

Health *Voices*

Journal of the
Consumers Health Forum
of Australia

Representing consumers on national health issues



**Consumer voices
on health funding
and reform:
maintaining a
sustainable health
system**



Health Voices

Health Voices is published twice each year. Each issue has a theme that promotes debate on issues of interest to health consumers, government and industry.

Readers are encouraged to write letters to CHF in response to journal articles or other issues in Australian healthcare.

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The Consumers Health Forum of Australia

The Consumers Health Forum of Australia (CHF) is the national peak body representing the interests of Australian healthcare consumers.

CHF works to achieve safe, quality, timely healthcare for all Australians, supported by accessible health information and systems.

CHF does this by:

1. advocating for appropriate and equitable healthcare
2. undertaking consumer-based research and developing a strong consumer knowledge base
3. identifying key issues in safety and quality of health services for consumers
4. raising the health literacy of consumers, health professionals and stakeholders
5. providing a strong national voice for health consumers and supporting consumer participation in health policy and program decision making

CHF values:

- our members' knowledge, experience and involvement
- development of an integrated healthcare system that values the consumer experience
- early intervention, prevention and early diagnosis
- collaborative integrated healthcare
- working in partnership

CHF member organisations reach Australian health consumers across a wide range of health interests and health system experiences. CHF policy is developed through consultation with members, ensuring that CHF maintains a broad, representative, health consumer perspective.

CHF is committed to being an active advocate in the ongoing development of Australian health policy and practice.

Editorial

We live in a time of challenge, opportunity and reform - especially in the area of health and wellbeing.

Medical advances, supported by new and improved technology and research achievements, save and extend our lives, both in time and quality of life.

Meanwhile, our strained and fragmented health system faces the pressures of an ageing population and increasing chronic conditions in the years to come.

The Australian Government's push for broad reform and a sustainable health system is welcome. We need things to change, we need healthcare to work, and we need it to keep working without bankrupting the nation or its individual citizens.

This issue of *Health Voices* sees consumers tackling the thorny issues around deciding how limited health dollars should be spent. How do we balance the needs of the many and the needs of the individual in healthcare funding decisions? What do consumers value most in healthcare? What should the funding priorities be, and what parameters should guide equitable and ethical decision making within a sustainable system?

In *Lessons from other countries; consumer input into health reform*, Jennifer Doggett draws on international experience, pointedly questioning whether the health system was the place to start the health reform debate. When attempting to realign a system that deals with life and death, affects quantity and quality of life, and spends billions of taxpayers' dollars, shouldn't we first ask, not what's wrong with the system we've got, but what, fundamentally, does the community value?

John Daye, picks up on this issue, challenging our political leaders to find a way to take health out of the political bargaining arena, and address sustainability - not just by arguing how to spend limited funds, but by asking the community how much it is willing to direct and contribute to health through the taxes it pays.

Karen Carey, in *Public versus individual benefit – a moral dilemma*, calls on us to have a values-based discussion around cost/benefit analysis, rationing and how and where to draw the line.

Michael Janssen emphasises that health reform without clear mechanisms for consumer involvement needs to be challenged. The integral role of consumers in continuous quality improvement processes is discussed by Russell McGowan in *Consumers as critical friends*.

Lif O'Connor in *Big issues, small voices* speaks to the wisdom of investing in addressing health issues for young Australians and the shameful potential for the next generation to face a shorter life expectancy than their parents.

As John Paterson explains in *Now for an Intervention we'd like to see*, shorter life expectancy is not potential, but reality for Indigenous Australians. Like Diana Aspinall, he calls for priority to be placed on coordinated, local healthcare that keeps consumers out of hospital.

We hear of the struggle for rural and remote health consumers to keep their local health services functioning with bottle drives and 'cakeless' cake stalls, only to see the doors close a few years down the track. Advanced care planning, issues raised by our culturally and linguistically diverse (CALD) community and the

challenges faced by some of our most marginalised groups are highlighted in the pages that follow.

It's clear, from the perspectives offered and the questions raised, that consumers must have a strong say in planning the future of our health system, and the delivery of healthcare. Not just because they are the end-users and ultimate funders of healthcare, but because there must be community debate about the fundamental issues central to making ethical, equitable and effective decisions around health reform and health funding.

Carol Bennett, Executive Director, Consumers Health Forum of Australia



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Bucking the health reform debate

Michael Janssen

Health reform without clear mechanisms for consumer involvement needs to be challenged.



Does Victoria have something to lose through the PM's health reform proposal? Perhaps? Maybe? *Dunno!* You may be hearing a lot of that in the near future.

The mantra of every bureaucrat at every consultation on health reform has been 'the devil is in the detail', closely followed by shrill requests for Canberra to 'show us some detail'! No one seems to have enough detail to assess the probable impact of national reform on state and local health services.

So, yes, the huge investments Victoria has made in community health services, case-mix funding for hospitals, development of Boards of governance and their legislated Community Advisory sub-committees, Primary Care Partnerships and the many projects around integrating acute, sub-acute and community care; all these may be under threat. But gazing into the crystal ball of parochialism to imagine what calamities may befall Victoria through health reform remains speculation. More immediate are the losses we may *already* be experiencing because of health reform. I can think of two.

First, health consumers in Victoria (and perhaps other states) have suffered a step backwards because the health debate has shifted from whether our health services are meeting community needs and expectations, to which government is going to pay what percentage of the healthcare budget.

On the day of writing this article, Premier John Brumby issued his Ten Questions, described by *The Age*¹ as a 'devastating critique' on Kevin Rudd's hospital reform proposals. How delighted the Premier must be to find himself attacking the PM and his proposals rather than defending

the performance of his own State's hospitals and healthcare services! Keep in mind, many of the parts of Victorian health now being lauded in the context of the health reform debate have been sore points for successive State ministers. But gone are the headlines decrying hospital waiting lists, ambulance by-pass statistics and hospitals rorting funding formulae. Instead, Victorians find themselves unexpectedly enjoying the 'best' healthcare in Australia! Best? Well, maybe - when compared to the parlous state of health in NSW and Queensland, into whose muddy waters national reform seems to be threatening to toss and dilute the jewel that is Victoria.

This 'agenda creep' is illustrated by the last of the Victorian Premier's ten devastating questions – 'where will the buck stop?' It is a question that only someone playing the 'blame game' would be interested in – the answer tells you *who* to blame. This question pushes consumers and concerns for equity, quality and access to the periphery, precisely because it defines the debate as about governments, bureaucrats and funding formulae.

Second, the health reform debate has created an enormous distraction for senior health providers, policy-makers and services. I could attend one or two workshops, seminars, or consultations a week on health reform if I was not careful. Of course, such effort may be a worthwhile investment and is perhaps the responsibility of leaders in the health sector to engage in, but, we should also ask 'what *efficient price* health reform debate?'

The current lack of reform detail tends to lead to a reasonable suspicion about the value of the potential outcomes of health reform. This suspicion is encouraged by the strong opinion of some analysts and media commentators that the whole thing will end up as an unwinnable referendum question, the loss of which will absolve the PM from his promise to

fix hospitals, taking us all back to square one. At that point, there might be a few people in the health sector standing around wondering why we put so much time into the health reform debate in the first place (and what else we might have achieved with that time).

As CEO of a small, largely unfunded, consumer health organisation I'm happy to risk the charge of cynicism for being cautious about committing resources to the health reform debate, especially until the process looks less political and more about tangible consumer outcomes.

And (gazing into that crystal-ball for just a moment) the current distraction of the health sector by health reform might be a forewarning of worse to come if significant reform does go ahead. Quite apart from what Victoria or any other State or Territory may lose or gain in the long term, what assessment has been done of the immediate reduction in health service delivery as reform is implemented? I repeat, while the benefits for consumers remain unclear, the time consumed by health services and bureaucrats implementing reform could be too high. My experience of health departments, health services and health professionals is that change is their weakest suit. Where will the expertise and staffing come from? And, where will the buck stop if services to consumers are affected?

So, how can the consumer health movement make a positive contribution to health reform debate in Australia?

First, we can start getting government and communities thinking about 'where does the buck come from'. Apart from the tax-payers dollars in the health system, analyst Jennifer Doggett² recently noted that one dollar in six spent on healthcare comes directly from consumers. That is more than double the amount covered by private health insurance and the third largest source of health funding (after Federal and State/Territory Governments) in Australia. But do consumers, through their various

organisations, have as strong a place in health reform debate as the health insurance industry or academics and bureaucrats? Health reform without clear mechanisms for consumer involvement needs to be challenged. The lack of funding for an effective and national network of consumer health organisations betrays the health systems essentially tokenistic attitude to consumer engagement.

Second, we can remind governments and communities where the buck *really* stops. Every cancelled operation, every extra year on a dental waiting list,

every missed opportunity to provide preventative healthcare, every drug not listed on the PBS; the 'buck' of inadequate healthcare stops with us, the consumer. As both the funders and the users of healthcare, consumer voices need to be equal to the associations, unions and cartels of vested interests.

In President Obama's recent health reform victory in the US, I'm told a personal letter from a health consumer was instrumental in bringing about a significant shift of votes. In Australia, consumers should act with similar moral confidence. If that means bucking the

health reform debate and challenging assumptions about what is and isn't in the debate, then that is surely an important contribution for us to make.

- 1 Rood, D., Brumby blasts holes in Rudd's health plan, *The Age*, March 26, 2010, front page.
- 2 Doggett, Jennifer., OUT OF POCKET: Rethinking health copayments, JULY 2009 CENTRE FOR POLICY DEVELOPMENT ISSN 1835-0135 OCCASIONAL PAPERS - NUMBER 9 <http://cpd.org.au/paper/out-of-pocket>

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Keep governments honest on health

John Daye OAM

It's time to keep governments accountable, de-politicise health, tie taxes to specific funding and ensure minorities are not marginalised.

As someone who has lived with a chronic illness for half of my adult life, I have come to value Australia's health system for its quality and access to the latest medical technologies and treatments. I have no doubt that excellence in healthcare and our Medicare and social security systems have all helped to keep me alive against the odds. As a patient using our health system on an all-too-regular basis, I have also seen the flaws in our current system, the pressures on resource-strained hospitals and the woeful lack of attention to areas like mental health, aged care and drug and alcohol treatment services.

