



**SUBMISSION**

# ACT Government: **ACT Budget 2021-22**

July 2021

**Health Care Consumers' Association**

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## Background

The **Health Care Consumers' Association (HCCA)** is a health promotion agency and the peak consumer advocacy organisation in the Canberra region. HCCA provides a voice for consumers on local health issues and provides opportunities for health care consumers to participate in all levels of health service planning, policy development and decision making.

HCCA involves consumers through:

- consumer representation and consumer and community consultations;
- training in health rights and navigating the health system;
- community forums and information sessions about health services; and
- research into consumer experience of human services.

The comments in this submission were informed by from our work with a wide range of health care consumers across the ACT and particularly our Health Policy and Research Advisory Committee. This submission also draws on the HCCA Priorities for Investment (2020) which can be found here: <https://www.hcca.org.au/wp-content/uploads/2020/09/HCCA-Priorities-for-Investment-for-ACT-Election-2020-FINAL.pdf>

This submission was prepared by Kathryn Briant, Anna Tito and Darlene Cox based on feedback from HCCA members and the Health Policy and Research Advisory Committee.

## 1. Executive Summary

Our priorities for funding are based on the overarching philosophy that:

- Decisions regarding health services for the people of the ACT and surrounding areas should be based on the best publicly available, evidence based, current information; and
- Consumers and carers must be meaningfully involved in all facets of health service design, development and delivery and priority setting.

In general terms we want to see the ACT Budget address three key areas: resource allocation, access to services and workforce.

- **Resource Allocation:** Increase the percentage of the overall ACT budget allocated to health to meet the needs of our growing communities. Demand for publicly funded health services continues to grow and funding should reflect population increase and the complexity of our health care needs.
- **Access:** Develop a strategy to continue funding support for a range of options for consumers to access health services, allowing the right care to be accessed at the right time in the right place and using the right model of care. This includes continuing to improve investment and support for services like telehealth, virtual healthcare, hospital in the home, walk in centres, GP Pathways etc.
- **Workforce:** Greater workforce investment, improving staff numbers, culture, career progression options and university pathways, with the aim to make ACT health services an attractive place to work. This in turn will help address the persistent issues relating to waiting times for elective surgery and initial appointments at outpatient clinics as well as staff retention and recruitment outcomes.

On this basis, HCCA's 13 key budget priorities are below, divided under thematic subheadings for ease of reference:

### Health Services

1. Implement a model of patient navigation, co-designed with HCCA, in the ACT, to rectify current problems for consumers with serious or continuing illness.
2. Improve support for families with children accessing specialist care interstate by implementing the recommendations from HCCA's report on The Kids Interstate Shared Care Project.
3. Improve the delivery of palliative care services in the ACT by:
  - a. Establishing a dedicated palliative care unit at the Canberra Hospital;
  - b. Ensuring an ACT-wide palliative care service;
  - c. Enabling access for more staff to train in the palliative approach; and

- d. Introduce a 24-hour, 7-day telephone support service for consumers and families accessing palliative care.
4. Broaden the range of, and improve access to, mental health services in the ACT by increasing mental health pathways available to help reduce demand on acute mental health services.
5. Enhance pain management services in the ACT to reduce wait times and better meet consumer needs.
6. Extend and expand consumer access to the Rapid Access Assessment Team and cancer services by including evenings and weekends.

### **Health System**

7. Develop and implement a Disability Health Strategy in the ACT.
8. Improve communication with consumers, and their families whose main language is other than English by:
  - a. Including training on recognising the need for and accessing interpreter services as an integral part of all staff training;
  - b. introducing a communication campaign to consumers and communities about accessing interpreters; and
  - c. increasing availability of health information in community languages.
9. Provide funding for a Dedicated Coroner in the ACT to ensure the timely and expeditious review of avoidable deaths, as well as identify and rectify any patterns of systemic failings in service safety and quality.
10. Support individual advocacy by funding a project to scope, pilot and evaluate a broad-eligibility consumer health advocacy service for the ACT, to meet significant unmet community need.
11. Establishment of Healthcare Sustainability Unit in the Health Directorate.

