

Queensland Clinical Senate

Connecting clinicians to improve care

All great stories need a good ending—consumer and clinician perspectives on end-of-life care

25 July 2014
Meeting Report

Brisbane Convention and Exhibition Centre, Brisbane, Queensland

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- Dr Liz Kenny, Radiation Oncologist, Metro North Hospital and Health Service
- Ms Melissa Fox, Health Consumers Queensland
- Ms Gai Lemon, Consumer
- Ms Karni Liddell, Consumer
- Ms Jacqueline Lock, Nurse Unit Manager, Emerald Hospital
- Dr Col Owen, General Practitioner, Inglewood Medical Centre
- Associate Professor Jane Turner, Discipline of Psychiatry, University of Queensland
- Dr Sarah Winch, Health Care Ethicist, University of Queensland
- Dr Will Cairns, Director Palliative Care, Townsville Hospital

Meeting facilitator

Dr Norman Swan

Abbreviations

Advance Care Plan	ACP
Council on the Ageing Queensland	COTA Q
End-of-life care	EoLC
Health Consumers Queensland	HCQ
Hospital and Health Service	HHS
Queensland Clinical Senate	QCS

1. Summary

Health Consumers Queensland (HCQ) and the Queensland Clinical Senate (QCS) have commenced a joint initiative to stimulate a community conversation that tackles the issues surrounding decision making for end-of-life care (EoLC). Central to this endeavour was a forum bringing clinicians and consumers together to table the challenges inherent in talking about death from both their perspectives and to explore opportunities for the health system to deal more effectively with consumer wishes.

On 15 July 2014, HCQ and The Council on the Ageing Queensland (COTA Q) hosted a community forum to seek feedback from consumers and carers on high priority issues, solutions and ways forward in regards to 'futile care'.

On 25 July 2014, one hundred and fifty clinicians, consumers, carers and academics participated in the forum *"All great stories need a good ending – consumer and clinician perspectives on end-of-life care"*.

Having considered the outputs from the earlier HCQ forum and the challenges presented at the combined forum, participants identified actionable strategies aimed at informing and empowering all those involved in these difficult conversations.

2. Recommendations

Clinicians from all healthcare settings have a responsibility to provide appropriate EoLC to patients. This requires them to work together, across settings and sectors, to provide care that reflects the patient's wishes.

To enable the health system to deal more effectively with consumer wishes surrounding EoLC, the QCS and HCQ recommend:

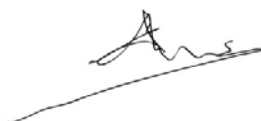
- A. developing an EoLC charter for display and adoption in all health facilities across Queensland. The charter will be developed and championed by HCQ and the QCS in collaboration with relevant professional colleges and stakeholders
- B. improving EoLC literacy and knowledge through a community engagement and public awareness campaign. The campaign should focus on: normalising the inevitability of death, raising awareness of what is involved in EoLC decision making, the importance of making individual wishes known and encouraging discussions with clinicians about care options

- C. investing in clinician and student clinician education and training on EoLC so that they are more knowledgeable and better equipped to participate in EoLC discussions and better supported to deliver EoLC
- D. developing integrated EoLC models of care that focus on improving the service integration between primary and acute care sectors to provide seamless support to the patient and their carers.

Central to any strategy for improving the quality of integrated EoLC is strong clinician and consumer leadership. There is currently no clinical governance 'home' which can bring together the multidisciplinary and multi-sectoral stakeholders and ensure a coordinated and strategic implementation of ongoing work around these recommendations. Identification of such a 'home' and adequate resourcing requires urgent consideration.



Dr David Rosengren
Chair Queensland Clinical Senate
28 August 2014



Mr Mark Tucker-Evans
Chair Health Consumers Queensland
28 August 2014

3. Introduction

Quality EoLC is a subject that is important to both clinicians and consumers and has vast impacts for society as a whole. It is an essential component of the health care system and is the responsibility of all health care professionals.

HCQ and the QCS welcomed the opportunity to bring clinicians, consumers, carers and academics together in a forum on 25 July 2014 to identify opportunities for change within the health system to better enable informed EoLC decision making and care.