The current Federal Government came to power, it could be argued, partly because of a promise to do something to improve a hospital system suffering under inefficient Federal-State funding and administrative models, and insufficient resources. The Government set up the National Health and Hospitals Reform Commission which, among many findings, showed that pressures on the health system will only grow. With an ageing population and increasing numbers of people living with chronic conditions, the quality of health services is a concern. The growth in costly medical technologies and treatments will continue, and there is a need for



John Daye (centre), Ainslie Cahill (left), Stephen Murby (right)

more training of highly skilled healthcare workers to address problems of health workforce supply.

I believe that there exists an appetite for making health reform a greater priority in our community. Whatever party is in power over the next decade should build on this momentum to see an appropriate shift of resources and tax priorities to health. The public expectation is access to the best possible healthcare and I think that the electorate is now willing to pay for it. Governments that are willing to ring-fence health funding through specific taxes dedicated to health spending may

find a receptive audience at this time in our political history, possibly more than in the past. Tax changes should not come with vague promises like former Treasurer Peter Costello's pledge that the GST would fix the woes of the health system. The States put those tax dollars into their general funds. Only a specific contract that links taxes and health funding will, I believe, be accepted by the public in the future.

If am right about the current political environment, I think the following principles should guide implementation of properly-funded health reform:



We need our leaders to focus more on consumer health outcomes, less on political point-scoring. Prime Minister Kevin Rudd and Opposition Leader, Tony Abbott debate health in Canberra on 23 March 2010. Photo Mark Graham.

1. **Structural change to the health system must be bipartisan.** Health reform will not survive if it is politicised and subject to political point-scoring from the major parties. A way to ensure some level of bipartisanship is to give some of the control of health reform to independent commissions with briefs that are agreed to by all political parties. The work of the commissions should be evidence based, and the members carefully selected to bring the right expertise in health administration, workforce knowledge and health ethics. A useful mechanism to achieve a bipartisan approach might be a referendum on health reform and its funding which, if successful, would tie future governments to specific health reform commitments and enshrine in the Constitution the principle of equity of access to healthcare for all citizens.
2. **Consumers must be included in the reform process and in the highest level of decision-making.** Transparency and accountability must be the hallmarks of the reform process to ensure the confidence of the broad population. Consumers have a unique perspective that will help to ensure that there is a link between political promises and delivered results. Consumer input is critical in ensuring that health reform is focussed on health consumer outcomes.
3. **A Charter of Human Rights in Health should be considered as an underlying commitment from government to equity and access to healthcare.** There will always be a temptation for governments to prioritise the majority at the expense of minorities in health expenditure. A

Charter of Human Rights in Health would seek to ensure that minorities with significant health needs (for example, people with chronic illnesses or Aboriginal and Torres Strait Islanders) are not disadvantaged in terms of access to, or quality of, healthcare.

We have seen recent trends for governments to provide 'middle class welfare' such as baby bonuses and private health insurance rebates (at the expense of the public health system). Such generosity will probably not survive a re-prioritisation of funds by governments, if our politicians are made to learn how to be robust, by something like a Charter of Human Rights in Health.

This doesn't mean that the wealthier in society should be slugged by higher taxes to pay for the health costs of the less well-off. Governments should look at re-prioritising other expenses in their budgets, or raise specific taxes just for health, if that is the wish of the electorate.

4. **Preventative health measures have to be accorded a greater priority in health expenditure.** We know the value of vaccination and other prophylactic programs in preventing specific diseases. We have seen the value of tobacco prevention and are now hearing loud pleas from health professionals for programs to combat obesity and diabetes. In-school preventative health programs must be funded, and General Practitioners provided with incentives to address preventative healthcare effectively with their patients. That said, we need to ensure programs are well targeted to reach at-risk populations.

5. **Research needs to be driven by a quality of health agenda; not scientific curiosity.** Occasional controversy has been raised in the community when expensive medical research is seen to be driven by scientific curiosity rather than specific outcomes around quality of healthcare. Medical research is a vital part of improving healthcare; consumer participation in setting the research agenda is an effective way of ensuring a primary focus on consumer health outcomes. Advisory structures that make decisions about research priorities and funding must involve health consumers.
6. **Debate needs to be held in the community about the value of extending life through expensive medical technologies versus concentrating on quality of healthcare outcomes.** Western society places a premium on longevity, which some would argue is not healthy. To experience 'quality of life' with minimum pain, adequate mobility and independence is a state many would prefer to a life extended at great cost. Society is already making these choices to some degree; witness the reluctance of hospitals to perform exceptional medical interventions on the elderly, for instance.

Australia has one of the better health systems in the world, despite its failings. We are in a time when governments are being asked to deliver quality healthcare outcomes as a matter of high priority. The decisions politicians make in the next few years will be crucial to ensuring that our standard of living is maintained and our health outcomes improved, particularly with the projected expansion of the population. We have to keep governments honest in this process; de-politicise health in as many ways as possible, commit specific tax dollars and a top priority to health, and not leave out the marginalised in the process.

John Daye is a member of the CHF Governing Committee. He was awarded a Medal of the Order of Australia in 2003 for service to the community as an advocate for people with HIV/AIDS, particularly in the provision of support and treatment services. John thanks David Menadue, Tony Keenan, Therese Hume, Carol Bennett, Ainslie Cahill, Stephen Murby and Tim Benson for their assistance in developing this paper.

Consumer input into health reform: lessons from other countries

Jennifer Doggett

Reform in health should start with fundamental questions about what the community values, and what role consumers should play in decision making.

The cover of the final report of the National Health and Hospitals Reform Commission (NHHRC) features a collage of faces of 'ordinary people', interspersed with a select few photos of doctors and other care providers. The overall impression created by this image is of a reform agenda being driven by 'average Australians', rather than by health professionals, politicians or bureaucrats.

However, the content of the report reflects the reverse perspective. Overwhelmingly, the Commission approaches health system reform from the standpoint of those who fund, manage and deliver healthcare rather than those who use it. This has resulted in a report which, despite its many merits, has some glaring gaps on issues central to the consumer experience of healthcare.

This is clear when the NHHRC report is compared with reform processes undertaken by other countries. Looking beyond our borders we can learn from the way other countries have given consumer interests a more central role within their health systems and have established mechanisms for funding and organising healthcare that aim to reflect community values and priorities.

One of the most significant health reform processes in recent years was the Commission on the Future of Healthcare in Canada (often called the 'Romanow Commission') which reported in 2002. The Commission had a similar broad mandate and addressed many of the same health system funding and governance issues as did the NHHRC. However one important difference was that the Romanow Commission included a strong focus on identifying the key values and principles that underlie the Canadian health system, an issue which was largely ignored in the NHHRC's report.

For example, in its final report the Romanow Commission found that 'Canadians view Medicare as a moral enterprise, not a business venture,' and 'Canadians have been clear that they still strongly support the core values on which our health care system is premised – equity, fairness and solidarity'¹

In contrast, the NHHRC did not attempt to elicit from its community consultation the core values which Australians bring to their understanding of healthcare. The report includes only general statements about the Commissioners' views on relevant issues, such as the balance between public and private funding, and does not attempt to answer key questions such as: 'What level of resources should we devote to healthcare?' and 'What proportion of healthcare costs should individuals pay for directly and what proportion of costs should be shared among the community?'

These are crucial questions for the future of the Australian health system. A community's core values and principles on issues such as fairness and equity are fundamental to all other decisions about how healthcare resources are obtained and distributed. The failure of the NHHRC Report to address the underlying values of the Australian health system is echoed in the lack of a consumer focus in its other recommendations on healthcare funding and resource allocation.

In contrast to this approach, a more consumer-oriented reform process was taken by the state of Oregon in the USA. In 2007, a public board of seven citizen leaders was created to develop a comprehensive plan to ensure access to healthcare for citizens of Oregon, contain healthcare costs, and address issues of quality in healthcare. The



Board reported in November 2008, and one of its key recommendations was the establishment of a Health Authority to be responsible for health resource allocation within the state.

Central to the proposal from the Oregon Board is that the recommended Authority be run by a Citizen Board. The recommendation states that 'The group will be advised by industry and technical experts, but the decision-making power will lie in the hands of citizens whose livelihoods are not tied to the health care system.'²

If accepted, this recommendation would give a citizen-run body overarching control over the development of health policies and programs and the allocation of health funding within the state of Oregon. It is an interesting contrast with the approach taken by the NHHRC which focuses instead on establishing a 'Healthy Australia Accord' between federal and state/territory governments as the basis for allocating health funding and barely acknowledges the powerful role that special interest groups currently play within the health

system in influencing resource allocation decisions.

It is worth speculating that the difference between the approaches taken by the NHHRC and the Oregon Health Board are a direct consequence of their differing memberships. While the Oregon Health Board was made up entirely of lay community members, membership of the NHHRC consisted of healthcare experts, clinicians, private health insurance leaders and ex-politicians, without any consumer representation.

The consumer-focussed approach taken by Oregon contrasts starkly with the health reform process unfolding at a federal level in the USA. The progress of President Obama's healthcare reforms was opposed at every turn by campaigns run by interest groups, in particular the medical profession and private health insurance organisations. In fact, *Bloomberg News* reported last year that efforts to influence the passage of the reforms constitutes the biggest lobbying effort in the history of US politics, with 3 700 registered lobbyists working in Washington on this issue (which represents about seven lobbyists for every member of Congress). The total cost of this lobbying effort was estimated to be over a million dollars (US) per day, over the past year and a half.

While the specifics of the US reforms are tied up intimately with its political system and history, there are some lessons for us as we move down the path of reform. In particular, the powerful force that interest groups exerted to influence the US healthcare agenda should make all healthcare consumers concerned about the role of Australian lobby groups in the current debate on health reform in Australia. It should also make us wary of giving increased funding (and therefore political clout) to the private health sector, without demanding some returns for this investment in terms of consumer input into private health insurance policy and regulation.

It's easy to feel complacent about the equity of our own health system when we watch the seemingly intractable forces which opposed the proposal to give all US citizens access to health

What can Australia learn from the Marmot Review?

Jennifer Doggett

Change focused on the health system may fail to address the major drivers of health inequality within the community.

