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*of Australia*

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Consumer-centred  
health care in the  
21st century

representing  
consumers  
on national  
health issues

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# Patient first – innovation in consumer-centred care



## Leanne Wells

Consumer-focused health messages are everywhere, even on loaves of bread, as the former Chief Scientist, **Ian Chubb**, notes in his thought-provoking article opening this issue of *Health Voices*. He emphasises the value of science and education to health, and he says we ought to be doing all we can to advance consumer health innovation. “But I’d suggest we need to bring the ‘consumer’ part to the fore to realise any benefit from the ‘innovation’ — and I’d be looking very seriously at the next generation in schools today. In 20 years’ time we won’t care about the magic bread in their lunch-bags. We will care about the things in their mental toolkits.”

Professor Chubb’s words underline a fundamental but often overlooked point concerning what should be the aim of modern health care: an educated patient as an engaged partner in care. When we think of innovation in consumer-centred health care we need to realise and expect that we as consumers take a central role. As Andrew Knight reminds us in his article “only the patient sees the whole journey” in the health system.

It should go without saying that the consumer experience should be central to health care decisions. This principle may seem a truism yet somehow it can get lost in the thicket of administrative and professional agendas of the modern health system.

This edition of *Health Voices* takes us on a journey where each stop provides evidence of the way in which the consumer experience can play a pivotal role in the advance of health care. We see pioneering developments in disability care choices, the growth in patient-centred primary care and the benefits of individually-focused suicide prevention programs as examples of the rise of the individual in effective health

care. The power of the smart phone and now the development of genomics points to a deepening role of individual decision-making in health care.

As Australia gears up for a federal election at a time when health has registered as an issue of leading concern to voters, we need to see policies that exploit the potential of the consumer-clinician partnership to promote the best interests of patients, particularly the chronically-ill.

The articles that follow present a series of valuable insights beginning with the contribution of **David Bowen**. The CEO of the NDIS describes how his organisation is leading the way on consumer-directed care aimed at enabling what most Australians take for granted: an ‘ordinary life’. “The notion of an ‘ordinary life’, rich in choice and control, underpins the work of the NDIS.” It aims to generate a market place of providers who deliver high quality and innovative supports in response to the individual choices of NDIS participants. “Ultimately, we want to create an enabling environment which encourages innovation and new entrants, as well as established players.”

We need to unpack what patient-centred care actually means, both from the clinician’s and the patient’s point of view, says **Jeffrey Braithwaite**. This steers us into the tricky waters of individuals’ attitudes and organisational cultures. “Promising innovations are already appearing like e-health and shared decision aids. By combining medical and communications expertise into useful consumer information, we can arm patients with mobile phone apps that help them manage their condition.”

And on that technological note, **Paresh Dawda** describes his observations of how the use of iPads and mobile technology can help counter chronic conditions like diabetes and heart

disease. The determinants of these conditions often come down to the common elements of smoking, excessive alcohol intake, lack of exercise, not ideal diet and being overweight or obese. Having trialled iPads as a tool in care, he says consumers are in a powerful position to draw on digital tools that can help them manage their own health and wellness. “Policy makers and health care providers need to support this and give direction to the right set of tools that are clinically appropriate and safe.”

**Helen Christensen** has led agenda-setting research on suicide prevention to develop a “Systems Approach” which analysis indicates should reduce suicide rates by at least 20 per cent. Effective strategies include high school prevention programs, training of first responders to tackle suicide intent, particularly of those who have made a previous attempt. “We know what strategies need to be implemented and we know they need to occur together. Figuring out how this can happen in the real world, with the resources we have available, is the important next step. This is where we believe new evidence-based technology such as virtual clinics, online tools and smartphones have an enormous role to play.”

**Karen Carey**, consumer voice on the NHMRC, explores the challenges of turning good science into good care and suggests solutions. “Getting value from innovation requires a lot of change, and if history has told us anything it is that the healthcare system remains too impervious to change. Hopefully the new generations of healthcare professionals will be different and as the dinosaurs fade away, we will see a much more professional attitude to the business of keeping Australians healthy.” If there is one frontier of patient-centred care where we often still struggle to innovate, it is care of the dying.

**Stephen Leeder** says of his profession that medical and surgical heroics “can detach us from the ground of the person receiving treatment and float us off into the stratosphere of hi-tech wonder. If we can do something we mistakenly conclude that we *should* do it”. He cites the American writer and surgeon, **Atul Gawande** who makes the point repeatedly that medicine should aim to enable life according to the wishes of the patient. “The goal of medicine, he says, is surely to enable good life. Death will look after itself.”

Patient experience is central to driving health care standards. **Nicola Dunbar** writes how the Australian Commission on Safety and Quality in Health Care standards spurs consumer influence. It can be a chemotherapy patient speaking to oncology nurses about what it was like to receive chemotherapy, or a consumer after a difficult labour talking to a session of junior and senior medical staff about her clinical and emotional experiences. “Clinicians are positive about the involvement of consumers in clinical training, and have reported that it has reconnected them to their purpose.”

**Andrew Knight** demonstrates the significance of mapping the consumer’s health journey. He advises that Primary Health Networks will be wise to construct effective consumer consultation mechanisms. If we are to improve the patient journey, consumer involvement is clearly essential, he says. “Together we are more likely to find the way to a more consumer-centred and effective health care system because only the consumer sees the whole journey.”

But as **Walter Kmet** says, in the Australian health system of diverse funding structures, partnership development becomes a critical mechanism for service integration. An excellent example of this has been Health Pathways. The benefit of enablers such as Health Pathways is that they highlight the incentive to work together beyond single organisation

motivations. “The objective becomes to organise patient care around the patient’s needs, not having them determined by existing structures.”

**Ian Learmonth**, who is turning his high-level investment expertise to social impact ventures, points to the NDIS model of consumer influence. “In many cases, the best business ideas may come from people with lived experience of disability who understand the needs of consumers and can develop innovative and effective responses.”

Longtime patient advocate, **Twanny Farrugia**, would agree with that. Twanny looks to his six decades as a chronic health system user to inform his views on patient-centred health care. He cites four standards which should guide clinicians:

- Treat me with respect and dignity
- Share information
- Allow the patient to participate in the decision making about care
- Ensure collaboration between my various specialists so I am not treated as a collection of individual health issues but as the one individual with the complex health issues I happen to be.

One focus of moves towards greater collaboration between health practitioners has been pharmacy.

**Bronwyn Clark** tells how a shift in focus from the supply of medicines to a greater level of patient-centred responsibility has occurred over recent decades, and pharmacists are now providing new services, working with consumers and other healthcare professionals in new models of care and in new environments.

**Peter Brooks** explores the thorny issue of patient charges and as he says, greater transparency concerning medical fees is an innovation that has some way to go in Australia. “This is a difficult issue but one that must be addressed if we are going to have a health system that looks after all Australians.”

The future holds out the scope for potential advance of personal healthcare innovation on an exponential scale, as described by **Jack Nunn**.

Genomic sequencing looks likely soon to be as routine as a blood test, enabling a profound array of individual health choices and treatment pathways. He suggests the possible creation of a free service offering options that could include full genome analysis and genome and lifestyle sharing for research purposes — developments which individually at least are already happening somewhere in the world already.

“This hypothetical free service may never materialise, but it raises important ethical questions that need answering. Crucially, it also gives a real and achievable mechanism for people to get involved in genomic research in a way which is systematic, open access, free and universal,” Jack concludes.

His scenario paints a picture that is both disturbing and exhilarating.

The more we know, the more we don’t know. But whatever its future, consumer-centred care has a long way to travel.

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# The Well-Bread Society



## Ian Chubb

I recently discovered a new brand of bread. The package informed me that it lowers cholesterol, prevents heart disease, wards off anaemia and osteoporosis, increases 'feelings of wellbeing' and contributes to the vitality of one's pancreas. Manna from the supermarket, indeed. We know it's genuine, of course, because 'research suggests' it.

If I could have ham sandwiches in the place of health insurance, I would. Health ministers would probably swap the PBS for subsidised picnics just as gladly. But I don't think perfect health comes with a daily dose of 45 grams of bread, and it troubles me that marketers would think we'd swallow it – the bread that is, because of the raft of claims attached.

Are we consumers really such mugs that the flash of a Bunsen and the hint of lab coat is enough to persuade us we're onto a good thing? Can't we distinguish between puffed-up marketing and peer-reviewed evidence? Do we understand that the former can be bought off the shelf, but the latter takes time, constant effort, complex skills?

And do we recognise that if we don't work at it, if we let the real source of the good things wither away, it might not be there when we need it in the future?

I'm not sure. But I think I'd want to be sure, because whatever the margin of ignorance today, we can be certain it will be larger tomorrow.

Science will not stop advancing. It will accelerate, and so will the rate at which we add to the vast body of knowledge from which the pills and the procedures come.

There are already about 58 million scientific publications in the Thomson Reuters Web of Science collection.

To give some indication of what that means, consider the American researcher who set out to investigate a specific protein linked to many cancers. He identified some 70,000 papers on this protein alone. If he could read five a day, he worked out that he'd be reading for 38 years.

There will be more to know, ever more complex ways for scientists to set about discovering it, whole branches of knowledge that didn't exist when today's high school textbooks went into print.

And ignorance will also advance, because those who profit from it will continue to their utmost to use it. We know their types, even if we can't always pick them out in a line-up. The snake-oil salesmen. The doubt-mongers. The commentators who think their brand of 'common sense' ought to triumph over

some imagined global conspiracy of scientists.

Did you know we have a word for the study of culturally induced ignorance, and how societies like ours create it? It's 'agnotology'. I suspect we'll be needing it.

My point is not that scientists deserve our unthinking trust. As Noël Coward once said I have no more faith in men of science being infallible than I have in men of God being infallible, principally on account of their being men.

So I'd say the men and women of science ought to have our intense interest and scrutiny. The overwhelming majority would welcome it, because they understand their mission to be not simply the expansion of knowledge but the improvement of people's lives.

We have to work out as a society what 'improvement' means, and what means we are prepared to take to get to it. If we can't have that conversation on any terms other than 'trust me, I'm a scientist', we're in trouble.

Consider the looming crisis of antibiotic resistance. The World Health Organisation has described it as one of the key global health issues facing our generation, and with good reason. In the last year on record, close to half a million new cases of multi-drug resistant tuberculosis were reported across the world. Extensively drug resistant tuberculosis has been identified in over 100 countries, including countries in our immediate region.

Up to now we have dealt with the development of resistance by replacing the ineffective antibiotic with a new class that acted in a novel way. That pipeline has effectively collapsed. In the last 50 years, only two new antibiotics have been discovered and developed for use in humans.

And yet we still treat antibiotics as chicken feed – quite literally, shovelling





them into agricultural production chains with the reckless abandon of a society that chooses cheaper drumsticks over an unborn generation's rights.

We also misuse them - knowingly - in healthcare, as the latest Government strategy paper on the subject confirmed. Two-thirds of Australian health consumers surveyed in 2014 thought antibiotics would aid their recovery from viral infections. Three in five GPs would give antibiotics to patients to satisfy their demands.

