Consumers Health Forum of Australia

Submission to the Federal Treasurer for Federal Budget 2018-19

December 2017

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Executive Summary

The Consumers Health Forum in this 2018-19 Budget submission urges the Government to ensure the health system is consumer centred: providing care which is accessible, affordable and for whole-of-person needs.

We acknowledge the commitment from the Government to developing and delivering on a National Health Plan which delivers improved health outcomes and moves to make the health system sustainable.

Key commitment

- That the Federal Government to move away from the current budgetary requirement for all new health expenditures to be offset by savings in the health portfolio.

Prevention and social determinants of health

- Establish obesity prevention as a national priority, with a national taskforce, sustained funding, regular and ongoing monitoring and evaluation of key measures and regular reporting around targets
- Legislate to implement time-based restrictions on exposure of children (under 16 years of age) to unhealthy food and drink marketing on free-to-air television until 9:30pm
- Set clear reformulation targets for food manufacturers, retailers and caterers with established time periods and regulation to assist compliance if not met
- Make the Health Star Rating System mandatory by July 2019
- Develop and fund a comprehensive national activity strategy to promote walking, cycling, and use of public transport
- Fund high-impact, sustained public education campaigns to improve attitudes and behaviours around diet, physical activity and sedentary behaviour
- Federal government to place a health levy on sugary drinks to increase the price by 20%
- Develop, support, update and monitor comprehensive and consistent diet, physical activity and weight management national guidelines.
- Additional investment in family and early childhood health with an emphasis on health promotion and prevention.

Primary and integrated care reform

- Greater funding of primary and integrated care through both Primary Health Networks and hospitals in the context of COAG national health and hospital reform bilateral discussions.
- For the next hospitals agreement to be broadened to allow local hospital networks to fund services in a manner which addresses the impediments current funding arrangements present to integrated care.
- Clearer Federal Government plans and funding for self-management innovations such as appropriately trained and paid peer support workers and health coaches to help people look after themselves and get the right care. These should be integrated into future implementation of patient centred health care homes.

- The government to fund a Council for inter-professional education and collaborative practice to provide national leadership for health workforce reform.

Private health insurance

- The Government to send a reference to the Productivity Commission to conduct an inquiry into the benefit of government involvement in the Private Health Insurance sector.
- The Government to make it mandatory that health funds make readily available, and in plain language, the costs and coverage of all their insurance packages.
- The development of a plan for greater disclosure and information provision about medical practitioner fees, medical practitioner qualifications, years of experience and, ideally, some indicators of performance outcomes. This plan should be developed with input from practitioner groups, consumers and government to ensure that it is sustainable and appropriate for consumers.

National medicines policy and pain management

- The Federal Government to reform the PBS safety net so consumers with high usage of PBS medicines have smoothed out annual co-payments.
- The Federal Government to update, adequately fund and implement the national pain strategy, as developed by Pain Australia and the Australian Pain Management Association.

Safety, quality and consumer participation

- The Federal Government to support a programme of action to ensure healthcare consumers participate in shaping the underpinning policy and implementation of the health reform agenda including innovative ways to gather and synthesise consumer sentiment.
- The Federal Government to fund the development of a national centre in consumer and community involvement in health and medical research through the Medical Research Future Fund.
- The Federal Government to steward the development of programs to build a network of patient and consumer leaders who can work in partnership with PHNs, local clinicians and other stakeholders to ensure evidence-based, needs-informed regional commissioning plans.

Moving to a consumer centred healthcare system

Health is an important and growing sector. It represents 10 per cent of the Australian economy[1]. At 82.2 years, life expectancy in Australia is the sixth highest in the OECD, but we have the fifth highest rate of obesity. Health expenditure is 10.3% of GDP[2], around the OECD average. 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[3].

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. We have higher out-of-pocket health care costs than the OECD average[4]. The impact of this is evidenced in the high rates of missed appointments and failure to fill prescriptions due to cost - one in five people avoid visiting a GP and one in six fails to fill a script due to cost[5].

The near future will bring with it the need to adapt to unavoidable changes in the health context. 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[6]. 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[7].

