Consumer Priorities for a National Health Plan

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Consumers Health Forum of Australia is funded by the Australian Government as the peak healthcare consumer organisation under the Health Peak and Advisory Bodies Programme.
Our key directions

Health systems need to maximise the effectiveness and efficiency of health services and long-term care; deliver seamless care across services and providers; they also need, fundamentally, to deliver improvements that matter to patients and their changing care needs. We share with our people and clinical leaders the view that “people-centred care” should better guide the course taken by health care in the future.


Despite Australia’s favourable performance ranking overall when compared to other OECD countries, all too often the Consumers Health Forum of Australia (CHF) frequently hears from our members and networks that that the consumer experience of the Australian health system is one of disconnected and poorly coordinated care.

Too often we only rely on measures of what health systems do, and how much they cost, rather than their effects on patients. It is time to ask patients: what matters to you and for the system to respond accordingly.

In modern health systems in developed economies we must take experience of care to be an equal measure of the performance of our health system and whether or not it is meeting the expectations of the community. Experience of care measures must have prominence within the ‘quadruple aims’ that are commonly accepted as measures of health system performance: enhancing patient experience; improving population health, lowering costs; and improving work life of health care providers.

This issues paper outlines a consumer perspective on the key design principles and elements which should be incorporated in the four pillars envisaged as part of a national health plan for Australia. It has been developed with the input of over 20 CHF members, representing a cross-section of our members, who expressed interest in attending a Consumer and Community Ministerial Roundtable in August 2017, the Mental Health Consumers and Carers Forum and other key informants such as representatives from Primary Health Networks (PHNs).

We believe there are two essential priorities that we must start with:

- Reforms to strengthen Australia’s primary health care system to make it more consumer-centred, prevention oriented, better integrated with hospital and social care and with more capacity to support transitions of care; and
- Greater investment in health systems research and arrangements to ensure the national research agenda is shaped by consumer and community priorities, that the findings stimulate improvements in services and our national medical and health research funds are spent wisely.

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New approaches to consumer and community involvement in decision making at all levels in the system should be part of the process for developing a long term national health plan. Whether it is at the point of care or in policy design, when consumers are activated and supported to be involved, better experiences of care, quality of care and health outcomes result.

New ways of working with consumers and communities

- Resource health consumer organisations (HCOs) in a long term sustainable manner to support knowledgeable and skilled people to participate in all areas of the health sector, including through: health policy, decision making, health service standards setting and monitoring, health research, and co-design of service development, accreditation and evaluation.

- Support a programme to ensure healthcare consumers are involved in shaping the underpinning policy and implementation of the health reform agenda including:
  - Innovative ways to gather and synthesise consumer experience and knowledge about the health system at regular intervals
  - A consumer and community panel, independent of government which is chaired by CHF as the peak body for Australian health care consumers and those with an interest in healthcare consumer affairs, to harness the views of consumers, engaged citizens, the volunteer sector, carers, and other stakeholders with a window on the system such as representatives from PHN Consumer and Community Advisory Councils and synthesise these insights in order to best inform the development of a long term national health plan.
  - Develop and adopt validated Patient Reported Experience and Outcomes Measures consistently across key service settings such as hospitals and Health Care Homes, link them with current and future accreditation processes, and work with these organisations to ensure that the findings from these measures are considered and meaningfully implemented
  - Support programs to build a network of consumer leaders to work in partnership with PHNs, local clinicians and other stakeholders to ensure evidence-based, needs-informed regional commissioning plans.

Integrated primary health care: one system

At point of care delivery:

- The internationally recognised concept of a patient-centred health care home (PCHCH) is the optimal model of consumer and family-centred primary health care delivery that Australia should be working towards.

- The current Commonwealth Health Care Home (HCH) programme should be appropriately resourced, implemented and independently evaluated as a first step toward moves to feature patient centred health care home practices more broadly in the Australian primary health care landscape. The evaluation must be co-designed and include measurement of consumer experience and outcomes using validated tools. Wide stakeholder consultation with both clinical and consumer groups should determine future stages.

- Concurrently, the limitations of the HCH programme should be recognised and PHNs should be funded to work with local clinical and consumer advisers to build on and extend
the model in order to accelerate the spread of the PCHCH approach. While the international evidence is that there is no one single way to implement PCHCH\textsuperscript{2}, there are a range of elements which are consistently found in the best performing models and should be mandatory features in any wider implementation in Australia such as self-management support, decision support, electronic shared health records, voluntary enrolment and a patient-team partnership\textsuperscript{3 4}.

- Regionalised implementation of PCHC homes should occur within a policy framework. This framework must assure a level of consistency in design and be a guarantee that ensures quality, safety and high standards. It should facilitate PHNs to work with local clinical leaders and their communities to locally adapt HCHs to demonstrate how additional features such as social prescribing, flexible preventive care arrangements evidence-based self-management programs could be integrated.

- Pharmacists and other allied health professionals should be better equipped to work in collaboration and their roles better integrated with general practice. An enhanced primary health care role for pharmacists within their scope of practice should be implemented and evolving models of non-prescribing pharmacists working in general practice should be made more widespread, particularly in the context of the Health Care Homes Programme. The $30 million earmarked by HCH Programme support in the 2017 Federal Budget should be devolved to either participating practices or PHNs to ensure integration with HCH implementation at the service delivery level. This will ensure the funding is best targeted to the needs of enrolled patients in HCH practices.

