

HEALTH CONSUMERS' COUNCIL of WA

CONSUMER REPRESENTATIVE PROGRAM

REPORTS for 2006

Introduction

These reports have been written by the Consumer Representatives who were the representatives on these committees in 2006. The purpose of the reports is to inform other health consumers and the community on what the consumer issues are in the planning, policy, research, delivery and evaluation of health services. If you would like more information about any of these reports please contact the Consumer Participation Project Officer on 9221 3422 or kathiem@hconc.org.au. Arrangements can then be made to put you in touch with the relevant Consumer Representative.

Thank you to all the Consumer Representatives who have written reports. The time and effort taken to write the reports is appreciated but the Health Consumers Council believes that it is an important aspect of consumer representation.

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Aged Care Standards & Accreditation Agency

Representative: Lois Johnston

Consumer Issues

Young people with disabilities ó Commonwealth has allocated \$244 million over 5 years to relocate young people with disabilities out of aged care facilities

Unannounced visits ó WA Agency has been doing these over the last 5 months. Aims for an unannounced visit to every home in WA at least once per year (some homes may require more than one visit). Support contacts will continue as before

Terminology changes ó ‘elder abuse’ changed to abuse of older people; ‘mandatory’ changed to ‘compulsory’ reporting.

Abuse of older people ó Commonwealth considering changes needed to implement compulsory reporting.

Miscellaneous information

Existing aged care providers are getting bigger

Very high turnover of Directors of Nursing in Aged Care facilities

Escalating cultural/racial conflict between staff and staff and staff and residents with the influx of overseas-trained carers (especially Africans).

**Alzheimer’s Australia WA Dementia & Memory
Community Centre Reference Group**

Representative: Kathie McLure

Purpose of the Committee

To contribute to the ongoing design and development of the Dementia & Memory Community Centre program and activities

To assist in raising the profile and increasing public awareness of the Dementia & Memory Community Centre program

The Dementia and Memory Community Centre is a new program run by Alzheimer's Australia and funded by the Dept of Health & Ageing. Alzheimer's Australia WA has equipped a drop in centre and van with a range of resources. They also have a number of activities designed to help people delay/prevent the onset of dementia. The van travels to shows and expos in the metropolitan and country areas to promote the program to the community. People can drop in to the Community Centre. Resources available include videos, books, pamphlets and website.

Consumer Issues

The main issue is accessibility as the Centre is located in Bedbrook Place in Shenton Park and is not convenient for people to drop in particularly if they do not have private transport. There is however, an excellent range of resources available.

BreastScreen WA Consumer Reference Group (CRG)

Representative: Hope Alexander

Purpose of the Committee: To assist in the development of specialist resources and strategies for the BreastScreen program.

In December 2006 Dr Liz Wylie, the Director, gave me a Certificate of Appreciation
in recognition of your commitment and valuable contribution as a member of the CRG.

Consumer issues

Having the consumer information changed to reveal that mammograms will NOT reveal all types of breast cancer. 2
Having the Family History/Breast Cancer information brochures sent out to GPs and others after a delay of TWO YEARS.

Issues/decisions that could affect Health Consumers' Council or consumers

The inability of BreastScreen WA to admit on their information leaflets that lobular carcinoma in situ (LCIS) does not show up on mammograms. It is agreed by medical staff (the Director) that it does not show up, but women are not warned of this.

The confusion of some women over 70 who think they cannot still have a free mammogram, because they are not sent an invitation letter. They can.

Consumer Advisory Group, Joanna Briggs Institute (JBI) Adelaide

Representative: Hope Alexander

Purpose of the Committee:

To advise on consumer matters, eg information for consumers

To give a consumer perspective on health issues eg by inviting consumers to submit abstracts of original papers for the JBI Conventions

Consumer issues

Being invited to participate in the Conventions as an equal member among health professionals, allied health professionals, academics and consumers. Being treated with respect and having one's opinions sought out and respected.

One question I was asked in 2005 by a number of the Directors (21) from around-the-world collaborating centres when I met them was "How do we get consumers involved?" My answer "Do as the Health Consumers WA do - feed them and thank them! For any further information ask Michele."

Issues/Decisions affecting the Health Consumers Council or consumers

The JBI is revamping its JBI CONNECT resource, an electronic consumer information service. I have been asked to look at it and give feedback before it is up and running.

