



healthUPdate

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Nominations called for CHF Honorary Life Members

Do you know someone who has made a significant contribution to CHF? Please nominate them for a 2008 Honorary Life Membership.

Awards will be made at the 2008 Annual General Meeting and include a certificate acknowledging their award and complimentary entitlement to all benefits of CHF membership.

Previous recipients have included Christopher Newell, Hilda Bastian and Janne Graham.

Nominations close on 1 June 2008. For more information and the nomination form, see <http://www.chf.org.au/PopUps/popup.asp?ID=384>.

Symposium calls for more support for consumer participation

Proof that researchers recognise the value of involving consumers in research was very evident at the successful Involving People in Research Symposium held in Perth on 5-6 March. It brought together researchers, students, consumers and community members, health professionals, administrators and health policy makers.

The national symposium concluded by calling for the National Health and Medical Research Council (NHMRC) to support an organisation to assist consumers to participate in all levels of research.

CHF Executive Director Helen Hopkins said the symposium was a watershed for consumer participation in research. It recognised the success and value of the *Statement on Consumer and Community Participation in Health and Medical Research* that CHF developed with the NHMRC in 2001, followed by the *Model Framework for Consumer and Community Participation in Health and Medical Research* in 2004. Their acceptance has created the need for more formalised assistance for consumer participation.

The symposium communiqué recognised the enormous value and potential for consumer involvement to improve Australian health and medical research outcomes and the tens of thousands of consumers already formally involved in groups, networks and non-governmental agencies. It reinforced that consumers should be meaningfully involved at all stages and all levels of the research process.

To achieve this, it said consumer resources should be more formally involved in research design, priorities, funding and dissemination.

'The NHMRC can ensure this happens by finding ways to fund or support the creation of an independent coordinating body which would include consumers, carers, funders and researchers,' the communiqué said.

'This body will develop:

- A strategy and program to advocate and market consumer participation.
- Advise NHMRC, other funding bodies and agencies on changes needed to their structures, funding, and processes to support this body.'

Symposium participants expect this work to begin within the next twelve months.

Helen and CHF Governing Committee member Christopher Newell made the closing address to the symposium, which was sponsored by the National Health and Medical Research Council, University of Western Australia, Health Consumers Council of WA and WA Department of Health.

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From the Secretariat

In the news

Health insurance premium increases

The Australian Associated Press sought CHF comment before and after the proposed increases to the health insurance premiums. Executive Director Helen Hopkins said CHF supported the Government's call for justification of the increases and called for the insurers to ensure the premium rise reflected only the increased costs to the insurers and not profits. At the same time, she said insurers should improve their services to reflect a greater value for the consumers' money; for example, by helping consumers with their choice of package to ensure it fitted their current health needs.

What consumers want from health care reform

Consumers want several things from the health care reforms. Helen spoke to the ABC in Brisbane while Chairperson Mitch Messer spoke to the British Medical Journal. Foremost, consumers want a properly funded, streamlined and navigable system that is inclusive of primary care, hospital care and community health support. Such a system would help give everyone access to safe, good quality health care and was particularly important for rural areas. They said consumers also wanted transparent reporting on performance and accreditation of health services, national registration of health professionals and the introduction of electronic health records.

Patient perspective seeks medicines information

In the final Patient Perspective for the *Weekend Australian*, Mitch wrote about the regulatory system for medicines managed by the Therapeutic Goods Administration (TGA). He said the need for post-market surveillance of medicines was crucial to monitor the longer term effects of medicines on the larger population; a situation recently highlighted with the Stilnox sleeping tablets. Consumers and clinicians have an important role to play in this post-market surveillance, by reporting unexpected side effects.

A single 'hotline' is needed for people to call with questions about their medicines or to report any problems. Mitch also called for more information for consumers on the regulatory process and for the TGA to host all Consumer Medicines Information so consumers have easy access to it. This would enable consumers to weigh the benefits and risks of medicines and make informed decisions.

National dialogue needed on health rights

The proposed national charter on health rights will only work if all stakeholders join the consultations to make a document that works for everyone, Mitch said in a CHF media release on 4 March.

He said the charter, developed by the Australian Commission on Safety and Quality in Health Care, let consumers know what to expect from their health service and gave health professionals and health services a framework for the delivery of the best health care as it would support their demands for the necessary funding to improve safety and quality.