**At the regional level:**

- PHNs need to be given the mandate, resources and explicit responsibility for creating more effective and efficient primary health care systems in their local areas in conjunction with the consumers and communities in their areas. They should have the flexibility to introduce innovative, regionally integrated care arrangements that fill gaps in the needs of their communities and operate under a performance and accountability framework that includes measures of system impact such as reductions in unnecessary hospital admissions through keeping people well in the community. Flexible funds that allow PHNs to commission or better link with services that allow rural and remote consumers to access the same level of healthcare provision as their metropolitan counterparts such as patient transport and dental care, should be built into the funding guidelines.

**At the Commonwealth-state agreement level:**

- Bilateral Primary Care Agreements should be negotiated between the Commonwealth and states and take the form of an overarching, agreement for each state supplemented by localised agreements between the Commonwealth, state and the PHN that feature agreed goals, joint commissioning and joint accountability. These agreements should set the funding and accountability framework to stimulate PHNs, local hospital networks and the

\begin{itemize}
  \item Wagner, E. H., Davis, C., Schaefer, J., Von Kroff, M. and Austin, B. A survey of leading chronic disease management programs: are they consistent with the literature? Journal of Nursing Care Quality 16 (2) pp. 67-80
\end{itemize}
community sector to jointly plan, co-commission services and work together on system improvements. Localised agreements should contain common goals and measures for strengthening and better integrating primary and hospital care and include pooled funding.

- Transparent outcome and performance data should be developed for both the primary healthcare system and the acute care system.

**At the national policy level:**

- Modernise Medicare payment arrangements by moving toward value based funding models which combine a mix of fee for service and other forms of incentive payments to shift the focus and financial drivers away from the provision of episodic care to reward and encourage long term, coordinated team based chronic disease management and preventive care which is based on value, not volume.
- Invest in more primary health care system research through the Medical Research Future Fund, utilising co-design methodologies and ensure its translation and implementation through strategies that raise awareness of service and system implications among providers and PHN commissioners among others.

**A national research agenda shaped by consumer and community priorities**

- Establish a Consumer and Community Advisory Panel to work with the Medical Research Future Fund (MRFF) Advisory Board to advise the Minister for Health on annual priorities for MRFF disbursements. The panel could convene annual priority setting fora as part of its terms of reference. The fora would use structured, evidence based deliberative decision making methods for identifying, ranking and recommending research priorities within the broader strategies and priorities framework already approved for the MRFF.
- Implement frameworks and infrastructure to set a new culture and strengthen consumer and community involvement practices in all aspects of health and medical research, specifically:
  - Develop an Australian Health Research Consumer Involvement Strategy and plan of action jointly between the NHMRC, ARC, MRFF and CHF with advice from leaders in the field of practice such as the Western Australian Consumer and Community Health Research Network. This plan should be supported by tools and resources for both consumers and researchers.
  - Establish a national centre of excellence for consumer and community involvement in health and medical research. Key functions would include building the capacity of the research sector to use consumer and community involvement meaningfully in all stages of research – including supporting the translation of research findings into meaningful service improvements - and support greater consumer involvement in research, including clinical trials. The centre should be a collaborative, partnership-based, ‘hub and spoke’ model and should extend and scale programs with track record that already exist at state level such as the WA Health Translation Network’s Consumer and Community Health Research Network. It could also lend itself to the co-fund model featured in the development of NHMRC Partnership Centres and should centrally involve NHMRC Advanced Research Translation Centres and peak consumer organisations.
Background

The Australian Government’s 2017-18 Federal Budget was accompanied by an announcement that it intends to develop a long term National Health Plan (the Plan). Minister Hunt describes four pillars for the Plan:

- Guaranteeing Medicare and the Pharmaceutical Benefits Scheme
- Supporting hospitals
- Prioritising mental and preventive health
- Investing in medical research.

He has also outlined three waves of reform:

- Wave 1: underpinned by five major compacts with medical and industry bodies, a focus on guaranteeing Medicare, agreement by COAG on an opt-out model for My Health Record and some further investments in mental health psychosocial support
- Wave 2: ensuring the sustainability and affordability of private health insurance, strengthening mental health particularly in rural areas, workforce strategy, aged care reform
- Wave 3: reform of public hospitals and post 2020 agreements with the states, strengthening primary health care and strengthening preventive care.

The Consumers Health Forum of Australia (CHF) has welcomed the commitment to develop the Plan. In March 2016 we hosted a Special Policy Roundtable with The George Institute for Global Health involving consumers, researchers, clinicians, entrepreneurs and researchers. The headline recommendation was that we should “develop a National Vision for Australia’s Health 2025” through the Council of Australian Governments (COAG), that describes and commits to the principles of consumer-centred care.5

In discussions with Minister Hunt’s office in early 2017 it was agreed that CHF would convene a Consumer and Community Ministerial Roundtable (the Roundtable). The event will provide first-hand consumer insights into the current pressures points in the system and, most importantly, informed views from the consumer sector about priorities for the Plan.

