The Health Advocate

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The official magazine of the Australian Healthcare and Hospitals Association

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Cover photo by Priscilla Westra

DEBORAH COLE
Chair of the Australian Healthcare
and Hospitals Association (AHHA)

Patient-centred care

I was recently chatting to a group of health researchers from another country about consumer engagement. I asked if consumers were involved in the design of their research projects and they seemed shocked by my question. In the health sector, we seem to be very good at involving consumers once a project is established—we invite them onto our ethics committees and we ask them to participate in the project itself—but very seldom, if ever, do we work with them during the planning stage. While there are exceptions, generally the same could be said for service design or care provision.

This approach to consumer engagement makes it difficult for us to develop patient-centred models of care because by the time we involve consumers in their development, we are often too far down the track to make significant changes. We tend to put our heads down, get the project done, then get the okay from our consumers. Consumer engagement—tick! If we truly want to transform healthcare through a more values-based, patient-centred approach, we have to co-design our services in partnership with consumers right from the start. The historical approach of developing the model and then asking for feedback isn't enough.

Whenever I talk to people about patient-centred care, I always walk away with one certainty—that there is no certainty! Everyone seems to have a different definition about what patient-centred care is. Consumers, clinicians, researchers, health administrators—each group or individual will give you a different answer.

There are many definitions of patient-centred care floating around, but one of my favourites is from the Health Innovation Network in South London that defines it as ‘a way of thinking and doing things that sees the people using health and social services as equal partners in planning, developing and monitoring care to make sure it meets their needs’. This definition puts people and their families at the centre of the decision-making process and encourages health professionals to work in partnership with them to achieve better health outcomes.

Delivering patient-centred care doesn't mean taking on board every suggestion and doing everything the patient asks. It's about understanding the perspective and unique circumstances of our patients and collaborating with them to improve health outcomes with minimal waste of time and resources.

Often the desires of a patient or their family cannot be met or don't result in a better health outcomes. For example, many patients want to spend their final months at home but often that just isn't possible. The care they need may be too complex and the strain on their loved ones too great.

> “Emma's wish was to spend her final days at home with her partner Serge and their dog, Ralphy. The expert care she was receiving in hospital couldn't be replicated at home so the ward team pulled out all the stops to make Emma's last weeks as homely as possible.”

I recently heard of the passing of Emma Betts, who ran the popular blog Dear Melanoma, a glimpse into living with Stage 4 melanoma. Emma's wish was to spend her final days at home with her partner Serge and their dog, Ralphy. The expert care she was receiving in hospital couldn't be replicated at home so the ward team pulled out all the stops to make Emma's last weeks as homely as possible. On their third wedding anniversary, the team surprised Emma and Serge with a chocolate mud cake cooked and decorated in the hospital kitchen. They also organised for Emma's dog to come in and visit more than once, much to Emma and her family's delight. That's patient-centred care—care that takes into account the person and the family behind the illness, care that is delivered with empathy, compassion and heart.

Our patients are all different. They come from different backgrounds with different beliefs, interests, needs and wants. As health professionals, we must deliver care that takes into account this diversity and provides the desired care within the parameters of safety, appropriateness and cost effectiveness.

If we really want to commit ourselves to delivering patient-centred care that improves health outcomes, we have to engage consumers in co-designing our services, not just down the track but from the very start. We also need to ensure that we never allow our environments to desensitise us, because leading with heart could make all the difference in the world.

ALISON VERHOEVEN
Chief Executive
AHHA

Budget 2017: an AHHA perspective

Budget 2017 was a winner for doctors and pharmacy interests as the Medicare rebate freeze was lifted (progressively over the next few years) and a new collaborative approach has been embedded in a series of compacts with industry groups.

Health Minister Greg Hunt has placed substantial trust through formal compacts with the Australian Medical Association, the Royal Australian College of General Practitioners, the Pharmacy Guild, Medicines Australia and the Generic and Biosimilar Medicines Association—in a budget which partly overturns horror budgets of the past.

It is now up to these groups and the Minister to ensure that this trust, and the funds being directed towards their interests, are well-invested for a healthy Australia.

There is a very real risk that Budget 2017 will reward an increased volume of services and products, rather than incentivising a shift to greater value-based care and better health outcomes, particularly for the most vulnerable members of our community.

We commend the Minister's pursuit of a more strategic approach to health policy, but the four pillars must be expanded to include primary care, aged care, Indigenous health, and better health outcomes.

The Minister has pointed to three waves of reform as a guide for the remaining years of this Government's term—but it is most disappointing that hospitals, primary care, prevention and Indigenous health are in the last wave of priorities.

MEDICARE: The progressive lifting of the freeze on Medicare payments for GP and specialist consultations and procedures may assist in shoring up Medicare, but risks continuing to drive volume in use of health services at the expense of value.

PRIMARY CARE: AHHA welcomes the Commonwealth's ongoing commitment to its previously-announced Health Care Homes trial as the beginning of a much-needed reform journey for primary health care in Australia (see our article in this issue). The funding for pharmacists to play a role in the trial is welcomed.

Moving to an opt-out mechanism for the My Health Record, and ensuring substantial investment for this, is commendable.

HOSPITALS: While growth funding for public hospitals is settled until 2021 with just over $2 billion in additional funding, there remains considerable uncertainty over post-2020 hospital funding and the method of indexation for future years. Hospital funding requires a sustainable, long-term solution that is part of an overall strategy to shift from volume to value-based care, and that leverages the investments being made in primary care and in Primary Health Networks.

PREVENTIVE HEALTH: It is disappointing that the Prime Minister's interest in preventive health, announced in a National Press Club speech earlier this year, has not been a greater focus of this budget.

MEDICINES: AHHA supports the Commonwealth's move to encourage doctors and patients to choose generic medications when appropriate over the more expensive brand name drugs.

PRIVATE HEALTH INSURANCE: AHHA is disappointed by the lack of progress in reforming private health insurance as part of the Federal Budget. This is a major let-down for policy holders who who remain very concerned about the value and transparency of their policies.

ORAL HEALTH: Budget 2017 was a lost opportunity for greater equity in dental care by not restoring funding previously agreed to under the National Partnership Agreement for public dental services to adults.

MENTAL HEALTH: AHHA welcomes the $80 million investment for community psychosocial services for people who do not qualify for the National Disability Insurance Scheme. We note this is contingent on matched commitments from the states and territories.

Investment in mental health services for veterans is also welcome—although we note that much of the $350 million allocated is for improvements to IT systems for claims processing.

ABORIGINAL AND TORRES STRAIT ISLANDER HEALTH: We welcome the commitment of $7.6 million over 4 years for a National Partnership Agreement on Rheumatic Fever Strategy. But COAG's recent re-commitment to prioritising improving outcomes for Australia's First Peoples should have been supported by appropriate funding and support for locally developed responses.

A commitment should have been made to appropriately fund the National Aboriginal and Torres Strait Islander Health Plan 2013-2023 and its Implementation Plan. ha

AHHA Board

I am pleased to advise that the Council has agreed to the appointment of Jill Davidson, CEO of SHine South Australia, to the AHHA Board to fill the casual vacancy following the loss of Board member, Jeff Cheverton. Jill's appointment is effective immediately, and will continue through to the 2019 Annual General Meeting.

AHHA in the news


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Your choice of doctor, your choice of public or private hospital

'The right of privately-insured hospital patients to choose their own doctor, whether in a private or public hospital, is fundamental to our healthcare system', Alison Verhoeven, Chief Executive of the Australian Healthcare and Hospitals Association, said in early April.

'This fundamental right, outlined clearly in the Commonwealth Government's Private Patients Hospital Charter and in the National Health Reform Agreement, seems to have been glossed over in recent negative statements about patients electing to use private health insurance in public hospitals.

'The allegation that this is somehow driving annual increases in private health insurance premiums does not make sense when private health insurers generally pay more to private hospitals for an admitted patient than they pay to public hospitals.

'It doesn't make sense when the amount private insurers pay to public hospitals is just 7% of what they pay out in benefits overall.

'It doesn't make sense when profit-making private health insurers, regulated by the Australian Government, are already being subsidised to the tune of $6 billion a year by the Australian Government.'

'It doesn't make sense if you are in a rural area, and the public hospital is the only hospital around, and you would like your own doctor to be there.

'It doesn't make sense when your kids are seriously ill—there are very few private hospital options available to support very seriously ill children, and parents naturally want the security of having the doctor of their choice wherever their children are treated—which by necessity will almost always be in a public hospital.'

'And finally it doesn't make sense when several health insurers offer lower-cost policies that only allow treatment in a public hospital—a tacit admission that public hospitals are cheaper—yet they don't want you to use the policy!'

'Those criticising the use of private health insurance in public hospitals could also spare a thought for the doctors who work in both public and private sectors, as many do. Any move to limit this flexibility will have a serious impact on continuity of care for patients as well as workforce implications, especially in rural and regional areas.

'Private insurers would be better off working with private hospitals to drive efficiencies in the private system—in other words the 93% they spend in areas other than public hospitals. The Senate's current inquiry into prosthesis pricing, which is substantially higher in the private system than the public system, is a good place to start—and a place where the Commonwealth could act quickly to realise savings.'

HAVE YOUR SAY...

We would like to hear your opinion on these or any other healthcare issues. Send your comments and article pitches to our media inbox: communications@ahha.asn.au

Australian Health Review article prompts Parliamentary questions on funding treatments for rare diseases

In early March an article published in the AHHA's peer-reviewed academic journal, *Australian Health Review* (AHR), prompted Senators in the federal Parliament to question how decisions are made in Australia on subsidising treatments for rare diseases.

"Morquio A affects just 21 Australians"

The line of questioning was directly prompted by the AHR article 'Funding therapies for rare diseases: an ethical dilemma with a potential solution', by Colman Taylor, Stephen Jan and Kelly Thompson.

AHHA Chief Executive Alison Verhoeven said it was 'very pleasing to the Association and its members that a well-considered and thoughtful article in the AHHA's peer reviewed journal could have a direct influence on policy-making in this way'.

The issue of funding rare disease therapies was brought to light through the plight of a 6 year old boy with the rare condition Morquio A.

Morquio A affects just 21 Australians, impacting the development of their bones, respiratory system, eyesight, hearing, teeth, liver and other body parts. People with Morquio A live an average of 25 years.

'The only available treatment is the drug Vimizim', Ms Verhoeven said.

At Senate Estimates hearings, Senators asked questions of the Department of Health about subsidising Vimizim. The Department said it was considering the drug for listing on the Life Saving Drugs Program.

The AHR article advocates that the federal government urgently re-assesses how it funds treatments for ultra-rare diseases to reflect ethical and community values as well as commercial considerations.

Photo by Familia e Amor

18 hospitals sign up to close the gap in heart health

On National Sorry Day 2017 (26 May) AHHA joined the Heart Foundation and NACCHO in announcing that 18 hospitals from around Australia had signed up to the Lighthouse Hospital Project aimed at improving the hospital treatment of coronary heart disease among Indigenous Australians

Lighthouse is operated and managed by the Heart Foundation and AHHA. It is funded by the Australian Government.

The 18 hospitals cover almost one-half of all cardiac admissions in Australia for Aboriginal and Torres Strait Islander peoples.

Heart Foundation National CEO Adjunct Professor John Kelly said closing the gap in cardiovascular disease between Indigenous and non-Indigenous Australians was a key Heart Foundation priority, and it was highly appropriate that today's announcement coincided with National Sorry Day.

'Cardiac care for Aboriginal and Torres Strait Islander peoples is serious business. Australia's First Peoples are more likely to have heart attacks than non-Indigenous Australians, and more likely to have early heart disease onset coupled with other health problems, frequent hospital admissions and premature death.

'Deaths happen at almost twice the rate for non-Indigenous Australians, yet Indigenous Australians appear to have fewer tests and treatments while in hospital, and discharge from hospital against medical advice is five times as high', Professor Kelly said.

AHHA CEO Alison Verhoeven said that Lighthouse aims to ensure Indigenous Australians receive appropriate evidence-based care in a culturally safe manner.

'A critical component of success will be close and genuine collaboration with local Aboriginal and Torres Strait Islander leaders, communities and organisations in the design and implementation of the activities.

'To borrow from the words of the Prime Minister, Lighthouse will encourage and support hospitals to do things '**with**' Aboriginal people not '**to**' them.

CEO of the National Aboriginal Community Controlled Health Organisation (NACCHO), Patricia Turner, said NACCHO 'will provide leadership and guidance to the Lighthouse team in enabling the local Aboriginal and Torres Strait Islander community and Aboriginal health workforce to be intimately involved in designing and implementing the program'.

'We are very supportive of this program and its contribution to National Sorry Day and to Reconciliation Week', Ms Turner said.

AHHA in the news

Abolition of 457 visas could lead to rural health service shortages

The Australian Government's abolition of 457 visas could have adverse effects on the supply of health services in rural areas, the Australian Healthcare and Hospitals Association (AHHA) and National Rural Health Alliance (NRHA) said on 20 April.

'While we fully support education and training strategies to build a strong health workforce within Australia, it's a fact that it is still a challenge to fill some roles, particularly in regional and rural areas', said AHHA Chief Executive Alison Verhoeven.

National Rural Health Alliance Chief Executive David Butt said there were nearly 4,000 medical practitioners in Australia on 457 visas, as well as 1,800 nurses, 500 allied health workers, nearly 400 specialists, around 200 dental professionals, and nearly 650 other health professionals, including aged care, disability, health administration and medical science workers.