Advocacy

CHF in demand

Many organisations seek CHF input into their initiatives or projects. The following are some of the current requests CHF will participate in:

- an economic analysis of blood products and services, being undertaken by the Centre for Health Economics Research Evaluation on behalf of the National Blood Authority
- aspects of the Aged Care GP Panels Initiative on request by the Australian General Practice Network
- a consultancy on e-Prescribing that KPMG is undertaking for the Australian Government Department of Health and Ageing.

We have also been invited to provide submissions to:

- the Australian Government Department of Health and Ageing on the management of the transition to digital imaging
- the Privacy Commissioner's frequently asked questions on health privacy, and
- the Patient Identification Program of the Australian Commission on Safety and Quality in Health Care.

CHF birthday

Help CHF celebrate the profound impact the health consumer movement has had on the way health care is delivered in Australia. As we prepare for our 21st birthday celebration on 16 October, please share your memories, thoughts and ideas with us.

- What do you think were the momentous moments in CHF history?
- What aspect or activity of CHF has made a difference to your organisation?
- Do you have any anecdotes about the organisation, its people and its events?
- What are the next frontiers for health care in Australia and how can consumers contribute?
- Who would you like to speak at the birthday summit?

You might like to send a sentence or a page – or even more. All comments are welcome. Please send them to info@chf.org.au attention to Birthday Summit.

Project updates

Community Quality Use of Medicines (QUM) Project

Consumer places at the National Medicines Symposium

CHF is calling for expressions of interest for six fully funded consumer places at the National Medicines Symposium, 'Quality Use of Medicines – What does it mean for you? The Science, the Policy, and the Practice'. CHF negotiated the places in collaboration with the National Prescribing Service (NPS). They will include registration, travel and accommodation at the Canberra symposium 14–16 May 2008.

This is an exceptional opportunity to confirm that information about medicines is of great interest to health consumers, who have much to offer the national dialogue. The National Medicines Symposium 2008 will be the fifth national forum on Quality Use of Medicines (QUM), hosted by NPS and Pharmaceutical Health and Rational use of Medicines committee. It will bring together international and national experts, health professionals, consumers, policy makers, project and program coordinators, researchers and academics, the pharmaceutical industry, government departments, health organisations and medical writers to debate and discuss the current state and future of QUM.

Further information about the symposium is available at:

http://www.nps.org.au/site.php?page=3&content=/resources/content/mediainfo_nms2008.html.

Expressions of interest

If you are interested in a complimentary consumer place at the symposium, please send a half page expression of interest to CHF by **COB Friday 28 April 2008**. Please state:

- 1 Your affiliation with health consumers, care or community organisations.
- 2 Why you should receive one of the funded places.
- 3 How you would pass on what you learn at the symposium to a wider group of consumers.
- 4 Whether you have received a complimentary place to an NPS medicines conference in the last 12 months.

Please email your application to info@chf.org.au, fax it to (02) 6273 5888 or call (02) 62735444. CHF will oversee the selection process.

Carolyn Brody

Policy Development Officer

Implementing Private Health Reforms: Consumers have a say

Consumer choice and informed financial consent

CHF recently held a consumer workshop in partnership with the Heart Support Australia branch in Ipswich and West Morton. Discussions included how prostheses are made available to privately insured consumers, the issues around consumer choice and out-of-pocket expenses around prostheses.

Prostheses are surgically implanted devices such as pacemakers, defibrillators, heart valves, cardiac stents and knee/hip joints. Under current private health arrangements, the cost of some prostheses is set with a gap to be paid by the consumer. This makes the issue of informed financial consent particularly relevant to consumers.

Participants shared their prosthesis experiences and reported they have a great level of trust in their doctors to do best by them. They are generally very pleased with treatment outcomes. Participants also identified it was really important to be given information to help them make choices about treatments, including costs, and discussed the negative impact that unforeseen out-of-pocket expenses can have on consumers.

They raised concerns that doctors may react negatively when consumers ask about cost issues as they may see this as inappropriate inquiry which may affect the patient/doctor relationship and/or timely and quality treatment.

When considering the Australian Medical Association (AMA) brochure *Let's talk about fees...*, developed to assist privately insured consumers talk to their doctors and health funds about treatment costs, participants said it helped them to think about how and when to discuss issues around costs. However, they were concerned the messages were not being passed on or promoted to consumers. They called for doctors to play a greater role in ensuring informed financial consent, suggesting many doctors may need more education about the importance of discussing cost issues with their patients.

CHF will use the workshop in its policy work on private health arrangements and to prepare its advice to stakeholders on the information needs of consumers.