Throughout this paper consumers are defined as people who use or are potential users of healthcare services. This group includes children, women and men, people living with a disability, people from diverse cultural and religious experiences, socioeconomic status and social circumstances, sexual orientations, health and illness conditions.6

This issues paper has been prepared to guide discussion and key directions for health reform to discuss with the Minister at the Roundtable. It canvasses key elements which are important to all four pillars because of their interconnected nature. Our emphasis is on longer term thinking and priorities to inform waves 2 and 3 of the Minister’s reforms, which take us up to and beyond the next round of Commonwealth-state hospital agreements. This paper draws on the positions previously taken by CHF, the views input of over 20 CHF members – representing a cross-section of our members – who expressed interest in attending a Consumer and Community Ministerial Roundtable in August 2017, the Mental Health Consumers and Carers Forum and other key informants such as representatives from Primary Health Networks (PHNs).
Why we need a national health plan

Health is an important and growing sector. It represents 10 per cent of the Australian economy. On the whole, when compared to other OECD countries, Australia performs well in terms of overall population health status. At 82.2 years, life expectancy is the sixth highest in the OECD, and our record on breast and colorectal cancer survival is among the best. Australia has one of the lowest rates of tobacco consumption but it is the fifth most obese country in the OECD. These outcomes are achieved relatively efficiently. Health expenditure is 8.8% of GDP, commensurate to the OECD average.

However, there are areas where we can improve. Our high rates of hospital admission for chronic conditions could be managed more effectively and efficiently in primary care and we spend more on out-of-pocket health care costs than the OECD average. This is a concern when we know that one in five people avoid visiting a GP and one in six fail to fill a script due to cost. In a recent Commonwealth Fund comparative study of health systems Australia ranked second behind the UK against performance measures such as care processes, access, equity, administrative efficiency, and health outcomes.

The near future will bring with it the need to adapt to unavoidable changes in the health context. We will use hospitals less, clinics and telehealth more. For consumers this will be most clearly realised in the blurring of the retail, health and social care sectors. The line that has long separated healthcare from retail will disappear over time as retailers, wellness coaches, pharmacies, insurers and tech companies start to play a far more significant role in keeping us well. So too will our understanding of the boundaries between health and social care. Healthcare that works independently of housing, disability and social services will always be less effective than when these systems work together.

These considerable challenges can only be adequately addressed by a 21st century health system which ensures quality, affordable health care for all Australians and maximises the potential of the advances which accompany these challenges articulated in a long term health plan supported by all governments.

The pressure points and policy challenges in our system are complex and profound. We have persistent inequality in terms of both access and outcomes. Many groups in the

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community have poorer access to comprehensive services and we have data to show they have poorer health outcomes. This is most notably the case for Indigenous Australians, people in rural and remote Australia and people living with a mental illness\textsuperscript{13,14}. We need a vision that acknowledges those inequities and seeks to reduce them by improving access to quality healthcare and improving their access to education, housing, employment and other services.

There are concerns about affordability and sustainability, and concerns about whether or not we are investing in value-based care and the right mix of services. Most importantly, we need to ask: is our system and plans for it are meeting the expectations and needs, now and into the future, of the ultimate beneficiaries and funders of the system: patients and the community?

While attempts have been made by both Commonwealth and state governments to introduce integrated care initiatives, these have been piecemeal, not sustained and poorly coordinated. We currently lack an integrated, coherent system. There is no clear vision for how high quality care can, or should, be delivered in an ever-changing environment with increasing pressure due to medical innovation, technological change and the changing structure of our population. We have fragmentation, disconnect and poor information at every level. The community survey conducted by the Government’s Primary Health Care Advisory Group (PHCAG) was extremely telling about the patient experience\textsuperscript{15}. Results told of:

- A fragmented system and providers working in isolation not as a team
- Uncoordinated care and duplicate tests and, at times, critical tests being delayed overlooked due to lack of a ‘patient home’
- Difficulty finding services
- Low uptake of and trust in eHealth and other health technology
- Access problems due to cost, transport, language, mobility and remoteness
- Feelings of disempowerment.

We have primary, aged and acute care running on parallel lines. The disconnection is exacerbated by the split in Commonwealth and State responsibilities with no one level wanting to take responsibility to join up the system. In primary and community care, there is considerable investment by states and territories such as NSW’s Integrated Care Strategy and Victoria’s Health and Wellbeing Hubs and Supercare Pharmacies initiatives however it is unclear as to how these will integrate and relate to Commonwealth developments such as the Health Care Homes Programme.

We have a complex private-public mix with private clinicians, hospitals and health insurers working alongside publicly funded and run hospitals with systems that don’t communicate and differing imperatives driving their business models. At the workforce level, we have

\textsuperscript{14} Commonwealth of Australia (2016) Closing the Gap: Prime Minister’s Report 2016
\textsuperscript{15} Commonwealth of Australia (2016) Primary Health Care Advisory Group Final Report: Better Outcomes for People with Chronic and Complex Health Conditions
reports of health providers feeling under strain with too much to do with too few resources, a maldistribution of some healthcare providers nationally and scope to consider ways we can use Australia's existing workforce more effectively and efficiently.

Long term sustainability is a key challenge for the Australian healthcare system, as it is for other countries. A sustainable health system is one that endures and adapts to constantly changing pressures\textsuperscript{16} \textsuperscript{17}. To achieve sustainability we need to address waste and low value care in the system, ensure we are investing wisely in the right programs, services and interventions and anticipating future challenges that are in the pipeline for which we need to plan now. Most importantly, we need to design the system and services around consumer and community needs and preferences.