'Many of these people are working in rural and regional areas', Mr Butt said.

'These skilled clinicians and other health professionals who have come to Australia on 457 visas have made a substantial contribution to our capacity to provide to provide health services, particularly to people in the bush.

'Many have stayed on to become permanent residents, and are highly valued members of our community.'

Ms Verhoeven said feedback from AHHA members 'on the ground' in rural areas is that the opportunity to transition from a 457 visa to permanent residency was a significant incentive for much-needed overseas-trained doctors to take up positions in Australia, and especially in rural areas. This ability to transition is not part of the replacement 2- and 4-year visas now being offered.

'We think that there could well be a negative impact, not only on availability of clinicians, but on continuity of care if visas are only issued for 2 or 4 years', Ms Verhoeven said.

'We also think that this impact will stretch beyond medical practitioners to a range of health and disability and aged care workers, including administrative staff who code and collect the health data that are so important to health services planning and funding.'

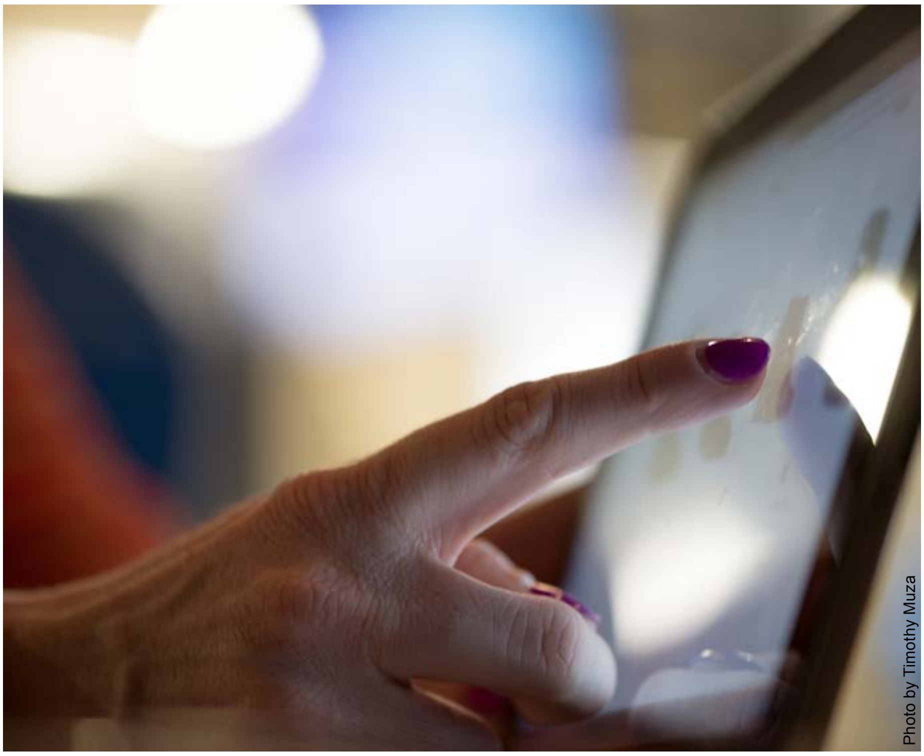
Photo by Timothy Muza

Trial shows 'opt-out' model favoured for My Health Record

'We are supportive of the "opt out" model for My Health Record, but with some important provisos', said Alison Verhoeven in early May.

Ms Verhoeven was commenting on the release by the Australian Government Department of Health of a government-commissioned evaluation of participation trials for My Health Record, involving 'opt-in' as well as 'opt-out' regimes.

My Health Record is a way of securely sharing an individual's health information between registered healthcare providers involved in a person's care. Currently, both individuals and healthcare providers have to opt in, that is, register to participate.

'The report released today comes down overwhelmingly in favour of the opt-out method', Ms Verhoeven said.

'Under this model, a My Health Record is automatically created for individuals. For individuals, not having to do anything to create the record was seen as a major plus, while for healthcare providers, assisting in creating My Health Records, which would have been needed for some patients under the 'opt-in' model, was seen as impractical without additional funding and ultimately would be unsustainable.

'Once the system and its benefits were explained, individuals had minimal confidentiality or security concerns.

'And, interestingly, most consumers were strongly of the opinion that healthcare providers should not be able to opt out of the system.

'We support the opt-out model. We are however concerned that the existing infrastructure may not have the appropriate capacity to support the recommended change—anecdotal evidence indicates that the current system is already operating at close to capacity and will need to be significantly upgraded to effectively manage the millions of additional records.

'It would therefore not be wise to rush into this if we want to get this important change right.

'Given a national rollout is likely to require support by the PHNs, they must be afforded adequate time to undertake collaborative planning, local mapping of digital capacity and capability and the flexibility to respond to local issues and contexts. The phase-in should be well-planned, with comprehensive training and a very strong communications strategy—both to consumers and healthcare providers.'

Public hospital funding key to addressing elective surgery wait times

'Today's (17 May) release of figures showing waiting times for privately funded patients in public hospitals are shorter than for public patients is not a reason to finger-point or jump to unsupported conclusions', said Alison Verhoeven.

Alison was commenting on the release by the Australian Institute of Health and Welfare (AIHW) of its *Admitted patient care 2015-16: Australian hospital statistics* report.

'While the AIHW has highlighted the difference in median waiting times for a group of patients that represents 6.9% of all patients admitted to public hospitals for elective surgery, the key issue is that public hospitals need to be appropriately funded to treat all patients on their waiting lists.

'This includes the Commonwealth and the states and territories reaching a sustainable funding agreement beyond 2018, as all first ministers agreed at the COAG meeting in April 2016.

'There are valid reasons for using private health insurance in public hospitals, including the lack of availability of private hospital care in some regional areas, visiting officer practice rights in public hospitals and patient choice of clinician, all of which are longstanding fundamental features of our health system.

'Hospitals across Australia have different arrangements in place with surgeons, other private providers and in the way they manage elective surgery waiting lists and use of private health insurance. To present only a national figure is a blunt approach which tells an incomplete story.

'For data of this type to usefully inform the debate, more detailed information needs to be provided that isolates where and how private health insurance is being used by patients in different hospitals across the country, and the circumstances in which it is used.

'Better data will usefully inform future National Health Reform Agreement discussions between the states and territories and the Commonwealth on the impact of private patients in public hospitals.

'The outcome of such discussions must ensure that public hospital resources are sufficient to deliver services to public patients, including elective surgery, in a timely manner.'

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Australian Health Review explores patient-centred care and care system efficiency and outcomes

Contemporary issues in patient-centred care, and the efficiency and effectiveness of various care systems, are the two common threads in the April 2017 edition of *Australian Health Review* (AHR) according to the AHR's chief editor, Professor Gary Day.

'With several articles aligning with these two themes, a good entry point is a study of the two main national approaches to controlling chronic disease in Australia—the 2005 National Chronic Disease Strategy (NCDS), and the 2008 National Partnership Agreement on Preventive Health (NPAPH)', Professor Day said.

'With increasing life expectancy in Australia, chronic diseases, especially combinations of chronic conditions at older ages, are in several ways driving current efforts to provide patient-centred and integrated care services.

'The 29 health leaders interviewed for the study saw the NCDS as providing national leadership and coordination, but limited by a lack of associated funding, or commitments to infrastructure or implementation plans. Conversely, the NPAPH was welcomed for its associated funding and flexibility in catering to unique populations, but needed stronger national leadership, and more guidance on the evidence base for decisions.'

A study from Victoria examines various models of population-based regional health planning and management, which are aimed at individual medical and social care. These are compared with a regional operating model developed in the North West Metropolitan Region in Victoria, with the Victorian model performing very well.

An article on health systems integration in local health districts in New South Wales concludes that more needs to be done in terms of genuine community involvement, and staff education and training.

Care coordination for older people living in the community is the subject of one study, while another looks at systematic approaches to developing the rural health workforce to improve Aboriginal and Torres Strait Islander health outcomes.

'There is an interesting article on the average time taken from presentation to treat pain through analgesics in emergency departments, and the effects of the current "90% seen in under 4 hours" national target. Emergency departments are also under scrutiny in an article on "rapid disposition" techniques used by emergency clinicians to save unnecessary waiting time', Professor Day said.

Other articles cover GP Practice Nurses, clinician perceptions of discharges from public hospitals for trauma patients, a comparison of costing methods for hospital services, and advocacy for workplace screening for early detection of heart failure using a new biomarker test.

Mental health issues are to the fore in a 'perspective' item on the need for a consistent national clinical pathway for suicidal patients presenting to emergency departments. There is also a comparison of the demographic characteristics of people with mental illness in various types of residential rehabilitation units in Queensland.

'We also have some international perspectives—the work intentions of public hospital doctors in a middle level city in China, the effects of social integration on depression in older people in Korea, and some observations on non-communicable disease control policy in Indonesia, where the health burden due to tobacco smoking is the highest in the world.'

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- **Promote collaborative and innovative practices**
- **Share and promote best practice**

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Data Collaboration Network

The Data Collaboration Network seeks opportunities for better use of health data in Australia, including promoting the potential for cross-sector collaboration.

Innovation Collaboration Network

The Innovation Collaboration Network provides an opportunity to promote innovation and innovative ideas in the health sector and exposes participants to new ideas, technologies and techniques.

Mental Health Network

The Mental Health Network provides opportunities to share information and expertise around mental health initiatives with a focus on primary health care

Data and Innovation Collaboration Network Meetings in 2017

27 June - Perth

29 August - Brisbane

6 December - Dubbo

Mental Health Network Meetings in 2017

28 June - Perth

7 December - Dubbo

For more information or to register visit: http://ahha.asn.au/events

For more information contact AHHA at admin@ahha.asn.au or on 02 6162 0780

JUILIE LETTS
Director
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Medical futility

Ambiguous yet enduring language.

In common language, the word ‘futility’ is synonymous with being ‘*incapable* of producing any *useful* result’[1]. Already, two unquantified and subjective elements emerge that are also intrinsic to medical futility: a probabilistic component (what are the odds of this being effective and below which this becomes futile); and a qualitative one (what counts as a useful or beneficial result). Both involve value judgements about what chance of success and what quality of outcome are ‘worth it’.[2] And both have begged questions in the healthcare context about who gets to decide—doctors, patients, families, or a combination.

In the 1980s the futility debate grew exponentially out of increasing and difficult conflicts about continuing life-sustaining treatment in cases where the prospect of patient benefit seemed vanishingly small. These were generally in the intensive care unit, and generally where a family requested life-sustaining treatment (as often the patient has lost decision capacity). At stake was a complex nexus of issues, including quality-of-life assessment and its proper location with patients; prognostic uncertainty that’s ubiquitous in medicine; integrity and decision-making in medicine; and professional obligations not to harm patients, among others. These were underscored with concerns that the burdens of futile treatment extended beyond those who receive it to others whose care is delayed or unavailable, especially for time-critical, scarce resources like ICU treatments. A definition of futility was hoped would create the threshold beyond which clinicians could, on good ethical and legal grounds, refuse to provide such treatments.

Several formulations emerged—‘quantitative futility’ and ‘qualitative futility’[3], then ‘physiological’ futility. None have been conceptually robust enough to do such heavy lifting. More recent terms have emerged—‘non-beneficial treatment’ and ‘potentially inappropriate treatment’. The former seems too emphatic and latter too vague. Another, ‘medically inappropriate’[4] has been proposed as preferable to futility in that it makes plain that the value judgement is being made by doctors. Further, that it avoids the ‘pseudo-objectivity’ conveyed by the word ‘futile’. However, even within the profession, clinicians vary substantially in their attitudes and practices about the sorts of treatment that should be provided at end-of-life.

Using a descriptive concept as the foundation for policy has proved highly problematic. Nonetheless, various formulations of futility continue to appear in national policy statements, including from the Australian Medical Association[5], and the Australian College for Emergency Medicine[6]. The Australian Healthcare and Hospitals Association’s 2016 Deeble Issues Brief[7] exhorts policy-makers to continue seeking an agreed definition. It is probably better to avoid codifying the ambiguity at all, where possible. End-of-life policy can nonetheless focus on important matters like:

- supporting good clinical practice that enables timely conversations with patients and families about shifting goals of care as end-of-life approaches
- clarifying the prevailing law relevant to end-of-life decisions for clinicians and health managers who are still often unclear and anxious about its requirements
- outlining sound processes for resolving disputes that may arise about futile treatment.

None of these semantics would matter, if the provision of futile medical treatment—however defined—was not a real and serious challenge for the Australian health system.

Recent Australian studies[8,9] reflect that futile treatment is not an uncommon occurrence in our hospitals and confirm that the term ‘futility’ has an enduring currency among Australian medical practitioners.[10]

What does this mean for patients, families and the wider community?

A recent study[11] revealed that Australian doctors ranked the ‘trained to treat’ ethos of medical education, that renders death a form of failure, as one of the two principal drivers for futile treatment.

The second principal driver was requests for further treatment from patient and families. Patients and families need help to understand the full ramifications of what it is they want or don’t want, and need to be informed in a timely way about the patient’s trajectory towards dying. That is part of achieving properly informed ‘patient-centred care’. Realism in conveying prognoses and appropriate therapeutic or palliative options, albeit with skill and sensitivity, is essential. This needs to be cultivated in our doctors.

