Ms Kate Harkins
Committee Secretary
Email: kate.harkins@parliament.act.gov.au

**Re: ACT Legislative Assembly *Inquiry into the future sustainability of health funding in the ACT***

The Health Care Consumers' Association (HCCA) was incorporated in 1978 and is both a health promotion agency 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.

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.

HCCA is a member based organisation and for this submission we consulted with our members through the HCCA Health Policy Advisory Committee. We also draw on recent HCCA research projects that involved wide consultation with ACT consumers. The findings of this work are available in the HCCA publications: *Spend Time to Save Time: What Quality and Safety Mean to Consumers and Carers in the ACT* (forthcoming), *Consumer and Carer Experiences and Expectations of After-Hours Primary Care in the ACT* (2017), *"Of Course It's Better if We're There": Consumer Involvement in Health Infrastructure in the ACT, 2009 to 2016* (2017), and *Capturing the User Experience of the Obesity Management Service* (2016).

Thank you for the opportunity to put forward consumer views on the future sustainability of health funding in the ACT.

Yours sincerely

Darlene Cox
Executive Director
9 February 2017

# HCCA Submission to the ACT Legislative Assembly: Inquiry into the future sustainability of health funding in the ACT

Submitted 9 February 2018

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# 1. Executive Summary

As the peak member-based consumer advocacy organisation in the ACT, the Health Care Consumers' Association (HCCA) has a keen interest in ensuring our health care system is sustainable into the future. Health care accounts for approximately 30 per cent of the 2017-18 ACT Budget.[1] Anticipated population growth, demographic change, and swift advances in medicine and health care technology mean that this cost is likely to continue to grow - unless the ACT can *innovate* to deliver better health care and better consumer health outcomes while using resources more effectively. HCCA's submission to this Inquiry suggests a number of opportunities for health services, health funders and consumers to work together to change the way services are delivered – with the aim of protecting the future sustainability and viability of the health care we value. **The key message HCCA communicates in this submission is that consumer-centred care is essential to achieving a sustainable ACT health system.** Care that is safe, high quality and consumer-centred *will* achieve better health outcomes with fewer resources while also supporting health care professionals in their essential work. Our ACT experience in the past and present shows that partnering with consumers in designing and implementing health care reforms maximises the possibility of consumer-centred care being put in place in the most cost-effective manner.

This submission:

- Highlights the importance of sustained whole-of-government and community efforts to reduce health inequality and address the social determinants of health;
- Flags the need to carefully monitor new Commonwealth hospital funding arrangements that penalise hospitals for avoidable complications in patient care;
- Suggests opportunities to use existing health care resources and funding more efficiently, particularly within ACT public hospitals but also across the continuum of care;
- Notes HCCA's strong support for initiatives, in particular Choosing Wisely, that aim to reduce the incidence of unnecessary tests and treatments;

- Makes the case for identifying and celebrating high-value health care, while disinvesting in low-value health care;
- Argues that consumers and carers are, unfortunately, an underutilised resource for contributing to improving the safety and quality of care in the ACT and makes some practical suggestions for improvement in this area;
- Identifies the value consumers place on accessible primary health care services that reduce avoidable hospitalisation, and that improve continuity of care between hospital and primary health care. HCCA specifically acknowledges the work of services including Geriatric Rapid Acute Care Evaluation (GRACE), the ACT Obesity Management Service, the Walk-In Centres, Transitions of Care and Hospital in the Home in these areas.
- Suggests the need for a sustained public information campaign to ensure people are aware of, and understand the services offered by, primary and community-based health services - in particular the Walk-In Centres;
- Raises concern about the prevalence of unacceptably high out of pocket costs for holders of Private Health Insurance (PHI) who receive treatment in ACT hospitals, and the paucity of information provided to private patients in ACT public hospitals to support their informed financial consent;
- Indicates the value of an ACT-wide Digital Health Strategy;
- Suggests opportunities to improve the process of discharge from hospital to primary health care services;
- Notes that future infrastructure development will only meet consumer needs and expectations if consumers are meaningfully involved in decision-making at all levels.

HCCA also makes a number of comments in relation to:

- The value of transparent reporting on safety and quality;
- The importance of health literacy in achieving a sustainable heath system;
- Health workforce planning;
- ACT Health's capacity to innovate;
- Opportunities to leverage partnerships with non-government organisations (NGOs);

- Opportunities to provide better co-ordinated care to people living in South East NSW who access ACT health care services;
- The health effects of climate change; and
- Opportunities to improve end of life care in ACT hospitals, while reducing the costs associated with non-beneficial end of life care.

HCCA is hopeful that ACT Health will identify opportunities to progress these issues under the aegis of the Territory-Wide Health Services Framework 2017-2020 and through the development of Speciality Services Plans.

## 2. Key points and recommendations

- HCCA would welcome a longer process to enable the public, consumers and health professionals to work together to identify practical solutions to the sustainability challenges facing the ACT health care system. The Western Australian *Sustainable Health Review* provides a model for work of this kind (See Page 9) .
- To support consumers to be actively involved in managing wait lists and wait times for health care, HCCA encourages ACT Health to seek opportunities to provide transparent information about waiting times for surgical procedures in public hospitals. Until quite recently people requiring surgery or their referring doctors could view this information on a website which has unfortunately now been discontinued (See TOR A, *Section i.*).

**HCCA recommends that:**

2.1 ACT Health and all ACT Government Directorates, as well as community and consumer organisations and health services, prioritise the social determinants of health and co-ordinate efforts to reduce health inequality in the ACT. The development of the ACT Preventive Health Strategy provides one opportunity to progress this work (See TOR A, *Section ii.*)

2.2 ACT Health, health professionals and consumers monitor any unintended negative consequences of new Commonwealth hospital funding

arrangements that penalise hospitals for avoidable complications in patient care (See TOR A, *Section iii.*);

2.3 ACT Health and health services, including primary health care services, identify areas in which validated patient experience and health outcomes measures - such as Patient Reported Outcome Measures (PROMs) and Patient Reported Experience Measures (PREMs) - could be more widely used (See TOR A, *Section iv.*);

2.4 ACT Health implement a process to identify and disinvest in low-value care, and celebrate and acknowledge high-value care, in the ACT. The recent work of the Queensland Clinical Senate provides a useful model in this area (See TOR A, *Section v.*);

2.5 Clinicians and health service managers in the ACT who are not already engaged with Choosing Wisely Australia become involved in this initiative, and follow the research emerging from the National Health and Medical Research Council-funded *Wiser Health Care* research collaboration (See TOR A, *Section vi.*);

2.6 ACT Health and ACT public hospitals formally partner with Choosing Wisely by becoming Choosing Wisely Champion Health Services, joining a number of leading health services which are demonstrating the value of Choosing Wisely in hospital settings (See TOR A, *Section vi.*);

2.7 ACT Health, ACT public hospitals, and clinical areas within the hospitals identify opportunities for cost saving (See TOR A, *Section vii.*);

2.8 ACT Health enhance consumer-centred care by (See TOR A, *Section viii.*):

- Improving multidisciplinary team work within ACT hospitals, particularly between medical and surgical specialities;
- Improving information sharing practices and infrastructure, so that consumers and carers are not required to be the central repository of health information;

- Improving service coordination (e.g. if a person requires three different outpatient appointments, then these are combined or happen on the same day); and
- Making it easier for health professionals to co-ordinate procedures and treatments (e.g. if a patient requires a number of procedures under general anaesthesia, then where possible these happen under one general anaesthetic or one visit to hospital).