To a large degree the solutions lie in how the Commonwealth deploys the substantial levers and funding it has at its disposable to drive improvement and skew the system to provide best care in settings where most people expect to be able to seek and received it: in the community and in their homes. This is where the notion of a long term national health plan has promise.

\textsuperscript{16} Coiera, E., Hovenga, E. J. (2007) Building a sustainable health system. \textit{Year B Med Inform} 11-8
\textsuperscript{17} Braithwaite (2016) With an ageing population is healthcare sustainable? \textit{Sydney Morning Herald}
Elements of a long term national health plan

Australia needs a 21st century national health system which meets current needs and adapts to the inevitable changes in population needs and health treatments. This system should be one which supports consumers to take control of their care through engaging them and enabling them to be involved in shared and informed decision making.

The system should also be one which prioritises and adequately resources a strong primary care backbone to shift us away from a preoccupation with hospitals back to timely and resource efficient primary and preventative care. The world’s highest performing health systems have activated consumers who engage with primary care first - Australia should be one of these systems. For this to happen, primary health care has to work as one system.

At the centre of this system is a robust, appropriately funded, modernised Medicare which gives universal access to medical care and medicines through the Medicare Benefits Schedule (MBS) and Pharmaceutical Benefits Scheme (PBS).

Based on feedback from members, surveys, consultations, roundtable discussions and the literature CHF believes there are fundamental design principles that should feature in any Plan and recommend key elements for incorporation in the Plan’s pillars.

Design principles

Principles of consumer-centred care

The Plan needs to be built around the following principles of consumer-centred care, many of which are drawn from the CHF Strategic Plan18.

- Care is accessible and affordable with access determined by health need
- Care is appropriate and meets the needs and preferences of individuals and is also evidence based, high quality and safe
- Care looks at the whole-person and takes into account people’s lives and personal and cultural needs and values. It is also inclusive of family and carers.
- Care is comprehensive and coordinated with a multi-disciplinary approach. It facilitates continuity across the different levels of the health and human services system
- There is trust and respect at all times between consumers and health service providers
- Support is provided to enable informed decision making including access to clear and understandable information about treatment options, risk and costs – including provider costs and performance outcomes
- Consumers are involved at all levels of planning, system design, and service development and in key governance structures

• Care is driven by value not volume. We strive for a sustainable system that encourages high value and discourages low value care.

*A national-regional system*

Integrated care will deliver a system that is more consumer-centred. Achieving integration where consumers and the community will benefit most – between primary, hospital, aged and community care - will require structural change and different ways of planning, funding and organising healthcare. This is the best way to take into account and respond to differences in population, need and local services. It is a widely held view that integration is best achieved through systems that are organised around national-regional constructs where national policy sets the framework, performance expectations and accountability arrangements, and decision making rests with the lowest form of social organisation capable of performing that effectively

Another way of thinking about regional integration is ‘place based approaches’ that meet local health needs. Place based health is gaining traction globally. The arguments for why we need to look at reconfiguring the way national health priorities are implemented with flexibility on the ground is highlighted by the variation in health outcomes evident in the latest Atlas of Healthcare Variation and the diversity of priorities across PHN needs assessments and plans.

Australia has the infrastructure to deliver place-based integrated care in the form of Primary Health Networks (PHNs) and local hospital networks. Yet we are yet to fully realise their potential to work together for better health outcomes for their communities under new integrated governance arrangements with consumer interests at the centre. While it is challenging to bring together historically disparate partners together into formal agreements, they are essential to creating the ‘business rules’ and sustainable environment required to achieve the new models of care we seek

Better utilising and accelerating the extent to which we use this existing PHN and local hospital network infrastructure - in which there is already substantial investment - for joint planning, to commission integrated services, and to serve as managers and stewards of ‘one system’ is essential to any reform intended to shift our system towards one that is more consumer and community centred. The merits of doing so have been recognised by organisations such as the National Mental Health Commission and the National Rural Health

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21 Nicolson, C., Jackson, Marley, J. E. Best Practice integrated health care governance – applying evidence to Australia’s health reform agenda, Med J Aust 2014 201 (3) 64-66
alliance who have advocated for the pooling and devolution of Commonwealth funds, currently administered centrally, to PHNs\textsuperscript{22,23}.

**Elements**

**New ways of working with consumers and communities**

“Make life easier and more convenient for me, let me take ownership and empower me, include and respect me in the relationship, keep me informed, enable transparent access to my information, give me the best care you can, reduce my costs”.

Our system must support consumer-directed self-care and involve consumers in shared and informed decision making about their health and care. When people have the knowledge, skills and confidence to manage their own health care, the benefits multiply. Consumer experience, health outcomes and quality of care improves, costs reduce and clinicians also reap rewards because we can see the results of working with patients in this way.

Consumers are the experts: only we can say how their health conditions impact on their lives and what will work for them. Our stories and experiences can shed deep insights that can shape policy and health services and we can be catalysts in identifying policy opportunity and gaps in services. Consumer experience can accelerate change and inform the development of practical and local health and social care solutions.

**Integrated primary care: one system**

Moving towards health for all requires that health systems respond to a changing world and growing expectations for better performance. This involves substantial reorientation and reform of the ways health systems operate and involve the renewal of primary health care. Investing in primary health care is the way to a successful health system\textsuperscript{24}.