Consumer Participation Project: Cancer Council WA
(member since 2003)

Representative: Hope Alexander

Purpose of the Committee: To advise on consumer matters, eg information leaflets, patient-held records, patients' rights. To attend consultations with other stakeholders to give a consumer perspective.

Being invited to participate in the CCWA biennial Conferences.

To give talks to industry on the cancer experience.

Issues/decisions could affect Health Consumers' Council or consumers

After one Project Co-ordinator left we did not have any meetings, until we were informed of a new person taking on the role. For 6 months, nothing happened.

Curtin University Nursing Advisory Committee

Representative: Neville Ward

Consumer Issues

This committee has not met for twelve months cancelling two scheduled meetings. Will investigate this situation.

ECU School of Nursing and Midwifery Advisory Committee

Representative: Michele Kosky

Purpose of the Committee

To advise and review the current curriculum for nursing students

Consumer issues are advocacy, communication, marginal health issues, communication competence, compassion.

Issues which could affect the Health Consumers Council or consumers include consumer participation in health care decision making, community engagement, advocacy with patients, expanding role of nurses

Items of Interest to the Health Consumers Council ó Expanding the role of nurses in health care settings, public support, community engagement.

Executive Advisory Group Infections and Immunology Health Network

Representative: Michele Kosky

Purpose of the Committee

Development of patient centred, sustainable and effective clinical services across all parts of care, prevention and treatment

Consumer Issues

Early days but probably 'patient centred' issues

Health Reform Implementation Taskforce (HRIT) Hospital in the Home (HITH) Steering Group

Representative: Kathie McLure

Purpose of the Committee

To strengthen the health reform process by assisting HRIT with the implementation of the HRIT Ambulatory Care Reforms into the Area Health Services

Hospital in the Home is a program where patients can receive treatment in their home rather than being admitted to hospital. The patient receives health care from the hospital staff. At this stage only patients with Deep Vein Thrombosis or Cellulitis are eligible. Other eligibility criteria include a carer being available, a suitable home environment and no co-morbidities. The patient and carer must also be agreeable.

Most metropolitan hospitals are providing this program and the Steering Group concentrated on facilitating co-ordination of the program between the hospitals. Each hospital covers certain postcodes in the metropolitan area with Silver Chain covering the remainder mainly the outer areas.

Consumer Issues

The main consumer issues to arise was the fact that while patients are under HITH they should use the hospital doctor for all their medical needs eg prescriptions and are not eligible to use their GP. It was felt that this may not be well understood by patients.

Human Research Ethics Committees

Representative: Bruce Campbell

Purpose of the Committee

Clinical trials using patients is carried out ethically, morally and physically.

Consumer Issues

As above

Medical Board of WA

Representative: Ann White

Purpose of the Committee

- Registration of Doctors in WA
- Disciplinary matters concerning Doctors in WA as per 1894 Act

Consumer Issues

- Complaints re practice, competency, behaviour etc
- Trying to ensure only competent & qualified Doctors are registered to practice in WA

Items of interest for Health Matters

Items from 2005/2006 Medical Board Annual Report recently tabled in Parliament and available on Medical Board website could be published in Health Matters

Medical Radiation Technologists Registration Board of WA

Representative: Ann Revell

Meeting date: Inaugural meeting 18 December 2006
2nd meeting 9 January 2007

Next meeting: 13 February 2007

Publish report: Yes

In mid-2006, Parliament passed the *Medical Radiation Technologists Act 2006* (the Act). The Act will be proclaimed once its Regulations are established. Once the Act is proclaimed all people who work as medical radiation technologists in WA will be required to register with the Board and it will be an offence under the Act to practice without registration.

The Act, administered by the Board, will ensure that health care is delivered to consumers in a professional, safe, competent way through uniformity of qualification and standards.

The Act covers imaging technologists, radiation technologists and nuclear medicine technologists and will be administered by a Medical Radiation Technologists Registration Board of Western Australia (the Board). WA is currently the only State where medical radiation technologists are not required to be registered. It is believed an estimated 800 medical radiation technologists currently practise in WA.

On 27 November 2006 the Minister for Health appointed members of the Board following receipt of expressions of interest. The Board comprises two medical imaging technologists, two nuclear medicine technologists, two radiation therapists, a consumer representative and a lawyer.

