

Health Consumers Queensland



... your voice in health

Health Advocacy Framework

Strengthening health advocacy in Queensland

Tomorrow's Queensland:
strong, green, smart, healthy and fair

Toward **2**
Tomorrow's Queensland

 **Queensland**
Government

Health Consumers Queensland's (HCQ) mission is to support the voices of Queensland consumers (patients) to achieve better health outcomes and contribute to the continued development and reform of health systems and services. HCQ achieves this by providing the Minister for Health with information and advice from a consumer perspective and by supporting and promoting consumer engagement, capacity building and health advocacy.

HCQ comprises a 12 member Ministerial Consumer Advisory Committee and a Secretariat supported by Queensland Health.

HCQ's term of reference four commits HCQ to working collaboratively with government, health sector and community stakeholders to develop and promote an advocacy framework to inform and strengthen individual and systems consumer health advocacy activities in Queensland.

This framework underpins HCQ's commitment to individual and broader systems health advocacy to empower consumers to protect, promote and defend their rights to affordable, safe, high quality healthcare and to improve and influence health policy, planning and service delivery and systems.

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Health Consumers Queensland wishes to thank individuals and organisations for their time, effort and expertise in assisting us with the development of the Framework. We would especially like to acknowledge:

- Queensland Council of Social Services Inc
- QCOSS Health Advocacy Reference Group members
- Participants at Health Consumers Queensland's September 2009 health advocacy workshop

Disclaimer

The views and opinions expressed in this paper are those of Health Consumers Queensland and other relevant stakeholders. This paper does not contain or reflect the views of the Queensland Government or Queensland Health.

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Message from the Minister for Health

A key ambition of the Queensland Government's Toward Q2: Tomorrow's Queensland vision is to make Queenslanders Australia's healthiest people. To this end, Queensland Health is committed to providing high quality, safe and sustainable health services to meet the needs of our communities. It is widely recognised that effective health advocacy plays an integral role in the delivery of these services.

Health Consumers Queensland (HCQ) is committed to strengthening the consumer perspective in health matters, through acting as 'your voice in health'. HCQ's Health Advocacy Framework: Strengthening health advocacy in Queensland promotes a consistent understanding of and integrated approach to health advocacy across public and private health services.

The Advocacy Framework complements implementation of the Australian Charter of Healthcare Rights recently endorsed by the Queensland Government. The Charter promotes consumers, their advocates, clinicians and providers working together towards safe, high quality healthcare and an improved health system. Effective health advocacy empowers consumers to actively participate in their healthcare decisions to ensure their needs and rights are addressed.

I congratulate HCQ's Chairperson, Mark Tucker-Evans, Ministerial Advisory Committee members and HCQ's Secretariat on this initiative and encourage all those involved in the health system including consumers, consumer and community organisations, statutory agencies, health professionals and policy makers to use the Advocacy Framework to help achieve better health outcomes for all Queenslanders.

*Geoff Wilson MP
Minister for Health*

March 2011

Message from the Chairperson

I am pleased to introduce HCQ's Health Advocacy Framework: Strengthening health advocacy in Queensland. Health advocacy is integral to dynamic health services and systems and leads to better outcomes for individuals and communities.

HCQ's term of reference four commits the body to working collaboratively with government, health sector and community stakeholders to develop and promote an Advocacy Framework to inform and strengthen individual and systems consumer health advocacy activities in Queensland.

The Advocacy Framework provides a useful mechanism to inform consumers, communities, government and non-government organisations about health advocacy, assess the effectiveness of current health advocacy approaches and support consumers, families and carers, and public and private health sector organisations to strengthen health advocacy in Queensland. Comprising five core elements, the Advocacy Framework outlines HCQ's definition of health advocacy, who can be a health advocate, principles which HCQ believes underpin effective advocacy and possible future directions for improving and promoting health advocacy approaches.

I would like to take this opportunity to thank the wide group of people and organisations who have played a role in the development of this framework. They include health consumers from across Queensland as well as consumer and community organisations, health professionals, health bodies and networks and Queensland Health. Their diverse views and perspectives have helped to shape this document and contributed towards the development of a strong and independent consumer voice and ongoing reform of the health system.

I would also like to thank Queensland Council of Social Services, HCQ's Advocacy Working Group, Committee members, Secretariat staff and contractors who have been involved in producing the Advocacy Framework.

*Mark Tucker-Evans
Chairperson, Ministerial Consumer Advisory Committee
Health Consumers Queensland*

March 2011

1. Strengthening Health Advocacy in Queensland

Health advocacy is integral to achieving better health outcomes for individuals and communities and to improving health services and systems. It ‘...challenges services, systems and the broader community to respond genuinely in meeting the expressed requirements of consumers...’¹

Health Consumers Queensland (HCQ) has developed the Health Advocacy Framework (the Advocacy Framework) to provide structure and support to individual health consumers, their families/carers and organisations to advocate for better health outcomes. The Advocacy Framework is a practical guide for health advocates – it defines health advocacy, explains who can be an advocate, establishes principles to achieve effective health advocacy and outlines possible future directions to inform and strengthen health advocacy in Queensland.

The Advocacy Framework provides a mechanism to:

- Inform consumers, communities, government and non-government organisations about health advocacy;
- Assess the effectiveness of health advocacy approaches and identify ways in which each of those approaches can be improved; and
- Promote safe, quality healthcare and health systems by giving health advocates a solid framework in which to advocate for change at both an individual and systemic level.

In essence, health ‘advocacy can open doors to participation. It can right wrongs, change the balance of power, address injustice, improve ... health services and alter attitudes and values. It inevitably empowers people in their everyday lives.’² The consumer voice is central to health advocacy and to achieving better health outcomes.

Ultimately, HCQ envisages that mainstream adoption of the Advocacy Framework will:

- Promote and better protect health consumers’ rights; and
- Support the delivery of more effective, responsive healthcare and improved health policies, practices, services and systems.

1 Department of Health and Ageing, *The Kit – A guide to the advocacy we choose to do* (1998) 26 <[www.health.gov.au/internet/main/publishing.nsf/Content/2CC3845B576CC54ECA2572F9000EBA99/\\$File/kit.pdf](http://www.health.gov.au/internet/main/publishing.nsf/Content/2CC3845B576CC54ECA2572F9000EBA99/$File/kit.pdf)> at 10 May 2010.

2 Sandra Carlisle, ‘Health promotion, advocacy and health inequalities: a conceptual framework’ (2000) 15(4) *Health Promotion International* 373.

The Australian Charter of Healthcare Rights and Health Reform

Health Advocacy empowers consumers and their advocates to actively participate in decision-making around their healthcare and the broader health system.

The Australian Charter of Healthcare Rights (Appendix 2), launched by the Queensland Government in 2010, reinforces the role health advocacy plays in the delivery of safe, quality healthcare and an improved health system.³ Significantly, the Charter entrenches consumers' rights to open communication of any issues or concerns they may have in relation to their healthcare and the role of family or patient advocates in supporting them if they are experiencing difficulty in communicating.

Current state and national health reform agendas also reinforce the roles individual and systemic advocacy play as mechanisms towards achieving the vision of health reform – person-centred, accessible, safe healthcare and a responsive health system.

³ The Australian Charter of Healthcare Rights can be accessed at <http://www.health.gov.au/internet/safety/publishing.nsf/Content/PriorityProgram-01>.

2. The Health Advocacy Framework

The Advocacy Framework includes:

- Contemporary advocacy definitions, categories and approaches,
- HCQ's definition of health advocacy,
- Information about who can act as a health advocate,
- HCQ's principles for effective health advocacy, and
- Possible future directions for improving and promoting individual and systemic health advocacy in Queensland.

How was the Advocacy Framework developed?

The Advocacy Framework has been developed in consultation with a range of individuals and organisations throughout Queensland - individual health consumers and health practitioners, consumer and community organisations, health professional bodies and networks, statutory agencies, Queensland Health and other government departments. This consultation highlighted the diversity of views about what constitutes health advocacy.

In early 2009, HCQ engaged the Queensland Council of Social Service (QCOSS) to explore existing consumer/patient advocacy structures, mechanisms and practices in Queensland and the understandings of health advocacy that underpin current practices, to inform a first draft of the Advocacy Framework.