The key elements of consumer centred system are:

- Patient-focused care where patients are informed, active partners in their own care
- Comprehensive multi-disciplinary team-based care
- Coordination of care across the care delivery system
- Accessibility for patients using multiple communication modes
- Evidence-based care and data driven quality improvement

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[1] Australian Institute of Health and Welfare (2016) Health Expenditure Australia 2014-15
[2] Australian Institute of Health and Welfare (2017) Health expenditure Australia 2015-16
[3] Commonwealth Fund (2017) Mirror, Mirror 2017. *International Comparison Reflects Flaws and Opportunities for Better U.S. Health Care.* http://www.commonwealthfund.org/publications/fund-reports/2017/jul/mirror-mirror-international-comparisons-2017
[4] OECD (2017) Health at a Glance 2015
[5] Australian Bureau of Statistics (2016) 4839.0 Patient Experiences in Australia: Summary of Findings, 2015-16, http://www.abs.gov.au/ausstats/abs@.nsf/mf/4839.0 accessed 21 August 2017
[6] Main, T., Slywotzky, A. (2014) *The Patient-to-Consumer Revolution: How high tech, transparent marketplaces, and consumer power are transforming U.S. healthcare.* USA: Oliver Wyman Health and Life Science
[7] Ham, C., Dixson, A., Brooke, B. (2012) *Transforming the Delivery of Health and Social Care: The case for fundamental change.* London: The King's fund.

- Payment models that support all the above[8]

Key to the development of these integrated systems is the philosophy of consumer-centred care[9]. Consumer centred care is care which is accessible and affordable and whole of person[10]. When correctly implemented it supports consumers with informed decision making, being involved in planning and governance and promotes trust and respect from all parties. Through this it leads to appropriate, comprehensive and coordinated care.
There are concerns about affordability and sustainability, and concerns about whether 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?

In its recent report *Shifting the Dial: 5-year Productivity Review* the Productivity Commission called for the health care system to be reconfigured around the principles of patient- centred care within a five-year time frame[11]. According to the report this would improve clinical outcomes, empower consumers and so encourage more self-management and fewer problems which would ultimately lower costs. Our recommendations are designed to facilitate movement to this end goal.

The Australian Government's 2017-18 Federal Budget was accompanied by an announcement that it intends to develop a long term National Health 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.

CHF welcomed and have supported the plan and the waves of reform. We have participated in the work that has been commenced through a range of activities, including: our partnership

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[8] Consumers Health Forum of Australia, The George Institute for Global Health, The Royal Australian College of General Practitioners and The Menzies Centre for Health Policy (2016) *Patient-Centred Health Care Homes in Australia: Towards Successful Implementation*
[9] Australian Commission on Safety and Quality in Health Care (2011) *Patient-centred care: Improving quality and safety through partnerships with patients and consumers,* ACSQHC, Sydney, p 7
[10] World Health Organisation (2017) *WHO Framework on integrated people-centred health services*
[11] Productivity Commission (2017) Shifting the dial; 5 year Productivity Review, Canberra p11

with the Australian Digital Health Agency[12], our participation in the Private Health Ministerial Advisory Committee (PHMAC) and the Consumer and Community Ministerial Roundtable in August 2017. At the Roundtable, CHF presented the Minister with an issues paper which presented consumer's views and insights into the plan[13]. The issues paper, and the roundtable, canvassed key elements of the plan which are important to all four pillars of the plan because of their interconnected nature.

Our key commitment to move away from the current budgetary requirement for all new health expenditures to be offset by savings in the health portfolio builds on the work done in Wave 1 of the reforms where the Government has signed agreements with key stakeholders. These agreements are designed to help Government look at reforms which make the system sustainable and engage the stakeholder in finding the solutions. The precursor to these agreements was the PBS Access and Sustainability package in the 2015 which provided significant savings to offset much needed investment in other areas of health.

Health is an investment and many of the reforms need additional expenditure now for society to reap the longer-term benefits.

Our specific recommendations are focused on system wide changes and waves 2 and 3 of the Minister's plan. As the national peak for health care consumers we have many consumer organisations among our membership that advocate for their population groups, conditions and regions. Many of these put in their own submissions to the Budget process. CHF supports their advocacy through this mechanism and does not duplicate their submissions.

This year there has been significant public debate around end of life care and palliative care. This is an area of health care that we must improve on. CHF supports all Palliative Care Australia's budget recommendations designed to improve this important area of care. We support the call for palliative care to be recognized as a National Health priority and that palliative care should be being available for all stages of life and for all life limiting conditionsconditions and all settings, including primary health care and aged care, rural, remote and regional. The recommendation to establish a multi-jurisdictional Palliative Care Commission would help to drive a truly national approach and to work towards improving access to palliative care for all Australians.