The recent inquiry into health inequalities in the UK (the 'Marmot Review') poses a number of challenges for the health reform agenda in Australia. In particular, the focus of the review on the social determinants of health raises questions about whether our approach to reforming the health system is the best way to reduce health inequalities and deliver optimum population health outcomes.

The Marmot Review Report states that the link *'between social conditions and health is not a footnote to the 'real' concerns with health – healthcare and unhealthy behaviours – it should become the main focus.'*¹ It outlines an agenda which encompasses broad social and economic policy issues, including parental leave, childcare, education, schools and vocational training, labour market programs, retirement policies, taxation, social

security and pensions, energy and environment policies, urban planning, transport, food supply, social isolation and community building.

These findings challenge an approach to health reform which focuses primarily on the health sector and its components, such as primary care, hospitals and preventive health. According to the Marmot Review, the health sector itself has a limited influence on health status and changes within healthcare will not address the major drivers of health inequality within the community.

The current health reform agenda in Australia has thus far been focussed on health policies and programs. In fact, the Report to support Australia's First National Primary Care strategy states *'Whilst recognising the importance of the social determinants of health, the Draft Strategy does not*

insurance. However, we cannot afford to ignore the failures of our own health system to reduce the health gap within our community, particularly the shameful gap between Indigenous and non-Indigenous life expectancy. We should also remember that for most of Australia's history we did not have a universal health insurance system and that we are really only one generation away from a time when many people faced the prospect of crippling medical and hospital bills in the event of accidents or illnesses. We should not assume that we will never return to a similar situation in the future. Indeed, when we look at the wide variation in access to dental care within our

community and the consistent failure of governments to address this issue, it is clear that we have a long way to go before we can claim our health system is equitable.

Closer to home, Australia can also learn from the way in which the New Zealand health system involves consumers in health service planning and resource allocation decisions. In New Zealand, local health services are managed by District Health Boards (DHBs) consisting of seven publicly elected members and a potential four additional members appointed by the Minister of Health. By law, Maori membership of each board must be proportional to the number of Maori in the DHB's resident

*attempt to actively address the range of non-health issues which impact on health outcomes and inequalities.*¹²

If the findings of the Marmot Review are accepted, this decision will significantly impact upon the ability of the Primary Care Strategy to achieve its objectives.

There are many reasons why governments would seek to limit health reform within the existing health system. Government policies and programs are structured within these boundaries and budgets are attached to specific health program objectives. Moving outside this structure is risky, and historically Ministers and government departments have resisted collaboration across program areas. Also, it is difficult to measure outcomes in many of these broad social and environmental areas and attach these outcomes to government expenditure. A new hospital or health service is tangible and measurable. A program to reduce social isolation or improve community resilience is diffuse, difficult to define and measure, and inherently less attractive in a political environment dominated by short-term interests and the need to maximise media opportunities.

The Marmot Review also raises issue for individuals and groups working within the health sector to improve health outcomes and reduce health inequalities. If the scope of their

population (with a minimum of two Maori members).

DHBs oversee the allocation of annual budgets up to \$870 million and are responsible for providing health services for populations ranging from 32 000 to over 500 000. Board meetings are generally held in public to increase transparency and accountability of resource allocation and other decisions. As part of their contracts, each DHB is also required to consult its district population when writing its District Strategic Plans.

Despite being well-established within the New Zealand health system, none of these options for involving consumers in health funding and service provision

activity is limited by the boundaries of the health sector, they will fail to address some of the most significant factors influencing health status. However, tackling the broad social and economic issues identified by the Review is difficult for groups with limited resources and budgets constrained by narrowly defined activities and objectives.

As always, when it comes to driving policy changes, a balance has to be reached between what ideally could be achieved and what is possible – both practically and politically. The Marmot Review reminds us of the need to include broad social and economic issues within the health reform agenda and provides some valuable data and evidence to support this finding. As we move further down the path of health reform, the lessons from the review and its implementation by the UK government should continue to inform our efforts to reduce health inequalities in Australia.

1. The strategic review of health inequalities in England post-2010 (the Marmot Review) Report: Fair Society, Healthy Lives <http://www.ucl.ac.uk/gheg/marmotreview>
2. *Primary Health Care Reform in Australia: Report to Support Australia's First National Primary Health Care Strategy 2009* Pg 24

at the local level are discussed by the NHHRC. The Final Report mentions the importance of promoting community participation in healthcare,³ however, it provides scant detail on how this is to be achieved, identifying only Citizens' Juries as a potential mechanism. When compared with the detailed plan provided for governance reform, this lack of focus by the Commission is disappointing.

The limitations of the NHHRC report in relation to the role of consumers in healthcare provide a challenge to all working within the consumer health movement. Major health reforms happen rarely but when they do, they present valuable opportunities



to strengthen the role of consumers within the health system. It is therefore crucial for the future of the Australian health system that we use the current reform environment to move beyond the NHHRC recommendations, and promote the benefits of increased consumer involvement in healthcare planning, delivery and resource allocation. By learning from the experiences of other countries, we can inform our own approach to health system reform and ensure that we develop the best possible options for Australia's future.

1. Romanow R *Building on values, the future of health care in Canada. A message to Canadians* 2002
2. Oregon Health Fund Board *Aim High: Building a healthy Oregon* 2008 pg 24
3. National Health and Hospitals Reform Commission *A Healthier Future for all Australians* 2009 pg 123

More information on the reform processes discussed in this article can be found at:

The Romanow Commission (Canada) <http://www.hc-sc.gc.ca/hcs-sss/hhr-rhs/strateg/romanow-eng.php>

Oregon Health Board (USA) http://www.oregon.gov/OHPPR/HFB/about_us.shtml

District Health Boards (New Zealand) <http://www.dhbnz.org.nz/>

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Public versus individual benefit – a moral dilemma

Karen Carey

Is cost/benefit analysis the fair way to decide who will get what in our healthcare system?

Whether or not it is openly discussed, rationing has become a common factor in determining access to healthcare, diagnostics and treatments. It is an easy argument to support when we see the burgeoning cost of healthcare moving towards 10% of GDP. In its latest report on health expenditure, the Australian Institute of Health and Welfare (AIHW) reported health spending of \$104 billion for the financial year 2007–08¹. If the trend data is accurate, no one could argue that we can continue to fund healthcare at the current rate; but supporting rationing raises the ethical dilemma: who will get what?

Many consumer representatives sit on committees whose role it is to determine exactly this issue. What pharmaceuticals will be subsidised for which conditions? What medical devices should be available at no gap? What services are best delivered in hospitals versus in the community? We debate these issues using relative cost and cost/benefit analysis in order to determine the optimal position in the public interest. That is – given a finite amount of money, how can we best spend that money to give the greatest collective value to all Australians? Whilst we argue about what constitutes ‘value’ (e.g. area of greatest need or biggest ‘bang for buck’) and try to avoid political manoeuvring, in the end we must come to a decision that (hopefully) achieves this aim.

What happens though, when we face these rationing dilemmas personally? Do we apply the same value principles? Let’s say I require a pacemaker. Will I be willing to accept the old technology that may well do the job and cost 20% of the new models? Or do I want the best there is, even though many of the new features will have no impact on my health outcome?

I was first challenged by my own double standard when my son fell from his bike

and broke his arm. I had previously been on a committee looking at triage in hospital emergency departments and fully supported the concept that those patients in greatest need should be seen first – I even helped design the posters to adorn the walls of hospital waiting rooms asking patients for their understanding and patience. But once it was my son lying in agony in my arms in the hospital waiting room, my priorities suddenly changed – I wanted him treated, and I wanted it now.

It is this double standard that is putting huge pressure on the cost of medical devices. For example, most of the evidence shows that in the first instance, a bare metal stent is at least equally effective as a drug eluting stent, but less than half the cost. It seems a reasonable expectation that most doctors would recommend, and most patients would choose, a bare metal stent with a huge saving to the healthcare system – money that can be used to fulfil other health demands. But in practice this isn’t occurring. Many doctors recommend drug eluting stents because they want to be able to tell their patients that they have the latest device (and some may argue there are influences of a more sinister nature) even though it is unlikely to provide any additional benefit in terms of the patient’s health outcome. Doctors may also be concerned that, in the small number of patients who will suffer restenosis of a bare metal stent, they will be found to have been in error in not implanting a drug eluting stent in the first instance. It also seems that patients, given the choice of a basic bare metal stent or a drug eluting stent coated with a substance that will prevent restenosis (even though the data is controversial), will choose the more expensive device.

The reason that this happens is often complex but we do know some of the drivers. Firstly, the cost of the device is

not directly met by the patient, so choosing a more expensive device has no financial impact on the patient or the doctor.

Secondly, the benefit of choosing a cheaper device is gained by a ‘faceless’ public at the cost of the individual so it is a hard concept to sell. It’s not like the patient gets a share of the money they saved to spend on something else! Lastly, patients are making these decisions when they are at their most vulnerable and most in need of reassurance. The promise of technological advance provides a façade of exactly that.

One of the emerging cost areas for medical devices is drug delivery systems. These include partially implanted pumps that release specific amounts of drug on an ongoing basis and alleviate the need for multiple injections. There are many uses for these pumps including pain management, chemotherapy and insulin delivery. The clearest argument is for insulin infusion pumps for people with severe diabetes. You would have to have a hard heart not to feel compassion for people who have to test their blood sugar many times a day and then inject insulin. When you take into consideration children (who cannot self test while at school) and other groups who for various reasons are unable to adequately manage their insulin, it is easy to see the benefits these pumps can deliver – they will literally save lives and there are large numbers of people suffering diabetes who would gain value from having a pump. However, the cost



of the pump and the consumables required for it to work are so high that it would consume a large part of the healthcare budget to provide them to everyone who would benefit, denying key health services for other conditions. From a public perspective it is clear that we can't afford to fund the pumps, but when I think of a child whose mother has to go to school and prick them several times per day to manage their diabetes, I think – how can we afford *not* to fund them?

We need to have a robust public debate about community values, rationing and how and where lines should be drawn, so that individual consumer representatives are not acting alone in advocating for or against the inclusion of such devices in funding models, with the risk of failing to be 'representative' at all.