In conducting this research, QCOSS identified significant gaps in current health advocacy practice in Queensland, including:

- Little formal (funded) health advocacy is performed.
- Most advocacy is unfunded and conducted informally by consumers themselves, carers, family members or friends.
- There are multiple and conflicting definitions of health advocacy resulting in diverse approaches to the practice of health advocacy.
- There is a lack of clarity as to who can legitimately act as a person's advocate and the nature of their role.

Given these inconsistencies and to ensure the Advocacy Framework truly reflected consumer and community perspectives, HCQ and QCOSS conducted a subsequent workshop in September 2009 with approximately fifty participants from various health, community and government stakeholder groups. In addition to further refining the structures through which health advocacy can occur, attendees raised additional key issues relevant to current health advocacy in Queensland, namely:

- Health advocacy is often misunderstood and sometimes occurs on a “tokenistic” level, rather than being perceived as adding value to health outcomes for individuals, the health system and broader communities.
- A health advocacy framework is an abstract concept, that there is no ‘one right way’ to go about it and no ‘one right answer’ to the issues posed.
- There is a need for overarching principles to underpin the formal recognition and support of health advocacy as a legitimate mechanism to improve individual and systemic health outcomes.

Given overall stakeholder feedback, HCQ’s Committee engaged in extensive dialogue and robust debate about many elements of the Advocacy Framework, particularly the definition of health advocacy and who can legitimately perform the role of an independent health advocate.

HCQ has endeavoured to incorporate these diverse perspectives and approaches in a practical Advocacy Framework for broad application by consumers, community, government and non-government sectors.

3. Health Advocacy

The concept of health advocacy is not new. Health consumers⁴, or those acting on their behalf, have always been active in influencing the delivery of health services and programs. However, the significance and value of health advocacy has recently been more formally acknowledged by government, most notably through state and national health reform agendas. These reforms recognise that ‘strengthened consumer... voice’ is vital in moving towards safe, high quality person-centered health services, and ‘creating an agile and self-improving health system’⁵.

At an individual level, health advocacy performs a crucial role in supporting health consumers, families and carers to receive healthcare that meets their needs. At a systems level, health advocacy serves to inform, influence and improve health policy, planning and service development and delivery. It initiates debate around critical consumer health issues.

Why is health advocacy important?

Health advocacy is vital to the attainment of better health outcomes for consumers and communities.

Effective health advocacy ensures:

Health consumer needs and rights are promoted and addressed	Health consumers benefit by having their needs, rights and interests promoted and addressed. ⁶ This may include being heard, obtaining the information or services they need, feeling more in control of their healthcare and having their issues and/or concerns addressed. It may also result in the needs of marginalised groups being better responded to (Indigenous and Culturally and Linguistically Diverse communities). ⁷
Health consumer confidence	Individual health consumers, the general public and consumer groups have greater confidence in the health system and support the way it operates.
Accountability and transparency	There is increased accountability and transparency for individuals, families and the community.

4 Health Consumers Queensland defines ‘Health consumers’ as people who use, or are potential users of health services including their family and carers. Consumers may participate as individuals, groups, organisations of consumers, consumer representatives or communities. The Carers (Recognition) Act 2008 (Qld) identifies a carer as an individual who provides, in a non-contractual and unpaid capacity, ongoing care or assistance to another person who, because of disability, frailty, chronic illness or pain, requires assistance with everyday tasks.

5 National Health and Hospitals Reform Commission, A Healthier Future for all Australians: Final Report June 2009 (2009) 121.

6 Disability Services Queensland and Federal Department of Families, Community Services and Indigenous Affairs, Strategic Reporting Framework for Advocacy (2007) 4.

7 Ibid, 8.

Empowerment of health consumers	Health consumers who might otherwise remain voiceless and invisible are empowered to raise their concerns, issues and complaints and to seek redress.
Health consumer views are central to policy and practice decision making	Government and health professional bodies have access to the views of health consumers when developing and implementing policy and practice decisions. Health advocacy serves to generate government and health professional understanding, awareness and action around a diversity of health issues. ⁸
Continuous improvement	The health system is responsive and continually improves its policies, procedures and services in response to advocacy efforts. Health inequalities and perceived injustices at an individual and systemic level are addressed. ⁹
Access to support	Health consumers can be connected with appropriate support networks, community groups and services. ¹⁰

What are the benefits of health advocacy?

Health advocacy contributes to:

- Positive changes to legislation, policies, practices, service delivery and developments and community behaviour and attitudes.¹¹
- Promotion of wellness and resilience in individuals, families and communities in conjunction with health literacy and patient activation strategies.
- Raised awareness of the significant impact on an individual's health and wellbeing of broader social and environmental factors (such as housing, education, employment, cultural identity, gender and sexuality identities), thereby enabling health advocacy to facilitate individual and systemic change in these areas.
- Empowering health consumers to become more involved in their healthcare decision-making and broader health policy and initiatives.
- Resolution of consumers' issues as they arise, mitigating escalation and lengthy complaints processes.
- Consumer focused, affordable and responsive health services that are cost-effective.

⁸ Ibid.

⁹ Sandra Carlisle, 'Health promotion, advocacy and health inequalities: a conceptual framework' (2000) 15(4) *Health Promotion International* 373.

¹⁰ Ibid, 8.

¹¹ Ibid, 7.

What is happening in Queensland?

In Queensland, individual and systemic health advocacy is currently undertaken by a variety of individuals, groups and organisations.

Formal (funded) advocacy groups report that limited funding and resources restrict the activities and services they can provide when compared to community need.

Informal (unfunded) advocacy is usually conducted by individuals, families and carers in response to health issues as they arise. It is often provided in an unplanned, ad hoc and unsupported way.

While these approaches may meet consumers' needs and interests, the quality and effectiveness of such approaches is variable.

Many health populations, particularly those in rural and remote areas and marginalised social groups may entirely miss out on health advocacy support and services, resulting in poorer health outcomes for consumers.

Further details about health advocacy in Queensland are detailed in Appendix Three – QCOSS Discussion Paper extract.

4. Defining Health Advocacy

Health advocacy is difficult to define because ‘*multiple and conflicting definitions and usages exist*’¹², a variety of advocacy approaches are used and diverging perspectives exist among individuals, consumer groups, academics and the government and non-government sectors. There is in fact a striking lack of community consensus on what constitutes an acceptable and appropriate definition of health advocacy.

This lack of consensus is not restricted to Queensland. HCQ has examined current national and international definitions and has concluded that no universal or commonly accepted definition exists. However, feedback gathered by HCQ suggests that most health advocacy practice in Queensland does align with common elements identified in various advocacy definitions that have been adopted by government and community agencies across a range of human services.

The following discussion examines current definitions and approaches to advocacy which form the basis for HCQ’s definition of health advocacy.

What is advocacy?

There are diverse views and approaches to advocacy as reflected in contemporary definitions, and considerable debate as to its definition.¹³ One of the best known and widely accepted definitions is that of Dr Wolf Wolfensberger:

*... Advocacy is functioning (speaking, acting, writing) with minimum conflict of interest on behalf of the sincerely perceived interests of a person or group, in order to promote, protect or defend the welfare of, and justice for, either individuals or groups, in a fashion which strives to be emphatic and vigorous, and/or which is actually, or very likely to be, costly to the advocate or advocacy group.*¹⁴

Other advocacy definitions incorporate elements of Wolfensberger’s definition, including the following definition adopted by the **Commonwealth Department of Families, Community Services and Indigenous Affairs** and the **Queensland Department of Communities-Disability and Community Care Services**:

12 Sandra Carlisle, ‘Health promotion, advocacy and health inequalities: a conceptual framework’ (2000) 15(4) Health Promotion International 369.

13 Queensland Parents for People with a Disability, What is advocacy? (2010) <<http://www.qppd.org/advocacy.html>> at 10 May 2010.

14 A.C.T. Disability, Aged and Carer Advocacy Service, Guide to commonsense advocacy (2010) <<http://www.adacas.org.au/advocacy.htm>> at 20 August 2010.

