

Report on the consultation process

Consumer health council project —
engaging Queensland
consumers in health care

March 2007



Queensland Government
Queensland Health

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**Report on consultation process
undertaken as part of the
Consumer Health Council Project
Queensland Health**

March 2007

Supporting document:

**Developing a consumer health council
for Queensland**

*engaging Queensland
consumers in health care*

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Report on consultation process undertaken as part of the Consumer Health Council Project Queensland Health

March 2007

Background

In 2005 the Queensland Health Safety and Quality Board approved an Agenda Paper which detailed a proposal for a Consumer Health Council to be considered for Queensland. This Agenda Paper was written by a consumer representative on the Board and a representative from the Safety and Quality Strategy Team (which had the secretariat function for the Board). The Consumer Health Council Project was established in April 2006 following approval from the Director-General and the Minister for Health. Funding for the Project was provided through the Reform and Development Division.

It was agreed a three month consultation process would be undertaken including the development of a discussion paper and public consultation forums to be held across the State. The consultation process was to finish on 27 October; however this was extended to 17 November 2006 due to the impact of the State election process on the consultation in its first month. The Minister's office requested that the District Health Councils in the Districts where the public consultation forums were to be held be contacted and offered the opportunity to participate in the forums.

Scope and purpose to the project

The scope of the Consumer Health Project involved completing the following three tasks:

- Conducting a community consultation process to determine community responses to developing a Consumer Health Council for Queensland. This involved the development of a Discussion Paper which was submitted to Cabinet for approval in mid 2006, prior to it being released to the public for consultation. An attempt was made during the planning the consultation forums and other strategies, to ensure that people from a diverse range of cultural and indigenous backgrounds, health conditions and disabilities, and geographical locations across Queensland were able to participate in the process.
- Reporting back to Cabinet on the results of the consultation process and the response of the community to the proposal to develop a Consumer Health Council, including a discussion of the options for establishing the Council.
- The establishment of the Consumer Health Council should Cabinet decide it is to proceed.

Purpose of the consultation process

The consultation process was undertaken as a way of involving the community and health consumers across Queensland in the process of developing the Consumer Health Council.

The community were also asked if they supported its development and to contribute their opinions regarding its potential functions. Information was provided to the community during the public consultation forums and other meetings held, on the current initiatives of the Queensland Government, and how the Consumer Health Council was seen to address current needs and recommendations from the Queensland Health Systems Review (Foster 2005).

Part 1 How the consultation was undertaken

1. Development and distribution of the discussion paper

The discussion paper was developed with input from the Principal Project Officer, the Senior Director Data and Reporting Analysis Centre, the Executive Director Reform and Development Division, the office of the Director-General, the office of the Minister for Health, and the Department of the Premier and Cabinet.

A total of 1700 copies of the discussion paper were printed and a state-wide mail out was undertaken incorporating key stakeholders and peak community and consumer organizations across Queensland, interstate Consumer organizations, relevant University departments, and key government departments (354 organizations and departments). During the planning of the public consultation forums which occurred in 11 different health service districts, a targeted mail out was also undertaken to organizations in that location, inviting them to attend the forum (as well as participate in the consultation process by responding to the attached discussion paper). Table 1 below indicates the total number of discussion papers that were mailed out to community and consumer organizations across the state.

Table 1 Mail out numbers for the discussion paper

Location of public forum	Date	Mail out number
State-wide mail out		354
Bundaberg	28 – 29 September	81
North Burnett	3 October	N/A
Visit to far north Queensland	9 – 13 October	N/A
Mount Isa	19 October	57
Gold Coast	23 October	60
Fraser Coast	31 October	52
Sunshine Coast	6 November	50
Cairns	8 November	57
Rockhampton	10 November	46
Townsville	13 Nov and 1 December	62
Toowoomba	16 November	66
Brisbane	17 November	362
Total		1247

Following these mail outs, a number of organizations requested additional to enable them to distribute the discussion paper throughout their own organization.

At the beginning of the Project, on the 11 August 2006, a Media Release was distributed from the Minister's Office announcing the project and providing information on how to access the website and discussion paper. A web page was also established on the Queensland Health public internet web site to enable access directly to the discussion paper from this site as well as web-based responses to the consultation questions. The discussion paper also invited open submissions and detailed process for lodging submissions by phone, mail, fax, or other methods (for example by inviting the Principal Project Officer to attend meetings).

2. Contact with Queensland Health staff

Queensland Health staff were advised of the Project and the discussion paper via Broadcast to all staff from the Director-General. Key staff with an interest in the area were also provided with correspondence and information directly from the Principal Project Officer.

3. Contact with Indigenous communities

During the process of passing the discussion paper through Cabinet, the Department of Aboriginal and Torres Strait Islander Affairs requested that the Project Officer include a visit to organizations and remote indigenous communities in far north Queensland. This visit was agreed to and arrangements were made for the Project Officer to spend a week in the far north area. Further information will be provided in part 2 of this report on this part of the project.

4. Contact with community organizations

Following the Minister's media release and the distribution of the state wide mail out a number of community organizations contacted the Project Officer and requested individual meetings. In most cases this was to discuss the discussion paper and issues relating to the Consumer Health Council. In a small number of cases consumer groups or individuals used the meeting process as their actual submission and requested the Project Officer to record the comments made. Part 2 of this report provides information on the results or themes raised during these meetings.

5. Contact with District Health Councils

The Chairs of the District Health Councils in the 11 District where public consultation forums were being planned were contacted directly to discuss the project and the involvement of the Chair or the Council in the process. Prior to this contact, an email was forwarded to the General Managers of the Northern, Central and Southern Area Health Services, and the District Managers of the Districts where consultations were to be held, to notify them in person of the intention to plan a public consultation forum in their District and to contact the District Health Council Chair as part of this process.

A separate mail out was then sent to all other District Health Council Chairs to notify them of the project, provide a copy of the discussion paper and invite the participation of the District Health Councils in the consultation process. An offer was also made to provide reimbursement of the travel costs for one member of each of these District Health Councils to attend one of the planned forums (the closest to them), should they wish to do so.

6. Public consultation forums held across the State

Public consultation forums were planned for a range of Districts across Queensland, (including: North Burnett, Bundaberg, Mount Isa, Cairns, Townsville, Rockhampton, Fraser Coast, Sunshine Coast, Gold Coast, Brisbane and Toowoomba. An effort was made to select Districts that included both larger and more metropolitan based areas and health services, as well as more rural and remote areas or smaller Districts. Information on the themes raised during these forums is provided in Part 2 of this report.

7. Contact with service providers

In order to discuss aspects of the model and functions of the proposed Consumer Health Council in more detail, as well as the implementation and establishment process for the Council, a workshop was planned with peak non-government organizations and other key stakeholders. This workshop planned to draw on the experience of existing non-government organizations that had established services similar to those proposed for the Consumer Health Council, or who may be key stakeholders.

8. Contact with other Government Departments

Key government departments that were thought to have a stakeholder interest in the establishment of the Consumer Health Council were invited to participate in the consultation process through a direct letter from the Director-General of Queensland Health. The Government Departments invited included: the Department of Housing; the Department of Justice and Attorney General; the Departments of Communities and Disability Services Queensland; the Department of Aboriginal and Torres Strait Islander Policy; the Department of Education, Training and the Arts; the Department for Local Government and Planning, Sport and Recreation (including the Office for Women); and the Department of Child Safety.

Part 2 What The consultation revealed

1. Written submissions received

Overall there was a strong response from the community with 150 submissions received. A total of 26 of these were open submissions and the remaining 124 were responses to the consultation questions contained within the discussion paper. Responses were fairly evenly distributed across the four identified groups including 23.4 per cent from consumers; 27.3 per cent from consumer representatives; 28 per cent from service providers and 19.3 per cent from government employees or departments. A small number of respondents identified themselves as other (2.0 per cent). Table 2 below provides a list of the number of responses received, from each group and their primary method of responding (i.e. via the web site, via mail etc).

In addition to the submissions received later sections of this report will provide information on themes raised through other processes used during the consultation including: the public consultation forums, meetings with community and consumer groups and District Health Councils; and during the workshop conducted with peak community organizations and key stakeholders.

Table 2 *Total Written Submissions Received*

Group	Number of submissions
Consumers 23.4%	
Web-based	13
Phone/mail/fax	14
Email	5
Open submissions	3
Total	35
Consumer representatives 27.3%	
Web-based	10
Phone/mail/fax	13
Email	8
Open submissions	10
Total	41
Service providers 28%	
Web-based	19
Phone/Mail/fax	3
Email	13
Open submissions	7
Total	42

Government employees	19.3%	
Web-based		16
Phone/mail/fax		3
Email		4
Open submissions		6
Total		29
Other	2.0%	
Web-based		3
Phone/mail/fax		0
Email		0
Open submissions		0
Total		3
Total		150

2. Overall summary of responses to the consultation questions

This section will provide information on the overall responses provided to each of the consultation questions by respondents. A total of 124 submissions were received that responded directly to these questions. The themes raised in the open submissions will be discussed in section 3, immediately following this discussion.

2.1. Types of respondents

The majority of respondents did not identify with the key disadvantaged groups specified in the response questions (approximately 61.3 per cent). The largest group that did identify themselves included 21 people who either had/or represented people who had a disability (16.9 per cent of respondents). An additional 11 people identified as being from/representing people from a culturally diverse background (or 8.9 per cent of respondents). A small number of people indicated they had more than one characteristic identified for example they had a disability and also identified as being from a culturally diverse community (8.1 per cent). Table three below provides a summary of the types of groups each respondent identified with.

Table 3 *Types of respondents*

Identified group	Consumer	Consumer representative	Service provider	Government employee	Other	TOTAL
Aboriginal, Torres Strait Islander			1			1
Australian South Sea Islander			2			2
CALD/NESB background	3 Norwegian, Greek, Latin	3 Africa, Pacific Islands, Philippines, New Guinea, Indonesian, South American	4 Peru, Persian/Iranian, Trans-cultural centre	1		11
Person with a disability	10	3	6	1	1	21
Other	1 CALD and Disability	3 All of above 5 DHC's	1 All of above 1 DHC member		2 Private service and consumer	13
Did not identify with a specific group	18	17	20	21	0	76
Total	32	31	35	23	3	124

It was noted that the numbers of respondents from or identifying with Aboriginal, Torres Strait Islander or Australian South Sea Islander communities were very low in the written submissions (2.4 per cent). However, information from indigenous organizations and communities was collected directly during a visit to the far north Queensland area, which was undertaken specifically for this purpose. The results of this visit will be discussed in section 4.