The Board held its inaugural meeting on 18 December 2006. Mr Neil Hicks was elected Presiding Member (Chairman). The election for a Deputy Presiding Member was held over until the following meeting.

The Board discussed the requirement to work with Parliamentary Counsel to establish its Regulations and enable the Act to be proclaimed. In order to do this, the Board first needed to set appropriate qualification standards, registration and licensing protocols and fees and establish its administrative procedures.

The Board established a Qualification Committee from its membership. The Act also provides for a Complaints Assessment Committee and an Impairment Review Committee that will be established at a later time.

The Board agreed it would meet monthly from February to December. However, it was decided to hold an extra meeting in January 2007 to deal with pressing establishment matters.

The second meeting of the Board took place on 9 January 2007 and Mr David Cutt was elected Deputy Presiding Member.

The Board interviewed potential registrars and agreed to request further information before making a final decision on an appointment.

A letter to medical radiation technologists through their professional organisation and to employers of medical radiation technologists outlining the requirements for registration and licensing once the Act is proclaimed was agreed for distribution ASAP. Further strategies to inform medical radiation technologists were discussed and it was agreed every opportunity should be taken to address relevant professional bodies to raise awareness of the Act and the role of the Board in its administration.

Over the next few months the Board will continue to work on appointing a registrar, putting in place its administrative processes and identifying content for inclusion in the Regulations so that the Act can be proclaimed at the earliest opportunity.

Oral Health Centre Quality Improvement Committee

Representative: Hope Alexander

Consumer Issues:

Improvement of quality of services throughout the whole organisation, not just ad hoc. For example, improving conditions for patients where there is a demonstrated need, listening to both patients and staff, and requesting feedback and acting on it if appropriate.

Also such things as making sure clinic staff have the items from stores WHEN the need them, to minimise or avoid patient waiting times.

Inclusivity of all members of staff and patients of organisation with regard to quality improvement.
<, o:p>

Osteopaths Registration Board

Representative: Jenny Cramer

Purpose of the Committee includes:

Ensure laws pertaining to the registration of Osteopaths are upheld.

Register osteopaths as practitioners

Deal with complaints

NOTE:

*No meetings have been held since my appointment. I have not yet met with or received information from the Osteopaths Registration Board. At this time, therefore, I am not able to comment on the following questions in relation to my consumer representative position.

Pap Smear Provider Credentialling Review Group

Representative: Jenny Cramer

Purpose of the Committee:

To assess, accredit and issue certificates of competence as a Pap Smear Provider to registered nurse applicants (met once, December 7th 2006).

What have the consumer issues been?

The monitoring of nurses performance as Pap Smear Providers.

To date only PathWest is able to process specimens obtained by accredited nurses.

PathWest records show that accredited nurse providers have equal if not better results in the reliability and accuracy of tests.

Qualified Nurse Pap Smear Providers have the potential to improve access and acceptability for women to have this test.

What issues/decisions could affect Health Consumers' Council or consumers?

Ensuring that the criteria for credentialling Pap Smear Providers are enforced affects the quality of services women receive. This is of most importance where women may have less access to good health care, such as in some rural and remote areas and in disadvantaged urban neighbourhoods.

Post Coma Unresponsiveness Working Party

Representative: Michele Kosky

Purpose of the Committee

To develop treatment and care guidelines

Consumer Issues

Very vulnerable group of patients, end of life decision making, role of families, communication, access

Issues/Decisions Affecting HCC or Consumers

The issues of role of the State, families and individuals in end of life decisions, Quality of life
What it means to be alive
Costs of emotional and economic

Items of Interest to HCC Discussed

All of the discussion is around the best care and treatment of consumers in pcu so of great interest

Items of Interest for Health Matters

Executive summary of Guidelines when developed and approved by AHEC

Primary Health Care Research, Evaluation and Development Program (PHCRED) Consumer Advisory Group

Representatives: Jenny Cramer

Purpose of the Committee: Acts as a reference group for the State PHCRED, to contribute consumer perspective on research strategies and projects undertaken by participating universities (UWA, Curtin and ECU) Meetings held monthly.