2.9 A sustained information campaign be implemented to alert health care consumers that they can access community-based health care services (in particular the Walk-In Centres, to which people self-refer), and detail what health issues these services can and cannot treat (See TOR B, *Section ii.*);

2.10 ACT Health consider an expanded role for Walk-In-Centres in the provision of public and community health services (e.g. immunisations, flu shots, some sexual health and family planning services, and as a coordinating point in the event of natural disaster or public health emergency), however the fundamental service model should be retained (namely it is an extended hours, nurse-led, alternative to ED presentation and as such offers episodic rather than ongoing care) (See TOR B, *Section i.*);

2.11 The Australian Government establish an authoritative website to transparently share information about the fees charged by individual specialists for procedures. This would make it easier for consumers to anticipate their likely out of pocket costs and also highlight the variation in fees charged by different specialists for the same procedure (See TOR C, *Section ii.*);

2.12 ACT Health and hospitals improve the quality of information provided to people about the option of being a private patient in a public hospital, to support consumers' fully informed financial consent (See TOR C, *Section iii.*);

2.13 ACT Health develop a Digital Health Strategy, to provide a framework for digital health initiatives across ACT Health services (See TOR D, *Section iii.*);

2.14 Future cross-border agreements between ACT and NSW must accurately estimate population growth in SE NSW and realistically calculate and reimburse the ACT for the costs of health care provision. HCCA

encourages collaboration between ACT and SE NSW health services, to provide integrated care for SE NSW residents who use health care services located in the ACT (See TOR D, *Section iv.)*;

2.15 Hospitals, General Practitioners (GPs) and their professional organisations and ACT Health work collaboratively with consumers to identify opportunities to improve the process of discharge from hospital, including improving the administrative and IT systems through which discharge notes are provided to GPs (See TOR E, *Section ii.)*;

2.16 Care coordination and patient navigation assistance be improved to meet the need of participants in the National Disability Insurance Scheme (NDIS) in the ACT (See TOR E, *Section ii.*);

2.17 The ACT Government resource and support consumer involvement in infrastructure planning and development so that capital developments meet consumer needs and expectations (See TOR F, *Section ii.*);

2.18 ACT Health publish an annual Safety and Quality report that details how ACT Health services have used consumer feedback to improve services, clinical outcomes and complications rates, infections and infection rates and staff wellbeing and morale (See TOR H, *Section i.*).

2.19 To progress this work and to support public confidence in the data that ACT Health collects about consumers, ACT Health continues to share information about the progress of the ACT Health system-wide review of data and reporting, which is due to report in March 2018 (See TOR H, *Section i.*);

2.20 ACT Health's forthcoming Health Literacy Improvement Plan needs to provide a meaningful framework for consumer, clinician and health service action to improve both individual and environmental health literacy (See TOR H, *Section ii.*);.

2.21 ACT Health develop an ACT Health Workforce Strategy in consultation with community and other stakeholder groups, to build on the soon-to-expire ACT Health Workforce Plan 2013-2018 (See TOR H, *Section iii.*);

2.22 ACT Health consider how best to increase the capacity of our health system to deliver innovation to support sustainability. Queensland's Department of Health offers an interesting example in this area (See TOR H, *Section iv.*);

2.23 ACT Health identify opportunities to further leverage the value delivered by partnerships with non-government organisations, including through longer contracts with key non-government partners (See TOR H, *Section v.*);

2.24 ACT Health consider which health care services currently delivered by government could be delivered by non-government agencies with appropriate expertise and community networks (See TOR H, *Section v.*);

2.25 Collaborative work be undertaken to develop an ACT climate change mitigation and adaptation strategy that addresses the risks to human health posed by climate change, including that it will further exacerbate existing health inequalities (See TOR H, *Section vi.*).

2.26 ACT Health continue to support people to complete Advanced Care Plans, and ensure hospital clinical staff have opportunities to develop skills in shared decision-making – in order to reduce the incidence of non-beneficial end of life care that is not desired by consumers (See TOR H, *Section vii.)*.

# 3. Introductory comments

Health care consumers are also health care funders. Our taxes are allocated to health care budgets, and we pay directly for health care services including through Medicare co-payments, out of pocket costs and (for those who hold PHI) public health insurance premiums. Indeed, Australian health care consumers pay among the highest direct costs for health care services in the OECD.[2] Consumers are therefore highly invested in ensuring that our health care system delivers safe, high quality and cost-effective care.

All Australian jurisdictions recognise that health care faces sustainability challenges, including:

- Rapid advances in medicine and medical technology, including in genomics and personalised medicine, which can deliver better health outcomes but are also costly;
- A demographic transition in which our population is ageing, requiring health services to ensure people can enjoy the best health possible in older age; and
- Persistent health inequalities driven by social determinants of health that require co-ordinated effort across a range of areas of service delivery and government policy.

In the ACT, as across Australia, there's an urgent need for government, health services and consumers to work together to identify how *health care can be delivered differently* - so that our health system can deliver better care and health outcomes, while using limited resource more effectively.

This Inquiry is a welcome opportunity to raise issues related to the future sustainability of health care funding. It allows a more sophisticated discussion beyond the overly simplistic notion that consumers have an unquenchable want for health services, especially as we grow older. What most consumers want is not more health services. What we want is for our health and well-being to be as good as possible, with the minimum of health care services. Where services are necessary to deliver improved well-being, or quality of life where health improvement is not possible, consumers want services that are timely, effective, high quality and delivered in a kind and caring manner. Sometimes, the solutions for better health, well-being and quality of life for

consumers lie outside health policy altogether, within other realms of government responsibility, and within communities. This is why a focus on the social determinants of health is so important. HCCA is hopeful that the development of the ACT Preventative Health Strategy will provide a valuable avenue for ACT Health, other ACT Government Directorates, and community and consumer organisations, to jointly establish practical efforts to address the social determinants of health and reduce health inequality in the ACT.

Australia's health system is complex and has numerous funding and administrative arrangements. Given this complexity - and the entrenched character of some of the barriers to sustainability - this Inquiry is not in itself sufficient to map a viable path towards a more sustainable health system for the ACT. HCCA encourages the members of the Standing Committee on Health, Ageing and Community Services to consider the merits of a longer process to involve the public, and invite meaningful consumer and clinician participation, in identifying practical solutions to the challenges facing our health care system in the ACT. There are processes currently underway in other Australian jurisdictions that provide a model for work of this kind. In particular, HCCA draws the Committee's attention to the Western Australian (WA) Sustainable Health Review, which has taken more than 12 months to support consumers, clinicians and academic experts to collaborate to identify workable initiatives to improve the sustainability of WA's health care system. Queensland Health has recently led a similar process of clinical and consumer engagement to inform the development of a 10 year plan for the State's health services, aiming to ensure that health services are aligned to the current and future needs of Queensland's communities.[3]

Public engagement, clinical leadership and partnering with consumers are essential if health care consumers and professionals are to have ownership of the necessary efforts to achieve sustainable health care. The timeframe of the current Inquiry into the Future Sustainability of Health Funding is unfortunately too short to allow serious consideration of these complex issues. HCCA therefore suggests that a process similar to the Sustainable Health Review would be of significant benefit in the ACT.

Consideration of health care sustainability is well-advanced in Australia. In particular, the 2008-2009 Health and Hospitals Reform Commission undertook a rigorous process to identify workable solutions in this area. The Commission's recommendations remain entirely relevant for governments, consumers and others

involved in the financing of health care and the delivery of health care services. The Commission's many recommendations were organised around four priority areas, namely:

- **Taking responsibility:** supporting greater individual and collective action to build good health and wellbeing.
- **Connecting care:** delivering comprehensive care for people over their lifetime, by strengthening primary health care, reshaping hospitals, improving subacute care, and opening up greater consumer choice and competition in aged care services.
- **Facing inequities:** taking action to tackle the causes and impact of health inequities, focusing on Aboriginal and Torres Strait Islander people, people in rural and remote areas, and access to mental health and dental services, and
- **Driving quality performance:** having leadership and systems to achieve the best use of people, resources and knowledge, including "one health system" with national leadership and local delivery, revised funding arrangements, and changes to health workforce education, training and practice. [4]

Though the Commission reported almost 10 years ago, these four areas continue to provide a helpful framework for action to protect health care sustainability, both nationally and at the State/ Territory level.

In Australia and internationally, leading health services and innovative health funding agencies are increasingly focused on the benefits of *value-based health care*. A value-based health care system is organised on the principle that it is possible to "improve patient outcomes with lower health care costs"[5] *if* we prioritise and fund the health care interventions and health outcomes that "patients most value". [6] This submission discusses the concept and practice of value-based care in more detail under TOR A *(Section iv.)*, and outlines a number of strategies by which the ACT could move toward value-based health care. For example, at TOR A *(Section vi.)* HCCA discusses Choosing Wisely Australia's success in reducing the incidence of unnecessary and potentially harmful tests and treatments, with associated reductions in wasteful health care expenditure. The discussion at TOR A *(Section v.)* describes practical initiatives undertaken by the Queensland Clinical Senate to drive disinvestment in low-value care.

Value-based health care can demand behaviour change from both clinicians and consumers, including a shift toward consumer-centred care and a more active role for consumers in decisions about our health and care. Health literacy – which allows health care consumers to make informed decisions about our health and care – is therefore essential to achieving value-based care. The discussion at TOR H *(Section ii.)* identifies strategies to support health literacy while TOR A *(Section viii.)* sets out some key consumer priorities that would support the delivery of consumer-centred care in the ACT. HCCA's comments against each of the Inquiry's Terms of Reference (below) support the overarching aim of a sustainable, consumer-centred and value-based health care system for the ACT.

