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HCCA Submission to the Local Hospital Network Community Consultation on ACT Public Health Services

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Background

The **Health Care Consumers' Association (HCCA) of the ACT** was incorporated in 1978 to provide a voice for consumers on local health issues and now provides opportunities for health care consumers in the ACT to participate in all levels of health service planning, policy development and decision making.

HCCA involves consumers through:

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

In 2008, State and Territory Health Ministers endorsed the Australian Charter of Healthcare Rights. The Charter was developed by the Australian Commission for Safety and Quality in Health Care and applies to all people receiving, seeking or delivering health care in all settings in Australia. The Charter was launched in the ACT in December 2009 by the Health Minister, Ms Katy Gallagher MLA. HCCA believes that a shared commitment to the Charter will improve the safety and quality of health care for all consumers.

The Australian Charter of Healthcare Rights states that all consumers have the right to:

- **Access** – to have timely access to health services that address our needs
- **Safety** – to receive safe and high quality care
- **Respect** - to be shown respect, dignity and consideration
- **Communication** – to be informed about services, treatments, options and costs in a clear and open way
- **Participation** – to be included in decisions and choices about our care as well as health service planning
- **Privacy** – to have our privacy maintained and proper handling of our personal health information assured
- **Comment** – to comment on or complain about our care and have our concerns addressed properly and promptly

It is with reference to these rights that the HCCA has developed its submission to the Local Hospital Network (LHN) Council Consultation on Canberra's Public Health services.

Introduction

HCCA welcomes the opportunity to provide feedback to the LHN Council on the consumer experience of Canberra's public health services. Our feedback is based on the key issues raised in our submissions in recent years as well as a number of case studies received from our members as a result of our call for input. Our focus has been on public hospital services.

A number of our members have expressed frustration over the lack of engagement with the feedback they provide to the ACT Health Directorate in the past. Consumers put a lot of effort into recording and compiling their experiences accessing health services in the hope that they will be able to contribute to improving the health system. For many consumers the process is emotionally draining, requiring them to take risks in disclosing personal information which often involves recounting highly personal and at times traumatic details. It is disappointing, then, for consumers to learn that although their feedback has been received, few if any changes have actually been made or sustained.

Similarly, in working with the Health Directorate and consumers, we often witness a divide between what is happening on paper and what is being experienced by consumers first hand. Clinicians and frontline staff need to be more effectively engaged with reform processes if real progress is to be made.

The consumers who have provided their stories for this submission have all commented that their main reason for contributing was to ensure that what happened to them would not happen to anybody else.

For this reason, it is absolutely essential for the LHN Council to ensure that the actions taken following this consultation do justice to the consumers who have provided feedback. Although we understand that not all systemic issues can be addressed straight away, there needs to be clear strategies put in place to continue working towards improvements in these areas. Consumers also need to be kept up to date with process following community consultations. Two-way communication will ensure that members of the community are able to maintain faith in the LHN and continue to engage in consultations in the future. As one of our members has commented:

“One remains very sceptical as my efforts appeared to be unwelcome and I was not kept informed on progressive changes on the issues raised”

We encourage the LHN Council to consider how you will respond to the submission and report on any changes made as a result of the material collected.

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1. The Good News

HCCA understands that health reform is an enormous task and that there is no one simple strategy or solution to solve all of our problems. While there is much work still to be done, there has been some encouraging progress made over the past few years. For instance, new health facilities such as the Belconnen and Gungahlin Community Health Centres and the Neonatal Intensive Care Unit (NICU) and Special Care Nursery (SCN) in the Centenary Women and Children's Hospital (CWCH) are addressing previously unmet need in our community and are highly valued by our members.

Programs such as the Health Services Directory website and mobile app are helping consumers to navigate the system and to access the care they need, when they need it. COMPASS and Early Recognition of the Deteriorating Patient has been one of the most exciting initiatives at the Canberra Hospital and has shaped the quality and safety agenda at the national level. COMPASS is a set of tools that assist the bedside nurse in the early recognition of deteriorating patients, and empower them to initiate an appropriate medical review and timely medical management before the patient deteriorates to the point to which they require dramatic intervention. In addition, tele-health initiatives are providing essential health care advice on demand that consumers are able to access from their homes.

We are also happy to see that seclusion rates have been reduced for mental health consumers, which is a positive step towards addressing a serious issue of safety for consumers.

The ACT Health Directorate is a national leader with regard to consumer representation. We want to particularly commend the decision to include consumer representatives in the clinical review and audit processes, and see that this will lead to significant improvement in the quality and safety of health services. Other examples of good practice include: involving consumers in selection panels of senior staff, involving consumers in key decision making committees (Executive Council and Redevelopment Committee) and the appointment of the Patient Experience Leader.