In every facet of this problem, unthinking trust is our enemy. Trust that science will come through with another pill. Trust that the media would talk about antibiotic resistance, if it

were a real and pressing problem. Trust that a GP can make up the consumer knowledge deficit in the space of a five minute consultation.

How many more complicated problems call on us to understand not just scientific evidence, but how science works? Zika - with the nature of the relationship between the virus and microcephaly still so little understood? Vaccination - where we seem to be engaged in a cultural war, far more than a scientific discussion?

Yes, we ought to be doing all we can to advance consumer health innovation. But I'd suggest we need to bring the 'consumer' part to the fore to realise any benefit from the 'innovation' - and

I'd be looking very seriously at the next generation in schools today.

In 20 years' time we won't care about the magic bread in their lunch-bags. We will care about the things in their mental toolkits.

*Professor Ian Chubb, AC, is the former Chief Scientist of Australia. He has been Vice-Chancellor of the Australian National University and president of the International Alliance of Research Universities. He has a Masters in Science, a DPhil from the University of Oxford for his thesis on neuronal proteins, and honorary doctorates from Flinders University and Monash University. His term as Chief Scientist ended on 22 January 2016.*



## Disability shows the way on consumer choice in care

### David Bowen

The National Disability Insurance Scheme (NDIS) is the new way of providing support to Australians with disability. It is the biggest social reform in Australia since the introduction of Medicare. It is not welfare and the difference is important.

As an insurance scheme, the NDIS provides peace of mind to every Australian. Disability can affect anyone and the NDIS ensures that we will all be covered if our lives are affected by disability. It takes a lifetime approach, meaning it invests in an individual early on for as long as they need it, to improve their life and increase their social participation. Importantly, the NDIS also raises awareness about the needs and rights of people with disability and will deliver societal change.

If people with disability are supported to have relationships, belong, make decisions, be active in the community and make a contribution, they will experience what most Australians take for granted: an 'ordinary life'. The notion of an 'ordinary life', rich in choice and control, underpins the work of the NDIS.

Reasonable and necessary supports funded through the NDIS are aimed at bridging the gap between the life being led by the person with disability and other Australians that are enjoying an ordinary life.

The NDIS replaces a system of complex disability supports funded by governments around Australia with a single, national scheme that will support all Australians with a significant and permanent disability. This provides certainty and consistency for people with disability. Block-funded arrangements will be replaced with person-directed funding. The NDIS will also provide people with information about, and referrals to, other existing support services in the community where these are more suited to meeting their needs than NDIS funded supports.

In the NDIS, every participant has control over the services and supports they receive. Services are individualised and decentralised, with local area coordination of locally-based care. Support through the NDIS will be nationally consistent and portable. That means if a person with a disability wants

to move to another state with their family, their entitlement to the NDIS - and therefore the level and standard of care they receive - will move with them. If a person with a disability wants to choose to receive services from a new provider in the disability sector they can.

The NDIS works individually with people with disability because we know each person has different needs, preferences and aspirations. The Scheme provides choice and control to people with disability, their families and their carers to determine what supports they need to lead the life that they want and achieve their goals.

Each NDIS participant has a funded plan with goals that focus on maximising their independence and social and economic participation. This requires participants and their families and carers to become informed consumers when putting their plan in to practice, which will take time.

For the first time, the NDIS is harnessing the power of markets to serve people with disability. Consequently, the NDIS is creating major business opportunities and these extend well beyond the disability sector.

*'The NDIS...is implementing the consumer-directed approach to service delivery on a scale not seen anywhere in the world.'*

Earlier this year Professor Ian Harper completed his review of Competition Policy. Professor Harper recommended that government human services should be consumer directed as this would drive significant improvements in efficiency and effectiveness. The NDIS has anticipated that thinking – and is implementing the consumer-directed approach to service delivery on a scale not seen anywhere in the world. Currently, governments spend billions of dollars every year on disability services, with only fraction of funding going towards individualised services.

Under the NDIS, the annual cost of disability supports will grow to \$20.6 billion by 2019-20. That means the total market for disability supports will more than double in the next four years.

If companies want to win a share of this market, they will need to be competitive. They will need to think national and act local. They will need to adapt to the individual needs of the NDIS participants. The business opportunities are not just limited to traditional providers of specialised disability services. There will be opportunities for organisations in adjacent sectors such as health, education and aged care. There will also be opportunities for other community services and local governments to expand, as part of services which are more inclusive of people with disability. The workforce needed to service this

new market under the NDIS is expected to grow by around 60,000 to 70,000 people on an FTE basis.

The Scheme aims to generate a market place of providers that deliver high quality and innovative supports in response to the individual choices of NDIS participants. We also know this market will take time to develop and mature. The National Disability Insurance Agency has an important role as market steward. Ultimately, we want to create an enabling environment which encourages innovation and new entrants, as well as established players. Over time, consistent with the recommendations of the Harper Review, this will lead to increased efficiency, effectiveness and creativity. We expect improvements will accelerate as we aggregate more data about the Scheme and its participants and share this with the market.

To shape future directions of the NDIS and ensure continuous improvement, we built an actuarially based outcomes framework. It measures the medium and long-term benefits of the NDIS for participants and their families. The measures include choice and control, independent living, relationships, health and well-being, home, lifelong learning, work and social, community and civic participation. Monitoring the outcomes across these domains over time, as well as the financial metrics, will help ensure the Scheme is sustainable. It will also help participants in the NDIS build better lives by encouraging and demonstrating best practice.

The Scheme is on time and on budget – and client satisfaction is above 90

per cent. In other words, we're exactly where we need to be.

One of the key goals in the NDIA's Strategic Plan is to keep building public confidence in the Scheme. That means continuing to meet goals and maintaining and building a performance culture within the Agency. In short, performance is everything and that means continuing to achieve the quarterly targets set by governments. For the NDIS though, there's more to performance than just meeting quarterly targets. We must also keep learning as we build the Scheme so that it performs over the lifetime of each and every participant. Because the real impact of the NDIS will be measured in the quality of people's lives and over generations, rather than quarterly reports. We never lose sight of that.

*David Bowen is the inaugural CEO of the National Disability Insurance Agency. He has worked as a consultant to the insurance industry and health and disability sector. He is one of the architects of the NSW Lifetime Care and Support scheme and as inaugural CEO was responsible for implementation of the initiative. Prior to this he was General Manager of the Motor Accidents Authority for 11 years. David is a lawyer with a strong background in administrative and insurance law. He has been actively involved in development of the disability reform program, being a member of the Independent Panel advising the Productivity Commission in its inquiry into the feasibility of a National Disability Insurance Scheme and as initial chair, and ongoing member of the National Injury Insurance Scheme Advisory Group.*

## A sustainable healthcare system has patients at its centre

### Jeffrey Braithwaite

Implementing consumer-centred healthcare is bit like turning an oil tanker at sea. At first it seems not much is happening. There's a long, slow-run up, then a wide, gradual turn to execute.

But, once a new direction has been set, the momentum is such that there's no going back. In healthcare we are now moving, inextricably, towards a future in which patients will play a more active and decisive role in their own care.

Consumer movements have been advocating for more consumer-oriented, or patient-centred, healthcare since the 1960s. That is, healthcare which is less about expert clinicians telling patients how it is and dictating



what happens next and more about clinicians asking patients, or their carers, for input into important decisions about their treatment and care. This long, slow run-up has been characterised by the rise of a range of energetic, informed—but still all-too-often discordant—consumer voices. At the same time new terminology, approaches and initiatives have emerged that are neither well understood, nor adequately tested.

It's usually assumed that the key elements of consumer-centred care, like shared decision-making (SDM), or a seat for consumers, patients or community representatives at the management or policy-making table, will lead to better, happier outcomes for patients. This could, in turn, reduce demands on healthcare services and curtail costs.

Anecdotally, such approaches seem promising and evidence is emerging to back this up. For example, a research project into young adult patients with type 1 diabetes mellitus found that SDM and other strategies for empowering younger patients could help them avoid diabetes-related disease complications and improve glycemic control<sup>1</sup> because those patients who felt their treating clinicians were listening to them were more likely to stay connected to diabetes health services. In another study, consumers who were on a committee to provide input into a Sydney-based health service saw the needs of patients from a refreshingly different perspective compared to 'insider' clinicians and managers.<sup>2</sup>

But we need to know a lot more as the inevitable shift towards consumer-centred care unfolds. I say 'inevitable' because several key push factors are now coinciding.

First, the industrialised world is ageing rapidly, and many developing countries, in particular China, are not far behind. By the 2030s, 30% or even 40% of the population of industrialised nations will be aged over 60. At the same time, significant advances in biomedical science are helping us all live longer. Consequently, a tsunami of older patients is building, many with co-morbidities, complex medical histories and chronic conditions.<sup>3</sup> To remain sustainable into this future, healthcare systems must recruit these patients as genuine partners as they begin to need more care.

Second, the rise of "Dr Google" has triggered plenty of discussion about patients turning up for consultations armed with a less-than-helpful smattering of facts and opinions. The issue, however, is not whether Dr Google is disrupting care but that many patients and their carers have a real thirst to know more about their own condition. If we don't provide clear and accurate information they will look for it elsewhere anyway.

The challenge is to turn these circumstances into an opportunity. In theory at least, instant digital connectivity should allow us to help patients play a more active, more autonomous role in their own care and, in doing so, help alleviate growing pressures on healthcare systems. But we need evidence-based tools and models to translate good ideas and aspirations into better patient outcomes and experiences.

For a start we need to unpack what patient-centred care actually means, both from the clinician's and the patient's point of view. This steers us into the tricky waters of individuals' attitudes and organisational cultures. There will always be some patients, and some clinicians, who will continue to prefer the status quo. But, we know we need much more flexibility. That involves training clinicians to both ask questions, and listen. We also need to direct patients towards credible resources, information, and even training, to support more 'self-care'.

Promising innovations are already appearing like e-health and shared decision aids. By combining medical and communications expertise into useful consumer information, we can arm patients with mobile phone apps that help them manage their condition. Providing on-line education for the two million full or part-time carers at home supporting family members would be also very useful.

We know, too, that particular areas of care are far from patient-centred. Take acute hospitals. Patients often find themselves on mindless conveyor belts that relentlessly move them from one medical intervention to the next, without considering their wishes or best interests.

<sup>4</sup> This is especially as patients move towards end-of-life care. Likewise, aged care facilities often don't take the time to ask about the wishes of their residents.

Consequently, we too often subject our elderly to emergency medical interventions for ailments and conditions that are a normal and expected part of the process of dying. In the United States one third of the elderly spend at least part of their final month of life in intensive care units receiving care that can neither save their lives nor improve its quality. Australia's experience is similar. If we stopped to ask, as patient-centred care advocates suggest we do, we'd likely find that few patients would choose to spend this time in a \$4,000-a-day intensive care bed hooked up to machines. Most would say they'd like to be supported at home surrounded by their loved ones. Such support services, then, which are currently few and far between, would become an essential part of patient-centred care.