### **Community Sector**

12. Redress the chronic shortage of affordable community facilities for community, not-for-profit organisations particularly in the central north but also across the ACT.
13. Address the inadequacy of Indexation to cover increases in costs for community organisations.

Please do not hesitate to contact us if you wish to discuss our submission further.

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## 2. Details for each key area of investment

### 2.1 Health Services

#### 1. Implement a model of patient navigation, co-designed with HCCA, in the ACT, to rectify current problems for consumers with serious or continuing illness.

We seek commitment to co-designing and implementing a patient navigation service to support consumers in accessing services, as well as building levels of health literacy, as set out in the HCCA report: [A model for patient navigation in the ACT for people with chronic and complex conditions](#)<sup>1</sup>.

The ACT Auditor General's 2020 Report on the Management of Care for People Living with Serious and Continuing Illness<sup>2</sup> found that measures to date in the ACT have not been effective in improving the care of consumers living with serious and continuing illness in the ACT. Establishing patient navigation services in the ACT would be one effective strategy for helping improve care for those experiencing chronic and complex conditions.

Patient navigation could form an integral part of a successful expansion of the chronic disease management program across the territory. Improved patient navigation for chronic and complex conditions could see reductions in Emergency Department presentations and hospital admissions, along with better health outcomes for consumers.

#### 2. Improve support for families with children accessing specialist care interstate by implementing the recommendations from HCCA's report on The Kids Interstate Shared Care Project.

Many families need to travel long distances to access treatment for their children, this is frequently prolonged and expensive. The emotional, physical and social costs to the young people and their families is considerable. We are calling on the ACT Government to implement recommendations from the [Consumer and Family Experiences and Expectations of Accessing Interstate Specialist Care: The Kids Interstate Shared Care Project Final Report](#) provided to ACT Health in May 2020<sup>3</sup>. This is in line with Labor's election commitment made by Minister Stephen-Smith on the 17<sup>th</sup> of September<sup>4</sup>. Even with this commitment and the desire from all sides of care to improve situation for children and families managing care for a child with a chronic or life limiting illness, there has been little progress so far<sup>5</sup>.

We want to see commitment to codesign to develop a navigation service for families whose children access specialist care interstate.

#### 3. Improve the delivery of palliative care services in the ACT.

HCCA wants to see action on the commitments made in the 10<sup>th</sup> Legislative Assembly Parliamentary and Governing Agreement around palliative care. HCCA's priorities include:

- A dedicated palliative care unit at the Canberra Hospital;
- An ACT-wide palliative care service, including afterhours palliative care;
- Enable access for more staff to train in the palliative approach; and
- A 24/7 territory wide phone support and information line for patients and carers.

HCCA has undertaken consumer research into the experience of consumers and families who have accessed palliative care in the ACT. This includes palliative care in a variety of settings – home, hospital and hospice.<sup>6</sup> Unfortunately, many of the hospital-based experiences they shared with us were less than ideal. Areas for improvement are outlined in HCCA's Report on [Consumer and Carer Experiences and Expectations of Home-Based Palliative Care in the ACT](#)<sup>7</sup>. The report highlighted issues around:

- 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.

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. However, we know that the specialist palliative care workforce is inadequate to meet the services required by consumers, even without considering the additional demand for services from surrounding areas in NSW. These gaps have been reflected in the transcripts of evidence from hearings of the Select Committee on End of Life Choices in the ACT.<sup>8</sup>

Excellent training for general staff in the palliative approach is available through various sources including the Program of Experience in Palliative Approach (PEPA)<sup>9</sup> run by Clare Holland House. We support enabling greater access for staff to train in the palliative approach.