The Health Infrastructure Program (HIP) is a significant body of work for the ACT Government and has great potential to bring about structural changes to clinical practice, and to improve efficiencies as well as health outcomes for consumers. We commend the decision to provide funding for strong, effective consumer input to this Program to assist in developing solutions to intractable problems in our health system.

In particular, funding provided for a Multicultural Liaison Officer (MLO) at HCCA is proving to be an effective means of increasing the engagement of the ACT's Culturally and Linguistically Diverse Communities (CALD) with regard to health reform.

2. Access

Consumers need to be able to access the health care they need, when they need it. Our comments refer to both general barriers to care as well as problems accessing particular types of health services.

2.1. End of life care

As the ACT population continues to age, end of life care will increasingly become one of the most important challenges for the health system to address. Our members are very keen to see a strong focus on improving palliative care services and ensuring that end of life care is provided in accordance with the wishes of the consumer. Initiatives such as Advance Care Planning have been welcomed as positive steps towards achieving this, but more needs to be done to ensure that health system will support staff to engage with palliative care reform.

2.1.1. Reducing futile care

Futile care continues to be a major health issue throughout the world, not only subjecting the consumer to unnecessary aggressive treatments that reduce their quality of life, but also wasting valuable health resources that could be put to better use treating other patients. Despite clinicians' understanding of futile care, it remains a common issue in acute care settings. Futile care needs to be reduced, particularly in the emergency department (ED) which tends to focus on saving lives rather than preventing unnecessary discomfort. This will require both systemic change across acute health services and open discussion between clinicians and consumers.

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

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

Better engagement with clinicians in the acute sector will be essential in order to reduce futile care. Palliative Care staff at TCH, such as the Palliative Care Nurse Practitioner working in the ED, allow clinicians to minimise futile care and to move patients to services outside TCH. Increasing both the nursing and medical palliative care staff at TCH would provide ready access for palliative options and provide better alternatives for patients and support for alternative options to futile care for TCH clinicians.

2.1.2. Reducing burdensome transitions at the end of life

Another issue that needs to be addressed is burdensome transitions. These are defined as transitions between the hospital, nursing homes and their own home within the patient's final three days of life¹. As with futile care, these transitions are of little, if any, benefit to the

¹ Pedro Gozalo, et al. (2011). 'End-of-Life Transitions among Nursing Home Residents with Cognitive Issues' in *The New England Journal of Medicine*, 365: 1212-1221.

patient and can cause considerable discomfort, while transport resources, that could have been better allocated elsewhere, are wasted. It also puts pressure on the patient's family, who have to arrange the transport themselves, in some cases, and make sure the patient has the necessary belongings with them. This was the case for one of our consumers, who spent the final days of her father's life frantically running around Queanbeyan and the ACT trying to furnish a room in a RACF and assist the father to attend specialist appointments outside of the hospital. One specialist realised that the father was not in a fit state to come to his clinic for an appointment and made arrangements to visit him in hospital instead.

2.1.3. Improving access to palliative care services

One of the main issues with palliative care that still needs to be addressed is ensuring that both clinicians and consumers are able to recognise when palliative care needs to commence. If palliative care begins too late, the quality of the care will also be compromised. We have received many consumer stories where this has been the case, resulting in distress to both the patients and their families and lost opportunities for a good death.

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

2.2. Pain Management

Access to pain relief is considered a human rights issue. Nationally, it is estimated that less than 10% of people experiencing chronic non-cancer pain receive adequate treatment. Regarding acute pain, it is also estimated that 50-75% of patients are not receiving adequate pain relief in hospitals. In both cases, there exists potential to effectively treat 80% of these patients.²

2.2.1. Acute pain management

Pain is an important area of focus for hospitals as inadequate treatment of acute pain (after surgery, for example) increases the risk of progression to chronic pain³. Anecdotally we know that acute pain remains undertreated in many Australian hospitals. One of our members suggested that a patient education brochure along with verbal explanation of the how to score pain be developed in partnership with consumers to increase patients' understanding of pain assessment and measurement in public hospitals.

² National Pain Strategy (2010). Pain Australia. <http://www.painaustralia.org.au/the-national-pain-strategy/national-pain-strategy.html>

³ P. 5 NSW Pain Management Report of the NSW Pain Management Taskforce (2012) <http://www.health.nsw.gov.au/cdm/Documents/NSW%20Pain%20Management%20Taskforce%20Report.pdf>

We note that in the Report 5 of the Healthcare Survey that there has been some improvement for patients in having their pain levels reduced as inpatients in the Canberra Hospital. We would like to continue to see improvement in this area. This raises a question about the performance of Calvary Public Hospital in this regard. We are keen to see an improvement in the way in which the performance of all public hospital services in the Local Hospital Network is reported on.

