



healthUPdate

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Seasons greetings

The Secretariat staff and Governing Committee thank all CHF members and consumer representatives for their valued contributions to health care in Australia over the past year. Together we have been able to shape health in Australia in many different areas and have developed excellent relationships with other health stakeholders.

We wish you a restful break and look forward to working with you again in 2008 to continue to seek safe, good quality health care for everyone in Australia.

Holiday office hours

The CHF Secretariat will be closed from COB Friday 21 December and will reopen at 9.00 am on Wednesday 2 January 2008.

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A good year for CHF

As 2007 comes to a close, we are pleased to say that it has been a productive year. The new CHF corporate logo reflects the change that has occurred for health consumers – recognition as equal partners with other stakeholders in shaping health. The hands on the logo represent consumers, governments and health providers.

The team of four policy staff wrote information papers in each project area, made 16 submissions, conducted 20 consultations around the country and attended numerous meetings to present consumer perspectives to health stakeholders in our three priority areas: safety and quality in health care; health care for people with chronic conditions; and quality use of medicines.

Through policy work and advocacy, we have contributed to national debate on the PBS reforms, Private Health Insurance Reforms, access card, National E-Health Transition Authority, Prostheses Review, quality use of medicine and chronic condition self-management. We have continued to develop excellent working relationships with health stakeholders and our partners in health care, including the Australian Commission on Safety and Quality in Health Care, which has recognised the importance of involving consumer perspectives as it rolls out its work plan.

The consumer representatives program made significant contributions on behalf of consumers. In particular, consumer representation led to the Medical Services Advisory Committee decision to include consumer issues in all its evaluation reports for new technology.

To improve our communications, CHF now publishes *HealthUpdate* twice-monthly and has introduced a bi-monthly newsletter *Consumers Shaping Health* to promote CHF positions to health stakeholders and government. Our media profile has increased with the monthly Patient Perspective column in *The Weekend Australian*. Direct communications with members will improve with the roll out of our new database of members in the new year.

We published three brochures to help consumers use e-health information and co-branded seven fact sheets on medicines with the National Prescribing Service as part of the Community Quality Use of Medicines Program.

A date to remember

CHF will celebrate its 21st birthday with a summit at Old Parliament House in Canberra on 16 October 2008.

Members, consumer representatives and health stakeholders will be invited to join us as we celebrate our achievements over the last 21 years and look forward to the challenges of the next decade.

From the Secretariat

(continued from page 1)

As we head into the new year, we look forward to a continuation of current projects, some new projects, and the development of a pilot, with the Pharmaceutical Benefits Advisory Committee (PBAC), of consumer impact statements for particular health conditions to inform decisions about Pharmaceutical Benefits Scheme listing. The pilot is being developed in consultation with the Chair, Secretary and consumer member of the PBAC with funding from the Australian Government Department of Health and Ageing.

Strong consumer voice needed

The Australian Health Care Agreements (AHCA), which set the relationship between the Australian Government and the states and territories regarding health funding and expectations, are due to be negotiated by June 2008.

CHF is keen to put a strong consumer position to the Australian Government on consumers' expectations of what the AHCA should deliver. We are hoping that members will also take up the cause at state or national level as appropriate.

CHF welcomes input from members about the positions CHF could take. Some suggestions include: better care coordination across the health system; and implementation of improvements to the Patient Assisted Travel Scheme. We will develop this work in the new year to achieve a strong and coordinated consumer voice on key messages relating to AHCA.

Please send your suggestions to Helen Hopkins at info@chf.org.au.

In the news

CHF warns about health insurance premium rise

CHF Chairperson Mitch Messer was quoted in the Melbourne Herald Sun saying that consumers may have to choose to dump private health insurance if health insurance premiums increased next year. He asked government to look closely at the rises being sought before approving them.

To see the full article, cut and paste the following link into your web browser
<http://www.news.com.au/heraldsun/story/0,21985,22915695-662,00.html>.

Mackay media shows interest

Two consumer consultations in Mackay in early December attracted local media attention. The ABC and 4CRM Radio (Community Radio Mackay) ran interviews on the consultations, which explored access to health care, open disclosure and health rights (see Project page for more information).

