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HCCA submission on the draft Palliative Care Services Plan 2012-2017

6 December, 2012

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Background

The Health Care Consumers' Association (HCCA) of the ACT was formed over 30 years ago to provide a voice for consumers on local health issues and now provides opportunities for health care consumers in the ACT to participate in all levels of health service planning, policy development and decision making.

HCCA involves consumers through:

- consumer representation
- consultations
- training in health rights and navigating the health system
- community forums
- information sessions about health services
- advocating for issues of concern to consumers

HCCA is an organisational member of the *International Alliance of Patient Organisations* (IAPO). IAPO is a unique, global alliance representing patients of all nationalities across all disease areas and promoting patient centred healthcare around the world. HCCA, like IAPO, supports the view that consumer-centred healthcare is the way to a fair and cost-effective healthcare system. We believe that consumer-centred health care can be successfully achieved through the application of five key principles:

1. Respect
2. Choice and empowerment
3. Consumer involvement in health policy
4. Access and support
5. Information

It is with reference to these principles that the HCCA has developed its submission to the draft Palliative Care Services Plan.

Introduction

HCCA welcomes the opportunity to provide feedback on the draft Palliative Care Service Plan. Palliative care is a very important issue for our membership and is often the most difficult aspect of the health system for consumers to comprehend and navigate. We are very encouraged by the steps being taken to improve access to quality palliative care and ensure that the care provided is in accordance with the wishes of the patient.

On Wednesday 21 November, 2012 HCCA held a consultation forum for members to discuss the goals and strategies of the Plan. Members also had the opportunity to provide direct feedback to the consultant for the Plan, Richard Gilbert, as well as several members of

the ACT Health Directorate who attended the meeting. The main issues raised at the meeting have been incorporated into our submission.

General Comments

Overall, we are happy with the layout of the Plan as it is easy to determine where different information can be found. We think the planning documents, such as the Clinical Services Plan, would benefit from using this as a template.

It is good to see a strong focus on raising the awareness of end of life issues in the community as well as among health professionals, as this has been recognised by consumers as one of the key barriers to accessing timely and quality palliative care. There is a pervasive culture of death denying throughout health systems in Australia¹, which can prevent open and honest communication about dying and impede palliative care. It is essential that the Plan targets this culture and works to develop a new culture of acceptance and a willingness to discuss issues around death and dying.

However, we are concerned that the existing palliative care services and models of care used in the ACT have been excessively idealised. Consumers' experiences of palliative services are often very different to the seamless care models that are described, and it is somewhat jarring to see the services presented in this way. Consumers are more interested in having the gaps in existing services identified and working with the ACT Health Directorate to develop strategies to address problems and provide better care. It is important to engage consumers in service planning to ensure that the system is able to meet our needs.

We are also concerned that there has been little distinction between designated palliative care services and more general palliative approaches that can be used by any health practitioner. This needs to be explained more clearly in the document by first providing a definition of each and then clearly indicating which of these is being referred to in later sections. Where the document is encouraging health providers to use a palliative approach, it must back this up by specifically outlining the time and resources that would be necessary to ensure that this can be achieved. The reliance on other health providers to provide care based on a palliative approach may also obscure the actual demand for palliative care services.

Throughout the document, there is reference to a workforce shortage, an increase in demand for services and the challenges that this will create for the effective delivery of palliative care services. Considering this, we would urge caution with regard to inpatient projections based on an anticipated increase in the use of home based palliative care (HBPC). Although many consumers would prefer to receive care at home and ultimately die in their homes, workforce and resource pressures often mean this is unlikely, leading to a continuing demand for acute care services and beds.

It is important that HBPC is sufficient to support families and caregivers. If too much burden is placed on the caregivers, it is likely that the patient will end up being transferred to the Emergency Department (ED) for end of life care, even when this was not their preference. This needs to be reflected in the workforce strategy.

¹ Ken Hillman. (2009). 'Diagnosis of Dying' in *The Health Advocate*, Issue 3.