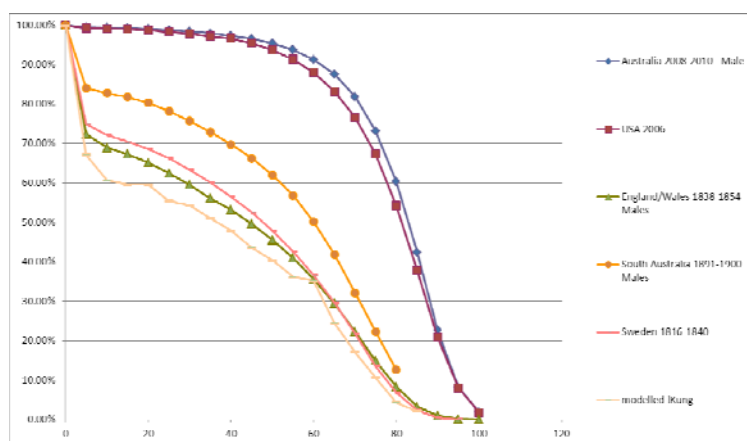
This report outlines the key issues, opportunities and practical recommendations raised at the forum *"All great stories need a good ending – consumer and clinician perspectives on end of life care"* for consideration by the Queensland Department of Health and the Queensland Government in relation to improving EoLC for all Queenslanders.

4. Dealing with dying

End of life is naturally something each individual will experience. It can occur at any age. Over the past 150 years there has been a significant change in the way we live our lives.

Understandably there has been a demographic shift in life expectancy over time: while the maximum life expectancy has not increased, the average life expectancy for Australians has extended considerably - albeit usually with some associated illness or disability in the latter years.

Comparison of mortality



Life expectancy (additional years of life) for people at selected years of age

	Males				Females			
	at 0	at 25	at 45	at 65	at 0	at 25	at 45	at 65
1881-1890	47.2	37.1	23.0	11.1	50.8	39.7	25.6	12.3
1891-1900	51.1	38.9	24.0	11.3	54.8	41.7	26.7	12.8
1901-1910	55.2	40.6	24.8	11.3	58.8	43.4	27.6	12.9
1920-1922	59.2	42.7	26.0	12.0	63.3	45.7	29.0	13.6
1932-1934	63.5	44.4	26.9	12.4	67.1	47.2	29.7	14.2
1946-1948	66.1	45.0	26.8	12.3	70.6	48.7	30.5	14.4
1953-1955	67.1	45.5	27.2	12.3	72.8	50.2	31.4	15.0
1965-1967	67.6	45.4	27.0	12.2	74.2	51.2	32.3	15.7
1975-1977	69.6	46.9	28.3	13.1	76.6	53.1	34.0	17.1
1985-1987	72.7	49.5	30.8	14.6	79.2	55.4	36.1	18.6
1995-1997	75.6	51.8	33.1	16.1	81.3	57.1	37.7	19.8
2004-2006	78.7	54.7	35.7	18.3	83.5	59.2	39.7	21.5
2007-2009	79.3	55.2	36.3	18.7	83.9	59.5	40.1	21.8

Source: ABS [Australian Historical Population Statistics 2008](#) (cat. no. 3105.0.65.001); ABS [Deaths, Australia, 2009](#) (cat. no. 3302.0)

Degenerative conditions associated with death in old age include cardiac and vascular diseases (e.g. heart attacks and strokes), cancer, kidney failure, respiratory failure, neurological degeneration (e.g. dementia) and general frailty (e.g. osteoporosis and falls).

As a whole the beliefs of society have also changed. Most individuals now expect to die in very old age and even in old age, people are often surprised when a life cannot be saved or further prolonged.

The reality is that for every individual there comes a time when modern medicine can no longer prolong life, or prolong life with a level of quality acceptable to the individual and/or their loved ones. Death can often be postponed however this does not always deliver desired quality. The community and the health system are faced with many challenges in order to achieve the best possible care at the end of life and in the ways in which we deal with dying and grief.

Challenges to be addressed include:

- understanding the limits of modern medical technology

- making sense of our beliefs, hopes and fears in the context of the inevitability of death
- addressing cultural issues that shape current decision making paradigms
- development of processes for decision making that reflect the medical realities faced
- development of services to provide optimal care for people at the end of life
- political recognition and health service buy-in and will to enact positive change.

