

Consumers' Health Forum

Annual Report

2000/2001

Consumers' Health Forum

The Consumers' Health Forum of Australia Inc, established in 1987, is Australia's leading non-government organisation representing consumers on health care issues. CHF establishes policy in consultation with its members, more than one hundred health consumer organisations. It provides a balance to the views of government, industry, service providers and health professionals.

The vision of CHF is to see consumers shaping health policy and health delivery systems in Australia. Our mission is to provide a respected and informed national voice for health consumers.

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Chair's Foreword

Welcome to the Consumers' Health Forum Annual Report. The Annual Report gives us a chance to reflect on what we have achieved throughout the year. It is also a chance to report to you, our members and strategic partners, not only about the way we have managed the organisation's finances, but how we have been able to advocate, inform and shape policy on your behalf.

Our job as the national consumer health non-government organisation has become more and more complex over the last few years. Consumer participation is on everyone's lips at all levels of the system, though at times I would be happier if it moved more from their lips to their wallets. As the health debate has become more complex, we are being called upon to provide consumer representatives to hundreds of committees and reform processes across the broad spectrum of health activity.

Is this success though? We are still, at a national level, struggling to meet the demands placed on us, despite the rhetoric of consumer involvement. Throughout this financial year we have had an average of only five full-time staff, and while they do an extraordinary job with the limited financial resources available to us, there is seldom enough time to do the things that we really think are important.

In the International Year of Volunteering, our volunteer Governing Committee members and numerous volunteers who take up positions as consumer representatives on committees have worked harder than ever to bring the consumer perspective to health reform processes.

But is this success? We, as a health consumer organisation, are striving to make the health system safer, more responsive, more sensitive to the needs of individuals and communities and more accessible to all Australians. While the demand for providing consumer representatives to committees has increased dramatically in the last two years, I am left to wonder if this is the only way that we can make a difference.

It seems that while we sit at all these tables reminding the people there of the humanity of the patients and families that they are dealing with, we are unable to pursue our own agenda for change. I am not trying to diminish the contribution made by our many consumer representatives, as this is clearly very important work and I am in awe of the commitment made by our representatives. But I am left to wonder sometimes why, despite this mammoth effort, the system remains unsafe for some, inaccessible for others and unfriendly for many.

I wonder why the basics have not yet been fixed. Why, for instance, many people find no connection between hospital and community services? Why they are turned out of hospital on Friday afternoon with no support services arranged for the weekend? Why they cannot get their teeth fixed because the waiting list for public dentist is too long? Why they can't get someone to take a particular interest in their needs and help them to plan how they can get services? Why they keep hearing about the need to pay doctors more money, yet they cannot find a GP who bulk bills?

The challenges are enormous and thanks to the enthusiasm and commitment of our members, we will continue to bring a consumer face to the health policy debate.

Lou McCallum
Chair

What We Do

Aims

The aims of the Forum as stated in its Constitution are:

- (i) to provide a means of optimising the participation of consumer and community groups in national policy, planning and service decisions which affect the health of consumers
- (ii) to promote a public and preventive health approach which recognises the health impact of other government policy areas
- (iii) to promote a just and equitable distribution of resources to redress inequalities in the health status of different groups of the Australian population, noting the pluralistic nature of our society
- (iv) to encourage the development of health services which are:
 - (a) effective in enhancing the capacity of people to participate as fully as possible in community life
 - (b) responsive to consumer needs and preferences
 - (c) community based and managed
 - (d) respectful of human rights
 - (e) culturally relevant
 - (f) universally accessible
 - (g) cost effective
- (v) to promote the rights of all consumers to be involved in health policy, planning and service decisions.

Objectives

The objectives of the Forum are:

- (i) to develop and promote an understanding of consumer experiences and views and identify priorities and goals by consulting consumer and community groups
- (ii) to facilitate the development of and enhance the capacity of consumer and community groups (particularly those currently disempowered) to participate in national issues which affect their constituencies by:

- (a) providing information and advice on health issues, policies and decision making processes
- (b) facilitating stronger relationships, cooperation and coordination between the groups
- (c) facilitating closer links and more open communication between these groups, the Federal Government and relevant Federal Government departments
- (d) convening workshops and seminars and providing an appropriate interface between consumers and experts
- (iii) to raise and represent consumer views and, in particular, advise the Commonwealth Minister for Health and Department of Health of these views
- (iv) to monitor the opportunities and processes for consumer participation and to work with the Commonwealth Department of Health to assist it to become more open, accountable and responsive to consumers
- (v) to monitor and analyse national health policy development, planning, resource allocation processes and outcomes
- (vi) to facilitate, and in some instances, fund research and conduct education projects on matters affecting consumers
- (vii) to advocate, publicly, measures which will contribute to achieving the Forum's aims and objectives.

Strategic Plan

The Forum's current Strategic Plan focuses on three themes or work areas:

- Health policy, practice and outcomes
- National Voice
- Governance and Management

Key Work Area 1: Health policy, practice and outcomes

Aim: To contribute towards the improvement of peoples' health and well-being

- Objective 1: Ensure accessibility to a high quality and responsive public health system, and to high quality outcomes through public and private health care

- Objective 2: Strengthen the ability of consumers to participate in and strategically influence health policy, planning and service delivery
- Objective 3: Address inequities in health outcomes for particular groups
- Objective 4: Improve information from the health system to health consumers to use in their decision making and problem solving about their health

Key Work Area 2: National Voice

Aim: To represent the views and interests of health consumers at a national level

- Objective 1: Strengthen relationships with consumer organisations.
- Objective 2: Provide advice to government in a constructive and timely manner
- Objective 3: Establish, promote and maintain a range of strategic alliances with other organisations to further the aims of CHF
- Objective 4: Promote the views and interests of health consumers through the media, publications and other channels

Key Work Area 3: Governance and Management

Aim: To support the work of the Forum through effective governance and management

- Objective 1: To strengthen CHF's governance and management structures and processes
- Objective 2: To enhance the effectiveness of CHF's Secretariat
- Objective 3: To optimise the use of funds available to CHF

Submissions and reports

Copies of all the submissions and reports completed by CHF during the year are available for download from our website (www.chf.org.au) except where indicated.

- Submission to the Labelling Project, **July 2000**
- Discussion Paper 'Effective by Design', **July 2000**

- Submission to the eHealth Council: Draft Health Impact Assessment Implementation Guidelines, **September 2000**
- Submission to the Senate Legal and Constitutional Legislation Committee: *Inquiry into the Provisions of the Privacy Amendment (Private Sector) Bill 2000*, **September 2000**
- Submission to the Regulatory Reform Taskforce: Joint submission by Australian Consumers Association & CHF, **October 2000**
- Submission on the Draft Gene Technology Regulations 2000, **October 2000**
- Submission to the External Review of Consumer Outcomes of the Quality Use of Medicines (QUM) Strategy in Australia, **October 2000**
- Consumers and E-Health Briefing Paper No. 1 — The Better Medication Management System, **October 2000**
- Submission to the Review of Drugs poisons and Controlled Substances Legislation (Galbally Review), **November 2000**
- Consumers and E-Health Briefing Paper No. 2 — HealthConnect, **November 2000**
- Consumers and E-Health Briefing Paper No. 3 – Computers in General Practice **February 2001**
- Consumers and E-Health Report on State and Territory Workshops, **March 2001**
- 'Medicare Online' Consumer information product concepts. Report on the Consumers and E-health Workshops **March 2001**
- A Guide for consumers doing health research, **May 2001**
- Position Paper: Issues in Developing HealthConnect, **May 2001**
- Guidelines for consumer organisations receiving pharmaceutical industry funding for consumer education, **June 2001**
- Consumer Medicines Information – Ask for it! Final Report, **June 2001**
- Guidelines for consumer organisations receiving pharmaceutical industry funding for consumer education, **June 2001**
- Position Paper: The Better Medication Management System, **June 2001**.

Using medicines safely

Studies have estimated that up to half of the 80,000 hospital admissions in Australia each year for medication-related problems may be avoidable.¹ Inappropriate prescribing and overuse of medicines have become major concerns for consumers in recent times. Some of the quality use of medicines (QUM) issues raised by CHF members include:

- problems for older people on multiple medications
- adverse drug reactions and interactions
- the need for more independent and accurate information about medicines
- better education of all stakeholders about prescription and use of medicines.