Advocacy ... is speaking, acting and writing with minimal conflict of interest on behalf of the interests of a person or group in order to promote, protect and defend the welfare and justice for either the person or group by:

- *being on their side and no-one else's;*
- *being primarily concerned with their fundamental needs;*
- *remaining loyal and accountable to them in a way which is empathetic and vigorous.*¹⁵

Cancer Voices Queensland Inc considers that advocacy is:

*... Representing and/or working with a person or group of people who need support to exercise their rights. It may involve speaking, acting or writing on behalf of another person or group and working against established or entrenched values, structures and customs and therefore needs to be independent of healthcare service providers and authorities.*¹⁶

Queensland Aged & Disability Advocacy Inc refers to advocacy as:

*The process of standing alongside an individual who is in need of support, speaking out on their behalf in a way that represents the perceived best interests of the person, even if that cause or interest does not necessarily coincide with one's own beliefs, opinions, conclusions, or recommendation.*¹⁷

Categories of advocacy

Contemporary advocacy practice in Queensland tends to fall within two broad categories, namely **individual** and **systemic** advocacy. A range of advocacy approaches are embedded within both categories.

Individual advocacy in the health consumer context is sometimes referred to as patient advocacy. It involves supporting and promoting the rights and interests of individuals, assisting individuals to achieve or maintain their rights and empowering and representing their needs. Individual advocacy strategies include: representing the consumer, supporting the consumer to represent his or her own interests and ensuring people are empowered to voice their perspectives.¹⁸

15 Disability Services Queensland and Federal Department of Families, Community Services and Indigenous Affairs, Strategic Reporting Framework for Advocacy (2007) 3.

16 Cancer Voices Queensland Inc, Advocacy – what is it? Retrieved (2010) <http://www.cancervoicesqld.org.au/advocacy/what_is_advocacy.html> at 20 January 2010.

17 Queensland Aged and Disability Advocacy Inc, QADA advocacy framework 2004 (2004) <http://www.qada.org.au/what_is_advocacy.pdf> at 20 January 2010.

18 Disability Services Queensland and Federal Department of Families, Community Services and Indigenous Affairs, Strategic Reporting Framework for Advocacy (2007) 3.

Systemic advocacy seeks to introduce, influence or produce positive long-term changes to attitudes, systems, policies and procedures, to remove barriers, address discriminatory practices and to ensure the collective rights and interests of health consumers are attained and upheld.¹⁹ It is primarily concerned with encouraging changes to the law, government, policies and community attitudes.²⁰ It also seeks to influence ‘... the social and political structures that promote and sustain injustice and inequality’.²¹

Advocacy approaches

A range of advocacy approaches are currently practiced in both individual and systemic advocacy, including:

- Self advocacy,
- Citizen advocacy,
- Peer advocacy,
- Parent advocacy, and
- Family/group advocacy.

These advocacy approaches are explained in more detail in the **Glossary**.

These advocacy approaches can be undertaken on an informal (unpaid) or formal (paid) basis. For example, a person may informally self advocate about a matter or their family, carers and friends may informally advocate on the person’s behalf. Alternatively, professional advocates may formally undertake advocacy on behalf of a person, family or group (such as people from culturally and linguistically diverse communities) or a distinct health population (rural and remote health consumers/communities).

Within the scope of this work, HCQ has determined that most health advocacy currently practiced in Queensland reflects key elements of Dr Wolfensberger’s definition, namely:

- Standing beside another;
- Remaining loyal and independent;
- Absence of conflicts of interest;
- Defending human rights; and
- Speaking out in support of and representing the needs and interests of a vulnerable or disadvantaged individual or group.

19 Ibid. Office of the Public Advocate, *Challenging Behaviour: five years of public advocacy in Queensland* (2005) 16.

20 Endeavour Foundation, *Advocacy Information Paper June 2007* (2007) 8.

21 Department of Health and Ageing, *The Kit – A guide to the advocacy we choose to do* (1998) 24 <[http://www.health.gov.au/internet/main/publishing.nsf/Content/2CC3845B576CC54ECA2572F9000EBA99/\\$File/kit.pdf](http://www.health.gov.au/internet/main/publishing.nsf/Content/2CC3845B576CC54ECA2572F9000EBA99/$File/kit.pdf)> at 10 May 2010.

5. HCQ's Definition of Health Advocacy

Given the lack of a universally accepted definition of health advocacy and the divergence in perspectives about the meaning of advocacy, HCQ has developed a definition that captures stakeholders' views as to what constitutes health advocacy in Queensland. HCQ considers that:

Health advocacy is speaking, acting or writing with minimal conflict of interest to support a health consumer or group's wellbeing, and to promote, protect and defend their right to accessible, safe, quality healthcare.

Health advocacy can be undertaken by the consumer themselves, or by an independent advocate loyally representing the individual or group's perceived interests.

HCQ's definition of health advocacy embodies key elements of Dr Wolfensberger's definition, the definitions noted above and feedback received from key stakeholders. It acknowledges that various health sector stakeholders define advocacy and health advocacy as similar concepts. This definition also reflects individual and systems advocacy practiced in Queensland and the various advocacy approaches being undertaken within those categories as detailed in section 4.

This definition embodies the key values of independence, loyalty, promotion and protection of a consumer's wellbeing and rights, and absence of conflicts of interest. These elements and values lie at the heart of successful advocacy.

'**Independence**' entails the 'advocate's willingness and ability to stand alone'²² from those who deliver health services and programs, and to be 'on the side' of the person.²³ Advocates who are independent give health consumers confidence that they will act with integrity without being influenced by others.

'**Loyalty**' concerns the advocate's and/or advocacy organisation's ability to ensure its primary allegiance is to the individual or group being advocated for.²⁴ An advocate and/or advocacy organisation must do their utmost to identify with, understand, and think, speak and act truthfully on behalf of the consumer.²⁵ 'A true advocate

22 Georgia Advocacy Office Inc, The Principles (2010) <www.thegao.org/theprinciples.htm> at 10 May 2010.

23 Disability Services Queensland and Federal Department of Families, Community Services and Indigenous Affairs, Strategic Reporting Framework for Advocacy (2007) 3.

24 Ibid.

25 Ibid.

supports the decision of the patient regardless of whether they (the advocate) agree'.²⁶

'Promotion and protection of a consumer's wellbeing and rights' focuses on a core function of health advocacy. The Australian Charter of Healthcare Rights outlines the rights of health consumers in accessing health services. Advocates act to ensure that health consumers' rights are recognised and respected which supports good outcomes for the consumer in regards to their health and wellbeing.

Absence of conflict of interest is a fundamental element of health advocacy. Conflicts of interest may arise when an advocate in a position of trust has professional or personal interests which conflict with the person for whom they claim to be advocating. A conflict of interest prejudices an advocate's ability to perform his or her duties and responsibilities objectively. For a person to be a truly effective advocate, they should understand that their needs, interests and values may conflict with those of the person for whom they advocate.²⁷

Ethical challenges in health advocacy practice

To truly fulfill their role, health advocates must diligently avoid any conflict of interest – perceived or actual.

Health advocacy often involves dealing with personally and professionally challenging situations and ethical issues around 'independence', 'best interests' and 'conflict of interest'. Tensions may also arise for advocates when, in seeking to achieve change, they are challenged by accepted practices, processes, attitudes and inflexible systems.

A health advocate and/or advocacy organisation needs to be mindful of their purpose and goal and assess whether they can truly act in the best interests of and be fully accountable to the health consumer for whom they are advocating. This involves the potential advocate assessing whether they can be on the health consumer's side and no-one else's, be primarily concerned with the health consumer's fundamental needs and remain loyal and accountable to the health consumer/s in a way which is emphatic and vigorous.²⁸

26 Ivy F. Oandasan, 'Health Advocacy: bringing clarity to educators through the voices of physician health advocates (2005) 80(10) Academic Medicine S38.

27 Endeavour Foundation, Advocacy Information Paper June 2007 (2007) 9.

28 Disability Services Queensland and Federal Department of Families, Community Services and Indigenous Affairs, Strategic Reporting Framework for Advocacy (2007) 3.

Historically, some health professionals, community service workers and public servants have seen themselves as advocates for consumers and have played a role in influencing and producing positive long term change within the health system. An advocate working from within the 'system' may have the advantage of understanding how the system operates and be in a position to influence policies and processes. Such advocacy can facilitate resolution of issues. However, HCQ notes the potential sensitivity and conflict of interest confronted by those groups when advocating from within a service and/or system which also remunerates them. While such advocacy may be well intentioned and may achieve effective outcomes for consumers, at times these groups will be placed in a situation of real or perceived conflict for the reasons noted above. It is important that these groups exercise caution in such circumstances, and that the consumer's rights, interests and needs prevail. Wherever possible, the advocate should remove themselves from the position of conflict, or arrange alternative independent advocacy for the consumer.