Despite this, pain is often poorly managed and stigmatised in the community. When consumers present with pain symptoms to the ED, they are often met with scepticism or accused of hypochondria, particularly when the cause of the pain is not readily apparent. Consumers also express frustration when they are given a particular pain medication despite explaining that they have used it in the past to no avail.

Timely access to analgesia is essential not only for the short term relief of the patient, but also to prevent the risk of the pain becoming chronic. In our submission on qualitative indicators in the ED, we argued that 'time to analgesia' should be considered as an indicator.

2.2.2. Chronic pain management

In March, 2013, HCCA was involved in facilitating that Australian Pain Management Association's Living Well with Pain Consumer Symposium and Forum. The forum was attended by over 200 consumers from the ACT and surrounding regions. During discussion in small groups, consumers were asked to identify areas in our health services that could be improved in order to provide better chronic pain management.

In general, the main barriers to accessing effective treatment were considered to be waiting times and costs of services. The Canberra Hospital is currently the only public treatment centre for chronic pain for Canberra and the south-east region of NSW, catering to a population of more than 500,000.

Consumers agreed that the Canberra Hospital Chronic Pain Clinic was a valuable service, but that the wait times created access problems for some people. The Chronic Pain Team at Canberra Hospital currently has a wait list of 15 months, with an increasing number of urgent cases further affecting people already on the wait list. Consumers also expressed frustration regarding the need to travel interstate to access Rheumatology and Paediatric Pain services.

Another concern was access to education programs informing both consumers and clinicians on managing pain and the side effects associated with different pain medications. Consumers would particularly like to see more cross-speciality consultation and collaboration through means such as case conferencing.

2.3. Women's sexual and reproductive health services

The Women's Centre for Health Matters (WCHM) is a member of HCCA and has raised with us concerns that Calvary Public Hospital is not meeting the sexual and reproductive healthcare needs of ACT women to an acceptable standard. They are keen to complete further research to understand the impact of Calvary Public Hospital's Catholic ethical code on the quality of care it provides to its patients.

They are particularly concerned about how Calvary Health Care ACT's policies and procedures related to sexual assault victims, emergency contraception, advice and access to contraception, and ante-natal screening are defined. We agree with the WCHM that it is unacceptable that the services that Calvary Public Hospital provides to women in this critical situation remain, at the very least, undefined, and at worst, inadequate.

2.4. Transport

Consumers who are unwell or live with a disability often find it difficult to arrange transport to their various medical appointments. They may be unable to drive due to their condition or the medication they are taking, and financially restricted as a result of having to take time off work and their medical costs.

Public transport is also problematic, as bus schedules often do not align with appointment times and may be jarring and uncomfortable for some consumers.

Although there are some community transport services available, eligibility requirements and high demand prevent many consumers from accessing them. One consumer told of being informed over the phone that they were no longer eligible to receive transport due to a change in policy that meant they would only transport consumers over the age of 65. As a result, the consumer must rely on friends or family being available to take them to their appointments at the Canberra Hospital. We are aware that Belconnen Community Services seem to be more flexible in their approach and are able to provide transport for people under 65 years, this may explain why we have not received the same level of comment about consumer access to Calvary Public Hospital.

2.5. Waste in the system: delays in discharge

We have heard a number of stories from consumers about delayed discharge from hospital. We know that these stories refer to the problem of 'bed block'. We understand this to mean that people who are occupying a hospital bed when they no longer need the services provided in an acute setting. This is a breakdown in the health and social care system which cannot provide the type of care they need. This can be because the decision to discharge was taken too late in the day to put appropriate plans in place, delays in patient transport services (including family availability), delays in accessing appropriate equipment for use at home or delays in receiving the take home medication.

We understand that the discharge lounge at the Canberra Hospital is underused and would encourage further work into this area.

In 2011 Calvary Public Hospital undertook significant work in improving their patient flow through the hospital to address access block issues⁴. They introduced Patient Journey Boards and the Patient Flow Unit to have a more coordinated approach to the way in which patients move through the hospital. The Patient Journey Board is a large magnetic whiteboard that is near the nurses' station. It contains de-identified information about the patients and it means that the commonly asked questions are answered at a glance: When is the patient going home? Has the patient been referred to Allied Health? What is the status of the referral? The treating team, the patient and their family can all see this information.

⁴ HCCA Blog 23 September 2011. <http://hcca-act.blogspot.com.au/2011/09/patient-journey-boards-improving.html>

The manual whiteboard is a common method for tracking patients and their care planning within the clinical space. The HCCA blog post identifies other facilities using similar approaches. There needs to be a common approach across the LHN for managing patient flow to remedy the delayed discharge processes experienced by consumers.