Adverse effects of biphosphonate medicines

An ABC report on the incidence of osteonecrosis of the jaw as a side-effect of biphosphonate medicines used for osteoporosis and cancer treatment was published on ABC Radio PM and the 7:30 Report on 11 December. CHF Executive Director had given background information and an interview on the need for better Consumer Medicines Information about the possibility of side-effects and the need for doctors to discuss side-effects and options with the consumer ahead of treatment. She emphasised the importance of good post-marketing monitoring to pick up early warnings of side-effects so doctors and the community knew how best to use needed medicines safely.

Advocacy

Chairperson writes to Minister

CHF Chairperson Mitch Messer has written to the Minister for Health and Ageing Nicola Roxon to congratulate her on her appointment and to seek an opportunity to visit her and discuss health consumer priorities.

He said CHF was seeking a recognised consumer voice on the new National Health and Hospitals Reform Commission to ensure the people who use the health system contribute to policy decisions. He noted that Ms Roxon had recognised the fundamental call of CHF that everyone has the right to safe, good quality health care when and where they need it.

National Stakeholder Accreditation Workshop

On 30 November, CHF Chairperson Mitch Messer attended a National Stakeholder Accreditation Workshop hosted by the Australian Commission on Safety and Quality in Health Care. Twenty other consumer representatives nominated by CHF including Policy Officer Sarah Jones attended with 160 other stakeholders representing a diverse group of health providers.

The draft paper *An Alternative Model for Safety and Quality Accreditation November 2007* formed the basis of discussions. The workshop explored areas where previous consultations had not provided a clear direction or where significant differences remained between stakeholders. Participants also had the opportunity to raise specific concerns in relation to safety and quality in health care and accreditation.

Morning discussions focussed on the guiding principles for the alternative model while the afternoon discussions looked at the role of consumers in the accreditation process. Consumer participants said the workshop was very useful and were pleased at the recognition given to consumer perspectives.

Organisational policies 2007

The Governing Committee is committed to best practice in governance. During 2007 CHF developed and reviewed a range of organisational policies.

Major policy initiatives included the development of:

- a succinct, updated *Privacy Policy*
- a *Health Policy Development Process* that highlights that CHF is committed to a transparent, best practice and consistent process in accordance with the Strategic Plan
- budget and Financial Reporting Principles
- a description and terms of reference for the Speakers' Program

Some of the major policies that were reviewed and amended were in the areas of ethical expectations (*Code of Conduct* and *Grievance Procedure*), finance (*Asset Management Policy*) and organisation and structure, including the description and terms of reference for Strategic Committees and Key Consumer Representatives Program Committees.

The CHF policy manual index is on the website and CHF will provide a current policy to a voting member on request for assistance with their own policy development.

Project updates

E-health for consumers

What's next in e-health?

CHF held an e-health industry and consumer workshop with the theme 'What's next in e-health' in Sydney on 27 November. The workshop was an exciting opportunity for a small group of consumer representatives, industry, government and health provider representatives to discuss e-health success stories and sticking points in order to focus on practical next steps for making e-health work for consumers.

Participants at the workshop included representatives from the Australian General Practice Network, National E-health Transition Authority (NEHTA), Health Informatics Society of Australia, Intel and the Australian Commission of Safety and Quality in Healthcare.

CHF challenged the participants that the real consumers of e-health are the people who are using the internet for their health information and expecting better service provision and coordination through e-health. NEHTA Chief Executive Officer Ian Reinecke spoke about NEHTA's progress on e-health building blocks. Participants also heard four e-health success stories and identified next steps to progress the e-health agenda for consumers.

A report from the workshop will be available on the CHF website's e-health project page early next year.

The E-health for Consumers project is funded by the Australian Government Department of Health and Ageing.

I would like to thank everyone who has been involved in the project over the year and I wish everyone a safe and happy holiday season.

Catherine Ellis
Policy Officer

Safety and Quality Project 2007-08: It's all about communication

Open disclosure on the agenda

Four events on open disclosure in the past fortnight have reinforced that consumers want to be kept informed and involved in their health care, particularly when something goes wrong.