1. Health expenditure Australia 2007-08, Australian Institute of Health and Welfare, September 2009. Available at <http://www.aihw.gov.au/publications/index.cfm/title/10954>

Karen Carey is the consumer representative on the Australian Government Department of Health and Ageing Prosthesis and Devices Committee and the Prosthesis Policy Advisory Committee.

Left: Photo courtesy of Juvenile Diabetes Research Foundation. The Type 1 Diabetes Insulin Pump Program aims to make insulin pumps more affordable and accessible for Australian families through a means-tested subsidy for purchase of an insulin pump for children under 18 years.

More information is available from the Juvenile Diabetes Research Foundation at <http://www.jdrf.org.au/our-community>



Vibrant, productive rural communities are integral to the long-term sustainability of Australia

Margaret Brown AM

It is critical that people who live and work in rural and remote Australia have access to high quality, relevant and affordable healthcare, education, training and social support at all ages and stages of life.

Living in rural and remote Australia is very special, but there are unique issues surrounding healthcare, support services and care in general.

Often the people responsible for providing policy advice (to governments and others), and those who design and manage a myriad of programs intended to benefit country people and communities, live and work in urban communities. Respected voices such as Sydney Myer, Chair of Rural Education and Communities, and Professor John Halsey have emphasised the need for these people to develop a deep understanding of 'rural'.

People living in rural and remote communities constitute a minority within the Australian population, but they should retain a right to the same levels of healthcare available to Australians living in metropolitan areas. Resource allocation must recognise this, and be balanced to reflect need and equity.

But it's not just about more health dollars per capita for rural and remote communities. Rural and remote providers must become very creative and show great initiative in the way they utilise their health dollars; tailoring solutions to the rural and remote context.

Over many years, people in rural and remote communities have striven to keep services such as local hospitals, aged care and hostel services afloat through community fundraising e.g. fêtes, bottle drives and cakeless cake stalls (innovative fat-free fundraisers - you pay for the cake you didn't have to bake!). Community input has saved many a service from disaster. It is now





very difficult for these people to accept forced closures and down-grading of health units.

Closure, down-grading and the regionalisation of healthcare services can deny some rural and remote health consumers access to healthcare close to their home. This adds the burden of travel, in some cases across long distances, to access appropriate services.

Public transport is a major issue. Patient transport and reimbursement of people's expenses and accommodation provision are vital, and are the subject of review by Government. A number of states have commenced their own reviews and have recognised that system change is long overdue.

Access to a resident general practitioner provides a sense of security and confidence. Understandably, older residents in particular find it very difficult to grapple with losing their local doctor. We do need to recognise, however, that nursing staff at the local hospitals and centres are very dedicated and skilled to triage cases.

Resource allocation to enable further training and upskilling of workforce is vital. Unfortunately, it is often the case that rural and remote health workers cannot leave their district to undertake training because there is insufficient locum back-up to cover their shifts.

Localised palliative care is acknowledged as being worthy of funding. In some places, specific rooms have been set up to provide the special services required for people to receive quality care and to be able to spend time with family and friends in the final stages of life.

Important indicators of an overall lack of community well being in rural and

remote Australia (such as mental health problems and elevated suicide rates), show that there is still a need to develop models of care that can be more flexible in their use so as to cater for all people and not just those who are able to access appropriate services.

We need to remember that people often live and work in very isolated areas of Australia. They can suffer from hardship, depression and low self esteem, and sometimes end their lives, because they cannot 'battle on alone'.

For those living with children, young adults and older persons with any form of disability in rural and remote Australia, life brings many challenges. Some disability and respite services have been provided, but many parents must cope with all of the day-to-day issues alone.

It is often very difficult for people dealing with these challenges to impart understanding of them to others outside the family circle; only those who have experienced similar circumstances can truly understand. It is clear that people caring for anybody with a disability need support close to home. Respite for a day or a weekend is a blessing and a vital requirement for health and survival.

Once again, some funding and work have been directed toward this area, but more and new initiatives, adaptable to rural and remote conditions, are needed.

Chronic disease self management programs are certainly assisting people to manage their chronic care. Training of healthcare workers to take a hands-on, proactive approach, and the inclusion of promotional material in media and magazines, encourage people to take a holistic lifestyle view of their care.

In closing, rural and remote dental care cannot be ignored. Progress in areas such as the recruitment and retention of dentists, and encouraging students to take up the scholarships being offered for rural dentistry places in some states, must be acknowledged. Extra funding to support public dental care remains essential.

To sustain rural communities, and their contributions to food production and the Australian economy, per capita funding for healthcare must equate to a greater proportion than the regional/urban ratio. Failure to address equity and context for rural and remote health consumers will ensure rural and remote communities continue to decline.

Health Care Consumers of Rural and Remote Australia was very disappointed at the lack of emphasis on consumer participation and consultation with consumers of rural and remote Australia in the Government's recent National Health and Hospital Networks announcements. Is there going to be an opportunity for consumers to have meaningful participation in the decision making of the Networks? Or will they be run by the 'chosen few'. Experience tells us that some of the current local area boards do not consult widely, nor do they see the need. As one board chairman said to me, 'They (consumers) trust us.' Consumers do not want to 'trust' Networks, they want to work within them; with a voice, as partners in decision making.

Margaret Brown AM is the National Chair of Health Consumers of Rural and Remote Australia.

Now for an Intervention we'd like to see

John Paterson

Reform aimed at funding and developing clinical and social practice that is founded on a strong and central commitment to comprehensive primary health care should be a key priority.

Since the release of the findings of the National Health and Hospital Reform Commission last year and Prime Minister Rudd's subsequent consultation roadshow, most attention has focused on hospitals. Not surprising: in terms of impact on consumers and cost, hospitals are the pointy end of the health system.

But the Aboriginal Community Controlled Health services in the Northern Territory have been looking far more closely at the Commission's ideas about primary health care.

The reason for that is quite simple: we are in the business of keeping people out of hospital. The idea that the Commonwealth might take over all funding of primary health care funding makes a lot of sense to us, and fits in with work that the Aboriginal Medical Services Alliance Northern Territory (AMSANT) has been carrying out for more than a decade.

There is a certain irony in the Prime Minister's support for the Reform Commission's recommendations on primary health care. While the detail is yet to be spelt out—and not all our ideas have been accepted—the importance of primary health care is something the Aboriginal health sector has been pushing for nearly four decades.

At the heart of our work is the development of a practice—both clinical and social—that displays our strong and central commitment to Comprehensive Primary Health Care.

This model was codified at an international level at Alma Ata in 1978, and subsequently endorsed by the World Health Organisation (WHO) and the United Nations:

Primary health care is essential health care based on practical, scientifically sound and socially acceptable

methods and technology made universally accessible to individuals and families in the community through their full participation and at a cost that the community and country can afford to maintain at every stage of their development in the spirit of self-reliance and self-determination.¹

Primary health care is socially and culturally appropriate, universally accessible, scientifically sound, first level care.

It is provided by health services and systems with a suitably trained workforce comprised of multidisciplinary teams supported by integrated referral systems in a way that:

- gives priority to those most in need and addresses health inequalities;
- maximises community and individual self-reliance, participation and control, and;
- involves collaboration and partnership with other sectors to promote public health.

Comprehensive Primary Health Care includes health promotion, illness prevention, treatment and care of the sick, community development, advocacy and rehabilitation services.

Comprehensive Primary Health Care prioritises dealing with health as a holistic process, which includes a strong emphasis on working with families and the communities we live in.

It seems likely that a core recommendation of the Commission—to establish a national Aboriginal Health Authority—will not be adopted. That's a pity. We believe such a body would give the strongest possible signal to the process of Closing the Gap of Aboriginal health disadvantage.

We believe such a health authority should receive all of the current Primary



Health Care funding for Aboriginal people: \$550 million recurrent from the Office of Aboriginal and Torres Strait Islander Health, \$400 million recurrent from CoAG and the state and territory Aboriginal Primary Health Care funding. This would achieve a total allocation of about \$1.2 billion for Aboriginal Primary Health Care services, which would enable an average expenditure across Australia of about \$3000 per person for the 470 000 Aboriginal people.

But not all is lost. We propose that, based on the joint work of AMSANT and the Territory and Commonwealth Governments over the last two years, the Northern Territory could easily provide such a model for Aboriginal Primary Health Care for the rest of the nation.

The one undoubted benefit of the Northern Territory Emergency Response—commonly known as the Intervention—has been a substantial increase in Commonwealth funding to the Aboriginal Comprehensive Primary Health Care sector supported by a joint process of system wide reform. Building on the work of regional community controlled services, such as Katherine



West Health Board and Sunrise Health Service, we are moving to build around 15 regional services across the Territory. It is a process that has been endorsed by AMSANT along with the Territory and Commonwealth governments through a policy known as *Pathways to community control*.

And it is an evidence-based policy—not empty rhetoric. There is clear evidence that such regional services are improving health outcomes for Aboriginal people, some achieving measurable results better than general practices treating non-Aboriginal Australians. This is based on regional bodies servicing populations of 3 000 or more people, thereby having the economies of scale and capacity necessary to provide the full range of Comprehensive Primary Health Care Services with initial funding benchmarked at \$2 700 per capita for a very remote regional community controlled service.

For the first time in the Territory's history, we are moving towards an equitable health system for Aboriginal people across the Territory. We are moving to resource levels that will fund the core services required to really make a difference.

But there is more to be done, and Prime Minister Rudd's ideas about funding primary health care might point the way.

Under those proposals, all Commonwealth and Territory Indigenous Primary Health Care funding could be pooled under the umbrella of a single funding agency for the whole of the Territory. Such a model would provide far greater transparency, eliminate cost shifting and put an end to the blame game. With the system oversight of such a single body the successes of organisations such as Sunrise and Katherine West can be replicated system-wide and sustained.

In fact we are well on the way— through

the joint work of partners of the Northern Territory Aboriginal Health Forum, the Territory is at least two years ahead of the rest of Australia in rolling out Comprehensive Primary Health Care to its Aboriginal citizens.

Apart from the devil of detail, politics might get in the way. It seems unlikely at this stage that there'll be much movement until after the federal election later this year. At this stage, the states and territories have been largely silent on the issue of national funding of primary health care. Our fear is that it will become mired in the usual bickering between the Commonwealth and the states.