Since its inception in 1987, CHF has been involved in promoting the better use of medicines. In 1989, CHF released *Towards a National Medicinal Drug Policy for Australia* that foreshadowed three arms of the National Medicines Policy (quality of product, appropriate use, and equity of access).

Australia's first National Medicines Policy, agreed by all key stakeholders, came to fruition in 1999 when it was officially launched by the Parliamentary Secretary for Health and Aged Care, Senator the Hon. Grant Tambling.

CHF believes the way to achieve the wise use of medicines is dependent on the strengthening of consumer organisations and consumer networks. CHF favours the consumer-driven model that has already begun in Australia with some successes, but is pitifully under-resourced and cannot fulfil its potential as a vehicle of information to effect community changes in behaviour.

Without a strong consumer framework, QUM initiatives for consumers will continue to be piecemeal and subject to the interests of health care professional and provider groups.

¹ Roughead, E. *Drug-related hospital admission: a review of Australian studies published 1988-1996*. MJA 1998; 168: 405

CHF's submission to the "External review of consumer outcomes of the Quality Use of Medicines (QUM) strategy in Australia", proposes the formation of a network, coordinated by CHF, that would use existing consumer networks to provide consumer-driven research and policy development. It would also provide a sustainable program of community level grants to consumer organisations and other community groups where consumers are working for and with consumers.

The CHF submission proposes five strategies as future activities to increase consumer awareness of QUM and change behaviour in medium to longer term.

Establish a consistent QUM educational policy for consumers to be implemented by consumers at the local level, in partnership with health professionals, embracing the following elements:

- a transparent and consistent source of funding for consumers for QUM activities
- resources to support and bring together local consumer and self help networks around QUM information activities
- support from local structures such as divisions of general practice, pharmacists and community nursing
- development of programs of evidence-based QUM activities and medicines information to meet the needs of local populations.

This strategy would rely on consumer QUM coordinators at the local level, supported and coordinated by CHF. The coordinators would need to be adequately resourced and trained in QUM messages and the workings of the Pharmaceutical Benefits Scheme (PBS), with ongoing training and provision of evidence-based information and written materials about medicines as is now available for health professionals with the support of the National Prescribing Service.

The coordinators would facilitate educational meetings about medicines for local consumer networks and work with the NPS facilitators and local pharmacists around evidence-based medicines issues.

They would liaise with other local health and community services including hospitals, nursing homes and hostels and local schools to promote the quality use of medicines. They would work with NPS facilitators to build understanding in the divisions and with their local general practitioners about the local communities' needs in relation to the quality use of medicines and run educational sessions about consumer QUM issues in relation to hospitals stays and discharge planning.

1. Establish a funding mechanism for QUM educational projects targeted to consumers who are high users of medicines or have special information needs:

- people with chronic conditions on multiple medicines
- older people
- young people
- people from non-English speaking backgrounds
- Aboriginal and Torres Strait Islander (ATSI) people.

2. Develop a program to explain the Pharmaceutical Benefits Scheme (PBS) to health consumers and support them in optimising cost-effective use. This should include:

- establishing a network of organisations working with high use consumers to explain changes and listing decisions
- building upon existing peer education processes and resourcing new ones to work through these organisations in providing support for consumers in making choices about medicines
- systematically evaluating the process and outcomes of the peer education activity as a means of delivering more effective advice and assistance to consumers.

Growth in spending on the PBS has been steadily rising over the last decade despite the attempts to curb the growth. Australian taxpayers are now paying \$3.5 billion a year to fund the PBS and it is the fastest growth component of the health budget.

Recent measures to curb the steady growth in spending on the PBS have included introduction of a cost effectiveness analysis for PBS listing, therapeutic group premiums, generic substitution and tough price negotiations.

Consumers value the PBS and CHF believes that promotion of QUM is another way to contain the costs of the PBS. To do this, consumers will also need evidence-based messages about optimising use medicines to support those produced by the National Prescribing Service for general practitioners and pharmacists.

3. CHF to develop, in consultation with pharmacists, doctors, the NPS, PHARM (Pharmaceutical Health and Rational Use of Medicines Committee) and government a mechanism for coordinating the delivery of consumer messages in the community through community organisations in support of messages to health professionals.

For example, community programs to support National Prescribing Service prescriber messages on appropriate use of antibiotics and evidence-based treatment for hypertension, consumer materials about pharmacists' or doctors' medication review programs and balanced information for consumers about new medicines.

4. Re-establish regular meetings convened by CHF for consumer advocates working in national QUM policy to achieve the following broad aims:

- improve knowledge about and coordination of QUM policy issues, examine options for sustainability of the PBS and facilitate communication between consumers and health professionals
- oversee access to accurate, balanced and independent information about medicines for all consumers
- work towards a process for consumer reporting of adverse drug events through new mechanisms such as the BMMS and the Consumer Drug Information Service

- facilitate informed discussions and debate about emerging medicines issues such as advertising, use of information technology, and gene technology.

CHF supports strategies to increase consumer awareness about QUM including healthy lifestyle alternatives which are developed and promoted by consumers in partnership with health care professionals at both the national and community level.

Indicators that can be used to measure the effectiveness of these strategies and targets should be set.

While the national indicators are an important step forward, there is still a need to develop consumer quality use of medicines indicators. For example, indicators could be developed for the following questions for individual consumers.

- Do consumers know what medicines they are taking and why?
- Did the doctor and the pharmacist explain the purpose of the prescribed medicine and how long to take it?
- Did the consumer receive any written information about the medicine during the consultation or pharmacy counselling?
- Did the prescriber ask the consumer about any side effects or adverse reactions as a result of taking the medicine?

At the community level, similar targets to those established by the NPS evaluation working group could be set where consumers receive QUM messages to support the prescriber programs being run by National Prescribing Service or Divisions. For example, consumer education would be expected to contribute to the targets set for reductions in the use of antibiotics for treating upper respiratory tract infections and reductions in use of non-steroidal anti inflammatory drugs (NSAIDS).

However, in the longer term at the national level, perhaps the most important targets for consumers are:

- improvements in the rate of admission to hospitals for drug-related emergencies;
- improved (and earlier) reporting of adverse events for new medications and new combinations of therapies such as complementary and prescription medicines; and
- more cost-effective use of the PBS to improve its sustainability.

Consumers' Health Forum resources

Choosing your medicine – Making an informed decision about complementary and non-prescription therapies
ISBN: 1 876034 21 1, CHF Ref: 178, May 1999, 49 pp + Appendices, \$22.00

Easing the burden: The Pharmaceutical Benefits Scheme and people with chronic conditions
ISBN: 1 876034 20 3, CHF Ref: 180, March 1999, 51pp + Appendices, \$25.00

Understanding consumer behaviour and experiences in relation to the use of medicines: Literature Review
ISBN: 1 876034 24 6, CHF Ref: 232, July 1999, 64pp, \$25.00

Guidelines for consumer organisations receiving pharmaceutical industry funding for consumer education
ISBN: 1 876034 36 X, CHF Ref: 270, June 2000, 5pp, \$10.00

Cost of Chronic Illness & Quality Use of Medicines
ISBN: 1 876034 12 2, CHF Ref: 141, April 1997, 68pp, \$20.00

Hospitals and Quality Use of Medicines
ISBN: 1 876034 16 5, CHF Ref: 145, June 1997, 58p, \$25.00

Submission to the external review of consumer outcomes of the Quality Use of Medicines (QUM) strategy in Australia
ISBN: 1 876034 36 X, CHF Ref: 264, October 2000, 17pp, \$15.00

Consumer Medicine Information – Ask for it!
ISBN: 1 876034 37 8, CHF Ref: 271, June 2000, 23pp + Appendices, \$15.00

Criteria for Exemptions from Therapeutic Group Premiums
ISBN: 1 876034 39 4, CHF Ref: 157, December 1997, 7pp, \$10.00

Consumers and electronic health records - The Better Medication Management System

Health consumers currently face a fragmented health care system in which each doctor, pharmacist and hospital keeps their own separate records. Information about an individual consumer's health care, including the medications they are prescribed, is spread among these records. One result of this fragmentation is that consumers must generally rely on their own memories or records to keep track of their medications.

