



Consumers  
Health Forum  
*of Australia*

# Health Voices

JOURNAL OF THE CONSUMERS HEALTH FORUM OF AUSTRALIA



Primary care at the  
turning point

representing  
consumers  
on national  
health issues

# Health Voices

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

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

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## The Consumers Health Forum of Australia

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

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

CHF does this by:

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

CHF values:

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

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

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

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# Editorial



Most consumers and health practitioners, whatever their expertise, will agree that Australians generally, and particularly the chronically ill, would benefit greatly from a better-connected primary care system. That would encourage patient-centred care, stimulate coordination among clinicians and carers and match local services to local needs.

This issue of *Health Voices* comes out as primary healthcare arrangements are poised at a watershed. The fate of the 61 Medicare Locals established by the previous Government to strengthen local primary care services is unclear.

*Health Voices* has gathered the views from across the range of players in primary care: from consumers and clinicians to scholars and administrators. Common themes emerge: the need to focus services on patient needs which are provided in a coordinated way by a GP-led team, in a community setting, led by locals.

The Coalition before its election to Government declared Australia needed “strong primary care”. It also pledged to review the Medicare Locals structure. It would “rebuild primary care” and said there was a need for a “strong primary care workforce” led by GPs.

The focus of the policy statement rested very much on maintaining the leadership role of GPs. It did state that quality primary care relied on nurses and allied health professionals, but added: “Their important services complement and support the role of GPs.”

The new Health Minister, **Peter Dutton**, and former Health Minister, **Tanya Plibersek**, were approached to write for this issue of *Health Voices*, but the timing unfortunately precluded them from contributing their thoughts.

The Consumers Health Forum strongly supports the development of a vibrant primary care system that is accountable to and works with consumers and local communities as partners in improving health and wellbeing. We need to

move beyond provider-driven care and a paternal notion of healthcare delivery to healthcare that is co-created with communities to deliver effective local solutions for local priorities. Good examples are emerging. The upcoming review of Medicare Locals is an opportunity to find out what is working and what isn't. The yardstick has to be what is changing for consumers in terms of health outcomes and their experience of care.

We welcome the review. We are at a turning point in primary care and there are exciting opportunities if we chose to grasp them and build on the great work already being done. We hope that we can realise the potential for MLs to deliver multidisciplinary, community and consumer-centred healthcare that keeps people well and out of hospital and provides a cost effective option when they need it, in the communities where they live.

**Deborah Smith**, CHF's Consumer Relationships Manager, who has worked with Medicare Locals since their beginnings three years ago, says healthcare should be “a team sport”, unlocking the potential for consumers and communities to contribute to healthier lives.

A long-time advocate of primary care reform in Australia, GP **Di O'Halloran**, writes that when GP and community health leaders in Western Sydney got together some years ago, they found to their surprise that they had much in common: that providing person-centred “wrap around” models of care to meet complex health and social needs requires involvement of both GPs and community health workers.

Dr O'Halloran, who chairs Western Sydney Medicare Local, says there are now “firm expectations” that Medicare Locals will work with their communities to influence socio-economic determinants of health; that collaborations extending well beyond health are needed to change inequity in health access and outcomes.

**Dr Arn Sprogis**, who chairs the Australian Medicare Local Alliance, says that Medicare Locals have been a “disruptive innovation”, by emphasising local issues and integrating primary care in communities. “Medicare Locals have made people who were invisible to a centralised health system visible to a local healthcare system.” They have been the “success story” of the 2010 health reforms announced by the previous Government, says Dr Sprogis.

**Diana Aspinall** and **Annette Wickens** have presented the view from the consumers' perspective. Both became active consumer advocates in the Blue Mountains after their own challenging experiences with the health system which led them to advocate for a joined-up and responsive health system. Their efforts have helped prompt consumer participation and engagement (with the help of resources from CHF) that identified the issues of concern to users, ranging from the need for centralised health information to patient transport issues and workforce shortages.

Workforce is an issue targeted by **Kathy Bell**, CEO of Australian Primary Healthcare Nurses Association. There is a ballooning demand for such nurses yet efforts to realise their potential remain inadequate. A national report has identified a looming shortage of 110,000 nurses by 2025 as a critical issue. The current payment system in general practice rewards GPs to maximise throughput instead of rewarding team care in which practice nurses play an integral role. Exploiting the full potential of primary care nurses will help ensure quality, affordable care to the community, keeping people well and out of hospital care. “That is in everybody's interest,” says Ms Bell.

Health inequality remains the fundamental issue for Indigenous Australians. **Dr Tammy Kimpton**, president of the Australian Indigenous Doctors Association, says primary healthcare has an important role to play in improving indigenous health

outcomes. Yet it has been estimated that Indigenous Australians should be seeking primary care at two to three times the current rate. Dr Klimpton calls for all health professionals to adapt their practice to improve patient engagement and care and embed culture in primary healthcare services.

And on the issue of cultural norms, consultant clinical pharmacist, **Debbie Rigby**, says pharmacists need to step outside normal approaches and take more responsibility for identifying and resolving medication problems.

**Dr Liz Marles**, president of the Royal Australian College of GPs, says Australians should have a “medical home” where the patient enrolls with the general practice to provide continuity of care and savings in reducing avoidable

hospital admissions and redundant tests.

To achieve more multidisciplinary coordinated care, several other countries, including Britain and New Zealand, have moved to patient enrolment or registration, says **Dr Lesley Russell**, senior research fellow at the Australian Primary Healthcare Research Institute. But international evidence about what works is confused, she says.

**Professor Pat McGorry**, mental health leader and innovator, calls for linking mental healthcare with primary care and says the plight of patients in the sector is likely to worsen unless community mental healthcare is included in activity-based funding.

**Melissa Sweet**, founder and editor of *Croakey*, the health news website, writes of the primary health-giving power of Twitter. Social media enables patients to

give feedback to health services which increasingly is being heard and acted upon.

**Leanne Wells**, CEO of Canberra’s Medicare Local, and a former CEO of the Australian Medicare Local Alliance, says that agile, regionalised approaches to health governance and leadership will deliver best.

The Greens health spokesman and GP, **Senator Richard Di Natale**, says we need to protect our relationship with our GP and allied health providers should become even more prominent in healthcare.

**Disability Care Australia** has given its perspective on individual choice and control as proposed under the National Disability Insurance Scheme and says it may offer pointers for the development of primary care.

**Carol Bennett is CEO of CHF.**



## Working with the locals for better health and wellbeing – what works and what doesn’t

### **Deborah Smith**

Complete this sentence in **five words** or less:

*Our Medicare Local works to improve \_\_\_\_\_ our community.*

We will come back to this, but first, I’d like to introduce you to Jack, the patient pictured. Believe it or not, Jack is an expert on how well primary care in his local area is working, or not working.

If Jack is visiting the doctor today because he has become aware that he is at risk of some poor health outcomes and he would like some advice and support on improving his health, primary care is working. However, if he has here because the persistent pain in his back has become so bad that he couldn’t go to work yesterday and so scraped together the \$30 gap to visit the only GP in town on the first available appointment one day later, primary care perhaps isn’t working so well.

Regardless of how well the health system has supported Jack on accessing

care in a timely or not so timely manner, Jack has more to tell us. Now that he has made contact with the health system, if he reduces his health risk, avoids developing diabetes or cardiovascular disease and potentially a trip to hospital with complications, the Jack-indicator tells us that primary care is working well. If not, we need to ask why. Because at the end of the day, primary health has to be about what happens to people in local communities – that’s the measure that matters.

Jack has been doing the rounds of the CHF Health Consumer and Community Leaders’ Workshops over the last 2 years and he has a question for the CEOs, Chairs and consumer and community Board members of Medicare Locals and Local Hospital Networks attending these workshops: ‘*Am I the problem, or part of the solution?*’

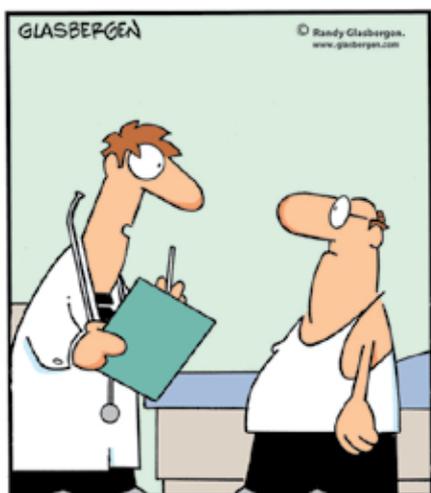
We don’t get better health and wellbeing unless Jack is part of the solution and is engaged and supported as a partner in his healthcare. The

medicines won’t work if Jack doesn’t understand the instructions, the healthy lifestyle won’t happen if Jack doesn’t agree that it’s necessary or possible for him to make change and the check-up in six weeks will be a waste of everybody’s time and money.

When it comes to primary care, there’s nothing new about the realisation that consumers have to be partners and co-creators of care. At the individual level, and at the community and policy level.

Here lies the greatest opportunity to improve the health and wellbeing in local communities, because healthcare can and should be a team sport, with every health dollar spent bolstered by unlocking the potential for consumers and local communities to contribute to better healthcare.

Take the Mental Health Integration and Coordination Unit (MHICU) launched by Bayside Medicare Local. A four minute video (<http://www.youtube.com/watch?v=sM55p3RdH3A>) tells how they are working with Victoria Police and the



“What fits your busy schedule better, exercising one hour a day or being dead 24 hours a day?”

Alfred Hospital to deliver emergency mental healthcare instead of a ride in a police paddy wagon.

Or Tasmania Medicare Local who chose not to be blind to the people who do not normally access health services, working with community organisations such as the Salvation Army, Wesley Mission and others to take vaccinations to some of the people at most risk.