But it's an intervention we'd like to see, and we don't want to have the reforms delayed. If necessary, we'd like to see a single Indigenous Primary Health Care funding agency rolled out in the Territory as a model for the rest of the nation—and let the rest of the country catch up.

It can't happen soon enough for us. The life expectancy of Aboriginal men in the Northern Territory still remains 17 years short of that of their non-Aboriginal brothers nationally. We've got some catching up to do.

1. Declaration of Alma-Ata, International Conference on Primary Health Care, Alma-Ata, USSR, 6-12 September 1978. Available on the World Health Organisation website at: http://www.who.int/hpr/NPH/docs/declaration_almaata.pdf

John Paterson is the Chief Executive Officer of Aboriginal Medical Services Alliance Northern Territory.

Excluded from the table: LGBT health and wellbeing

Gabi Rosenstreich

Targeted efforts are required to ensure that the voices of marginalised groups are heard.

The health budget pie often doesn't seem large enough to satisfy the hunger pangs of those around the table. Currently lesbian, gay, bisexual, transgender, and other sexuality, sex and gender diverse (LGBT) people don't

even get the crumbs, because they've actually been shut out of the dining room.

The Federal health agenda currently contains no targeted strategy, no designated departmental unit, no advisory or consultative mechanisms, no

dedicated funding, not even a mention of LGBT people in policy initiatives.

Why should they? While many LGBT individuals live healthy, happy lives, as a population, LGBT people have significantly poorer health outcomes

than other Australians in a number of key areas, including general health ratings, use of tobacco, alcohol and other drugs, and mental health. For example, 14 percent of same-sex attracted young women inject drugs once a week or more.¹ This compares with one to two percent of young people in general.

This is not because of sexual orientation, sex or gender identity in, and of, themselves. The poor health outcomes of LGBT people are largely related to social factors, such as discrimination, prejudice and social isolation, which in turn interrelate with drug use, homelessness, poverty and a range of other risk factors and behaviours.^{1,2,3,4,5} Social exclusion is known to be the most important social determinant of health outcomes.⁶ Exclusion extends to healthcare: the failure of generic health interventions and prevention strategies to be inclusive of LGBT people and their health needs.^{1,2,3} LGBT people who are also members of other high risk groups, such as the aged and those from Indigenous or migrant communities, face multidimensional marginalisation.

LGBT people are frequently not accessing preventative and responsive healthcare services at all, or are delaying their access to services because of fear of discrimination and stigma. Those who do access services frequently fail to disclose their sexual orientation, sex or gender identity even where they are relevant to their health concerns, and/or receive ill or uninformed advice and inappropriate treatment.⁷ Gay and bisexual men presenting for self-harm fail to address, or get help for, some of the underlying causal factors and their social resources are not utilised in interventions. Many transgender people do not feel safe disclosing their gender status to their GP.² This clearly precludes many physical examinations, in particular gynaecological or prostate examinations. Lesbians who have disclosed to their GP continue to report that they are assured (wrongly) that they don't require pap smears. Many sex and gender diverse people face additional barriers to health services that are provided on the basis of sex, for example, those transsexual men who have been able to change their



official sex do not qualify for pap smear rebates.

Impacts include late diagnoses^{8,9} and increased incidence of preventable diseases¹⁰, contributing to the burden on health services.

What do LGBT consumers value most in healthcare? Being included. Being able to access services with confidence that they will be treated with respect and provided with appropriate service. It would be safe to say that this is something all Australians value – and many take for granted, as they rightly should. Unfortunately, it is far from reality for a great many LGBT Australians.

We quite rightly insist that the health and wellbeing needs of other high-risk populations, such as Aboriginal and Torres Strait Islander people, rural populations etc, are appropriately addressed, yet there is a conspicuous lack of response to these issues on the Federal policy menu. LGBT people haven't even made it in the door.

Not one Federal policy framework specifically addresses LGBT health issues, although various policy initiatives have a particular relevance to LGBT people, e.g. the National Preventative Health Strategy and the National Women's and Men's Health Policies. Although rates of depression, suicidal ideation, and self-harm are between 3.5 and 14 times higher for LGBT people than any other population group^{2,7,11,12,13} and evidence indicates that up to a

horrifying 50 percent of all transgender people attempt suicide at least once,¹⁴ neither the National Mental Health Strategy, nor the National Suicide Prevention Strategy, mention this group.

In their recent position paper, Suicide Prevention Australia made a series of strong recommendations, including inclusive and specific LGBT initiatives funded under the National Suicide Prevention Strategy, resources to enable LGBT health and community service providers to undertake targeted health promotion activities and capacity building of mainstream service providers.¹³ Currently, the ability of both the mainstream and LGBT health sectors to effectively act on these recommendations is limited. Mechanisms to build knowledge and develop capacity are required. This applies to all areas of health need, not just mental health. While there is extensive expertise within LGBT community organisations, they are under-resourced and working in relative isolation. There are no robust structures to enable their expertise to be shared, further developed and implemented collaboratively, thus inhibiting effective use of their resources for the greatest benefit of LGBT communities and Australia as a whole.

Barriers hindering consultation with LGBT people contribute to the exclusion of these health equity issues in policy development and service planning. The types of barriers faced by LGBT

people reflect those experienced by other marginalised groups. For example, the vulnerability of the population and its poor health outcomes mean that it has less access to both material and immaterial resources that would facilitate input into policy processes. At the same time, the manifestation of these barriers is particular. Therefore, targeted efforts are required by government to ensure that the voices of marginalised groups are heard.

The recently released National Compact calls for 'partnership' between the community sector and government. These are very unequal 'partners' if one is standing outside the door and cannot afford to enter. The LGBT community sector has established a consultative framework in the form of a peak body. The National LGBT Health Alliance is currently entirely funded from community-raised money. Genuine partnership must be enabled, especially in a sector as poorly resourced as the LGBT community sector.

The benefits of strategies that target marginalised population groups both within and across program areas, such as the Closing the Gap Strategy, are increasingly being acknowledged. However, the specific issues of LGBT people remain invisible. Engagement with LGBT people, both as a target group in its own right and within other target groups, will ensure that health initiatives are representative of the full diversity of these communities. Only by addressing diversity within, and across, population groups will the real complexity of health issues be addressed and substantive change possible.

What does this mean in terms of drivers for funding decisions?

Government funding of health-related programs and services should be dependent upon the demonstrated and proactive inclusion of LGBT people and other marginalised groups. If the sign on the door says 'everyone', then everyone should be able to enter and receive the service as indicated. We know that just saying the door is open is simply not adequate.

Policy frameworks and action plans should include specific consideration of issues for LGBT people where there are specific health risks, with explicit provision for targeted services and programs for LGBT people, tied to designated funding. Experience shows

all too clearly that if it is not anchored, it will not happen.

Investment is required in mechanisms that enable the perspectives of LGBT people to effectively feed into policy and service development. The maxim 'not about us without us' is not only appropriate as a principle of social participation and inclusion, but also sensible in order to ensure that work being undertaken actually 'works'.

Investment is required in LGBT community sector capacity to engage in health and wellbeing policy and programs. This will enable the provision of targeted services that are effective in both outcomes and costs. This will also enable cooperation with mainstream providers of health and related services, assisting them to work inclusively of LGBT people and their health needs, providing them with high quality, culturally appropriate care.

And, finally, prevention is more effective than intervention, and cheaper. We require an investment in mechanisms to reduce the prejudice and discrimination that underlie many of the poor health outcomes of LGBT people, build diversity competence, and promote respect and inclusion.

Until LGBT people are at the table, no Federal health reform, no matter how well intentioned, is going to achieve better health outcomes for all Australians. We need to ensure that the pie contains the most nutritious ingredients available and that everyone is able to participate in both baking and eating it.

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Big issues, small voices

Lif O'Connor

'The destiny of any nation at any time depends on the opinion of its young people, those under twenty-five.' Johann Wolfgang von Goethe

There is currently much debate about healthcare administration, design and funding. Possible solutions to meeting the ever increasing burden on healthcare spending due to Australia's ageing population is a topic of great interest to politicians, health professionals and the public. One notable feature in all that has been said and written is the absence of the voices of our young people who will ultimately be responsible for the funding and provision of healthcare in years to come. Health professionals working in youth specific services cite the inherent difficulties in engaging with young people on topics related to health reform and design, and there are very few published studies that incorporate the views of young health consumers.

In 2005, the Centre for the Advancement of Adolescent Health (CAAH) based at the Children's Hospital Westmead in NSW published a study into access to healthcare among NSW adolescents which included extensive consultation with young people aged 12 to 24 years. This study found that although young people have a broad range of health concerns, they are generally reluctant to seek advice from healthcare providers. The primary barriers identified were fear of confidentiality breaches, lack of knowledge about services and how to access them, and cost.¹

Some of the risk factors linked to the development of chronic disease in adulthood such as obesity, substance abuse, poor nutrition and mental health issues are present or begin to emerge in adolescence, with far reaching consequences for the individual and for the health system.

In 2007, Dr Fiona Stanley predicted that for the first time in Australia, the next generation will have a shorter life expectancy than their parents. In the

book *Children of the Lucky Country* (Stanley et al, 2005)², the health and well being of our children was described as mostly not improving and in some cases worsening, despite economic growth and increasing wealth.

The Greater Metropolitan Clinical Taskforce (GMCT) Transition Care Network for young people with chronic illness and disability was established in 2004 by the NSW Department of Health. It aims to address the issues faced by healthcare providers and facilities and young people and their families when moving from paediatric to adult services. The need for this network arose from the advances in medicine that have led to increasing numbers of children surviving into adulthood with conditions previously unseen outside paediatric facilities. This is a great credit to years of dedicated research and management. Increased life expectancy brings increased need for services and education.

The care these young people receive and the lifestyle and self management choices they make have far reaching consequences, for both the health and well being of the individual and the cost of future service delivery. In addition to their existing health conditions, they are likely to develop similar conditions associated with ageing as those of their 'healthy' peers.

