

Making a noise:

40 years of consumer health advocacy in the ACT

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MAKING A NOISE:
40 years of consumer health
advocacy in the ACT



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Never doubt that a small group of thoughtful, committed citizens can change the world; indeed, it’s the only thing that ever has.

Margaret Mead

Foreword

The Health Care Consumers’ Association (HCCA) has been a voice for consumers in the ACT on local health issues for four decades, working to create opportunities for health care consumers to participate in health policy development, service planning and decision making.

This history tells us how HCCA began. It tells of some of the challenges that HCCA has faced at different times, and highlights just some of HCCA’s significant achievements. Most importantly, this history reflects on the work and experiences of HCCA members and consumer representatives, those who have supported HCCA activities, and other organisations who worked with HCCA on particular issues. For every story told in this history, there are many more people who contributed to the ongoing task of ensuring that our health system is consumer-centred and delivers safe and high-quality care.

This hasn’t been without its struggles. The idea that consumers have a valuable role in shaping health care has not always been readily accepted by the medical profession, government or policy makers. It is the passion and tenacity of health consumers that has enabled the consumer voice to take its place. Many individuals over many years have committed their time, experience, and expertise in the shared conviction that health consumers have a right and a responsibility to participate in decisions that affect them.

HCCA shares its 40th birthday year with the Declaration of Alma-Ata, which was adopted at the International Conference on Primary Health Care on 12 September 1978. The Declaration called for urgent action by all countries to protect and promote the health of people across the world. It emphasized community and individual participation in the planning and control of health care.

For 40 years, HCCA has promoted the principle of consumer participation in health care and contributed to significant change in the ACT health system. HCCA works to achieve better health care outcomes and will continue to do so into the future.

Dr Sue Andrews
HCCA President
October 2018

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Contents

Foreword	3	Conclusion:	
Acknowledgements	4	The HCCA family	45
Chapter 1: Challenging the status quo		Select bibliography	51
Chapter 2: Getting organised	6	Appendix 1: Chronology	52
Chapter 3: A ‘critical friend’	10	Appendix 2: Health Care Consumers’ Association Executive Committees	56
Chapter 4: Walking a middle path	19	Appendix 3: Health Care Consumers’ Association of the ACT — Patients’ Bill of Rights and Responsibilities (1980)	62
Chapter 5: Complaints are like gold	28	Image captions	67
Chapter 6: ‘First, do no harm’	33		
	39		

Chapter 1: Challenging the status quo

The ACT Health Care Consumers' Association (HCCA) was a creation of its time — 1970s Australia. It came into being under the stewardship of a small group of consumers in Canberra who believed that collective action could influence positive change in the ACT health system. It took courage to speak up in a sometimes hostile, sometimes dismissive environment. But the time was also right. It was an era of strong political mobilisation — both nationally and internationally — generating increasing consumer and community activism.

In Australia, the early 1970s marked a short but momentous era of social change under the leadership of the Whitlam Labor Government, which was swept into power amid this swell of community activism. Whitlam's campaign mantra, 'it's time', mirrored and fuelled the mood of those agitating for change. In the 1071 days of office (5 December 1972 to 11 November 1975), a range of reforms were enacted that sought to address structural inequality and acknowledge the rights of marginalised groups — perhaps most notably, Aboriginal and Torres Strait Islander Peoples.

The Whitlam Government viewed health care as a right — the right of all Australians to have access to adequate health care regardless of their financial means. From this core principle flowed an increased expenditure on health, including on school dental services, Indigenous health and community health programs, and the introduction of a national universal health insurance system, Medibank.

The consumer movement

It was back on 15 March 1962 on the first World Consumer Rights Day that United States of America President, John F Kennedy, gave voice to the guiding principles of the consumer movement, outlining four fundamental consumer rights in a speech to Congress: the right to safety, the right to be informed, the right to choose, and the right to be heard.¹

In Australia, Ruby Hutchison — the first woman to be elected to the Western Australian Legislative Council (1954) and widowed mother of seven children — founded the Australian Consumers' Association (now known as CHOICE). The year was 1959. Ruby Hutchison, with a degree of diffidence, said:

*I am only a housewife, but I know how the housewives of [WA] are being robbed. I am not too learned in legal phraseology, but I would say that unfair trading practices would mean the taking of profits by big concerns up to a saturation point.*²

Locally, a group of concerned citizens joined forces to form Canberra Consumers, with the first edition of its journal released in May 1963. Each edition of the journal compared the price and quality of different products and services, which were voluntarily assessed by members of the Executive.

The consumer movement was closely entwined with social and civil rights movements — feminist, anti-racism and environment movements and self-help and support groups — which similarly sought recognition of the interests and rights of marginalised groups.³

In a health context, the women's movement was particularly powerful. In the late 1960s, feminist women began to focus on women's control over their own bodies, particularly with regard to reproductive rights. Access to birth control, de-medicalisation of pregnancy and birthing, and access to safe and legal abortion were all part of a movement that challenged the medical model of 'illness care' — a model at odds with the World Health Organisation (WHO) 1946 model of health care and its focus on physical, mental and social well-being.⁴ In the mid-1970s, a number of Women's Health Centres were established in Australia that promoted a 'self-help' approach to health care in which women were encouraged to learn more about their bodies and advocate for their health care needs. "Partnership with the consumer was the philosophy espoused".⁵

It was a time when people felt empowered to speak: "engaging in civil society was legitimised".⁶

Challenging the status quo

While the broader political context enabled community and consumer activism to thrive in the 1970s, this did not mean it was easy for those who spoke up for change. Change was met with resistance and, in the context of the health care system, resistance was fierce. The medical profession was robustly represented by its professional bodies and steeped in a tradition that saw itself as largely independent from state control. Other vested interests came into play — the pharmaceutical industry and health insurance, for example. Together, the medical profession and aligned groups ran well-funded campaigns that dominated the way policy was shaped.

As former health policy and planning expert — later writer — Sidney Sax was to observe in the mid-1980s, "powerful vested interests dominate the policy-making process".⁷ This observation remains as true in 2018 as it was in 1984.

Against this backdrop of power and control, the risks to those who spoke out were very real. For many, their involvement with the health consumer movement grew out of personal experiences — stories that were often of damage and depersonalisation in a medical system that at times failed to stand by its own maxim: 'first do no harm'.

Health advocacy gave those consumers a way to channel their hurt, turning their experiences into an evidence base that could inform improvements for others.

Janne Graham⁸

Janne recalled that when she first joined the health consumer movement in the late 1970s she was ready for a good stoush — with the professions, with industry, with government. She had been damaged through failures in the health system; physically and emotionally.

As a wheelchair user, Janne was facing daily barriers to access and understanding. The more she became involved in the consumer movement, the more she saw her experience as only one of many which were pointers to the need for systemic change. Janne realised her anger had to be directed strategically.

Janne’s confidence grew slowly. In 1981 she was cured, and over time her mobility improved until she no longer needed a wheelchair. Janne’s emotional recovery was aided by the strength she drew from meeting other consumers and sharing stories.

Janne was a driving force of HCCA in its early years and since then she has continued to bring new members into the fold and to mentor them. She first served on the Executive Committee in 1983–84, and was later President from 1994–95 to 1997–98.

In 1989, Janne was elected as Chair of the Consumers Health Forum from where she influenced health policy at a national level.

In 1996, Janne was awarded membership of the Order of Australia for services to the consumer movement and the National Health and Medical Research Council (NHMRC).

Janne remains an active and influential representative of health consumers and a deeply respected member of HCCA.

At times however, advocacy came at great personal cost. Outspoken consumers were derided or ignored, sometimes repeating the tone of a past trauma. In the case of women, protest was all too readily written off as hysteria.

At a political level, the interests of medicos and industry held enormous sway. The Australian Labor Party’s attempts in the 1940s to introduce various national health schemes fuelled by the “vision of comprehensive health services available free of charge to all citizens” had limited success. For the medical profession, professional freedom including control over medical/health policy, fee for service remuneration and the “sanctity of the doctor-patient relationship”, were off limits.⁹

Fast forward to 1974, when the Labor Government successfully introduced Medibank, a national health system based on universal health insurance. This change was fiercely opposed by the majority of the medical profession and the Government opposition at the time, and proved to be a painful journey of negotiation and stand-offs. Soon after the Labor Government lost office in November 1975, the incoming Government set up the Medibank Review Committee. Medibank would be dismantled over the next six years.¹⁰

Not all medical professionals supported the dominant medical view, however. A small group of doctors, supportive of the Whitlam Government’s directions in the early 1970s, formed the Doctors Reform Society, which advocated for the concept of “shared decision-making with the patient”.¹¹ The Doctors Reform Society (DRS), which started in Victoria in 1973 and spread to NSW and the ACT in 1974, was a small but influential group which courted both Government and media and stood alongside health consumer advocates to champion their interests.

While the Australian Capital Territory was still under the authority of the Federal Government in the 1970s, local agitation for change continued to grow. Both the ACT division of the Doctors Reform Society, Canberra Consumers, and the soon to be formed Health Care Consumers’ Association, were ready to fight for the rights of ACT residents at the local service level as well as on the broader national policy stage.

A ‘common old housewife’

Canberra resident, self-described ‘common old housewife’ and health consumer advocate, Dawn Chamberlain, was one of the founding members of HCCA. According to those who remember her, Dawn was a passionate and tireless advocate who strongly believed that people should have a say in decisions that affected them.

Like Ruby Hutchison before her, Dawn Chamberlain joined a growing number of ‘common old housewives’ taking on uncommon challenges for their families and communities and forging social change.

Prior to HCCA becoming an official entity in 1978, Dawn was known for her health consumer campaigning. In early 1976, a review of Medibank, the national health insurance scheme introduced by the Labor Government in 1974, was underway.

The principal argument at stake was the merit or otherwise of Government providing health services through salaried medical professionals, delivering services out of community health centres. The Australian Medical Association and the Royal Australian College of General Practitioners lobbied fiercely against such Government funded services. In response, Dawn Chamberlain initiated her own campaign, interviewing ACT locals and seeking their support for a petition to Government.

On 25 April 1976, Dawn was interviewed by local radio program, Canberra Insight, on her campaign activities. Reflecting on the views of the public, she said:

[T]he general attitude is look we pay our taxes, public health care is a public right and we should get it as we want it and have some say in what we get.¹²

Dawn had managed to get over 450 signatures on a petition delivered to the then Commonwealth Health Minister, Mr Ralph Hunt, outlining health care consumers’ wish for choice — choice of both salaried medical services and private medical services. This was no small feat. As Dawn explained in her radio interview, many Canberra locals — particularly those employed in the public service — were reluctant to put their names on a public petition fearing it could negatively affect their careers.

While ultimately Medibank would be incrementally wound back (and then reintroduced as Medicare in later years), Dawn’s campaign was a clear and courageous challenge to the status quo and a precursor of what was to come.

Chapter 2: Getting organised

I am very concerned that the AMA, the GP Society, Insurance Companies, in fact anybody that's organised can state to the Government...their point of view. But patients are extremely isolated and not organised and they are not in a position to express their satisfaction or dis-satisfaction...

Dawn Chamberlain¹³

The momentum to get 'organised' was steadily building. On 26 October 1976 a small group of people, an offshoot of the Canberra Consumers Association, as well as people living with chronic or undiagnosed health conditions, and disability activists, held a meeting in the local Griffin Centre to discuss the establishment of a health consumers organisation.

Less than a month later – at their second meeting – an Executive Committee was appointed and a working party established. Plans to draft a constitution were already underway. Those present agreed that the organisation would be named the 'Health Services Consumers' Association of the ACT'. Records from the second meeting show that a Consumer Feedback Group was already in place. The focus of this Group was community education, surveying consumers' needs, and encouraging participation of consumers in health care – priorities that to this day continue to be core activities. The Health Services Consumers' Association (HSCA) would provide a formal holding space for these activities.

Dawn Chamberlain, inaugural HSCA President Eve (Eva) Holmes, and others recognized what Sidney Sax would later put in print: the political market "favours interest groups that are cohesive, soundly organised, well-informed and wealthy".¹⁴ It was time to get organised and introduce another voice into the political market.

Guest speaker, Dr Erica Bates, President of Medical Consumers' Association of NSW, addressed the second meeting of HSCA and answered questions on her experience with health consumers in NSW. This sharing of knowledge and cross-fertilisation of consumer groups was to continue in the ensuing years, with guest speakers from consumer, community and government health agencies building the knowledge of the HCCA (as it came to be called). In turn, HCCA shared its expertise and insight with other consumer and community-based groups.

It was this mutual support that helped sustain consumer-based organisations. Locally, for example, HCCA sponsored a meeting on the crisis in mental Health Services in the ACT in July 1984. Subsequently, it supported the establishment of the ACT Mental Health Organisation,¹⁵ and Self-Help Groups United Together (SHOUT), which continues to provide services to support self-help groups in the ACT region.

With more than 20 years of experience under its belt, in the 2000s HCCA was able to support emerging health care consumer organisations in other jurisdictions. The Health Consumers Alliance of SA was established in 2002, Health Consumers Queensland in 2008 (first as a Ministerial Advisory Committee, becoming an independent body in 2013), and Health Consumers NSW in 2010. The relationships between these organisations remain strong and supportive.

In Victoria, the Health Issues Centre has enabled a consumer voice in health since 1983. The Health Issues Centre was initially established under the auspice of the Victorian Council of Social Services. In 1985 the Health Issues Centre secured funding from philanthropic sources enabling it to operate as an independent entity.

A slow journey to incorporation

The relative speed with which the newly formed organisation drafted its constitution – a matter of just a few months – was not to be matched in kind by the incumbent registrar and it would take another 18 months before incorporation was finally achieved in October 1978. A particular sticking point was the proposed name – Health Services Consumers' Association – which was judged unacceptable by the registrar due to its 'governmental connotations'. Other options were floated – 'Patient Power', 'Health Services Citizens Association', 'Citizens Health Association of the Capital Territory' and 'Medical Consumers' Association' for example. The last of these monikers held its own challenges, with the then (Commonwealth) Department of Business and Consumer Affairs expressing concern about the term 'consumer'. Because the word 'consumer' formed part of the Department's name, public officials thought the general public might be confused.

In the end, the term 'consumers' did make its way into the organisation's name and Health Care Consumers' Association of the ACT (HCCA) made the final cut. The idea of the health consumer has come to hold a deeply felt significance for HCCA members. HCCA has its origins in the shift to a new form of health interaction that saw the patient not as a passive body to be treated by an all-knowing medical authority, but as a consumer and whole person with the right to be fully informed about health and health care options, an active agent able to judge for themselves what is in their best interests. This way of reconceptualising the patient was embraced by HCCA when they used the term health care consumer in their title.

What's in a name? Sue Andrews reflects

HCCA is a consumer organisation advocating for consumer interests in the health system. Sometimes in our work we may use other terms such as patient or carer to help communication around an idea. We always value individual patient experience as authoritative experiential knowledge which contributes to broader consumer perspectives on the health care system. The term consumer may be contested but at the moment it has specific meanings that work for us and are mostly accepted and understood in the broader health space.

In 1978, Professor John McMillan became involved with HCCA. Later to hold office as the Commonwealth Ombudsman (2003–2010) as well as several other senior government appointments, McMillan was then a locally based legal practitioner deeply involved in the public interest movement and a committed advocate of freedom of information. McMillan had spent time studying and working in the United States with different public interest organisations, including groups spearheaded by the now infamous American political activist, author, lecturer, and attorney, Ralph Nader. Ralph Nader has been influential since the mid-1960s, with a motto 'There can be no daily democracy without daily citizenship'. As a consumer advocate, Nader established several public interest and consumer rights organisations.

It was McMillan’s skills in activism and advocacy and, critically, his legal skills, that helped get HCCA’s bid for incorporation over the line. On 13 October 1978, the Health Care Consumers’ Association of the ACT achieved incorporation, in turn affording legal protections to its Executive Committee and providing the organisation with formal credibility in government and public eyes. HCCA was officially born.

President Eve Holmes recorded her frustration and relief:

*The last two years have been a long, weary struggle to become incorporated. It is a great pity that so much energy had to be diverted to what seemed so simple a task. ... Now that we have achieved incorporation we can turn our attention to the real task: getting a fairer deal for the patient.*¹⁶

A broader community of concerned citizens

While they were a minority of the medical profession, the Doctors Reform Society (DRS) was an active and informed group, and supportive of the directions of HCCA, with its mission squarely focused on patient needs. Aligning with health consumers was a bold step for medical professionals, and the DRS’ call for reform questioned the ethical basis of the medical profession:

*DRS came about because there was a crying need for an organisation of doctors which could put patients before politics.*¹⁷

The idea of putting patients before politics and consumers at the heart of health care was to be a constant thread through the work of HCCA. As HCCA President (2012–13 to 2017–18) Sue Andrews commented, “we remain a consistent identifier of the purpose of health care services: the consumer”¹⁸

It was not just doctors who struggled with the culture of the health system at that time. HCCA’s membership was boosted by disaffected allied health workers who were working out of community centres and saw hospitals swallowing up a lot of resources. Health workers too, rallied against the dominance of the hospital culture and the medical model in which the work they did, and ultimately health care consumers, got a raw deal.

While people employed by the ACT Health system were, and remain, limited in the positions they can hold on the Executive Committee of HCCA, they were welcomed into its membership, and they brought valuable experience, expertise and perspectives about how to improve the health care journey for consumers.

Wendy Gray

Wendy Gray was the first Community Dietitian in Canberra (appointed in 1977) and the third paid member of HCCA. Raised in small Country Towns in NSW (Crookwell and Tumut), Wendy recalled that her parents were both deeply involved in community work, “you cared for the people around you”. She later studied Pharmacology under the tutelage of Professor Roland Thorp at the University of Sydney. Professor Thorp and his wife Dorothy were involved in the establishment of the Australian Consumers’ Association and Wendy found herself as a student testing various pharmacological and food products. Her early family life, her introduction to the consumers’ movement as a student, and her own work as a health professional in the Canberra community, made the HCCA a natural home for Wendy.

Making a noise

There was really no big picture. The object was to make a noise. The object was to be heard. And I think that was a realistic object. The object was to make people slow down before they made decisions and not to make assumptions.

John McMillan¹⁹

Putting forward the interests of a previously overlooked group — the consumers of health care services — was front and centre of HCCA’s mission. In a space dominated by the medical fraternity and Government, one of the primary goals of HCCA was to be heard.

As a small group of volunteers, long-term planning was not a realistic option. Activities were relatively piecemeal — and often discussed in members’ homes. Decisions on whether to advocate on a matter were necessarily based on the knowledge and capacity of members. In early 1977, for example, the Executive Committee agreed it “would not initiate public comment” on the ‘abortion issue’ as an HCCA policy on the issue had not yet been developed.