Multi-cultural and Indigenous residents of Mackay told two CHF workshops on 3 December how they would like to see open disclosure working. Their perspectives were reflected by representatives at two national teleconferences co-facilitated by CHF and the Australian Commission on Safety and Quality in Health Care.

Key messages were:

- Consumers want honest, detailed and timely communication when something goes wrong in their health care.
- Consumers want an apology, or at least a sincere expression of regret that something has gone wrong.
- Consumers want to know the outcomes of open disclosure processes, to know that something has changed to ensure that errors do not reoccur.
- Communication during the open disclosure process must be culturally sensitive.
- Consumers want to see high level national support for the implementation of the National Open Disclosure Standards.

CHF held the Mackay workshops in partnership with the Mackay Division of General Practice and the Aboriginal and Torres Strait Islander Community Health Service Mackay respectively.

The key messages above were reinforced by an emphasis on the need for consumers to be kept informed in culturally sensitive language they can understand. Participants also asked to be told the outcome of any investigation into their adverse event and how the system would be changed to prevent it happening to anyone else.

Mackay has similar problems to many other regional and rural areas of Australia around access to health care. The need to travel to other cities for specialist care added emotional stress to patients and their families and caused significant financial burden that was not adequately covered by the Patient Assistant Travel Scheme.

The two national teleconferences included 11 consumer representatives from six Australian states and territories. Information from the teleconferences will help inform the recommendations from the internal evaluation of the Safety and Quality Commission's Open Disclosure Pilot Projects, with decisions on the future of the Open Disclosure project due early next year.

Charter of health rights consultation

The Australian Commission for Safety and Quality in Health Care, in collaboration with CHF, will conduct two National Stakeholder Round Table meetings as part of the consultations around the development of a National Patient Charter of Rights. CHF advocated strongly for the meetings, which will seek input from consumers and health care providers on the role, content and implementation of the charter.

The meetings, in Sydney on 27 February and Melbourne on 29 February, will include 6-10 consumer representatives and 6-10 other stakeholder representatives. Nominations to attend will be called in the next edition of HealthUpdate. CHF will develop an information paper and questionnaire for members on the draft charter to help inform the development of the CHF submission to the Safety and Quality Commission.

This project is funded by the Australian Commission on Safety and Quality in Health Care.

Sarah Jones
Policy Officer

Implementing Private Health Reforms: Consumers have a say

Consumers discuss inadequacies of health care for consumers with chronic conditions

Greater access to coordinated health services are needed for consumers with chronic conditions. This was the message given to CHF at its consumer discussion sessions in Melbourne and Sydney last month, run as part of its *Implementing Private Health Reforms: Consumers have a say 2007-08* Project.

The sessions were co-hosted by CHF and Multiple Sclerosis Victoria and NSW in association with the Chronic Illness Alliance of Victoria and NSW respectively.

They explored what care coordination services are currently available to consumers with chronic conditions within the public health system, and discussed reforms to private health insurance which now allow funds to cover broader health products and services, such as chronic disease management programs.

Consumers considered the value of Enhanced Primary Care plans, which allow consumers with chronic medical conditions to claim Medicare rebates for allied health services once they have a management plan in place with their GP. They said the uptake and communication of these programs by GPs is limited and suggested that a clinic nurse may be better placed to manage such programs. Authority to implement such plans could be extended to a broader range of health care professionals to allow better access to such programs.

CHF will run six more consumer discussion sessions in the first half of 2008 to further inform this project, which is funded by the Australian Government Department of Health and Ageing.

New health technologies and medical devices workshop a success

Nineteen CHF members and consumer representatives attended the workshop on new technologies and medical devices in Canberra on 10-11 December 2007 to consider consumer issues relating to how new health technologies and medical devices (including prostheses) are approved for marketing in Australia and how they are monitored for safety, quality and cost effectiveness once in use. They also had the opportunity to consider and share views on the recommendations from the recent review of the prostheses list arrangements.

