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6th August 2012

Mr Peter Dowling MP (Member for Redlands)
Chair of the Health and Community Services Committee
Parliament House
BRISBANE Qld 4000
Email: hcsc@parliament.qld.gov.au

Dear Mr Dowling

Re: Inquiry into palliative, home and community care services in Queensland

COTA Queensland welcomes the focus of the Health and Community Services Parliamentary Committee as palliative care and HACC (home and community care) services are of great importance to all Queenslanders as they age.

Palliative Care

COTA Queensland supports the United Nations Principles on Older Persons and, in particular, the right of older people to make decisions about their care and the quality of their lives. Palliative Care Australia (PCA) stated recently: "Adequate pain management and access to quality palliative care is a fundamental human right, yet this is not something we can guarantee for all Australians, especially those in marginalised groups, such as rural and remote Australia and Indigenous populations." (PCA Media release 24 April 2012 - http://www.palliativecare.org.au/Media/Mediareleases.aspx)

COTA Queensland supports the aim that all Queenslanders should have access to good quality palliative care when they need it and preferably where they want to have it. There is a large unmet need for specialist palliative care in aged care facilities, public hospitals, and the community, as well as a shortage of palliative care nurses. We support measures to improve training in palliative care for all health professionals to help improve referrals and care for people. Good palliative care should also provide grief and bereavement services to the patient's family, friends and other support networks.

There has been a tendency in Australia for palliative care to be viewed as only being available for people dying from cancer. It has been seen as time limited and often available only in the last few weeks or months of a person's life. Some of the funding models put time limits, usually no more than three months, on services, and resources are not available to support people through longer periods.

People with dementia often do not receive adequate access to palliative care. Dementia care as palliative care requires a different approach than for conditions such as cancer, as the process takes place over a longer period of time, involves early engagement in advance care planning, and requires more flexibility. People with other degenerative conditions such as motor neurone disease, multiple sclerosis, and chronic lung disease also do not have enough access to palliative care.

COTA Queensland supports campaigns to increase community awareness about palliative care services. There are many models for doing this, and one might be a peer education model where older people go out to community groups of older people to talk about the issues. Each State and Territory COTA runs popular peer education sessions about depression and the use of medicines. With sufficient additional funding, such sessions could potentially be useful in providing information about advanced care planning and other important health messages.

We would also be supportive of any Queensland Government campaign to improve the uptake of Advance Health Directives and Enduring Power of Attorney documents. Any material and information developed should be linguistically appropriate, culturally sensitive and respect the religious diversity of Queenslanders. Advanced care directives could also be included in the personally controlled electronic health record where one exists. Older people have expressed their fears that their health professional may not be aware of their preferences for treatment.

Palliative care services should respect the rights of Aboriginal and Torres Strait Islander peoples to have their cultures respected and have equity of access to the same level of services as other Australians. Health professionals also need to better understand the culture and needs of the ageing Gay Lesbian Bisexual Transgender Intersex (GLBTI) population. This is particularly important as GLBTI people approach the end of life when they may be vulnerable to discrimination or inappropriate treatment.

Home and Community Care

The Home and Community Care (HACC) program assists people who need basic support services to continue to live in the community with dignity. Clients include older and frail persons, and younger persons with disabilities who are at risk of inappropriate residential care if basic support services are not available. More than three-quarters of Queensland's 170,000 HACC clients are 65 years of age and older.
(http://www.ag.gov.au/Humanrightsandantidiscrimination/Pages/AnnexFHACCclients200809.aspx)

Since 2005 COTA Queensland, Carers Queensland, and Queensland Aged and Disability Advocacy have facilitated consultations with HACC consumers and carers about the planning, funding, delivery and development of HACC services. These 'C3' consumer consultations have been an invaluable opportunity to listen to HACC consumers, potential consumers, and their carers, and to gather information about their experiences of HACC services.

As the attached summary indicates, the C3 collaboration has met with more than 1800 consumers and carers in person throughout Queensland, including Aboriginal and Torres Strait Islanders, Australian South Sea Islanders, and people from culturally and linguistically diverse backgrounds. A smaller number of people have responded through surveys and written submissions.