Both of these programs address an identified need, focus on health outcomes, structure the healthcare response around the needs and circumstances of the patient and work with the community to achieve a local solution. This is primary care that works.

It is also primary care that answers the question at the beginning of this story like this:

*Our Medicare Local works to improve consumer health outcomes...WITH our community.*

It is the focus on consumer **health outcomes** (not simply ‘better coordinated care’, ‘improved health services’ etc) and working **WITH** consumers and the community (not ‘for’, or ‘in’) that marks a fundamental difference in the approach of primary healthcare planners and providers in these two programs. Getting primary healthcare to work better requires a shift in thinking – a shift in culture, and that’s easier said than done.

It means that consumer and community engagement and participation must be at the core of successful primary healthcare delivery – not hived off to the communications department or rolled out as a series of activities. Consumer

and community engagement are not add-ons or extra things to do – they are core business and should be an integral part of the strategy, culture and operation of primary care organisations – at the practice level and the Medicare Local.

Engagement to achieve better health outcomes comes in many forms – it can be as ‘simple’ as the right information, in the right form at the right time. Like the work of Wide Bay Medicare Local in the Queensland flood disasters which coordinated and disseminated up to date information through the media, social media and emergency centres about what health services were operational and accessible in a time of crisis. Or it can involve consumer and community members in advisory and decision-making roles that shape healthcare delivery. Like in the Nepean-Blue Mountains example detailed elsewhere in this issue, or at the Cootamundra Medical Centre where former local GP (and primary healthcare champion), Dr Tony Hobbs ran a Critical Friends Group (CFG) of consumers and community members. This CFG informed and improved the practice and built trusted relationships through community leaders that saw improvements, for example in dramatically increasing access by Aboriginal consumers.

There is no shortage of consumer and community engagement frameworks – but most say the same thing – engagement can happen in many different ways at all levels. CHF has developed an online information module and offers a Five Step guide to strategic planning for effective engagement.

Over two years learning from our work with Medicare Locals and Local Hospital Networks, a few critical ingredients for success are apparent:

- A genuine belief in patient-centred care
- ‘Know your community’
- A culture that says ‘we get things done by working with people’, that builds, values and leverages relationships and partnerships
- Embrace transparency and community accountability

The work of Medicare Locals hands them two incredibly powerful levers

for positive change in the health and wellbeing of local communities – information and relationships.

Medicare Locals are required to undertake a population health needs analysis of their community. This means that they develop a valuable picture of what and where the problems are and, if they ‘know their community’, they also know who might be interested in working on those problems. Sometimes achieving change can be as simple as putting the right information in the right hands.

The Gold Coast Medicare Local saw the population health needs analysis task required of it as an opportunity to establish partnerships, build relationships across the community and really get to know their community by inviting them to help build a Health and Wellbeing Plan. They now have a plan that has community ownership, a Medicare Local, Hospital and Health Service and Local Government working from the same page, and trusted, working relationships across the community. That’s a great start.

They also addressed one of the big fears expressed earlier on in the formation of Medicare Locals – ‘how do we manage community expectation?’ The easiest way to ‘manage expectations’ is to have the community understand the problem and help build the solution. Primary care has to be less about what Medicare Locals and health services can ‘do’ for consumers and local communities and more about what can be achieved together.

Some of the biggest challenges in improving primary care lie in rural and regional Australia where the distances are big and the services are sparse. So I will leave the last word to Bob Wells (at the time, Director, Menzies Centre for Health Policy and the Australian Primary Healthcare Research Institute, ANU) who presented at the National Rural Health Conference in Adelaide earlier this year. Bob drew on the work of John Wakerman and John Humphreys. You can read Bob’s presentation on the Conference website, but here are the key factors for success:

- Strong community engagement, from the outset.

*Get the community to agree what the needs are in that community and what services reasonably can be expected to provide those needs. If you don’t get that, the obverse of the*

coin is you probably won't succeed no matter what else you do.

- A good governance structure that people are confident with
- Some flexibility to apply funding, but within the mainstream programs.

And one of the key indicators for failure? 'Professional dominance. If a system is designed in the interest of the providers of the services rather than the needs of the community, that's a pretty clear marker whether a service survives all that long.

So who should you ask about primary care in local communities? The people — the consumers — in those communities. They can tell you what works, and what doesn't.

*Deborah Smith is the Consumer Relationships Manager at the Consumers Health Forum of Australia. She manages CHF's Consumer Representative Program and the Our Health, Our Community Project, a major national initiative by CHF funded*

*by the Australian Government to strengthen the consumer voice in health reform. This work provides leadership development for health consumer and community leaders in consumer and community engagement and provides avenues for everyday Australians to have their say in improving healthcare.*



## Medicare Locals and the social determinants of health

### Di O'Halloran

How are Medicare Locals dealing with the social determinants of health? That was the question asked of Western Sydney Medicare Local recently. The short answer is: with great enthusiasm and many close collaborators.

Some years ago general practice and community health leaders in Western Sydney began sharing their views on equity, the nature of patient-centred care and local priorities. They work in an area where socio-economic and health disadvantage falls below state averages, with Mt Druitt and surrounds suffering deeper disadvantage.

The leaders found to their surprise they had much in common. So they began developing person-centred 'wrap around' models of care for those with complex health and social needs that neither GPs nor Community Health by themselves could adequately help.

One minute a GP may be struggling to support a young mother with a developmentally delayed toddler, a new baby who won't sleep, and perhaps an absent or abusive husband; the next, a frail older person with multiple morbidities, a carer almost as frail, no other family support and unable to afford transport, specialist appointments or medications.

There are now firm expectations that Medicare Locals will work with their communities to influence the socio-economic determinants of health. While this was outside expectations for the former divisions of general practice, many had already begun to work in this area, recognising strong links between socio-economic and health disadvantage. They saw that collaborations extending well beyond health were needed to change inequity in health access and outcomes. Now, this work will be greatly facilitated by formal definition of ML responsibilities in this crucial area.

For Western Sydney ML, this journey started some years ago when the GP division and community health colleagues partnered to establish HealthOne Mt Druitt.

Models of care evolved to enable GPs and their practice staff to team up with community health nurses, allied health professionals and other specialised health services. The circles of involvement widened to other sector services and local community groups, as their contributions to whole person and whole family care emerged.

Now, HealthOne is spreading to every Community Health Centre in western Sydney, with each centre acting as a hub

for design and implementation of local priorities. Community organisations are increasingly approaching their local HealthOne to help shape the most appropriate services.

At the next level up in the health system, local community partnerships have been formed in each of the five local government areas: Blacktown (which includes Mt Druitt), Parramatta, Holroyd, Auburn and the Hills. Managed and supported by the Western Sydney ML, the partnerships bring together people from local health and hospital services, professional groups, local councils, schools, Department of Community Services, Home and Community Care services and non-government organisations.

While HealthOnes are primarily service providers and coordinators, the community partnerships, working within a local health district-ML regional framework, are primarily involved in 'next level up' population health planning, community consultation, and development of local government-specific initiatives.

The initiatives now emerging from the local community partnerships are both practical and diverse. See inset next page for examples:

- Language and speech programs provided in partnership with the Department of Education, local schools and community groups in eight primary schools which have significantly compromised educational development index levels;
- SHAPE Programs: a weight, fitness and nutrition program offering sustained results for participants, and easily modified to suit schools, workplaces, aged care facilities and specific community groups;
- Support programs for refugee communities, including parenting support and youth training and employment support for refugee students;
- Community Access Program which increases support, involvement and access to primary care and specialised services for a range of disadvantaged groups, aided by Blacktown Community Transport's 'Trekker' Bus.

Moving up again to regional level, the Western Sydney Local Health District and the Medicare Local have an established formal partnership with the agreed health priorities of: Child and Family, Chronic and Complex Illness, Aged Care, Mental Health (including Partners in Recovery) and Aboriginal Health (including Close the Gap in partnership with the Aboriginal Medical Service of Western Sydney). Work is well underway in all priority areas, and it is clear that all areas necessarily involve integrated approaches to health and social care and ongoing consumer-community consultation.

So a commitment to achieving strong, integrated primary healthcare automatically targets the socio-economic determinants of health, enhancing equity in health access and outcomes. For the Western Sydney Medicare Local, or WentWest, this commitment permeates everything: our vision, values, objectives and models of care.

At the top end of the health system, how well do government policies support the vast health system in this regard? After many years of waiting,

we do now have several more pieces of the jigsaw in place, and the opportunity to create, for the first time, a “top down, bottom up” health system.

At the very top is the COAG *National Primary Healthcare Strategic Framework*, and below this, Commonwealth-state Bilateral Plans. These key policy documents provide the much needed framework for our collaborative efforts, and both go to the importance of influencing the socio-economic determinants of health. The latter, at least in NSW, looks to partnerships between Local Health Districts/Networks and Medicare Locals to take this forward. That is exactly what we are determined to do.

*Dr Di O'Halloran chairs Western Sydney Medicare Local. She is a Conjoint Professor, Department of General Practice at the University of Western Sydney and is a member of the Western Sydney Local Health District board and the Australian Medicare Local Alliance board. She has worked for a strong, integrated and equitable primary healthcare system, with quality general practice at its centre, for two decades.*

## What Medicare locals have achieved so far

### Arn Sprogis

In a remarkably short time, Medicare Locals have become embedded in the Australian healthcare system and have changed the environment for local communities and consumers in healthcare delivery.

