Chief Minister
Treasury and Economic Development Directorate
ACT Government

Email: budgetconsultation@act.gov.au

Dear Chief Minister

Health consumer priorities for 2019-20 budget

Thank you for the opportunity to provide input into the preparation of the ACT Budget for 2019-20.

The Health Care Consumers' Association (HCCA) is both a health promotion charity and the peak consumer advocacy organisation in the Canberra region. HCCA provides a voice for consumers on health issues and provides opportunities for health care consumers to participate in all levels of health service planning, policy development and decision making. This year marks the 40th year since the association first incorporated.

HCCA is a member-based organisation and for this submission we consulted with our members and other member organisations in the development of this input. In particular, we worked collaboratively with

- the ACT Mental Health Consumer Network to develop the submission on trauma-informed care and practice, and
- the AIDS Action Council ACT to develop our submission on sexual health services.

Please find attached the following submissions:

- Palliative care
- Trauma-informed care & practice:
  - Adult Mental Health Day Service, University of Canberra Hospital
  - ACT Emergency Departments
- Improving the quality of support and management of chronic conditions

- Better pain management services
- Canberra sexual health services
- Response to transvaginal mesh
- National code of conduct for health care workers

HCCA supports a submission from ACT Council of Social Services (ACTCOSS) for

> *a formal mechanism for community, tenant and industry representatives to work collaboratively with the ACT Minister and Officials on more detailed design, implementation, scrutiny of implementation and monitoring of progress, over the life of the Strategy.*

Finally, HCCA has identified a growing need among health care consumers for support when trying to have their voice heard, including when expressing concerns or making complaints. Over the following 12 months, HCCA will be gathering evidence and assessing the need for individual health advocacy in the ACT.

Thank you for this opportunity and we look forward to discussing these proposals with the relevant areas. This is a public submission and HCCA is happy for it to be publicly available.

Yours sincerely

Darlene Cox
Executive Director

31 October 2018

HCCA Submission to the ACT Government Budget Consultation 2019-20

Submitted 31 October 2018

Contact: Darlene Cox
Executive Director, HCCA
02 6230 7800

Palliative care

HCCA wants to see

- a dedicated palliative care unit at the Canberra Hospital,
- an ACT-wide palliative care service, and
- more staff with training in the palliative approach

Why is it important?

Last year HCCA gathered the stories of 15 people who had cared for a loved one while they were receiving palliative care in a variety of settings – home, hospital and hospice – and one person who had received palliative care.[a] Unfortunately, many of the hospital-based experiences they shared with us were less than ideal. There is substantial room for improvement in the following areas:

- routine observations, unnecessary tests,
- ongoing treatment being ordered for patients when it will do little to improve their quality of life,
- late or no referral to palliative care services within and outside the hospital,
- staff with variable and often unsatisfactory understanding of the palliative approach,
- unsuitable environments (for instance, noisy and public),
- late, disruptive and sometimes traumatic transfers to specialist palliative facility outside the hospital, and
- infrequent access to specialist palliative care nurses and physicians within the hospital.

What's currently available?

Clare Holland House provides specialist palliative care services in the ACT, including outpatient clinic services, care in the home or residential setting, and inpatient hospice services.

Both Canberra and Calvary public hospitals employ palliative care physicians and palliative care nurse practitioners. However, according to testimony given to the Select Committee on End of Life Choices in the ACT, the specialist palliative care workforce is inadequate, even without considering the demand from surrounding NSW.[b] As evidence of this, there is no-one at Canberra Hospital who can refer a patient to Clare Holland House on the weekends.[c]

Canberra Hospital has spent considerable effort introducing systems whereby the wishes of consumer requiring intensive care are respected.

In addition, Palliative Care ACT trains and provides volunteers to support residents who are receiving palliative care in the ACT.[d]

How can it be improved?

- ACT health professionals and aged care workers should
  - know when and how to take palliative care approach
  - recognise the need for, and appropriately initiating conversations about, advance care planning[e]
  - be aware that a consumer has undertaken advance care planning
  - consult advance care documents quickly, when needed

- Enhancing consumer and carer understanding of palliative car

New ideas, services or programs?

HCCA strongly supports the establishment of a dedicated palliative care ward at the Canberra Hospital, and has outlined its reasons to the Executive Director, Cancer, Ambulatory Care and Community Health Services (Attachment 1). HCCA provided considerable feedback on the draft Acute Integrated Palliative Care Unit Model of Care (Attachment 2) and encourages further development and implementation of this model.

HCCA strongly encourages the government to allocate necessary resources to the Palliative Care Clinical Network's plan to establish an ACT-wide palliative care service with a single point of entry, including a single patient record.

HCCA believes that training in the palliative care approach should be undertaken by more ACT health professionals. Training for general staff is available through various sources including the Program of Experience in Palliative Approach (PEPA)[f] run by Clare Holland House.

---

[a] Spiller S. "Consumer and Carer Experiences and Expectations of Home-Based Palliative Care in the ACT". 2017. Health Care Consumers' Association. https://bit.ly/2D1dYxr (Accessed 24/10/2018).

[b] Select Committee on End of Life Choices in the ACT. *Transcript of Evidence*. 2018, 12 July, Canberra, Page 392.

[c] See note (b), Page 394.

[d] Palliative Care ACT https://www.pallcareact.org.au/ (Accessed 24/10/2018).

[e] Select Committee on End of Life Choices (p395)

[f] Program of Experience in the Palliative Approach. "What is PEPA?" Palliative Care Education and Training Collaborative. https://pepaeducation.com/ (Accessed 24/10/2018).

Trauma informed care & practice

HCCA and the ACT Mental Health Consumer Network (the Network) want to see

- **training in trauma-informed care and practice for all staff in the Canberra Hospital and Calvary Hospital Emergency Departments, and**
- **trauma-informed care and practice embedded in the Adult Mental Health Day Service**

Why is it important?

A very high proportion of people using public adult mental health services have experienced single or multiple incidents of trauma.[a] North American research suggests that 90% of public mental health service users may have experienced multiple traumatic life events.[b] Consequently, we can reasonably conclude that the majority of participants who have attempted suicide and present to an Emergency Department (ED) have experienced trauma. Similarly, many individuals receiving care and support through the Adult Mental Health Day Service will have experienced trauma in their lives.