2.2 Responses to Question 1. *Do you support the establishment of a Consumer Health Council? In what ways do you think that a Consumer Health Council would be of benefit in the Queensland Context? Where might it fit in relation to other bodies?*

By far the overwhelming response from the community was in support of establishing the Consumer Health Council, with over 90 per cent of these submissions in agreement.

This agreement was also spread fairly evenly across all five groups of respondents, with all of the government and other respondents in full agreement. A very low number of respondents, at 5.6 per cent, disagreed with its establishment. Table 4 below provides information on the respondents to the first part of Question 1, indicating overall agreement with the establishment of the Council.

Table 4 *Response to the establishment of the Consumer Health Council.*

Type of respondent	Number of responses		Comments
Consumers	Yes	26	Must be independent and open to all consumers, Improve quality and responsiveness of services, Close connection with communities, Good for bush/remote areas, Needs good relationships with DHC's, Must represent all groups and communities, People with mental illness have no voice, Needs to have authority to advise services, Advocacy role very important, Must give feedback to community and have broad membership base
	No	4	
	No response	1	
	Unclear	1	
	Total	32	
Consumer Representatives	Yes	30	Must be outcomes focused, Represent all of Qld, Inform of needs and concerns of public, Needs links/partnerships with other organizations, Transport issues, Only successful if adequately resourced, Advocacy important, Accountability and voice for consumers, Ensure representation of all groups and areas, Specific engagement strategies required, Not to replicate other roles, Report to Minister
	No	1	
	No response	0	
	Unclear	0	
	Total	31	
Service Providers	Yes	30	Need to consider carers as well, Transparency important, inform government of consumer views, Better informed consumers and services, Represent diversity of population and needs, all consumers, Must be independent, Coordinate consumer responses, Need to include private and non-government services, Need to clarify role of HQCC, Need to network with other advocacy services, Opportunity for remote areas to participate, No eligibility criteria should be accessible for all consumers, Duplication of DHC role?
	No	2	
	No response	1	
	Unclear	2	
	Total	35	
Government employee/ service	Yes	23	Overarching framework, Consumer and carers perspective in planning and service delivery, Increased say by public in health system, to drive change, increased responsiveness, Don't get hijacked by intemperate voices, Cover all including private and NGO's, Close relationship with DHC's and HQCC
	No	0	
	No response	0	
	Total	23	

Other	Yes	3	Great initiative, Flexible to engage all consumers.
	No	0	
	No Response	0	
TOTAL	Yes	112	90.3% of respondents (of the whole) said yes they support the establishment of the CHC, 5.6% said no they did not support the establishment of the CHC; 1.6% did not respond and 2.4% did not make their opinion clear in their response.
	No	7	
	No response	2	
	Unclear	3	
	Total	124	

Additional comments from respondents included the need to consider carers within the scope of the Council, the need to ensure improved engagement with specific consumer groups; acknowledgement that the Council would provide some ability to respond to the recommendations of the Forster report; the need for quite different strategies to be employed in order to achieve some of the functions proposed for the Council; and acknowledgement of the specific disadvantaged groups recognized within the proposed model. The need for clarification of the role of the council and the establishment of positive relationships with a range of community groups and networks in the implementation of its functions, was also raised.

2.3 Responses to Question 2. *Please comment on the proposed name “Consumer Health Council” or would you like to suggest another name for consideration?*

There was some interest in the proposed name of the Council. While almost 50 per cent of respondents indicated they liked or did not mind the proposed name Consumer Health Council, approximately 31 per cent offered an alternative proposal. A summary of the overall responses of all groups of respondents is provided below in Table 5.

Table 5 *Responses to the proposed name: Consumer Health Council*

Response	Consumer	Consumer representative	Service Providers	Gov. Employees	Other	TOTAL	Percentage
Keep the CHC name	12	22	18	15	1	68	48.3%
Made an alternative suggestion	9	10	17	6	2	44	31.0%
No response	8	0	3	3	0	14	10%
Don't like the name	1	1	3	1	0	6	4.3%
Unclear	2	1	3	3	0	9	6.4%
Total	32	34	44	28	3	141	100%

NB: some respondents may have given more than one answer

Many respondents, despite some liking the proposed name, also agreed it is very close to the new name for District Health Councils, that of Health Community Councils, that will be implemented some time over the next six months. It should be noted also, that Queensland Health has used the word 'Council' in these two instances, to denote both a committee type structure (Health Community Council) and an organisation (Consumer Health Council). This simultaneous use of the word with two different meanings may cause confusion for the general public, particularly when attempting to understand the respective roles of the two new structures.

Within the overall responses received suggesting an alternative name, there appeared to be general agreement to consider adding the word 'advocate' or 'advocacy', and/or the word 'Queensland' to the name of the Council. These words were suggested as advocacy is perceived to be one of the main functions of the Council and it was believed there should be some identification with the state of Queensland as it is planned to be a state-wide body. There was also agreement to remove the word 'Council' from the name and consider a name that is perceived as more 'consumer friendly and less bureaucratic. One suggested name that appears to encompass the majority of the most popular comments might be: Queensland Consumer Health Advocacy (organisation). A list is provided below in Table 6, of the primary proposed alternative names offered by respondents.

Table 6 *Alternative names suggested by respondents*

Alternative suggestions include:

- Health Quality and Consumer Advisory Council
- Community Representative Council
- Queensland Health Consumer Council
- Statewide Consumer Health Council
- Consumer Advisory Panel
- State Consumer Health Council
- People's Health Council
- Community Board of Advice
- Consumer Feedback Forum
- Consumer Health Partnership
- Consumer Health Advocacy Council (3)
- Consumer Health Partnership
- Office of the Advocate for Health Consumers
- Consumer Health Focus Group
- Health Consumers Queensland
- Queenslander's Health Council
- Consumer Health Support, Training and Advocacy Council
- Citizens Advisory Health Board
- Consumer Advocacy Coalition

- Consumer Health Watchdog
- Collaborative Health Council
- Consumer Health Engagement Council
- Community Health Council
- Consumer Advocacy and Engagement Alliance
- Participant’s Health Council
- State Health Advisory Group
- Queensland Consumer Health Council (3)
- Community Health Engagement Team
- Queensland Consumer and Advocate Health Council

2.4 Responses to Question 3. *Please Comment on the roles described for the Consumer Health Council (for example: providing opportunities for consumers to engage with government and services).*

Again the overall response to the proposed roles of the Consumer Health Council was that of support from all groups responding, with 68 per cent of respondents in agreement. A smaller number of suggestions were also provided on how these functions might be improved. A very small number of respondents, at 1.3 per cent, did not agree with the proposed functions.

Service respondents who had agreed with the overall role described also made some comments on how these roles might be implemented (almost 20 per cent). The most significant comments included the recognition of the need for a stronger voice for consumers; that the contribution of the Council should not be merely tokenistic but it must be perceived by the community and government as having credibility and ‘teeth’, and that it should also involve a formalized structure to represent consumers and build capacity in local areas. It was also thought that carers and private health services should be considered in the roles described, and that the Council should have a role in identifying unmet needs in local communities. The proposal for individual advocacy services was generally strongly supported, as were the six regional officer positions. Consumers and community representatives considered the reports to government on consumer issues to be very important, as was the provision of feedback to the community or consumers on issues that have been raised with the Council and what outcomes might be undertaken by government as a result.

In relation to the individual advocacy positions, respondents strongly felt these positions should be paid positions, and that this function should not rely solely on volunteers (9.7 per cent). Table 7 below provides a summary of the response from all groups to this question.

Table 7 Responses to the described roles of the Consumer Health Council.

Response	Consumer	Consumer representative	Service providers	Govt. employees	Other	TOTAL	Percentage
Agree with role	22	30	35	18	2	107	68.2%
Other suggested roles:							
Suggested to remove a role or a caution:	9	7	11	4	0	31	19.8%
No response	4	1	1	2	1	9	5.7%
Negative response	1	0	1	0	0	2	1.3%
Unclear	1	3	3	1	0	8	5.1%
Total	37	41	51	25	3	157	100%

NB: some respondents may have given more than one answer

In addition to these positive responses a number of cautions were also raised by respondents. A number of concerns were raised regarding whether the Council might become bureaucratic and not be successful in presenting the consumer voice, as perceived by the community. It was felt that all consumer groups should be strongly represented on the Council and that there needs to be clarity of roles between the Council, the Health Quality and Complaints Commission and the Health Community Councils. A number of respondents expressed concern regarding whether there would be adequate funding to establish the Consumer Health Council and enable it to perform the identified functions effectively. The need for remuneration of volunteers for their participation was raised, as was the need for flexible methods of engagement, and clear strategies to escalate issues that require a response through the Council and with government.

2.5 Responses to Question 4: *Are there any other roles you consider the Consumer Health Council should perform? If so, please describe these and how you think they may be of benefit.*

Consistent with the responses to the previous questions, the majority of respondents indicated in their responses to this question that they agreed with the roles described for the Council (54 per cent). A larger number of respondents either did not respond to this question at all (almost 15 per cent) or provided a suggestion for improvement (29 per cent). Table 8 below provides a summary of the responses across the five identified groups of respondents. It is noted that by far the highest number of suggestions for improvements were received from service providers.

Table 8 *Suggestions for improving the role of the Consumer Health Council*

Response	Consumer	Consumer representative	Service providers	Govt. employees	Other	TOTAL	Percentage
Agree with proposed roles:	20	30	22	15	1	88	54.9%
Suggested additional roles: <i>See below</i>	8	11	19	8	1	47	29.0%
No response	8	4	7	5	1	24	14.9%
Negative response	0	0	1	0	0	1	0.7%
Unclear	0	0	1	1	0	2	1.3%
Total	36	45	50	29	3	163	100%

NB: some respondents may have given more than one answer

The most significant comments made by people who were in full agreement with the proposed roles of the Council included that they felt there was a need for representation for indigenous and culturally and linguistically diverse (CALD) communities on the Council; that the Council should not be a ‘talkfest’ but it should actively seek to address discrimination of key groups of consumers within the community; and that advocacy services for individuals should be available twenty four hours a day.