[12] Consumers Health Forum of Australia (2017) Consumers' voice drives digital health: https://chf.org.au/media-releases/consumers-voice-drives-digital-health
[13] Consumers Health Forum of Australia (2017) Consumer Priorities for a National Health Plan: https://chf.org.au/sites/default/files/chf_ministerial_roundatble_issues_paper_final_0.pdf

Prevention and social determinants of health

"We should be proactive rather than reactive. There will be savings and better outcomes."

Consumer focused commitments

CHF calls for the development of a comprehensive, community-focused strategy to address the growing issue of obesity in Australia. This national strategy should comprise elements including:

- Establish obesity prevention as a national priority, with a national taskforce, sustained funding, regular and ongoing monitoring and evaluation of key measures and regular reporting around targets
- Legislate to implement time-based restrictions on exposure of children (under 16 years of age) to unhealthy food and drink marketing on free-to-air television until 9:30pm
- Set clear reformulation targets for food manufacturers, retailers and caterers with established time periods and regulation to assist compliance if not met
- Make the Health Start Rating System mandatory by July 2019
- Develop and fund a comprehensive national activity strategy to promote walking, cycling, and use of public transport
- Fund high-impact, sustained public education campaigns to improve attitudes and behaviours around diet, physical activity and sedentary behaviour
- Federal government to place a health levy on sugary drinks to increase the price by 20%
- Develop, support, update and monitor comprehensive and consistent diet, physical activity and weight management national guidelines.

CHF calls for additional investment in family and early childhood health with an emphasis on health promotion and prevention

Why this matters

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 provides a model to use for current public health challenges such as obesity.

Australia was once considered a leader in public health and prevention e.g., tobacco control, prevention and early treatment of HIV/AIDS, sun safe messaging and healthy eating and activity programs. Most developed economies have invested in public health programs to prevent illness, disease and promote wellness e.g. UK, Canada and many European countries. Our lack of long term investment in these critical health programs has resulted in a loss of credibility internationally.

Obesity is recognised as one of the greatest public health challenges of our time. It is a major risk factor for chronic and preventable conditions such as type 2 diabetes, heart disease, hypertension, stroke, musculoskeletal disorders and impaired psychological functioning. Nearly two-thirds of the Australian adult population is overweight or obese and these rates are some of the highest in the world[14]. Of more concern is that more than quarter of Australian children are overweight or obese. The health impacts of obesity are well documented with marked increases in diseases such as type 2 diabetes, cardiovascular disease and cancers.

There is an urgent need to reverse this trend and put much more effort into combatting obesity if we are not to lose many of the gains we have seen over the last decades and to see our children and grandchildren have lower life expectancy than we have.

The recent report *Tipping the Scales; Australian Obesity Prevention Consensus* from the Obesity Policy Coalition and Deakin University's Global Obesity Centre sets out a blueprint of what needs to be done to address the problems. That report makes the point that diet and weight now have a higher burden of disease than tobacco smoking. The total annual cost of overweight and obesity in 2011-12 was estimated to be $8.6 billion[15]. Clearly it makes economic sense to act to reduce these costs which will grow overtime.

There needs to be a national priority and to have a whole of government multi-sectoral approach to what is a complex issue. We know that investment in prevention is an important part of moving to a sustainable health system by helping to avoid expensive treatment in the future. We also know from our experience with tobacco control and reduction that we need a sustained effort with a range of strategies to tackle different dimensions of the problem.

[14] OECD (Organisation for Economic Co-operation and Development) 2015. *Health at a Glance 2015: OECD Indicators*. Paris: OECD. Viewed 16 August 2016

[15] Obesity Australia (2015) Obesity; its impact on Australia and a case for action No time to Weight 2 Sydney

Primary and integrated care reform

"Health impacts on models of care and care delivery. We need to focus on prevention and early detection - wellness not just illness."

Consumer focused commitments

CHF calls for greater funding of primary and integrated care through both Primary Health Networks and hospitals in the context of COAG national health and hospital reform bilateral discussions. CHF calls for the next hospitals agreement to be broadened to allow local hospital networks to fund services in a manner which addresses the impediments current funding arrangements present to integrated care.