While we welcome the shift towards more palliative care being provided in community and primary care settings, this needs to be supported by an adequate shift in resource allocation. A palliative approach is often costly and time consuming for GPs, which may make them reluctant to take on palliative care cases. Although this is beyond the remit of the ACT Health Directorate, GPs would need to be recompensed in some way for the additional time spent in supporting patients requiring palliative care patients, similar to those caring for consumers living with Diabetes. They may also require additional funding for home visits to support Community Nursing.

The remainder of this submission relates to specific areas of the Plan and we have used the corresponding headings and numbering from the draft.

1. Executive Summary

We would like to see chronic pain listed in the Executive Summary in the paragraph about chronic conditions that may require palliative or end of life care. Chronic pain is highly prevalent in our community and has a significant impact on the person's quality of life. In many cases, it is considered to be a life limiting illness. As such, it is essential that chronic pain is recognised in this Plan and that palliative care services are available for those consumers living with the condition.

2.1 What is Palliative Care

Although it is implicit throughout this section, we would like to see a statement included here which explicitly mentions that palliative care is not only for the imminently dying. This common misconception often makes consumers feel uncomfortable when the topic is raised, or prevents them from seeking out palliative care early enough for appropriate treatment.²

We suggest that this section might also be the best place to discuss the difference between palliative care services and a palliative approach.

In the list of aspects and goals of palliative care, we would like the following point:

- *Will enhance quality of life, and may also positively influence the course of illness*

placed at the top of the list, as we believe this is the most important component of palliative care and therefore the top priority.

2.2 Vision and Principles

We would like to include the terms 'timely' and 'quality' to the vision statement so that it reads "...families and carers will have *timely* access to *quality* palliative care..." One of the main issues with palliative care that still needs to be addressed is ensuring that both clinicians and consumers are able to recognise *when* palliative care needs to commence. If palliative care begins too late, the quality of the care will also be compromised.

² Kennan Moore. 10 October, 2012. "Pain 'Management' means ... what?", *Journal of Palliative Medicine*. <http://networkedblogs.com/DhsYY>

It is unclear why the principle of advocacy refers to respecting the wishes of the dying when the rest of the document focuses on the notion that palliative care is not just for the imminently dying. Palliative services need to be based on the expressed wishes of all consumers with both terminal and chronic conditions and at all stages of their illness.

3.1 National Policy Context

It would be good to consider whether the new Work Health and Safety regulations for clinicians providing services in an off-campus environment will affect HBPC services. In the draft policy, clinicians are required to remove themselves from the premises if they think there is any potential for the patient to become aggressive. This may have implications for older people with dementia seeking to receive care in their homes. We would hope that the Health Directorate would consider advising staff to take precautionary measures to reduce the likelihood of violence before removing themselves from the situation altogether.

Section c) refers to the increasing tendency of Residential Aged Care Facilities (RACFs) to act as hospices for the elderly. This is concerning given that RACFs are often considerably under resourced for their normal role, let alone for providing palliative care services. Even if palliative care training is provided for staff, the high turnover rates often mean that ongoing training cannot be sustained. Consumers living in RACFs are among the most vulnerable groups in our community and have often been neglected by policy and decision makers. The Plan needs to demonstrate that sufficient resources, funding and staff development are allocated to RACFs to support their key role in providing palliative services for older ACT and NSW residents.

We strongly endorse the need to provide more seamless care across health settings for patients with a terminal illness. A number of our members have provided us with detailed case studies describing their difficulty finding a bed for their dying family member and ensuring that they were in the right setting to receive the care they needed. However, lack of communication was one of the most common problems experienced by these consumers. Consumers are often provided with contradictory information from different service providers who seem unclear about role delineation and are unable to reach an understanding. This confusion can lead to delays in the patient accessing effective palliative care and cause enormous frustration and anxiety for their families. By improving effective communication between service providers, patients and their families, it will be easier for families of dying patients to arrange their transfer between different health settings when necessary.

3.2 ACT Government Health Directorate

We note that the latest draft version of the Health Directorate Clinical Services Plan 2012-2017 does not include the development of the new sub-acute Northside Hospital, as it was not due for completion until after the timeframe had ended.