Interestingly, two major studies in the United States found that most clinicians pursue aggressive treatments for terminally ill patients, most of whom (over 80% surveyed) do not want life-prolonging medical interventions. Yet almost 90% of the same doctors—if they were the patients—would not subject themselves to a medicalised end of life.<sup>5</sup>

The oil tanker is already turning. It points to a sustainable future for healthcare systems—but only if patients are involved in setting the course.

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# Bringing technology into everyday health



## Paresh Dawda

How can your iPad help you to improve your health? What would you do? How would you use it? How can the time you spend in the waiting room to see your doctor or nurse be used to help you?

These are exactly the sort of questions a collaboration of researchers and a large integrated care clinic in the ACT are trying to answer. The Health Hub is a collaboration between Ochre Health and University of Canberra and houses Canberra's first GP Super Clinic as well as the University's student led clinics. It is also home to the 'living lab', hosted by data61. This is a large collaboration between a group of organisations, who want to improve healthcare outcomes through the innovative use of information and communications technology.

The group has just finished one study and are commencing another. The first study looked at mHealth, the use of mobile and wireless technologies to support the achievement of health objectives. In this pilot study funded under an ACT Government Strategic Opportunities Funding grant, the participants were patients with diabetes who were invited to be part of the study. They were provided with an iPad together with digital training on how to use the device (if necessary). Its purpose was to explore the possibility of increasing an individual's sense of responsibility for the self-management of type 2 diabetes by introducing a mobile tablet device. They were given

one of six invitations and were at liberty to choose any combination:

1. Use 'diet' app(s) to explore, plan and evaluate their food intake
2. Use 'exercise' app(s) to improve physical health
3. Keep a journal on their tablets to reflect on their daily challenges and success
4. Engage with other participants and/or participate in online support group(s)
5. Measure and record aspects of their diabetes on their tablets via recommended app(s)
6. Access authoritative information via an online repository on their tablets

A third of the participants had never used an iPad and almost a tenth had never used the internet. Over two-thirds of the participants found the iPad helped them to manage their diabetes better. It helped them to achieve broader and deeper knowledge of their condition, a greater understanding and acceptance of the disease and enabled behavioural change. One of the key findings was the strong need for an mHealth program that integrates digital literacy training.

*"It has helped me come to grips with my diabetes by helping me to understand more about the disease" (Emily) and "the ease of access to nutritional information, food alternatives and recipes has made this much easier than having to locate books and locate the information I needed by trawling through pages of irrelevant information" (Zayne)*

Another finding was that mHealth to be successful must be embedded in patients' everyday lives, as well as in the broader healthcare context. The words of one participant illustrate how powerful enabling consumers can be:

*"I also used it to research different types of diabetes and found that Latent Autoimmune Diabetes of Adults (LADA) symptoms are very similar to my symptoms so I took my iPad to the doctor and showed her and she then tested me for this rare type of diabetes. Unfortunately it appears my research is correct because the blood tests have returned positive for this type of diabetes. If I didn't have this iPad I probably wouldn't have researched to the depths I did" (Rachel)*

The second study is in progress in the same clinic and is funded by a grant from the Royal Australian College of General Practitioners and HCF Research Foundation. It starts with the premise that health prevention information is not always routinely or regularly collected by doctors and nurses for a whole range of reasons. It also recognises that between arriving at a clinic and seeing the doctor there is often a wait. In this study consumers will be invited to visit a private kiosk or pod, most likely during that waiting time. The pod will ask users to enter some key health information using an interactive screen and will use an automated height and weight measure.

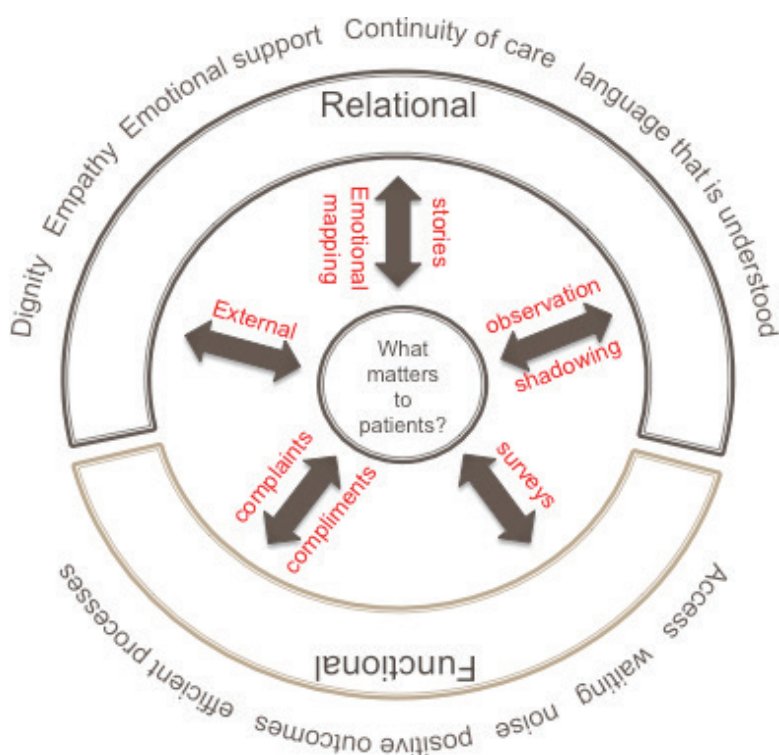
Depending on how much time users have they will be able to enter some

**Figure 1: The Engagement Cycle**

This diagram is reproduced with permission. The Engagement Cycle was developed by David Gilbert of InHealth Associates.



**Figure 2: What happens to patients?**



additional information either at the same visit or a subsequent visit. This additional information will be related to questions about alcohol consumption, physical activity and an option to assess their risk of developing diabetes. After completing the self-assessment, they will be issued with a personalised report card. The report card will explain what the assessment has shown, what it means for them and what they can do to improve it with signposting to further information and resources through a dedicated web page.

The rise of chronic conditions like diabetes and heart disease is a growing problem around the world. The determinants of these conditions often come down to the common elements of smoking, excessive alcohol intake, lack of exercises, not ideal diet and being overweight or obese. Many of these issues can be addressed by individuals but are hard to maintain and require motivation and commitment. A recent report of technology in healthcare in the UK surmised “there is enormous potential for digital technology to improve many aspects of health and social care provision” yet at the same time concluded that the “question remains whether developments will provide little more than hype for the healthcare industry, or whether they will truly transform care?”

<sup>1</sup> Consumers are in a powerful position to create a pull for digital tools that can help them manage their own health and wellness. Policy makers and health care providers need to support this and give direction to the right set of tools that are clinically appropriate and safe.

*Paresh Dawda is a GP and ACT Regional Medical Director with Ochre Health which operate medical centres across Australia. He has academic affiliations with University of Canberra and ANU. He holds a number of leadership roles at regional and national level including Royal Australian College of General Practitioners and is a board member at Heart Foundation (ACT). He has widespread interests in health services design, clinical leadership, quality and patient safety improvement with a passion for consumer centred care being the golden thread that unites all his interests.*

<sup>1</sup> <http://www2.deloitte.com/content/dam/Deloitte/uk/Documents/life-sciences-health-care/deloitte-uk-connected-health.pdf>

# A new approach to suicide prevention in Australia



## Helen Christensen

Suicide is the most common cause of death in Australians aged 15-44 years – more common than deaths from motor vehicle accidents or skin cancer. More than 2,500 people die from suicide in Australia each year and more than 65,000 make an attempt.

Despite the implementation of significant initiatives such as the Australian Government *Living is for Everyone framework* in 2007, the suicide rate has remained static over the past decade.

Even those people we know to be at highest risk of suicide are not adequately cared for, as the recent *Care after a Suicide Attempt* study conducted by researchers at Black Dog Institute and University of NSW demonstrated.

Clearly we need to make some significant changes to how we address suicide and suicidal ideation in Australia. To do this, we need to think with our head, not our heart.

## Why have we not reduced the suicide rate?

There are a number of medical and community interventions that have been shown by the evidence to reduce and/or prevent suicide and suicidal ideation. Many of these strategies are currently implemented in Australia, however both funding and usage is fragmented and non-systemic.

Evidence has emerged over the past decade that these good quality interventions need to be combined to reduce suicide rates substantially and sustainably.

Research conducted by the NHMRC Centre of Research Excellence in Suicide Prevention at Black Dog Institute has identified the relative likely impact of strategies shown to have been effective in the past. We mapped which strategies were likely to yield the

greatest impact and have developed a framework that incorporates them all, as shown in the accompanying illustration.

Put simply, our work has shown that implementing the most impactful strategies simultaneously can help to overcome the limitations of individual strategies and enable maximum effectiveness across different geographic, cultural and socio-economic populations. This new approach has been termed the “Systems Approach” to suicide prevention, and analysis strongly suggests it will reduce suicide rates by at least 20%.

## The ‘Systems Approach’ to Suicide Prevention

So what are the most impactful strategies? At the population level, they include limiting access to lethal means, establishing a national awareness program, managing media reporting of suicide, implementation of mass screening and prevention programs amongst high school students and training people in frequent contact with those at risk to act as “gatekeepers”.

At the individual level, strategies include training GPs, Emergency Department staff and first responders to identify and tackle suicidal intent, ensuring universal access to high quality psychological treatments and providing continuing care to those who have made a previous suicide attempt.

We know what strategies need to be implemented and we know they need to occur together. Figuring out how this can happen in the real world, with the resources we have available, is the important next step. This is where we believe new evidence-based technology such as virtual clinics, online tools and smartphones have an enormous role to play.

## Putting research into practice

In the 2014 Review of Mental Health Programmes and Services<sup>1</sup>, the National Mental Health Commission recommended that 12 sites be selected to investigate whether the Systems Approach to suicide prevention would reduce the suicide rate.

With the support of the NSW Mental Health Commission, we have analysed community-based risk and resources to develop a Suicide Prevention Framework for NSW. This proposed Framework was formally submitted to the NSW Government in 2015.

As with all new programs, funding is the biggest hurdle to timely implementation. We are extremely grateful to the Paul Ramsay Foundation, who recognised the strong evidence and the urgent need, and stepped into fund the first ever trial of the Systems Approach in four NSW regions. Starting in 2016, this trial will be coordinated through NSW-based Primary Health Care Networks.

## The future of suicide prevention in Australia

Despite considerable public pressure from clinicians, academics and the community, the Australian Government has not yet developed a formal plan for suicide prevention.

The recent announcement by the Government to bring about mental health reform<sup>2</sup> by empowering primary health networks to commission services and programs was favourably received. However, many of us in the suicide prevention field were disappointed. In addition to the important national trial concept being abandoned, there is no guarantee that these newly consolidated and vastly diverse networks will preferentially fund evidence-based programs.



As we embark on one of the world's biggest suicide prevention trials in NSW, we hope that this work encourages the Federal Government to commit to a national data-driven and scientific response to suicide prevention.