Other popular responses received overall included: that the Council should also have a role in research (requested by 5 service providers); it should assist services to set up consumer engagement strategies; it should oversee, replace or amalgamate with District Health Councils (requested by 2 services and 2 consumers); it should monitor accountability of health services (requested by 1 consumer and 2 consumer representatives); and that it should be allowed to develop its functions over time (requested by 2 consumer representatives and 2 government employees).

A number of the suggested additional roles for the Council included: it could resource and coordinate engagement strategies being undertaken in the community; it could develop and set guidelines for consumer representation in health areas; it might assist services to set up engagement programs with local communities; it might establish annual round tables with the community; it should engage with the private health sector; it might assist in selecting District Health Council members; it should link with national and other state bodies in the area of consumer participation in health; and that it might also showcase positive health service and engagement strategies. Only 2 service provider respondents in this question indicated they felt the Consumer Health Council should not undertake individual advocacy.

2.6. Responses to Question 5. *Do you think there is a need for the Consumer Health Council to provide training and support to the District Health Councils? If so, how do you think this support should be delivered?*

The general response to this question was positive with approximately 65 per cent of

respondents agreeing that the Consumer Health Council should provide training to District Health Councils, or Health Community Council members, to perform their roles. Quite a large number of respondents either did not respond or their responses to the questions were unclear (17 per cent) with approximately 8.5 per cent indicating they did not agree with this function being performed by the council. Table 9 below provides information on the number of respondents from each of the groups of respondents.

Table 9 Responses to the provision of training to DHC's by the Council

Response	Consumer	Consumer representative	Service providers	Govt. employees	Other	TOTAL	Percentage
Agree with Support being given to DHC's:	18	20	27	15	3	83	64.3%
Disagree:	3	3	2	3	0	11	8.5%
No response	8	2	4	4	0	18	14.0%
Unclear	3	6	6	2	0	17	13.2%
Total	32	31	39	24	3	129	100%

Of those people who agreed with training being provided to the DHC's, a number of these respondents also made additional comments. The most significant of these included: there should be respect for differences among people; the Council should develop self paced on-line packages; training should be provided through teleconferencing, research papers, workshops, rotating memberships, phone links, buddy systems, flexible approaches, and small peer groups; training should include real life scenarios, community development principles, district/area based needs, legal issues, ACHS requirements, explanations of technical jargon, public speaking, consumer perspectives, community consultation processes, rights and responsibilities, and targeted promotional strategies; this training support should be ongoing; and that training include health staff were possible.

2.7 Responses to Question 6. *In what ways do you consider the proposed Consumer Health Council model and functions are suitable in the Queensland Context?*

The majority of respondents to this questions indicated they felt the model was generally adequate and suitable to the Queensland context (over 75 per cent) with a number of these also providing comments regarding the model. Table 10 below provides a summary of the responses from each of the identified groups of respondents.

The primary comments made by respondents regarding the suitability of the proposed model for the Consumer Health Council included: there should be a centralized pool of carer representatives as well as consumer representatives; there is a need for representatives from all communities across Queensland as well as from mental health; two respondents indicated a concern that the Council should not try to be all things to all people; six respondents specifically indicated support for the six regional positions; a number of

respondents indicated support for the 1800 number; and support was given for consumers being reimbursed for some services and not just used in volunteer roles.

A clear preference for the Council maintaining its independence and autonomy was indicated; as well as the need to engage the private sector; general support for the Western Australian model for this type of organisation and the inclusion of ordinary consumers. It was felt the Council should clarify its own role and that of key stakeholders, and it will work with and develop links with state and commonwealth bodies.

Table 10 Responses regarding suitability of the proposed model

Response	Consumer	Consumer representative	Service providers	Govt. employees	Other	TOTAL	Percentage
Agree model is suitable:	24	29	33	14	1	101	75.3%
Disagree:	0	2	0	0	0	2	1.5%
No response	7	1	6	8	2	24	17.9%
Unclear	1	2	3	1	0	7	5.3%
Total	32	34	42	23	3	134	100%

2.8 Responses to Question 7. *If you think the proposed Consumer Health Council model and functions are inadequate, how do you think these can be improved?*

Again, approximately 26.5 per cent of the respondents indicated in this questions they agreed with the proposed model, with a percentage of these also suggesting some improvements to the model (almost 39 per cent), with almost 32 per cent either not responding to this question or giving responses in which their positions were unclear. Table 11 provides a summary of the responses to this question and suggested improvements made by respondents are discussed following this table.

Table 11 Responses and suggestions for improving the proposed model

Response	Consumer	Consumer representative	Service providers	Gov. employees	Other	TOTAL	Percentages
Agree with proposed model (may have also suggested improvements below)	11	16	11	4	0	42	26.9%
Suggested Improvement	16	17	15	11	1	60	38.5%

Did not agree with model	0	4	1	10	0	5	3.2%
No response	9	1	16	1	0	37	23.7%
Unclear	2	4	3	1	2	12	7.7%
Total	39	42	46	26	3	156	100%

NB: some respondents may have given more than one answer

Suggested improvements by the respondents included: ensuring the Council has adequate authority to respond to issues raised by consumers; the Council needs to develop a true understanding of consumer issues through their active involvement; it should demystify the process of engaging with government; it should undertake strategies that address issues to do with negative cultures within health services; it should have a capacity to provide reimbursement for volunteers who assist the Council in performing its roles. The Council should be seen to have an adequate budget; be able to draw on the experience of other consumer organizations of this type around Australia; and develop its functions and strategic directions over time.

On the issue of representation, respondents indicated they felt the advocacy role of the Council should focus clearly on disadvantaged groups as well as providing support for and representation from mental health consumers as well as local representatives from the western areas of state. The respondents also expressed the belief that the Council should expand notions of 'health' to incorporate the perspectives of different cultural and indigenous groups; and it should consider having a dedicated position to represent people from culturally and linguistically diverse position. The membership of the Council must be open to all consumers as well as organizations and there was a request for representation from the Mackay and Mt Isa areas. There was a strong feeling that the Council must be made up of consumers, rather than health services or professionals, and it should work by contacting consumers and communities directly, rather than operating solely through peak bodies.

Additional comments included that the Council should be allowed to develop its functions over time; the type and frequency of contact of the Council with the Minister and Director-General should be clarified; and that it should consider developing a research function. The linkages between the Council and existing groups and organizations (for example local government and regional development organizations, the Health Quality and Complaints Commission, advocacy organizations such as QADA, the Office of the Public Advocate and Anti-discrimination Commission etc) should be clearly defined and this may include developing referral pathways where appropriate.

Less popular comments included the suggestion that each district have its own Consumer Health Council, and that the Council should undertake a secretariat function for District Health Councils. It should be noted that comments such as these, which indicated a closer relationship between the District Health Councils and the Council than that proposed, were reasonably unpopular with the general community when raised during the public consultation forums and to some degree seemed to indicate some mis-understanding of the proposed role of the Consumer Health Council.

2.9 Responses to Question 8. *Would you like to propose any strategies for the Consumer Health Council that would better meet the needs of specific groups in the community? For example: people with a disability, people who are Aboriginal, South Sea Islanders or Torres Strait Islanders, people from rural and remote communities and people who are from culturally and linguistically diverse communities.*

While there was general overall support for the strategies indicated in the discussion paper for ensuring the Council support would be accessible by all disadvantaged groups in the community (42 per cent), a slightly larger number of respondents also provided comments on how this access might be improved (almost 46 per cent). By far the most important comments raised regarding access strategies included the strong belief that representation of consumers must be provided on the Council and/or the Board of the Council (i.e. this was raised by 14 consumers, 17 consumer representatives, 13 service providers, 16 government employees, a total of 60 responses or 48.4%). A summary of the responses by different groups of respondents to this question is provided in Table 12 below.

The second most important issue discussed was that of the proposed locations of the six Regional Officers for the Council. It was repeatedly proposed that one position should be provided in the western parts of the state, and one should be provided in the far north Queensland and Cape area. Other requests were for an officer to be placed at: Rockhampton, Longreach, Weipa, the Wide Bay/Burnett area, Charleville, and Mt Isa.

In addition to the disadvantaged groups recognized within the discussion paper (i.e. people with disabilities, and those from indigenous and culturally and linguistically diverse communities), additional groups were also identified that respondents believed should be included in the functions of the Council. These included: people living below the poverty line and who are long term unemployed, the frail and aged, people with a mental illness, people who are homeless or who have a drug addiction, people diagnosed with terminal illness, people requiring access to maternity services, prisoners, people with neurological conditions, people with impaired capacity, children and young people, and single parents and mothers.

Table 12 *Responses regarding access strategies*

Response	Consumer	Consumer representative	Service providers	Govt. employees	Other	TOTAL	Percentage
Agree with proposed strategies in model: (may have also made comments about these)	22	24	26	25	2	99	42.3%

Proposed additional comments/ strategies	21	31	29	26	0	107	45.7%
No response	7	4	7	5	1	24	10.3%
Unclear	0	1	2	1	0	4	1.7%
Total	50	60	64	57	3	234	100%

NB: some respondents may have given more than one answer

A number of respondents that indicated they supported the strategies described in the discussions paper also made comments about improving these strategies. These included comments such as: the Council should use outreach models to access indigenous and CALD communities; subgroups or committees with representatives from key disadvantaged groups should be developed as part of the Council's functions; the Council should consider and adopt strategies in existing strategic plans and key documents; the Council should establish trust with key communities and groups and demonstrate its accountability to all these groups; the Council should use flexible engagement strategies that are relevant to specific communities (e.g. storytelling and dance); the Council should develop mentorship roles (i.e. for consumers); and it should ensure key community groups are also represented on District Health Council's.