While being sensitive to potential trauma and its consequences, services that are meant to help individuals are often "trauma-blind". [c] Staff can be unaware of how trauma affects the way people approach potentially helpful relationships.[d] Hence, self-protective mechanisms such as vigilance, suspiciousness and anti-social behaviour may be confronting and cause staff to respond inappropriately. For instance, they may use a harsh or dismissive tone, and avoid or marginalise the individual.[e]

Trauma-Informed Care and Practice offers a framework for providing services to individuals who have experienced trauma.[f] Trauma-informed services seek "safety first" and commit themselves to "do no harm".[g] All aspects of the service are informed by the recognition and acknowledgement of trauma, an understanding of its prevalence, and an awareness of, and sensitivity to, its dynamics.[h] Thus a trauma-informed care and practice approach meets the physical, emotional and psychological needs of consumers, and is responsive to an individual's unique circumstances and goals, thereby constituting ideal consumer-centred care.[i]

Canberra Hospital and Calvary Hospital Emergency Departments

Unfortunately, interviews recently conducted with nine participants of The Way Back Support Service, a suicide prevention program,[j] indicated that participant experiences in the Canberra Hospital and Calvary Hospital EDs were almost uniformly poor. The following quote shows how a person who has attempted suicide can feel worse after admission to ED, because psycho-social care was not provided and only the clinical element was adequately addressed.

> *I think if they could be more attentive. I believe if you bring someone who is suicidal, someone who is hopeless, they just don't need to be left there alone. They feel more alone and it is making the situation even worse. … If you take me to the hospital and leave me there and not check on me, it makes everything worse. It doesn't help me. … Just try to make some conversation. Chat with the patient.* *(Participant C)*

These quotes by participants A and G exemplify the experience of being stigmatised by health professionals who weren't specifically trained in managing patients with mental health challenges.

I've had people [nurses] tell me … that you have to be thankful because you don't have a physical illness. … "There's some people that have physical illness that want to be fine." *(Participant A)*

I mean yeah, emergency departments don't really treat you that well … Sometimes they just act as though … you don't really matter, that you're doing it for attention. *(Participant G)*

The staff in the Short Stay Mental Health Unit at Canberra Hospital had little to offer people who had attempted suicide and the environment itself made some people feel worse.

If they'd ask … I would tell them honestly that I'm not feeling too good. And all they'd offer me was medication. So, then I got to the stage that I was sick of taking their medication. I was like, "This isn't helping me." So, I was just like, "Yeah, I'm fine." *(Participant A)*

It almost feels like it's designed to make you feel worse about wanting to die. It's like saying, "How stupid are you for attempting this," or, "How stupid are you for feeling this way. We're just going to make you feel more isolated and stupid by putting you in this little tiny space, and have people say they're here for you, but they actually just sit in a box watching you." *(Participant B)*

The one woman who was admitted to Ward 2N at Calvary fared little better. She was effectively ignored in 2N for "a couple of days" until her parents advocated on her behalf and she got to see a psychiatrist. Furthermore, she was treated as a drug addict by a nurse because she needed analgesia to manage an acute episode of a long term physical complaint.

It's that thing of being treated like you're just after medication, which I'm sure they come across as well, … But, that's also part of being [physically] unwell … in a place like that. That's, that's something to accept. *(Participant I)*

Experiences like those recounted above have not helped the people concerned and arguably have contributed to their trauma.

What's currently available?

Canberra Hospital

- Emergency Department
- Short Stay Mental Health Unit
- Adult Mental Health Unit

Calvary Public Hospital

- Emergency Department
- Ward 2N

How can it be improved?

Services can be improved in Canberra's emergency departments by staff taking a trauma informed approach to care. The NSW Mental Health Coordinating Council is one of several providers that offer training for health professionals. They also provide training to embed trauma-informed care and practice in health services. [k]

New ideas, services or programs?

HCCA and the Network strongly encourage the ACT Government to fund trauma informed training for all staff working in the Canberra Hospital ED, including the Short Stay Mental Health Unit, and in Calvary ED.

Adult Mental Health Day Service, University of Canberra Hospital

The Adult Mental Health Day Service (AMHDS) moved to the Canberra Public Hospital in 2018. Prior to this HCCA reviewed its model of care and concluded that

> *the Model of Care does at present not reflect the principles of trauma-informed care adequately, nor does it provide enough information to reassure consumers that the care provided by AMHDS will offer "opportunities in a safe and supportive environment" (page 5, lines 19-21).*[l]

In addition,

> *HCCA feels that the current AMHDS Model of Care represents a medical approach to mental health care.*

Regarding the Adult Mental Health Day Service Model of Care, one consumer representative from the Network articulated that

> *…the real issue in embedding recovery oriented principles is about having staff who understand and practice recovery oriented care (Mental Health Consumer Representative).*

Given it is unclear how the Service will acknowledge and fully incorporate trauma informed care and practice into its stated recovery-oriented approach to care, it is unlikely to achieve its goals. By embedding trauma-informed care and practice, the AMHDS will be able to offer the safest, and most respectful and effective care possible.

What's currently available?

Mental health day services

- Adult Mental Health Day Service at University of Canberra Hospital

Trauma-informed care

- The ACT Women's Health Service has adopted a trauma-informed model of care. This model of care has been externally evaluated and provides a good benchmark for what is possible within an ACT Health service.
- The ACT Government's reforms of the Out of Home Care sector for children and young people, through the *A Step Up for Our Kids (2015-2020)* strategy[m], includes significant investment in better responses to trauma, through training, new specialist services, and support for organisations to embed trauma-informed practice.
- In 2018 the ACT Community Services Directorate has worked with ACT Shelter to identify opportunities to strengthen trauma-informed practice in the ACT specialist homelessness services sector.[n]

How can it be improved?

The AMHDS will be better able to provide person-centred, high quality and safe care if it adopts a systematic approach to embedding a trauma-informed approach. Recent Australian research has found that successfully implementing a trauma-informed approach requires:

- A rolling program of staff training with clear learning outcomes that match job requirements;
- A structured and rigorous organisational assessment or self-assessment process;
- Time, to build relationships of trust internally and with external organisations;
- Review, change or development of policies, procedures and protocols; and
- Introduction of new practices, which will vary according to setting but may include new approaches to supervision to better address vicarious trauma, new or more proactive referral to trauma-specific services, or the introduction of respectful trauma screening.[o]

A number of organisations specialise in the provision of organisational assessment and review, training, mentoring and external supervision related to trauma-informed care and practice. These include:

- Phoenix Australia (formerly the Centre for Post-traumatic Mental Health)
- Blue Knot (formerly Adult Survivors of Childhood Sexual Abuse)
- NSW Mental Health Coordinating Council
- Australian Childhood Foundation

ACT universities and Canberra Institute of Technology may also offer appropriate training opportunities.