Similarly, family members and/or carers regularly act as advocates for their family member or care recipient around health issues. This may be a successful arrangement. However, at times the consumer (patient) may not want their family member as an advocate, or their family member may not want to act as their advocate due to conflict of interest. These circumstances require advocacy by an impartial third party who is able to act in the consumer's best interests rather than the interests of the family.

HCQ believes 'no one size fits all' and there is a need and place for diverging advocacy models for health consumers.

6. Acting as a Health Advocate

Who can be a health advocate?

As indicated by the diagram below, a variety of individuals and groups may choose to act as health advocates.

The consumer is at the heart of the diagram, reinforcing that the consumer should always be the central focus of any advocacy effort. Other individuals and/or groups of people who may act as advocates are clustered around the consumer. The individuals and groups may change over time, depending upon the nature of the advocacy effort, any potential conflicts of interest that may hinder the individual/group in acting in the consumer's best interests and the health advocacy approach most likely to achieve a positive outcome for the consumer.

Health Advocacy Diagram



The diagram demonstrates that the practice of health advocacy is not 'fixed'.²⁹ Rather, health advocacy is subjective in that the type of health advocate, the method of advocacy undertaken and the approach adopted (i.e. whether the advocacy occurs at the individual, systemic or some other level) will be specific to the nature, circumstances and context of the issue being advocated about.³⁰

²⁹ Sandra Carlisle, 'Health promotion, advocacy and health inequalities: a conceptual framework' (2000) 15(4) Health Promotion International 375.

³⁰ Ibid.

What are the different types of Health Advocates?

Health advocates can include:

- Individual consumer,
- Friends/family/carers/volunteers,
- Independent patient advocates,
- Non-profit organisations,
- Non-government policy/advocacy organisations,
- Statutory authorities,
- Health professionals and patient liaison officers, and
- Public servants.

Consumer

Individuals can be very effective self-advocates and where possible should be the starting point for advocacy. Self-advocacy can have many advantages such as building a consumer's confidence to analyse options and actively communicate their informed decisions. However, it can also be difficult and draining, especially in times of illness and vulnerability. As such, a consumer may seek the support of an advocate.

Example

A health consumer takes action to seek access to his/her health records after his/her general practice centre closes without making arrangements for the transfer of those records to another practice of the consumer's choice.

Friends, family, carers, volunteers

Families, friends and carers frequently act as informal (unpaid) advocates for those who are in their care or are close to them. This form of advocacy may require an investment of time and effort and at times the advocate may be perceived as not completely independent in pursuing the best interests of the consumer if potential conflicts of interest exist in the relationship.

Example

At the consumer's request his/her family member actively seeks out information about the consumer's range of treatment options and requests a case conference with the treating health team.

If formally appointed as substitute decision-makers for a consumer with impaired decision-making capacity, families, friends and carers assume a more formalised advocacy role. They may have been appointed by the consumer (when he/she had capacity) as the consumer's attorney under an Enduring Power of Attorney.³¹ Alternatively the Queensland Civil and Administrative Tribunal may appoint an adult/s to act as guardian/s for personal and health matters for an adult with impaired capacity.³² Even where there is no such formal appointment, families friends or carers may assume the role of a substitute health decision-maker as Statutory Health Attorney where a person no longer has capacity to make decisions about their health matters.³³

Patient advocates

Patient advocates may have a formal (paid) advocacy role through their employment with a non-government organisation, community service or advocacy organisation. Conversely, they may undertake this role informally (unpaid) as individuals with an interest in upholding the rights and interests of others. Patient advocates 'stand beside' individuals with particular needs in order to represent those individual's interests.

Example A

A person with a mental illness may be about to be discharged from hospital without accommodation support. A patient advocate works with accommodation services around support options for the consumer.

Example B

An older consumer is due for discharge from hospital but their carer is unwell. The person's patient advocate negotiates with the hospital to keep the consumer in hospital for a further period of time while the carer recovers.

31 Powers of Attorney Act 1998 (Qld) s 32(a).

32 Guardianship and Administration Act 2000 (Qld) s 12.

33 Powers of Attorney Act 1998 (Qld) s 63(1)(a) – (c).

Non-profit organisations

Throughout Queensland there are a range of non-profit community service organisations which are either funded or voluntarily represent the needs and interests of their clients around healthcare matters. It is important to be aware of conflicts of interest which may arise in these situations due to advocacy being undertaken by a person from within the organisation which remunerates them.

Example A

A non-profit organisation identifies that their service users' general health and wellbeing requires longer consultation times with General Practitioners on an annual basis because of their complex and multiple health needs. The organisation advocates for improved services and works with other organisations to achieve a specific Medicare item number for this particular consultation.

Example B

Some staff in a non-profit organisation undertake advocacy with their manager on behalf of an individual service user about the level and type of services that the organisation is providing. The manager reviews the service and decides to change it to better respond to that individual's support needs.

Non-government policy/advocacy organisations

Some health consumer bodies advocate at the national and state policy, program or systems levels to bring about quality improvements to the health system to benefit health consumers and the wider public. Similarly, throughout Queensland there are a limited number of funded and non-funded organisations which undertake individual and systemic health advocacy, utilising the range of advocacy approaches outlined in section 3.

Example

HCQ held a state-wide consumer forum to gather feedback regarding the issues and challenges experienced by consumers in undertaking advance care planning and using/making Advance Health Directives. The feedback obtained will be used to advise the Minister for Health about consumers' perspectives and to provide options to the Queensland Government for systemic reform to improve consumer outcomes.

Statutory authorities

In Queensland, the Office of the Adult Guardian and the Office of the Public Advocate undertake individual and systems advocacy on behalf of people with impaired decision-making capacity. Broadly, the role of the Public Advocate is to undertake systemic advocacy to promote and protect the rights and interests of groups of adults with impaired decision-making capacity, including systemic advocacy about health-related matters. Conversely, the Adult Guardian represents the rights and interests of individual adults with impaired capacity around matters including health.

Example

The Adult Guardian was appointed as the guardian for personal matters (including health matters) for a person with an intellectual disability. Prior to the Adult Guardian's appointment, the individual had been prescribed a number of medications by different General Practitioners and was experiencing side-effects which impacted upon his quality of life. The Adult Guardian advocated on behalf of the client to have a consistent health care plan implemented which involved regular consultation with one General Practitioner.

The Adult Guardian subsequently advised the Public Advocate that during the past six months a number of clients had experienced similar problems with medication and inconsistent treatment. The Public Advocate proceeded to write to the State and Federal Ministers for Health and the relevant state and national health professional bodies to advise them of this issue and to make suggestions for reform to improve outcomes for people with impaired capacity in similar situations.

Health professionals and patient liaison officers

Although health advocacy may not be formally included in their role, a number of health and allied health professionals and patient liaison officers ‘step outside the square’ and use their influence to achieve better health outcomes for their patients/clients (health consumers) and to produce positive changes in the health system. However, it is important to note that at times, health professionals will be placed in a situation of real or perceived conflict of interest when advocating from within a service and/or system which also remunerates them.

Example

An older patient who lives alone has been discharged from hospital after a serious fall. Upon visiting him at home, his community-based Occupational Therapist noted that his mobility has decreased and his support needs had increased since his hospital admission. The Occupational Therapist advocated on his behalf with the hospital-based assessment team to have his level of care reassessed to ensure his safety and wellbeing at home.

Public servants

People who work in Government may also act to influence how the system operates. These activities, when consumer-focused, are equally valuable. However, if engaging in advocacy on behalf of a consumer, family or group in relation to Government funded or delivered services, conflicts of interest may also arise. Again, it is important to note that at times public servants will be placed in a situation of real or perceived conflict of interest when advocating from within a service and/or system by which they are remunerated.