For too long, the focus in discussion and funding has been on hospital bed days and emergency departments. Now, Australians have an organised primary healthcare system through 61 Medicare Locals which are identifying health needs within their local communities, planning effective and efficient health service pathways and supporting integrated delivery of health services all at local community level. This is taking place by working

with and consulting general practice, allied healthcare professionals, and most importantly with consumers and thought leaders at the local level who best know their community's needs. This is about delivering the kind of healthcare communities need and where it counts — at the frontline. One of the major early benefits has been the delivery of healthcare to people who previously didn't receive care or received inadequate care. MLs have made people who were invisible to a centralised health system visible to a local healthcare system.

Medicare Locals are shifting the balance of care towards primary healthcare which gives people an opportunity to receive care in their own space as well

as providing a greater choice in services and access. The ultimate goal is to keep people well and out of hospital and to have the right care delivered by the right person in the right place and not just rely on the hospital system.

With Australia's ageing population and the increasing proportion of adults who are either overweight (35%) or obese (28%), as highlighted in the COAG Reform Council report *Healthcare 2011-12: Comparing performance across Australia*, there is even more demand for an effective, local and integrated primary care sector and MLs are the systems solution.

For the first time in Australia's health history, population health planning is underway in an organised fashion.





Perth Central & East Metro Medicare Local's 'StreetDoctor' truck delivers health services to people who otherwise struggle to access basic healthcare.

LHN. To date it has supported more than 200 clinicians to develop local, web-based pathways accessible at the point of care. By the end of 2012, there were nearly 40 live pathways and more in development.

A fundamental purpose for Medicare Locals has been to improve the nation's after hours care and to find solutions that match the needs of communities. This is challenging but critical for people with young families in particular. Medicare Locals are coming up with innovative solutions that target those most in need. For example: Metro North Brisbane and Greater Metro South Brisbane Medicare Locals are running a 'Street to Home' after hours program to help the region's homeless; and Perth Central & East Medicare Local's 'StreetDoctor' mobile general practice is taking primary healthcare services directly to the most vulnerable people on the streets of Perth's inner city and eastern suburbs.

General practice will remain the cornerstone of Australia's primary healthcare system but it's Medicare Locals' ability to support the GP sector and integrating the allied health to deliver locally-tailored services particularly in immunisation, smoking cessation, Indigenous health programs, chronic disease management and mental health, to name a few areas, which make the consumer experience a more integrated and effective experience.

For those within the health system, Medicare Locals have been a 'disruptive innovation' with their emphasis on local issues, integrated primary care and their communities. The old way of running health systems is giving way to a community way and Medicare Locals have been the success story of the 2010 National Health and Hospitals Network reforms with more to come.

*Dr Arn Sprogis is chair of the Australian Medicare Local Alliance. He has worked on general practice policy with Commonwealth and state governments and Area Health Services for over 20 years. He was CEO of Hunter Urban Division of General Practice, 1992 – 2007.*

Medicare Locals are creating 61 snapshots of Australia's health. They are positioned to inform the nation and health policy drivers about the real state of the nation's standards of health. They are producing a true picture of what's working and what's not working. This is informed decision-making in action.

Medicare Locals are doing the hard, essential and long overdue work to identify where patients are falling through the gaps in terms of access to health services and where duplication is occurring.

For consumers the biggest change that has occurred through Medicare Locals is that finally they are able to have a say in their health system. Medicare Locals are consultative bodies and are listening to their consumer constituents about health service needs. They are not limiting that discussion to just the clinical aspects but the social determinants of health as well and expanding the conversation to healthy environments, preventative health and equity of access. This consumer and community consultation and input is a work in progress not just for MLs but for communities themselves. How this evolves will be a real test for the future of MLs. I look forward to this interaction being a dynamic and exciting part of the work of MLs and is what will deliver real, local community benefits.

This is big picture reform. The health of the populations for which they are responsible, is expected to improve

over time. By embedding a primary healthcare system that can track and map health trends, gaps and needs, it's the work of Medicare Locals through funding the right services and programs that address the gaps and needs, which will ultimately lead to healthier communities. This is about taking a smarter approach with the taxpayer dollar and being transparent.

One of the critical parts of the reform from a consumer perspective are the links between Medicare Locals and Local Hospital Networks (LHNs). For consumers, hospital care can be a major event and making sure they enter and exit the hospital system for the right reason and have a seamless transfer of care is imperative to improve not only their experience of care, but the care itself. An example is the South Adelaide Fleurieu Kangaroo Island ML working with its LHN to improve the safety and quality of discharge plans and clinical handovers.

The Western Sydney and Western NSW Medicare Locals are working with their respective LHNs to better coordinate and connect patients between the primary healthcare and the hospital sectors. Their respective programs are focusing on preventing and managing chronic disease in the community and reducing avoidable hospital episodes through an exchange of information – proof the silos have broken down.

Health Pathways at the Hunter ML is a project running in partnership with its

# Improving primary healthcare: two consumers' views

## **Diana Aspinall and Annette Wickens**

Diana and Annette are health consumers who wanted to contribute positively to health services because they have conditions that require monitoring and care. When consumers are listened to, placed at the centre of care and their voice is heard by the health organisations, positive changes can happen.

Diana is a retired health professional with multiple health conditions. Annette is an accountant. Annette says her experience as a consumer in health goes back to her childhood as her mother had multiple admissions to hospital for life threatening conditions. She helped her mum and dad navigate our complex health system. In 2007, Annette was diagnosed with cancer and underwent surgery twice, along with chemotherapy and radiation. She experienced firsthand the importance of having good processes and communication with her medical team.

Diana got involved because she wanted to ensure that health services were retained in her area. Personally she wants to ensure her health journey whether in acute or primary care is joined up and not fragmented. This can only happen when the health system listens to consumers and changes are made.

Initially the Blue Mountains GP Network formed a Consumer Reference Group (CRG) for people with chronic conditions which led to the opportunity as health consumers to contribute to the submission for the establishment of the Medicare Local organisation for our area. We as consumers advocated for us to be represented at all levels of the Medicare Local including stating in the company's constitution that a Director who had consumer engagement skills would be appointed.

The most important decision was made by the CEOs and the Boards of

the Nepean Blue Mountains Medicare Local (NBMML) and the Nepean Blue Mountains Local Health District (NBMLHD) to join together with consumers to form an Interim Joint Consumer Engagement Committee which Diana chairs and Annette is a member.

Diana used her health skills and worked with consumers to create the Joint NBMML and NBMLHD model of consumer engagement for the four Local Government areas of Lithgow, Blue Mountains, Hawkesbury and Nepean. This model has been showcased at the Australian Medicare Alliance Forum in Adelaide in November 2012, The Consumer Health Forum – "Health Consumer & Community Leaders Workshop" in March and at the Primary Health conference (PHC RIS) in July 2013.

Members of the committee are active consumer representatives on various health committees, contributing to feedback on the development of health resources and programs to ensure they are consumer-friendly, improve quality of care and are evaluated. The Medicare Local recently funded a consumer-led research project to assist people living with a cancer diagnosis in the Blue Mountains and Nepean area.

We have discovered that implementing consumer participation and engagement at all levels means we have to become like a mini Consumer Health Forum of Australia (CHF) in our local area across both the acute and primary healthcare sectors. Thanks to the resources that CHF has developed, we can orientate, train, support and network with all our consumers in both health organisations.

The consumer committee decided to consult with the community and community forums were conducted with 490 local health consumers contributing via workshops and surveys. Consumers with the assistance of the Secretariat analysed and wrote up the results of these consultations including recommendations into four reports that are available at <http://www.nbmml.com.au/> (click on the Community Report box in the right hand bottom corner).

- Consumers identified many different health issues. Some of them were:
- A centralised health information access point for both consumers and staff.
- Major transport and parking concern's in the four areas; high travel costs and compromised access for disabled people.



Consumer advocates Diana Aspinall, left, and Annette Wickens, right, with Nepean Blue Mountains Medicare Local CEO Sheila Holcombe at centre.

- Need for improved communication from health services to consumers.
- Workforce shortage

The reports outline what action the health service organisations have taken to address consumer issues raised. For example a high level transport stakeholder meeting has been held to address transport issues, a submission advocating for increased workforce for the area was sent to Government and there has been updating of information contributing to the National Healthcare Directory. Consumer stories relating their experiences are tabled at Board and Committee meetings via consumer representatives and staff and action is taken to quality improve service delivery and incident reporting.

We as the more experienced health consumer advocates can mentor and support new recruits. This becomes even more important when consumers are representatives on committees that have clinician members who need to be accountable. Annette is the

consumer representative on the Quality Improvement and Safety committee of the NBMLHD Board and her questions of that committee have bought about analysis and change.

From 2011 to 2013 the journey for consumer participation has been very positive but the road has not always been smooth and there have been bumps that have had to be negotiated.

A difficulty is that the NBML has majority funding from the Commonwealth Government and the NBMLHD is funded by NSW Government so collaboration is required.

Both organisations need to work in partnership with consumers and staff to achieve a cultural change that ensures strong consumer participation. How you engage with consumers in the Mental Health and Drug & Alcohol areas requires sensitive support. Consumers' contributions and skills need to be valued. Trust and respect should underpin a two-way experience by staff and consumers.

Annette and I want to acknowledge the commitment of both Boards and the CEOs in the implementation of our comprehensive consumer engagement model. We are working on processes and policies to ensure consumer engagement remains robust. A positive start has been made with more still to be achieved.

*Diana Aspinall has represented consumers as a director on the boards of Arthritis NSW and PainAustralia Ltd and is now on the Nepean Blue Mountains Medicare Local board. She aims to be a voice for consumers in the health system so consumers can play a positive role in the delivery of health services.*

*Annette Wickens is an accountant, married with four children, who contributes her skills and time to Blue Mountains Cancer Help to support people living with a post cancer diagnosis. She is a health consumer representative on local committees.*



## In practice, nurses offer a healthier future for primary care

### Kathy Bell

Without doubt, the pressures on our health system will continue to intensify. Our ageing population along with the way we live is producing an increasing burden of chronic disease. More and more people are being hospitalised with the complications of diabetes, heart disease, kidney disease, and many other illnesses, often in combination. Depression and other mental health problems are part of this picture. Add in the complications of ageing, including a rising tide of dementia, and we clearly have a great deal of work to do.

