

**Committee Chair**

Health and Community Services Committee  
Parliament House, Brisbane Qld 4000  
By email: [hcsc@parliament.qld.gov.au](mailto:hcsc@parliament.qld.gov.au)

6 August 2012

Dear Mr Peter Dowling MP,

**Inquiry into palliative care services and home and community care services in Queensland.**

This submission is directed to the current inquiry into palliative care services and home and community care services in Queensland. We thank you for this opportunity to contribute our Greater Metro South Brisbane Medicare Local perspective into the inquiry.

**About Us**

The Greater Metro South Brisbane Medicare Local (GMSBML) was one of the first Medicare Locals to be established in 2011 as part of the Australian Government's national health reform program. Our aim is to respond to local needs, improving access and delivering locally designed, effective and coordinated primary health care services to our community. Performing a critical planning, coordination and integration role GMSBML works to identify and respond to gaps in service delivery with our partners, brokering access to services across the community, and working collaboratively with health and community service partners to achieve the best patient centred care outcomes possible.

**About Our Community**

Geographically, the GMSBML catchment includes a wide range of diverse localities including inner urban high density communities and many newly developed housing estates, suburban belts, as well as rural, remote and island areas. Diversity across the region includes a broad and high ethnic and cultural population mix with 1.9% Aboriginal and Torres Strait Islanders, 12% CALD with over 100 different ethnic backgrounds represented by residents of Logan City and its surrounding areas.

GMSBML's population demographics show a significant proportion of aged and children 0-5, with projected total population growth in South East Qld (including Brisbane East, Brisbane South, Scenic Rim and Moreton Bay South SL 4) by 2031 by 30% (Table 1), and an extreme 114% population growth for those aged >65% to 2031<sup>1</sup>.

Within these boundaries are almost one million consumers, hundreds of primary health care providers (Table 2) including 249 general practice clinics, 1033 general practitioners, 189 community pharmacies, 228 allied health providers and 62 community organisations. The GMSBML had over 8.9 Million billable services in

2011. The majority of the region (67%) records a SEIFA Index of Relative Socio-economic Disadvantage above the national average but significantly lower than the average for Metropolitan Brisbane<sup>2</sup>.

Population of Medicare Local	Number
Total population	897,594
Aged under 5 years	64,647
Aged 65 and over	97,837
Aged 85 and over	12,566
Indigenous population	15,336
Population born NES countries	99,972
Estimated unemployed	34,494
Pensioner concession card holders	146,308

Table 1: Population Demographics

### Health Care Services in the GMSBML Region:

Health services	Number
General Practices	249
General Practitioners	1033
<b>Palliative Care Services</b>	<b>3</b>
Public hospitals	7
Other Qld Health facility	1
Aboriginal Torres Strait Islander Community Health Service -(ATSICHS) sites	4
Aboriginal Medical Services	2
Community Health Centres	6
Residential aged care facilities	79
Private hospitals	6

Table 2: Health Services

The Health Services in the GMSBML region are summarised in the table above and although the metropolitan areas are well serviced by a range of primary health care services, specialist Palliative Care services are represented by only three main specialist service providers:

- St Vincent's Hospital, Kangaroo Point
- Mater Hospitals, South Brisbane
- Metro South Palliative Care Service which services the following hospitals
  - Logan Hospital, Meadowbrook
  - Princess Alexandra Hospital, Woolloongabba
  - Redland Hospital, Cleveland
  - Queen Elizabeth II Jubilee Hospital, Coopers Plains
  - Beaudesert Hospital (visiting palliative care specialist)