Find out more about the systems approach to suicide prevention at <http://www.blackdoginstitute.org.au/public/research/suicideprevention.cfm>

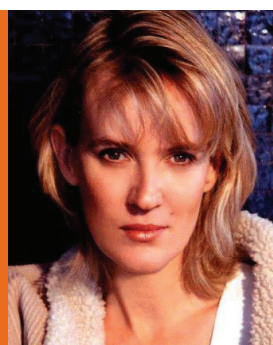
**Should you feel distressed by this article or need to talk please contact Lifeline on 13 11 14.**

*Scientia Professor Helen Christensen, BA (Hons) (Syd), MPsych, PhD (UNSW), FASSA, is Director and Chief Scientist of the Black Dog Institute and a Professor*

*of Mental Health at the University of New South Wales. She is one of two NHMRC John Cade Research Fellows, Chief Investigator for the NHMRC Centre for Research Excellence in Suicide Prevention, Fellow of the Australian Academy of Social Sciences, past President of the Australasian Society for Psychiatric Research, and the immediate past President of the International Society for Research in Internet Interventions. She is the author of more than 400 journal articles, seven consumer books and three open access websites. Professor Christensen is an international leader in the use of technology to deliver evidence-based psychological therapies. Her*

*work has been recognised nationally and internationally, her citation counts position her in the top 1% of researchers internationally. Over the past decade Professor Christensen's research has involved the development of eHealth applications aimed at reducing or preventing anxiety, depression and suicide risk.*

- 1 National Mental Health Commission, 2014: The National Review of Mental Health Programmes and Services. Sydney: NMHC <http://www.mentalhealthcommission.gov.au/our-reports/contributing-lives,-thriving-communities-review-of-mental-health-programmes-and-services.aspx>
- 2 Australian Government, 2015. Australian Government Response to Contributing Lives, Thriving Communities - Review of Mental Health Programmes and Services. <http://www.health.gov.au/internet/main/publishing.nsf/Content/mental-review-response>



## Innovation now! Let's unblock health research

### Karen Carey

As consumer demands change from 'more, more, more' to 'better, better, better', innovation becomes crucial, but innovation is both a benefit and a risk and, as consumer representatives, we need to ensure that the benefits of the new outweigh the risks.

Currently there is a huge focus in health on whether we are getting value for money for our large health expenditure, and as the evidence builds, it appears more and more that we are not. Whilst this may seem to have only a tenuous link with innovation, it is innovation across the whole healthcare system that is required to buy better health for all Australians.

For health consumers, getting the right healthcare is about more than just money because when you are sick, undergoing a therapy that doesn't work means you lose the benefit of having a treatment that does work, and for people with cancer or other critical conditions, this lost time can cost them their life.

So consumers have huge 'skin in the game' and we must ensure that

consumers have a voice at every table to craft innovations that meet the needs of health consumers and not just the health service providers and funders.

Currently there are five key areas in which innovation could help health consumers get better health outcomes across the healthcare system:

**Innovative funding for research** that limits investment in 'researcher curiosity' driven projects and instead focuses on the research that can deliver real improvements in health outcomes by answering the most pressing of research questions – what works in whom?

To answer this question researchers need access to large data sets including those collected for administrative and payment purposes, e.g. MBS and PBS data. Using these large data sets will give research sufficient power to deliver definitive findings that are relevant for an Australian population. These findings can then be used to inform future funding models for MBS and PBS based on evidence about what works in real people.

This type of innovation would also fill a gap in 'real world trials', which would

give us much better information than the current method of trialing in perfect populations, which exclude people with comorbidities, pregnant women and children from trial populations.

**Innovation in how we use research findings** to reduce the massive lag between meaningful research findings and implementation of those findings in healthcare, either as new therapies or changed services. This lag is currently estimated to be 10-12 years from the commencement of the research project.

One of the biggest hurdles for translating research into practice change is the current process generally requires that once the research project is conducted and findings are made, that they be published in a peer-reviewed journal to test their validity.

While this makes sense in terms of testing the evidence, it creates a massive barrier to meaningful research findings being implemented quickly, because the peer-reviewed journal publishing industry is incredibly slow. It is a long process that largely relies on the goodwill of other researchers reviewing papers for free, it includes



exclusion clauses that make researchers apply to a single journal at a time, and then move onto a second, third or fourth journal only once their paper has been refused, and if accepted, often involves long negotiations as to the content.

### *'Every stage invites failure'*

And the process doesn't finish there. We then rely on clinicians, who already fill 100 per cent of their time treating patients, to read the journals (often several kilos of paper per month), and then change their practices accordingly. Every stage invites failure.

There is no doubt that some good research, which could have contributed to better health outcomes for Australians, and for which we paid good money through NHMRC funding, has never seen the light of day simply because the researchers could not get published. This means the public is funding research whose value is unlikely to be realized for a decade, if at all, is dependent on the publishing industry, an independent third party, with very different objectives. We need innovation either of the peer-reviewed journal publishing industry, or an alternative mechanism that would short cut validity testing of the research findings and allow implementation in a much more efficient manner.

**Innovation in medications** including a more nimble PBS that will afford new drugs by defunding those drugs that are currently funded but don't work. This type of disinvestment will not only improve the cost effectiveness of our healthcare dollars, it will reduce the unnecessary harm that patients risk when they use a medication that has no potential therapeutic benefit for their condition.

**Innovation in medical devices**, including an effective post-market surveillance system so that we learn as early as possible long-term safety, efficacy and cost effectiveness profiles for all devices. The current system doesn't work largely because the TGA and healthcare providers don't appreciate the value of reporting known as well as unknown adverse events and complications. This may be because historically the TGA has only been focused on safety, quality and effectiveness of specific devices, and not cost effectiveness or relative



safety and effectiveness between similar devices, as this has been the role of funding bodies or clinical groups.

Expanding the TGA's role to include assessing cost effectiveness and relative safety and relative effectiveness would provide a useful driver for the collection of more data and bring to light potential negative effects much earlier in the product life cycle.

**Innovation in models of healthcare delivery** so that the lessons from pockets of excellence are shared and rolled out across the wider system. The Australian Commission on Safety and Quality in Healthcare has made a great start by publishing the Australian Atlas of Healthcare Variations but now we need governments and health consumers to be outraged by the huge variation in services that sees some Australians adversely affected by massive over-servicing (e.g. arthroscopy) while others miss out completely on essential services.

Getting value from innovation requires a lot of change, and if history has told us anything it is that the healthcare system remains too impervious to change. Hopefully the new generations of healthcare professionals will be different and as the dinosaurs fade away, we will see a much more professional attitude to the business of keeping Australians healthy.

From my own experience, we might start with reducing the current separation between the therapeutics industry, healthcare service providers,

consumers and researchers. We need to forge closer ties between these groups so that promising research is converted into new therapies rapidly, new therapies are adopted into clinical practice more efficiently, the effectiveness data for every patient is used meaningfully to determine what works from whom and to identify problems early, together with a dynamic healthcare system that responds to problems quickly and efficiently. And not least, we need consumers who actively participate in data collection, reporting and decision making at all levels.

I should also mention the eHealth record, which could provide a wealth of data and solve lots of problems, but after so many years I just couldn't bring myself to call it an 'innovation'.

*Karen Carey has represented consumers for more than a decade across several levels of the healthcare system. She is the consumer representative on the NHMRC Council, the Chair of the NHMRC Community and Consumer Advisory Group, the immediate past Chair of Consumers Health Forum of Australia and former Chair of Health Consumers Council of WA. Karen is the Executive Producer of the evidence-based health program, Tonic, broadcast on ABC TV and in more than 25 countries. She is co-founder of Tonic Health Media, which narrowcasts evidence-based health programs to consumers in healthcare environments such as GP waiting rooms.*



## Maintaining the good life

### Stephen Leeder

In his most recent book, *Being Mortal*, Harvard general surgeon and writer Atul Gawande reflects on the purpose of medical and surgical care and relates it to what people want to do with the time remaining to them, given that many who come seeking care are old and sick and can see that life is limited.

Taking account of that desire, optimally through direct conversation or if not that then via advance directives, is fundamental to good medical practice. This is the ultimate consumer contribution. No generalised statistic can provide sufficient information for the surgeon to know what to do when faced with the question of how far to press. The voice of the consumer is that to which we must listen.

It is possible that, in anticipating with anxiety our last days or those of a close friend or relative, we search for too much certainty in advance. When those days arrive, the context may be different and desires may have changed. A work colleague was caring for her spouse who had advanced liver disease. He had signed an advance care directive saying that he did not wish to receive intensive care when his end was near. He changed his mind when faced with the reality of impending death. Everyone other than him judged the decision to be unwise. But that was what he wanted.

Gawande writes about a colleague who had made major contributions to the advance directives movement in the US. Her father had signed up. When

he became critically ill his daughter thought his directive would come into play and he would slip away. Driving home from hospital it occurred to her that his view about what was happening was not clear. She had not asked him. She turned her car and went back. "What things would you wish to be able to do to justify more treatment to extend your life?" He replied, "I'd like to be able to eat ice-cream and watch football." That was all. His daughter thought this odd: he had never been a football fan!

This information was fed into the decisions being made about how he should be managed. His life was prolonged – for six months he enjoyed his football and ice-cream.

We need to be ready to adapt to changing circumstances of patients right to the very end. Gawande makes the point repeatedly that medicine should aim to enable life according to the wishes of the patient. The goal of medicine, he says, is surely to enable *good life*. Death will look after itself.

It is possible to lose traction here. Medical and surgical heroics can detach us from the ground of the person receiving treatment and float us off into the stratosphere of hi-tech wonder. If we *can* do something we mistakenly conclude that we should do it. Conflicting views among relatives in the last days or months of life easily distract us.

We can only do our best and not every case, as Gawande reminds us, will end

happily. But if we rehearse regularly what the purpose of medical care really is – to ensure the best quality of life consistent with the desires of the patient – then mistakes will be few and satisfaction will be higher.

*Stephen Leeder is Emeritus Professor of public health and community medicine at Sydney University. He has held numerous public health positions including as chair of the Western Sydney Local Health District Board. He was editor-in-chief of the Medical Journal of Australia. He has practised medicine in the highlands of Papua New Guinea, held a research position at Columbia University, New York, and has directed the development of the Menzies Centre for Health Policy.*



Atul Gawande





# Innovation and consumer-centred care: What role can standards play?



## Nicola Dunbar

Standards are often seen as being a blunt and bureaucratic tool: they can be perceived to encourage a 'tick-box' culture with an emphasis on compliance rather than innovation and improvement. This may be true in some situations, however they can also be a strong driver for change and improvement. Recently we have seen how standards can help to embed consumer-centred care into the health system in Australia.

## Standards protect you

The National Safety and Quality Health Service Standards were designed to protect the public from harm and improve the quality of health service provision. The standards were developed by the Australian Commission on Safety and Quality in Health Care (the Commission) and cover areas where it is known that patients experience higher levels of harm, and where evidence shows how to provide safer and better care. Since January 2013 all hospitals and day procedure services in Australia must be assessed to these NSQHS Standards when they are accredited.