The ACT Chronic Disease Strategy 2008-2011 also needs to be replaced with the Strategy for Improving Care and Support for those Living with Chronic Conditions 2012-2015, which is soon due for release.

4. Current Population Need for Palliative Care Services

Wherever possible, this document needs to be updated with data from either 2011 or 2012. It is also important to define the term 'separation' the first time it is used.

5.2 Current Staffing

This section needs clarification on whether the current staffing for palliative care services is sufficient or if existing staff are already working to capacity, as has been done for allied health and pastoral care staffing. Although this area is discussed further on in the document, it would be good to include this here to provide context for the information being provided.

5.3.1 Clare Holland House (CHH)

The previous section mentions a shortage of allied health staff, and we would be interested to know whether the services described here are easily accessible for consumers or whether there is likely to be a long waiting period.

6.1 Generic Model of Care

It is unclear whether this section is outlining the current model of palliative care used in the ACT, or is just a typical example of the current palliative care service delivery model in Australia. This should be explained in the first paragraph.

The section talks about the treating specialist and palliative care physician sharing the palliative care in some acute public hospitals. We are concerned that this practice might lead to confusion with regard to role delineation. This is also an example of where the palliative approach is being taken by the treating specialist, but their work is not encompassed within palliative care services, making it difficult to ascertain the real demand for palliative services.

There is a perception in the community that Calvary Health Care ACT provide all palliative care services in the ACT, yet we know that a significant number of consumers experience palliative care at The Canberra Hospital (TCH). If this is not even being recognised, it is unlikely that sufficient resources will be allocated to TCH to be able to provide effective palliative care services. Reported TCH services also underestimate the palliative services provided by TCH as early palliative care services tend to be admitted under another specialty.

The paragraph covering literature around death at home is confusing, particularly as most consumers would feel as though dying at home is a 'gold standard' of palliative care. It would be useful to include the additional information that is provided later in the document about the need to focus on the nature of the death as well, i.e. dying with adequate care and support in an appropriate location.

There is also very little reference to respecting the wishes of the patient and providing consumer centred care. Although there is a paragraph about the needs of the patient, without meaningful discussion with the patient and their family, the needs of the patient are unlikely to be met.

It would be good to see some care principles included either here or in section 6.5, to demonstrate the commitment of palliative care service providers to providing quality, safe and consumer centred care for all consumers. We would like to see palliative care being provided based on the rights of the consumer to receive adequate pain support and to refuse treatment they do not wish to have. As consumers also have the right to fully informed consent, it is the duty of care providers to fully and clearly discuss treatment options and indicate the likely outcomes of any curative treatments.

In figure 6.1, the diagram indicates that bereavement services only commence for the family after the patient has died. However, proactive grief therapy can be highly beneficial to the dying patient as well as the family, as it can alleviate some of the anxiety or guilt the patient may have over leaving their loved ones to cope without them.³ This in turn can make it easier for patients and their families to make the most of their last days together.

6.2 Primary Care Services in the ACT

This section paints a particularly idealised portrait of palliative care in primary settings in the ACT, which is very different to the actual experience of many consumers. Often, primary care providers are reluctant to talk with consumers about the need to begin palliative care, or they do not have sufficient training or resources to engage in clinical leadership when deciding to cease futile care.⁴

We would argue that these health care providers are not “provided with support to ensure that they are skilled in this [palliative] approach”, nor are community nurses and GPs “strongly supported” to undertake the role of HBPC. The Plan even acknowledges that workforce pressures put great strain on the system.

In sections that describe the existing palliative care services in the ACT, we would like to see where the gaps are, and an indication of which areas are suffering under high demand. We note that this has been done to some extent in section 6.3. By putting ACT services in context, it will be easier to identify the steps that need to be taken to provide sufficient palliative care services in the future.

6.5 New and Emerging Models of Care

a) Day Hospice

Consumers have told us that respite care is most desperately needed at night, outside of regular business hours. Many carers are sleep-deprived, because they need to get up so often throughout the night. Over time, the carers’ own health is likely to deteriorate, meaning they may no longer be able to fulfil their role. Without providing carers with adequate respite and support, the pressure on RACFs and hospital inpatient facilities will continue to increase and fewer people will have the choice to die in their homes.