During a stakeholder panel session with representatives from the Therapeutic Goods Administration, Medical Industry Association of Australia and Australian Private Insurance Association, participants asked

questions and heard stakeholder perspectives. CHF consumer representatives involved in the Prostheses and Devices Committee and the National Joint Replacement Register also spoke.

The workshop discussions and format were influenced by responses received to the CHF 'New health technologies, medical devices and prostheses' information paper. CHF would like to thank all those who responded to the paper and attended the workshop for their valuable contributions.

The workshop outcomes will be published on the CHF website early next year and will assist CHF to pursue its policy work around health technology assessment, develop guidance for consumer representatives on health technology committees and support more informed choices for consumers.

See the information paper at

http://www.chf.org.au/Docs/Downloads/462_New_health_technologies_medical_devices_prostheses.pdf.

Tamara Shanley
Policy Officer

Health News

Safety and quality forum calls for abstracts

The 2008 National Forum on Safety and Quality in Health Care has the theme 'Safety and quality is everyone's business'. It will be held in Adelaide on 29-31 October 2008 and be hosted by the Australian Council on Healthcare Standards in collaboration with the Australian Commission on Safety and Quality in Health Care and the South Australian Department of Health.

Any interested parties, including health consumers, have been invited to submit abstracts on a forum theme: workforce, evidence into practice, knowledge and information management, and governance and accountability. Abstracts can be for either an oral presentation in a formal concurrent session or a poster presentation. Abstract submissions close 3 March 2008.

If you need any assistance with drafting your abstract please contact Sarah Jones, CHF Policy Officer.

For more information, go to <http://www.sapmea.asn.au/forumsqhc2008>.

Frank Fisher wins environment award

CHF congratulates CHF Governing Committee member Frank Fisher on his award as the Inaugural Australian Environmental Educator of the Year for his contribution to promoting the environment and sustainability over the last 30 years.

The Australian Association for Environmental Education Inc is a national professional association that represents and advocates for the interests of environmental education and educators. Frank was nominated for the award by the Association's Victorian Chapter.

Frank was Director of the Graduate School of Environmental Science at Monash University until 2005 and is currently an Associate Professor and Director of the Understandscope within the Faculty of Medicine, Nursing and Health Sciences. He is also an Adjunct Professor at the Swinburne University of Technology National Centre for Sustainability. He lectures graduate students and holds public forums on the environment in Melbourne's Federation Square.

New resource for women with disabilities

CHF member Women With Disabilities Australia has published a resource manual on violence against women. The manual comprises four booklets: *A Life Like Mine! – Narratives from women with disabilities who experience violence*; *Forgotten Sisters – A global review of violence against women with disabilities*; *It's Not Ok It's Violence – Information about domestic violence and women with disabilities*; and *More Than Just a Ramp – A guide for women's refuges to develop disability discrimination act action plans*.

Order forms are available at <http://www.wwda.org.au/vrm2007.htm>.

Consumer Representatives Program

Vacancies

Consumer representatives are encouraged to apply for the following vacancies. Do not be discouraged if you are not successful the first time you apply as your application will assist us to know who might be interested when similar positions are offered in the future.

Nominees must complete a CHF nomination form, provide a current CV and a letter or email of endorsement from a Voting Member organisation of CHF or relevant consumer network. Please note that committee selection is based on your written application, which should address the selection criteria for the particular vacancy you are applying for.

The nomination form can be downloaded from the Members' Area of <http://www.chf.org.au> or by contacting CHF Committee Services Manager, Debbie Smith, on (02) 6273 5444 or d.smith@chf.org.au. Debbie can also provide further information about most committees. CHF has ensured that sitting fees and travel costs are paid for the following vacancy.

National Health and Medical Research Council (NHMRC) – National Human Genetics Information Site Working Group

The NHMRC Human Genetics Information site will provide a national gateway or portal for links to on-line genetics material available from peak professional and lay organisations, government agencies and educational and research institutions. Resources will cover genetic conditions, genetics services, genetics support groups and ethical, social and legal issues associated with the impact of genetics technologies. The target audience includes lay and professional communities, the general community, individuals and families affected by genetic conditions or at risk of a genetic condition and medical practitioners, allied health professionals and other professionals whose work has relevance to genetics conditions.