5. Consumer perspectives on end-of-life care

While members of the community have diverse attitudes, beliefs and experiences when it comes to life limiting illness and old age, maximising the quality of care received at the end of life is of great concern to all universally. On 15 July 2014, HCQ and COTA Q hosted a community forum to seek perspectives from consumers and carers on the support needed from the health system to enable consumers to make well-informed decisions when medical treatment is considered to be futile. Participants identified the following high priority areas for improvement:

- normalising death, dying and care expectations through an ongoing, informed community conversation
- personalised, connected, supportive, team-based care focused on the individual towards the end of life
- the need for expanded health literacy to enable consumers to participate in an informed way, and to facilitate shared understanding and effective patient advocacy
- holistic decision making involving clinicians, patients, carers and family members
- the role of advocacy in assisting consumers to be informed – by whom, when, and how.

Additional issues raised at the 25 July 2014 forum include:

- the importance of recognising the wide variety of cultural beliefs and practices in the Queensland Community and incorporating cultural and religious beliefs in EoLC decision making
- the importance of coordinated/integrated care and services within all healthcare settings and sectors to minimise the burden on the patient, family and carers. Consumers living in rural and regional settings often face additional challenges and frustrations due to a lack of local support services
- the importance of health literacy within the community and specifically the lack of (or insufficient) awareness and knowledge of patient rights, EoLC options and services. This has been identified as a significant barrier

- additional obstacles faced by Indigenous Australians and consumers from culturally diverse backgrounds. The use of technical terminology with which the patient and their loved ones are not familiar can add to confusion and hinder understanding.



"Only the individual themselves can judge what quality of life means to them"

Karni Liddell

"It is critical that we educate ourselves, as consumers, on the questions we need to ask and be relentless in finding the answers"

Gai Lemon

Ms Karni Liddell, Ms Gai Lemon, Dr Norman Swan

Appendix 1: "When medical care is futile" forum 15 July meeting report.

6. Clinician perspectives on end-of-life care

A panel discussion highlighted the diverse range of perspectives and challenges faced by clinicians in relation to EoLC. Issues include:

- care integration, coordination and referral pathways across and within healthcare sectors
- recognising futility and the subsequent difficulty clinicians face dealing with the change in care model from a 'curative' approach to 'supportive/comfort-focused' approach
- prognosticating life expectancy is intrinsically difficult for clinicians which makes having EoLC conversations with patients and families difficult
- detecting underlying depression – research shows that when depression is treated, a palliative care patient's wish to 'hasten death' reduces
- ethical considerations regarding patient capacity and competence to make informed EoLC decisions in some circumstances (complicated by dementia and depression) and informed consent
- understanding the legal implications of existing tools (e.g. ACPs and Advanced Health Directives) and 'futility'
- education and training for clinicians and clinicians in training – health professionals do not generally receive specific training in how to deal with dying, death and grief and can feel poorly equipped to deal with these conversations.

- the importance of having EoLC discussions early – before a health crisis – ideally with the patient's primary care team and the communication of plans (e.g. ACPs) between sectors.
- dealing with personal and family issues – understanding what 'quality' EoLC means to patients and negotiating care options with the patient, family and carers when there is no consensus amongst these groups
- using resources wisely.



Clinician Panel: Ms Jacquelyn Loch, Dr Jeremy Croker, Dr Liz Kenny, Dr Col Owen, Dr Sarah Winch, A/Professor Jane Turner

Meeting participants were invited to participate in a survey on EoLC perceptions prior to the meeting. Sixty-seven clinicians and 20 consumers responded to the survey. Key results included:

- Respondents were more afraid of the dying process than of being dead.
- While more than 70% of respondents believed their family were aware of their [EoLC] wishes, only ~35% had completed an ACP.
- Eighty-five per cent of respondents believed that EoLC discussions with patients and their families could be initiated by any health professional that has a clinical relationship with the patient.
- More than 95% of respondents indicated there is value in investing in improving skills for clinicians around end-of-life conversations.
- All those who completed the survey saw value in investing to increase awareness of EoLC planning.