## Local Issues

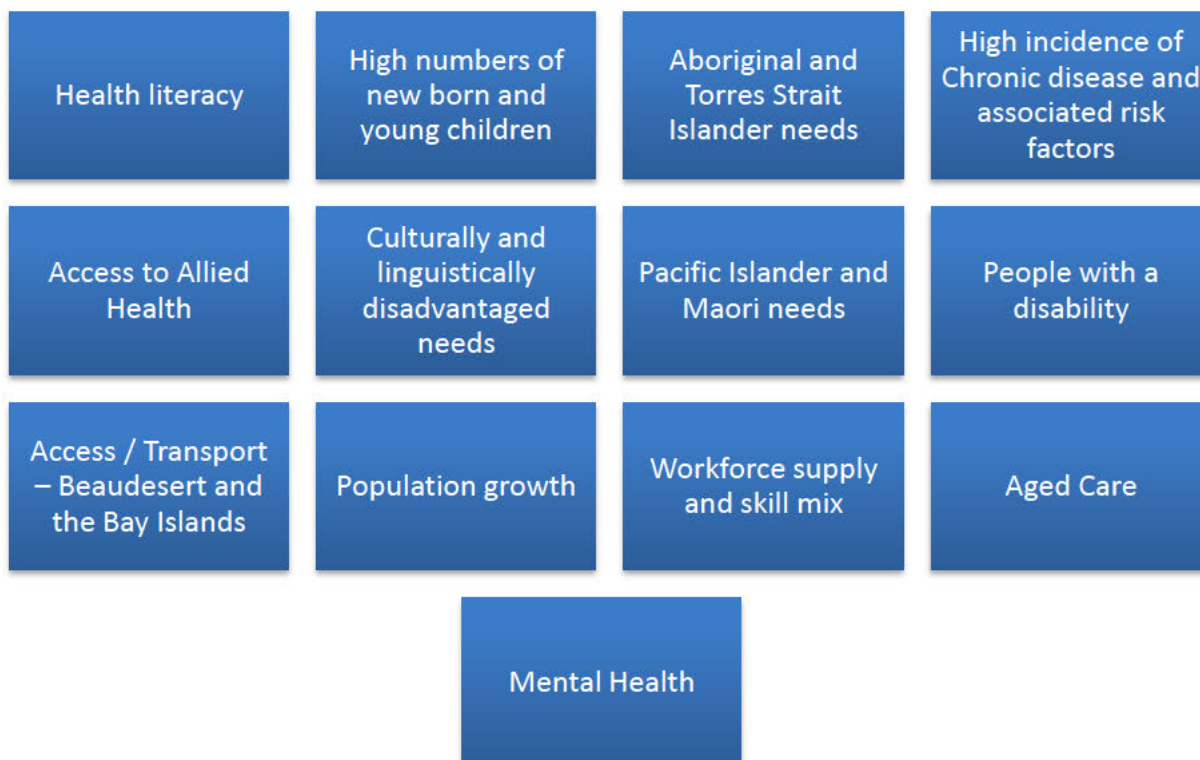
The 2012 Health Quality Complaints Commission (HQCC) survey of consumers perceptions of primary health care services in the GMSBML catchment indicated that 93 % of consumers surveyed in the GMSBML region had accessed a doctor as their primary care provider in the past six months and overall 95 % felt safe with their primary care provider. When considering palliative care services this survey reaffirms that from a patient's perspective many would prefer a general practitioner to provide their palliative care needs while they reside in their own home, in a way that would corroborate their direct wishes as well as further enhancing the patients' continuity of care<sup>3</sup>.

Overall in the region 61 % of people reported they had no concerns with the health system however for those who had concerns, the three top concerns in Greater Brisbane were waiting times, bed shortages and lack of confidence in treatment. From a palliative care perspective these concerns are of relevance because in the absence of an advanced care directive many palliative patients receive fragmented care from multiple service providers once their general practitioner feels they no longer have the expertise or scope to continue administering their care.

## Issues Identified in the GMSBML Whole of Region Community Needs

### Assessment:

The GMSBML whole of region needs assessment completed in March 2012 highlighted issues impacting on the health service needs of the communities that reside in the GMSBML region, these included:



While these issues relate to all health service needs there are some that have been identified which relate directly to the provision of palliative care services. For the purposes of this submission they have been grouped under the four subheadings of chronic disease, coordination and access, quality and safety and cost<sup>4</sup>.

**1. Chronic disease**

Across the region there appears significant prevalence of musculoskeletal system diseases (including arthritis), respiratory diseases (including asthma) and diseases of the circulatory system (including hypertension). Currently 14.2% of patients accessing palliative care services have a primary diagnosis associated with a chronic disease and as the incidence of chronic disease in our community is becoming more prevalent it is expected that an increasing proportion of people who will require palliative care services are expected to suffer and eventually die from chronic progressive illness<sup>5,6</sup>.