Remembering medication information can be difficult, particularly for those people who require a number of different medications (for example, many older people and people with a chronic condition). However, failure to recall a particular drug currently being taken, or the details of a past adverse reaction to a drug, can have serious consequences.

While there are various State initiatives currently underway to reduce this fragmentation of health records, the Commonwealth's proposal for a Better Medication Management System (BMMS) is an attempt to address the issue fragmented medication records at a national level. The aim is to provide health care providers and consumers with better access to information about current medications and relevant medication history.

It is intended that improving access to medication information will assist in reducing adverse medication events and hospitalisations, with BMMS forming one element of the broader Quality Use of Medicines framework. If fully implemented, the BMMS will make it possible to create an electronic medication record for each consumer who chooses to participate.

The Consumer's Health Forum (CHF) 'Consumers and E-health' consultations conducted during 2000/2001 favoured the following statement of purpose for the BMMS proposal, as shown in Box 1.

Box 1: Statement of purpose of BMMS

Problem: Poor access by prescribers, dispensers and consumers to accurate information about a consumer's medicines can result in adverse outcomes, including unnecessary hospitalisation.

Goal: To improve provider and consumer access to medicines information.

Means: Personal electronic medication record, centralised database and a communication network.

Success measures:

- Improved levels of access to information about a consumer's medicines
- Reduction in adverse outcomes
- Reduction in hospitalisation.

Under the draft BMMS Bill, a consumer's Medicare number would be used to link information about medications prescribed for the consumer by different doctors and supplied by different pharmacists. With the consumer's consent, doctors and pharmacists would also be able to add information about non-prescription medications (for example, over-the-counter or complementary medicines). This information will then be available, with the consumer's consent, to future prescribers and dispensers.

CHF's consultations indicated that many consumers see value in a system such as the BMMS, particularly for consumers who use a lot of medicines. As well as valuing its potential to reduce adverse medication outcomes, CHF members considered that the availability of medication information to consumers and their health care providers through the BMMS could improve communication between consumers, doctors and pharmacists.

However, even the most enthusiastic consumers in CHF's consultations emphasised the need for safeguards to ensure that consumers only participate on the basis of fully informed consent and that security and privacy issues are addressed.

Many people were also concerned that the BMMS has the potential to further marginalise people who currently have relatively poor access to health information and services, and considered it important to address their needs in both system design and implementation.

The views of participants in the Consumers and E-health consultations contributed to the development of consumer principles for developing and implementing an electronic health record network (Box 2). As the outcome of substantial consultation, CHF considers that the principles provide a useful background to the discussion of consumer concerns in relation to the draft BMMS Bill, Health Connect and other electronic health record databases.

Consumers' access to their own records

A major potential benefit of the proposed BMMS identified in CHF's consultations, was improving consumers' access to information about their own medications. Consumers and E-health participants also considered that having access to their own information is a pre-requisite to making informed decisions about who else can access the information and for what purposes it can be used.

However, participants in CHF's consultations noted that people have a range of requirements when it comes to accessing information. Therefore, CHF has consistently stated that consumers must be able to access or obtain a copy of their BMMS information in a range of ways, including:

- from Medicare offices
- through doctors and pharmacists
- in the longer term and assuming sufficient security is available, over the internet.

CHF has also recommended that consideration be given to developing a network of kiosk computers in Medicare offices and other government agencies, where appropriate support would be available to consumers who wanted to access their record electronically.

CHF's consultations identified three broad areas of consumer concern regarding participation in the BMMS.

Box 2: Consumers and e-health principles

In assessing any proposal to enable electronic linkage of health records or event summaries across organisational and administrative boundaries, consumers will expect:

Objectives

1. An electronic health record network will improve health outcomes by empowering consumers and developing stronger partnerships between consumers and health care providers.
2. An electronic health record network will improve access to services, encourage participation in the health system and reduce disadvantage.

Information and participation

3. Consumers will be informed and consulted about an electronic health record network, including potential uses of the information it contains.
4. A consumer's decision about whether to participate in an electronic health record network will be voluntary, free from coercion and based on full information.
5. Consumers will not be discriminated against on the basis of their participation or non-participation in an electronic health record network.

Consumers' control over their own information

6. Consumers will have access to their own personal health information.
7. Consumers will decide who else can access their personal health information.

Operation and oversight

8. Consumers' personal health information will be held and transferred securely.
9. Governance of electronic health record networks will be transparent and accountable.
10. Audit and monitoring systems will be in place to protect against privacy breaches.
11. Consumers will be fully informed about any privacy breaches that occur in relation to their information.
12. Consumers will have access to an independent complaints system and strong penalties will apply if a consumer's information is misused.
13. The development and operation of any electronic health record network will be independently evaluated, including its impact on consumers.

First, the need to ensure that consumers are able to make fully informed decisions about participation in the BMMS. Second, some scepticism about whether participation in the BMMS would be truly voluntary for consumers. Third, the potential for some consumers to be disadvantaged in the registration process for BMMS, and the need to ensure that all consumers who want to participate are able to do so.

The draft BMMS Bill requires that consumers only participate if they have given consent. However, the definition of 'consent' in the draft Bill states only that consent must be express (rather than implicit), not that it be informed or voluntary. By contrast, the Federal Privacy Commissioner's *Draft Health Privacy Guidelines* (p. 27) state that the key elements of consent are:

- consent must be provided voluntarily
- the person [giving consent] should be adequately informed
- consent should relate to a specific situation
- the person must have the capacity to provide and communicate their consent.

While the last two of these elements are covered in some detail in the draft BMMS Bill, CHF considers that adopting the first two elements as requirements for BMMS consent will go some way towards addressing the consumers' concerns about participation.

Implementing BMMS in the community

CHF recognises that legislation cannot address all the issues that arise in implementing initiatives such as the BMMS. Successful implementation would require:

- ensuring secure technology is in place for maintaining the database and transmitting information to and from the database
- completion and evaluation of field tests
- informed participation by doctors and pharmacists
- public understanding and confidence.

Public confidence in the BMMS will only be achieved if the governance body is seen to be responsive to consumer concerns, having identified those concerns through meaningful consultation with a broad range of consumers.

In CHF's view, it is imperative that, in making the transition from the existing stakeholder process to the governance arrangements under the draft Bill, broader stakeholder involvement is maintained across the range of issues that are yet to be fully addressed.

Another key element of achieving public understanding and confidence will be the communication campaign that is put in place to inform consumers about the BMMS. CHF's consultations highlighted the need to ensure that information about the BMMS for consumers is factual and unbiased, as well as being available in a variety of formats and languages. Members were particularly concerned that the BMMS should not further disadvantage those people who are already the least well served by the health system.

Hospital participation

A major concern for consumers in CHF's consultations was the lack of participation with hospitals at the introduction of the BMMS. The BMMS could address consumer concerns about adverse medication outcomes which result from poor communication between hospitals and community health care providers, particularly in emergency situations and at times of hospital discharge.

In addition, for some groups of health consumers (for example, people living with HIV/AIDS in NSW) the participation of hospitals is particularly important because some medications are only available through hospital dispensaries, not in community pharmacies.

CHF considers that participation of both public and private hospitals in BMMS should be pursued as a priority, both throughout the transition period and by the Board when it is appointed.

Consumer participation in research

Health consumers believe they have a great deal to offer health and medical research. It is clear to them that those most affected and intimately acquainted with the issues should be involved in shaping its ongoing development. CHF has a long-standing interest in health research and has promoted consumer and community involvement in research during many years, with the strong support of its member organisations.

CHF made submissions to the 1999 Wills Review, recommending that researchers 'involve the community in the research process and communicate about the role, benefits and results of research, consequences of new fields such as genomics and ethical issues.'