7. Issues, challenges and opportunities to improve end-of-life care

Meeting participants, through small group work, identified and discussed six key areas for system improvement and brainstormed strategies to address them:

- 7.1 Development of an EoLC charter for adoption in all health facilities in Queensland
- 7.2 Education and training of clinicians and students on EoLC
- 7.3 Community engagement strategy on EoLC
- 7.4 Improving health care literacy on EoLC within the community
- 7.5 Trigger points for EoLC discussions
- 7.6 Models of care and integration issues for EoLC
- 7.7 Minimum data set for quality of death

7.1 Development of an end-of-life care charter

Participants developed a draft EoLC charter (appendix 3) for display and adoption in all health facilities across Queensland. The charter will be championed by the QCS and HCQ. Key stakeholder groups will be consulted prior to the charter being finalised.

7.2 Education and training of clinicians and students on end-of-life care

Initiatives should focus on up-skilling clinicians and clinicians-in-training so they are better able to participate in EoLC discussions and care. Listening and communication skills are of critical importance. Other strategies might include:

- encouraging the inclusion of EoLC education and training in undergraduate and postgraduate training of healthcare professionals
- acknowledging the difficulty of adding to the existing undergraduate curriculums, consider scoping and redefining existing education packages to include EoLC
- consider incentivising postgraduate training in EoLC and communication through key performance indicators and CPDs
- include the introduction of legal implications of EoLC as content in training – as a method of engagement
- endorsement of a tool to identify patients approaching end of life. (e.g. Supportive and Palliative Care Indicators Tool)
- making existing EoLC tools easily accessible to healthcare professionals
- the use of electronic systems to flag potential EoLC patients

- the implementation of policies around communication and coordination of care with general practitioners and community care professionals
- mandating the requirement for EoLC discussions to occur across the health system (in a similar way to other quality and safety issues e.g. cardiopulmonary resuscitation training)
- links between EoLC education and training with accreditation.

7.3 Community engagement strategy on end-of-life care

- A comprehensive process of community engagement is required to raise awareness, set realistic expectations regarding EoLC choices and to change attitudes and beliefs about death and dying. The campaign focus should be on quality of life as defined by each individual.
- A governing committee would be required to drive the campaign and might include representatives from key stakeholder groups such as the Department of Health, non-government organisations, representatives from the private sector and consumers.

The engagement strategy would adopt a multipronged approach by targeting existing organisations with a health focus (e.g. Multiple Sclerosis Queensland), without a health focus (e.g. sporting clubs, RSLs), social clubs (e.g. grey nomads), cultural groups/clubs (e.g. ATSI, the Greek Club), religious groups and universities.

Additional support for existing programs was also highlighted, e.g. Death Over Dinner, Death Cafes, The Groundswell Project.

Information must be culturally appropriate and easily understood. The use of arts and humour could be employed to make these conversations less threatening and assist in the transition to a 'normalised' subject of discourse.

The inclusion of key EoLC messages could be incorporated into mainstream media (e.g. the storylines of well-known Australian television shows), mailings from civic organisations (City Councils etc.) and community events.

Health professionals and non-health professionals (e.g. lawyers and financial planners, community leaders) should be encouraged to take steps to raise the importance of EoLC discussions in the public domain whenever possible.

7.4 Improving healthcare literacy on end-of-life care for consumers

The community will be empowered by an expanded technical knowledge (healthcare literacy) of conditions that are commonly associated with EoLC. This will support shared decision making whereby consumers and clinicians will be able to engage in more informed and sophisticated discussions.

Information must be easily accessed, ideally through the creation of a consumer portal that is written for consumers in jargon-free, plain English, featuring intuitive navigation and links to related sites.

It is acknowledged that any project successful in achieving expanded healthcare literacy in the community must be adequately resourced over the long-term.

7.5 Trigger points for end-of-life care discussions

There are many triggers and cross-sectoral opportunities for EoLC discussions to take place. While conversations about EoLC can take place any time, they are most critical on those occasions when it is realised that a patient may be on an EoLC trajectory.