Condition	Prevalence among total population	% total population
Musculoskeletal	236,660	29.4
Arthritis	112,231	14.6
COPD	18,331	2.3
Asthma	94,092	11.0
Circulatory	119,348	15.4
Diabetes	25,383	3.3

Table 3: Chronic Disease Prevalence GMSBML Region

**2. Coordination and Access**

**Issues identified are:**

Fragmentation:

- The healthcare market is highly fragmented making care coordination for clinicians and service navigation for consumers difficult. Often lack of timely communication, absence of complete electronic record keeping and segregated services lead to system inefficiencies. Further compounding this, unlike other large service industries, healthcare lacks a middle person or broker that can match demand with supply and drive more competitive options.
- Continuity of care for the patient can be disrupted if all the service providers are not creating sufficient pathways for their care including home based services.
- Continuity of care in the palliative period where patients may no longer meet HACC criteria

Availability:

- Specialty palliative care services are urban with no access to palliative care speciality services in the Bay Islands with limited palliative specialist service in the rural area. Lack of access necessitates palliative patients and families having to re-locate near hospices and palliative care units.

- Palliative care services for young people and children are very limited, with community nursing providers predominantly caring for adult patients and many doctors working in palliative care not having any training in paediatric or adolescent palliative care<sup>7</sup>. Although Ronald McDonald House provides some services for these patients and their families they are only in the metropolitan areas, so those living in rural areas and on the Bay Islands have to co-ordinate their travel to be able to access these services.
- Currently, almost one third of people who are admitted to residential aged care facilities as high care residents die within six months of admission and 61% will die within one year<sup>8</sup>. With the demand for residential aged care in Australia anticipated to increase more than threefold by 2045 access to suitably trained RACF staff and access to specialist palliative care is essential<sup>9</sup>.
- The impact of the recent Federal Government reform package for aged care which provides support to RCF staff education, linkages to specialist palliative care services, and other multidisciplinary care providers is yet to be seen. The shortage of palliative trained GPs and specialist palliative care services is anticipated to remain as an impediment to high level support to palliative RCF residents. Currently, the Aged Care Funding Instrument (ACFI) funding is only for complex pain management not for complex nursing care which is required in palliative care.

### ***The difficult transition – Chronic Disease to Palliative patient:***

*Mary was diagnosed at 45 with COPD after a history of smoking for the last 25 years, and was placed on a health care plan by her GP. Over the years as her health deteriorated Mary was referred to HACC services for home care and shopping support. Mary investigated Disability and Community Care packages and on application and assessment was not found eligible for a Disability Lifestyle Package.*

*Now at 65 Mary has been admitted to hospital with a number of COPD related ailments and on return to her local GP has been advised her condition has become palliative. Based on this she is now no longer entitled to access her previous HACC services, however they continue to provide her with this support unfunded as they feel they have a duty of care. Additionally, now Mary is over 65, the HACC services are no longer state funded and the service provider is trying to seamlessly navigate funding arrangements now converted to federal sources to offset the costs.*

*Mary can apply for either an Extended Aged Care in the Home (EACH) package or palliative care funding should either be available. There are no available EACH packages through local providers and if a package was available Mary may incur out of pocket expenses for this service. A referral is made to palliative care services and a nurse visits daily to support Marys pain management, however this is all Mary is entitled to for support. Mary has no family locally that can assist her and is dependant on the HACC services even though technically she is no longer eligible.*

*Marys' friend Jane has also recently been diagnosed with COPD, however due to high demand is unable to access HACC services. Mary feels bad for her friend as she knows she receives these services even though she is no longer eligible and now her friend is one of many unable to receive much needed support.*

*Marys' needs have now exceeded HACC capacity and Mary is hospitalised. Mary is unable to return home, there is no hospice service in her area, and hospital fees are mounting as she awaits Aged Care Assessment Team (ACAT) assessment for Residential Aged Care (RACF) admission.*

*A RACF bed is available outside Marys' community which makes visiting difficult for family/friends and a new GP attends Mary.*

*Entry costs to the RACF and ongoing cost of equipment and medical supplies may necessitate sale of Marys' assets.*

### **3. Quality and Safety**

Across palliative care service delivery, adherence to best practices is inconsistent with GP continuity of care being a significant issue.

Results of a GMSBML Palliative Care Survey of the 1033 GPs within the GMSBML catchment (July 2012) indicate 34 (61%) of the 56 respondents ( 5% of total GPs) provide palliative care services 'in hours' with 18 (53%) of those providing palliative care services also offer in home after hours services.

Issues for GPs in palliative care management were; the time consuming nature of palliative care service – 9 GPs (16%), financial incentives/remuneration - 5 GPs (9%) and fragmentation across medical and allied health providers – 8 GPs (15%) and knowledge – 2 GPs (3%).