Words have power, sometimes despite

GraphicStock

> **“Defining what is medically ‘futile’ is less important than finding ways to minimise use of futile treatments at end-of-life for patients and health professionals in the Australian health system.”**

elusive definitions. The term ‘futile’ endures in healthcare. Its most useful function is probably as a flag and catalyst for conversations—more, better, or different communication with patients and families.[12] It is critical that clinicians, managers and policy-makers stay mindful of the limitations of this powerful yet ambiguous term. ha

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Championing what matters most to patients

Our experience at Bowel Cancer Australia.

We know bowel cancer is more than just a conversation killer. Claiming the lives of 80 Australians each week, it is our nation's second biggest cancer killer, after lung cancer. Each year, around 15,000 people hear those four words, 'you have bowel cancer.'

While the statistics are startling, what deserves attention are the patients' issues following a bowel cancer diagnosis: the unbearable waiting for test results; the helpless feeling that cancer is present, yet not knowing the full extent of what that will mean; the fear of having to live with a bag; or that the bowel cancer may progress or recur.

These are issues our bowel care nurses hear every day while supporting, informing and caring for people affected by bowel cancer. Patients share stories about living on diets of bland foods and dry biscuits for years after treatment has ended and not being able to leave home because their bowel control can't be guaranteed when they are out.

While treatment does not last forever, bowel cancer affects the most basic of bodily functions and patients must master a 'new' normal—forever. Issues that matter most to bowel cancer patients include 'being able to have a bowel movement like a regular person, without the need for painkillers, or sitting on the toilet for hours'.

In Australia, treatment is currently based on clinical practice guidelines and at some point in the future will be guided by the Optimal Care Pathway. But guidelines are not tailored to patient circumstances or patient preferences, and standardised pathways do not guarantee standardised outcomes.

Neither measure patient-report outcomes, which is the only metric that directly captures what a patient cares about most, and whether or not health procedures actually make them feel better.

For example, the guidelines are the same whether patients are treated in the public or private health system. However, a 2014 Victorian study found metastatic bowel cancer patients receiving care in the private system were more likely to have surgery and chemotherapy than if they received care in the public system. The study also found that the patients in the private system lived 30% longer than those treated in the public system—identical guidelines, different outcomes.

> **"The study also found that the patients in the private system lived 30% longer than those treated in the public system—identical guidelines, different outcomes."**

Would you seek out the better performing provider, knowing that doing so could potentially extend your life by an additional eight months?

What if patient and GP consultations could be informed by lived-experience outcome data that showed fatigue and lack of emotional support influenced survival outcomes, or that patients treated in the public system are more likely to decline recommended treatment?

Currently, we don't have the lived-experience outcome data to inform patient and GP consultations on the quality of care available, and so referrals don't address the issues that matter most to patients. But what if we did? How might such information guide discussions between patients and their GPs about specialist or hospital referrals? Overseas evidence suggests some patients would seek out better-performing providers based on transparent reporting of specialist and hospital outcomes.

We want patients to be able to make informed decisions, and we want GPs to be able to make informed referrals to specialists and to hospitals, based on what matters most to their patients, in terms of treatment and long term outcomes.

As part of our commitment to helping those affected by bowel cancer to live the life they want with access to high quality treatment and the best care, Bowel Cancer Australia co-sponsored the development of the world's first International Consortium for Health Outcomes Measurement (ICHOM) Colorectal Cancer Standard Set launched in 2016.

The ICHOM development process represented genuine patient engagement. The original Set was developed by a

Working Group and was further validated, at our request, by surveying an additional 276 patients globally—81 % of whom believed the list captured the most important outcomes.

With annual updates based on feedback and treatment advancements, the Set remains relevant over time.

Patient-reported outcomes will support patients to be active participants in decision-making about their care with their specialist, based on what matters most to them. They will also allow specialists to respond and tailor treatment as closely as possible to patient preferences.

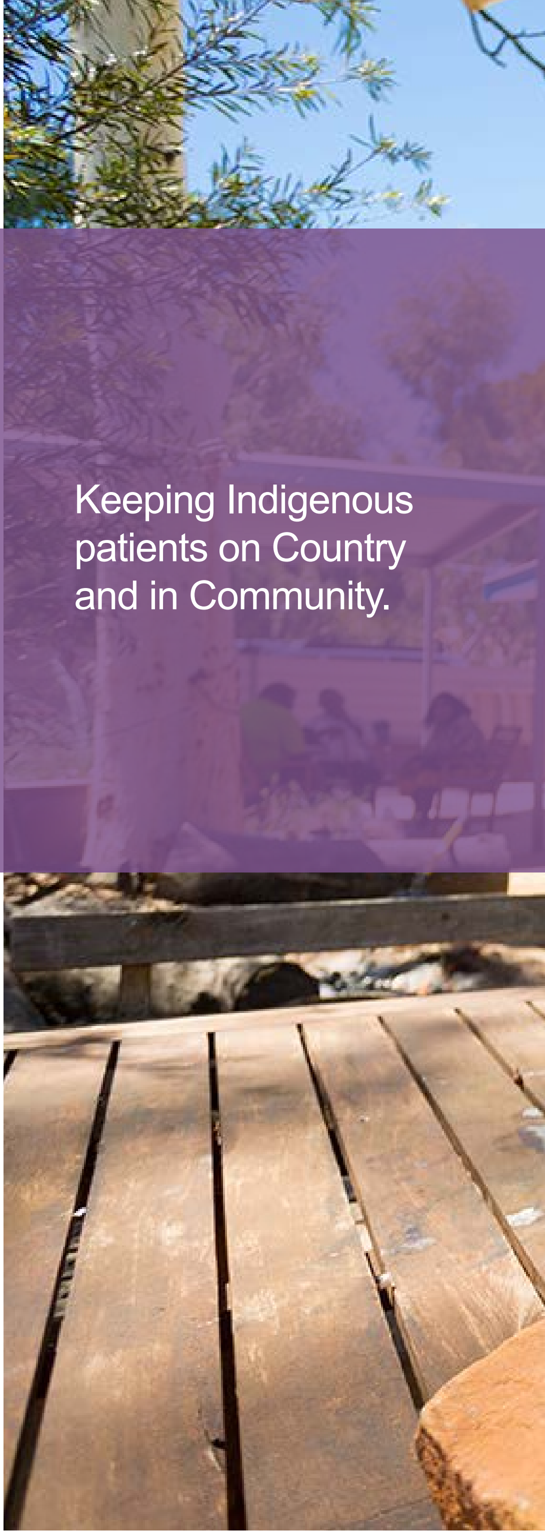
We believe the time has come for the international standard to be adopted in Australia so patients, insurers, specialists, and private and public hospitals can measure, compare and learn from each other to deliver the best care for patients.

Bowel Cancer Australia is moving to implement a patient-led outcomes reporting program. We will provide a platform for patients to share details about quality of life issues as they occur, along their treatment pathway and for 10 years beyond treatment—issues like social functioning and dietary restrictions, which can directly affect an individual's ability to engage in activities they previously enjoyed.

We intend this to be an open program, and welcome like-minded partners to join this initiative to assist our efforts in reaching as many patients as possible. This will help us continue to make real change happen by championing what matters most to patients—who remain the constant within the continuum of care. ha

Bowel Cancer Australia is a 100% community-funded organisation, dedicated to prevention, early diagnosis, research, quality treatment and the best care for everyone affected by bowel cancer. For more information visit www.bowelcanceraustralia.org

Dialysis in remote Australia



Keeping Indigenous patients on Country and in Community.

Western Desert Nganampa Walytja Palyantjaku Tjutaku Aboriginal Corporation embarked on a journey 16 years ago to offer renal treatment and care in Kintore, Northern Territory. Since then, their innovative and patient-centred approach has been established in eight remote Indigenous communities across the Northern Territory and Western Australia.

Known as Western Desert Dialysis, their name means ‘Making all our families well’. So that remote patients can receive care while remaining connected to their families, Western Desert Dialysis provides culturally appropriate dialysis services on Country and in Community.

This model was developed by Aboriginal people, for Aboriginal people, in response to a community desire for local access to dialysis and renal treatment. Prior to this, patients travelled to receive renal treatment in someone else’s Country, away from their home and families. This led to distress and longing among patients, and an absence of senior members in remote communities.

Dialysis patient Carol Joy-Reid explains: ‘Without dialysis we get sick. But lucky that we have dialysis out in a remote area. Lucky peoples; we’re happy’.

‘Before our service was established, Aboriginal people had to leave their homes and families to access treatment in far-away places, and this was very upsetting’, adds Western Desert Dialysis Chief Executive Officer, Sarah Brown.

‘Aboriginal people from a remote part of Australia said “enough is enough”, and from there came the determination to establish renal dialysis and treatment closer to home. Two years later and we had our first dialysis machine from funds raised by the community—and the rest, as they say, is history.’

Western Desert Dialysis aligns with patient preferences, needs and values to provide care that is beneficial to both the patient and community. Through this approach, Aboriginal patients maintain personal connections, and can enjoy their best physical and emotional wellbeing by receiving care in a familiar and appropriate location. Patients continue to participate in community life and share cultural knowledge to build a stronger and healthier community.

Northern Territory PHN (NT PHN) provides funding to Western Desert Dialysis as part of the Integrated Team Care Program. The Program aims to close the gap in life expectancy by improving access to culturally appropriate mainstream primary care services for Aboriginal and Torres Strait Islander peoples.

‘By increasing Aboriginal and Torres Strait Islander peoples’ access to culturally appropriate services, they can achieve their best health outcomes. Providing care and treatment that responds to their patients’ needs, preferences, values and culture is what makes Western Desert Dialysis a truly patient-centred service’, said Nicki Herriot, Chief Executive Officer of NT PHN.

NT PHN is committed to supporting and strengthening Aboriginal community control of primary health services and directing resources towards high quality health care so Territorians can enjoy their best health and wellbeing.

‘Western Desert Dialysis is improving health outcomes for remote Indigenous patients by providing renal treatment and care. They are also demonstrating the positive outcomes that can come from

Lorraine Young grinding Aratja outside the Purple House.

patient-centred and culturally-appropriate service delivery', said Nicki.

Run entirely by Aboriginal people, Western Desert Dialysis was awarded the 2016 Indigenous Governance Award Category A (incorporated organisations) for their outstanding governance and work to empower the Western Desert communities. ha

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For information about Western Desert Dialysis, visit westerndesertdialysis.com and for more information about the Integrated Team Care Program, visit ntphn.org.au/integrated-team-care.

Daniel Brumby playing guitar for Lorraine Young and other dialysis patients outside the Purple House, Western Desert Dialysis's headquarters in Alice Springs.

NOELENE COOPER
Country SA Primary Health Network

TRACY MAYNARD
Country SA Primary Health Network

Silver Connections

A video consultation pilot program is successfully connecting aged care residents with their general practitioners in South Australia's Barossa Valley.

The Better Health Care Connections: Aged Care Coordination program, known as *Silver Connections*, is being conducted by Barossa general practitioners and local residential aged care facilities. It is improving timeliness of care and reducing after hours calls and hospital transfers.

Country SA PHN is one of nine organisations federally funded from 2013 to trial general practitioners (GPs) conducting video consultations with aged care residents.

'*Silver Connections* aims to improve patient care and support older people with complex health needs by coordinating treatment and improving access to multidisciplinary care', said Country SA PHN Nurse Consultant, Tracy Maynard.

'It is reducing frustration between residential aged care facility staff and GPs, and improving residents' care needs in a timely manner without GPs having to leave their practice. In turn, this is reducing the need for after-hours consultations and hospital transfers.'

'In addition about 30% of GP video consultations have prevented hospital admissions and transfers to emergency departments.'

Video consultations have proven to be particularly useful for residents with functional limitations. Importantly, they enable all aged residents to have their medical consultations in comfortable, familiar surroundings.

A nurse sits in on all consultations to provide assistance and ask any additional questions. This assists residential aged care facility nursing staff to be directly familiar with residents' medical needs. Family members are also invited to be present.

The video consultations follow the same privacy and confidentiality agreements as any medical appointment. All medical records remain confidential.

The *Silver Connections* pilot program has involved around 900 video consultations involving just under 30 Barossa GPs across 5 general practices to 4 local residential aged care facilities with nearly 300 beds. Due to the success of the program, the number of video consultations is expected to increase to 30 to 40 per month.

'Country SA PHN is very happy to be a part of the *Silver Connections* program. Helping rural aged care facility residents receive timely medical advice in their own surroundings provides great benefits to the residents and streamlines the process for rural GPs', said Country SA PHN Chief Executive Officer Kim Hosking.

'This is particularly useful in many areas

Supplied image

of regional South Australia, where GPs have large distances to travel.'

Currently, Medicare billing supports telehealth video consultations for specialists and consultant physicians only. GPs are Medicare-funded for face-to-face visits within the facility only, and not for video consultations.

Desktop computers and iPads, connected via the Cisco Jabber program, are being used to support *Silver Connections* video consultations. Residential aged care facilities are funded to participate and GPs are funded per consultation, with the amount based on the duration of the consultation.

Prior to the *Silver Connections* pilot program, health advice for residents occurred via telephone conversation between the nurse and GP, without resident input. Giving residents and their families the opportunity to be directly involved in their care is one of the key advantages of this program.

> “Silver Connections aims to improve patient care and support older people with complex health needs by coordinating treatment and improving access to multidisciplinary care.”

A residential aged care facility nurse captured the essence of the program's benefit with the following anecdote:

'A resident woke with a medical condition that needed assessing, but the monthly GP visit had happened the day before.