Other trigger points for EoLC conversations or opportunities to distribute information on EoLC could include:

- when established medical assessments occur (e.g. over 75 checks, ATSI checks, drivers licence medical assessments, and the like)
- after highly interventional healthcare treatments (e.g. acute resuscitation, ventilation) and the prescription of certain drugs (e.g. opioids and beta blockers) for life threatening illness
- with the diagnosis of multiple conditions or chronic diseases. Information on EoLC could be distributed with relevant screening kits or processes (e.g. breast and bowel cancer)
- EoLC messages being included in media reports for disasters which incurred a loss of human life (e.g. aviation accidents) in a similar way to how information on depression is provided when the media report on suicide
- at the time of payment of certain social security benefits (e.g. registration with Centrelink)
- at forums or gatherings of varying cultural/linguistic groups
- on admission to residential aged care facilities (as a fall-back).

7.6 Models of care and integration issues for end-of-life care

Improvements in service coordination and the ability of consumers, families and healthcare professionals to navigate EoLC services is dependent on better connections between private and public primary, community and acute care sectors. Strategies to achieve this might include:

- development of patient-centric models of care and continuous care pathways (into and out of hospital). Care models would aim to keep patients in the community for as long as possible and would address allocation and acceptance of responsibility for care, and the appropriate use of services
- models that include GP in reach (into hospitals), acute care outreach services (e.g. Hospital in the Home) and ease of access to specialist knowledge and advice
- stronger engagement with primary care and the private sector, including incentives where appropriate

- better discharge coordination through case conferencing and care coordinator roles. Care co-ordination would include a review of existing support systems for the patient and additional support systems that might be required)
- considering options to provide better support to GPs as care coordinators.

To achieve success, the model to open pathways between stakeholders must be sustainable.

Identification of the principles of EoLC is important. In addition to an international review on EoLC best practice, process mapping of existing services and roles should be undertaken in order to understand the current state and the skills and resources required to achieve the goal state.

The Queensland Government should negotiate with the Commonwealth regarding incentives for general practice to enable GPs to take on the role of care coordinator.

7.7 Minimum data set for 'quality of death'

Two important elements of 'a good death' could include the person dying with dignity and the wishes of the person having been recorded and respected.

Such a data set would need to cut across all relevant systems to measure the quality of death.

Death reviews might include documentary evidence that the death was expected and steps were taken to respect the individual's wishes. Evidence of patient preferences could include the presence of an Acute Resuscitation Plan, ACP or Advanced Health Care Directive. In addition, this data set should record evidence of actions taken as a result of such documentation. Surrogate markers might include the prescription of EoLC medications, the number of Medical Emergency Team calls made within the 24 hours prior to death, referral to palliative cares services, and bereavement contact after death.

Mechanisms to help mandate these practices may involve inclusion within ACHS standards, and the addition of a question about 'quality of death' on death certificates.

Meeting participants identified the following recommendations as priorities for action:

- A charter for EoLC
- Improving EoLC literacy through a community engagement and public awareness campaign
- Clinician and student-clinician education on EoLC
- Integration of models of care for people approaching the end-of-life

The QCS, in collaboration with HCQ and the organising committee tasked with coordinating the meeting (appendix 2), will refine the recommendations and present them to the Minister for Health and Director-General, Queensland Health, for consideration.

Appendix 1: Health Consumers Queensland Forum Report 15 July 2014

**REPORT****COMMUNITY FORUM: *WHEN MEDICAL TREATMENT IS FUTILE*****8.45am – 3.00pm, Tuesday 15 July 2014**

The Greek Club, 29 Edmondstone Street, South Brisbane

Seventy-five Queensland consumers, carers, doctors, nurses, social workers, mental health, aged care and disability workers and academics gathered for a community conversation on the issue of "*When Medical Treatment is Futile*" on Tuesday 15 July at the Greek Club in South Brisbane.

Jointly hosted by Health Consumers Queensland (HCQ) and Council on the Ageing Queensland (COTA Q) and facilitated by ABC National's Dr Norman Swan, the purpose of the community forum was to seek feedback from consumers and carers on high priority issues, solutions and ways forward in regards to "futile care" - what can we do as consumers, what can the system do and what can clinicians do?

This report documents the main outputs for consideration at a joint Health Consumers Queensland / Queensland Clinical Senate Forum "*All great stories need a good ending – consumer and clinician perspectives on end-of-life care*" being held Friday 25 July at the Convention Centre, South Brisbane. This forum will be attended by a number of the attendees from the first forum, members of the Clinical Senate and invited clinicians. The outcome of the forum will be recommendations to be considered for action by the Queensland Health Minister Hon Lawrence Springborg.