At the same time, the fledgling organisation worked hard to establish special interest groups precisely so that policy positions on different health issues could be developed and consumers adequately supported. These interest groups also served to put people with similar concerns in touch with each other, for example, parents of children in hospital, people living with chronic pain, and people with cancer.

HCCA members or members of the public would raise concerns with HCCA and the HCCA would act if and when it could. Numerous letters on issues were sent to relevant Federal Government Ministers, and followed up if responses were not forthcoming. Letters to the Editor were frequently published in the Canberra Times.

Submissions were made to government inquiries.²⁰

At least they know we exist

In 1980, HCCA received a small grant of \$450 from the Capital Territory Health Commission (CTHC) to undertake a survey on children in hospital as an International Year of the Child Project. HCCA surveyed over 550 parents whose children were admitted to Royal Canberra and Woden Valley hospitals during a three-month period. HCCA published its report in September 1981, outlining several recommendations to improve the experiences of children and their parents in the hospital system. Recommendations included, for example, that admission procedures should solicit children's preferences and routines and that more provision should be made for parents to accompany a child until he/she is anaesthetised and to be present on the child's recovery. Recommendations were promoted through media channels — predominantly print media.

Any parent who has supported a child through surgery in the ACT in recent years will know that accompanying a child pre-anaesthetic and in recovery is now standard.

The \$450 grant was to later provoke a question by then Liberal member, Mr Bungey, to the Minister in Parliament: "What is the Health Care Consumers Association and what qualified it for a grant of \$450 from the CTHC in 1979–80?" Commentating on this exchange, HCCA President John McMillan drily remarked, "At least they know we exist".²¹



HCCA certainly did *make a noise*. It became a focal point for people with concerns about their experiences of poor health care. It campaigned on specific issues, such as cuts to children's hospital services. However, HCCA also projected itself as a unified group with a common set of concerns through the production of a Patient Bill of Rights and Responsibilities (see Appendix 3). This was part of an international movement inspired by the Universal Declaration of Human Rights to develop the idea of patient rights being based on the principles of human dignity and the equality of all human beings. The 1978 Declaration of Alma-Ata gave weight to this exercise by reaffirming that health is a fundamental human right.²²

To this day, HCCA's underpinning philosophy reflects those principles as stated in the Declaration of Alma-Ata — a belief in the human rights of all health care consumers. The passion and commitment of its members kept the organisation focused and moving forward despite the resource constraints that members laboured under.

A rights-based agenda

The health consumer movement in the latter half of the twentieth century was deeply based in an interest in rights, and the belief that through organised, collective activity, the rights of individuals could be realised. In part, this activity took the form of health education and literacy. It was also about creating a common understanding of what those rights should be.

HCCA took its lead from the Medical Consumers' Association of NSW, which in the mid-1970s was developing a Patient Bill of Rights and Responsibilities for health consumers in NSW. In 1978 HCCA sought legal advice on the applicability of the draft NSW Bill of Rights to the ACT context. Dr Erica Bates, President of the Medical Consumers' Association of NSW, had presented the document to HCCA members to support the organisation's plan to develop a similar Bill in the ACT. Dr Bates' travel expenses to attend HCCA meeting were covered by the Doctors Reform Society, showing the collegiality and support that helped sustain HCCA and similar organisations at the time.

The ACT Patient Bill of Rights was publicly circulated in 1980. The Australian Federation of Consumer Organisations (later to be called the Consumers Federation of Australia), the peak body for state-based and specialised consumer organisations founded in 1974, provided a modest amount of financial support so that HCCA could distribute the Bill to member organisations.

In 1981, under an initiative devised by Dr Valerie Brown, Director of Canberra College of Advanced Education and HCCA member, health education students from the College embarked on an education project with HCCA. Under the supervision of the College and an HCCA mentor, the students prepared a brochure for consumers, 'Your Guide to More effective Health Care', which was based on the ACT Patient Bill of Rights.

The issue of rights continued to drive HCCA and other consumer organisations, while government interest in consumer rights waxed and waned. In the early 1990s, for example, ACT Labor member, Rosemary Follett, made a call to her colleagues to introduce participatory Government:

*There are two principles from which we should begin to rebuild the democratic system in the ACT, that people have a right to know and that they have a right to make decisions that affect them.*²³

The idea that people have a right to be involved in the decisions that affect them is neatly captured in the catchphrase "nothing about us without us",²⁴ which was adopted by disability rights activists in the 1990s and has been promulgated by other activist and consumer groups ever since.

The Consumers Health Forum (CHF)²⁵ — the national peak body for health care consumers — embarked on a charter of rights when it was formed in 1987. A charter of rights was subsequently developed under the auspices of the Australian Commission on Safety and Quality in Health Care. The Australian Charter of Health Care rights was endorsed by Australian Health Ministers in July 2008, for use across the country. In December 2009, HCCA partnered with the ACT Government to launch the Australian Charter of Health Care Rights in the ACT. Development of the Charter was driven by consumers and crafted by all stakeholders, including clinicians and governments.

Janne Graham recalls that at various times over the years ACT Health endeavoured to respond to the consumer expectation for recognition of consumer rights, but for various reasons enthusiasm faded. The ACT launch of the Australian Charter of Health Care Rights was viewed by HCCA as both a practical and symbolic recognition by the ACT Government of a legitimate health consumer voice.

A two-way street

HCCA did need to make a lot of noise in the early days to challenge the status quo. However, even in the time before incorporation, the relationship between HCCA and government was not a monologue of advocacy and protest. In 1977, for example, the Capital Territory Health Commission invited then HSCA members to join a committee to investigate public complaints about the level of noise in the ACT’s hospitals.²⁶ Two HSCA members joined the Committee, which subsequently made a number of recommendations to improve noise levels.

In the following years, the relationship between HCCA and government would evolve, albeit with peaks and troughs, and become a true dialogue.

Health promotion

As well as advocating on single issues and providing one-off support to individual consumers battling the health system, in its early years HCCA also focused much of its energy on health promotion. It was one thing to advocate for consumer rights, but HCCA realised that without education and information many consumers would remain unaware that these rights existed.

HCCA could see that a number of patients were in the dark when it came to informed consent and informed choice. Health services were paternalistic, and women in particular were not treated as health care partners capable of making decisions about managing their health and that of their families.

HCCA, therefore, worked hard to equip health care consumers with the resources they needed. This involved speaking with local community groups and making information available wherever possible. Janne Graham recalls that in the early days HCCA developed a ‘speakers kit’ and visited church and community groups talking about health issues from the perspectives of users. Speakers showed a slide set of illustrations, which promoted active consumer engagement in general practice consultations.

This benign activity was met with a mixed reception. “Many thought we should just trust our doctor”, Janne said. The reverence felt for the medical profession was part and parcel of the narrative that the medical profession perpetuated about itself. Within this authoritarian paradigm there was limited space for consumer participation or agency.

Janne credits Dawn Chamberlain’s encouragement of parents of children in hospital to form a support group, and the focus on the needs of children in hospital, as a key driver for broader consumer engagement in health issues.

Audrey Guy reflects

Health care in the ACT before and after the establishment of HCCA

I arrived in Canberra in 1976, before the establishment of the consumers association, with my husband and my 18-month-old son. Not long after we arrived my son had an adverse reaction to the measles vaccination. At the time, visiting hours on the children’s ward was 2–4 pm. I complained to the doctor, who said I could visit whenever I wanted, although this was not accepted by the nurses who gave the impression that we (the other mothers and I) were interrupting their work. The first time I visited my son he had no toys, bedding or clothing other than his nappy, in his cot. He held out his dummy, his only possession, to me.

A group of us mothers in the same situation determined to improve things. We got a Canberra company to donate camp beds so that we could put them up beside the children’s beds and stay overnight. In an interview with the Canberra Times, the matron — who was the all-powerful person at the hospital at the time — said we would be much better off having a good night’s sleep in our own beds. We muttered amongst ourselves about how little knowledge she had of mothering.

Fast forward to February 2017. My granddaughter was admitted to the children’s ward in the same hospital. She had her own room, with a proper bed for her mother to sleep in beside her and a view looking straight on to the Helipad, so the children could watch the activities of the helicopter. In the two days she was there she was invited to two parties organized by charity groups working in the hospital. Change may happen slowly, but it does happen if you work for it.

*People were prepared to be active on behalf of their children.
It took a lot longer for people to be active on behalf of themselves!*

HCCA continued to spread the word that, “you and your family are entitled to be treated with care, compassion and respect, regardless of your social status, source of payment, age, sex, religion or political beliefs”. HCCA continued to look into matters of concern for parts of the community — for example, services for aged persons in the ACT. And HCCA continued to educate, to inform and to advocate.



Health promotion — an ongoing priority

Health promotion — now most strongly reflected in HCCA's health literacy program — remains a priority for HCCA and is a focus through all of the organisation's activities including in its Consumer Representative Program, policy work, communications, and work of its Multicultural Liaison Officer.

HCCA ran a consumer-led project, *Health Literacy for All* (from June 2011 to June 2014) which was funded by a Health Promotion grant from the ACT Government. Through this program HCCA promoted consumer participation in the health system by providing opportunities for consumers to improve their knowledge of support, community and health services. The goal of this project was to increase consumers' capacity for self-reliance — that is, their capacity to advocate for themselves and their families in a range of health contexts.

With over a quarter of the Canberra population born overseas and over twenty percent of the population speaking a language other than English at home, working with culturally and linguistically diverse (CALD) communities to improve health literacy is a priority for HCCA.

In 2012, and with an increasing diversity of CALD communities in the ACT, HCCA made a case to the ACT Government for additional funding for a dedicated Multicultural Liaison Officer. The bid was successful, and the role is now built into HCCA's tri-annual funding cycle.

Funding for this position was a big win for HCCA, which could see that its work was not reaching significant parts of the Canberra community — people who were particularly vulnerable because they were new to English as well as to the ACT health system.

As Yelin Hung, HCCA's Multicultural Liaison Officer explained, “when you first arrive in any new city, in any country, you don't know how it works”. Yelin spoke from personal experience, having arrived in Canberra from Venezuela 21 years ago. “When I first arrived I didn't have any information ... I only knew to go to emergency and that was it. I felt lost!”

Lack of information about what health services are available and how the system works is something Yelin sees all the time in her work. To try and bridge this gap, HCCA runs information sessions for community groups about Navigating the Health System, Understanding Medicare, After-Hours Primary Health Care Options and Advance Health Care Planning. The sessions also collect comments, concerns and different issues raised within these groups when accessing health services in the ACT. These are fed back to the ACT Health Directorate so that improvements can be made.

Health literacy remains an integral part of HCCA's work building the capacity of individuals and communities.

Chapter 3: A ‘critical friend’

For many people within health care systems, turning to the community for guidance simply follows from a belief in people's right to have a say in the way their health care is shaped and offered ... Ideological commitments can also blend with more practical considerations. Working with and through communities may be the only effective way of achieving many health, service, and research goals.

Hilda Bastian²⁷

HCCA is driven not only by the principle that health care consumers have a right to have a say in the way their health care is shaped and offered, but also the principle that all consumers have a right to safe, quality health care regardless of their circumstances. Consumer input to health services design and decision-making is one way of ensuring that health care adequately meets the needs of those who use the services. To put this another way, involving consumers in health care design and decision-making not only ensures better health outcomes, it also makes good business sense.

Consumer involvement, done well, adds “demonstrated value to health decision-making”.²⁸ This includes better design of new initiatives, improvements to existing services and the quality of care provided, and improved communication between health professionals and patients.

Focusing on the value that consumer voices can bring to health care services is critical. Understanding the outcomes of consumer involvement can make the difference between tokenistic inclusion and meaningful participation. In fact, HCCA was inspired in 1999 to run a seminar themed, ‘Not a Token Rep’.

Often it is the personal experience of the consumer that makes the difference. For example, Anna Saxon, one of HCCA's members and former consumer representative, who is living with a visual impairment, offered practical design advice to ACT Health Services that met the requirements for people with visual impairment.

*Usually what we have to say is quite obvious, such as me saying that I can't read the signs in emergency departments, but they [clinicians and policy makers] don't think of it because they don't need to.*²⁹

In this instance, the consumer as expert about her own experience added value and insight into the design of health care services. In the same way that a medical doctor might become the spokesperson for the effect of a pharmaceutical drug on the body, a health care consumer representative can present a kind of social knowledge of how the health system affects users.

HCCA has worked to bring a representative voice to health services policy and planning. In this scenario, the consumer representative is expected to understand the health needs and concerns of other consumers and communities and to be able to communicate that in an advocacy forum or as a member of a health department committee. This is a process of democratic strengthening through the participation of previously unheard or marginalised voices.

Consumer representation and advocacy is a complex business; it “involves balancing the rights of individuals with the rights of others and the community’s overall needs.”³⁰ To address this, HCCA developed training for consumer representatives, with an emphasis on moving from the specifics of a particular consumer’s experience, which perhaps motivated their interest in becoming a consumer representative, to taking a broad view of the health system from the health consumer perspective, being able to think through an issue or a strategy in its entirety from a consumer perspective. This does not mean disassociating oneself from one’s own experience of the health system; it means being able to bring one’s own and others’ personal experiences into negotiations on a wide range of issues effectively, without becoming stuck on a personal agenda.

HCCA supports this transformation of individuals into collective representatives not only through training but also by placing consumer representatives into networks. For example, HCCA has convened reference groups on cancer, on the ACT’s first health call centre (Health First) and on the e-health patient record. Ad hoc groups open to all members and sometimes publicly advertised meet on particular issues like rehabilitation and chronic disease.

HCCA’s intention, from the start, has been to balance the role of consumers as individual experts with the role of consumers as representatives. Efforts to represent a collective voice had some early successes. These were either self-initiated (for example, the children in hospital survey) or ad hoc invitations by government to participate (for example, the noise in hospitals investigation). Both were powerful interventions in and of themselves. They were not indicative, however, of a formal or ongoing partnership with government.

In the early to mid-1980s, HCCA’s influence began to grow. The heyday was around the time that preparations for self-government in the ACT were being put in place, involving establishing ACT services as separate from their parent federal departments

Governance changes in the ACT

On 31 May 1983, the recently elected Commonwealth Labor Government’s Health Minister, Dr Neal Blewett, announced the establishment of a Task Force into ACT Health Services. The Task Force was to advise the Minister on appropriate governance for the Capital Territory Health Commission (CTHC) and the best way to enable community and worker representation in its organisational structure. The Task Force was to report within three months.³¹

The CTHC was first established on 1 July 1975. Prior to that, health services in the ACT were administered by the ACT Health Services Offices, which was a branch of the Commonwealth Department of Health. CTHC reported directly to the Commonwealth Health Minister and was consequently afforded greater independence from the Commonwealth bureaucracy and a greater capacity to respond to local needs.

Between 1975 and 1983, the CTHC underwent various permutations under different governments, with control being shifted away from community and back to government. Under the leadership of HCCA President, Dr Valerie Brown, HCCA made a submission to the Task Force into ACT Health Services that recommended that mechanisms be provided for consumer representation and advice at all levels of policy formation, and that an explicit complaints procedure be established for all health service delivery. HCCA consulted with a range of not-for profit organisations and consumers in preparing the submission.

Subsequently — and following the Community Action for Health seminar — HCCA set up its own Task Force to look at communication channels between the community and the CTHC.

In late 1985 the CTHC was replaced by the ACT Health Authority, which was supported by two boards — the Community Health Services Board and the Hospital Services Board. Both boards included community representation.³²

With growing government independence at a local level, it was expected that new government connections with the local community would strengthen.

A turning point for HCCA was a one-day community seminar that HCCA jointly ran with the ACT Council of Social Service (ACTCOSS) on 30 March 1984. The seminar, ‘Community Action for Health’, had the tag-line ‘Health is everyone’s business’, and its aim was to provide an opportunity for all interested in personal health and health in the community to take part in planning for the future. A follow up meeting was held on 15 June 1984. One of the drivers behind the seminar was to facilitate consumer representation on the advisory boards that were proposed as part of the move towards ACT self-government.³³

The seminar — to the astonishment of HCCA — was attended by almost 200 people. Suddenly there was the energy of an unmet need. It was, as Janne Graham recalls, “one of the most exciting times”.³⁴

Attendees were a mix of health care consumers, self-help groups, health care workers, including doctors, interested individuals and policy makers and administrators. Alan Foskett, Chair of the Capital Territory Health Commission (CTHC) provided some opening comments on his paper — ‘Planning Health Services in Canberra’. The paper reiterated the CTHC’s commitment to a plan for health services in the ACT that “emphasises participative planning and consultation”, and outlined potential mechanisms for consumer involvement in planning and managing health services.³⁵

The seminar discussed eight areas of health focus: mothers and babies, children, adolescents, occupational health, unemployment, ageing, personal health, and people with special needs. By the close of the day, an ‘action program’ had been agreed that included a mix of principle-based and practical actions. For example, attendees agreed to put into action eight principles for personal empowerment identified at the seminar, and a working party was established to contribute to a review of geriatric services in the ACT. In the end, a ‘shopping list’ was given to ACT Health.

Janne Graham reflected,

*Without knowing it we were establishing what is now called “buy-in” from the community. Certainly, we had developed an understanding of accountability.*³⁶

These eight areas reflect HCCA’s continuing commitment to understanding ‘health’ in the context of the social determinants of health,³⁷ and the broader WHO definition of health as more than just the absence of illness. Adhering to this understanding of health enables HCCA, as the peak body, to advocate for, and work in partnership with, other community organisations on issues such as climate change and health, employment and socio-economic issues, housing, gender and sexual identity.

Onwards and upwards

Throughout the 1990s consumer participation in health policy and planning grew slowly but steadily. Driven by the passion, experience and energy of its volunteer board and its membership, HCCA won support for consumers to join health policy and planning committees as consumer representatives. By 1997 HCCA had 15 nominees sitting on a range of ACT health decision making bodies and, through Consumers’ Health Forum, another five on national committees.

HCCA member and former President (1998–99 to 2007–08), Russell McGowan, identified the appointment of Michael Moore as ACT Minister of Health and Community Care in 1998³⁸ as a decisive moment in formalising consumer representation on Government committees. Minister Moore established a blueprint for reform called *Setting the Agenda* that included, in part, getting allied health positions freed up from acute services in the hospitals to be available in the community. The Minister’s reform approach was to work with consumers and to have them on the steering groups of individual programs. Government recognised the value and power of the consumer voice.