One such provision is Standard 2: Partnering with Consumers. It describes the systems and strategies to create a health service that is responsive to patient, carer and consumer needs. Australia was one of the first countries internationally to include partnering with consumers in mandatory standards for health services. This innovative approach provided a platform for integrating consumer-centred care into safety and quality, and the everyday business of health services in Australia. There is now evidence that this approach is bringing benefits.

## Early outcomes generate urgency

In 2014 and 2015 the Commission reviewed aspects of the implementation of the NSQHS Standards, finding that they have provided a sense of urgency for change – 'the burning platform' which is necessary to change organisational culture to support and embed consumer-centred care. Standard 2 has helped to drive changes by:

- raising the profile of consumer-centred care, providing a sense of urgency for services and empowering staff to act
- leading services to engage additional staff to support consumer-centred care
- providing a list of actions that allow services to identify gaps in their consumer-centred care approaches.

The review also found that health services are reporting positive outcomes associated with their consumer-centred care work. In particular, feedback from consumers is improving the quality of health service communications, design and planning, and having an influence on the overall governance and accountability of the health service.

While many health services have reported that Standard 2 is one of the more difficult NSQHS Standards to implement, the results of accreditation processes show that more and more health services are successfully putting systems in place to support consumer-centred care. Between 2013 and 2015 the proportion of health services meeting all of the actions in Standard 2 at their first accreditation visit increased from 71 per cent to 82 per cent.

## Standards driving local innovation

Many health services have responded innovatively to the requirements of the NSQHS Standards, often building

on activities that had been underway for some time. Examples from two health services that have been high performers in the area of partnering with consumers show some of the innovations that are emerging.

Eyeteck Day Surgeries in Brisbane has acted on feedback from consumer focus groups about the need to provide information for consumers in ways that do not rely on written booklets. They have developed a series of short videos about the care people will receive in the day surgery, and simple procedures such as administering eye drops. The videos involve staff from the day surgery, and made simply using a tablet computer for filming. The videos can be seen at: <https://www.youtube.com/channel/UCZPLOPSwnrNT8Y1ln8Rvmg>

At the Royal Women's Hospital in Melbourne consumers were involved in all formal day-long clinical training sessions in 2015. At a training session for oncology nurses, one consumer spoke about what it was like to receive chemotherapy, while at a session for junior and senior medical staff, another consumer, who had a 4th-degree tear during labour, talked about her clinical and emotional experiences. Consumers who present to training sessions are supported and where appropriate offered counselling or debriefing meetings. Clinicians are positive about the involvement of consumers in clinical training, and have reported that it has reconnected them to their purpose. Many clinicians are now actively identifying their own consumers who could be involved in future training sessions.

## Where to next – achieving consumer-centred care

While the NSQHS Standards in general and Standard 2 in particular have been instrumental in strengthening processes for partnering with consumers in health



services, challenges remain. Some health services have found it difficult to partner with consumers, and a culture that recognises consumers as true partners has not yet been achieved. It is important for the Commission and others to continue to work to embed consumer-centred care in the health system, and standards remain an important tool for this purpose.

The Commission is currently revising the NSQHS Standards, with the new version available in 2017/18. This provides an opportunity to examine how to strengthen consumer-centred care in the NSQHS Standards to support better experiences and outcomes for consumers and clinicians.

An extensive process of review and consultation has recommended the following changes to the NSQHS Standards relating to consumer-centred care:

- include a new criterion about partnering with consumers in their own care, including processes for clinicians and consumers to work together to share decisions and plan care
- include a new criterion about health literacy, so that health services communicate with consumers in a way that supports effective partnerships
- include a new standard about the provision of care that is based on identified goals for that episode of care, is aligned with the consumer's

expressed preferences and healthcare needs, considers the impact of the consumer's health issues on their life and well-being, and is clinically appropriate.

The NSQHS Standards have acted as a 'multiplier' for many safety and quality activities, including consumer-centred care. There has been a focus on consumer-centred care in Australia for decades, and a lot of good work has been done by consumer groups, health services and governments. The NSQHS Standards have acted to reinforce and augment this work, and further embed consumer-centred care in the health system.

*Nicola Dunbar is the Director of Strategy and Development at the Australian Commission on Safety and Quality in Health Care. As well as taking a coordination role across the whole organisation, she also oversees a number of areas of work including partnering with consumers, healthcare variation and end-of-life care. Dr Dunbar has a background in health research, program management and policy development and has worked for government, universities and non-government organisations at local, state and national levels. She has a PhD in neuropsychology and HIV infection, and a Masters in policy.*



## Mapping the patient journey for consumer-centred improvement

### Andrew Knight

Tiger, his family, his GP, pharmacist, physiotherapist and local Townsville hospital staff sat around a table covered in a long sheet of paper. Using sticky notes and marker pens, we mapped his recent admission for chest pain. Step by step, we documented when his chest pain commenced, how he coped at home, and his call to the after-hours advice line. We worked through his ambulance transfer and presentation to the ED. We recorded his hospital progress and discharge. We sought to

understand his decisions, the responses of the health system and opportunities for improvement. Everyone could add parts to the picture. Only Tiger could describe the whole journey.

We learnt the pivotal role that Tiger's mental health had in his decision to go to hospital. We saw opportunities in working with ambulance and in improving general practice access. We heard Tiger's frustrations with seeking psychological intervention while in hospital and the discharge delays. We learnt about the pressures on the hospital in responding to Tiger's needs.

Ideas for improvement identified by Tiger, his family and his health team included

- more vigorous mental health treatment;
- improved access to his general practice during episodes of chest pain;
- increased participation of community pharmacists and hospital based outreach services;
- working with ambulance to manage his chest pain optimally while minimizing hospitalisation



- improving inter-service communication including use of the My Health Record.

We were trying to get at the tension between individual experience and system processes. The ideas we harvested were all about Tiger's individual case. But each idea prompted thoughts about potential improvements that were worth testing in the systems which affect everyone. That is, his individual experience provided insight into problems in the health system he uses.

This patient journey mapping exercise was one of the most exciting activities of the Townsville Integrated Care Collaborative (TICC). With Tiger's permission it was recorded<sup>1</sup> and shared with the cohort of health services participating in the collaborative. Evaluations of the project indicated that the patient journey mapping exercise was one of the experiences most valued by participants.

The TICC was delivered by the Improvement Foundation working with the Townsville Mackay Medicare Local as part of the Australian Primary Care Collaboratives (APCC) program. Through the APCC program the Improvement Foundation has worked with more than 2,000 primary care services since 2004 using the Breakthrough Collaborative methodology pioneered by the Institute for Healthcare Improvement and adapted for primary care by Sir John Oldham<sup>2</sup>. The Collaborative methodology takes a systems approach, which recognises the expertise of front-line clinicians in understanding their context and empowers them to make changes in a structured way using quality improvement methods. It employs the Langley and Nolan Model for Improvement (see Figure 1)<sup>3</sup>. As the patient journey mapping exercise demonstrated, consumers are integral to finding effective and innovative answers to each of the three quality improvement questions of the Model for Improvement.

#### **“What are we trying to accomplish?”**

The consumer answer to this first improvement question is central if change is to be of high value to consumers. It is only with consumers that we can progress towards the “triple aim”: improved health outcomes,



improved consumer experience and better value for the health dollar<sup>4</sup>.

#### **“How will we know the change is an improvement?”**

Quality work rests on measurement to ensure that change is an improvement. What we measure determines what is done. If we are to move towards a consumer-centred health system that achieves the triple aim, it is essential to incorporate appropriate consumer-centred measures into quality improvement work.

Increasingly patient reported outcomes are being used. IF is supporting a further development of the integrated care collaborative on the north coast of NSW, in which patient reported outcomes are one of the main improvement measures. A random sample of participating consumers assesses their perception of how well integrated their care has been each month by completing a simple questionnaire on a tablet device.

#### **“What changes can we make that will result in improvement?”**

Through the patient journey mapping exercise Tiger's experience uncovered innovative answers to this question. In other Collaboratives patients have presented at the learning workshops and sat in “team time” with participating practices to contribute to the design of change ideas. A patient support role was created to provide peer training and act as a contact point for patients contributing to the Collaborative.

Consumers presented at learning workshops for the “eCollaborative”<sup>5</sup> which pioneered general practice processes for implementing the Australian electronic health record. They participated in breakout sessions to design approaches to jointly develop and upload shared health summaries. During action periods for the eCollaborative, patients were champions for local change and worked with their general practices to recruit others to participate in the project. Most recently consumers were interviewed during the North Coast Integrated Care Collaborative to focus on system issues and trigger thinking around solutions for the participating hospital and general practice teams. The experience of the Collaboratives is that clinicians working alongside consumers to consider data and seek effective change ideas creates an exciting dynamic which throws up innovative and effective ideas for change.

If we are to improve the patient journey, consumer involvement is clearly essential. Without consumer input we will not understand the problems, design the right aims, measure the right things or identify effective change ideas. The primary care sector, is in a good position to centre improvement efforts on consumer perspectives as it builds on existing long-term relationships. Primary Health Networks will be wise to construct effective consumer consultation mechanisms, enabling them to include consumer perspectives in their strategic planning, in the development



Patient "Tiger" talks about his health care journey.

of local performance indicators and in the design of effective interventions. Together we are more likely to find the way to a more consumer-centred and effective health care system because only the consumer sees the whole journey.

*Dr Andrew Knight MBBS MMedSci FRACGP FAICD has been in clinical family practice for 26 years primarily in the Blue Mountains west of Sydney and more recently at the Fairfield GP Unit, an academic unit of UNSW. He has*

*had senior roles in vocational training of family practitioners and has been involved in quality improvement in Australian primary care since 2002. He is chair of the Nepean Blue Mountains Primary Health Network and a director of NPSMedicinewise. He is a clinical advisor to the Improvement Foundation, which conducts the Australian Primary Care Collaboratives program. Andrew is a conjoint senior lecturer at UNSW and Western Sydney University and a clinical*

*senior lecturer at the University of Sydney. His areas of publication include medical education, quality improvement and rare diseases in family practice. Thanks go to Mia Dhillon, improvement consultant with IF for her advice and feedback on this article.*

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## Joining the 'islands' of primary health care

### Walter Kmet

As described by the AIHW, primary health care is typically a person's first point of contact with the health system and is most often provided outside the hospital system. Functioning well, this part of the health system can make a sizeable contribution to improving health outcomes particularly for underserved communities. Policy makers in Australia and around the world are increasingly cognisant of the potential contribution that good primary care can make especially in the management of

chronic and complex health conditions.

However good primary care needs to be organised care to operate most effectively, especially with the knowledge that our primary care system is defined by high levels of fragmentation which create unnecessary barriers to good continuity of care. Primary Care Trusts, Accountable Care Organisations, Independent Practitioner Associations and Primary Health Networks are all examples of governments' response to organised primary care. All such organisations

have a central role in improving how primary care systems delivery better continuity of care.