Example

Planning for a new health service in a culturally diverse area of Brisbane was being undertaken, led by a unit within a large health organisation. One of the employees outside the unit noted that some cultural groups had not been consulted during the planning process, despite comprising a large proportion of the population served by the new health service. The employee subsequently advocated with the unit leading the work around the need to have the groups’ views represented, leading to a review of the project’s consumer and community engagement strategy. Subsequently, the groups were included in the consultation process and as such, the organisation was able to plan for inclusive services that best met local community needs.

7. Principles for Effective Advocacy

What are the principles?

HCQ has developed six core principles for effective health advocacy which align with state and national health reform principles and complement the Australian Charter of Healthcare Rights. These six principles apply to advocacy approaches that span individual and systems health advocacy. The principles reinforce the legitimacy and value of effective health advocacy as a mechanism to improve health outcomes. They are designed to enable consumers, consumer and community organisations, statutory agencies, health professionals, health policy makers and others to:

- Assess the current effectiveness of health advocacy approaches, in particular whether they are working well and whether they can be improved; and
- Strengthen current and future health advocacy approaches to promote safe, quality healthcare and health systems.

Principle	Description
Consumer centred	The consumer is at the centre of the interaction.
Opportunities	Stakeholders promote and support opportunities for both individual and systemic advocacy.
Recognition	Stakeholders recognise that advocacy is legitimate and that it can take many forms.
Relationships	All those involved work together with respect and recognise each other's roles and contribution to the process.
Response	Matters raised are acknowledged and responded to.
Resolution	The aim of all parties is to find a solution which is acceptable to the consumer.

The six principles build upon HCQ's definition of health advocacy, advocacy categories and approaches currently practiced in Queensland as well as the variety of people and groups who may act as advocates (refer to sections 4, 5 and 6). The principles highlight the need to maintain the consumer as the central focus of all advocacy efforts and that advocacy approaches and types of advocates are not 'fixed'. Approaches and advocates may vary depending on the circumstances of the consumer and the issue at hand.

The principles are therefore designed to accommodate a wide range of health advocacy situations.

Health advocacy case studies

To illustrate how the principles for effective advocacy could operate, the case studies below provide a practical example of health consumer issues and advocacy approaches at individual, family and systemic levels. The principles are applied and discussed in the context of the issues raised by the case studies.

The case studies have been provided by HCQ stakeholders. The analysis is that of HCQ. The individuals and groups in the studies have been de-identified but are based on true events.

1

Case Study One

Kathy's Story (individual advocacy)

The Problem:

'The medication they gave me is making me feel so ill. I feel sick and dizzy and it doesn't help my problem. The doctor says I have to stick with it for a period of time. I don't think he is listening to me and I don't know what to do to get some real help for my condition....'

Applying the Principles:

The hospital in which Kathy is being treated recognises that situations such as Kathy's will occur from time to time and is committed to giving consumers a voice in their treatment. This is recognised in a formal policy and in staff training (recognition).

On the wall of the clinic, there is a poster from a community agency with a 'help line' number that Kathy can ring to get information and support (opportunity). A worker from the community agency listens to Kathy and helps her get all the information she needs. The worker also attends the next appointment Kathy has with her doctor (opportunity). Kathy is able to make an informed decision about her medication in a respectful way with her doctor (relationships, response and resolution). Kathy's needs are at the centre of the discussion.

Given that advocacy can take many forms, other possible advocacy avenues could have included giving Kathy the skills to self-advocate, or the intervention of a patient advocate or another health professional. Had Kathy remained unhappy, her advocate could have explored other options with her, such as asking for a second opinion or making a complaint.

2

Case Study Two

Jo's story (family advocacy)**The Problem:**

Jo is an 85 year old Polish Jewish man. He immigrated to Australia after being held in a concentration camp during World War II. After years of manual labour Jo has ongoing back trouble and is often reliant on his Polish wife of 50 years and his three adult children for assistance with domestic tasks. Jo has recently been diagnosed with lung cancer and is not expected to live for more than a year. He also has a number of health conditions requiring daily medications. Although Jo has resided in Australia for many years, his English skills are quite limited and his adult children generally accompany him to medical appointments to act as his interpreters.

One day, Jo slips in the kitchen of his home and has a nasty fall. He is immediately hospitalised, where he presents as confused and disoriented. Jo's nurses are very concerned about his ongoing disorientation, as well as his frailty and limited mobility, and whether Jo's wife can properly care for him. When they attempt to discuss with him the prospect of moving into a nursing home, Jo becomes very agitated and his wife becomes distressed as she feels she will lose him. Jo's adult children, who are also at the hospital, are told that the hospital staff would like to arrange an ACAT (Aged Care Assessment Team) assessment for Jo due to their concerns about his ongoing care arrangements. They are all upset by this as no one has explained what an ACAT assessment is and they feel that this automatically means he will be put in a nursing home.

Applying the Principles:

The hospital social worker arranges a meeting between Jo, Jo's family and the treating team to discuss Jo's prognosis and ongoing care arrangements (recognition, relationships). Jo's children express their disappointment at not having the ACAT process clearly explained initially. They clearly state that they wish to be involved in all discussions regarding Jo's care (recognition/opportunities).

Jo's children provide detailed advice to the treating team about Jo's domestic care arrangements prior to his fall, and their ongoing involvement in his day-to-day care, which includes providing transportation, gardening and household maintenance. They also clarify that Jo has previously told them many times that he 'wants to die at home' and that he fears being 'imprisoned' in a nursing home due to ongoing trauma from his experiences in World War II. Jo's children, as their parents' interpreters, confirm they have spoken to their father and mother and both agree that Jo should be cared for at home (opportunities).

Jo's children, through advocating about Jo's care and wishes to the treating team, are able to arrange to be at the ACAT assessment to represent their family (opportunity). Through being involved in the ACAT assessment and

Case Study Two Continued

providing information about Jo, Jo's family are able to negotiate a mutually acceptable outcome for Jo, whereby Blue Care will provide ongoing domestic care and Jo's children will provide further domestic support and assistance (relationships, response, resolution).

3

Case Study Three

A health consumer group's story (systemic advocacy)

The Problem:

A State Government proposed to redevelop a hospital in a regional area in Australia. A redevelopment plan was developed. A local health consumer group saw the plan and noted that the redevelopment plan included only 15 hospital beds, and no private rooms or palliative care beds.

Applying the Principles:

During the consultation process community stakeholders were consulted by the Hospital Development Project Management Team, including the health consumer group (recognition). The group were invited to and participated in several meetings with the Project Management Team, during which the redevelopment proposal was finalised (opportunities and recognition).

The health consumer group voiced their concerns about the inadequate number of hospital beds to service the local region; the absence of private rooms for patients with private health care and the failure to accommodate patients in need of palliative care. The health consumer group undertook research and presented statistical evidence to the Project Management Team justifying consumer/patient need for more beds, private rooms and palliative care beds, and engaged in ongoing discussions and negotiations about these issues (consumer centred and relationships).

As a result of the health consumer group's systemic advocacy, further funding was allocated to the hospital redevelopment project, which enabled 32 hospital beds, including six private rooms and two palliative care rooms to be built. The Government also amended its Health Service Planning Policy to include consideration of local community needs in relation to palliative care and private rooms in the development of new services across the State (response and resolution).

How can the principles be recognised, promoted and implemented?

These principles could apply to many situations and issues encountered by consumers in the health system. Detailed below are some examples of the ways in which the principles can be recognised, promoted and implemented across government and non-government health services. These examples are not intended to be exhaustive, but rather illustrate how the principles can work towards achieving accessible, safe, quality healthcare and improved health systems.