By the early 2000s, consumer involvement in the formal structures and processes of health policy and services had been normalised. There was consumer representation on several planning, oversight and review committees and representation in a number of areas of clinical practice. By 2012, Katy Gallagher, the then ACT Chief Minister and Minister for Health, was able to say

*Health Care Consumers Association here has always been a very strong organisation, so they’ve always taken part in things like budget processes and community consultation and government — the machinery of government. ... They really are involved in almost everything the Health Directorate does, whether it’s looking at models of care, designing buildings, sitting on the Health Council, sitting on the Local Hospital Network, policy, service delivery ... I think the consumer movement in health is essential because consumers look at things differently ... and it’s enormously powerful to be sitting there talking about patient experience as opposed to clinical outcomes and weighting those equally.*³⁹

An enabler — government financial support

In late 1997, HCCA received its first significant annual government grant. Under the guidance of HCCA Executive Committee Secretary, Sheila Holcombe, an application was submitted to ACT Health, and the bid was successful. HCCA was able to engage its first paid part-time project officer, Prue Borrman (later, Prue Gleeson).

Prior to this, the organisation had achieved extraordinary success due to the goodwill, commitment and expertise of its volunteer Executive Committee. The ACT Health grant enabled HCCA to ramp up its activities and increase its support for consumer representatives. In her newly created role, Prue was able to increase HCCA’s outreach to more consumers and community-based organisations, and to begin to develop training materials for consumer representatives. HCCA’s capacity to bring the voice of consumers to bureaucrats, clinicians and service providers was greatly enhanced.

Then, in 2004–2005, HCCA’s fortunes grew further, marking a pivotal point in the organisation’s ascending trajectory. A successful bid for tri-annual funding from ACT Health meant that HCCA could offer an increased and sustained focus on consumer representation and participation, and increase its contribution to health policy development. The organisation could forward plan.

In 2004, HCCA formally introduced its Consumer Representatives Program, which continues today. The Program recruits, trains and supports health care consumers to participate in health-related committees and other consultative forums in the ACT. The Consumer Representatives Program is one of the longest-running programs of its kind in Australia and has helped to consolidate HCCA’s partnership with ACT Health.

In 2005–06, HCCA entered a Memorandum of Understanding with ACT Health to embed principles of consumer engagement within ACT Health’s Access Improvement Program. The program looked to change the way health services in the ACT were provided by focusing on the patient’s journey through the health care system. HCCA consumer representatives were subsequently involved in each of the patient journey projects⁴⁰ undertaken by the Access Improvement Program. These included, for example, the Canberra Hospital Emergency Department Project, the Mental Health project and the Calvary Hospital Intensive Care project.

Some are more equal than others

In 2001, the ACT Government entered into a social compact with the community sector. The social compact was a statement about the relationship between the two sectors, and outlined principles and responsibilities that underpinned the working relationship. The compact reflected community expectations that government would support democratic citizen participation.

The strength of the compact lay in its bi-partisan support. It was first introduced when Liberal MLA Gary Humphries was Chief Minister and then continued under the Labor Stanhope Government. The compact was reviewed and re-released in 2004 (and again in later years). The Joint Community Government Reference Group was established to advance the working relationship between the ACT Government and the community sector, which continues to this day.

Phillip Gleeson

Phillip was a longstanding member of the Health Care Consumers’ Association of the ACT and served on the Executive Committee from 2000–01 to 2002–03. He made a significant contribution to the shaping of the Social Compact in the ACT.

Phillip was a strong consumer advocate with a great respect for others. He worked alongside Darlene Cox, Pat Daniels, and Anna Saxon on the Feedback Project Consumer Reference Group and introduced a significant consumer perspective into the work of the Disability Reform Group set up to address deficiencies in disability services highlighted in the Gallop report to the Chief Minister, ACT Government, in 2002.

Phillip had a talent for using the stories of people with lived experience to identify system-level issues. He had a way with words and was an extremely thoughtful contributor.

Phillip made a difference to facilities for people with MS in the ACT as well as to the advancement of health care services to consumers generally.

He is remembered with great affection and respect by his friends and colleagues at HCCA.

By 2004–05, when HCCA first received its triannual funding, a range of ACT community organisations across a range of services and roles were receiving funding — Women’s Centre for Health Matters, women’s refuges and other crisis support services, Sexual Health and Family Planning, ACT Council of Social Services, AIDS Action Council and ACT Shelter, for example. Government relied on these services and the advice from peak bodies as an important part of the whole health and community services system.

While consumer representation in government planning and decision making was growing, consumer representatives remained on the back foot in one important area: remuneration and reimbursement. Remuneration and reimbursement of expenses incurred by consumers in their participation activities was uneven across different health areas, and often absent.

In 2004–05, under the leadership of then HCCA President, Russell McGowan, HCCA worked with ACTCOSS to seek recognition and implementation of a system-wide ACT Government policy on reimbursement for consumer representatives on Government committees.

The issue for HCCA was two-fold. First, from a practical perspective, having to carry the cost of out of pocket expenses meant that some otherwise interested health consumers were precluded from participation because they could not afford to be involved. Second, from a symbolic perspective, it suggested an imbalance in the relationship as government members were paid. HCCA argued:

Remuneration levels the playing field and is a way of minimising ‘tokenism’, where consumers are involved only to ‘tick a box’. There is a strongly held perception that advice you pay for is often more valued than that which is provided for free.⁴¹

It took some time for the case to be accepted by Government but in 2007 recognition of the time and expertise that consumer representatives bring to advising Government and contributing to robust, well-rounded decision-making was reflected in an agreed reimbursement package.⁴² On some committees, consumer representatives are paid a sitting fee.

Agreeing to consumer representative reimbursement put consumer representatives on a more equal footing with other committee members, whose membership was a part of paid employment. Consumer representatives were no longer contributing their expertise at a personal financial cost. It was one further, critical step in recognising and valuing consumer representatives as equal members at the table.

Consumer involvement in health infrastructure

In 2009, the ACT Government provided funding to support HCCA to engage consumers and the community in health infrastructure planning and governance as part of a jurisdiction-wide program of health services expansion and redesign. Initially called the Capital Asset Development Program (CADP), it later became known as the Health Infrastructure Program or HIP.

While consumers and communities are involved in health infrastructure projects in other Australian jurisdictions, this is generally focused on the physical design of buildings and, in particular, the design of areas used by patients. What set apart the ACT’s approach from 2009 to 2016 was the degree of involvement that consumers had in strategic decision-making and governance, participating at all levels of decision making.

In most instances HCCA’s involvement in infrastructure projects took place through HCCA-endorsed consumer representatives. In some cases, this meant facilitating appropriate representation from organisations such as the Mental Health Consumer Network and People With Disabilities ACT.

HCCA also talked at length with consumers and communities. What, for instance, should a building delivering cancer services look like, and what shape should be taken by the model of care? What about the then new Community Health Centres planned for Gungahlin and Belconnen?

Gungahlin Community Health Centre

The Gungahlin Community Health Centre opened in September 2012. It incorporated both patient and staff preferences in its design for the reception desk. In the planning of the facility, user groups, which included consumers, had been established in a range of areas including reception, patient flow and Information Technology. Staff on the reception user group had been particularly concerned with safety as the centre ran a needle exchange program, and saw many people with drug and alcohol problems and other health conditions that sometimes lead to unstable behaviour. Whilst violence was rare, when it occurred it was difficult for staff. Reception staff had become concerned following a violent incident the year before planning for the new health centre began. They wanted bars or glass screens adopted by some banks to protect tellers. Consumer representatives were persuasive in putting forward their views that the new health centre needed to have a welcoming reception area that was consumer-friendly. The design adopted was proposed by the architects who were aware of a design solution developed for a Victorian justice service reception area. The reception desk did not have bars or screens, but it was beautifully shaped so that patients remained at arms-length from counter staff while being able to talk comfortably to them.

HCCA, through its network of consumer representatives, members and patient organisations, was able to involve health care consumers with planners and designers.

The presence of consumers to advocate for consumer perspectives, interests and needs can have a big impact on the design of both buildings and care processes. What would a more consumer friendly space feel like? Health care consumers can give feedback and tell personal stories about what features of physical space make them feel welcome.

Between 2009 and 2016, HCCA supported consumer involvement in over twenty CADP and HIP projects — the Mental health Assessment Unit at Canberra Hospital, the Centenary Hospital for Women and Children, Canberra Regional Cancer Centre, and the Nurse-led Walk-In Centres in Tuggeranong and Belconnen, for example.

University of Canberra Hospital

On 16 June 2018 the University of Canberra Hospital (UCH) or Yurwang Mura — Canberra's third public hospital — held an open day to celebrate its completion. Yurwang Mura are Ngunnawal words meaning 'strong pathway'. The name was gifted to the hospital by the United Ngunnawal Elders Council and reflects a pathway towards physical and mental healing that will be provided to people at the hospital.

The first patients were admitted to the hospital in July 2018. UCH is a sub-acute rehabilitation hospital and will ease the pressure on Canberra Hospital and Calvary Hospital, so that they can focus on acute care services such as emergency, intensive care and surgery.



HCCA was an important partner in the decision to construct what was then referred to as University of Canberra Public Hospital, having long advocated for the benefits of a sub-acute facility. As HCCA reasoned, a sub-acute hospital would meet consumer needs as well as offer cost savings to government by providing opportunities for people to heal without the high cost of a long stay in an acute hospital.⁴³

HCCA Health Infrastructure Program Manager, Kerry Snell, noted that the UCH project was where consumers had the biggest impact on patient-centred design. While it was one of the later projects to be delivered under the Health Infrastructure Program, the purpose and role of the hospital was under debate from early on in the former Capital Asset Development Program:

[T]he views we took as health care consumers and as representatives of users of services is that services should be provided in the appropriate place using appropriate clinicians at the appropriate time. ... The deficiency that we kept pointing out was this inability to cope with the sub-acute, the rehabilitation of people who were not ready to go back into the community but did not need to occupy acute care beds.

Consumer Representative to the CADP Redevelopment Committee⁴⁴

HCCA was involved in the UCPH project from its inception through to its final design decisions. The organisation supported consumer representatives on the overarching HIP committees, the UCPH Project Control Group and on User Groups tasked with decision-making in relation to the design of different areas of the new hospital, and the models of care to operate in these areas. In later stages HCCA supported consumer representatives on Operational Commissioning Working Groups. HCCA undertook significant member and community consultation to inform the advice provided to the ACT Government on the planning and design of the new hospital.

Consumer involvement in the UCPH project delivered tangible outcomes, including more natural light, dementia-friendly spaces, openable windows, a higher ratio of single bed rooms, more on-site car parking, better public transport access, and a larger number of accessible car spaces.

During this period, the critical shift that HCCA made was from its role as an external advocate influencing (often powerfully) an issue here or there, to having a seat at the decision-making table — to a partnership between government, consumers and health services.

This partnership has waxed and waned. HCCA President (2008–09 to 2011–12) Adele Stevens explained that as with all partnerships, relationships are critical. HCCA has always held a policy of bi-partisanship engagement.⁴⁵ However, one personality in a position of relative power can influence directions both positively and negatively. At the same time, a shift in Government direction or a restructuring of public services can shift attention inward and away from some stakeholders⁴⁶ — or, conversely, it can widen the space for dialogue.⁴⁷ Sometimes trust takes a knock, and relationships falter.

From the mid to late 2000s, relocation of rehabilitation and aged care services to Village Creek was on the ACT Government agenda. The service was relocated to what had been an old school site in Kambah. A number of people using the service were living with disabilities and dependent on public transport services. The site decision was made without consumer involvement and the advice about the problems for disabled consumers' access to the facility fell on deaf ears. Promises to provide taxi vouchers were not met. Trust was eroded.

HCCA describes its relationship to government as that of a 'critical friend'. It is a relationship of mutual respect but like all relationships, it must be worked at. It is also a relationship in which HCCA plays a dual role — to be both a contributor to health policy and services, as well as an independent observer that holds Government to account to the consumers and communities it serves.

Chapter 4: Walking a middle path

HCCA, like all advocacy bodies, plays a critical role in our system of democratic government. It does this, in part, by supporting elected representatives to understand the health service issues affecting different constituent groups. In many ways, HCCA operates as an intermediary or interpreter between different stakeholders in the health system. Executive Director, Darlene Cox, has reflected that,

One of our greatest strengths is to translate experience of care and experience of the system in policy terms. We understand how the policy people and the administrators work. We understand their processes, we understand the language they use.

As a ‘critical friend’ and an effective advocate, HCCA must be sensitive to the full range of interests at play and understand the drivers and the pressures of government, the bureaucracy, and industry as well as health consumers. Sometimes, as HCCA member Louise Bannister has noted, it involves a bit of give:

You’re walking a middle path. You stay strong to your values and your objectives. At the same time, sometimes you have to compromise to get the outcomes.⁴⁸

The University of Canberra Hospital project was one of many projects in which consumer representatives influenced design decisions. Yet not all consumer-initiated recommendations were adopted. While this was hard for consumer representatives who felt the weight of those decisions deeply, it was better to be at the table than not.

At the same time, HCCA cannot afford to be so embedded in bureaucratic structures that community voices are lost. When the directions of Government collide with the needs and interests of consumer groups, HCCA will up the ante and take dramatic, direct action to authentically represent the consumer voice.

Clare Holland House

The proposed sale of ACT’s hospice, Clare Holland House, in 2009–2010 deeply troubled — and to some extent, divided — the Canberra community.

Clare Holland House is located on the foreshore of Lake Burley Griffin. It is owned by the ACT Government, and the Little Company of Mary Health Care has a contract to deliver palliative care services to the ACT and region.

Clare Holland House became what some described as a ‘bargaining chip’ in the proposed sale of Calvary Public Hospital from the Little Company of Mary Health Care to the ACT Government. The ACT Government proposed to buy Calvary Hospital, which had been owned by the Little Company of Mary Health Care since 1979, and in return sell Clare Holland House to the Little Company of Mary Health Care.

On 1 October 2009, the ACT Minister for Health announced a six-week consultation process on the possible transfer of Calvary Public Hospital to the Government and the sale of the hospice. The Government committed to developing a long term (30-year) contract for the operation of the palliative care facility and the delivery of palliative care services by Clare Holland House on behalf of the Territory. Clare Holland House would continue to operate as a public palliative care service, with conditions stipulated in the agreement that the facility would be used for public palliative care services.

The proposed sale was controversial and HCCA worked extensively with consumers and carer organisations to hear people’s views. Community meetings attracted significant numbers and emotions ran high. While not all were opposed to the proposed sale, a majority voice was clear. The people of ACT did not want Clare Holland House to be sold. The hospice was seen as an integral community asset which provided services without judgment and with great compassion and care. The community wanted Clare Holland House to retain its status and saw no reason to disrupt the existing management arrangement.

HCCA argued that the proposed transfer of ownership of Calvary Hospital to the ACT Government and the sale of Clare Holland House should be treated separately. In particular, the future of Clare Holland House should be considered within an encompassing review of palliative care needs in the ACT. HCCA was also critical of the proposed 30-year contract, which it argued would restrict the ACT Government’s ability to adapt to changing funding and health care service models.

Ordinarily, HCCA’s preferred approach to changes in Government direction is to deliver differing views to the Health Minister and senior public officials behind closed doors, and to try and negotiate an acceptable position without expressing strong disagreement in the public domain. It is a ‘no surprises’ approach that enables all views to be heard and time for reflection and compromise. The Government’s resolve to press forward with the sale of Clare Holland House and the level of community disquiet it raised, called for a different approach.

HCCA was outspoken in delivering the community’s message and under the leadership of then President Adele Stevens came out as a vocal public critic.

Adele Stevens

Adele joined the Executive Committee in 2006 and was the President of HCCA from 2008 to 2012, then Vice President from 2012 to 2014.

Adele has represented HCCA on a number of committees and remains passionate about improving safety and quality in health care, particularly regarding end of life care. Adele represented HCCA on the ACT Palliative Care Clinical Network, Standard 9 Committee — Recognising and Responding to Clinical Deterioration in Acute Health Care and the Goal Setting and End of Life Committee which is a sub-committee of Standard 9. In 2015, she became an Ambassador for palliative care with the national Push for Palliative group.

Adele’s commitment to improving end-of-life care has been driven by both professional and personal experience. It is the memory of her father struggling with dementia in hospital that cemented Adele’s drive for person-centred palliative care services and for end-of-life planning.

Adele’s passion contributed to the development of a range of advanced care planning resources in 2014. These resources were subsequently translated into simplified Chinese, Tagalog, Greek and Spanish and used by HCCA Multicultural Liaison Officer in community information sessions.

In the lead up to the Government's six-week consultation period HCCA Executive Director, Darlene Cox, urged the Government to treat the consultation process seriously. Speaking to ABC News, she said,

*We're not seeing this as a fait accompli. We'll be going out and consulting with our consumer and carer organisations in good faith that the Government will actually be considering the views that our members and networks will be putting forward.*⁴⁹

In the end the Government's deal with the Little Company of Mary Health Care fell through,⁵⁰ and the sale of Clare Holland House was taken off the table. HCCA kept the pressure on and maintained its call for an independent review of palliative care services in the ACT to assess future service needs including workforce demands, home-based palliative care services and Territory-wide integration of services.

The focus on improving access to palliative care has continued since then, with active membership of the ACT Palliative Care Clinical Network and significant involvement in the development of the model of service. HCCA advocated (unsuccessfully) for a palliative care hub to be included in the University of Canberra Hospital and is currently involved in advocacy to establish a dedicated palliative care ward at Canberra Hospital.

A place for the consumer voice

Consumer participation in health policy, design and decision-making is not a linear pathway towards a neat resolution or end point. Like all aspects of democratic decision-making, consumer participation is ongoing. It may be cyclic – for example, the return of the health services purchaser-provider model,⁵¹ or it may be wave-like, mirroring the pattern of changing governments who themselves move between greater and lesser government control and, correspondingly, lesser and greater degrees of consumer participation.

At times governments have struggled with the concept of consumer representation. Back in March 1976, Canberra Consumers included an interview with former Prime Minister, John Howard, in an edition of their journal. At that time, Howard was the Federal Minister for Business and Consumer Affairs, and the consumer movement was still in a stage of relative infancy. Mulling over the role of consumers Minister Howard said, "I agree with the concept that the consumer viewpoint ought to be represented more in Government decisions. But one of the difficulties, of course, is where, to what extent, and really I suppose, how you arrive at selecting somebody who is a representative of a consumer viewpoint..."⁵²

How to ensure meaningful consumer representation is an issue that all consumer organisations grapple with, and Howard's response at the time was, perhaps, surprisingly liberal and genuinely thoughtful. For HCCA, consumer representation is something that must be worked at and supported. Ironically, however, the issue of consumer representation isn't that different – and far less difficult – than trying to represent a political constituency, many of whom have cast a vote for another candidate and, consequently, another party.

