Ethical challenges in Australian health care
The Consumers Health Forum of Australia

**The Consumers Health Forum of Australia Inc (CHF) is the national voice for health consumers. As an independent non-government organisation, CHF helps shape Australia’s health system by representing and involving consumers in health policy and program development.**

Health consumers have a unique and important perspective on health as the users and beneficiaries of health care and, ultimately, those who pay for it. CHF takes consumers’ views to government and policy makers, providing an important balance to the views of health care professionals, service providers and industry to achieve a health system that reflects the needs of all stakeholders.

Current priorities include safety and quality in health care, safe and appropriate use of medicines and health care for people with chronic conditions. CHF facilitates the appointment of consumer representatives on 200 national health-related committees.

CHF believes all consumers should receive affordable, safe, good quality health care at the time they need it. The best outcomes are achieved when consumers are involved in decisions about and management of their own health care. Consumers should receive health care information when they need it in a form they can understand.

Established in 1987, CHF seeks external funding for priority projects and receives funding from the Australian Government Department of Health and Ageing and membership fees.

With its ability to access a variety of health consumer networks and extensive knowledge of consumer issues, CHF is a respected and influential contributor to the Australian health debate.
Health Voices helps consumers shape health in Australia

By Penny Gibson

Welcome to the first issue of Health Voices, the new journal of the Consumers Health Forum of Australia. It will be published three times a year in hard copy and on-line.

Health Voices replaces The Australian Health Consumer as a forum for publishing opinions on the Australian health system. While some articles are CHF policies and opinion, the majority are the voices of members and friends.

We look forward to Health Voices informing, challenging – and occasionally amusing – readers. As such we hope it will stimulate discussion and generate articles and letters to the editor. In fact, we hope it will evolve into a forum where topics are unravelled and explored from different angles.

This first issue seeks to set the ball rolling by raising some of the ethical issues that exist in Australia today for health consumers. Is genetic testing a good thing and how private should the results be? What are the ethical ways to care for young people with dementia, people in a post-coma unresponsive state or at the end of their life? What alternatives are there to organ donation? How can health professionals communicate better with people with chronic conditions to support their health choices? How ethical is website advertising?

Health Voices is one of several improvements to the way we are informing members, stakeholders and friends. In the last year we have also introduced the advocacy newsletter Consumers Shaping Health and upgraded the member newsletter Health Update to a twice-monthly e-newsletter.

Consumer voices – loud and clear

CHF celebrates its 21st anniversary this year. It is a celebration of the increasing recognition of consumers as partners in health care and the achievements of consumers in shaping health in Australia.

The assumption that health decisions were best left to the doctor has evolved into the current wisdom that people who are actively involved in their own health care have better health outcomes. This happened as our understanding about the delivery of health care changed and expanded with new information, research, experiences and understanding. CHF has been instrumental in getting this new wisdom accepted into the public domain.

The theme of consumer participation permeates all aspects of our work to improve Australian health care to ensure everyone has access to safe, good quality health care.

Time and again we have shown that consumers have an important role to play in both determining their own health care and contributing to the debate surrounding health policy and programs. We have made significant contributions to the health agenda, influencing decision makers at the policy level and informing consumer networks of ways to improve their health care.

Our current projects include safety and quality in health care, health care for people with chronic conditions, e-health and quality use of medicine. We are well placed to contribute consumer views to the National Health and Hospitals Reform Commission deliberations and all aspects of the implementation and monitoring of the reforms. We are confident the reforms will improve the delivery of health care.

Health Voices will help us continue the discussion on reforms and other issues that concern consumers and to present them to other stakeholders as part of our overall advocacy plan. You are welcome to join that debate with us.

In the next issue: Health reform and consumers

If you would like to contribute an article that takes a consumer perspective on any of the current or proposed reforms, or have another suggestion for improving Australia’s health system, please contact the editor at info@chf.org.au.
Consumer participation in research

By Helen Hopkins

Many health consumers and health professionals think about ethics in terms of ethics committees and clinical trials. This first issue of Health Voices takes us far beyond this narrow scope. However, it is also important to look at the role of health consumers in research, and the CHF role.

Back in 1999 the Wills Health and Medical Research Strategic Review, titled the Virtuous Cycle, recognised that many consumers wanted to understand and have a say in the research priorities of our nation beyond having a lay person on an ethics committee. Many researchers wanted the support and understanding of the community for their research efforts.

In response to this changing community view, that went beyond the ethical requirements for research at the time, CHF and the National Health and Medical Research Council (NHMRC) developed the Statement on Consumer and Community Participation in Health and Medical Research in 2001. The way that consumers and researchers worked together to develop the Statement on Participation started us all thinking more widely about the challenges and the benefits of involving the community in research. The CHF consultations clearly showed that people wanted to understand some of the ethical challenges at that time – such as gene technology – and have a say in how priorities for research were set. They wanted to know the results of research, not only for individual participants in clinical trials but as a community. Surely a good researcher could explain the relevance of their research and the findings over time in a way ordinary people could understand? Researchers wanted their work to be relevant to the community but raised some practical challenges and concerns.

As a starting point, consumers and researchers in the consultations committed to the shared vision for the Statement on Participation: Consumers and researchers working in partnerships based on understanding, respect and shared commitment to research that will improve the health of human kind. In 2004, the model framework for the implementation of the Statement on Participation was developed.

The recent Involving People in Research Symposium in Perth showed just how important the Statement on Participation is. It was exciting to hear about the practical examples of consumers and researchers working together towards its objectives:

- Consumers and researchers will draw on each others’ 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 responsibility giving consideration to what each can reasonably expect from each 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.

The Perth symposium had excellent outcomes in terms of helping researchers and consumers recognise the value and potential of consumer participation to improve Australian health and medical research outcomes.

However, is it time to reassess the Statement on Participation and model framework? Since it was developed by CHF in collaboration with the NHMRC, many organisations have taken up the challenge – but many others continue to seek practical advice on its implementation. Do the objectives for consumer and community participation still fit? Do they need to be applied more widely for ethical advances in health in Australia? Can we build on the success of the Statement on Participation to make it a better tool?

Is it also time for CHF to review its priorities around consumer involvement in research? It was a large focus of our work in earlier times, but should we reprioritise it in light of its relevance to the huge amount of research being undertaken that involves – or should involve – consumers?

Helen Hopkins is the Executive Director of the Consumers Health Forum of Australia

The Involving Consumers in Research Symposium brought researchers and consumers together (Photo courtesy of The University of Western Australia School of Population Health and Telethon Institute for Child Health Research)
As scientific research expands its horizons, the ethical challenges are wide ranging and complex for all stakeholders, particularly where research involves people. The Australian Health Ethics Committee has an important role to guide research to protect individuals and the greater populace.

As one of the principal committees of the National Health and Medical Research Council (NHMRC), the Australian Health Ethics Committee (AHEC) advises on ethical issues relating to health and develops guidelines for the conduct of research involving humans.

Its membership includes people with expertise in medical research ethics, research in public health and social science, clinical medical practice, nursing, disability, law, religion, health consumer issues and philosophy.

AHEC gathers information from expert working parties and develops guidelines and recommendations through a careful process of public consultation which aims to seek wide ranging community views. Consumer representation ensures thinking from a consumer point of view.

AHEC considers a range of issues, such as: privacy and how health information is used; guidelines about communicating with people to ensure they are well informed and involved in the decision making and planning around their care and treatment; and decision making about organ and tissue donation by living donors and after a person has died.

AHEC also supports and works with institutions and human research ethics committees to ensure ethical health and medical research at their institutions. For example, a successful National Research Ethics Conference was held in October 2007 in Melbourne. Research participants, consumers, researchers, members of human research ethics committees and sponsors of research attended. Hot topics included integrating ethics in designing human research, issues around ethics governance and public trust in biobanks and databanks, consent (who needs to give it, when, and how), institutional governance and what constitutes ethically good research and how to involve people in research. A continuing education day for chairs and members of human research ethics committees was held before the conference and included discussions on clinical trials and qualitative research.

New challenges

As medical science expands into increasingly new horizons the ethical challenges are wide ranging and are becoming more complex for all stakeholders. New scientific research in previously uncharted waters brings new challenges for the community and for human research ethics committees.

