and not measured in WAU activity. The move to ABF based on WAU allocations works against the required flexible model.

Community care capacity of our S&PCS needs to be enhanced before any meaningful engagement can be achieved with the Gold Coast Indigenous health services and indigenous patients can be cared for at home, with the attendant cultural requirements met..

A Community-Based system that formally changes the nature of ACAT from just a gate-keeping to a more integration of care provision role and links Palliative Medicine Physicians, other Specialist Palliative Care Service providers, Geriatricians and other Aged Care Service providers with Primary Care providers is long overdue and needs to be sorted out within HHS boundaries to best integrate the coordination of Community Care. A good model for this was proposed by the National Aged Care Alliance and submitted to AHMAC in 2006 - AHMAC & beyond - A Strategic Framework for Health Care for Older People: At home, in residential care, in hospital and in transition between settings. 12 There is also an urgent need for our S&PCS to establish links with the 89 RACFs on the Gold Coast, even if it is just for better integration of the Terminal Care Pathway validated for RACFs by Metro South Specialist Palliative Care Service and up-skilling of nursing staff and GPs to provide high quality Terminal Care in an RACF setting.

#### **Health Reform agenda issues**

#### **HHS & Systems Manager and an EoL & Pall Care policy**

Under the health reform agenda Qld. now has 17HHS, one Statewide Paediatric HHS and a Systems Manager to try to monitor patient safety and quality variances via purchasing agreements and linked transparent KPIs. Developing a rational and evidence based EoL Care Strategy (last 12 months of life) and a Palliative Care Strategy that aligns with and is implemented and funded in-line with the National Palliative Care Strategy is going to be a challenge. However, if any "block-funding" distribution is population based and uses a version of the Vic. PCRAM that is adapted to Qld. geographical and demographic characteristics and is specifically tagged for Palliative Care Service provision then we may see the development of an equitable system for Palliative Care access based on need for all patients and families living in Qld. Purchasing agreements based on ABF for

 $<sup>^{12}</sup>$  NACA Report to AHMAC 2006 : <code>http://www.naca.asn.au/pdf/AHMAC\_and\_beyond.pdf</code>

Community & Consultancy-Liaison Palliative Care service provision need to be designed and the Gold Coast S&PCS is very keen to work with Purchasing Branch to ensure that outcomes measured are evidence based, high quality and patient and family needs focused. We would be only too willing to pilot any ABF style systems to properly purchase quality, evidence based Palliative Care. The integration and use of the PCOC v3<sup>13</sup> minimum dataset across all arms of our service will have been completed very soon and will make ABF data collection more outcome based and meaningful when it is linked with benchmarking and other Continuous Quality Improvement activities. A critical issue is how community and consultation work activity is to be counted weighted and related to WAU purchasing – an issue that goes beyond palliative care services to several other community/ambulatory services.

At present the GCHHS S&PCS is self rated as a level 4 service under the Clinical Services Capability Framework. This level is reiterated in the service agreement for 12/13. The future vision is to develop a level 6 service by 2016.

#### ABF and purchasing quality, evidence based EoL Care in the setting of patient choice

Purchasing agreements under ABF need to be properly designed to buy high quality:

- Consultancy-Liaison services: one-off assessments and shared care measured and linked to outcomes in PCOC v3 dataset), multidisciplinary
  care coordination with community providers, advance care planning, family
  meetings etc. to enhance patient flow and decrease ALOS in acute care
  beds);
- Multidisciplinary Community Care and purchased bed-equivalents to
  maximise high quality out-of-hospital care. This needs to be round-the-clock
  support for generalist or specialist outOof-hours community nursing care
  providers +/- respite care in the home
- 3. **Flexible care packages** need to be purchased under ABF (as bed equivalents or via some other purchasing mechanism) to allow for the funding of equipment and consumables in the home setting.
- 4. Inpatient Purchasing needs to be monitored to ensure that care for very complex patients is appropriately purchased and that the multidisciplinary nature of Palliative Care is taken into account as well as the need for family/carer support.
- 5. **Up-skilling and capacity building** of the generalist, non-palliative medicine specialist workforce, junior staff and medical, nursing and allied health students in high quality EoL Care needs to be a standard feature of any Specialist Palliative Care Service. The time (approximately 20%) needs to be put aside for every discipline in the Specialist Palliative Care Service.
- 6. Expectations for measurement of high quality outcomes for EoL Care should be expected for generalists and non-specialist providing Palliative Intent Care if safety and quality care is to be guaranteed and access to quality palliative care based on need is seen as the right for all

9

<sup>&</sup>lt;sup>13</sup> Palliative Care Outcome Collaboration v3 data set March 2012 http://ahsri.uow.edu.au/content/groups/public/@web/@chsd/@pcoc/documents/doc/uow126175.pdf