'Thank goodness we had access to video consultations—the resident was medically reviewed that day, a course of antibiotics commenced, the GP remunerated for their time, and, most importantly, the resident was on the road to recovery quickly.'

The *Silver Connections* trial concludes in June this year and will be followed by an external evaluation.

Silver Connection's success clearly demonstrates the benefits in Country South Australia of extending Medicare Telehealth beyond specialists and consultant physician to include GPs. Apart from improving timeliness of care, and reducing after hours calls and hospital transfers, the key benefit is putting residents at the centre of their own care. ha

Comprehensive, community controlled health care

The often convoluted and fragmented Australian health care system has evolved through a messy 'strife of interests', as the late Dr Sidney Sax called it, driven by the needs of federal and state and territory governments, professional interests, and private sector motives.

Continuing, integrated care that can respond to people's individual, family and community circumstances across their lifespan and take a helicopter view of the health needs of the local population remains elusive. There are however models of primary health care that are much closer to this ideal, and a recent study by the Southgate Institute for Health, Society, and Equity has described such a model: community controlled health care.

The community controlled service, Central Australian Aboriginal Congress in Alice Springs, stood out as a leader in the delivery of comprehensive primary health care in a six-year study by Flinders University researchers which partnered with six primary health care services in South Australia and the Northern Territory.

The service's strengths include its ability to provide a multi-disciplinary one-stop-shop and outreach services, along with free medicines and support, and advocacy on community issues such as improved access to health services, excess alcohol consumption, and early childhood needs, according to the study.

The research leader, Flinders Professor Fran Baum, who is Director of the Southgate Institute at Flinders, says the strengths of Aboriginal community-controlled primary health care service model emerged clearly:

'In fact, this model when done well could be described as a world leader in the global push under the UN's Sustainable Development Goals for Universal Health Coverage'.

'Central Australian Aboriginal Congress was the best example of all six services studied because it so effectively provides the community with self-determination, and greater control over their own health and healthcare, rather than other more top-down programs run by government and other agencies.'

Congress began as a result of a public meeting of Central Australian Aboriginal people in 1973, acting as an advocate for Aboriginal rights, and later came to provide a primary health care service in 1975. Congress CEO, Ms Donna Ah Chee noted, 'When Congress started, infant mortality rates were around 170 deaths per 1,000 live births and now they are around 12. Our babies are now only very rarely dying from preventable causes, and the challenge

Good for the community, good for practitioners.

has moved to the promotion of healthier development. Since 2001, there has also been about a 30% decline in all-cause mortality for Aboriginal people in the Northern Territory'.

As well as positive health outcomes, the impact of community control on practitioners was positive. 'The staff interviews at Congress were characterised by a strong sense of "agency" and ability to keep improving, which was absent in the state-managed staff interviews," says Dr Toby Freeman, the project manager.

'At the government services, staff were instead trying to reconcile the difference between the ways of working they were passionate about, and the approach demanded by government policies and priorities.'

One Congress Medical Officer talked about the 'dynamism' of bringing community input and evidence-based medicine to the table, while another Medical Officer explained their work satisfaction as 'our clients are actually our bosses'.

Government services had been experiencing declines in their ability to respond to client needs, and to tailor care and the service environment to populations experiencing inequities, such as Aboriginal and Torres Strait Islander peoples, and migrants and refugees. In contrast, Congress was able to expand their outreach and home visitation services while providing a strong transport service and running community development and engagement activities that ensured the service was well known and well trusted in the community.

A similar primary health care model to Aboriginal community controlled health services are community health centres. These were established nationally in the early 1970s, but after federal funding was discontinued, they have languished in most states, and have moved away from community boards of management (with the exception of some Victorian centres).

Professor Baum argues that the Southgate Institute study findings show community control is a powerful model for all communities. She also says that revitalising the model across the community would have many benefits: 'Community control can complement and strengthen professional views of health, and through community management take an overview of the health of the local community. This model offers relevant, effective and efficient health care to promote the health of all Australians'. ha

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Dr Toby Freeman, Senior Research Fellow, Southgate Institute for Health, Society, and Equity, Flinders University

Prof. Fran Baum, Director, Southgate Institute for Health, Society, and Equity, Flinders University

Dr John Boffa, Public Health Medical Officer, Central Australian Aboriginal Congress Aboriginal Corporation

Ms Donna Ah Chee, CEO, Central Australian Aboriginal Congress Aboriginal Corporation

Poor people management

Some of the pressing issues facing Australian hospitals may be alleviated by empowering highly skilled hospital workers—including doctors and department heads—to make their own decisions.

Studies in 20 Australian hospitals by UNSW Business School researchers reveal human resources (HR) practices rely too much on control and are preventing medical staff from using their discretion to make autonomous decisions on some basic people management tasks, including hiring to replace a departing staff member.

The upshot of too much control is disengagement and burnout among healthcare professionals and a delay in the introduction of improved standards for patient care.

'We believe there's an overuse of control for management in hospitals', says Julie Cogin, a professor, deputy dean, and director of AGSM@UNSW Business School.

'The primary human resources management (HRM) approach to people working in hospitals is about control, with prescribed procedures—for everything from hand-washing to hiring—and excessive bureaucracy', she reports.

While control in hospitals is indisputably vital for some routine tasks and responsibilities, in others it is counterproductive and impinges on the efficiency of the hospital system and the morale of staff.

Control issues are just part of a series of confounding dilemmas in the hospital system that also include tight budgets shifting the emphasis from patient care to financial outcomes, and a culture in which many external stakeholders set training requirements for hospital staff, suggests Cogin and her co-researchers.

On top of this is a delay to better patient outcomes due to an unrealistic approach to healthcare reform that has set the bar too high, giving unachievable goals to the complex hospital system.

'They are committed to their jobs and patients, but not the hospitals they work in or their employers'

Patient-centred care

Healthcare is a thorn in the side of governments across the world with common outcries about rising costs, inequality of access and increasing demand for hospital services exacerbated in no small part by ageing populations.

In Australia, news stories capture tales of newborn babies accidentally gassed, babies born in hospital toilets, insufficient hospital beds, protracted waiting times in emergency departments, ongoing staphylococcus infections and patients inappropriately treated.

There's been a keen focus in advanced economies—across Europe, North America, Australia and New Zealand—on 'patient-centred care', a central tenet of healthcare reform, which takes a holistic approach to the patient based on their needs.

It requires healthcare workers and hospital services to revolve around the needs of the patient rather than the needs of the hospital, and for the patient to be educated and informed, as an important stakeholder in their own treatment.

Uptake of patient-centred care has been slow, though 'research has shown its benefits include improved efficiency, fewer delays, increased diagnostic referrals and reduced overall costs due to less waste of hospital resources', notes Cogin.

'Making patient-centred care happen takes teamwork, a collaborative environment and high levels of employee engagement among hospital workers, so everyone from housekeeping staff to the CEO is part of the patient's care experience.'

Typically, recommendations have been that hospitals adopt a 'high commitment' approach to HRM, much like the tried-and-tested best practice approaches of private sector employers that depend on trust, job security, empowerment, teamwork and involvement in decision-making.

However, there's a heft of data showing that's far from the status quo in hospitals where employees are disengaged.

'They are committed to their jobs and patients, but not the hospitals they work in or their employers', Cogin says. With a research team, she set about exploring the barriers to delivering best practice HRM in hospitals and, ultimately, to identify what's hindering the delivery of patient-centred care.

Breakdown in the line of sight

In their paper, *Controlling healthcare professionals: how human resource management influences job attitudes and operational efficiency*, the researchers note a multitude of issues at play when it comes to the tools for behavioural change.

Training is a problem. For starters, hospitals don't have a lot of discretion in he management of staff.

'Hospitals are constrained by many different external enterprises, including professional colleges, universities and medical associations which determine the training required for doctors, nurses and allied health workers', says Cogin.

'HR practitioners are unable to [have]

How it's debilitating the hospital system.

PROFESSOR JULIE COGIN
Director, Australian Graduate School of Management, UNSW Business School, University of New South Wales; and Deputy Dean UNSW Business School.

influence in this system, so their role becomes auditing and monitoring that the necessary training or performance review is undertaken, rather than formulating new strategies for professional development.'

Another impediment is the tenure of senior doctors stymying performance appraisal. As a senior physician told the research team: 'We're not on fixed contracts so essentially although performance appraisals can be useful discussion points, they are irrelevant for senior physicians'.

According to Cogin, doctors aren't the only ones missing out: 'We found much evidence that people don't have appraisals or performance reviews—and they don't get feedback unless something goes wrong or patients are not checked out quickly enough'.

Such constraints make it difficult to get a workforce to embrace a new strategy—such as patient-centred care—and to align their day-to-day tasks with healthcare reform or where the hospital wants to take them.

'Strategies around patient-centred care are well known at executive level, but they aren't penetrating the layers. We found healthcare workers and unit managers didn't know a lot about what it meant or how it looked for the way they work each day', says Cogin.

'There's a real breakdown in the line of sight from the executive level to unit managers to staff. So while healthcare workers' focus is on having the best possible outcome for the people they are taking care of, they don't necessarily see the alignment between what they do each day and how this contributes to the hospital's strategy and healthcare reform.'

'Executives may be measured by the number of patients checked out on time… but if they're being checked out too early, the metrics don't capture the revolving door for readmissions.'

Disempowered yet accountable

On top of this is the demotivating, rule-bound, control-based hospital environment.

In the paper, a nurse outlines how her bureaucratic workload—answering phones, working rosters, covering audit requirements—left her no time for patients.

When hiring, the bureaucratic process was so lengthy, by the time a 'successful' candidate had been selected and delivered the good news, the candidate had often moved elsewhere. Meanwhile, the rest of the unit continued to pick up the slack for the vacant position.

In one case a physician who manages a unit lamented the lack of delegation to department heads: 'At the moment, only risk is devolved to department heads so we carry the can for adverse outcomes, but we're not given any trust to hold the purse-strings to manage the department or motivate people'.

'People were disempowered from managerial decision-making yet held accountable for effective operation', says Cogin.

A divide has also grown with HR divisions. 'HR is perceived as being part of the problem', says co-researcher Ilro Lee. 'In one of the hospitals we surveyed one HR department manages several hospitals so they're often waiting days or having to chase down multiple people for responses or approvals'.

Hospital HR practitioners interviewed for the research, however, were outspoken about their frustration.

'They want to partner, be more strategic and provide support with operational tasks but are under-resourced', Lee says.

Rethink of expectations

There's been widespread coverage of public hospitals' escalating costs and trepidation over government cost-cutting—with a restoration of $2.9 billion in federal funds in April 2016 dismissed by experts as a pre-election stop-gap measure.

Financial constraints may also mask some hidden problems, claims Cogin.

'Executives may be measured by the number of patients checked out on time… but if they're being checked out too early, the metrics don't capture the revolving door for readmissions.'

The researchers recommend that a major rethink of expectations is required.

'Hospitals are subjected to rules of many external stakeholders who prescribe how a variety of HR practices are undertaken so it's overly optimistic to think that hospitals will be able to replicate best practice HR from the private sector', Cogin concludes.

A full commitment-based approach may be a step too far

'We need more realistic incremental changes to people management to give department heads and managers the autonomy to make people decisions, and the skills and resources to give feedback, and motivate and engage people with non-financial rewards.' ha

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This article was originally published by the University of New South Wales Business School, and has been reproduced here by permission of the University of New South Wales. The original article is available at https://www.businessthink.unsw.edu.au/pages/how-poor-people-management-is-debilitating-the-hospital-system.aspx//#sthash.e1Pt3dla.dpuf

2018 World Hospital Congress

Across the world, health and hospital systems are under pressure from influences as diverse as changing disease profiles, financial and structural issues and changing societal expectations. Rather than crumbling when confronted by such challenges, many organisations are developing innovative responses that are leading to improvements in outcome and quality. Some of those innovations are taking place here in Australia, but many others are happening across the globe.

While there is much to learn from the experiences of others, few in our publicly funded health sector have the means to undertake international travel to learn directly from those innovators. To overcome this, in October 2018 AHHA will bring the world to Brisbane as the World Hospital Congress returns to Australia for the first time in over 20 years.

The World Hospital Congress, under the umbrella of the International Hospital Federation, brings hospital and health service leaders from around the world together annually to share views and experiences, network and develop excellence in healthcare and hospitals leadership. Each year it is hosted by a member, and in 2018, the AHHA will be that host, bringing the Congress to Brisbane supported by our host partner, Queensland Health.

Hosting the World Hospital Congress is a highly contested honour, and AHHA competed against bids from Paris and Oman to secure the hosting rights for the 2018 Congress. In announcing AHHA's successful bid, the IHF CEO Eric de Roodenbeke commended the quality of the submission as 'the best ever received'.

AHHA is determined to have that sentiment hold true for the Congress as a whole, and looks forward to building on the strong history of World Hospital Congress

AHHA to host the 42nd International Hospital Federation World Hospital Congress in Brisbane.

events in Australia. The Congress has previously been held in Sydney in 1981 and Melbourne in 1997. Each time the events attracted record levels of delegates and were hailed as great successes.