At the same time, our ageing population means the proportion of retirees to taxpayers will continue to challenge our ability to fund quality, affordable healthcare for all in the years to come. How can we rise to these challenges?

The key to any sustainable solution lies in keeping people as well as possible, out of hospital, and able to live in the community for as long as possible. This not only supports the sustainability of our health and aged care systems – it reflects what people actually want. Studies consistently show that given the choice, the vast majority of people prefer to stay in their own homes and be cared for in the community, rather than being admitted to hospital or residential aged care.

The question is how to achieve this – and the answers are really clear.

We need to stop being over-reliant on hospitals and the aged care sector, and instead make a real investment in building the capacity of general practice and primary healthcare. This will ensure the physical and mental health needs

of our community can be met in the most efficient and person-centred way, supporting Australians to live and age well.

And it can't be all about doctors. There will never be enough doctors to do all that needs to be done in primary healthcare, nor would they want to do it, and nor can the system afford that approach. We need to pay more than lip service to the concept of multidisciplinary primary healthcare teams.

The work nurses perform in general practice and primary healthcare will be a critical part of any solution. Nurses are the largest health profession, and are well equipped to deal with a wide range of health and wellbeing issues.

So, what is the potential for nurses to play a greater role in primary healthcare, what are the barriers to this, and how can these barriers be addressed?

## Nurses show enormous potential but barriers remain

The potential is enormous. There are now around 11,000 nurses working in general practice in Australia<sup>1</sup>, one of the fastest growing workforces in Australia. The majority of general practices employ at least one practice nurse<sup>2</sup>, which is a significant development from where we were in Australia just a couple of decades ago. Primary healthcare nurses, including those working in general practice, play a key role in the management of long-term conditions and in caring for the sick and ageing in our community. The care primary healthcare nurses most commonly provide — preventative health interventions, chronic disease management and coordination, and care for the elderly — is vital in keeping people well and out of hospital and aged care.

But there are a number of barriers to realising the full potential of the primary healthcare nursing workforce.

The first is the lack of a national workforce plan to ensure the future sustainability of the profession. There are major risks to the capacity of the nursing workforce going forward. The *Health Workforce 2025*<sup>3</sup> report predicts a shortage of almost 110,000 nurses in Australia by 2025, and identifies this as a critical risk. This shortage will undoubtedly impact on general practice and primary healthcare. The nursing population in general practice is ageing. Already, more than four in five nurses working in general practice are aged over 40, with the largest cohort being in their fifties<sup>4</sup>.

We need better defined and supported pathways into and up through primary healthcare nursing, so we can attract young nurses to the profession and keep developing their skills and expertise over time, so they stay in the workforce and keep contributing more value.

Another barrier is the financing system currently in place for general practice. Fee-for-service payments to GPs, alongside limited block grants for general practice nurses, perversely reward general practices to maximise GP consultations and throughput, instead of rewarding quality team care.

The financing system must be reformed to support and promote high quality,

person-centred multidisciplinary team care, and ensure good access for all. We need to incentivise the right care, delivered by the right person, in the right setting. The financing system should encourage and reward continuity of care, quality of care, achievement of targeted population health outcomes, and efficiency. Increasing out-of-pocket costs must also be addressed, as they are a real barrier to access for the most disadvantaged in our community.

Finally, we have major institutional and legislative barriers inhibiting full development and utilisation of the skills and expertise of primary healthcare nurses. There has been strong opposition by some professional groups in Australia to the development of advanced nursing roles. Why are primary healthcare nursing roles and scope of practice in Australia so under-developed (and the ratio of primary healthcare nurses to primary care physicians so much lower), in Australia compared with a number of other comparable countries? Are our nurses intrinsically less capable than those in other countries? That is surely not the explanation.

We need to address the institutional and legislative barriers in place in Australia, using a lens that focuses on what is best for the community, not what is best for a particular professional group.

Developing and utilising the full potential of the primary healthcare nursing workforce will help ensure we can deliver high quality, accessible and affordable primary healthcare to our community into the future, keeping people well and out of hospital and aged care. That is in everybody's interests.

*Kathy Bell is CEO of the Australian Primary Healthcare Nurses Association, the peak professional body for 3500 nurses working in primary healthcare including general practice. Previously Kathy was CEO of the Victorian Division of the Heart Foundation, and before that she was CEO of General Practice and Primary Healthcare in the Northern Territory. She has also held positions including in rural health education, the Australian Federation of Homelessness Organisations, and as a senior policy adviser to the National Aboriginal Community Controlled Health Organisation and the Commonwealth Department of Health.*



Photo: Australian Primary Health Care Nurses Association

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# Are current primary health services for Indigenous Australians improving or otherwise? What are the challenges?

## **Dr Tammy Kimpton**

Primary healthcare has an important role to play in improving health outcomes for Aboriginal and Torres Strait Islander people, with research showing that effective primary healthcare can contribute to closing the gap in life expectancy between Indigenous and non-Indigenous populations<sup>1</sup>. Considerable effort and investment in primary healthcare by governments, institutions and other stakeholders over recent years, has led to improvements in some areas of Indigenous health, such as increased birth weights for Indigenous babies and an increase in the number of Indigenous people receiving Chronic Disease Management Plans<sup>2</sup>. Yet, health inequality for Aboriginal and Torres Strait Islander people remains.

According to current data, Aboriginal and Torres Strait Islander people access primary healthcare at a rate that is similar to that of non-Indigenous Australians however this is not at a rate that is appropriate to their needs<sup>3</sup>. Given poorer health outcomes experienced by Aboriginal and Torres Strait Islander people, it is estimated that Indigenous Australians should be seeking primary healthcare, 2-3 times more than the current rate. Partnership and collaboration is required between governments, health professionals, Indigenous peak health organisations and Indigenous communities to address factors that impact on Indigenous people's access to primary healthcare, such as physical barriers, cost and lack of culturally appropriate services to facilitate, promote and increase Indigenous people's access to and utilisation of primary healthcare services.

As a peak Indigenous health organisation, the Australian Indigenous Doctors' Association (AIDA) recognises the importance of culture to the health and wellbeing of Aboriginal and Torres Strait Islander people and understands

that cultural safety issues impact on the decisions of Indigenous people to access and utilise primary healthcare services. By making primary healthcare services more culturally appropriate, Indigenous people are more likely to access primary healthcare, leading to better health outcomes for the Indigenous population. AIDA calls on primary healthcare services to adapt their practice to be culturally safe for Indigenous people and their families by having structures, policies and programs in place that strengthen cultural safety.

A best practice example of addressing cultural safety issues is the Inala Indigenous Health Service, which increased their Aboriginal and Torres Strait Islander client base from 12 in 1994<sup>4</sup> to 10,000 in 2013<sup>5</sup>. By undertaking research at the Health Service, it was revealed that a lot of local Indigenous people avoided using the service for a range of reasons including a lack of flexibility around appointment times and lack of Indigenous staff. After addressing these and other issues and working with local community on making the health service more culturally appropriate, the Inala Indigenous Health Service, now has 10,000 Indigenous patients registered and 8,000 Indigenous clients regularly attending the service, which has led to many important community health gains.

Australia's primary healthcare system must be culturally safe, reflect the needs and integrate the values of Aboriginal and Torres Strait Islander people. AIDA believes that crucial to achieving this are; growing the Indigenous health workforce and increasing the cultural competency of the entire health workforce to work effectively with Indigenous people.

The Aboriginal and Torres Strait Islander community-controlled health sector plays a central role in the provision of culturally safe services to Indigenous people and has an important role in increasing the Indigenous health

workforce. Led by Indigenous people, Aboriginal and Torres Strait Islander community-controlled health organisations compare favourably with mainstream services in providing improved health outcomes for Aboriginal and Torres Strait people<sup>6</sup>, reaffirming that Indigenous people working to improve the health of Indigenous people must continue as the way forward. With a network of over 150 health services, Aboriginal and Torres Strait Islander community-controlled health organisations are one of the largest employers of Indigenous people in Australia<sup>7</sup> and continue to train and empower Indigenous people in the communities in which they live.

Australia's Indigenous health workforce is growing, however Aboriginal and Torres Strait Islander people remain significantly underrepresented across many health professions, including medicine. There are currently around 175 Indigenous doctors in Australia, comprising only 0.3% of the total medical workforce<sup>8</sup>. To ensure that the Indigenous health workforce continues to grow, AIDA asserts that partnership between Indigenous and non-Indigenous people is essential. Such partnerships can be seen in AIDA's Collaboration Agreements which span the entire medical education and training continuum and are recognised as best-practice frameworks for improving the health of Australia's Indigenous people<sup>9</sup>.

While Indigenous health professionals play a central role in the health of Aboriginal and Torres Strait Islander people, it is important that members of the non-Indigenous mainstream health workforce play their part in delivering equitable services for Indigenous people. In mainstream primary healthcare, there is often a low degree of experience in working with Indigenous people, limited cultural competency and clinical focus is often on specific health conditions rather than on comprehensive care<sup>10</sup>. It is

important that Indigenous people feel comfortable in accessing and utilising primary healthcare services and are able to understand and navigate the primary healthcare system. AIDA recommends that all health professionals provide leadership through adapting their practice to improve patient engagement and healthcare outcomes and embed culture in the provision of primary healthcare services to Indigenous people.