Health Consumers Queensland (HCQ) is the peak health consumer organisation representing the interests of Queensland health consumers and empowering Queensland health consumers to lead and drive better health outcomes. HCQ is committed to a health system which delivers quality and safe health services providing the right care, at the right time and in the right place. HCQ supports the consumer engagement activities of Health and Hospital Services (HHSs), Queensland Department of Health's Patient Safety Unit & Queensland Clinical Senate, private health organisations and Medicare Locals, through facilitating workshops for consumers and staff, and appointments via HCQ's Consumer Representatives Program and Statewide Consumer Network of consumers, carers and consumer organisations. HCQ also meets with the Health Minister and provides high level advice.

<http://hcq.org.au/>

Council on the Ageing Queensland (COTA Q) exists to influence decision makers to advance the rights, needs and interests of people as they age. COTA Q has been selected by the Queensland Government as the Seniors Peak Service to help build the capacity of non-government organisations to deliver quality services for older people; improve the dissemination of information on Queensland Government initiatives for older people and provide input into the development and implementation of policies, programs and priorities for older people across Queensland.

<http://cotaqld.org.au/>

The **Queensland Clinical Senate** provides a forum for a multidisciplinary group for clinicians to share their collective knowledge in the deliberation of strategic clinical issues and to make recommendations to Queensland Health on how to deliver the best care to Queenslanders. Recent areas of focus include the development of an alternative model for the National Emergency Access Target (NEAT), Clinician Education and Training Performance Measures and Advance Care Planning (ACP).

<http://www.health.qld.gov.au/qldclinicalsenate/>



Workshop Summary

Presentation: Dealing with dying - the great healthcare challenge for the community in the 21st century

Dr Will Cairns OAM, Director Palliative Care, Townsville

Dr Cairns described the demographic shifts in the Australian population and the increasing age at death with some associated increase in length of time living with disability. His main points were that this is not a debate about cost, it's about normalising dying, and that prognosticating life expectancy is intrinsically difficult for doctors, which makes accurate conversations with patients and families difficult. (See slides attached).

Panel: Traversing the issues – unpacking the word “futility”

Dr Norman Swan, Facilitator with:

- **Liz Crowe, Program Facilitator, Advance Care Planning Project, Griffith University. Advanced Clinician Social Worker, Paediatric intensive care unit, Mater Children's Hospital.**
- **Dr Liz Kenny, Senior Radiation Oncologist, Royal Brisbane and Women's Hospital and Medical Director of Central Integrated Regional Cancer Service.**
- **Gai Lemon, Director, Healthy Communities Program, Qld AIDS Council.**
- **Gabrielle Quilliam, Co-Founder, Queensland Kids.**
- **Associate Professor Jane Turner, Discipline of Psychiatry, University of Queensland, and Consultation-liaison psychiatrist, Royal Brisbane and Women's Hospital.**
- **Prof Colleen Cartwright, Director, Cartwright Consulting Australia, previous Professor of Aged Services, Southern Cross University.**

Key points from this discussion included:

- Patients and families want and need supportive, team based care towards the end of life.
- There were several stories from participants about being abandoned by specialists when their treatment options were not wanted by the patient (“my way or the highway”).
- Doctors need to recognise futility and understand the patient's preferences – which may in fact be for more to be done rather than less.
- Expectations need to be understood and managed.
- The media make all this harder by building up modern medicine as ‘can do’.
- Associated depression and anxiety must be detected and treated which will in turn reduce people's desire to hasten their deaths.

The other most critical issue is the **desire for consumers to know when they are going to die**. This is a painful discussion for health professionals. The grief resonates with their own losses. We don't acknowledge the emotional burden of the caring role. Are **Advanced Care Plans (ACPs) the answer**, given people don't trust them because they believe doctors are free to ignore them. Prof Colleen Cartwright stated that **doctors aren't free to ignore them** and work/research is being done to help doctors understand the legal implications of ignoring them. Pain management shouldn't be considered a futile treatment. **Patients need timely access to oncologists and pain specialists.**

Case management and a multidisciplinary response is very important for children. A large number of paediatric patients will have an intellectual disability as well, and some don't have capacity to be involved in the decision making.