In 2007 AHEC prepared Challenging Ethical Issues in Contemporary Research on Human Beings to illustrate how researchers and research committees deal with a range of complex and sensitive issues including: patient consent, safety and welfare; privacy, disclosure and confidentiality; protection of people who are vulnerable; and the scientific merit of research proposals.1

While none of these issues in themselves are new to either the community or to human research ethics committees, they now arise in increasingly more complex environments – the capability of medical science is ever extending, human research has extended beyond drug trials to behavioural, attitudinal and sociological research, the globalisation of research through the influence of large pharmaceutical companies with world wide interests, and science has become much more specialised with relatively few sharing the same level of expertise as the researcher in a research topic,2 making it even more critical that there is a full and frank consideration of ethical issues and ethical guidelines are in place.

An important 2007 publication is the National Statement on Ethical Conduct in Human Research which replaced the 1999 National Statement on Ethical Conduct in Research Involving Humans.3 The document contains guidelines for the ethical conduct of research involving humans and identifies the values which should underpin research design and the conduct of research. The key tenet of the guidelines is to ensure that the people participating in the research are respected and protected. A framework of principles to guide the design, review and conduct of human research is described and includes guidance for different types of research such as research using human tissue, qualitative research and research with specific types of research participants including children and adults who may have a disability affecting their ability to give consent. The document includes guidance for processes for ethical review by researchers, review bodies, institutions and funding organisations. Institutions are required to provide information annually to NHMRC about their ethical review processes and to be registered to receive NHMRC funding.


Sharon Caris is the Executive Director of Haemophilia Foundation Australia and the Health Consumer Member of the Australian Health Ethics Committee.

1 Challenging Ethical issues in Contemporary Research on Human Beings, NHMRC, Australian Government, June 2007
2 Ibid p63 ff
3 NHMRC, Australian Research Council and Australian Vice-Chancellor’s Committee, Australian Government, March 2007
As we continue to unravel the human genome, the potential for ethical – and unethical – uses of the resulting discoveries increases. How do we harness this knowledge?

Many ethical concerns for consumers are arising in the rapidly unfolding human genomic adventure.

Science, technology and commercial interests are pretty much driving the genetics agenda, with medical research peak bodies, consumer advocates, ethicists and those with religious or philosophical concerns often finding themselves on the back foot. However, they have every right and duty to ask questions of an ethical nature of medical and biological scientists, biotechnologists, commercial interests, insurers and others wanting to use the knowledge.

The thing will be to ask without either rushing to accuse, or being Luddite about new developments. Or to assume the worst. The dialogue of consumers with the whole range of ‘providers’ is part of a process which may shape our society so that the human genomic adventure unfolds as a good news story; one that maximises the benefits to outweigh the harms.

Ethical oversight

Some of the advice arising from recommendations from the inquiry conducted by the Australian Law Reform Commission and the National Health and Medical Research Council’s (NHMRC) Australian Health Ethics Committee, reported in *Essentially Yours* (2003), and from current activities of the NHMRC’s Human Genetics Advisory Committee (HGAC) has gone some way to ensure effective ethical oversight in the processes of framing relevant law and research protocols.

These include important amendments to the Privacy Act regarding disclosure of genetic information to at-risk relatives and revision of the National Statement on Ethical Conduct in Human Research (see following article). The HGAC workplan includes the development of an information paper to provide advice on issues associated with the infrastructure and governance of biobanks (collections of biological samples or genetic information for research purposes), maintaining constructive dialogue with the insurance industry, building on work to educate GPs and medical students, and optimising local access to advice for the general consumer.

Proliferation of genetic testing

Even so, while much has been done, genetics is a field that continues to break new ground. Progress is so rapid that breaking issues must be addressed. Without doubt, the biggest issue is the proliferation of genetic tests being marketed direct to consumers (DTC), along with claims as to their value.

You see an advertisement in a newspaper, magazine or online, you order a test (typically online), you receive an envelope with instructions about providing a sample of your DNA (usually a cheek swab) and you post it off, receiving a report some days later. Such tests do not require the advice or authorisation of a doctor.

You can get your whole genome identified, although the results are largely uninterpretable with our current state of knowledge. So far this has been costed in the millions, although one US company offers it for US$350,000 and it’s expected the cost will come down to $1,000 within five years.

There are, however, as many as 1,400 genetic tests with clinical and pseudo-clinical application now available worldwide. Some are used in everyday medical practice. Some promise recommendations to limit the affect of ageing, of better dietary principles and of cosmetic improvements.

The speed with which this industry is growing is almost overwhelming, offering a considerable challenge to the consumer. On one hand, it is hoped that proven benefits will emerge in the form of reliable and useful information about one’s genome or parts thereof and prospects of new therapies and helpful guidance for lifestyle choices. On the other hand, it’s hard not to feel that the profit motive is leading to irresponsible marketing of genetic testing with the risk of discrediting the whole enterprise.

There are many examples of the tension between the commercial marketers of DTC tests, who often boast credible scientific and medical qualifications, and the respected journals and national health administrations. There is money to be made. While the curious and the gullible may not attract our sympathy (caveat emptor – ‘let the buyer beware’), there are those who are genuinely anxious about

Will genetic testing protect the next generation?

The Rev Martin Robinson and his wife Jann at their daughter Emma’s recent wedding
their health and will clutch at straws even, or especially, if the tests cost around $1,000.

In terms of genetic disorders, it is still broadly the case that your family's medical history is the most reliable predictor of health outcomes. One medical journal editor suggests a gym membership is presently a better use of money than a DTC genetic test.

Why? Each of us has so much genetic material; each person’s genome is literally spelled out in a sequence of about three billion ‘letters’. Moreover, environmental factors influence how our genes express themselves as we grow.

However, the increasing capacity of computers to process enormous amounts of data at high speed suggests that useful analysis of the information will become the norm within five to ten years and doctors will be able to translate this into day-to-day practice.

Inherent harm
People are inclined to take the tests’ potential seriously because marketers suggest they will provide data about one’s susceptibility to cancer, heart disease, cystic fibrosis, Crohn’s disease, and blood disorders (to name a few). But a US Federal Government panel has signalled its concerns:

With use of the tests growing at an explosive rate, the panel concluded that patients could be harmed. In most cases, the tests do not pose a direct physical risk; but, the panel said, if a test is inaccurate, patients may be given risky, unnecessary treatments or denied treatments that would be highly beneficial.

In addition, the panel said, most doctors lack the training and expertise needed to interpret genetic tests, and many are unfamiliar with professional guidelines for their use. Although professional societies play an important role in making sure their members get up-to-date information, the panel said, ‘they cannot keep up with the pace of development of genetic tests.’

While the report does not focus on the ethical and social consequences of genetic testing, it does note that companies now market many tests directly to consumers, bypassing doctors, a trend that it said has raised ‘significant ethical concerns’.

(The New York Times 18.1.08)

The line between raw genetic information and information in the hands of a clinical specialist is being blurred. Geneticists recently complained about a British TV programme which followed four high-profile personalities as they were offered (and accepted) genetic screening tests to discover their risks of serious illness such as certain cancers, heart disease and dementia due to Alzheimer’s disease.

Dr Rob Elles, chairman of the British Society for Human Genetics (BSHG), said in the letter of complaint: ‘The BSHG is concerned that the uncritical journalistic and broadcasting standards demonstrated in this programme risk undermining the confidence of the public in the application of genetics, which has great potential to improve healthcare’. He added that the programme could have shown the balance between the benefits of health advice, against the potential harm following assurances given to the clients that they were at low risk of particular health conditions.

The BSHG complaint accuses ITV and Genetic Health, the company that offered the on-screen tests, of failing to provide any information about the scientific validity of the tests. The tests, say the BSHG, are ‘unsubstantiated and unvalidated’ as a way of discovering who will and will not develop the illnesses being tested for. ITV is also accused of providing ‘undeclared advertising’ for the company, without giving the audience sufficient detail or discussion to allow viewers to understand the content of the programme.

(BBC News Online 15.11.07)

At present the DTC genetic tests on offer in Australia are largely from overseas, via the internet, so regulation is almost out of the question. Local versions are on the increase. But even in the USA, where most originate, authorities may be reluctant to try and regulate a field that is changing so quickly and growing so fast.