2.6. Principles of Access in Site Selection

The selection of the sites for health services is very important; they need to be accessible, which means close to major transport routes. HCCA has been very supportive of the decision to build a sub-acute hospital at the University of Canberra. The University of Canberra is located to arterial roads and public transport, has sufficient area for dedicated parking, is close to the Belconnen Town Centre and is within easy travelling distance for people living in Gungahlin and the future Molonglo Valley development. In addition, it will create valuable connections with the Faculty of Health Science and provide clinical placements for students. Similarly the site selection of the Belconnen and Gungahlin Community Health Centres are excellent. In future work for the Health Infrastructure Program we would like to see access and proximity to major transport routes as a major criterion for site selection.

Consumers need to be able to access quality health services regardless of where they live in the ACT or surrounding regions.

One of the failings of the Village Creek Rehabilitation Centre was the site selection. Once you are inside the building, the services are excellent but being tucked away in a suburban setting has caused difficulty for some consumers and carers when accessing the Centre.

2.7. Service integration and role delineation

HCCA is supportive of role delineation and integrated, networked hospital services. We have previously raised concerns about the efficiency of running two hospitals (Calvary and TCH) with different governance structures. An example of duplication is the current work on developing a Care of the Dying Clinical Pathway and Quality and Safety Framework. We would like to see stronger collaboration in developing policies and strategic framework that apply to both public hospital. We believe overall improvement in services would be enhanced by a clarification of the role of the existing Calvary Public Hospital.

Integration of the services across both The Canberra Hospital and the new hospital campuses will provide huge benefits, including improved staffing arrangements, integrated health care, clinical information and improved health outcomes.

We support the assertion made by Professor John Dwyer in 2007 when he wrote about role delineation in the Mersey Hospital in Tasmania:

“The community must understand that all hospitals cannot provide a full range of services. Their ability to offer services of quality and safety must be the major factors determining role delineation. The distressing level of misadventure in our hospitals is most often related to a mismatch between patient needs and the available skills. It is essential, therefore, that hospital services be networked ... Individual hospitals must no longer act as islands in an

ocean of health care but rather be part of a network of hospital services where the role of each hospital is carefully delineated, safety and quality being major determinants.”⁵

We believe that delineating the roles of these facilities allows the health system to operate more efficiently, by integrating support services, staff profile, safety standards and requirements, thereby ensuring clinical services are provided safely and with appropriate support. The ACT Health Directorate is in the process of finalising the ACT Clinical Services Plan for public health services. We strongly recommend that a communication strategy be developed regarding role delineation and networking of clinical services.

3. Safety

Safety and quality of health care is one of the top priorities for consumers and is integral to consumer-centred care. Consumers place a lot of trust in clinicians to deliver effective treatment and take care of their health. In many cases, our lives are in your hands. It is therefore essential that we are able to identify problems within health services that can compromise safety and that the ACT Government makes it a priority to address these areas.

3.1. Medication safety

We are concerned that some nursing staff lack the training and risk awareness to accompany the prescription of strong pain medication such as Endone. While staff are often on high alert for adverse reactions to opiates in elderly patients, this does not appear to be the case for younger consumers. One consumer has described suffering a severe allergic reaction to this medication as well as oxycodone on two separate occasions. Their symptoms included strong and sudden suicidal drives, with no history of depression or suicidal behaviour. Despite the large number of highly visible symptoms, including an inability to gain consciousness, none of the nursing staff or doctors suspected that this was a result of the medication even though the consumer was only being treated for a lower back and leg injury.

It is also essential that hospital staff are aware of each patient's allergies as well as the medications they have been taking prior to being admitted to hospital. We have received a number of stories describing instances when this information has been overlooked, resulting in severe and at times life-threatening adverse reactions.

3.2. Clinical handover

Improvements in this area can avoid lengthy delays for consumers. Communication between hospital staff and patients' GPs is important to ensure relevant medical histories are taken into account. Significant information about the patient's medical background is often overlooked because there has been no exchange of information between ED staff and the patient's GP. Medical history is particularly important when patients have one or more pre-existing chronic conditions.

HCCA is aware of several instances where consumers' have presented to the ED with a referral from their GP containing comprehensive information about their condition only to be

⁵ John Dwyer, Splintered healthcare, divided responsibilities, Online Opinion retrieved on 30 March 2011 <http://www.onlineopinion.com.au/view.asp?article=6430&page=0>

placed in the queue to see an ED doctor for another diagnosis. One woman reported presenting the ED with a detailed referral from her GP only to have to wait to be seen by a junior doctor in the ED who appeared to have far less experience than the woman's GP.

Consumers have also spoken of overhearing their condition and treatment being discussed loudly in hallways during shift changes in the ED and inpatient wards. This issue relates to respect as well as safety, as their privacy is being breached.