Principle	How this principle could be promoted/implemented
Consumer Centred The consumer is at the centre of the interaction.	<ul style="list-style-type: none"> Consumer centred principles should be included in all policy documents, from those in the office of a local General Practitioner to those at a major teaching hospital
Opportunities Stakeholders promote and support opportunities for both individual and systemic advocacy.	<ul style="list-style-type: none"> Information for consumers about where to access advocacy services or about how to self-advocate is easily available Patient advocates are available to act on behalf of a consumer Health professionals have a mechanism for identifying systemic problems arising from their interaction with patients Consumer Non-Government Organisations are in place to identify systemic issues and advocate for change
Recognition Stakeholders recognise that advocacy is legitimate and that it can take many forms.	<ul style="list-style-type: none"> Health professionals receive training about what advocacy is and why it is important The existence of opportunities for advocacy are promoted in various ways
Relationships All those involved work together with respect and recognise each other's roles.	<ul style="list-style-type: none"> There may be formal role statements where appropriate If individuals do not treat each other with respect, there are avenues to pursue complaints
Response Matters raised are acknowledged and responded to.	<ul style="list-style-type: none"> There are timeframes for responses in appropriate cases Responses in appropriate cases are in writing Reasons are given
Resolution The aim of all parties is to find a solution the consumer can live with.	<ul style="list-style-type: none"> The solution is implemented as agreed There is a way of measuring how effective the solution has been Where an acceptable solution is not agreed, it is acknowledged that advocacy may continue in a different manner or format

8. Future Directions for Health Advocacy in Queensland

Given the strong feedback HCQ received throughout the development of the Advocacy Framework regarding the benefits of effective health advocacy in improving consumers' health outcomes and their overall confidence and satisfaction with the healthcare system, HCQ has developed four possible options to stimulate further discussion and action around health advocacy.

The options are designed to complement and build upon each other and are based on current gaps in health advocacy practice identified during the course of this work including:

- Lack of consistency in approaches to health advocacy and advocates,
- Lack of clarity around who can act as an advocate and their role,
- Lack of resources, information and tools to support consumers, families, carers undertaking informal advocacy,
- Lack of dedicated funding to support individual and systemic health advocacy for individuals and families/carers, and
- Lack of an ongoing independent peak body for health consumers in Queensland.

HCQ acknowledges that further work would need to be undertaken to explore the options in more detail, especially in the context of the changing health environment.

The options carry policy and program implications for Queensland Health, private and community health organisations and the Queensland and Commonwealth governments. Additionally, HCQ is aware that the health landscape is undergoing a time of rapid transition with significant changes occurring as a result of health and hospital reform agendas being implemented in Queensland and nationally.

As such, HCQ offers the options as a starting point to explore and inform future health advocacy activities and thereby support the delivery of more effective, responsive healthcare and improved health policies, practices, services and systems.

Option One – Development of a formal advocacy policy and integrated approach

Development of a formal health advocacy policy, and promotion of an integrated approach to health advocacy, underpinned by HCQ's Advocacy Framework

- a) Queensland Health, private and community health organisations adopt and implement a formal health advocacy policy based on HCQ's Health Advocacy Framework.
- b) Queensland Health promote an integrated and collaborative approach to health advocacy across the public and private health sectors, and other consumer and community stakeholders.

Development of a formal advocacy policy based on HCQ's Advocacy Framework would achieve:

- Consistency with the principles and rights enshrined in the Australian Charter of Healthcare Rights endorsed by the Queensland Government.
- A consistent understanding of who may act as a health advocate and ethical issues relating to conflict of interest.
- Acknowledgment of the legitimate role of advocates in supporting consumers to achieve better health outcomes.

An integrated and collaborative approach to health advocacy across the public and private health sectors, and other consumer and community stakeholders would achieve:

- Reinforcement of the commitment by the public, private and community health sectors to the principles and rights enshrined in the Australian Charter of Healthcare Rights.
- A consistent understanding and approach to health advocacy across public, private and community sector stakeholders.
- Greater consumer confidence in the public and private health systems.
- Empowerment for health consumers to undertake health advocacy and exercise their responsibilities as decision-makers.
- Support and assistance for health consumers in their advocacy.

Option Two – Better support for informal health advocacy

Queensland Health, private and community health organisations seek opportunities to enhance informal health advocacy initiatives.

Enhancing informal health advocacy would achieve:

- Empowerment of informal advocates, whether individuals or a person acting on their behalf, to conduct health advocacy.
- An approach to health advocacy which offers government a cost-effective mechanism for supporting consumers.
- Increased capacity of individuals to advocate effectively and independently.
- Increased likelihood of successful outcomes for consumers and therefore decreased stress on the consumer and their informal advocate.

In particular, HCQ received strong feedback about four specific initiatives that Queensland consumers thought would enhance and support informal advocacy. These include:

- User-friendly information resources around health advocacy which are appropriately tailored to meet the needs of a variety of health populations and social groups (such as Indigenous and culturally and linguistically diverse populations) and presented in accessible, user-friendly formats.
- A state-wide freecall health advocacy helpline similar to the one currently operating in Western Australia. The helpline could promote consumer awareness about health advocacy and provide a suite of health-related information, referrals and support for consumers and/or their advocates. It could be established and operated as a stand alone service, or the functions could be added to one of Queensland Health's existing helplines, for example 13 Health or other existing community sector helplines.
- Peer support/consumer linking mechanisms to provide informal support and assistance to consumers and advocates who have experienced, or are experiencing similar situations through enabling them to share strategies and solutions. Such mechanisms have achieved successful outcomes for consumers in the disability, mental health and community services sectors.
- Tertiary health advocacy programs. Formal health advocacy training programs could be offered through tertiary organisations such as TAFE, with a focus on a 'how to' for advocates, including what health advocacy is; whether a person can effectively act as an advocate regarding a matter and what health advocates do in their health advocacy.

Option Three – Support for enhanced individual and systemic formal health advocacy

Queensland Health, private and community health organisations explore options to:

- a) Enhance formal individual and systemic health advocacy initiatives with a focus on marginalised health populations and social groups; and
- b) Establish an ongoing independent peak health consumer body in Queensland. This function is currently performed by Health Consumers Queensland however, this option proposes adopting a non-government governance model rather than HCQ's current Ministerial Consumer Advisory Committee structure. This would reflect the governance arrangements of other existing national and state peak health consumer bodies.

Enhancing individual and systemic formal health advocacy would facilitate:

- A broader range of formal individual and systemic health advocacy activities across Queensland.
- Improved capacity of non-government community organisations to deliver individual health advocacy within the community, public hospital and community health services.
- Improved capacity of non-government community organisations and/or peak bodies to deliver systemic health advocacy on behalf of specific health populations and social groups.
- Implementation of a key strategy of the Department of Communities' 10 year plan for supporting Queenslanders with a disability: 'Priority one: Rights and Responsibilities Secured': 'people with a disability should have improved access to both individual and systemic advocacy'.
- Broader support for marginalised health populations and social groups including people with a disability, people with impaired decision-making capacity, people from lower socio-economic backgrounds, Indigenous people and culturally and linguistically diverse communities.

Option Four – Promotion of a national health advocacy strategy underpinned by a national Framework.

The Queensland government promotes with the Commonwealth:

- Development of a national health advocacy framework.
- Development of a national health advocacy strategy, underpinned by the national framework.

Promotion of a national health advocacy strategy underpinned by a national Framework would achieve:

- A nationally consistent approach to health advocacy which operates at individual, service, agency and systems levels.
- Alignment with the design and governance principles which the National Health and Hospitals Reform Commission's final report recommended should underpin the future direction of the Australian health system. These principles include:

Design Principles

- *People and family centred*
- *Equity*
- *Shared responsibility*
- *Value for money*
- *Recognising that broader social and environmental influences shape our health.*

Governance Principles

- *Quality and safety*
- *Transparency and accountability*
- *Public voice and community engagement*
- *A respectful, ethical system*
- *A culture of reflective improvement and innovation³⁶*
- Recognition of the current state and national health reform agendas with the focus on 'strengthened consumer ... voice' as a vital component in moving towards person-centered, integrated health services, and 'creating an agile and self-improving health system'.
- The delivery of consumer focused, affordable, responsive services that are cost-effective for government.

36 National Health and Hospitals Reform Commission. *A Healthier Future For All Australians* June 2009, 194-197.

9. Glossary

Citizen Advocacy

Citizen advocacy seeks to 'promote, protect and defend the rights and interests of people who have intellectual disability'.³⁷

Conflict of Interest

Conflicts of interest may arise when an advocate in a position of trust has competing professional or personal interests with the person for whom they claim to be advocating. A conflict of interest prejudices an advocate's ability to perform his or her duties and responsibilities objectively. For a person to be a truly effective advocate, they should understand that their needs, interests and values may conflict with those of the person for whom they advocate.

Formal advocacy

Formal advocacy involves staff or members from an organisation, agency or group who, in a paid capacity undertake advocacy on behalf of an individual, family or group, or a distinct health population.