CHF is holding several more consumer discussion sessions in partnership with member organisations in the coming months to further inform its 'Implementing Private Health Reforms: Consumers have a say' project, which is funded by the Australian Government Department of Health and Ageing.

Tamara Shanley
Policy Advisor

E-health for Consumers Project

The Australian Institute of Health and Welfare (AIHW) in collaboration with the National E-Health Transition Authority (NEHTA) are holding a series of workshops focusing on e-health and statistics.

CHF Policy Advisor Catherine Ellis attended the first workshop on 'Data Supply Chains and Scenarios under E-health' on 12 March. During the workshop, participants explored ways that health information that will be stored in the Shared Electronic Health Record (EHR) being developed by NEHTA can be used for secondary purposes. These may include research and statistics to inform health policy and the provision of health services. Key points that CHF raised with the AIHW were that the primary purpose of shared EHRs is to provide health care and that health consumers must be informed about possible secondary uses of their health information.

Participants at the workshop included the Office of the Privacy Commissioner, NEHTA, the Australian Department of Health and Ageing and state health departments.

Catherine Ellis
Policy Advisor

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

CHF discusses health rights

CHF would like to thank everyone who has sent a response to the health charter information paper and/or participated in the various workshops, round tables and meetings on the draft charter. Based on your comments and feedback, we are preparing our submission on the draft charter for the Australian Commission on Safety and Quality in Health Care.

As part of the consultation, CHF attended two roundtable discussions with nominated consumer representatives and other health stakeholders in Sydney and Melbourne on 5 and 7 March respectively. The discussions were robust and productive. A significant outcome was the acceptance by the health providers that were present that the charter will provide them with a framework through which they can improve safety and quality in their health service.

CHF also thanks its member Health Consumers Alliance of South Australia for hosting an informal consultation on health rights that included the opportunities and challenges posed by the South Australian Charter for Health System Users. Thanks also to Health Rights and Community Action SA, COTA SA and a number of South Australian consumer advisory committee members for their input to the consultation.

Sarah Jones
Policy Advisor

Health News

Consumer Medicines Information on line

In response to the CHF Patient Perspective column in *The Weekend Australian*, CHF received a reminder from Healthlinks.net that it has set up a web site that contains over 2100 Consumer Medicine Information (CMI) and Product Information documents. The free, non-promotional website aims to provide access to the most up to date CMI and product information statements, adding new information within an hour of its release.

For more information, see <http://www.medicines.org.au>.

Workshop on health care agreements

Australian Health Care Reform Alliance will hold a workshop in Canberra on 18 March on the new Australian Health Care Agreements to refine and promote its views. Speakers will represent the states, the Commonwealth, the Australian Healthcare and Hospitals Association and the Australian Health Care Reform Alliance. CHF remains concerned that consumers should have a 'one-stop shop' for all CMI.

For more information, see <http://nrha.ruralhealth.org.au/?IntCatId=14>.

Early treatment for type 2 diabetes

The National Prescribing Service has rolled out an educational program for health professionals on early use of insulin and oral antidiabetic drugs to focus on earlier treatment to reduce the progression of the type 2 diabetes, reduce the risk of vascular complications and maximise overall health.

Evidence practice gaps in emergency care

The National Health and Medical Research Council has published three new brochures in its series Emergency Care Evidence in Practice that aims to inform best practice and help improve the quality of care.

For more information, see

http://www.nhmrc.gov.au/nics/asp/index.asp?page=programs/programs_article&cid=5263&gid=207&id=485.

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.

Pharmacy Guild of Australia – Medication Compliance Advisory Panel

This Panel will assess applications for research and development funding provided under the Fourth Community Pharmacy Agreement Research and Development Program. It will also provide ongoing expert advice and support to successful applicants throughout the term of their project, consider the interim and final reports and provide advice and support to the Research and Development Program Manager, and the Professional Programs and Services Advisory Committee Research and Development Steering Committee (PPSAC) on the selection process, outcomes and progress of each project.

The research applications are expected to focus on developing and evaluating strategies that can be integrated into community pharmacy practice to assist people who are not taking their medicines as prescribed. Strategies must be sustainable and economically viable for consumers, pharmacy and the health system in general. More information is available on the Pharmacy Guild website at <http://www.guild.org.au/research/content.asp?id=1705>.

While assessing applications, the panel may have face to face meetings or tele/videoconference interviews with applicants. The Medication Compliance Advisory Panel will meet 3-6 monthly, usually in Canberra or via teleconference. The first meeting is planned for 23 May.