This is why primary care matters. It is the setting where we prevent and treat most, it is efficient and accessible, it delivers good outcomes on the whole, it is the ‘gateway’ to other parts of the system, and with the right organisation and incentives it has the potential to assist greatly with other ‘pain points’ in our system such as poor transitions of care and avoidable hospital admissions\textsuperscript{25}.

The current primary health system works well for most Australians but it is not designed to meet the needs of the growing number of people with complex and chronic conditions and of families with children. Services are fragmented, which leads to sub-optimal health outcomes

\textsuperscript{22} National Mental Health Commission (2015) Contributing Lives, Thriving Communities – Report of the National Review of Mental Health Programmes and Services

\textsuperscript{23} National Rural Health Alliance (2016) Submission to the Department of Health and Ageing responding to the Government’s response to the National Mental Health Commission’s Review of Mental Health Programmes and Services

\textsuperscript{24} Caley, M. BMJ 2013 347 Remember Barbara Starfield: primary care is the health system’s bedrock

for consumers. Experts generally believe that funding arrangements are outmoded, constrain the extent to which flexible care can be provided and there is a need to make better use of existing health workforce for team-based care. Payments to general practitioners need to be reconfigured to reward long term preventive approaches to good health and treatment rather than episodic care. We need to move away from a situation where consumers don’t seek treatment until problems are advanced. This requires action to address barriers such as cost and low health literacy.

Our primary care health system needs to be integrated, coordinated and universally accessible. Future models of care need to make the best possible use of all primary health care providers including general practices, pharmacists and allied health in private practices and community health services. The Patient Centred Health Care Home model and its characteristics of comprehensive care, patient-centred care, care coordination, accessible services and quality and safety have been shown to drive patient engagement in better managing their own healthcare and a positive primary care experience. The evidence is growing that they may cut costs and improve patient care\(^{26}\).

While the Commonwealth’s Health Care Home Programme is a step in the right direction, the current focus on people with existing chronic and complex conditions and the fact it is not a whole-of-practice approach may limit its effectiveness. Over time, we would want to see all practices moving in this direction, with the right incentives and organisational change support, so that children and families and people at serious risk of developing chronic illnesses could also benefit.

**Prevention first**

Any health reform agenda needs to incorporate strategies that enhance preventive health care and the health literacy of the community. Chronic diseases have become Australia’s biggest health challenge, accounting for over 80 per cent of premature deaths and 85 per cent of the total burden of disease. Chronic diseases are closely associated with modifiable risk factors such as tobacco and alcohol use, physical inactivity and poor diet. These behaviours increase the risk of developing biomedical risk factors including overweight, obesity and high cholesterol levels, which subsequently can lead to chronic disease. Action to address these risk factors is urgently needed to reverse the increasing burden of chronic disease. The success Australia has had in reducing tobacco consumption through a sustained, multi-faceted and evidence based public health efforts gives us a model to use for current public health challenges such as obesity.

Australians’ low rates of health literacy\(^{27}\) has consequences in terms of costs and poorer health outcomes\(^{28}\). Without the ability to understand information about health and health care,


how we can apply that information to their lives, use it to make decisions and act on it, we may struggle to be motivated and enabled to take steps to modify lifestyle risk factors, to self-manage chronic conditions, to make informed choices about treatment and to navigate the system to get the services that consumers need.

**Rethinking hospital funding and care**

We need hospitals to be part of an integrated care system with the responsibility for delivering acute care and more complex interventions in partnership with other services. As we strive for an integrated, consumer-centred system, there is scope to look at new models of care that link hospitals to primary, community and social care providers in different ways. Researchers have examined different ways in which consultants can - or could – work beyond their traditional boundaries outside the hospital walls. These broadly split into two groups:

- Services that enable more complex patients to be treated at home or in primary care via joint delivery of care, multidisciplinary team working and education of primary care practitioners and patients such as outreach clinics jointly staffed by hospital consultants and other health care professionals and consultant-run email and telephone helplines that provide advice for GPs and nurses
- Intermediate services that treat patients who need specialist care that cannot be provided in general practice

The potential benefits of this new way of working for patients are clear. It can improve patient experience and lead to better management of chronic conditions, more co-ordinated care and lower waiting times. Conversely, there is also merit in looking at the patient benefits of GPs providing in-reach services in hospital settings, particularly to have input into care transition planning as patients prepare to discharged back to the community or aged care.

In Australia, there have been some moves in this direction through initiatives such as the NSW Integrated Care Strategy. However, current Activity Based Funding (ABF) is confined to hospital care and is arguably an impediment to the extent to which hospitals have the incentive and means to explore innovative ways of coordinating and integrating with out-of-hospital services that can reduce activities within hospitals. In the same way that PHNs should be incentivised to keep people well and out of hospital, there should be scope to explore how future hospital funding arrangements can incorporate incentives to avoid hospitalisations through investments in preventive health and care in the community, particularly in collaboration with PHNs within regional boundaries.

**Integrated mental health services**

Around 20 per cent of the Australian population will experience some form of mental illness in any given year and, despite increases in investment and the development of national mental health plans, the consensus is we are not doing enough. People living with mental illness have

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poorer physical health, yet we less and lower quality care than the rest of the population – and die younger. People with psychosis die between 14 and 23 years earlier than the general population\textsuperscript{31}.