Additional strategies that were proposed by respondents included: using shop front exposure; working through existing mental health advocates and committees etc (e.g. Health facilitators and multicultural Health Liaison Volunteers); providing education for service providers regarding consumer needs and how to work with consumer representatives effectively; involving carers and family in engagement strategies; developing a board and holistic definition of health that will incorporate a range of different cultural perspectives; using targeting strategies for different communities; ensuring committed staff are employed on the Council; working through local representatives and community leaders especially in indigenous communities; actively visiting communities; and ensuring the right representatives are selected and recruited that are endorsed by their local communities and then providing training for them to undertake their roles.

Strategies suggested that would ensure that people from remote communities are involved in the workings of the Council included contacting key people in these communities and providing travel and reimbursement for costs of participation in activities and meetings for representatives. Meetings could also be held within particular communities to ensure broad representation, perhaps using the regional officer positions. The use of standing agenda items for the Council and Board was also raised to ensure that indigenous and cross cultural health issues remain key items or are considered 'core business' for the Council. Additional strategies included ensuring the needs of disadvantaged groups are built into the outcomes required within the service agreement for the Council and ensuring strong representation on all of the Council's activities from these groups. Training, information and resources should be provided in culturally appropriate ways to ensure

they are accessible by the communities and consumers they seek to assist and this should also involve using appropriate language and examples (for example indigenous and multicultural communities do not recognize the word 'consumer', so more suitable wording will be required when attempting to reach these groups).

Advice from multicultural and indigenous groups was to ensure that the Council was proactive in seeking the engagement of these communities, as they may not be able to be engaged due to the multiple barriers they face without this assistance. Staff and consumer representatives should also be provided with cultural awareness training to perform their roles more effectively. It will also be important for the Council to be aware of the specific cultural and disadvantaged groups across Queensland and ensure that each region has an understanding of the communities and groups within its area of responsibility. This 'cultural map' would assist in ensuring that the key groups are represented appropriately for all key health issues across the state, as local issues can vary quite markedly. The training of the Council and for its own staff should focus on the key disadvantaged groups across the state as a matter of priority, to ensure it is able to function in its core roles effectively. It was also felt that there should be a focus on recognizing the citizenship and rights of all disadvantaged groups, and how to ensure they are empowered within the health system, as part of the core mission of the Council.

2.10 Responses to Question 9. *What factors do you consider will be important in ensuring the Consumer Health Council is successful and achieves the best outcomes for Queenslanders?*

Over 54 per cent of the responses received included comments regarding factors that were perceived to impact on the success of the Council. Approximately 36 per cent of the responses however still indicated support for the proposed model in their answers. Table 13 below provides information on the overall comments and answers to this question by all groups of respondents. Further information is provided following this table on the most frequent factors identified as impacting on the success of the Council by respondents from all groups.

Table 13 *Responses indicating factors impacting on the potential success of the Council.*

Response	Consumer	Consumer representative	Service providers	Govt. employees	Other	TOTAL	Percentage
Agree with model/ proposals	25	29	31	15	3	103	35.9%
Comments regarding success	33	52	52	16	4	157	54.8%
No response	6	4	5	7	0	22	7.6%
Unclear	3	0	2	0	0	5	1.7%
Total	67	85	90	38	7	287	100%

NB: some respondents may have given more than one answer

As indicated in Table 14, there were 6 main factors repeatedly identified by respondents as potentially having a significant impact on the success of the Council. These factors include: that there should be representation on the Board or Council from each of the key groups of consumers identified (19.7 per cent proposed this factor); the Council must be independent from government (6.7 per cent raised this issue however this factor has been raised consistently in other questions as well as through other aspects of the consultation process as a significant issue for consumers and respondents overall); the Council will need a significant community awareness or communication strategy to ensure that all consumers across the state know of its existence once it is established (almost 7.1 percent raised this issue); an appropriate budget should be developed to ensure it is able to perform its identified functions (almost 8.3 per cent raised this factor); the Council should report back to the community on actions it has taken regarding issues raised (almost 7.1 per cent raised this factor); and that there should be appropriate evaluation of the Councils' functions at some stage. The issue of credibility was raised as a central theme as evident in the following statement which identifies the key factors for the community:

“Public perception of CHC in terms of credibility, independence, and ability to influence the health agenda” (Service provider)

Table 14 Comments regarding increasing the likelihood of success:

Key comments	Number supporting	TOTAL	Percentage	
Broad representation of key groups on CHC and Board	Consumer	6	31	19.7%
	consumer representatives	13		
	service providers	9		
	government	2		
	other	1		
Must be independent	Consumer	3	10	6.7%
	consumer representatives	2		
	service providers	3		
	government	2		
CHC needs a consumer/public awareness campaign	Consumer	2	11	7.1%
	consumer representatives	1		
	service providers	6		
	government	2		
Appropriate budget required to support functions	Consumer	3	13	8.3%
	consumer representatives	3		
	service providers	6		
	government	1		
CHC to report back to communities and consumers regarding issues raised	Consumer	2	11	7.1%
	consumer representatives	3		
	service providers	5		
	other	1		
Appropriate evaluation of CHC outcomes	Consumer representatives	4	7	4.5%
	service providers	3		

NB: some respondents may have given more than one answer

Additional factors noted by respondents included that the Council should be realistic in its expectations; it should in the first instance listen to consumers; and it should publish its positions and representative roles on the Board as broadly as possible to attract consumers. There was some support for ministerial appointments to the Council, although this was inconsistent, however it was felt that the Council would need direct access to the Minister and Director-General in order to perform its work. There should also be some contact with the Commonwealth government and a clear limit placed on input into the Council by clinicians or members of the health sector or professions.

Most respondents were in favor of appropriate training and support for consumers to enable them to perform the roles of representing their communities; and a belief that communication by the Council should be kept open and transparent, with open public meetings being held where possible, particularly in rural or remote areas. It was felt that a good knowledge of the health system was important. It was also believed that the Council itself would need to be valued by the Queensland Health department and that government should demonstrate that it is willing to listen to all appropriate criticism and take issues raised by the Council seriously, as demonstrated in the following comment:

“There must be the capacity and commitment on the part of the Council to unashamedly represent the views of health consumers. There must also be a demonstration of good faith by Queensland Health to be receptive to the views of the Council and its members.” (Consumer representative)

Some respondents even suggested that the Council would benefit from a memorandum of understanding being developed with government to support this occurring. This might also include processes through which issues might be escalated, in order to ensure they are dealt with by government.

Some respondents indicated they believed that the Council requires a clear role that is understood by all parts of the community and government, and a strong mission statement, with regular consultations being conducted to ensure it remains connected with local communities. It was also felt that the Council would need to collaborate with other organizations and establish effective linkages with key stakeholders as well as its own policies and procedures.

It was generally felt by respondents that the Council membership needs to include all groups, both organizations and individual consumers; it should demonstrate clear accountability to the community for its operations; and the contributions by consumers should not be treated as ‘tokenistic’ in any way. A small number of respondents also indicated they believed the Council should attempt to counteract the culture of bullying and intimidation evident in some health services, by encouraging consumers to ‘speak openly’ about their experiences.

2.11 Responses to Question 10. *Would you like to propose any additional strategies for engaging the Queensland community and consumers of the health care system that the Consumer Health Council might be able to undertake?*

Approximately one third of respondents indicated they supported the proposed model as it is and another third of the respondents indicated in their answers that they had some thoughts about additional strategies that might be considered by the Council to enhance engagement with the Queensland community. Of the answers given within this question, the majority supported and confirmed those strategies raised in Question 9 previously.

The two strongest issues raised include therefore: that the Council would require a media and community awareness strategy to ensure that the community and consumers across Queensland are aware of its development (a total of 3 consumers, 6 consumer representatives, 5 service providers, and 1 government employee, or 12.9% raised this issue); and that there should be representation from key communities and groups/cultures on the Council and/or its board (3 consumers, 7 consumer representatives, 5 service providers, and 2 government employees, or 13.7% of respondents raised this issue). Table 15 below indicates the overall responses by each group of respondents to this question.

Table 15 *Responses to the suggestion of additional strategies to support engagement.*

Response	Consumer	Consumer representative	Service providers	Gov. employees	Other	TOTAL	Percentage
Agree with model	20	27	16	8	1	72	37.3%
Proposed further strategies	14	29	18	10	1	72	37.3%
No response	10	3	11	11	2	37	19.2%
Negative response	0	1	1	0	0	2	1.0%
Unclear	2	3	4	1	0	10	5.2%
Total	46	63	50	30	4	193	100%

NB: some respondents may have given more than one answer

In addition to these comments, other strategies listed included: the need for a Regional Officer in Charleville, Fraser Coast, Bundaberg, Mackay, and Brisbane, as well as more regional and remote positions; there is recognized a need for the Council to maintain its impartiality (referring to its relationships with both the government and the community); there is a need to understand the limitations placed on Queensland Health currently (referring to low morale and staff numbers in some areas); that the Council should conduct monthly open meetings with the public, consumers and its partners as well as report regularly back the community on its outcomes and actions; that there should be remuneration for consumers available through the Council for volunteer work done

on behalf of the Council; that the Council above all else must remain connected to the community and consumers; that the Council should consider also conducting focus groups with key communities, a state-wide phone in, monthly newsletters, and use a wide range of engagement techniques; that the Council should be able to evaluate itself and develop over time; that public speaking training should be available for consumer representatives; that the Council should train one or two representatives from each culturally and linguistically diverse community or group; and that it should publish quarterly reports.

There was a consideration of the coordination role needed between the Council and other organizations to assist to develop more seamless advocacy for consumers; and the possibility of arranging workshops and information sessions on health issues of interest to the community on a regular basis. Multicultural groups advised the use of existing community engagement strategies and pathways, particularly those that are well coordinated and collaborative in nature and that support or communicate with specific cultural groups, to enable access into these communities. There was a sense of 'why bother' being reported from some cultural diverse groups, due to past experiences of attempting to engage with government, that have been unsuccessful, that would need to be proactively addressed by the council. Hosting meetings and gatherings in more remote and rural areas was a popular strategy from respondents from these areas.