Thirteen (24%) of respondent GPs indicated that they had completed palliative care training. This figure includes 1 GP who does not currently provide a palliative care service.

Of the 13 GPs who completed training, 2 (15%) completed significant training of 1 week and 6 (47%) completed training of 1 day duration and 5 (38%) completed training of 2 hour duration. Of all GP respondents, time was seen as the most significant barrier to participating in palliative care training 18 (33%), along with access to education 6 (11%) and remuneration 4 (7%).

All respondent GPs who provide palliative care services develop Advanced Health Directives (AHD) with their patients, 17 (50%) report that they often complete care plans however, only 5 (15%) participate in case conferences.

Results from the 'Survey' indicate a significant interest in palliative care service provision by GPs who responded, however only half of these provided after hours palliative care support and completed care plans often, there is limited uptake of palliative care education and low participation in case conferencing.

Service provider feedback also indicates that many general practitioners do not provide home visits during the day with fewer providing after hours home care. Suggested reasons for this include:

- Individual practices policies;
- Non accredited practices;
- Doctors not comfortable providing palliative care due to cultural issues or personal experience;
- Poor uptake of specific palliative care training;
- concern for litigation due to treatment they providing;
- Deputising service GPs providing after hours in home care not being familiar with patient; and
- Anecdotally, after hours calls are primarily around pain relief and often result in admission to hospital due to GPs uncertainty to prescribe the higher doses of required analgesics.

Issues identified by other service providers during consultation have been:

- Access to GPs for assistance with end of life certificate. Where this is not available this process instigates a coroners case which prolongs the grieving processes and distresses relatives;
- GP role in the development of advanced health directives (AHD) as a tool to assist in decision making for any health staff not familiar with the patient. Barriers to AHD being time consuming nature of AHD development and lack of MBS item number;
- Lack of a shared electronic client record to enable access to AHD;
- Residential Aged Care Facility (RACF) access to GPs is generally an issue but particularly a challenge after hours;
- deputising services providing after hours support to RACFs are not familiar with patients; and
- Currently RACFs have difficulty providing high quality end of life services due to palliative funding and staff levels and lack of palliative care training.

Access to quality information

- Poor data collection techniques that have been used in the past have meant that accurate data to assess the needs for palliative care patients is unavailable. Resulting in constraints to health care providers in providing the best solutions to correspond with their patients needs. This requisite for high quality data to support the delivery of effective and accountable palliative care services has been well documented by a study that aimed to develop strategies to overcome the current inefficient data collation system<sup>10</sup>.
- The lack of comparable national data on palliative care activity occurring in community (that is, non-admitted patient) settings has also been well recognised (NHIMG 2002), and continues to remain an evident gap given the emphasis within palliative care on providing palliative care patients and their families with choices about settings of care<sup>11</sup>.

#### **4. Costs**

The financial models for chronic disease, aged and palliative care services are not outcomes based. Added to this, services are provided across a wide range of disconnected providers. This results in high levels of duplication of services across

multiple providers of any given patient journey driving up the overall cost of the services to financiers and consumers.

Currently those with a chronic disease would be referred to a funded Home and Community Care (HACC) service, however once the patients condition is diagnosed as palliative they are no longer entitled to this needed service. Unfortunately without an alternative service provision, often HACC service providers attempt to bridge the gap, operating outside of their scope to support the patient.

## **Our Recommendations**

### **1. Improved Coordination and Access**

A health brokerage model between consumers and clinicians is required, which would allow consumers and clinicians, in consultation, to access complete service packages that would encompass entire care pathways for patients<sup>12</sup>.

GMSBML is currently developing a “Mediselect” service – to become the broker of available services in the community, connecting clinicians (and their patients) to other health care providers. This brokerage approach aims to:

- build upon the capability of the GMSBML service directory
- broker services between providers based on patient need and locality, as well as
- identify local provider capacity across the GMSBML region, enabling provider and consumer options that span both public and private services eg. Patient X requires an endoscopy and has been told they will be on a public waiting list for a number of years. Knowing many undiagnosed deaths from bowel cancer occur while on waiting lists Patient X is happy to be told, via GMSBML’s “Mediselect service”, that a local private hospital has capacity for a small gap fee within the next 3 months.

### **2. Driving Higher Quality Care**

Medicare Locals have the capacity to work with all aspects of primary health services to ensure that clinicians, allied health professionals and hospital specialists are able to build relationships, leverage interconnected learning opportunities, enhance continuity of care and work as multidisciplinary teams. Medicare Locals can also have a role in integrating the education and training that is offered to the current primary care providers.