# 4. Specific Issues

## TOR A: The efficiency of current health financing; particularly examining the alignment of funding with the purpose of the ACT's health services, including the provision of quality and accessible health care to patients when they need it.

### i. Improve access to the ACT's health services

Residents of the ACT and surrounding areas of South East NSW (SE NSW) enjoy a world-class health system. However it is unfortunately the case that health care is not always available to people when we need it in the ACT. For example, many people categorised as having a non-urgent need for surgical procedures including tonsillectomy and treatment of varicose veins languish on indefinite public hospital waiting lists, unable to access the health care they require. In the 2016-17 financial year, 14 per cent of people who required surgery within 365 days at The Canberra Hospital (TCH) did not receive this care within the clinically recommended time.[7] A similar situation applies to non-surgical interventions: for example, HCCA hears regularly from people who wait an inordinate length of time to access pain management services in the ACT public health system. Access to services delivered in primary care and community settings in the ACT can be similarly delayed. For example, a 2016 review of the ACT Obesity Management Service found that people experienced the long wait times to enter the service (typically of three to six months or

longer) as de-motivating and demoralising, and a significant barrier to lifestyle changes that they recognised as necessary to improve their health.[8] As this example suggests, there can often only be a small window in which people have the time and motivation to change the way we manage our health. If the right primary care or community-based service is not available at this time the opportunity can be lost permanently. This has flow-on effects in terms of the prevalence of chronic ill-health and acute health events requiring hospital-based intervention.

In the ACT as nationally, people with disability can face great difficulty accessing health services due to unacceptable wait times, cost, inaccessible buildings and discrimination from health professionals.[9] While physical access to buildings is not in itself sufficient to overcome this challenge, at TOR F HCCA makes some further comment in relation to the involvement of people with disability in future infrastructure planning and development in the ACT.

In addition, the management of waiting lists for procedures could be significantly improved. At one point, potential patients requiring surgery or their referring doctors could access a website, where the length of waiting lists for doctors, who operated in the public sector, were available. Patients could then choose their practitioner based on how long they may have to wait. In other Australian jurisdictions, there was an active waiting list management process where people who were happy to go to the first available clinician were able to go on such a list. HCCA understands that these organisations kept in touch with neighbouring states and were able to suggest interstate arrangements for consumers, where this was appropriate. The website was not kept up to date and last year was removed when this was drawn to ACT Health's attention. This removed one of the only tools which allowed consumers and primary care clinicians to be active in assisting with waiting list management. HCCA encourages the ACT Government to seek opportunities to re-instate a service of this kind.

### ii. Address the social determinants of health

As across Australia, in the ACT good health outcomes are not shared equally across the population. The internationally recognised work of epidemiologist Michael Marmot has made very clear that the *social determinants of health* including early childhood

experiences of parenting and care; quality of education, housing and employment; income; social inclusion; and nutrition are *more important* than access to health care services or the quality of health care services in determining both morbidity and mortality across the lifespan.[10] It is well-understood that some population cohorts experience marked socioeconomic disadvantage Australia-wide as well as in the ACT. For example, Aboriginal and Torres Strait Islander people, and people with experiences of homelessness and/or sub-standard housing, are recognised as having poorer health outcomes at the population level. However, research into the social determinants of health also makes clear that a *social gradient* applies to health outcomes across the entire population: "even among middle-class office workers, lower ranking staff suffer much more disease and earlier death than higher ranking staff".[11] In short, "the lower people are in the social hierarchy", the more commonly we experience not only material but also psychosocial and psychological circumstances that predispose us to ill health: these circumstances include "low self-esteem, social isolation and lack of control over work and home life".[12]

A sustained and co-ordinated effort to address the social determinants of health will improve population health, and reduce the incidence of avoidable ill-health (with consequent benefit to health budgets). HCCA recognises that this demands a substantial re-organisation in how health policy is made, as efforts outside of the health system must be recognised as essential to protecting good health and reducing ill health. Policies, programs and services that support people to undertake life's important transitions well (e.g. moving from primary to secondary school, beginning work, moving out of the family home, changing jobs, redundancy and retirement[13]) mitigate the social determinants of health, as do targeted efforts to work with communities and people experiencing health inequality to design appropriate interventions. The development of the ACT Preventive Health Strategy provides an opportunity for ACT Health, other ACT Government Directorates, health services and community and consumer organisations to jointly establish an approach to addressing the social determinants of health and to reduce health inequality, within the scope of the ACT's ability to act on these issues.

### iii. Monitor the impact of hospital funding arrangements

HCCA understands that changes to Commonwealth funding arrangements introduced in July 2017 mean that Commonwealth funding for hospitals is now reduced when avoidable complications in patient care (such as hospital-acquired infections) occur.[14] HCCA supports the principle that health care professionals and organisations should make every effort to improve the safety and quality of care, but is not convinced that financially penalising hospitals for shortcomings in care will improve consumer health outcomes. Although the financial penalty to underperforming hospitals may ultimately be minimal,[15] there is little Australian or international evidence to support the assertion that threat of financial penalty will improve the safety or quality of care in hospitals in our context.[16] Moreover, this approach is likely to encourage under-reporting of medical error[17] - which has been recognised internationally as a very significant problem[18]. It is also the converse of open disclosure, which is not only the strong preference of consumers and carers affected by medical error but also encourages a culture of safety, quality and improvement and ensures that consumers have an option to seek restitution through a pathway other than litigation.[19]

In addition, faced with the threat of funding reductions, hospitals may adopt a more risk averse approach to selecting patients for particular surgical or other interventions, excluding cohorts (such as older people, or people with multiple chronic conditions) who can be more likely to develop complications following surgery. [20] This would enhance existing health inequalities and deny people the care they require[21]. In short, HCCA sees that there are potential unintended negative consequences associated with financially penalising hospital underperformance**.** HCCA therefore encourages ACT hospitals, ACT Health, health care consumers and the members of the Legislative Assembly to monitor this area closely over time.

### iv. Move toward value-based care and funding

HCCA supports a hospital funding model that *rewards* hospitals for strong performance on safety and quality indicators (including the patient experience of care), rather than penalising underperformance.[22] Broadly, HCCA is supportive of funding models that reward positive consumer health experiences and health outcomes, rather than funding the *activities* of health services. Unfortunately, our current activity-based

model tends to reward “throughput” within hospitals (e.g. the number of hip replacements performed during a given time period), rather than health outcomes (such as improved mobility or quality of life). This is to the detriment of quality and accessible care, particularly because many of the most effective health services *prevent people from needing hospitalisation,* and are therefore often neglected in activity-based funding models. While it can be challenging to measure or attribute cause to health outcomes, it would be helpful if well-established methods such as Patient Reported Outcome Measures (PROMs) and Patient Reported Experience Measures (PREMs) were used more widely in hospitals and in community/primary care settings, where these are appropriate. HCCA encourages ACT Health and health services, including primary care services, to consider in which areas of their activity this might be possible.

Recent and ongoing discussions in other Australian jurisdictions and internationally have identified the benefits of shifting from activity-based funding to **value-based** funding models. A value-based health care system aims to “improve patient outcomes with lower health care costs”[23] and importantly it focuses on the interventions and outcomes that “patients most value”,[24] thereby ensuring limited resources are directed toward high-value interventions. For example, a clearer focus on areas of wellbeing that provide value to older people and people living with chronic illnesses – such as social and community participation – could allow a more practical and thorough assessment of value in health care.[25] Shifting toward a value-based approach to care can demand change in attitudes and behaviours, both from health care professionals and from consumers. Each party may require information, tools and/or assistance to assess the value of health care treatments or interventions, and to practice shared-decision making (in which consumers and clinicians are equal partners in identifying the goals of treatment and a treatment plan). Value-based care demands that consumers be actively involved in our care, and health literacy is a necessary basis for this involvement. The discussion at TOR H *(Section ii.)* shares key learnings from HCCA’s work in support of health literacy, while *Section v.* to *Section viii.* below describe practical initiatives that would support a shift toward consumer-centred and value-based care in the ACT.