National policy documents such as the recent *National Aboriginal and Torres Strait Islander Health Plan 2013-2023*, outline key strategies to contribute to improving health outcomes for Aboriginal and Torres Strait Islander people, with some specific to primary healthcare. These strategies are comprehensive, embedded in culture and address the social and emotional determinants of health which are crucial to the health and well being of Aboriginal and Torres Strait Islander

people. Through implementation of such strategies and collaboration and partnership, we can truly make a change for the better in health outcomes for Indigenous Australians.

*Dr Tammy Kimpton is President of the Australian Indigenous Doctors Association. She is a Palawa woman from Tasmania. Having graduated from the University of Newcastle in 2003, Dr Kimpton undertook her internship training on the New South Wales Central Coast and is currently enrolled in the Australian General Practice Training program. Dr Kimpton is a GP registrar based in Scone, New South Wales*

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## The pharmacists' role in primary care

### Debbie Rigby

Better integration of pharmacists into primary care is an old story to those within the profession, but the need to actually make it happen has never been greater. The ageing population with an increasing burden of chronic disease coupled with a high rate of medication-related problems creates an environment where pharmacists need to contribute more to society than just a dispensing role. An estimated 190,000 medication-related hospital admissions occur each year, with estimated costs of \$660 million.

Pharmacists' knowledge of medicines, their benefits and side effects, is second to none. And yet, too often pharmacists are viewed by consumers and the rest of the medical profession as shopkeepers. Perceptions around being a retailer and healthcare provider create understandable uncertainty in the minds of consumers.

Large warehouse-style discount pharmacies often contrast poorly with smaller suburban pharmacies that do provide quality service and advice on prescription medicines and a vast array of health-related products. Treating minor ailments, information and resources about medicines, and monitoring and screening for many conditions such as diabetes, asthma and high blood pressure are just some of the services available through community pharmacies. Consumers should expect these services from every one of the 5,200 pharmacies in Australia.

Pharmacists also work in hospitals, providing medicines during the stay and on discharge from hospital. However an increasing number of pharmacists are working directly with GPs. Recently Dr Brian Morton from the AMA Council of General Practice stated that pharmacists would be 'an asset in general practice teams' and called for a trial with pharmacists working with

GPs on medication reviews to minimise medication-related problems.

Innovative practice models have evolved in which a pharmacist works from a GP practice, primarily conducting Home Medicine Reviews (HMRs). A HMR is a service provided to any consumer living at home, where a pharmacist visits them for around one hour to discuss their medicines, including herbs and vitamins and over-the-counter medicines. It helps to build consumer's confidence in managing their medicines and identifies any problems or side effects. Consumers can tell the pharmacist 'silly little things' in the privacy of their own home. Those issues may have a huge impact on a consumer's health and well-being, that have not been discussed with their GP or community pharmacist.

One key area where pharmacists can have a significant impact is around improving adherence — medicines don't work in people who don't take them! It is estimated that about half of





consumers with chronic conditions do not take their medications as prescribed. Poor adherence to medications is often a hidden problem.

### Informing consumers on choice

The essence of being a consumer is choice. But that choice needs to be informed. Consumers need information to take care of themselves, and question the options that are available to them. The wealth of information on medicines from the internet, television and radio, newspapers and social media often creates a confusing picture for consumers. Poor adherence to medicines is often due to relationship failure, with GPs and community pharmacists not taking the time to discuss the benefits and harms of medicines. Pharmacists, whether through HMRs or other services, can discuss the necessity of taking a medicine and concerns about taking it.

Other services offered within a community pharmacy, such as dose administration aids, MedsChecks, and medication lists can redefine a pharmacist's role to one of engagement rather than the technical role of dispensing. Consumers want greater access to a pharmacist.

There has been discussion for some time about the concept of a patient-centred medical home (PCMH). International evidence has shown the benefits of

this model in an environment of an ageing population with multiple chronic conditions and spiralling healthcare costs.

The medical home is not a place, but rather a model for providing comprehensive coordinated primary care by multiple healthcare providers, including a pharmacist. PCMH provides structured and coordinated care around the specific needs of each patient with sustained relationships between patients and their PCMH team practitioners. Pharmacists have much to offer this model.

#### Features of a medical home

- Integrated and comprehensive medical practitioner-led team care
- Clinical information systems to support this care, including decision support functions
- Ready access to care when the patient needs it
- Routine patient feedback to medical practitioners
- Patient engagement in care and decision-making
- Patient-centred care with an emphasis on dignity and respect

### Implementation steps

At an individual level, pharmacists need to step outside the cultural norms and take more responsibility for identifying and resolving medication-related problems. Pharmacists with appropriate

skills and experience must be allowed to provide an advanced level of care, in collaboration with GPs in a variety of settings. Medicare Locals have a key role in supporting pharmacists in new environments, outside the four walls of a community pharmacy or a hospital.

Consumers may not understand or appreciate the pharmacists' abilities and potential in a medical home model, so this role may need to be promoted.

Pharmacists are a trusted and accessible source of information and advice about medicines, no matter where they work. Pharmacists have the skills and knowledge to contribute to the quality use of medicines and help consumers to achieve the most benefit from their medicines. They must be given an opportunity to make a greater contribution to primary care.

Pharmacists can incorporate their medication therapy expertise into primary care through a medical home model, to meet the challenges facing an ageing population with increasingly complex medication needs. The scope of practice of a pharmacist needs to expand beyond the current HMR services to a holistic patient-centred approach delivering optimal medication therapy outcomes.

Only with ongoing education, support and encouragement will consumers realise the full benefit of medication therapy. Only when pharmacists work together with general practitioners will they significantly impact on consumer's lives. Consumers need to be sure their care is provided by the right pharmacist, with the right skills, doing the right tasks, with the right support, in the right place.

*Debbie Rigby is a consultant clinical pharmacist from Brisbane with qualifications in pharmacy, clinical pharmacy, geriatric pharmacy, nutritional pharmacy and as an asthma educator. She is a Director on the NPS MedicineWise Board and was recently appointed to the Australian Therapeutic Goods Advisory Council. She has served as Chair and Director of the Australian Association of Consultant Pharmacy (AAPC), and as national vice-president of the Pharmaceutical Society of Australia (PSA). She is also a Fellow of PSA, the Australian College of Pharmacy and the American Society of Consultant Pharmacists. In 2001 she was awarded the PSA Australian Pharmacist of the Year and in 2008 was the inaugural recipient of the AAPC Consultant Pharmacist Award.*

# Medical home can keep patients out of hospital



## Liz Marles

We can count ourselves lucky to live in a country with some of the best healthcare services and facilities in the world. Yet we are often challenged with finding our way through Australia's multifaceted healthcare system, especially when experiencing or helping a loved one with complex and chronic health issues.

As specialists in people, GPs work best when they have an established relationship with a patient. Although each appointment may only be for 15 minutes, over the years this adds up to many hours of conversation, allowing your GP to know your past history, understand your family circumstances, know how you respond to illness, know the other practitioners you see and how you relate to them, and most importantly, what your health priorities are likely to be.

Knowing the patient enables us as GPs to be much more efficient in diagnosis, avoiding repeat tests, identifying patterns, and enhancing the patient journey. We know that where there are more than four prescribers (no matter their background) for an individual, the rate of adverse events and medication errors increases. Fragmenting care opens up cracks, as the GP only receives

part of the story, and responsibility for follow-up becomes much less clear.

The 'medical home' is essentially a high quality general practice where the patient enrolls with the practice to provide that continuity of care. There is now clear evidence that having a 'medical home' saves money in terms of avoidable admissions and redundant tests, and enhances patient satisfaction through a better patient journey. Enrolment allows the creation of registers to facilitate recall and reminders, document improvement and monitor issues such as access.

The Royal Australian College of General Practitioners (RACGP) has long advocated for every Australian to have a nominated 'medical home' and an ongoing therapeutic relationship with a personal GP and is pleased that the notion of a 'medical home' is fast gaining momentum in Australia. The GP's crucial role in the healthcare system has been recently cited as offering patient health, social and economic benefits in prominent healthcare reports and by ministerial representatives.

Primary healthcare services, particularly those provided in general practice, are the most financially and geographically accessible forms of healthcare. Given its accessibility to the vast Australian

population, primary healthcare is the best location for the patient-centred 'medical home' to be facilitated.

So how can we ensure every Australian benefits from a 'medical home'?

The RACGP has made a range of recommendations regarding the need to better support the delivery of patient services in primary healthcare, and encourage the 'medical home', that are designed to enhance, rather than reduce, access to high quality, continuous and coordinated healthcare.

The RACGP believes that all Australians should have the right to have a 'medical home' and that when this is achieved we will see great improvements in the safety and quality of primary healthcare. Having an established and ongoing relationship with a nominated GP should not be underestimated and can prove highly beneficial to patient health outcomes. Have you got a 'medical home'?

*Dr Liz Marles, president of the Royal Australian College of General Practitioners, was a mathematics teacher before returning to university to gain her medical degree. She is a GP supervisor at both the Aboriginal Medical Service in Redfern and at the Hornsby-Brooklyn General Practice Unit in Sydney.*

# International lessons about improving coordination in primary care



## Lesley Russell

The former Australian Government's policy placed primary care at the centre of the healthcare system and to this end, invested \$1.8 billion in Medicare Locals, which were mandated to deliver innovative services responsive to the

needs for the communities they serve.<sup>1</sup>

This potentially means that healthcare services will be better coordinated and increasingly delivered through multidisciplinary teams to ensure the effective management of chronic conditions. It also offers possibilities

for the development of a more comprehensive, preventive focus on health and wellbeing.

Patient enrolment or registration is seen as one means by which continuity and coordination of patient care can be improved. While a high proportion of



Primary care at home in New Zealand. Photo: Waikato District Health Board.