- Queenslanders irrespective of diagnosis, prognosis, geography, economic status or ethnicity.
- 7. Quality, safety and continuous quality improvement are possible in Palliative Care using two national programmes: PCOC & NSAP. These complementary national systems allow for excellent continuous quality improvement and benchmarking based on outcome measures, self assessment against national standards and patient and family experiences. These need to form part of standard and expected Palliative Care practices and service should be funded appropriately to collect this data and undertake benchmarking processes. GCHHS S&PCS utilises both systems
- 8. Evidence Based EoL and Palliative Care need to be purchased Evidence of linkage with CareSearch<sup>14</sup> as the updated knowledge base for Evidence Based Clinical Decision Making. Evidence based Clinical Performance Indicators for EoL care can be developed in the 5 domains identified by the ANZSPM Clinical Indicator working Group: symptom management, advance care planning, carer support, ensuring continuity of care and Terminal Care.<sup>15</sup>

## Wider workforce related benchmarks need development and endorsement in Qld. Health for Palliative Care Service Planning across all settings

Benchmarks for Specialist Workforce need to be developed and accepted via Purchasing Agreements under ABF for all settings (Community, Consultancy-Liaison & Inpatient), currently the only Service Planning Guidelines are those provided by PCA in 2003, based on expert opinion (these are actually gaining more standing as time goes on both here and in the UK & Europe - EAPC). Some examples of generally used ratios are:

- 1.0-1.5 Specialist doctors /100,000 population
- Inpatient Unit nursing hours baseline is 6.5 Nursing Hours Per Patient Per Day (to allow for complex care and support of families/carers). However on modelling done in Townsville based on PCOC data analysing dependency scores for complex patients and families referred to Specialist Palliative Care it would seem that a baseline of 7.5 NHPPD would be closer to the necessary service benchmark to avoid staff burnout in a CSCF Level 4-6 Specialist Palliative Care Unit. There needs to be further work done on defining complexity and functionality/dependency measures to allow for transparent increases in this ratio at times to avoid nursing "staff burnout" <sup>16</sup>. In addition the role of social workers, OTs,

http://www.anzspm.org.au/c/anzspm?a=sendfile&ft=p&fid=1320265764&sid=

<sup>&</sup>lt;sup>14</sup> Care Search - the Palliative Care Knowledge Network database http://www.caresearch.com.au/caresearch/tabid/62/Default.aspx

<sup>&</sup>lt;sup>15</sup> ANZSPM EoL Clinical Indicators - draft Pain Indicator set:

<sup>&</sup>lt;sup>16</sup> N.B. UK ratios of 1.0FTE nurse/1.5 Patients have been endorsed for some complex palliative care patients Royal College of Physicians Report on working in Palliative Care 2008 http://bookshop.rcplondon.ac.uk/contents/7920ccc4-1b69-40ff-ab2a-3bbb383023a7.pdf

- physiotherapists, pharmacists, allied health assistants, personal care assistant and adequately trained and supervised volunteers needs to be properly considered as well, as this component of the workforce influences the degree to which nurses might have to pick up additional tasks.
- Case loads for Community staff e.g. 50-75 patients for shared care coordination with generalist community care providers for CN level Specialist Pall Care nurse or 75-100 patients for a CNC Level nurse

#### **Recommendations**

- Develop a Qld. Palliative Care Strategy to align with the National PC Strategy with timelines to measure implementation targets against (e.g. SA Plan, Vic Strategy and implementation & PCRAM funding strategy)
- Commission CPCRE to do a study into determining population-based palliative care needs across Qld. (e.g. NZ study - Wayne Naylor 2011)<sup>17</sup>
- Develop an EoL Care Strategy for Qld. (last 12 months of life) with relevant Clinical Indicator set to measure quality and evidence based EoL care provision.
- Promote Palliative Care Services as significant players in the last 12 months of a patient's life in any Service Planning or Purchasing Agreement design undertaken in the future by Qld. Health.
- Develop a strategy for promoting a sustainable and skilled multidisciplinary Palliative Care
  workforce with transparent and accepted benchmarks for service provision based on
  population need projections, linked to accepted key competencies across the professions
  and a means of developing those competencies
- All advanced disease MDT case conferences and OPD Clinics to have a Palliative Medicine Physician and Specialist Palliative Care Nurse Practitioner/CNC present
- Fund Palliative Care Services to build capacity for high quality EoL Care amongst generalist and non-palliative care specialist providers in hospital and community.
- Develop Service Planning Benchmarks for Palliative Care beds that include both Community & Consultancy-Liaison services provision to allow for increased home care (virtual beds or bed equivalents) and improve patient flow from acute care beds to subacute care or directly back to community.
- Develop Purchasing Agreements that allow for the funding of Hospice Beds with adequate
  nursing staff cover to manage patient symptoms and cares in the last 12 weeks of life, where
  they cannot be managed at home (e.g. the patient has no carer or the partner is too "frail"
  to manage the care needed N.B. these beds can be contracted in RACFs or stand-alone
  hospices, if available, but will need increased and varying levels of trained nursing staff
  support depending on the level of patient complexity).
- Service Planning Benchmarks need to be developed that include ratios for a sustainable skilled workforce that has capacity to provide high quality, evidence based Palliative Care (based on WHO definitions) and population need across all settings round-the-clock and able to build capacity for high quality EoL Care amongst generalist and non-Palliative Care Specialist service providers.