The National Health and Medical Research Council (NHMRC) subsequently agreed to fund CHF's proposal to develop a *Statement for Consumer and Community Participation in Health and Medical Research*. On the basis of the input from its members and other key players and a search of the literature, CHF developed its *Statement*. The vision for this *Statement* is:

Vision

Consumers and researchers working in partnerships based on understanding, respect and shared commitment to research that will improve the health of humankind.

Many health consumers believe they have the right to participate in health and medical research, not simply as passive subjects or token representatives, but as equal partners in the development of research goals, questions, strategies, methodologies and reporting.

Historically, patients have been involved in health and medical research as 'subjects'. However, the subsequent development of recognised ethical principles for research involving humans ensured significant steps in the protection of the welfare and rights of 'participants' in research.

These steps include providing information for consumers considering participating in research to support their informed consent, issues of safety for research participants, and lay involvement in ethics committees. Yet more and more researchers, as well as consumers, see this progress continuing further towards involvement of consumers and community in the various stages of research and informing them of the results of research. That is, working forward from the currently accepted ethical principles, which focus on protection of individuals, to build and strengthen partnerships between researchers, the community and the individual participants in research.

There are benefits to consumers, the community and researchers in following this path. Consumers have first-hand experience of the health and research outcomes that will make most difference to them and can contribute this experience to research.

Involving the community in setting the research agenda can inform the community about research and help to tailor research to be more relevant to community needs. Researchers can benefit from wider discussion of research hypotheses and from the support of a more informed community for health and medical research.

Objectives

The following objectives, which are based on consultations with consumers and researchers, were developed as a guide to consumer participation at all levels and across all types of health and medical research in Australia:

- Consumers and researchers will collaborate and draw on each other's knowledge to build on and strengthen the quality of health and medical research in Australia.
- This collaboration will be achieved through partnerships of consumers and researchers based on mutual trust and shared social responsibility, giving consideration to what each can reasonably expect from the other.

- The partnership of consumers and researchers will shape decisions about research priorities, specific research questions and design of research projects in a way that recognises and responds to the rights of all voices to be heard.
- The partnership of consumers and researchers will support the rights of research participants to their own results, be accountable to them for the results of the research, and encourage and facilitate dissemination of balanced information about the research and its results to the community.
- Consumers and researchers will advocate for the resources needed for effective consumer and community participation in health and medical research.

It is acknowledged that consumer participation in health and medical research will be implemented in a range of different ways. For example, a national committee setting research priorities may seek nominations for consumer representatives from national peak organisations and provide resources for them to consult with their members, as well as fund public consultations. Decision making committees of funding bodies may seek nominations for consumer representatives relevant to the funding area, and provide resources for them to consult with their constituencies. Institutional research committees may focus on their accountability to the community that they serve. At the research project level, consumer participation may involve representatives of groups of people likely to be affected by the research.

The nature of consumer participation will also vary with the type of research that is being conducted. For example, action research to improve a mental health service will directly involve research participants who use the service. Representatives of relevant illness or self-help groups may provide an effective means for consumer participation in clinical research or even applied gene technology research.

However, consumer participation in basic research may involve the researcher(s) or research institutions building their accountability to society for the direction of their research through information exchange and discussion with people from the wider community.

Consumers and researchers are encouraged to consider who will be most affected by the research, others that may have an interest, and how to ensure effective consumer participation in a cycle of continuous improvement of the quality of research. After all, health consumers as the end users of health and medical research, have a strong commitment to improving the relevance and quality of health and medical research in Australia.

Consumers' Health Forum resource

A guide for consumers doing health research

Health consumers are passionate about research. They know that research is essential to improving health outcomes and they want to make sure that research asks the questions that consumers really need answered. Consumers can often contribute better than anyone else in identifying the important questions that researchers need to ask.

Many health consumers want to work collaboratively with researchers or undertake their own research. CHF has written a consumer guide aims to help consumers understand how research is carried out and assist, in a practical way, those consumers who want to undertake their own research.

The guide addresses the key issues to be considered in undertaking any research project and offers advice about how consumers can overcome some of the difficulties they are likely to face during their research.

ISBN: 1 876034 35 1, 119pp, May 2001, \$25

Governance and Management

Legal status

The Consumers' Health Forum of Australia Incorporated is an association incorporated under the *Associations Incorporation Act 1991* (ACT).

Governing Committee

The Governing Committee is responsible for all facets of the Forum's management. The Governing Committee meets face-to-face three times a year.

Voting members of the Forum elect a Governing Committee once every two years at an Annual General Meeting (AGM). The next AGM will be held on 19 November 2001. The Constitution provides for a 12 member Governing Committee, comprising:

- five members from organisations that are constituted on a national basis
- seven members from organisations that are not constituted on a national basis.

At the previous AGM, CHF's members elected the following Governing Committee:

- Jenna Bateman (Mental Health Coordinating Council)
- Marg Brown – Treasurer (Health Consumers of Rural and Remote Australia)
- Amanda Cornwall (Health Consumers Network NSW) Resigned July 2001.
- Peter Dhu (Australian Speak Easy Association)
- Margaretha Hanen (Federation of Ethnic Communities' Council of Australia)
- Lou McCallum – Chair (Australian Council of Social Service)
- Russell McGowan – Secretary (Health Care Consumers Association of the ACT)
- David Menadue (National Association of People Living with HIV/AIDS)
- Mitch Messer – Vice Chair (Health Consumers' Council of WA)
- Christopher Newell (Tasmanians with Disabilities)
- Sheila Rimmer (Council on the Ageing)
- Cyril Wyndham (HUNCH). Resigned December 2000.

Jenna Bateman

Mental Health Co-ordinating Council

Jenna is the Executive Officer of the Mental Health Co-ordinating Council and has been involved in the mental health sector for 20 years. She has experience in acute care, research, and community based/not-for-profit mental health services and has a strong commitment to service providers taking account of a person's community setting when planning care.

Her position and experience mean she is well acquainted with the issues arising from the interface between the health and community sectors, particularly as it affects people with a disability. She is keen to see the development of clear guidelines on how, and at what point, care is transferred to community-based services. Jenna is also a member of the NSW Health NGO Advisory Group, the Quality Management Services NGO Reference Group and the Advisory Group for the implementation of the National Suicide Prevention Strategy in New South Wales.

Marg Brown – Treasurer

Health Consumers of Rural and Remote Australia

Marg is Chair of Health Consumers of Rural and Remote Australia (HCRRA), a national organisation that looks after the special health needs of people living in rural, remote and isolated areas. The organisation represents consumer views at the 'grass roots' and works in collaboration with health professionals and other consumers/organisations and the Council of the National Rural Health Alliance. Marg lives on a property at Kulkami in South Australia's Mallee. She represents rural and remote consumers on a number of committees:

- Treasurer of CHF
- Convenor of the Consumer Standing Committee of the General Practice Partnership Advisory Council
- Health Insurance Commission Consumer Advisory Committee
- Murray Mallee Division of General Practice Outcomes Based Funding Group
- Scientific Program Committee for the 5th World Conference on Rural Health.

Amanda Cornwall

Health Consumers' Network (NSW)

Amanda has been a legal policy officer at the Public Interest Advocacy Centre (PIAC) since 1995. She was also Executive Officer for the NSW Cosmetic Surgery Inquiry in 1999. PIAC is an independent, non-profit legal and policy centre that strives to foster a fair, just and democratic society by empowering disadvantaged citizens, consumers and communities. PIAC has worked on health consumer rights issues since its inception in 1982. It was a founding member of CHF. The Centre's work emphasises effective public access to information and participation in society's governance.

With previous experience in government, the private sector and the community sector, Amanda is an effective advocate who has represented consumers on a number of committees and advisory groups on health, environment and social impact issues.

Peter Dhu

Australian Speak Easy Association

Peter is President of the Australian Speak Easy Association (ASEA), a self-help group for people who stutter. He has been involved in ASEA since its establishment 21 years ago (and as President for the past five years), helping people who stutter through public awareness, advocacy, support and information.

As President of ASEA he represents the views of the 190,000 people in Australia who stutter. Peter has worked as a hospital scientist for about 22 years, giving him a good background in a wide range of health issues, including diabetes, pharmacology, drugs, genetic diseases and general pathology. He has worked in rural and metropolitan hospitals. He is the father of three children.