Australians use only one general practice for their care,<sup>2</sup> more formal, structured approaches to patient enrolment have been proposed as a platform for policy and program initiatives to facilitate improved coordination of care, particularly for patients with chronic and complex care needs. There is also evidence that such initiatives offer real possibilities for addressing disparities in access and quality, communication failures and medical errors.<sup>3</sup>

Patient enrolment models are features of the healthcare systems of many countries, including the United Kingdom, the Netherlands, Norway, Denmark, New Zealand, and for specific populations and/or provinces in Canada, Germany and the United States.<sup>4</sup> The formal patient links with an identifiable source of care are variously known as registration, enrolment, rostering or personal lists.

In many cases, care coordination is not the primary goal of enrolment. However increasingly, countries such as those listed are instituting policies and incentives to hold primary care practices accountable for managing chronic conditions and meeting associated clinical standards. The main drivers include financial incentives and primary care practice redesign, with an emphasis on information technology and teams to support effective, safe, patient-centred, coordinated and efficient care.<sup>5</sup>

The evidence about what works is confused. In the Netherlands, evidence indicates that the use of patient enrolment strengthens continuity of care and provides the capacity and incentive to focus on community health.<sup>6</sup> Germany traditionally has had a weak primary care system, but the implementation of

disease management programs with voluntary enrolment has had reasonable success.<sup>7</sup> In contrast, despite a strong primary care sector, mandatory enrolment, financial incentives for quality and good integration with social services, England's National Health Service is assessed by authoritative sources such as the Kings Trust as not having good care coordination.<sup>8</sup> And Denmark, where a strong primary care system is supported by e-health records and incentives for patient enrolment, is struggling to implement care coordination programs.<sup>9</sup>

The New Zealand experience has been described as endorsing the concept of the Patient Centred Medical Home (PCMH)<sup>10</sup> and there is evidence that it has also helped ameliorate health disparities.<sup>11</sup> However information about care coordination is scarce and it is not clear if the health gains achieved are attributable to changes in the primary care system or to the introduction of enrolment arrangements. Ironically the United States - always an outlier - presents the best examples of how enrolment and care coordination programs can improve health outcomes and reduce healthcare costs, particularly when this is done through the PCMH approach.<sup>12</sup>

While enrolment is clearly not the silver bullet needed to deliver reforms in care continuity and coordination, it does offer other real opportunities. Patient enrolment, at a geographic or practice level, enables a population health approach to prevention, the assessment of regional healthcare needs so that resources are effectively targeted, and future planning.

Although most of the literature states that Australia does not have patient

enrolment,<sup>13</sup> this has been part of several initiatives that are (or were) explicitly about care coordination.<sup>14</sup> In addition, calls have been made in the context of recent healthcare reform for Australia to consider implementation of some form of patient enrolment.<sup>15</sup>

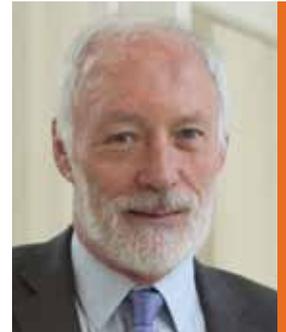
It is imperative that we look at where Australian and similar healthcare systems internationally have been in this regard and make an explicit and accurate analysis of costs and benefits, what worked, what failed and why. That evidence then offers a real possibility, through the auspices of Medicare Locals, or similar regionally-based organisations, to reconfigure primary care into a primary healthcare system that can cope with the sort of health and healthcare challenges Australia is currently facing.

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# Mental health needs mature attention



## Pat McGorry

With one in four of us experiencing some form of mental ill-health in our lifetime, mental illness poses one of the greatest threats to our own health and wellbeing, as well as to the social and economic health of the nation. We now understand that mental health is everyone's business, and want a better deal for those living with mental illness, whether it be a family member, friend or colleague. Greater awareness has been fostered, especially by *beyondblue* and SANE. Repeated National Mental Health Surveys reveal substantial unmet need, and a shameful gap in access and quality of care between physical and mental healthcare. This results in so much unnecessary suffering and wasted potential.

The old system of asylum based care for the mentally ill was dismantled because it did a lot more harm than good. I remember very well the crude and traumatic care that was a hallmark of those days. We all hoped that with the mainstreaming of mental healthcare with physical healthcare in the 1990's that those days were behind us. Evidently not. Historically, from the 1970s, beds were created within acute hospitals and a minimalist community mental health system was established as a "base camp" for ongoing care. State governments never really got beyond this base camp and have actually

retreated down the mountain. The post-asylum system was not built to scale, and has buckled under the strain of rising demand and population growth. Mental healthcare has retreated from its embryonic community base, with risk management now overshadowing care and the magnetic pull of the emergency department taking over. The ambulances are all at the bottom of the cliff. The system has largely abandoned acute care in the community to the ambulance system, the police and the emergency departments, in that order. The poorly-targeted investment in NGO-based programs has fragmented care further, with poor coordination and widespread confusion the rule. Rather than dealing with the fundamental problem here, we are apparently to have more coordinators. Even the grossly inadequate budgets that are allocated to mental health within the public health system have not been ring-fenced, and in the cash-strapped environment of acute hospitals, the block-funded community mental health resources are a soft target for the insatiable needs of other health areas that are perceived to be more pressing. Things are likely to worsen unless community mental healthcare is included in activity-based funding.

## Inpatient care in parlous state

Heartened by the lessons of the NDIS, our best hope is for a dramatically

stronger Federal Government stake in the leadership, design, funding and governance of community mental healthcare, which should be linked conceptually and operationally to primary care, with the States retaining responsibility for hospital care. It would allow them to concentrate on fixing a serious problem. Inpatient care is in a parlous state Australia-wide with very negative experiences for staff and patients alike. It is in urgent need of root-and-branch redesign, with a serious review of work practices and an expansion of alternatives also needed.

However, there has been more positive evidence of transformational reform from the Federal side, though its future is in the balance. The advent of much stronger support for the role of primary care and allied health in mental healthcare and for a wide variety of psychosocial programs was a major contribution of the Howard government. The establishment in 2006, of **headspace**, Australia's National Youth Mental Health Foundation, was a major innovation that built on these reforms.

The Gillard government, through the leadership of Mark Butler and with the personal support of the Prime Minister, continued and added to these reforms, producing a significant initial package of investment and reform in 2011, which did cover the full lifespan. This was claimed to be a first step in a ten-year program

of further growth and investment in mental healthcare, though competition from other policy initiatives distracted the government from this commitment.

For the next government, there are several examples of what we can be prioritised with assertive community treatment, employment programs, “housing first” programs and early intervention for young people all ready to go nationally. We must go with the best buys and the transformational investments.

The partnership between EPPIC and **headspace**, which has bipartisan support, represents a transformational reform in the provision of mental healthcare not only in Australia, but world-wide. There is intense interest in this Australian innovation in Europe and North America, where youth mental health is increasingly seen as a major priority. In addition to completing this reform agenda, we also need similar federally funded and led initiatives in housing, employment and primary care-

based community mental healthcare for children, older adults and the elderly.

I have said many times that the structural issues of system design, health financing and governance need urgent review and especially the morass of State-Federal responsibilities. This will need a national inquiry into the mainstreaming of mental healthcare and the roles of State and Federal governments. It is pleasing to see both major parties sign up to this in one form or other.

Above all, the public need to take some responsibility here and demand the same quality of healthcare for mental health as they expect when they develop cancer or diabetes. My personal view, fueled by the harsh day-to-day experiences of so many ordinary Australians, is that while we have solutions at hand we need to mature as a sector, fight a lot harder for those impacted by mental ill-health and not merely for our own organizational goals, and in the current financial

environment ensure that we invest wisely in transformational evidence-based programs that will be successful and represent the “best buys” in mental healthcare.

*Professor Patrick McGorry AO is executive director, Orygen Youth Health Research Centre which includes a clinical service targeting the needs of young people with emerging serious mental illness. He is also Professor of Youth Mental Health at the University of Melbourne and a founding member of the National Youth Mental Health Foundation (headspace) Board, and the current President of the Australasian Society for Psychiatry Research. He is a leading researcher in early psychosis and youth mental health and has played an integral role in the development of effective treatments that have helped transform the lives of tens of thousands of young people the world over. He has been the recipient of numerous awards, including Australian of the Year 2010.*



## Connecting for better health

### **Melissa Sweet**

**Kate Granger** is a young doctor in England who enjoys looking after older people. She is also a social media enthusiast, using her blog The Other Side and Twitter (@GrangerKate) to share her experiences of being a patient with terminal cancer.

In August, Kate was admitted to hospital with a potentially serious case of sepsis after an operation. Over the next few days, she tweeted about some of the good and bad aspects of her care.

She described having to ask staff to wash their hands before touching her, and how some did not call her by her name, even referring to her as “bed 7”.

In response, she created a Twitter hashtag “#hellomynameis” to encourage wider discussion about the importance of health professionals and other healthcare staff taking the time to know patients’ names. (A hashtag is a way of

creating topics for discussion on Twitter and tracking them).

“I have had to ask the names of four members of staff as they did not introduce themselves,” she tweeted. “I’ll keep banging on about them but the little things are so important when you’re in a vulnerable place as a patient. A smile costs nothing...”

After a near-miss with a potentially serious mistake with her medication, she made some suggestions for how the hospital might avoid such mistakes in future.

Later she tweeted, “Patients can sometimes be very active participants in patient safety...The secret patient observer is an incredibly powerful position to make radical changes to how we work in the NHS.”

Kate also tweeted about the positives of her time in hospital, the staff who were kind and helpful, and the people on Twitter who had provided useful

suggestions to help improve her care.