2.12 Responses to Question 11. *Would you like to make any comments about how you think the Consumer Health Council should be set up? For example, do you think there are any other skills or expertise that members of the Board should have?*

In general, while almost 30 per cent of the responses received indicated that they agreed with the proposed model, approximately 50 per cent of responses also provided some advice regarding how both the Council and its Board should be set up. Table 16 indicates a summary of the numbers of responses indicated to this question while a summary of the general comments by respondents made are provided below.

Table 16 *Responses to the establishment of the Council and its Board*

Response	Consumer	Consumer representative	Service providers	Gov. employees	Other	TOTAL	Percentage
Indicated agreement with model and strategies	20	30	15	15	1	81	29.5%
Additional comments suggested re: Board	27	42	20	37	2	128	46.6%

Additional comments regarding setting up CHC	3	14	4	8	0	29	10.6%
No response	9	5	8	6	2	29	10.6%
Unclear	2	1	1	2	0	6	2.7%
Total	61	92	48	68	5	274	100%

NB: some respondents may have given more than one answer

The comments made by respondents regarding the Board included a concern that the chair of the Board should be skilled in conflict management and participatory governance strategies; and that the Board itself should be comprised of representatives from diverse groups and should have a sense of caring passionately for the community. There was a suggestion that consideration should be given to inviting some members of the board for individual meetings only, or even a rotating membership and that the recruitment process for Board members should include all areas of Queensland and communities or cultural groups.

There was a concern that the Board should avoid conflicts of interest among members as well as strong political affiliations, but rather, its membership should reflect the environment in which the Council will be operating and use a participatory model of working. In some instances more innovative strategies to discuss issues relevant to key disadvantaged groups were suggested, for example establishing panels of consumers to provide advice on particular issues, rather than relying solely on a Board or committee meeting discussion.

Over 50 per cent of respondents (including 12 consumers, 21 consumer representatives, 12 government, 16 service providers, one other respondent) indicated that they believed Board members should exhibit a range of different skill areas including: community development, service governance and provision, project management, counseling, complaints processes, strategic management, community engagement, mediation, legal skills, knowledge of the health industry and public health management, advocacy, and communication. They should also have a good public profile or a level of community endorsement to attain a position on the Board.

Again the issue of representation on the Board was raised in almost 40 per cent of responses (i.e. by 12 consumers, 17 consumer representatives, eight government employees, 11 service providers, and one other). These responses indicated the strong and fairly broadly held belief that it should have representation from the following key groups: older people, children and younger people, indigenous groups and communities, culturally and linguistically diverse communities, regional and remote areas, and mental health services.

Additional comments that were made regarding the establishment of the Consumer Health Council included: that individual advocates should be able to use interpreters as required; all staff of the Council should be employed on a full time basis; its governance

arrangements should be carefully considered to ensure its functions are able to be implemented; representatives on the Council and Board should be selected through clear and transparent processes; its mission and aims should be developed by the membership; it should have a broad membership base (seven responses); and it should have a strong relationship with the Health Quality and Complaints Commission and other key partners/ services (eight responses).

There was a belief by some respondents that the Council should be provided with sufficient core funding to perform its functions and this funding should be provide for at least five to 10 year cycles to ensure stability for the organization. It was also felt the Council should also be able to tender for additional funding within its charter (four responses). There was both a small degree of support and opposition for Ministerial appointments to the Council; the Council having an ability to provide reports to Parliament; and the use of an auspicing organisation to assist its establishment.

2.13 Responses to Question 12. *Could you describe any other model you think should be considered in developing a Consumer Health Council so that it can operate effectively in Queensland?*

While approximately 30 per cent of the responses indicated agreement with the proposed model, a larger percentage (39.2 per cent) offered no response to this question. Approximately 24 per cent of the responses did offer a suggestion of alternative models that might be considered however no one particular model was offered a strongly supported alternative. Table 17 provides information the overall responses given to this question. A list of alternative models discussed or offered for consideration are included in Table 18.

General comments were also made concerning the implementation of the Council's model, for example: the Council should clarify the types of advocacy it will be using; the strategies and mission of the Council should reflect the holistic nature of health (e.g. it should consider lifestyle issues such housing, and be able to engage with all government departments as required); specific responses should be developed to engage with culturally and linguistically diverse communities and other marginalized groups; and that the Council should maintain its independence despite the fact that is will receive its funding from government. There was a small degree of support for either Queensland Health or District Health Council representatives being part of the Council.

Table 17 Responses to the request for alternative models to be considered

Response	Consumer	Consumer representative	Service providers	Gov. employees	Other	TOTAL	Percentage
Indicated agreement with model	7	21	16	4	1	49	30.0%
Provided suggestions of other models	3	20	11	4	1	39	23.8%
No response	20	11	18	14	2	64	39.0%
Negative response	1	1	1	1	0	4	2.4%
Unclear	3	3	1	1	0	8	4.6%
Total	34	56	47	24	4	163	100%

NB: some respondents may have given more than one answer

Table 18 Alternative models suggested for consideration

- Consider the Ministerial Advisory Council
- Ottawa Charter for Health and WHO
- Liaise with mental health sector
- RBWH/TPCH heart failure service model
- Local forums to bring together consumers, DHC's, key partners, services etc..
- Annual meeting with National and other State Consumer organizations
- Recovery self responsibility models
- Establish regional consumer councils
- Look at Disability Councils
- Noosa hospital Community Board of Advise
- Western Australian Consumer Health Council model
- Lifeways and Plan in USA/UK and Canada
- Mental health consumer participation models
- Australian Mental Health Consumer Network (AMHCN)
- Adult Community Further Education model with Department of Training in Victoria
- UK/French/Canadian and USA models
- Set up think tanks to discuss ideas (like the Cochrane Collaboration)

2.14 Responses to Question 13. Do you have any additional comments that you would like to make regarding the proposed Consumer Health Council?

Almost 50 per cent of the responses to this question did offer additional comments while approximately 25 per cent again indicated they agreed with the proposed model in the discussion paper. Those comments that made additional suggestions however did not indicate a clear expectation to divert from the proposed model, but rather generally provided ideas to strengthen or embellish the model as it was presented in the discussion paper. Table 19 indicates a summary of the numbers of responses provided to this question. Almost 24 percent again offered no further response.

Table 19 Responses to the request for any additional comments

Response	Consumer	Consumer representative	Service providers	Gov. employees	Other	TOTAL	Percentage
Indicated agreement with model proposed:	13	14	12	11	2	52	25.3%
Other comments made:	21	27	28	18	2	95	46.1%
No response	12	12	12	11	1	48	23.3%
Negative response	3	1	2	1	0	7	3.4%
Unclear	1	1	2	0	0	4	1.9%
Total	50	55	6	41	5	207	100%

NB: some respondents may have given more than one answer

Quite a number of responses were received to this question that indicated a very positive response to the proposal by Queensland Health to establish the Consumer Health Council and the consultation process, with a number of commendations being made regarding either the project or the concept of enhancing the involvement of consumers in the health system. Commendations were made by a total of 27 responses (or 21.8 per cent; including 3 Consumers, 12 consumer representatives, 7 service providers, 4 government employees and 1 other respondent). Examples of the types of comments made include:

“A proposal to involve ‘consumers’ is to be commended. Bundaberg’s problem was that consumers had no one to listen to them”.
(Government employee)

“I congratulate QH on this initiative...” **(Service provider)**

“It is a great move – there will be many interested people who will want to participate” (Consumer)

“It is a step in the right direction and when operational it will benefit all Queenslanders and provide a better health system”.
(Consumer representative).

Alongside these very positive comments, a number of respondents also raised concerns that they felt a number of factors might impact on its overall success. A total of 9 respondents considered clear ownership of the Council by consumers (rather than the government) as being vitally important (including 3 Consumers, 2 consumer representatives, and 4 service providers). Almost 9 per cent of responses also raised the need for the Council to have formalized advocacy and communication strategies in place in order for it to be truly successful. Suggestions included the Council being outcome focused and that a Memorandum of Understanding should be developed between the Council and the government to ensure the government takes its role seriously (including 3 Consumers, 4 consumer representatives, 3 service providers, and one government employee).

Other issues raised by respondents included: a recognition that the Council needs to be fully accessible by all consumers and groups; that it would need adequate resourcing to perform its role effectively; and that specific strategies are required to ensure certain groups of consumers are able to be ‘engaged’ by the Council. A concern regarding the use of volunteer consumers as consumer advocates was raised, indicating the need for highly skilled professional staff for this type of role. The issue of remuneration for consumers performing volunteer roles or for advocating on behalf of consumer groups was raised again as was the need for the Council to develop a clear mission and vision.

The view of one respondent was that the first task of the Council would be to ensure the ‘right’ people are selected as representatives who would also include representation from key groups across the community. Some responses again discussed the idea of Ministerial appointments for the Executive Director position and the Board; as well as the need for the Council to ensure that it provides feedback to the community

Less popular responses included the idea of adding funding to existing advocacy organizations (e.g. QADA) rather than funding a new body and the notion of ‘bringing back hospital Boards’. There was some support in the written comments received for the features contained within both the Western Australian and Victorian models of consumer engagement organizations, as well as the inclusion of private facilities and carers as part of the scope of the Council.

3 Results of open submissions

A total of 26 open submissions were received, with six of these being lodged by government employees or departments; seven by service providers; ten by consumer representatives; and three by consumers. Government departments who provided open submissions included: Department of Justice and Attorney General; Department of Education Training and the Arts; Department of Housing; Department of Communities and Disability Services Queensland.

A number of submissions were also received from networks or services representing the interests of people from culturally and linguistically diverse communities, one open submission was received from an indigenous organisation, and one was also received from a rural network. In addition, two key consumer bodies in Australia with very similar functions to those proposed for the Queensland model submitted responses to the discussion paper.

While some submissions were quite brief, on the whole, the open submission format enabled a deeper exploration of issues and the proposal of more detailed strategies relating to the proposed consumer engagement and advocacy roles of the Council. The key issues raised through these open submissions are represented in Table 20.