3.3. Clinical documentation

Our members have often expressed frustration over the lack of accurate clinical documentation in hospitals as well as the failure to integrate information from different wards, specialists and GPs. We see this as a serious safety issue. Both patients and their family members describe watching as a nurse or clinician writes down something in the patient's file that does not reflect reality or is belittling. In one instance, a patient presenting to the ED saw a nurse write 'hypochondria' on their file, only to be later diagnosed with a life-threatening infection. Other comments indicate that the patient has been acting belligerently, which is exasperating to consumers who are trying to get someone to listen to their health concerns.

In some cases, nurses have even refused to record events or symptoms that the patient considers highly significant in their file. One nurse refused to record seizure events in a patient's file despite witnessing the patient collapse and lose consciousness on several occasions. Failing to record information like this puts the patient at risk of receiving inaccurate diagnosis and increases the likelihood that medical errors will occur.

At other times, family members and patients have witnessed important consultations take place that have led to a health care incident or indicated that something had gone wrong, but on investigating further found no record of these consultations or conversations ever taking place. When this happens, the consumer then has nothing to support their claims regarding what has happened, and no one can be held accountable for the errors that are made.

3.4. Care of mental health consumers

3.4.1. Mental health consumers in the ED

EDs represent the primary source of 24 hour care available to consumers suffering from an acute episode of mental illness. EDs were not designed to deal with mental illness, therefore treatment for mental health consumers within the ED is usually unsuitable. A recent Australian study found that many ED staff are not confident in their ability to effectively manage mental health consumers and have expressed concerns about personal safety and security. In many cases, people presenting with mental health problems require urgent attention, but often have to wait for long periods of time due to a lack of available resources.

Having a volunteer or staff member in the ED with Mental Health First Aid training would be highly beneficial for mental health patients experiencing a crisis. For instance, if a person presented to the ED and felt as though they were about to have a panic attack, the volunteer could help them to calm down and control their breathing.

3.4.2. Health care for consumers with mental health flags

HCCA has received a number of particularly disturbing accounts of patients being discriminated against and having the quality of their care compromised as a result of their history of mental illness. In one situation, the person's mental health diagnosis had been withdrawn, but this was not recognised and still impacted negatively on the person's care. It is alarming that this level of stigmatisation is present among health professionals who have a duty of care to these consumers.

It is the right of every individual to receive quality health care and be treated with respect at all times. Clinicians need to be willing to listen to what patients have to say and take their concerns seriously. For mental health consumers, this often does not occur due to stigmatisation and clinicians believing that the patient is merely making up their symptoms. The use of strong medications that decrease cognitive function or alter mental states also means that the patient will be less able to engage with their health care, ask questions and raise concerns if they believe the care they are receiving is insufficient.

One person commented that it wasn't until many years after struggling with the health system that a doctor from Calvary finally sat down with her and said 'tell me what's wrong with you'. Making assumptions about patients based on their past history is not only disrespectful, but can also be life threatening. In this instance, doctors and nurses assumed that the patient was exaggerating their symptoms and failed to recognise that they were actually suffering a severe allergic reaction to the pain medication they had been prescribed. This incident resulted in severe emotional and physical trauma to the patient, who is still recovering to this day.

3.5. Hepatitis C Management

HCCA supports the recommendations made by the ACT Hepatitis Resource Centre (ACTHRC) in their submission to the LHN:

3.5.1. Improving access to Hepatitis C treatment

Nationally and locally, Hepatitis C is undertreated, with fewer than 2% of the infected population is treated each year. Despite effective treatments being available, the size of the infected population continues to grow. ACT Health must find ways to treat more people for hepatitis C. This could be done by increasing treatment capacity at the Liver Clinic, piloting new models of care whereby Hepatitis C treatment is provided at Building 7's Opioid Treatment Service and/or residential drug treatment services, or driving the transition to treatment being provided by GPs in the community.

In order to understand the ACT's performance compared with other jurisdictions and national targets, the public must have access to simple data about the provision of hepatitis treatment in the public hospital. HCCA strongly urges that ACT Health works with the ACTHRC to put this data to good use.

3.5.2. Access to needle and syringe programs

Needle and syringe programs are an evidence-based cost-effective intervention proven to prevent hepatitis and HIV infections in the community. Currently there is no public access to

sterile injecting equipment at the Canberra Hospital. In comparison with most other hospitals, this is an anomaly. Whether through the Walk-In Clinic, Emergency (as is done in very many hospitals in Australia), Building 7, Building 5 or via a syringe vending machine (already ACT Health operates about 6 of these machines in the community), the Canberra Hospital needs to provide access to sterile injecting equipment for those who need it. The Government's own Drug Strategy commits to expanding access to sterile injecting equipment via health services, and therefore the Canberra Hospital should lead in this regard. These comments apply also to Calvary Hospital.