What you can do
The best hope is for a culture of education: self education, aided by responsible journalism, encouraged by public discourse by health authorities, consumer advocates, medical practitioners (universities, research hospital units etc) and genetic counsellors.

The HGAC is committed to providing advice to the chief executive officer of the NHMRC about the need for consumer awareness and protection, urges a critical eye to be cast on all new developments, and is exploring the formulation of guidelines for best practice by Australian-based companies offering genetic tests.

The Rev. Martin Robinson is the rector at St Martin’s Anglican Church in Killara and a member of the Human Genetics Advisory Committee of the NHMRC
Privacy and genetic information

By Sharon Van der Laan

When a person is diagnosed with a genetic condition, where does their right to privacy end and their family’s right to know begin?

Privacy infers confidentiality, but is actually a much broader concept involving the right to be free of intrusions, to remain autonomous or simply be left alone. Privacy involves the right to control our own personal information and to determine if and how our information should be collected and used.

When considering genetic privacy, an important question is whether genetic information is simply one form of medical information, or whether it is so different from other clinical data that it deserves special legal protection. Public perceptions have a significant impact on this question.

An individual’s genetic makeup is generally considered to be different from other medical information. Genetic testing information has a number of characteristics that distinguish it from other forms of health or personal information, which may have only a few of those characteristics:

• a person shares part of his or her genetic makeup with genetic relatives, so genetic testing information about the person can also provide information about genetic relatives
• there is potential for discrimination against people with a range of genetic characteristics, just as people with disabilities are often discriminated against now
• a person’s genetic characteristics influence many of the things (like physical appearance and some psychological characteristics) that affect his or her sense of personal identity
• by-and-large, a person’s genetic characteristics are with him or her for life – they cannot be changed

Privacy and confidentiality are at the heart of the doctor/patient relationship, with confidentiality an important tool for protecting privacy. The obligation upon doctors not to disclose information about patients can be found in medical professional ethics, legislation and the common law.

For consumers, the position appears to be clear. A doctor can only disclose information when permitted by a patient or required by law and a practitioner who breaches this duty of confidentiality may be subject to disciplinary proceedings and serious consequences. Indeed, this duty has provided an appropriate means by which personal health information has been kept secure. In the case of genetic information, however, there is the potential for that duty of confidentiality to become strained.

Advances in genetic technology provide an increasing number of genetic population screening tests, diagnostic tests and treatments. Such advances have the potential to bring great benefits, but there will also be human costs and consequences. Information from genetic testing reveals information not only about the individual, but also about their blood relatives. This information may therefore be valuable to other family members potentially at risk.

From an individual rights perspective, other family members would not be entitled to have access to this information without the patient’s consent, even if disclosure was in their best health interests. As a consequence, persuasive arguments are now being made for a more family or community-oriented view of genetic information in which information should be shared for the benefit of all family members.

Legislative changes

In Australia, the protection of genetic information and its use relies on a number of commonwealth, state and territory legislative instruments, self-regulatory guidelines and the common law. Federally, the Privacy Act 1988 contains privacy principles which regulate the disclosure of personal information; Information Privacy Principles (IPPs) apply in the public sector and National Privacy Principles (NPPs) apply in the private sector.

Similar principles are contained within relevant state and territory legislation. Under this legislation the disclosure of personal information without the person’s consent has been prohibited.
However, a 2003 joint enquiry by the Australian Health Ethics Committee and Australian Law Reform Commission recommended that privacy legislation be amended to broaden the circumstances in which health practitioners may disclose patients’ genetic information to genetic relatives, with or without consent.

The federal government has now implemented an amendment to the National Privacy Principals (NPP 2.1) that provides that disclosure of genetic information to genetic relatives (‘an individual who is related to the first individual by blood including, but not limited to, a sibling, a parent or a descendant of the first individual’) must be conducted in accordance with guidelines to be issued by the National Health and Medical Research Council and approved by the Privacy Commissioner. The amendment will not make it obligatory for health care professionals to make such disclosure.

As a privacy advocate I believe that individuals are best placed to assess their privacy interests and the interests of potentially affected relatives in deciding whether to disclose genetic information to other family members. Generally, disclosure should not be permitted without patients’ consent. Yet due to the nature of genetic information, exceptions are anticipated, especially where treatment and prevention may be possible. In this instance, comprehensive best practice standards and guidelines that apply uniformly to both the public and private sectors need to be developed. An independent complaints process that is transparent and able to apply strong consequences for breaches of the guidelines is also needed.

**Have your say**

A public consultation paper (Disclosure of genetic information to a patient’s genetic relatives under Section 95AA of the Privacy Act 1988 (Cth) – Guidelines for health practitioners in the private sector) has been made available by the National Health and Medical Research Council to ensure that interested organisations and individuals have the opportunity to provide input to the guidelines.

I encourage health consumers to download this document from http://www.nhmrc.gov.au/consult/index.htm#b. and submit their comments and concerns as these enabling guidelines will play a key role in clarifying the understanding as to the appropriate circumstances where disclosure should be made.

Building consumer confidence is central to the acceptance and success of these guidelines. It is essential that the guidelines reflect societal values such as fairness, confidentiality, autonomy and democratic deliberation. These are not easy issues. Striking a balance between an individual’s right to autonomous decision-making regarding their genetic information and a physician’s responsibility to at-risk family members will require collaboration between medical professionals and health consumers to ensure an outcome that will serve the best interests of all.

Sharon Van der Laan is the Executive Director of the Genetic Support Council of WA Inc

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**Too young for aged care**

*By Joy Mallett*

**People with Younger Onset Dementia have special needs. In particular, it’s wrong at many levels for them to be housed in aged care residences.**

After losing my husband to Younger Onset Dementia (Alzheimers), it was particularly distressing to realise in January 2004 that my 43-year-old daughter, Lisa, was facing a similar diagnosis.

Our sad, eventful journey has been beset with so many difficulties that I have become an advocate for people with this condition. I have been driven by my personal ethic, which I believe is shared by most Australians, that we should ‘do the right thing’ whenever possible to give everyone a decent quality of life.

If we accept this ethic, I believe we have an even stronger obligation to do the right thing for people who are no longer able to care, or seek help, for themselves. My particular concern is the need for adequate residential care for younger people, as their quality of life is severely compromised without it.

Lisa’s story exemplifies the difficulties many young people with dementia face, as well as others with limited capacity. If their lives – and their carers’ lives – are to improve, we have a collective responsibility to address them at legislative, community and social levels.

Our first hurdle was to sort out the legalities. Fortunately, I had been through this with my husband, so knew it was better to have enduring guardianship and power of attorney formalised while Lisa still understood what was happening and could give her consent. Being guardian gave me the legal clout to make decisions for Lisa, use her bank...
account and, importantly, be consulted about her care. Otherwise, I may have had the extra administrative and emotional burden of applying to the Guardianship Board.

In a ridiculous anomaly, the guardianship and power of attorney is only legal in the state in which it is drawn up. People who want to move interstate, for example to be closer to other supportive family, must then apply to that state. The next hurdle was to get Lisa to a dementia specialist. She was in denial, and fought against this. However, she was behaving very erratically, had lost a lot of weight and was no longer able to care for her children, then 15 and 12, or her affairs. She was agitated, couldn’t stay still, and was very rapid in her movements.

Although assessed as ‘acute’ and ‘high care’, I brought her home to live with me for nearly a year until my health began to suffer. I was shocked at how difficult it was to get residential care. I have now become a passionate advocate for appropriate housing and facilities for younger people as I feel the current situation of putting them in facilities for elderly people is completely unethical.

Younger Onset Dementia is classified for people under the age of 65, though younger people are now being diagnosed in greater numbers. Unfortunately, there are no accurate figures available as dementia is not a notifiable illness.

Refused admission

Many facilities flatly refused to accept Lisa, saying it was ‘an aged care facility’ or ‘did not take people under the age of 65’. I eventually managed to find a less than desirable place for old, sick people, but was asked to remove her after seven weeks as they couldn’t cope with her. She is now in a state run facility. I suspect the difficulty in securing a place is partly due to the fact that aged care comes under federal jurisdiction whilst mental health (which includes dementia) is a state issue.