A number of themes emerged from these consultations which should inform the design and delivery of future community care services. Models of service delivery which are consumer-centred, responsive and flexible, rather than 'one-size-fits-all', will be most successful in achieving the objective of supporting consumers to be more independent at home and in the community.

Throughout the consultations, consumers reaffirmed the importance of cost effective services in maintaining their ability to live independently. They told us: *"thank you for your help, I could not stay in my own home without it"* and *"I appreciate the help I now get from HACC, and hopefully can manage with this assistance for some time yet"*. HACC services have not only been important to seniors and people with a disability, but also for people who have experienced sudden and debilitating changes in their health and wellbeing.

While some consumers and carers actively sought out information about community care, many consumers found it difficult to know who to contact or where to go to find assistance. Many consumers 'stumbled upon' a service through the suggestion of a neighbour or friend. The reputation of the service provider within the community also appeared to be an important factor in determining whether people accessed community support services. The perception that a service did not provide culturally appropriate assessment or services was sufficient to deter many Aboriginal and Torres Strait Islander consumers, as well as consumers from culturally and linguistically diverse backgrounds, from approaching such services for support.

The importance of continuity, communication and coordination across the service delivery spectrum was emphasised by many consumers. Hospital admission and discharge is clearly a critical opportunity for linking people with appropriate service providers. For example a woman in a regional centre told us she had been purchasing incontinence aids from the chemist and was not aware of the Continence Aids Scheme until she saw a social worker while in hospital with an acute illness.

Service providers reported difficulties in meeting the demand for domestic assistance. Strategies for managing this included the introduction of waiting lists and reducing the hours or frequency of service. Some consumers who were placed on a waiting list developed coping strategies that increased the risk of injury from incidents (such as falls). For example one consumer explained how she used a milk crate as a shower chair while waiting for an Occupational Therapy assessment. The carer of another consumer told us about her weekly trip of more than one hour each way to clean her daughter's house. Her daughter was on a waiting list for domestic assistance for nine months before her General Practitioner referred her to another provider (where she was able to receive a service within two weeks).

The difficulties arising from the lack of portability of HACC services are exacerbated when consumers are forced to make lifestyle changes beyond their control; for example having to find accommodation when a retirement village closes or following evacuation from a natural disaster zone. A HACC consumer who had been evacuated from her home due to the Queensland floods was relocated to a family living outside the catchment of her service provider. The service provider was unable to make a referral to another HACC service provider and, although the family could assist the woman with showering, physiotherapy for her recent knee replacement ceased.

We are yet to fully appreciate the impact of the recent transfer of operational and funding responsibility for HACC services for older Australians from all states (except for Western Australia and Victoria) to the Commonwealth. Service providers have identified potential issues with the transition of consumers and carers from one system to another; for example when turning 65 years of age or when transitioning between the state health system and community care. Some service providers have also expressed concern about the support available for consumers who are frail due to the effects of mental illness, degenerative illness, or HIV/AIDS.

I hope the above comments about palliative, home and community care services assist your Committee's Inquiry. I look forward to speaking with the Committee further at the public hearings on Wednesday 22 August 2012 if required.

Yours sincerely

Mark Tucker-Evans
Chief Executive

C3 HACC Consumer Consultation

What is the C3 HACC Consumer Consultation Collaboration?

"C3" is a collaborative partnership between three consumer focused organisations, COTA Queensland, Carers Queensland and Queensland Aged and Disability Advocacy (QADA). In 2005 the C3 partnership initiated a series of consultations with HACC eligible Queenslanders and their carers so that consumers and carers could have a voice in the planning, funding, delivery and development of HACC services. Ongoing consultation with HACC consumers and carers has been funded by the Queensland HACC program since 2007.

COTA Queensland has coordinated the collaborative partnership between the three consumers focused organisations. The consumer focused work of each of the organisations involved in the C3 Collaborative Partnership has meant that the C3 Collaboration has been well placed to work with consumers and bring their issues to the funders of HACC services.

Why do Consumer Consultation?

