Ensuring the consumer voice is heard
Health Voices

*Health Voices* is published twice each year. Each issue has a theme that promotes debate on issues of interest to health consumers, government and industry. Readers are encouraged to write letters to CHF in response to journal articles or other issues in Australian healthcare.

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The Consumers Health Forum of Australia

The Consumers Health Forum of Australia (CHF) is the national peak body representing the interests of Australian healthcare consumers.

CHF works to achieve safe, quality, timely healthcare for all Australians, supported by accessible health information and systems.

CHF does this by:

1. advocating for appropriate and equitable healthcare
2. undertaking consumer-based research and developing a strong consumer knowledge base
3. identifying key issues in safety and quality of health services for consumers
4. raising the health literacy of consumers, health professionals and stakeholders
5. providing a strong national voice for health consumers and supporting consumer participation in health policy and program decision making

CHF values:

- our members’ knowledge, experience and involvement
- development of an integrated healthcare system that values the consumer experience
- early intervention, prevention and early diagnosis
- collaborative integrated healthcare
- working in partnership

CHF member organisations reach Australian health consumers across a wide range of health interests and health system experiences. CHF policy is developed through consultation with members, ensuring that CHF maintains a broad, representative, health consumer perspective.

CHF is committed to being an active advocate in the ongoing development of Australian health policy and practice.
Editorial

Consumers are more than recipients and funders of healthcare. They are essential partners – like it or not. To treat consumers otherwise is to both miss an opportunity for optimising healthcare delivery, and to court misunderstanding, ‘non-compliance’ and compromised self-management. In short, to waste time, money, resources – and as Karen Carey points out – sometimes lives, when we need to get the most from every health dollar we invest.

That is what this issue of Health Voices explores. The role of consumers in healthcare planning and delivery; the value consumers can bring to the decision-making table; and the challenges and opportunities we face in developing, empowering and realising the full potential of the consumer resource.

The first step is leadership. Minister Roxon clearly articulates the Government’s vision of achieving better health for all Australians in Consumers and health reform. She emphasises the need for partnership between all stakeholders and the critical importance of decision-making that values the lived experience of healthcare as we shift the focus of our health system to delivering health outcomes for people, not just health services. Chair of the Senate Community Affairs References Committee, Senator Rachel Siewert, provides an insight into the Senate Committee process. Here we see our democracy at work; review of decision-making at its highest level in a forum of equity where the consumer and community voice is as essential as that of Government and other stakeholders.

Next comes implementation. Secretary, Jane Halton, talks to the Australian Government Department of Health and Ageing’s commitment to, and breadth of, consumer participation in policy development. She also highlights ‘patient experience’ as a reporting requirement in the performance framework for the National Healthcare Agreement.

We hear of the value of consumer representation and consumer partnership from industry (Dr Brendan Shaw, Medicines Australia), those pursuing clinical excellence (Dr Karen Luxford) and in research (Professor Kathleen Griffiths and Anne McKenzie). Dr John Aloizos AM (former Chair, Australian Pharmaceutical Advisory Council) and Janne Graham AM (consumer representative) share an insight into the progress that is possible when partnership, respect and a focus on solutions drive decision-making.

We hear of success and challenge. Bev Cook tells us how community action ‘saved Sea Lake Health!’ Long-time consumer advocates Kate Moore and Janet Meagher AM look at the change that has been achieved over a number of decades; the cultural shift to including consumers at the table and the challenge we now face in ensuring that consumer participation is not only present, but continually effective. Consumer capacity is out of step with demand - the time for resourcing, support and strategic thinking around consumer participation is now.

For examples of what can be achieved in a short period of time, we look to Health Consumers Queensland. For stepping in to address a long-standing gap, we hear from Toni van Hamond (PSM) and the Youth Future Crew at headspace, Barwon. For looking beyond our shores to the global messages around the value of patient-centred care, we hear from Joanna Groves of the International Alliance of Patients’ Organizations.

And at home, in the area of greatest need, Laura Elkin looks at how Indigenous Australians can and must shape the healthcare planning to close a shameful gap.

Healthcare is about people working with people. Consumer participation is more than a ‘right’. With support and investment, consumer participation will be an essential contributor to getting our health system right, for all Australians.

Carol Bennett, Chief Executive Officer, Consumers Health Forum of Australia
Consumers and health reform

The Hon Nicola Roxon MP.

Putting the patient at the centre of health service delivery is easy to say, but much harder to do.

For too long, our health system has been focussed on processes, structures and professionals and not on the patient’s needs. This has become a particular problem for the growing number of Australians with chronic and complex illnesses, and the increasing number of older Australians.

For them, navigating the system has become very difficult, whether because of long distances, complex systems, or lack of information.

To make our system easier for patients, more responsive to their needs and more effective in dealing with our 21st century health problems, major health reform is essential. And consumers must be partners in that reform.

A determination to bring consumers into their rightful place at the centre of the system is at the core of the Labor Government’s health reforms.

We consulted extensively with over 100 face to face meetings across the country, and key themes emerged as consumers articulated their problems with the current health system.

They spoke of problems that they encountered on the ground, that require a mixture of practical and policy changes to address. Reports of difficulties accessing services in a system that is not designed to be easy for consumers to navigate resonated across the country.

We heard what consumers had to say, and have worked to deliver a range of initiatives to address these concerns, with consumers involved in key decision-making and design of many of these programs.

One immediate frustration that emerged was how difficult it can be to see a doctor or health professional, particularly after hours.

It’s easy to imagine, the parent with a sick child agonising over whether to face the queue at the emergency department or waiting to see if the high temperature will be gone by morning, or maybe someone has had an eye infection and knows that they need antibiotics but also knows that they won’t get in to see their GP for another two days.

The struggle to see a doctor was exacerbated by the previous Government putting a lid on medical places at University, without bothering to do the necessary national planning to see what the needs of the future would be. They even capped GP training places, driving many young graduates to other specialties.

The Gillard Government has started to turn that around.

The Government is making it easier to see and contact a doctor when you need one.

We got rid of the GP training cap. There are 175 extra GPs already training in our community right now, with the number growing annually to 1,200. Over the next 10 years we are training an extra 5,500 GPs and more specialists too.

The Government is also providing more on the job training for up to 12,000 more undergraduate students in health professions, in addition to the 4,600 practice nurses that will be based in GP clinics.

All this is part of making healthcare more accessible – getting patients timely and convenient access.

We are also getting GPs and specialist services into the community, especially regions and outer suburbs that have been underserviced in the past.

We have introduced incentives for health professionals to work in rural and regional Australia, as well as training an extra 680 specialist doctors over ten years.

These are practical measures that will have real benefits for consumers.

Another part of the solution is the Gillard Government’s new After Hours Service - a real way that we will better connect patients with health professionals.

When the local GP surgery is closed, a phone call will let a patient access a doctor or nurse by phone or by video conference.

The emergency department will cease being the only option after 5pm and on the weekend. There will be another option to get care, another way to get reassurance or advice.

As consumers have often told us, a real problem in the system is the medical merry-go-round that so many people, especially those with a chronic disease, are on.

Referral after referral, wait after wait, to see someone who can check your blood pressure, someone else to provide you with information, another to tell you what your test results mean.

How much easier would it be if more of those services could be provided under one roof?

That’s why the Government is building 64 GP Super Clinics in areas where it has been difficult to get doctors or where there is high population growth. Thirty-one are already operational, providing early services, or are under construction.

These clinics are a really exciting development. Some practices have already been developing this type of centre – but not enough, and not in enough places. We’re using our program to kick start these services in places that have been underserved.
This will cut down on the amount of time that people are forced to travel, removing a real barrier for consumers and getting people off the medical merry-go-round.

Another issue that emerged is the lack of information that is made available in a simple format for the consumer. If consumers want to know, for example, where they can get an orthopaedic procedure done and how long it will take, it’s virtually impossible to find out.

I want to make it easier for the person waiting for a hip replacement or a gall bladder operation to know their options. It’s not secret business, it should be a right.

Information is power – it allows consumers to manage their own health better. That’s why the MyHospitals website is so important.

For the first time, there will be a nationally consistent record of how hospitals are performing.

Now if you are waiting for an operation you will be able to look at one website which will give you the information to be able to ask questions and make decisions about your care.

It will also give the consumer an insight into the performance of their hospital and, if it falls below the standard, allow them to demand better.

This is an example of how we want to make it easier for consumers to navigate their way through the system.

Imagine the patient journey for someone with diabetes, and how many interactions with the health system they have.

How many times are they forced to tell the same story to a GP, a medical specialist, dietician, podiatrist, eye specialist, perhaps a physiotherapist – each time repeating their symptoms and their treatment history?

Perhaps this is even worse than navigating through a bank’s overseas call centre. In comparison, your banking is simple – but even that you can now do online – accessing your records and conducting transactions securely.

We need to step into the world of technology in healthcare as well. That’s why the creation of eHealth records for all Australians who want them will be so groundbreaking.

The benefits of the records are enormous.

Patients won’t have to continuously tell their medical history to every new health professional that they see. Patients won’t have to try and remember when they were sick, when they took which antibiotics or what their last pathology test showed.

With patient permission, each health professional will be able to see the patient’s history allowing for quicker and more accurate diagnosis.

The eHealth record, easier access to services and more information for patients are tangible signs of the health system following the patient, not the other way around.

To continue this change and put consumers where they belong at the centre of the system, we will continue to listen, continue to respond and continue to reform to ensure that our health system delivers not only health services, but health outcomes. We look forward to a reformed health system in which all stakeholders, including consumers, work together to build a health system with consumers at the centre.

The Hon Nicola Roxon MP is the Minister for Health and Ageing. She was first elected to the House of Representatives as the Member for Gellibrand (Victoria) in 1998, and has been Minister for Health and Ageing since 2007, having previously been Shadow Minister for Health.
The importance of the consumer perspective in Senate Committee processes

Senator Rachel Siewert

It may – or may not – surprise many to know that some Senators spend significantly more time in Senate Committees than they do in the Senate itself.

By referring responsibilities for investigation and examination to Senate committees, the Senate is able to undertake detailed examination of legislation and key issues which would otherwise not be possible.

Consumer consultation and participation is one of the most important and rewarding aspects of Senate Committee Inquiries. An Inquiry creates the opportunity for conversation and knowledge sharing with people from all walks of life – each bringing a unique and valuable opinion.

Inquiries and their terms of reference can vary greatly in their scope, ranging from the very broad and comprehensive to the quite specific. All allow organisations and individuals to be consulted and have their representations to Parliament placed on the public record.

I take a very active role in the Committee process, particularly the Senate Community Affairs Committee, as Chair of the References Committee and Deputy Chair of the Legislation Committee. I find the Committee consultation process to be a valuable and fundamentally important part of Parliamentary life.

Consumer engagement is essential in any Inquiry or discussion which deals with issues of health, well-being and community. Such issues cannot necessarily be reduced to facts and figures.

In the discussion of our current health reforms, the Government at times appears to overlook the fact that effective reforms should be built around the needs of consumers. Unfortunately our current arrangements deliver a predominantly provider-based system, not a patient-based one.

A successful Senate Inquiry is one in which engagement occurs in a productive manner with a focus on reaching outcomes through collaboration. Productive stakeholder engagement should then be repaid through thoughtful consideration and accurate reporting of the issues raised by the Committee, who will then put their minds to how best to achieve the desired outcomes in the recommendations of the Committee’s report.