Consumer Issues

1. Representation of consumers in developing and assessing research and project proposals
2. Consumer input into the priorities of PHC research and projects
3. Consumer representatives connecting with and informing community groups

The place of consumers in drawing attention to gaps in primary health care research and to relevant specific needs and priorities of various community groups

Items of interest to the Health Consumers' Council

A paper submitted for the Consumers in research segment of the GP and PHC Research Conference May, 2007. The paper is titled, -Integrating consumers in primary health care researchø It -mapsøthe development of the PHCRAD Consumer Advisory Group and the processes formulated to improve consumer input into the research.

Renal Diseases Health Executive Network Advisory Committee

Representative: Brian Stafford

Consumer Issues

Resignation of one of the Chairs

Traditional manner of committee

Consumer representatives not receiving the same information as other representatives

Launch on 15th March ó Dr Simon Towler as guest speaker

Lack of consultation with all members of the committee

Waiting for people waiting for dialysis

Need for more home hemo units

People having to travel to Perth from remote areas fro treatment

Royal Perth Hospital Community Advisory Council

Representative: Margaret Anne Ryan

Purpose of the Committee

To bring the consumer point of view to the attention of the hospital administration on matters such as:

- The quality of food
- Access to and within the hospital
- Problems that people generally have either as a patient or visitor at RPH

Consumer Issues

- Problems with parking when attending the RPH Outpatients Clinics
- Theft/loss of personal items
- Food
- State of rooms/bathrooms
- Closure of RPH

If the administration was to fall into the trap of thinking that we are closing so we do not need to worry about things so much this could be a problem (it has not happened at this stage). Parking issue if not addressed could affect people. Same thing can be said of falling into the trap of not listening to all other complaints.

It has been finally decided to help make us more effective as an advisory group. We are going to have a strategic planning day to map out a proper agenda for the coming year.

As it will be at least 2020 or later before RPH closes (if still closing) people must still let the committee know (via HCC if need be) of issues they would like raised so the problem/s can be fixed.

Sir Charles Gairdner Hospital Community Advisory Council

Representative: Michele Kosky

Purpose of the Committee

To improve patient care and patient focus by involving consumers/community in health service decision making

Consumer Issues

- Health information
- Communication
- Way-finding
- Access
- Discharge
- Carers

Issues/Decisions Affecting Health Consumers' Council or Consumers

HCC has assisted in a range of ways at CAC from policy development to facilitating forums. This may increase and may not be sustainable.

Items of Interest for Health Matters

A report on way-finding exercise in October/November 2006 would be of interest.

SMAHS AREA CLINICAL SERVICES PLANNING STEERING COMMITTEE

Representative: Kathie McLure

Purpose of the Committee: To provide a steering group to advise on the SMAHS Clinical Services Planning process which includes the development of the Fiona Stanley Hospital.

Consumer Issues

The main consumer issue to this point has been the lack of consumer involvement in the planning process. This is being addressed and it is anticipated that consumers and the community will be consulted and informed about what is happening particularly with the development of the Fiona Stanley Hospital.

University of Technology Sydney (UTS) Research Committee Sustainable Health Futures

Representative: Michele Kosky

Purpose of the Committee

To oversight Research project on model of partnerships between patients and health professionals called "Co-Production" about the development of health information.

Consumer Issues

The committee has not yet met but relevance might be one.

WA Aged Care Advisory Council

Representative: Lois Johnston

Consumer Issues

Younger People with Disabilities Living in Nursing Homes

- Currently about 55 people aged under 50 living in nursing homes in WA
- COAG wants a net decrease in the number of young (i.e. less than aged 50) people in nursing homes in the next 5 years and has allocated \$160 million thereafter
- WA to get \$16 million (to be matched by state funds) over the next 5 years and \$3.8m pa thereafter
- Aim to provide alternative accommodation for existing young people in NHs, reduce admissions of further young people and provide additional support for those that remain in the NHs
- An advisory group is to be established to oversee the project

Continence Management & Subsidy Scheme

- Scheme to commence in first quarter of 2007 (probably March)
- Funds for the scheme will allow supply of products to approximately 5,000 people (records indicate there are at least 25,000 people with self-reported incontinence).

WA Association for Mental Health

Representative: Brian Stafford

Consumer Issues

A new Chair and new directions for WAAMH.