The recent National Mental Health Commission review\textsuperscript{32} confirmed what all the other reviews had said; the mental health system is fragmented and has fundamental structural shortcomings. Most importantly the Review showed that these problems had a negative impact peoples’ wellbeing and participation in the community—on jobs, on families, and on Australia’s productivity and economic growth. The Review also found that despite almost $10 billion in Commonwealth spending on mental health every year, there are no agreed or consistent national measures of whether this is leading to effective outcomes or whether people’s lives are being improved as a result.

We need a whole of government approach to addressing mental health needs that brings together integrated health services with improved education and employment opportunities to ensure people with mental illnesses have the same opportunities as others in the community. There needs to be a long-term commitment that links funding to demand to ensure the momentum of reform is not stalled.

\textit{Workforce development and innovation}

If we are to move to more integrated models of care which put the consumer at the centre, we need a more flexible workforce which has the principles of consumer centred care integral to their education and who are trained in ways which allow them to move between care settings and work collaboratively. The importance of including workforce considerations in any reform agenda should not be underestimated and providing support to the workforce to adjust to the new models and to embrace new ways of doing their work will be critical to success.

As shown by CHF’s survey of consumer-centred practices in the Australian health workforce, gaps exist between the intent expressed in policy and current practice\textsuperscript{33}. We found that organisations representing health professionals recognise the benefits of patient-centred care, but only 50% of respondents felt that their members had access to adequate resources to support a patient-centred approach. Consequently, there is a role for consumer groups, including CHF, to help these organisations understand how to include consumers throughout their work.

The new health system needs a flexible workforce that has been trained in consumer centred principles. We need to make optimal use of the differing skills that consumers bring which means breaking down some of the existing professional boundaries and may also mean looking at different training and remuneration to better reflect new ways of working. The

challenge will be getting the right workforce in the right place to address local needs and this links back to the need to take a regional approach to planning and development of new models.

A digital health future

The COAG Health Ministers’ Council has endorsed the National Digital Health Strategy developed by the Australian Digital Health Agency. The Strategy sets out an ambitious plan to ensure that digitally enabled models of care and digital enablers of better care coordination and information flow will support safe, seamless and secure care. The Strategy places a premium on digital solutions supporting the health care delivery now and in the future that gives people more choice, control and transparency. A centrepiece of the Strategy is the MyHealth Record Opt Out Expansion Programme. Consumer awareness and confidence in both the security and utility of MyHealth Record and new modes of care delivery that don’t involve face-to-face contact with their doctor is going to be critical to success. Improving digital health literacy and making MyHealth Record easy to use will also be important.

Research driven priorities, innovation and improvement

Governments, funding bodies and research organisations across the globe are increasingly recognising the importance of including the ‘lived experiences’, values and priorities of consumers and community members into research policies and practice. This supports an aim of increasing translation of research evidence to improve health outcomes. In 2002 the National Health and Medical Research Council (NHMRC) and the Consumers Health Forum (CHF) developed a Statement on Consumer and Community Participation in Health and Medical Research, but the Statement is high level and has seen limited direct application. The lack of a national approach for implementing consumer and community involvement has resulted in ad-hoc uptake of involvement activities and varying community input into health research prioritisation. As such, consumers who are the end recipients of evidenced based health care, are often excluded from decision making about research priorities and what is likely to be of most value to the community.

Australia is a world leader in health and medical research, and as such should be one of the world leaders in the involvement of consumers in developing and prioritising this research. With the advent of the Medical Research Future Fund (the MRFF) there is an opportunity for consumer involvement to be embedded in health and medical research like never before. One model of how this might be achieved is the Canadian Institute of Health Research’s Strategy for Patient-Oriented Research. This patient engagement framework is an example of how consumers can and should be involved throughout research and practice.

The MRFF five year strategy and priorities for the next two years include consumer engagement and collaboration, particularly the establishment of a consumer-driven health and medical research agenda. Recent developments such as the NHMRC Advanced Research Translation Centres and Partnership Centres as well as the leadership shown by some universities such as University of Western Australia’s Consumer and Community Health Research Network present opportunities for collaboration. These include the opportunity to
build the capacity of the research community to meaningfully involve consumers in all aspects of research, and to build consumer confidence in such involvement.
How we can get there

Australians have positive experiences of their personal health and wellbeing. When asked to self-rate our health, 85% of us rate it as ‘good’ or ‘better’ and our life expectancy is higher than it’s ever been. However when we look at health through other lens’ the trends are not as positive. Rates of obesity, chronic illnesses and ‘healthy’ years being lost to ill health are increasing. It’s the trends in these areas that worry us.

Outlined below are some of the main measures that could be implemented in the near to medium term that would start to move the system in the right direction.

New ways of working with consumers and communities

There are some promising developments towards a more systemic and strategic involvement of consumers in Australian health policy, standards setting and system development. Consumer membership features in the governance structures advising the government on major health technology assessment decisions such as which medicines and treatments should receive government subsidy, and new areas of health policy such as the Health Care Homes Programme. The Australian Commission for Safety and Quality in Health Care has a partnering with consumers programme and the Australian Digital Health Agency is committed to working closely with consumers. At the regional level, PHNs are required to have Community Advisory Councils (CACs) involving consumers as a mandatory part of their governance arrangements.