### v. Disinvest in low-value care

In the ACT as in all Australian jurisdictions **there is an urgent need to identify and disinvest in low-value care** (that is, care that delivers no or little benefit to consumers, and which may cause harm[26]). HCCA would like to draw the Committee's attention to a process undertaken by the Queensland Clinical Senate in 2016, in which clinicians were invited to work together over a two-day meeting to identify examples of low-value and high-value care delivered in Queensland, and to develop *practical action plans* to drive a shift away from low-value care. The group identified examples of low-value care including:

- Medical imagining for patients with non-specific acute lower back pain without indicators of a serious cause; and
- Routine non-targeted risk screening administered by nursing staff in hospital.[27]

HCCA encourages the members of the Standing Committee on Health, Ageing and Community Services to consider the merits of a similar process, in which ACT clinicians, consumers and health services could be invited to identify priority examples of low-value health care in the ACT and develop practical action plans to disinvest in these procedures. HCCA also suggests that there is value in supporting clinicians, consumers and health services to identify examples of high value care, and in providing opportunities for ACT Health employees and all health services in the ACT to celebrate the successes of these services.

As an example, the Queensland Clinical Senate invited participants in its process to propose examples of high-value care that achieve health outcomes valued by consumers while using resources and funding judiciously. These included a supportive model of kidney care that provides patients with a lower-cost model of care that meets their individual needs more flexibly than traditional high-cost pathways; the delivery of home-based palliative care via telehealth; and a program supporting volunteers to assist older people experiencing delirium. Processes of this kind provide health professionals with an opportunity to highlight, celebrate and share successes, and thereby foster workplace cultures that value sustainability and innovation. The ACT has a Clinical Council which would be well-placed to consider these issues.

### vi. Reduce unnecessary tests and treatments, including through involvement in *Choosing Wisely*

There are significant opportunities for ACT Health to reduce the incidence of unnecessary tests and treatments, thereby delivering improvements in patient care while reducing wasteful heath care spending. Unnecessary tests and treatments do not improve consumers' health, and can expose patients to harm (for example in the form of anxiety and false positives requiring further testing). Unnecessary testing is also associated with the growing challenge of over-diagnosis (that is, unnecessary diagnosis), which can cause patients harm (in the form of unnecessary concern about their health as well as unnecessary and sometimes expensive or even harmful treatments) and also diverts health care resources that could be better spent addressing genuine needs.[28]

It is essential that clinicians are involved in identifying unnecessary tests and treatments and leading action to change these practices. As Berwick et al (2015) argue:

> *"To achieve unprecedented improvements in care will require trust from the public. Messages about needless care coming from clinicians stand a much greater chance of public acceptance than the same messages from insurers or the government"*.[29]

The Choosing Wisely Australia initiative, in which members of 37 Australian and Australasian health professional colleges, societies and associations[30] have identified unnecessary tests and treatments in their areas of expertise, is an example of how this can be done well. Choosing Wisely supports behaviour and attitude change on the part of both clinicians and consumers, making it easier for clinicians to start conversations about unnecessary tests and treatments and assisting consumers to make better choices to ensure high-quality care.

HCCA encourages clinicians and health service managers in the ACT who are not already engaged with Choosing Wisely to become involved in this initiative, and to follow the research emerging from the National Health and Medical Research Council-funded Wiser Health Care research collaboration. This collaboration is currently producing a National Action Plan to guide efforts to reduce over-diagnosis and over-treatment. An initial statement to underpin development of the National Action Plan

has been published and is endorsed by (among others) the Consumers' Health Forum of Australia (CHF), the Australian Commission of Safety and Quality in Heath Care and a number of medical Colleges including the Royal Australian College of Physicians and the Royal Australian College of General Practice. HCCA encourages ACT Health and health services to actively participate in the development of the Plan, and to use the Plan – when it is finalised - as a guide for activities to reduce the incidence of unnecessary tests and treatments in the ACT.

HCCA also specifically encourages ACT Health and hospitals to partner formally with Choosing Wisely by becoming Choosing Wisely Champion Health Services. Nationally, eleven Choosing Wisely Champion Health Services are showcasing the benefits to be gained from using the Choosing Wisely approach in hospital settings, including by putting into the practice the recommendations about areas for disinvestment made by participating medical Colleges and other health professional associations.[31] These hospitals have achieved considerable improvements in patient care while reducing wasteful costs. For example, by involving clinicians in identifying unnecessary pathology testing, the Gold Coast University Hospital reduced public pathology testing by two per cent over a fifteen-month period (from 96,000 public pathology tests a month to 93,500) during which patient activity increased by 10 per cent. This led to budget savings, and improved the safety, quality and consistency of care offered to patients.[32] In its first year of partnership with Choosing Wisely, the Royal Brisbane and Women's Hospital put in place more than 130 initiatives to reduce unsafe and costly care practices across 30 hospital departments. These include:

- A *fasting clock* initiative, which is a bedside visual aid that assists patients and health professionals to ensure patients don't fast for longer than necessary prior to scheduled surgery. This has led to reduced food and fluid fasting times, lessening hunger and thirst for people undergoing surgery;
- The CREDIT scheme (Cannulation Rates in the Emergency Department Intervention Scheme), which has reduced the rate of unnecessary cannulation in the Emergency Department (ED) by 10 per cent, saving the ED time and money and reducing the possibility of infection to patients.
- The hospital's audiology and ear, nose and throat (ENT) areas have worked together to improve the triage process for referral to ENT services.[33] This is an

area of particular interest for consumers in the ACT, where there are long wait lists for ENT referral, and many consumers feel they need to access more timely care in the private system, or interstate.

These examples demonstrate the practical benefits to hospitals and health services of formal partnership with Choosing Wisely. If ACT Health and ACT hospitals were to become Choosing Wisely champion health services, there would potentially be significant benefits for consumers, the ACT Health budget and to health care staff (in terms of encouragement and support to identify and lead improvements in work practices).

### vii. Seek opportunities to use health care resources judiciously, particularly in ACT public hospitals

As in all Australian jurisdictions, there are significant opportunities to use existing health care resources and funding more efficiently in the ACT. The ACT Minister for Health acknowledged during the Annual Report hearings that "waste within health services is fairly significant".[34]. Across the country hospital settings account for the majority of health care spending, and there are particular opportunities to improve efficient use of resources in hospital settings[35]. HCCA encourages ACT hospitals, clinical areas within hospitals and ACT Health to identify opportunities for cost saving. At the level of particular surgical areas there may be opportunities to use existing facilities in ways that would allow swifter patient access without compromising safety or quality.

For example, reducing the use of TCH surgical theatres equipped with specialist equipment for diagnostic procedures (such as flexible cystoscope and prostate biopsy) could reduce the wait time for major surgical interventions that can only be performed in an area with this equipment. Clinical specialities working from ACT hospitals could give consideration to jointly identifying a preferred manufacturer from which surgical kit sets for all consultants would be purchased (rather than each consultant identifying an individually-preferred manufacturer). This could allow ACT Health to benefit from the economy of scale delivered by purchasing in bulk, and also mean that junior doctors would not need to learn to use multiple surgical kit sets to perform the same procedure.

HCCA also recognises that ACT hospitals produce a significant volume of clinical waste that must be managed, and at an undisclosed cost to the ACT budget.[36] While HCCA is entirely supportive of the ACT Government and ACT Health's commitment to appropriate management of clinical waste (given the very serious environmental health impacts of mismanagement of hazardous clinical waste), HCCA is also aware that nationally there is scope to achieve considerable gains in the sustainable management of hospital clinical waste through reducing, reusing or recycling where this is appropriate. As much as 90 per cent of medical waste in Australia is misclassified as hazardous rather than general medical/clinical waste, in part due to a lack of education and clinical leadership in this area. A commitment on the part of ACT Health and ACT hospitals to review and improve policies, processes and staff education in this area could deliver significant cost savings (given that disposal of hazardous medical waste costs somewhere between eight and 20 times that of general waste) with no negative outcome for the safety and quality of care, while also reducing the very significant environmental footprint generated by all hospitals.[37] Future infrastructure planning and development initiatives could also identify opportunities to enable staff to more easily classify waste appropriately (e.g. by considering the location of hazardous and general clinical waste bins).

### viii. Focus on the provision of consumer centred care

The best available evidence tells us that **high quality, safe and consumer centred care also uses resources and funding more sustainably**. Efforts to ensure a sustainable ACT health care system should focus first and foremost on delivering high quality, safe and consumer-centred care. Costs savings will follow. For example, in 2017 HCCA sought the views of more than 500 ACT health care consumers, and diverse consumer and community organisations, on the safety and quality of ACT Health services. Some key findings from this work, forthcoming as *Spend Time to Save Time: What Safety & Quality Mean to ACT Health Care Consumers*[38] were that:

- Currently, people who wish to be actively involved in the care of their loved one at The Canberra Hospital are not always permitted to do so. If carers were permitted and supported to undertake tasks they routinely perform at home (for example, changing a catheter), this would recognise both the skills and the essential role of the carer, while also reducing the demand on nursing staff time

(with the caveat that it should not be assumed that people should or will perform personal care or other caring tasks for a person in hospital);

- Consumer and carer input is not routinely sought at critical opportunities when patients are admitted to ACT hospitals, for example in relation to clinical deterioration. While ACT Health has put an appropriate system in place to encourage consumers and carers to escalate concerns about the clinical deterioration of a loved one at TCH (through the Call and Respond Early (CARE) Program for Patient Safety[39]), there is a broader need to re-orient hospital care so that all clinical, nursing and allied health staff have the time and are supported to seek this information routinely and respond to consumers and carers when this information is provided.
- Consumers and carers in the ACT do not always feel they receive the information they need from clinicians, nor do they always feel they have opportunities to provide necessary information to clinicians or that this information is valued by staff who display empathy with them.