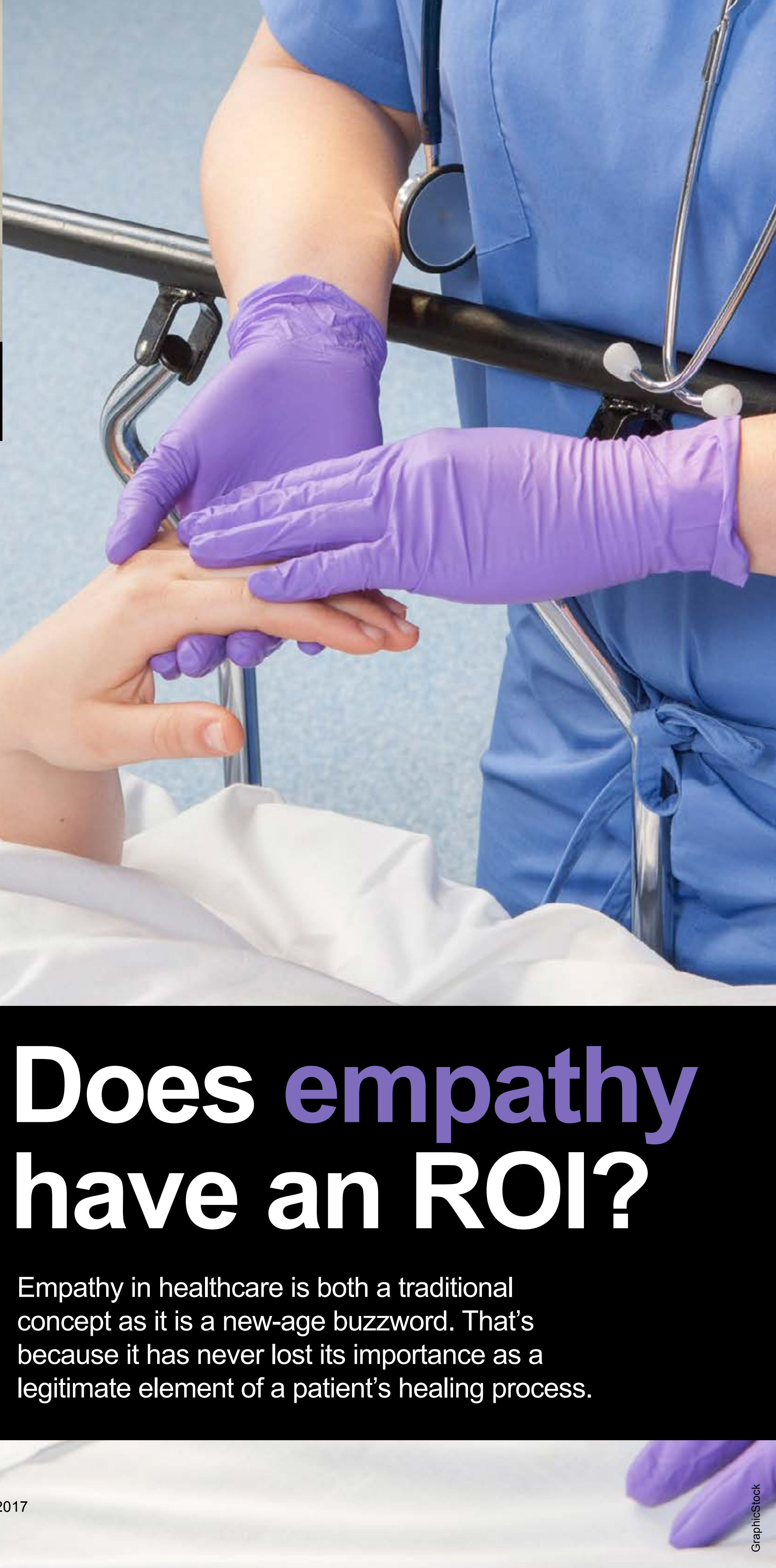
After a 20 year wait, there is much to showcase to the world and AHHA will ensure that the 2018 World Hospital Congress is more than just another conference. It will truly be an opportunity for delegates to make tangible connections, find real solutions and be inspired about the different way people are improving the health system around the world. To support this, the Congress will be accompanied by a series of topical one day symposiums, hospital site visits and a range of networking opportunities.

Hosting the World Hospital Congress will provide the opportunity for Australia to showcase our leading solutions and methods as well as learn from the best in the world.

There will be many ways to be involved with the Congress, from attending, to presenting, sponsoring, exhibiting and acting as a champion to encourage others to participate.

To get involved and stay in the loop sign up for our email notifications at: ahha.asn.au/ihf-world-hospital-congress-2018

DR AVNESH (AVI) RATNANESAN
MBChB, CEO, Energesse



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Does empathy have an ROI?

Empathy in healthcare is both a traditional concept as it is a new-age buzzword. That's because it has never lost its importance as a legitimate element of a patient's healing process.

Simply defined, empathy is the capacity to walk in the shoes of another. Essentially, it's the ability to understand, appreciate and relate to someone else's emotions.

There is more chatter in the industry now about defining, teaching, learning and measuring empathy in healthcare than there has ever been.

Making emotions a visible part of your (formal or informal) measurement validates the feelings of patients, which in turn promotes patient satisfaction[1], enhances the quality and quantity of clinical data, improves adherence and generates a more therapeutic patient-physician relationship.

Ultimately, it all links back to the US-derived Net Promoter Score (NPS) (for measuring customer loyalty) or the Friends and Family Test (FFT) (used in the UK to measure patient satisfaction). A key Hospital Consumer Assessment of Healthcare Providers and Systems (HCAHPS) question, both the NPS and FFT ask the patient point-blank if they would recommend the hospital to family and friends.

> **"There is more chatter in the industry now about defining, teaching, learning and measuring empathy in healthcare than there has ever been."**

There's your ROI (return on investment).

Emotions and patient experience

Human emotions are core to every patient experience. At every stage of the patient journey, there is a feeling, sentiment or attitude that will, collectively, define the experience for the patient at the end of their engagement with a healthcare setting.

Hospitals are often obsessed with benchmarking against other hospitals in term of their respective performance indicators—however there is a need to first benchmark against the expectations of your own patient population:

- If the *experience* < *expectations*, then you have a satisfaction deficit which leads to frustration and anger.
- If the *experience* > *expectations*, then you have a satisfaction profit which leads to delight and excitement.

Frustration and anger are detractors to the patient experience. If these emotions are experienced, then you can be sure that the patient is on their way to relay their negative experiences to others or not return, or both! Feelings of delight and excitement, on the other hand, naturally motivate patients to 'promote' your healthcare setting to others.

Measuring emotions

Measuring emotions is a key part of the Energesse 6E Framework, a step-by-step guide to producing a true holistic picture of patient experience. Emotions measurement impacts the full spectrum of the following process:

Understanding the real patient EXPERIENCE through EMOTIONAL data ENERGISES staff in their purpose and EXECUTION of solutions. Successes are repeated to produce EXCELLENCE in delivery, and organisational capability in patient experience EVOLVES.

How do you draw these emotions out of a patient so you can understand, measure and respond appropriately?

Some state it boldly[1]; some hide their emotions through seemingly rational questions, or casually drop a comment about their emotions, to test the waters on how it would be received in the healthcare setting. Pick up on these clues—do not ignore them or change the topic.

For the uncertain and non-forthcoming patient, surveys are a great way to get emotional data. One would imagine that a survey asking about their emotions would not only surprise them but send a clear message that there is a space in that setting to talk about emotions, that a culture exists that encourages and supports emotions.

Intelligence from emotional data

When the clinician and non-clinician are able to recognise the emotions around a patient, it allows them to be more authentic and honest in the support given to the person (not patient).

Clinicians are able to view the person's emotions within a more accurate context, and address them in specific ways[2]:

- **Learning:** Where the patient is *fearful* because of a lack of information, there is an opportunity for staff to help educate the patient to reduce his fear.
- **Empowerment:** Where the patient feels *helpless* in the face of his health, there is an opportunity for staff to develop the patient's sense of power over the situation through education, tools and technology.
- **Self-discipline**: Where the patient is *frustrated* over their personal management of their health, there is an opportunity for staff to help the patient develop discipline through motivation, tools and technology.
- **Feelings of control:** Where the patient is *overwhelmed* with the amount of information around their diagnosis, there is an opportunity for staff to ensure that the communication of information is at a pace and volume that the patient is comfortable with and to involve the patient's family members or friends in managing feelings of being overwhelmed.

When an organisation can undertake the above in a systematic way, an 'energy' or a 'vibe' starts to emerge. Clinicians and non-clinicians start to discover or re-discover the meaning in their roles and the organisation becomes more congruent with its purpose.

What's the vibe like where you are?

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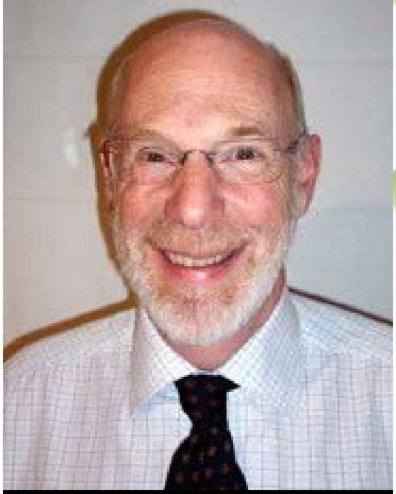

DR DAVID BRUMLEY OAM
Medical Director
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Compassionate communities for palliative care

‘It takes a village’

It takes a village to raise a child’ is an African proverb of uncertain origin that promotes the need for whole-of-community involvement in childhood education for life. The proverb encapsulates the Ubuntu philosophy of many African societies, which expresses the ideal of a universal human bond.

It also ‘takes a village’ to care for the dying.

We need other humans around us to fully express our humanity. In helping we create meaning, happiness and fulfillment. Palliative Care workers know that their work provides a deep sense of doing the meaningful and necessary. This includes volunteers, who have traditionally been an essential part of the palliative care workforce. They are full team members and serve as a community voice inside palliative care services. Thus there is nothing new about the idea of compassion in palliative care!

Nevertheless something new began in 2015 with the birth of the Compassionate Communities Network at Latrobe University. It is one of a number of groups to have formed worldwide with a focus on the intersection between public health and palliative care. Prominent among these are the Compassionate Cities Charter in the UK and the Todos Contigo program in Spain, based on the Compassionate Communities Charter.

Alan Kellehear, past Professor of Palliative Care at Latrobe University in Melbourne and now Professor of End-of-Life Care at the University of Bradford, UK, wrote:

> *‘A Compassionate Community therefore recognises that all natural cycles of sickness and health, birth and death, and love and loss occur every day. It is about acknowledging that care for one another at times of crisis and loss is not only a task for health and social services, but is everyone’s responsibility.’*

Bringing communities to work together to this end is difficult because our society is fearful of dying and separated from it. We rarely see normal dying because the work has been given to professionals—the doctors, the nurses, the undertakers. Dying happens in hospitals and nursing homes. It happens much less often at home, despite this being most people’s preference. There is a cost to this professionalisation of dying, and that is the loss of the opportunity for family and friends to demonstrate their love by acts of kindness—practical compassion.

The idea of community needs to be re-thought if we’re to succeed in growing resources to better care for the sick and dying. There is a limit to the capacity of governments to provide all the care needed by patients and families. In any case the care that the community itself can provide is of its nature different. George Monbiot, writing in the *Guardian* this year, suggested that community might:

> *‘complement state provision with something that belongs neither to*

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“A Compassionate Community therefore recognises that all natural cycles of sickness and health, birth and death, and love and loss occur every day. It is about acknowledging that care for one another at times of crisis and loss is not only a task for health and social services, but is everyone’s responsibility.”

> *government nor to the market, but exists in a different sphere, a sphere we have neglected’.*

Compassionate Communities is a vibrant new development in Australia. It’s a collaboration between Palliative Care Australia (PCA), the national lead organisation for palliative care, and The Groundswell Project, a not-for-profit organisation whose purpose is to create ‘a more death-literate society, one where people and communities have the practical know-how needed to plan well and respond to dying, death and grief’.

These two organisations jointly staged a two-day symposium in Sydney in February 2017—a vital and exciting mix of people intent on making a difference to the way in which Australians look after their own.

Interest is also growing in government. Speakers from PCA and the Groundswell Project presented at a Parliamentary Friends of End-of-Life ‘lunchbox’ meeting on 28 March 2017.

Within my rural area in Victoria there is also a surge of interest, and new groups have formed to improve the support to dying people and the people around them. Examples include the ‘It Takes a Village Macedon Ranges’ organisation. This is a charity established to harness community capacity to provide support and resources for the dying. Another example is Shannon’s Bridge, a group that provides packs of essential medicines to patients who live away from accessible pharmacies. These groups have arisen in response to the particular needs of that community, and can’t therefore be mass-produced.

Community members can provide support in many ways. Examples are providing food and transport, staying in the home to allow family members to shop, or staying at night to provide family respite. Talking about choices at the end of life is essential, and there is evidence that trained volunteers can do effective advance care discussions that reduce the rate of hospitalisation.

The result of the development of more compassionate communities is that the whole community will be more comfortable and capable of caring for itself. In such a society, better knowledge, acceptance and understanding of death and dying can provide great improvements in care.

If for any reason a death is difficult and the patient and family are not cared for appropriately, unhappy memories continue and blight other lives. With community support the experience can be greatly improved for the patient, the family and the community.

We will not be able to predict all the results of these community projects, but as Irvin Yalom says,

> *‘….the one thing I’ve come to know with certainty is that if I can create a genuine and caring environment, my patients will find the help they need, often in marvellous ways I could never have predicted or imagined’.*

Let’s get on with the job. ha

Making a real difference in closing the gap

General Practitioner from Victoria wins Indigenous health award.