The ACT Community Service Directorate is overseeing work to strengthen trauma-informed practice in the out of home care and homelessness sectors. This presents an excellent opportunity to work collaboratively across government agencies. For instance, the agencies could share relevant cross-sector learning, and identify possible opportunities to achieve shared priorities and economies of scale in relation to training and development needs.

New ideas, services or programs?

HCCA and the Network strongly encourage the ACT Government to fund the process of embedding trauma-informed care and practice in the AMHDS. This will require engaging a specialist provider (or providers) of trauma-informed care training, and quality improvement services related to trauma-informed care. These services should at minimum include organisational assessment, support to identify and implement priority changes, and periodic review over a minimum three to five years.

---

[a] Hussain & Chapel, 1983; Emslie & Rosenfeld, 1983; Mills and others, 1984; Bryer and others, 1987; Jacobson & Richardson, 1987; Craine and others, 1988; Swett and others, 1990 in Mental Health Coordinating Council 2013; see note (d)

[b] Dunne M, Purdie D, Boyle F, & Coxeter P. 2005. see note (d)

[c] Mental Health Coordinating Council (MHCC) 2013, *Trauma-Informed Care and Practice: Towards a cultural shift in policy reform across mental health and human services in Australia, A National Strategic Direction,* Position Paper and Recommendations of the National Trauma-Informed Care and Practice Advisory Working Group, Authors: Bateman, J & Henderson, C (MHCC) Kezelman, C (Adults Surviving Child Abuse, ASCA)

[d] Fallot D & Harris M. “Trauma-Informed Services: A Self-Assessment and Planning Protocol”. *Community Connections*. 2006. Version 1.4, Issue 3-06.

[e] Mental Health Coordinating Council (MHCC) 2013, *Trauma-Informed Care and Practice: Towards a cultural shift in policy reform across mental health and human services in Australia, A National Strategic Direction,* Position Paper and Recommendations of the National Trauma-Informed Care and Practice Advisory Working Group, Authors: Bateman, J & Henderson, C (MHCC) Kezelman, C (Adults Surviving Child Abuse, ASCA)

[f] Hopper EK, Bassuk EL & Olivet J. “Shelter from the Storm: Trauma-Informed Care in Homelessness Services Settings”. The Open Health Services and Policy Journal. 2010, Volume 3, Pages 80-100.

[g] Fallot D & Harris M. “Trauma-Informed Services: A Self-Assessment and Planning Protocol”. *Community Connections*. 2006. Version 1.4, Issue 3-06.

[h] See note (e)

[i] Health Care Consumers’ Association. “Consumer-Centred Care Position Statement”. HCCA. Canberra. 2018. https://www.hcca.org.au/about/position-statements/ (Accessed 30/10/2018).

[j] HCCA’s report is currently in draft form.

[k] NSW Mental Health Coordinating Council. "Trauma Informed Care & Practice Organisational Toolkit". (http://staging.mhcc.org.au/sector-development/recovery-and-practice-approaches/ticpot.aspx). They also offer do-it-yourself option. http://mhcc.learningcart.com/content/TICPOT.aspx) (Accessed 24/10/2018)

[l] HCCA Correspondence with Executive Director, Mental Health, Justice Health, and Alcohol & Drug Services, 18 May 2017.

[m] ACT Government. A Step up for Our Kids – One Step Can Make a Lifetime of Difference, Out of Home Care Strategy 2015-2020. http://www.communityservices.act.gov.au/__data/assets/pdf_file/0009/682623/CSD_OHCS_Strategy_web_FINAL.pdf (Accessed 26/10/2018).

[n] ACT Shelter “Implementing trauma-informed practice in ACT specialist homelessness services project. Report back to specialist homelessness services and invitation for feedback and discussion”. Prepared by Sarah Spiller and Rebecca Vassarotti, ACT Health, July 2018.

[o] Quadara A & Hunter C. “Principles of trauma-informed approaches to sexual abuse: A discussion paper. Royal Commission into Institutional Responses to Child Sexual Abuse”. Australian Institute of Family Studies. Sydney. 2016. https://trove.nla.gov.au/version/235883546 (Accessed 31/10/2018)

Improving the quality of support and management of chronic conditions

HCCA wants to see

- **ACT Health pilot a three year Patient Navigation Service for people with chronic and complex conditions**

Why is it important?

People with chronic and complex conditions are high users of health services and their needs are rarely met by a single health professional.[a, b] Indeed, having multiple conditions and high levels of complexity can mean that people need treatment from numerous specialists, administered through separate health care providers and funding entities, in various locations. This fragmented health care does little to support the long-term and multidisciplinary care required for managing chronic and complex conditions. Considerable focus on coordinating this fragmented system is required if patients with chronic conditions are to receive the best possible care. Engaging patient navigators can help patients find their way through the health care system and coordinate the fragmented clinical and social services they need to manage their conditions.

According to the ACT Chief Health Officer's Report 2018 chronic diseases now cause most of the poor health and premature death in the ACT.[c] In the ACT, about 80 percent of diseases are chronic conditions that can be managed but not cured. The ageing of the ACT population, in combination with risk factors such as obesity, smoking and lack of physical activity present a major challenge for ACT Health placing a greater burden on the health care system.[d] **Chronic conditions account for half the total preventable hospital presentations in the ACT.[e]**

ACT health's Chronic Conditions Strategy 2013-2018 "sets out a basis for improving the quality of support and management of chronic conditions in the ACT through a person centred approach."[f] The Strategy emphasises the commitment that "every person with a chronic condition receives the right care, in the right place, at the right time from the right team". On this point, the Strategy stresses the importance of comprehensive patient support through team-based care yet falls short of suggesting who should coordinate such care.

In 2017, the ACT Government commissioned the Health Care Consumers' Association (HCCA) to develop a model of patient care navigation in the ACT. The intent of the model is to improve the health and wellbeing of consumers with chronic and complex conditions.