In summary, consumers and carers are an over-looked resource from whom clinicians could be drawing to contribute to the safe and high quality care of the patient, to gain a full picture of a patient's situation, and to ensure that the goals of care and the treatment plan are appropriate to the person's situation. It is unfortunate that ACT consumers and carers are not always involved in shared decision-making or supported to self-manage our own health. Involving consumers and carers in decision-making, and demonstrating respect for our knowledge of our own health, will deliver care that responds to patients' priorities and situations – thereby improving the safety, quality and sustainability of care.

Many of the priority health care improvements consistently identified by ACT health care consumers as desirable would use existing funding and resources more efficiently. For example, participants in HCCA's 2017 research into consumer perceptions of the quality and safety of ACT Health services identified a number of possible improvements to ACT Health services. All of these changes would contribute to what Berwick et al (2015) describe as the "triple aim", or "simultaneous pursuit of better care for individuals, better health for populations, and lower per capita costs of health care"[40] while also improving the work life of health care professionals and others

working in health care services.[41] Focused largely on improvements to the care delivered in ACT public hospitals, the report recommendation's included that:

- Multidisciplinary team working be improved and supported, particularly between medical and surgical specialities;
- Information sharing practices and infrastructure be improved so that there is less requirement for the consumer and carers to be the central repository of information;
- Service coordination be improved (e.g. if a patient with multiple co-morbidities or follow-ups requires three outpatient appointments, then they are combined, happen on the same day, or that the consumer is consulted to understand what works best for them); and
- Coordinating procedures and/or treatment be made easier for health service professionals (e.g. if a patient requires a general anaesthesia for a number of procedures, then where possible these happen under one general anaesthetic or one visit to hospital).

This project also identified that consumers can readily identify variation in clinical practice, including in relation to the consumer-centredness of care. For example, some clinical areas within ACT hospitals were regarded by participants in the research as providing excellent multidisciplinary care, while other areas were seen to struggle to provide this kind of care. There is an opportunity through the current development of Territory-Wide Health Services Framework 2017-2027 and Speciality Services Plans to foster an ACT-wide culture of improvement, and consistently excellent multidisciplinary practice. It is also important for ACT health services to monitor their performance relative to their national peers, and to identify opportunities for improvement if unwarranted clinical variation is identified.

## TOR B: The nature of health funding and how it improves patient outcomes including innovative or alternative programs such as hospital in the home and Walk-In centres.

### i. Consumers value primary and community care

It is HCCA's longstanding position that an enhanced focus on primary health care could prevent inefficient spending in tertiary care and create a healthier community. The term primary health care describes "universal, community-based preventative and curative services" that aim to deliver better health for all.[42] Provided by health professionals including GPs, nurses (in general practice and community settings), nurse practitioners, allied health professionals, pharmacists, Aboriginal health workers and dentists, primary health care services are the first, or day-to-day, layer of the health care system, and involve a co-operative approach to the care of the person over time.[43]

A clear research consensus demonstrates that investment in primary care is the most cost effective way to deliver better population health.[44] For example across Australia, the average cost of health care delivered in general practice is significantly less than the average cost of care provided by specialist clinicians (which is almost double the average cost per service of general practice) or in hospital Emergency Departments.[45] When care can be provided safely and affordably in the community, consumers will generally prefer to access care here (rather than in an acute setting). For example, HCCA's 2017 research into experiences and expectations of after-hours primary care,[46] in which more than 1000 consumers participated, found very strong consumer appreciation of models that provide affordable, accessible out-of-hours primary care. The Walk-In Centres in particular were highly valued: most users of the Walk-In Centres who took part in the research felt that these services treated their health issue swiftly and professionally, and at times of the day or week when other medical or health services would not be available. One participant described that:

> *"When I cut my finger, I cut it on the edge of the tin lid, and at that time it was evening, I was cooking and ... I tried to put it together with a band aid, and then… I was looking, thinking, 'ah, actually, this is worse than I what I thought it was'… My partner did some searching around and found it online,*

*the Walk-In Centre… I was actually getting more nervous, … thinking, 'ah, actually, this is bleeding quite a lot'.*

*We actually didn't really wait... five to seven minutes at the most. We went straight in. Somebody came out straight away to check that I could do certain particular movements, which I could do, but they were very clear that if I couldn't, I would be sent to Accident and Emergency. They were superb. The woman that helped us was absolutely superb… She was really, really skilled. When I walked in they did that quick assessment, 'Okay, no, you haven't cut through the tendon' or whatever. 'We can still do X, Y and Z [here].' It was sort of a huge sense of relief [to know], 'Right, we are in the right place'. They cleaned the wound out, and she stitched it together… Very quick, very easy… Straight in, fixed up".*[47]

This health care consumer is typical of participants in this project, who felt that the Walk-In-Centres provided the right care, at the right time, and were staffed by the right health care professionals.

HCCA supports consideration of an expanded role for Walk-In-Centres in the provision of public and community health services, but it is essential that any alteration to the service model ensure that the fundamental aspects of the service are not diluted (that is, it is an extended hours, nurse-led, alternative to ED presentation and as such offers episodic rather than ongoing care). There may be scope for Walk-In Centres to provide additional services including immunisations for infants and children, flu shots, some sexual health and family planning services, and to be the focus of public health protection efforts in the event of natural disaster (such as bushfire) or threat to public health (such as thunderstorm lightning or an outbreak of health-threatening viral illness such as SARS).

HCCA recognises that the establishment of the Hospital in the Home (HITH) program that currently operates from TCH is a positive move to offer people continuity of care and earlier discharge from hospital, where their needs can be safely met and where this is their preference. From HCCA's perspective, it is essential that the aims of services of this kind are articulated in terms of meeting the *preference* of consumers who wish to receive care at home, rather than in terms of making hospital beds

available to others who require them. Being perceived as “pushing people” home before they are ready will not contribute to the delivery of safe, high quality care. However, offering people the choice to receive care in their own home where it is safe to do so does deliver high quality and consumer-centred care and this will, in turn, use resources more efficiently and cost-effectively.

Elsewhere in this submission (see TOR A, *Section i.*) HCCA draws attention to ACT Health’s Obesity Management Service as an example of an evidence-based, multidisciplinary preventative health service that meets a priority community need and may assist people to avoid the need for acute hospital services. HCCA also draws attention elsewhere (TOR E, *Section i.*) to the new Geriatric Rapid Acute Care Evaluation (GRACE) program managed by the Capital Health Network and Calvary Public Hospital, which seeks to improve the care experiences of people living in aged care facilities, by improving coordinating and communication between hospital staff, aged care facility staff and GPs, with the aim of avoiding hospital admissions where this appropriate, and supporting earlier discharge from hospital when it is safe to do so.[48] At TOR E, *Section ii.*, HCCA draws attention to the Transitions of Care Program managed by the Capital Health Network and TCH Emergency Department and Department of Medicine a further example of an innovative service that aims to enhance continuity of consumer-centred care and reduce avoidable hospital admissions.

### ii. Consumers need information about community-based health services

A major challenge for all of these services is to ensure that the public, and referring clinicians, understand what these services offer, what they cannot offer, and when and how consumers can access these services. With particular regard to the Walk-In Centres, to which consumers self-refer, HCCA suggests there would be value in a sustained public information campaign designed to alert health care consumers that the service exists, and to detail what health issues the service can treat and what it cannot treat.

## TOR C: The sources and interaction of health financing in the ACT through ACT Government funding, Australian Government funding through Medicare, private health insurance, consumer out of pocket costs, and other sources.