The National Human Genetics Information Site Working Group will provide direction on the content of the site to the project manager and NHMRC Webmaster. This group will comprise a health professional whose speciality is impacted by genetics issues; a genetics counsellor, a media representative, a consumer representative, a state representative and a representative from a genetics service provider.

It is expected the group will meet five times either face-to-face in Canberra or via teleconference.

Expressions of interest close 11 January 2008

Medicines Australia – Monitoring Committee

Medicines Australia is the peak industry body representing Australian research-based pharmaceutical companies. The Code of Conduct (the Code) sets out standards of conduct for pharmaceutical companies engaging in the marketing of prescription medicine products.

Code provisions include standards for appropriate advertising, the behaviour of medical representatives and relationships with health care professionals. The Code of Conduct has two arms, firstly the adjudication of complaints undertaken by the Code of Conduct Committee and, secondly, the proactive monitoring of promotional activities undertaken by the Monitoring Committee.

The Monitoring Committee monitors selected promotional activities of member companies, thereby supporting the quality use of medicines. CHF would like to thank Susan Mitchell for her contributions as the consumer representative on this committee. CHF also nominates a consumer representative to the Code of Conduct Committee (Sharon Caris) and the Code of Conduct Appeals Committee (Anne McKenzie and alternate representative, Patti Warn).

The Monitoring Committee meets in Sydney on the third Monday of each month.

Please note that consumers interested in nominating should include with their CV details of membership of Advisory Boards or any associations with individual pharmaceutical companies to ensure no conflict of interest with complaints or companies as sanctioned under the provisions of the Code.

Expressions of interest close 11 January 2008

Medical Services Advisory Committee (MSAC) Advisory Panels

Applications from new consumer representatives are encouraged for MSAC Advisory Panels.

The Medical Services Advisory Committee (MSAC) engages an independent contractor to conduct much of the evidence-based assessment of applications. This involves the development of an evaluation protocol, conducting a systematic literature review, and assessing the available evidence on the safety, efficacy and cost-effectiveness of the technology/procedure.

The role of the Advisory Panel is to oversee the evaluation and ensure that it is clinically relevant. The Advisory Panel meets with the contractor early in the process to provide guidance in determining the specific research questions, scoping the task and providing valuable clinical and consumer perspectives on the technology/procedure being considered.

Subsequent meetings are then held as necessary. This may not be until the contractor has completed a draft assessment report for the Advisory Panel's consideration. Development of the draft report takes approximately four to six months, depending on the complexity of the application.

The usual time commitment required of members is attendance at the initial half day meeting, generally held in Sydney or Melbourne, and participation in three to four teleconferences of 1-1.5 hours' duration.

MSAC Advisory Panel – Review of Application 1124 – Cryotherapy for Renal and Recurrent Prostate Cancer

Cryotherapy uses extremely cold liquid nitrogen (at -196°C) to freeze and destroy cells that need removal. Renal cryotherapy is relevant for older patients, those with other medical problems and as a kidney-sparing treatment particularly appropriate for those with pre-existing renal disease, single kidney or a genetic predisposition to renal cancers. It is a minimally invasive treatment for small localised renal cancer (less than 4cms) that has fewer complications than current surgical procedures and has been studied more than other minimally invasive therapeutic options.

Renal cryotherapy can be performed via laparoscopic surgery or, in selected cases, via a transcutaneous route (through unbroken skin). Both approaches have demonstrated low morbidity, reduced procedure time, reduced hospitalisation duration and reduced recovery time for patients.

Salvage cryotherapy provides a local treatment option for the difficult problem of recurrent prostate cancer. It has less procedural morbidity than the alternative salvage prostatectomy.

Expressions of interest close 11 January 2008

Reports

Royal Australian and New Zealand College of Radiologists Curriculum Advisory Committee

Pam Bell, Breast Cancer Network Australia

This is an important committee as it concerns the education of medical specialists. Involvement in the development of a new curriculum provides an opportunity for consumers to have input to training practitioners who can meet consumer's needs. One of the chief concerns for consumers when undergoing radiological procedures is patient safety. Another concern, relating to all medical practitioners, are the so-called non-medical skills involving patient communication and health advocacy.