To inform this model HCCA sought to understand the care coordination experiences of both consumers and health professionals. The voices of consumers and health professionals in our report revealed that there are varying degrees to which coordinated care is given and received. Health professionals told us that they would like more support to enable them to provide coordinated care. Consumers told us that they would like to be assessed as a whole person, and be provided with information that suits their very specific circumstances.

Major barriers to providing good care coordination identified by health professionals:

- There is not enough time to provide a comprehensive, holistic assessment of patients, including everyone involved in their care, before they are discharged
- Coordinator roles and responsibilities are not clearly defined
- Processes for coordinating care, including discharge, are not standardised
- Poor flow of patient information generally, but especially among/between treating clinicians when a patient has multiple conditions
- There are not enough dedicated discharge roles such as discharge liaison nurses and social workers
- Added complexity and time delays caused by government systems such as My Aged Care and National Disability Insurance Scheme (NDIS)

Major barriers to receiving good care coordination identified by consumers:

- Significant gaps in information about their conditions, treatment options and staying healthy, and difficulty sharing information between health services and professionals
- Cost barriers
- Time barriers
- Cursory hospital discharge planning

What's currently available?

There are care coordination programs aimed at providing patient-centred care in areas of need in the ACT, but they are often disease-specific and do not **comprehensively address the needs of patients with chronic and complex conditions**. The Chronic Care Program at the Canberra Hospital and the Capital Health Network's Transitions of Care aim to provide coordinated care for consumers with chronic and complex conditions, yet according to our research, barriers to good coordinated care remain.

How can it be improved?

Clear gaps remain between the current coordination of care and the needs of people living with chronic and complex conditions. According to our analysis of the consumer data, these unmet needs warrant improvements to the current state of care coordination, such as

- better and more personalised information for self-management,
- greater acknowledgement of the interaction of multiple conditions,
- more attention to personal and social issues,
- better knowledge of and linkage to community-based services, and
- more time for comprehensive assessment and planning.

Consumers feel that these gaps make it harder for them to stay well, look after their own health, and stay out of hospital. Rather than coordinated care, consumers with multiple conditions experience a fragmented health care system, often as a series of ad hoc interventions by a diverse range of health professionals and lay people. Consumers want and need individualised care because the number and progression of their conditions, as well as the particular interactions of their conditions, is individual. This desire for

customised care demands that care coordination be tailored to the individual patient rather than a one-size-fits-all approach to chronic conditions management. Revealingly, consumers felt that better information, tailored to their circumstances could remove a number of barriers. For example, ensuring consumers understand their conditions and are aware of available services and care options potentially reduces costs, time and anxiety as well as aiding self-management. Consumers particularly, need coordinated care at times of change such as hospital discharge and/or a new diagnosis or new medication.

New ideas, services or programs?

Done properly, HCCA feels that a patient navigation service would address some of these barriers and meet the priority needs of consumers.

A patient navigator anticipates and identifies barriers to good patient care and helps to remove them.[g] **In doing so they improve patient outcomes and the overall quality of health care delivery.**[h] Most importantly, from a consumer perspective, navigators teach patients about steps they can take to successfully navigate the health system. **They help patients gain skills to take ownership of their health**.[i]

Using the information collected through interviews, case studies and stakeholder feedback, the HCCA has developed a model for patient navigation in the ACT. **The outcome of the model is to improve the quality of life for consumers and partner with them to achieve the best health and wellbeing possible.**

Underpinning the model are four Key Principles:

Advocacy

- Promote patient centred care
- Provide personalised and holistic assessment and planning
- Be the single point of contact

Linkage

- Provide links to existing services and resources
- Expedite centrally coordinate care
- Create partnerships with everyone involved in the patients' care
- Include carers and families
- Build professional relationships

Education

- Improve health literacy
- Plan and set goals for self-management

Health system improvement

- Assess and monitor systems for improvement
- Enhance existing services
- Ensure succession planning
- Promote research, assessment and development

The model consists of eight criteria for a successful navigation service:

1. **Patient need and service response**

A navigator service must determine the needs of the patient and respond with the appropriate level of service.

2. **Roles and responsibilities**

It is essential that the parameters of a navigation service are made clear, and that navigators are enabled to adapt their role to suit a patient's individual needs.

3. **Referral and eligibility**

A straightforward and open referral system, with simple eligibility criteria is essential to ensure the service reaches the people who most need it.

4. **Training**

Training navigators in a chronic disease management program can strengthen the service by providing consistency and reassurance for patients and navigators.

5. **Evaluation and data collection**

Data must be systematically recorded from the beginning of the service to ensure accurate and complete service evaluations, and wider health system assessments.

6. **System support**

For a navigation service to be successful, it must be implemented with Territory-wide support from consumers, health professionals, and health services as well as ongoing clinical and corporate support.