The Remote Area Health Corps (RAHC) has named Dr Margaret Niemann, a General Practitioner from Bairnsdale, Victoria, as the recipient of its annual Annette Walker Award for 2016.

The award recognises health professionals who exceed the requirements of their role, demonstrate resilience, inspire their team and display a 'can do' attitude that has realised a positive outcome for remote health in the Northern Territory (NT).

A GP truly passionate about Indigenous health, Dr Niemann has been on placements with RAHC since 2011 and completed her 56th placement at the beginning of March 2017. She has undertaken placements in both the Top End and in the Central communities of Maningrida, Mount Allen, Ali Curung, Finke and Ti Tree, and Lake Nash.

Tanya Brunt, National Manager of RAHC said Dr Niemann 'has had a remarkable journey with RAHC. She has been consistent and committed to the project at hand and her experience and superior clinical skills and knowledge have been very helpful in the challenging environments of a remote setting.

'Her true dedication and passion has been displayed through her ongoing monthly placements to Lake Nash since 2014. We would like to thank her for being part of the effort and making a real difference in closing the gap in Indigenous health.'

Dr Niemann worked for 25 years in the Victorian town of Bairnsdale. She still lives there with her husband, also a GP, and their three children. She delivered babies for 12 years, obtained a Masters in Psychological Medicine from the University of New South Wales and has worked in most aspects of General Practice.

In the late 1990s, the family lived in the Aboriginal community of Maningrida, Arnhem Land, for nearly two years. Both Margaret's children were schooled there. Dr Niemann then worked in the local Aboriginal Medical Service (AMS), as well as the mainstream clinic in Bairnsdale before deciding to return to remote work in 2011 with RAHC, mainly in Central Australia communities. Since mid-2014, she has been regularly visiting the community of Alpurrurulam.

Speaking of her experience, Dr Niemann said, 'I find it challenging, exciting and fascinating to be part of one community, sharing its ups and downs and watching as it grows and develops. Working in remote communities, you do get to see different aspects of Australia. Exposure to different cultures, even within our country, always expands your self-awareness and challenges your world views'. ha

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The Annette Walker Award was launched in 2013 and is named after a valued member of the RAHC team, who passed away on 30 December 2012.
Since 2008, RAHC has completed over 4,500 placements into remote communities in the Northern Territory.

Dr Margaret Niemann with Aboriginal Community Worker, Clifford Billy.

2016 Annette Walker Award.

The Remote Area Health Corps (RAHC) was established in 2008.

It is funded by the Australian Government Department of Health under the Indigenous Australians Health Program *Stronger Futures Northern Territory*.

The aim of the program is to 'address persistent challenges to accessing primary healthcare services for Aboriginal and Torres Strait people in the Northern Territory'.

RAHC recruits, culturally orientates and deploys health professionals to enable the provision of increased primary healthcare services to assist in addressing the shortfall in health service delivery in remote Indigenous NT communities.

RAHC's focus is on recruiting urban-based health professionals.

PROFESSOR ADRIAN BARNETT
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Regression to the mean or why perfection rarely lasts

Have you ever experienced the perfect evening out? The weather was great, you got the best table in the house at your favourite restaurant, the food was delicious and the wine superb, and the conversation was sparkling.

Then have you made the mistake of trying to repeat the experience and ended up disappointed? This is because your perfect evening was due to a series of chance events that all fell in your favour. A great experience is like tossing a coin and getting a long run of heads—unusual and difficult to repeat.

When you try to repeat a perfect experience, at least one thing is likely to be imperfect the second time around. The couple at the next table are loud and boorish, the waiter gets your order wrong, your jokes fall flat, and so on.

Happily, it works both ways. So if you're forced to repeat a terrible experience, it's likely that it won't be so bad the second time around.

This phenomenon is called "regression to the mean" or "reversion to mediocrity", which sums up how unusual events are likely to be followed by more typical ones.

The polymath Sir Francis Galton coined the term when he noticed that tall parents tended to have children shorter than them, whereas short parents often had children who were taller than themselves.

For a parent to be unusually tall, the genetic coin had to be 'heads' many times in a row. Repeating that feat of chance for their children is not impossible, but it is unlikely.

Is that a trend?

Regression to the mean is driven by chance, and so it occurs wherever chance occurs, which means it occurs almost everywhere. It is prevalent in sport and can explain the 'manager of the month curse' in football. This award is usually won by managers who have had four or more wins in a row, often because of a combination of skill and luck. When the luck runs out, the 'curse' strikes.

Regression to the mean will even occur in this article as unusually long sentences will tend to be followed by shorter ones. Check if you don't believe me. It occurs in the published literature on regression to the mean, as years with many published papers on the phenomenon tend to be followed by years with fewer papers.

This article will itself cause some regression to the mean if it spikes interest in the Wikipedia page, but that interest will inevitably wane.

Regression to the mean is mostly harmless, but it becomes a problem when the change it creates is misinterpreted.

For example, imagine you ran a hospital and were told that hospital-acquired infections were five times higher than average last month. A colleague tells you they know the cause and it can solved by using more prophylactic antibiotics.

You agree and in the following month you're told that prophylactic antibiotic use is through the roof and infections have come down. Your mind makes a causal connection and you're now convinced of the need for widespread prophylactic antibiotics, a potentially dangerous connection given that the unusual infection rate could have been due to chance events.

Now your hospital budget will be tighter because of the costs of using more antibiotics, and you're contributing to serious problem of antibiotic resistance.

Making sham treatments look good

Regression to the mean is unwittingly exploited by quacks who often see patients when they are at their lowest. As many diseases have a natural ebb and flow, seeing patients when they are at their worst is the best time to exploit regression to the mean, Statistics is a useful tool for understanding the patterns in the world around us. But our intuition often lets us down when it comes to interpreting those patterns. In this series we look at some of the common mistakes we make and how to avoid them when thinking about statistics, probability and risk.

because any treatment will appear to cause improvements in enough patients to make it look broadly effective.

Telling the difference between regression to the mean and a real change can be difficult. A chronically ill patient may have a very bad day, but is that the early warning of a downward trajectory or just a blip due to a random cluster of events, such as a bad meal, poor sleep, or an ill-judged sprint for the bus?

Gathering more data using watchful waiting can be useful, as once a clear pattern emerges in a patient's well-being, it is less likely to be the random ups and downs of regression to the mean.

Regression to the mean is everywhere. Being aware of it might help you avoid overreacting to unusual events. However, if you didn't find this article interesting or useful then why not read another one on *The Conversation*—the chances are you'll enjoy it more! ha

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This article was originally published in The Conversation on 27 March 2017 (https://theconversation.com/au).

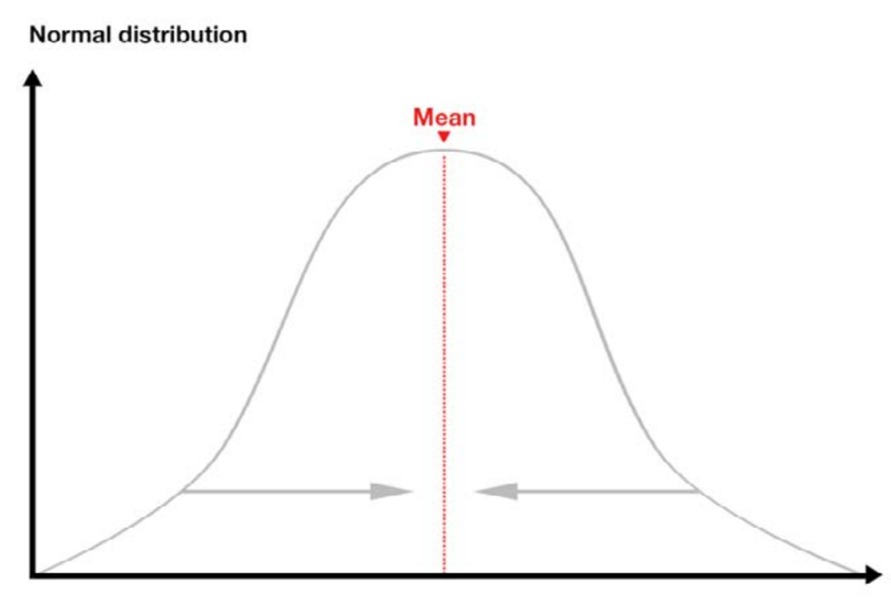

Figure 1: Outliers in a population, such as very short or tall parents, will tend to gravitate towards the mean, such as by having children that are closer to the average height in that population.

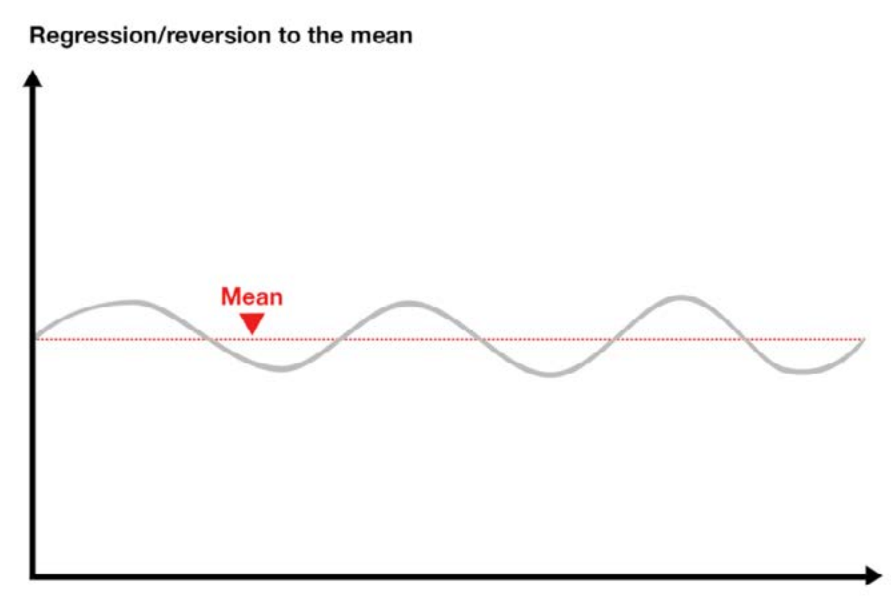

Figure 2: If you track the quality of your nights out, they might fluctuate up and down, but will still hover around the mean.

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Using telehealth for patient-centred care

Telehealth provides an unprecedented opportunity to develop new models of patient-centred care. Smart technologies, such as home monitoring devices, enable both patients and health care professionals to access individualised biometric data over longer periods of time. The readings are reviewed by a health professional who can make recommendations or medicine adjustments for the patient. This differs from current models of care where data, such as blood pressure, is collected by a heath professional during a visit to a clinic.

In 2015 we evaluated a National-Broadband-Network-enabled telehealth trial for older people, Feros Care's 'My Health Clinic at Home' (MHCAH).[1] In this study, 200 older people aged 50 years and over (average age 73) were provided with a range of home monitoring devices, such as blood pressure monitors and glucometers, depending on their chronic disease. Every day they took their vital signs readings which were communicated electronically to a Telehealth Nurse.

If the readings fell outside pre-determined 'normal' parameters set by the GP, the Telehealth Nurse would videoconference the senior in their own home and provide advice and support in managing their chronic condition and, if necessary, accelerate a referral to their GP. Alongside this process we ran patient education groups by videoconference (The Telehealth Literacy Project)[2] where group members engaged in health literacy and chronic disease self-management programs, which were co-designed with participants.

Outcomes from the study indicated a range of significant improvements, including better general health and self-efficacy scores, reductions in health service use, and, of particular interest to patient-centre care, improved participant understanding of their vital signs monitoring, which consequently enabled better self-management behaviour.

For the first time, seniors were in charge of taking their vital signs readings, and when these readings were explained during the education sessions and by the Telehealth Nurses, seniors were able to better understand the effect of their health behaviour on physiological changes. For example, seniors were clearly able to link the effects of drinking alcohol on their blood pressure levels or blood glucose levels, prompting them to modify their drinking. In addition, the videoconference education sessions provided easy access to group education from participants' homes, enabling participants to connect and learn from others in similar circumstances. An unexpected outcome from the weekly education sessions was the level of social support that participants derived—particularly important for those who were socially isolated or suffering from anxiety or depression.[3]

> **"The technology is available and has shown that it is capable of greater patient-centred care and costs savings."**

However, participants' enthusiasm for using the home monitoring equipment and videoconferencing to access health care was not matched by their health care providers. Participants' GPs were sent regular trend reports of home monitoring data. Despite the pilot providing payment for GPs to use videoconferencing with their patients, only one GP took up the offer. GPs were surveyed


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on their opinions of the MHCAH. They felt that the home monitoring had increased their workload, although they acknowledged that there had been a positive effect on their patients' adherence. Seniors were able to use telehealth to better control their chronic conditions, but their GPs were unable and/or unwilling to fully use the technology for their health care.

Following the pilot, over one-half of the participants said they would consider using videoconferencing with their doctor and around one-third would do so with their specialist or pharmacist. In addition, they had several suggestions for using group videoconferencing for health education and social support, including diabetes education and book clubs.