CHF calls for clearer Federal Government plans and funding for self-management innovations such as appropriately trained and paid peer support workers and health coaches to help people look after themselves and get the right care. These should be integrated into future implementation of patient centred health care homes.

CHF calls on the government to fund a Council for inter professional education and collaborative practice to provide national leadership for health workforce reform.

Why this matters

Universally accessible quality primary health care through general practice and similar settings such as Aboriginal Community Controlled Health Organisations is the backbone of sustainable healthcare. Countries with the highest performing health care systems have a strong primary health care sector.

Contemporary primary health care needs to be inclusive and consider the diverse needs of the communities it is serving. Models of care must be flexible to incorporate the needs of groups including: Aboriginal and Torres Strait Islander peoples, culturally diverse communities, those in our community with an identified disability or mental ill-health, those who identify as LGBTI and those who are homeless. The Health Care Home model which looks to better coordinate care and fund it appropriately is an important first step to improving primary care.

However, we need to do more to link hospitals to primary, community and social care providers so that consumers can move more easily through and across the various parts of the system. We want to provide the right care in the right place at the right time which requires us to look at the services not being place specific and at ways to deliver more specialised services 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[16]

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[15]. 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.

We also need to look at better integration across the primary health care system. One key area is the role of community pharmacy and pharmacists more generally as part of the primary care team. The recently completed Review of Pharmacy Remuneration and Regulation highlighted the need for some structural reform to deliver on better integration and to treat pharmacists and pharmacy as part of the system with similar payment structures and accountabilities.

Health coaches can greatly assist with self-management, service coordination and compliance with chronic care plans. Thus, we call for clearer plans and funding in the form of structured, evidence-based self-management programmes to help people better look after themselves and get the right care. This will require investment in consumer health literacy and empowerment. These are areas which have had little to no attention on a national basis, which was highlighted in a national report on health literacy which pointed out that only 40 per cent of adults have the health literacy to meet the demands of everyday life[17]. CHF has consistently found that one of the biggest drivers of complaints and dissatisfaction with the health system is almost always that consumers feel as if they aren't being respected as individuals, and partners, in their own health care decision making

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.

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[16] Robertson R, Sonola L, Honeyman M, Brooke B, Suruchi K (2014) Specialists in out-of-hospital settings. Findings from six case studies. Kings Fund, United Kingdom. October 2014
[17] ABS (Australian Bureau of Statistics) 2009. *Health Literacy. ABS Cat. No. 4102*. Canberra, ABS.

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[18]. 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 diversification of the health workforce, including through new professions such as health coaches and service coordinators is a building block of any meaningful move to consumer staking more responsibility for their health care. As with other parts of the economy the jobs of the future do not even exist yet, but we need to be thinking about how they will be created and the skills they will need.

We need to make optimal use of the differing skills that various healthcare providers 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.

[18] Randall, R. (2016) *Patient-centred care – a gulf between theory and practice?* Health Voices. Consumers Health Forum of Australia

Private health insurance

"Private Health Insurance is confusing at the best of times (and I have a PhD in engineering!). Better communication of information and more transparency is always a good idea to facilitate consumer empowerment for decision-making."

Consumer focused commitments

CHF calls on the Government to send a reference to the Productivity Commission to conduct an inquiry into the benefit of government involvement in the Private Health Insurance sector.

We also ask that it is made mandatory that health funds make readily available, and in plain language, the costs and coverage of all their insurance packages.

CHF calls for the development of a plan for greater disclosure and information provision about medical practitioner fees, medical practitioner qualifications, years of experience and selected performance indicators. This plan should be developed with input from practitioner groups, consumers and government to ensure that it is sustainable and appropriate for consumers.

Why this matters

Private health insurance (PHI) is important to the Australian health care system: it is intended to assist with the costs of care in the private system, to support choice of private provider and to help take the pressure off public hospitals. However, it is also overly complex, confusing to consumers and costs the federal government more than $6 billion per year[19]. It affects a considerable proportion of Australians, with 45.8% of the population currently having hospital policies and over half (54.8%) having extras, or general policies[20].

While rising premiums have reflected surging health costs, Government policy including regulation, tax incentives and a rebate over the past 17 years has failed to translate into effective protection for consumers from rising premiums and out-of-pocket costs. The system and the government policies that underpin it should take pressure off the public health system not contribute to it.