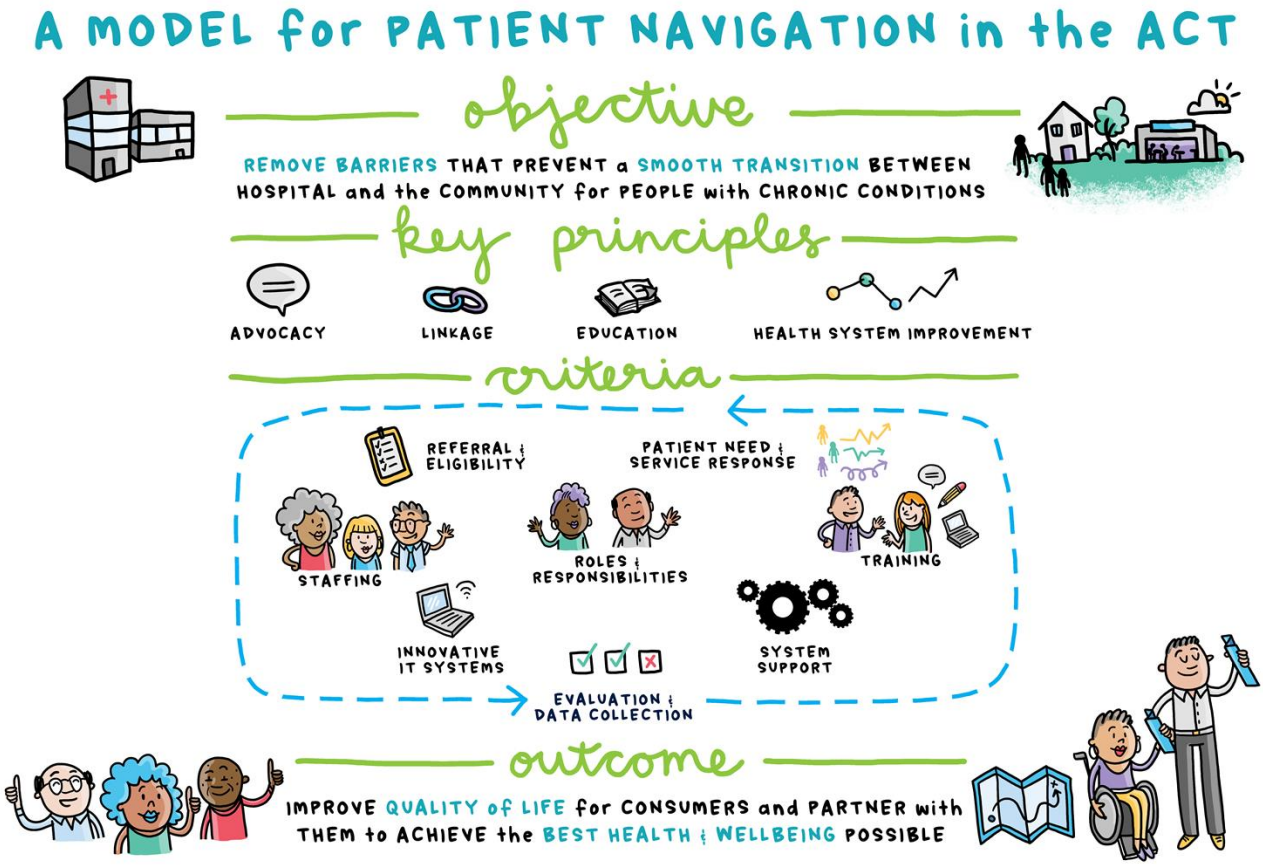
7. **Staffing**

Whether clinical, non-clinical, or a combination of both, a navigator team needs to be knowledgeable, experienced, highly skilled and excellent communicators.

8. **Innovative IT systems**

HCCA recommends that ACT Health pilot a three year Patient Navigator Service.

HCCA have developed a model for patient navigation in the ACT (see illustration below) that includes criteria necessary for the successful implementation of a navigator service.



A patient navigation service would need to be well-resourced, with access to patient records and established links to hospitals and community. Some possibilities for a three-year pilot program are:

- To contract an external provider
    - For example, the Silver Chain Health Navigators Program, used as a case study in this report, provides an excellent model of outsourcing a patient navigator service.
- Use existing ACT Health services
    - For example, an expansion and enhancement of the current Chronic Conditions Program at Canberra Hospital and Health Services.

---

[a] National Strategic Framework for Chronic Conditions, Australian Health Ministers' Advisory Council, 2017, Australian Government, Canberra

[b] Better Outcomes for People with Chronic and Complex Health Conditions, Report of the Primary Health Care Advisory Group, 2015

[c] ACT Health (2018) *Healthy Canberra, Australian Capital Territory Chief Health Officer's Report 2018*. Canberra ACT: ACT Government.

[d] ACT Population Health Division (2013) *Population Health Division Strategic Framework 2013–2017*. Australian Capital Territory, Canberra: ACT Government.

e ACT Health, 2012 Australian Capital Territory Chief Health Officer's report 2012.

[f] ACT Health, 2013. ACT Chronic Conditions Strategy – Improving Care and Support, Australian Capital Territory, Canberra: ACT Government

[g] Harold Freeman "A model patient navigator program". Oncology Issues. Volume 19, Pages 44-47, 2004.

[h] Allison Pedersen and Thomas F Hack, "Pilots of Oncology Health Care: A Concept Analysis of the Patient Navigator Role" Oncology Nursing Forum, Volume 37, Issue 1. January 2010.

[i] Calhoun, E. *et al.* (2009) 'A National Patient Navigator Training Program', *Health promotion practice*, 11, pp. 205–15.

Better pain management services

HCCA wants to see

- **more financial support for Canberra Hospital Pain Management Unit**
- **local implementation of the National Pain Action Plan**

Why is it important?

Almost a fifth of the Australian population report chronic pain.[a] This is pain is experienced every day for three months or more. While waiting they are reliant on over the counter medication and consultations with GPs. Patients' quality of life and psychological well-being may deteriorate significantly while waiting for treatment.[b] Unsurprisingly then, one fifth of general practice consultations relate to managing chronic pain.[c] Capital Health Network identified GP management of chronic pain among older people as a key issue in the ACT.[d] Furthermore, the new codeine regulations are likely to exacerbate this negative situation. A recent report shows that the ACT has the equal highest average capital city consumption of fentanyl nationally in April 2018. The ACT also reported an increase in oxycodone and fentanyl consumption.[e] These data indicate the dependence on these drugs in the ACT for pain relief, as both are used in the treatment of chronic pain.

Chronic pain with or without diagnosis is highly stigmatized,[f] even by the very health professionals who are meant to be assisting. Consumers have reported that health professionals (including GPs and those working in pain clinics) respond to any request for assistance with pain as drug seeking behaviour. This leaves consumers feeling embarrassed, offended and no closer to getting help.

What's currently available?

Pain management services Australia-wide are unable to meet demand, and the situation is worse for people using publicly funded services.[g] The ACT has two public clinics – Canberra Hospital Pain Management Unit and Canberra Endometriosis Centre. Currently, the Canberra Hospital Pain Management Unit website states that "significant wait periods may exist" and encourages people to "make an appointment as soon as possible".[h] Furthermore, parking is limited immediately outside the building and patients parking in the multi-story carpark must labour up a considerable number of stairs to reach the Unit. Even the Minister admitted, earlier in the year, that wait times for chronic ongoing issues is much longer than four weeks.[i] Canberra also has two private clinics (i.e. ACT Pain Centre; Capital Pain and Rehabilitation Clinic).

How can it be improved?

The ACT Government needs to put more financial and workforce resources into supporting publicly available pain management services. No public services are located on the northside of Canberra.