Health advocacy

HCQ sees advocacy as speaking, acting or writing with minimal conflict of interest to support a health consumer or group's wellbeing, and to promote, protect and defend their right to accessible, safe, quality healthcare. Health advocacy can be undertaken by the consumer themselves, or by an advocate representing the individual or group's perceived interests.

Healthcare

The provision of services that help individuals achieve an optimal state of wellbeing, in any setting or stage in the human life cycle.³⁸

Health consumers

Health consumers are people who use, or are potential users, of health services including their family and carers. Consumers may participate as individuals, groups, organisations of consumers, consumer representatives or communities.

The Carers (Recognition) Act 2008 in Queensland defines a carer as an individual who provides, in a non-contractual and unpaid capacity, ongoing care or assistance to another person who, because of disability, frailty, chronic illness or pain, requires assistance with everyday tasks.

³⁷ Endeavour Foundation, *Advocacy Information Paper June 2007* (2007) 8.

³⁸ WA Department of Health. (2007). *WA health consumer carer and community engagement framework: For health services, hospitals and WA Health following consultation across WA Health*. Perth, WA: Author.

Health policy

The laws, rules and financial and administrative decisions made by governments and other relevant organisations to influence the management of and planning for the health system and the provision of health services.³⁹

Health professional

A health professional is a person who uses skills and knowledge to treat people and work towards them getting well in a clinical situation. Some examples: nurse, doctor, physiotherapist, dentist, counsellor.

Individual advocacy

Individual advocacy involves supporting and promoting the rights and interests of individuals, assisting individuals to achieve or maintain their rights and empowering and representing their needs.⁴⁰

Informal advocacy

Informal advocacy is unpaid and may be undertaken at the individual or systemic level (refer to definitions of individual and systemic advocacy). This is the most common kind of advocacy for people who are using the health system. Informal advocacy can be undertaken by the individual consumer, or by their family, carers or friends, or by a group or groups of consumers around a common issue or issues.

Parent Advocacy

Parent advocacy is concerned with ‘advocating on issues that affect the person with a disability and their family. The focus is on the needs of the person with a disability, not the parents or family. However, some parent advocacy focuses on the needs of parents first.’⁴¹

Perceived interests

Perceived interests refer to what an individual consumer identifies as being best for himself/herself. At times, this may differ from what others (such as family, carers, advocates etc) view as being best for the person.

39 Nilsen et al cited in Gregory (2008).

40 Disability Services Queensland and Federal Department of Families, Community Services and Indigenous Affairs, Strategic Reporting Framework for Advocacy (2007) 3.

41 Queensland Advocacy Inc, Types of Advocacy (2010) <http://www.qai.org.au/documents/doc_156.doc> at 19 May 2010.

Peer Advocacy

Peer advocacy involves ‘one-on-one support by a service user, past or present, to help another to express and fulfill their wishes.’⁴²

Self Advocacy

‘Self advocacy’ is a process in which an individual or a group of people speak or act on their behalf in pursuit of their own needs and interests.⁴³

Social determinants of health

The social determinants of health are the circumstances in which people are born, grow up, live, work and age and the systems in place to deal with illness, which are all shaped by wider societal factors i.e. early life, education, employment and working conditions, food security, gender, healthcare services, housing, income and its distribution, social safety net, social exclusion, unemployment and employment security.⁴⁴

Stakeholder

A stakeholder is a person, group or organisation who affects or can be affected by the actions of an organisation or group.⁴⁵

Systemic advocacy

Systemic advocacy seeks to introduce, influence or produce positive long-term changes to attitudes, systems, policies and procedures, to remove barriers, address discriminatory practices and to ensure the collective rights and interests of health consumers are attained and upheld.⁴⁶ It is primarily concerned with encouraging changes to the law, government, policies and community attitudes.⁴⁷ It also seeks to influence ‘... the social and political structures that promote and sustain injustice and inequality’.⁴⁸

Wellbeing

Wellbeing is a state of complete physical, mental, social and emotional wellbeing, which is not merely the absence of disease or infirmity.

42 Jan Smithies and Georgenia Webster, *Community Involvement in Health: From passive recipients to active participants* (1998) 106.

43 N Bateman, *Advocacy Skills for Health & Social Care Professionals* (2000) 18.

44 Department of Health and Ageing. (2009). *Development of a new national women’s health policy consultation discussion paper 2009*. Canberra: Author.

45 <http://en.wikipedia.org/wiki/Stakeholder> accessed on 4th September 2010.

46 *Ibid.* Office of the Public Advocate, *Challenging Behaviour: five years of public advocacy in Queensland* (2005) 16.

47 Endeavour Foundation, *Advocacy Information Paper June 2007* (2007) 8.

48 Department of Health and Ageing, *The Kit – A guide to the advocacy we choose to do* (1998) 24 <[http://www.health.gov.au/internet/main/publishing.nsf/Content/2CC3845B576CC54ECA2572F9000EBA99/\\$File/kit.pdf](http://www.health.gov.au/internet/main/publishing.nsf/Content/2CC3845B576CC54ECA2572F9000EBA99/$File/kit.pdf)> at 10 May 2010.

Appendix One

HCQ Term of Reference Four

Term of Reference Four

Working collaboratively with government, health sector and community stakeholders develop and promote an advocacy framework to inform and strengthen individual and systems consumer health advocacy activities in Queensland.

Goals (broad objectives)

- Develop a common understanding and definition of health advocacy.
- Develop a framework that promotes formal and informal advocacy approaches at grass roots and systems levels.
- Identify gaps and unmet needs in current health advocacy approaches.
- Strengthen relationships between Queensland Health, HCQ, community organisations and advocacy groups.
- Strengthen the capacity of advocates to engage with health and community service providers on behalf of consumers.

Strategies (what we will do)

- Develop discussion papers, which present options for the development of formal and informal health advocacy in Queensland.
- Provide information and advice to the Minister for Health around health advocacy.
- Engage with health consumers and other stakeholders around health advocacy.
- Identify opportunities to increase and promote health advocacy.
- Develop and implement a health advocacy toolkit and training package for consumers and/or advocates.

Key Performance Indicators (indicators of success)

- Increased consistency of understanding of advocacy across broad stakeholders.
- Discussion papers completed.
- Number of pieces of advice provided to the Minister relating to health advocacy.
- Health advocacy framework completed and promoted.
- Number of engagement activities facilitated around health advocacy.
- Formalised relationships established between HCQ, advocates and Queensland Health.
- Number of health advocacy promotion opportunities identified and followed up.
- Advocacy toolkit and training package developed.

Appendix Two

Towards the development of a health consumer advocacy framework for Queensland (extract) – QCOSS research for HCQ, 2009⁴⁹

Health consumer advocacy in Queensland

1. Individual (patient advocacy) – informal provision

QCOSS has canvassed the merits and limitations of informal patient advocacy delivered by (i) a person for themselves (self advocacy) and (ii) families, friends and carers. While it is not possible to gauge the extent of this, patient advocacy has always been provided in these informal ways in Queensland. It is, arguably, the most widespread and reliable patient advocacy being provided across the State.

The role of health professionals as patient advocates has also been discussed. The conclusion reached was that health professionals employed in a healthcare setting can/do advocate for patients on an informal basis but that this is limited by potential conflicts of interest and professional and organisational dilemmas. Still, it can be assumed that informal patient advocacy is provided in this way in Queensland.

At this juncture it is worth noting that, in line with the Foster Review report and consistent with similar initiatives in other jurisdictions nationally and internationally, Queensland Health has established a Patient Liaison Service, employing Patient Liaison Officers (PLOs), in every Health District.⁵⁰ They are not seen as patient advocates but play an important redress/resolution role managing feedback and complaints about health services. They also assist patients in addressing their concerns so could be said to provide limited informal patient advocacy. While their roles vary across the State, there are some important commonalities in their work which interface with patient advocacy and are advantageous for patients:⁵¹

- PLOs manage complaints and compliments in a Health District and work at a facility level to diffuse conflict. If a concern cannot be resolved a PLO will provide a patient with the necessary information to make a formal complaint to the HQCC.
- PLOs oversee procedural fairness by ensuring that all policies and procedures are followed when patient concerns are raised.

49 QCOSS Advocacy Research Paper for HCQ, 2009

50 This initiative is linked to a Foster Review proposal but with the distinction that a patient support service be independent, arranged with the NGO sector and managed by the HQCC.