HCCA member and former Consumers Health Forum Executive Director, Kate Moore, has explained that not only do consumers bring an important perspective to policy and decision-making, they are also in a position to put forward an alternate view while Government maintains more neutral ground. She made this point about the establishment of the Consumers Health Forum,

*Neal Blewitt had made a commitment to fund the Consumers Health Forum because he saw it as a constituency for Medicare and as a way of challenging what those very powerful vested interest groups were saying and putting the patient at the centre of health policy. Blewitt could see what so many other politicians couldn't; that first, health consumer interests should take primacy in health policy, and second, a consumer advocacy body could speak publicly in a way that Government couldn't.*⁵³

At the ACT level, while sitting apart from Government, HCCA is well-placed to make a strong and, if need be, uncompromising case on behalf of consumers in a way that the executive arm of ACT Government cannot with its parliamentarians, nor can parliamentarians often in the face of determined lobbying by medical and pharmaceutical interests.

This freedom to speak authentically sometimes attracts people to HCCA who have worked hard for improved health care within the system of government. Former government employees bring an important voice to consumer advocacy, building the understanding of the broader consumer representative community about government processes.

The freedom to speak can have its downside, though. For consumer representatives, the toll of advocacy can be high. Most of the time, consumer representatives are treated as equals at the table. But this is not always the case. HCCA members have described times when they have felt their participation was unwelcome or seen as a necessary evil.

Sometimes, as the only consumer representative at the table, they can feel as though they are always fighting to be heard. As a former staff member and consumer representative said,

It's hard to be the only one at the table. I'm sure a lot of people didn't like having me there when I pointed out the faults!

Kerry Snell

A time of heightened advocacy

The last decade of HCCA's history has been a time of heightened advocacy. In part this has been enabled by greater certainty of funding and the accumulation of expertise and resources. HCCA's Consumer Reference Groups and its policy development work all contribute to HCCA's capacity for informed advocacy across a range of health service areas.

HCCA has developed solid policy in championing the interests of consumers on a range of health care issues. This has included a sustained focus on primary health care, which is the cornerstone of our health care system.

Primary health care is usually the first point of contact for consumers with Australia's health care system and it is the area that most people interact with most of the time. HCCA has long advocated for a greater focus on primary health care within the community. A strengthened primary health care system can lead to improved health outcomes for consumers who receive more appropriate care before they become too ill, which then contributes to reduced spending in the hospital system.

Through its advocacy work HCCA has developed a longstanding relationship with primary care stakeholders. HCCA had a consumer representative on the ACT Division of General Practice Community Reference Group (Marion Reilly), a Board member on the Medicare Local (Darlene Cox), and consumer members on the Primary Health Care Council. More recently, HCCA has had consumer directors on the Board of the Capital Health Network (Rick Lord, followed by Darlene Cox).

GP taskforce

With a track record in Primary Care, HCCA was invited to put forward a consumer representative when the ACT Health Minister, Katy Gallagher, announced the GP Taskforce in 2009.

HCCA had raised concerns about a GP shortage in the ACT following the closure of a GP Practice in Wanniasa in 2008. With further sudden closures of suburban practices and growing community concern, on 26 March 2009 the then ACT Minister for Health, Katy Gallagher, announced that the Government would establish a GP taskforce to investigate GP workforce issues in Canberra.

HCCA was invited to nominate a representative to join the taskforce and HCCA member Ann Wentworth joined clinicians, academics and senior public officials to lead the investigation. Janne Graham also served on the taskforce during the development of the Issues and Challenges for General Practice and Primary Health Care Discussion Paper.

HCCA worked hard to build a picture of issues facing the Canberra community. The organisation ran an online survey — GP Snapshot 2009 — to capture consumer experiences and expectations of general practice in the ACT. It explored issues such as whether consumers have regular GPs, waiting times for appointments, the quality of the interaction and demographic information.

HCCA drew on the experiences of HCCA membership and also interviewed advocates for people with disabilities, culturally and linguistically diverse backgrounds, and carers.

Building on its years of activity around primary health care and the point in time picture of consumers’ experiences, HCCA was able to put forward a comprehensive submission to the GP Taskforce.

HCCA has also supported consumer representatives to participate in a range of projects, for example, the Heart Failure Project and Transitions of Care. And, there have been a number of projects where HCCA has received funding to work with primary care organisations, for example, the ACT Medicare Local Needs Assessment in 2014.

HCCA’s capacity and reputation have enabled it to advocate and ultimately contribute to the many health and well-being issues facing the ACT community.

**Chapter 5:
Complaints are like gold**

I don’t see the complaints as something you should worry about. Actually, complaints are like gold. They’re a gift from that user to the organisation, but you just can’t be defensive about it. If you’re defensive, then no one wins.

Darlene Cox⁵⁴

While there is always more to be done to enable the transformative power of consumer complaints, things have come a long way in the ACT since HCCA first came into being over 40 years ago. Consumer feedback standards — the first of their kind in Australia — were introduced in the ACT over fifteen years ago, and the more recent emphasis on safety and quality in health care has brought the issue of complaints to the foreground.

HCCA continues to play a strong role in building a robust health care complaints system in the ACT — a system that offers recognition and resolution for the individual and seeks system-wide improvement based on themes arising in complaints data.

From the outset, HCCA members recognised the value of collecting complaints data. As a collective, the newly formed organisation was well placed to build a picture of the sorts of issues that health consumers faced. Patterns that emerged signalled a systemic problem.

At the fourth meeting (pre-incorporation, 21 March 1977) of the then named Health Services Consumer Association the issue of how to handle consumer complaints was discussed. The Executive Committee noted it did not have the requisite skills or authority to seek resolution of complaints; it was only able to provide “moral support” to consumers experiencing difficulties with the health system. However, the Committee agreed that issues attracting a cluster of complaints would warrant establishing a special interest group to develop policy and promulgate policy attitudes.

As the organisation gained stability, achieving incorporation and establishing local connections, the capacity to advocate on behalf of individuals emerged — albeit in a limited and ‘ad hoc’ way. Executive Committee members would act on behalf of concerned health consumers however they could. This could mean writing a letter or making a phone call on behalf of someone. It could mean helping a person prepare a series of questions to ask their GP or medical specialist. Or it could mean accompanying someone to lodge a complaint with their health service provider, or to request their health record.

HCCA records show, for example, an exchange of letters between the HCCA President and a local hospital in 1981. The President sought an investigation on behalf of a mother whose concerns about her child’s in-hospital care were dismissed by the doctor on duty; she was subsequently allegedly berated by the same doctor when she returned to the hospital with her child due to a perceived decline in the child’s physical state. On a different matter, a letter from the HCCA President politely requested a former patient’s x-ray prints after the patient was told by the service provider that the prints had been lost.

Providing a voice for those who are unable to speak for themselves, or who have tried and have been silenced, is an important aspect of health advocacy. HCCA's mission has always been to promote health literacy — to build the confidence and competence of health consumers to advocate for themselves. But when someone is navigating a complex system for the first time (or indeed, the second or third...) or they are just not well enough to advocate for themselves, external support can be a lifeline.

In the 1970s and 1980s, in a staunchly paternalistic paradigm of health care where the assumption was always that doctors knew best, the capacity for patients to self-advocate was difficult. What it took to cut through this professional authoritarianism was another authoritative voice. John McMillan explained:

[W]hat I learnt at the time, and this is from public interest activity on a few fronts, was that the two critical things at that time were one, having a letterhead. If you had a letterhead — even though they were pretty amateurish in the way they were produced — nobody knew who was behind it. And secondly, you've got to get a few reputable people with a bit of stature in the community to be your patron.⁵⁵

While not recognised by all — or in all circumstances — there is now an acknowledgment of the authority of consumers' experiential knowledge. The women's health movement, the community advocacy and policy response to HIV/AIDs, and the disability rights movement can be credited for having driven this change in attitudes.

Building a complaints system

In the 1980s HCCA began working with health care consumers and health care providers to strengthen the complaints system and transform it from something negative into a valuable source of consumer information for improving the quality and safety of services. Working with the broader Australian health care consumer movement, HCCA pressured hospitals to record and review complaints and to make the process of lodging a complaint less combative and forbidding for consumers. This began with consumer representatives on hospital committees trying to feed in information they were receiving from consumers, raising their concern about the alarming rate of accidents in hospitals. Others on the committee would say “no, no, no, no.” But there was no evidence being collected systematically that could counter or confirm the anecdotal evidence coming to HCCA.

In 1985–86 HCCA began advocating for an ACT Health Authority Complaints body. The vision was for an independent body that included representatives of professional health providers, consumer organisations and legal organisations.

In 1986, John McMillan, who had returned to HCCA for a short period of time, wrote an article, Health and Medical Complaint Procedures, under the umbrella of the public interest association he had set up with Kate Beauchamp and John Braithwaite in 1976 — the Rupert Public Interest Association.⁵⁶ McMillan noted that recognition of the valuable role that consumers play in the health system would never be fully realised until the rights and interests of consumers were not only acknowledged but also protected. He said, “a public complaints procedure is the only effective way of safeguarding individual rights and interests”.⁵⁷

At the time, consumers argued for an independent — ideally statutory — body. It would not be until 1994 when the Health Complaints Unit (under the Community and Health Complaints Commissioner) was established that this vision would be realised. The ACT Department of Health had an internal complaints process but, from HCCA's perspective, this was not sufficiently independent or well-publicised.

In 1990 HCCA held a phone-in inviting people to share their experiences of ACT health services and, in particular, recent changes to the health service system.

The Phone-in

In 1990, HCCA received increasing complaints from consumers about changes in the ACT health services — in particular, about the interim arrangements for transferring The Royal Canberra Hospital to other sites.⁵⁸ An HCCA member wrote to the Administration of Royal Canberra Hospital with five specific complaints of long waiting times and lack of beds for urgent cases. The Hospital Administration replied that “such incidents were infrequent and that in each of the cases the hospital services were justified in their actions”.⁵⁹

To establish whether these were isolated incidents, or part of a bigger picture, HCCA organised a one-day confidential phone-in for ACT residents inviting people to share their current experiences, good and bad, of hospital and health care in the ACT.

The phone-in was publicised through ACT Community Associations, a press release, and a small advertisement in The Canberra Times and The Chronicle. The advertisements were funded with the assistance of the Community Health Association of the ACT.

The phone-in was held on 8 December 1990. Over the course of six hours, 14 volunteers worked shifts to take and record details of each call. By the time the phones closed at 4pm, HCCA had received 136 calls on behalf of 187 individuals from across the ACT region describing experiences with 24 different ACT health care services. Of these calls, the majority reported problems, which were categorised across several themes.

HCCA concluded that there was sufficient evidence to justify a review of current health service provision in the ACT. HCCA also noted that the Health Department's complaints processes were below par, concluding that there was evidence that the Departmental Complaints Unit is not well known or used by consumers. It proposed an increase to its visibility and independence.⁶⁰

HCCA's criticism of the Department's complaints procedures did not stop there.

In the absence of a publicly recognised consumer complaints procedure within the Department of Health, this Association has used the phone-in as the only available source of health care consumer experience in the ACT.⁶¹

The number of calls taken over the six-hour period — 136 — reflected community disquiet with the changes that were happening and the impacts these were having on consumers. The phone-in provided a solid snapshot of the systemic issues experienced by consumers. It also brought into sharp relief the need for an accessible and proactive health complaints unit.

HCCA provided copies of the phone-in report to the then Health Minister, Gary Humphries, and lobbied other political figures. Executive Committee members, Janne Graham and Deborah Matrice developed a proposal for a complaints unit in the ACT and sent copies of the proposal to the ACT Board of Health and the Health Minister. A public meeting to raise public awareness about the need for a non-government, independent complaints unit was proposed.

At the same time, health reform at the national level was showing an increased focus on complaints. Then Federal Health Minister, Brian Howe, set out several reforms in the 1992–93 Commonwealth Budget Papers that would be incorporated into the new Medicare Agreements. These included the right to have complaints resolved by an independent complaints unit.⁶²

However, despite an agenda being set at the Commonwealth level for all states and territories to establish independent complaint bodies, there was resistance. In the end, the ACT was the only jurisdiction at the time to establish an independent unit. This was brought into effect by the *Community and Health Services Complaints Act 1993*.⁶³

Listening and Learning

Sometimes it takes a crisis or adverse event for activist goals to be realised. The slow “drip, drip, drip” of consumer activism⁶⁴ suddenly takes hold in the broader public and political imagination and change happens. In the early 2000s repeated serious concerns raised by a colleague about the head of neurosurgery, Dr Raymond Newcombe, at Canberra Hospital — who was later to be found guilty of malpractice by the ACT Medical Board — were finally beginning to be taken seriously.

At What Cost?

It took a formal investigation in the early 2000s, an investigative report by ABC TV’s Four Corners Program in 2007, and well over 12 years after Dr Gerard McLaren formally blew the whistle, for Dr Newcombe finally to be found guilty of malpractice. The ACT Civil and Administrative Appeals Tribunal decision noted that during the 1990s and early 2000s, Dr Newcombe had “performed surgery on the wrong part of a brain, used the wrong instruments and failed to provide adequate post-operative and clinical care.”⁶⁵

The personal and professional cost to whistleblower Dr McLaren was devastating. In an interview with ABC TV’s Four Corners program in 2007, Dr McLaren revealed he’d been ostracised by colleagues and attempted suicide. “I’m seen as a filthy rat because I’ve actually joined the cause of the patients”, he said. “I’ve decided that you can’t actually be part of the doctor party and the patient party — you’re in one camp or the other.”⁶⁶

Against this backdrop, and in line with a recommendation from the 2001 ACT Health Quality and Safety Plan, the Community and Health Services Complaints Commissioner, Ken Patterson, and ACT Health executives sought to improve governance processes. Bolstering patient feedback was seen as one of the planks of a strengthened system of clinical governance.

HCCA joined forces with the Canberra Hospital, Calvary Health Care, Community Health, Mental Health ACT, and the Community and Health Services Complaints Commissioner to streamline feedback mechanisms across ACT Health. It was recognised that an ACT wide process for collecting and monitoring consumer feedback was needed.

The project unfolded in an emotionally charged setting. Crucially, there was a shortage of clinical staff across the health system, who were being called on to undertake an ever-growing range of competing tasks. Clinical staff constantly carry the responsibility of making critical — at times, life and death — decisions. In this context, the project team worked hard to raise the profile of consumer feedback, shifting from the idea of criticism and blame to that of valuable information and an opportunity to learn.

HCCA consulted widely with consumer groups across the ACT, including vulnerable communities, to identify barriers to providing feedback. This fed into the development of the standards — *Listening and Learning*, which were introduced by the ACT Government in 2002–03.

These standards continue to set the benchmark for recognising the consumer voice as essential to the ongoing improvement of the quality, safety and accountability of health services, and the understanding of what quality, safety, responsiveness, and respect mean from the perspective of health care consumers.

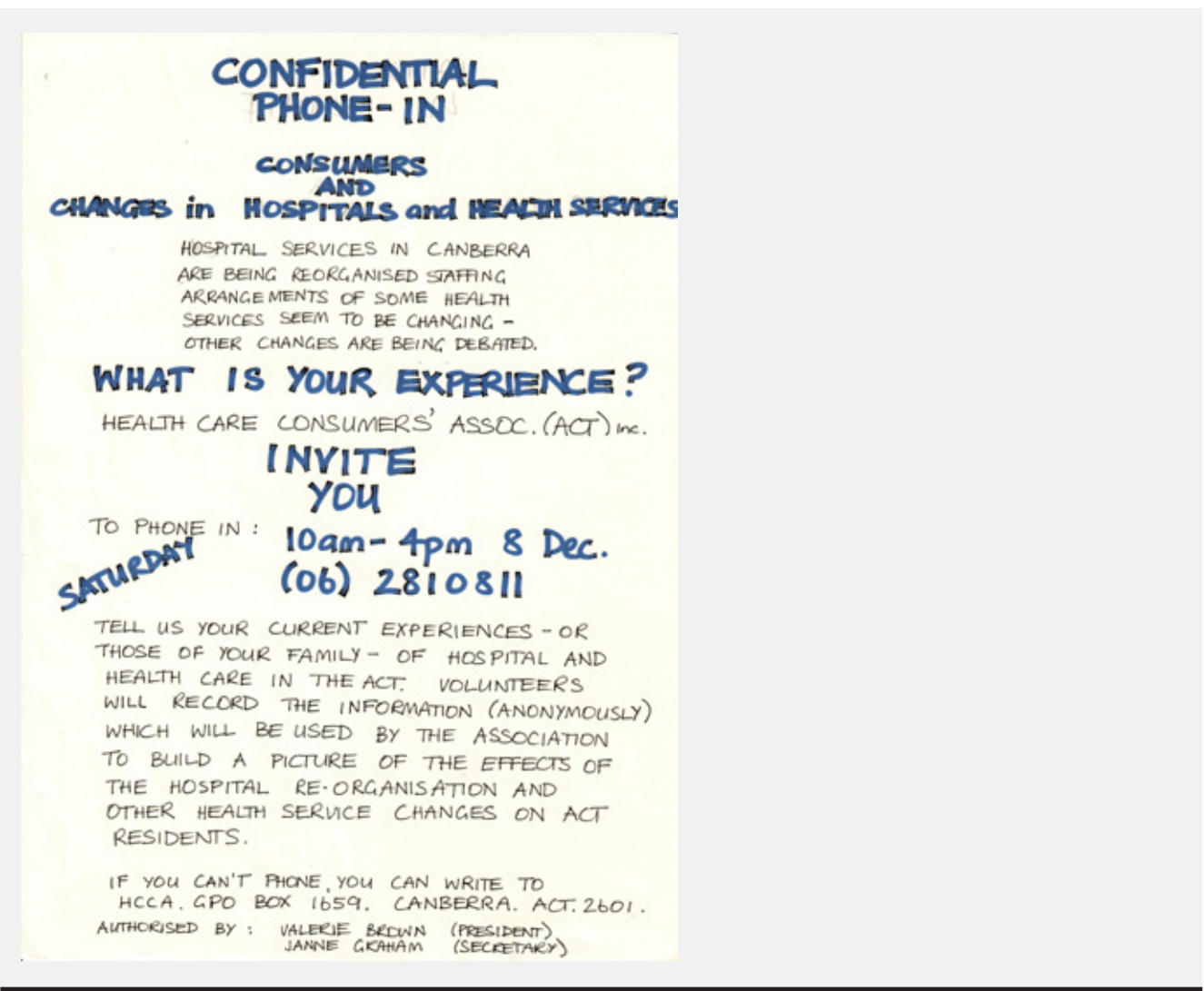
Getting the culture right (turning straw into gold)

The Consumer Feedback Standards were a bold step in changing the complaints culture, and a first in Australia for consumer-centred feedback. They were an important step in the right direction, but they were not a cure-all. Close to fifteen years down the track, in a study undertaken with consumers in 2017, HCCA found that many people who have experienced poor or unsafe care were unwilling to provide feedback.