If a stay in hospital was not accompanied by a reasonable level of care continuity we would be concerned. However within the primary care environment we often lack even the most basic elements of continuity of care. Disconnected patient information, high out of pocket costs, confusing referral options are things we often hear from consumers, and also general practitioners who in Australia are well



placed to be more effective in a more connected health system.

The evidence-based Patient Centred Medical Home (PCMH) describes the importance of continuity of care through the principles of comprehensive, coordinated and accessible care. PCMH principles also outline the need for a commitment to quality and safety and perhaps most of all “person centeredness”. It is person- centred care that we most often aspire to but find so difficult to achieve, sometimes as a result of personal or professional barriers, but overwhelmingly due to the operational structure of the system itself.

Our primary health care system looks more like a series of free standing services, strategically isolated from regional health and equity challenges and system supports. Many services actually do amazing work but moving beyond these “islands” consumers, patients and families are literally forced to navigate this system. This is often with help from GPs and care coordination professionals, but continuity of support is far from optimal and patients can feel isolation including isolation from the information and financial means to make choices about their needs.

This problem is compounded by the way we train health professionals, pay them, organise them to work together in teams and enable them to communicate. We also lack the critical investment to make change.

In this environment it is simplistic to argue that organised primary care is only more bureaucracy, as it is that more of the same funding will make the lasting improvements needed to our primary care system. Improving person-centeredness needs industrial strength policy, strategy and regional implementation in primary care as it does in such things as the multibillion dollar redevelopments of hospital campuses. PHNs in Australia will be central to regional implementation but will need to be given the time to develop fully following a time of significant change in the primary care sector.

So then in Australia what can organised primary care do to improve health outcomes? Most fundamentally at a regional level, PHNs can ensure that they understand and communicate



the needs of their region and planning is a foundation stone of effective commissioning, a developing responsibility of PHNs.

Needs analysis and planning is good opportunity to engage with communities and consumers in a “ground up” and “top down” approach which is outlined in the Health Consumers NSW/WentWest Engagement Framework. Ground up refers to a process of partnering with the community, understanding what they see as the needs of the community, and working with them to fill them. Top down refers to a process of engagement with consumers and their families when services are being planned, designed, delivered and evaluated. This process should be informed by good data collection, sound methodologies for consultation, and structurally embedded in the governance of PHNs themselves.

One example of the governance processes is implementation of Community and Consumer Committees at the PHN regional level and with this support for consumer engagement at the service delivery level. This includes how consumers can be supported to work with general practices in strengthening the implementation of PCMH principles and practices, something that is gaining momentum regionally, nationally and internationally. It is not only reasonable but also value adding to see consumers engaged actively in primary care teams that operate at both a practice and network level of service delivery.

It is also necessary for PHNs to maintain their role of capacity and capability building at general practice level. The NSW Integrated Care Demonstrator in Western Sydney does this by investing more in general practice based quality improvement, risk stratification, shared care planning, rapid access to secondary services, and change management itself.

Organised primary care is a platform for service integration within health and human services systems, both in the public and private sector. In this regard PHNs have a leadership role to develop this opportunity in aspects of planning and service delivery. In a plural health system such as we have in Australia, coupled with diverse funding structures, partnership development becomes a critical mechanism for service integration. An excellent example of this occurring throughout the country is the take-up of Health Pathways.

The benefit of enablers such as Health Pathways is that they highlight the incentive to work together beyond single organisation motivations. The objective becomes to organise patient care around the patient's needs, not having them determined by existing structures. Making this happen is perhaps the most challenging aspect of reform and requires not only high levels of competency but also any eye to effective change management. A good start is the Triple Aim Plus One: improving the patient experience of care; improving the health of populations; reducing the per capita cost of health care; and improving provider satisfaction.

In looking at organised primary care in Australia right at this time it is fundamental to acknowledge how PHNs can contribute to better outcomes for Aboriginal peoples and those living with mental illness. Both areas are often categorised by underserved communities and poor outcomes. These poor outcomes are sometimes the result of varying levels of service quality and capacity, and poor service integration, but certainly exacerbated by a lack of consumer empowerment.

Working with consumers in these areas to understand their needs will influence the structure of services and levels of investment required to improve outcomes. In this regard PHNs have a

role in the implementation of robust commissioning processes which include consumers as well as partnership structuring and development in the process. PHNs should also be free to innovate such that solutions are both flexible and responsive to local circumstances and not determined by a “cookie cutter”. I have seen some exceptional examples emerge from the Western Sydney Partners in Recovery Program in areas such as service mapping, stepped care and peer led recovery.

Whether it be these examples or hopefully many, many more, the time for organised primary care in Australia and the role of PHNs is very much upon

us, and with this an opportunity to improve the capacity our system to be truly more person centred.

*Walter Kmet has over 25 years' experience in health care and human services in Australia, South East Asia and the United Kingdom. He is CEO of WentWest, the Western Sydney Primary Health Network. He has qualified for a Bachelor of Commerce and Graduate Diploma in Health Services Management, is a Master of Business and Technology and a graduate of the Australian Institute of Company Directors. He is Adjunct Associate Professor with Western Sydney University.*



## How impact investing might boost preventive care

### Ian Learmonth

Impact investing, which involves deploying capital with the intent of achieving both social and financial returns, has become increasingly widespread in Australia since the Goodstart transaction in 2009 where four non-profits bought the failed ABC Learning Centres. Over the past two years the potential role for impact investing in healthcare delivery has also started to gain more attention.

There are two main areas of opportunity in the Australian market at present. The first is in funding preventative care through social impact bonds (SIBs); and the second is financing the new models of consumer centred care that will emerge as the NDIS is rolled out.

The idea behind social impact bonds in health is that investment in prevention will mean better outcomes for patients as well as save the government money. For example, through directing new funding to effective preventative programs the government will realise savings in expenditure on acute care. If target outcomes like reductions in

hospital visits are achieved as a result of the funded preventative programs, investors in the bond receive returns from that pool of government savings.

The NSW government has invited SIB proposals in the areas of chronic and mental health with the announcement of the successful tenderers expected in in coming months.

The consumer centred focus and clear revenue streams of the NDIS open up significant opportunities as well. Through the NDIS people with disability will be able to make decisions about their own care and service providers will need to offer greater service at a lower cost.

There is a high likelihood of disruption from new providers with strong service offerings and revenue models that will seek impact investment to get started and grow. In many cases, the best business ideas may come from people with lived experience of disability who understand the needs of consumers and can develop innovative and effective responses.

Recently an online start-up that enables people with a disability to choose their

own care workers, HireUp, received grant funding from NAB to help them become ‘investment ready’ along with subsequent investment from the Myer Foundation and a number of other prominent investors. These investors offered attractive terms on the basis of the positive social outcomes HireUp anticipates delivering.

So what do these developments mean for healthcare consumers?

One of the reasons SVA advocates for impact investing is that it encourages a rigorous focus on outcomes. In the case of SIBs, clear measurement frameworks are put in to place that will help policy makers and service providers understand the efficacy of specific preventative approaches and the resulting impact on demand for acute care. SIBs can also play a role in strengthening the case for more resources to be put into preventative care, which in turn should mean that more individuals will receive the care they need before chronic symptoms emerge – helping them to stay healthier for longer.

In a similar vein, organisations and



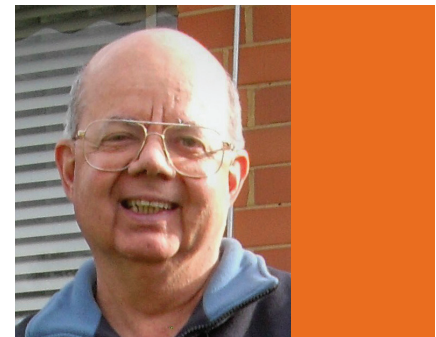
entrepreneurs seeking impact investment for their disability service solutions will need to be both commercially viable and high impact. Winning business under the NDIS will require delivering superior services to people with a disability, placing consumer needs at the heart of what they do and being willing to innovate in response to feedback.

Its early days still. As new SIBs and ventures emerge it will be important to monitor developments closely and to share insights and learning with health community. The driving force behind any investment must be better health outcomes for the cohorts concerned.

*Ian Learmonth joined Social Ventures Australia in 2011 to lead the Impact Investing team. SVA accesses investment capital from investors including high net worths, trusts, foundations and superannuation funds such as HESTA. Ian was formerly an Executive Director of Macquarie Bank for 12 years and has over 20 years of investment banking experience in Sydney, Hong Kong and London. He has been involved in establishing businesses including asset finance, direct investment (including carbon and renewable energy) as well as corporate advice in the infrastructure sector. He has degrees in Law and Commerce from the University of*

*Queensland and is a director of Australian Affordable Housing Securities, Sydney's Belvoir Theatre and e-waste recycler PGM Refiners.*

## A chronic consumer's casebook: doctors, duck tape and a big red bus



### Twanny Farrugia

Born in Malta over six decades ago, I migrated to this Lucky Country in 1965 which was to prove life-saving for me. I was fortunate to have a kidney transplant 44 years ago which now makes me the second longest living kidney transplant patient in Australia, according to Donate Life.

Apart from my kidney transplant, I have many other health issues needing specialist care both within Monash Medical Centre and outside the Centre. I see an ophthalmologist (I am blind and use a guide dog for mobility), cardiologists due to open heart surgery, orthopaedic surgeons as I had knees and hips replaced, rheumatologists for rotation cuff issues and osteoporosis, and dental, dermatology, podiatry and pain management clinic practitioners, just to mention a few.

If it wasn't for the medical profession, duck tape and blue tack I would probably fall apart. However, having been kept together, I have been gainfully employed since my transplant. The last 15 years prior to retiring five years ago was to establish and manage my own private practice as a Loss and Grief counselor/educator in the Human Services area.

Socially I have been kept busy by participating in ballroom dancing for the past 30 odd years, cycling, ten pin bowling, lawn bowls among many other activities.

Some of my achievements to date which I am proud of include the honorary life memberships bestowed on me for my work in the renal field: by Kidney Health Australia in 1983, and in 1986 by the Dialysis and Transplant Association (the first Victorian Patient Self Help Group) of which I have been President, Secretary and on the Executive Committee for 25 plus years.

Then in 2014 the City of Greater Dandenong during its Australia Day Celebration presented me with the Citizen of the Year Award for my 40 plus years of community work. Later the same year, the Australian Rotary bestowed on me the Shine on Award. Nominees were people like myself with a chronic illness and or a disability.