Much of the current discussion on health funding is focused on the cost of providing hospital based services. Surgical waitlists, emergency department access block and length of hospital stay are frequently quoted as indicators of how well the health system is meeting the needs of our communities. The 2005 CAAH access to healthcare study found that most young people choose primary healthcare providers such as GPs and Youth Health Centres for health advice and management.³ Although cost was identified as the third most frequently

cited barrier to access in urban areas, a study by Quine et al. in 2003 found that for rural young people, because of an almost total absence of bulk-billing by rural GPs, cost was a major factor influencing timely access to care.⁴ A study by GMCT Transition Care Network in 2008, found a direct link between the availability of medical specialists and affordable General Practitioners and the number of preventable admissions to hospital for young people with diabetes.⁵

Any health reform agenda must take into account how, and where, young people access healthcare and health information.

Young adulthood is a time of many transitions: from dependence on family to independence; school to further study or work among others; and typically not a time of great affluence. I would like to quote a young woman's thoughts on private healthcare:

'It is like flying in first class; you get better food, get on and off quicker, have better seats but at the end of the day the result is the same, you get to where you want to go. It is a choice and no one should be forced to do it just because they can afford it.'

Australia's health system must be designed to address the needs of all Australians across the age continuum. The needs of our children and young people must not be forgotten as it is they who will provide, administer, fund and access care in the future. We have a duty to try to prove Dr Fiona Stanley's prediction wrong.

Healthcare: you need to know how important you are... you affect us all and





you need to get your act together before we can take you seriously...we should be concerned with who you are and how you work. Anonymous young man.

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Advanced Care Planning and Palliative Care

Coral Rizzalli OAM

Taking the guesswork out of end of life decision-making is one way to spend our health dollars wisely, and use palliative care health resources to meet consumer need.

In the 21st Century, Australians have access to some of the most amazing medical advances to prolong our lives and cure our illnesses. New medical treatments, better pharmaceuticals, and high tech nuclear treatment tools, as well as incredibly sophisticated diagnostic tools for radiology and pathology, have opened a brave new world for medicine.

This comes at enormous cost to the tax payers of this land. Expenditure associated with new and better training regimes and the escalating wage bill for healthcare providers contribute to an exponentially expanding demand for funds.

Advances have also created pressures. The ability to treat more conditions, with limited resources, has led to a system of health care with long waiting lists, and

a great disparity between healthcare for high income groups and those in lower socio-economic groups. If you are lucky enough to be able to afford healthcare then we do have some of the best healthcare in the world. If you cannot afford it - well if you wait long enough, you may eventually receive some help.

We all want a fair and equitable health system that provides the right level of care when required. How can we achieve this when escalating costs and demands are making it impossible to provide such a service?

It is time for open and frank public debate around the many issues in healthcare provision that are causing increasing financial burdens on each and every tax payer. If we want a fair and equitable system of healthcare then we have

to make some hard decisions for the future. We need to examine the whole of the health care system and have open debate around the issues. One issue I am particularly interested in is that of Advanced Care Planning.

Recently I attended a discussion around the provision of Advanced Care Planning. I was amazed at the lack of clear guidelines to assist consumers and the families who care for them. Even many medical practioners face ethical and moral dilemmas when dealing with this issue. Advances in treatment options make it possible to keep people alive for many more years than what was once the norm, but is this the road we should take?

We need to ask consumers what they personally want! Do consumers know what they want? Do they have a plan for

this contingency? This is such a personal issue that we all need to begin planning for that time when we will near the end of our life. Should only the elderly take this action? What about younger people? Should they think about and plan for something that may not be needed for another eighty years? If you look at the road accident statistics, maybe they should.

What would help us to plan for the end of our lives?

There are no easy answers, every person, every family, every carer will have a different view, but to even begin to plan we must have the answers to these questions:

1. Who decides

At present, most of us do not have any idea of what we want to do when our medical condition deteriorates to point of no return. It is often left to family members, carers, or even a public advocate, to make decisions around palliative care. Sometimes a doctor or nurse may discuss the issues but often they feel reluctant to do this, because professionally they are trained to save lives and cure patients.

We need to discuss our wishes regarding palliative care issues with the people in our lives - family, carers and our doctor or health care provider. We need to ensure that there is no doubt what we want, while we can make these very important decisions.

2. Legal issues

Since every state has different legal requirements and responsibilities we need to know what documents we need to sign.

Do you have a power of attorney? Do you have an Enduring Power of Attorney? Do you have an Advanced Health Directive? Do you have a Do Not Resuscitate order on file? Is all this information known to the treating facility and staff.

It is essential that you speak to your legal advisor or someone like the Public Trustee so you know the legal requirements of your state.

3. What information is available?

It is often difficult to obtain the information we need. Healthcare providers, and especially doctors, need training pertinent to this issue

so that they can provide the most comprehensive information possible. These decisions are fraught with anxiety and angst so access to reliable information at this time is crucial for all concerned.

In my home state, Queensland Health is developing documents for consumers that will enable people to have the information they need to develop their own Advanced Care Plan. Three consumer representatives (myself included) have been involved on the project team and it is expected *Choices for Advanced Care Planning* will be published and made available in June 2010.

4. What options are there?

Options for treatment or palliative care should be openly discussed.

Should palliative care be in a hospice-like setting, a hospital, aged care facility or even at home?

Are there facilities available in the local area?

If electing to stay at home, are community services going to be available?

5. What on-going support is available?

It is essential that on-going support be provided, including counseling and open lines of communication. This is a very difficult time. Consumers, families and carers need to have their questions answered, and to feel that they and their loved-one are respected and treated with dignity at all times.

The great ethical dilemma around Advanced Care Planning is not something we can solve easily, but we can and must debate this issue. End-of-life planning is not, and can never be, about euthanasia. It is about being able to choose to end treatment (which is often costly to the patient, family and the health system) and to choose a palliative care option which is right for the individual. It is about you making your choice and being able to die with dignity and respect.

Coral Rizzalli OAM is a consumer representative working on local community, Queensland and national health related committees. She was awarded an Order of Australia medal in 1993 for her work in establishing services for the disabled.



In 1971, when I gave birth to our longingly awaited second son, my husband and I were catapulted into a world vastly different to what we expected as

parents. Suddenly we were in a world of medical terminology, of procedures we never knew even existed, and a time when incredibly stressful decisions had to be made and made quickly. Our world changed forever as we fought for 30 years to keep our boy alive and to give him the best possible chance of life.

My interest in medical matters stem from then, particularly my passion to ensure that our health systems understand that all care HAS to be focused on the consumer, and that all treatment needed should be available when needed.

My particular interest in Palliative care comes from the last two years of his life when we had to care for him at home - because that was his wish.

We struggled greatly to provide the care he needed 24/7. Despite applying for assistance we were unable to get any help at all until the last few months when we received enough funding to employ someone to give us two hours a day—but never for night time support. Even then we never received any nursing assistance because the local services would not come.

So, I understand how hard it is to live through this experience and I know how important it is for advanced care planning to be done. End of life is a very important issue for all of us - let us debate the issues and establish the best possible standards so that we can die with dignity and respect in the place of our choice, and with the support we need.

Coral Rizzalli

The Respecting Patient Choices Program

The Respecting Patient Choices Program is an advance care planning program that began in 2002 as a pilot project at the Austin Hospital, Melbourne. Details are available at: <http://www.respectingpatientchoices.org.au/>

How would you like health dollars allocated? A family's journey through the health system

Diana Aspinall

Access to coordinated local services should be at the core of our health system.



We all have personal expectations and experiences of healthcare service delivery. Even if you don't often intersect with the health

system, you may have an opinion on how health dollars - your tax dollars - should be spent.

While everyone's needs will be different, this outline based on a real family's health journey, may trigger thought about where health dollars should be directed, and whether the models and focus of reform currently offered by our political leaders is well-directed to make a difference for health consumers and the Australian community. Poor health outcomes inhibit an individual's ability to contribute to the community - economically and socially; so it's also worth considering that hidden 'cost' of not funding, or not spending effectively.

The health journey illustrated in the table opposite, even if only partially traversed, outlines just how vital, how continuous, and how resource intensive healthcare is over a lifetime.

We see how healthcare occurs in a mix of settings that often need to work in a coordinated and complementary way to ensure appropriate healthcare. 'Non-health' components such as Centrelink play an important role. The crucial importance of primary healthcare is obvious; it being the setting that gets called on most often. It's interesting to see the support provided by community

based services, especially as the journey takes us through middle age and later life.

We know from the current health reform debate, that funding is a contentious and complex area. The table shows a simple illustration of just how often our healthcare calls on multiple sources of funding - from the consumer, community and all levels of government. This interplay needs to be addressed so that funding decisions focus on consumer outcomes, not political tug-of-war.

It's also evident that there is a large consumer out-of-pocket component (including gap payments and medicines) - something that must be kept under control if all Australians are to obtain and maintain access to the healthcare services they need.

In the context of health reform, it's obvious that we can't seek to address (and resource with our tax dollars) pieces of the puzzle unless we understand how they come together to deliver healthcare to, and for, the individual.

As we consider how our health system should evolve, it's worth looking back at the changes, progress and reforms that have delivered the health system of today. We've undoubtedly gained much, but have we lost anything that needs to be reclaimed?

Where have we come from? A personal reflection.

My first memory of a doctor was in 1943. I was four years old when my two-year old brother became very ill. Mum called the local doctor who came to our house and told us that he had Diphtheria. I was listening to the conversation around the table as our family doctor explained

that we needed to make sure he was isolated in his cot (for me, that meant I could not play with him). Our doctor was like one of the family who would sit down with us, chat and perhaps have a cup of tea. For routine health visits we walked 4 km to his surgery, in the front part of his family home. When I was nine, my sister was born in the cottage hospital; a house that was around the corner from home and was run by a midwife with GPs helping when necessary. Our GP knew our home, who we were as a family, and how we lived. He never said he was worried about being sued or being the subject of litigation, I suppose he would have been insured.

I became a nurse in 1957. My family doctor visited patients in the hospital where I worked. My mother was admitted and he took out her appendix. He would have called a specialist if needed. As a nurse, I assisted the visiting Honorary Doctors to conduct free outpatient clinics for various diseases and complaints at this hospital.

Child endowment payments authorised in 1941 were important to our family, helping to pay for medicines when needed. Along with rationing of food, clothes etc. we were made to understand it was important to drink the free milk supplied at school.

In 1953, Fluoride was added to the water supply, causing much debate in the community. It was too late for me - my top teeth had all been removed because of decay when I was eleven.