WA Drug Evaluation Panel

Representative: Janney Wale

Use of expensive new drugs or formulations in WA public hospitals

The Western Australian Drug Evaluation Panel assesses the efficacy and cost-effectiveness of expensive new drugs or formulations for use in WA public hospitals. This is an evidence-based assessment and as such is reliant on the existence of high quality 'gold standard' randomised controlled trials looking at relevant outcomes in the group of people (population) for which the drug is to be used in WA.

As most of these drugs are new, such evidence is not always available or is very limited. Some drugs are very expensive for the often small possible benefits over existing drugs and treatments. Clinicians put forward applications for the drugs that are considered, as they consider them to be useful in their practice.

For a cancer drug, for example, from a patient point of view it is not simply that the new drug will prolong life (sometimes in terms of months), but that life will be more bearable. For someone with mesothelioma this may mean less difficulty in breathing. Sometimes treatment options are extremely limited (for example for chronic pain) or those available may have debilitating side effects that limit their use by some people. Few new drugs dramatically change life for people with a disease but 'biologics' have been an example of this, for rheumatoid arthritis sufferers. Cancer therapy has improved dramatically over the last few decades and drugs are available that markedly reduce metastatic cancers for some.

WADEP looks purely at drugs and formulations for public hospital pharmacy formularies (each hospital has its own formulary, decided by its own therapeutic committee) with differing levels of restrictions on use. Other types of treatment options are administered separately with very different budgets (psychosocial support, counseling, education, physical therapies etc).

Medicare was introduced in Australia to ensure that all citizens have access to health care. Australia prides itself, justifiably, on its provision of quality health care. We are unique in our balance of public and private health care. Clinical specialists are able to work in both systems and in this way to keep themselves on the cutting edge of new treatments and healthcare developments. Now we also see private (fee paying) and public patients in our public hospitals. This is aimed at helping with the rising costs of health care, largely driven by the

increasing costs and use of medicines. Both types of patients receive their drugs from the hospital pharmacy.

With increased availability of healthcare information and knowledge about new drug developments (indirectly through the pharmaceutical industry), people are becoming more and more aware of what therapies are available globally. Patient and doctor are on the look out for new, more effective treatments. Patients are often vulnerable ó they are sick and want to feel better. They find themselves in a world (the healthcare system) that they are not at ease in and do not understand a lot about.

The Pharmaceutical Benefits Advisory Committee (PBAC) assesses new drugs and formulations as to whether or not they should be available to Australian healthcare consumers at reduced or no cost (on the PBS). This system operates outside the public hospitals, mainly in community pharmacies. The PBAC also determines any restrictions on the use of a drug. These drugs have been approved by the Therapeutic Goods Administration (TGA) for use in Australia. As soon as a drug has TGA approval the pharmaceutical industry is able to provide the drug to doctors, generally specialists working in hospitals. This is a way of enabling the doctors to familiarise themselves to the drug, to give it to patients (sometimes termed seeding trials). Some patients may really benefit from the new drug. However, this can pre-empt the availability of the drug under the subsidy scheme of the PBS. Some of the new drugs becoming available are very expensive. What this means is that they may be approved for subsidy but with very clear restrictions for their use, such as when other treatments have failed. This happened with the biologics and restrictions on their use for rheumatoid factor-positive rheumatoid arthritis. One of these was infliximab (Remicade) that has to be given directly into a vein (by intravenous infusion) and so required a visit to an outpatientsøclinic.

In the past, people were selling their houses, or paying for private health insurance that they could ill afford, so that they could have a new hip or knee (joint replacement). They were living with severe pain and restricted mobility but the waiting lists in the public hospital system were (and are) so long that timely treatment was not available. Now, are we heading down a similar path with expensive new drugs? How clear is the guidance to patients that these drugs are necessary and will achieve appreciably more than cheaper treatments? This is a complex situation with potentially many vested interests. If people manage to pay for the drug, where is it to be administered ó in public hospitals as a public patient where they have no private health cover? Already people bring in with them the medications they are currently on, including their complementary therapies.

Equity is a difficult philosophy to address and that is why the PBS is in place.

WA Medication Safety Group

Representative: Nancy Pierce

Purpose of the Committee

Address issues relating to medication safety across all state jurisdictions

Consumer Issues

Availability of patient information

Issues/decisions could affect Health Consumers' Council or consumers

All the above