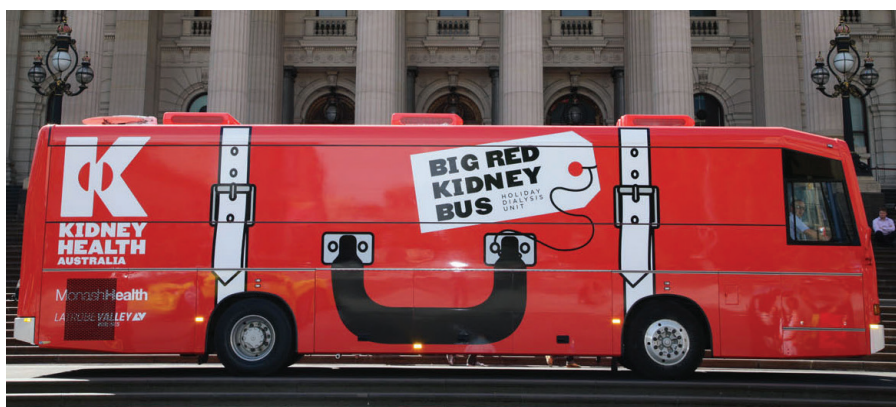
This year Monash Medical Centre nominated me for the Victorian Senior Citizen of the year. The only problem with this it now means I am officially a senior – bugger.

I have always been a strong advocate for patient-centred care. I am often asked what gives me the right to talk on this subject. Simple really. Since I have

been chronically ill from the age of six months. I have been in military hospitals (my father was a career British soldier), public and private hospitals both in Malta and here in Australia. My family and I have had ample opportunity to observe various patient-centred care models or lack thereof.

There are Australian Quality and Safety Standards on this issues which are many but I prefer to discuss and advocate four of them which make sense to us as patients.

- 1) Treat me with Respect and Dignity. But this is a two-way street, I as a patient need to treat you as a clinician with Respect and Dignity.
- 2) Share information. Not just medical information but whatever else may help me as a patient, perhaps about peer support groups, self help group or other agencies in the community that may help me. Importantly though, this information needs to be in a format that I will understand.
- 3) Allow the patient to participate in the decision making of his/her own care. As medical clinicians you may have the medical knowledge that may save my life, but I as the patient have the right to either accept or reject such advice.



4) Ensure collaboration between my various specialists so I am not treated as a collection of individual health issues but as the one individual with the complex health issues I happen to be. This collaboration should go outside the hospital to include the GP, other health professionals, patient's family, carers and/or interested others nominated by the patient.

Of course I am not medically trained but I have lived in this body for over six decades and I understand it very well. So medically I as a patient need you the doctor to keep me alive, but please remember you doctors without us patients do not have an industry.

The Monash Medical Centre (MMC) which I have attended for the past 20 years has had many innovations along the way and is constantly looking for new ones. However, I like to talk about just one innovation about which I am very proud of this hospital for doing.

Unlike the average human being, a dialysis patient finds it very difficult to attend or go on holidays. The Dialysis and Transplant Association for many years had this issue as a goal to fix. They partially succeeded by raising enough funds to purchase two holiday homes (one in Rosebud and one in Yarrowonga). But their ultimate dream of a mobile dialysis unit was never realised because of lack of resources.

That is where MMC came in with its innovation of providing the service of a mobile dialysis unit, the Big Red bus. In partnership with Kidney Health Australia they now managed to provide this service for which they won the 2015 Winner of the Victorian Public Health "Innovative Model of Care Award."

For more details refer to web site: [https://www.monashhealth.org/en/page/Big\\_red\\_kidney\\_bus\\_mobile\\_dialysis\\_unit](https://www.monashhealth.org/en/page/Big_red_kidney_bus_mobile_dialysis_unit)

While MMC have many other innovations in progress, what the Big Red Bus has shown for people like me is that we can also have what most take for granted: a holiday away.

*Twanny Farrugia's has for more than 40 years been an active consumer health representative, sharing his deep experience with the health system as a result of several health conditions to advocate on behalf of people with disabilities, and chronically ill people. He is now changing directions towards educating health practitioners on patient-centred care. He is a patient teacher's associate at Eastern Health and on the Clinical Handover Governance Committee at Monash Medical Centre, where he provides presentations to medical, nursing and allied health students. Twanny has worked as a consumer health representative on subjects ranging from ethnic issues to xenotransplantation, the latter on a working party of the National Health and Medical Research Council. He has served on many organisations, including the Chronic Illness Alliance, the Health Issues Centre, Kidney Health Australia, the Dialysis and Transplant Association of Victoria and South East Palliative Care.*

*In the City of Greater Dandenong named him Citizen of the Year.*



## Pharmacy's shifting focus: from medicines supply to patient-centred care

### Bronwyn Clark

In Australia, the ageing population has impacted on services provided by healthcare professions. Increasing age brings with it an increase in the number of co-existing and chronic disease states, and a resultant increase in therapeutic intervention and complexity.

Pharmacists have a unique mix of knowledge and skills which they use

to optimise health outcomes for the community. With an ageing population, and the complexities of chronic diseases and comorbidities, the role pharmacists can play in society has never been more important.

The practice of pharmacy has evolved with time. A shift in focus from the supply of medicines to a greater level of patient-centred responsibility has occurred over recent decades, and

pharmacists are now providing new services, working with consumers and other healthcare professionals in new models of care and in new environments.

With these new models of care, and the desire for pharmacists to work within interdisciplinary teams, comes the need for pharmacists to have advancing competence and capabilities. These attributes are both within expert areas

of practice, and in more general areas of communication, leadership, research and collaboration.

The integration of pharmacists into General Practices to improve chronic disease management and quality use of medicines is a key strategy in a number of countries including the United Kingdom, New Zealand and Canada. Such practice pharmacists can have diverse roles, including providing education to the practice team and the public, patient consultations, medicine information, medicines use evaluations and liaison roles. These pharmacists are advanced pharmacists, and have developed general and expert skills.

A recent survey demonstrates that Australian consumers would like to see pharmacists have a greater role in patient care in the community, and to provide expanded services.<sup>1</sup> This includes working in teams with GPs to help chronically ill patients better manage their medication, as outlined above. The Pharmaceutical Society of Australia and the Australian Medical Association<sup>2</sup> have proposed a new model of pharmacists working within GP practices for Australia, and the 2013 Grattan Report, *Access All Areas: New Solutions for GP Shortages in Rural Australia*<sup>3</sup> also indicates a greater role for pharmacists.

However, Australian consumers have also identified that they wanted assurance that pharmacists had appropriate training and the right skills for them to have confidence to safely practice in such expanded services.<sup>4</sup> Delivery of a competent and capable workforce requires clear articulation of expectations, coupled with an effective process for ensuring these are consistently met. Expectations should be reflective of current practice, based on accepted standards and partnered with quality education and training.

Until recently in Australia, there was no formal recognition for a pharmacist with extended or advanced practice competence who was working in a scope of practice beyond their initial registration. The Advanced Pharmacy Practice Framework (APPF) for Australia was developed by the pharmacy profession in 2012, and is a nationally-endorsed framework that describes advancing practice from that of a recent graduate to an advanced

pharmacist. A recent International Pharmaceutical Federation (FIP) global report<sup>5</sup> shows the use of national frameworks, such as this, are key workforce development enablers.

In 2015 the Australian Pharmacy Council undertook a pilot program to evaluate a process of recognition of pharmacists who are advancing in their practice against the nationally endorsed competency framework – the Advanced Pharmacy Practice Framework (APPF). The pilot program used a peer-review process which involved inter-professional evaluation teams of both pharmacists and other health professionals (doctors, physiotherapists and nurses).

In this pilot, 48 pharmacists were evaluated against the framework, and were awarded recognition against the stages of the framework; those who achieved Advanced – Stage 3 were awarded the credential of Advanced Practice Pharmacist and are entitled to use the credential *Adv. Prac. Pharm.* All evaluated pilot participants received feedback for their future professional development discussions with their member organisation.

Following this pilot, in March this year the Australian Pharmacy Council announced that a National Credentialing Program for Advanced Practice Pharmacists will commence in June 2016.<sup>6</sup>

This National Credentialing Program will give pharmacists the opportunity to be independently evaluated against the Advanced Pharmacy Practice Framework (APPF). The self-assessment process, and independent evaluation through peer review, supports the professional growth of all pharmacists in all pharmacy practice environments.

The public has the right to be assured that new pharmacy services are provided by pharmacists who have independently demonstrated their safety and competence to work at the top of their scope of practice. This is in line with the government's reform of primary health care to provide quality, affordable and accessible health care for those with complex and chronic health care conditions.

Credentialing and recognition of pharmacists practising at an advanced level and offering highly complex care is an important step in transforming the pharmacy profession to be a more

integral part of servicing the public's health care needs and reducing the blockage within the Australian health care system.

This National Credentialing program for Advanced Practice Pharmacists is an independent credentialing program that provides the assurance, trust and safety for the public. It supports and acknowledges that pharmacists are competent and qualified to work in new models of practice.

*Bronwyn Clark DipPharm, MClinPharm, FPS (NZ), MPS, GAICD is Chief Executive Officer of the Australian Pharmacy Council, the accreditation council for pharmacy education in Australia. Previously she led the Pharmacy Council of New Zealand. She has had a varied career in health that spans practice in hospital and community pharmacy, primary care academic detailing, education and regulation in Australia, New Zealand and the United Kingdom. Bronwyn has a keen interest in the development and support of new and expanded scopes of practice for pharmacists, and in developing cultural competence in pharmacists. She was instrumental in leading the implementation of independent pharmacist prescribers in New Zealand, and is now leading the recognition of advanced pharmacists in Australia. She is Deputy Chair of the Australian Pharmacy Leaders Forum.*

1 Consumers Health Forum of Australia Pharmacists and Primary Health Care Consumer Survey; Results and Discussion, July 2015

2 Australian Medical Association (AMA) and Pharmaceutical Society of Australia (PSA). Pharmacists working within general practice – the way ahead. Media Release. AMA Family Doctor Week, 20-26 July 2014.

3 Access all areas: new solutions for GP shortages in rural Australia – 2013 Grattan Institute report Consumers Health Forum of Australia Pharmacists and Primary Health Care Consumer Survey; Results and Discussion, July 2015

4 Advanced Practice and Specialisation in Pharmacy: Global Report – International Pharmaceutical Federation (FIP)

5 National Credentialing program for Advanced Practice Pharmacists Launched, March 2016 <https://www.pharmacycouncil.org.au/media/1112/20160309-mr-national-credentialing-program-launched-by-apc.pdf>





# Understanding what you pay for and why - transparency in Medicare payments

## Peter Brooks

When you go to see your health professional, the question of the fee is an issue you may think about but never get around to asking. Greater transparency concerning medical fees is an innovation that has some way to go in Australia.

If you are seeing a GP then there will likely be a notice at the reception desk indicating that it is a bulk billing practice or charges AMA rates, but when you see a specialist the billing process is less clear.

The fees that you are charged when you see the doctor may be Medicare only (ie the fee is completely covered by Medicare) or it may be the AMA fee for that item – how this is calculated and its justification seems shrouded in mystery – or it will just be the fee set by that particular doctor – on what basis we know not. You are required to pay that fee – or at least the part of that fee not covered by Medicare or perhaps your private health insurance if it relates to hospital care. What you have to pay out of your own pocket – the so called gap fee (or out of pocket expense – OOPe) has been the subject of much discussion over the past few years since it now makes up some \$23 billion per annum and the most rapidly rising part of the health budget.