Margaretha Hanen OAM

Federation of Ethnic Communities' Council of Australia

Margaretha represents The Federation of Ethnic Communities' Councils of Australia (FECCA) on the Governing Committee of CHF.

FECCA is the national voice of Australians from culturally and linguistically diverse backgrounds.

Born in the Netherlands, Margaretha was a social worker in Europe and in Canada helping newly settled immigrants, before coming to Australia where she taught at Flinders University for many years.

During her years with South Australia's Commissioner for the Ageing, Margaretha developed some of the most innovative models of multicultural aged care that led the field on a national basis. She was a member of the Advisory Council on Multicultural Affairs that developed the National Agenda for a Multicultural Australia (1985-89).

In retirement she continues membership of numerous committees and boards, including Chair of the Board of the Croatian, Ukrainian and Belarusian Aged Care Association of South Australia and member of the Australian Pharmaceutical Advisory Council on behalf of FECCA.

Lou McCallum – Chair

Australian Council of Social Service

Lou is nominated to the CHF Governing Committee by the Australian Council of Social Services (ACOSS). Lou has worked in non-government health organisations for many years as a policy analyst and manager. He was Executive Director of the Australian Federation of AIDS Organisations from 1996 to 1998. Lou was a co-founder and coordinator of Ankali Project in Sydney, a volunteer home-based care and emotional support service for people with AIDS and their carers. He has been on the CHF Governing Committee for six years, as Deputy Chair from 1999 to 2000 and as Chair of the Governing Committee since September 2000.

Russell McGowan

Health Care Consumers' Association of the ACT

Russell is a bone marrow transplant survivor who became an active health consumer through his experiences in treatment during the early 1990s.

Despite apparent cure of his original condition (myelofibrosis), Russell suffers consequences of treatment, a chronic condition called Graft versus Host Disease (cGVHD). This led to his early retirement from employment that had included teaching, fieldwork and policy development in community and indigenous education and training programs.

His activities as a national consumer representative include surveying for the Australian Council on Healthcare Standards, and a Commonwealth Department of Health and Aged Care bowel cancer screening committee. Russell also sits on a steering committee developing a national Cancer Advocacy Network. Through his position as President of the ACT's Health Care Consumers' Association, Russell is currently trying to develop a consumer health information access centre.

David Menadue OAM

National Association of People Living with HIV/AIDS

David is the voting delegate to CHF for the National Association of People Living with HIV/AIDS (NAPWA). He is a person living with AIDS and has been involved in AIDS organisations in Victoria and nationally for over 10 years. He is currently Vice President of People Living with HIV/AIDS Victoria, Executive Member of the Victorian AIDS Council and Executive Member of the NAPWA.

He has extensive experience in health advocacy and has been a member of various Victorian Ministerial Advisory Committees on health issues, the National Caucus of Disability Consumer Organisations and the former Fairfield Hospital Board. NAPWA is keen to play a significant role in the work of CHF, particularly in issues such as arrangements for the Pharmaceutical Benefits Scheme. NAPWA is also interested in addressing issues of poverty and how the Government's welfare reforms will impact of the health and welfare of people in the community.

Mitch Messer – Vice Chair

Health Consumers' Council of WA

Mitch is Executive Director of Cystic Fibrosis Western Australia. He is President of Cystic Fibrosis Australia, Vice Chair of the International Association of Cystic Fibrosis Adults and Secretary of the International CF Association. Mitch has been involved in health consumer issues in a broader way through the Health Consumers' Council (WA) and its predecessor organisations and through the Chronic Illness Alliance in WA. During his involvement with these groups he has served in the position of Chairperson, Treasurer and Board member.

He has been involved in many committees and working groups dealing with a range of issues including aged care, pharmaceuticals, genetic services and lung transplant. He is also a member of the Human Research Ethics Committee of the Fremantle Hospital and Health Service.

Christopher Newell AM

Tasmanians With Disabilities

Christopher has been the nominee of Tasmanians with Disabilities (TWD) to the Governing Committee of the CHF for some years. Tasmanians with Disabilities Inc. is a trans-diagnostic organisation that focuses on advocacy, policy development and self-help for, and on behalf of, people with all types of disability.

TWD and Christopher have a broad interest in the work of CHF and issues for all consumers. Consumer rights, ethics and consumer research are several particular interest areas, as is general practice reform, and pursuing areas where personal experience as a consumer facilitates effective advocacy for consumer rights. People with a disability are a significant social grouping disadvantaged in today's society.

Christopher has been a consumer representative for many years for TWD and other consumer bodies on a number of National and State forums in many fields including telecommunications, rights, advocacy, ethics, education and health. He is also Chair of the CHF Editorial Committee.

Sheila Rimmer

Council on the Ageing (Australia)

Sheila is National President, Council on the Ageing (Australia), known as COTA. COTA is a key national organisation that exists to protect and promote the well-being of all older people. It is an advocate for older Australians by providing information, publications, policy analysis, consultation, representation, referral and advisory services.

Sheila was born in the United Kingdom and was educated at the London School of Economics at London University and Columbia University, New York. She migrated to Australia in 1964 and worked as a tutor at the University of Tasmania and as a political commentator on television. In 1969 she moved to the University of Technology, Sydney, and later became a lecturer at Macquarie University.

In 'retirement', Sheila is President of COTA (NSW), a member of the AMA Advisory Group on Care of Older People and serves on the boards of the National Ageing Research Institute, the Minister's Forum of Aged Care, and related working groups.

Executive Committee

The Governing Committee elects an Executive Committee, comprising the Forum's Chair, Vice Chair, Secretary, Treasurer and one other. The Executive is responsible for implementing the policy decisions of the Governing Committee, and for the management and finances of the Forum. The Executive meets by teleconference once a month.

- Lou McCallum (Chair)
- Mitch Messer (Vice Chair)
- Amanda Cornwall (Secretary)
- Marg Brown (Treasurer)
- Matthew Blackmore (Ex officio)

Sub-committees & Working Parties

As a membership organisation driven by the needs and views of its members, CHF has established a range of sub-committees, steering committees, advisory committees and working parties to assist it developing its policies and responses and managing grants. The following committees met during the year:

- Consumer Representatives Subcommittee
- Membership Subcommittee
- *Australian Health Consumer* Editorial Committee.

Management

Day-to-day management of CHF is undertaken by the Secretariat, based in Canberra. The Executive Director, Matthew Blackmore, is the senior employee of the Forum and has responsibility for the Secretariat staff, day-to-day finance and administration, and other delegations and powers given by the Governing Committee.

As at 30 June 2001, the staff at CHF were:

- Helen Hopkins, Senior Policy Advisor
- Rachel Stephen-Smith, Manager E-health Project
- Emma Awizen, Manager, Members and Representatives
- Kay Barney, Manager, Community Relations
- Kate Seselja, Administrative Assistant

Staff departures

Heather Percival retired on 22 September 2000. Her good cheer and hard work have been missed by many. Teresa Dowling took 12 months Maternity Leave from 21 September 2000 and she and husband David are proud parents of Kaitlyn. Melinda Brady joined CHF for 6 months during the year.

Relocation

During the year, the Secretariat relocated from Lyons to offices in Deakin: Unit 3, 3-5 Phipps Place, Deakin, ACT 2600 (Friday 11 August 2000). The telephone and fax numbers remained the same.

Contact details

Consumers Health Forum of Australia
PO Box 170
CURTIN ACT 2605

Telephone: (02) 6281 0811

Fax: (02) 6281 0959

E-mail: info@chf.org.au

Website: www.chf.org.au

Our Consumer Representatives

Health consumers are represented on 160 Government, Department of Health & Aged Care, and professional and research project committees. Representatives may be sought to represent the broad interests of health consumers, or to represent CHF, sometimes alongside other consumer groups.

Consumer representatives are chosen by canvassing member organisations for people with the necessary skills, experience or interest to be able to make an effective contribution to the work of the committee or working party. A Consumer Representatives Subcommittee of the Forum chooses the representative from the nominations received.