A Senate Committee Inquiry produces a report, which can feature additional or dissenting comments from members or even a minority report. This report is then formally presented to the Senate and debated. Of course, hopefully the ultimate result of a Committee Inquiry would be adoption by Government and others of the recommendations, such as changes to legislation.

Committee reports can allow a Parliamentarian to raise issues of concern where there is not agreement within Government or across parties and they can ultimately choose to move amendments in the Parliament.

I consider that as a Senator, portfolio spokesperson and Committee Chair, I am obliged to take my role within the system seriously and to stand up and be counted when I am concerned that an Inquiry has exposed problems or issues that urgently need to be dealt with.

Under these circumstances it would not be conscionable for me to fail to make critical comments or dissenting remarks or to attempt to move amendments.

I do not believe we should hold an Inquiry simply for the sake of doing so. If the Senate takes on an issue it should be serious about listening to the problems and doing its best to solve them.

The results and impact of some reports are easier to see than others. Some, such as the second inquiry into the Health Legislation Amendment (Midwives and Nurse Practitioners) Bill 2009, create a wave of public discussion, whereas others may make fewer waves but still play an important role in assisting Parliament to effect meaningful changes to legislation.

The National Health and Hospitals Network Bill 2010 was examined by the Community Affairs Legislation Committee, which reported back in November 2010. The findings of the Committee Inquiry led to amendments which significantly strengthened the legislation in a number of areas.

Significantly, this ensured an increased level of engagement with consumers and carers in the development of a better health and hospital system. The ultimate result of better consultation with health consumers is better healthcare and better health outcomes.

The amendments ensure consumers will see better safety and quality in healthcare, and also help to enshrine the role of consumers and carers in the process.

In the same mould as the wider health reform discussion, the current Inquiry into Planning Options and Services for People Ageing with a Disability is...
one which has the capacity to be very important at a time when we urgently need to examine the issues surrounding disability support, social security and positive ageing as a community.

It is crucial that we take a holistic view of these issues so that we can join up the gaps between services and ensure that the needs and interests of consumers, carers and service providers are balanced.

The Inquiry is examining the options and services which exist and what is needed to assist people with a disability and their carers to plan for the future. This includes issues around the inadequate choices and planning options currently available to people ageing with a disability and their carers, together with how we look to ensure the continued quality of life for people with a disability as they (and their carers) age.

I hope the report will create an important opportunity for Parliamentarians and the community alike to develop and discuss policy, legislation and future directions from an informed perspective.

The report and recommendations of an Inquiry are only arrived at following a period of submissions, public hearings and Committee discussion. During this process of the Inquiry, the need for effective consumer engagement is clear, as is the need to create and maintain a respectful and productive environment in which to allow this communication to occur.

While undertaking the Senate Inquiry into Suicide in Australia, we found it imperative to take the utmost care to maintain the trust being placed in us by those people who had chosen to participate.

Due to the nature of many submissions this was a fine balancing act. It was important that we displayed sensitivity and honesty regarding the information being examined, while at the same time coping with our own, and others’, emotional reaction to distressing and challenging subjects and stories. This is a good example of the importance of nurturing the engagement process in order to ensure people are able to participate openly and fully. By doing this well, a Committee Inquiry can create a valuable opportunity for meaningful discussion in what can often be an emotionally charged environment.

I have to say that, while they can get overwhelming at times, I find these kinds of inquiries both rewarding and exhausting.

In late 2009 the Senate referred the Health Legislation Amendment (Midwives and Nurse Practitioners) Bill 2009 and two related Bills, together with the Government’s proposed collaborative arrangements amendments, to the Community Affairs Legislation Committee.

As part of this Inquiry, the Committee was tasked with considering whether the legislation or amendments would have a negative impact on safety and continuity of care for Australian mothers, with the legislation expanding the role of nurse practitioners and midwives to allow them to take a greater role in providing quality healthcare.

As a result, the issue of homebirths was discussed widely during the Inquiry and in the media. The public discussion of the issues it raised has continued to this day. This is a subject around which many submissions raised concerns about a ‘disconnect’ between consumers, care providers and Government.

At times during this Inquiry we received deeply personal and sometimes emotive submissions from people who held strong beliefs and contrasting opinions, many derived from their own experiences.

It served to demonstrate the positive role effective engagement can play, even when tackling a subject regarded by some as controversial, when sensible discussions of the issues have been few and far between.

By creating a safe and respectful environment, the formal processes of an Inquiry give key stakeholders an opportunity to be heard and questioned. A good Committee Chair can ensure the process is frank but fair without being confrontational. The Committee Inquiry can create a forum through which any person, group or organisation can make a meaningful contribution.

Consumer consultation is an integral part of the Senate Inquiry processes. The role of the consumer in effective consultation cannot be replaced.

Put simply, the best outcomes come as a direct result of consultation.

Senator Rachel Siewert is the Australian Greens spokesperson for Health, Mental Health, Ageing and Community Services. A Senator since 2005, Rachel was elected for a second term at the 2010 Federal Election. Rachel is Chair of Senate Community Affairs References Committee and is a member of the Expert Panel on Constitutional Recognition of Indigenous Australians.

The value of consumer participation to the Department of Health and Ageing

Jane Halton PSM

From birth to death, all Australians are health consumers. For that reason we are all direct or indirect clients of the Department of Health and Ageing.

The department’s vision is “better health and active ageing for all Australians”. We develop policies, manage programs and undertake research and regulation to give Australian people better health, better care and a better life.

In fine tuning policies and program implementation, we rely on input from health consumers, who bring a different perspective from other partners in the health system. This is explicitly recognised in our charter which states: “We … engage in open and constructive consultation with professionals, providers, industry and community groups”.

Constructive engagement with consumers, health professionals and interest groups has been an important part of the department’s practice for many years. During my time as head of the department, which is now more than nine years, I have emphasised the importance of seeking and acting on the views of consumers and community groups.

The Consumers Health Forum is one of the key groups to which the department turns for advice and information about consumer experiences. CHF and a number of other health consumer groups receive funding from the department under our Community Sector Support Scheme: in the current financial year, CHF received $380,330 to fund its national secretariat. CHF from time to time also receives funding from program areas under separate contracts to undertake specific tasks.

The health reform process has been a huge part of the department’s work for more than three years. Throughout this process, consumers of health and aged care services have been acknowledges as a key stakeholder group and the department actively encouraged their participation in the national debate on our health system.

All Australians were invited to read the reform proposals and contribute their views through the www.yourHealth.gov.au website. More than 100 face-to-face consultation meetings were held around the nation, including a special consumer-specific consultation co-hosted by the Minister for Health and Ageing, the Hon Nicola Roxon MP, and CHF in October 2009.

Consumers will continue to be consulted as the reforms are implemented, and even more importantly will have an ongoing role in the reformed health system through the new health structures, Medicare Locals and Local Hospital Networks. Local community members including consumers will have their voices heard through new governance bodies for these organisations, giving them a real influence on planning and management of local health services.

To assist consumers in this role, the Government has approved funding of up to $2.95 million for the Our Health, Our Community project. As part of this project CHF will develop and implement training designed to provide consumers with the knowledge and skills that will assist them to participate in community, state and national health policy forums, including new governance arrangements established to support national health reform. The online resources developed by the CHF through the Our Health, Our Community project will be available to the general public and will enable increased engagement with health reform by consumers across Australia.

Aside from health reform, as part of ongoing policy refinement the department holds regular public consultations on both new policy proposals and existing programs. There are usually a number of consultations under way at any one time and these are prominently listed on the department’s website to allow members of the community as well as consumer groups to keep informed.

Currently there are consultations underway on:

- plain packaging of tobacco products;
- a review of existing MBS subsidised medical items under the MBS Quality Framework
- the proposed National Carer Strategy, and
- the direction of aged care reform and ‘front end’ access points for aged care.

The department is also currently implementing reforms to strengthen the Aged Care Complaints Scheme. In February and March 2011, Australians had the opportunity to comment on a proposed new framework for how aged care complaints are managed, through the www.yourHealth.gov.au website. The department received 42 submissions from a range of stakeholders, including consumer representatives and advocacy groups. In addition, the department has held
The value of consumer participation to industry

Brendan Shaw

Consumer participation along the continuum of new medicine development is critical in terms of achieving positive health benefits for all Australians. This common shared interest is central to the process of achieving a sustainable Pharmaceutical Benefits Scheme (PBS), affordability, greater transparency, and access to new medicines. The value of consumer participation to industry and the importance of working together underpin the delivery of these positive health outcomes for consumers, and as such are fundamentally important for the health system to work effectively. Some examples to support this statement are as follows.

Recently, the Federal Government made a decision to block the listing of eight new medicines and vaccines on the Pharmaceutical Benefits Scheme – the 'Cabinet deferral' issue. This severely impacts timely access to medicines, and contributes to greater cost to patients. The decision followed a recommendation

a number of meetings with consumer groups and other stakeholders on the proposed framework and the new consumer information materials. In undertaking these reforms, the department is also working with a sub-committee of the National Aged Care Alliance, which is the representative body of peak aged care provider, consumer, union and health professional groups.

On 16 November 2010, Parliamentary Secretary for Health and Ageing, the Hon Catherine King MP announced a comprehensive review of the way in which the Therapeutic Goods Administration (TGA) communicates its regulatory processes and decisions.¹ The review will focus on improving the TGA's transparency.

The purpose of the project is to improve public knowledge of regulatory decision-making and to enhance public understanding of the benefits and risks of therapeutic goods so that the Australian community can understand how the TGA operates and the reasons for its key decisions.

The review panel is chaired by Professor Dennis Pearce AO and CHF is taking a key role in this review with CEO Carol Bennett as one of the Panel members.

In addition there are numerous standing committees, advisory councils and reference groups that work with the department on specific issues. Most of these permanent committees are set up in accordance with legislation and in nearly all cases they are required by law to include a representative of consumers or community interests.

These committees cover a great variety of issues which arise in the broad health and ageing portfolio, from the Australian Community Pharmacy Authority to the National Blood Authority and the Therapeutic Goods Committee.

There are also a number of governance bodies within the portfolio to which appointments can be made only after consultation with consumer organisations. Examples of this are the Australian Radiation Protection and Nuclear Safety Agency – Radiation Health and Safety Advisory Council and the Gene Technology Ethics and Community Consultative Committee.

The independent statutory authority, Food Standards Australia New Zealand, must have one board member who is a nominee of consumer organisations. The Australian Institute of Health and Welfare board must by law include not one but three people with “knowledge of the needs of consumers”. Each of these three must have a particular area of consumer expertise, one in health services, one in welfare services and one in relation to housing assistance.

Another way in which consumers’ views and experiences of the health system are now being gathered and heard by the department is through a new national survey.

The Council of Australian Governments requires annual reporting on the National Healthcare Agreement performance framework, including patient experiences in health and aged care. To provide this, the department funded the Australian Bureau of Statistics to conduct the first national Patient Experience Survey (PExS) in the second half of 2009. Information was collected from 7,124 households on their health care experiences over the previous 12 months, including waiting times for treatment.

The second PExS began in July last year and will run for 12 months, with a sample size of around 27,000 households. The Bureau is now funded directly to conduct the survey annually.

In all of these ways, consumers and consumer representatives are working day by day and week by week with the Department of Health and Ageing and our portfolio agencies. Each type of input is essential to the department and the Government, to enable us to assess the quality and effectiveness of the health system, and therefore to improve it.