³ Nicole Johnston. August 29, 2012. ‘Care Plan After Death’, *Journal of Palliative Medicine*. <https://palliativejournal.stanford.edu/?p=7101>

⁴ Brendan Murphy. (2008). ‘What has happened to clinical leadership in futile care discussions?’ in *MJA*, 188(7): 418 – 419.

We would like to have 24-hour respite services available in Canberra. While there is one bed 'notionally designated for respite care' at CHH, this has not been sufficient to meet the needs of carers.

One suggestion has been to provide respite facilities in the new Northside subacute facility. In the short term, it would also be worth considering increasing the number of designated palliative care beds at TCH in order to meet the increasing demand over the next five years.

b) Rapid Response Teams / c) Palliative Care Packages

These programs look very promising to consumers. However, it is not clear why they have been covered in such detail but not suggested for use in the ACT. If they are not feasible in the ACT, we would like to know why. Otherwise, this could be covered under Goal 2.

7.1 Palliative Care Services Provided by the Home Based Palliative Care Team

This section clearly outlines the different reasons for the increasing demand for HBPC and we are concerned that workforce shortages will mean that HBPC services will not be able to meet the demand in the ACT. Inpatient services must have the capacity to take on the overflow of patients as our ageing population continues to increase. While this is not an ideal solution, it is a pragmatic step that must be taken to meet population needs in the short term while solutions to the workforce shortage are implemented.

7.3 Palliative Care Services Provided at the Canberra Hospital

While the footnote in this section explains that a contact is not the same as an occasion of service, it is also important to explain exactly what the term 'contact' refers to.

8. Current Issues in Service Delivery

We note that this section covers some of the intended solutions to the issues with palliative service delivery as well. This makes it a bit confusing to determine which steps are going to be taken to improve palliative care. There is also some overlap with Section 9.

Another issue that needs to be covered in this section is burdensome transitions. These are defined as transitions between the hospital, nursing homes and their own home within the final three days of life⁵. As with futile care, these transitions are of little, if any, benefit to the patient and can cause considerable discomfort, while transport resources, that could have been better allocated elsewhere, are wasted. It also puts pressure on the patient's family, who have to arrange the transport themselves, in some cases, and make sure the patient has the necessary belongings with them. This was the case for one of our consumers, who spent the final days of her father's life frantically running around Queanbeyan and the ACT trying to furnish a room in a RACF and assist the father to attend specialist appointments outside of the hospital. One specialist realised that the father was not in a fit state to come to his clinic for an appointment and made arrangements to visit him in hospital instead.

⁵ Pedro Gozalo, et al. (2011). 'End-of-Life Transitions among Nursing Home Residents with Cognitive Issues' in *The New England Journal of Medicine*, 365: 1212-1221.

8.1 That the Health Directorate plays its part in ensuring reliable access to quality palliative care services that are appropriate to individual needs

We would like to see chronic pain included in the list of conditions in the paragraph beginning “A wide range of people...” to emphasise that this is a life-limiting condition that requires access to palliative care services.

We welcome the recognition that insufficient palliative care resources in acute hospital and community settings will lead to last minute transfer of patients to hospital and result in ‘crisis management’ responses. This needs to be avoided in order for consumers to die comfortably in accordance with their advance care directives. Another factor contributing to this problem is inadequate resourcing of RACFs. Without sufficient training and resources to use a palliative approach in RACFs, older consumers will continue to be transferred from the RACF to the ED at end of life, where they are more likely to receive futile care.

It needs to be certain that the strategies in the Plan will ensure proper engagement with clinicians in the acute sector to reduce futile care. Palliative Care staff at TCH, such as the Palliative Care Nurse Practitioner working in the ED, allow clinicians to minimise futile care and to move patients to services outside TCH. Increasing both the nursing and medical palliative care staff at TCH is another option not considered in the draft Plan. This would provide ready access for palliative options and provide better alternatives for patients and support for alternative options to futile care for TCH clinicians.