The next hurdle was to be heard. Many facilities ignore the information and advice given by family about a person’s condition and/or behaviour. Although I am Lisa’s legal guardian, at first I was not advised or consulted about Lisa’s health and decisions about her health care, including changes in medication that I had expressly prohibited. This only improved when I demanded to know and gained the reputation as an outspoken advocate. I want systems to be implemented that ensure guardians are consulted before any medical decision is made.

Due to staff and resource shortages, residential care facilities are often only interested in making a person manageable, severely impacting on quality of life. Lisa’s situation typifies the difficulties of keeping younger people in aged facilities. To prevent her ‘bothering’ the elderly residents, she is kept in isolation. To prevent her lying in bed during the day, she is locked out of her room and in a corridor with a single chair. Her television, radio and windows are in her room. I believe this isolation has caused her condition to advance considerably faster than normal.

Lisa has suffered some dreadful experiences, which I believe amount to unethical treatment, even abuse, and will only be addressed when facilities are made available for young people and staff properly trained and resourced. Staff overuse physical and chemical restraints to prevent a person moving around or ‘escaping’. These leave the person confused and physically weakened, and their family distressed. Lisa has been tightly strapped to a bed, and injected with a sedative that took her three days to recover from. She has been restrained in a chair and left zombie like with chemical restraints.

While the hospital and residential care staff do their best in a difficult situation, they require special training in dealing with younger people with dementia. They are used to handling older residents who are slower and can sit for hours. Younger people are not interested in bingo, Bing Crosby or other activities for older people. They need mental stimulation suited to their age and which keeps their minds as active as possible. They need to go outside, have some exercise and go on excursions. They need the mental stimulation of games, computers and people their own age.

These are what give them quality of life and this is why I strongly advocate for the building of secured cottage style accommodation for people with Younger Onset Dementia.

I visit my daughter several times a week and take her for drives and to see her family. From reading about her condition, I know that memory remains strong for a long time but aphasia (the loss of speech) occurs reasonably early. She doesn’t speak much now but occasionally opens up. Her concentration span is becoming shorter. My daughter has lost everything – her family, home, independence and dignity. I know she will continue to deteriorate but I will continue to fight for her and help her in any way I can to have the reasonable quality of life that every person is entitled to.
Post-coma unresponsiveness

By Michele Kosky

Consumer involvement in the development of guidelines for caring for people in post-coma unresponsiveness has led to a clear document that addresses the ethical issues associated with making decisions for people unable to make them for themselves.

Brad, 19, suffered a severe head injury in a car accident six months ago. He lay in a coma until just the other day, when he opened his eyes. Nothing else. No movement. No reactions. No sign of recognition. That night he closed his eyes again as if sleeping. This pattern has continued every day.

This state is known as post-coma unresponsiveness and it challenges the person’s family, carers and health team with providing the best medical, social and other care. They must make decisions about possible rehabilitation, where the person will live, who will look after them and what to do if their health or social circumstances change. Some people progress to the minimally responsive state, where they may have limited movement and speak a few words. Some people recover some of their faculties; most people, however, never regain the ability even to move or communicate.

The need for ethical guidelines for the care of people in a post-coma unresponsive state was identified following the development of Post-Coma Unresponsiveness: Clinical Framework for Diagnosis by the National Health and Medical Research Council in 2003. I was appointed as the consumer representative to the Post-Coma Unresponsiveness Working Group in 2005; the Ethical Guidelines for the Care of People in Post-Coma or a Minimally Responsive State and the Family Guide, a consumer document, was approved by the Council in December 2007.

Complex ethical issues

The guidelines assist families, carers and health professionals grapple with complex ethical issues. When do you commence or stop attempts to rehabilitate the person? How do you talk to, care for, entertain the person? How do you decide what is in their best interests? Who is responsible for the person? When is treatment burden-some? When should treatment be withdrawn? Is palliative care needed? What do you do if you feel the medical care is not adequate, or believe the person’s ‘representative’ (the person with the legal authority to speak for the person) is making poor decisions?

The guidelines work on the basic principles that people in post-coma unresponsiveness and minimally responsive states are totally dependent on others for their care and providing that care is an expression of human solidarity and connectedness. Decisions about care should demonstrate respect for all aspects of human dignity, respect the person’s previous wishes and be in their best interests. While promoting the idea that decisions should be made collectively with the expertise and knowledge of the health team, family and/or other significant people in the person’s life, the guidelines also talk about the responsibilities of the representative.

Perhaps the most difficult ethical question for people caring for someone in a post-coma unresponsive state is around deciding their ‘best interests’. The guidelines address this clearly, but warn that even if the person appointed someone to make decisions before they were incapacitated, or had an advance care plan, there are still ethical complications. Decisions need to respect the person’s own beliefs and values and the things they hold to be most important, even if they differ from the family’s views. Any advance care plans or directives must be proven to have been well-informed, considered decisions that included situations like post-coma unresponsiveness or minimal responsiveness. The assumption is that decisions will be made jointly between the family, carers and health team, but where there are conflicts about the best interest, the guidelines discuss conflict resolution and how decisions can be challenged legally.

The consumer perspective

Creating the guidelines was a challenge. It was a long and arduous journey to bring a strong consumer perspective on behalf of this group of most vulnerable people who are looked after at home, in nursing homes, acute hospitals and in rehabilitation settings. I talked to some carers of people in post-coma unresponsive state or in comas and had wonderful feedback from 15 consumers in Western Australia who really worked the draft family guide through the consumer perspective process so the final document was practical, readable and useful.

I was surprised to find that the availability of care really depends on where you are in Australia. The variation in treatment and care was remarkable in a country that prides itself with the orthodoxy of equal access to health care. Victoria appeared to be the top of the ‘league tables’ in terms of access to slow stream rehabilitation. In addition, there is the disparity between third party insured patients and non insured patients, which creates policy challenges for people in post-coma unresponsive state. There is also the vexed question of resource allocation, which is touched on in the guidelines.

The working group were marvellous people to work with. The two chairs, initially Reverend John Morgan and then Nicholas Tonti-Filippini, led this robust, hardworking, challenging group to produce two really important documents. While targeted at post-coma unresponsiveness and minimally responsive states, the principles can be applied to many other states where decisions must be made for a person who is unable to make them for themselves.

Michelle Kosky is the Executive Director of the Health Consumers Council of Western Australia and the consumer representative on the Post-Coma Unresponsiveness Working Group.

Making decisions for end of life

By Professor Margaret O’Connor AM and Bruce Shaw

If we want control over how we die, we need advance directives and open communication with our family and health practitioners.

Dying has changed in the last 50 years. Australians live longer than ever before. People are more likely to die in hospital or institutional care. Increasingly, people die following lengthy periods of illness and disability due to serious chronic conditions that bring with them a wide array of physical, psychological and social problems.

Health care and other care services do not always perform well for people who are dying. Our existing models of care do not necessarily match the needs of many with terminal illness, creating unnecessary stress and pain at this crucial time.

Addressing the needs and aspirations of people with terminal conditions has become a significant public health issue if Australia is to become a genuinely socially inclusive society with a social goal of achieving quality care at the end of life for all.

Given that, care at the end of life has come a long way in recent decades in Australia. We have come to recognise that the type and level of end of life care required by individuals is not a fixed quantity, but rather differs for each individual, and for each person over time. Informed choice about the place and type of care, matched with equitable access, is a shared aspiration for policy makers and planners.

An important part of informed choice or consent is our individual right to accept or reject any treatment or procedure. However, a dread common to many of us is the thought, ‘How can I govern what happens to me if I lose the competence to make decisions for myself?’

We need to act on that dread now if we want to die in a way that we want, as is our right. Palliative Care Australia advocates that the nation embrace end of life planning as a way to improve the circumstances of dying.

The most common, simple and informal mechanisms are for each of us to make our wishes about our needs – our physical, spiritual, cultural, lifestyle, health and social needs – known to people whom we trust to act in our best interests if the need arises.

This can be by appointing (formally or informally) a proxy decision maker – someone you choose to make personal or lifestyle decisions, including medical decisions, on your behalf when you are no longer capable of doing so. This person is given different names in different jurisdictions. As the appointing person, you would usually choose the type of decisions or functions you want the proxy decision maker to make.

Another, more formal answer whose time is hopefully coming is ‘advance directives’, which Palliative Care Australia is advocating for and seeks to work with other stakeholders on.