Table 20 *Key issues raised through the open submissions*

Issue raised in open submission	Number of responses
Both system and independent advocacy roles should be adopted	19 or 82.6%
Council to advocate for larger consumer issues eg travel costs, remote models and services, holistic health issues eg housing and environmental issues, impaired capacity etc	16 or 69.5 %
Advocacy strategies to be developed for discrete communities	14 or 61%
Develop appropriate linkages with partners and other organizations.	14 or 60.9%
Advocate for consumer rights	12 or 52 %
Council must be independent; include private sector; be credible and have sufficient charter, autonomy and funding; and have competent leadership	11 or 49%
Protocols, policies and role statements for consumer advocates and programs are needed	10 or 43.5%
Resource advocacy role and ensure paid advocates available	10 or 43.5%
Support, training and supervision for consumer advocates (eg training in legal issues)	8 or 34.8%
Representational positions on Board and/or Council	8 or 34.8%

Ensure marginalized groups included in mission statement e.g. CALD and indigenous groups	5 or 21.8%
Culturally appropriate methods and engagement strategies required	5 or 21.8%
Reimbursement for consumers	4 or 17.4%
Culturally competent staff required	4 or 17.4%
Culturally responsive governance structure required	4 or 17.4%
Multicultural position on Council requested	3 or 13.1%

There was a majority of support for the inclusion of both the individual and systemic advocacy roles in the Council's functions as well as for the Council undertaking an advocacy role for issues that impact on the a broader community and consumers in general across large areas of the state for example the issue of transport costs for accessing services by people in more remote or rural areas.

One submission did not support the establishment of a consumer advocacy service indicating that these services already existed. However, this submission did acknowledge that these existing organizations are limited in their eligibility criteria and are not available to the majority of Queenslanders accessing the health system.

There was recognition that there would need to be specific strategies developed for discrete communities including for example people from indigenous or culturally diverse backgrounds and the development of culturally specific strategies for engagement and advocacy for these communities. The request for representational positions on the Board of the Council was most common (at 34.8 per cent), with a request for a multicultural position on the Council being least common (13 per cent). It was identified that appropriate linkages would be required with other organizations in order for the Council to perform its operations, as well as appropriate training, policies and role statements for staff.

The issue of the Council potentially advocating for lifestyle issues that impact on consumers, for example living and environmental conditions, or transport issues, was raised in one submission, with the suggestion that there may be a role in providing feedback into population health planning processes, for some communities. This type of advocacy might be more likely to occur for remote or indigenous communities, or with cultural communities that take a broader or holistic view of health.

In relation to culturally and linguistically diverse communities, it was recognized that there is a need to undertake outreach strategies into these communities, using the existing networks and key community representatives and leaders, to ensure they are included in membership of the Council as well as ensuring the needs of these communities are considered by the Council. It is recognized that the issues impacting on these communities, as well as indigenous communities, are quite complex and the Council will need to be clearly linked with existing networks and organizations with skills in this area to include these groups in its representational advocacy role. The need for active strategies to reach these communities is evidenced by the National Resource Centre for Consumer Participation in Health:

“unless outreach activities are engaged to seek feedback, consumers from groups who cannot access services will not have a voice.”¹

Significant barriers exist for people from culturally diverse backgrounds participating in health policy and service development and advocacy strategies. Some of these are recognized as being discriminatory attitudes on the part of service providers who tend to place marginalization with the consumer rather than with the health service system; and a limited capacity to engage with these communities in a manner that is appropriate to ensure their continued engagement. A past history of poor engagement by the Queensland government with culturally and linguistically diverse communities on a range of issues, which has led to high levels of frustration on the part of many of these communities was also raised. It is noted that any engagement strategy that is undertaken within these communities in the future by the Council will need to be consistent, culturally responsive and sustainable, to assist to combat some of this history.

A number of concerns regarding the development of the Council raised included the need for a ‘robust charter’, competent leadership, a limited representation from Queensland Health on the Council, and a need to quarantine funding for systemic and individual funding to ensure both functions are implemented and staff with the different skill sets are employed. There was also the need for knowledge by advocates for consumers, of the appropriate legislation, decision making processes, key bodies and their roles within Queensland and skills required when working with people with impaired capacity or increased vulnerability within the health system.

One comment in support for the development of the Council expressed the view that it would provide:

“...benefits to Queenslanders through stronger engagement in accreditation, consultation, information provision, training, advocacy and support for the District Health Councils”.

One response indicated it did not support the individual advocacy function proposed for the Council, but rather suggested funding be provided to existing advocacy bodies to perform this function. This would leave the Council to undertake community engagement as its core function.

There was also acknowledgement from one response that many people with disabilities access the health system, and support was expressed for the plans for the Council to ensure the needs of people with disabilities are considered. There was also a request for clarification of the interaction of the Council with the Disability Council of Queensland. It is expected that issues such as the direct relationship of the Council with specific bodies such as this, are likely to be addressed at a later stage in the development of the Council, should it proceed.

1 National Resource Centre for Consumer Participation in Health. Feedback, Participation and Consumer Diversity. A literature review. (online) 2000 cited in 7 November 2006) available from: <http://www.participateinhealth.org.au/ClearingHouse/Docs/cfcfeedbacklitreview.pdf>

4 Themes from meetings with community organizations

A number of meetings with community organizations were held as part of the consultation process, either to provide additional information regarding the project and the Council's development and model, or as the method through which a particular organization chose to submit its response to the discussion paper. In relation to the indigenous organizations visited, the Department of Aboriginal and Torres Strait Islander Policy requested that a number of indigenous communities and organizations be visited as part of the consultation process and provided the list of organizations to visit. A visit was undertaken to Cairns and the far north Queensland area between 9 and 13 October, with meetings held with six indigenous organizations and visits conducted to two indigenous communities. The Multicultural Festival held in Brisbane 15 October 2006 was also attended which enabled discussions with the general public and distribution of the discussion paper to attendees. Table 21 which provides a list of the key themes raised during the discussions held with these organizations and representatives from the communities.

The major issue raised in these meetings and visits (by 67 per cent of responses), was the need for the community to perceive the Council as an independent and credible body that is listened to by government and that is solely a consumer organization, (ie it is not comprised of large numbers of health professionals or government representatives). Again the issue of effective representation by culturally diverse and indigenous communities on the Council and its board was raised as was the need to use culturally responsive strategies and to consider the diverse perception of health and language differences across these communities in the way that the Council functions. One organization indicated that there was some concern by some remote communities that the peak bodies acting on behalf of indigenous communities are seen by some individuals as not always acting on their behalf, but rather there was a perception they can become focused more on the issues relevant to the organization. As a result of this perception, it was requested that engagement strategies not just involve peak organizations, but also include direct communication with and representation from remote communities themselves as this will enable validation of information provided.

The complexity of issues relating to indigenous health was made evident during the visits conducted to these remote communities and organizations, indicating the need for indigenous specific strategies and programs and strong representation on the Council in order to ensure the needs of these communities are met. The complexity of factors impacting on remote indigenous communities (for example employment, nutrition, changes in funding arrangements and health service lines of accountability, social and environmental factors, isolation and lack of transport options, poverty of the community etc) will also require the Council to work closely with existing organizations and Aboriginal Community Councils in order to ensure the indigenous voice is heard clearly and positive changes can be achieved.

There was interest in the Council developing close partnerships with existing bodies, networks and organizations to ensure it is linked with current strategies for engagement in this area. There was also a degree of skepticism from some organizations who reported having attempted to engage with government over health matters in the past yet have

found the process unsuccessful, and who still remain disengaged and frustrated with these experiences. The Council will need to undertake active outreach services as suggested by some organizations, if these groups and networks are to be successfully re-engaged, and this will require a sustainable and consistent commitment on behalf of both the Council itself and the government, to demonstrate its interest in positive change.

Table 21 *Key issues raised through meetings with community organizations and visits to communities*

Issue raised in meeting/visit	Number of responses
Council needs to be seen as independent, credible, and must be a consumer body	8 or 67%
Representation of CALD communities/indigenous communities and diverse groups or people with disabilities	5 or 42 %
Regional Officers to be located to access remote communities e.g. far north Queensland, and be seen as independent from government	4 or 33 %
Council needs to advocate for boarder heath issues e.g. transport and access, reform in health services etc	4 or 33%
Representation a key issue: i.e. selection of Board members to be representative of different groups and communities and to consider portfolios of responsibility for Board and Council, consider selection criteria such as community endorsement, skills and experience, outcomes to be linked to service agreement etc.	4 or 33%
Don't 'lump' needs of people from diverse cultural and indigenous communities together	3 or 25%
Consider language differences for example the word 'consumer' often does not have relevance for CALD and indigenous groups, need to use culturally appropriate language and strategies	3 or 25%
Acknowledge different perceptions of health and advocacy and different 'world views' in strategies for engagement and advocacy	3 or 25%
Develop culturally appropriate services and engagement strategies	3 or 25%
Develop partnerships with existing networks and organizations, but also directly with communities, not just peak bodies	3 or 25%
Lack of successful engagement in the past with government leading to skepticism for future role of Council	2 or 17%

5 Themes from meetings with District Health Councils

A number of District Health Councils were approached in order to set up the public forums that were to be held around the state in the early part of the consultation process. These included: the Cairns, Townsville, Mount Isa, Rockhampton, Fraser Coast, Bundaberg, Sunshine Coast, Toowoomba, Gold Coast and Princess Alexandra Hospital District Health Councils. A member from the North Burnett District Health Council also contacted the Project Officer and requested their District be included in the consultation process and assisted to set up a teleconference consultation for this District. In most cases, these Councils assisted in setting up the public consultation forum in their District or attended the forum itself. Feedback provided during these forums will be discussed in the next section of this report.

As a result of correspondence sent out to all the remaining District Health Councils notifying them of the consultation process and inviting their input, a number of additional Councils requested a separate meeting to discuss the Project, answer questions from Council members and provide comments and feedback from the Council. In most cases the Project Officer attended the next District Health Council meeting. A forum held by the Minister and the Director-General to which all District Health Council Chairs were invited, was held in early November and a presentation was provided at this forum on the Council and the project. Table 22 below provides information on the additional meetings held with District Health Councils.