Need to have very empowered advocates and sensitive, aware clinicians who are willing to work with them.

Patients losing confidence in their own decision making when they come to hospital with an ACP and doctors ask “are you sure this is what you want to do?” Important to **nominate a strong substitute decision maker** who can make sure the patient’s wishes are carried out. **Cross cultural and religious issues must be incorporated into end of life decision making.** A **common complaint from carers who have brought a loved one to hospital is that the hospital immediately assumes they know more about the patient than the carer does.** Should educate staff that carers often know far more about the complexity of the patient’s condition.

Small group work:

Defining the agenda - what are the highest priority areas/issues?

Five priority issues were identified:

- **Having a Community Conversation** about death/dying/and realistic expectations of care.
- **Personalised, connected and supportive care towards the end of life** – team care focused on the individual to meet their needs coordinated across primary health care, hospitals, and community services). Generate expectations that you expect a personalised, connected care system.
- **Technical knowledge** is needed for effective patient advocacy (for themselves or by others on their behalf). Knowledge should be in hands of consumers so they can argue for rational care. Technical knowledge for both consumers and clinicians around palliative care, pain management, end of life care, the psychological impact of chronic illness, how to recognise symptoms.
- **Advocacy** – who advocates, for who, for what purpose and how?
- **Better decision making** – involving clinicians, patients, carers and family and making decisions. Power, advocacy, knowledge.

Attendees agreed on a definition of futility: “When the burden of treatment exceeds the benefit. The concept of burden is in the eye of the consumer and family and includes physical, social and psychological issues”.

What can we do as consumers, what can the system do and what can clinicians do?

- **Community discussion** –
 - Forum/method – education and conversations with kids, friends, families, schools, seniors groups, community centres, clubs. Who is doing it not sorted yet.
 - National “Talk About Death” day, perhaps on All Souls Day.
 - Community conversations – apps, games, hypotheticals.
 - Manipulate the media – initiatives as particular days arise.
 - Annual days to commemorate the dead.
 - Work across NGOs relating to death, chronic illness and end of life care.
 - Address language and euphemism.



- Death cafes.
 - License dept on Adv Care Plans.
 - Financial planners.
 - Resources – “Tender” Port Kembla, Kenny Rogers “The Gambler” on the Muppets (<http://www.youtube.com/watch?v=kNnrTNFWcsg>), Billy Connolly, “Dumb Ways to Die”, Getup, Facebook.
 - Preparation of family plans.
 - Sustained conversations – training for health professionals in experiences and processes of shock, grief and loss, which relate to their own life and hopes and fears and emotional capacity. This is telling health professionals what they need to do to educate themselves. They would need support in that.
 - Resources – AHD, EPA, will, care plan, community service announcements, pal care peaks, famous people(Dawn Fraser, footy players/sports people, comedians).
- **Decision making**
 - Needs time.
 - Often should be GP led.
 - Patients often need technical knowledge and support to be able to participate.
 - GPs and patients need pathways identified to navigate the system.
 - Younger patients will more often have access to web. Older patients may rely on others to access web or rely on telephone support as they think of questions.
 - Trying to encourage a culture that the patient should be able to take a stronger role in that decision making. At the moment we have documents that say this but in truth the patient isn’t really informed to a reasonable degree. We just don’t involve patients early enough in actively discussing their treatments. Patients usually accept what the doctor is telling them.
 - Need education especially of the elderly about what help is available at home.
 - Medicare number for palliative care planning.
 - Need education regarding the advanced care document and the extent that they must be followed.
 -
 - **Advocacy**
 - Self advocacy (ACP), family members, friends, priest, spiritual advisor, multidisciplinary team (could be conflict of interest), paid independent advocates, guardianship, through e-health.
 - Systemic – having policies on advocacy.
 - Advocacy is that the individual’s wishes are met and that the individual has sufficient information to be able to understand. Having cultural and spiritual needs met.
 - Websites, pamphlets, media - consumer driven.
 - Having your ACP on a USB stick.
 - How organisations can train advocates – education (nursing, medicine, etc.).
 - Access to trained advocates face-to-face, conf call, Skype, 24 hour in hospital.
 - Multicultural advocates on call.
 - Having a government or private agencies to provide advocacy, potentially on a national basis. Health consumers organisations' members being upskilled to be able to be independent advocates.
 - Discussion around awareness and looking at health rights and responsibilities for patients, info sheets put in hospitals, residential and community care. Need funding, grant to do proof of concept. Should also include legal obligations and more impetus for health professionals to uphold those.