Consumers also highlighted the need for a 24/7 territory wide palliative care phone support and information line for patients and carers. NSW and Victoria offer different models for this type of free to call service. The NSW *Palliative Care After Hours Helpline* is available outside of business hours and provides professional information, support and advice for palliative care patients, their carers and their families as well as health professionals<sup>10</sup>. The Victorian

*Palliative Care Advice Service* has shorter hours than the NSW scheme running from 7am-10pm, but it still operates 365 days a year. It provides free, confidential advice for anyone who needs information about a life-limiting illness, palliative or end-of-life care, including health professionals<sup>11</sup>. Both these services recognise the 24/7 nature of end-of-life care and the need for consumers, carers and medical professionals to access information and support outside of standard business hours. Such a service, if co-designed with consumers, can help to begin to address some of the support gaps in the ACT palliative care system and help improve the end-of-life experience for Canberrans.

Investment in palliative care makes sense - the evidence demonstrates a reduction in pressure on the emergency department intensive care and inpatient hospital stays, and also makes a difference to the quality of life for consumers and their families. The KPMG report *Investing to Save – The economics of increased investment in palliative care in Australia (2020)*<sup>12</sup> suggests excellent returns on investment across a wide range of palliative care services.

**4. Broaden the range of, and improve access to, mental health services in the ACT by increasing mental health pathways available to help reduce demand on acute mental health services.**

ACT residents have a higher rate of mental health and behavioural challenges compared to the national average<sup>13</sup> and anxiety disorders are second only to coronary heart disease as in the leading causes of the total disease burden in the ACT<sup>14</sup>. We are seeking a commitment for the investment in improving access to, and broadening the range of, mental health services available in the ACT in line with the rising demand.

As with physical health care different models of care are appropriate at different times. Consumers need to be able to access the services that are appropriate to their needs. This would include greater investment in physical services for mild to moderate cases, peer support programs, improved mental health patient navigation information, better co-ordination of cross service discharge planning, youth mental health services, investment in non-clinical mental health safe spaces and improved mental health pathways.

**5. Enhance pain management services in the ACT to reduce wait times and better meet consumer.**

Almost a fifth of the Australian population will experience chronic pain in their lifetime.<sup>15</sup> 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.<sup>16</sup> Unsurprisingly then, one fifth of general practice consultations relate to managing chronic pain.<sup>17</sup>



Capital Health Network identified GP management of chronic pain among older people as a key issue in the ACT.<sup>18</sup> Chronic pain with or without diagnosis is highly stigmatized<sup>19</sup>. 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. Furthermore, the implementation of the new National Real Time Prescription Monitoring system, while helpful in some respects, may risk exacerbating the stigma for consumers that can be attached to treatment of chronic pain.

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.<sup>20</sup> 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.<sup>21</sup>
- 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.<sup>22</sup>
- Ensure clear, accurate and timely communication about pain management between practitioners and patients, and between practitioners.<sup>23</sup>
- Ensure tertiary specialist pain clinics have resources needed to support key strategies.<sup>24</sup>

### **Consumers and carers**

- Improve community understanding of the nature of chronic pain and best-practice management.<sup>25</sup>
- 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.<sup>26</sup>

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.<sup>27</sup>

HCCA wants to see:

- Increased funding for Canberra Hospital Pain Management Unit to better meet consumer demand for services; and

- local implementation of the National Pain Action Plan.

## **6. Extend and expand consumer access to the Rapid Access Assessment Team and cancer services by including evenings and weekends.**

Recognising that the reality of serious illness is that it does not follow business hours, we are advocating for support to extend the availability of the rapid access assessment team and cancer services to include evenings and weekends.

We know that these areas are a priority because demands for hospital Emergency Department services have been at an all-time high (with particular needs in mental health, aged care and paediatrics<sup>28</sup>), and that cancer is one of the leading causes of disease burden in the ACT<sup>29</sup>. The impacts on the timely provision of care have been significant<sup>30</sup>.

Following on from the successful introduction of the rapid access team in cancer we would like to see this approach expanded to other health priority areas for the ACT, such as diabetes and heart failure. Establishing these services could better meet consumer needs across a range of health priority areas and reduce the pressures on acute services.