PHI policies are complex, with some current regulations helping consumers and others hindering their ability to use and understand them. A re-design of these policies is necessary to improve the usability of these products and ensure that function as health products. Key elements of this redesign should be the continuation of community rating, improving the basic

[19] Commonwealth Government of Australia (2016) *Budget Paper number 1: table 8.1* Commonwealth of Australia, Canberra: Australia
[20] Australian Prudential Regulation Authority (2017) *Private Health Insurance Quarterly Statistics, September 2017*

Complying Health Insurance Product (CHIP) and removing within treatment category restrictions.

We have, in principle, welcomed actions taken by the Health Minister over the last year to address some of these changes but believe there is still more to do.

The value proposition of government investment into the Private health insurance sector is yet to be firmly established. Because of this, we are calling on the Government to send a reference to the Productivity Commission to conduct an inquiry into the benefit of government involvement in the Private Health Insurance sector. Given the large cost to both individual consumers and to the Australian government a measure should be developed, tested and data regularly collected. This data should feed into ongoing discussion and reform of the system.

Australian health consumers face considerable out of pocket costs, both when using PHI and when using the broader health system. In fact, Australian consumers bear among the highest out of pocket costs across the OECD countries. These out of pocket costs are often hard to estimate or are not able to be estimated prior to treatment. Changes to how health professionals publicise their fees and how insurers work with health professionals and hospitals to communicate this to consumers are needed. We welcomed the establishment of a working group through the Private Health Ministerial Advisory Committee to examine these issues. This is an urgent issue requiring joint leadership by both government, professional associations and consumer groups.

Considerable changes are possible, and necessary, to reduce these gaps. We are concerned that if consumers can predict that they will face significant out of pocket costs for hospital treatment when using PHI, they may choose to use the public system. This means that, despite their investment through premiums and the government's investment, no pressure is being taken off the public hospital system. Quite the opposite is occurring counter to the stated policy objectives associated with the various PHI incentives and subsidy.

One way in which these gaps could be addressed is through the development of a plan for greater disclosure and information provision about medical practitioner fees, medical practitioner qualifications and years of experience. This plan should be developed with input from practitioner groups, consumers and government to ensure that it is sustainable and appropriate for consumers. A starting point could be the Australian Atlas of Healthcare Variation from the Australian Commission on Safety and Quality in Healthcare. This Atlas shows variation by mapping use of healthcare according to where people live. A complementary atlas of healthcare cost variation would allow consumers to see how the costs of healthcare they pay compare to those in other areas. The aggregate level of the atlas may be more acceptable to individual practitioners, who have expressed resistance to price disclosure in the past.

Consideration should also be given to complete fee disclosure arrangements. Given the degree to which the cost of medical specialists' services is paid for by the taxpayer through Medicare and private citizens through out-of-pocket expenses, we suggest that their fees and performance measures should be easily accessible to the community at large. One way in

which this could be achieved is through the establishment of an authoritative and independent website containing this information would be an appropriate platform.

National medicines policy and pain management

"There are people who do not have prescriptions filled or halve their medication rates to eke them out for longer. This compromises their health."

Consumer focused commitments

We call on the Federal Government to reform the Pharmaceutical Benefits Scheme (PBS) safety net so consumers with high usage of PBS medicines have smoothed out annual co-payments.

We call on the Federal Government to update, adequately fund and implement the National Pain strategy, which was developed after the 2010 National Pain Summit.

Why this matters

National medicines policy is a key element in the strong and sustainable primary healthcare system that Australia needs. The PBS provides timely, reliable and affordable access to necessary prescription medicines and is valued by consumers. The inclusion of a concessional rate of co-payment and the PBS safety net are both designed to ensure people who need them can access medicines, particularly people who use medicines either for chronic conditions or acute conditions.

However, ABS data shows that 7 per cent of people who are given a prescription either delayed or decided against filling it due to cost[21]. This is of concern as it has the potential to compromise their health. CHF opposed increases to the co-payment and to the PBS thresholds because we know people are price sensitive and we did not want to see this figure increasing.

CHF believes one way to reduce this figure it to improve the way the safety net works by allowing consumers with consistently high usage of PBS medicines to smooth out their total co-payments in any given year will reduce uncertainty and the ill health of this vulnerable population by ensuring continued medication. This issue is raised consistently by consumers, particularly those on low and fixed incomes who sometimes struggle to afford even the concessional co-payment. This could be of particularly for general patients who benefit by the safety net reducing their co-payments from $38.80 to $6.30 when it takes effect.