Another access issue that needs to be addressed is access to public palliative care services following discharge from private facilities. There is currently a disconnect between these services that prevents consumers from being referred on to receive palliative care, even if they are discharged from the private facility *because* it has been recognised that they are dying. We understand that the interface between private and public services is a complex and wide ranging issue, but improvements in this area need to occur. Alternatively, there needs to be a system of self-referral developed for consumers needing to access palliative care services who cannot be referred by their private health service provider.

8.3 An informed community able to make informed choice regarding end of life care

Effective communication is a key issue for consumers. Often, clinicians fail to adequately convey likely outcomes or fully explain the nature of palliative care. As a result, consumers and their families may not comprehend that curative treatment may be futile or that palliative care is not just for those on ‘the brink of death’.

The eligibility and referral processes for palliative care also need to be made clearer, as many consumers as well as health professionals are unsure of what services are available to them. For example, a family from Bungendore did not know they were eligible to access CHH in the ACT even though they lived interstate. Their GP did not understand the process for access either. Consumers need to know whether they can self-refer to access HBPC services, or whether they need a clinician to unlock the process for them.

Futile care continues to be a major health issue throughout the world, not only subjecting the consumer to unnecessary aggressive treatments that reduce their quality of life, but also

wasting valuable health resources that could be put to better use treating other patients.⁶ Despite clinicians' understanding of futile care, it remains a common issue in acute care settings. This is partly because clinicians are unable, or reluctant, to explain to families that curative treatment is unlikely to prolong their loved one's life and may even cause them more pain. As this is one of the most difficult conversations to have with terminally ill patients and their families, clinicians need to be given more support and training to be able to communicate effectively and tactfully with their patients and patients' families and carers.

Improved communication means it is more likely that consumers will access palliative care when they need it, instead of putting it off until it is too late. If the palliative care team is not engaged early enough, they may be unable to provide sufficient end of life care to make the consumer as comfortable as possible.

Advance care planning needs to be introduced to consumers early on. As noted in the Plan, many consumers would be interested in having an advance care directive but are unaware of this option unless a health professional brings it to their attention and explains the benefits. One strategy for increasing the uptake of advance care planning is the provision of incentives for clinicians to discuss advance care planning with their patients. Advance care planning could also be made part of the RACF admission process.

Consumers need to be adequately informed about their rights, including their right to refuse treatment, including artificial nutrition and hydration.⁷ By taking a rights based approach, consumers and their families are likely to be more confident to make these decisions and feel they are engaging in discussion with clinicians on an equal footing. It also needs to be made clear that refusing one particular treatment does not mean that other aspects of care will cease.

It is important for clinicians to clearly explain the different treatment options available to the patient. Many consumers are happy for clinicians to take the lead in selecting the most appropriate treatment option, as long as they fully understand the reasoning behind any decisions taken. This means that a clinician must explain exactly why curative treatment is not going to benefit the patient and how palliative care can improve their quality of life.

8.4 Ensuring sufficient capacity and resource to meet future projected population demand for palliative care services

We strongly agree that EDs need to be better resourced to provide palliative care in the short term. By bringing more palliative care into the ED, it will be possible to reduce the culture of aggressive treatment that currently prevails.⁸

⁶ Deborah Kasman. (2004). 'When is medical treatment futile?' in *Journal of Internal General Medicine*, 19(10): 1053–1056.

⁷ Colleen Cartwright. (2011). 'Planning for the end of life for people with Dementia' – a Report for Alzheimer's Australia. Paper 24, Part 1.

⁸ Tammie Quest, et al (Roundtable discussion). (2012). 'Palliative Care in Emergency Medicine: Past, Present, and Future' in *Journal of Palliative Medicine*, 15(10): 1076-1081

9. Goals and Strategies

Goal 1 – The Health Directorate plays a leadership role in ensuring reliable access to quality palliative care in the ACT, appropriate to needs and respecting the wishes of the consumer

Strategy a)

While we strongly support this goal, we are concerned that this strategy is very limited. For example, there is no mention of the sub-acute facility planned for University of Canberra or the possibility of having a palliative care hub as part of that facility. There is also no mention of the need to improve palliative care services at TCH by appointing a palliative care specialist at TCH with admitting rights.