## **2.2 Health System**

### **7. Develop and implement a Disability Health Strategy in the ACT.**

We strongly support the development and implementation of a Disability Health Strategy that meets the ACT Government's human rights obligations under the National Disability Strategy.

The Strategy must address the complex social determinants of health that result in poor health outcomes for people with disability<sup>31</sup>, these issues include:

- Economic disadvantage;
- Diagnostic overshadowing (where a person's disability is treated as the problem rather than a person's presenting medical condition);
- Poor attitudes and stigma;
- Insufficient access to care and support in the community (to help prevent or delay higher care needs);
- Inadequate digital and physical infrastructure; and
- Service gaps, including access to appropriate specialist care.

More details about how to improve access to health care for people with disabilities in the ACT can be found in the ACTCOSS Report: Imagining Better Reflections on access, choice and control in ACT health services for people with disability<sup>32</sup>.

**8. Improve communication with consumers, and their families whose main language is other than English.**

We are seeking a commitment to a focussed campaign around communicating with consumers, patients and their families whose main language is other than English. This would include a targeted strategy for training clinical and administrative staff on accessing interpreters at all hours.

We know that miscommunication in the health sector can be life threatening. Given the increasing numbers of consumers and clinicians who have diverse cultures and language background, there is increasing potential for communication errors between a healthcare practitioner and patients/carers<sup>33</sup>. Complex language and the use of jargon are a barrier to consumers and carers being actively involved in our own health care. This includes being able to participate in and provide informed consent, along with shared decision making. Where diverse cultures and languages are involved, communication becomes even more challenging. To address the problem of language barriers successfully, we must inform and train clinicians to know the nature of these issues and when these issues are likely to arise<sup>34</sup>.

We also want to see more health information in community languages so consumers can make informed decisions about their health. This includes communicating to consumers so that they know their rights in terms of access to interpreters. It is vital that access to professional interpreters is provided in order to ensure effective communication, along with safety and quality care, across the total population.

**9. Provide funding for a Dedicated Coroner in the ACT to ensure the timely and expeditious review of avoidable deaths, as well as identify and rectify any patterns of systemic failings in service safety and quality.**

We strongly support the call from Coronial Reform Group for a dedicated coroner in the ACT. HCCA supports advocating for improved coronial processes to ensure families and/or carers of those who have lost their lives can have an equal voice in the coronial process. This would ensure the timely and expeditious review of avoidable deaths, as well as identifying and rectifying any patterns of systemic failings in service safety and quality.

Using a restorative approach in building the reform process, as well as in the reforms themselves, has the best chance of delivering the changes needed to transform the current coronial process.

Funding a dedicated coroner is in line with current budgetary priorities by:

- Aligning with the ACT's Wellbeing Framework, which notes the need to ensure programs work in support of the Canberra as a Restorative City initiative.
- Offering a key service for vulnerable Canberrans through the timely investigation of the avoidable deaths of vulnerable Canberrans.

- Improving overall governance in institutions, including overall accessibility to the justice system - a key human right.
- Delivering key economic efficiencies and savings by improving the timeliness of coronial processes.
- Improving the safety of all Canberrans by investigating avoidable deaths at the earliest possible instances, ensuring the delivery of timely and relevant recommendations, that could then reduce the risk of similar avoidable deaths.

As part of this we have the opportunity to help reduce the load on the coronial system by providing other mechanisms for the community to find out what happened in cases of patient harm. By improving open disclosure processes in the ACT, and subsequently the ACT's compliance with the Open Disclosure Framework<sup>35</sup>, the community will have alternative avenues to raise concerns and find out what happened to their family members outside of the drawn-out coronial process. Strategies such as, allowing quality and safety investigations to report findings and outcomes to families, will help to improve the ACT communities trust in the ACT health system and create clear mechanisms for improving accountability around patient safety.