Advance Directives

If you want to specify in advance the types of medical and health procedures you would or would not want to undergo in the event you become incompetent, you can make a written advance directive and/or appoint a proxy decision-maker.

Advance directives allow you to set out your wishes for the future so you can stop worrying and live well. They help reduce family conflict at a time of great trauma and stress. They give doctors legal protection for withholding or withdrawing life sustaining medical treatment, if that is your wish.

The ideal role of advance directives (or appointment of a proxy decision maker) may be to stimulate reflection, communication, partnership and exploration of fears and possibilities between you and your family and significant others, and your medical practitioners and other health care professionals.

Are there any obstacles? Well, yes there are.

Firstly, the legal situation varies in each state and territory. There are differing powers in different jurisdictions. There are also uncertainties around whether someone with an advance directive in one state or territory can expect to have it recognised and honoured in another.

Palliative Care Australia (PCA) is advocating greater harmonisation of the rules, and a raising of the level of community awareness of the importance of advance directives.

Secondly, people frequently believe that an advance directive to refuse lifesaving or sustaining measures will be honoured under all circumstances. The reality of medical practice often means that this is not so. If an advance directive is specific to a particular set of circumstances, the directive will not necessarily have force when these or similar circumstances do not exist.

Thirdly, on the other hand, if an advance directive is so general that it applies to all possible events that could arise, it is usually too vague to give any useable direction to the medical practitioner or other health professional.

Even written advance directives have their problems and limitations. At the end of life they do not replace the need
for a working partnership, involving optimal communication between the treating doctor, you the consumer, your proxy, family and significant others.

We should all discuss with our close family members the kind of treatment that we would want should we become too ill to speak for ourselves. That will help them do the ethical thing by us, that is, the things we want as we die.

If no advance care planning has been undertaken, Palliative Care Australia would advocate that a consultative approach with the family or significant others be adopted, using both substituted judgement and best interest.

**The way ahead**

Ensuring quality care at the end of life has many aspects. Palliative Care Australia gave momentum to the issue at a national forum *A Matter of Life and Death: Confronting the new reality* in early March. It offered an opportunity for stakeholders to help shape the health policy agenda for care at the end of life and promote the broader applications of the principles of palliative care within the health care system.

A significant outcome of the forum was the commitment by key stakeholders to create an End of Life Alliance to seek consensus on issues such as uniform, system wide practice of advance care planning and advance directives.

Professor Margaret O’Connor AM is the President of Palliative Care Australia and holds the Vivian Bullwinkel Chair in Nursing, Palliative Care at the School of Nursing and Midwifery at Monash University. Bruce Shaw is the National Policy Manager at Palliative Care Australia.

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**Keep quality improvement ethical**

*By Dea Thiele and Dr Sophie Couzos*

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As the line between quality improvement activities and research blur, do we need to change the guidelines about ethics committee approval? Aboriginal community controlled health services provide a case in point.

‘Ever since Captain Cook landed, they have been turning us upside down and researching us to death.’

The late Dr Puggy Hunter, inaugural Chair of NACCHO.

The quality of health care has always been a concern for those using health services. Consumers have, in fact, been the drivers of quality improvements. Aboriginal Community Controlled Health Services (ACCHSs) for example, were first established more than 35 years ago by Aboriginal peoples as a response to the urgent need to provide decent and accessible health services in an environment where many health care providers engaged in unethical, racist and suboptimal practice.¹

As with every other primary health care provider, it is an ethical obligation for ACCHSs to participate in quality improvement activities. In turn, quality improvement activities should be evidence-based, supported by the profession and the community, and be ethical.

However, there are some aspects of quality improvement activities that consumers and services must be wary of, such as research and funding body requirements (for accountability purposes) that masquerade as quality improvement activities. Such activities distort clinical practice and may in fact divert services away from quality care.

ACCHSs are culturally appropriate, autonomous primary health care services initiated, planned and governed by local Aboriginal communities through their elected Aboriginal board of directors. There are now over 140 ACCHSs across Australia in all states and territories. The National Aboriginal Community Controlled Health Organisation (NACCHO) is the national peak Aboriginal health body representing these services.

The types of quality improvement activities undertaken by ACCHSs range from peer driven mainstream initiatives through to initiatives driven by the Australian government, ACCHS and research.

**Research dressed up as quality improvement**

Because efforts towards quality assurance can ensure accountability to the funding body as well as the public, some ‘policy creep’ may occur. This is when subtle changes in public policy lead to accountability requirements.

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NACCHO’s Dr Sophie Couzos and Dea Thiele
increasingly being designated as quality assurance or improvements when they are really research or externally driven performance appraisals and productivity standards.

Quality improvement activities are believed to not require ethics committee oversight because they are systematic, data-guided activities designed to bring about immediate improvements in health care delivery as by-products of usual clinical activity. Moreover, the knowledge gained is relevant internally, such as when a clinic checks vaccination coverage and implements improvements accordingly. Research, on the other hand, is a systematic investigation designed to enhance generalisable knowledge from activity that is not usual for the clinic. Human research requires ethics committee clearance.

Thus, if some quality improvement activities are in fact research, the failure to assess the ethical implications of the activity may pose a risk for consumers and health services if they don’t comply with recognised ethical standards and values of the community. It has been said that because a quality improvement activity might be commendable, [this] does not imply that any given project is acceptable. Consequently, it has been argued that certain quality improvement activity should be subject to ethical oversight.

Risks to consumers

What are some of the risks for services and clients of poorly considered quality improvement activities? They may be minimally relevant to the service and client population, inflexible and poorly integrated to core clinic activity (i.e. not a by-product), costly, cumbersome, diverting activity away from service provision, compromise confidentiality of clients and services, and technically invalid.

The risk is that poorly considered quality improvement may be used by external bodies and/or funding agencies for accountability and the imposition of penalties, with potential political uses of the findings. These factors are especially important when they apply to minority populations like Aboriginal peoples.

Poorly contrived quality improvement activities risk ACCHSs disengaging from them and/or ‘gaming’ the performance indicator results.

This phenomenon is well known amongst the health care profession. Too great an emphasis on indicators from quality improvement activity can lead to ‘dilution of professional responsibility, distortion of professional judgment, stereotyping of practice, discouragement of innovation, legal hazard and an ambience of fearfulness that leads to resistance, evasion, concealment and ultimate demoralisation.‘

Funding bodies may develop and mandate quality improvement activities and subsequent performance indicators as a condition of funding to health services, independent of the profession and consumers. This distorts priorities and the delivery of health care in favour of the needs of funding bodies which may be in conflict with the needs of consumers. For example, the Healthy for Life program provides much needed funding for core primary health care directed towards maternal and child health and chronic disease and is designated a quality improvement program. However, data provision from ACCHSs in return for funds are extensive, externally driven and progressively expanding to the point where individual client data may be mandated in the future. Clinic software development is being driven by the needs of funders and not by the profession. There is no ethics committee oversight and Aboriginal people’s control over how that data is used when aggregated by government bodies is restricted. Research agencies may use the aggregated data without consent from Aboriginal representative bodies.

NHMRC Guidelines (2003) on this subject recommend ethics committee review if the proposed quality assurance activity potentially infringes the rights, privacy or professional reputation of carers, health care providers or institutions.

Who assesses the risks?

We ask how such risks are assessed in Australia and by whom? Should it be left to government agencies? Or should consumers and their representative bodies be the arbiters?

The Ethics Committee of the Aboriginal Health and Medical Research Council (an Aboriginal community controlled body) believes that it should provide oversight to programs like Healthy for Life, particularly if there is any change to the proposed use of clinical health data, if there is any publication that relates to data use, and prior to any dissemination of a formal report. The National Aboriginal Community Controlled Health Organisation believes that the ACCHS sector should have oversight over quality improvement information collected from ACCHSs in the same way the medical profession (RACGP, AGPN) has oversight over quality improvement information collected from general practices.

Government may impose all sorts of medical interventions onto the public which bear little relation to best practice and quality improvement of health care provision. An infamous example is the Howard government’s funding of health checks for sexual abuse for every Aboriginal child in the Northern Territory in June 2007. Opposed by Aboriginal groups and the medical profession in unison (which led to subsequent amendments), such stark examples of externally and politically driven health interventions are a reminder of how vital it is for consumers and their representative bodies to have a role in the quality improvement of health services.