There is a lack of recognition of the palliative care initiatives already being undertaken at TCH such as the outpatient and liver clinics. Other options are outpatient clinics at the Community Health Centres, such as the new Tuggeranong Health Centre which is planned to open in 2014. We encourage the Government to make use of these Centres for palliative care clinics.

Consultations with the community during discussions for the sale of CHH to the Little Company of Mary (LCM) made it very clear that a substantial section of the community wants alternative palliative care services to those run by the LCM. The Health Directorate can provide this by improving and adequately resourcing Health Directorate palliative care services.

Strategy b)

There is no mention of consumer involvement in developing an ACT Palliative Care Clinical Network. Other clinical networks have managed to work well with consumers and benefit from their input. Consumer involvement in palliative care is particularly important to ensure it is consumer oriented.

Strategy c)

Again, we support this strategy but are concerned that the needs of the community have been under-estimated. For example, despite 15% of ACT residents speaking another language at home, amongst ACT dementia patients it is 25%.⁹ The needs of dementia patients are not addressed sufficiently in ACT planning, despite earlier reference in the section under the National Policy Context. There are presently more than 250 early onset dementia clients in ACT.¹⁰

In order to meet the needs, and respect the wishes of consumers, care plans must be developed in close consultation with the consumers themselves. Under strategy c), the Plan aims to achieve the best possible outcome for patients and their carers. It is important to acknowledge here that patients and carers may have different opinions about the best possible outcomes, which may cause conflict with the clinician. This is yet another reason

⁹ Jane Allen, CEO, Alzheimer's Australia.

¹⁰ Ibid.

why communication is so important, as it ensures that patients and their families understand what can reasonably be expected through different treatments.

We note that children requiring palliative care services need to travel to Sydney hospitals to receive treatment. This can cause considerable stress to their parents, who may also be caring for other children. We would like to see cross-border collaboration between ACT and NSW paediatric service providers and education available to allow GPs and paediatric specialists to provide as much of the child's care as possible in the ACT.

Palliative care services provided for Aboriginal and Torres Strait Islander peoples must be 'trauma informed' as well as culturally competent. This means recognising the continuing impact of colonisation and a dominant white culture on Aboriginal and Torres Strait Islander peoples and not just their traditional culture. It would be good to engage the Aboriginal Liaison officer at TCH in identifying any special needs that these families may have and also to support Aboriginal and Torres Strait Islander palliative care workers to play a greater role.

Goal 2 – To ensure that palliative care services are provided in the ACT using innovative and best practice models of care that provide greater continuity of care and smoother transitions between settings

We see that the Medicare Locals have a role in educating and supporting GPs with identifying palliative care options. Program of Experience in the Palliative Approach (PEPA) and reverse PEPA are excellent programs but there are still reports over the last year from consumers whose GPs advise their patients to call the ambulance and go to hospital rather calling the specialist palliative care service that could support the patient to die at home.

A number of intensivists such as Professor Ken Hillman and Dr Peter Saul (intensivist and ethicist) have written about the problem of Intensive Care units becoming the graveyard of the old. This is not the desire of many older people, whose preference is to die at home; but they often find themselves on the conveyor belt to intensive care.

This goal relates to futile care in the acute care setting and so is a critical concern of the acute sector. If well addressed and implemented, it could relieve unnecessary pressure in the ED and ICU at TCH. There is a leadership role for ACT Health Directorate in this area and the possibility of a Clinical Senate on Futile Care and End of Life Care may engage clinicians in innovative methods to reverse this costly and unsatisfactory trend. In addition, the Local Hospital Network Council is planning an End of Life Forum in May 2013 as a way of engaging with the community on this issue.

The federal government's Care of the Dying Pathway initiative is an example of an innovative program, which is not addressed in the current draft Plan. We hope the proposal to undertake such a program at TCH is taken up.