#### **10. Support individual advocacy by funding a project to scope, pilot and evaluate a broad-eligibility consumer health advocacy service for the ACT, to meet significant unmet community need.**

We want to see support for individual advocacy with funding for a project, co-designed with HCCA and health services, to scope, pilot and evaluate a broad-eligibility consumer health advocacy service for the ACT. This will help to meet significant unmet community need for individual advocacy in our region. Services that provide individual health advocacy in the ACT operate over their capacity. To cope with demand, the ACT Disability, Aged and Carer Advocacy Service (ADACAS) has had to implement a *Priority of Access Policy* in addition to usual eligibility criteria. To access individual advocacy related to health or any other matter, a person must not only have a disability, be an older person or carer, they must also be at immediate risk of significant social, financial or economic loss or harm. The transition to the National Disability Insurance Scheme (NDIS) has led to a sharp increase in demand for individual advocacy from people with disabilities.

At a minimum the pilot service will provide 9am to 5pm (Monday to Friday) telephone support, and in-person advocacy. The scope of work will include supporting people to:

- Understand and act on their health rights;
- Access health and other necessary services;
- Receive and understand health information;
- Navigate health services;

- Make health decisions;
- Understand and consider alternative options when not satisfied with their care;
- Participate in feedback and complaints resolution processes; and
- Increase their self-advocacy confidence and skills.

HCCA proposes to draw on and adapt the successful health advocacy model implemented for over a decade by the Health Consumers' Council of Western Australia (HCCWA) with support from the West Australian Government. This model has been in place for more than a decade. This project is an opportunity for the ACT to adopt a nationally leading model of health advocacy that supports consumer health literacy and shared decision-making. An independent 2017 evaluation of the WA model found that it delivers tangible benefits to consumers:

- Consumers are more involved in developing their treatment and care plans.
- Consumers have a better understanding of their treatment and care plans.
- Care plans better reflect consumer concerns and priorities.
- Consumers have opportunities to consider options and identify their preferences, meaning they have more informed discussions with clinicians about their care.
- Advocate involvement prevents instances of health care rights being unintentionally violated or ignored.
- Advocate involvement promotes positive rights including access to appropriate health care and welfare services.

Individual health advocacy supports people to participate in decisions about their own care. This is a focus of the Australian Commission on Safety and Quality in Health Care's (ACSQHC) National Quality and Safety Health Service (NQS) Standards<sup>36</sup>, and other health care standards including the Royal Australian College of General Practice's Standards for General Practice<sup>37</sup>. Organisations and professionals that engage positively with an advocacy service of the kind proposed in this submission will be well-placed to demonstrate their achievements against accreditation and professional standards<sup>38</sup>.

## **11. Establishment of Healthcare Sustainability Unit in the Health Directorate.**

HCCA recognises the overwhelming evidence that climate change will have adverse impacts on human health, and these effects are projected to worsen if action is not taken<sup>39</sup>. There are significant environmental and financial costs of health care that need to be addressed. The health care sector is a significant contributor to greenhouse gas emissions, waste products and natural resource consumption. This threatens our present and future health. In Australia emissions are estimated at over 7% of Australia's total CO<sub>2</sub>

emissions<sup>40</sup>. We need health care to be delivered in ways that are both financially and environmentally sustainable.

Reducing unnecessary testing and treatment is an important element of this. We support the Choosing Wisely initiative as this will bring about financial and environmental benefits.

We have watched with interest the work of the UK's National Health Service (NHS) Sustainable Development Unit<sup>41</sup>. The NHS has achieved an 11% reduction in greenhouse gas emissions between 2007 and 2015 while other countries saw an increase. The report *Delivering a Net Zero Health Service*<sup>42</sup> sets a clear ambition and target for the NHS and we are keen to see equivalent action in the ACT.

We are very pleased that Canberra Hospital will be the first 100 per cent renewable energy-powered hospital in the country, using electric heat pumps and no gas. This is an achievement to be celebrated. Energy use is only one aspect that needs to be addressed.

Health professionals and administrators also have a role to play.