Principles

For HCCA, the following principles lie at the heart of health and medical services complaints processes:

- That consumers should know they have a right to complain about their care, and know where and how to do so (including in the case of complaints about private medical specialists);
- That the complaints process should recognise and minimise the personal toll to consumers of making a complaint;
- That clear information should be provided to consumers about the medical complaints process, including the role of agencies involved, likely time-frames and possible and likely outcomes of their complaint;
- That complaints are taken seriously, learnt from and acted on (at the level of the health professional, the health service and the health system); and importantly,
- That the outcomes of the complaints process and any change resulting from it are communicated to the consumer.



What was going wrong? HCCA worked with consumers to uncover the obstacles. The answer was relatively straightforward. In short, it came down to the willingness of health service providers to take feedback on board. Consumers will only give feedback, or make a complaint, if they feel that the health service and its staff will listen to and act on the information they give. Talking to deaf ears or worse, fearing reprisal, inhibits the offering of feedback.

When you have a need for ongoing care, whether that is mental illness or a physical illness ... your care is a revolving door, you're going to be there again and again and you need the door to open for you.⁶⁷

Despite the inroads made with the Consumer Feedback project in 2002–03, the problem often came down to workplace culture. Even with the best complaints system in place, it is the culture and staff attitudes about consumers' complaints that will determine the success of the system. If there is a culture of blame rather than responsibility and learning, staff will view complaints as a threat and fail to learn from their mistakes.⁶⁸ A culture of blame within the health system invariably leads to poorer quality outcomes for health consumers. A culture of learning from complaints is an integral part of a safe, high quality health environment.

Chapter 6: 'First, do no harm'

The case of Canberra neurosurgeon, Dr Raymond Newcombe, was a watershed moment in the ACT. The fact that the neurosurgeon had been able to continue unchallenged to perform surgery on unwitting patients for almost a decade, despite repeated complaints and mounting evidence of malpractice, was hard to fathom.

Yet, the problem was more widespread than the ACT. The Commonwealth Government's Professional Indemnity Review, 1991–1995, led by then Health Minister, the Hon Brian Howe, commissioned the *Quality in Australian Health Care Study* in 1995.⁶⁹ This study revealed a startling level of preventable harm to patients in Australian hospitals, claiming that 18,000 people were dying each year because of avoidable error.

The results of the study sent shockwaves through the community. While some academics and medical professionals challenged the robustness of the data, the Commonwealth Government conceded that "the occurrence of adverse events in health care settings is high".⁷⁰ The findings were at odds with the fundamental principle of health care – 'first, do no harm', and governments turned their attention to patient safety.

Given the alarming outcomes of the study, those advocating for patient safety felt that Government moved too slowly. It took close to five years before anything truly substantive was put in place at a national level. The *Quality in Australian Health Care Study* had emphasised the "need to monitor safety and quality of health service provision systematically and routinely".⁷¹ In response, Australian Health Ministers established a National Expert Advisory Group on Safety and Quality in Australian Health Care, which four years later recommended the establishment of an Australian Council for Safety and Quality in Health Care. In the interim, the Commonwealth funded initiatives to improve the quality of health care through the 1998–2003 Australian Health Care Agreement.

In the ACT, this spotlight on quality and safety led to the development of a *Patient Safety Action Plan for the ACT* (February 1999) under then ACT Health Minister, Michael Moore. Development of the Plan included an audit of all public and private hospitals and registered day surgery facilities in the ACT. The plan sought to minimise the human and financial costs arising from unsafe practices and poor-quality services.

Around the same time, the ACT adopted Professor Bill Runciman's Advanced Incident Management System (AIMS), which he had developed with colleagues through the Australian Patient Safety Foundation. Professor Runciman was also an author of the *Quality in Australian Health Care Study*. ACT Health would later replace AIMS with another system, RiskMan.

In 2001, Minister Moore led the development of *Quality First: A commitment to quality and safety in ACT Health Services*.⁷² *Quality First* provided a framework for improving quality and safety in the ACT health system. HCCA welcomed the release of the *Quality First* framework and the emphasis it gave to a principle long advocated by consumers; that the consumer should be the centre of all the system does. The framework, like the *Patient Safety Action Plan* before it, recognised that human error is inevitable and that the health system should be designed to mitigate human error, rather than to place unrealistic performance expectations on health professionals.

What had become clear to the ACT Department of Health was that there was a dearth of accessible information about health care and health services in the public domain. The Department of Health asked HCCA to bridge this gap with two related projects under the umbrella term, *Navigating the ACT Health System*. First, HCCA developed a consumer-friendly description of the health system. Second, HCCA developed decision-making tools to help consumers make informed decisions about the health care that was appropriate for them.

The influence of advisory bodies

The role of advisory bodies in shaping and promoting the safety and quality agenda is noteworthy — not least because consumers are able to influence activities through direct participation.

In 2000, ACT Health established a Safety and Quality Forum and three HCCA nominated consumer representatives — Russell McGowan, Kristine Clement and Mary Baumgarten — were appointed to the Forum. They attended their first meeting on 9 May 2000.

Russell McGowan

Russell is a bone marrow transplant survivor who has been active in the health care consumer movement since the early 1990s.

Before his own experience with health services, Russell had assumed that the health system would deal with all the things that come up in the course of one’s treatment in an integrated way. In fact, he had to intervene; he had to make decisions; and he had to commit resources. In the process, Russell accumulated knowledge about the health care system, both in Australia and overseas.

It was a critical — and avoidable — incident that cemented Russell’s commitment to improving safety and quality in health care. Not long after his bone marrow transplant, Russell experienced a severe case of sepsis triggered by a pneumococcal infection. Doctors assessed his chance of coming out of a coma as 30 percent. Russell had travelled to Adelaide for his bone marrow transplant and then returned to Canberra for his recovery. In the move between two health systems, both failed to have him re-vaccinated — a requirement for bone marrow transplant recipients as their historical immunity is erased.

Russell’s experience with the health system drove him to contribute to improving the way in which services are delivered. His involvement was, in many ways, a natural evolution of past activities. As a university student in the sixties there was a very strong push for students to become involved in university administration — which Russell did. It was about the democratisation of learning places. In the same way, Russell felt at ease with the concept of a democratised health system.

He was involved, for many years, with a consumer driven Oncology Users Group. Russell joined the HCCA in 1998 and served on the Executive Committee for 14 years (1998–99 to 2011–12) — ten of those as President.

As a consumer representative, Russell was involved in a number of committees in ACT Health, including a group overseeing the transfer of allied health services out of the hospitals and into the community, and various Safety and Quality Committees.

In 2000 Russell took up the opportunity to train as a surveyor of hospitals under the Australian Council of Healthcare Standards. Following this, in 2001, Russell was nominated by the Consumers Health Forum and served for nine years on the Board of the Australian Council on Healthcare Standards — the main developer and administrator of health care standards in the country at the time.

Russell remains involved in a number of community and consumer organisations. He is a Fellow of the Public Health Association of Australia, where he has served as the President of a local Branch as well as a member of its national board

Consumers met as equals with their Forum counterparts.

Then, in 2002–03 HCCA Executive Committee members Kate Moore and Russell McGowan were appointed to the ACT Health Council, which was initially chaired by the ACT Health Minister/CEO ACT Health, and later by Kate Moore with Russell McGowan in the role of Deputy Chair. As well as consumers, the Council comprised senior managers and clinicians, from both inside and outside the public health sector. It was charged with responsibility for monitoring health system performance as well as conducting regular community engagement forums on health issues. Consumer representatives were well placed on the Council to advocate for incorporation of performance and outcomes monitoring of multiple quality performance indicators. The Health Council continued for almost a decade, ceasing operations on 30 June 2011 when the ACT Local Hospital Network was established.

ACT Health governance structures such as the Clinical Review Committees are another avenue for seeking improvements to safety and quality. Prior to 2007, involvement in Clinical Review Committee processes was restricted to doctors. In this enhanced era of partnership, the doors were opened not only to other health clinicians such as nurses, but also to consumers, enabling more rounded perspectives to be brought to bear on quality assurance processes.

Russell McGowan recalls the first decade of the 2000s as a time of significant activity on quality and safety. With Prue Borrman’s funded position, HCCA was able to build up health literacy and training in quality and safety. HCCA representation on the Safety and Quality Forum and the ACT Health Council meant that consumers could push for a system to monitor adverse events and learn from them.

Not long after HCCA helped develop the *Listening and Learning* feedback standards in 2002–03, consumers were trained and deployed to participate in Root Cause Analysis for sentinel events in the ACT — particularly serious injuries and deaths while in the care of mental health services. It was understood that health consumers could bring a different perspective to these analyses, potentially identifying factors leading to safety events easily missed by those embedded in the health system. HCCA member Fiona Tito Wheatland described her experience in root cause analysis investigations:

I found them to be a real eye-opener in terms of how the system operated. You had to work very closely with doctors and nurses and from my angle it was a very respectful process. I found that my external view was always much more important than I realized it was going to be. While the doctors and nurses were ready to jump to early conclusions, I saw things through different lenses and asked a lot of questions, and they would say “I hadn’t thought of that”. So we would look further into the matter and usually come up with different answers than they had at first thought of. That was pretty rewarding. It made me realize that consumers can bring something unique to these processes.”⁷³

HCCA consumer representatives and organisational members met regularly to discuss safety and quality issues and strove to identify common themes and risks for possible escalation to the ACT Department of Health.

One of the issues identified in successive studies about why the health system was so ‘harm tolerant’ was the extent to which the medical profession appeared to be beyond the reproach of state and broader public control.⁷⁴ As the culture of health care began to change and consumers came to be seen as partners in their own care, the perceived omnipotence of the medical professional diminished. That medical professionals could and did make mistakes could be acknowledged. They were, at the end of the day, human. That consumers could reflect intelligently on their health issues and their health care could be acknowledged, too. The imbalance of power was shifting — albeit, by degrees.

National safety and quality health service standards

On 1 January 2006 the Australian Commission on Safety and Quality in Health Care (the Commission) was established.⁷⁵ In April 2008, in response to a previously fragmented quality control environment in health, Australian Health Ministers gave in-principle endorsement to a national accreditation scheme. The scheme was developed by the Commission, with five standards released for consultation in November 2009, and a further five standards released for consultation in August 2010.

During the consultation phase, HCCA advocated for a greater focus on encouraging quality improvement as well as simply compliance with minimum standards. In 2010, the Commission contracted HCCA to coordinate an ACT-based consumer workshop for feedback on accreditation reforms and revised draft standards.

In September 2011, Health Ministers from all states and territories in Australia endorsed the Standards and a national accreditation scheme, which commenced in 2013. Illustrating the influence the health consumer movement had over the years, one of the ten standards, Standard 2, was dedicated to partnering with consumers. Standard 2 recognises the important role of patient participation for the improvement of safety, quality and efficiency and requires health services to institute effective and meaningful engagement of consumers in ‘the review, design and implementation’ of services.

Around the time the Standards were endorsed, HCCA developed the role of ‘Consumer Leads’ as part of the governance process to support monitoring of the Standards. This has proved to be a powerful model of consumer participation with a consumer lead on each of the ACT national standards committees supporting clinician and administrative leads.

In 2014 HCCA made a significant contribution to the process in the lead up to, and successful accreditation of, ACT Health. The Australian Council on Health Standards Survey team’s draft report noted that:

The presence and strength of consumer input impressed the survey team, who saw evidence of initiatives which were a direct result of this consumer focus.”⁷⁶

The current state of play

The shift to a nationally endorsed, patient-centred standards and accreditation system was welcomed by HCCA. However, some health advocates feel that recently the focus on reporting adverse events has diminished. Recent concerns with accreditation results for the Canberra Hospital⁷⁷ and the flux in ACT Health leadership roles signal disruption.

While ACT Health regains equilibrium, HCCA has adapted its approach to safety and quality by integrating a safety and quality focus in all of its interactions with ACT government.

A critical part of HCCA’s approach today in dealing with safety and quality is through its Quality and Safety Consumer Reference Group. This is one of four reference groups currently active, the other three being the ACT e-Health Consumer Reference Group, ACT Health of Older People Consumer Reference Group, and the ACT Maternity Consumer Reference Group.

The Quality and Safety Consumer Reference Group provides a forum to raise consumer issues around the quality and safety of health services and to work collaboratively with ACT Health to address these. The membership of this group consists of Consumer Leads on National Quality and Safety Health Service Standards Committees.

At a national level, while progress has been slow, it appears to be moving in the right direction. The second edition of the Standards was endorsed by Health Ministers in June 2017 and released in November 2017. Health service organisations will be assessed against the second edition standards from January 2019.

The national standards and accreditation scheme guides local practice. At the same time, consumer experience and expertise at the local ACT level informs national developments. For example, in December 2017, HCCA made a submission to the Australian Commission on Safety and Quality in Health Care’s consultation on patient safety and quality improvement in primary care. HCCA was able to draw on prior research, which looked at consumer experiences and expectations of General Practice and after-hours primary care in the ACT, to inform its recommendations to the Commission’s consultation.

Locally, HCCA continues to support and promote the recently launched ACT Health Quality Strategy.

‘Spend time to save time’

On 15 March 2018 ACT Minister for Health and Wellbeing, Meegan Fitzharris, launched the new ACT Health Quality Strategy.

ACT Health co-designed the Strategy with HCCA and clinicians to improve the quality and safety of health care and to reduce the incidence of preventable patient harm. Minister Fitzharris said,

*The Strategy was developed with input from consumers and clinicians to ensure a shared understanding of quality and a commitment to place quality at the heart of the organisation.*⁷⁸

HCCA undertook consumer and community consultations to identify what quality and safety means to consumers and carers and to record experiences and perspectives of care provided by ACT Health. Consultation included: 22 key informant interviews, four focus groups, as well as 452 responses to an online survey, and comments on the HCCA Facebook page.

Consumers told the HCCA about when they feel unsafe in health care:

- I don’t understand what is happening.
- I don’t feel like I can ask questions.
- I feel like an episode or case and not in control.

Consumers and carers also told the HCCA about what good quality health care looks like:

- I have a clear understanding of the diagnosis, condition and expected outcome.
- Care is coordinated around my needs, I do not have to chase staff or repeat myself.
- I have the information on how to manage my condition and care for myself.
- The health care providers respect my values, preferences and expressed needs.
- When I am referred to other services I understand who, when and why I am seeing them.
- When I leave the health service I know what will happen next.⁷⁹

For HCCA, ensuring safe and appropriate health services is an ongoing challenge requiring the vigilance of all parties.

Conclusion: The HCCA family

HCCA was a creation of its time – founded in an era that saw new ways of thinking rub up against tradition and hierarchy, when there was still enough space for fresh voices in public debates about health care to come forward and be heard.

HCCA was also a creation that evolved and adapted to continue to influence and shape the ACT health care environment. It is this ability to adapt, and an enduring stewardship in which the values and goals of HCCA are passed, intact, from one Executive Committee to another, that has enabled HCCA to survive, and ultimately thrive, over the forty years of its life so far.

Several HCCA members described HCCA as ‘family’ and talked about a supportive environment in which members work together to achieve common goals. HCCA member and President, Sue Andrews, reflected,

You feel part of something bigger. The personal story speaks to the bigger system. ... The value of having an organisation that’s so strong around working with its members is that it makes us incredibly potent when it speaks with and to the system.

It was striking, talking to former and current members of HCCA, how often individuals were brought into the fold by other members and the extent to which they were supported and mentored in their journey. It is more than an organisation: it is a community.

What attracted people to HCCA varied. For many, a personal experience navigating the health system – for themselves or on behalf of a family member or friend – was the catalyst. Louise Bannister described the tragic and preventable death of a close friend in the USA many years ago as her motivation:

I lost my very best friend in America due to medical negligence and I didn’t know where to go with that. And then a friend mentioned HCCA and here I am nearly 24 years later! I didn’t want what happened to my friend to happen to anyone here in Australia.

For others, a long involvement in health policy or health services and a commitment to consumer centred health care was the trigger. Shelley McInnis worked as a health educator, program manager and researcher for many years prior to joining HCCA. HCCA Treasurer and consumer representative, Indra Gajanayake, brings her experience in health policy, and strong interest in population health issues and safety and quality of health care in the community and hospitals to her role with HCCA.

For some, it is a mix of personal and professional experience that brings them to HCCA. Executive Committee member, Marcus Bogie, for example, described his personal experience having lived with HIV for over 20 years and navigating the health system as a driver for his involvement. At the same time, Marcus has worked with the AIDS Action Council of the ACT for over 17 years in various roles and brings this understanding of the needs of people accessing health services to his work with HCCA.

Other HCCA members were encouraged to join to bring their broader skills and experiences to bear on health consumer activity. Executive Committee member, Marion Reilly, for example, came to HCCA with finely honed policy making and political skills as a former senior public servant and ACT Parliamentarian.

“Our fortunes do rise and fall”⁸⁰

Remarkably, the first twenty years of HCCA's life were without any substantive funding, relying on modest membership fees, help from other like-organisations, and the time and generosity of its Executive Committees and members. While many small, member-based organisations across Australia closed at one time or another, HCCA kept going.

Following the introduction of self-government in the ACT in December 1988 — and just over a decade since HCCA achieved incorporation — all incorporated associations were required to reactivate their incorporation. The records of HCCA's AGM, which was held on 13 November 1989, show that the requirement triggered a decision point in the life of HCCA: do we stay, or do we fold? Members at the AGM expressed concern about the capacity of a small group to adequately provide the needed services. The meeting record went on to note that the history of the organisation had been one of growth followed by one of decline and uncertainty. The time, energy and cost to members, it was noted, was not insignificant.

However, in the end the small group of members⁸¹ in attendance was resolute; HCCA must continue, with the Minutes noting:

the Association was needed to meet the objectives in the Constitution and that an effort should be made to keep it going.

Momentarily, HCCA faltered. Two weeks later, however, it appeared to be back to business as usual with the Committee recording proposed actions around consumer complaints and looking to identify consumer representatives for consultative and advisory bodies.

HCCA did not have office space until the mid-1980s when it was able to share an office in Pearce ACT, with the then newly established organisation — Self Help Organisations United Together. In 2009, and with greater security of funding, HCCA moved from Pearce to its present location in Hackett.