Dea Thiele is the Chief Executive Officer and Dr Sophie Couzos is the Public Health Officer at the National Aboriginal Community Controlled Health Organisation

Ethics around organ donation

By Chris Thomas

As donations remain stagnant and need increases, what are the ethical issues that we, as a society, face around organ transplants.

We are all familiar with the concept of rationing of limited resources. The tradition of women and children first into the lifeboats is well-accepted. In the Sydney petrol strikes in the early 1980s, a rule of odds and evens days was an effective method of distributing a limited supply.

The rationing of other limited resources – organs and tissues – occurs every day in health care and presents transplant physicians and surgeons with demanding ethical dilemmas.

Who receives an organ? How old is too old? Is Hepatitis C infection a contraindication to transplantation? Should a habitual alcoholic be denied a liver transplant? Whose organs are they anyway? How do the rights of the individual stack up against the needs of society?

It could be assumed that a child may take preference over an adult for a donated organ. However, if you examine which of the two patients may achieve the most ‘Quality Adjusted Life Years’ from that organ, the 25-50-year-old possibly has a better chance of keeping the organ longer than the child. The child needs to face adolescence where often there is a pattern of non-compliance with their medications; failing to keep up medication gives a 75 per cent chance of losing the organ.

Why should doctors at the coalface be left with these crucial and sometimes unpalatable decisions when, realistically, all society should have a say? The medical profession and organ and tissue donation carers face even more complex ethical dilemmas.

- Does a healthy person expose themselves to potential psychological damage if they decide to give an organ to a person they don’t know?
- As our population ages (through good health care), does a person aged 80 plus who has paid taxes all their life have the right to demand a transplanted organ when it may only potentially extend their life for a few years?
- Can a person who is prepared to be an organ donor be given some form of preferential treatment over a non-registered patient, as we are seeing in the USA?
- Can a terminally ill person expressly indicate that a certain family member in need for a transplant receive their organs?
- Is it ethical for the production and subsequent commercialisation of tissue products when those tissues derive from altruistic donations but that very investment and development has the potential to improve the quality of life of many people?

The scale of the problem

More than 1,800 Australians are now waiting for an urgent transplant. More than a person a week dies waiting, with the greatest mortality occurring in patients waiting for hearts, lungs and livers, where no real alternative short-term treatment exists.

Conversely, Australia’s rate of organ donation has remained static for the past 25 years. Last year Australia only achieved 198 organ donors, equal to about 10 donors per million people, half the rate of the USA and only a quarter of Spain, the leading proponent of organ donation.

Among the many reasons for our low rate of donation are several we can’t complain about. We fortunately don’t have the same gun crime as that of America resulting in fewer trauma patients arriving in hospital. Our very successful road death prevention campaigns have helped reduce road trauma deaths. The quality of our general health has greatly reduced stroke and other causes of premature brain damage.

Australians should not be complacent with their rate of donation. It is accepted that about 1,300 people die in Australia each year in a situation where they could be considered for organ and tissue donation – in other words they are intubated on life-support in hospital and have suffered some form of irreversible and catastrophic brain damage.

Doubling our rate of donation should be a feasible and realistic goal. It would provide organs for an additional 740 patients waiting for kidneys; 368 more patients given 3.7 organs are used on average from a donor. It would make serious inroads into the waiting lists, saving lives and answering the prayers of those severely traumatised by watching their loved ones suffer.

There are significant economic dimensions to this problem. Take kidneys for example. Based on UK analysis, there is a saving of approximately $47,000 to the Australian health system for every year after a kidney recipient is transplanted in comparison to the costs of dialysis. With a median graft survival time of nine years, there is a saving of $429,763 for each kidney recipient over dialysis. Given 368 people received a kidney transplant in 2006: the ongoing saving would be $17,627,000 after...
taking into account the costs of the procedure and subsequent immunosuppression. The total saving to the health system would be $158 million. If all 1,381 patients waiting for a kidney received a transplant, the saving would be around $593 million. This does not take into account the additional benefits of these patients returning to the workforce and undertaking productive lives, off pensions and paying taxes.

Ways to fix the problem
Leaders of the organ and tissue donation sector have met over the past year as an initiative of the Federal Government and have recently delivered a comprehensive report to the new Labor Government. The report points to comprehensive systemic change, standardising different state laws, better education and a more cohesive communications strategy to present the community with simplified messages about donation.

Transplant Australia is confident the recommendations will lead to a significant increase in donations. Either way – an increased pool or a continuance of the rationing that currently occurs – doctors and the sector will be faced with new and challenging ethical dilemmas.

New challenges
Live donation has increased significantly and provides a new and potentially compatible source of kidneys for many patients. This is clearly a wonderful and unique gift from one family member or close friend to another. But we are seeing a new pattern of healthy people consciously deciding to give their kidney in a non-directed way – to someone with whom no relationship can be established.

On the one hand this can also be considered a wonderful gift. However, many doctors worry about the potential future psychological problems that may arise, particularly if that patient subsequently develops renal disease and needs a kidney transplant. It is also an ethical problem for surgeons to cut into a perfectly healthy body and remove an organ when there is no underlying connection, love or friendship between donor and recipient.

A successful increase in donations would also give rise to new ethical dilemmas coupled with our ageing population. How old is too old? What are the ethical and indeed economic considerations of transplanting 80-year-olds and who should make these decisions?

Many patients are currently excluded because of the presence of hepatitis or other infectious or contrary conditions. Do we have this right? And should the habitual smoker receive a new heart or lungs? Should a patient be given a second, third or even fourth transplant?

If we are not successful in increasing the rates through the change process recommended in the Taskforce, how else can we jump-start Australia into better supporting organ donation?

Should we follow the Spanish experience and introduce opt-out legislation where there is a presumption of donation. Many authorities in Australia believe it would not work here, saying Australians wouldn’t ‘cop it’. Intriguingly we have never asked those Australians and it should not be assumed that we would not be in favour of such a system.

Another issue which has been raised overseas is financial incentives. Nobody agrees with paying for organs; however, what about some form of financial incentive post-death, such as a contribution to funeral expenses? If we are talking about doubling our rate of donation to 400 donors then a $5,000 contribution would cost taxpayers $2 million but could potentially be a powerful and innovative incentive to reward those who make such a generous gift.

Perhaps the answers lie in a different direction in stemcell research and tissue replacement. The possibility of growing our own tissues, of becoming essentially our own donors, is on our doorstep. But as a nation we need to commit to this research if we want to reap the rewards.

Chris Thomas is the Chief Executive Officer of Transplant Australia

CHF facilitates the appointment of consumer representatives to national health-related committees. There are about 200 committees operating at any one time. Consumer representatives have strong networks from which to draw consumer perspectives, which add value to committee work, leading to more robust decisions for health care in Australia.

Pictured, from left, are Janney Wale, Karen Carey, Sheila Rimmer and Frank Fisher
Keeping consumer e-health transparent

By Bernard Kealey

One of the most popular e-health portals of the late 1990s was DrKoop.com. Dr Everett Koop was the United States Surgeon General (Health Minister) during the Reagan administration. He was a part-owner of the website, and his name gave it kudos with the public. However, as the brand and scope of the site grew, Dr Koop was unable to control all that was said or promoted on the site.

Public perception about DrKoop.com turned very quickly from good to really bad in late 1999 when it was revealed that significant amounts of the content was actually paid product placement and, more disturbingly, the site provided referrals to clinical trials without disclosing it was receiving recruitment fees for patients who took up clinical trial options.

This scandal drove many who were striving to develop a more transparent e-health sector to declare ‘enough is enough’ and decide to differentiate the ‘serious’ sites from the ‘cowboys’. A code of conduct had to be agreed on, marketed to consumers and enforced. After intense if hurried consultations, the Journal of Medical Internet Research (JMIR) developed and published in early 2000 a code of conduct with the following guiding principles, each with definitions and guidance:

• Candour and trustworthiness
• Quality
• Informed consent, privacy and confidentiality
• Best commercial practices
• Best practices for provision of health care on the internet by health care professionals

The full code can be found at http://www.jmir.org/2000/2/e9/ but this code basically outlines the obligations of providers of information.