My family and I benefited from the co-ordination and continuity of care which was part of the health system at that time. GPs were self-employed professionals. Specialists served

AGE	HEALTH ISSUE	HEALTHCARE SERVICES/SETTING	TODAY'S FUNDING MIX
1939-1957 0-18 yrs	Two Births Local cottage or public hospitals with GP or Hospital Doctor	Public Hospital Primary Care	State Funding, Commonwealth Funding, Consumer Funding
	Vaccinations GP or Local Council	Primary Care	State Funding, Commonwealth Funding, Consumer Funding, Local Government Funding
	Medical Checks GP or Hospital Doctors Joined Health Insurance at 15 yrs when employed	Public Hospital, Private Sector Primary Care	State Funding, Commonwealth Funding, Consumer Funding, Private Funding
	Infections, Flu, Colds etc GP	Primary Care	State Funding, Commonwealth Funding, Consumer Funding
	Car accident — Hospital inpatient	Public Hospital	State Funding, Commonwealth Funding
1958-1989 19-50 yrs	Family Planning Clinic for Contraception	Primary Care	Commonwealth Funding, Consumer Funding
	Miscarriages GP or Hospital Doctors	Public Hospital Primary Care	State Funding, Commonwealth Funding, Consumer Funding
	Diagnosis: Endocrine Disorder GPs, Specialists and Pathology Services	Private Sector Primary Care	State Funding, Commonwealth Funding, Consumer Funding, Private Funding
	Pregnancy, Birth with Caesarean Delivery x 2 GPs, Specialists	Public Hospital Primary Care	State Funding, Commonwealth Funding, Consumer Funding
	Diagnosis: Chronic Condition (child) GPs, Specialists, Pathology Services	Private Sector Primary Care	State Funding, Commonwealth Funding, Consumer Funding, Private Funding
	Accident: Fall and Hospital Emergency, GPs, Radiologist, Physiotherapist,	Public Hospital, Private Sector Primary Care	State Funding, Commonwealth Funding, Consumer Funding, Private Funding
	Vision Tests Eye Hospital and Specialists	Public Hospital, Private Sector	State Funding, Commonwealth Funding, Consumer Funding, Private Funding
	Prevention: Routine Medical Checks (eg, pap smears) GP	Primary Care	State Funding, Commonwealth Funding, Consumer Funding
	Cardiomyopathy: Virus Infection GP	Primary Care	State Funding, Commonwealth Funding, Consumer Funding
1990-2009 51-70 yrs	Blood pressure – medicines commenced GP	Primary Care	State Funding, Commonwealth Funding, Consumer Funding
	Mental Illness: Depression GPs, Specialists, Community	Community based Primary Care	State Funding, Commonwealth Funding, Consumer Funding, Local Government Funding, Private Funding, Community Funding
	Gynaecology Operation GPs, Specialists, Private Hospital	Private Sector Primary Care	State Funding, Commonwealth Funding, Consumer Funding, Private Funding
	Cardiac Failure GPs, Specialists	Public Hospital, Private Sector Primary Care	State Funding, Commonwealth Funding, Consumer Funding, Private Funding
	Arthritis and Back Pain GP, Arthritis NSW	Community based Primary Care	State Funding, Commonwealth Funding, Consumer Funding, Community Funding
	Liver Failure and Transplant GPs, Specialists, Public Hospital Liver Unit, Red Cross Blood Services, Pathology Services	Public Hospital, Private Sector, Community based Primary Care	State Funding, Commonwealth Funding, Consumer Funding, Private Funding, Community Funding
	Diagnosis: Type 2 Diabetes GP, Diabetes Australia, Pathology Services	Private Sector, Community based Primary Care	State Funding, Commonwealth Funding, Consumer Funding, Private Funding, Community Funding
	Quality Use of Multiple Medicines GPs, National Prescribing Service	Primary Care	State Funding, Commonwealth Funding, Consumer Funding
	Diagnosis: Sleep Apnoea GPs, Specialist, Private Hospital Sleep Assessment	Private Sector Primary Care	State Funding, Commonwealth Funding, Consumer Funding, Private Funding
	Hearing Aids Australian Hearing Assessment (Health Care Card)	Private Sector Primary Care	Commonwealth Funding, Consumer Funding, Private Funding
	Osteoporosis Checks GP, Radiologist	Private Sector Primary Care	State Funding, Commonwealth Funding, Consumer Funding, Private Funding
2010+ 70 yrs+	Ongoing Chronic Condition Self-Management GPs, Specialists, Pathology Services	Private Sector Primary Care	State Funding, Commonwealth Funding, Consumer Funding, Private Funding
	Advance Care Planning, Palliative Care, Funeral GP, Local Government and Palliative Care, Community Services	Community based Primary Care	State Funding, Commonwealth Funding, Consumer Funding, Local Government Funding, Private Funding, Community Funding
	Increased Health Costs, Reduced Income, Sustaining Health Insurance Community Health, Local Government and Centrelink	Private Sector, Community based	Commonwealth Funding, Consumer Funding, Local Government Funding, Private Funding, Community Funding
	Carer's Assistance Community Health, Local Government Services, Centrelink	Community based	Commonwealth Funding, Consumer Funding, Local Government Funding, Community Funding
	Local Interdisciplinary Care GP, Regional Hospital, Community Health, Local Government Services, Pathology Services, Physiotherapy and Podiatry	Public Hospital, Private Sector, Community based Primary Care	State Funding, Commonwealth Funding, Consumer Funding, Local Government Funding, Private Funding, Community Funding

- Public Hospital
 Private Sector
 Community based
 Primary Care
- State Funding
 Commonwealth Funding
 Consumer Funding
- Local Government Funding
 Private Funding
 Community Funding



Haslehurst Family, 1949

as 'honorary' in public hospitals. Local government looked after water, sanitation and food safety.

In 1973 the Government set up the Hospital and Health Services Commission to build a bridge between service providers and the funding sources, as well as to improve preventative activities with a move from institutional to community care. This became the Community Health Program.

In 1983, Medicare brought major changes to the health system and how it related to me as a worker and a consumer. I could be bulk billed by some doctors, but, over time, I was increasingly required to pay a gap between the Medicare rebate and what my GP or specialist charged. As a health professional, I found outpatient services at local hospitals were reduced dramatically and GPs were required to assist more people or refer them to specialists. Large private medical clinics were established and there were equity issues for some people in the population to access health care.

Today, my excellent GP does not offer home visits – we drive (not walk) to see him at his surgery which is in a shopping centre. I am not bulk billed and I have to budget to pay the gap. It seems that GPs who bulk bill are not as available as they once were.

If I was too ill to go to my GP's surgery, I would call an ambulance and be taken to my local hospital Emergency for assessment and care. Being a regional hospital, it is connected to the main hospital some 50 km away.

My GP knows me as a person and knows my husband who is also his patient. But he does not know anything about how we live, what our home is like and anything about our family as a whole unit.

My GP and I have had several conversations about litigation in recent times. He prefers, and usually insists, that he see me and my husband separately to protect our privacy, even though, at 70 years of age, we are doing a degree of caring for each other's health. He does listen to me when I explain what my concerns are regarding my husband's health. He explains that he cannot afford litigation and therefore is conservative in his management of privacy and communications like email.

So we are now individuals in the health system; not a family or a couple. In our regional area there is a shortage of GPs. Waiting times to see a doctor are a reality and are distressing if you require services quickly. This, in turn, overloads the local hospital.

Where to now?

It's true that modern medicine has delivered some services that are nearly impossible to put a value on. The amount of money required to keep a specialist unit like the Liver Transplant Unit at Royal Prince Alfred Hospital and/or a Specialist Cancer unit at Westmead Hospital functional is undoubtedly astronomical and yet, when you are a consumer that has been a recipient of these successful services for your loved one, you do not think about the cost.

You are just immensely thankful for the expertise and the technology that has helped save your loved one's life.

But progress has also pressured or dismantled some of the strengths of old-time community healthcare and doctor-patient relationships along with reducing access to the health system by people on low incomes.

For me, that earlier focus on local, personally appropriate, affordable continuity of care has much to commend it.

The National Health and Hospitals Reform Commission's *Healthier Future for All Australians: Final Report (2009)*¹, reflected themes for community health similar to what was proposed in 1975 - a move to local Primary Health Care networks. Will the Government's proposals in the primary health area provide adequate and equitable access to local healthcare for people on low incomes?

As we age, we should be able to rest easy, knowing that as our health and conditions become more complex, we will be able to choose and receive whatever appropriate care is needed to help us manage our health and remain pain free. This includes community services available in our home. The other key area is retaining the safety net for PBS medicines, without which many could not afford the medicines necessary to remain stable and manage conditions.

We need our health system to be responsive, proactive and supportive of intervention at the most effective time. Priority must be given to:

- the provision of accessible, coordinated, standardised care in our local area;
- keeping out-of-pocket healthcare costs affordable for all consumers.

1. National Health and Hospitals Reform Commission *A Healthier Future for all Australians* 2009.

Diana Aspinall is a consumer representative from the Blue Mountains, NSW, with a long time interest in health consumer issues through Arthritis NSW and CHF.

An outline of the history of Australia's health system, changes and health achievements since 1901 can be found on the Australian Government Department of Health and Ageing website at:

<http://www.health.gov.au/internet/main/publishing.nsf/Content/health-history.htm>

The ageing of the post-war migrants: a challenge for health promotion and service delivery

Pino Migliorino

Issues faced by our culturally and linguistically diverse (CALD) communities must be central, not marginal, to planning, funding and implementing a better health system for Australia.

While government and health planners commonly acknowledge the significant impact the ageing of the baby boomer generation will have on healthcare services in Australia, little consideration has been given to the other major social phenomenon of our time, the ageing of the post-war migrant generation. This is an issue which requires urgent attention as the care needs of this group already impact on health services, community care services and the family life of many CALD communities. Given this, it is important to consider the characteristics of this group and their capacity to negotiate the 'seniors' world in Australia. In this article I provide a range of insights into CALD seniors gleaned from the research projects undertaken by my company, CIRCA Research, and in my capacity as the Chairman of the Federation of Ethnic Communities' Councils of Australia (FECCA).