CHF extends its thanks and appreciation to all consumer representatives for their dedication, enthusiasm and time devoted to the cause of consumer participation. Many consumer representatives are volunteers and not paid for their participation (except for travel and accommodation expenses incurred in attending the meeting). The Committees, together with the names of the consumer representatives, are provided below.

Year	No. of committees
1995/96	139
1996/97	127
1997/98	130
1998/99	118
1999/00	158
2000/01	160

Australian Bureau of Statistics
Health Survey Program Advisory Committee
Ms Manoa Renwick

**ACOSS and the Brotherhood of St
Laurence: Working Together to Improve
Dental Health Committee**
Ms Kay Robinson

Adelaide and Sydney Universities
S2/S3 Research Project
Ms Kathy Mott

Australian Cancer Network
ACN Council
Ms Sally Crossing

Australian Cancer Network
ACN Non Melanoma Guidelines
Mr Malcolm Whyte

Australian Cancer Network
ACN Prostate Cancer Working Party
Mr Ron Halpin

Australian Cancer Network
ACN Medical and Scientific Committee
Ms Sally Crossing

Australian Cochrane Centre
Steering Committee
Ms Rebecca Coghlan

**Australian Council on Healthcare
Standards**
ACHS Board
Mr Lou McCallum, Mr Russell McGowan

**Australian Council on Healthcare
Standards**
ACHS Council
Mr Russell McGowan

**Australian Council on Healthcare
Standards**
Standards Committee
Mr Hanno Stanojevic

**Australian Council on Healthcare
Standards**
ACHS Day Surgery Working Group
Ms Lorraine Glover

**Australian Council on Healthcare
Standards**
Guidelines & Indicators for Dental Services
Ms Maxine Drake

Australian Gastroenterology Institute
Mr Clive Glover

Australian General Practice Accreditation
Board Director
Ms Kathy Mott

Australian Health Ministers Advisory Committee

National Drugs & Poisons Schedule Committee: Revision of First Aid Directions on Labels Working Party
Ms Margaret Charlton

Australian Institute of Health & Welfare

National Screening Information Advisory Group
Ms Carlene Butavcius

Australian Medical Council

Interim Advisory Committee on the Recognition of Medical Specialities
Ms Sally Crossing, Ms Kirsty Machon

Australian Medical Workforce Advisory Committee

Anaesthesia Workforce Working Party
Ms Shirley Shaw

Australian Medical Workforce Advisory Committee

Radiology Working Party
Ms Ann White

Australian Patient Safety Foundation Inc

Ms Margaret Charlton

Australian Pharmaceutical Advisory Council

APAC Council
Mr Mitch Messer

Australian Pharmaceutical Advisory Committee

APAC Subcommittee on the Intentional Misuse of Pharmaceuticals
Mr Timothy Moore

Australian Pharmaceutical Advisory Council

APAC Standing Committee on Consumer Medication Information
Ms Sarah Fogg

Australian Pharmaceuticals Manufacturers' Association

APMA Code of Conduct Committee
Ms Sarah Fogg

Australian Prescriber Editorial Board

Advisory Board
Ms Lynne Hancock

Australian Red Cross

Independent Review Panel for HTLV-1
Mr Geoff Sue

Australian Self-Medication Industry

ASMI Promotional Monitoring Committee
Mr Derek Weir

Brisbane North Division of General Practice General Practice: Building on Quality Project

Mr Lou McCallum

Cancer Council NSW

Board
Ms Sally Crossing

Cancer Council NSW

Cancer Control Network Governing Committee
Ms Sally Crossing

Centre for Health Economics Research & Evaluation

Economic Analysis in the Formulation of Clinical Practice Guidelines
Ms Sheila Rimmer

Clinical Oncological Society of Australia

Guidelines for Colorectal Cancer
Mr Clive Glover

Clinical Oncological Society of Australia

Consumer Advocacy Network Steering Committee
Mr Russell McGowan

Consumer Law Centre Victoria Ltd

Ms Meredith Carter

Department of Health & Aged Care

Australasian Cochrane Centre Review Groups Selection Committee
Ms Rebecca Coghlan

Department of Health & Aged Care

General Practice Well-Being Project
Ms Tatiana Borisow

Department of Health & Aged Care

Development of a National Sexual Health Strategy Reference Group
Ms Sera Pinwall

Department of Health & Aged Care
Evaluation of the Australian Childhood
Immunisation Register Steering Committee
Ms Maxine Drake

Department of Health & Aged Care
National Reference Group for the Partnership
Project
Mr Fred Delbridge

Department of Health & Aged Care
Breast Screen Australia Advisory
Committee
Ms Sue Lockwood

Department of Health & Aged Care
National Resource Centre for Consumer
Participation in Health Advisory Group
Mr Matthew Blackmore

Department of Health & Aged Care
Cancer Strategies Working Group
Mr Clive Deverall

Department of Health & Aged Care
National Evaluation Reference Group for
Coordinated Care Trials
Ms Sue Pluck

Department of Health & Aged Care
National Immunisation Advisory Committee
Ms Jenni Howlett

Department of Health & Aged Care
Quality Use of Pathology Committee
Ms Sally Crossing

Department of Health & Aged Care
Southern Tasmania After Hours Primary
Medical Care Trials
Ms Robin Wilkinson

Department of Health & Aged Care
General Practice Immunisation Incentives
Advisory Group
Ms Irene Shaw

Department of Health & Aged Care
National Health Priority Action Council
Ms Hilda Bastian

Department of Health & Aged Care
GP Data Model & Core Data Set Steering
Committee
Ms Heather Grain

Department of Health & Aged Care
Podiatric Surgery Trial in Melbourne Steering
Committee
Ms Rebecca Coghlan

Department of Health & Aged Care
Better Medication Management Systems
(BMMS) Hospital Working Group
Ms Judith Skinner

**Department of Health & Human Services,
Tasmania**
Home & Community Care Program Advisory
Committee
Ms Robin Wilkinson

Department of Health & Aged Care
Locum Services Review Group
Ms Debra O'Connor

Department of Health & Aged Care
Chronic Disease Self-Management Education
& Guidelines Technical Advisory Committee
Mr Lou McCallum

Department of Health & Aged Care
Better Medication Management Systems
(BMMS) Development Group
Ms Helen Hopkins

Department of Health & Aged Care
Steering Committee to oversee the
implementation of the private health insurance
industry key features statement
Mr Matthew Blackmore

Department of Health & Aged Care
GP Links Amalgamation Incentives Program
Steering Committee
Ms Judith Skinner

Department of Health & Aged Care
National Immunisation Strategy Development
Group
Ms Jenni Howlett

Department of Health & Aged Care
Better Medication Management Systems
(BMMS) Technical Working Group
Ms Sue Healy
Ms Heather Grain

Department of Health & Aged Care
Blood and Blood Product Working Party
Mr Christopher Carter

Department of Health & Aged Care

Bowel Screening Pilot Implementation Committee

Mr Russell McGowan

Department of Health & Aged Care

Private Health Industry Quality Working Group

Mr Christopher Newell

Department of Health & Aged Care

Statutory Immunity Advisory Group

Ms Robin Toohey

Department of Health & Aged Care

Working Group to oversee the implementation of the recommendations from the review of the pre-existing ailment rule

Mr Matthew Blackmore

Department of Health & Aged Care

Better Medication Management Systems (BMMS) Evaluation Working Group

Ms Sue Pluck

Department of Health & Aged Care

Tender Evaluation Committee for Positron Emission Tomography Services

Mr Clive Deverall

Department of Health & Aged Care

Surgically Implanted Prostheses & Homograft Items Committee

Ms Karen Carey-Hazell

Department of Health & Aged Care, NT

NT Rural Health Strategy Advisory Group

Ms Liz Scott

Department of Health & Aged Care, NSW

Risk Management Strategy

Ms Sylvia Shepherd

Department of Human Services SA

South Australian Safety & Quality Council

Ms Pam Moore, Mr Gerald Graves

Dietitians Association of Australia

Council on Dietetic Standards Recognition

Ms Sheila Rimmer

Divisions Development Advisory Committee

Subcommittee Divisions Data Sub-Group

Ms Debra O'Connor

Divisions of General Practice

Divisions National Consortium on Quality Use of Medicines for General Practitioners