The specialist should inform you as to the out of pocket expense, but how often does that occur? Patients are in pretty vulnerable positions at this time. Are you really going to debate the out of pocket expenses with someone who is going to operate on you next week?

So what do you need to know about OOPes? Firstly these charges are significant – with Australia ranked in the middle of the OECD countries in terms of the proportion of health care costs paid for by OOPes. Secondly there is good evidence to show that OOPes impact more on those who need health care most and that they are stopping patients consulting health professionals for care that they need.

One of the major issues with OOPes is that there is very little transparency – it is hard to find out what the usual charge for a particular procedure is – how is that figure calculated let alone to be able to compare fees between providers. Surely that is what competition is all about – being able to see prices and act accordingly – but not so apparently with medical fees. But finally we are seeing some lifting of the transparency ‘veil’ on these fees. Some members of the health insurance industry, (BUPA and nib) are promoting more openness particularly in the area of surgical fees.

Data from nib suggests that some surgeons charge between \$2000 and \$10,000 for a prostatectomy when the Medicare Benefits Schedule item is \$1935, and the AMA recommended fee is \$4465.

Knee replacements are another example of what can only be described as greed on the part of some surgeons – the Medicare rebate is \$1318, AMA fee \$3690 and yet some surgeons are charging up to \$5500.

Surely it is reasonable to ask why this variation in fees for the same operation occurs? It may be reasonable for one surgeon to charge four or five times as much as the Medicare fee on the basis of his or her expertise and outcomes. The trouble is we have absolutely NO data on which to judge these practices. The health insurance firms should be applauded for at least starting this conversation – but they do have all the data on what fees doctors charge and should be able to release it for public scrutiny. That would really allow some decision-making to occur.

Some countries such as Canada don't allow doctors to charge over the schedule fee if they remain recipients of Medicare funding – now that's a thought!

In the USA, Medicare, the health insurance agency for the over-65s, provides a website where you can see what every doctor has received from Medicare across the US. Why not do

that in Australia? Medicare is financed by your taxes – so let us request the Federal Government to require Medicare to provide this data. That would start the transparency roll-out and should tell us more about the fees individual practitioners charge. Greater transparency and accountability should encourage better charging practices by health providers. This is the reason BUPA and nib are making these data somewhat more transparent.

To be fair the Royal Australasian College of Surgeons has begun to discuss this issue, as shown by the report

### **Excessive surgical fees unethical and inappropriate – RACS.**

But this is not just about surgeons – this issue also relates to proceduralists in general, cardiologists, dermatologists, ophthalmologists and gastroenterologists. High OOPe is getting out of hand and consumers need to confront this issue and join an informed and transparent debate. Perhaps there are reasons why surgical/procedural fees for the same operation should vary by a factor of 5 to 10 times – it is just that without any justification how can we decide!

The Grattan Institute has produced an excellent summary of out of pocket expenses, ([http://grattan.edu.au/wp-content/uploads/2014/07/Grattan\\_Institute\\_submission\\_-\\_inquiry\\_on\\_out-of-pocket\\_costs\\_-\\_FINAL.pdf](http://grattan.edu.au/wp-content/uploads/2014/07/Grattan_Institute_submission_-_inquiry_on_out-of-pocket_costs_-_FINAL.pdf)).

And last year the Senate held an inquiry into the issue of out of pocket expenses and again this makes interesting reading, **Out-of-pocket costs in Australian healthcare**. That inquiry made a number of recommendations but it is hard to determine whether any have progressed.

Separately, the Government should be congratulated on instituting the review of Medicare items of low value – that is things that really don't improve patient outcomes.

So how might we (consumers) address the OOPe issue?



Firstly always ensure you know what the OOPE for a procedure (operation, endoscopy, investigation) is going to be – well before you agree to take the doctor's advice and go ahead with it. You have every right to know the costs – full disclosure is required by law. You should also ask what the outcome will be if you don't go ahead with what is recommended and how will your health be improved by the procedure.

If you are still concerned then you might discuss the issue of fees with the GP. You could ask your GP for a second opinion. The GP should be your advocate and help you decide what you should have done – this is the brave new world of consumer choice and shared decision

making – your GP usually knows you better than your specialist and is well placed to assist.

This is a difficult issue but one that must be addressed if we are going to have a health system that looks after all Australians. One of the basic rules of medicine is 'first do no harm' (to patients). Perhaps that should extend to financial harm as well!

*Peter Brooks, AM MD FRACP is a professorial fellow at the Centre for Health Policy- School of Population and Global Health University of Melbourne and until recently the Executive Director Research at Northern Hospital Epping. He has held previous posts as Executive Dean of Health Sciences at the University*

*of Queensland, Professor of Medicine at St Vincent's Hospital, Sydney, and was the Foundation Professor of Rheumatology at the Royal North Shore Hospital and the University of Sydney. He is a recognised international expert in the therapy of rheumatic diseases. Over the past decade he has developed a major interest in health workforce reform in particular new models of care – pharmacist prescribing and the establishment of the first Physician Assistant program in Australia at the University of Queensland. He has published more than 400 papers on the treatment and outcomes in arthritis, psychological aspects of rheumatic diseases and on medical education and health workforce.*

## Genomics: How we can all play a role in shaping the future of health research



### Jack Nunn

In the near future the affordability of genomic sequencing will make it as routine as a blood test, offering people a new frontier in understanding their own identity in relation to genomics and treatment pathways.

Around the world, genomics developments of profound potential are already occurring. These range from extending individuals' knowledge of their own genetic features, to enabling them to have their genetic makeup available for research, to contacting others who may share certain genes or mutations.

However, without a clear ethical framework to guide the prioritisation of research and treatments, there is a risk that profitability will be the stronger force in influencing the shape of the research agenda, and thus, treatments to diseases which are available to us all.

We need to take a giant imaginative leap to ensure that the public remains involved in every stage of genomics research, invited to be active partners in shaping the future of research that can improve lives.

Australia urgently needs to work with the public and across international borders

to support innovative ways to harness the positive potential of the genomic era, while ensuring that the research remains prioritised on the needs of people.

### Involving the public in research

The National Health and Medical Research Council defines public involvement as:

“research being carried out with or by consumers and community members rather than to, about or for them”.

To involve the public in research means that people can influence each stage of research – from identifying what should be researched, prioritising which of these topics should be funded right through to doing the research or helping disseminate and translate the findings.

I will avoid the word ‘consumer’. I will use ‘the public’ or ‘people’, as I feel this implies an equal partnership. The Health Research Authority in England came up with what I think is the best description of ‘the public’:

“When we use this term, public means patients, potential patients or members of the public including those with known

genetic dispositions, carers and people who use health and social care services as well as people from organisations that represent people who use health and social care services.”<sup>1</sup>

Involving the public in science, specifically genomic research, allows us to walk the line between two poles which UNESCO describes as ‘morbid distrust and blind confidence’<sup>2</sup>.

Similarly there is often a ‘disconnect between the views of those handling the findings of research and those participating in research’, and involving the public in how the research is done is an essential stage in working through this disconnection in an ethical way.

### Re-imagining public involvement

Just as there has been a shift in bio-banking from seeing donors as participants to seeing the public as partners and ‘collaborators’, the same shift must happen with genomic data repositories.

“The role of patients and the public in bio-banking activities has been viewed traditionally as bio-bank participants



rather than as collaborators in the design, development and ongoing operation and governance of bio-banks. However, there is growing acceptance and appreciation of the value that patients, patient advocacy organisations and the public can bring as stakeholders in bio-banking and more generally in research.”<sup>3</sup>

In genomics, this is a mental shift comparable to books being digitised - with the physical books still precious, but the fundamental data shareable and open to analysis by anyone in ways that have never before been possible.

## The Wiki-genome

Social media is a powerful tool. Let's agree that broadly speaking, Wikipedia is a social media tool. What if we took the same approach to human knowledge and applied it to genomics?

Let's imagine a hypothetical scenario. The Wikimedia Foundation, or another not-for-profit organisation with good intentions, sets up a free online service where anyone can upload their entire genome (when compressed it is around 4mb, this is less than a high-resolution photo or about the size of song download). Let's assume they have unbreakable security and encryption. The service provides free learning resources in every known human language to support people to make informed decisions.

Please note that everything described below is happening somewhere already, just not necessary as part of the same linked-service.

The free hypothetical service offers a number of options and choices, which may be altered at any point:

- **Full genome analysis:** they will interpret your genome with the most

up-to-date analysis available - looking for 'known significances'. You can choose what level of information you would like to know, ranging from 'nothing' to 'everything'.

- **Full genome sharing:** You are invited to submit your genome so that it can be accessed by researchers who have gained ethical approval. You may even chose sub-sets of research you are happy to share your genome for if it is not a case of 'select all'.
- **Phenotype, lifestyle and medical history sharing:** There is an option for people to complete surveys or pre-approved data fields that would be of use and interest to researchers now and in the future. Many aspects of this would involve self-identifying.
- **Contact:**
  - You are offered the choice to find other people on the service who may share certain genes or mutations with you, or others including researchers to contact you. This may include the option of finding family members (much as many for-profit ancestry websites currently do). This may involve invitations to be participants in research.
- **Involvement:** You are invited to get involved in shaping the future of research.
  - You can search for and join or start discussions with the public and researchers about research which is planned or already taking place.
  - You may work with researchers others to identify and prioritise areas of research and work with others to help generate and evaluate outcomes.

- **Researchers** with approved credentials could, if they wished, be contacted by those in the service about their research and be alerted when people with certain genes or mutations joined the service, and recruit participants to research.

This hypothetical free service may never materialise, but it raises important ethical questions that need answering. Crucially, it also gives a real and achievable mechanism for people to get involved in genomic research in a way which is systematic, open access, free and universal.

This scenario doesn't answer who will pay for the sequencing itself, but it is likely that the cost of having a 'direct to consumer' test will become significantly more affordable to a greater number of people in the near future. Similarly, full genome sequencings will be offered by some health services for free in Australia in the near future, as routinely as a blood test is now.

## Next steps

There are a number of organisations trying to improve genomic research and involve the public (DNADigest, GenomesConnect), but the more people who are aware of how they can get involved, the greater the chance of future research meeting the needs of the public.

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- 1 <http://web.archive.org/web/20160309063134/http://www.hra.nhs.uk/documents/2013/10/hra-public-involvement-strategy-circulation-september-2013.pdf>
- 2 [http://web.archive.org/web/20160309063045/https://depot.erudit.org/bitstream/003001dd/1/Involving\\_the\\_Public\\_in\\_Public\\_Health\\_Genomics.pdf](http://web.archive.org/web/20160309063045/https://depot.erudit.org/bitstream/003001dd/1/Involving_the_Public_in_Public_Health_Genomics.pdf)
- 3 <http://link.springer.com/article/10.1186/s40900-015-0001-z/fulltext.html>

# 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.

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