As discussed above, we are concerned that the current day hospice service is not enough. In addition to overnight respite care, there is also a need for secular hospice services for consumers from different religious backgrounds who may not be comfortable relying on services provided by the LCM. Given its ageing population, it would be good to investigate the possibility of providing respite services in the Southside of the ACT as well.

As part of improving the quality of palliative care services, it is worth considering the development of performance measures for hospices and other palliative care facilities. . Voluntary reporting has recently been introduced throughout the U.S, with one hospice publicly revealing patient quality data reflecting improvements in pain management and the level of information and education provided to patients and their families.¹¹ We strongly support the use of qualitative measures in evaluating services as opposed to quantitative measures, as this provides a better indication of consumers' experience.

Goal 3 – The ACT Community is well informed about all aspects of death and dying, and that individuals and their families are able to make an informed choice about their treatment options and the settings in which palliative care is provided

In accordance with our comments regarding section 8.3, we would like to see strategy a) amended to include consumers' awareness of their rights as well as their options.

Again, consumers want not only to be informed, but to be engaged with palliative care service delivery and planning. The strategies for achieving this goal seem to mainly focus on acting on passive consumers. We recommend running a funding program, such as the health promotion grants for community groups, to conduct advance care planning education and workshops, possibly with the Respecting Choices (RPC) team. This would allow NGOs and community groups to be active participants in improving advance care planning in the community.

We strongly support the use of the percentage of clients and RACF residents with advance care plans as a performance indicator for this goal, as shown on page 82.

The human element in end of life conversations seems to have been overlooked in this goal. Aside from discussing clinical information, health professionals need to empathise with patients and their families, be sensitive to their concerns and beliefs, and offer reassurance that the patient will be given the best possible care. It is this interpersonal aspect of difficult conversations at end of life that is often one of the biggest obstacles.

We would like ED staff to be included in the strategy to promote greater collaboration with palliative care services. This is where many consumers end up when they are on the brink of death due to the incapacity of carers or RACFs to provide sufficient care. This situation could be improved by ensuring that ED staff can recognise when curative treatment is futile and recommend the engagement of a palliative care team. We have heard many stories about people who have received inappropriate, aggressive treatment in the ED or ICU, only to pass away shortly after in more discomfort than before receiving the treatment.

Goal 4 - To ensure that an optimal capacity of palliative care services will be in place to meet the demands of the current projected population demand

We are concerned that the recommendation to provide 25 designated palliative care beds by 2017 does not adequately account for the projected difficulty in addressing workforce deficits, particularly with regard to HBPC. Without sufficient staffing of HBPC and other primary palliative care providers, consumers will continue to be admitted to acute care

¹¹ <http://www.bioportfolio.com/news/article/1249704/Hospice-Provider-Releases-Quality-Data-Setting-Benchmarks-For-Industry.html>

facilities and being denied the opportunity to die in their home or RACF. Section 10.2 acknowledges that a more conservative estimate has been provided by Palliative Care Australia (PCA), suggesting that 30 beds will be required for the ACT by 2017. We urge the Health Directorate to consider using this estimate instead.

Goal 5 – to ensure an appropriately qualified and sustainable workforce to provide the projected level of palliative care services in the ACT

Developing the palliative care workforce at TCH as soon as possible could be a cost effective strategy which will increase the use of palliative care with all the attendant benefits for consumers. This would also be a good first step in preparing and obtaining a workforce for the proposed palliative care hub in the new sub-acute facility at the University of Canberra site.

Goal 6 - to develop a local research and knowledge base to inform service and workforce development and quality improvement

We strongly support the need to develop a local knowledge and research base in the ACT. This is an excellent incentive to attract quality clinicians to the region.

However, we question whether it is necessary for a program of research to be restricted to Calvary. We also see a role for primary care research and research programs within public health services. There are excellent opportunities Calvary Centre for Palliative Care Research to work with TCH staff to develop research projects.

An audit of nurse to resident ratios in RACFs would assist in determining how many additional staff are required to deliver effective palliative services.