Although we have to be concerned with funding and processes, especially in relation to the system’s sustainability, the only true measure of our health system – and therefore of the department’s work – is the good health and wellbeing of all Australians.

Jane Halton PSM is Secretary of the Department of Health and Ageing.

from the Government’s own clinical and health economics expert committee, the Pharmaceutical Benefits Advisory Committee (PBAC), that the medicines and vaccines should be listed on the PBS. Minister Roxon’s decision to take all future PBAC recommendations to Cabinet, introducing an extra layer of bureaucracy, is extremely alarming because it may translate to delays in patients getting access to medicines they need. As the Chief Executive Officer of the Consumers Health Forum of Australia, Carol Bennett, argued, allowing Federal Cabinet to now be the final arbiter of which drugs should be funded under the Pharmaceutical Benefits Scheme is short sighted and, in the long run, could actually add to the costs for consumers and the public health system as well as preventing access to the best available treatment.1

This is an example of an issue where consumers and industry share significant concerns. Pharmaceutical industry bodies joined with CHF and other health consumer organisations to share these concerns at a Forum on 29 April 2011, attended by the Minister for Health and Ageing, the Hon Nicola Roxon MP.

Clinical trials are another example of where consumer participation is highly valued by industry, and are an essential element in providing early access to innovative medicines for Australians that otherwise would not be available. Sometimes these are life-saving medicines for which there is no alternative treatment, particularly in cancer therapy and for rare diseases. Moreover, the Government estimates that clinical trials save the Pharmaceutical Benefits Scheme over $100 million a year. So the more clinical trials we conduct in Australia, the greater the saving for Australian taxpayers. Unfortunately however, new figures from the Therapeutic Goods Administration (TGA)2 show a third consecutive fall in the annual number of new clinical trials in Australia. In 2010, only 574 trials were started in Australia, which is the lowest number since 2001 and 291 fewer than in 2007. The competition for Research and Development (R&D) investment from countries in Asia and Europe is extremely fierce. Only with the right policy settings can we hope to grow our R&D industry and keep cutting-edge medical science in Australia. This is why the Government must implement the recommendations of the Clinical Trial Action Group report.3 If clinical trials go offshore, Australian patients won’t get early access to innovative medicines.

Consumers also participate in the evaluation processes of both the regulatory agency, the TGA and the reimbursement system, the PBAC. Patient contributions inform the determinations these agencies make, the value placed on individual medicines and the value placed on the clinical impact of these medicines. The industry continues to advocate for greater consumer participation in this important area.

Collaborations are another area of shared interest, and health consumer organisations and pharmaceutical companies have collaborated for many years to address the needs of health consumers. With the number and complexity of these collaborations increasing, Working Together: A Guide to Relationships between Health Consumer Organisations and Pharmaceutical Companies5 was developed in 2005, and reviewed in 2008. The Guide provides best practice principles of working together, with the essential components being honesty, integrity, trust, and respect.

As an indication of the importance industry places on the adherence to the principles in the guidelines, these have been incorporated into the Medicines Australia Code of Conduct6 with which all member companies must comply. The Code of Conduct sets the standards for the ethical marketing and promotion of prescription pharmaceutical products in Australia, and it complements the legislative requirements of both the Therapeutic Goods Regulations and the Therapeutic Goods Act.

The National Medicines Policy7 illustrates the fact that consumers and industry stand shoulder to shoulder on some major policy issues. The central objectives of this policy underpin the primary imperative of all stakeholder groups within the sector:

• timely access to the medicines that Australians need, at a cost individuals and the community can afford;
• medicines meeting appropriate standards of quality, safety and efficacy;
• quality use of medicines; and
• maintaining a responsible and viable medicines industry.

The Government mandate of Health Reforms will achieve far better outcomes when consumers are involved in health policy and program decision making. There is an opportunity to take this forward at the Third Joint Medicines Policy Conference being held.


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in Canberra at the Hotel Realm on 30-31 August 2011. Further details on this conference are available via the Medicines Australia website.\(^7\)

Greater dialogue and cooperation between health consumers and the industry can only be beneficial to both. Industry better appreciating consumer needs and consumers better understanding how industry works can only benefit industry, government, the health system and, ultimately, consumers.

For more information about Medicines Australia visit: www.medicinesaustralia.com.au


Dr Brendan Shaw has been CEO of Medicines Australia since January 2010.

Providing a global voice for patients

Joanna Groves

Patients’ organisations provide vital support and information to patients, families and carers on an individual level around the world. This role is evolving to include an increasing focus on advocacy, bringing a valuable perspective and knowledge to health policy debates. However, among the many other stakeholder groups – such as the health care professions, academia and industry – patients’ views are not always considered in policy-making, in particular at the global level.

The International Alliance of Patients’ Organizations (IAPO) is a global alliance of over 200 organisations representing patients of all nationalities across all disease areas and promoting patient-centred healthcare around the world. Our full members are patients’ organisations who work at the international, regional, national and local levels to represent and support patients, their families and carers. IAPO promotes the patients’ perspective in global healthcare policy arenas and helps to build the capacity of patients’ organisations to be effective advocates, whether they work at the local, national, regional or international level.

Why have an international cross disease group?

During the mid-1990s, patient representatives from around the world met and found that patients in all disease areas and countries frequently face the same issues. Access to safe and quality treatment and information, the right to participate in health and healthcare decisions at the individual patient level and patient involvement in policy making are universally relevant to patients.

We are now in a period of globalisation where health decisions are being made at all levels and healthcare issues are increasingly crossing national and regional borders. Public health issues are global; for example, infectious diseases affect people across boundaries. Healthcare policies such as clinical practice guidelines are debated internationally and progress in science, medicine and technology can generate ethical issues, new treatment choices, and funding and regulation questions, all of which affect national policies.

Other healthcare stakeholders, from health professionals to health research organisations, are organised and influential internationally, and therefore it is important that there is a global voice representing patients.

A patient-centred approach is essential because health systems in all world regions are under pressure and cannot cope if they continue to focus on diseases rather than patients. They require the involvement of individual patients who adhere to their treatments, make behavioural changes and self-manage. There is growing evidence that a patient-centred approach leads to greater patient responsibility and optimal self-management, which in turn leads to improved health outcomes, quality of care and patient satisfaction.

What is patient-centred healthcare?

Patient-centred healthcare is a concept that, while it is now common terminology, is not always well understood. It is part of a shift in focus that has been occurring over time. Historically the disease and how to ‘treat’ it has been the focus in healthcare.
The traditional biomedical management model involved ‘paternalistic’ treatment in which the health professional decided the appropriate course of treatment, often without any significant patient involvement in the decision. This situation has been changing as, over the years, people have become more interested in their health and taking more responsibility for their personal healthcare.

The significance of patient-centred healthcare is that it moves the healthcare focus from the disease to the patient. This should not detract from equality in the patient-health professional relationship, but helps to recognise that a person’s quality of life does not depend solely on their disease but also encompasses how the disease impacts on their participation in society and their physical and mental wellbeing. Only the individual can judge how a treatment affects them, and this information can make an important contribution to decisions about what the aims of the treatment should be and what a successful outcome would be for their personal situation.

IAPO launched a Declaration on Patient-Centred Healthcare1 which is the first globally accepted definition of patient-centred healthcare developed by, and representing, the global patients’ movement. It identifies five principles necessary for patient-centred healthcare:

- Respect;
- Choice and Empowerment;
- Patient Involvement in Health Policy;
- Access and Support; and
- Information.

A key principle of patient-centred healthcare is patient involvement. It is increasingly recognised that the long-term users and beneficiaries of healthcare – the patients themselves – and the organisations that can effectively represent them – the patients’ organisations – should be involved in health policy. Healthcare decisions, at whatever level they are made, will ultimately affect patients’ lives and, therefore, patients and patient representatives have a right to play a meaningful role in developing health care policies. In addition, they can help to ensure that policies that address patients’ needs and preferences are developed.

The World Health Organization (WHO) stated its commitment to the involvement of people in their own healthcare at an individual and community level in the design and delivery of healthcare systems 30 years ago in the Alma Ata Declaration, which states that, “The people have the right and duty to participate individually and collectively in the planning and implementation of their healthcare”.2

IAPO represents the patient voice in a number of WHO programs and has official relations with WHO. One example of patient involvement at an international level is in the area of patient safety. IAPO is on the Steering Group of Patients for Patient Safety (PFPS), part of the WHO Patient Safety Programme, which promotes a patient-centred approach to patient safety.

Since 2004 PFPS has been:

- Creating networks and providing training through regional and in country workshops for patient advocates and long term support such as the provision of toolkits and other support activities. Over 170 patient advocates have participated in training and many advocates work on a national level in partnership with the healthcare system towards improving patient safety.
- Ensuring the involvement of skilled patient advocates at a global level in WHO patient safety work such as research for patient safety, developing patient safety solutions and the global challenge on clean care.

While we continue to advocate for patient-centred healthcare, we also now want to measure and evaluate what progress has been made in patient-centred healthcare on a global basis. With a theme of Achieving Patient-Centred Healthcare: Indicators for Progress and Success, the Fifth Global Patients Congress3 to be held in London, United Kingdom on 17-19 March 2012 will focus on these issues and be an opportunity for around 200 patients, patient representatives, health professionals, policy-makers and others to share evidence of patient-centred healthcare in policies and practice, to assess success so far and to develop strategies to promote patient-centred healthcare more widely.

There are many different starting points for patient-centred healthcare and patient involvement depending on national wealth, culture and attitudes. What is important is that throughout the world, people understand about patient-centred healthcare, and patients and patients’ organisations work in partnership with healthcare professionals, providers and policy-makers, helping to shape their health systems for the future.

Joanna Groves is Chief Executive Officer of IAPO. Joanna joined IAPO in March 2004 as Policy and External Affairs Director and was promoted to IAPO CEO in March 2007. With a science policy background and a particular interest in how health policy is formulated, she supports a stronger role for patient consultation and social and ethical considerations in health policy making.

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1 Available online at: www.patientsorganizations.org/declaration
2 Available online at: http://www.who.int/hpr/NPH/docs/declaration_almaata.pdf
3 Further information available online at: www.globalpatientscongress.org
From consumer to consumer representative

Karen Carey

Being a consumer representative requires a combination of passion and a really thick skin – sometimes the greater the passion, the thicker the skin has to be. My passion comes from knowing that, with the right support, a single person can bring about meaningful change in the healthcare system. The thick skin comes from several years of being the most disliked person at the table and despite the head shaking, raised voices and rolled eyes of other stakeholders, taking up precious meeting time repeating the same things over and over and over and over and over (you get the idea).

In saying the same thing so often I have formed my own set of key principles, although they change all the time:

* Healthcare is a complex environment, and despite everyone’s best efforts there is always risk – but it can be minimised, fewer people injured, lives saved and the severity of injuries reduced if the right people take the right action.
* No one should be denied access to appropriate healthcare based on cost.
* New is not always better, even though it usually costs more.
* If an activity isn’t going to improve health outcomes, don’t do it.
* It is the right of the individual consumer to choose whether the benefits of a treatment outweigh the risks according to their own circumstances and values.
* The greater the evidence gap about whether a specific treatment is safe and effective, the more important it is that the consumer knows about the uncertainty.