- Advocacy portal which listed all advocacy services available. Make discharge facilitators and social workers aware of this resource.
 - Changing attitudes of medical specialist so accept legitimacy of advocates.
 - Open community conversations – who will speak for you if you can't speak for yourself? Would reduce complaints.
 - Community radio, billboards, free to air television, news and media to break down the taboo of speaking about death and dying.
- **Personalising and connecting care**
 - Developing local initiatives in collaboration with health and community agencies to deliver ongoing seminars/info sessions to promote Advanced Health Directives (ie. purpose/alternatives) across the life span.
 - Support the employment and up-skilling of acute and community consumer reps who can provide info about AHDs and facilitate opportunities with consumers to complete an AHD or articulate their wishes/point of view.
 - Promote AHDs being incorporated into e-health to further underpin national standards - support or train GPs to ask at first point of contact if they have an AHD and make a plan how to support them in the future to create one.
 - Community and health care staff to collaborate with consumers and family to discuss how an AHD or the patient's wishes will be operationalised to best meet consumer values/needs against available resources and realistic treatment. Create an action plan to be signed by a consumer, family and team. To be evaluated in an ongoing way.
 - **Technical knowledge**
 - Goals – 1. Good life care (not futile treatment), 2. Patient feels their needs are being met, 3. Involved, informed decision making.
 - Everyone needs technical knowledge.
 - There is desire from clinicians for family to have shared understanding but it's hard. Can also be hard to stop treatment.
 - Technical knowledge needs to be in spoken and written format, possibly using formats that exist already – e-records, telehealth.
 - Should GPs have more technical knowledge to allow people to remain/live in their communities?
 - Best place to find information, treatment and community support info:
 - o GPs with special interests – where is this info? Should Medicare Locals have this? Coordination.
 - o Primary Health Teams/Integrated Healthcare
 - o Community Health Centres
 - o Community organisations – clinical and patient resources
 - Need better literacy to understand technical knowledge.

Issue to be raised at the joint HCQ/QCS forum that a number of community/non-Government organisations have been defunded or had their funding cut.

Appendix 2: “All great stories need a good ending – consumer and clinician perspectives on end-of-life care” organising committee members

Mr Mark Tucker-Evans (Chair)	QCS Executive Lead. Chair, Health Consumers Queensland, Chief Executive COTA Q
Dr Will Cairns	Director, Palliative Care Service, Townsville Hospital
Ms Liz Crowe	Program Facilitator, Advance Care Planning, Griffith University
Dr Jon Field	Deputy Chair, Statewide Intensive Care Clinical Network
Ms Melissa Fox	Coordinator, Health Consumers Queensland
Dr Anthony Herbert	Member, Statewide Child and Youth Clinical Network
Ms Julie Hulcombe	Chief Allied Health Officer
Dr Liz Kenny	Chair, Statewide Cancer Clinical Network
Mr Simon Mitchell	Registered Nurse, Townsville
Dr Cliff Pollard	Chair, Trauma Network
Dr David Rosengren	Chair, Queensland Clinical Senate
Dr Jeff Rowland	Co-Chair, Statewide General Medicine Clinical Network
Ms Mina Smith	Manager, Statewide Policy and Performance Division
Dr Norman Swan	Meeting facilitator

Appendix 3: Draft end-of-life care charter

You matter because you are you and you matter to the last moment of your life and we will do all we can, not only to let you die peacefully, but to help you live until you die.

(Dame Cicely Saunders)

Draft

Our commitment to you. We will:

1. respect your choices and your right to independence with compassion and understanding
2. ensure your privacy, dignity and confidentiality
3. facilitate consultation and discussion with you and the people who are important to you as often as required
4. co-ordinate documentation and communication of care between all treating teams including hospital and community
5. optimise symptom and pain management ensuring you are kept comfortable
6. provide emotional, spiritual, cultural and psychosocial support
7. support the people who are important to you, both as you approach the end of your life and in their bereavement.