Consumer consultation provides consumers with an opportunity to share their views, needs, interest and aspirations. HACC Consumer consultations place consumers at the centre of the process providing a mechanism for HACC programs and service providers to find out consumers', potential consumers' and carers' perspectives about the 'lived' experiences of HACC policies, programs and services. Information shared by consumers during the consultation process is an invaluable resource for service planning, design, delivery and evaluation and can highlight issues such as integration of service delivery, unmet need and the need for responsive service delivery.

How does the C3 HACC Consumer Consultation process work?

The C3 HACC Consumer Consultation process has used a variety of methods to ask consumers to share their experiences and insights. To date over 1800 consumers and carers from throughout Queensland have shared their stories in person at forums, interviews, focus groups and meetings. A smaller number of people have responded through surveys and written submissions.

Who have we talked to so far?

The C3 Collaboration has met with more than 1800 consumers and carers in person throughout Queensland including Aboriginal and Torres Strait Islanders, Australian South Sea Islanders, people from culturally and linguistically diverse backgrounds and lesbian, gay, bisexual, transsexual and intersex people. The consultations have taken place in metropolitan, regional and rural and remote Queensland.

The C3 Collaboration acknowledges the assistance of the many HACC consumers, carers and potential consumers who have taken the time to contribute to the C3 HACC Consumers consultation process.

COTA

Carers QUEENSLAND
Placing Carers First

Queensland Aged & Disability advocacy Inc.

What have HACC Consumers and Carers told us?

Consumers and carers throughout Queensland have a variety of different experiences of HACC services and many insights based on those experiences. They have an enormous depth of expertise about what works and what doesn't work for them:

Many consumers lack an understanding of the range and scope of services provided by HACC.

There are numerous ways people find out about HACC services, but many find the process difficult and frustrating. People have very clear ideas about what would have worked better for them.

> even at the hospital they only just say we can put you down for this or that...but you're being bombarded right at the very beginning and I had to get him home and start sorting things out a bit

> thank you for your help I could not stay in my own home without it

Many people appreciate the assistance they receive through the HACC program because it enables them to continue to live independently.

HACC services are critical in helping carers to continue in their caring role.

> I was standing alone caring for my parents...they were the glue which held me together

> they take the time if you ask questions...you can tell if someone's listening properly or if they're just paid to listen

For many consumers, the personal contact with staff delivering the service is a critical component of receiving a quality service.

Although consumers are aware of complaint and feedback processes, they frequently don't use those processes. Consumers often report cancelling a service if they are dissatisfied.

> I didn't want to feel uncomfortable or judged...so I just told the person that I didn't need them anymore

There continue to be unmet needs in a range of areas. Domestic support, home and garden maintenance, better access to appropriate transport and more suitable respite options were key recurring themes throughout the consultation process.

> ... Indigenous and culturally and linguistically diverse communities had heard negative things about the assessment process...and consequently could not access HACC services...