The last principle is the most important of the principles because everyone who is involved in e-health provision is either a ‘health professional’ or an organisation providing health or product information and this principle binds together the preceding principles. It says:

Health care professionals and organisations who provide health information, products, or services on the Internet have an obligation to

(A) adhere to the highest standards of professional practice

(B) help patients to understand how the Internet affects the relationship between professional and patient while adapting the highest professional standards to the evolving interactions made possible by the Internet.

Part (B) is particularly interesting, and I have been unable to really find any good examples of this in action.

At the time of publication it was acknowledged that the nature of internet businesses meant it would be impossible to enforce so the code would have to be voluntarily adhered to, at best.

What happened to the code and why are we not all familiar with it? The answer is found, to some extent, in events of a few months later. On 10 March 2000 the ‘internet bubble’ burst. The ability to raise fast cash to develop and advertise commercial websites dried up overnight. And so the ‘e’ market changed. And it has changed numerous times since.

The best way to advertise services on the net is via a search engine such as Google or Yahoo. Advertisers bid through an auction-type system based on ‘key words’ that someone puts into a search engine; the more an advertiser is willing to pay, the higher their website will appear on results lists. More recently it has become incredibly easy to sell the advertising space through a
broker who on-sells the space based on keywords that are attractive to advertisers. Once this happens, most sites lose most control over whom or what is advertising via their web pages.

**Case study**

Without naming specific sites here is a hypothetical situation.

A regional asthma support group gradually builds a website which is a library of articles and links on various aspects of asthma management. It is full of information, easy to read and understand and provides linkages directly to other sites with scientific or medical information from free-access journals etc.

Most sites of this type provide good information; however, they do not explain to their users why this information is good, and how it was chosen for inclusion. Visitors to that site take it on trust that the information is accurate and trustworthy. The more information and linkages within the website, the easier it is to find from a search engine. Likewise, the easier it is for advertising brokers to find advertisers who find that site attractive.

Once the advertising floodgate is opened, you could expect to see a changing roster of advertisements for everything from respiratory specialist clinics, herbal supplements, air flow meters, de-ionisers, allergenic-free cats, vacuum cleaners, exercise machines – any of which could be of specific interest to some people who are searching for asthma-related information.

While a medical journal or a patient support newsletter may retain significant control over the advertising content in a printed publication, most ‘non-commercial’ sites are not set up to scrutinise what is advertised via their web site. Paradoxically, the sites with the best content are likely to be attractive to advertisers of dubious products and services.

**Recommendations**

Ethically speaking, what are the benchmarks that an information-only website needs to be measured up against? I would suggest that rather than just publishing useful and/or interesting information that is consumer oriented and run, sites should take a better lead in explaining and demonstrating why their information is good, and showing consumers how to judge quality for themselves.

Rather than just a statement that says the information has been assessed by an editorial board, or an expert committee or some such, there should be a prominent and user friendly checklist of assessability guidelines that are specific to the sort of information on the site. This information should make it clear how to ask advertisers for information to back up any claims they are making, or how to check for negative feedback about individual products or companies.

If the only commercial activity that a website engages in is allowing paid advertising, then it is preferable that it retains direct control over what advertising it allows on its site and makes clear to all users what guidelines are used to assess the worthiness of the products or services promoted. Where that is impractical, it is absolutely necessary to provide prominent and easily accessible information to help consumers assess for themselves the worth of any such products; providing a disclaimer that it has no control or specific endorsement is not enough.

As the JMIR noted, any ethical code of conduct adopted for e-health has to be self regulating; it is probably impossible to expect commercial sites to offer such transparency in the near future, and it falls upon consumer groups and sites to educate their constituents and their users how to assess information.

While this task may seem daunting, the sooner that it is started, the sooner we will see better outcomes for consumers.

**Bernard Kealey** is a research analyst and a consumer representative on national e-health committees and research steering groups.

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**Talk with me, not to me**

*By Jonathan Marshall*

**Health care professionals have an ethical responsibility to include people in the management of their own health care. Good communication is essential to this, particularly for people with chronic conditions.**

Ethics are hard to discuss. There is no agreed basis, or terminus point, for ethics. People can consider almost any position to be ethical depending on the complexities of the situation they are in.

The current fashion for shifting ethics into the domain of ‘the practical’ does not solve the issue either, as practicality also involves judgement and evaluation. It is, for example, an ethical judgement as to whether a treatment takes too much time, money or staff effort etc. Introducing God does not solve the problem: for is a judgment ethical because someone says God says so, or does God issue that command because the judgement is ethical? In the second case ethics is independent of God, and in the first case we are implying that ethics comes down to obeying someone because they are more powerful than we are.

Rather than engaging in an endless ethical questioning, I shall suggest that a ‘good’ ethical position for health workers is to help the patient to the best of their abilities in accordance with the desires of that patient. This is particularly the case with chronic conditions as a once-off immediate life saving decision does not have to be made, and ongoing management becomes the focus.

However, straight away there is an ethical problem: what happens if the patient’s desires will lead to their death...
or to further suffering for themselves or those around them? Should the practitioner go along with those desires? There is no easy answer here, partially because treatment is rarely simple in chronic cases. Not everything can be healed or will heal. However, when the patient becomes as much a part of the treatment as they can, managing the condition will be easier and less likely to go wrong. If they do not wish to become intimately involved, or are incapable of becoming involved in the treatment then, it seems by the ethical position proposed above that health practitioners, to some extent must go along with them; at least initially. The degree of this extent is also a complex ethical decision dependent on the situation of the patient and the practitioner.

**Ethical communication**

Communication and mutuality are central to the proposed ethical position to help the patient in accordance with the patient’s desires.

The health practitioner attempts to become willing to accept the patient as a source of knowledge about, or experience of, their condition. In particular, the patient may have experience of how medical treatment might fail and thus have a legitimate nervousness of treatment. Such mutuality may also help people with chronic conditions maintain their morale amidst the often boring, or painful, processes of treatment. Giving a person a sense of being heard is often likely to make them more communicative, participatory and cooperative.

Sadly, communication is not simple. It more closely resembles a process of exploration than it does of transferring ‘bricks’ of information from one person to another. Each person perceives everything that is said through their own cultural conventions, knowledge and experiences. As a result, words do not just mean what the speaker intends them to. They mean what the listener interprets them to mean. Therefore, even apparently successful communication must be checked for accuracy. Indeed checking the accuracy of your listening could be a fundamental ethical duty as it involves judgement of the other person, and generates their response to that judgement.

This reminder might seem unnecessary, but a common experience for myself and other people with chronic conditions is the tendency for medical practitioners (particularly specialists) to give up listening when they cannot easily identify the cause of the problem. Lack of understanding can then lead them to suggest the chronically ill person is malingering, which further alienates the person from the medical profession and any ongoing ‘orthodox’ treatment.

Even if a condition is generally treatable, the treatment may not work that well for some people and if this issue is bypassed, it will affect the way the patient will participate in communication and condition management. It is thus important for the health practitioner to listen to the patient’s ongoing experiences, not once, but on an ongoing basis. If health practitioners agree with the ethical position proposed here, they will find they need to keep open and keep exploring.

**The wider context**

Communication is also surrounded by the patient’s wider life and this provides a context for their understanding and their actions. People exist within a social ecology and will not often want to separate from that. They need the social support of their family and friends to live a meaningful life. Sometimes the ‘healthy lifestyle’ recommended by a practitioner means terminating a person’s previous social connections, in effect producing social, or ethical, death. This may not be that healthy or that survivable.

Similarly, the patient’s experiences influence the priorities they place on treatment and whether they can find the energy to complete the treatment. Money, transport, energy, pain and survival in chronic illness can be all consuming. The patient may be worrying about keeping their house, finding enough to eat, supporting their family and so on. If they can get a job, constantly taking time off for medical treatment may threaten that job or, at the least, harmony in the workplace. If they can’t keep a job, they might not be able to get any government support either. This may be more of a worry than issues around treatment; especially if they know the treatment will not cure them. These issues will affect treatment and management and can only be discovered by listening and questioning.

As a result of constant pain, or constantly being on the edge of survival, people with chronic conditions may not always be that pleasant or deferential. If they are managing at all, chances are high they are stubborn and a little aggressive and might well violate the practitioner’s conventions about good communication. This does not mean that they don’t want help or they don’t want someone to listen, just that they might be fed up of not getting results or of dealing with support systems that do not work that well. Good communication can produce conflict that otherwise could be ignored and thus it can be uncomfortable.