Health professionals need to be educated in how to respond appropriately to consumers with chronic pain. Specifically, general practitioners need better skills in managing patients with chronic pain.[j] The Medicare Benefits Schedule does not currently remunerate GPs to manage chronic pain, except as part of a chronic disease consultation. Incentives are needed for GPs to gain necessary knowledge and skills.

Health professionals need to be encouraged and supported to work in an interdisciplinary manner.

People who care for those with chronic pain also need support to improve their understanding of pain management [k]

New ideas, services or programs?

HCCA strongly supports increased funding for the Canberra Hospital Pain Management Unit.

A draft National Pain Action Plan is currently with the Commonwealth Department of Health and will be considered by COAG shortly. The National Pain Action Plan is based on the National Pain Strategy. [l] Several of the activities proposed will require local funding to ensure their implementation. Those listed below are based on the National Strategy and therefore expected to be included in the Action Plan.

Health professionals

- Train and support health practitioners in best-practice pain assessment and management[m]
- Health professionals need to be supported to develop interdisciplinary clinical networks to foster regional relationships and collaboration between primary care providers, relevant specialists (not just pain specialists), specialist pain units, palliative care services and aged care services.[n]
- Ensure clear, accurate and timely communication about pain management between practitioners and patients, and between practitioners[o]
- Ensure tertiary specialist pain clinics have resources needed to support key strategies[p]

Consumers and carers

- Improve community understanding of the nature of chronic pain and best-practice management[q]
- Provide easily accessible information and support programs to assist people with pain, carers and other supporters, and practitioners to understand and be more proactively involved in managing pain[r]

HCCA would like to see the ACT Government support for more educational activities like Capital Health Network's planned masterclass to improve GPs' understanding of pain and its management.[s]

---

[a] Blyth FM, March LM, Brnabic AJM, Jorm LR, Williamson M and Cousins MJ, 2001. Chronic pain in Australia: a prevalence study. *Pain* 89:127-134.

[b] Lynch CF, Clark AJ, Dunbar MJ, Goldstein D, Peng P, Stinson J, Tupper H. "A systematic review of the effect of waiting for treatment for chronic pain". 2008. *Pain*. Volume 136, Issues 1-2, Pages 97-116.

[c] SAND abstract No. 150 from the BEACH program 2009–10. Chronic pain in general practice patients. Sydney: AGPSCC University of Sydney, 2010. http://sydney.edu.au/medicine/fmrc/publications/sand-abstracts/150-Chronic_Pain.pdf (accessed Jan 2012).

[d] Capital Health Network. "Baseline Needs Assessment 2016". Canberra: Capital Health Network. 2016. Page 138. https://www.chnact.org.au/sites/default/files/CHN_ACT_PHN_Baseline_Needs_Assessment_2016.pdf (Accessed 24/10/2018).

[e] Australian Criminal Intelligence Commission. "Wastewater results show fentanyl use equal highest in ACT." 2018, 9 October. https://www.acic.gov.au/media-centre/media-releases-and-statements/wastewater-results-show-fentanyl-use-equal-highest-act (Accessed 24 October 2018).

[f] International Association for the Study of Pain. "Declaration of Montréal. Declaration that Access to Pain Management Is a Fundamental Human Right". 2010. International Pain Summit Of The International Association For The Study Of Pain. https://www.iasp-pain.org/DeclarationofMontreal?navItemNumber=582 (Accessed 24/10/2018).

[g] Hogg MN, Gibson S, Helou A, DeGabriele J, Farrell MJ. “Waiting in pain: a systematic investigation into the provision of persistent pain services in Australia”. 2012. *Medical Journal of Australia*. Volume 196, Issue 6, Pages 386-90.

[h] Canberra Hospital Services, *The Canberra Hospital Pain Management Unit*, 2018 at http://www.painsupportact.org.au/pain-clinics/the-canberra-hospital-pain-management-unit/ (accessed 23 October 2018).

[i] Sally Whyte, S. “Lack of private clinics increases wait for pain management at Canberra Hospital” *The Canberra Times,* 2018, 18 January.

[j] Cousins MJ, Brydon L. “Unrelieved pain: are we making progress? Shared education for general practitioners and specialists is the best way forward.” 2014. *Medical Journal of Australia*. Volume 201, Issue 7, Pages 379-80.

[k] Cousins MJ, Brydon L. “Unrelieved pain: are we making progress? Shared education for general practitioners and specialists is the best way forward.” 2014. *Medical Journal of Australia*. Volume 201, Issue 7, Pages 379-80.

[l] Pain Australia “National Pain Strategy. Pain Management for all Australians” 2010. Pain Australia. https://www.painaustralia.org.au/improving-policy/national-pain-strategy (Accessed 24/10/2018).

[m] Pain Australia (Objective 9)

[n] Pain Australia (Objective 12, Strategy 12.5)

[o] Pain Australia (Objective 13)

[p] Pain Australia (Objective 15)

[q] Pain Australia (Objective 5)

[r] Pain Australia (Objective 6)

[s] Capital Health Network. GP Masterclass - Chronic Pain Management. Planned for 22 June 2019. https://www.chnact.org.au/chn-events (Accessed 24/10/2018).

Canberra sexual health services

HCCA wants to see

- **public sexual health service on Canberra's northside**
- **more funding for the existing service on the southside**

Why is it important?

The Canberra Sexual Health Centre (CSHC) is a free service that provides testing for and treatment of sexually transmissible infections. This specialist clinic provides confidential and high quality care in a safe environment, which includes providing care for people who feel they cannot get the care they need elsewhere. One of the great strengths of this service is that consumers receive non-judgemental care.

The demand for sexual health services is projected to increase significantly. The ACT's Chief Health Officer has reported an increase in the reported rates of chlamydia and gonorrhoea.[a] Of particular concern is the discovery of strains resistant to penicillin and ciprofloxacin.[b] There has also been a modest increase in the number of people contracting HIV.[c]

HIV in the ACT

There are about 450 people with HIV living in the ACT and region,[d] and the Sexual Health Centre plays a key role in providing support and care so they can maintain their health and wellbeing. In addition, the SHC provides some services to people living in the surrounding regions of NSW which include Queanbeyan, Googong, Bungendore, Murrumbateman, Sutton and further afield. The SHC does this in close association with a small number of general practices and the AIDS Action Council ACT.