Polypharmacy in the Elderly Project

Ms Nancy Pierce

Electronic Distribution Working Group

Mr Bill Willcox

Federal Privacy Commissioner

Reference Group for Health Privacy Guidelines

Ms Helen Hopkins

General Practice Computing Group

Management Committee

Ms Debra O'Connor

General Practice Computing Group

Electronic Health Records Architecture Working Group

Ms Debra O'Connor

General Practice Partnership Advisory Council

Divisions Subcommittee

Ms Sheryl Rainbird

Health Insurance Commission

Consumer Advisory Committee

Ms Debra O'Connor

Health Insurance Commission

Consumer Advisory Committee (CAC)

Ms Amanda Cornwall

Heart Foundation of Australia

Cardiovascular Disease National Minimum Data Set (CVD~NCaMDS) Working Group

Ms Dianne Spilsted

Medicare Services Advisory Committee

Ms Hilda Bastian

Medicare Services Advisory Committee

MSAC Lung Volume Reduction

Mr David Martin

Medicare Services Advisory Committee

MSAC Visual electrodiagnosis

Mr Frank Fisher

Medicare Services Advisory Committee

Reference 04a, nuchal fold translucency screening supporting committee
Ms Dell Horey

Medicare Services Advisory Committee

Near patient cholesterol testing supporting committee
Mr Cyril Wyndham

Medicare Services Advisory Committee

Autogenous cartilage transplantation supporting committee
Ms Shirley Shaw

Medicare Services Advisory Committee

Fragile X Syndrome supporting committee
Ms Denise Birney

Medicare Services Advisory Committee

C-I-C Treatment of Hepatic Metastases supporting committee
Mr Russell McGowan

Medicare Services Advisory Committee

Rotational Atherectomy (Rotablator) supporting committee
Mr Ivan Kayne

Medicare Services Advisory Committee

Review of Magnetic Resonance Imaging (MRI) supporting committee
Mr Leo Pomery

Medicare Services Advisory Committee

Review of Transoesophageal Echocardiography supporting committee
Mr Tony Wilkinson

Medicare Services Advisory Committee

Minimally invasive direct coronary artery bypass surgery performed off pump supporting committee
Mr Peter Edwards

Medicare Services Advisory Committee

Intravascular Brachytherapy supporting committee
Mr Ivan Kayne

Medicare Services Advisory Committee

Treatment of heart failure by permanent tri-chamber resynchronisation supporting committee
Mr Ivan Kayne

Medicare Services Advisory Committee

Trombophilia testing in pregnancy supporting committee
Ms Rosi Trencher

National Cancer Control Initiative

A clinical registration common data set
Ms Rosetta Manaszewicz

National Cervical Screening Program

Quality Assurance Working Group
Ms Cathy Reade

National Health & Medical Research Council

Ms Michele Kosky

National Health & Medical Research Council

Australian Health Ethics Committee
Mr Robert Griew

National Health & Medical Research Council

NHMRC Dietary Guidelines for Older Australians Expert Panel
Mr Frank Fisher

National Health & Medical Research Council

HAC (Health Advisory Committee) Guidelines for the Prevention, Early Detection & Management of Colorectal Cancer
Mr Clive Glover

National Health & Medical Research Council

HealthInsite – Interim Editorial Board
Ms Sue Healy

National Health & Medical Research Council

Development of Guidelines for Water Quality Management Coordinating Group
Mr Alec Percival

National Health & Medical Research Council

HAC Review Recommendations on Responsible Drinking Behaviour
Mr Donald Cameron

National Health & Medical Research Council

NHMRC Xenotransplantation Working Party
Mr Twanny Farrugia

NHMRC Strategic Research Development Committee

Ms Nancy Pierce

National Health & Medical Research Council

Clinical Practice Guidelines for the
Diagnosis of Persistent Vegetative States
Ms Mary Baumgarten

National Health & Medical Research Council

Mental Health Research Working Group
Ms Suzanne Knapman

National Health & Medical Research Council

Electromagnetic Energy Research Committee
Mr Clive Deverall

National Information Service

NIS GP Evaluation Program Advisory Group
Ms Robin Toohey

National Prescribing Service

NPS Board
Ms Jan Donovan

National Prescribing Service

NPS Program Information/Communication
Working Group
Ms Jan Donovan

National Prescribing Service

Program Prescribing Interventions & Feedback
Ms Rebecca Coghlan, Ms Sarah Fogg

National Prescribing Service

Program Telephone Advisory Service,
Rural Working Group
Ms Carolyn Lyons

National Public Health Partnership

Advisory Group
Mr Lou McCallum

Newcastle Mater Hospital Radiation Oncology

Re-Certification Committee
Ms Sally Crossing

NHMRC/Newcastle Bone & Joint Institute Guidelines for Acute Low Back, Neck and Shoulder Pain

Ms Rebecca Coghlan

Northern Territory Remote Health Workforce Agency Board

Ms Liz Scott
Mr Brian McCarthy

Northern Territory Remote Health Workforce Agency

GP Training in the Northern Territory
Working Party
Ms Liz Scott

Pharmaceutical Benefits Advisory Committee

Mr Matthew Blackmore

Pharmaceutical Benefits Pricing Authority

Mr Geoff Honnor

Professional Services Review

Determining Authority
Ms Michele Kosky

Australia Self Medication Industry

Complaints Panel
Ms Fran Hausfeld

Quality Assurance Reference Group

Consumer Medicines Information
Ms Fran Hausfeld

Royal Australian College of General Practitioners

Outcomes Evaluation Advisory Committee
Ms Jenna Bateman

Royal Australian College of General Practitioners

Chronic Fatigue Syndrome Guidelines
Working Party
Mr Craig Ellis

Royal Australian College of General Practitioners

RACGP Ethics Committee
Mr Andrew Allen

Royal Australian College of General Practitioners

RACGP Practice Standards Committee
Ms Sue Pluck

Royal Australian College of General Practitioners

RACGP Quality Assurance and Continuing Education

Ms Heather Johnson

Royal Australian College of Physicians

Clinical Support Systems Project Reference Group

Mr Lou McCallum

Royal Australian College of Surgeons

Australia Safety & Efficacy Register for New Interventional Procedures – Surgical (ASERNIPS)

Ms Wendy Brown

Royal College of Nursing Australia

RCNA Palliative Care Making the Difference Reference Group

Ms Barbara Crane

Royal College of Nursing Australia

RCNA Accreditation & Credentialling Feasibility Study Management Committee

Ms Dawn Thorp

Safety and Quality Council

Consumer Reference Group

Mr Matthew Blackmore

Safety and Quality Council

Consumer Working Group

Mr Lou McCallum

Speech Pathology Australia

Ethics Board

Mr Peter Dhu

Standards Australia

IT/14 Health Informatics Committee

Ms Heather Grain

Standards Australia

HE/1/8 Packaging Systems & Devices Subcommittee

Ms Mary Davies

The Pharmacy Guild of Australia

Selection Committee of the Research and Development Grants Program

Ms Stephen Gallagher

The University of Melbourne

Action on Health Inequalities through General Practice: Enhancing the role of RACGP

Reference Group

Ms Tatiana Borisow

Therapeutic Device Evaluation Committee

TDEC Committee

Ms Wendy Brown

Therapeutic Device Evaluation Committee

TDEC Device Tracking Advisory Panel

Ms Wendy Brown

Therapeutic Goods Administration

European Harmonisation of Medical Devices Working Party

Ms Wendy Brown

Therapeutic Goods Administration

Disinfectant Working Group

Ms Jude Byrne

Therapeutic Goods Administration

Trans Tasman Co operation on Therapeutic Products Liaison Group

Mr Tony Wade

Therapeutic Goods Administration

National Drugs & Poisons Scheduling Committee

Rebecca Coghlan

Therapeutic Goods Administration

PAC (Project Advisory Committee) ELF

Listing of Drug Products

Ms Karen Carey-Hazell

Therapeutic Goods Administration

Crisis Management Task Force

Ms Helen Hopkins

Therapeutic Goods Advertising Code Council

Mr Derek Weir

Therapeutic Goods Committee

Child Resistant Packaging Subcommittee

Ms Mary Davies

Therapeutics Goods Administration Code Council

Complaints Resolution Panel

Mr Derek Weir

Our Members

CHF comprises a wide variety of consumer organisations, which represent a broad range of health consumers such as illness groups, disability groups and specific population groups such as youth, older people and women. CHF comprised 104 Voting members and 150 Associate members in 2000/2001.