There is a common misconception that the passion that fires a consumer representative starts with an injury caused by an adverse event, and that the emotion that drives us is closer to revenge than goodwill. My passion started, not with failed heart surgery, but when I realised that there was nothing unique about what happened to me, which meant that it would continue happening to others if I did nothing – a bit like not reporting a rape, and knowing that the rapist will remain out there, with the risk he will harm someone else. Once I understood that many other people were at risk, not taking action was not an option.

In my case, had anyone in authority, from the doctors, to the hospital, to the manufacturer, to the Therapeutic Goods Administration (TGA), given me a sensible explanation for what happened and what they were going to do to stop it happening again, I wouldn’t have needed to act myself. While an injured patient’s experience can bring an important sense of reality and urgency to an investigation, in lots of ways it is entirely inappropriate for the injured patient to be the one who has to not only overcome their injuries, but also engage a massive, opaque and reluctant healthcare system to fight for change.

In the decade that I have been a consumer representative I have had periods when the passion is simply not enough, and at times like those it is essential to be part of a network of peers, being able to share stories from the coal face and continually dipping into the pool of real-life stories of hardship caused by under-performance of the healthcare system. Health Consumers’ Council of WA and the Consumers Health Forum of Australia have provided me with a solid base from which to advocate, ensuring that my activities are truly ‘representative’ rather than personal. I continue to be impressed that consumers have a seat at almost every decision-making committee working on policy nationally and in many states, a situation that has only been achieved through the hard work of champions involved in these organisations.

There are a few things about my own experience that I revisit in my mind whenever my thick skin wears too thin, reminding me of why it is worthwhile. One is the admission of the heart surgeon that, despite my being a competent adult, he didn’t tell me about the risks of heart surgery because he thought it would “upset me”. Only a doctor can believe he is a hero with the right support, a single person can bring about meaningful change in the healthcare system. The thick skin comes from several years of being the most disliked person at the table and despite the head shaking, raised voices and rolled eyes of other stakeholders, taking up precious meeting time repeating the same things over and over and over and over and over (you get the idea).

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Two perspectives on consumer representation: the experience of the Australian Pharmaceutical Advisory Council

A Consumer Perspective

Janne Graham AM

When I was elected Chair of the Consumers Health Forum of Australia (CHF) in 1991, the Federal Government was addressing many of the recommendations in CHF’s publication Towards a National Medicines Policy through the office of the Hon Peter Staples MP, Minister for Aged, Family and Health Services.

An immediate outcome was a response to our recommendation for a roundtable of stakeholders to discuss and advise government on medicine safety, access, quality use and industry viability: the Australian Pharmaceutical Advisory Council (APAC) was launched. CHF was one of several consumer and community groups invited to nominate representatives so that, in addition to general health consumer interests, the specific concerns of Indigenous, aged, multicultural and veteran communities, as well as welfare service agencies, had a voice alongside those from industry, health professions, academia and Government, about 35 in all. Professor Lloyd Sansom, a pharmacist, was appointed as Chair. Dr John Aloizos was Chair between 2001 and 2008.

I had previously been on a standing committee of the National Health and Medical Research Council in the early days of CHF and had been a lone and lonely voice making the first claims many health providers had ever heard that consumers should be represented in the development of health policy and the direction of health practices. As CHF representative on APAC, although my voice was too often heard, it was exciting to know that other community representatives, though often speaking for a specific interest group, were essentially telling of the same experiences, making the same arguments, sharing the same concerns and articulating the same values.

At the first meeting of APAC, Minister Staples emphasised the centrality of the consumer in the development of health policy and highlighted the concept of “quality use of medicines” as a central concern for consumers. I was already on the offensive. I emphasised that we had as much interest in health financing as it affected both equitable access and provision of resources, and in regulatory processes which could secure safety of product and appropriateness of information. It was several years before we tried to come to grips with health financing issues and by then APAC was no longer central to Government’s policy thinking. Nevertheless, I thought it was important to define our territory and not allow us to be confined.

Early meetings involved strong position statements from all the disparate interests, but with a Chair who consistently said, “Don’t tell me the problem; offer me a solution,” we slowly came to work as a somewhat cohesive group, learning from each other about what the barriers to change were perceived to be and together finding ways around or through. Initially a committed secretariat from the then Department of Health, Housing and Community Services was available and this helped move the work of the Council and its working groups.

There were significant and successful outcomes driven by other community representatives such as the development of a mechanism for delivering medicines in remote Aboriginal communities arising from powerful advocacy by the late Puggy Hunter and the tenacity of the Chair.

I will mention two areas in which I was, with CHF, directly involved. Information flow, information reliability and communication about medicines was a continuing area of discussion and debate. The Pharmaceutical Health and Rational Use of Medicines Committee (PHARM), a sister group to APAC, had a focus on promoting and applying research and took the major running on many aspects of the quality use of medicines, including education, while APAC carried on (excuse the pun) with the policy debate. Following a workshop at which each sector had committed to the development of electronically available product information designed for consumer use, later to be called Consumer Medicine Information (CMI), APAC worked on the development of policy and guidelines to give force to this. The history of CMI has been documented elsewhere and evaluations have been salutary.

However, in trying to deliver reliable information to consumers, all APAC members learned a great deal about the regulatory process in negotiating the “approved information”, technical issues about effective written communication and many, many lessons about the responsibilities of all the people in the medicine chain. Every block along its way exposed new issues in the medicine arena and many problematic practices changed along the way.
A Chair’s Perspective

John Aloizos AM

The Australian Pharmaceutical Advisory Council (APAC) was formed in 1991. APAC represented an opportunity for all interested parties to contribute positively on a multi-lateral and consensus basis to the development and conduct of the National Medicines Policy (NMP). The NMP is a well-established endorsed framework based on partnerships launched in December 1990. It aims to improve positive health outcomes for all Australians through their access to, and wise use of, medicines through four central objectives based on active and respectful partnerships, taking into account elements of social and economic policy:

- Timely access to the medicines that Australians need, at a cost individuals and the community can afford;
- Medicines meeting appropriate standards of quality, safety and efficacy;
- Quality use of medicines; and
- Maintaining a responsible and viable medicines industry.

Through APAC, Governments – Commonwealth, State and Territory – health educators, health practitioners, and other healthcare providers and suppliers, healthcare consumers, the medicines industry, and the media worked together to promote the objectives of the policy from 1991 to 2008. In June 2008, following a review of the operational arrangements of the NMP advisory structure, the Minister for Health and Ageing approved the introduction of new arrangements to support the future implementation of the NMP under the same NMP principles and partnerships.

On reflection, I now believe that the partnership worked within APAC because consumer/community representatives comprised about one quarter of the membership, thus off-setting the power imbalance then apparent in the health service culture. To the extent that the Council’s deliberations achieved positive change for consumers, it also depended on the drive of the Chair, his strong advocacy for its policies and support of the consumer voice.

A colleague once told me that “medicine was not so much a product as a process”. Through APAC I learned more than I thought I ever wanted to know about these products and the processes. A benefit in being a consumer rep is the opportunity to offer this information to others. CHF and my local consumer organisations provide opportunities for me to continue to do that. I hope others in the professions, industry, academia and Government learned something of the consumer perspective as well.

Janne is a Life Member of CHF. She was CHF representative on APAC from its inception in 1991 till her retirement from it in 2003 after a period as its Vice-Chair. This year she was appointed by the Health Minister to the Advisory Committee on Prescription Medicines (ACPM), “proving”, she says, “that she can’t stay away from drugs”.

Consumers complained that sometimes they received the wrong product or the wrong strength of a prescription medicine. Professional groups blamed each other. Industry watched the debate. Over time, it became clear that pharmacists often confused products because companies favoured packaging which maintained a consistent logo and colour scheme where brand had prominence over product strength. Industry became engaged in the debate. APAC developed policy advice that industry should clearly distinguish products and strength in packaging. APAC forwarded this advice to the regulator (the Therapeutic Goods Administration). CHF and the Pharmaceutical Society of Victoria held discussions with the industry body and various companies to encourage improved packaging in the interests of safety. Many companies made changes.

In these cases, as in others, I found it was a great strength being closely engaged with the policy consultations and development within CHF and being able to be involved in some of CHF’s lobbying to follow through on the APAC activities. Before and since, I have been a consumer representative on other national and local committees where this hasn’t been as relevant or affected my capacity to be an effective representative.

As a consumer on APAC I felt at first that we consumers were the bones the dogs were fighting over. Other stakeholders wanted to take the high moral ground and claim that they were acting in the interests of consumers. It became increasingly difficult for them to hold to this when the various consumer and community representatives were there to make their own statements about our interests. It was not always pretty. There were some tough debates and many frustrations along the way.

Over the life of the Council, however, I believe we built a healthy respect for each other and each other’s own challenges within their own networks. When sector representatives communicated through their respective networks, other members of stakeholder groups came to understand their roles in the complex medicine process. Partly because of the connections made and understanding developed, direct interaction between groups was occurring; professional and industry invited consumers to participate in their conferences; and organisations were asking consumers informally for advice on consumer oriented practices. While we agreed to differ on some issues, we also formed friendships across the various divides.

By the time APAC belatedly produced a National Medicines Policy publication (2001), we all understood the strength of a partnership approach to policy. 

John Aloizos AM
Building consumer capacity: the Our Health, Our Community Project

Kate Moore

I was privileged to serve as Chair of APAC (2001-2008) and to have had the opportunity to work with many extraordinary, committed and visionary people. For me, working with all the members of APAC and in the true spirit of partnership across NMP was a heartfelt experience and our journey and achievements together over those seven years is a testimony to the strong support from the individual members and their organisations’ engagement and commitment to our NMP. The key reason for our success, across a wide spectrum of the four pillars of NMP, rested on the principle that all partners need to enact their part of progressing the NMP in a manner which is both cognisant and respectful of the interrelationships and expertise of other partners. Central to achieving our successful outcomes over my term as Chair were the contribution and commitment of the healthcare consumers and the Consumers Health Forum of Australia (CHF) in particular.

Given the extensive use of medicines (prescription medicines and non-prescription medicines, including complementary healthcare products) to achieve quality and safe healthcare outcomes in all aspects of healthcare and in all healthcare settings, it is imperative that there is healthcare consumer engagement and participation in all aspects of NMP. The contributions and carriage of work to represent the consumer perspective on the various APAC committees and working parties by the CHF as well as the work of other healthcare consumer members of APAC to address the challenges and advance the NMP agenda were an essential contribution and critical to APAC’s outputs, outcomes and achievements. This all important role will continue to be essential across the new NMP advisory structure.

I was fortunate to work with Ms Janne Graham AM, in her role as Deputy Chair of APAC in my first term (2001- 2004). Working with Janne and the benefit of her vast experience in healthcare and the NMP, as well as her consumer healthcare networks, highlights the benefit and recognition of the consumer partnership and participation which set the scene for my term as Chair of APAC.

There were many outputs and outcomes during my term and I know that they would not have been finalised and achieved without the balanced contribution of the members and the partnership approach. In each case, the value, importance and relevance of the healthcare consumer contribution has been essential. For example, during my term as Chair of APAC, I feel that the following outputs and their role in the ongoing NMP agenda could never have been achieved without the healthcare consumer contribution:

- Guiding Principles to Achieve Continuity in Medication Management
- Guiding Principles for Medication Management in the Community
- Consumer Medicine Information
- Future of the Pharmaceutical Benefits Scheme
- Complementary Medicines
- Brand Substitution
- Medication Safety

History will ultimately judge APAC’s role in serving to advance Australia’s NMP and its contribution to our healthcare system. I believe that NMP and the APAC experiment with implementing the partnership approach in the healthcare debate have clearly demonstrated the value and benefit of the healthcare consumer contribution.