She said: “I was utterly overwhelmed by the Twitter response to my illness. I received literally hundreds of tweets. It was hard to keep up with them all, but got me thinking about how Twitter will respond when I die too...”

After being discharged home, she compiled a Storify, turning all her tweets into a “story” based on her tweets from hospital. (<http://storify.com/katemgranger/the-other-side-live>) (Storify is an online platform for combining tweets into a type of Twitter-based story).

I first came across this Storify thanks to Dr Tim Senior, a GP whom I follow on Twitter and admire for his patient and community focus.

### Health’s MUST READ

Tim tweeted a link to Kate’s article describing it as a “beautiful, brave honest use of Twitter to improve patient safety”

and “a MUST READ for all working in health services.”

As a result of Kate’s Storify, a nurse called Hayley, who works in acute care in Wales, wrote on her blog about what she took from Kate’s experiences. Hayley’s blog is called “Improving my practice by reflecting on it”, and she titled this particular post “#mynameis”.

Hayley described how she makes a conscious effort to ask patients how they’d like to be addressed, and to speak to them by name, as a way of helping patients feel they can ask for the things they need or want.

“I firmly believe that seeing care from the patient’s perspective can only improve the quality of the care we provide,” Hayley wrote.

While this particular example of how social media is transforming the way the world interacts centres upon hospital care, its broader themes also resonate for primary care.

Social media is enabling patients to provide real-time feedback to health services and health professionals wherever they work — and platforms like Patient Opinion (<https://www.patientopinion.org.au/>) are increasing the chances that this feedback will be heard and acted upon.

Patients have shared their stories through this site about their experiences, good and bad, with GPs, Medicare Locals and primary care services. And I’m sure everyone reading this journal knows about the Consumers Health Forum’s website, *OurHealth*, which also enables consumers and consumer advocates to share their experiences and reflections.

Kate’s story is also a reminder of how anyone with an Internet connection can potentially crowd-source the world — whether you are looking for information and advice, or support and help.

While there are many examples of health organisations and health services providing excellent information and advice for patients and communities online, my guess would be that much more could be done in this area. It can be difficult for busy services to prioritise online development but if they do not, an important opportunity is wasted.

For those who like writing about their experiences with health matters — whether it’s about how to prepare cheap, healthy meals or how to manage chronic pain — it’s easier than ever to become a published author or a DIY publisher.

Not only does this help enable writing as therapy, it helps increase the chances that you can connect with people who share your interests and needs.

### Twitter therapy

The Internet is also powerful tool for community development — whether developing a community of interest around a particular health issue or condition, or around geography, or even a particular health service.

A good example of this is how the Twitter hashtag #hcsmanz has been used to develop a network of people — including researchers, health professionals and community members — who are interested in social media and health. If you haven’t already, check out this hashtag and the Twitter chats held by this group.

And of course we’ve seen the rise of all sorts of online community activism for health, whether it’s a small Victorian community like Tecoma saying no to McDonald’s, or the Game Changer campaign run by **Aaron Schultz**, a Tasmanian father who wants to stop alcohol and fast food marketing in sport.

As the mass media fragments into masses of media, issues that once struggled to get a voice in the mainstream media — like Aboriginal and Torres Strait Islander health — are carving out a vibrant space on social media channels.

As I write this article, I am watching a rich flow of tweets from the 12th Australian Palliative Care Conference in Canberra. I can’t be there in person, but thanks to the energetic “citizen journalists” at the conference, I can still get a good sense of the speakers and discussions and also online links to useful new resources.

Indeed, **Ita Buttrose**, the national president of Alzheimers Australia, urged conference delegates to use social media to share stories and encourage discussions about death and dying in the community.

When social media hits the mainstream media headlines, it tends to be a “bad news” story about abusive or inappropriate behaviour. But what I see every day is how the Internet is enabling connection for social good and better health.

Given the potential of our “global commons” for enhancing health and healthcare, the need to address the digital divide is pressing.



Photo: Carter Moore CHF

Digital literacy is a critical component of health literacy, and it is vital that governments, health services and the community work together to increase the digital literacy of the general public, particularly those in greatest need and who are most vulnerable. Medicare Locals have an important role to play here.

We don’t all have the specialist knowledge of doctors like **Kate Granger** to help us negotiate the complexities of healthcare.

But if we are connected and digitally literate, we can find their expertise at our fingertips, learn from their wisdom and experiences, and share this enrichment with our own digital networks.

See: <http://storify.com/katemgranger/the-other-side-live>

*Melissa Sweet is an independent health journalist who moderates the public health blog Croakey (@croakeyblog), and is doing a PhD in Indigenous health and journalism at Canberra University. She has an honorary position as Adjunct Senior Lecturer in the School of Public Health at the University of Sydney.*



# Are medicare locals delivering value for money?

## Leanne Wells

Our systems, financing regimes and structures have held us back in health. This is a policy conundrum that has transcended both Coalition and Labor national governments. A 2006 Parliamentary inquiry into health funding recognised that the 'blame game' between the Commonwealth and the states for the failings of the health system does not benefit patients. Patients don't care which level of government manages or pays for their healthcare<sup>1</sup>. The 2009 National Health and Hospitals Reform Commission described a fragmented health system ill-equipped to respond to the challenges it faced<sup>2</sup>. The Commission and the many stakeholders who made submissions concluded that the case for health reform was compelling. Structural change and a more patient-centric system based on the healthcare home were seen as key solutions.

The establishment of Divisions of General Practice prior to both these reviews was considered by many to be the most significant structural reform since Medicare. The 2003 Howard Government review of the Divisions (Phillips Review) found that their value was in achieving systemic improvements in local primary healthcare that could not be achieved by individual GPs working alone. Phillips concluded that the entire Divisions network should play a stronger and more consistent role in primary healthcare and serving communities<sup>3</sup>.

There are several 'take out' messages from these particular reviews and inquiries relevant to the question of the value of Medicare Locals. They are messages backed by the international literature. Strengthening primary healthcare and the way in which it is organised, supported and funded is required if we are to improve the health system and the degree to which healthcare is better coordinated and connected. Some form of 'meso' or regional structure that has strong clinical leadership, responsibility for some elements of health resources and local

knowledge of the health economy and the factors that impact it is essential to a more organised, responsive and integrated healthcare system. These structures are typically known as primary healthcare organisations (PHCOs).

Medicare Locals are Australia's PHCOs. We are not alone in establishing these types of organisations as part of our health architecture: there is a global movement towards this more organised form of primary healthcare. In countries where they exist, PHCO's core work is to improve health outcomes, manage demand and control costs, to engage primary care physicians, enable greater integration of health services, develop more accessible services in community and primary care settings, enable greater scrutiny and assurance of the quality of primary care services<sup>4</sup>.

Just over two years into their formation Medicare Locals are making inroads to tackling the 'wicked problems' that have eluded us in the past. Medicare Locals' value lie in their capacity to harness local knowledge, link the system, drive community-led best solutions and deliver and coordinate front-line services.

Medicare Locals are planners and have conducted whole-of-region population profiles and health needs assessments. These will become deeper and richer as more data emerges and community insights are gathered. All are available for public scrutiny. Medicare Locals identify gaps in services and fill them by coordinating, funding or directly providing new or enhanced services. All provide solutions to urgent after hours care across the country and coordinate primary care-based psychological services. With flexible funding, a myriad of other gaps in services are also being filled with solutions that draw on local input and partnerships. These range from pain clinics, to GP aged care day services to family care centres.

In many regional, rural and remote areas of Australia the Medicare Local is the main provider of primary healthcare services - without them the services would not exist. Medicare

Locals integrate by working with their hospital, aged care and social care sectors to redesign, strengthen and improve services so that the patient and community experience of care is better joined up and the transitions of care are smoother. They support local primary healthcare clinicians who would otherwise remain isolated to network and develop as a workforce through a range of multidisciplinary learning opportunities. These are all the system benefits of Medicare Locals.

From a consumer and community perspective, the value of Medicare Locals also lies in their capacity to support public voice, public participation and community engagement in the design of local programs and services. Involving the whole community in priority setting and decision making alongside clinicians about local health solutions is something that centralised administrations are challenged to do well. It is useful to conceive of Medicare Locals as 'backbone' organisations. Backbone organisations are typically the 'neutral brokers' that bring stakeholders together to set a common vision and strategy, support aligned activity, established shared measurements of success, build public will, advance policy and mobilise funding<sup>5</sup>. Medicare Locals bring value as change agents to the acute, social and aged care sectors. The role they have played in designing and coordinating local responses to the Partners in Recovery mental health initiative illustrates this function well.

On the proposition that Medicare Locals will foster another layer of bureaucracy in the health system, we have to accept that a certain level of management and administration is required to translate policy into programs and services. What we should really be asking is: at what level in the system is health leadership and management most effective? Is it best centrally done or on a more decentralised, devolved basis? In a country with the geographical and socio-economic diversity of Australia, agile, regionalised approaches to health

governance and leadership will deliver the best gains.

Medicare Locals are independent, locally governed not-for-profit organisations. They operate and are regulated under company law and are accountable directly to both their members and the community. They are independently governed by local lead clinicians and other skills-based directors who are close to the system and the issues. They are staffed by front line workers and people experienced in health management, program and service design. Together this governance and staff profile mean that Medicare Locals are well placed to make decisions about solutions and services that respond to local need. Both clinicians and managers are needed in leadership roles in Medicare Locals – it is not a ‘either/or’ debate. There’s a body of thinking which largely stems from the UK that effective primary healthcare organisations require and should nurture “clinically intelligent” managers and “managerially-intelligent” clinicians. This is a very different paradigm to the way we think about traditional government bureaucracy and is the best way to think about Medicare Local governance, leadership and management.