Within the population of post WWII CALD seniors, the number of Eastern European migrants is diminishing, while the age profile of Southern European migrants is fast increasing. This transition is impacting on hospitals and community health facilities who must develop strategies to meet their specific health needs and requirements. At the same time, CALD seniors tend to under-utilise community based and domiciliary services. This duality must be taken into account in future planning for service provision to this group. In many urban areas, CALD seniors have now become the majority service area population, where they once were the minority. The current and potential future impact of this transition makes the development of strategies for health promotion and service delivery an urgent priority. The first step is to consider the relevance and impact of

the main health approaches currently practiced in Australia.

Health Promotion

Health promotion, as defined by the World Health Organisation, is the process of enabling people to increase control over, and to improve, their health.¹ In the Australian context, the practice of health promotion involves two key facets: health education and social marketing. Taken together, the two approaches rely on providing rational information about cause and effect, along with instructional information to assist voluntary behaviour modification by the individual or older person. There are three key questions that should be considered in health promotion for the ageing CALD population. These are:

1. *What are the cultural and linguistic enablers and barriers to communicating the health promotion message?*
2. *Do CALD groups see these issues as being relevant?*
3. *Do they have a history or interest in changing their behaviour to achieve health outcomes?*

These questions are not often answered by mainstream services, and the reality is that CALD seniors need to be understood before they can be engaged and behavioural change achieved. The challenge is that many older people from CALD backgrounds are not ready to engage and often demonstrate a passive response to their health. This passivity is explained in two ways: firstly, the strong belief in the power of medical science and, secondly, an acceptance of fate, the will of God/Allah, and other expressions of benign acceptance.

These factors may result in this group

not being open to health promotion messages and to actively resist such initiatives. In order to make health promotion messages more effective,



they need to be developed in a culturally relevant form and delivered through the most relevant media. A good example is the current focus on obesity as a health promotion issue. In order to get CALD seniors to eat less and more healthily, however, it is important to understand the nature and position of food for cultural maintenance, family life and the community. Health promotion strategies need to consider culturally specific notions of body image and beauty and the implied relationship between girth and wealth, which is accepted in many CALD communities. The food behaviour message needs to use culturally relevant information and provide behaviour changing advice that translates the food message into the ingredients, cuisine and consumption patterns relevant to ethno-specific groups.

This issue has been a recent focus for the National Health and Medical Research Council (NHMRC), which has developed a framework for cultural competency and has made health and environment (obesity) a focus for future research.² If we get the health promotion messages wrong, the result will be a high level of morbidity in CALD communities from preventable conditions. This will translate into far



higher health service demands and costs for the healthcare system in the future.

Service Access and Delivery

The projected demand for health services and resources is complicated by a number of factors of which service providers and planners need to be aware. The first is a perceived hierarchy of illnesses amongst CALD communities, which has a major affect on whether assistance is sought and services accepted. Physical ailments, such as high blood pressure and diabetes, are openly discussed and commonly result in visits to a bilingual doctor. Mental health problems, on the other hand, such as depression, schizophrenia or dementia, receive a negative response in many CALD communities. The cultural sensitivity around these conditions creates a strong sense of shame and fear of community rejection and often results in CALD seniors retreating into the home, where the burden of their care falls on their spouse and family. This cultural response not only delays diagnosis and the development of appropriate interventions, it also removes the person from the normal catchment radar for mental health services.

If people with these conditions do not seek medical help, mainstream services remain oblivious to their needs, a situation that leads to a significant skew between potential and actual service populations. This is not a criticism of mainstream services, but highlights a fundamental barrier to service access, which will require more substantial and significant education to redress.

This service gap has two significant

ramifications. The first is the reliance of CALD seniors on their spouses and families for care and support. A recent study by the NSW Department of Ageing, Disability and Home Care suggests, given low English Language Proficiency (ELP) amongst CALD seniors is common, the need to redefine the notion of carer from one person who provides personal care, information brokerage, service liaison and overall case management to a more complex one, which acknowledges the multiple roles carried out by many family members in brokering between CALD seniors and health service providers.³

The second is the increased importance of ethno-specific services, especially those funded to deal with the ongoing needs of older community members. These services meet the linguistic and cultural expectations of older people and can provide the proactive intervention and service referral required for the individual. There is an ongoing debate about whether ethno-specific services should be resourced to provide aged care services directly through programs such as Home and Community Care (HACC) and Community Aged Care Packages (CACAP), or whether mainstream service should have the capacity and competency to meet the needs of CALD clients.

The evidence is mounting that mainstream aged care services are generally under utilised by CALD clients across the service spectrum. Therefore, there is a need to understand the service barriers, to become proactive in engaging CALD seniors and to seek service partnerships with ethno-specific welfare organisations and workers. The research evidence strongly suggests that

the most effective models are brokered services which allow the service provider to purchase capacity and buy in those services that are relevant and can cater for specific linguistic and cultural needs.⁴ Once CALD seniors start receiving services, however, it has been found that their requirements for the service to be provided in their own language and by a person from the same cultural background diminishes over time.

Conclusion

The ageing of post-war migrants is a challenge for aged care services throughout Australia. There is a need to rethink both health promotion strategies and service provision, so that the behaviours and needs of CALD seniors are central, rather than marginal, to the health planning and policy formulation process.

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Consumers as critical friends – a different perspective on quality

Russell McGowan

Consumers can add essential value to continuous quality improvement processes; listen to them as partners who want to help improve outcomes and ensure we get the most benefit from health spending.

Crucial to cost effective spending and decision making within a quality, sustainable health system is a commitment to, and integration of, continuous quality improvement processes that measure and use consumer health outcomes to inform and drive change.

Beyond reform decisions around where and how to spend health dollars, we must ensure that when those dollars are spent, they deliver the consumer health outcomes they target. Continuous quality improvement processes check our return on investment (are we getting the outcomes expected?), and flag where and how efficiency and effectiveness gains can be made (where are the problems, how can things be improved?).

Since our health system's fundamental purpose is to help people achieve better health, it's logical that healthcare consumer outcomes and consumer experience must be at the core of these programs. But are they?

This article looks at the role healthcare consumers have played to date in maintaining safety and quality in healthcare, and the potential for healthcare consumers to be essential partners and friends in a health system that strives to meet the constants of changing demands, opportunities and circumstances in the future.

Where have we come from? Consumers and accreditation.

Healthcare consumers have been playing an organised role in maintaining the safety and quality of healthcare services in Australia for over 30 years. As far as I am aware, the first acknowledged healthcare specific consumer group was established in

the ACT in 1978 as a spinoff from the Canberra Consumers Association, an affiliate of the Australian Consumers Association now known as Choice.

However it was probably not until the publication of studies into the quality and safety of the healthcare system in the US and Australia during the 1990's that a specific role was defined for consumers in relation to safety and quality.

My own involvement in this began in 2000 when I trained as an accreditation surveyor with Australia's largest hospital accreditation agency, the Australian Council on Healthcare Standards (ACHS). The ACHS had a history of involving consumers as surveyors of performance against mental health standards, but my training with one other consumer was the first time they attempted to involve consumers as surveyors for more general healthcare accreditation purposes.

Was it a success? Not immediately, but I will outline some positive aspects of my training and experience as a surveyor. In the ten years I have been qualified to survey, I have participated in about seven surveys – only three as an actual surveyor, but another four as a participant in processes leading up to surveys. My expertise in the former role is rather less than polished due to lack of practice, but my confidence in my contribution in the latter role has increased with each survey.

For one thing, I am now familiar with, and indeed have influenced, the standards against which hospitals are surveyed. I think they are now more consumer friendly than they have ever been. They are certainly based on continuous quality improvement principles rather than mere compliance.



Those that relate specifically to consumer participation and engagement are much clearer in defining consumers and their role in healthcare organisations (HCO's).

Where to now?

Many HCO's persist in relegating the consumer participation in their service delivery and policy formulation to relatively token roles. The formal engagement of consumers is at best, through consumer advisory committees - often ad hoc groups convened just for the purpose of meeting accreditation standards. We consumers can offer much more to HCO's.

The construct that I would like to see developed is emerging from a process developed in the UK for accreditation of GP's. This involves the convening of 'critical friends' groups to critique the performance of general practices against standards. These groups are comprised mainly of people who utilise GP services, but also of citizens who want the services to be there and to be of high quality in case they may need to use them in future. Their focus is on

assessing feedback from people using the services (often by way of accessing patient experience or satisfaction surveys) and then discussing with the clinicians within the practice possible solutions to problems highlighted by such feedback.

By way of contrast, patient satisfaction surveys of HCO's are often considered confidential management-only information, not shared with the general public. One hospital I am working with is starting to change this and I look forward to consumers playing a greater role in this. To be fair, there are some processes in place designed to gain feedback from people who have recently used services. These involve clinical staff interviewing people recently discharged, with a view to re-designing clinical practice on the basis of feedback given. Known in the ACT as the Access Improvement Program (and in NSW originally as the Maggie Project), this program has been helpful in developing new models of care for use in services emerging as a result of an extensive Capital Assets Development Program in the ACT.

Organised consumer groups have been quite critical about their exclusion from these processes. There seems to be an attitude in some quarters of the healthcare system that we represent 'professional' consumers and that our input taints the relationship between clinicians and 'real' consumers. I think they resent the fact that some consumers are trying to wrest power and control from them.

Let me tell you, that in my experience, nothing could be further from the truth.

As members of organised consumer groups, we have continuing lived experience of health conditions and personal interactions with clinical services, we analyse them carefully

and we know how to distinguish system issues from mere clinical under performance ones. I have recently done this in relation to a serious adverse event which happened to a member of my family, and I believe that working through the system issues with the clinicians involved and sharing the decision making will bring about a better result for me and my family and for the healthcare system as a whole. This is, after all, what most consumers value about having their complaints and feedback considered – that it will help avoid someone else going through the same trauma that they themselves have experienced.

I want to finish by offering some values which consumers contribute to the maintenance of safety and quality in healthcare. As this is the Chinese year of the Tiger, and I was myself born in such a year, I have dubbed these the TIGER values. T is for tenacity, I for integrity, G is for gratitude, E is for enthusiasm, and R is for respect.

By applying these values, consumers can contribute to the continuous quality improvement of our healthcare system and organisations.

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