Table 22 *Meetings held with District Health Councils not involved in the Public Forums*

Location of DHC meeting	Date	Attendance
RBWH	20 October	4
Chinchilla/Northern Downs	23 October	11
Minister's Forum	2 November	35+
North Queensland DHC Chairs meeting	14 November	11+
West Moreton	15 November	8
Sunshine Coast	30 November	4
Total		73+

The main themes raised by District Health Council's during these meetings included a strong support expressed for the Council being an independent body with sufficient resources to perform its functions. Some members expressed the consideration of the funding for the Council coming from a department other than Queensland Health to assist to enhance this perception of independence. A number of members also expressed a view that a community awareness strategy would be required early in the establishment of the Council to ensure the community is aware of its existence and services. There was also general support for the proposed model and the regional positions; and for regional officers to be situated in the western and far north parts of the state, and representation for all key consumer groups on the Council.

A major theme for most District Health Council members was also the issue of role clarification, with the clarification of the roles of the new Health Community Councils alongside the Consumer Health Council, by far the issue considered most important. Clarification of the role of the Health Quality and Complaints Commission and its linkages with the Council as well as the Health Community Councils, was also raised and discussed at each meeting.

Some Council members expressed dissatisfaction with not being consulted regarding the changes to District Health Councils and the Health Services Act 1991. Some also expressed a dislike of the new name 'Health Community Councils' and preference to retain their current name. Considerable interest was expressed in the recruitment processes for the Health Community Councils and when this information will be made available, as well as what resources might be made available in the future for these bodies to perform their functions. Feedback provided on issues relating to these changes was forwarded to Brad Smith, Manager Health Community Council Coordination, for follow-up with these Councils.

6 Results of public consultation forums

A total of 10 different Districts across the state were visited in order to conduct public consultations including Cairns, Townsville, Mount Isa, Rockhampton, Fraser Coast, Bundaberg, Sunshine Coast, Toowoomba, Gold Coast and the Princess Alexandra Hospital health Service Districts. A consultation was held by teleconference in one additional District, North Burnett, as advice was received that this was the best option for conducting a consultation process in this District (due to the dispersed nature of the services across the district).

Public consultation forums were held in all of these Districts except Bundaberg. In each case, the Chair of the District Health Council was approached in the first instance to invite their participation in the consultation process. In most cases, District Health Council Chairs or members were actively involved in setting up the forums. In many cases, the Chairs of the District Health Councils accepted the invitation to undertake the welcome address for the public forums (Gold Coast, Sunshine Coast, Fraser Coast, Townsville, Toowoomba and Brisbane).

In the case of Bundaberg, advice from the District Manager and the Chair of the District Health Council indicated that a public forum was not the preferred consultation strategy. A meeting instead was held with the local patient support groups, as a request had been received for a meeting with one of these groups early in the consultation process. It was noted that a public forum was not likely to be well attended by other services in this area and that responses to the consultation process would more likely be received from these services through a targeted mail out, and this was then undertaken. Table 23 below provides a summary of the public forums/meetings held in each District and the attendances to each forum.

In each case where a forum was arranged contact was made with the District Managers office to discuss the forum as well as the District Health Council. In some instances support

was provided from staff in the District Manager's office (for example District Public Affairs Officers) to assist with setting up the forum. A request was made to either the Chair of the District Health Council or other staff within the District, to provide an up to date service listing for community, consumer and health services within their District.

An invitation was then mailed out to each service identified on the listing, with a copy of the discussion paper. Services were invited to attend the forum, or to consider submitting a response to the discussion paper if they were unable to attend. Where possible, local media were also notified of the forum and made aware of the forums being open to the general public to assist to access consumers directly. Services invited were also asked to ensure that their consumers were made aware of both the discussion paper and the forum, and to provide support to enable their attendance, or to complete a submission, where this might be required.

In the case of Gold Coast and Rockhampton, the attendances were noted to be lower than in other forums. In some cases community organizations indicated there were some difficulties with receiving their invitations which were sent by mail. This may have been due to local postal services or in some cases out of date contact information for services. Other reasons for the lower attendance rates included the recognition that a longer time frame might have been required for some communities (due in part to the postal difficulties in regional areas), or that public forums are not a preferred consultation strategy for some communities and that more time (than that available within the project) would be needed to engage some communities to improve responses.

It was noted that attendances to the forums were significantly improved when the following strategies were used:

- Active support was provided from the District Health Council Chairs and members to provide up to date information, and a linkage to local communities through their strong local networks and established relationships with services.
- A phone call was made to the services on the mail out listing a couple of days prior to the forum to confirm attendances. This acted as a reminder, as well as capturing services who had not received their correspondence and notifying them of the forum date and time.
- A media release, or advertisement in local newspapers (or both), undertaken in the week prior to the forum, which was often followed by media attention being received at the forums.

The forums were generally attended by a range of representatives including: a number of District Managers and other staff from the District Office (for example Public Affairs officers); consumers; consumer representatives and organizations; health service providers and community services; advocacy services; members of the general public with an interest in health matters, District Health Council members and Chairs, and in some cases the local media (Townsville and Cairns).

Table 23 *Public consultation forums/meetings held across the state.*

Location of Public Consultation Forum	Date	Attendance
Bundaberg	28/29 September	26
North Burnett	3 October	9
Visit to far north Queensland	9 - 13 October	N/A
Mount Isa	19 October	9
Gold Coast	23 October	5
Fraser Coast	31 October	16
Sunshine Coast	6 November	28
Cairns	8 November	18
Rockhampton	10 November	5
Townsville	13 November and 1 December	17 8
Toowoomba	16 November	18
Brisbane	17 November	25
Total attendances		184

The Public consultation forums resulted in a large number of issues or comments being raised by the general public, consumers, consumer groups and services. The main themes raised are listed in Table 24. This table includes the themes raised also from the consultations held in Bundaberg and North Burnett. A number of themes were consistently raised across all of the public forums conducted, and these included:

- The view that there should be representation from all consumer groups, including culturally diverse and indigenous communities, people with disabilities etc) on the Council and/or its Board.
- The view that the roles between the Health Community Councils and the Consumer Health Council should be clarified. This issue was consistently raised by District Health Council members who were present at the forums and may have been raised due to the fact that the changes to the District Health Councils were being presented to them by the Minister's office at the same time that the Consumer Health Council consultations were being conducted. There was some degree of confusion regarding these changes expressed by members of the current District Health Councils. This was not an issue consistently raised by other members of the community or the general public, the majority of whom indicated they were not familiar with the roles of the current District Health Councils (or in some cases, the fact that they existed).
- There was consistent support for the regional officer's positions to be situated around the state with considerable feedback on where these positions might be located.

Other themes that were raised in the majority of forums (although not all) included the need

for the community and government to perceive the Council as a credible and independent body; the clarification of roles of the Council and the Health Quality and Complaints Commission as well as other community organizations, particularly in the area of advocacy and complaints management; and general support for the individual advocacy role proposed for the Council and for the proposed model for the Council overall. Responses received during a large number of forums indicated the view that the Council should be expected to report back to the community or consumer groups that first raised issues or provided feedback, to advise them of the outcomes of any advocacy process undertaken. There was also a view that the individual advocacy role should be undertaken by paid staff (rather than volunteers); and that local and community specific engagement strategies would be required to ensure community engagement. It was also thought important that the community be made aware of the Council, if it is established, so that consumers know where support can be accessed.

Table 24 Major themes arising from public consultation forums

Theme title	Mt Isa	Cairns	Fraser	S C	G C	Rocky	Townsv	Twmba	Brisb	Bunda	NBurn
Other consumer groups should be supported by the Council: eg illiteracy, homeless, younger people...	x	x			x	x			x	x	x
Representation by all consumer groups and a broad membership base is required	x	x	x	x	x	x	x	x	x	x	x
CHC needs to report back to community on issues raised		x		x	x			x	x	x	x
All health services should be included in the scope of the Council	x				x		x		x	x	
Local health issues raised during forum	x	x			x			x	x		x
Consumer reimbursement	x					x	x		x		
Fear of retribution for raising issues									x		
Clarify roles of HQCC, DHC and other organizations		x	x		x	x	x	x	x	x	x

Theme title	Mt Isa	Cairns	Fraser	S C	G C	Rocky	Townsv	Twmba	Brisb	Bunda	NBurn
Clarify roles between DHC's and CHC	x	x	x	x	x	x	x	x	x	x	x
Credibility of CHC	x	x	x	x	x		x	x	x	x	x
Support for Regional Officers (RO)	x	x	x	x	x	x	x	x	x	x	x
Support for RO in west and far north	x	x	x	x	x	x	x	x			x
Ongoing consultation re core functions by Council	x	x			x			x		x	
Adequate funding to support functions	x	x			x		x	x	x	x	
Clarification of complaints processes		x	x	x	x	x	x	x	x	x	x
Paid advocates (not just volunteers)	x		x				x	x	x	x	x
Consumers as advocates – with support and training			x				x		x		x
Support for access strategies within Discussion Paper	x		x		x						x
Support for individual advocacy role	x	x	x		x	x	x	x	x	x	x
Community awareness strategy re CHC			x	x	x		x	x	x	x	
Encourage younger representatives					x				x		
Strong consumer representation/limit industry on CHC	x			x			x		x	x	x

Theme title	Mt Isa	Cairns	Fraser	S C	G C	Rocky	Townsv	Twmba	Brisb	Bunda	NBurn
Developmental approach, review CHC after 12-24 months	x			x	x						x
Work with existing services/bodies	x			x	x	x	x	x	x	x	x
Positive response to CHC and model		x	x	x	x	x	x	x	x	x	x
Report back to parliament				x				x	x		
Independence of CHC	x	x	x	x	x		x	x	x	x	x
Local engagement strategies needed	x				x	x		x	x	x	x

NB: the 'X' indicates that the issue was raised at that particular forum.

Other themes raised during the Forums that were less frequently discussed but still considered important included: that all health services, including private and non-government and aged care services, should be included in the scope of the Council; that the Council should conduct ongoing consultations regarding its functions and direction if it is set up; that there should be strong consumer representation on the Council and limited representation by health professionals and Queensland Health; and that it should provide reports to Parliament to ensure the independence of the issues raised by the Council and to limit any perceived interference from Queensland Health.