It is time to take consumer involvement in healthcare to the next level and our suggestions for this are:

- Resource health consumer organisations (HCOs) in a long term sustainable manner to support knowledgeable and skilled people to participate in all areas of the health sector, including through: health policy, decision making, health service standards setting and monitoring, health research, and co-design of service development, accreditation and evaluation.
- Support a programme to ensure healthcare consumers are involved in shaping the underpinning policy and implementation of the health reform agenda including:
  - Innovative ways to gather and synthesise consumer experience and knowledge about the health system at regular intervals
  - A consumer and community panel, independent of government which is chaired by CHF as the peak body for Australian health care consumers and those with an interest in healthcare consumer affairs, to harness the views of consumers, engaged citizens, the volunteer sector, carers, and other stakeholders with a window on the system such as representatives from PHN Consumer and

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Community Advisory Councils and synthesise these insights in order to best inform the development of a long term national health plan.

- Develop and adopt validated Patient Reported Experience and Outcomes Measures consistently across key service settings such as hospitals and Health Care Homes, link them with current and future accreditation processes, and work with these organisations to ensure that the findings from these measures are considered and meaningfully implemented
- Support programs to build a network of consumer leaders to work in partnership with PHNs, local clinicians and other stakeholders to ensure evidence-based, needs-informed regional commissioning plans.

Integrated primary health care: one system

Primary health care has been described as a renovator’s opportunity and calls for ambitious changes to the way we organise and pay for primary care services have been made\(^{36}\). Our primary health care system has several component parts including national policy and programmes; Commonwealth and state agreements; state governments who make varying and different investments in the delivery of care in the community; a regional system of Primary Health Networks and, at the service level; and a network of largely private providers such as general practitioners who deliver care. These are our recommendations for change at each of those respective levels. Many reflect those recommended by the Grattan Institute Report: *Building better foundations for primary care*\(^{37}\).

At point of care delivery:

- The internationally recognised concept of a patient-centred health care home (PCHCH) is the optimal model of consumer and family-centred primary health care delivery that Australia should be working towards.
- The current Commonwealth Health Care Home (HCH) programme should be appropriately resourced, implemented and independently evaluated as a first step toward moves to feature patient centred health care home practices more broadly in the Australian primary health care landscape. The evaluation must be co-designed and include measurement of consumer experience and outcomes using validated tools. Wide stakeholder consultation with both clinical and consumer groups should determine future stages.
- Concurrently, the limitations of the HCH programme should be recognised and PHNs should be funded to work with local clinical and consumer advisers to build on and extend the model in order to accelerate the spread of the PCHCH approach. While the international evidence is that there is no one single way to implement PCHCH\(^{38}\), there are a range of elements which are consistently found in the best performing models and should be mandatory features in any wider implementation in Australia such as self-

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management support, decision support, electronic shared health records, voluntary enrolment and a patient-team partnership.\(^{39}\)\(^{40}\)

- Regionalised implementation of PCHC homes should occur within a policy framework. This framework must assure a level of consistency in design and be a guarantee that ensures quality, safety and high standards. It should facilitate PHNs to work with local clinical leaders and their communities to locally adapt HCHs to demonstrate how additional features such as social prescribing, flexible preventive care arrangements evidence-based self-management programs could be integrated.

- Pharmacists and other allied health professionals should be better equipped to work in collaboration and their roles better integrated with general practice. An enhanced primary health care role for pharmacists within their scope of practice should be implemented and evolving models of non-prescribing pharmacists working in general practice should be made more widespread, particularly in the context of the Health Care Homes Programme. The $30 million earmarked by HCH Programme support in the 2017 Federal Budget should be devolved to either participating practices or PHNs to ensure integration with HCH implementation at the service delivery level. This will ensure the funding is best targeted to the needs of enrolled patients in HCH practices.

**At the regional level:**

- PHNs need to be given the mandate, resources and explicit responsibility for creating more effective and efficient primary health care systems in their local areas in conjunction with the consumers and communities in their areas. They should have the flexibility to introduce innovative, regionally integrated care arrangements that fill gaps in the needs of their communities and operate under a performance and accountability framework that includes measures of system impact such as reductions in unnecessary hospital admissions through keeping people well in the community. Flexible funds that allow PHNs to commission or better link with services that allow rural and remote consumers to access the same level of healthcare provision as their metropolitan counterparts such as patient transport and dental care, should be built into the funding guidelines.

**At the Commonwealth-state agreement level:**

- Bilateral Primary Care Agreements should be negotiated between the Commonwealth and states and take the form of an overarching, agreement for each state supplemented by localised agreements between the Commonwealth, state and the PHN that feature agreed goals, joint commissioning and joint accountability. These agreements should set the funding and accountability framework to stimulate PHNs, local hospital networks and the community sector to jointly plan, co-commission services and work together on system improvements. Localised agreements should contain common goals and measures for strengthening and better integrating primary and hospital care and include pooled funding.

\(^{39}\) Wagner, E. H., Davis, C., Schaefer, J., Von Kroff, M. and Austin, B. A survey of leading chronic disease management programs: are they consistent with the literature? *Journal of Nursing Care Quality* 16 (2) pp. 67-80

Transparent outcome and performance data should be developed for both the primary healthcare system and the acute care system.

At the national policy level:

- Modernise Medicare payment arrangements by moving toward value based funding models which combine a mix of fee for service and other forms of incentive payments to shift the focus and financial drivers away from the provision of episodic care to reward and encourage long term, coordinated team based chronic disease management and preventive care which is based on value, not volume.
- Invest in more primary health care system research through the Medical Research Future Fund, utilising co-design methodologies and ensure its translation and implementation through strategies that raise awareness of service and system implications among providers and PHN commissioners among others.