4. Respect

The way in which consumers and carers are treated by staff while accessing health services has a great impact on their experience and well-being. Patients almost always recall nurses or doctors who treated them with respect and comment on the huge difference that it made. In contrast, when staff treat patients with disrespect by ignoring them or displaying a negative attitude towards them, it is highly distressing and often identified as compromising the patient's recovery.

4.1. Listening to the patient

In many of the stories we have heard from our consumers, they speak about raising their concerns with staff prior to or during an incident only to be ignored. Often, it turns out that the consumer was right, and had they been listened to and treated with the respect they were entitled to, the incident would not have occurred.

One woman described having a junior doctor attempt to carry out a draining procedure three times without success, causing her excruciating pain. After the first attempt, both the woman and her partner repeatedly asked for a senior doctor to take over the procedure, as the pain relief being provided was inadequate, but were ignored. Eventually, a nurse stepped in and asked for woman to be returned to her ward, as she was obviously traumatised. This experience had a severe impact on the consumer, who required counselling for anxiety and acute stress disorder.

While still in the hospital, the same woman was visited by three junior nurses who said they would 'have a go' at collecting a blood sample from her even though she was considerably dehydrated. Although the woman had recently undergone neck surgery and informed them of this, the nurses removed the pillow supporting her head to use to prop her arm up. This left the woman in a very uncomfortable position. While attempting to take the blood sample, the nurses ignored the woman's suggestion that they would be more successful if they went for a vein in her elbow as well as her request that a senior nurse be called to collect the blood. Once again, the junior nurses were unsuccessful in their attempts, leaving the woman distressed and in pain. No apologies were offered.

In these instances, lack of respect for the consumer and their concerns also becomes a serious safety issue. It is the responsibility of all staff to listen to their patients and take their concerns seriously, particularly where it involves their safety and well-being. It must be recognised that we are experts on our own body.

4.2. Choosing not to follow recommendations

Another issue relating to informed consent is the care of patients not selecting to follow clinical recommendations. Clinicians must respect the decisions of patients whenever they have been judged as having capacity to provide or withdraw consent. The feedback we have received in this regard revolves primarily around the decision to opt for palliative rather than curative treatment. If a patient does choose not to follow the recommendations of their clinicians, they need to be reassured that this will in no way compromise the quality of other care they may be receiving.

5. Communication

Without effective communication, there can be no consumer-centred care. This broad issue has implications not only for informed consent but also for the safety and quality of health services. Throughout the health system, communication loops between clinicians and consumers are integral to ensuring that care is administered appropriately and that patient's conditions do not deteriorate unnecessarily.

5.1. Arrival – Hospital ED Admission

Most people are admitted to the hospital via the Emergency Department (ED). This is often a distressing experience for consumers, particularly when they cannot be accompanied by a friend or family member. While we recognise that EDs are under immense pressure to deal with a large number of urgent cases, more needs to be done to ensure that all consumers coming to the ED understand their triage assessment and how long they are likely to have to wait. This also applies to consumers waiting in the admissions area.

Poor communication at triage is highly frustrating for consumers, who often feel that the triage nurse has not taken their concerns seriously enough. While this may not actually be the case, consumers need to have the triage process explained to them so they can understand why they have been asked to wait. Another source of frustration is the lack of communication following the initial triage assessment. For instance, many members have described experiences where their condition had changed but were virtually ignored when they approached the triage desk. We understand that the recently introduced Volunteers Program is geared to addressing this issue and would be keen to hear about the effectiveness of their role.

There are also issues regarding the physical amenities that have been raised regarding the comfort of patients while they are waiting to receive treatment. One of our members described having to wait in a chair despite debilitating back pain, unable to lie down anywhere. Another member described a situation where their friend had to go and find a bucket for them to throw up in, as they could not receive any assistance from staff. We consider these to be matters that can be dealt with without significant cost or disruption.

Discussions with CALD community groups has demonstrated that these consumers often find the ED highly confusing. This is partly due to language and communication barriers, but also a lack of clarity regarding the function of the ED. For instance, we have been told that for Chinese consumers, the ED is viewed as a fast-access health care service, rather than a facility for serious health concerns only. Improving health literacy across the CALD community offers the opportunity to ensure that consumers know the most appropriate service to access for their health needs.

5.2. Treatment

Consumers also need to understand and be involved in the decisions being made about their treatment and care. A number of our members have described experiences where they have been left alone in a room in the ED, still in pain and without any idea of what was being done to treat their condition. Under the Australian Charter of Health Care Rights, consumers have the right to Communication, which states they should “be informed about services, treatment, options and costs in a clear and open way”. Without effective communication, the consumer is powerless and unable to make informed decisions regarding their care.