In 2017–2018, HCCA had an income of \$923,305, 15 staff members,⁸² and 33 Consumer Representatives and seven Organisational Representatives sitting on committees. HCCA supported consumer representatives on 92 committees in the ACT and nationally, of which 58 were ACT Health Committees. HCCA staff undertook research projects and contributed to policy reform at a local and national level, and trained and provided support to an active pool of consumer representatives. In 2017–18, HCCA prepared nine submissions to government inquiries and reviews.

As it looks to emerging challenges, HCCA's current Executive Committee identified a number of areas where HCCA will need to direct its attention — the implications for consumers of new and emerging technologies such as genomics, personalised medicine, bio-ethics, and an increased focus on tele-health. Increasing HCCA's outreach to vulnerable communities and culturally and linguistically diverse communities as ACT's population changes and grows is also important.

Finding new ways to facilitate consumer involvement in shaping health care services is a priority. Participation on health care committees is one important way to contribute to health care design and decision making. The time pressures on people in 2018 mean that increasing online participation will be important — particularly to be able to effectively engage with younger health care consumers about issues that concern them.

Executive Committee member, Alan Thomas, emphasised what he sees as the need for HCCA to re-invigorate and formalise an individual advocacy role. He explained that while it may be impractical for HCCA to play the kind of advocacy role that a family member might do, HCCA is well placed to point family members, friends and other support people in the right direction. This could take the form, for example, of finding appropriate resources available in the hospital system, such as social workers, or talking someone through rehabilitation and home-care options.

Alan was inspired to join HCCA over ten years ago after advocating for a critically ill family friend who was trying to navigate the health system. He was blunt in his assessment, “If you don't have advocates or know the system, it can be very difficult for a patient”.⁸³

HCCA's work is an integral part of the ACT health system. Sometimes, for longstanding members, it will feel like history repeats; *déjà vu*. Other times, change will feel too slow. However, looking back over 40 years, there are clear points where change has happened and held tight. Parents can now stay with their children at hospital, consumer rights in the field of mental health are well recognised, and, as Executive Committee member, Bernard Borg-Caruana notes, “Government comes and asks consumers now. Ten years ago, Government would've asked clinicians how consumers felt!”⁸⁴

HCCA continues to influence many different aspects of the health care system. This history delves into just a few of those health care areas to illustrate the nature of HCCA's work over the past 40 years. One only needs to look at the breadth of submissions HCCA has made or the range of ACT Health committees that include consumer representatives, to see HCCA's scope of interest and influence.

HCCA will continue to play its part in bringing to life the 1978 World Health Organisation Declaration of Alma-Ata, which recognised the rights and responsibilities of people to participate individually and collectively in the planning and implementation of their health care.

Since HCCA's beginnings, many individuals have brought passion, insight and commitment to a quality health care system for all; they are “the unsung heroes”.⁸⁵

Endnotes

1 In 1985, the United Nations, through the United Nations Guidelines for Consumer Protection, expanded the four rights outlined by President Kennedy, adding a further four: the right to satisfaction of basic needs, the rights to redress, the right to consumer education, and the right to a healthy environment. The guidelines were revised in 1999 and again in 2015.

2 www.choice.com.au/about-us/the-choice-story/who-was-ruby-hutchison (accessed 2 August 2018)

3 Elix, Jane and Moore, Kate (2014), “Consuming interests: Women’s leadership in Australia’s consumer movement”, in Damousi J, Rubenstein K and Tomsic M (eds.), *Diversity in Leadership: Australian women, past and present*, ANU Press, p. 316

4 Baldry, Eileen (1992), *The development of the health consumer movement and its effect on value changes and health policy in Australia*, PhD Thesis, University of New South Wales, p. 124.

5 Baldry, Eileen (1992), p. 125.

6 Sue Andrews, HCCA President 2012–13 to 2017–18, in conversation, 15 June 2018.

7 Sax, Sidney (1984), *A strife of interests: politics and policies in Australian health services*, Allen and Unwin, Sydney, p. xi.

8 Parts of this profile are drawn directly from a profile on Janne Graham, “Getting up and running”, in *The Australian Health Consumer* (Spring 1999), number 3, pp. 10–14.

9 Dwan, Kathryn (2004), *Challenges to the Professional Ideal: interactions between doctors and bureaucrats in Australia in the closing decade of the twentieth century*, PhD thesis awarded by University of Queensland, p. 88–89.

10 Dwan, Kathryn (2004), 92–93.

11 Baldry, Eileen (1992), *The development of the health consumer movement and its effect on value changes and health policy in Australia*, PhD Thesis, University of New South Wales, p. 127.

12 Dawn Chamberlain, radio Interview, Canberra Insight, 25 April 1976

13 Dawn Chamberlain, radio interview, Canberra Insight, 24 April 1976

14 Sax, Sidney (1984), *A strife of interests: politics and policies in Australian health services*, Allen and Unwin, Sydney, p.237.

15 Baldry, Eileen (1992), *The development of the health consumer movement and its effect on value changes and health policy in Australia*, PhD Thesis, University of New South Wales, p138.

16 President’s Report, *HCCA Newsletter*, no. 7, March 1979, p.2.

17 Editorial, April–June 1976, *New Doctor*.

18 Sue Andrews, In conversation, 15 June 2018.

19 HCCA interview with John McMillan, 2012

20 For example, HCCA made a submission to the ‘Inquiry into Health and Welfare Services in the ACT 1984’ and a joint submission with the Australian Federation of Consumer Organisations (AFCO) to the ‘Inquiry into Medical Fraud and Overservicing 1984’.

21 *HCCA Newsletter*, No. 10, March 1981, p.3.

22 International Conference on Primary Health Care, Declaration of Alma-Ata, clause I, 12 September 1978, http://www.who.int/publications/almaata_declaration_en.pdf?ua=1&ua=1 (accessed 5 October 2018).

23 Insider, Newsletter of the ALP Members of the Legislative Assembly, June 1990

24 Nothing about us without us — Nihil de nobis, sine nobis in Latin — is said to have its origins in the 16th century politics of Poland.

25 Movement between CHF and HCCA has been strong over the years. For example, early HCCA member and former President, Janne Graham later served on the CHF Board, while former CHF Executive Director in the 1990s, Kate Moore, served on HCCA Executive Committee from 1999–2000 to 2007–2008.

26 *HCCA Newsletter* No. 3, November 1977

27 Bastian, Hilda (1998), “Speaking Up for Ourselves: The Evolution of Consumer Advocacy in Healthcare”, *International Journal of Technology Assessment in Health Care*, 14:1, pp. 3–23, Cambridge University Press, p. 5.

28 This project was undertaken by independent researcher and health policy consultant, Jennifer Doggett, on behalf of CHF. It involved a literature review of evaluations and trends in consumer involvement as well as six in-depth interviews with consumer representatives. Doggett (May 2015), “*Unique and essential*”: a review of the role of consumer representatives in health decision-making, Consumers Health Forum of Australia

29 HCCA interview with Anna Saxon, 2008

30 Bastian, Hilda (1998), “Speaking Up for Ourselves: The Evolution of Consumer Advocacy in Healthcare”, *International Journal of Technology Assessment in Health Care*, 14:1, pp. 3–23, Cambridge University Press, p. 15

31 News Release, the Hon. Neal Blewett, 31 May 1983.

32 This section is drawn from Foskett, Alan, (November 1994), *Community Participation in Public Sector Decision-Making: ACT Health as an example — an historical perspective*, Canberra

33 The ACT (Self-Government) ACT 1988, came into effect on 6 December 1988.

34 Janne Graham, in conversation, 15 June 2018.

35 Foskett, Alan (1984), *Planning Health Services in Canberra*, pp. 6–9.

36 HCCA interview with Janne Graham, 2008.

37 The World Health Organisation describes the social determinants of health as “the conditions in which people are born, grow, live, work and age.” They include for example, employment conditions, social exclusion and early child development. www.who.int/social_determinants/en/ (accessed 29 July 2018).

38 Michael Moore AM was Australia’s first independent minister. He was appointed under Chief Minister, Kate Carnell’s, Liberal minority government.

39 HCCA Interview with Katy Gallagher, December 2012.

40 For example, the Canberra Hospital Emergency Department Project, the Mental Health project and the Calvary Hospital Intensive Care project (HCCA Annual Report 2005–06).

41 HCCA, *Communicator*, Winter 2004, p.7.

42 ACT Health provides a set reimbursement rate to cover out of pocket expenses, which is reviewed periodically.

43 ACT Legislative Assembly, Debates, *Weekly Hansard Seventh Assembly*, 31 March 2011, p1149; Health Care Consumers Association, *Submission and Feedback on the Model of Care and Model of Service Delivery for the University of Canberra Public Hospital*.

44 Consumer Representative to the Redevelopment Committee, September 2016.

45 Adele Stevens, in conversation, 15 June 2018.

46 For example, long-standing HCCA members described the negotiation period in the lead up to receiving triannual funding in 2016 as protracted and “very stressful”. Health ACT was in the midst of a restructure and turmoil followed. HCCA’s Service Funding Agreement was eventually signed on 5 December 2016 but in the interim, HCCA lost three staff members.

47 For example, HCCA current and former Executive Committee members reflected positively on the time when Dr Peggy Brown was Director-General of ACT Health (2010–2015) as an era of high engagement.

48 Executive Committee member Louise Bannister, in conversation, 26 July 2018.

49 *Government Urged to take Calvary Consultation Seriously*, ABC News Online, 2 October 2009, www.abc.net.au/news/2009-10-02/govt-urged-to-take-calvary-consultation-seriously/1087976 (accessed 21 September 2018).

50 An article by ABC news noted that “The Catholic healthcare provider needed Vatican approval before it could go ahead with the sale. But it says it has now become clear the Vatican would take several years at least to consider the deal.”, 8 February 2010, <http://www.abc.net.au/news/2010-02-07/no-deal-calvary-sale-falls-through/2594574> (accessed 10 August 2018).

51 A purchaser-provider model was introduced in the ACT on 1 October 2018. The restructure of ACT Health was announced by Ministers Fitzharris and Rattenbury on 23 March 2018. As Darlene Cox writes, “the restructure will see ACT Health separated into two different parts. The oversight function will rest with the Health Department and it will be responsible for the strategic policy and planning and stewardship of the health system. The other part of the directorate will be responsible for the delivery of health care” (HCCA Consumer Bites Vol 5, Issue 6, 4 April 2018). Back in the late 1990s, a purchaser provider arrangement was introduced by the Carnell Government. This model was subsequently overturned by the Stanhope Government.

52 The Hon. John Howard quoted in *Canberra Consumers*, Edition 53, p.10.

53 HCCA interview with Kate Moore, 2008.

54 HCCA interview with HCCA Executive Director Darlene Cox, 2012.

55 HCCA interview with John McMillan, 2012.

56 The Rupert Public Interest Association (named after Rupert Murdoch) was established to advocate for greater transparency and accountability of government and private business services. The first newsletter was published in February 1976.

57 Rupert Public Interest Journal, January 1986, p. 20.

58 In 1990, the ACT Government made the decision to close the Royal Canberra Hospital based at Acton. The Hospital finally closed on 27 November 1991.

59 HCCA (1990), *ACT Consumers’ experience of changes in Canberra’s health services: report on phone-in, 8 December 1990*, p.1.

60 HCCA (1990), p.12.

61 HCCA (1990), p.12.

62 cited in Patterson, Jan (August 1996), *Consumers and Complaints Systems in Health Care*, unpublished PhD Thesis, University of Adelaide, p. 399, <http://hdl.handle.net/2440/19008>

63 The Act was later repealed and replaced by the *Human Rights Commission Act 2005*. A Health Services Commissioner was subsequently appointed as one of three commissioners within the ACT Human Rights Commission.

64 This expression was coined by former President of the HCCA (2008–09 to 2011–23) Adele Stevens, who recognised the need for patience and small steps when advocating for change.

65 Anna Morozow, Former Canberra Hospital Surgeon Guilty of Malpractice, ABC News online, 29 June 2012, <http://www.abc.net.au/news/2012-06-29/former-canberra-hospital-surgeon-guilty-of-malpractice/4101426> (accessed 3 September 2018).

66 Paula Kruger, “Doctor Pays high price after whistleblowing”, ABC News Online, 27 August 2007, <http://www.abc.net.au/news/2007-08-27/doctor-pays-high-price-after-whistleblowing/652254> (accessed 3 September 2018).

67 HCCA Member cited in HCCA (2 May 2016), *Submission to the Senate Community Affairs References Committee Inquiry into the Medical Complaints Process in Australia*, p. 6.

68 HCCA (2 May 2016), p. 11.

69 Fiona Tito Wheatland chaired the Professional Indemnity Review.

70 National Expert Advisory Group on Safety and Quality in Australian Healthcare, Information Sheet, September 1997, cited in Enduring Solutions (February 1999), *Patient Safety — An Overview: A Background Paper examining the ACT’s hospitals and day surgery facilities and national and international developments in patient safety*, p.5.

71 ACT Government (2001), *Quality First: A commitment to quality and safety in ACT Health Services*, p.5.

72 In the lead up to Quality First, Fiona Tito Wheatland’s consultancy, Enduring Solutions, was commissioned to prepare a *Patient Safety Action Plan for the ACT* (1999).

73 HCCA interview with Fiona Tito Wheatland, 2008.

74 Fiona Tito Wheatland went on to write a PhD thesis to try and understand the “harm tolerant” nature of the health system. She concluded that “patient harm and medical error can be perceived psychologically by a doctor as a fundamental threat to his or her identity” and therefore is subsequently blocked by a range of psychological defences that “can make it hard for a doctor to recognise, identify or accept the risk of patient harm”, (2017), *Patient harm and medical error as threats to the Doctor Identity – a new lens for improving patient safety?*, PhD Thesis, Australian National University, p. v.

75 It was first established as an unincorporated body. Subsequently it was established by statute under the *National Health Reform Act 2011*(Cth). With this came greater powers, including the power to compel compliance”, Tito Wheatland (2017), p.11.

76 National Standards Accreditation Newsletter, 7 July 2015, cited in HCCA Annual Report 2014–2015, p. 14.

77 The ACT Government released an interim accreditation report in April 2018 which found the Canberra Hospital failed to meet 33 core criteria. Two of those criteria were ranked as extreme risk, while six were listed as high. After remedying the issues and risks over the past few months it is anticipated that Canberra Hospital will retain its accreditation.

78 Minister Fitzharris, media release, 15 March 2018.

79 From the HCCA report (2017) *Spend Time to Save Time: What quality and safety means to health care consumers and carers in the ACT*.

80 Kate Gorman, HCCA Manager Consumer and Community Participation, in conversation, 26 July 2018.

81 Sheena Dadge, Deborah Doney, John Drabble, Erica Fisher, Janne Graham, Lynne Grayson, Trish McDonald, Helen Slazenger, Regina Slazenger and Geraldine Spencer

82 As per the financial statements provided in the Annual Report 2017–18.

83 Alan Thomas, in conversation, 3 August 2018.

84 Bernard Borg-Caruana, in conversation, 26 July 2018.

85 Former HCCA employee Kerry Snell, reflecting on consumer representatives, in conversation, 31 August 2018.

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Appendix 1: Chronology

1946	World Health Organisation defines health as “a state of complete physical, mental and social well-being and not merely the absence of disease or infirmity”.
15 March 1962	World Consumer Rights Day – USA President, John F Kennedy outlines four fundamental consumer rights in speech to congress.
May 1963	Canberra Consumers releases first edition of its journal.
5 December 1972 – 11 November 1975	Whitlam Labor Government (Commonwealth).
1973	Doctors Reform Society established in Victoria.
1974	Doctors Reform Society established in ACT and NSW.
1974	Labor Government introduces universal health cover – Medibank.
1 July 1975 – 1985	Capital Territory Health Commission (CTHC) established to administer health services in the ACT. CTHC reports directly to Commonwealth Health Minister.
11 November 1975 – 11 March 1983	Fraser Liberal Government (Commonwealth).
26 October 1976	First meeting held to establish HCCA (then called Health Services Consumers’ Association).
12 September 1978	World Health Organisation Declaration of Alma-Ata – the first international declaration underlining the importance of primary health care.
13 October 1978	Health Care Consumers’ Association of the ACT (HCCA) incorporated.
1980	HCCA releases ACT Patient Bill of Rights.
October 1981	Commonwealth Government abandons Medibank.
1983	Health Issues Centre established under auspice of Victorian Council of Social Services.
11 March 1983 – 20 December 1991	Hawke Labor Government (Commonwealth).

February 1984	Labor Government reintroduces universal health cover – Medicare.
30 March 1984	HCCA runs joint seminar with ACTCOSS – Community Action for Health. It proves to be a seminal moment of community action.
1984	HCCA has office space for the first time, sharing an office with Self Help Organisations United Together (SHOUT) in Pearce, ACT.
1985	Health Issues Centre, Victoria, becomes an independent entity.
Late 1985	ACT Health Authority established to replace Capital Territory Health Commission.
1987	Consumers Health Forum of Australia (CHF) established.
December 1988	Self-Government introduced in ACT.
11 May 1989 – 5 December 1989	Follett Labor Government (ACT).
5 December 1989 – 6 June 1991	Kaine Liberal Government (ACT).
8 December 1990	HCCA holds one-day confidential phone-in to get consumer feedback on ACT health system. Response is unprecedented.
6 June 1991 – 9 March 1995	Follett Labor Government (ACT).
20 December 1991 – 11 March 1996	Keating Labor Government (Commonwealth).
1991–1995	Commonwealth Government’s Professional Indemnity Review.
9 March 1995 – 17 October 2000	Carnell Liberal Government (ACT).
1992–93	Commonwealth Budget Papers include consumer complaints reform – to be incorporated in Medicare Agreements.
1993	ACT Government introduces an independent complaints unit under the <i>Community and Health Services Complaints Act 1993</i> .
1995	Commonwealth Government commissions <i>Quality in Australian Health Care Study</i> .
11 March 1996 – 3 December 2007	Howard Coalition Government (Commonwealth).