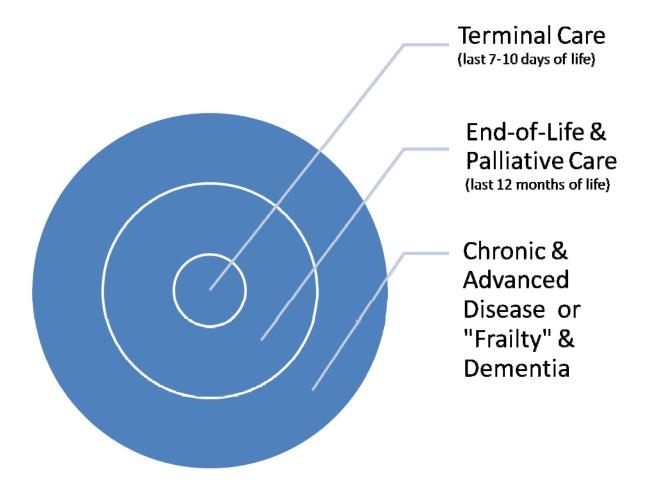
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<sup>&</sup>lt;sup>17</sup> National Health Needs assessment for Palliative Care - N.Z (Wayne Naylor) 2011 http://www.southerncancernetwork.org.nz/file/fileid/38055

 Develop Purchasing Agreements for Palliative Care for all Queenslanders based on population need and incorporating the principle of purchasing quality, evidence based care with proper measurement of evidence based outcomes and patient and family experiences via the two validated measurement systems we have PCOC & NSAP. This work will require a collaborative effort between HHSs and the system manager to properly cost and non ABF S&PC services.

Appendix 1

Are Seamless Transitions through Health Care paradigms and across health care settings based on need possible in the last few years of life?



Many G.P.s and other non-Palliative Medicine/Care Specialists need urgent up-skilling in end-of-life care. However, education and building generalist capacity for skilled end-of-life care is rarely funded as an essential part of Specialist Palliative Care activity

#### Appendix 2

The patchiness of Specialist Palliative Care in Qld. can be easily demonstrated by looking at the following table from the Planning Branch of the Systems Policy and Performance Division (2012)

Table 1: Public facilities with designated palliative beds

HSD	Facility	Designated beds	CSCF v3.0 Level
Darling Downs	Toowoomba	4	4
Central Queensland	Rockhampton	9	4
Gold Coast	Gold Coast Hospital	16	4
Metro north	Redcliffe	16	5
	The Prince Charles	16	6
Metro South	Logan	8	5
	QEII	10	6
Sunshine Coast	Caloundra	10	5
	Gympie	2	3
Townsville	Townsville	20	6
West Moreton	Ipswich	10	5
Total	211 20024 200	121	

population
300,000
225,000
540,000
900,000
1,000,000
390,000
240,000
220,000

Source: Designated bed numbers sourced from the Monthly Activity Collection in May 2012. CSCF v3.0 service levels sourced from Access Improvement Service, Centre for Health Care Improvement.

#### **Corrections:**

Townsville is currently funded for 15 beds and organised to nominally open another 5 beds as demand increases over the next several years

#### **Specialist Palliative Care Services missing from this list from are:**

#### **Metro South HHS**

Mater Level 5-6 Service with 10-12 beds in an integrated Onc/Haem Ward (Public)St.

Vincent's Level 5-6 Service with 32 beds (18 public and 14 private)Greenslopes Level 4

Service with ?6-8 beds (Private or DVA only)

Wynnum/Redlands 6

beds (Public)

#### **Metro North HHS**

Wesley Level 5-6 Service 20 beds (Private or DVA only)

#### **Gold Coast**

Hopewell Hospice Level 2-3 Service 8 beds (Private or DVA only)

#### West Moreton/Ipswich

Ipswich Hospice Level 3 Service 6 beds (Public & Private)

#### **Darling Downs/Toowoomba**

Toowoomba Hospice Level 3 Service 6 beds (Public & Private)

Toowoomba Hospital now increased by 8 beds (Total = 12 Public Beds)