HIV medications require an S100 prescriber qualification. All of the doctors at the SHC are S100 prescribers. There are nominally only five general practices who have an S100 prescriber on their staff and most of these doctors are not taking new patients. HIV medications need to be prescribed every six months (patients are given a two month script with two repeats). A full blood screening is required at least once per year to confirm medication effectiveness via pathology report. Most people living with HIV also undertake regular STI screening, at least annually.

PrEP – Pre-Exposure Prophylaxis

The SHC was a trial site for a new preventive medication for HIV (PrEP). Consequently, 200 new patients accessed the Centre in the past 12 months. With the announcement of a new PBS item in April 2018, we expect that the people using the SHC will increase.

As of October 2017 – early in the trail enrolment and before PrEP was PBS listed – there were already around 12% of all gay men using PrEP in the ACT.[e] In Sydney, where the EPIC trial began much earlier, around 20% of gay men are using PrEP. It is therefore anticipated that the percentages are now similar in the ACT and increasing across Australia, however the data is not yet available.

PrEP requires a new prescription and consultation every three months. Prescriber Guidelines recommend sexual health checks and testing for STIs at each consultation. During the EPIC trial the full STI screen was part of the trial procedure. As such, each consultation is quite specialised and time-intensive. Many GPs are reluctant to commit to the time necessary to undertake this work, given the current Medicare payment schedule.

PrEP is working and has been credited with a 33% drop in new HIV infection in NSW in the year ending July 2018[f]. It is difficult to extract significant statistics for the ACT given the small sample size. ACT has approximately 10-12 new HIV diagnoses each year, but it may be too early to see a significant change due to PrEP at this stage.

SHC and needs of vulnerable groups

Young people, people who identify as LGBTI, and those who identify as Aboriginal or Torres Strait Islander are three vulnerable groups. Secondary school students' knowledge of sexually transmitted diseases remains poor, especially around chlamydia, Hepatitis and HPV.[g] The vast majority of sexually transmitted infections in young people (15–29 years) remain undiagnosed and untreated.[h] The sexual health of people who identify as lesbian, gay, bisexual or transgender may delay seeking treatment in the expectation that they will be subject to discrimination or receive reduced quality of care.[i] Therefore, LGBTI people are more likely to be under screened and risk presenting later in disease progression with the potential for reduced treatment and health outcomes.[j] Notification rates of sexually transmissible infections remain considerably higher in the Aboriginal and Torres Strait Islander than in the non-Indigenous population, especially for gonorrhoea, infectious syphilis and chlamydia.[k]

As a free service, the SHC are the first choice for people who are not eligible for Medicare, including embassy staff and other foreign workers, and for overseas students. This is a significant portion of the population and many are from countries where the prevalence of HIV is high.

The SHC is also known to be the provider of choice for sex workers in the ACT. The AIDS Action Council refers sex workers to SHC through their Sex Worker Outreach Program (SWOP). This is a critical part of the legal sex work framework in the ACT so that sex workers can be tested regularly for STIs. The SHC provides separate specialised clinic times for sex workers, as well as for men and for the Kink community. Each of these clinics are outside of normal clinic hours, requiring extra staff and resources.

Outreach services provided by the SHC are also important for reaching minority or at-risk groups. The SHC provides monthly outreach STI testing in a men's sex venue in Fyshwick, as well as at the AIDs Action Council.

The AIDS Action Council ACT began an online petition to the ACT Assembly because it considers the Sexual Health Centre is under-resourced to meet current (and future) demand.[l] HCCA supports this call for additional resources.

The Canberra Sexual Health Centre works collaboratively with non-government services who are also providing sexual health services, including to people with, or at risk of contracting, blood borne virus and other sexually transmitted infections. These organisations are Hepatitis A, Sexual Health and Family Planning ACT and AIDS Action Council ACT.

What's currently available?

The current physical premises of the SHC are crowded. It has had the same footprint on the Canberra Hospital campus since the service opened in the 1980s. In any redevelopment of the Canberra Hospital site it is important to consider the buildings on the east-side of Hospital Road to potentially expand the space available for the SHC services.

We are aware of cost pressures on the services provided by the SHC as there are limited opportunities for MBS rebates and the pathology costs are significant. However, we are not supportive of any move to introduce co-payments as this may be a barrier to access for consumers, especially given services provided to a range of vulnerable groups across the ACT, as well as services provided to surrounding areas of NSW.

How can it be improved?

The ACT government needs to put more infrastructure, financial and workforce resources into supporting publicly available sexual health services.

There are no publicly available services for sexual health located on the northside of Canberra. Given the continuing population growth on the northside of Canberra, it would be wise to consider a service located here. This would improve access for consumers and increase resources to meet the growing demands for sexual health services. It could also allow for further outreach services into northside areas of Canberra.

New ideas, services or programs?

HCCA strongly supports increased funding for the Canberra Sexual Health Centre.

HCCA strongly encourages the establishment of a publicly available sexual health centre on the northside of Canberra.

---

[a] ACT Health. "Healthy Canberra, Australian Capital Territory Chief Health Officer's Report, 2018", ACT Government, Canberra ACT 2018. Page 44

[b] See note (a), Page 45

[c] See note (a), Page 44

[d] Kirby Institute. "HIV in Australia: annual surveillance short report 2018". Sydney: Kirby Institute, UNSW Sydney; 2018. https://kirby.unsw.edu.au/sites/default/files/kirby/report/supplHIV2018_content_20180920r.pdf

[e] Centre for Social Research in Health. Gay Community Periodic Surveys. 2018. University of NSW, Sydney. https://csrh.arts.unsw.edu.au/research/publications/gcps/ (Accessed 31/10/2018).

[f] The Kirby Institute. Home page. 2018. University of NSW, Sydney. https://kirby.unsw.edu.au/news/australian-prep-trial-leads-unprecedented-reductions-hiv-transmission?utm_source=PL+full+mailing+list&utm_campaign=9b5533e46b-EMAIL_CAMPAIGN_2018_10_18_08_07&utm_medium=email&utm_term=0_e4f77dc29a-9b5533e46b-370433869 (Accessed 31/10/2018).

[g] Mitchell A, Patrick K, Heywood W, Blackman P, Pitts M. "5th National Survey of Australian Secondary Students and Sexual Health 2013", (ARCSHS Monograph Series No. 97), Australian Research Centre in Sex, Health and Society, La Trobe University, Melbourne, Australia. 2014. Pages 11-21.