### i. Out of pocket costs unacceptably limit access to health care

Medicare underpins Australia's universal health care system. It is important to recall that Medicare was introduced by the Australian Government more than three decades ago in order to subsidise the cost of health care to the consumer, thereby ensuring equitable access to health services. The introduction over time of further costs to the consumer through co-payments for Medicare-funded services has eroded the Medicare and Medicare rebate system, and its ability to deliver equitable access to the health system.[49] Some 17 per cent of total health care expenditure in Australia is now funded by individual consumer co-payments, significantly higher than most OECD countries.[50] HCCA is aware that the requirement to make co-payments for Medicare services does cause financial hardship for many health care consumers, particularly people living on low incomes, and people with multiple chronic conditions.[51] HCCA supports the concern expressed by CHF in January 2018 that continued increases in out of pocket health costs – both gap fees for specialist consultations outside hospital, and hospital-based procedures - that are not covered either by Medicare or (for those who hold it) PHI is "eroding access to health care in Australia".[52]

### ii. Consumers in the ACT are reconsidering the value of PHI

In the ACT, people who hold private health insurance often find it very difficult to know precisely what their insurance covers. It is complex and difficult for most people to compare policies, both in terms of value for money and to minimise out of pocket costs. HCCA's consultation with our members to inform our 2017 submission to the Australian Government Senate Inquiry into Private Health Insurance found that people's reasons for taking out PHI vary: some people see private health insurance as providing peace of mind, others see it as an option to avoid long public waiting lists for some procedures, while some inaccurately believe that it is compulsory to have private health insurance cover. Not everyone can afford PHI, and HCCA's consultation found that many people in the ACT are reassessing the value of their cover, whether they should continue, or downgrading their cover. Consumers' increasing concern that their PHI may not offer value for money is warranted: in the 12 months to September, health fund revenue from members' premiums rose at a faster rate than the amount they paid in benefits to their members.[53]

Out of pocket costs for people who hold PHI, particularly for hospital stays, can be very high. "Bill shock" is not at all uncommon in the ACT. People who hold private health insurance have told HCCA that they know that their out of pocket costs could be high, that is very difficult to know what these costs are likely to be, and that they have little control over these charges. Out of pocket costs for hospital stays continue to rise: Australian Prudential Regulation Authority figures quoted by CHF this month show that the average out of pocket "gap fee" for privately insured hospital patients currently stand at $299 per person. Gap costs when doctors bill extra rose by 19.3 per cent in the 12 months to September 2017.[54] Consumers in the ACT may reasonably but incorrectly assume that because they have paid their PHI premiums, sometimes for many years, they will therefore be fully covered in the event of hospitalisation for ill-health. Consumers can be horrified to discover we must pay hundreds from our own pockets. HCCA is supportive of CHF's recent proposal that the Australian Government support establishment of an authoritative website that would share information about the fees charged by individual specialists for procedures: this would make it easier for consumers to anticipate their likely out of pocket costs and also highlight the variation in fees charged by different specialists for the same procedure.[55]

### iii. Private patients in public hospitals need better cost information

The practice of being a private patient in a public hospital is not well understood by consumers in the ACT, nor is it well explained by hospital staff. Consumers are sometimes asked to 'do the public system a favour' by using their private insurance in a public hospital, without being given sufficient information to make a fully informed decision about the personal cost. Unfortunately, consumers are not always fully advised about out of pocket expenses, time limits, or claim limits on particular services. This raises questions about whether consumers have an opportunity to give their informed financial consent to being a private patient in a public hospital. HCCA suggests that the information provided to consumers in the ACT at TCH about using their private health insurance in a public hospital be reviewed and improved in consultation with consumers. If consumers are asked to consider using their private health insurance in a public hospital, information should be of sufficient quality as to give the consumer some assurance and confidence about the process and clear statements about out of pocket costs involved.

One consumer shared this story with HCCA, where the public hospital pressured use of private health insurance in the interests of the local community:

> *"My experience was being approached, while still in ED, by a young.. training doctor in the early hours of… [the] morning. He had taken a medical history from me. I think he had been sent down to enquire by his boss…I was just given the line about how using my private health insurance would help the hospital. That was when I agreed. Subsequently, when I was in the.. ward I was given appointments for a further test and consultation in the private rooms of the [specialist]. No information about costs was provided. What troubles me about this is a question about whether Specialists are able to use the system to recruit vulnerable private patients. Although I am normally on the ball, in the early hours of the morning after a sleepless and rather scary night, I was very vulnerable and unable to make a proper informed financial consent. I know nothing about the [specialist], and I still do not know anything about the fees and out of pocket costs (though I will enquire) or what the further downstream costs will be".*

HCCA's position is that both the public and private systems, and where they intertwine, need to deliver safe and high quality care. It is important that PHI deliver value for money at all levels.

## TOR D: The impact of health financing on i) population growth and demographic transitions in the ACT and the surrounding region and ii) technological advancements and health innovation

### i. Improve IT integration across ACT hospitals and primary care

There are significant opportunities for ACT hospitals to share information more effectively using a shared IT system, or better integrated IT systems. Currently, the lack of a shared IT system across Calvary Public Hospital and TCH can make it very time-consuming for specialists to follow-up information about individual patients. Better integration of patient information across ACT hospitals (including the soon to be opened University of Canberra Rehabilitation Hospital) would allow for more efficient use of clinicians' time and specialist skills (namely, focused on direct delivery of care to people) as well as a more navigable process for consumers.

Patient outcome monitoring both by professionals and consumers/carers and a reduction in testing would also be substantially assisted by ensuing the rapid transit of information between public and private providers, and between hospitals and primary care. Consumers who are using My Health Record complain that this often requires significant effort on their part and their record remains incomplete without universal cooperation in the implementation of a patient controlled health record. This would be a particular advantage for people with chronic conditions, who have various interactions that each need to know of each other.

### ii. Consider the benefits of telehealth and digital consultations

The ACT provides important health services, in particular acute hospital services at TCH, to people from South Eastern NSW. HCCA encourages consideration of innovative systems, such as telehealth and digital consultations, which could potentially benefit consumers from these areas by allowing them to receive high quality, safe and appropriate care in their own homes, at a lower cost than would be incurred (both to them personally and to the health system) by travelling to the ACT. Telehealth/digital consultation may also be the preferred option of some ACT-based consumers, and HCCA would encourage ACT Health to explore this area.

### iii. Develop an ACT Digital Health Strategy

HCCA is aware that several areas of ACT Health are undertaking work in the area of digital health innovation, and suggests that this work could be best supported if ACT Health were to develop a Digital Health Strategy that made clear the role and benefits of digital health initiatives across ACT Health and its services.

HCCA recognises health services often struggle to realise the potential that digital health and information technology have to deliver better care. HCCA also recognises that health IT is rapidly developing, potentially offering innovations that could improve care and save costs. However, this challenges health services to remain abreast of new developments and assess the benefits and risks of these. Developing a Digital Health Strategy could allow ACT Health to support discussion and action in this area, and provide an opportunity for health services to understand the implications of new technologies such as Blockchain, which may allow consumers to control and share

their data with a variety of services and clinicians, delivering better integrated health care while protecting data confidentiality. [56]

### iv. Improve cross-border collaboration to meet the needs of residents of South East NSW.

As described at *Section ii.* (TOR D) above, the ACT plays an essential role in the delivery of health services for residents of SE NSW, particularly through the tertiary referral services provided at TCH. It is essential that sustainability planning take into account expected population growth and demographic change in SE NSW as well as in the ACT. HCCA understands that cross-border funding agreements have not always recognised the full cost to the ACT of providing these services[57], and acknowledges that future cross-border agreements must accurately estimate population growth in SE NSW and realistically calculate and reimburse the ACT for the costs of essential regional health care provision. HCCA also recognises the need for collaboration between ACT and SE NSW health services, to provide integrated care for SE NSW residents who use services located in the ACT. HCCA draws the Committee's attention to the ACT and Southern NSW Local Health District Cancer Services Plan 2015-2020 as an example of collaborative cross-border planning to provide integrated care to a cohort of consumers who access essential health services in both the ACT and in SE NSW.[58] HCCA is supportive of the principle that care should be provided as close as possible to the home and personal support networks of consumers, where these services can be provided safely and where this is the preference of consumers.

## TOR E: the relationship between hospital financing and primary, secondary and community care, including the interface with the NDIS and residential aged care.

As discussed at TOR A and TOR B, it is HCCA's position that an enhanced focus on primary health care could prevent inefficient costs and spending in tertiary care and create a healthier community.