Voting members

Voting members of CHF are organisations that:

- represent consumer and community opinions and do not act primarily as representing professional, provider or commercial interests
- has membership open to consumers who can be elected to the bound or governing body of the organisation
- has aims and objectives that are significantly for representation of the opinions of consumers
- fully support the aims and objectives of the Consumers' Health Forum.

A

ACCESS Australia National Infertility Network Ltd
ACT ME/CFS Society Inc
ACT Repetitive Strain Injury Support Group
Action Research Issues Association Inc
AIDS Council of NSW
Allergy and Environmental Sensitivity Support and Research Association
Anorexia Bulimia Nervosa Association Inc
Arthritis Foundation of Australia
Arthritis Victoria
Asthma Australia
Australian Association for the Welfare of Child Health
Australian Breastfeeding Association
Australian Chemical Trauma Alliance Inc
Australian Complementary Health Association
Australian Council of Social Service
Australian Crohns and Colitis Association
Australian Federation of AIDS Organisations
Australian Hepatitis Council
Australian Mental Health Consumer Network
Australian Multiple Birth Association
Australian Pensioners' and Superannuants' Federation
Australian Quadriplegic Association

Australian Women's Health Network

B

Breast Cancer Action Group NSW
Breast Cancer Action Group Inc
Breast Cancer Network Australia
Brisbane Consumers' Association

C

Carers Association of Australia
Child Health Association Inc
Club SPERANZA
Coeliac Society of NSW Inc
Continence Foundation of Australia Ltd
Council on the Ageing Australia
Council on the Ageing SA
Country AIDS Network Vic Inc
Cystic Fibrosis Association of Victoria Inc
Cystic Fibrosis Australia Inc
Cystic Fibrosis WA

D

DES Action Australia NSW
Diabetes Australia
Diabetes Australia ACT
Diabetes Australia SA
Diabetes Australia NSW
Diabetes Australia QLD
Donor Conception Support Group of Australia Inc
Disability Support Pensioners Australia Inc

F

Federation of Ethnic Communities' Council of Australia

G

Geelong Mental Health Consumers Union

H

Haemophilia Foundation Australia
Headway Victoria
Health Care Consumers' Association of the ACT
Health Consumers' Council WA Inc
Health Consumers Network NSW Inc
Health Consumers of Rural and Remote Australia Inc
Health Issues Centre
Health Rights & Community Action
Heart Support Australia
Hepatitis C Council of NSW Inc
Hornsby Ku-ring-gai Association Action for Mental Health
Hunter Urban Network for Consumers of Healthcare

L

Lower Hunter Health Council

M

Maternity Coalition Inc
Medical Consumers Association NSW
Mental Health Association QLD Inc
Mental Health Co-ordinating Council
MS Victoria

N

Narcolepsy & Overwhelming Daytime Sleep
Society of Australasia Inc
National Assoc of People Living with
HIV/AIDS
Northern Rivers ME/CFS/FM Support Assoc
NSW Association for Mental Health Inc

O

Obsessive Compulsive Disorders Support
Service
Older Persons' Action Centre
Older Women's Advisory Committee SA
Older Women's Network Australia Inc
Older Women's Network Inc NSW
Ovarian Cancer Awareness

P

Palliative Care Australia
People Living with HIV/AIDS NSW Inc
Post-Polio Network NSW Inc
Public Interest Advocacy Centre

Q

Queensland Council of Social Service
Queensland Rural Women's Network Inc
Queensland Women's Health Network Inc

S

Schizophrenia Fellowship of SA
Self Help Queensland Inc
Shellharbour District Community Health
Watch
Shoalhaven North Health Consumers Action
Group
SIDS Australia
Sleep Apnoea Association
SOMA Health Association of Australia
South Australian Consumer Reps Network
South Australian Council of Social Service
Stillbirth and Neo-natal Death Support NSW
Stillbirth and Neo-natal Death Support QLD
Support & Advocacy Committee of Prostate
Cancer Foundation of Australia

T

Tasmanians with Disabilities Inc
The Link Youth Health Service
Tranquilliser Recovery and New Existence Inc

V

Victorian Mental Illness Awareness Council

W

WA Association for Mental Health
Wollongong Health Consumers Advisory
Group
Women's Health Victoria Inc

Associate Members

Associate members of CHF are professional
and service organisations that support the aims
and objectives of CHF.

A

Aboriginal & Islander Community Health
Service
Adelaide Central Community Service
Alison Hunter Memorial Foundation
Alliance of NSW Divisions Ltd
Anti-Cancer Foundation of South Australia
Australian Self medication Industry
Asthma Victoria
Australian Nursing Homes & Extended Care
Association
Australian Association of Consultant Pharmacy
Australian Cancer Society
Australian College of Health Service Executives
Australian College of Midwives Inc
Australian Crohns & Colitis Association (Qld)
Australian Institute of Health & Welfare
Australian Nursing Council Inc
Australian Nursing Federation (Vic Branch)
Australian Physiotherapy Association
Australian Physiotherapy Association (NSW)

B

Ballarat & District Division of General
Practice
Brisbane Southside Central Division of
General Practice

C

Canning Division of General Practice Ltd
Carers Association of Victoria Inc
Caroline Chisholm Centre for Health Ethics
Central Australian Division of GP Inc
Central Highlands Division of General Practice
Centre for Health Services Research

D

Doctors Reform Society NSW Inc

F

Family Planning Australia Inc

G

General Practice Divisions of Western
Australia

GlaxoSmithKline

Goulburn Valley Division of General Practice
GP North

Greater Bunbury Division of General Practice

H

Health Department of WA

Health Outcomes Policy and Planning

Health Services Management Group

Healthy Cities Illawarra

Hornsby Ku-ring-gai Ryde Division of
General Practice

I

Illawarra Area Health Service

Ipswich & West Moreton Division of General
Practice

L

Liverpool Women's Health Centre

M

Mackay Community Health Centre

Mallee Division of General Practice

ME/CFS Society of Victoria Inc

Mornington Peninsula Division of General
Practice

N

National Asthma Campaign

National Heart Foundation

National Musculoskeletal Initiative of the
Newcastle Bone & Joint Institute

North East Valley Division of General Practice

North East Victorian Division of GP

North West Melbourne Division of General
Practice

North West Tasmania Division of GP

Northern Metropolitan Community Health
Service

Northern Queensland Rural Division of
General Practice

Northern Rivers Division of General Practice

Northern Sydney Area Health Service

NSW Central West Division of General
Practice

NSW Nurses' Association

NSW Therapeutic Assessment Group Inc

P

Paraplegic & Quadriplegic Association of Qld
Pfizer Pty Ltd

Pharmaceutical Society Australia

Pharmacy Guild of Australia

Q

Queensland Cancer Fund

R

Redcliffe Bribie Caboolture Division of
General Practice

Royal College of Nursing, Australia

Royal Flying Doctor Service (Australia
Council)

Rumbalara Aboriginal Cooperative

S

Sherbrooke Pakenham Division of General
Practice

Society of Hospital Pharmacists of Australia

South East NSW Division of General Practice

South Western Sydney Area Health Service

Southern Area Health Service

Southern Child & Adolescent Mental Health
Service

Southern Division of General Practice

Southern Division of General Practice - South
Australia

Southern Tasmanian Division of General
Practice

Speech Pathology Australia

St George District Division of General
Practice

St Joseph's Hospital

Sunshine Coast Division of General Practice

Sydney Counselling Centre

Sydney Legacy Appeals Fund

T

The Pharmaceutical Alliance

Top End Division of GP

W

Wentworth Area Health Service

West Victorian Division of GP

Westgate Division of Family Medicine

Women's Health West

Women's Health Queensland Wide Inc

Y

Yarra Valley Division of General Practice.