Dr John Aloizos AM is a graduate of the University of Queensland and has worked as a general practitioner at Upper Mt Gravatt, Brisbane since 1977. He was the Chair of APAC between 2001 and 2008.

for consumer engagement at a state and local level.

Gradually it came to be seen that consumers were an invaluable resource for committees. We brought a different perspective, one that was not influenced by self-interest, but that came from the lived experience of people whose primary experience was that of those who used the services.

Now, in 2011, the scene looks very different. There is a wide recognition that having consumers at the table leads to a better health system. The fortress is rapidly crumbling, and the major players within the health system recognise that consumers should be at the table, or indeed anywhere where health policy and services are discussed. Some services are starting to genuinely focus on their consumers; some information about a range of products (including prescription medicines), treatments and services is provided; and doctors and other providers are becoming better at communicating with their patients.

Importantly, consumers are now recognised as strategic partners in the current national reforms. As the Commonwealth Government now moves to ensure greater local governance of health services, so the consumer movement needs to focus its efforts on ensuring that more and more consumers can be involved at the different levels – and that policy makers and service providers hear more and more of our voices. We know that there are a whole range of techniques through which consumers can be engaged – ranging from community meetings to consumer reps at the table, and even citizen juries. Over the past 20 years I have sat in on many forums where consumers and community members willingly give up their time to talk about their experiences of healthcare, and how they think it could be improved. Those forums vary – from simple community meetings to citizen juries. The participants may not want to participate in a committee, but they always welcome the opportunity to help to improve the health system. An important job for our consumer representatives on committees is to now open even more doors for consumers to be involved in the reforms – in whatever way suits them.

The dialogue that is needed has many facets. It needs to happen both between consumers and policy makers and service providers, and between the consumers themselves. Consumers’ contributions are greatly enriched when they are able to connect with others, and to share and learn from the experiences of a range of people.

Fostering this connectivity is a challenge for the consumer movement. It is the focus of a new project for CHF – the Our Health, Our Community Project. Through this project CHF will provide training and support for a national network of 120 consumers who could contribute at the governance level of Local Hospital Networks and Medicare Locals – the bodies which will be responsible for the delivery of acute and primary health services. They may also contribute to other health advisory structures.

It is essential that consumer members who contribute a consumer perspective to high level decision making are in touch with consumer experience. A key element of the CHF work in supporting a national network of health consumer representatives is the development of an interactive online resource that will connect consumers, consumer networks and consumer representatives – www.ourhealth.org.au. www.ourhealth.org.au (supplemented with telephone support) will help consumers to engage with health reform by providing information that helps them better navigate the health system.

This leads to the primary purpose of www.ourhealth.org.au: to support consumer advocacy by providing consumers with the opportunity to share their healthcare experiences in a supportive, consumer friendly environment. Those collective experiences will be an invaluable resource for all consumers who want to contribute to the reform process. Consumer/community members on the governing bodies of Local Hospital Networks and Medicare Locals will be appointed through different methods and different criteria, determined by state governments or local organisations. However, they will have access to national networks and support through CHF training workshops, online training modules and www.ourhealth.org.au.

CHF is consulting with consumers and stakeholders to determine the training and support needs, and to build on the resources already available through other health consumer organisations. Some Medicare Locals are currently being formed and CHF has been quick to seize the opportunity to provide advice to these emerging bodies. It has developed an advisory document about good practice in consumer engagement, and poses a range of questions which the organisations should think about in undertaking consumer engagement.

This is an important project for CHF and for the whole consumer movement. It works towards ensuring that
consumer participation is entrenched and supported as an integral part of the structure of the health system, so that we can build a system that is truly focussed on providing the sorts of services that consumers need. Twenty years after I first started working for CHF, I have seen many positive changes. We in the consumer movement have built considerable recognition and respect among governments and service providers. We have a stronger organisational base at federal and state level and a broader network of consumer and health groups. While this growth brings its own challenges, it positions us well to make the most of the opportunities to connect and extend our networks, deepen our learning, and develop a more locally responsive health system.

Kate Moore is an experienced consumer representative, and was the first Executive Director of the Consumers Health Forum of Australia. She is Chair of the Reference Group for the Our Health, Our Community Project.


Partnerships with patients

Karen Luxford

In this age of changing healthcare expectations, how do you ensure that patients are recognised as integral “care team members”? As valued partners in the drive to improve the quality and safety of health care delivery? In health, we have focused on the need to improve our clinical systems and processes. We have rightly focussed on risk management, incident reporting, process redesign and quality assurance. However, one of the key tenets of quality improvement is also to have a “client focus”.¹

Many healthcare services are grappling with how to ensure not only that the consumer voice is heard, but then how to be actively responsive at the level of individual care as well as at the organisation level. For the healthcare organisations who have succeeded, there are benefits for patients through improved care experience, improved clinical outcomes (eg reduced mortality, lower surgical complications, reduced readmission rates) and benefits for the organisation through improved staff satisfaction and business metrics (eg decreased length of stay and medicolegal litigation).² After spending time in the USA in 2008-2009 with a range of such healthcare facilities, I became enthused by the degree of patient and family engagement that I had witnessed there. How could such partnership work in Australia particularly in driving safety and quality forward? The Clinical Excellence Commission (CEC) in NSW has recognised the value of such partnerships by establishing a new Directorate of Patient Based Care and a new program entitled “Partnering With Patients.” The CEC has a key role in building capacity for quality and safety improvement in NSW health services and acknowledges patients, family and carers as integral to building this capacity. With patient-based care, the CEC is emphasising that safe, quality care for every patient is everyone’s responsibility and not just the purview of caregivers in closest physical contact with the patient.

Through the Partnering With Patients program, the CEC is working with health care services to foster the inclusion of patients and family as care team members to promote safety and quality. Recognising patients as partners in quality and safety is not about transferring responsibility to the patient. Delivery of safe quality care remains firmly the responsibility of the health care service. Rather, a true partnership is about recognising the value of what each party “brings to the table”, recognising knowledge that is unique to each party. To foster true consumer engagement within organisations takes the strong commitment of governance and clinical staff. Encouragement of patients by clinicians is crucial to engaging patients in improved care. For example, patient willingness to ask challenging questions is increased when patients are encouraged by doctors and nurses.³

The CEC Partnering With Patients program is developing several streams to promote engaging patients, families and carers including:

- patient and family activated escalation and rapid response to assist deteriorating patients
- engaging patients and family in bedside handover
- engaging patients and family in medication management to avoid errors during care
- “ranging” on patients by patient representatives/patient friends to provide real time feedback to management about concerns whilst still in care
- promoting patient-based values and associated communication skills to doctors and nurses, particularly


Consumers driving health research

Kathleen M Griffiths

In the mid-1990s I was involved in writing Australia’s National Health and Medical Research Council’s (NHMRC) guide for developing clinical practice guidelines. An underlying principle of this framework was that consumers should be active participants in the guideline development process. Unimpressed, a senior academic commented wryly that he was glad that the pilot rather than the passengers had flown the plane to the meeting to discuss the guidelines. There is little doubt that some academics hold similar views about consumer participation in research. They consider that only they are licensed to fly the research plane. But what if the academic pilot is not on the plane as a passenger but is piloting it from a distant city where the climate and the circumstances have no relevance to the prevailing conditions in the air? What if it is the pilot rather than the passengers who decide the destination of the plane? Perhaps, for example, the pilot decides to set navigation settings of the research plane to the city of “Find a way to zap-the-symptoms at any cost” when the passengers wish to travel by a variety of means and routes which best suit them to the city of “Recovery” where they can find mutual support and the best means of living with their condition.

In recognition of the need to increase the relevance, quality and impact of health research, some governments and organisations have created policies intended to facilitate active consumer participation in the research process. In Australia, in 2002, the NHMRC in collaboration with CHF endorsed a Statement on Consumer and Community Participation in Health and Medical Research.1 In the UK, it is a statutory requirement that government funded research must

4 Robert Wood Johnson Foundation, USA
involve consumers as active participants. In addition, the UK government has funded “Involv”2, an organisation designed to promote and support this participation. But what does consumer involvement mean? First, it is not about the passive participation of consumers as research “subjects”. Active participation in research is a process whereby the consumer is involved in one, several or all of the research processes, including setting research priorities and questions, designing the research and the associated protocols, collecting, analysing and interpreting the data, writing up and disseminating the research findings. In practice, the nature and degree of participation of consumers in health research varies. At one end of the consumer participation spectrum, consumers participate primarily in a consultative role or as a member of the research project advisory panel; at the other consumers lead the research. In the past, discussions about consumer involvement in health research have been premised on the concept of a dichotomy between “lay consumer” and “academic researcher”. However, academic researchers may also be consumers, just as the pilot on the plane is also a passenger. The academic consumer researcher may not understand entirely the experience of other consumers, just as the pilot on a plane cannot perfectly the experiences of their passengers. However, if the plane loses an engine or encounters turbulence, the pilot’s priorities for action are likely to be similar to those of his or her passengers. It was with these concepts in mind that we established the “Depression and Anxiety Consumer Research Unit”, or CRU for short, at the Centre for Mental Health Research in 2002. The unique concept underpinning CRU is that it is led and staffed by researchers with both formal academic qualifications in mental health research and lived experience of depression or an anxiety disorder. CRU’s aims are:

- to conduct high quality consumer-oriented research that focuses on depression and anxiety from a consumer perspective;
- to provide post-graduate training in consumer-oriented research to qualified consumers;
- to influence mental health research priorities and practice;
- to ensure that the Unit’s research findings are accessible to consumers as well as researchers, health professionals and policy makers;
- to facilitate active participation in research by lay consumers;
- to contribute to mental health policy; and
- to reduce the stigma associated with depression and anxiety disorders by breaking down the distinction between consumer and researcher.

CRU has made significant contributions to research, policy and practice. Among its research contributions, CRU’s staff and students have identified consumer priorities for research in depression and demonstrated the disparity between these priorities and the current Australian research effort. We have investigated and validated consumer tools for assessing the quality of depression information websites. We recently undertook the first randomised controlled trial of the effectiveness of an online mutual depression support group, with positive results. Stigma is known to be one of the primary concerns of consumers with depression. However, at the time CRU was established, there were no specific, validated measures of depression stigma. Without such measures it was not possible to measure the prevalence of depression stigma, explore its risk factors or consequences or most importantly investigate methods for reducing it. So we developed and validated a number of depression measures (now used around the world and translated into many languages). We have conducted, in conjunction with other researchers, a national survey of stigma, explored the association between stigma and help seeking and demonstrated the effectiveness of an intervention for reducing stigma. CRU has also undertaken a number of other studies such as the What Works 4 Us survey to document consumer reports of the effectiveness and side effects of interventions for depression, as well as qualitative and quantitative studies of consumer information needs.