- An element of this is reducing low-value care (care where the harms and risks of medical tests and procedures outweigh any benefits);
- Review prescribing habits;
- Expand low-carbon models of care such as telehealth to reduce travel;
- Shift to lower carbon anaesthetic gases;
- Reduce single use plastics in surgery;
- Changing the food available at hospitals to reduce food miles and packaging and reduce food waste;
- Reduce landfill and improve repurposing and reuse of materials and equipment; and
- Review procurement decisions to prioritise environmentally friendly options.

The establishment of a small unit in the Health Directorate could progress this critical work for now and the future.

We acknowledge that the Government has the Zero Emissions Government Team (from the Environment, Planning and Sustainable Development Directorate) but feel that there needs to be a unit focused exclusively on health care.

## 2.3 Community Sector

### **12. Redress the chronic shortage of affordable community facilities for community, not-for-profit organisations particularly in the central north but also across the ACT.**

HCCA is concerned about the lack of availability of accommodation for lease for community organisations in the not-for-profit sector, particularly in central north Canberra. Community organisations provide important support, advocacy and social services for ACT residents.



The sale of community premises, such as the proposed sale of Maitland House to Blue Gum Community School (Blue Gum) (Building 3 at the Hackett Community Centre, previously Sports House) is only exacerbating this issue. HCCA have leased rooms at this location since 2010 along with a wide range of other community groups including the Embroiderers Guild ACT, Swimming ACT, Cycling ACT, School Sport ACT and the ACT Council of Parents and Citizens Association. Folk Dance Canberra occupy space in an adjacent building (Building 2) between Maitland House and the Blue Gum in Building 1. Folk Dance sublet space to four or five other community groups in that building. The Environmental Collective Housing Organisation (ECHO) Inc is also located in Building 2. This sale would force all of these community groups to find alternative premises and the sale of other publicly owned properties around the area, eg Canberra Technology Park, makes finding appropriate and affordable accommodation in the same area incredibly difficult.

Most organisations have limited capacity to purchase property or lease other high-cost premises. The commercial rental prices in the ACT are out of reach for many of these organisations and if they forced into is market, they would have to reduce costs though cuts in other areas such as staffing levels and range of services they can provide. Ensuring that there are a range of affordable community facilities available for community organisations in the not-for-profit sector across the ACT is important in guaranteeing that these critical organisations can continue to offer the range of high-quality services.

### **13. Address the inadequacy of Indexation to cover increases in costs for community organisations.**

There are increases in costs that community organisations are facing in 2021-22 that will not be covered by the 1.75% indexation rate. For example,

- In June 2021 the Fair Work Commission announced a 2.5 per cent increase in the minimum wage and related award minimum wages. This is good news for workers. This is also raising questions about the increase that is likely to be announced for the SCHADS award in December.
- The rental costs in ACT Government accommodation increases 3% each year. HCCA will pay \$32,500 in rent in 2021-22. This is an increase of \$960 from the 2020-21. These numbers are raw numbers for a normal year for demonstration purposes and do not take into consideration the COVID-19 community tenants rent relief provided in 2020.
- The Superannuation Guarantee increases by 0.5% from 1 July 2021 and this will result in an increase of \$4,383 that HCCA will need to find.
- There is also an increase in the amount employers are required to contribute to as a levy to the Long Service Leave Authority. In 2020-21 the levy was set at 1.2% of the gross ordinary wages of those employees. This will increase to 1.6% from 1 July 2021.

In isolation these amounts may not seem significant, but they have a cumulative impact on the financial position of community organisations.

Community organisations are focussed on improving outcomes for people at risk of poor health and vulnerability around their housing status, and living with disadvantage, these cost increases reduce their capacity to deliver on these services. For the most part these organisations are not-for-profit and rely heavily on funding from various levels of government to deliver services. Advocacy organisations, like HCCA, who provide a vital voice for consumers in the development of government policy, are almost entirely dependent on government funding. This funding needs to be adequate and reflect the true cost of delivering services.