1997	HCCA receives first significant annual government grant.
February 1999	<i>Patient Safety Action Plan for the ACT</i> developed under ACT Health Minister, Michael Moore.
2000	HCCA representatives appointed to ACT Health’s newly established, Safety and Quality Forum.
18 October 2000 – 12 November 2001	Humphries Liberal Government (ACT).
2001	ACT Government enters into ‘social compact’ with the community sector.
2001	ACT Government develops <i>Quality First: A commitment to quality and safety in ACT Health Services</i> . HCCA subsequently commissioned to develop <i>Navigating the ACT Health System</i> (tools for consumers).
12 November 2001 – 12 May 2011	Stanhope Labor Government (ACT).
2002	HCCA representatives appointed to ACT Government’s Health Council, which runs until 2011.
2002	Health Consumers Alliance of SA established.
2002–03	ACT Government introduces Consumer Feedback Standards, ‘ <i>Listening and Learning</i> ’. HCCA integral to their development.
2004–05	HCCA receives its first round of triannual government funding.
2004	HCCA formally introduces its Consumer Representative Program.
1 January 2006	Australian Commission on Safety and Quality in Health Care established.
3 December 2007 – 24 June 2010	Rudd Labor Government (Commonwealth).
2008	Qld. Health Consumers Ministerial Advisory Committee established.
2009	HCCA secures office space in Hackett, ACT.
2009 – 2016	ACT Government funds HCCA to be involved in its Capital Asset Development Program – later to be called, Health Infrastructure Program (HIP).
2009	ACT Government announces GP Taskforce and invites HCCA to nominate a representative.
December 2009	HCCA and ACT Government launch Australian Charter of Health Care Rights in the ACT.

2009–10	ACT Government proposes sale of Canberra’s hospice, Clare Holland House. HCCA campaigns against the sale.
24 June 2010 – 27 June 2013	Gillard Labor Government (Commonwealth).
2010	Health Consumers NSW established.
16 May 2011 – 10 December 2014	Gallagher Labor Government (ACT).
30 June 2011	ACT Government establishes ACT Local Hospital Network, replacing the ACT Health Council.
September 2011	Health Ministers from all state and territories endorse National Safety and Quality Health Service Standards and Accreditation Scheme.
2012	HCCA successfully bids for funding of a Multicultural Liaison Officer.
2013	Qld. Ministerial Advisory Committee established as an independent body – Health Consumers Qld.
11 December 2014 –	Barr Labor Government (ACT).
27 June 2013 – 18 September 2013	Rudd Labor Government (Commonwealth).
18 September 2013 – 15 September 2015	Abbott Coalition Government (Commonwealth).
15 September 2015 – 24 August 2018	Turnbull Coalition Government (Commonwealth).
June 2017	Health Ministers endorse second edition National Safety and Quality Health Service Standards.
15 March 2018	ACT Health Minister, Meegan Fitzharris, launches new ACT Health Quality Strategy (co-designed with HCCA and clinicians).
16 June 2018	University of Canberra Hospital (Yurwang Mura) sub-acute rehabilitation hospital opens. HCCA involved in development and design of the hospital.
24 August 2018 –	Morrison Coalition Government (Commonwealth).

Appendix 2: Health Care Consumers’ Association Executive Committees

Prior to incorporation

1976–77

Eve Homes — President
Dawn Chamberlain — Vice President
Elizabeth Carpenter — Secretary
Maureen McAlary — Treasurer
Rick Allen — Publicity Officer

1977–78

Eve Holmes — President
Emmanuel Klein — Vice President
Dawn Chamberlain — Secretary
Maureen McAlary — Treasurer

(HCCA incorporated 13 Oct 1978)

1978–1979

Eve Holmes — President
Dawn Chamberlain — Secretary
Maureen McAlary — Treasurer
Helen Turley — Ordinary Member
Emmanuel Klein — Ordinary Member

1979–1980

Eve Holmes — President (resigned end 1979)
Ian Robertson — Vice President
(Acting President, 1980)
Dawn Chamberlain — Secretary
Heather McClaren — Treasurer
Maureen McAlary — Ordinary Member
Helen Turley — Ordinary Member

1980–1981

John McMillan — President
Valerie Brown — Vice President
Dawn Chamberlain — Secretary
Doug Lloyd — Treasurer
Helen Turley — Ordinary Member
Dorothy Moore — Ordinary Member

1981–1982

John McMillan — President
(resigned 28 June 1982)
Heidi Ramsay — Secretary
(resigned 28 June 1982)
Doug Lloyd — Treasurer
Dawn Chamberlain — Ordinary Member
(Acting Secretary to 25 October 1982)
John Drabble — Ordinary Member
Geraldine Spencer — Ordinary Member
Valerie Brown — Ordinary Member
(Acting President to 25 October 1982)

1982–1983

Valerie Brown — President
Dawn Chamberlain — Secretary
Doug Lloyd — Treasurer
Geraldine Spencer — Ordinary Member
John Drabble — Ordinary Member
Peter Wilson — Ordinary Member

1983–1984

Valerie Brown — President
John McMillan — Vice President
Dawn Chamberlain — Secretary
Charles Lucre — Treasurer
Thelma Hunter — Ordinary Member
Janne Graham — Ordinary Member
Geraldine Spencer — Ordinary Member
Peter Wilson — Ordinary Member

1984–1985

John McMillan — President
Valerie Brown — Vice President
Janne Graham — Secretary
Charles Lucre — Treasurer
Dawn Chamberlain — Ordinary Member
Peter Wilson — Ordinary Member
Merrill Cook — Ordinary Member
Geraldine Spencer — Ordinary Member
Helen Turley — Ordinary Member

1985–1986

No record

1986–1987

Erica Fisher — President
M Hutson — Secretary
Patricia Macdonald — Treasurer
Charles Lucre — Ordinary Member
Jana Taylor — Ordinary Member
John Darby — Ordinary Member
Valerie Brown — Ordinary Member
Regina Slazenger — Ordinary Member

1987–1988

Erica Fisher — President
M Hutson — Secretariat
Patricia Macdonald — Treasurer
Charles Lucre — Ordinary Member
Jana Taylor — Ordinary Member
John Darby — Ordinary Member
Valerie Brown — Ordinary Member
Regina Slazenger — Ordinary Member

1988–1989

Erica Fisher — President
Patricia Macdonald — Treasurer
No other records

1989–1990

Valerie Brown — President
Janne Graham — Secretary
Patricia McDonald — Treasurer
Deborah Doney (later Matrice)
— Ordinary Member
Regina Slazenger — Ordinary Member
Helen Slazenger — Ordinary Member
Erica Fisher — Ordinary Member
Judith Cole — co-opted 12 June 1990
Kate Lipsett — co-opted 12 June 1990
Bobby Saxby — co-opted 12 June 1990

1990–1991

Valerie Brown — President (to 19 March 1991),
Treasurer from 19 March 1991
Janne Graham — Secretary (to 19 March 1991)
Patricia McDonald — Treasurer
(to 19 March 1991)
Deborah Matrice
(President from 19 March 1991)
Linden Orr (Secretary from 19 March 1991)
Pat Gold — Ordinary Member
Erica Fisher — Ordinary Member
Regina Slazenger — Ordinary Member
Judy Cole — Ordinary Member

1991–1992

Deborah Matrice — President
Linden Orr — Secretary
Janne Graham — Treasurer
Regina Slazenger — Ordinary Member
Erica Fisher — Ordinary Member

1992–1993

No records

1993–1994

No records

1994–1995

Janne Graham — President
David Roberts — Vice President
Helen Fisher — Secretary
Jane Cobley — Treasurer
Shane Marsh — Ordinary Member
Regina Slazenger — Ordinary Member
Anthony Roben — Ordinary Member

1995–1996

Janne Graham — President
David Roberts — Vice President
Anthony Roben — Secretary
Shane Marsh — Treasurer
Janet Phillips — Ordinary Member
Jane Cobley — Ordinary Member
Helen Fisher — Ordinary Member
Prue Borrman — Ordinary Member

1996–1997

Janne Graham — President
David Roberts — Vice President
Sheila Holcombe — Secretary
Shane Marsh — Treasurer
Thelma Hunter — Ordinary Member
Anthony Roben — Ordinary Member
Regina Slazenger — Ordinary Member

1997–1998

Janne Graham — President
Sheila Holcombe — Secretary
Shane Marsh — Treasurer
Regina Slazenger — Ordinary Member
Helen Slazenger — Ordinary Member
Thelma Hunter — Ordinary Member
Fiona Tito — Ordinary Member
Prue Borrman — Ordinary Member

1998–1999

Janne Graham — President
Russell McGowan — Acting President
(dates unclear)
Sarah Stringer — Secretary
Shane Marsh — Treasurer
Regina Slazenger — Ordinary Member
Fiona Tito — Ordinary Member

1999–2000

Russell McGowan — President
Marion Reilly — Vice President
Janne Graham — Secretary
Alec Percival — Treasurer
Regina Slazenger — Ordinary Member
Kate Moore — Ordinary Member
Prue Borrman — Ordinary Member

2000–2001

Russell McGowan — President
Darlene Cox — Secretary
Phillip Gleeson — Treasurer
Kate Moore — Ordinary Member
Marion Reilly — Ordinary Member
Regina Slazenger — Ordinary Member

2001–2002

Russell McGowan — President
Marion Reilly — Vice President
Phillip Gleeson — Secretary
Allan Hicks — Treasurer
Kate Moore — Ordinary Member
Barry Loughton — Ordinary Member
Regina Slazenger — Ordinary Member

2002–2003

Russell McGowan — President
Marion Reilly — Vice President
Phillip Gleeson — Secretary
Allan Hicks — Treasurer
Kate Moore — Ordinary Member
Regina Slazenger — Ordinary Member
Mary Sexton — Ordinary Member
Carolyn Minchin — Ordinary Member

2003–2004

Russell McGowan — President
Allan Hicks — Treasurer
Marion Reilly — Ordinary Member
Kate Moore — Ordinary Member
Regina Slazenger — Ordinary Member
Carolyn Minchin — Ordinary Member
Louise Bannister — Ordinary Member

2004–2005

Russell McGowan — President
Marion Reilly — Vice President
Kate Moore — Secretary
Allan Hicks — Treasurer
Regina Slazenger — Ordinary Member
Carolyn Minchin — Ordinary Member
Louise Bannister — Ordinary Member
Paula Calcino — Ordinary Member
Lynn Skinner — Ordinary Member
(to 20 June 2005)

2005–2006

Russell McGowan — President
Marion Reilly — Vice President
Kate Moore — Secretary
Sarah Stringer — Treasurer
Louise Bannister — Ordinary Member
Paula Calcino — Ordinary Member
Catherine Settle — Ordinary Member
Darlene Cox — Ordinary Member

2006–2007

Russell McGowan — President
Marion Reilly — Vice President
Kate Moore — Secretary
Vacant — Treasurer
Paula Calcino — Ordinary Member
David Lovegrove — Ordinary Member
Darlene Cox — Ordinary Member

2007–2008

Russell McGowan — President
Marion Reilly — Vice President
Kate Moore — Secretary
Bev McConnell — Treasurer
Adele Stevens — Ordinary Member
David Lovegrove — Ordinary Member
Judith Manning — Ordinary Member

2008–2009

Adele Stevens — President
Marion Reilly — Vice President
Russell McGowan — Secretary
Bev McConnell — Treasurer
Judith Manning — Ordinary Member
Dalane Drexler — Ordinary Member
Angela Wallace — Ordinary Member
David Lovegrove — Ordinary Member

2009–2010

Adele Stevens — President
Caroline Polak-Scowcroft — Vice President
Russell McGowan — Secretary
Bev McConnell — Treasurer
Dalane Drexler — Ordinary Member
Angela Wallace — Ordinary Member
David Lovegrove — Ordinary Member

2010–2011

Adele Stevens — President
Caroline Polak-Scowcroft — Vice President
Bev McConnell — Treasurer
Russell McGowan — Ordinary Member
Marion Reilly — Ordinary Member
David Lovegrove — Ordinary Member

2011–2012

Adele Stevens — President
Russell McGowan — Vice President
Bev McConnell — Treasurer
Caroline Polak-Scowcroft — Ordinary Member
Marion Reilly — Ordinary Member
David Lovegrove — Ordinary Member
Therese Findlay — Ordinary Member
Sharon Eacott — Ordinary Member
Sue Andrews — Ordinary Member

2012–2013

Sue Andrews — President
Adele Stevens — Vice President
Bev McConnell — Treasurer
Caroline Polak-Scowcroft — Ordinary Member
Therese Findlay — Ordinary Member
Sharon Eacott — Ordinary Member
David Lovegrove — Ordinary Member
Bill Heins — Ordinary Member
Michelle Banfield — Ordinary Member

2013–2014

Sue Andrews — President
Adele Stevens — Vice President
Bev McConnell — Treasurer
Caroline Polak-Scowcroft — Ordinary Member
Sharon Eacott — Ordinary Member
David Lovegrove — Ordinary Member
Bill Heins — Ordinary Member
Michelle Banfield — Ordinary Member
Fran Parker — Ordinary Member

2014–2015

Sue Andrews — President
Michelle Banfield — Vice President
Hugh Crawford — Treasurer
Adele Stevens — Ordinary Member
Bev McConnell — Ordinary Member
Bill Heins — Ordinary Member
Fran Parker — Ordinary Member
John Didlick — Ordinary Member
Marcus Bogie — Ordinary Member

2015–2016

Sue Andrews — President
Michelle Banfield — Vice President
Fiona Tito Wheatland — Treasurer
Louise Bannister — Ordinary Member
Marcus Bogie — Ordinary Member
John Didlick — Ordinary Member
Indra Gajanayake — Ordinary Member
Bill Heins — Ordinary Member
Marion Reilly — Ordinary Member

2016–2017

Sue Andrews — President
Michelle Banfield — Vice President
Indra Gajanayake — Treasurer
Fiona Tito Wheatland — Ordinary Member
Louise Bannister — Ordinary Member
Marcus Bogie — Ordinary Member
Marion Reilly — Ordinary Member
Shelley McInnis — Ordinary Member
Alan Thomas — Ordinary Member

2017–2018

Sue Andrews — President
Michelle Banfield — Vice President
Indra Gajanayake — Treasurer
Louise Bannister — Ordinary Member
Marcus Bogie — Ordinary Member
Marion Reilly — Ordinary Member
Shelley McInnis — Ordinary Member
Alan Thomas — Ordinary Member
Bernard Borg–Caruana — Ordinary Member

Appendix 3: Health Care Consumers' Association of the ACT — Patients' Bill of Rights and Responsibilities (1980)

Introduction

This document sets out your rights as a consumer of health care services. Some of these rights are protected by law, while others are simply moral rights which you can secure only by ensuring that the health practitioner you choose to attend is well disposed to observe the kind of relationship which you favour.

The first 12 rights outline those areas in which the law extends protection to people seeking the attention of a health practitioner. Each of the 12 rights has been expressed cautiously, since our law does not guarantee positively the rights of people, but leaves those rights to be inferred from various rules of law. It is important to bear this in mind.

Firstly, these rules of law govern the nature and extent of application of the 12 rights. For instance, the arrangement which you have with your health practitioner may afford you the protection of rights 7 and 8, although by implication or expression you may have agreed to waive those rights. This may occur, for example, if you raise no objection to a proposal by your health practitioner to forward your treatment records to another person, or if you comply with instructions for the rendering of a service without first asking about the cost, receiving an answer to your satisfaction and expressing your acceptance of whatever agreement is finally reached. The law of assault protects you from unauthorised bodily interference (rights 5 and 2), although consent may be inferred from silence or acquiescence on your part. Some of the other rights describe lawful conduct only in the sense that no law renders such conduct unlawful. Some rights which arise in this way (e.g. right 6), you may be asked to sign away upon admission to a hospital.

Secondly, in many of the instances outlined, the law affords protection only in the sense that there may be a remedy available (e.g. an action for damages). Every case, however, has to be looked at on its own merits, and a remedy may be available in one case but not in a very similar case.

Thirdly, legislation (existing or future) may take away any of these rights, either in general or in particular cases. This might occur, for instance, in legislation relating to infectious diseases, quarantine, or the care of mentally disturbed persons.

Rights 13–22 are not in general protected by law, although you may wish to take such matters into account in defining your relationship with the health practitioner of your choice, or in selecting a health practitioner who is well disposed to observe the kind of relationship which you favour.

The document concludes with 8 responsibilities and courtesies which you should observe in the interests of maintaining a sound relationship of mutual consideration and respect with your health practitioner.

Legal rights

You should be given a clear, concise explanation in lay person's terms of your condition, problems or disease.

Before any treatment or investigation is carried out, you should be given a clear, concise explanation in lay person's terms of the procedure which is proposed and any alternative procedure which may be available. Where applicable, the explanation should comment on risk of side effects or after effects, problems relating to recuperation, likelihood of success, risk of death, and whether the proposed procedure is of an experimental nature.

At any time you may seek a second opinion on your condition or treatment.

You are entitled at any time to seek alternative health care from any person you wish. Such people may include acupuncturists, chiropractors, osteopaths, herbalists, homeopaths, hypnotherapists, naturopaths and the like.

Your consent is required to any procedure carried out on you. At any time you may withdraw your consent and refuse any treatment or investigation you wish.

You should be informed if your treatment or investigation is an experimental procedure, or if it is purely associated with research objectives, or if it is to be administered by or in the presence of students or a person other than your health practitioner. You may refuse any treatment or investigation of this kind or manner.

You have a right to have the details of your condition and treatment kept confidential by your health practitioner and his staff, except where such information is required to be divulged by law.

Before any investigation or treatment you may request an estimate of expected costs and information to enable you to identify the intended procedure for health insurance purposes. You may also indicate how much you are prepared to pay. You may refuse the intended procedure if your health practitioner will not provide this information or if he will not accept the sum you indicate as full payment. After the procedure has been carried out, you are entitled to receive an itemised account.

You may specify in writing how you wish to be treated if you lose consciousness or the ability to communicate.

You may decline admission to hospital or any other health care facility. You may also leave at any time you wish. The facility, however, will have no liability for any injury or illness this may cause or aggravate.

You have a right to recover damages for injury or illness incurred or aggravated as a result of the failure of your health practitioner to exercise the standard of competence of the ordinary person professing his special skill. Negligence on the part of your health practitioner may also exist in cases where he fails to provide adequate instruction on self-care after investigation or treatment.

If you are a parent or guardian, you may exercise any of the above rights on behalf of your children or wards.

Moral rights

Where it is appropriate to your condition or treatment, you should be given advice about self-care, drug administration, special precautions which may be necessary or desirable, and the existence of special associations, facilities, aids or appliances which may be of assistance to you.

You are entitled to be treated with care, consideration and respect, regardless of your social status, source of payment, age, sex, race, religion or political beliefs.

You are entitled to ask the identity, professional status and qualifications of any health practitioner who attends you.

You should be allowed to inspect or claim all records of your own health care and to be given on request, a summary record of your condition and treatment. You should also be able to nominate another health practitioner to obtain independent access to your health records and inform you of what they contain.

If you are in hospital, or any other health care facility, you should be given full access to visitors and the telephone. Children and the terminally ill should be given access (on a full-time basis if they wish) to a relative or friend.