Another area for reform of the safety net is to change the way it is administered. Currently it is up to pharmacists to keep the record and we suspect that many people who would be eligible

[21] ABS (2017) *Patient experiences in Australia; Summary of findings* 2016-17 Cat No 4839.0

miss out because of incomplete records, using different pharmacies etc. CHF has asked that the work on modernising the health and aged care payments system address this issue and look at ways for it to be centralised and automatic.

It is becoming apparent that Australia has a problem with the overuse of opioids, through both prescription and over the counter medicines. The Government has moved to address the over the counter problem by making all medicines containing codeine prescription only from 1 February 2018. Medical professionals are also looking at prescribing patterns for opioids and other pain medicines, to reduce over prescription and to look at ways to limit over use of which leads to addiction and further problems.

Clearly there needs to be alternative evidence-based approaches if access to painkilling medicines is to be restricted and reduced. There is renewed interest in the implementation of the National Pain Strategy[22] which was developed in 2010. The Strategy's six goals are: making people in pain as a national health priority; creating knowledgeable, empowered and supported consumers; ensuring there are skilled professionals and best-practice evidence-based care; there is access to interdisciplinary care at all levels; there is quality improvement and evaluation; and resources for research.

We suggest that the Strategy needs to be reviewed with the idea of updating as necessary to ensure it has looked at the most recent evidence and considers changes in policies such as the up-scheduling of codeine. It also needs to better reflect consumer views on pain management and the areas where they see the need for improvement. After that has been done we need the commitment of resources to implement the Strategy. We need to move away from the quick fix of painkillers and this requires education and awareness raising for consumers and health professionals as well as resources to sure that people in pain have access to specialised pain clinics and to the inter-disciplinary teams that are the key to successful pain management.

[22] Pain Australia (2010) *National Pain Strategy*

Safety, quality and consumer participation

"Consumers are the experts: only we can say how their health conditions impact on our lives and what will work for us."

Consumer focused commitments

CHF calls on the Federal Government to support a programme of action to ensure healthcare consumers participate in shaping the underpinning policy and implementation of the health reform agenda including innovative ways to gather and synthesise consumer sentiment.

CHF calls on the Federal Government to fund the development of a national centre in consumer and community involvement in health and medical research through the Medical Research Future Fund.

CHF calls on the Federal Government to steward the development of programs to build a network of patient and consumer leaders who can work in partnership with PHNs, local clinicians and other stakeholders to ensure evidence-based, needs-informed regional commissioning plans.

Why this matters

Consumer stories and experiences can shed deep insights that can shape policy and health services and they 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.

The goal of health reform must be to improve the health and wellbeing of the community. This reform depends on the inclusion of consumers at all stages of the process: better decisions and value-based care will be the outcome when policy and programs put people at the centre.

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.

Participation needs to go beyond consultation by having consumers actively engaged at all stages of the reform process so that they are empowered to become partners in their care. Consumers can be and are catalysts for change, but they need to be supported in that role if it is not to be a tokenistic approach.

CHF has welcomed PHNs and wish to see their efforts to involve consumers and the community in governance and commissioning well supported. The communities they serve will benefit from more responsive, better designed services as a result. However, there is limited focus on building the capacity and expertise of consumers to serve as leaders, agents of change and service improvers despite the literature recognising the important co-creation

role consumers can play. CHF recommends that the Federal Government steward a program where all PHNs can nominate consumers, clinicians and community leaders to participate in a bespoke leadership development and service improvement programme.

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 involving consumers as a mandatory part of their governance arrangements.

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.

As part of the consultations for the 2017 Consumer Roundtable with the Minister for Health consumer organisations suggested that one way of ensuring consumers are involved in identifying areas for research would be to 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.

About CHF

The Consumers Health Forum of Australia (CHF) is the national peak body representing consumers and those with an interest on healthcare consumer affairs on national health issues. We have an interest in developing and promoting consumer-centred health system policy and practice to governments, stakeholders, providers and clinicians, and we aim to ensure that consumers are involved in influencing health system change and innovation. Accordingly, our interests and remit are broad and encompasses the whole of the health system. We aim to capture this breadth in the following submission by highlighting the five key areas that we believe there are small, but significant, changes to be made that would improve the lives of all Australians.