### i. Improve RACF residents access to care

HCCA recognises that people living in Residential Aged Care Facilities (RACFs) are often poorly served by the health system, may not have a regular GP, can have difficultly accessing specialists, and may be less likely to access good pharmacy and

medication review services. HCCA draws the Committee's attention to the Geriatric Rapid Acute Care Evaluation (GRACE) model recently established by the ACT Capital Health Network and Calvary Public Hospital. GRACE provides a hospital-to-home service that improves continuity of care to residents of RACFs, with the aim of preventing unnecessary hospitalisations and supporting earlier discharge from hospital where care can be safely provided in an RACF setting. This is a promising model that seeks to reduce avoidable hospital admissions, encourage collaborative care between RACF staff, GPs and hospital nursing and clinical staff, and improve the health of RACF residents.[59]

### ii. Improve hospital discharge processes

Discharge from hospital to primary health care is a particular point where care could be improved and significant efficiency gains made. HCCA hears regularly from people whose GPs have not received discharge notes from hospital and have had to follow these up in an inefficient and time-consuming process. HCCA encourages hospitals, GP organisations and ACT Health to work collaboratively and with consumers to identify opportunities to improve discharge planning and liaison, including improving the administrative and IT systems through which discharge notes are provided to GPs.

HCCA is currently developing a model for a Patient Care Navigator program that could operate in the ACT in the future, with a focus on improving the transition from hospital to primary health care in the community. Patient Care Navigators identify and remove barriers to good care, and a program of this kind could support a smoother discharge process while also reducing the likelihood of avoidable hospital readmissions for individuals. HCCA will complete this work in July 2018.

HCCA also draws the Committee's attention to the Transitions of Care pilot project which is currently underway in the ACT. Managed by the Capital Health Network in partnership with the Division of Medicine and the Emergency Department at TCH, this project aims to improve the coordination of care across acute and primary health care services. Targeted at people with a high risk of readmission to hospital, Transitions of Care improves coordination of care as people leave hospital, return home and access primary health care services, and assists people to self-manage their health after a hospital admission. The pilot will conclude in mid-2018.[60]

HCCA's consultation and research for the Patient Care Navigation project indicates a significant unmet need for Care Navigation services for NDIS participants, who are required to self-manage their NDIS funding while navigating a complex array of disability, social and health care services. While assistance related to the NDIS falls largely outside the scope of HCCA's Patient Care Navigator project, HCCA recognises that this remains a critical and poorly-met need in the ACT.

## TOR F: Funding the future capital needs of the health system in the ACT

### i. Digital health opportunities

HCCA recognises the need to plan for capital renewal to ensure that health services can meet needs into the future. As discussed above at TOR D *(Section iv.)*, it is important that planning take into account expected population growth and demographic change in SE NSW as well as in the ACT, given the regional catchment for ACT Health services. Innovation in e-health and telehealth could ameliorate the need for some physical and face-to-face services or appointments, supporting the most efficient possible use of physical building. As discussed at TOR D *(Section iii.)* above, this work could be supported by the development of an ACT Digital Health Strategy.

### ii. Consumer involvement in capital planning and development

Consumer involvement in infrastructure planning and development is essential, to ensure that capital developments meet consumer needs and expectations. Between 2009 and 2016 HCCA supported significant consumer involvement in infrastructure development in the ACT, under two large-scale programs of capital development in the ACT: the Capital Asset Development Program (CADP) (2008-2012) and Health Infrastructure Program (HIP) (2012-16). While consumer involvement in the design of new health buildings is common nationwide and internationally, consumer involvement in the CADP and HIP provided consumers with an unusual and welcome level of involvement in the governance of these major health infrastructure programs. With consumer representation on decision-making committees at all levels and

opportunities to involve consumers and the community in broad consultation about the development of new and redesigned health services, this work:

- Ensured that consumer perspectives, priorities and concerns were consistently articulated and considered by decision-making committees;
- Ensured that consumer issues that would likely otherwise have been overlooked were considered and frequently addressed;
- Kept consumer priorities 'on the table' as iterative infrastructure design processes evolved; and
- Brought a unique consumer perspective to deliberations that helped committee members participating in a clinical or health service capacity to make decisions that put patients and consumers closer to the centre of their considerations.[61]

Over the seven years of this work, HCCA's partnership with ACT Health enabled significant consumer input into the design of numerous new or significantly redesigned health services including Walk-In Centres in Tuggeranong and Belconnen, the Village Creek Centre, the University of Canberra Rehabilitation Hospital and the Canberra Regional Cancer Centre. This program of work also allowed HCCA to involve consumers and carers in assessing and suggesting improvements to signage and wayfinding assistance at ACT health services, including at The Canberra Hospital. This work has resulted in health services that meet the needs of health care consumers better than they would otherwise have. This outcome was possible because of ACT Health's clear commitment to this work during this period of time, and the allocation of dedicated resources to support consumer involvement. Future capital planning and development, including in the areas of focus set out in Section 3.1.3 of the draft Territory-Wide Health Services Framework[62], would benefit from a similar approach, in which the role of consumers is articulated and supported in partnership with consumer and community organisations.

Future capital development initiatives will require clear processes for the involvement of people with disability and their representative organisations. This is essential to ensure that health services are universally accessible and appropriate. A guiding principle in this area is that new or redesigned services should be modular (allowing future growth to meet need), multi-purpose, adaptable and universally accessible.

## TOR G: Relevant experiences and learnings from other jurisdictions

As noted elsewhere in this submission, the Western Australian Sustainable Health Review, and the Queensland Clinical Senate's efforts to introduce and systematise a value-based approach to health care are examples of innovation in this area from which ACT could usefully learn. At TOR H *(Section iv.)* below, HCCA also draws the Committee's attention to Queensland Health's efforts to build its capacity to measure and report on innovation in value-based care.

## TOR H: Any other relevant matter.

### i. The use of safety and quality information for improvement in health care

It is well-established that transparent public performance reporting helps keep health services accountable to the public, and can improve the safety, quality and cost-effectiveness of care.[63] HCCA appreciates the ACT Health Minister's recognition that community stakeholders have an interest in publication of ACT Health data, to understand the quality and performance of the ACT health system.[64] ACT consumers and carers would like to see ACT Health release more public information on the safety and quality of health care services. Participants in HCCA's 2017 research on consumer and carer perceptions of the quality and safety of ACT Health services most often requested information on improvements made to ACT health services based on complaints and feedback. Consumers also want public information on clinical outcomes and complications rates, infections and infection rates and staff wellbeing and morale. HCCA suggests that ACT Health consider publishing an annual Quality and Safety review, which reports on these areas, and makes this information widely available to health care consumers.

To enable this work, HCCA encourages ACT Health to continue to improve the integrity of its data and to report transparently on progress in this area. As has been widely publicised, in recent years ACT Health has been unable to assure the public of the integrity of its published performance data.[65] This risks undermining public confidence in data published about our health system's performance, and by

extension, risks undermining confidence in the performance of our health services. HCCA welcomes the ACT Health-wide review of data and reporting processes, that is currently underway, and awaits the findings of this review due in March 2018.

As detailed at TOR C *(Section ii)*, HCCA also supports public reporting on the average cost of particular hospital procedures, and the price charged by individual specialists for procedures covered by private health insurance.

### ii. Invest in health literacy

Providing health care consumers with opportunities, information and skills to develop our health literacy is essential to a sustainable health care system. HCCA is pleased that ACT Health and the ACT Health Minister recognise the importance of health literacy to health reform:

> *"Recently health ministers have agreed to three key things to shape health reform over the next decade. One of those is the right care in the right place at the right time. The second one is a real focus on prevention and helping people manage their health over their lifetime,* ***which goes to issues of health literacy*** *but a lot more than that."*[66]

HCCA defines health literacy as the "combined knowledge, skills, confidence and motivation used to make sound decisions about your health in the context of everyday life."[67] HCCA recognises that health literacy has an individual component, which is about the individual's access, understanding and ability to judge the quality of health information; and an environmental component, which relates to the setting in which people seek health information and use health care services. This includes the buildings where care occurs, signage and maps, websites, policies and processes, as well as the way staff speak with consumers and carers.[68] HCCA anticipates that ACT Health's forthcoming Health Literacy Improvement Plan will be an opportunity for ACT Health to set out goals and a plan of action to address both individual and environmental health literacy.

A key message emerging from HCCA's program of work on health literacy is that it is "OK to ask" questions of health professionals about our health and care. This can be daunting for consumers, and for clinicians - who undergo extensive professional

training in order to confidentially diagnose and treat consumers' health issues, but are not always trained or supported to engage in shared decision-making. Health literacy requires a shift in thinking and practice toward a more collaborative approach to information sharing and decision-making between consumers and clinicians. Recognising both the challenges and the opportunities that this situation creates, HCCA delivers public education for consumers and carers to provide them with the skills, knowledge and confidence to ask questions about their health and care. Through our health literacy program, HCCA also supports consumers to improve signage and wayfinding at ACT health services in the ACT and has recently worked with the Capital Health Network to review the consumer information available to GPs who use the Health Pathways IT system. Through these initiatives HCCA provides practical information and assistance to people so that they can acquire and practice health literacy skills; and supports health services to provide an environment that enables and supports health literacy.