But there have been many challenges along the way. When CRU was first established, my non-consumer colleagues at the Centre were mortified when a member of the Centre’s advisory panel and a representative of the NHMRC suggested that as a consumer I must necessarily lack objectivity and should therefore be supervised by the CEO of a peak mental health body, who had considerably less research experience than I. An HR manager, unfamiliar with the relevant legislation, informed me that it was discriminatory to advertise for a consumer research assistant (and in response to the argument that lived experience was one form of expertise, responded that you wouldn’t employ a thief as an auditor!). The legislation does of course make provision for employing a person with a disability and, with respect to concerns about lack of objectivity, no researcher is entirely objective. Health professionals frequently evaluate the efficacy of the treatments they provide and from which they benefit financially, and researchers routinely formulate hypotheses about the anticipated outcomes of their research studies prior to undertaking them, a scientific practice which could compromise research objectivity. Another challenge in leading CRU has been the reluctance of academic mental health consumer researchers to formally join the unit due to the community and structural stigma associated with depression and anxiety.

However, without doubt the major challenge is the lack of financial support available for consumer research. The CRU plane is off the ground; the challenge is to find the aerodynamic lift (funding) to keep it there. Academic staff at the Centre for Mental Health Research are necessarily almost entirely supported by competitively obtained external grants or fellowships. Unfortunately, conservative grant bodies do not understand the value of consumer-oriented health research. Although I am fortunate to have secured a personal NMHRC fellowship, such funding is highly competitive and based on a track record of achievement that may not be easily achieved by someone experiencing repeated episodes of a chronic illness. I have argued, albeit unsuccessfully so far, that the NHMRC
should introduce a special Academic Health Consumer Research Fellowship scheme. This would encourage consumer participation in research just as the NHMRC’s special targeted practitioner fellowship schemes enable clinicians to participate in research. The funding and support gap is even more serious with respect to supporting “lay” consumer participation in health research. In 2008, an Involving People in Research Symposium endorsed a communiqué requesting that the NHMRC establish a unit to support consumer participation in health research. The NHMRC CEO responded that it was outside the legislative brief of the NHMRC. Consumers might be forgiven for questioning the value of organisations such as the NHMRC endorsing policies that are so divorced from the realities of funding and accountability mechanisms that they cannot be implemented. In my view, Australia needs a Consumer Health Research Centre charged with supporting and funding consumer involvement in health research, perhaps established with a Department of Health and Ageing grant. What is less clear is how we can convince the Commonwealth Government, policy makers and other funders of the importance of creating such an organisation. Would the Consumers Health Forum of Australia care to step into the cockpit?

2 More information is at http://www.involve.org.uk/

Consumer and community participation in health research

Anne McKenzie

Consumer and community participation in research is the term used to describe the active involvement of health consumers and community members as members of research teams, management committees or advisory groups. Many people describe this participation as undertaking research with or by consumers and community members, rather than to or about them. Creating opportunities for consumers and community members to have a ‘voice’ at all levels and in all stages of health research has been the driving force behind the consumer and community engagement program at the University of Western Australia’s School of Population Health (the School) and then the Telethon Institute for Child Health Research (the Institute).

This engagement program, which began at the School in 1998, was aligned to the recommendations made by health consumers to the National Health and Medical Research Strategic Review (the Wills Review) that consumers should be able to participate in decisions about prioritising health-related research; that those who take part in that research are informed of the outcomes; and that researchers involve the community in decision making relating to research. In 2002 a joint consumer and community engagement program between the School and the Institute commenced. This joint program was underpinned by the principles outlined in the National Health and Medical Research Council (NHMRC) and the Consumers Health Forum of Australia (CHF) joint Statement on Consumer and Community Participation in Health and Medical Research (2002)

Model Framework for Consumer and Community Participation in Health and Medical Research (2004). Having a long-term strategic plan to manage organisational and cultural change that is inclusive of both staff and community aspirations and values has resulted in a strong, sustained engagement program that is consistent with, and to a great extent exceeds, the recommendations outlined in the NHMRC and CHF Statement and Framework.

The engagement program at the School and the Institute has included the following components:

• Senior level support and commitment:
  • A dedicated Consumer Advocate on staff;
  • Development of a formal governance and policy framework for participation, including the establishment of Consumer and Community Advisory Councils at both institutions;
  • Budgeted participation activities/roles in research grant applications;
  • Development of a range of models for consumer and community participation in individual research projects;
  • Creation of training workshops relevant to participation for researchers and consumer representatives;
  • Development of resources for researchers, consumers and community members on implementing consumer and community participation; and

Professor Kathy Griffiths is the Founding Director of the Depression and Anxiety Consumer Research Unit at the Centre for Mental Health Research at the Australian National University. She is also co-Director of ehub: emental health research development and Deputy Director of the Centre for Mental Health Research. She has lived experience of depression.
• Forums that bring researchers, other professions and consumers and community members together to make decisions about research priorities, methodologies, results and dissemination to the community.

Program Activities
The activities of the engagement program have arisen from a variety of events, forums, workshops, presentations, representation at meetings, training sessions and delegations. Attendees at these diverse events and activities have included researchers, students, consumers, community members and staff from government agencies and non-government organisations.

The Health Consumers’ Council of WA has had an integral role in providing advice, mentoring and support for many of these activities.

Since 2004, over 500 consumers and community members have attended events to provide input into priorities for current and future research as evidenced in the graphs below. The steady increase of consumers and community members in attending participation events (Graph 1) as well as the increased formal involvement in research-related committees (Graph 2) demonstrates the immense benefits of this program to both the organisation and the wider community.

Key achievements
Highlights of the consumer and community engagement program to date include:

• Establishing Consumer and Community Advisory Councils at both organisations. The Councils, which include consumers, community members and senior research staff, work together to develop strategies to increase participation at an organisational level.

• Collaborating with a leading UK Consumer Advocate, Ms Bec Hanley, to publish a resource manual for researchers.3

• Initiating and hosting the inaugural national Involving People in Research Symposium in 2008. This event was jointly sponsored by the NHMRC, the Health Consumers’ Council WA and four Western Australian universities. The Symposium was attended by over 240 researchers, consumer and community members from across Australia, New Zealand and the United Kingdom.

• The unexpected additional benefits from consumer and community involvement in individual research projects such as a consumer panel highlighting major safety and quality issues relating to non-specific dosing instructions on prescription medicines. This has led to ongoing advocacy with relevant government agencies for changes in national policy to address this unsafe practice.

• Further collaboration with UK Advocate Bec Hanley to develop training workshops for researchers on the ‘how and why’ of implementing consumer and community participation in research.

• Developing a Fact Sheet Series on Consumer and Community Participation in Health Research in direct response to requests from researchers for simple, easy to access web resources.4

The consumer and community engagement program at the School and the Institute has so far shown a steady up-take from both researchers and consumers who have a common interest in increasing participation in research.

At the Involving People in Research Symposium, researchers identified a need for training and ongoing support to enable greater participation. We responded to this request by developing specific training packages on implementing consumer and community participation in health research. A recent addition to this ongoing support has been the creation of a Fact Sheet Series which is now available as a web resource and will complement the training workshops.

In the past two years, over 200 researchers, students and policy and administration staff from across Australia have now attended the training workshops on implementing consumer and community participation in health research. The workshops have proven to be very effective in providing researchers with practical skills and support. Eighty-two percent of attendees indicated...
they intend to change their practice to increase participation. These claims have subsequently been validated by an increase in requests for advice and support and the adoption of strategies to increase participation. Our engagement program actively supports researchers as well as providing consumers and community members with appropriate access and supports to be meaningfully involved in a wide range of research projects. There has been a shift in attitude with researchers now asking “how do we do this” rather than the “why do we need to?” While there is still a way to go before it can be said that consumer and community participation is standard practice in all levels and in all stages of research, there is a definite increase in awareness of the positive benefits and contribution consumers and community members can make to health research at both the School and the Institute. Anne McKenzie is an experienced consumer representative, and works as a Consumer Advocate at the University of Western Australian School of Population Health and the Telethon Institute for Child Health Research.

Breaking down barriers: the importance of Aboriginal consumer engagement

Laura Elkin

The Health Consumers’ Council WA is an independent community based organisation advocating for patients’ rights in the WA health system. We provide advocacy to individuals who have a problem or query, and also support consumer engagement in service delivery, policy and planning. Our Aboriginal Consumer Participation Program employs two Aboriginal staff members who have been travelling the state since 2006 to listen to Aboriginal people’s experiences and views about accessing health services; promoting consumer health rights; and hosting forums for consumers and services to come together.

Invite services to come to our table

When our program began, one of our aims was to recruit and support individual Aboriginal consumer representatives. However, many of the people we spoke with were reluctant to be the only Aboriginal person on a committee trying to advocate for what they saw as large gaps that must be filled in order to meet the needs of their community. Many felt that some of those gaps were in understanding, and that the issues were too big for one person to advocate for and to also be accountable back to their community for. Those who had already done consumer representative work often came to be in very high demand and quickly felt “over-committed.” They also reported that many of the areas they felt needed to be addressed were about gaps between services, and therefore often outside the agenda. Instead, they wanted us to work with them as a group and when they identified issues about particular services, to then ask the service to come to their table. This allows everyone, including those who find it harder to speak up and often harder to access services, to have a say and hopefully address their issues.

Many Aboriginal consumers have reported difficulties accessing and orienting their way through health services. These include physical distances and having limited services locally; they include the difficulties people face when they have to travel away from home to access services; they include lack of access to interpreters; and lack of understanding about their cultural beliefs; they can include racism and discrimination; and a perception that services don’t care.

Discrimination

A young mum took her newborn to the hospital, unsure of what was wrong with bub. A nurse immediately told her that her baby must be suffering from alcohol and drug related withdrawal, but as the young mum pointed out she never drank alcohol or smoked. Many Aboriginal consumers expressed they have felt negatively discriminated against when accessing a mainstream health service, which has usually meant they are too uncomfortable or upset to raise this with the service. Others feel services have been culturally insensitive or unaware. We encourage and support consumers to raise individual concerns with their health service, and we raise them as community issues in our visits to mainstream services, but we also know that the actual perception of racism in the community needs to be addressed by services in a proactive way. This can be as simple as flying the Aboriginal flag, or celebrating NAIDOC week and other gestures that acknowledge and support Aboriginal Culture and community.
The need to have Aboriginal people working in mainstream health services

Many Aboriginal consumers are not comfortable raising their concerns with health staff, especially if they have a complaint. Having the option of an Aboriginal Liaison Officer, Health Worker or Outreach Worker would give more Aboriginal patients an opportunity to access further services or information or resolve a problem, and would make the service more likely to identify any issues or barriers Aboriginal patients are experiencing. These are strong steps in providing a providing a Culturally Secure health service, as is learning from and linking with Aboriginal Community Controlled Health Services.

Miscommunication

A woman receiving dialysis treatment for renal failure was given a new tablet to assist with her condition. She then stopped attending her dialysis appointments. When they asked her why she hadn’t come, she told them she thought she only had to take the tablets for her treatment now! Many Aboriginal people do not speak English as their first language, and it is common for people to revert to first languages in times of stress or sickness. Understanding what your doctor is advising is crucial for consent and compliance with medication regimes and is a serious patient safety issue. It is equally important that the doctor understands what the patient is saying. We are concerned that health staff don’t always realise when an Aboriginal person needs an interpreter or doesn’t understand what is happening and being said, especially elderly patients who may nod at the doctor to indicate they are listening. We have seen some very sad stories where patients have missed the opportunity to have treatment because they had not understood their options.