51 A teleconference with PLOs was part of the environmental scan undertaken for this project.

- PLOs can refer a patient to an external advocate if that is agreed to by the patient. In this sense, a PLO can facilitate patient advocacy and empower a patient to seek advocacy support.
- PLOs refer internally within the Health District so that a patient accesses specific supports provided by, for example, an Aboriginal and Islander Liaison Officer or a social worker.

Alongside PLOs, Queensland Health employs other liaison officers to support specific population groups such as Aboriginal and Islander Liaison Officers and Consumer Liaison Officers in mental health. Again, these are not defined as patient advocates but are strategically located across Queensland to support patients to access and negotiate the health system. They may receive referrals from both informal and formal patient advocates and also refer patients for advocacy when the need arises. Like PLOs their roles interface with patient advocacy and service to empower health consumers/patients. In conversation with a number of PLOs, the image of ‘a web of informal advocacy’ emerged as a way of describing how these liaison roles interact and interface together and with patients.

Informal patient advocacy is being delivered to health consumers in Queensland. However, this is difficult to gauge and functions in an ad hoc way. By virtue of its nature it is unplanned and delivered only when the need arises. Arguably, it is a good ‘fit’ for many patients. It can meet people’s needs and address their concerns. On the other hand, there are limits to this ... Specifically, relying on an ad hoc informal approach can put equity at risk – some may miss out altogether and these could be the most vulnerable, ‘hard to reach’ groups who need an advocate. Further, the quality and effectiveness of patient advocacy will vary with such an approach. For example, untrained patient advocates may not understand what is involved in respecting a patient’s autonomy and, with the best of intentions, may find themselves in a situation where conflicts of interest abound.

In the end, simply relying on informal patient advocacy offers limited choice to patients. If the mix of informal options does not work for some, the question emerges – “where do they go to get the advocacy they need?” This leads into a consideration of the formal provision of patient advocacy in Queensland.

2. Individual (patient) advocacy – formal provision

The formal patient advocacy in Queensland is provided mainly by NGOs – some of which are dedicated to providing advocacy services and others which combine advocacy with a suite of other services. In some of the latter services, advocacy is part of their core business and in others it is provided in an irregular, ad hoc way if/when a client requires this support, for example, when urgent health needs are part of a case plan.

Disability and aged care advocacy NGOs are funded by Disability Services Queensland and, in some cases the Commonwealth Departments of Health and Ageing (DHA) and Families, Housing, Community Services and Indigenous Affairs (FaHCSIA), to provide a range of advocacy services for and on behalf of their client groups. The strength of these organisations is that they are dedicated to advocacy work only and, in Queensland, include member organisations of the Combined Advocacy Groups Queensland (CAGQ) and Queensland Aged and Disability Association Inc (QADA). The organisations that provide individual advocacy frequently cross over into patient advocacy. For example, the environmental scan revealed that PLOs and other health professionals in Queensland Health refer patients to these advocacy organisations. However, the extent of this across the State is unknown. They also receive referrals from the Adult Guardian to provide advocacy support for people in healthcare settings.

The strength of disability and aged care advocacy groups being involved in health advocacy is threefold: (i) they recruit and employ trained, professional advocates whose work is integrated into a strategic framework that includes measurement and reporting; and (ii) the disability and aged care sectors have well-developed advocacy philosophies and principles which inform their work; and (iii) they are located in regional centres of Queensland and form part of local human service systems which include Queensland Health. Their geographical spread enables access by people from rural and regional areas. Notwithstanding this, the role played by these groups in health advocacy is limited by eligibility criteria – they are not open to the wider Queensland community. Organisational resources are also limited.

The role played by other NGOs and networks providing advocacy for specific population groups in systems advocacy in Queensland has been acknowledged.

Meetings with selected NGO services as part of the consultation for this project revealed that they did cross-over from their systems advocacy work into some form of patient advocacy albeit on an infrequent basis – mainly when a client required this and had no other option. For example, an NGO providing homelessness services may also provide a limited health service to clients and there are times, when a client is admitted to hospital or an emergency service, that patient advocacy is required as part of a case plan. Other services provide 1800 numbers which are set up mainly for health-related information and advice but which at times call for an advocacy response. Of course, this could be problematic for funded services if they deviate too far from what their service agreements with funding bodies specify. They clearly cannot make patient advocacy a priority.

The full extent of patient advocacy being provided by these services is impossible to ascertain without a comprehensive survey of when, how and why patient advocacy might be provided to a client.

However, it can be assumed that these organisations have a small and limited role in the provision of formal patient advocacy in Queensland. As with the disability and aged care advocacy services, these NGOs mostly work with specific population groups and do not provide services beyond that.

3. Systems advocacy

At present, Queensland does not have a formally recognised, independent, generalist health advocacy Non-government organisation mandated to undertake health advocacy from a consumer perspective. This has not been part of the health landscape in Queensland since 1996.

This is not to deny or diminish in any way the important systems advocacy work currently being undertaken in Queensland by:

- peak bodies such as the Queensland Council of Social Service Inc, Queensland Aboriginal and Islander Health Council, Queensland Carers Inc, the Ethnic Communities Council Queensland Ltd, or the Queensland Alliance of Mental Health and Psychiatric Disability Inc and Health Consumers Queensland (Ministerial Advisory Committee and Secretariat).
- disability and aged-care advocacy groups.
- health-related NGOs and networks that advocate for specific population groups, such as gay, lesbian, bisexual, transgender and intersex (GLBTI) people; people from culturally and linguistically diverse populations and recently arrived refugees; people with mental illness; and homeless people.
- local citizen groups such as the Bundaberg Patient Support Group that advocate locally but whose reach can be state-wide and national.
- community services that combine health advocacy with a suite of other services for clients such as prisoners and the homeless population.
- community controlled health organisations such as the Aboriginal and Torres Strait Islander Medical Services.
- academic institutions across Queensland.

These, combined, work at a systems level to bring change and improvements to all levels and facets of healthcare in Queensland. Notwithstanding this, the systems advocacy undertaken by these groups is focused specifically on the health needs of the population groups they represent, local issues and concerns and, as in the case of peak bodies and academic institutions in particular, health reform linked to health research. A gap still remains for a mandated independent peak health non-government organisation to represent a consumer perspective for the Queensland population as a whole.

Appendix Three Australian Charter of Healthcare Rights

The Australian Charter of Healthcare Rights describes the rights of patients and other people using the Australian health system. These rights are essential to make sure that, wherever and whenever care is provided, it is of high quality and is safe.

The Charter recognises that people receiving care and people providing care all have important parts to play in achieving healthcare rights. The Charter allows patients, consumers, families, carers and services providing health care to share an understanding of the rights of people receiving health care. This helps everyone to work together towards a safe and high quality health system. A genuine partnership between patients, consumers and providers is important so that everyone achieves the best possible outcomes.

Guiding Principles

These three principles describe how this Charter applies in the Australian health system.

1. Everyone has the right to be able to access health care and this right is essential for the Charter to be meaningful.
2. The Australian Government commits to international agreements about human rights which recognise everyone's right to have the highest possible standard of physical and mental health.
3. Australia is a society made up of people with different cultures and ways of life, and the Charter acknowledges and respects these differences.

What can I expect from the Australian health system?

MY RIGHTS	WHAT THIS MEANS
Access I have a right to health care.	I can access services to address my healthcare needs.
Safety I have a right to receive safe and high quality care.	I receive safe and high quality health services, provided with professional care, skill and competence.
Respect I have a right to be shown respect, dignity and consideration.	The care provided shows respect to me and my culture, beliefs, values and personal characteristics.

MY RIGHTS	WHAT THIS MEANS
<p>Communication I have a right to be informed about services, treatment, options and costs in a clear and open way.</p>	<p>I receive open, timely and appropriate communication about my healthcare in a way I can understand.</p>
<p>Participation I have a right to be included in decisions and choices about my care.</p>	<p>I may join in making decisions and choices about my care and about health service planning.</p>
<p>Privacy I have a right to privacy and confidentiality of my personal information.</p>	<p>My personal privacy is maintained and proper handling of my personal health and other information is assured.</p>
<p>Comment I have a right to comment on my care and to have my concerns addressed.</p>	<p>I can comment on or complain about my care and have my concerns dealt with properly and promptly.</p>

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