**Please listen**

In summary, ethical issues are complicated and may be unresolvable, but a good basis for the ethics of managing chronic conditions could be to listen to the patient and attempt the complex process of communicating with them, showing respect for their knowledge and experience and for the difficulties in their life and life culture. It seems probable that if this is attempted the process of managing the condition is more likely to be successful than if the patient is ignored or simply instructed what to do.

Finding out what the patient might need takes time and a willingness to be disconcerted, and the patient’s willingness to participate may alter over the communication period. Giving people help is complex, but being prepared to listen is a good start.

So, when I, or some other chronically ill person comes to you, please do not do what you think is best for us without consultation, please don’t think that we are ‘stupid’ or don’t know what’s best for us, or lack the will, moral fibre and so on to do it. If we could do what you are asking of us or if it made sense, then we would probably already be doing it. Talk with us about it. Listen. Explore options. The patient wants an answer even more than you do.

Jonathan Marshall is a research fellow with Transforming Cultures at the University of Technology, Sydney.
Learning from the bush

By Melissa Sweet

When I was growing up in central Queensland many years ago, I thought the country was boring and conservative, and couldn’t wait to escape to the bright city lights.

How times change. After 20-odd years as a journalist reporting on health and medical issues, I now find that rural health is one of the most fascinating areas of my round.

These days I associate the country – at least when it comes to health issues – with innovation, and a sense of social justice and concern for equity.

I’ve also been struck by the differences between doctors who work in the cities and those in rural and regional areas. As a sweeping generalisation, I’ve noticed that country doctors tend to be more closely connected to their communities. Health care in the bush seems to be more about public service than private profit.

Media headlines describing the problems of rural health often don’t acknowledge the other side of the coin; that necessity is the mother of innovation.

To give just two examples from recent stories that I’ve done:

- After years of struggling to attract and retain nurses, the remote Northern Territory town of Tennant Creek has come up with a novel solution to its perennial workforce problems. The town has begun training its own nurses, thanks to an unusual joint venture between the health and education sectors.

- At Albury-Wodonga, cancer patients now have better access to a wider range of services thanks to the Border Cancer Collaboration. These gains have occurred because a coalition of locals, including doctors, service managers and community representatives, has had the will and the acumen to break down the boundaries that once characterised the area – not only the geographic ones but also those between services and providers.

What these two stories have in common is a determined collaboration between health professionals, service providers and community representatives, with the aim of better care for their local communities.

They also hold important messages about the values that ought to underpin health care, the merits of a ‘can-do’ attitude, and the benefits that can flow when local communities are empowered to create their own solutions.

I’ve discovered that rural and remote Australia has many such stories to tell. If only the powerbrokers in the big cities would listen.

Melissa Sweet is a freelance health journalist and author

Discharge – the name says it all

By Antonio Russo

The process of leaving hospital must change if health consumers are to succeed in being accepted as partners in their health care. There are strong anecdotal views that the discharge process does not allow the discharging facility to fulfil its responsibility to the consumer.

Just consider the term ‘discharge’. In the jargon of the health profession, discharge is an undesirable pus or fluid that must be purged so it causes no more harm to the flesh. Can the analogy be extended to when a patient is discharged? Many patients would agree.

The discharge process – and name – must be changed if we are to have better health outcomes. At present, a discharge letter is sent to the treating GP, normally prepared by the most junior physician. In the public system it is the intern, with seemingly little or no guidance. This omnipotent epistle is meant to be the continuum of treatment of the consumer.

However, the consumer rarely sees it. The consumer is virtually never given the letter on discharge, presumably on the assumption the consumer is too unreliable to deliver it to the GP. Forget trying to get a copy of the letter as the patient or a family member. What motivation do treating facilities need before they inform the patients of what is needed for their continued health care after leaving the facility?

In future, I will refuse to be discharged! In my Utopia, the facility in question will provide ongoing support in my health care. On leaving the facility, it will provide me with an informed plan for my continuous well-being and enjoyment - and a means to realise it. My stay and leaving of the facility will be just one stepping stone to a healthier me, for which I have control.

I will release myself, fully informed, from the treating facility.

Antonio Russo is a member of Health Rights and Community Action and Treasurer of CHF
Where have the CMI gone?

By Sally Crossing AM

Several years ago, consumers won the right to be given information about their medicines that is written in plain language. Consumer Medicine Information (CMI) leaflets explain what the medicine is, how it works, how it is to be taken and what the risks are.

Ten years later, where are they? Many health consumers receive no information at all about the medicines they have been prescribed. This as a dangerous situation for individuals and of concern from a ‘common good’ perspective.

At first, pharmacists were paid to provide CMI leaflets with the medicines they dispensed, but that payment is now factored into their overall revenue support. Although few pharmacies routinely offer or provide CMIs, payment from the public purse continues.

Before CMI, pharmaceutical companies included an information leaflet with all their products. The CMI system relieved them of this responsibility for prescription medicines. Ironically, they still provide regular package inserts with most over the counter drugs. With many pharmacists not including CMI, we have the questionable situation of consumers being more likely to have good information about cough mixtures than anti-inflammatories or cancer drugs. Is this safe or morally responsible?

It is heartening to see some big pharma are restoring inserts, acknowledging that the present system doesn’t work and that, after all, these are their products which people are buying and using. Is big pharma showing more moral fibre than the rest of the CMI brigade?

So, what should be done to regain safety for health consumers and comply with their right to information about medicines? We get anxious if a packet of potato crisps doesn’t give us a full dietary run-down. How can this not be applied to the medicines we are advised to consume, or may choose to take?

Cancer Voices NSW wants to see stakeholders meet to decide on reform that includes fail-safe access to information by:

- Provision of a central, accessible repository for all CMIs for prescribed drugs
- Review of the CMIs at pharmacies scheme, to improve it, and
- Encouragement of pharmaceutical companies to provide printed CMIs with their product.

We owe this to the Australian community.

Sally Crossing is the Chair of Cancer Voices NSW and Vice Chairperson of CHF

The shock of the new

By Sue Lockwood

Hands up anyone who thinks new treatments, medicines and health procedures are improvements we should have immediate access to.

When the Japanese health consumer at a Cochrane Collaboration Colloquium in Baltimore tried to explain that Japanese people preferred tried and true remedies for health problems, he was greeted with gasps of shock. The Japanese are wary of new ideas; the older, the better, was their view of health treatments.

For the mainly American audience, this was almost incomprehensible. Americans embrace the new with great enthusiasm, so the thought of rejecting the latest treatment caused audible astonishment. And Australians are following in the American footsteps. We are encouraged to think that new developments are, by definition, improvements.

Every day the media reports the newest ‘breakthrough’, assures us that this will be a cure, or the magic bullet, or offer wonderful results. Researchers constantly present us with new ideas or treatments which promise significant improvements. Clinicians encourage us to use new drugs. Drug companies try to sell us new improved drugs.

But new is not automatically best. Before we embrace them, new treatments need to be assessed carefully by the criteria which we, as consumers of health services, find important. What is the reality? What are we basing our judgement on?

Researchers and clinicians often use statistical measures that are inappropriate and misleading for consumers. For example, when herceptin was introduced for the treatment of early breast cancer, the average collection time for clinical trial data was 1-2 years. The data collected related to disease progression, not five year survival data. The so-called long term survival figures were statistical estimates. And yet for women with early breast cancer, 70% of whom can expect to live for five years anyway, the real issue was whether the treatment was likely to increase their overall survival rate? No real information was forthcoming.

At the same time, there were known problems which had not been measured effectively, such as the extent of cardiac disease and the increased risk of brain metastases. The effect on future treatment options for women whose disease recurs had, of necessity, not been assessed. It was impossible for women to make a balanced judgment on the value of this new treatment option. A couple of years more data would have provided many of the answers. But clinicians rushed women into thinking this was their best option and the media concurred. Of course the drug company wanted herceptin on the PBS as soon as possible.

We all want the best for our loved ones; for them to be cured or out of pain, but let’s be a little more wary.

Sue Lockwood AM was the Chair of the Breast Cancer Action Group and a consumer representative