Away from Country

WA is a huge state and Perth can be a long way from home. We have provided advocacy to country patients who have been flown to Perth in emergency situations, and also for people who have had to travel there to attend a specialist appointment or test. For some, orienting their way through the city can be extremely frightening, and all kinds of things can get in the way of a patient making it to an appointment – from accommodation shortages to getting lost. Being away from family and friends and everything familiar can be very daunting. Being away from Country is also difficult for many – Country is both home and a source of belonging, identity and spirituality. It can be especially important to be on Country for births and deaths, but also during any kind of sickness.

“In between” services

Aboriginal consumers living in the city can also find it extremely difficult to orient their way through the system, between services.

An elderly woman who was suffering chronic pain and had a referral from her GP to a specialist but had not been advised of her appointment asked us to find out what was happening. The specialist clinic said there was a fourteen-month waiting list and she wasn’t even on the list. They said she would need an “urgent” referral from her GP to be seen, so we accompanied her to another GP appointment and ensured she had the referral she needed and an appointment at the specialist clinic within two weeks.

Mental health

Many Aboriginal consumers continue to raise issues and barriers they have in accessing mental health services, and there is a dramatic need for both suicide prevention and grief and loss support counselling. Some barriers relate to shame and misconceptions of mental illness, which show the need for community education designed by and for Aboriginal people. Some barriers are about different cultural beliefs; some are about the need for keeping families informed and involved in a person’s treatment. Often a family member asks for help for another family member in crisis, and many services have said they are unable to respond to requests for help unless it’s from the person or they have been referred by a GP. This negates the role of family support, often leaves a family in crisis feeling the service “just doesn’t care” and sometimes ends tragically with a suicide.

Many have reported a lack of services; lack of Aboriginal workers; lack of understanding about past policies that have removed children and separated families; difficulty trusting health practitioners; and feeling powerless in the system.

“Off the radar”

Many of the problems and concerns that individuals sought our advocacy to address would not otherwise be known about by the service. It is of concern to us that often the most vulnerable consumers (who may face added barriers because of language, culture, or not knowing how to ask questions in ways that are understood by health service staff) and the difficulties they experience are not being addressed and possibly aren’t even on the radar.

Culture is not a side-dish

Cultural beliefs encompass all beliefs, the way we see the world and ourselves and often the way we communicate. Cultural security encompasses all consumer rights and is essentially about patient safety. In order to improve the delivery of health services to Aboriginal people, it is essential to engage Aboriginal consumers at a grass roots, community level to seek their views on barriers they experience accessing services, and their views on what strategies will create improvements.

Laura Elkin works on the Aboriginal Consumer Participation Program at the Health Consumers’ Council WA.
Engaging with young people: The Youth Future Crew

Toni van Hamond PSM

headspace Barwon is one of 30 sites across Australia aiming to improve the health outcomes of young people aged 12-25. headspace centres deliver four core elements to address this challenging area:

- General health
- Mental health and counselling
- Education, employment and other services
- Alcohol and other drug services.

headspace is making a difference where it is needed most – our young people. The voice of young people is powerful, and has to be heard. This article presents some of the learnings from our youth participation program at headspace Barwon.

How do we ensure what we are doing is youth friendly, engaging, empowering and making a difference? ASK THEM!! The Youth Future Crew (YFC) is headspace Barwon’s youth advisory group, covering the Local Government Areas of Geelong, Surfcoast Shire, Golden Plains and Queenscliff Borough. This group has operated for the last two and a half years and comprises a group of young people who have been service users, or just want to make a difference. They come from a variety of life experiences and contribute to the planning and implementation of community events. Their involvement means that they have a sense of ownership in developments and know they have a voice to share their opinions to ensure young people’s needs and ideas are heard.

headspace Barwon has been determined to keep the voice of young people central to the developments of headspace Barwon. Even when funding has been restricted, the young people didn’t want the program to lose momentum and negotiated a different approach to participation. Financial remuneration was not the driving force behind their involvement – being heard and respected was. As outlined in the Australian Infant, Child, Adolescent and Family Mental Health Association (AICAFMHA) National Youth Participation Strategy Scoping Project Report, youth participation allows young people to have a role within an organisation’s structure where their opinions are valued. It was this view that supported the determination to maintain the YFC’s core role within our developing service system.

All young people are valued, and are paid to attend formal meetings once per fortnight in recognition of their out of pocket expenses. If they contribute to formal events or education they are again remunerated for their time. It is seen as essential that the young people of YFC feel a sense of power and motivation to make a difference to their community. To ensure the YFC is seen as significant part of headspace Barwon, they are represented in the organisational chart and are a regular item on the steering group agenda.

headspace Barwon supports the YFC through a Community Development/Youth Engagement Officer, who is employed to ensure active participation from our young people. Awareness of services available is a priority of our model. We also understand that there are a lot of voices so we endeavor to engage young people in a variety of ways:

- YFC in Schools: commenced in late 2009 and involved schools choosing students to come together to be the voice for their school about health issues. These groups were supported by the Community Development and Youth Engagement Officer and key issues were shared with the core YFC group to increase awareness of issues facing young people in different areas of the community.
- At all community activities, we ensure surveys are available to obtain feedback from young people about what they perceive to be the major issues affecting them.
- Surveys are also at each of the headspace Barwon hubs asking young people to “tell us what you think”.

We take our YFC seriously, and ensure that any feedback and reports are distributed to senior staff of our partner organisations. The reputation of YFC is well-recognised in other areas of the community, and we have regular requests for YFC members to contribute to focus groups and discussions about other key issues in the region.

From a personal perspective, the young people of YFC have ensured we all stay grounded, but it has also been enlightening as young people keep you honest, and once you earn their trust their input and contribution is invaluable. We believe that our youth participation model worked so far because we have been consistent in our approach and our message about the value of the role the young people have in the development of headspace Barwon, and we have given also young people the opportunity to have a voice that they may never have had previously.

Through focus group participation, undercover inspections of our facilities and interview panel participation, the views of young people are at the core of what we do. If we empower them now, they will become the leaders and advocates of tomorrow. We will not allow our young people to be exploited, as their wellness is our priority as well, and we will be there to support and guide them through a variety of pathways that challenge them.

Our biggest challenge is where these young voices can go after they turn 26, as at this point in time there are no consumer participation opportunities that we are aware of, and the need/want to make a difference doesn’t wane when young people turn that year older.
In conclusion the following statements from two of our YFC members say it all:

The YFC is an important part of my life as it allows me to give something back to a service that has literally saved my life. My continual involvement in YFC is also a great way for me to stay involved in my community and also strive to reach other youth so that they can also reap the benefits of headspace. – Andie

YFC has stood out from other programs I’ve been involved in simply because there’s less talk and more action! Having an opportunity to be involved in youth events and opportunities to improve the lives of youth is priceless. – Jamie-Lee


Why we needed a new health consumer peak body in NSW

Sally Crossing AM

Health Consumers NSW (HCNSW) is the new, independent peak health consumer organisation in our state, providing the voice of health consumers in shaping policy and services.

Until early 2011, NSW was the only Australian state or territory, except Tasmania and the Northern Territory, without a peak vehicle for the health consumer voice at the state level. So the short answer to the question of why we need a new health consumer peak is so that voice could be heard at state and national levels.

The long awaited advent of HCNSW early this year has resolved this gap, and NSW can now take its place at the national table of peak consumer health state organisations, and perhaps more importantly, offer a combined voice for consumers across the state health spectrum.

HCNSW thanks the Consumers Health Forum of Australia (CHF) and the other state peaks for encouraging, supporting and advising us as we journeyed towards “peakhood.”

Which was the best model for NSW?

In 2010, we scoped the models of CHF and other peaks, seeking “best practice” elements. Through meetings with a range of interested health consumer groups, underpinning principles were laid down early: we needed to be independent, to be membership-based and to relate to issues across the whole health spectrum in NSW. The independence principle was going to be the trickiest to establish and to maintain, as the only possible source of acceptable funding was from government.

Previous attempts to establish a peak in NSW had failed to gain government support, so this was crucial. We acknowledge the interest of the previous NSW Government in recognising not only the value of a well-informed state peak, but that its independence was paramount for the credibility of its voice. The new NSW Government has supported us in Opposition and has continued to do so. HCNSW is now funded by a Ministerial Grant.

HCNSW’s objectives are to:

• Provide an independent, informed and representative voice for health consumers in NSW
• Provide an independent source of advice and information to the NSW Minister for Health
• Influence decision-making to achieve better health and wellbeing outcomes, and a better health system
• Increase effective consumer participation across the health system
• Develop the capacity of health consumer representatives to participate in health policy and health system decisions and development
• Work with all aspects of the health system including public, private, allied health, non-government and
Getting the voices heard

HCNSW will soon be able to provide trained and informed consumer representatives – people who are able to convey the broader health consumer perspective – through our Consumer Representatives Program. Consumer representatives will be trained as equal participants in health services decision-making. Stakeholders will be able to request nominations of informed consumer reps though our website, www.hcnsw.org.au. We are also working with CHF, the national peak body of health care consumers. CHF has been federally funded to develop and deliver training and support for consumer/community members of Governing Councils of Local Health Networks (known as Local Hospital Networks in some states) and the Boards of Medicare Locals around Australia, among other structures.

In April, HCNSW contacted several hundred organisations and individuals to invite them to join us. We will also be inviting consultants and other clinicians who have shown an interest in our establishment to join us as “The Friends of Health Consumers NSW.” Their support is possibly unique in Australia, showing formal recognition by the medical world of the value of consumer participation in health services, public and private.

Membership is open to health consumer organisations operating in NSW (as Voting Members) and others who support the consumer role in shaping health policy and services (as Associate Members). Membership is free during our inaugural year. Visit the website www.hcnsw.org.au for a membership form.

Members will be networked by a newsletter and be invited to contribute towards putting the NSW health consumer view wherever decisions about consumers are made.

Benefits of membership are similar for all categories of membership. Those NSW health consumer organisations which meet the voting membership criteria (very similar to those of CHF) will also be able to nominate candidates for the Management Committee and vote at elections. This will ensure that HCNSW remains representative of organisations that most fully reflect the views of NSW health consumers.

HCNSW recognises the existing roles of our members and will not attempt to duplicate or become involved with them. Our purpose is to augment and focus our members’ voices in the NSW health (public and private) system, and to provide a presence and view at state and national levels.

A little history

After a failed attempt to establish a NSW peak early this century, mainly due to lack of government support, Sally Crossing AM and Betty Johnson AO approached the NSW Minister for Health seeking support and funding for their efforts to set up an independent voice for NSW health consumers. NSW was the only Australian mainland state without a peak organisation to reflect the views and interests of existing health groups within the state.

Initial meetings were held in July and August 2010, attended by people nominated by twenty organisations. Participants agreed on the establishment of Health Consumers NSW (HCNSW), its objectives and its membership criteria, and that an Interim Committee should progress the establishment phase once initial funding had been negotiated.

Current position

HCNSW became an Incorporated Association. On 25 November 2010, the NSW Health Minister announced a grant to assist establishment, the development of a three year budget proposal, and for commencement of operations. HCNSW has entered into an auspicing agreement with Alzheimer’s Australia NSW to host the new body, and has employed a Project Coordinator. We have been in touch with potential members, stakeholders and friends to invite them to add volume to the voice. We have commenced development of a training program of health consumer representatives to be nominated by HCNSW on request though our website www.hcnsw.org.au.