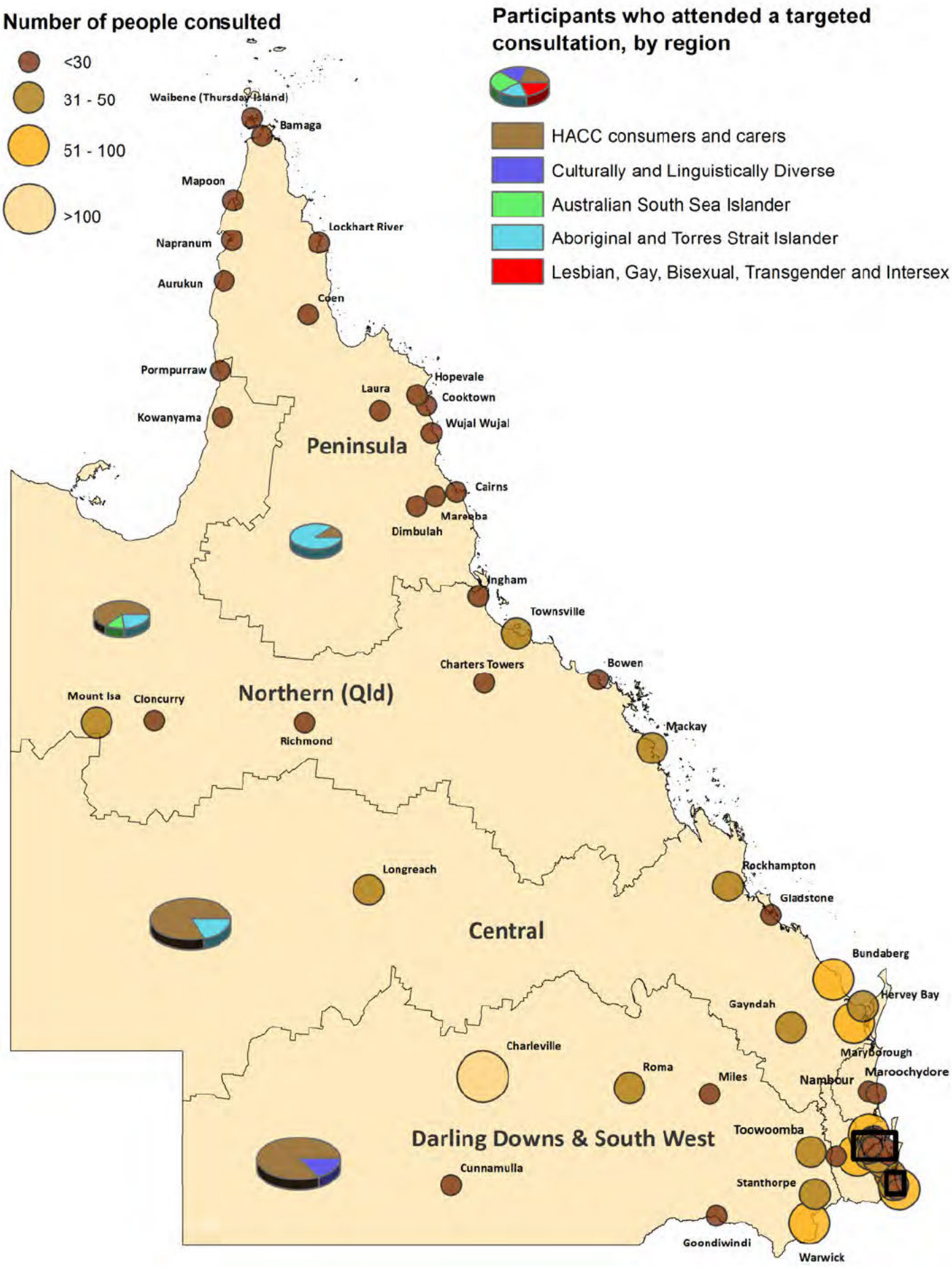
Consumers and carers prefer culturally appropriate assessment and services.

People appreciate services which are flexible and can respond to their needs and lifestyle.

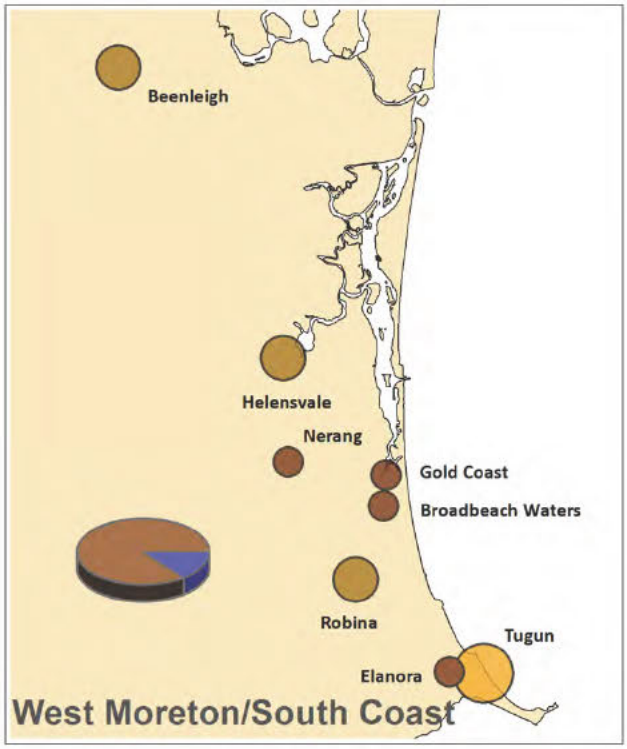
Where to from here?