[h] Kirby Institute. "HIV, viral hepatitis and sexually transmissible infections in Australia: annual surveillance report 2017". Sydney: Kirby Institute, UNSW Sydney; 2017.

[i] Heck JE, Sell RL and Gorin SS. (2006) "Health care access among individuals involved in same-sex relationships" American Journal of Public Health 96:6, 1111-1118;
Mayer KH, Bradford JB, Makadon HJ, Stall R, Goldhammer H, and Landers S. (2008) "Sexual and gender minority health: What we know and what needs to be done" *American Journal of Public Health* 98:6, 989-995.

[j] Leonard W, Dowsett G, Slavin S, Mitchell A, and Pitts M. (2008) "Crystal clear: The social determinants of crystal methamphetamine use among gay men in Victoria". Monograph Series Number 67. La Trobe University, The Australian Research Centre in Sex, Health and Society: Melbourne

[k] See note (d)

[l] Change.org. "Support Canberra Sexual Health Centre". 2018 https://www.change.org/p/act-legislative-assembly-support-canberra-sexual-health-centre (Accessed 31/10/2018).

Response to transvaginal mesh

HCCA wants to see

- **bio-psycho-social and financial support for women who had complications following mesh implants.**

Why is it important?

The Therapeutic Goods Administration (TGA) cancelled the approval of specific types of transvaginal mesh devices in November 2017, and these devices can no longer be supplied in Australia.[a] Almost a year later and after a Senate inquiry into the matter[b], the Commonwealth Government acknowledged the damage caused by transvaginal mesh implants and apologised to the women affected by mesh implants.[c] For women, who have had medical professionals deny their reports of pain and discomfort and who have been told that their symptoms are in their minds, the apology was very welcome. But it does not go far enough.[d] Most of the recommendations supported by the government were only supported "in principle" rather than in substance and require state and territory support.[e] What is missing is an announcement about any new funding to resource integrated care pathways for affected women. Removal of mesh will not occur in Canberra. Women will need to access specialist services in Sydney.

What's currently available?

The Canberra Hospital established a mesh clinic in early 2017 to provide support to women who had complications following mesh implants, or those who had concerns and questions about their care. This clinic is available to any woman who has had mesh implanted, regardless of whether the procedure was done privately or publicly, in Canberra or elsewhere. The clinic is staffed by an experienced nurse and two gynaecologists, all part-time.

HCCA has participated in the ACT Transvaginal Mesh Committee, which has oversighted this work.

How can it be improved?

There is a need for ongoing support and clinical care for women affected by transvaginal mesh. While the clinic is a good starting point, it has not met the needs of many women who have reported complications. A comprehensive service, rather than a clinic that is staff part-time is required.

We need a service that provides integrated care for affected women, which includes compassionate, multidisciplinary care for pain management and psychological support as well as access to removal by skilled clinicians. The service needs to include expertise from uro-gynaecologists, physiotherapists, pain specialists, psychologists and appropriate nursing support.

Removal of mesh does not occur in Canberra. Women travelling to specialist services in Sydney will need adequate financial support to access these services in addition to medical care. This should cover transport, accommodation and an allowance for other reasonable costs.

New ideas, services or programs?

The ACT Government needs to financially support women who require the specialist mesh removal services available in Sydney.

The ACT needs to fund a Mesh service that will meet the needs of women who are experiencing complications from mesh implants.

---

[a] https://www.tga.gov.au/hub/transvaginal-urogynaecological-surgical-mesh-hub

[b] Commonwealth of Australia. "Number of women in Australia who have had transvaginal mesh implants and related matters". Community Affairs References Committee. 2018, 28 March https://www.aph.gov.au/Parliamentary_Business/Committees/Senate/Community_Affairs/MeshImplants/Report

[c] Hunt G. Greg Hunt Facebook post. 21 October at 21:49. https://www.facebook.com/greg.hunt.mp

[d] Cox D. "Update from the office". *Consumer Bites*. 2018. Volume 5, Issue 20, Page 1

[e] Hunt G. "Strong Government support for mesh implant recommendations". Greg Hunt Media Release, 2018, 10 October. https://www.greghunt.com.au/strong-government-support-for-mesh-implant-recommendations/

National code of conduct for health care workers

HCCA wants to see

- **legislation enacted to implement the National code of conduct for health care workers, and**
- **additional resources for the Health Services Commissioner to promote the code and act on complaints.**

Why is it important?

The clear majority of health care workers practice in a safe, competent and ethical manner. However, a small proportion present a serious risk to the public. The *National Code of Conduct for Health Care Workers* was supported by COAG in 2015 and is designed to protect the public from these individuals. It does this by setting minimum standards of conduct and practice for all unregistered health care workers who provide a health service.[a] It covers healthcare workers who do NOT fall under the remit of the Australian Health Practitioner Regulation Agency (AHPRA). Each state and territory will need to enact legislation to implement the National Code of Conduct and assess its progress. Many states have already enacted appropriate legislation.

Implementation and enforcement of the code is aimed at health workers and many public and private organisations that provide healthcare services will be affected. The professions likely to be included are listed below.

- Nursing assistants
- Dental technicians and assistants
- Paramedics
- Pharmacy assistants
- Phlebotomists
- Personal care workers
- Disability support workers
- Complementary and alternative medicine practitioners
- Lactation consultants
- Speech pathologists
- Social workers
- Art, music, dance and drama therapists

What's currently available?

Legislation has been drafted in the ACT and is currently making its way through government processes.

Upon enactment the ACT Health Services Commissioner will be responsible, among other things, for considering complaints against individual practitioners and organisations. They will also be expected to promote an awareness of the rights and responsibilities of users and providers of health, aged care and disability services under the new code.

How can it be improved?

Both users of health services and the health professionals that fall under the new code need to be educated about their rights and responsibilities.

The Health Service Commission needs to be adequate resourcing to establish and maintain processes to investigate code contraventions and to act on any findings.

New ideas, services or programs?

HCCA strongly recommends increased resources for the Health Services Commissioner to

- promote the code,
- establish and maintain processes to investigate code contraventions, and
- act on any findings.

---

[a] Council of Australian Governments (COAG). "National Code of Conduct for health care workers." https://www.coaghealthcouncil.gov.au/NationalCodeOfConductForHealthCareWorkers (Accessed 29/10/2018).