The new Health Care Homes initiative and the National Disability Insurance Scheme provide immense opportunity to use new technologies in health care delivery.
The applications of telehealth have been demonstrated overseas, with organisations such as the US Department of Veterans Affairs providing healthcare to a widely dispersed population. At the very heart of their telehealth program is an aim to improve patient self-management. The Health Care Homes initiative clearly sanctions primary care's use of web technologies such as email and videoconferencing to engage with patients. To further support the deployment of telehealth, last year the Commonwealth Scientific and Industrial Research Organisation (CSIRO) reported that an annual expenditure of $2,760 to home-monitor patients who suffer from a wide range of chronic conditions and who frequently attend hospital, could generate a saving of between $16,383 and $19,263 a year, representing a return on investment (ROI) of between 4.9 and 6.0.[4]

Australia has an exciting opportunity to embed the use of telehealth into its health care provision at all levels. The technology is available and has shown that it is capable of greater patient-centred care and costs savings. However the appetite for uptake at a service delivery level appears to lag behind. In some cases this is due to poor IT infrastructure, and in other cases a resistance of practitioners to change their practice. Clear leadership is needed at all levels, including Local Health Districts and Primary Health Networks, to push the telehealth agenda forward.

We look forward to seeing innovative projects emerge from the new policies, and truly put telehealth on the map. ha

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Health Care Homes

Significant potential for patient-centred reform. **AHHA**

The first 20 medical practices in the Australian Government's Health Care Homes trial are due to start in October 2017, with the remaining 180 homes starting in December. The start has been delayed form the original date of 1 July.

Health Care Homes hold the potential for significant patient-centred reform, but without shared principles for success, and the right enablers, there is significant potential for failure and the risk that this important reform will be shelved.'

A Deeble Institute Issues Brief released by AHHA highlights the work that still needs to be done to ensure that the Health Care Home trial paves the way for enduring reform.

If done well, the Health Care Home model will drive better health outcomes by providing integrated and coordinated care and reducing unnecessary hospitalisations.

The AHHA view is that truly coordinated and efficient care that is patient-centred, flexible and tailored to local needs and the capacity of the local workforce will be difficult to achieve without first having shared principles. These principles need to be shared across government, the various Health Care Homes, the health system as a whole, and importantly, patients and their families and carers.

A workshop held at the 2016 National Primary Care Conference, building on Australian participation in a similar workshop hosted by the US Patient-Centered Primary Care Collaborative, considered shared principles for Health Care Homes in Australia. From this process, the following principles were identified as key to successful implementation of Health Care Homes:

- a holistic view of health and well being
- patient and family centred healthcare
- continuous and collaborative relationships
- a comprehensive-team based approach to healthcare

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> **“Public and expert debate must be fostered to ensure that the model to be more broadly implemented is accepted by funders, providers and consumers.”**

- shared decision making, patient activation and engagement
- coordinated care across the care system
- accessible, affordable, equitable and appropriate care
- high value, evidence based, safe and quality care
- well-supported health care workforce and workplace environment
- sustainable funding to support principles, implementation and practices.

To achieve change organised around these principles, the following enablers must be part of the Health Care Home model:

- institutional and professional leadership from all levels of the healthcare system
- a mutually shared understanding of principles and objectives
- collaborative, sector-led planning and change management
- appropriate funding and incentives
- broad workforce engagement
- patient-centred, co-designed care
- outcomes-focused data and technology to support innovation
- models of coordinated care adapted to local circumstances
- operational and equity considerations, balanced with risk stratification.

There is no doubt that some of these principles and enablers will challenge existing models of care and administration. The required changes will take time, up-front investment and strong leadership at all levels of the system.

While Health Care Homes are new to the Australian health system, there are many examples where health organisations have trialled or implemented models of coordinated care. These include Aboriginal Community Controlled Health Services and the Veterans Care Program. These programs share many of the attributes identified in AHHA Deeble Institute research as key principles for successful implementation of Health Care Homes.

Time will tell if the Health Care Homes trial is a success or otherwise. The opportunity for reform and the associated potential for failure are significant. Public and expert debate must be fostered to ensure that the model to be more broadly implemented is accepted by funders, providers and consumers.

We suggest that the shared principles proposed in the Deeble Issues Brief will inform this debate, and contribute to the change management required for successful implementation of Health Care Homes in Australia.

Now is the time to be ensuring that all stakeholders, including patients, are moving forward together and contributing to patient-centred care reform which will shape the type of health system we want in Australia in the future. ha

LIZ CALLAGHAN
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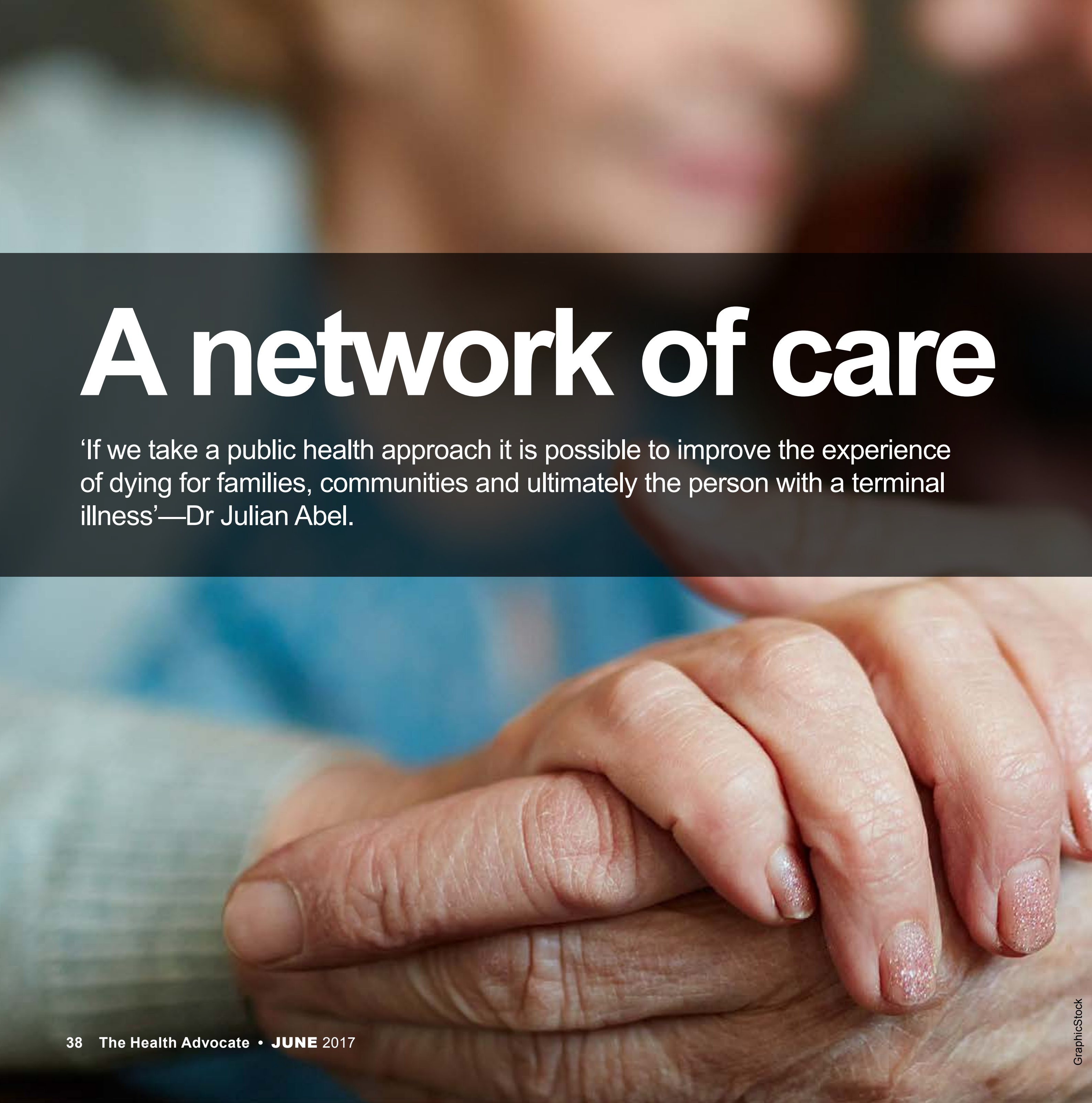
Palliative Care Australia



A network of care

‘If we take a public health approach it is possible to improve the experience of dying for families, communities and ultimately the person with a terminal illness’—Dr Julian Abel.

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Making a formal plan and having access to health services at end-of-life are important, but so is having a plan based around what the community can do to help.

The Compassionate Communities movement aims to bring together aspects of the formal caring network that exists alongside the informal caring network.

Think about the following question for a moment:

If I was facing the prospect of living with a life-limiting illness, even dying, what kind of support would I need, and what kind of support would my family and friends need?

There would likely be a range of responses—such as being around family and friends; having emotional support; dying at home, and being able to go outside for fresh air or having music nearby.

> **“The Compassionate Communities movement aims to bring together aspects of the formal caring network that exists alongside the informal caring network.”**

In an ideal world nothing else would need to be done and all the support outlined above would materialise. It is likely though that there may be a number of things that might get in the way of achieving that. It could be things such as having to ensure the children’s lunches are made every day; the lawn may need mowing or it could be feeding the pets and finding time to take them for walks.

Compassionate Communities champions a social approach to death, dying and bereavement by implementing a network of care that stems from the community.

This network focus highlights the different roles community members can play when someone is dying. It’s also a way of teaching people how to care, and prepare, for end-of-life, while giving them a sense of purpose and pride in their communities.

In the past 60 years the health care system has seen enormous changes. This has meant that greater support is provided for people who face with a life-limiting illnesses, particularly in pain and symptom management.

However, there is still plenty of room for improvement. About 70% of Australians would prefer to die at home, however only 16% actually do. This is where a Compassionate Communities approach to end-of-life care can make a difference.

A community network approach to end-of-life care allows the person faced with a life-limiting illness and their carers to focus on what’s truly important to them. By having this external support network there to help complete tasks that can burden carers or the person faced with the life-limiting illness, the end-of-life experience can become easier for all involved, and emergency admissions to hospitals can be reduced.

The Compassionate Communities movement also aims to normalise the seeking and acceptance of social, emotional and practical support. It can be difficult for people, including carers, to ask for help, but death is something that affects everyone. For those closest to the person dying, this type of approach can reduce carer stress and allow a focus and connection with the person they love.

This approach to networks of care could also have wider implications for Australia’s healthcare system.

A study in Frome in the United Kingdom conducted by Dr Julian Abel explored the capacity of communities to support people at end-of-life, and what that would mean for the health care system. (Dr Abel is a palliative care physician who works for the NHS in the Department of Palliative Care, Weston Area Health Trust, and is currently Vice President of Public Health Palliative Care International.)

Dr Abel focused on identifying vulnerable patients, mapping their networks and connecting the patients with formal care supports, as well as enhancing their informal networks.

Frome experienced a 30% reduction in all hospital admissions, resulting in a saving of A$3.25 million a year.

If these initiatives were successfully implemented in Australia, there could potentially be savings of up to $2.6 billion a year.

In their 2015 paper, *Palliative Care reimagined: a needed shift* (available at spcare.bmj.com/content/6/1/21), Dr Abel and Dr Allan Kellehear argue that adopting the principles of a public health approach to end-of-life care can achieve equality in the distribution of care, while extending their outreach.

With the majority of people with terminal illnesses not having access to palliative care teams (whose main focus of care remains patients with cancer), Dr Abel and Dr Kellehear say that a community approach to healthcare provides an equitable level of care for all people irrespective of diagnosis.

As this considered approach to networks of care builds momentum, Palliative Care Australia (PCA) is looking for new, innovative ways to create these networks of care.

In September 2017, PCA is launching a smartphone application with support from the NIB Foundation. The app will allow people living with serious illness and their primary carers to connect with others in their community in order to reduce the burden of care.

The app will be simple to use. People living with life-limiting or serious illness and carers can create a group and add people who are willing to help, enhancing their own network of care.

By creating this online community of care, PCA is aiming to ensure people living with life-limiting or serious illness and their carers feel supported at all times.

A community based on continuous support for one another, even after the death of a loved one, will get community members thinking about their own end-of-life, and the decisions that they will be required to make.

By creating compassionate communities and implementing various networks of care, people faced with life-limiting illness and carers will have a more supported end-of-life experience, and the wider community will know that when the times comes, they could experience the same. ha

ALISON VERHOEVEN
Chief Executive
AHHA

Private patients in public hospitals

There's more to the story.

Private health insurance policies are complex and do not readily support comparisons, accurate assessments of costs and, in some cases, may include possible misrepresentations of products and their value.[1]

While health costs keep rising by more than inflation the ease with which the Commonwealth approves insurance premium increases does nothing to exert downward pressure on those costs.[2]

Private insurers[3] and private hospitals[4] have stated that public hospitals treating private patients is largely to blame for premium increases, but their arguments ignore key data and do not consider the mixed public-private nature of Australia's health system.