CHF thanks Amy Zelmer for her advocacy for consumer representation on the Advisory Panels. Amy is the nominated consumer representative to the PPSAC.

Expressions of interest close 4 April.

University of Sydney (School of Public Health) – 'An interactive decision aid for prioritising health-check activities' Project Reference Group – Readvertised

The University of Sydney is developing an evidence-based tool to help tailor and prioritise preventive health activities for individuals recommended by the Royal Australian College of General Practitioners. The interactive tool will allow consumers to work with their general practitioners to develop an individual activity plan. It will include modelling for cancer screening and other preventive behaviours, cardiovascular risk reduction and mental health activities using a 'whole-patient' approach. The decision aid website will calculate personal benefit-risk ratios, eliciting patient values for these, and producing a prioritised preventive activity list to maximise individual health gains.

Consumer representation in this reference group will help ensure the interactive decision aid will meet consumers' needs in prioritising health care activities in the general practice context. Monthly meetings will be held either face-to-face in Sydney or by teleconference. The first meeting is expected to be late March/early April.

Expressions of interest close 4 April.

Therapeutic Goods Administration (TGA) – Therapeutic Goods Committee – Readvertised

The Therapeutic Goods Committee (TGC) is the expert committee established under the Therapeutic Goods Act 1989 to advise the Minister on standards for therapeutic goods; requirements for labelling and packaging; the principles to be observed in the manufacture of therapeutic goods for human use; matters relating to the adequacy of a medical device standard as it relates to the essential principles and matters relating to the adequacy of a conformity assessment standard as it relates to conformity assessment procedures.

Currently the work of the TGC has a major focus on medicines, in particular issues around packaging (child resistant and tamper evident) and labelling. CHF has been invited to nominate consumer representatives for consideration for appointment by the Minister. CHF thanks consumer representative John Stubbs for his work to date on this committee and understands that John is willing to be considered for a further term. Expressions of interest are invited from Senior Consumer Representatives. Please refer to the CHF Terms of Reference for Senior Consumer Representatives available on the CHF website at http://www.chf.org.au/consumer_reps_program/policies.asp.

Expression of interest close 28 March.

Speech Pathology Australia Ethics Committee – Readvertised

Speech Pathology Australia is the peak national association representing speech pathologists. All reported breaches of the association's code of ethics are investigated by the Speech Pathology Australia Ethics Board, which is responsible for receiving and investigating complaints and making recommendations on disciplinary action to the Speech Pathology Australia Council in line with the Association's Code of Ethics. Quarterly meetings are held by teleconference.

The Ethics Board has three consumer representative positions; two are due for re-appointment in May. Expressions of interest are invited from consumer representatives interested in participating on an ethics committee for a professional association (a specific interest in speech pathology is relevant but not essential).

Expressions of interest close 4 April.

Australian Government Department of Health and Ageing – Enhanced Medical Education Advisory Committee – Readvertised

The purpose of the Expanded Settings for Specialist Training Program (ESSTP) is to: establish a system for medical specialist trainees to undertake training in an expanded range of settings beyond traditional public teaching hospitals (possibly including regional and rural locations, the private sector, community settings and non-clinical environments); work with specialist colleges and training providers to enable medical specialist trainees to acquire appropriate skills and experience in a wide range of clinical situations; allow for more flexibility in the health workforce to meet emerging pressures of supply, demand and distribution as well as the challenges associated with an ageing population and technological advancement; and contribute to the provision of sufficient vocational training places for an increased number of medical school graduates.

The Enhanced Medical Education Advisory Committee (EMEAC) provides advice to the Australian Government Department of Health and Ageing on: the implementation of the ESSTP, including issues in relation to funding, medical indemnity, accreditation of training positions/settings and specialist training curricula; progress and outcomes of the ESSTP; the establishment of an evaluation framework; and strategies to address recommendations arising from evaluation of the ESSTP.

EMEAC meets face-to-face four times each year with other meetings or activities as agreed by members. The next meeting will be in Melbourne on 11 April (an interim consumer representative will attend). Expressions of interest are invited from senior consumer representatives. See the CHF Terms of Reference for senior consumer representatives at http://www.chf.org.au/consumer_reps_program/policies.asp.

CHF thanks outgoing consumer representative and CHF Vice Chairperson Jan Donovan for her work on this committee.

Expressions of interest close 4 April.