Divisions of General Practice and now Medicare Locals have delivered a range of successful primary care education programs to local health care providers over the last 15 years. In 2007-2008 Qld Health funding provided a palliative care mentorship program for GPs within parts of the GMSBML region and funded the development of a facilitators’ manual. This education was delivered in collaboration with Brisbane South Palliative Care Collaborative, Qld Health and Griffith University to address end of life pathways education.

Driving the education of providers to deliver higher quality care and consumer understanding of what level of service they should expect is critical to drive higher quality care for the chronically ill and frail. The key elements as identified by a



National Indigenous Palliative Care Needs Study<sup>13</sup> that will facilitate the delivery of higher quality care include:

- early referral;
- cultural advocacy and brokerage;
- good communication and relationship development;
- clear coordination so that everyone involved in a person's palliative care has a clearly identified role
- regular case management meetings, including cultural advocates;
- continuity of care; and
- flexibility and responsiveness which recognises individual needs.

Palliative care service providers therefore need to become coaches for the family, providing them with training and support so that they could look after someone at home. They also need to be able to provide specialist advice and coordinate other services as required (including access to residential facilities if necessary). This approach will enable family members to feel they are in control of their family members care and also allow palliative patients to be comfortable through their end of life experience<sup>13</sup>.

Additionally availability to patient history and treatment would enable informed safe treatment options and facilitate opportunities for improved care coordination

It is also imperative that ethical principles and values of clinical integrity, respect for persons, justice, and beneficence that are well recognised in the Australian community are upheld by the primary health care service providers and applied to meet the palliative care needs of all people with advanced chronic or terminal conditions<sup>14</sup>.

An integrated education program is required to build capacity and quality in the primary care sector. A training package called Program of Experience in the Palliative Approach (PEPA) is available to primary care providers however the uptake of this is reported to be poor due to the commitment requirements of the palliative care provider and the lack of support by organisations for palliative care providers to attend training. There is also little incentive to attend. Royal Australian College of General practitioners (RACGP) released the RACGP Curriculum statement - Palliative Care in 2011 and supports a multidisciplinary approach to palliative care.

Medicare locals have a role into the future to facilitate the provision of provider education, health literacy focused to educate consumers of the levels of care they should expect, and health service brokerage to enable consumer access to best practice pathways.

### **3. Increasing value for money**

Funding for aged, chronic disease and palliative care should be reformed to fund service providers for base funding calculated on client or population basis. Care outcome packages could then be held by a fund holder who can help consumers make informed decisions about the care package they want to purchase driving choice and responsive service in the market.

Funding for most chronic disease, palliative care and aged care packages which is output driven is sent directly to providers who then tell consumers, once assessed, what service they will receive. This system is unresponsive to consumer needs and restricts flexibility in service provision.

Funding complete patient journeys instead of occasions of service will give central focus to the quality and needs of the patients palliative care requirements. To achieve this we suggest a model of gradual market adjustment. This could be achieved over three years by allowing Consumers to choose the service that best meets their needs and allocating a % of their package to this, increasing this % over the following years with a review of effectiveness in year three. Medicare locals can support this provision by undertaking the honest broker role for consumers and clinicians, as Medicare Locals will never intend to directly deliver services themselves.

Additionally effort to ensure better data collection by clinicians will enable more accurate analysis of funding requirements so that the most good is done with the least amount of expenditure.

Whilst our region faces issues such as: continuity of care, palliative care education and palliative care service fragmentation in an environment of dramatic population growth, there is great opportunity through funding policy change and local action and oversight by Medicare locals. With Medicare Locals focussed on coordination of primary health care delivery and addressing local health care needs and service gaps this provides an opportunity to reduce fragmentation in a complex multifaceted health care system and to support families accessing palliative care services.

Greater integration of services and effective collaboration and communication between health professionals through a "Mediselect" service should enhance continuity of care for a person with advanced chronic or terminal conditions (including cancer) and facilitate the informed involvement of their carers, thus contributing to an improved quality of life.

If you have any questions relating to this submission or if I can be of further assistance please contact me on: (07) 3864 7555

Regards

A handwritten signature in black ink, appearing to read 'T Shepherd', written in a cursive style.

Tamati Shepherd

CEO, Greater Metro Brisbane South Medicare Local

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