

Building an Effective Voice for Health Consumers in South Australia

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The formation of the Health Consumers Alliance of South Australia Inc. (HCA) is an important milestone in the evolution of creating a strong and independent voice for health consumers in the South Australian health system. Health Consumers Alliance of South Australia's first year of operation was evaluated and this article summarises the findings, with a focus on the benefits and achievements of HCA and areas that require additional attention.

The commitment to consumer and community participation in the health system has come onto the agenda of the South Australian government and health sector, as well as being advocated for by individual consumers, health consumer groups and non-government advocacy organisations such as South Australian Council of Social Service (SACOSS). The establishment of a statewide health consumer organisation, such as HCA, was a recommendation from consultations conducted during 2000 and 2001—as part of the Healthy Voices Project, with health consumers—health care providers and bureaucrats in South Australia (Wishart 2002).

The Healthy Voices Project was an initiative funded by the SA government for three years commencing in January 2000, and auspiced by SACOSS, to identify and implement the most appropriate model for consumer advocacy and participation in the South Australian health system. Consumers strongly supported the development of an independent, consumer-driven organisation as

an important mechanism for advocacy and participation in the health system in South Australia. HCA was established to achieve this purpose, and was incorporated in October 2002, with the inaugural Annual General Meeting held in November of that year. The aims, objectives, basis of representation and strategic directions of HCA were developed through a series of working parties with experienced health consumers over a six-month period prior to incorporation. This ensured that there was broad support for the new consumer organisation's direction.

Despite the support for HCA by consumers, some health providers and bureaucrats there was no long-term financial commitment to support HCA by the government. This support was dependent on the performance of HCA in the initial establishment phase, and the outcome of the budget allocation arising from the *Generational Health Review Report*.

Evaluation

The Management Committee felt it was important for HCA to undertake an evaluation to ensure its future success in obtaining a secure funding base from the government. Funding for the evaluation was provided from the Flinders Institute of Health Research, Flinders University. The purpose of the evaluation was to investigate how the newly-formed HCA had met its aims and objectives, as defined in its constitution, and work plan (see box) in its first 12 months of operation, November 2002 to November 2003 (Johnson & Wishart 2004). Special attention was paid to the achievements and limitations experienced during this period



Key Activities of Work Plan 2003

1. Develop broad health policy (e.g., Medicare, Private Health Insurance).
 2. Develop protocol for consumer and community representatives on committees and working parties.
 3. Lobby for enactment of Health and Community Complaints Legislation.
 4. Advise on other relevant state-based legislation (e.g., Medical Practice Bill).
 5. Develop an approach to consumer training and support, and seek funding for scoping project.
 6. Conduct public forums on issues (e.g., Pharmaceutical Benefits Scheme and Medical Practice Bill).
 7. Participate in the South Australian Health System's Generational Health Review.
 8. Building membership.
 9. Develop membership communication system.
 10. Develop the capacity of HCA (e.g., management systems and seek funding).
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through the eyes of three different groups (HCA members, HCA Management Committee and key stakeholders). The evaluation's findings were to be used to determine the strategic directions for the HCA in its ongoing operational developments, consumer capacity development, and lobbying on policy and legislative issues. The findings will also contribute to the critique of, and emerging knowledge about, the effectiveness and role of a statewide consumer organisation, as well as key issues associated with consumer participation in health.

Evaluation

Four main methods were used to collect information for the evaluation:

1. Survey of HCA members.
2. Survey and focus group interview with the HCA Management Committee.
3. Interviews with key stakeholders with a broad spectrum of interests and backgrounds including bureaucratic, government, academic, Aboriginal, specific health condition related consumer groups, rural, health service management, non-government advocacy organisations, and service providers.
4. Analysis of the HCA documents.

Findings and Recommendations

What needs to be acknowledged at the outset is the significant amount of support for HCA that was apparent from the majority of participants

in the evaluation. It was evident the 'timing was right' for HCA to be established and there appeared to be widespread support for greater community and consumer input into the health system in South Australia. It was also evident that the consultative process and 'lead-in time' to develop HCA through the Healthy Voices Project ensured that there was widespread 'ownership' and support for the aim and purpose of HCA, and its directions.

Benefits and Achievements

The findings highlighted the considerable benefits and achievements of HCA during its first year of operation, and the important void HCA was beginning to fill. Particularly interesting was that even though the participants represented people from diverse backgrounds, with a wide range of interests and perceptions about consumer participation, the benefits and achievements identified were congruent. However, the way the benefits and achievements were framed by the various stakeholders was different. This appeared to be dependent on their role perspective (e.g. member, service provider, policy maker or bureaucrat) and their relationship with the HCA.

For example, members and the Management Committee identified benefits such as:

- recognition by the SA Department of Human Services (DHS) and the government that HCA is an organisation that represents health consumers;
- coordination of consumer voice and action, rather than many disparate consumer voices;
- providing a vehicle for participation into policy issues and decision making forums within DHS and government;
- providing individual benefit to consumers through access to information and networks; and
- providing a forum for debate/discussion about current issues and an arena where advocating for change was possible.

Key stakeholders identified benefits such as:

- "at last a health consumer voice in South Australia";
- power of a focused consumer voice;
- input into planning and development; and
- building consumer capacity.