University of South Australia – Quality Use of Medicines and Pharmacy Research Centre – Centre Advisory Committee - Readvertised

The Quality Use of Medicines and Pharmacy Research Centre is located in the Sansom Institute of the School of Pharmacy and Medical Sciences at the University of South Australia. It works across the interface between national medicines policies and strategies and local medicines issues. Working with professional, government and industry partners, the Centre seeks to build upon evidence based research to develop, trial and evaluate strategic initiatives. More details on the projects undertaken are available on the Centre's website at <http://www.unisa.edu.au/pmbps/qumprc/default.htm>.

The Centre Advisory Committee will advise the Centre Director on key QUM issues and directions for the Centre. It will meet biannually in Adelaide or by teleconference, with the first meeting planned for September 2008.

Expressions of interest close 4 April.

Reports

Australian Commission on Safety and Quality in Health Care – Australian Clinical Quality Registries

Coral Rizzalli, January 2008

The meeting focussed on the development of standards for clinical registries, such as the National Joint Replacement Registry. Representatives from the National E-Health Transition Authority attended the meeting to discuss the issues around the use of electronic health records and databases.

National standards are being developed for all clinical registries with timelines set for the first stage of development. At this stage, the expectations are that the project will be finished during the latter part of 2009. Issues include the Unique Health Identifiers (both for providers and consumers) and the adoption of terminology standards, such as Snomed.

The benefits for consumers are many but the two most important issues are: that national standards for all clinical registries will improve the way data collection is achieved and stored, with interoperability between registries ensuring that consumer information is accurate and up to date; and access to information in electronic form will improve safety and quality in health care by ensuring that all information is readily available to health care providers and consumers.

The meeting also discussed how jurisdictional variation on privacy adds to the complexities and impinges on the work of clinical quality registries.

NPS – Community Quality Use of Medicines Working Group

Coral Rizzalli, February 2008

Outcomes of a recent Community QUM program in several ethnic schools in Queensland were reported. A competition was held as an activity based after school project. The report showed that the program was successful in increasing understanding of Community QUM for participants, although it was difficult to know if grandparents within the Culturally and Linguistically Diverse (CALD) community improved their understanding. The meeting discussed the many issues around Community QUM in CALD communities. Getting the Community QUM message into these communities will be a major undertaking this year.

We would appreciate feedback from CHF members who can assist NPS get the CQUM message into CALD and indigenous communities.

CHF note: CHF member, the Federation of Ethnic Communities Council of Australia is a Community QUM Program partner.

Other reports received

Janne Graham AM, *Health Care Consumers' Association of the ACT*, TGA – Drug Safety Evaluation Branch Transparency Working Group

Christopher Newell AM, *CHF Governing Committee*, Australian General Practice Accreditation Limited Board

Sheila Rimmer AM, *CHF Governing Committee*, Medical Services Advisory Committee

Geraldine Robertson, *Breast Cancer Network Australia*, TGA – Complementary Medicines Implementation Reference Group

Appointments

Barbara Daniels from Health Consumers' Council WA to the Australian Medical Council (AMC) – Medical School Accreditation Committee

Sally Hodgkinson from Cancer Voices NSW to the Australian Government Department of Health and Ageing – Radiation Oncology Reform Implementation Committee (RORIC)

Janney Wale from Health Consumers' Council WA appointed by the Minister for Health and Ageing to the National Pathology Accreditation Advisory Council

Health Calendar

Addressing the Healthcare Skills Crisis

Sydney, 27-28 March 2008

Website:

<http://www.informa.com.au>

Chronic Disease Management Australia 2008

Sydney, 1-4 April 2008

Website: <http://>

www.terrapinn.com/2008/cdm/

3rd Biennial National Conference on Anxiety and Depression

Melbourne, 3-4 April 2008

Website: <http://>

www.reconnexion.org.au/main/news.htm

Australian Council of Social Service Conference 2008 - Taking steps for a fair go for all - social inclusion policies and processes

Melbourne, 9-10 April 2008

Website: <http://>

www.acoss.org.au/

[Events.aspx?displayID=1](http://www.acoss.org.au/Events.aspx?displayID=1)

Quality Carnivale - 4th International Conference in Primary Care

Melbourne, 17-19 April 2008

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

Health Outcomes 2008: Facilitating Knowledge Exchange and Transfer for a Dynamic Future

Canberra, 30 April - 1 May 2008

Website: <http://chsd.uow.edu.au/ahoc/upcomingconference.html>

healthupdate

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