If you cannot speak or understand English, you should be allowed the services of an interpreter.

If you wish, you should be able to nominate a friend, advocate or representative to join you and your health practitioner in making decisions about your health care.

If you are in hospital, or any other health care facility, you should be able to decline to see visitors.

If you are in hospital, or any other health care facility, you should be consulted about any decision to discharge you or transfer you to another facility.

You are entitled to die with dignity.

Responsibilities

You should ensure that you know and understand what your rights are, and exercise those rights as required.

You should ensure that you have understood the purpose and cost of any proposed investigations or treatment. You should insist upon explanations until you feel properly informed, and consult with all relevant people before reaching a decision.

You should know your own and your family's history of health and health care.

You should keep appointments, or inform those concerned of your intention not to do so.

You should comply with prescribed treatment, or inform your health practitioner of your intention not to do so.

You should accept the consequences of your own informed decisions and not change your mind about treatment without good reason.

You should inform your health practitioner if you are currently in consultation with or under treatment from another health practitioner in connection with the same complaint.

You should recognise that you are solely responsible for all judgements and decisions made in relation to your own health care. Your health practitioner is at fault if he gives you incorrect information, or fails to give you complete information, but can neither be held liable for the outcome of your informed decision, nor expected to arrive at a decision on your behalf.

Health Care Consumers' Association of the A.C.T.

Canberra 1980



Image captions (page 66)

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2		3
4		5

- 1** HCCA, 2015 (L-R) Christine Bowman, Nasreen Hafesjee, Eleanor Kerdo, Nick Wales, Darlene Cox, Khalia Lee Roger Killeen Sandra Avila, Caitlin Stamford, Sue Andrews, Kathryn and Stephen Briant, Kerry Snell.
- 2** Consumer Representatives Steering Committee, (L-R) Caitlin Stamford, Adele Stevens, Pat Branford, Bev McConnell, Marion Reilly, Kerry Snell, Anna Saxon, 2014.
- 3** HCCA Consumer Representatives and Staff, 2016.
- 4** HCCA Executive Committee (L-R) Bev McConnell, Marcus Bogie, Fran Parker, Adele Stevens, John Didlick, Bill Heins, Sue Andrews, Michelle Banfield (Absent: Hugh Crawford), 2014.
- 5** (L-R) Russell McGowan, Caroline Polak Scowcroft, Darlene Cox, Marion Reilly, Adele Stevens, Sharon Eacott, 2011.



Image captions (pages 68)

6	7	8
9	10	
11	12	
13	14	

- 6** Janne Graham, 2011.
- 7** Anna Saxon, undertaking an assessment of public transport access at Village Creek Rehabilitation Centre, 2012.
- 8** Roger Killeen and Darlene Cox, 2015.
- 9** Yelin Hung and Adele Stevens at the opening of Gungahlin Community Health Centre, 2012.
- 10** Michelle Banfield, Sue Andrews, Eleanor Kerdo, Fiona Tito Wheatland, 2015. Members of the Health Policy Advisory Committee.
- 11** Nick Manikis (Director of the Officer of Multicultural Affairs), Yelin Hung, Yvette Berry MLA (Minister for Community Services and Multicultural Affairs), Darlene Cox. HCCA – Winner of the Community Organisation Award in ACT Multicultural Awards 2015.
- 12** Consumer Training, 2011.
- 13** HCCA Executive Committee 2018, (L-R Back) Alan Thomas, Indra Gajanayake, Sue Andrews, Marcus Bogie, Bernard Borg-Caruana, Shelley McInnis, Nicole Banfield. Seated (L-R) Sue Andrews, Lou Bannister, Marion Reilly.
- 14** HCCA Election Form for 2016 ACT Election. (L-R) Indra Esguerra (ACT Greens), Meegan Fitzharris MLA (ACT Labor), Sue Andrews, Jeremy Hanson MLA (Canberra Liberals).



Image captions (pages 70)

15	16	
17	18	
19	21	
20		
22	23	24

- 15** HCCA Staff re Drop the Jargon Day 2017.
- 16** Darlene Cox, Bill Heins Bev McConnell, Sue Andrews, Adele Stevens, Sharon Eacott, Caroline Polak Scowcroft, Michelle Banfield and Janne Graham, 2013.
- 17** Executive Committee (L-R) Bernard Borg-Caruana, Michelle Banfield, Shelley McInnis, Marion Reilly, Marcus Bogie, Indra Gajanayake, Darlene Cox (Executive Director), Sue Andrews, Alan Thomas. Absent: Louise Bannister, 2018.
- 18** Kerry Snell and Marion Reilly, 2010.
- 19** HCCA meeting in 2002.
- 20** Sandra Avila, Darlene Cox, Eleanor Kerdo, Caitlin Stamford and Nick Wales, 2014.
- 21** Shelley McInnis, Meegan Fitzharris and Sue Andrews, 2017.
- 22** Darlene Cox celebrating HCCA's 30th anniversary, 2008.
- 23** HCCA Evaluation Working Group — Shelley McInnis, Russell McGowan, Alan Thomas. Other members: Michelle Banfield and Wendy Armstrong, 2017.
- 24** Sue Andrews, Adele Stevens and Bill Heins, 2013.

Image captions (cover)

25	26	27	28	29
30	31	32	33	34
35	36	37	38	39
40	41	42	43	44
45	46	47	48	49

- 25** Consumer and Participation Team, Jill Moran, Kate Gorman and Claudia Cresswell, 2018.

26 Janne Graham with Chief Minister Gallagher, 1 Sept 2011.

27 Kathryn Briant with her son Steven.

28 Darlene Cox and Sandra Avila.

29 Nicholas Wales and Kerry Snell.

30 Adele Stevens and Denise Mott.

31 Bernard Borg-Caruana and Roger Killeen.

32 Yelin Hung and Sam Wong.

33 Margaret Wolf and Margaret McCulloch.

34 Fran Parker and Alan Thomas.

35 Sue Andrews and Fiona Tito Wheatland.

36 Marcus Bogie.

37 Darlene Cox, Louise Bannister and Kerry Snell.
- 38** Bill Heins and Russell McGowan.

39 Jo Bothroyd and Trish Lord.

40 Pam Graudnez.

41 Roger Killeen.

42 Yelin Hung, Sally Deacon and Bernard Borg-Caruan at the Press Club My Health Record, 2018.

43 Kathryn Briant and Fiona Tito Wheatland.

44 Caroline Polak Scowcroft.

45 Bev McConnell, Marion Reilly, Kerry Snell and Anna Saxon, 2013.

46 Audrey Guy.

47 Khalia Lee.

48 Ian Trehwella.

49 Karen Jameson and David Lovegrove.

Image captions (page 26)

50	51	52
	53	54

- 50** Minister for Health Meegan Fitzharris and Darlene Cox, 2016.
- 51** HCCA Consumers looking a the new hydrotherapy pool, 2018.
- 52** Tina Bracher — Executive Director Mental Health, Kate Gorman, Linda Kohlhagen Executive Director — Rehabilitation, Aged and Community Care and Dr Sue Andrews, 2018.
- 53** Bea Vann and Dr Sue Andrews, 2018.
- 54** Kate Gorman and Minister for Health Meegan Fitzharris, 2018.

Image captions (page 74 and 75)

- Left:** Agenda of the first Annual General Meeting, 28 November 1976.
- Right:** Flyer of Health Care Consumers’ Association in 1981.

AGENDA 1ST ANNUAL GENERAL MEETING

HEALTH SERVICES CONSUMERS' ASSOCIATION OF THE A.C.T.

1. OPENING
2. MINUTES OF THE PRECEDING GENERAL MEETING
3. MATTERS ARISING FROM THE MINUTES
4. REPORT ON INCORPORATION
5. DISCUSSION OF PROBLEMS RELATING TO INCORPORATION
6. TREASURER'S REPORT
7. PRESIDENT'S REPORT
8. DISCUSSION OF CONSTITUTIONAL MATTERS
9. ELECTION OF OFFICE BEARERS AND APPOINTMENT OF AUDITOR
10. GENERAL BUSINESS
11. GUEST SPEAKER

DR. MALCOLM WHYTE OF THE CAPITAL TERRITORY HEALTH COMMISSION

WILL SPEAK ON PROPOSALS FOR TREATMENT OF ALCOHOL AND DRUG

ADDITION PROBLEMS IN THE A.C.T.

TO BE HELD ON NOVEMBER 28TH 3P.M. CONFERENCE ROOM GROUND FLOOR
MAIN BUILDING WODEN VALLEY HOSPITAL

HEALTH CARE CONSUMERS ASSOCIATION OF THE A.C.T. (INC)

WHO ARE WE

WE ARE A REGISTERED ASSOCIATION. WE SEEK TO IMPROVE THE QUALITY AND AVAILABILITY OF HEALTH CARE SERVICES THROUGH CONSUMER INVOLVEMENT.

WHAT DO WE DO

WE INVESTIGATE THE AVAILABILITY OF HEALTH CARE IN THE A.C.T.
WE ASSESS THE ADEQUACY OF HEALTH CARE SERVICES FROM THE CONSUMER'S POINT OF VIEW.

WE ADVISE PEOPLE ABOUT EXISTING HEALTH CARE SERVICES.

WE ADVISE PEOPLE OF THEIR RIGHTS AND RESPONSIBILITIES AS HEALTH CARE CONSUMERS.

WE SEEK TO IMPROVE HEALTH CARE SERVICES THROUGH CONSUMER CONTACT WITH HEALTH PROFESSIONALS AND HEALTH CARE AUTHORITIES.

WE PROMOTE GOODWILL BETWEEN THOSE WHO RENDER AND THOSE WHO CONSUME HEALTH CARE IN THE A.C.T.

WHY DO WE EXIST

SICK PEOPLE ARE VULNERABLE. WE EXIST TO HELP SICK PEOPLE OBTAIN APPROPRIATE HEALTH CARE, WITH PROPER ATTENTION TO THEIR RIGHTS AND RESPONSIBILITIES AS CONSUMERS OF HEALTH CARE SERVICES.

HOW CAN YOU FIND OUT MORE

CALL OUR SECRETARY, DAWN CHAMBERLAIN, ON CANBERRA 812074.

HOW CAN YOU JOIN

FILL OUT YOUR NAME AND ADDRESS IN THE SPACE PROVIDED BELOW AND SEND THIS FORM, WITH A CHEQUE OR POSTAL ORDER FOR \$10.00, TO:

THE SECRETARY,
HEALTH CARE CONSUMERS ASSOCIATION OF THE A.C.T. (INC)
G.P.O. BOX 1659,
CANBERRA ~~ACT~~ A.C.T. 2601.

I WISH TO JOIN THE ASSOCIATION, AND ENCLOSE ANNUAL MEMBERSHIP FEE OF \$10.00. (concessional membership \$5.00 - pensioners, students etc.)

NAME: _____

ADDRESS: _____

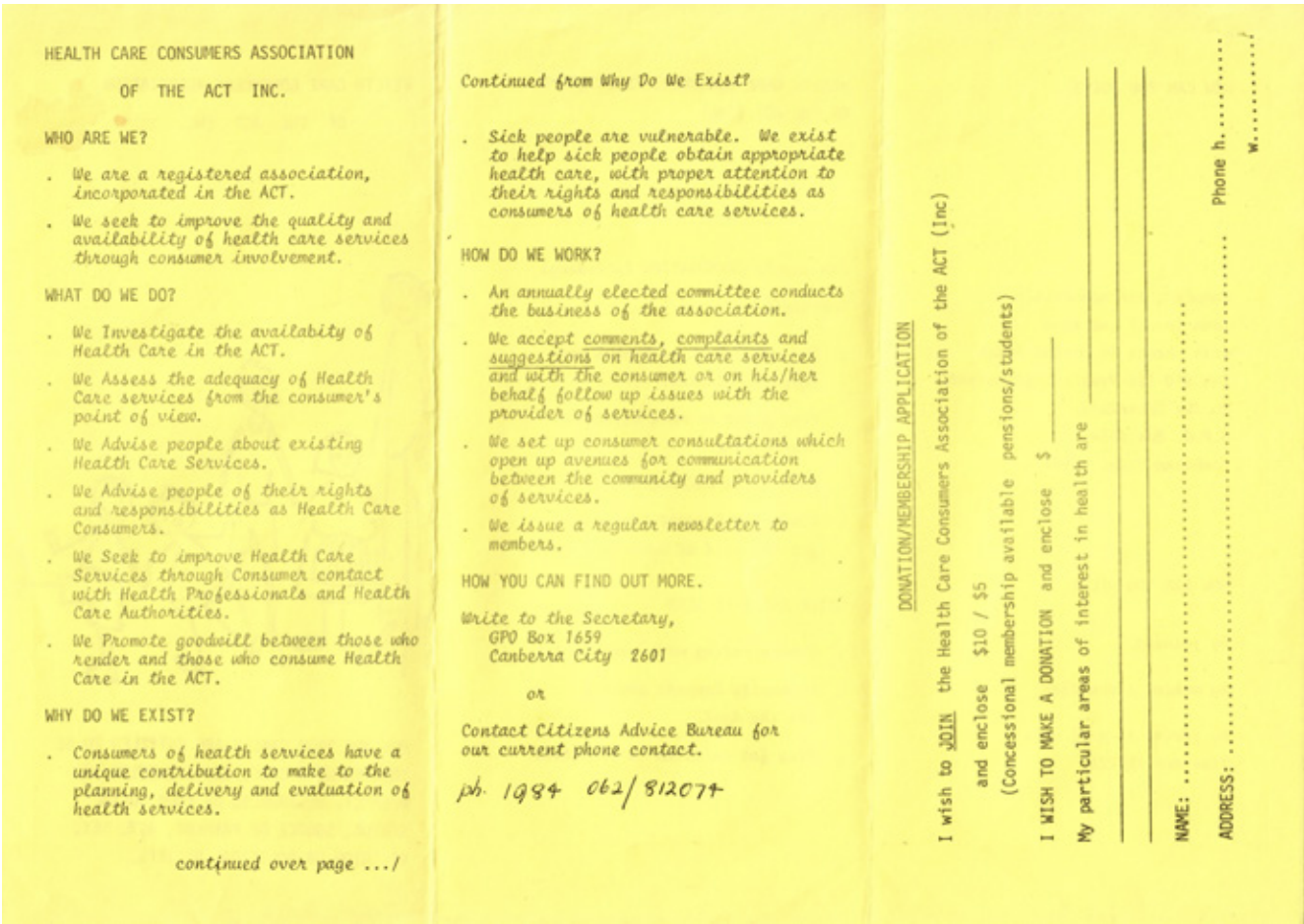
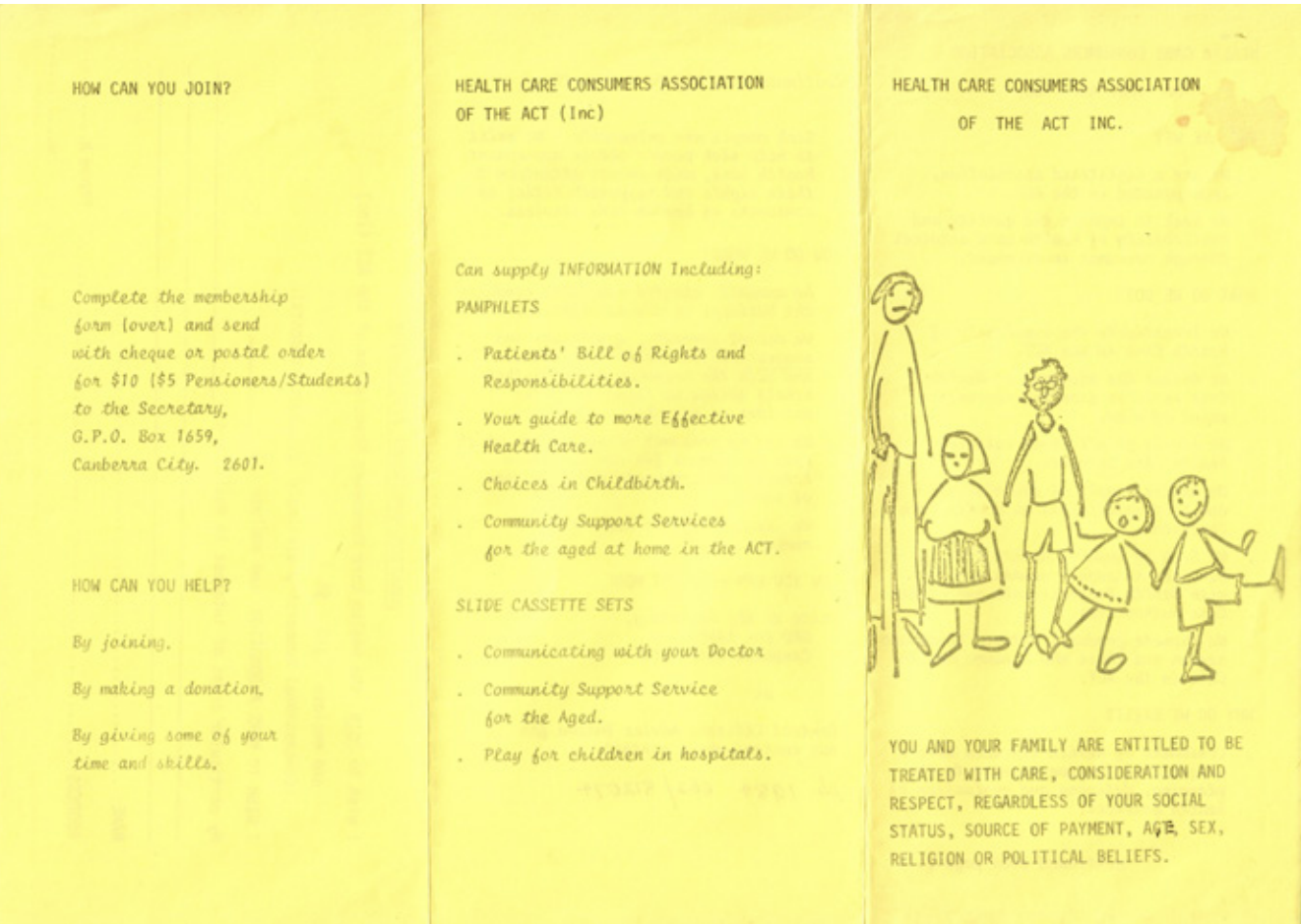
PostCode _____

(No. of) _____

(W) _____

HEALTH CARE CONSUMER'S ASSOCIATION OF THE A.C.T. (INC)
CANBERRA.

1981.



Above and right: Organisational flyer and membership application form, 1984.

Making a noise:
40 years of consumer health
advocacy in the ACT

hcca.org.au