Consumers and carers continue to have valuable information and insights about their experiences of community care. A robust consumer consultation process will be increasingly important as the reforms in the community care sector are delivered over the coming years and will help to shape models of service delivery and influence the manner in which services are delivered.

Queensland HACC Consumers and Carers consulted between 2005-2012



Queensland HACC Consumers and Carers consulted between 2005-2012

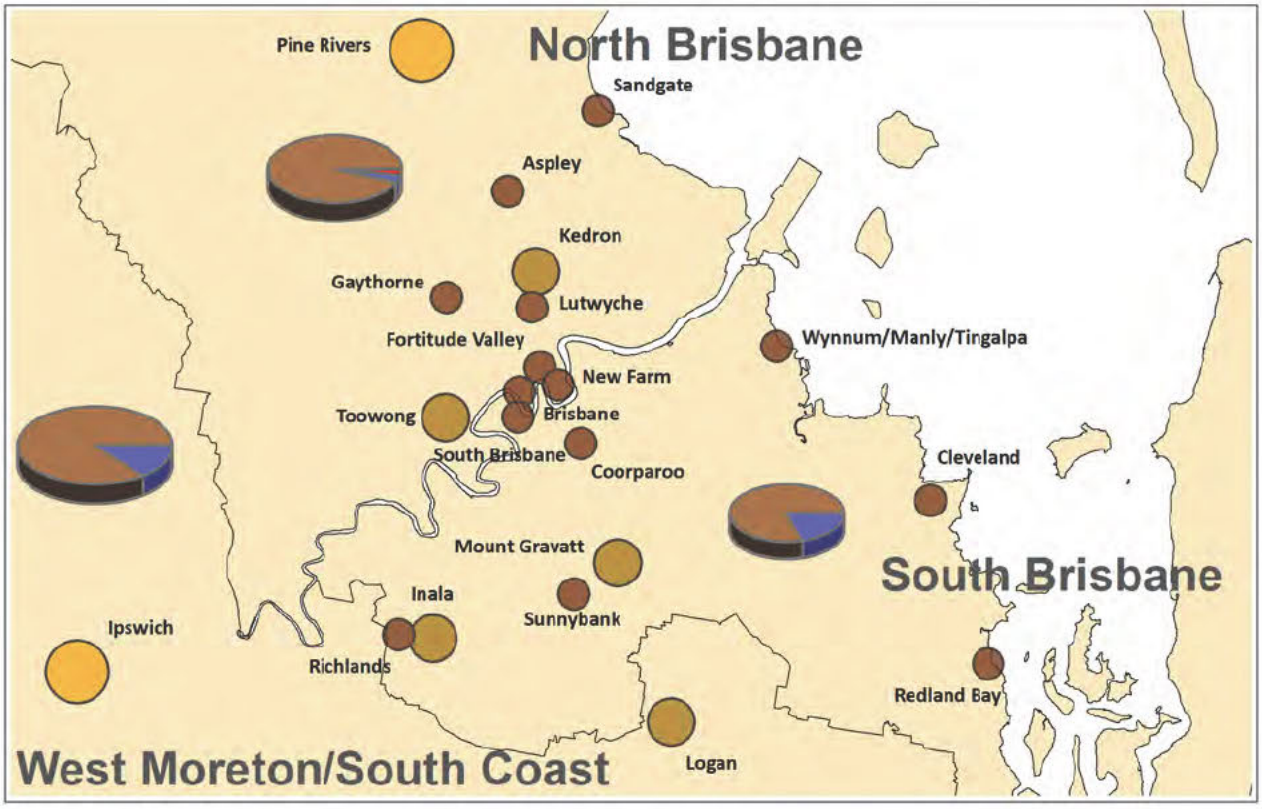


Number of people consulted

- <30
- 31 - 50
- 51 - 100
- >100

Participants who attended a targeted consultation, by region

- HACC consumers and carers
- Culturally and Linguistically Diverse
- Australian South Sea Islander
- Aboriginal and Torres Strait Islander
- Lesbian, Gay, Bisexual, Transgender and Intersex



The C3 HACC Consumer Consultation has been funded by the Queensland HACC program.

Prepared by COTA on behalf of the C3 Collaboration
May 2012