In essence there are overlapping benefits, but described from a different perspective.

The perception that HCA had made outstanding

achievements during its first year, with limited financial and paid human resources, was echoed throughout the study. However, it was also widely acknowledged that HCA's current dependence on its member's active volunteer effort was not sustainable.

The most important achievement identified by members, Management Committee and key stakeholders was "establishing credibility and being recognised as a valid, valuable and energetic consumer voice". This was evident by HCA's achievements in participating in policy and decision making forums, but also by developing membership support from a diverse constituency. This was seen as an important achievement and a good foundation for future success. Furthermore, it was recognised that HCA is breaking new territory in South Australia and, as such, is starting from a very low base.

Other important achievements were establishing operational functions or, as the key stakeholder group identified, "holding it all together, and information sharing and awareness raising". This has taken a lot of energy and commitment by a small leadership group, and the actual visible work of "lobbying on policy and legislative issues".

The model and approach developed by HCA has significant strengths, in particular its approach to building an alliance of consumers and community groups around key priorities and using a participatory approach to involve members in its activities.

HCA is beginning to fill a much needed gap in the South Australian health system as well as with health consumers and community organisations through their interface with DHS and the government. It was apparent from the findings that HCA should continue its important work and build on its solid foundations by continuing to:

1. Be strategic in its approach to "provide a strong, independent and effective voice for health consumers". It has to develop the capacity to be proactive on behalf of consumers, rather than falling into the trap of being reactive to DHS and government need.
2. Advocate a position on high-level issues, at both state and national levels, which have a consensus from a broad range of health consumers and groups, and key stakeholders in the health system.
3. Strengthen its commitment to explicit values of social justice, democracy and accountability.

4. Be highly consultative and continue to have an open process of policy and position development and negotiation.
5. Further develop its capacity to collect, interpret and disseminate information to its membership and the wider system.
6. Develop relationships of trust with all players and alliances as appropriate.
7. Base communication and negotiation on clear communication and mutual respect.

Areas Requiring Additional Attention

This evaluation brought into focus a number of issues that will need to be addressed over the coming years. Some will be required to be prioritised and addressed by HCA. Other issues are broader than HCA's mandate but influence HCA's work, and it is important that HCA lobbies for them and provides leadership where possible.

One important area of concern was the lack of clarity amongst some members and key stakeholders about issues such as:

- Who is a consumer?
- Who does/should HCA represent?
- Does the HCA represent consumers or do they provide a consumer perspective?
- What organisational structure, stakeholder consultation processes, and Management Committee membership and configuration, can best support HCA aims?

This lack of clarity has the potential to become a minefield for HCA and health consumers unless work is done to address this issue, especially among health sector workers and bureaucrats. This issue has the potential to undermine HCA's ability to achieve its mission to provide "a strong, independent and effective voice for health consumers". Another important issue linked to this debate is that consumer participation is not one-dimensional: for example, consumer representatives on committees—there are many ways for consumers to participate in the health system and the HCA should support this notion by advocating for appropriate and varied approaches. Debate and resolution needs to occur within the HCA and the health sector.

Other important areas requiring additional work include:

1. Further development of the HCA constituency. This should be both formal, through a broader membership particularly in rural areas, marginalised groups, among acute care

services and any other 'gap' areas, and informal through a higher public profile and awareness raising activities that reach the general population. In addition, there is potential for the further development of alliances with other organisations, especially those who represent traditionally marginalised groups/people.

2. Greater use of the media to promote and argue the HCA positions. This goes hand in hand with developing a broader constituency and higher public profile. The development of a capacity to deliver rapid response through the media to current health issues is also seen as important. This will require greater membership activism to ensure it carries the legitimate and endorsed views of the organisation.
3. Development of consultation processes to identify 'grass roots' consumer issues, raise awareness of them at higher levels, and to advocate for, and participate in, the development of policy solutions.
4. Development and provision of programs to increase the capacity of consumers to participate in policy development and other decision making forums.
5. Increase HCA's capacity to engage more members who can contribute to the achievement of HCA's goals. This could be through working groups, but consultation with the members needs to contribute to the strategies implemented.
6. Development and access to a basic research capacity to support issue and policy development from a consumer perspective.
7. Development of an independent identity apart from SACOSS, and the establishment and promotion of a public HCA identity.
8. Development of a structure that is responsive to the restructuring of the health system in South Australia (e.g., regionalisation) and the need to truly be a statewide consumer organisation.
9. Find ways to change the perceived impenetrability of DHS and government by breaking long-established cultures of excluding consumer voices in decision making.

The Future

At the time of completing this evaluation, HCA's future was uncertain. Interim funding was provided for six months without any guarantee of ongoing core funding. The first ten months of 2004 were a difficult time for HCA and its constituency. At the end of lengthy negotiations the South Australian government provided three-year core funding based on a service agreement negotiated between HCA and the Department of Health. HCA is to undertake the role of a state-based, peak health consumer organisation in a range of areas, which include:

- providing policy advice to government;
- providing consumer education, training and support;
- running a consumer nominee program;
- participating in health system reform; and
- assisting hard-to-reach groups (e.g., Indigenous, mental health and rural and remote consumers) with lobbying and advocacy.

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