10.2 Inpatient Bed Requirements

We are concerned the statistics on palliative care services show that TCH, with very limited resourcing, provides a substantial proportion of palliative care services in the ACT, such as utilising 5.2 beds at 90% occupancy in 2010 - 11. It seems that even the reported TCH services underestimate all palliative care services in TCH, because early palliative care services are mostly admitted under another speciality (due to the lack of a palliative care specialist with admitting rights at TCH) and therefore do not appear in TCH statistics as palliative care work. For this reason, we would like to see palliative care specialists at TCH being given admitting rights.

11. Workforce Requirements

We welcome the proposals to address the problems within LCM palliative care services, but are concerned there are no proposed resourcing solutions for unmet demand in TCH and Community Nursing. Nor are any solutions offered for the primary care sector (such as through the Medicare Local) or RACF staffing.

Better funding of palliative care in TCH, including the provision of an additional palliative nurse practitioner, is unlikely to increase the overall cost to the ACT health system because it would reduce futile care and demand on the ED and ICU. It may actually reduce the health budget and result in more peaceful deaths for patients.

11.1 / 11.2 Medical and Nursing

The early part of the Plan comments on the problems associated with having no palliative care specialist with admitting rights at TCH. However, neither Sections 10 nor 11 recommend the provision of a Palliative Care Specialist at TCH. Rather, the proposal is to increase the current 2.8 FTE Palliative Medicine Specialists to “four positions over the next five years” (P.62).

Similarly, there is a support for an additional Palliative Care Nurse Practitioner in the Home Based Palliative team, but no recommendation about another Palliative Care Nurse Practitioner in TCH. At present, the only Palliative Care Nurse Practitioner at TCH is funded through cancer services and is, therefore, primarily responsible for cancer patients. A second Palliative Care Nurse Practitioner in the sub-acute area for patients with other life limiting conditions would address some of the unmet need.

The report on p.63 that “The HBPC Palliative Care Aged Care nurse has had a substantial impact in addressing the previous unmet demand for end of life care for people living in residential aged care”, is encouraging.

An increasing number of people are reaching the end of their lives in RACFs, and it is essential that RACFs are equipped with enough staff and resources to provide adequate palliative care to consumers until end of life. RACF residents are an extremely vulnerable population who have had little representation with regard to health policy input. The Health Directorate must ensure that the needs of these consumers are made a priority with regard to palliative care.

This is an area which needs considerable improvement. Just this week, a carer whose husband was in an RACF with advanced dementia, told us that the RACF transferred her husband to the hospital where he was moved to intensive care to die of pneumonia.

Not only is there a need to “an increase in the nursing workforce in the HBPC team” (p. 63), there is also a need for supportive and trained staff in RACF to support dying patients in RACFs.

11.5 Volunteers

The contribution of volunteers throughout the health system is invaluable and we sincerely appreciate the services they provide; indeed, many of our members are involved in volunteer programs themselves. However, we are concerned that heavy reliance on the volunteer workforce is not feasible, given the high turnover rate and the difficulty in predicting availability in the long term.

12.2 Palliative Care Key Performance Indicators

We are concerned that the Steering Committee overseeing the development of specific actions to implement these goals will not have enough input from TCH. A TCH medical or nursing specialist would be a useful addition to the Steering Committee. It is important that there is adequate representation of all palliative care providers to ensure that the Plan can be implemented effectively across all areas.

Consumer and clinician feedback needs to be an integral component of the evaluation framework for this plan. Timely feedback must be collected on important quality indicators including pain management, early engagement of palliative care, information and education, and respecting consumer choices.

Quality indicators of pain management in palliative care facilities in the U.S include:

- Percentage of patients in pain at admission that have their pain controlled to their satisfaction within 48 hours;
- Percentage of patients that had pain above their self-identified threshold anytime during the last week of life.¹²

Measures such as these would go a long way to ensuring that pain management, an essential component of good palliative care, is effectively administered in all palliative care settings.

We are happy to discuss our submission further. Please contact Karen Jameson (hccapolicy@hcca.org.au; 6230 7800),

¹² <http://www.bioportfolio.com/news/article/1249704/Hospice-Provider-Releases-Quality-Data-Setting-Benchmarks-For-Industry.html>