The process of curriculum change is challenging because there is much competition for time and space in any professional education course. The RANZCR has offered consumer representatives equal time with medical representatives to present the patient's perspective and the other consumer representative and I are actively encouraged to contribute to the dialogue.

I sit on two curriculum advisory committees, Radiation Oncology and Diagnostic Radiology and have input into medical subjects as well as the non-medical expert roles which include patient communication, professional and health advocacy roles of the trainee radiologist. I am very impressed by the painstaking attention to detail that committee members bring to their deliberations regarding not only the skills required of the graduate radiologist but also patient safety. Attention is also paid to the training needs of the clinical supervisors of the trainees to ensure a uniform standard of assessment. Also very pleasing is the profession's awareness of the importance of the therapeutic relationship and the expectations of consumers.

Medical Services Advisory Committee (MSAC)

Sheila Rimmer AM, November 2007

Minutes from the previous meeting reported the Chair's agreement that a section on consumer issues, the patient's journey, be included in future assessment reports. All MSAC consumer representatives should ensure that this is included.

Despite this major step forward for consumers, work on MSAC can be difficult and sometimes frustrating. For example, consumer issues during discussion on one of the reports tabled at this session, consumer issues were dismissed as irrelevant to the technology considerations, despite empathy around the table.

The issue of streamlining assessments, already used in other countries, was discussed and thought appropriate in some cases.

Sheila's comments highlight the sometimes difficult and frustrating task experienced by consumer representatives working in the new health technology area where consumer issues may be apparent but dismissed as outside of a particular committee's terms of reference. This problem was discussed at the recent New Health Technologies and Medical Devices Workshop, which emphasised the need for consumer representatives to be able to identify where else in the health system a particular concern might be addressed. As a result of the workshop, CHF has some important input and a starting point from which to work with members and consumer representatives to better address this problem.

Other reports received

Amy Zelmer – RACGP Vocational Standards Reference Group

Diane Walsh – AGPAL Quality Carnivale Vision Committee 2008

Shirley Shaw – National Health Performance Committee

Brian Stafford – MSAC Reference 35b – PET for Colorectal Cancer and Melanoma

Isabelita McRae and Sheila Rimmer AM – Australian Medical Council – Specialist Education Accreditation Committee (full report next issue)

Seasons Greetings from CHF Staff

Helen Hopkins

Executive Director

Craig Hooper

Senior Policy Advisor

Catherine Ellis

Policy Officer

Sarah Jones

Policy Officer

Tamara Shanley

Policy Officer

Karolina Russell

Policy Officer

Helen Briggs

Policy Officer

Jan Finley

Director of Operations

Emma Awizen

Member Services Manager

Debbie Smith

Committee Services Manager

Penny Gibson

Communications Advisor

Janet Cameron

Office Manager

Health Calendar

17th Annual Medico Legal Congress 2008

Sydney, 27-29 February 2008

Website: <http://www.iir.com.au>

Involving People in Research Symposium

Perth, 5-6 March 2008

Website: <http://www.sph.uwa.edu.au/go/sph/involvingpeopleinresearch>

3rd Biennial National Conference on Anxiety and Depression

Melbourne, 3-4 April 2008

Website: <http://www.reconnexion.org.au>

The 4th International Conference in Primary Health Care

Melbourne, 17-19 April 2008

Website: <http://www.qip.com.au>

3rd Annual Conference Happiness & its causes

Sydney, 8-9 May 2008

Website: <http://www.happinessanditscauses.com.au>

4th National Conference Building Better Boards - Practicalities and realities for nonprofit boards

Sydney, 26-27 July 2008

Website: <http://www.betterboards.com.au>

healthupdate

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PO Box 3099
Manuka ACT 2603

Editor Penny Gibson

Layout Janet Cameron

Email info@chf.org.au

Phone (02) 6273 5444

Fax (02) 6273 5888