In many cases, it is the patient’s family members that suffer from a lack of information, as staff are too busy caring for the patient to address their needs. Community services need to be more effectively utilised to ensure that family members are kept up to date with the patient’s condition, what treatment they are receiving and their likely prognosis. Being left in the dark is highly distressing.

This is also an area where CALD consumers are extremely disadvantaged. Due to the hectic nature of the ED and the limited availability of interpreters, staff often rely on family members to translate information to the patient. This is concerning as family members may not have the necessary experience to accurately convey clinical information. Alternatively, we have also received stories of CALD consumers being treated without any communication at all. In one instance, this led to a failure to detect a fractured wrist for an elderly lady, who remained in pain for another week before she was able to return to the ED with a friend who could translate for them.

We do recognise that some progress has been made in this area, as mentioned in the 2009 Report by the National Health and Hospitals Reform Commission (NHHRC):

“Empowering consumers to make fully informed decisions is an important element of this shifting power balance between consumers and clinicians. For example, we recognise and support the increasing development of ‘decision aids’ that can be used to help patients make better informed decisions, incorporating their values and preferences about health treatment choices.

We also acknowledge the vital role of informal and family carers in supporting people in their use of health care services. Decision-making often involves more than the individual ‘patient’, so we have recommended that carers be supported through educational programs, mentoring and timely advice to allow them to participate in health decisions and communications (subject, of course, to the consent of those they care for).⁶

5.3. Discharge

Communication has also been identified as a major qualitative issue at the point of discharge from the ED and inpatient care. Consumers need to know what to do after leaving the hospital, otherwise they risk suffering a repeat of their illness or exacerbating their condition.

⁶ NHHRC (June 2009), A Healthier Future For All Australians: Final Report

A recent review by doctors working in an ED found that only two thirds of consumers were given adequate information on discharge.⁷ This means that one third of patients leave the ED with an incomplete understanding of the nature of their condition, in which could lead to deterioration and further presentation to the ED.

The devastating effects of poor communication at discharge have been clearly demonstrated through the experience of one of our HCCA members. Speaking about her husband's time at TCH in early 2010, she described numerous communication failures that contributed to a drawn out period of life-threatening complications. The Mid Staffordshire Report released in 2010 acknowledged this issue and identified a need to facilitate ongoing, bi-directional communication between health professionals, consumers and their families:

*"Admission to and treatment in hospital is almost invariably a time of great anxiety, not only for the patient but also for those closest to him or her. Patients and those closest to them naturally require to be kept informed of developments and will be worried if they are denied this or if they have to make great efforts to find out what they want to know. It is of the very essence of modern medical care that it is provided in partnership with the patient and always subject to the consent of the patient ... This requires a continual professional conversation with the patient and those authorised by him or her to receive treatment information, so that those involved are ... and enabled to play their full part in the process. Communication in a hospital setting is not a one-way process. It is as vital that patients and their relatives are listened to – for in many ways they are the experts on the patient and his or her needs – as it is for hospital staff to provide information."*⁸

5.4. Public reporting

A recommendation of the National Health and Hospitals Reform Commission (NHHRC) Report was that consumers should be kept well informed through public reporting of safety and quality data:

*"Listening to the views of all Australians about our health system and health reform is essential to the ongoing sustainability and responsiveness of our health system. Accordingly, we recommend regular monitoring and public reporting of community confidence in the health system and the satisfaction of our health workforce."*⁹

Over time consumers have strongly expressed our interest in public reporting of performance against accreditation standards and accessible explanation of what the accreditation standards have measured and what that means for the consumers using that service. We have also expressed our need for information to determine which treatment is appropriate to our circumstances. This includes information on relevant treatment options, including no treatment at all, and the benefits, risks and financial costs of these options.

We are keen to see the development of information for consumers that is easy to access about a range of things including:

⁷ Pilcher, C.A. 2011. *Talk to your patients before sending them home from the ED*. On KevinMD.com <http://www.kevinmd.com/blog/2011/08/talk-patients-sending-home-ed.html>
Accessed August 20, 2012.

⁸ The Mid Staffordshire NHS Foundation Trust (February 2010), *Independent Inquiry into care provided by Mid Staffordshire NHS Foundation Trust January 2005 – March 2009 Volume I*, p.127.

⁹ NHHRC (June 2009), *A Healthier Future For All Australians: Final Report*

- the skills and experience of any health care professionals and what they are credentialed to do (eg, is an orthopaedic surgeon credentialed to operate on knees or shoulders?)
- registration status of health care professionals and if there are any conditions on their registration;
- the availability, safety and outcomes of different treatments;
- what to do if something goes wrong with their health care;
- services and assistance that can help them if they have an adverse event; and
- how to access confidential information about their condition and treatment in their health care records

This is both a participation and communication issue. Consumers must be aware of services, activity levels and performance issues to be able to actively engage in health reform at a community level as well as access the care they need as individual consumers. Public reporting also has the potential to increase public confidence. Information, such as information on the availability, safety and outcomes of different treatments and services, is necessary to facilitate consumers and their carers in making informed choices. Information on the availability, safety and outcomes of different treatments and services are necessary to facilitate consumers and their carers in making informed choices.