Hospitals funding reflects our mixed public-private system

About 90% of care in public hospitals and 32% of care in private hospitals is funded by governments.[5]

The number of separations that were funded by governments in public and private hospitals combined increased by an average of 2.7% each year between 2010–11 and 2014–15. In the same period, the number of separations funded by private health insurance across the two sectors increased by 5.9%.[6]

Between 2009-10 and 2013-14, after adjusting for inflation, total funding for public hospitals increased by an average of 4.2% each year. However, the proportion of public hospital funding by the Australian Government decreased from 38% to 37%.[7]

More private hospital care is being funded by both governments and insurers

For private hospitals, the number of separations funded by governments increased by an average of 10.3% each year between 2010-11 and 2014–15. Since 2013–14, separations in private hospitals increased by 5.6% for both those funded by governments, and those funded by private health insurance.[8]

Private hospital funding from state and territory governments has almost doubled over the past decade—and is growing faster than funding for public hospitals. State and territory governments' recurrent expenditure in private hospitals in 2014–15 was $621 million, an increase of 19.4% on the previous year, and almost double the expenditure in 2004-05 (in constant prices, $314 million). This represents an average annual growth rate over the decade of 7.1%. In comparison, the average annual growth rate in state and territory government recurrent expenditure in public hospitals was 4.7% over the same period.[9]

More public hospital separations are being funded by insurers—but there's more to the story

In 2014-15, the net benefits paid by private health insurers in public hospitals was $1.06 billion. This was a growth of 8.7% over the previous year. In the same period, the net benefits paid by private health insurers in private hospitals was $7.974 billion, or growth of 6.4% over the previous year.[10]

There were almost 5 million separations in public hospitals during 2014-15, and of these 14.1% (815,000) were funded by private health insurers. Between 2008-09 and 2014-15, the

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number of separations in public hospitals funded by private health insurance increased by an average of 10.3% each year, or 4.4 percentage points over the period.[11] However, the rate of growth in the number of bed days funded and benefits paid by private insurers for care in public hospitals is slower. As a proportion of bed days paid by private insurers across both public and private hospitals, public hospital care represented 10.38% of bed days in June 2009, increasing to 12.4% in June 2016. As a proportion of benefits paid for public and private hospital care by private health insurers, the public hospital share increased from 3.4% in June 2009 to 4.3% in June 2016.[12]

Private health insurance used in public hospitals represents only 7.6% of private health insurance total expenditure

Private health insurers use more of their funds on their own administration (8.8% or $1.23 billion in 2014–15) than in funding public hospital services (7.6% or $1.06 billion in 2014–15).[13]

What factors have driven growth of private health insurance use in public hospitals?

The Independent Hospital Pricing Authority's recent report on public hospital service utilisation by private patients[14] examined the extent to which activity-based funding, and its implementation in the states and territories, had contributed to the increase in use of private health insurance in public hospitals.

Beyond the scope of the IHPA report was analysis of the type of insurance products

> **“The Australian health system and its model of universal health care are complex—with public and private providers, public and private sources of funding, and concepts of patient choice and equity of access, clinicians as business owners and as employees, sitting side by side.”**

used in public hospitals, and the impact of the increasing number of product offerings from private health insurers with high gaps and multiple exclusions, and including public hospital only insurance products.

Statistics published by the Australian Prudential Regulation Authority[15] do not identify public hospital only insurance policies; however data are published related to exclusionary and non-exclusionary hospital insurance policies. In the period covered by the IHPA report, the growth in exclusionary policies has been substantial. Of the approximately 9.5 million hospital policies in June 2009, around 10% were exclusionary policies. By June 2016, 37% of the 11,328,577 policies were exclusionary.

During the same period, changes to the private health insurance rebate income testing arrangements reduced the share of funding provided by the Australian Government through the rebate scheme. Coinciding with this, the proportion of overall hospitals expenditure funded by private health insurers increased from 7.4% in 2011-12 to 8.3% in 2013-14.[16]

It’s more than about who pays for what

Foundational principles of Australia’s universal health care system is that clinicians are free to provide their services as private providers; and that patient choice is available, both for services from clinicians and from hospitals. In many parts of regional, rural and remote Australia, there are no private hospitals available—and for patients to exercise choice regarding clinicians, the opportunity to use private health insurance in public hospitals must be preserved. Recruitment and retention of workforce in regional, rural and remote areas is also underpinned by the opportunity for providers to be able to offer private services in public hospitals.

State and territory health departments have protocols and guidelines regarding communications with patients about the use of private health insurance, and associated complaints mechanisms. A more fulsome analysis of public hospital service utilisation by private patients would examine how these protocols are implemented in hospitals, and any related complaints data.

The Australian health system and its model of universal health care are complex—with public and private providers, public and private sources of funding, and concepts of patient choice and equity of access, clinicians as business owners and as employees, sitting side by side. Changes to that system, such as potentially limiting the use of private health insurance in public hospitals, need to be made with care as there are many possible consequences: including funding pressures for public hospitals, difficulties with recruiting and retaining clinicians, reducing choice for patients whose preferred clinician may also prefer to practise in a public hospital, and decreasing the value proposition for private health insurance where private hospital services may not be available. This issue should be examined as part of an overall review of health system funding in Australia—to ensure that we maintain a strong universal health system with care available and affordable for all who need it, not just those who can afford it.

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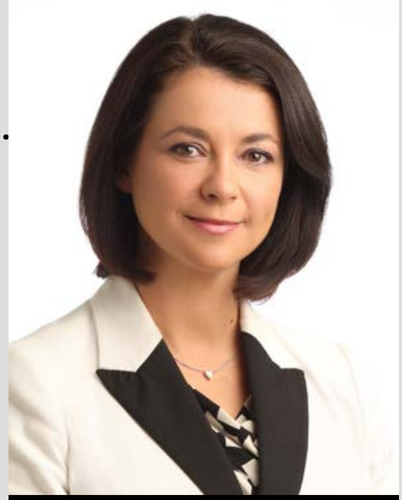


**CLINICAL PROFESSOR
MEREDITH MAKEHAM**
Chief Medical Adviser
Australian Digital Health Agency

Access to health information drives patient empowerment

New digital tools and systems such as Australia's My Health Record are helping us deliver modern patient-centred care.

Scientia potentia est, or in plain English, 'Knowledge is power'. This popular saying has been attributed to Francis Bacon (although the philosophical question has been studied since Aristotle's time). It conveys the idea that the more knowledge and experience about a specific matter we have, the better we are able to identify options to solve our problems and to make good and well-informed decisions[1].

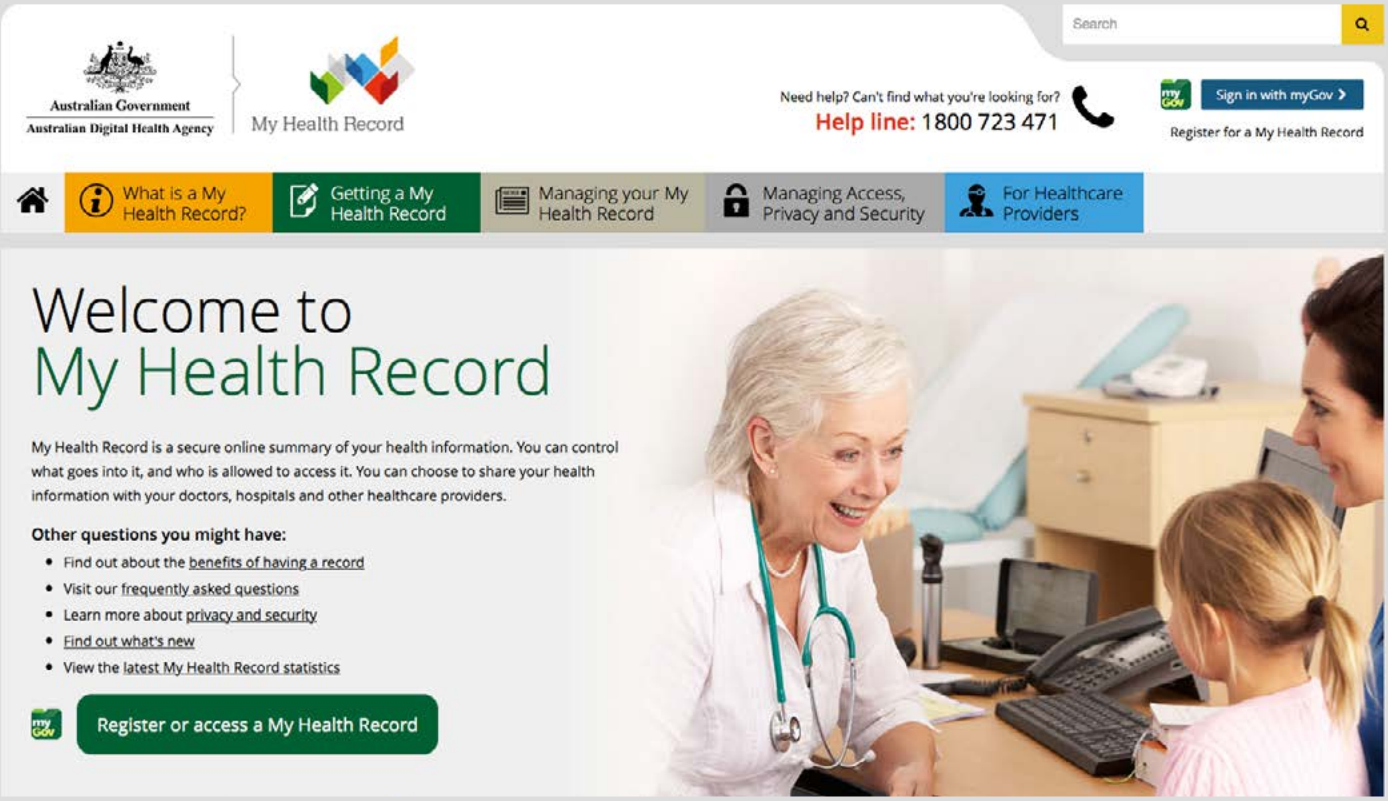
The same principles apply to our health and wellbeing. The patient-centred clinical method is a concept that was developed over 30 years ago and has its roots in primary care[2]. Being 'patient-centred' actually means taking into account the patient's desire for information, sharing decision-making, and responding appropriately[3]. When people are empowered with access to their own health information, it takes their ability to be true partners in the decision-making process to new levels, which is at the heart of patient-centred care.

It's not possible to overstate the effect that the Internet and digital technology have brought about with respect to our ability to access health information, both general and personal. And they have also enabled new communication methods that challenge traditional practices, allowing people to not just view their health records, but also co-create the information within them in partnership with their care providers.

Internationally, the movement towards this style of transparent access and co-creation of health information is emerging in a number of ways. Many countries, including Australia, have developed policy and legislation that clearly calls out our rights in this area[4], and the technology to make these rights a reality is also evolving with a variety of systems around the world now digitally supporting the way people interact with their medical records and care providers[5].

At a recent international meeting of clinicians, digital health innovators and patient representatives in Salzburg, the transformational power of that experience was described by users of the 'Open Notes' system developed in the USA. It allows people to view their full electronic health record and communicate online with their care providers. The resulting benefits for people are wide-ranging, with the vast majority gaining a better understanding of their health and medical conditions, taking better care of themselves, doing better with taking their medications, and feeling more in control of their care[6]. One patient 'expert', recently diagnosed with an advanced metastatic adenocarcinoma of the lung, described the way that access to her own health information had led to an immense improvement in understanding her complex care needs, and in her confidence to have a conversation with her care providers. She was able to share her information with her loved ones when she chose to, and was empowered to be able to ask questions and contribute to her treatment plans, which she could do from home between clinician visits, supported by digital technology.

Here in Australia, the My Health Record system is an important piece of national digital health infrastructure that will support the principles of patient-centred care. It places people at the centre of their own health and care needs, with access their own health information, and the ability to choose with whom they share it. It is a personally controlled, secure online summary care record and will soon be available to all Australians through the announcement of the Commonwealth's plans to move to a national 'opt-out' model for My Health Record.



Welcome to
My Health Record

My Health Record is a secure online summary of your health information. You can control what goes into it, and who is allowed to access it. You can choose to share your health information with your doctors, hospitals and other healthcare providers.

Other questions you might have:

- Find out about the benefits of having a record
- Visit our frequently asked questions
- Learn more about privacy and security
- Find out what's new
- View the latest My Health Record statistics

With our permission, our registered care providers can view the information in our My Health Record, which includes Shared Health Summaries from GPs, Discharge Summaries from hospitals, medication, allergy and immunisation records, and results of pathology and imaging tests from a growing number of health care organisations. And people can contribute their own notes and information, including Advanced Care Directives, over-the-counter medicine information, children's health records and emergency contact details.

There are numerous potential benefits for you and your care providers in having immediate online access to accurate health information within the My Health Record system, and it will be important to measure these as the system gains wider usage. These benefits are likely to include more efficient care and cost savings in healthcare delivery, as well as people experiencing better health outcomes and a deeper understanding of their health and care needs.

However, a commonly raised question about the system is how it will affect our right to privacy. It is important to understand that your My Health Record there for you to use and share with others as you choose. It is against the law for a health care provider to view a person's record without their permission, apart from a narrow range of circumstances such as a medical emergency when the person is unable to communicate.

The protections in our My Health Record legislation against people infringing our privacy rights include financial penalties and custodial sentences. They are supported by advanced cybersecurity measures and a range of optional privacy controls. These include access controls, so that people can set up codes that must be shared with a care provider organisation in order for them to view a person's record. People can choose to hide documents in their record from view, and even completely block organisations from being able to see documents in their record. A log of any health care organisation or representatives appointed by you who interact with your record is kept, and carers can access controls in the record on behalf of the individual they are representing, for example helping those who may be supporting an elderly person with their care needs.

The My Health Record system is an investment for Australia that will enrich people's experience of their interactions with health care providers and services as it continues to evolve. My Health Record will empower people by providing them with digital access to their own health information, and this will be fundamental to delivering patient-centred care in a modern health system.

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