Medicare Locals are an alternative form of health system management. Decision making by people close to the action who know what is happening in local health systems equates to more responsive services better targeted to the needs and profiles of communities. With these emergent governance, leadership and management characteristics, their genesis in the divisions of general practice, and the right policy levers that enable them to be ‘full function’ PHCOs, Medicare Locals are poised to spearhead a new paradigm of healthcare in Australia. This is where the potential future value lies.

*Leanne Wells is CEO of the ACT Medicare Local. She previously served as CEO of the Australian General Practice Network and was Transitional CEO of the Australian Medicare Local Alliance. She has also been a senior public servant in health, family and aged care portfolios. She is a member of the Australian Institute of Company Directors and the Australian Institute of Management.*

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Photo: ACT Medicare Local

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## Greens vision for primary healthcare

### **Richard Di Natale**

Sadly, when election time comes around the health debate often devolves into a superficial discussion of hospital emergency department waiting times and elective surgery waiting lists. With this election just gone, we didn't even get that. It was a wasted opportunity to discuss the most important issue to many people.

The Greens did our best to put some new ideas on the table. A big part of our health policy was aimed at bolstering primary and preventative healthcare. We understand that better primary care is crucial if we want to help people stay healthy instead of just treating them when they get really sick.

Taking steps to prevent illness and to minimise the risks to a patient's health is not only good for people, it's good medicine for our economy. The demographics of an ageing population and a rising burden of chronic disease signal an ever-increasing pressure on every single dollar of health expenditure. This makes investment in our primary healthcare system all the more important.

Our healthcare system will have to become more flexible in the future and strengthening primary care is the key to a more sustainable and efficient health system. The Greens believe that there are several reforms that could help keep people well for longer and meet some of Australia's more urgent health challenges.

Firstly we must address the false economy inherent in rising out-of-pocket costs. The good work done by the Consumer's Health Forum and other groups acting as the "Mend Medicare" coalition has helped to highlight this growing problem. If people are skipping doctor visits, medicines or allied health therapies it can only accelerate their next trip to the emergency department. We can start by properly funding Medicare – restoring the \$664 million taken out at the last budget first and foremost - and doing everything we can to keep bulk-billing rates high.

The time has also come for a review of how we fund things through Medicare. As a parliamentarian I often hear from health groups that want greater access

to the public purse – it's what lobbyists are paid to do. While it is not easy for an individual MP, or even the health minister, to make a call on each claim, it's clear to me that there are many instances where expanding Medicare coverage could save money in the long run. Whether it's properly funding podiatrists to manage diabetic foot or expanding the rights of physios to refer patients to specialists or imaging services, we need a more transparent process that will examine new proposals in a timely manner and examine their costs and benefits in a robust way.

There is also scope for us to be more innovative around the management of chronic disease. When conditions such as type 2 diabetes or chronic heart disease are not properly managed, an expensive hospitalisation is only a matter of time. Efforts to move beyond fee-for-service in this area have been difficult. Medicare Locals present an opportunity to do better population health planning, to tackle gaps in services and to make it easier for patients to navigate the healthcare landscape. Some might not be working at capacity yet but I hope they will be properly funded around the country so we can explore better models for the care of chronic disease patients.

As many readers will know, the Greens have made dental care reform one of our top health priorities. The high cost of dental care — with over 60% of oral health expenditure coming right out of the pockets of patients — is a huge barrier to treatment. As a result, your income is an excellent predictor of your dental health. This can have enormous consequences because untreated dental disease can lead to life-threatening complications and lengthy hospital stays.

The line that separates the mouth from the rest of the body has no physical basis; it exists only in the Medicare regulations. The Greens have long called for dental treatment to be brought fully under the primary care umbrella. We want to see dental treatment included in Medicare so that everyone can see a dentist as easily as they currently see a GP. This is about equity and fidelity to the idea of universal healthcare, but it is also about preventing the 60,000 annual presentations to hospital for untreated dental disease. As our fully-costed policy showed, Australia can afford to close this gap.

I understand that much more needs to be done to reduce out-of-pocket costs. That's why the Greens have committed to referring the issue of rising costs to a Senate Inquiry in this next term of Parliament.

We also need to ensure that more services can be delivered in the home, and that we take advantage of technological advances that allow people to be monitored while still at home. If doctors, nurses, pharmacists and allied health providers can communicate effectively with a patient and with each other we can keep people at home longer. Not only will this save money but it will spare us and our families the upset of a hospital stay and the risks inherent in any admission to hospital.

Health reform must start and end with primary care. We need to protect our relationship with our GP, and allied health providers should become even more prominent in our future healthcare. By prioritising, reforming and investing in primary healthcare we can all spend less time in hospital, save the health system money, and enjoy a higher quality of life.

*Senator Richard Di Natale is the Australian Greens health spokesperson. Before entering parliament in 2010 he was a GP and public health specialist. He worked in Aboriginal health in the Northern Territory, on HIV prevention in India and in the drug and alcohol sector. His key health priorities include preventative health, public dental care and responding to the health impacts of climate change.*

## Disability scheme a pointer for primary care

An individual's choice and control is at the heart of DisabilityCare Australia's delivery of the national disability insurance scheme.

And this approach under the National Disability Insurance Scheme (NDIS) may offer valuable pointers in the development of primary care in Australia, given suggestions for the need to strengthen patient choice in healthcare.

DisabilityCare Australia is a new way of providing individualised support for people with permanent and significant disability, their families and carers. It provides reasonable and necessary

supports needed for people to live more independently and work towards achieving their goals.

This reform, which commenced from 1 July 2013 for eligible people in four launch sites, has been long-awaited by many people with disability, their families and carers.

By 2019, it is estimated that the scheme will be supporting almost half a million Australians.

For too long, people with disability have faced a system described by the Productivity Commission as inefficient, unfair and underfunded.

Most people did not get the support

they needed or a choice about how the supports they needed were provided. Many were not in control about how they wanted to live their life.

DisabilityCare Australia will change the way a person with disability will be able to access the supports they need. It will also ensure that they have the same controls as others in society around who they seek to purchase supports from.

The scheme takes a lifelong approach to supporting people with disability through individualised funding. This means that rather than providing support based on the number of places in a limited number of programs, the

scheme will provide participants with the opportunity to plan for their future and will ensure that they are able to access mainstream and community supports that can help them work towards that future. The Scheme will also provide funding to enable the participant to access the care and support they need.

Importantly, a number of tools and information products have been developed to assist participants to think about their needs and scope what a good life would look like to them. The Agency also provides local area coordinators who can assist participants to plan and think about their goals.

DisabilityCare Australia is a nationally based scheme with funding and governance shared among all governments. The Agency holds all funds contributed by the Commonwealth, States and Territories in a single pool, manages scheme funds, administers access to the scheme and approves the payment of individualised support packages.

In his speech at the Scheme's launch on 1 July, Board Chairman Bruce Bonyhady said DisabilityCare Australia would hold true to its mission to give people with disability control and choice and to put people with disability, their families and carers at the centre of the system.

He said this organising philosophy was clearly stated in the legislation and regulations as well as set out in the objects and principles of the *National Disability Insurance Scheme Act 2013*.

"Control and choice is also central to the UN Convention on the Rights of People with Disability, which also forms part of the Objects of the NDIS Act and is listed first," Mr Bonyhady said.

"Control and choice is so important because it is an essential ingredient to the well-being of people with disability, their families and carers.

"It is simple. People who are in control experience much higher levels of self-esteem than those who are not in control and do not have choices."

Mr Bonyhady said choice and control was also essential if a new market for disability services was going to emerge.

"It is also essential to always keep central the primary purpose of the NDIS – to change the lives of people with disability, their families and carers for the better; to enable people with disability to fully participate in the social and economic life of the nation, to live ordinary lives and hence to break down the last barrier

to practical civil rights in this country; to ensure that in 20 and 30 years, when we look back on this time, we see this time as the Mabo moment for people with disability, their families and carers."

The NDIS Act 2013 states that the "preparation, review and replacement of a participant's plan, and the management of the funding for supports under a participant's plan, should so far as reasonably practicable: be individualised; and be directed by the participant; and where relevant, consider and respect the role of family, carers and other persons who are significant in the life of the participant".

The scheme's operational guidelines say that the "participant's statement of goals and aspirations is the crucial first step in preparing the participant's plan and provides the foundation for the subsequent selection of supports".

While developing and implementing a support plan, individuals have the flexibility to choose how and when supports are provided. This can include accessing mainstream and community supports, choosing support providers, choosing to change providers, and considering how formal supports fit best with those provided informally by family, friends and other carers.

Individuals choose how to manage their plan. For example, a person may decide to manage their plan themselves; nominate another person to manage their plan; choose to use a registered plan management provider; ask DisabilityCare Australia to manage the plan; or use a combination of these options.

The individual can arrange the details of their support, such as when and how they will receive their supports, directly with their chosen provider.

Everyone's life changes over time. Individuals can change their goals and plan, which will change the supports they need, how supports are provided, and who provides these supports.

DisabilityCare Australia recognises that some people want family, carers, friends or others to be part of decision-making or to take part in the planning process.

Lynne, of Geelong, was pleased with the control and choice she had in the development of her DisabilityCare Australia plan.

"I have a package that I can call my own," she said.

"Now I am finally getting the support I need."

Another participant, Catherine, of Newcastle, said: "It's around me saying this is the support I like, this is the support I need and this is what I would like to do with this support, and this is when I would like to have it."

*This article was prepared by DisabilityCare Australia at the request of Health Voices.*

*For more information about DisabilityCare Australia and the rollout of the scheme, visit [www.disabilitycareaustralia.gov.au](http://www.disabilitycareaustralia.gov.au) or call 1800 800 110.*

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