### iii. Plan for health workforce needs

Health workforce planning is central to ensuring the future sustainability of health services. HCCA encourages ACT Health to develop an ACT Health Workforce Strategy in consultation with community and other stakeholder groups, to build on the ACT Health Workforce Plan 2013-2018[69] which will conclude this year. A revised Workforce Strategy would assist to provide the community with confidence that the ACT has a clear plan in place to achieve the aim set out at Section 3.3.1 of the Territory-wide Health Services Framework, namely that "the ACT Health workforce must possess the required capabilities and mix of skills to flexibly respond to future service demands while providing safe and high-quality services".[70] As is the case nationally, innovative deployment of the ACT health workforce will be essential in achieving a sustainable health care system, and this will require commitment on the part of health policy-makers and health service managers.

For example, extended hospital pharmacy opening hours could significantly improve the quality of patient care and reduce the time it takes for patients to be discharged. In many jurisdictions, including the ACT, this has yet to occur. But it is possible: for example, the Gold Coast University Hospital has recently introduced extended hours for its Pharmacy Dispensary, which operates seven days a week from 8.30am to

4.30pm. This allows the hospital to collect outpatient prescriptions on weekends, and recognises the role of clinical hospital pharmacy in protecting patient safety.[71] The development of an ACT Health Workforce Strategy should provide an opportunity for ACT Health to draw on the community and on the knowledge and skills of its health professionals to identify similarly innovative ways to provide the services consumers value at the right places and times.

The scope of practice of many health professions is changing and expanding, and this presents both opportunities and challenges for health care sustainability. Pharmacists, physiotherapists, registered nurses and nursing assistants will continue to take on responsibilities that would once not have fallen within their professional remit. While this can allow care to be delivered more effectively without reducing safety or quality it presents challenges for the regulation of health professionals.[72] Where the evidence is strong that expanding a profession's scope of practice is appropriate, regulatory reform will also be required and it is not yet clear what the appropriate regulatory regime will be. Demand currently outstrips supply for some key professionals in the ACT (for example, occupational therapists and psychiatrists). There is a particular need to plan for well-managed workforce renewal among professions – notably nursing – which have an experienced and older workforce, and in which many workers will reach retirement age at the same time. A new ACT Health Workforce Strategy would provide ACT Health an opportunity to articulate how these challenges will be met.

### iv. Develop ACT Health's capacity to innovate

HCCA encourages ACT Health, health service managers and leaders to consider how best to increase the capacity of our health system to deliver innovation to support sustainability. Queensland's Department of Health offers an interesting example of how capacity to innovate can be enhanced. The Department has created a Deputy Director General of Purchasing and Performance to implement and manage the Queensland Government's stated priority of achieving value-based health care. This position delivers a report to the Queensland Treasurer each six months on progress toward value-based health care. This position is supported by the staff of a value-based health care unit, which employs a team including a senior medical officer, a nurse, one other health professional and a health economist to work across four

Queensland hospitals to identify clinical workforce needs, opportunities to deliver value-based care (see TOR A *Section iv.*), implementation plans and evaluation strategies. This has involved a commitment of around $1 million by the Queensland Government. The Queensland University of Technology offers a Graduate Certificate of Health Services Innovation with a focus on implementation research and translational research, in which approximately 20 people are enrolled each year. Participants are required to use their Professional Development leave and Professional Development allowance as a co-investment. HCCA encourages ACT Health and members of the Committee to consider whether there may be similar opportunities in the ACT for ACT Health to develop its capacity to deliver innovation related to value-based care.

There is enthusiasm among many staff of ACT health care services to make changes to improve the care they provide – often to bring practice in line with evidence. Harnessing and encouraging this should be a key responsibility for all managers. Providing positive reinforcement and continuous feedback loops so people can see the results of the changes made will encourage and embed a culture of safety and quality improvement. Good practices, such as checking information if a practitioner is unsure, and then calling back a patient to give them the best information, should be encouraged, talked about and used.

### v. Leverage partnerships with NGOs

Collaborative practice with non-government agencies (NGOs) and community-based services will also support ACT Health to innovate in response to sustainability challenges. HCCA encourages ACT Health to consider the benefits of longer contracts (for example, of five years' duration) with key community partners, in recognition of the stability and certainty that this provides community-based services to address work priorities. These benefits are recognised in other Australian jurisdictions. For example, the Northern Territory Government recognises that longer-term contracts with non-government agencies allows "staff retention, development of expertise and often, for Government, better value for money [as well as]… a reduction in red tape for both the… Government and the service provider and allows for an improved relationship between both sectors". [73]

HCCA also encourages ACT Health to consider which health services currently provided by the ACT Government could be provided by appropriately skilled, experienced NGOs under appropriate regulatory and contractual arrangements. In some circumstances, provision of services by not-for-profit NGOs can deliver the advantages of efficient pricing for high quality and safe health services, and well-established relationships with members of ACT communities who access and/or require these services.

### vi. Develop an ACT-wide climate change adaptation and mitigation plan

HCCA recognises that climate change poses significant threats to human health.[74] HCCA is aware that ACT Health's Sustainability Strategy (2015-2020) "is designed to assist ACT Health to meet the impact and challenges of climate change" and understands that the Strategy takes in infrastructure, and a carbon emissions reductions plan.[75] Given the significant carbon emissions generated by Australian hospitals, HCCA welcomes efforts to support recycling, re-use and reduction in resource use in ACT hospitals. TOR A *(Section vii.)* provided some specific suggestions in relation to potential opportunities to improve the management of clinical waste. Broadly, HCCA would welcome collaborative work to develop an ACT-wide climate change mitigation and adaptation strategy that addresses the risks to human health posed by climate change, including that it will further exacerbate existing health inequalities.[76]

### vii. Address non-beneficial end of life care

Improvements in the way end of life care is delivered in ACT hospitals could not only deliver more consumer-centred care but also have the secondary effect of reducing the cost of care and pressure on intensive care units. Ken Hillman, Professor of Intensive Care at the University of NSW, has convincingly argued what many consumers and carers already knew: that too many people receive futile and unwanted acute care in hospital at the end of their lives.[77] When asked, most people in Australia say they would prefer to die at home – yet approximately 70 per cent of us will die in an acute hospital setting.[78] Much of the care people receive in intensive care settings in the final weeks and days of life is futile: that is, it cannot reverse the progression of illness. It is also frequently non-beneficial, in that it "impairs the quality of remaining life".[79] For example, non-beneficial treatment at the end of life can include major

medical interventions such as being ventilated, tube-fed, undergoing emergency surgical procedures, and blood transfusions, dialysis, beginning or continuing chemotherapy and continuing with radiotherapy "in the last few days of life".[80] It is also distressing to many people to spend the end of their life in the institutional and highly medicalised setting of an intensive care unit or other hospital setting, rather than in familiar or home-like surrounds.

Several factors contribute to this problem. These include the fundamental curative orientation of medical professionals, the discomfort that many medical professionals have in discussing death and dying, a "lack of doctors who can stand back and recognise patients who are at the end of their lives",[81] and some consumers' hope and expectation that medical professionals can restore a dying family member to health.[82] In many instances, the tragedy of this situation is compounded because the consumer has no Advanced Care Plan in place making it impossible for their treating clinicians or family members to know what their wishes for end of life care are.

HCCA encourages ACT Health continue to support people to complete Advanced Care Plans, both during a hospital admission and in partnership with community-based organisations, through the Respecting Patient Choices program. HCCA also encourages ACT Health and ACT hospitals to ensure that all clinical staff working in areas where they are likely to come into contact with consumers who are either diagnosed with a life-limiting condition or nearing the end of their life (for example intensive care units, general medical wards, geriatric and rehabilitation areas) are trained and supported to undertake shared-decision making to ensure that consumers are equal partners in setting the goals of their care and the treatment plan. HCCA also encourages ACT Health to continue to promote home-based and community-based palliative care as alternatives to hospital admission for people with life-limiting health conditions.

# 5. Concluding Remarks

HCCA looks forward to seeing how our feedback and comments shape the ongoing work into the future sustainability of health funding in the ACT. Please do not hesitate to contact us if you wish to discuss our submission further. We would be happy to clarify any aspect of our response.

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