In promoting a greater emphasis on public reporting, we are conscious of the need to tailor reports to the audience. For example, we heard and agree with the view that:

“Public reporting should be provided in a way that supports and develops community health literacy...Lessons from work done in Australia suggests that public reporting to consumers needs a meaningful narrative and should address issues of consumer concern and not just be a by-product of clinical or bureaucratic reporting.”¹⁰

We encourage the LHN Council to consider public reporting framework that will meet the needs of the Canberra community.

6. Participation

6.1. Informed consent

HCCA strongly recommends adopting the key messages of the Patient First Program as has been done in Western Australia. This program aims to ensure that consumers are able to actively participate in their health care and are aware of the risks involved in their treatment.

Due to their busy schedule, clinicians often approach informed consent as simply a box that must be ticked rather than an integral component of quality and safety and consumer rights. Members have described being handed forms and asked to sign them without ever gaining a proper understanding of the treatment they were consenting to. Consumers need to be informed about the different treatment options available, the risks involved and the likely outcomes if they do or do not consent to the treatment.

¹⁰ M Draper (2008), Submission 265 to the National Health and Hospitals Reform Commission: First Round Submissions.

As clinicians seldom have the time to go through these discussions at length, it would be worth considering something similar to the Patient First Ambassador Program, which trains consumer volunteers to go through these issues with the patient.

6.2. Open disclosure

The comments above regarding communication and respect also reflect a failing of Open Disclosure. Open Disclosure is an integral component of consumer centred care and is of great importance to our membership. HCCA participated in the initial consultations ten years ago in the development of the Open Disclosure Standard. In reflecting of their experience of open disclosure, consumers have reported to us that they have been involved in fractious and highly emotional discussions and that health professionals at times did not seem to be equipped to deal with it adequately. Consumers value a culture that supports clinicians during open disclosure. Consumers want the clinicians involved in the incident to be involved in the disclosure process. They want to face them; they want to see their humility and humanity.

7. Privacy

7.1. Sharing of personal health information

At all times, care must be taken to ensure that patient health records and information are kept confidential and distributed only to the appropriate staff. We are aware of many occasions where confidential information has been shared in casual conversations between hospital staff, much to the distress of the patient. In other instances records have been inadvertently released or sent to the wrong address. It is of great importance to consumers that confidentiality protocols are carefully followed at all times to avoid these errors wherever possible.

7.2. Privacy during treatment and inpatient stays

When consumers come to the hospital for treatment, they are usually feeling vulnerable and anxious. Lack of privacy during treatment or waiting periods serves only to increase these feelings and can also lead to a loss of dignity for the consumer. When this happens, consumers feel disempowered and less able to engage with their health care, which can increase the risk of incidents occurring.

One member has described how during a recent visit to the ED, she was able to hear staff discussing her condition and those of other patients loudly in the corridor. She was able to gain sufficient information to determine that she actually knew a number of the other patients, along with exactly what was wrong with them.

It is essential that hospital staff only discuss patient information with the appropriate people and that this is done with discretion. We understand that casual discussions often occur due to time constraints, but urge consideration of the impact that this can have on the patient.

Overcrowding in the ED can also lead to patients being required to wait in hallways and waiting rooms while seriously ill and vomiting, where they are visible to all other patients and staff. Wherever possible, patients need to be provided with physical privacy, even if this means moving them to a quieter area, away from the majority of other patients.

8. Comment

8.1. Complaints handling procedures

Over the years, HCCA has been contacted by many consumers trying to register a complaint regarding a health service. This process can be confusing for consumers, who often don't know who to contact in the first place. The Consumer and Carer Feedback Form needs to be accessible and prominently displayed in all ACT public health services. In addition, consumers need to be encouraged to use these forms, as they often feel as though they will be penalised or blacklisted as a result of registering a complaint.

Even after consumers have managed to get in contact with the Consumer Engagement Team or the Health Services Commissioner, they are often dissatisfied with the response they receive. One member recently contacted us because she had been working with the Health Directorate to address a serious health service issue following the death of her partner. Without warning, the staff member she had been working with left the position and progress and communication had all but ceased.

Consumer complaints are an important component of identifying systemic issues and quality and safety risks. Without demonstrating a willingness to engage with consumers and address their concerns, it is inevitable that consumers will disengage with this process.