<sup>1</sup> Coe, K. "A model for patient navigation in the ACT for people with chronic and complex conditions". 2018. Health Care Consumers' Association. [https://www.hcca.org.au/wp-content/uploads/2019/04/HCCA-Report-Patient-Care-Navigation\\_ISBN.pdf](https://www.hcca.org.au/wp-content/uploads/2019/04/HCCA-Report-Patient-Care-Navigation_ISBN.pdf)

<sup>2</sup> ACT Auditor-General's Report – "Management of Care for People Living with Serious and Continuing Illness Report No.7. 2020". [https://www.audit.act.gov.au/\\_data/assets/pdf\\_file/0007/1626037/Report-No.7-of-2020-Management-of-care-for-people-living-with-serious-and-continuing-illness.pdf](https://www.audit.act.gov.au/_data/assets/pdf_file/0007/1626037/Report-No.7-of-2020-Management-of-care-for-people-living-with-serious-and-continuing-illness.pdf)

<sup>3</sup> You can access the full report online, either on the HCCA website or the ACT Health website; HCCA Website: <https://www.hcca.org.au/wp-content/uploads/2020/11/HCCA-KIP-Project-Final-Report-ACT-Govt-Logo-and-Appendix-B-1.pdf>; ACT Health Website: <https://cms.health.act.gov.au/about-our-health-system/planning-future/territory-wide-health-services/new-plan-childrens-health>.

<sup>4</sup> See announcement made on Rachel Stephen-Smith MLA's Facebook page [https://www.facebook.com/permalink.php?story\\_fbid=1590501044462240&id=449606781885011](https://www.facebook.com/permalink.php?story_fbid=1590501044462240&id=449606781885011)

<sup>5</sup> You can see that the issues raised in the report persists see Charlie's Story, posted on the Canberra Notice Board 12 June 2021 <https://www.facebook.com/melissa.clode/posts/10224578587350506>

<sup>6</sup> 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).

<sup>7</sup> Spiller S. "Consumer and Carer Experiences and Expectations of Home-Based Palliative Care in the ACT". 2017. Health Care Consumers' Association. [https://www.hcca.org.au/wp-content/uploads/2018/10/HCCA-Report\\_Consumer-and-Carer-Experiences-and-Expectations-of-Home-Based-Palliative-Care-in-the-ACT.pdf](https://www.hcca.org.au/wp-content/uploads/2018/10/HCCA-Report_Consumer-and-Carer-Experiences-and-Expectations-of-Home-Based-Palliative-Care-in-the-ACT.pdf)

<sup>8</sup> Select Committee on End of Life Choices in the ACT. *Transcript of Evidence*. 2018, 12 July, Canberra, Page 392.

<sup>9</sup> Program of Experience in the Palliative Approach. "What is PEPA?" Palliative Care Education and Training Collaborative. <https://pepaeducation.com/> (Accessed 24/10/2018).

<sup>10</sup> For more information see Palliative Care After Hours Helpline: <https://www.health.nsw.gov.au/palliativecare/Pages/after-hours-helpline.aspx>

<sup>11</sup> For more information see The Palliative Care Advice Service: <https://www.pcas.org.au/>

<sup>12</sup> Investing to Save – The economics of increased investment in palliative care in Australia, May 2020. <https://palliativecare.org.au/kpmg-palliativecare-economic-report>

<sup>13</sup> ABS, National Health Survey 2017 18, <https://www.abs.gov.au/statistics/health/health-conditions-and-risks/national-health-survey-first-results/2017-18>

<sup>14</sup> ACT Health, Statistics and Indicators: Leading causes of the total burden of disease, see Table: Leading causes of total burden (disability-adjusted life year DALY) by sex, ACT, 2015, <https://health.act.gov.au/about-our-health-system/data-and-publications/healthstats/statistics-and-indicators/leading-causes>

<sup>15</sup> One in five Australians will suffer chronic pain in their lifetime (National Strategic Action Plan for Pain Management. 2011: <https://www.painaustralia.org.au/policy-research/painaustralia-national-action-plan>) and Blyth FM, March LM, Brnabic AJM, Jorm LR, Williamson M and Cousins MJ. Chronic pain in Australia: a prevalence study. 2001. *Pain* 89:127-134.

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