The job ahead

A main task will be building processes for the voice of NSW health consumers to be heard by offering a vehicle for them to contribute wherever decisions are made, across the public and private systems. HCNSW will work by recognised best practice principles of consumer participation.

HCNSW will enable those stakeholders seeking health consumer representatives to work with their organisations, though projects and policy development, to be connected to informed consumer “reps”. HCNSW will regularly scope the issues, needs and ideas of its members. This will underpin its policy development and engagement with the health sector.

Co-chairs of the new peak, Sally Crossing AM and Betty Johnson AO

NSW Health Voices readers are most welcome to contact us directly!

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Sally Crossing AM is an experienced consumer representative. She is Co-Chair of Health Consumers New South Wales.
Health Consumers Queensland: What we’ve achieved and where we’re headed

Paige Armstrong

Who/What is HCQ?
Health Consumers Queensland (HCQ) was established by the Queensland Government following the Queensland Health System Review: Final Report September 2005 and subsequent state-wide consultation with health consumers, consumer and community organisations, statutory bodies and health professionals, around the need for a health consumer body in Queensland.

HCQ comprises a 12-member Ministerial Consumer Advisory Committee and a Secretariat supported by the Office of the Director-General, Queensland Health. The Committee is made up of a mix of health consumers from a broad range of health populations and social groupings.

HCQ’s Terms of Reference1 and Mission are to support the voices of Queensland consumers to achieve better health outcomes. HCQ contributes to the continued development and reform of health systems and services in Queensland by providing the Minister for Health with information and advice from a consumer perspective, and by supporting and promoting consumer engagement and advocacy. HCQ aims to strengthen the consumer perspective in health policy development and system reform and improvement.

Key achievements to date
Since its establishment in 2008, HCQ has undertaken a number of key initiatives. These include:

• In late 2010, HCQ published a Consumer Engagement Framework to assist health consumers to better engage with their healthcare and the health system to achieve better health outcomes at an individual, service, agency and systems levels. The framework has also been developed to support and influence health practitioners and agencies to achieve meaningful and responsive consumer engagement. The Consumer Engagement Framework includes the principles of engagement, a consumer engagement model, and an eight-step process for undertaking effective engagement activities.

• HCQ has also recently finalised a Health Advocacy Framework and Toolkit to provide structure and support to individual health consumers, their families/carers and organisations to advocate for better health outcomes. The Advocacy Framework defines health advocacy, explains who can be an advocate, establishes principles to achieve effective health advocacy and outlines possible future directions to inform and strengthen health advocacy in Queensland. The Advocacy Toolkit provides consumers with the information and practical tools they need to advocate more effectively with health professionals and exercise their rights and responsibilities as decision-makers towards better health outcomes. These documents are now available on HCQ’s website.

• Over the past two years, HCQ has also engaged with consumers and key stakeholders across the state around key health issues. In particular, HCQ has enabled consumers and their representatives to provide input into matters relating to health system integration, patient safety, clinical governance arrangements, Queensland Health’s end-of-life documents, the Blue Skies Scenario2, medication safety, quality use of pathology, advance care planning and Advance Health Directives, clinical handover, open disclosure, eHealth and the National Health and Hospitals Network for Australia’s Future reform paper.

• Statewide Queensland consumer feedback provided by HCQ to the Commonwealth on the reform paper, along with feedback from other state consumer bodies and the Consumers Health Forum of Australia, has been reflected in the April 2010 Council of Australian Governments Agreement and the February 2011 Heads of Agreement document, highlighting the Commonwealth Government’s commitment to consumer engagement and participation in the development of health policy and the planning, implementation and evaluation of health reforms.

• HCQ co-hosted the Queensland Minister for Health’s launch of the Australian Charter of Healthcare Rights in March 2010. The launch demonstrated Government’s commitment to the rights of health consumers in the provision of public and private health services in Queensland. The Charter recognises that people receiving care and people providing care all have important roles to play in achieving their healthcare rights towards a safer, high quality health system.

• HCQ has also established a strong Consumer Network which is the gateway to our Consumer Representatives Program. We have been able to provide consumer representatives to numerous health-related consultation activities...
arranged by Government and non-government agencies. We have also included consumers from across Queensland in face-to-face forums and workshops and used their feedback to provide informed comment on State and Commonwealth discussion papers.

Future directions for HCQ

HCQ believes the future will provide further opportunities for consumers to share in the decisions needed for positive change in our health system. In supporting Queensland consumers to have a stronger voice in health, we will continue to work alongside other state and territory consumer bodies and CHF towards more consumer-focused, safe, quality, affordable, accessible and timely services and a responsive health system.

Paige Armstrong is the Director of Health Consumers Queensland.

2 More information is available at http://www.blue-skies.info/scenario/

Changing perspectives on consumer involvement in mental health

Janet Meagher AM

Historical Perspective on Consumer Involvement in Mental Health

In Australia, the 1960s and 1970s saw the deinstitutionalisation process begin and gain momentum, culminating in the 1980s. Running parallel with this was the creation of, and nurturing/empowering of, the first consumer activists and advocates in the early 1980s. Into the 1990s there was a concerted effort to engage representative state and territory consumer and carer organisations. This was matched by Commonwealth Government initiatives to formulate mechanisms to respond and create consumer-friendly policy directions and provide means to ensure integrity of the representative voice. These were enshrined in the National Mental Health Strategy, through which the National Community Advisory Group and State Consumer Advisory Group gained momentum to a point of real influence and improved service and policy frameworks. This was definitely the high point which lasted for five to six years from 1992 to 1997/98.

When the Second Mental Health Plan (Strategy) came about, the mechanisms which drove it changed, as did the commitment of State/Territory and Commonwealth Governments.

Gradually over the ensuing five years the determination of this means of hearing the consumer voice completely and irrevocably changed. Parallel with the demise of this representative process was the rise of the National Mental Health Consumer Network. This network was realised in 1996 and it was eventually funded and continued to work dynamically and effectively until its demise in 2009. Efforts to have a replacement representative organisation for mental health consumers have not yet been rewarded by the Commonwealth Government.1 We hold much hope that the promises by Government officials in 2008-9 regarding commitment to such an organisation being funded into the future will be made good by current Ministerial goodwill.

Current situation

Consumer activism arising from the deinstitutionalisation era (1970-1989) was driven by the need for advocacy and rights awareness and protection. From 1990 to 2000, consumer engagement incorporated the original advocacy rights perspective but grew to include understanding of representation and the need for participation and equity. 2001 to the present saw changes which saw a much more “sophisticated” style of participation and an increase in “development” opportunities for consumers. There was, for some, an increased change to be “paid” to represent the consumer perspective. Ironically, along with these increased opportunities there came to be serious issues with the intensity and quality of some who spoke on behalf of others. There were, and are, many who were either disempowered or disenfranchised by other peers who lacked the necessary discipline or essential humility to be truly representative or even-handed in sharing roles. Along with all of this came a point where “preferred consumers” were being “hand-picked” by agencies who needed a consumer representative. This has meant that:

• some of us are picked because we are “tame” and will “go along” with whatever is said and done
• others of us are greedy to get “the money” and take on any/every role that pays its representative whether or not we have an interest in the particular topic
again others of us are picked to “represent” because we are known and it’s easier to pick us because we are a “known” element.

In summary, I see the last decade as one of frustration, slowing down and watering down of the ground gained for Australian consumers throughout the 1990s. There is much room for growth, development, unity and a regaining of dynamism in the Australian Mental Health Consumer Movement through the next decade. The few hopes for us lay in the development of some new impetus and initiatives

- around local groups who are forming fantastic new and revitalised consumer groups and engagement.
- around the possibility of the funding of a new National Mental Health Consumer entity sometime in the near future
- around the small national peer worker/consumer managed services sector where service innovation is exciting and the way of the future.
- around the development and instruction of a curriculum for certificate IV in Peer Work (mental health) – currently expected to be rolled out mid-2017.

Janet Meagher has been a Mental Health Consumer activist and advocate for over 25 years. She has lived with schizophrenia since early 1970s.

1 However, in the 2011-12 Federal Budget it was announced that through the Leadership in Mental Health Reform initiative funding will be provided to create a new national mental health consumer representative body.

Consumers making a difference: the Sea Lake experience

Bev Cook OAM

Sea Lake is a Victorian town with a population of approximately 500, located on the Calder Highway, 369 kilometres northwest of Melbourne and 189 kilometres southeast of Mildura. Sea Lake’s amenities include a hospital and nursing home.

For a period of over four years, the Sea Lake Health Service requested assistance from the Federal Department of Health and Ageing, as well as the Victorian Department of Health, as its financial situation was declining. A survey from the Victorian Department recommended that we close all beds and have an emergency bed only. This was one of six recommendations for the future of what was then an 18-bed hospital/nursing home and a 20-bed hostel for the aged.

The Health Service Board of Management strongly objected to these recommendations, and went through the detail of the survey and found flaws in the arguments. We quoted the Census figures relating to our hospital and our geographic area to counter these arguments.

We were then subjected to another survey and report, which presented matters in a different light but was rejected by the Department. All the while, we had many meetings with both the Federal and State Health Departments, as well as the Victorian Minister for Health. It seemed that there was some argument between the State and Federal Departments, and that it was the financial implications of ongoing funding that were the hold-up.

Finally it became obvious that we were in deep financial trouble and something had to be done. Until this juncture, we had not gone to the wider community with our problems, but the local politicians knew us well.

We were aware that we had to decrease the hospital’s capacity, and one of our solutions was to sell some of our hostel beds, if a buyer could be found.

A public meeting was held, and approximately 200 people came to hear about the plight of the hospital and its imminent closure if some funding could not be found. Some people wouldn’t accept that the Government would close our hospital, but many realised that this was the grim reality and argued that we should fight it with all our might.

A special action committee was formed, and the community was galvanised into some real action. A ‘plan of attack’ was worked out; buses were hired, and the whole community planned to go to Melbourne in protest. Our Chairman was in constant contact with the Minister’s office and had headed to Melbourne the evening before the buses were due to arrive in the city. At 9.30pm, there was a phone call from the Minister, informing us that our requests for assistance had been heard and there was no need for the buses to run.

Much jubilation was felt in the town, particularly as this coincided with the Christmas celebrations in the Main Street. When the Chairman’s car arrived home, most of the town was there to greet it with enthusiasm. T-shirts with the message Save Sea Lake Health were quickly changed to We Saved Sea Lake Health.
One of the main arguments was that Sea Lake Hospital should be accepted into the public health system, as we had been one of the last six Bush Nursing Hospitals in the state so were deemed to be private. We are still in the process of becoming integrated with the Mallee Track Health and Community Service, which is a multi-purpose service in the public system. We hope that by the end of June all the paperwork will be completed and the Sea Lake Campus will be recognised as part of the public system.

One condition of our funding was that we decrease our numbers to 27 beds overall, which must all be under one roof. This will require significant renovations. The current Hostel building will be used for community purposes.

Our experience shows what can happen when ordinary health consumers fight to maintain their access to essential health services. There is still work to be done, and more challenges to face, but we still feel that the T-shirts sum it up: We Saved Sea Lake Health!

Bev Cook is on the Committee of Health Consumers of Rural and Remote Australia. She was inducted onto the Victorian Honour Roll for Women in March 2010 in recognition of her work championing rural health.