A national research agenda shaped by consumer and community priorities

- Establish a Consumer and Community Advisory Panel to work with the Medical Research Future Fund (MRFF) Advisory Board to advise the Minister for Health on annual priorities for MRFF disbursements. The panel could convene annual priority setting fora as part of its terms of reference. The fora would use structured, evidence based deliberative decision making methods for identifying, ranking and recommending research priorities within the broader strategies and priorities framework already approved for the MRFF.
- Implement frameworks and infrastructure to set a new culture and strengthen consumer and community involvement practices in all aspects of health and medical research, specifically:
  - Develop an Australian Health Research Consumer Involvement Strategy and plan of action jointly between the NHMRC, ARC, MRFF and CHF with advice from leaders in the field of practice such as the Western Australian Consumer and Community Health Research Network. This plan should be supported by tools and resources for both consumers and researchers.
  - Establish a national centre of excellence for consumer and community involvement in health and medical research. Key functions would include building the capacity of the research sector to use consumer and community involvement meaningfully in all stages of research – including supporting the translation of research findings into meaningful service improvements - and support greater consumer involvement in research, including clinical trials. The centre should be a collaborative, partnership-based, ‘hub and spoke’ model and should extend and scale programs with track record that already exist at state level such as the WA Health Translation Network’s Consumer and Community Health Research Network. It could also lend itself to the co-fund model featured in the development of NHMRC Partnership Centres and should centrally involve NHMRC Advanced Research Translation Centres and peak consumer organisations.
Prevention first

- Develop a comprehensive, community-focused strategy to address the growing issue of obesity in Australia. The strategy should comprise elements including: a tax on sugar sweetened beverages, stronger controls on junk food advertising, improved nutritional literacy, healthy work environments and urban planning which encourages more physical activity.
- Increase expenditure on preventive health to at least 5 per cent of total health spending by 2020, whilst maintaining other health expenditure.
- Additional investment in family and early childhood health with an emphasis on health promotion and prevention.
- Implement other measures set out in the Prevention 1st platform41.
- Equip PHNs to ensure preventative health and health and mental health literacy programs are built into local primary health care services and settings in consultation with consumers and the community.

Rethinking hospital funding and care

- Hospital funding needs to be rethought so that local hospital networks can fund services in a manner which addresses the impediments current funding arrangements present to integrated care. This would include services that both prevent hospitalisations or readmissions, and smooth pre-admission and discharge experiences. The introduction of more flexibility into hospital funding arrangements would allow them to better meet the needs of consumers and their communities whether this be through more or different hospital services, community health services, enhanced pre-hospital admission services, services that prevent hospitalisation or services that facilitate smooth discharge from hospital.

Integrated mental health services

- Reallocate a proportion of Commonwealth acute hospital funding into more community-based psychosocial, primary and community mental health services. These services should have a focus on social connectedness, lived experience input and peer mentoring and support, helping people to focus on their strengths rather than just treating symptoms.
- Extend the scope of PHNs as the key regional organisations for equitable commissioning, planning and purchasing of mental health programmes, services and integrated care pathways in conjunction with consumers and carers. Evaluate and use the mental health commissioning role of PHNs as a blueprint for commissioning services for other chronic conditions.
- Develop and implement place-based models of care for consumers in rural and remote communities to improve access to and equity of healthcare services.

41 Prevention 1st (2016) Prevention 1st 2016 Election Platform
• Improve access to services through developing and leveraging e-mental health services that build sustained self-help, link to biometric monitoring and provide direct clinical support strategies or enhance the effectiveness of local services as one potential mode of treatment and assistance.

• Implement the areas for change outlined in Equally Well, particularly the need to strengthen care coordination and regional integration across health, mental health and other services and sectors by:
  o Including people with mental illness and associated conditions such as chronic pain in the Health Care Home trials
  o PHNs and LHNs to develop integrated mental health services across hospital and community settings to ensure continuity of care.

Workforce development and innovation

• Reform accreditation standards to include genuine consumer engagement and involvement, create greater consistency and commonality in the development and application of these standards across health professions

• Provide support and training for health workforce organisations to include consumer centred care principles in their training of health professionals and provide ongoing support to put these principles into practice.

• Continued work by peak consumer organisations with professional groups, service providers and educational providers to develop a more flexible workforce – a workforce that has flexibility and the right incentives will be more easily able to organise in teams around consumer’s needs.

• Develop a single organisation or set of coherent governance arrangements which set the agenda around health workforce arrangements. Ensure that this arrangement has consumer co-leadership at all levels.

• That professional medical and health education organisations (e.g. professional colleges and universities) involve consumer educators throughout health professional education.

A digital health future

• Implement the actions in the National Digital Health Strategy, with priority to accelerating MyHealth Record opt out.

• Facilitate and support the development of and implementation of accredited on-line self-management tools and apps for smart phones and other devices across a range of conditions and needs.

• Accelerate and put in place the right mix of incentives to encourage digitally enabled modes of care delivery including the widespread use of telehealth, telemedicine and remote monitoring.

• Training and education for consumers and health professionals in how to use the tools and incentives put in place to encourage the update and adoption of these – digital health literacy.