A small number of attendees raised the idea of reimbursement for consumers for performing volunteer functions for the Council or for undertaking consumer advocacy roles on behalf of consumer groups. The idea that consumer volunteers should be able to perform the role of an individual advocate with the appropriate support and training, even if only for less complex cases was also discussed with a range of viewpoints being expressed, both positive and negative. The idea that the Council should be able to undertake a developmental approach to its development with a review conducted possibly 12 to 24 months following its establishment was raised in a small number of forums.

One issue raised at the Brisbane forum, which was considered very important by a large number of attendees at this forum, was the issue of a fear of retribution by consumers and consumer groups for raising issues regarding the health system. Attendees expressed the view that the Council might have a role in assisting consumers and groups to raise issues in situations where this kind of concern existed, and to advocate on their behalf. Some feedback was also provided on other organizations thought to be key stakeholders to the work to be undertaken by the Council.

Local media representatives attended the forums held in both Cairns and Townsville and in

each case television crews undertook interviews of attendees to the forum. Other contact included newspaper articles and interviews for local radio stations.

7 Results from workshop held with service providers

A workshop was undertaken as part of the consultation process on 21 November with a small number of key non-government service providers and other key stakeholders. The purpose of the workshop was to discuss key issues related to the implementation of the Consumer Health Council and its establishment. A small number of organizations were invited to send representatives, to ensure the workshop was kept at a manageable size, and included organizations with experience in advocacy or issues related to consumer engagement, or who were thought to be key stakeholders should a consumer advocacy service be established.

Key issues that were discussed include: the model and structure of the Council and key risks involved in its establishment including how these might be managed; roles that consumers might be asked to perform within the Council and what support would be required; the scope of the council (i.e. what services might be included); access strategies to ensure the consumers who most need the support of the Council are able to access this; the unique functions that should sit with the Council rather than with any other body; reporting and accountability mechanisms; options for the establishment of the council; and the makeup and establishment process of the Board.

Key feedback provided by workshop participants included:

- Advise that strategies would be required to address a concern from consumers regarding the culture of health services and a fear of reprisals for raising issues regarding health services.
- Formal linkages, referral pathways and communication strategies between the Council and other community organizations will need to be developed.
- The location of the regional officer positions would need to be carefully considered due to sensitivities regarding perceived independence of these positions from other health services and Queensland Health or government bodies.
- The different models of individual advocacy and engagement strategies need to be clarified by the Council in the future. It was thought that consumers who undertook training to perform an advocacy role might undertake an accreditation process to ensure they are skilled to a certain level, and ongoing supervision would also be required.
- Training might also be required by health services in how to engage with consumer representatives and advocates in order to make these roles and experiences more likely to be positive and successful. The Council therefore might undertake 'bridging' work between the consumers and health services to assist with the establishment of the consumer representative framework.
- The Council would need to specify initially, its intention to develop flexible strategies for engagement with different communities and concern groups, i.e. to incorporate different frames of reference regarding advocacy, health and cultural competency etc.

These strategies should also include an active outreach process to specified communities to ensure their needs are presented and that complaints are received.

- There was some discussion regarding where the Council might report or forward any reports on its activities or issues of concern. Some felt there might be benefit from the Council requesting that these reports be tabled in Parliament, as this was seen as a very transparent and accountable process.
- The Non-government organizations present indicated they did not support the use of representative positions on the Council Board as this is not considered best practice within Incorporated Associations (does not comply with legislation) for the Council. Board members should rather be elected from the membership base on the basis of their experience in governance of non-government organizations. An interim board would be required until such time as the membership base was established and some attendees expressed the view that this interim Board should not be appointed by the Minister or Premier. An ability to appoint people from outside the council's membership base for key roles, for example a person with legal knowledge, would also need to be written into its constitution. A membership of nine people on the Board was considered a maximum, and consideration should be given to reimbursement for Board members for expenses (such as travel) and sitting fees.
- It was generally felt that any Council positions should in fact be full time and not part time.
- The suggestion was made by a number of attendees that consideration be made for developing a Memorandum of Understanding between the government and the Council. This would ensure that the government undertakes to listen to the Council and the issues it raises, and would also provide a degree of accountability and security for the Council.
- It was suggested that the government give an undertaking that a minimum of five years funding would be secured for the organisation (with a review in two to three years time) and that its ongoing funding would not be subject to changes in government.
- There was general agreement that the individual advocacy role was supported, however attendees expressed the view that this role should be predominantly undertaken by trained and qualified staff and ongoing support and supervision would be required.
- Support was expressed for the reimbursement of consumer volunteers and representatives who perform functions on behalf of the council and that a budget allocation is provided for discretionary funding to support this occurring.
- Funding to support the role of providing training to the Health Community Councils should be quarantined and consideration should also be given to appropriate accreditation of any training programs that might be required.
- It was generally agreed selection criteria specific to consumers and for consumer representatives, particularly those who might sit on working parties or committees as part of the Councils functions, could include aspects such as community endorsement, skills and experience. The Council might also be supported by other Non-government organizations who are sophisticated enough to be regularly engaging with their consumer groups, in selecting representatives and engaging with particular groups.

- On the whole, attendees expressed the view that the Council should support consumers of all health services, including the private and non-government sectors. However the notion of possibly using a staged process of developing its scope (i.e. limiting its scope in the first year or two to only supporting consumers from public health services) to enable the Council to develop its functions and structure was offered. It was also noted that QADA currently has a role in providing advocacy services to consumers within Commonwealth funded aged care services, and people with disabilities. Some thought could be given to whether the Council should also provide advocacy to these consumers, (as it may be seen as a duplication of role), and the issue of consumer choice of advocate (it is also noted that QADA does not provide systemic level advocacy for these consumers).
- It was suggested that the Council should develop a process for prioritizing issues that it deals with, as well as a focus on people who are more marginalized or less able to advocate on their own behalf and require additional support for their interests to be acknowledged.
- It was suggested that the Non-government sector would need to be engaged in the process of establishing the Council to ensure that it is supported by this sector in its funding. The idea of developing the Council through an auspicing arrangement with another non-government organization was strongly supported by most of those represented at the workshop.
- It was suggested that non-government organizations, that do not provide direct services, might assist to undertake a review of the Council's operations and that key performance indicators and data to be used for this process might be developed at the time the Council is established to ensure the data is available for the review process. Suggested indicators might include: measurable changes achieved to health systems (as the result of advocacy), satisfaction by consumers, requests for input from the Council by government bodies, numbers of consumers assisted etc.
- It is noted that the Council would not be eligible for PBI status and so the salary of the Executive Director would need to reflect an appropriate level to attract an appropriate applicant pool.

8 Overall summary of themes raised

The overall response of the community during the consultation process undertaken was positive to the establishment of the Consumer Health Council with approximately 92 per cent of written responses received indicating agreement with it being established. A number of these respondents also commended Queensland Health for undertaking the consultation process and for considering the development of the Council. A number of the responses during meetings and public forums also reflected this very positive response, however these were not quantified. Overall, the feedback received demonstrated a number of similarities across all respondents and the consultation strategies used with only slight variations in content and requests made regarding some aspects of the proposed model.

The name proposed was generally accepted by the community, however feedback was provided on possible alternatives, particularly in light of the name change proposed for

the new Health Community Councils. A possible alternative name, that brings together the most popular changes requested, is: Health Consumers Queensland.

Almost 70 per cent of responses to Question 3, regarding the proposed role of the council, indicated they were in agreement with this role. This agreement was also mirrored in responses provided to Question 4, which asked for alternative roles, with 54 per cent again indicating they agreed with the proposed role.

The model proposed in the discussion paper was generally also accepted with 75 per cent of responses to Question 6 indicating they felt it was suitable for the Queensland Context. The idea of providing training and support to the Health Community Councils was generally supported by almost 65 per cent of responses received. There was significant interest in some aspects of the model, in particular: the issue of representation and engagement with indigenous and culturally diverse communities and other disadvantaged groups, including the expressed preference for these groups having representation on the Board of the Council and within the Council staffing and functions (i.e. 48 per cent of responses to Question 8 indicated this).

The regional officer positions were generally supported with requests for an officer to be placed in the western and far north Queensland areas of the state most popular. A number of community specific strategies for engagement and representation were also requested by particular groups. There was a request for the Council to ensure it engages directly with consumers and communities, and rather than solely engaging with organizations and peak bodies. There was a request to ensure representation of disadvantaged groups within the mission statement, and functions of the Council, as well as developing consumer specific selection criteria, (for example recruiting people who have the endorsement of their community to be their representative).

The key factors perceived to impact on the success of the Council indicated most commonly across all strategies and groups included: adequate support and funding from government; representation from disadvantaged and cultural groups; ongoing funding to be provided, for at least five year contracts; the Council to be made up of consumers and not health providers and professionals; the Council being perceived as functioning independently from government; a public awareness campaign being undertaken at its establishment to ensure consumers are aware it exists; and the Council reporting back to the community on the actions it takes to address issues.

Suggestions to improve the perceived credibility of the Council included: being independent from Government; having a robust charter of responsibility and sufficient funding; developing a memorandum of understanding between the Council and government to indicate that government will listen and to enhance accountability for the Council for how it performs; role clarification between the Council and a number of key existing organizations and bodies; clear linkages with other bodies and organizations; clear policies and programs for its functions; full time paid positions for advocacy roles; limited use of consumer advocates with reimbursement and training provided; and culturally appropriate engagement programs and strategies.

Key funding issues raised included: the request for adequate funding to perform the range of functions required with discrete funding attached to each area of responsibility; reimbursement for Board members and consumers; adequate travel and consultation budget; active outreach strategies for access to community groups; and a request for a position on the Council to work exclusively with culturally and linguistically diverse communities.

The non-government service providers who attended the workshop expressed a clear preference for an auspicing arrangement to be used for the establishment of the Council (i.e. through an existing non-government organization). The community in general however did not express a clear view on how the Council should be established except the need for the perception of independence from government. Given the past experience in Queensland of establishing a service of this nature, alternative options will need to be considered carefully prior to a final decision being made regarding the approach taken to establishing the Council.